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Exploring the experiences of people with age-related macular degeneration (AMD) within their personal, social and relational contexts

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Abstract

Age-related macular degeneration (AMD) is a chronic, progressive eye condition causing gradual loss of central vision among older adults. This PhD thesis explores how individuals experience AMD in the context of their personal circumstances, close relationships, and their social and material environment.

Firstly, I present a secondary Foucauldian discourse analysis of published qualitative extracts on the experience of AMD, in order to map the discursive resources available to talk about AMD experiences. Drawing on theory from critical studies of ageing and disability, the analysis suggests that AMD is often discursively constructed in negative, medicalised and individualistic terms. This provides a rationale for research that avoids presuppositions of loss and tragedy, and instead explores AMD more openly within a broader range of everyday social, relational and environmental contexts.

Consequently, in the second study, I present the findings of an interpretative phenomenological analysis (IPA) study, exploring convergence and divergence of the experiences of eight participants within the following four themes: Reconfiguring a destabilised identity and struggling to find a new place in the world; the intensive effort of learning to live with AMD; navigating the hope-despair continuum; and negotiating one's place in the world.

In the third study, I analyse the accounts of a further eight participants using template analysis, in order to extend and further develop the IPA conducted on the initial eight accounts. This analysis provides new insights regarding, for instance: the influence of AMD on social interaction and communication; AMD as an intergenerational phenomenon; and the gulf between the self and others when seeking to disclose or verbalise the complex experience of AMD.

Finally, in the fourth study, I seek to more squarely explore how the environment around the person may shape their psychological experience of AMD, by conducting home tour interviews with two of the participants who took part in the IPA study, analysing these accounts using reflexive thematic analysis.

Throughout the thesis, I examine the challenges and affordances of using multiple research methods (methodological pluralism) to explore the personal, lived experiences of individuals with AMD, embedded within an understanding of how discourse and ideology influence the way individuals make sense of AMD. I also explore how the interview context (for example, the telephone interviews conducted for the IPA study, in contrast with the embodied, situated home tour interview) can shape the nature of the data collected.

In the discussion, I contextualise the overall findings within critical literature on ageing and disability as well as existential-phenomenological literature within broader health psychology. This prompts reflection on implications for practice, with my research suggesting that the onset of AMD may be seen as an existential crisis point. Some participants had experienced deep despair but emerged from this to find varying new degrees of equilibrium and purpose; while for others, there was a more continual process of navigating the ‘hope-despair’ continuum and consistently working hard to “plod along” and remain pragmatic and proactive. Collectively, the studies of the thesis suggest that the sense of existential crisis may be intensified not only by the inherent challenges and limitations of AMD but also by negative social constructions of vision loss and aging. This perspective underscores the need for interventions that foster hope, pragmatism, and confidence among individuals living with AMD, alongside structural efforts to make environments more accessible and inclusive for people with vision loss.

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Note to reader

Please see Appendix 22 for endnotes, which are denoted in Roman numerals in superscript, e.g. [i, ii, iii] etc. Endnotes contain additional reflection or points of detail, but are not essential to the arguments developed in the thesis.

In Chapters 4-6, verbatim extracts from participants have been edited for clarity and brevity. Please see Appendix 21 for the full unedited quotation.

Chapter 1: Introduction and Literature Review

This PhD thesis explores how individuals experience age-related macular degeneration (AMD), a chronic, progressive eye condition causing gradual loss of central vision among older adults (Lim et al., 2012). Risk of AMD increases with chronological age, and global estimates suggest that 196 million people were living with AMD in 2020 (Wong et al., 2014). AMD is often categorised as either ‘wet’ (neovascular) or ‘dry’ (non-neovascular); both forms can lead to visual impairment, although the wet form can develop very suddenly, while the dry form progresses more gradually. AMD is the underlying cause of just under half of all certifications of vision impairment in the UK (Brown et al., 2023). However, from a rehabilitation perspective, it is important to note that people with AMD, even with severe central vision loss, will not lose all vision and will still maintain some peripheral vision (Crossland et al., 2007). Alongside progressive vision loss, many individuals with AMD experience Charles Bonnet Syndrome, visual hallucinations that in certain cases may be benign but in other cases can be highly distressing (Vukicevic & Fitzmaurice, 2008). There is no cure for AMD. However, treatment for wet AMD has been available through the UK’s NHS since 2007, and involves repeated intravitreal (eye) injections of anti-vascular endothelial growth factor (anti-VEGF); these injections can not only slow down and stabilise the vision loss, but also sometimes lead to gains in visual acuity (Mehta et al., 2020). No treatment is currently available in the UK to treat the dry form of AMD (Ammar et al., 2020), although new eye injection treatments have been approved for clinical use in the US (Rajanala et al., 2023) and may in time become available through the NHS in the UK (Dinah et al., 2021).

The PhD’s aim is to consider this experience of AMD in the context of individuals’ personal home and family circumstances, close relationships and built environment. The overall research question this thesis sets out to explore, through a variety of qualitative methods, is: How do people experience AMD within their relational, social and environmental context? The PhD employs a number of distinct qualitative methodologies, introduced in Chapter 2, in the pursuit of considering how individuals live with and respond to AMD on a psychological level within their unique context. Regarding ‘context’, I am specifically interested in the social and relational dynamics in the external world – encompassing not only the person’s close relationships but also the ideologies, discourses and norms that circulate in our society – that may in turn shape the inner ‘life world’ of the person with AMD. My hope is that increasing our understanding of how people with AMD experience the condition within their real-world sociocultural and material environment will enable us to provide improved support and care for those living with AMD. Despite calls for more patient-centred care (e.g. Burton et al., 2013), many individuals with AMD receive limited non-medical support and information at the point of diagnosis (Boxell et al., 2017). My hope is that understanding lived experiences of AMD in their naturalistic, everyday context can help to inform provision of more holistic care and rehabilitation outside the eye clinic.

This introductory chapter aims to provide context and rationale for the thematic *content* of the PhD (while Chapter 2 focuses more on the rationale for using different methodologies to explore this content). Reflecting the journey undertaken in arriving at my PhD topic, discussed in section 1.1 below, I survey the literature on the psychological experience of AMD, both in terms of individual wellbeing and the more interpersonal dynamics, before considering medical sociological and existentialist perspectives on chronic illness, and then broadening out to consider broader theoretical perspectives from critical studies on ageing, disability and vision. I then conclude the introduction with a rationale for the research questions.

1.1. Personal background to the PhD study

The motivation for this PhD study stems from my interest in the psychological experience of living with sight loss, and how it affects individuals' way of experiencing their world and relating to other people. This is an interest that has grown from seeing my dad being affected by vision loss due to AMD since the mid-2000s, and from conversations about the condition with him and my mum. Aware that my dad enjoys many privileges including being able-bodied, financially comfortable, happily married and in generally satisfactory overall health, I became particularly interested in the idea of how far studies on age-related vision loss took participants' broader context, wellbeing and living situation into account. I came across both quantitative and qualitative articles that generally gave a bleak view of life with AMD, while a small number suggested that for many individuals it is a more minor inconvenience, especially in the context of broader challenges associated with ageing or other health conditions. These individual differences in experiences of and responses to

AMD, and whether these could be explained by the individual's psychological mindset, life story, values, relationships, socio-economic status and/or overall general wellbeing, became a source of profound interest.

Furthermore, in a previous Research Assistant role, I was lead author tasked with analysing and writing up results from a survey where members of the general public (mostly without sensory impairment) were asked to rank the importance of their senses, and also to imagine themselves living the rest of their life without sight and compare this to different amounts of time in perfect health (Enoch et al., 2019). Further reflection and research on this topic led me to become more critical of (often more medicalised) research approaches that exclusively focus on the 'loss' element of vision loss, aptly described by Tanner et al. (2020) as the "loss focus" in AMD research. This process of reflecting on the different kinds of assumptions underpinning vision loss research also led me to the social model of disability, that distinguishes between impairment (the specific issue affecting a person's body) and disability (the losses and restrictions stemming from physical barriers, economic discrimination, prejudicial attitudes or behaviours, and social oppression) (Barnes, 2012; Oliver, 1986).

I wanted the focus of the PhD to remain on the experiential, and - increasingly as the PhD progressed – existential (see section 1.4 below), dimensions of AMD; but also to find ways to consider how context, from the immediate surroundings of the home and family, all the way up to deeply-engrained social and cultural representations of vision loss, disability and ageing, play into individuals' processes of meaning-making about AMD. The feminist disability scholar Alison Kafer states, "I want to make space for people to acknowledge – even mourn – a change in form or function while also acknowledging that such changes cannot be understood apart from the context in which they occur" (Kafer, 2013, p.6). This perspective lies at the heart of the PhD, seeking to understand how people with AMD experience the embodied "change in form or function" while simultaneously seeking to consider alongside how the context inevitably shapes the experience of these changes.

1.2. Prior research on the psychological experience of AMD

The Macular Society, the principal charity supporting people with AMD in the UK, sums up many of the psychological and emotional challenges people with a diagnosis of AMD may face, with emotional reactions commonly including fear, grief (with sight loss often compared to a bereavement), isolation, depression, anger, shock and disbelief (Macular Society, 2021). Indeed, there is a significant – largely quantitative – literature exploring quality-of-life among people with AMD using structured questionnaires, which also explores associations between AMD and clinical mental illness diagnoses such as anxiety and depression. For example, a 2014 systematic review found that people with AMD were more likely to experience depression than controls, although were not overall more likely to experience anxiety (Dawson et al., 2014). Some evidence suggests that self-reported depression in AMD is more likely as visual acuity becomes more severely affected (Augustin et al., 2007). Furthermore, among individuals with visual impairment more generally, depressive symptoms have been found to increase as the individual experiences more functional limitations (Welp et al., 2016). However, other studies suggest that the relationship between AMD-related vision loss and depression/anxiety is far from clear-cut; a number of mediating or moderating factors may be significant in this association between visual impairment and depression/anxiety, such as the treatment status of the person with AMD (Senra et al., 2017), or the person with AMD's level of perceived social support (Hernández-Moreno et al., 2021).[i]

In qualitative research on AMD, including two qualitative meta-syntheses (Bennion et al., 2012; Thier & Holmberg, 2020), research participants have highlighted certain common psychological or emotional patterns when discussing their experiences of distress relating to AMD. These include:

- Fears for the future, particularly around no longer functioning independently (especially stopping driving (e.g. Moore & Miller, 2005)) and relatedly, fears of becoming a 'burden' to family members, friends or caregivers (e.g. Wong et al., 2004).

- Specific fears relating to the bodily consequences of changes in functional vision, such as increased fear of falling due to vision loss (e.g. McGrath et al., 2016; Taylor et al., 2020).
- The specific burdens associated with undergoing eye injection treatment for wet (neovascular) AMD, which can be an uncomfortable, distressing or painful experience for many (Boyle et al., 2015; Thier & Holmberg, 2020; Yiallouridou et al., 2023). Those undergoing treatment may still face significant uncertainty regarding the trajectory and continuing progression of AMD, given that the treatment provides a way of *managing* the condition rather than a cure (McCloud & Lake, 2015).
- Giving up valued functional activities and hobbies if sight loss makes these challenging or impossible (e.g. Taylor et al., 2020; Wong et al., 2004).
- Reduced social participation, or a lack of social support, leading to a reduction in social activities and consequently, increased loneliness and isolation (e.g. Stanford et al., 2009; Thetford et al., 2015). This social withdrawal can also stem from difficulties recognising faces and picking up on facial expressions, gestures and other forms of non-verbal communication, with individuals with AMD concerned about embarrassment in social situations, or being perceived as rude if they do not recognise someone (Lane et al., 2019). (See Section 1.5.)
- The challenge of living with a non-visible condition, which can make individuals with AMD "feel like a fraud" and struggle with disclosing their vision loss (e.g. Mogk, 2008; Wong et al., 2004). In these articles, much of the struggle related to participants' dilemmas around whether to conceal or reveal their vision loss in order to help others understand their difficulties; and participants had concerns about other people's reactions, especially pity (Moore et al., 2000).

Despite the assertion made above that much of the research on AMD appears to be located within a 'loss focused paradigm', certain studies have focused on the ways in which people with AMD adapt to the condition, and note the wide range of lived experiences and psychological impacts among those living with AMD. In their meta-synthesis of qualitative research on AMD, Bennion et al. (2012) discuss how participants across studies had found ways to adapt to life with AMD, finding ways around the limitations imposed by vision loss through extra concentration and planning. Drawing on Dahlin-Ivanoff et al. (1996), Bennion et al. (2012) suggest that individuals with AMD may use four principal strategies to adapt to AMD: changing how they perform certain daily activities; using assistive devices; avoiding certain activities; or asking for help from others. This aligns with a more recent study by McGrath et al. (2016, p.26), who summarised the practical adaptation strategies voiced by participants in their study as “asking for help, being cautious/careful, concentrating, or completing tasks more slowly”. Studies considering how individuals manage AMD at a more psychological level suggest that effective coping strategies include remaining socially engaged (Bennion et al., 2012; Taylor et al., 2020) and cultivating a positive mindset (Thier & Holmberg, 2020). A qualitative study by Kleinschmidt (1999) specifically explored how individuals who had adjusted positively to AMD (according to both the researcher’s and participant’s judgement) accounted for their successful adaptation. In sum, Kleinschmidt’s (1999) study suggests that participants often drew strength from their prior life experiences, often involving significant hardship which had instilled a mental “toughness” that they applied to coping with AMD-related vision loss. Furthermore, participants voiced drawing on what Kleinschmidt terms “internal resources”, including positive attitudes, humour, a problem-solving perspective, a resolve to remain active and productive, and their religious beliefs. In terms of “external resources”, participants in Kleinschmidt’s study discussed the importance of emotional support from family members and friends, and professional support from eye care and rehabilitation professionals. Participants also voiced modelling themselves on people they knew, who were dealing well with visual impairment or other forms of adversity (i.e. upward comparisons (Heidrich & Ryff, 1993)); while they also drew comparisons with those perceived to be worse off (downward comparisons). Notably, the participants in Kleinschmidt’s study did not deny the difficulties, frustrations and losses AMD entailed, often being especially distressed and overwhelmed soon after AMD diagnosis, but had eventually developed an accepting, balanced perspective. Kleinschmidt speculates that several factors may explain their positive adjustment to AMD, including being financially comfortable, having a strong sense of proactivity, self-efficacy and problem-solving skills, and enjoying close relationships with relatives and friends.

The most significant body of qualitative research exploring how AMD affects individuals’ everyday quality-of-life and wellbeing, and the scholarship closest to the perspective of my PhD research, is Amy Burton's (2013) doctoral research on the experience of living with age related macular degeneration. Burton's PhD research involved a longitudinal approach using interpretative phenomenological analysis to explore experiences of AMD dynamically over time. The first study of Burton's PhD compared responses to a quantitative questionnaire commonly used to measure vision-related quality-of-life (the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ)), and experiences of individuals with AMD as relayed qualitatively. This study illustrated how the NEI-VFQ fails to capture the myriad complex and highly contextual ways in which individuals experience AMD, as just one aspect of their overall daily life. The subsequent studies all used IPA, firstly with two participants with early-stage dry (non-neovascular) AMD, for which there is no treatment; secondly with seven participants with treatable wet AMD; thirdly with three participants with advanced wet (neovascular) AMD that could no longer be treated; and fourthly, a married couple where both partners were living with AMD. Four themes applied across the studies: making sense of diagnosis; getting on with life (which was replaced by "living together with AMD" in the study of the couple); interaction with the health services; and the future with AMD. However, Burton also highlighted the particular experiences and challenges unique to each set of participants. For the early-stage dry (non-neovascular) AMD participants in Burton's study, the most significant source of distress related to participants feeling uncertain about the future trajectory of their AMD progression and experiencing a sense of "looming loss" (Burton, 2013, p.204). Those with treatable wet (neovascular) AMD perceived treatment as a frightening but necessary experience, which was worth the distress and inconvenience if it could prevent further visual deterioration (or, in some cases, lead to improvements in vision). The participants with advanced, untreatable AMD discussed their extensive adaptations and coping strategies to get on with life with AMD, but also discussed concerns of being perceived as disabled by others and thus rejected symbols like the white cane that might draw attention to their vision loss. In the published version of the final study of the couple living with AMD (Burton et al., 2015), Burton and colleagues discussed how the partners negotiated their changing levels of autonomy and dependence, and found a sense of resilience and solace through their interdependence and sharing the experience of AMD (and ageing) together. Yet alongside this rootedness in their shared present, there was also a sense of foreboding about the challenges of either one of them having to face the experience of AMD alone. Burton's doctoral work concludes by recommending that the past, present and potential future contexts and experiences of individuals with AMD should be taken into account by healthcare professionals. On the basis of the findings, Burton advocates a ‘lifeworld-led’ healthcare model (drawing on Todres et al., 2007), moving away from a medical model focused on treating ‘abnormalities’ towards a form of care that takes service users’ broader experiences into account, focused on what health and illness *means* to patients, especially in terms of how illness impacts their aims and projects in daily life. This has parallels with more existential understandings of illness and ageing discussed below in 1.4.

While the literature on individuals’ psychological and emotional experiences of AMD is relatively extensive, there is a more limited qualitative literature exploring interventions to reduce distress and improve wellbeing in AMD. Arguably, the example of lifeworld-led healthcare discussed in the previous paragraph is itself a kind of recommendation for intervention, albeit one that would be more systemic than typical, time-limited interventions in healthcare. Certain psychological interventions, operating more at the individual or group (rather than system) level, have been found to measurably reduce distress and improve wellbeing among people living with AMD. For example, a systematic review of psychological and psychosocial interventions for alleviating depression and anxiety among people living with AMD found that group interventions encouraging self-management, and individual behavioural activation plus vision rehabilitation can help to treat and prevent depression (Senra et al., 2019).[ii] All such interventions included in Senra and colleagues’ review arguably fall within a (broadly defined) cognitive-behavioural modality, rather than the more existential, lifeworld-led model advocated by Burton and colleagues (2013, 2015) above. While my PhD is not aiming to develop and test out interventions, I align with the perspective of Burton, taking an interest in how AMD is experienced by individuals within their broader lifeworld, in the context of their home, relationships and other significant experiences, including other co-occurring chronic conditions. It is hoped that by deliberately focusing on this more existential dimension of life with AMD, situated within other meaningful, unique experiences and within a shared social context, that new possibilities for intervention can materialise that are responsive to individuals’ contextual realities.

1.3. A ‘lost’ or ‘disrupted’ self? AMD in the context of psychosocial research on chronic conditions

It is important to consider research on the experience of long-term illness more broadly, given that some of the experiences discussed in 1.2 above (such as giving up activities due to AMD-related sight loss, or fears of the future) are likely to be shared with – even if inevitably somewhat distinct from – experiences of other chronic conditions that progressively cause impairment or experiences of limitation.

Much of the foundational work on how individuals experience chronic illness or acquired impairment has been conducted within the field of medical sociology, particularly centring around the challenges posed by chronic illness to individuals’ identity and sense-of-self. For example, Kathy Charmaz documented a sense of “loss of self”, profound shifts in identity, and increasing loneliness and strained relationships as the person with illness becomes more acutely aware of how others respond to them (Charmaz, 1983). Charmaz illustrates how particular forms of suffering develop out of the “conditions and content of experiencing illness” (p.171) in everyday life. This suffering relates to four main sources, which overlap with the challenges voiced by people with AMD in the preceding section:

- Firstly, suffering can occur from “living a restricted life”, with life seeming to narrow and close in as activities are given up that formerly contributed to a person’s sense-of-self. In tandem, life often becomes taken over by discomfort or pain, as well as the mundanity of regular appointments and treatments. Charmaz suggests that the predominance of sociocultural values of individualism and independence can intensify the person’s sense of immobilisation and restricted autonomy. Charmaz also highlights how participants viewed the possibility of driving as a symbol of freedom, choice and independence, aligning with the AMD literature that equates driving cessation with a loss of independence (e.g. Moore & Miller, 2005).
- Secondly, Charmaz suggests that living a restricted life in turn contributes to social isolation, as individuals may have to give up certain group activities; or certain friendships may falter when people no longer share the same social world. This aligns with a diary study by Stanford et al. (2009) highlighting the

profound sense of isolation certain individuals with AMD may experience, with one participant writing "'I live in a sad world of my own."

- The third source of suffering posited by Charmaz relates to experiencing discrediting definitions of the self. For example, for those with visible impairments, more overt or "dramatic" (p.181) discrediting can occur if people make rude or jarring comments or judgements of the person's appearance. Alongside this, more tacit or subtle discrediting can occur, for example if the person who is living with illness or impairment is sidelined from conversations or activities.
- Such discrediting events can lead to the fourth category of suffering highlighted by Charmaz, relating to "becoming a burden", feeling a sense of uselessness as activities that helped to define the self are no longer possible, and struggling with the need to depend on others for help with certain tasks. The two latter categories of suffering (discrediting definitions of the self, and becoming a burden) are documented extensively within the qualitative AMD literature. For example, one participant in Taylor et al. (2020) spoke of feeling like his wife now made all the decisions while he "hides in the background", communicating a sense of feeling sidelined. Meanwhile, in a number of qualitative studies on AMD, participants described their concerns around being, or eventually becoming, a "burden" to others (e.g. Bian et al., 2019; McGrath et al., 2016; Wong et al., 2004).[1]

This alignment between Charmaz's findings and some of the qualitative AMD literature points to the ways in which AMD may affect individuals in similar ways to other diagnosed chronic conditions, alongside the more specific challenges associated with AMD and vision loss.

Michael Bury's sociological work on chronic illness as "biographical disruption" has also been pivotal in shaping understandings of how the onset of chronic illness occasions "a fundamental re-thinking of the person's biography and self-concept" (Bury, 1982, p.169), interrupting the trajectory individuals assume for their lives. Bury suggests a common

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[1] This concept of "burden" is discussed and deconstructed further in the secondary discourse analysis of published qualitative studies on AMD, in Chapter 3.

reaction is “disbelief mixed with anxiety” (Bury, 1982, p.171), aligning with experiences of AMD diagnosis documented in the literature. For example, one participant in Burton et al. (2015, p.1287) stated that AMD “chops your life in half”, in line with Bury’s notion of chronic illness diagnosis bifurcating an individual’s life story. Many participants in the qualitative AMD literature voice experiencing what Bury terms the “’what-is-going-on-here’ stage” (Bury, 1982, p.171), a sudden, stark awareness of normally unconscious bodily states that disrupt the person’s coherent sense of self. Often this shock is also bound up with fears of “a future of growing dependency and invalidity” (Bury, 1982). For instance, one participant in Taylor et al. (2020, p.467) described AMD diagnosis as “a tremendous psychological shock” and feeling “devastated” by diagnosis; however, gradually this participant came to “realise it’s not happening immediately and you can go on doing everything normally”. This aligns with what Bury terms the mobilisation of “cognitive and material resources” in an “attempt to normalise in the face of disruption” (Bury, 1982, p.177). Although using different language, Bury’s description of the impulse to “normalise” has parallels with Charmaz’s concept of the “reconstruction of the self” after the initial disruption of illness, often occurring unwittingly and progressively through new daily routines, habits and practices (Charmaz, 2002b). However, it is important to note that individuals with life histories of adversity, including previous illness or impairment, may consider chronic illness to be a more ‘normal’ and familiar experience than others (Williams, 2000); thereby potentially seeing illness as less unexpected, and more congruent with the “ebb and flow of their lives” (Pound et al., 1998, p.498).[iii] This points to the importance of considering the onset or diagnosis of a chronic illness like AMD within the unique context of circumstances of individuals’ life history, and also recognising how broader sociocultural factors or norms may determine responses to chronic illness.

The writings of Arthur Frank on illness narratives are also relevant to the experiences of individuals with AMD as represented in the qualitative literature. Frank (1998) proposed three fundamental types of illness narrative: restitution, chaos, and quest narratives. In the restitution narrative, illness involves initial suffering, treatment, and a restoration to the taken-for-granted, normative state of full health; Frank notes the predominance of this narrative in Western, industrialised societies such as the US. Restitution narratives represent the triumph of medical science, and while Frank emphasises the importance of medical cures that can provide such restitution, he cautions against such narratives becoming privileged to the point of demonising or sidelining stories where no restitution is possible. The qualitative literature on AMD starkly demonstrates this point, with numerous examples of healthcare professionals telling individuals with the dry (non-neovascular, currently untreatable) that there is ‘nothing they can do’. For example, one participant in Taylor et al. (2020, p.465) recounted how the doctor told him “you’ve got dry macular degeneration, end of story; […] there’s no cure for it so there’s nothing we can recommend you do”. Such a perspective, whereby restitution via a medical cure is perceived as the only worthwhile intervention, thereby potentially precludes discussion of non-medical support services and strategies to manage the effects of AMD in the here-and-now. The second archetypal narrative is the chaos narrative, associated with what Frank terms “deepest illness”, where impairment or pain will not remit and only increase over time. Frank suggests that in our modern culture and societies, such stories of chaos – of “life lived at the bottom of the funnel of these problems” (Frank, 1998, p.202) - challenge normative presumptions of health as the status quo, and act as reminders of “how cold and deep is the water we can suddenly sink into” (Frank, 1998, p.202). Frank suggests a key challenge is to honour the telling of chaos stories while also creating the space for possibilities of change, “to accept the reality of what is told without accepting its fatalism” (Frank, 1998, p.202). The third archetypal feature of illness narratives identified by Frank (1998) is “the quest story”, an experience from which the individual can learn and share this learning with others. In quest narratives, the emphasis is not on “gladness” or appreciation of illness, but rather a focus on “what can be reclaimed of life” (Frank, 1998, p.204). Frank argues that each of the three stories is valid and deserves to be honoured in the moment of its telling. There should not be a moral impulse to move towards the quest story, and nor should finding oneself stuck in the chaos narrative be considered a sign of individual failure. These archetypal kinds of narrative can intertwine and co-exist within the individual, who may oscillate between these narratives at different times and in different contexts.

Looking across the work of Charmaz, Bury and Frank, a key point to note is that all authors in different ways draw attention to the process of coping with and adapting to chronic illness[2] as socially or structurally patterned, rather than purely a matter of individual

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[2] While I use terms such as coping and adapting as a shorthand, it is important to bear in mind that “social scientists cannot reduce interview respondents’ expressive terms to instrumental terms, such as adaptation, adjustment, and coping, that contain moral judgments” (Charmaz, 2002a, p.322).

responsibility. For example, Charmaz suggests that much of the psychosocial suffering caused by chronic illness is located not only in the body but also the socio-cultural conditions of the "'American way' of illness" with its "traditional independence, privacy and family autonomy" (Charmaz, 1983, p.169). In a more recent paper, Charmaz (2020) engages with Goffman's (1963) concept of stigma as a "spoiled identity", arguing that the subjective experiences of a "discredited" or "discreditable" identity[3] are bound up with neoliberal logics of individual responsibility and self-sufficiency and with concomitant neoliberal structures of a limited social safety net and economic precarity. Charmaz thus makes a "call for more attention to relationships between structure and subjective experience" (Charmaz, 2020, p.23). Meanwhile, Bury emphasises how biographical disruption starkly accentuates the differences in both cognitive and material resources available to individuals, and suggests that inter-individual variability in illness experiences "aris[es] from the influence of structural constraints over the ability to adapt" (Bury, 1982, p.178). Furthermore, Frank notes that the possibility of experiencing an "epiphany" and phoenix-like rebirth during or after illness is "socially constructed", and "requires a cultural milieu in which such experiences are at least possibilities, if not routine expectations" (Frank, 1993, p.42).

Within the vision loss literature, a paper by Ferrey et al. (2024) is notable for its emphasis on how acquired vision loss (from conditions including, but not limited to, AMD) shapes identity, engaging with the medical sociological literature discussed above. Ferrey and colleagues suggest that beyond the practical, functional difficulties occurring in daily life, acquired vision loss causes individuals to re-evaluate or renegotiate their sense-of-self, as they navigate continuous dilemmas in daily life regarding how far they reveal or explain their vision loss to others. The authors summarise the constant, considerable mental effort required to negotiate these processes as the "cognitive penalty of disability" (Ferrey et al., 2024, p.6). They suggest that participants' efforts and work to (as Bury terms it) 'normalise' in the face of disruption could be summarised as identity work, "renegotiating their identity to include this new diagnosis", and self-presentation work, "managing the impression they convey of themselves to others"; particularly because the often non-visible nature of vision

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[3] Goffman (1963) distinguishes between a "discredited" stigmatised identity, when a stigmatised feature is clearly visible to others, and a "discreditable" identity, when a potential source of stigma is non-visible and can be concealed allowing for "passing" or "covering". There are parallels here with the distinction between "enacted" stigma, overt experiences of discrimination, and "felt" stigma, a more internal sense of shame and a fear of experiencing enacted stigma if the stigmatised identity marker were disclosed (Scambler, 2004).

loss means that individuals can sometimes “pass” (e.g. Goffman, 1963) as sighted. While Ferrey and colleagues identified aspects of the participants’ accounts that aligned with Bury’s (1982) notion of biographical disruption, they concluded that the process of disruption and normalisation in vision loss is often non-linear, and is better explained by Yoshida’s metaphor of the “pendulum of self” (Yoshida, 1993). Yoshida’s pendulum metaphor posits that identity reconstruction in response to acquired impairment is a dynamic rather than linear trajectory, and involves continual oscillation between non-disabled and disabled aspects of the self. Ferrey and colleagues also conclude that because of the work involved in deciding whether and how to disclose vision loss, the social model of disability can play a beneficial role, by making activities and spaces more accessible and inclusive by default, and thus reducing barriers that may accentuate the person’s disability.

1.4. Existentialist understandings of chronic illness, impairment and ageing

The medical sociological literature discussed above helpfully draws attention to the ways in which a person’s identity and sense-of-self, in the context of their broader life story, may shift due to chronic illness or impairment. However, there is arguably more limited literature exploring ways in which existential loss may arise in chronic illness, and how individuals (and healthcare professionals) perceive and respond to this loss (Fang et al., 2024). Due to limitations of space this section will only briefly consider some key existentialist ideas that may have relevance to the experience of a chronic condition causing impairment in later life such as AMD.

From an existentialist perspective, chronic illness can act as a reminder that our being-in-the-world is finite (Binder, 2022), in line with Heidegger's (1927/1962) notion of inexorably “being-towards-death”. Heidegger also writes of our being-in-the-world, using the term *Dasein* (“being there”) to describe the fundamental unity between a person and their world as the underpinning of existence (Cooper, 2021). Heidegger posits that ours is an existence we are “thrown into”, without our choosing, and throughout life we are also “thrown” into different adverse circumstances and situations, which could include chronic illness. Indeed, illness can represent an example of what Heidegger (1927/1962) terms “unhomeliness” or “uncanniness” (Unheimlichkeit), when the experience of taken-for-granted daily tasks and relationships is suddenly fractured, and aspects of the body or the world become radically alien or unintelligible (Svenaeus, 2011). Andersen et al. (2021) similarly suggest that diagnosis with a chronic illness is often experienced as what Kierkegaard termed “a stroke of fate” that can throw an individual into existential despair. Such despair may be attributed not only to the effects of the condition itself, but also to the sense of “chronicity” (2021, p.10) of an unremitting condition stretching forward into the future. Qualitative studies on AMD, though rarely drawing on existentialist ideas, resonate with these existentialist perspectives. For example, in a study by Mogk (2008), one participant stated, “This isn’t me—I mean, I’m a very visual person”. Existentialist thought often emphasises the “verb-like process” (Cooper, 2021, p.29) of existence, whereby the flow of experience is defined by the unfolding nature of our actions and activities rather than by fixed qualities or traits. From this viewpoint, for many individuals with AMD, a diminished ability to engage in or enjoy certain activities as before can challenge their sense of self that was previously defined by the very doing of such activities.

Jacobsen (2008) suggests that from an existentialist perspective, a crisis, “a sudden disruption of the normal life activity and continuous flow of life” (p.72), generally has three dimensions: loss, adversity, and the opening-of-existence. The loss dimension involves a grief reaction, and through grieving eventually coming to accept what has been lost. Crisis also involves responding to adverse conditions, into which individuals are (in Heideggerian terminology) “thrown”. However, in Jacobsen’s view, there is still an essential choice to be made in terms of how to approach and react to adversity. This aligns with certain experiences documented in the AMD literature, with many participants who voice feeling more accepting about AMD talking about their decision to adopt a positive, pragmatic attitude. For example, one participant in Kleinschmidt (1999, p.75) stated:

> “The process was just saying to myself, ‘Well, how am I going to deal with this one? One option is not to do it, sit back, and that is it. ... [Another is to think] Let's see, what can I do about this thing?’”

In Jacobsen’s typology, the third dimension of crisis is opening-of-existence, whereby the intense, extraordinary situation of “gazing” into the “abyss” (p.77) can encourage a kind of reset, and a “taking over your own life” (p.78). At first, this may not seem so applicable to AMD, because of the way the condition gradually progresses (in contrast to the more singular event of a vehicle accident used as Jacobsen’s example of crisis). Indeed, examples of this seeming opening-of-existence are notable in their relative scarcity in the AMD literature. One participant in Feely et al. (2007, p.46) discussed becoming a more “balanced” and “empathetic” person following vision loss, with “a better sense of humour than I had before”. Otherwise, even among those who had adapted well to AMD, the emphasis was often more on making the best of a challenging situation rather than having a more profound opening-to-existence or epiphany. Nonetheless, there may still be potential for applying existentialist concepts to understanding the experience of AMD, as an underexplored area, and one that closely aligns with the predominantly phenomenological approach of the PhD methodology (discussed in Chapter 2).[iv]

1.5. Being with others: AMD as an interpersonal and relational phenomenon

Continuing from the existentialist thread of the previous section, alongside existentialism’s emphasis on the individual’s internal processes of meaning-making, existentialist being-in-the-world also inherently involves being-with-others and in relation to others. For example, the existentialist philosopher Martin Buber critiqued “Western culture’s […] elevation of the isolated, self-sustaining individual” (Spinelli, 2014, p.20), instead viewing people as existing in an inseparable relation with the world and each other.

In general, the psychological and qualitative literature on AMD focuses on the individual as the unit of analysis. However, in both qualitative and quantitative literature on AMD, there is frequently an interpersonal and relational dimension in the concerns discussed, which suggests that the embodied, internal experience of AMD is still often bound up with relating to others. This relational dimension particularly comes to the fore in Burton et al.’s (2015) case study exploring the experience of a couple both living with AMD (discussed on p.7), where the partners in the couple supported each other practically and emotionally, but where their dependence on each other coexisted with a sense of broader isolation from the world at large. Quantitative studies involving participants with age-related eye disease (including AMD, but also conditions such as glaucoma and diabetic retinopathy) suggest that perceived social support (Hernández-Moreno et al., 2021) and being partnered (Amilon & Siren, 2022) are factors that may protect against depressive symptoms among this population. In qualitative studies, such as Taylor et al. (2020), participants discussed their appreciation of other people, such as partners and friends, on whom they could rely, but also simultaneously their misgivings about depending on others. This aligns with findings of McCloud et al. (2014, p.971), who discuss how spouses or partners with AMD may feel a loss of equality in the partnership, no longer feeling they contribute to “an equal share” of daily tasks.

While not uniformly evidenced across studies, some research on experiences of AMD suggests an increase in loneliness and loss of social connections since AMD onset. For example, in Stanford et al. (2009)’s diary study, participants with AMD describe being “trapped in a grey world” and highly isolated, often having very limited social contact outside their home. Wong et al. (2004) discuss how one woman with AMD found that her friends “dropped off” when they learned she was losing her sight. Giving up driving due to AMD may be a major contributor to social isolation for certain individuals, with reliance on family or friends for transportation restricting possibilities for spontaneous social activities (Wong et al., 2004), particularly in rural areas with limited public transport options (Thetford et al., 2015). As noted previously, this can lead to a perceived loss of independence and a fear of becoming a burden to relatives or friends (e.g. Moore & Miller, 2000). As McGrath and colleagues (2016) point out, there is often a pressure to live up to socio-culturally embedded norms of independence and self-reliance, which can cause people with AMD to limit their social and leisure activities due to the stigma around depending on others.

Given the importance of strong social networks - and encouragement and support from others - in coming to terms with AMD (e.g. Kleinschmidt, 1999; Moore et al., 2000), peer and social support could arguably help individuals with AMD adapt to the condition. There are few published studies documenting group support interventions for people with AMD. However, in one randomised study in Sweden, a health education group programme for people with AMD helped improve security in performing daily activities in 15 out of 28 domains at 28-months-follow up (Eklund et al., 2004). Qualitative research also attests to the value of meeting peers with AMD. Many people with AMD look to peers with AMD who appear to be coping well as inspiring and motivating; but as noted above, they may also find utility in engaging in ‘downward comparisons’, reflecting that “others have it worse” as a means of keeping their own situation in perspective (Kleinschmidt, 1999; Moore & Miller, 2000). However, some studies also suggest that people with early AMD, especially when asymptomatic, may be distressed by meeting others with more advanced AMD and subsequently worrying about their own AMD progression (Taylor et al., 2020).

Looking beyond close family members and friends, some studies also discuss the ways in which AMD may create social challenges in the context of interactions with less close or more casual contacts, such as neighbours or acquaintances, which in turn can potentially compound avoidance of social situations and thereby contribute to isolation. For example, McGrath et al. (2017) found that for many participants with AMD in their ethnographic study, eating out can be a challenge above all because of the fear of social embarrassment. Consequently, participants in their study often reported choosing “non-messy” meals, and expressed fear of spilling or knocking things over. Similarly, research participants with AMD have described challenges with facial recognition and interpreting facial expressions; this may be experienced not only as a loss in itself but also entail challenges in recognising others, sometimes leading to concerns about being perceived as rude or unfriendly by others (Lane et al., 2019). More broadly, often a lack of understanding and awareness about AMD and “invisible” vision loss from other people can create problematic social interactions and encounters. For example, McGrath et al. (2017) describe how for some participants, carrying a white cane could promote independence and mobility because of increased understanding and patience from sighted people. However, for others, a white cane could be stigmatising, marking them out as “other”. Relatedly, qualitative studies suggest that certain individuals with AMD sometimes feel like a “fraud” if they disclose visual impairment through such symbols (Mogk, 2008; Wong et al., 2004), especially if they have preserved peripheral vision or manage well in certain more familiar environments. Indeed, this challenge of defining their level of visual impairment may be linked to the tendency for older adults living with acquired, gradually progressing vision loss to eschew self-identification as “blind” (Nyman et al., 2012); a potentially devalued identity that – in some cases – may be seen to only offer a limited set of stereotyped roles to adopt, such as the inspiring hero or pitiable victim (Green et al., 2002).

Existentialist philosophers draw attention to this phenomenon of being defined and made into an object by others in a way that feels fundamentally incongruent with the self. Sartre, for example, famously wrote that “hell is other people” (Sartre, 1946/1989), encapsulating the sense of anguish that can come from seeing oneself through the prism of other people’s objectifying or judgemental gaze. Beauvoir (1977) addressed this issue specifically in the context of ageing in her work *Old Age*, discussing the double sense of alienation individuals may feel when ageing, of becoming both 'other' to the self and 'othered' by society (Gilleard, 2022). To some extent, this process of othering by society in the context of AMD may arise from dominant, deeply embedded, socially and culturally contingent norms and discourses around ageing, disability and vision, considered below (Section 1.6) and in Chapter 3. The research in my PhD thesis essentially works from this understanding, that not only is AMD experienced as a phenomenon in relation to close others, such as family and friends, but is also experienced within the social world, where embedded norms and discourses can influence internal, embodied experiences.

1.6. AMD as a phenomenon situated within broader social processes and representations[4]

In both the medical sociology and existentialist literature above, there is some level of awareness that the phenomenon of chronic illness as a disruption to one's identity and sense of self, or harbinger of a form of existential crisis in one's relation to the self or others, is mediated through social norms, structures, processes and/or representations. For example, Charmaz suggests that the loss-of-self entailed by illness or impairment occurs in relation to other people, with judgements towards the self based on "yardsticks" (1983, p.174) whose normative reference points are the "healthy and able". In the existentialist literature - especially the work of Beauvoir that was concerned with the social, cultural and historical contingencies that shape individuals' experiences and possibilities – there is also an emphasis on the social processes that interact with individuals' lived, embodied experience. With reference to Beauvoir's work on old age (1977), Deutscher (2003, p.289) states,

> "Biological facts are always already synthesised with historical, social, and psychological factors. […] Our bodies, Beauvoir argues, are always social."

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[4] Some of the material in this section features in the introduction of our published article, *How do research participants with age-related vision loss talk about their experiences? A secondary discourse analysis of published qualitative extracts* (Enoch et al., 2024) (Appendix 1). The research underpinning this article is discussed in Chapter 3.

With regard to AMD, there is only a limited literature engaging with the more social, cultural and historical factors that shape individuals' experience of the condition. One notable exception is an article by Mogk (2008), which considers the experience of AMD within the "sociocultural imperative to be 'normal'" (Mogk, 2008, p.588) and illustrates how study participants considered AMD and vision loss to be outside the normative experience of ageing. In this context, AMD was experienced as abnormal, and alien to and incongruent with their sense of themselves. At the same time, Mogk suggests that participants in this US-based study tended to see AMD as a marker of being old, rather than a marker of being visually impaired or disabled, demonstrating the kind of complexity and contradictions whereby AMD could simultaneously exist both outside and within imaginaries of "normal" ageing.

A central concern of my PhD is to consider in more depth how these norms and discourses around ageing, disability and vision – discussed in more detail below - may in turn shape subjective experiences of AMD.

1.6.1. Perspectives from critical disability studies

Critical perspectives on visual impairment, disability and later life draw attention to alternatives to common-sense understandings of chronic illness and disability, alert to how the medical model of disability has typically dominated in research on age-related vision loss (McGrath et al., 2017). This model has tended to dominate common-sense societal understandings of disability more generally (Barnes, 2012), locating the "problem" or "personal tragedy" (Oliver, 1986) of disability in the individual's "body-gone-wrong" (Michalko, 2002). In contrast, the social model of disability (SMD) distinguishes between *impairment* – the specific issue affecting a person's body – and *disability*, the losses and restrictions stemming from physical barriers, economic discrimination, prejudicial attitudes or behaviours, and social oppression (Barnes 2012; Oliver 1986). From this SMD perspective, a person with visual impairment from AMD is disabled when confronted with inaccessible features of the environment, such as small print on documents, or obstacles on pavements which hinder mobility and navigation (Bolt, 2005). The SMD is therefore a potentially transformative tool for political action and social change, shifting the focus away from perceived individual-level 'deficits' or 'problems', and towards collective action to confront barriers and discrimination at the social or environmental level (Oliver, 2004). Building on and nuancing the SMD, critical disability theorists have also highlighted the direct, bodily consequences of impairment that can often involve pain, suffering and fatigue (Crow, 1996; Morris, 1992), particularly when disability arises from chronic illness (Wendell, 2001).

There are rich, complex debates within the broad area of critical disability studies, for example regarding the SMD's distinction between impairment (stemming directly from the body) and disability (exclusions or restrictions that are environmentally or socially contingent). These debates have opened up a space for other models or frameworks, which accept many of the fundamental premises of the SMD, but also make more space for subjective, embodied experiences of disability.[5] These include Carol Thomas' social-relational model discussed above which "recognises the *social dimensions of the biological* and the irreducibly *biological dimensions of the social*" (Thomas, 2014, p.14); and the work of Donna Reeve, whose work on psycho-emotional disablism recognises that "the structural and psycho-emotional dimensions of disability can be intertwined and/or mutually reinforcing" (Reeve, 2004, p.97). This social-relational model of disability (Thomas, 2004, 2019) recognises the impact of "impairment effects" (the direct and unavoidable restrictions on embodied functioning attributable to impairment) alongside "disablism" (the avoidable restrictions imposed upon disabled people at interpersonal, institutional and/or societal levels). The social-relational model appears particularly pertinent for considering how the embodied and the social intertwine to shape individuals' AMD experiences. For example, challenges with face recognition experienced by a person with AMD could be considered as a direct "impairment effect" stemming from AMD itself, which would persist even if disablism or disabling barriers in the environment were to be addressed (McGrath et al., 2017). At the same time, there is arguably a form of (dis)ablism in sighted people's assumptions or judgements discussed above – for example in Lane et al. (2019) - that a person with AMD is being rude or standoffish if they cannot recognise other people's faces or expressions. To this extent, it could be argued that the qualitative literature on AMD has tended to focus almost exclusively on "impairment effects", to the relative neglect of "disablism". Therefore, seeking to pay more attention to the latter phenomenon, the kind of

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[5] As Reynolds (2022)Reynolds (2022) points out, it is also important to remember that all models or theories of disability, such as 'the medical model' or 'social model' of disability, are oversimplifications, obscuring the multiple different conceptualisations within these broad models.

"avoidable restrictions" of "disablism" people with AMD experience, is one objective for this PhD. This responds to the call of McGrath, Rudman, Trentham, et al. (2017) for research in age-related vision loss to place a greater focus on how the social, cultural and political environment contributes to the "creation and sustainment of disability" for people with conditions like AMD.

1.6.2. Critical perspectives on age-related vision loss

Although there may be much to be gained from applying a critical disability perspective to research in AMD, it is important to note that many people with acquired visual impairment, after a lifetime of living with sight, may be more likely to align themselves more with the medical than social model of disability (McGrath et al., 2017). Indeed, Leahy (2023) suggests that older adults who gradually develop impairments such as vision loss in later life are likely to eschew identification with a more political identity of disability; even as they navigate around and resist ableist norms, attitudes and behaviours from others in daily life. There is arguably a sociocultural tendency to conflate the ageing process and disability (Aubrecht et al., 2020; Grenier et al., 2016; Oldman, 2002).[v] This means that impairment often becomes regarded as an apparently 'natural' part of ageing, such that "older people with impairments are not seen, and do not see themselves, as 'disabled' in quite the same way as disabled children or younger adults" (Priestley and Rabiee, 2002: 609); aligning with Mogk's (2008, p.585) argument that people with AMD are likely to see themselves as "old, not blind". Also researching age-related vision loss from a more critical, sociocultural perspective, McGrath et al. (2016) explored how positive ageing discourses (associated with terms such as 'active ageing' or 'successful ageing') shape the experience of age-related vision loss. They trace how positive ageing discourses - initially a reaction against society's and the academic gerontological literature's disproportionate focus on the losses and limitations of ageing (Boudiny & Mortelmans, 2011) - can ultimately exclude frail and/or disabled older adults, including those living with visual impairment. Such discourses may risk an excessive emphasis on individual agency and personal responsibility for staying well, overlooking the societal and structural factors that exclude older adults with disabilities and present barriers to their participation in society. In particular, McGrath and colleagues (2016) illustrate how discourses of positive ageing (in combination with biomedical discourses around disability) construct independence as the valorised, idealised goal for older adults living with vision loss. By constructing independence narrowly in physical, functional terms as an achievement of the individual, such discourses in turn risk perpetuating stigma around depending on others (Fuchigami et al., 2022; McGrath et al., 2017). McGrath and colleagues' approach highlights the value of considering how deeply-rooted norms within participants' social and cultural context give rise to ideas and assumptions about ageing with vision loss than in turn can shape the psychological and embodied experience of the condition. This runs counter to the common split that Leahy identifies in psychosocial research on ageing with disability, often between more experiential exploration of the embodied experiences, grounded in psychological and medical sociological literature, versus more structural and/or rights-based analysis of disability, and resulting oppression or exclusion. Instead, it is possible to take a "both/and" approach (Spinelli, 2014, p.14), recognising that "older people experience disability and worsening disablement [both] in their bodies and in their contexts" (Leahy, 2021, p.1).

Alongside consideration around norms and discourses of disability and ageing, and their potential to influence the lived experience of individuals with AMD, it is also important to consider broader sociocultural representations of vision and how these could shape the subjectivity of individuals living with AMD. Across qualitative studies, participants voice fears of becoming "blind", often implicitly framed as the total absence of vision (e.g. Mogk, 2008; Moore & Miller, 2003) (rather than legal definitions of blindness based on specific levels of visual acuity). In *Sight Unseen,* a collection of essays exploring the place of vision and vision loss in Western culture, Georgina Kleege reflects that "the word [blind] connotes a lack of understanding or discernment, a wilful disregard or obliviousness, a thing meant to conceal or deceive" (Kleege, 1999, p.21). David Bolt similarly discusses the many connotations linked to discourses of 'blindness' in English, including imagery of darkness, confusion, ignorance and concealment (Bolt, 2005). Bolt suggests that using the term 'visual impairment' (rather than 'blindness') is more "pertinent to the discourse of the Social Model of Disability" (2005, p.547), and sees the notion of visual impairment as a continuum as a contrast to the "dominant, ableist discourse" (2005, p.550) of "*the sighted* and *the blind*", configured as binaries. Indeed, imaginaries of blindness as "irreversible, unremitting darkness" (Paterson, 2013) and a "complete absence of any visual experience" (Kleege, 1999, p.14) obscure the reality that only a small proportion of those certified as severely sight impaired have total visual impairment (without light perception). Such examples serve to illustrate how the language used around sight and blindness sets up certain assumptions and expectations that individuals may have in mind when diagnosed with AMD.[vi] This ties into a broader interest throughout the PhD, regarding how social norms and discourses – particularly around disability, ageing and vision as discussed above - may relate to the subjective experience of AMD; this relationship between discourse and experience is discussed more centrally in the Methodological Overview in Chapter 2.

1.7. Specifying the focus of the PhD

1.7.1. Evolution of the PhD topic

At the start of my PhD in 2019, the intention was to focus on the ways in which AMD affects social interaction and interpersonal relationships with others, as this seemed to be a relatively unambiguous 'gap' in the literature. I had identified one study (Heine & Browning, 2004), which explored how people with visual impairment experience their communication with others; Heine and Browning found that participants' difficulties picking up on non-verbal conversational cues could lead to embarrassment, fatigue and withdrawal during social interactions. I was keen to explore how these subtle challenges in interpersonal communication might then change how individuals with AMD experienced their relationships with others. As I embarked on the PhD, I realised that I was interested not only in understanding the internal experience of AMD and how individuals make sense of living with the condition, but also in exploring how interpersonal and societal dynamics shape their experience. Thus the focus of the PhD organically broadened out in the initial months, especially as I embarked on the secondary discourse analysis (in Chapter 3) which further bolstered my interest in the ways in which norms and discourses around ageing, disability and vision might influence subjective experiences of AMD. This reorientation of the PhD in the first year entailed a personal struggle around the 'novelty' of the PhD, especially being aware of Burton's work (2013) involving a series of longitudinal interpretative phenomenological analysis studies on individuals' experiences of AMD. Having started the PhD more grounded in what Kidder and Fine (1987) call "small Q" qualitative methodology and working towards becoming a “big Q” qualitative researcher over the course of the PhD,[6] this concern about novelty began to shift. Braun and Clarke (2022) suggest that in more positivist research, there is often an attempt to “establish the gap” in the literature, but writing from a “big Q” perspective, they suggest the notion of the “gap” is problematic for qualitative research where there is no single, unproblematic, objectively-defined truth. Instead, they suggest making an argument and rationale for the research questions that “conceptualise[s] our qualitative analyses as contributing something to a rich tapestry of understanding that we and others are collectively working on, in different places, spaces and times” (Braun & Clarke, 2022, p.120).

1.7.2. Rationale for further research based on critical appraisal of the literature

Having surveyed much of the qualitative literature on AMD in previous sections of this Introduction, this section critically appraises specific studies whose focus is particularly closely aligned to my own proposed research, and thereby help to present the rationale for further research.

Burton’s doctoral work used IPA to explore the lifeworlds of people living with AMD, and is therefore particularly relevant to the interpretative phenomenological elements of my PhD. Burton’s work draws on phenomenological and existentialist thought, and advocates for a “lifeworld-led healthcare” model (Dahlberg et al., 2009), considering how a condition like AMD changes one’s sense of being in the world and recommending that healthcare professionals engage more intentionally with this existential dimension. Burton suggests that lifeworld-led healthcare for people with AMD should also encompass an understanding of the intertwining of body and mind; for example, bringing an awareness that challenges with everyday tasks are inherently bound up with mood and emotional responses (Burton, 2013, p.209). While Burton’s doctoral work has represented an important source of inspiration and practical guidance for my PhD, there are however several key distinctions between the focus

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[6] Kidder and Fine (1987) suggest that “small Q” research is qualitative research that is grounded within the values of quantitative, (post-)positivist research, taking a more top-down, deductive approach. In contrast, “big Q” qualitative research is more open-ended, inductive and exploratory, working from the assumption that researcher and participant subjectivity is inevitable, and a positive resource, rather than a problematic source of bias.

of Burton's thesis and my own. In overarching terms, Burton defines her thesis as a pragmatic, mixed-methods approach, incorporating a quantitative component (see p.7-8), in combination with the longitudinal IPA which represents the bulk of the thesis. These IPA studies explored participants' distinct experiences of early dry AMD, treatable wet AMD and advanced wet AMD. This contrasts with my overarching approach at thesis level (elaborated upon in Chapter 2): exploring how experiences of IPA are rooted in context, by thinking about how both the discursive landscape of AMD, and also the relational and material environment in which the person with AMD is situated, may in turn shape their experience. Furthermore, while Burton considers the participants' context extensively,[7] drawing on the Heideggerian notion of *Dasein* and being-in-the-world, it is important to note that my data collection for the IPA took place in 2020, around a decade later than Burton's research and during the COVID-19 pandemic. The pandemic unexpectedly but inevitably introduced a new dimension to both the experiences in context relayed to me by the participants, and also to the data collection methodology (discussed in Chapters 2 and 8). The timing of my research also allowed for incorporating some of the new developments in IPA methodology into the analysis; this is explained in full in Chapter 4. In brief, Smith et al. – between the 2009 and 2021 editions of their foundational IPA text – moved away from developing "emergent themes" using somewhat more 'clinical', psychologised terminology towards "experiential statements" or "experiential themes", incorporating an explicit emphasis on more vivid, immediate lived experience.[8] Burton's (2013) work was therefore guided by this older terminology, and so the theme titles developed in Burton's IPA such as "making sense of diagnosis" or "getting on with life" provide less of this experiential dimension (even though this experiential dimension comes through in discussion of the themes). In my thesis, I aim to draw on these recent conceptual developments in IPA, to fully and intentionally bring out

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[7] For example, considering how participants experienced AMD alongside other major challenges in their life, such as various illnesses or bereavement. The situated, contextual nature of AMD experiences particularly comes to the fore in Burton's (2015) dyadic study on the experiences of a couple living with AMD, discussed previously (p.8).

[8] An example of an emergent theme from Smith et al. (2009) is "Lost self"; while an example of the updated equivalent from Smith et al. (2021), now conceptualised as an 'experiential statement' rather than 'emergent theme' is "Best friendship is marked by the passage of time and sharing of experience". As explained in Chapter 4, I began the IPA analysis shortly before becoming aware of the new terminology, and so while I used the old IPA terminology of "emergent themes", I made sure to infuse this with the more explicitly experiential character of the new terminology.

the experiential and existential aspects of living with AMD, within the broader relational, social and environmental context.

Broadening out to consider other studies neighbouring my thesis, but somewhat less closely aligned than Burton's work, studies by McGrath et al. (2016) and Mogk (2008) both involved interviews with participants with AMD about how sociocultural dynamics affected their sense-making around vision loss, in Canada and the United States respectively. The study by McGrath et al. (2016) employed ethnographic methods, collecting data using a narrative interview (focusing on their 'life story' with vision loss), participant observation and a final in-depth interview considering how cultural, social and environmental factors influenced their daily activities. McGrath and colleagues analysed the interviews in conjunction with theory from critical gerontology, in order to critically examine the assumptions around ageing and disability that underpinned the participants' conception of a "good old age" with vision loss. Meanwhile, Mogk's (2008) study aimed to consider how participants' perceptions around ageing, blindness, disability and generational norms influenced their response to AMD-related vision loss. In Mogk's study, data were "then reviewed for prominent themes and narrative patterns" (Mogk, 2008, p.583), although there is limited detail beyond this in terms of the data analytic approach. McGrath et al. (2016) provide somewhat more detail on the data analysis process, using open and theoretical coding as a team and then drawing in critical perspectives from gerontology. Both studies provide useful insights on what AMD means to individuals within broader dominant social representations of ageing, blindness and vision loss. For example, both studies reflect on the cultural imperative in their North American settings to be independent, self-reliant agents, to the extent that participants would give up valued activities if they risked requiring help from others and so potentially being positioned as a 'burden'. A particularly novel finding in McGrath et al.'s (2016) study concerned participants' assumptions that they had to remain efficient, even when limited in certain tasks by their vision impairment; and they potentially risked blaming themselves for failure to live up to idealised representations of 'positive agers'. Meanwhile, Mogk's findings notably suggested that participants were less concerned about being subject to negative stereotypes of blindness than they were to being negatively positioned as 'old'. While these are highly novel and important insights, both studies are relatively centrally focussed on the *ageing* dimension of age-related vision loss, and what this means and signifies for participants, rather than a more holistic, open-ended exploration of how AMD is experienced within the person’s lifeworld in context. I found the top-down, theoretical perspectives drawn upon in both studies highly illuminating and helpful, particularly when working on the FDA chapter. Yet arguably, perhaps inevitably, adopting a stance rooted in theory may struggle to hold space for the potentially more complex, mixed or mundane subjective experiences of individuals with AMD that may not naturally lend themselves to an incisive, critical perspective. In this thesis, by adopting a pluralistic approach (explained in Chapter 2), and analysing experiences of AMD against the contextual backdrop of discourses and ideologies around ageing, disability and vision impairment, I aim to bring together more ‘top-down’ theoretical perspectives with a more ‘bottom up’ focus on experience.

1.7.3. Defining the research questions

Taking the discussion of the literature above into account, this PhD thesis aims to understand the psychological experience of AMD not only in its embodied and existential dimensions, but also as a phenomenon inseparable from the person’s context of their home environment, their relationships with others, and the everyday backdrop of norms, discourses and ideologies that subtly shape the meaning we ascribe to experiences. The research question underpinning the PhD as a whole is: **How do people experience AMD within their (unique and shared) relational and social worlds?** As discussed above, there is a relatively extensive qualitative literature exploring the individual subjective experiences of people living with AMD, but only a small number of studies exploring how AMD impacts upon interpersonal interactions and relationships. Essentially, my PhD aims to build on this literature and connect these two fields, considering how social and relational dynamics in the external world – including the person’s close relationships but also the ideologies, discourses and norms that circulate in our society - may in turn shape the inner ‘life world’ of the person with AMD. From a policy and practice perspective, it is hoped that this exploration may help to consider how aspects of the relational, social and environmental context around the person could be potentially modified or remedied to help enhance the wellbeing and belonging of people living with AMD. Indeed, it is hoped that this dual approach, which sees AMD as a phenomenon experienced both in the body and in context, allows for honouring the sense of loss and despair individuals may experience, while also thinking about practical ways to mitigate this distress. An additional interest of the PhD is in individual differences in experience, and considering how far these are contingent on the person's context, or perhaps somewhat more rooted in their specific worldview and particular way of being-in-the-world; thus an additional overarching research question is: **How do individuals experience AMD differently, within their relational, social and environmental context?**

Throughout the thesis, I also aim to examine the challenges and affordances of using multiple research methods (methodological pluralism) to explore the personal, lived experiences of individuals with AMD, embedded within an understanding of how discourse and ideology influence the way individuals make sense of AMD. Therefore, a more methodological research question underpinning the PhD is: **How far does the use of multiple methodologies allow for an integrated exploration of AMD as an experience both rooted in the person and rooted in context?** The full rationale for using these different research methods, with their different epistemological underpinnings, is explored in the next chapter.

Chapter 2: Methodological and epistemological overview

This PhD as a whole uses a pluralistic design, to respond to the research question of how people experience AMD within their relational and social worlds, aiming to explore the embodied, lived experience of AMD within participants' specific contexts amid a shared discursive landscape.[9] Because of this interest in understanding the experience of AMD both at the more micro, granular level of analysis of the individual experience and at a more macro, wide-ranging level of social context, a pluralistic approach organically crystallised as a way to respond to the research question. As noted in Chapter 1 (1.7), the PhD topic evolved in the first year and with this the PhD arguably grew in complexity, moving away from a thesis that had been conceived as purely using an interpretative phenomenological approach.

Figure 1. Summary of overall PhD design and the constituent four studies

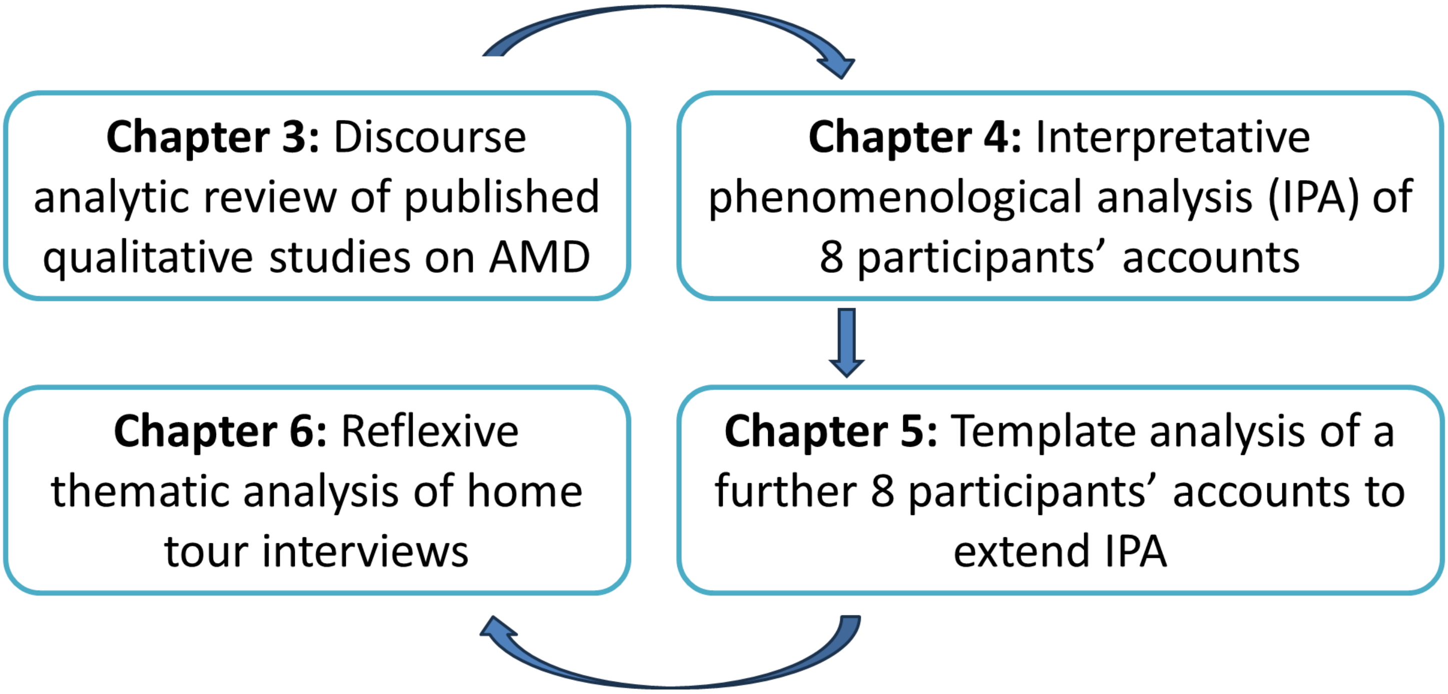

Figure 1 summarises the four studies that make up this PhD, covered in Chapters 3-6 inclusive. Within each of these chapters, more detail is provided about the specific methods

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[9] We can assume that participants share some degree of *access* to a shared discursive landscape, although the precise discursive resources they choose to actually draw on may be very different, and influenced by social and cultural differences between participants.

and decisions taken within the research process. By contrast, the present chapter aims to provide a methodological and epistemological overview, which covers:

- The value of pluralistic approaches in qualitative research, providing a rationale for exploring both discourses and experiences of AMD.
- The theoretical underpinnings of Foucauldian Discourse Analysis (FDA) and Interpretative Phenomenological Analysis (IPA).
- Overarching ontological and epistemological positions underpinning this PhD research.
- My approach to epistemological and personal reflexivity throughout the PhD.

2.1. The rationale for methodological pluralism: bridging discourse and experience

There is an increasing interest in pluralistic qualitative research (PQR), which uses multiple methodologies – sometimes with their own divergent epistemological and ontological underpinnings – to explore a phenomenon of interest from different angles and perspectives. As Frost states,

> “Using qualitative methods pluralistically allows multiple perspectives to be used to understand meanings and how they change, to explore spoken and unspoken meanings, and understand more about how meanings are expressed.” (Frost, 2021, p.14)

Frost (2021, p.11) suggests that PQR in psychology generally shares a commitment to eschewing reductionism, and honouring the diversity and complexity of human experience which is often best understood from many different epistemological perspectives. However, there are different ways in which PQR can be conceptualised, and the undertaking of PQR may take many different forms. One key distinction made in the literature on PQR is between “methodological pluralism” and “analytical pluralism” (e.g. Frost and Bailey-Rodriguez, 2020). Methodological pluralism involves using multiple modes of data collection to explore the different dimensions of an experience, for example combining visual data such as photos, or textual data such as diaries, with more traditional methods of qualitative data collection such as interviews or focus groups (e.g. Day et al., 2024). In contrast, analytical pluralism involves approaching the same dataset using different methods of analysis (Clarke et al., 2015); the rationale being that different analysis methods give rise to diverse forms of knowledge or multiple interpretations, that respond to the complex, multilayered nature of many phenomena of interest in psychology research.

Frost and Bailey-Rodriguez (2020) argue that a distinction can be made in analytical pluralism between within-method and across-method approaches. In within-method pluralistic research, the same method is applied in more than one way.[vii] In contrast, an across-method approach involves using different methods of analysis that may have different philosophical underpinnings. Examples include combining interpretative phenomenological analysis (IPA), with Foucauldian discourse analysis (FDA) that is underpinned by social constructionism (discussed further in section 2.2 below). This may sometimes be termed "dual focus methodology", itself a form of "binocularity" whereby several analytic lenses are used in order to arrive at a richer, more multi-dimensional understanding of a complex phenomenon in social psychology (Willig, 2017a). Dual focus methodology, combining IPA and FDA, can be particularly helpful for exploring how individuals experience and make sense of a phenomenon within a particular social context, where there is an assumption that language goes some way towards constructing – or at least shaping or delimiting the possibilities for – the experience of the phenomenon. As one example, Colahan et al. (2012) used both IPA and FDA to explore both the experienced and socially-constructed nature of 'satisfaction' in long-term heterosexual relationships. Colahan and colleagues relate how IPA and FDA were sometimes used in parallel, and sometimes overlapped, during the research process. They speak of managing tensions between the methodologies by developing a "relaxed awareness" whereby one particular lens (either IPA or FDA) was the deliberate focus of attention, while the other existed more in the background of the researcher's attention in a more "relaxed" way (acknowledging the impossibility of entirely suspending awareness of this 'background' lens). Drawing together findings from the IPA and FDA analyses, Colahan (2014) suggests that the experience of relationship satisfaction is situated within and made meaningful by discursive resources and practices; however at the same time, the IPA analysis also suggested that the experience of relationship satisfaction made itself known to participants in ways that were "'pre-discursive', and therefore difficult to identify or articulate" (Colahan, 2014, p.208). This points to the richness of insight a dual focus approach can provide, and implies the suitability of such a dual methodology for acknowledging the unique texture and quality of individual experiences, while also recognising these experiences are given meaning and communicated through a shared system of language and discourse. In this sense, analytical pluralism can be considered a pragmatic response to exploring the research question in its fullness and multidimensionality, resisting rigid allegiance to specific established methods in what Chamberlain (2000) terms “methodolatry”.

The evolution of the PhD topic discussed in the previous chapter (section 1.7) meant that several distinct methodologies were used to approach the research question pragmatically from different angles. Essentially, I wanted to explore both the contextual backdrop against which experiences of AMD are expressed through language, and then to focus squarely on the experiential, existential and embodied dimensions of living with AMD within this sociocultural context. This meant adopting a pluralistic approach at the level of the thesis; arguably, my approach could be defined more as methodological pluralism rather than analytical pluralism, because each of the four studies discussed in the thesis involved analysis of distinct datasets (see Section 2.4). Analysis of each dataset involved a distinct data analysis method, but in my thesis only one analysis method was used per dataset, in contrast with binocular approaches such as dual focus methodology where two different methodologies (and epistemologies) would be used to approach the same data.

2.2. The theoretical underpinnings of FDA and IPA

In the study presented in Chapter 3, a Foucauldian discourse analytic (FDA) approach was used, underpinned by a social constructionist epistemology. By contrast, the methods used in chapter 4 (IPA), chapter 5 (template analysis using a phenomenological approach) and chapter 6 (reflexive thematic analysis using a phenomenological approach) were all conducted from an interpretative phenomenological stance. The rationale for the choice of these two methodologies,[10] grouped for the purposes of this chapter into FDA and interpretative phenomenology, and the methodologies’ associated theoretical underpinnings, are discussed in turn in this section.

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[10] It is worth being mindful of Silverman's (2001, p.3) distinction between “methodology” as “a general approach to studying research topics”, versus “method” as “a specific research technique”.

2.2.1. Foucauldian discourse analysis and social constructionism

The first substantive chapter of the PhD is a Foucauldian discourse analysis carried out on published extracts from the qualitative literature on AMD, thus representing a form of 'secondary discourse analysis'. This project was conceived in March 2020. There was pragmatic reasoning in the decision to undertake a secondary analysis of already available data. This coincided with the start of the COVID-19 pandemic when there were uncertainties around how far, or for how long, the pandemic and associated social distancing measures would affect my ability to collect my own data. In conjunction, my critical interest in how broader discourses around ageing, illness, vision and disability might influence the way AMD experiences are expressed through language had been growing as I undertook my initial PhD literature review in early 2020. While a number of studies (discussed in Chapter 1) have focused on different - though mostly 'loss-focused' (Tanner et al., 2020) - aspects of AMD experiences, I had not come across any research exploring AMD discourse, the language used to construct meaning around AMD. My aim was to consider the discourses that are mobilised by people with AMD to construct their experiences, within the context of previously-published qualitative research.

This research involved a discourse analysis approach underpinned by social constructionist epistemology. 'Discourse analysis' can be considered a broad family of approaches - rather than distinct methods (Burr, 2015) - which differ depending on the discipline and the underpinning theoretical and epistemological foundations. Burr provides helpful definitions of a discourse, including:

> "A discourse refers to a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events" (Burr, 2015, p.75)
>
> "A discourse can be thought of as a kind of frame of reference, a conceptual backcloth against which our utterances can be interpreted" (Burr, 2015, p.78)

Fundamentally, discourse analysis concerns itself with close attention to language, and, frequently, how "language is organized into discourses which are culturally specific and whose availability depends upon social, historical and cultural contexts" (Willig, 2014). This view of language and discourse makes us question seemingly neutral, taken-for-granted concepts and categories that organise our psychological and social worlds. In psychology and health research, discourse analysis is often situated within a theoretical position of social constructionism. As with discourse analysis, there are differing strands and definitions of social constructionism. In common is a critical approach towards taken-for-granted knowledge (Burr, 2015). A social constructionist view posits that dominant concepts and categories within a society or culture are constructed and reproduced through language, rather than stemming directly from a material reality. As an example in the field of disability studies, Lennard Davis has traced how modern, Western notions of the non-disabled "normal" body came to be constructed in nineteenth-century Europe (Davis, 2013). This construction can be attributed to certain historical processes, such as the developing science of statistics which formalised ideas of the average 'norm' and deviations, and normalising practices of industrialisation, with its emphasis on the efficient, uniform, interchangeable worker as "a mere cog in the machinery" (Davis, 1995).

While not a clear-cut distinction, it is possible to differentiate between a more macro-level and micro-level social constructionism in terms of the theory's application in psychological research (Burr, 2015). The more 'micro' form attends to the micro-level processes of language use in everyday conversations and interactions, and the ways in which speakers use language to construct and account for a particular version of events. There is an interest in the interpersonal and social functions that speakers' talk aims to achieve, or their 'action orientation', in terms of how they construct and negotiate their position and stake in an interaction. From a psychological research perspective, in the field known as discursive psychology, an action-oriented approach to talk and text means that "discourse is studied for how action is done, rather than treated as a medium for access to putative mental objects (intentions, dislikes)" (Potter, 2013, p.107). Here, analysts work with naturalistic data, exploring the detailed features of interaction to understand the patterns, rhetoric and strategies adopted by speakers in different contexts.

In contrast, a more macro-level social constructionism is heavily influenced by post-structuralist thinking, particularly Foucault within psychology, who, for example, drew attention to the social and historical construction of the pathologised, 'mentally ill' individual.[viii] From a Foucauldian point of view,

> "Discourses facilitate and limit, enable and constrain what can be said, by whom, where and when […] Foucauldian discourse analysts focus on the availability of discursive resources within a culture – something like a discursive economy – and the implications of this for those who live within it." (Willig, 2013, p.133)

Therefore, Foucauldian discourse analysis (FDA) is interested in the available discourses in a particular culture, society and historical moment, and how these shape (and circumscribe) possibilities for individuals' subjective experience. Some discourses may be more dominant than others, and FDA considers how power structures and ideologies may amplify, co-opt or repress certain discourses. A 'dominant discourse' can be seen to reflect the prevailing ideology of a particular status quo (Hare Mustin, 1994), thus becoming more readily "available and accepted" (Becker et al., 1995, p.145) than alternative, more marginal discourses. While dominant discourses can become neutralised – taken for granted as the seemingly non-ideological 'common sense' position on an issue (Fairclough, 1985)– they may also be resisted through alternative discourses which can gain traction as social practices evolve (Burr, 2015). Indeed, discourses offer certain kinds of 'subject position' for individuals that can be taken up or resisted with implications for lived experience. Harré and Van Langenhove suggest that by drawing on a discourse, a speaker aligns themselves with certain "'moral' and personal attributes" within the "referential grid" of the social world (Harré & Van Langenhove, 1991). Positioning occurs in relation to others, and it "constitutes the Self and the others in certain ways" (Harré & Van Langenhove, 1991, p.398). As an example, the 'age-related' label in AMD constructs the condition as one strongly associated with biological ageing, and positions the subject with AMD (and others with AMD) as being 'aged' or 'an older adult', an identity which may or may not resonate with people with the condition.

Thus, FDA underpinned by social constructionism can draw attention to dominant, 'common sense' discourses and positions in circulation, which provide legitimacy for specific practices (ways of behaving) and influence our subjectivity (ways of being). By a similar token, FDA allows us to consider alternative discourses (or counter-discourses) that may have been marginalised due to prevailing social and cultural norms. From a social constructionist viewpoint where language precedes and thus constructs our experiences, Burr notes that discourses can be considered "structures that impose a certain kind of subjectivity" (Burr, 2015, p.188). Indeed, in tracing the discursive positions and constructions of research participants, I aimed to be mindful of "the myriad ways in which discourses are lived in the life of a person" (Eatough & Smith, 2017, p.27), and the role of language in constructing subjective experience.

The aim of this first study of the PhD was therefore to provide a kind of 'map' of the discursive terrain yielded by published qualitative research into the experience of AMD to date, as the kind of contextual, discursive 'ground' which provides potentialities for subjective experience for the 'figure' of the person living with AMD. However, while FDA can consider speculatively how the discursive resources we have to talk about AMD may shape how the condition is subjectively experienced, it cannot make claims as to how AMD is experienced as an embodied, existential reality. To explore this experiential dimension, an approach drawing on interpretative phenomenology was required.

2.2.2. Interpretative phenomenology

Although FDA and social constructionism was discussed first, as the approach underpinning the first substantive chapter of the PhD (Chapter 3), interpretative phenomenology can be considered to be the 'primary' approach more squarely at the core of this thesis. At the outset of my PhD, I had in fact intended my thesis to be fully located within an interpretative phenomenological epistemology, focusing on the embodied, existential dimensions of AMD experiences. It was only when thinking about and then embarking upon the secondary discourse analysis that I began to appreciate that FDA and a social constructionist lens can bring to light the discursive constraints to which individuals with AMD may be subject when seeking to express their experiences through language.

While interpretative phenomenology arguably complements FDA well in several ways (see p.40), the roots of interpretative phenomenology are underpinned by a very distinct epistemology. Edmund Husserl spoke of phenomenology as going "'back to the things themselves'" (Smith, 2021, p.1), aiming to distil the essential quality of human experiences, the "invariant properties" underpinning the subjective perception and experience of specific phenomena of interest. A key element of Husserl's phenomenological method was the notion of "bracketing", suspending (or 'transcending') our taken-for-granted, familiar ideas about the world. This allows for intentionally engaging with the phenomenon with a fresh, pre-reflective perception. Subsequent philosophers in phenomenology, such as Heidegger and Merleau-Ponty, built on Husserl's work while incorporating hermeneutic and existential dimensions. As discussed in Chapter 1, Heidegger's (1927/1962) notion of *Dasein* suggests that being-in-the-world is situated within and bound up with context, or as Smith et al. (2021, p.12) state, "with the lived world – the world of things, people, relationships and language". Heidegger's notion of *Mitsein* (being-with) posits that our understanding of experiences is intersubjective, gleaned in concert with and in relation to others; each person "exists in a world saturated with others, linked through shared social practices" (Moran, 2021).[ix] Equally, Merleau-Ponty (1962) emphasised how human experience is fundamentally embodied, and that as "body subjects", we exist in an embodied relationship with the world, actively communicating with, and developing understanding about, the world through our bodies. We can never directly access another individual's embodied, emotional, perceptual and/or sensory experiences; therefore, "the lived experience of being a body-in-the-world can never be entirely captured or absorbed, but equally, must not be ignored or overlooked" (Smith et al., 2009, p.19).

Drawing on hermeneutics, the theory of interpretation, interpretative phenomenology begins from the assumption that describing an experience involves a process of interpretation and sense-making (Smith et al., 2009). For Heidegger, our being-in-the-world is rooted in our context, and so we can only gain further knowledge in light of our current understandings. Interpretation thus relies on a "fore-structure", replete with preliminary "fore-conceptions", the contextual horizons within which we approach enquiry into a phenomenon of interest (Truwant, 2022). The act of interpretation that follows may then confirm, deepen, or lead us to modify these previous horizons of understanding. This idea feeds into the notion of the "hermeneutic circle" which is important in interpretative phenomenology, recognising how our understanding of the 'part' depends on understanding the 'whole', and vice versa.[11] In the same way, in hermeneutic phenomenology, we can only interpret an experience of interest in light of our prior fore-structure of preconceptions, but this whole fore-structure may then come to be fundamentally changed by our interpretative encounter with the new experience.[x] This hermeneutic perspective suggests that Husserl's

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[11] As an example of the hermeneutic circle, we often only understand the meaning of a word based on the overall context of a sentence; however, we only come to understand the meaning of a sentence by bringing together the different meanings of the component words.

notion of bracketing can only be taken so far, because importing presuppositions based on prior assumptions and preconceptions to the act of interpretation is inevitable, and indeed a necessary prerequisite to making meaning. However, we can still aim to be aware of the form our "fore-structure" and associated presuppositions take, a process that is supported by the practice of reflexivity fundamental to qualitative research (see Section 2.5).

Alongside phenomenology and hermeneutics, a third major underpinning tenet of interpretative phenomenology is idiography, a concern with the particular, as opposed to 'nomothetic' approaches in psychology which aim to make general claims about behaviour or experience at a group level. An idiographic stance in interpretative phenomenology recognises the importance of treating the individual's unique experience as the unit of analysis, with each individual bringing their own particular meaning-making perspective to bear on interpretation of their experiences (Eatough & Smith, 2006). At the same time, bearing in mind the Heideggerian perspective outlined above regarding *Dasein,* being-in-the-world, and *Mitsein,* being-with, there is an understanding that individuals are enmeshed in a world of relationships with others and shared social practices and ideas. Thus understanding unique, individual-level experiences of a phenomenon such as AMD can provisionally begin to shed light on a higher-level, more generalised understanding of the experience, among individuals situated within a similar socio-cultural context (Demuth, 2018).[12] Interpretative phenomenology therefore aims to understand a person's particular experience, but also posits that this individual can provide insight into certain shared characteristics of such experiences. Smith et al. (2021, p.32) draw on Schleiermacher, who stated that "everyone carries a minimum of everyone else within themself" (Schleiermacher, 1998, p.93), implying the possibility of intersubjectivity and shared meaning-making between individuals.

In light of Heideggerian *Mitsein* and the possibility of intersubjectively understanding and relating to each other, interpretative phenomenology invites the researcher to step into the participant's shoes in order to make sense of their personal world (Pietkiewicz & Smith, 2012), and their experiences, beliefs and concerns (Larkin & Thompson, 2012). Crucially, in

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[12] Generalisation in qualitative research can be a challenging issue. Qualitative research does not aim to make statistical generalisations, and claim that the experiences documented among the sample would apply universally. The kind of generalisability invoked here, and to which I subscribe, has been termed "theoretical (analytical) generalisability", which suggests that a rich, detailed analysis of a person's experiences – grounded and situated within their precise context - can provide more generalised understanding of such experiences within comparable contexts.

interpretative phenomenological analysis, the emphasis on hermeneutics extends to both the researcher and participant. The participant is considered to be interpreting and making sense of their own world in the account of their experiences conveyed to the researcher, who then interprets the participant's interpretation. This dual process of both the participant and researcher engaged in interpretative activity is known as the double hermeneutic (e.g. Smith, 2019). An interpretative phenomenological mode of inquiry requires close attention to the idiographic nuances, complexities and intricacies of an individual's account and interpretation of their experience. However, in light of the thesis' interest in the individual within their relevant social contexts, the phenomenological approach is flexible enough to allow the researcher to also recognise the influence of social, cultural and political "local worlds" (Todorova, 2011) on both the participant's experience and the researcher's interpretation. This aligns with Heidegger's emphasis on the person-in-context in a world of shared social practices, and where interpretation of experience is always shaped, limited and/or enabled by language (Smith et al., 2021, p.140).

Consequently, there is the potential for IPA and FDA to be highly complementary, since IPA is interested in the person's experience in their context, while FDA can analyse the structure of this context, the discursive resources available for individuals seeking to make construct their experiences through language. The view of language in IPA and FDA is fundamentally distinct. While IPA acknowledges that meaning-making takes place within the constraints and confines of language, it views individuals as "existential world disclosers in a world of situated concernful involvement" (Eatough & Smith, 2017, p.21). In contrast, FDA - underpinned by social constructionism – would consider this "existential world" (that is *disclosed* in IPA) as fundamentally *constructed* and constituted by means of language. The next section will consider my ontological and epistemological position underpinning the research as a whole, and finding cohesion between the differing theoretical underpinnings of FDA and IPA.[13]

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[13] While I have discussed IPA in detail here, the overarching interpretative phenomenological approach also applies to the template analysis (Chapter 5) and reflexive thematic analysis (Chapter 6) studies.

2.3. Ontological and epistemological positions underpinning the research

As noted in the preceding paragraph, there is an increasing appreciation for the ways in which pluralistic qualitative research can bring together the distinct but potentially complementary approaches of FDA and IPA. For example, Eatough and Smith (2017, p.27) suggest that IPA is compatible with a "pluralist sensibility" and can sit alongside discourse analytic approaches, because IPA can "attend to the myriad ways in which discourses are lived in the life of a person". On the 'other side', in social constructionism, theorists and researchers have problematised how discourse analysis conceptualises the role of bodily experience, subjectivity and agency. Radley (1995) for example wrote of the "elusory body" in social constructionism, suggesting that the body eludes discourse "not because of its physicality per se, but because it signifies in ways that discourse cannot adequately embrace" (Radley, 1995, p.12). Arguably, this aligns with the view of the body in existential phenomenology, where – as Cooper (2003, p.21) states – "from an existential perspective, our bodily-felt experiences are an immediate, direct and intuitive apprehension of our world that may precede our intellectual grasp". Burr (2015) draws on Radley's (1995) analysis, discussing the ways in which the body can directly express meanings and know the world in ways that are "extra-discursive".[14] Burr in fact suggests that phenomenology can be a helpful resource to tap into the meanings expressed by the body, given phenomenology's concern with embodiment and – in common with social constructionism – its rejection of essentialism. These perspectives from scholars working with IPA such as Eatough and Smith, and with social constructionism such as Burr, illustrate that within both epistemological stances there is a similar appreciation for the possible complementarity of the two approaches.[xi]

Willig (2017a) suggests the discourse/experience relationship may be typified as either: language-dominant (whereby discourse *constructs* experience); phenomenological (where experience precedes discourse, but discourse constrains how experiences can be talked about); or 'in-between', whereby discourse shapes experience by providing a context for it, which arguably corresponds to a critical realist perspective (Ledingham, 2018). At the

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[14] At the same time, Burr (2015) also suggests that this acknowledgement of an extra-discursive domain can sit alongside an awareness that discourses also shape and constrain certain possibilities for bodily experience.

level of the thesis overall, I ascribe to the latter, critical realist position,[15] in common with other researchers using IPA and FDA in tandem (e.g. Baboulene & Willig, 2023; Colahan et al., 2012). Such researchers have acknowledged the “contrasting epistemological commitments” (Colahan et al., 2012, p.4) or “epistemological conflicts” (Baboulene & Willig, 2023, p.3) presented by combining IPA with FDA with their different underpinning epistemological commitments. However, they suggest that adopting a critical realist position allows the researcher to subscribe to the epistemologies of both IPA and FDA; especially when the aim is not necessarily to try and integrate potentially incommensurate findings, but instead to adopt a dual perspective and allow the findings to sit side-by-side (Black & Riley, 2018; Willig, 2021). In my research, critical realism can be seen as an overarching position which helps me to clarify that my interest is above all in the subjective experience of the embodied realities of individuals with AMD, but also encompasses consideration of the discursive context that makes communication of this experience possible. Critical realism is grounded in the work of Roy Bhaskar (e.g. 1975), who critiqued the collapsing of distinctions between epistemology and ontology in what he termed the “epistemic fallacy”. Instead, critical realism allows for the possibility of subscribing to an ontological realism and an epistemological relativism, implying that I as a researcher can have different theoretical understandings of *what* I know (ontology) and *how* I come to know (epistemology).

Ontological realism means I am making the assumption that there is a material reality to the physiological processes underpinning what has become known and defined as “AMD”. This assumption aligns with the view of Willig (2016) that the majority of qualitative research assumes a realist ontology, because research questions are inherently grounded in assumptions that claims can be made about the ‘real world’, a world of phenomena that exist independently of the researcher’s engagement with them. Such phenomena arguably include not only the experience of AMD as a material physiological process,[16] but also the

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[15] As noted above, IPA is the methodology where I feel at home and aligns with my preferred approach to knowledge. Thus even if I am taking an ‘in-between’ critical realist position across the thesis, I generally remain more oriented towards the phenomenological than the language-dominant (constructionist) position.

[16] Baboulene and Willig (2023) note the realist ontology implicit in IPA, as “individuals give accounts of experience that have observable effects and are relatable to embodied experiences, that is to say, individuals are speaking about the experience of something, [...] the experientially real” (Baboulene & Willig, 2023, p.4).

discourses around ageing, disability and illness that are fluid and shifting but nonetheless remain ‘out there’, in the world outside the researcher, as broader social currents.

At the same time, I consider myself to be subscribing to epistemological relativism in both the FDA and interpretative phenomenological work in this thesis.[xii] When conducting the FDA, I saw my position as epistemologically relativist, with a constant, implicit awareness that my analysis of the discursive constructions of AMD was subject to my own interpretations, shaped by my (inevitably partial) knowledge of underpinning theory. This aligns with Willig’s (2016, p.2-3) view that “epistemological relativism constitutes a form of intellectual self-awareness and concomitant humility, and ought to characterise all research endeavours”. IPA also aligns with epistemological relativism given the methodology’s emphasis on the unique, subjective nature of experience, underpinned by phenomenology and hermeneutics. Indeed, the notion of the ‘double hermeneutic’ illustrates the highly provisional, situated, partial (and thus relative) nature of the knowledge that can be gleaned from IPA, when considering that both the participant and I as the researcher are engaged in interpretative activity.

While critical realism thus affords a position of epistemological relativism and ontological realism that can be seen to unite IPA and FDA, it is also worth noting as a ‘post-script’ that realism and relativism cannot always be conceptualised as binary, polarised positions. For example, Burr (2015, p.119) offers a critique of this tendency to dichotomise realism and relativism in social constructionism, as yet another dualism (like the mind/body, or individual/society) that unhelpfully invites us to privilege one domain over the other. Meanwhile, Willig (2016) notes the intertwining of realism and relativism in the context of research, if we conceive of research as a dialogue between the (relative) interpretative, meaning-making activity of research and the (real) social and material context in which research is always situated.

Additionally, there are also debates about how far IPA itself specifies an epistemological stance distinct from ‘interpretative phenomenology’, which arguably renders discussion of relativism or realism moot in IPA. For instance, Larkin (2022b) suggests that IPA’s epistemological focus is best explained as phenomenological and hermeneutic, rather than importing designations such as ‘critical realist’, ‘contextualist’ or ‘constructionist’, and states: “It would have been really helpful if we'd all just written that IPA's epistemological position is 'what it says on the tin': interpretative phenomenology." Larkin's comment here demonstrates the 'slipperiness' of terms and positions in epistemology and ontology, in contrast to how I perceived there to be distinct, rigid positions when I began the PhD. Arguably, conceptualising epistemological positions as more fluid and subjective itself supports a pluralist sensibility to research, moving away from the imaginary of universally-agreed, neatly demarcated 'camps' (such as realism and relativism) that overlooks the divergence of perspectives within each. Instead, if we move towards seeing the epistemological positions of different methodologies as overlapping circles as in a Venn diagram, then this also moves us away from a position where research findings from different methodologies are seen as 'incoherent' or 'incommensurate', and towards seeing these as different (but compatible) layers of understanding of the phenomenon. Indeed, this would align with Frost's (2021, p.141) perspective that the tensions arising in pluralistic research can be inherently valuable, contributing to a more holistic, multi-perspectival understanding of complex phenomena.

2.4. Structure and coherence of the substantive thesis chapters

In light of the discussion of the pluralistic theoretical, epistemological and ontological commitments discussed above, Table 1 below summarises the methodological and epistemological characteristics of the four substantive studies. Overall, this series of studies aims to explore experiences of AMD at different levels of the relational, social and material environment: exploring the individual's sense-making of their embodied experience (Chapters 4 and 5) within the context of macro-level socially contingent discourses (Chapter 3) and the material environment of home (Chapter 6). Seeing these research activities as exploring different layers of the AMD experience means that, rather than seeking to fully integrate disparate findings, these layers can sit side-by-side, accommodated within an overarching critical realist position.

Table 1. Methodological and epistemological characteristics of the four substantive PhD studies

Chapter number	Study title	Method	Primary focus on discourse or experience?	Epistemological stance
Chapter 3	How do research participants with age-related vision loss talk about their experiences? A secondary discourse analysis of published qualitative extracts	Foucauldian Discourse Analysis (FDA) [alongside some identification of interpretative repertoires]	Discourse	Social constructionism
Chapter 4	How do people experience AMD within their personal, social and relational contexts? An interpretative phenomenological analysis	Interpretative phenomenological analysis (IPA)	Experience	Interpretative phenomenology
Chapter 5	Extending the experiential findings of IPA using template analysis	Template Analysis	Experience	Interpretative phenomenology
Chapter 6	How do people with AMD experience the condition within the specific relational, social and environmental context of 'home'?	Reflexive Thematic Analysis	Experience	Interpretative phenomenology

Overall critical realist position across studies, with a relativist epistemology and realist ontology

2.5. My approach to epistemological and personal reflexivity

In writing this chapter, I have aimed to outline the underpinnings of the PhD from the perspective of what Braun and Clarke (2023, p.1) describe as "a *knowing* researcher", one who “strives to “own” their perspectives” and “is deliberative in their decision-making”. Throughout the PhD as a whole, and throughout the processes of research design, data collection and analysis, and writing, I have aimed to cultivate a reflexive approach in order “to make visible complexities that shape doing research” (Lazard & McAvoy, 2020, p.168). In this section, I will discuss in turn my approach to two different (yet intertwined) types of reflexivity, epistemological reflexivity and personal reflexivity (Willig, 2021). Epistemological reflexivity links to much of the discussion in previous sections, considering how the assumptions inherent within my chosen methodologies and the underpinning theoretical frameworks unavoidably shape the nature of knowledge produced through research. In contrast, personal reflexivity involves reflection on the ways in which my personal values, beliefs and identity shape the research. The discussion below is intended as a holistic, macro-level overview of intended reflexive practice at thesis level. Within each substantive chapter, I provide more granular reflections on the data collection and analysis procedures, and also discuss reflexivity, more retrospectively looking back across the thesis, in the methodological reflections chapter (Chapter 8).

Within discourse analysis (such as the FDA of Chapter 3), it has been argued that reflexivity has a crucial role to play in analyses of subjectivity and power, but is not always made explicit in the reporting of the findings (Zienkowski, 2017). Indeed, just like the texts that are the focus of analysis, FDA would recognise that the analysis itself is constructed through particular available discursive resources and practices (Willig, 2021, p.143). Thus it becomes particularly important for the researcher to own their role as the partial, subjective constructor of knowledge claims, whose personal and political values inform the interpretative processes that take place during analysis (Burr, 2015, p.177). In this case, I would argue that the epistemological reflexivity closely links to personal reflexivity, because my hope that research can be emancipatory, and help to change oppressive, exclusionary systems, stems from my personal perspective and political views. These views in turn shaped the choice of theory (for instance, from critical gerontology and critical disability studies) that resonated with me when conducting the FDA. Illustrating how dominant discourses, or “regimes of truth” (Foucault et al., 1982) that are often taken-for-granted as the natural order of things, are in fact social and historical constructions, can have an emancipatory potential (McCabe & Holmes, 2009). Yet as noted by Challenor et al. (2021, p.130), there is the challenge in discourse analysis that “participants themselves may not recognise the claims that are being made on their behalf", and this can be a fundamental tension for a methodology that seeks to illuminate, and arguably redress, power imbalances. I discuss this issue further in Chapter 3 (Section 3.4.1).

Moving to IPA, reflexivity is a vital element of interpretative phenomenological approaches, and is very much 'baked-in' to the process. The process of interpreting involves – even if not *bracketing* preconceptions as in Husserl's descriptive phenomenology – at least engaging with these preconceptions and understanding how they may influence the interpretative work. Indeed, Finlay (2003) discusses how Heidegger and Gadamer's theories of hermeneutics inherently involve a reflexive process of self-critique and revision of pre-conceptions, conceptualised as "fore-conceptions" (Heidegger, 1927/1962) or "horizons of understanding" (Gadamer, 1960/1990). During interpretation, the previous understandings and conceptions become modified through the encounter with and gleaning of new understandings, a cycle that proceeds spirally as per the hermeneutic circle. Similarly, in reflexive thematic analysis, the reflexivity element has been explicitly added to the name of the method in recent years, in order to foreground the importance of reflection by the researcher on their philosophical, theoretical and epistemological assumptions, as well as their personal positionality (Braun and Clarke, 2022, p.14). Embedded into Braun and Clarke's perspective on reflexivity is an understanding that insight into our assumptions and preconceptions is partial, and that these can shift over the course of the research.

In terms of my own epistemological reflexivity, I would argue, as discussed earlier in the chapter, that I always felt more "at home" within the interpretative phenomenological stance. In large part, this related to the "hermeneutics of empathy" encouraged within IPA, to draw on Ricoeur (1970, as cited in Eatough & Smith, 2017), while I saw the interpretation process within FDA as more rooted in "hermeneutics of suspicion". A hermeneutic of empathy (alternatively rendered as "faith" by certain scholars) may be considered more 'bottom-up' (Willig, 2017a), aiming to enter the participant's world and come as close as possible to the meaning they intended; while a hermeneutic of suspicion is more top-down, taking a more critical, questioning/'suspicious' approach which aims to reveal more latent meanings. As Tomkins and Eatough (2018, p.20) state, "Faith assumes the possibility of bringing meaning into the realm of conscious reflection, whereas suspicion aims to expose and reduce the lies and illusions of consciousness." Tomkins and Eatough see the hermeneutics of faith as closely allied to IPA, with its emphasis on empathy and attunement with the participant’s lifeworld, and suspicion as allied to more critical approaches that might include FDA. Crucially, both hermeneutics have a role to play, in contributing to understanding (through hermeneutics of faith) and explanation (through hermeneutics of suspicion) (Willig, 2017a). However, because of my personal connection to the topic of AMD discussed in Chapter 1, and a desire to be ‘on the side’ of research participants with AMD, I often considered a hermeneutics of faith as my default position. In Chapter 3, I discuss what felt like a move into a hermeneutics of suspicion, although still underpinned by a broader, more overarching hermeneutics of faith, in the hope that critical analysis of the discursive construction of AMD could ultimately be emancipating, as argued by Tomkins and Eatough (2018).

Lazard and McAvoy (2020, p.171) suggest that disclosure of personal positions and perspectives by the researcher should be guided by keeping the epistemological focus centre-stage, focussing on cultivating a reflexive stance towards the “processes of research” rather than treating reflexivity as a “confessional exercise”. When personal reflexivity is invoked, they suggest not solely listing personal characteristics and investment in the research, but thinking about how these impact upon “the process of *doing* a specific research project” (Lazard & McAvoy, 2020, p.167). In terms of the “doing” of reflexivity, I kept a reflexive journal, my PhD diary, throughout the five years of the research, including reflections on readings, the methodological processes, and the data analysis. (I draw upon and analyse some of these reflections throughout the thesis.) Much of my reflexive understanding also grew out of discussion with my PhD supervisors. While my commitment to epistemological relativism precluded full “bracketing” of preconceptions as a realisable (or desirable) aim, it was important to remain self-aware and mindful of my evolving positionality towards the research. For example, as outlined in Chapter 1, it was important to remain aware throughout the research process that I had a kind of ‘vested interest’ in trying to broaden the narrative away from the overwhelming “loss focus” in AMD research (Tanner et al., 2020).[xiii] Furthermore, exploring the discursive construction of AMD, and how the condition is bound up with sociocultural norms around ageing and disability, cemented my interest in the Social Model of Disability, which implies its own political commitments. The challenge was therefore to cultivate self-awareness when I moved from the FDA study to the IPA interviews (as I was conducting these concurrently in 2020), in order to conduct the interviews from an open-minded, phenomenological point-of-view; and trying hard to ensure I avoided ‘nudging’ any participants into articulating experiences that might provide a novel, refreshing counterpoint to the dominant constructions I was identifying. At the same time, my hope was that bringing together an understanding of the discursive construction of AMD and how it is subjectively experienced could challenge some of the taken-for-granted stories about living with this condition, that in turn could reveal new avenues for enhancing the wellbeing of people with AMD.

Chapter 3: How do research participants with age-related vision loss talk about their experiences? A secondary discourse analysis of published qualitative extracts

The study presented in this chapter, as well as relevant sections of Chapter 1 and 2, was previously published in the journal *Ageing and Society* (Enoch et al., 2024), with the article text included in Appendix 1.

3.1. Introduction

While there is now a substantial qualitative literature on the lived experience of AMD (i.e. what it is like to live with AMD, for example as synthesised by Thier and Holmberg (2020)), to my knowledge no studies have set out to explore AMD *discourse* (i.e. the language used to construct meaning around AMD). Therefore, the research presented in this chapter aimed to identify the discourses that are mobilised by people with AMD to construct their experiences, within the context of research interviews or focus groups in previously published studies. This secondary analysis of participant quotations in published qualitative studies on AMD aimed to focus on how people talk about their AMD experiences, in light of broader, dominant discourses about ageing, illness and visual impairment. This research involved discourse analysis underpinned by social constructionist epistemology, entailing a critical approach towards taken-for-granted knowledge (Burr, 2015), as detailed in Chapter 2 (Section 2.2.1, pages 34-37). Discourse analysis involves a ‘top-down’ approach to interpretation, whereby discourse analysts “come to their data with a set of conceptual tools derived from theory” (Willig, 2017a, p.279). In this study, the analysis was informed conceptually by critical perspectives on visual impairment, disability and later life, which were introduced in Chapter 1 (Section 1.6, pages 19-24). Having already provided detail regarding these theoretical concepts in Chapter 1, and presenting the epistemological stance in Chapter 2, in this chapter I present the more procedural steps of the methods, followed by the findings and a reflective discussion.

3.1.1. Research objectives

In Chapter 1 (Section 1.6), I aimed to illustrate that talk about age-related vision loss is informed by broader discourses around ageing, disability and sight/vision, deeply rooted in specific social and cultural contexts. As discussed in Chapter 2, such discourses may circumscribe or shape possibilities for individuals' practice and subjective experiences, by opening up and legitimising certain ways of talking about a phenomenon and closing down others. The present analysis therefore aims to explore whether and how these broader discourses are drawn upon in previous qualitative literature to construct the phenomenon of life with AMD. Foucauldian Discourse Analysis (FDA) is a particularly apt methodology for the purpose of exploring how AMD is socially constructed in discourse. FDA allows us not only to map the discourses circulating within qualitative research on AMD, but also to consider speculatively how these discursive resources may have implications for how the condition is subjectively experienced. This contrasts with other critical psychology methodologies rooted in social constructionist epistemology, such as discursive psychology, which is more fundamentally concerned with the micro-level features of language within social interaction, and largely focuses on naturally occurring talk or text (rather than interview-based data, especially as decontextualised in the present analysis). FDA by contrast allows for tentative consideration of how dominant discursive constructions of AMD within existing qualitative research may enable or limit possibilities for subjectivity and practice (Seymour-Smith, 2015). In this analysis, I therefore aim to identify discourses used to talk about AMD (with reference to social scientific scholarship on disability and ageing), and the implications of these discourses and repertoires for subjective 'ways-of-being' with AMD. The overall, broad research question is: How do research participants with age-related vision loss talk about their experiences? In particular, I aim to consider the dominant, 'common sense' discourses and positions represented in the qualitative research on AMD experiences – as well as those that are relegated to the margins – and consider how these discourses may in turn shape the practices and subjectivities of people with AMD.

3.2. Method

3.2.1 Secondary analysis of published qualitative data

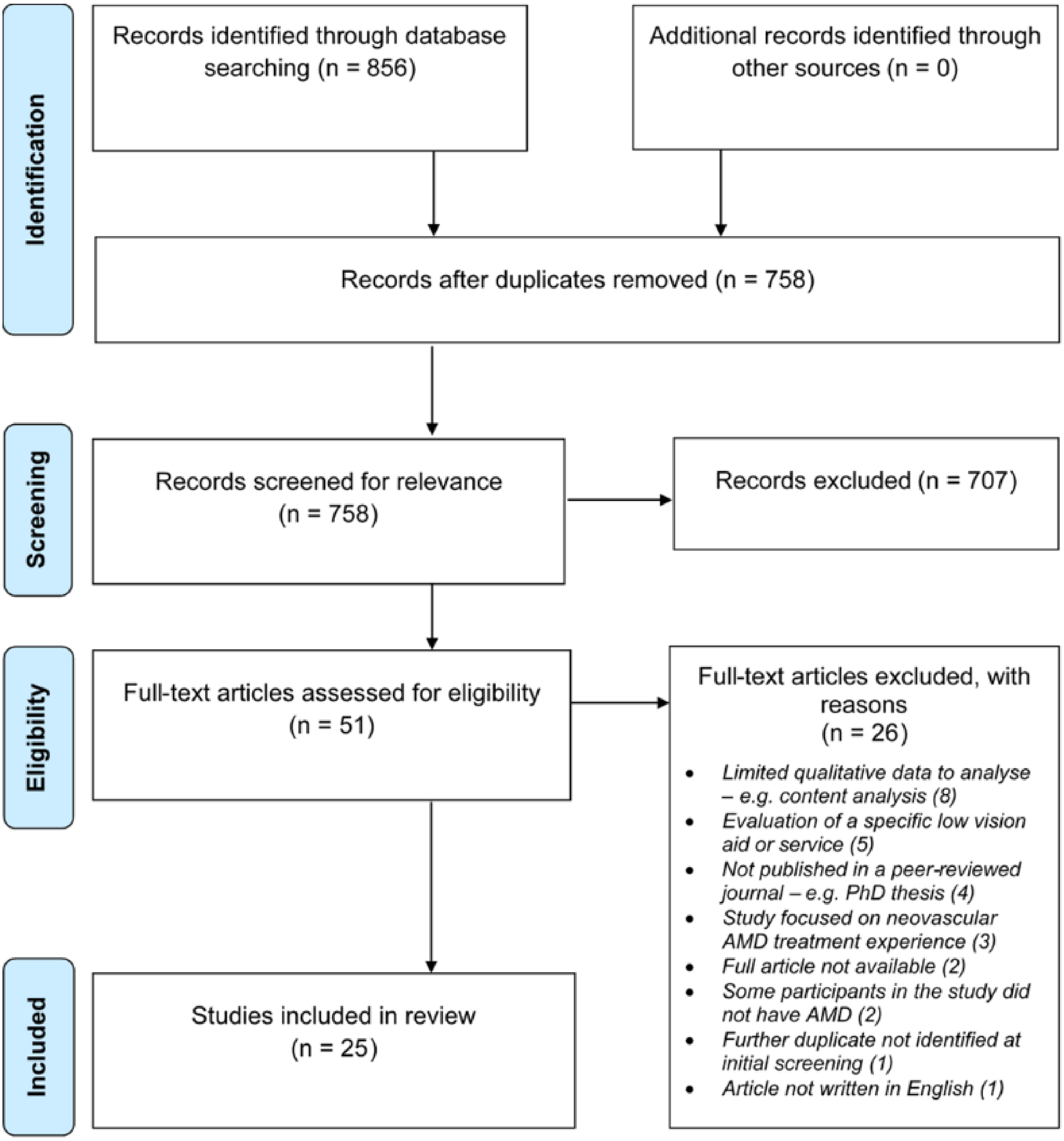
The present study employs a form of qualitative data re-analysis, availing of the option to draw on “other researchers’ data in the form of published excerpts” (Wästerfors et al., 2014, p.468) as the source data. Wästerfors and colleagues highlight the decontextualised nature of such data and the secondary analyst’s lack of knowledge of the original circumstances of data collection as potential issues in this kind of (re-)analytic exercise. Consequently, they recommend “cultivating a cautious and reflexive attitude” (Wästerfors et al., 2014, p.475), as in any qualitative analysis. However, they also note that drawing on decontextualised data can “motivate a fresh perspective in relation to contexts previously taken for granted” (Wästerfors et al., 2014, p.475). This perspective arguably lends itself particularly well to some of the underpinning tenets of discourse analysis, which involves interrogating and deconstructing taken-for-granted knowledge (Burr, 2015).

3.2.2. Compiling the dataset, using initial steps of qualitative meta-synthesis

To compile the dataset, this study drew on some of the procedural techniques used in qualitative meta-synthesis. Over the last decade, several meta-syntheses on AMD experiences have been conducted (Bennion et al., 2012; McGrath & Corrado, 2019; Thier & Holmberg, 2020). Qualitative meta-synthesis is an area of increasing methodological interest, as a method of integrating findings from an ever-growing number and range of qualitative studies (Beck, 2019; Finfgeld-Connett, 2018). A vital objective of meta-synthesis is to go beyond organising and collating existing findings, and to take a critical, reflexive approach which is “interpretive, rather than merely aggregative” (Thorne, 2015, p.1348). In the present study, I was focused less on integrating thematic findings, and more on using previously published studies as data sources, from which I could assemble a comprehensive corpus of qualitative extracts about living with AMD. In the early stages of the study, I therefore followed stages similar to those undertaken in other qualitative meta-syntheses. However, I ultimately conducted a form of secondary analysis, using existing data (in the form of published qualitative data extracts) to answer a new research question that differed from the research questions posed in the source research articles (Hinds et al., 1997). To assemble the corpus of extracts, structured searches were carried out using the databases

Academic Search Complete, CINAHL, MEDLINE, PsycINFO and PsycARTICLES, and citation tracking for further articles was conducted using Google Scholar. I combined two families of search terms: firstly, terms relating to qualitative research (qualitative OR interview OR ‘focus group’ OR ‘qualitative survey’ OR phenomenol* OR ‘thematic analysis’ OR ‘grounded theory’ OR ‘lived experience’) and, secondly, terms relating to AMD (AMD OR ARMD OR nAMD OR ‘age-related macular degeneration’ OR ‘macular degeneration’). Inclusion criteria were studies published in any year, that were: reported in English; where sufficient data extracts, with full sentences, were available for secondary analysis; and where all participants had a diagnosis of AMD. Studies specifically about experiences of people with neovascular (‘wet’) AMD undergoing treatment were excluded, as these often explore highly specific aspects of the treatment procedure or service delivery, in contrast to my interest in more everyday talk about AMD. The electronic database search – run on 9 December 2020 – yielded 856 records. Through a screening process (shown in Figure 2), I narrowed down to 25 articles, from which participant quotations were extracted for discourse analysis.

Figure 2. Diagram showing the study selection process



3.2.3. Analytic procedure: FDA and interpretative repertoires

This analysis used FDA, underpinned by a social constructionist epistemology, to explore discourses in published qualitative data extracts about the experience of living with AMD. Willig’s six-stage approach to FDA was used as a starting point (Willig, 2021), while omitting the third stage regarding ‘action orientation’, since this would require an understanding of where the relevant extract fits within the discursive context of the participant's entire account. After compilation and extraction of data extracts, and familiarisation with the extracts, the six stages were undertaken as displayed in Table 2.

Table 2. Summary of Willig's six-stage approach to Foucauldian Discourse Analysis (FDA) (Willig, 2021) with examples relating to age-related macular degeneration (AMD) for each stage

Stage of FDA	**Description**	**Example relating to AMD**
1. Discursive constructions	Identifying ways in which the discursive object (i.e. AMD) is constructed, especially in terms of causes and effects.	AMD constructed as a mysterious, unknowable condition.
2. Discourses	Examining extracts to identify the broader discourses used to construct the discursive object (i.e. AMD). At this stage, recurrent metaphors, vivid imagery, or tropes or figures of speech were noted as indications of interpretative repertoires.	Constructing AMD as a by-product of the ageing process draws on a discourse of ageing as decline. Interpretative repertoire: 'It's just age'.
3. Action orientation	Considering the function of discursive constructions within a particular context or point in the account.	Not applicable – analysis of decontextualised extracts did not allow for this to be considered.
4. Positionings	Identifying the subject positions made available within discourses or discursive constructions.	The position of the person with AMD as an 'older adult' becomes available within constructions of AMD as a by-product of biological ageing.
5. Practice	Considering how discourses legitimate or limit what can be said or done.	The discourse of AMD as a natural, inevitable part of ageing may foreclose understandings of how behaviours such as dietary changes and stopping smoking can reduce risk of AMD (Meyers et al., 2015)
6. Subjectivity	Considering 'ways-of-being' and possibilities for subjective experience afforded by the different subject positions, constructions and interpretative repertoires identified.	Constructing AMD as a by-product of ageing may allow the person with AMD to make sense of the condition as a 'normal' part of biological ageing, to consider AMD as coherent with their stage in life, and thus eschew self-blame or a potentially pathologised or stigmatised identity.

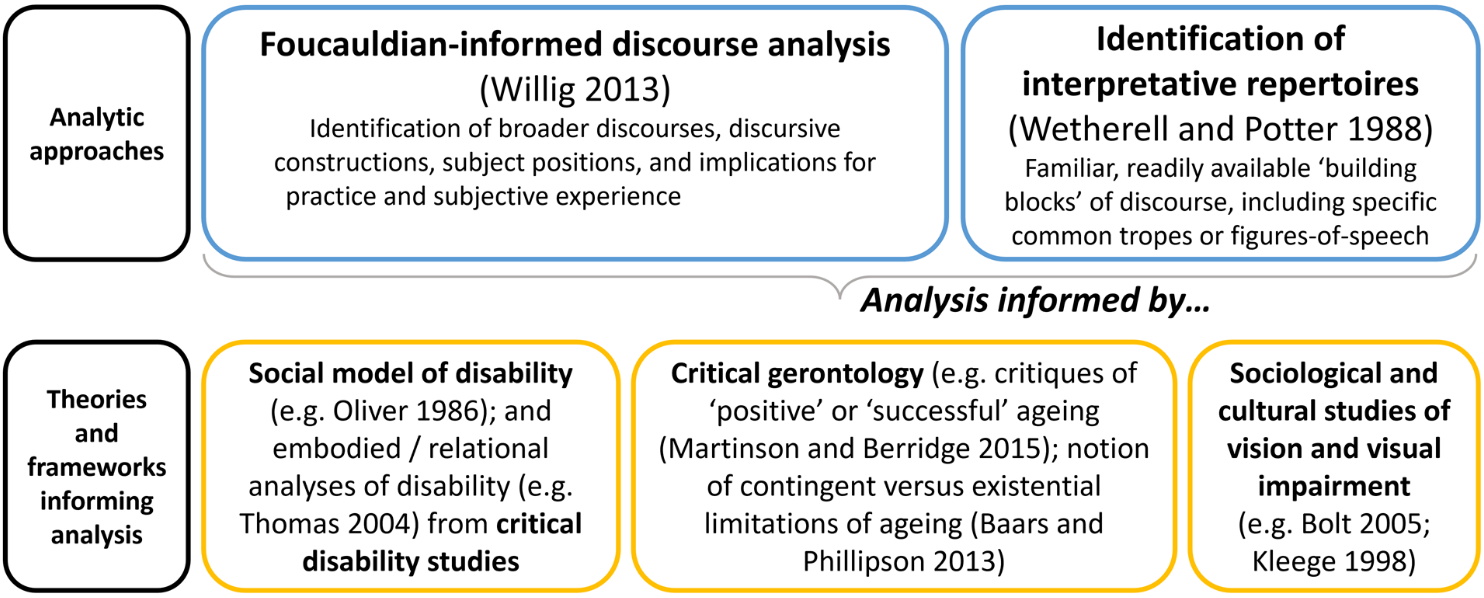
Within the analysis of broader discursive constructions and positions, I also considered 'interpretative repertoires' about AMD, defined by Wetherell and Potter as:

> "Building blocks speakers use for constructing versions of actions, cognitive processes and other phenomena … Commonly these terms are derived from one or more key metaphors and the presence of a repertoire will often be signalled by certain tropes or figures of speech" (Wetherell & Potter, 1988, p.172).

There are rich debates regarding the precise definition and distinctions between a discourse and interpretative repertoire (e.g. Parker, 1990; Potter et al., 1990). Here, I considered interpretative repertoires as operating at a more granular, micro level, as commonsensical everyday discursive resources (Golden & Pomerantz, 2015), in contrast to discourses as more macro-level "structures that impose a certain kind of subjectivity" (Burr, 2015, p.188). As such, a focus on interpretative repertoires allows the researcher to examine the more precise and localised ways in which discourses construct their objects and subjects.

Following the stages of FDA (in a recursive, non-linear fashion), I identified five distinct ways in which AMD was constructed in the data. Each of these five sets of constructions encompassed discourses and interpretative repertoires which recurred across the published extracts included in the dataset. Here, I present the discourses and repertoires found to be most dominant. Making a judgement of 'dominance' in part depended on how commonly discourses were found to recur across studies, since recurrence illustrated that certain discourses to construct the experience of AMD prevailed across different study contexts. However, recurrence alone was not the only criterion; I also focused on constructions that appeared to draw upon naturalised, dominant 'common-sense' discourses around disability, visual impairment, chronic illness and ageing. Furthermore, I was particularly interested in instances where there was a high degree of thematic or linguistic consistency in how a particular phenomenon was constructed across studies, that appeared to indicate the dominance of a given discursive construction. For example, in constructions of 'losing independence' due to AMD (Section 3.3.2), extracts from different studies showed striking similarities in terms of vocabulary and syntax used to construct this phenomenon. Figure 3 summarises the approaches and frameworks employed in the analysis.

Figure 3. Summary of analytic approaches used, and theories/frameworks informing the analysis and interpretation of results.



Analytic approaches

Foucauldian-informed discourse analysis (Willig 2013)
Identification of broader discourses, discursive constructions, subject positions, and implications for practice and subjective experience

Identification of interpretative repertoires (Wetherell and Potter 1988)
Familiar, readily available 'building blocks' of discourse, including specific common tropes or figures-of-speech

Analysis informed by…

Theories and frameworks informing analysis

Social model of disability (e.g. Oliver 1986); and embodied / relational analyses of disability (e.g. Thomas 2004) from **critical disability studies**

Critical gerontology (e.g. critiques of 'positive' or 'successful' ageing (Martinson and Berridge 2015); notion of contingent versus existential limitations of ageing (Baars and Phillipson 2013)

Sociological and cultural studies of vision and visual impairment (e.g. Bolt 2005; Kleege 1998)

3.3. Findings: key discourses identified

Details of the 25 studies selected are displayed in Appendix 3. My analysis identified five distinct ways in which AMD was constructed in research participants' talk about their experience of AMD. They included constructions of: AMD as a mysterious affliction, linked to biological ageing; AMD as a total loss of independence; AMD as grievous loss; AMD as a condition to be stoically accepted; and – to a more limited extent – AMD as an opportunity for discovery. In what follows, I present each construction individually, and examine its implications for how AMD may be experienced. Full quotations are displayed in the tables in Appendix 4, organised under the respective construction; the relevant quotation is numbered, e.g. as Q1 for Quotation 1.

3.3.1. Constructing AMD as a mysterious affliction, linked to biological ageing

In talk about the aetiology of AMD (quotations displayed in Appendix 4, Table 1) participants across studies used language to invoke a sense of surprise, mystery and unknowability to discuss how they first either became aware of AMD themselves, or were made aware by a professional. AMD was constructed as a profound surprise or 'shock', drawing on a repertoire I termed ‘I never would have expected this’ (Q1–Q3, e.g. “I never, never dreamed that … I was going to have this”).

Across studies, participants constructed AMD as ‘the unknown eye condition’ when compared to other diseases (Q4–Q6, e.g. “nobody knows a lot about it”). AMD was constructed as obscure and unknown relative to conditions such as glaucoma, and as poorly understood in relation to its high prevalence. As many of the study authors themselves conclude (e.g. Burton et al., 2013), from a practice point of view, such talk highlights implications for demystifying and improving awareness of the risk factors and symptoms of AMD.

In tension with AMD as a source of shock and encounter with the unknown, the condition was also constructed as a seemingly predictable consequence of age (termed the interpretative repertoire ‘It's just age’). This repertoire constructed AMD as an unsurprising by-product of bodily decline (Q7–Q10) due to “old age” or “getting older”, seemingly an “existential [inherent] limitation” of ageing (Baars & Phillipson, 2013, p.25). This may be unsurprising for a condition such as *age-related* macular degeneration, a name that explicitly associates the condition with later life. However, such constructions may foreclose a focus on what Baars and Phillipson (2013, p.25) term “contingent limitations” of ageing, which are more structural in nature (such as unsuitable housing, inaccessible transport or ageism) and could be modified or addressed. For example, one participant in Bian et al. (2019) stated (Q10):

> “I think this is a natural process. I'm getting older. My children have already grown up and do not need to be taken care of anymore. I'll stay at home, being blind.”

Here, the participant constructs “stay[ing] at home, being blind” as the seemingly inevitable end-stage consequence of AMD, a construction which appears to preclude possibilities of interventions to prevent the speaker from becoming isolated at home. Furthermore, such a construction, which simplifies the links between older age and AMD, risks erasing the potential contribution of health behaviours such as smoking cessation in reducing AMD risk (Lawrenson & Evans, 2013). Thus, it is possible that an overemphasis on the biological process of ageing – represented as “a natural course of functional decline” (Kelley-Moore, 2010, p.107) – can overshadow the social and structural lifecourse processes that could contribute to AMD risk.

Therefore, in participants' constructions of the origins of AMD, there is a seeming tension between AMD constructed as entirely unexpected and unknown, and AMD constructed as a fundamentally ‘natural’, unsurprising consequence of growing older. To explore this tension in all its complexity would require access to participants' action orientation, understanding how participants may deploy these different constructions at different points in their account in the service of specific discursive functions. In this analysis of de-contextualised extracts, it is not possible to explore how constructions might be differentially mobilised depending on discursive context. However, the tension alerts us to the potential for the co-existence of seemingly contradictory sets of constructions. One possible common thread uniting these sets of constructions are the “dividing practices” of normal versus abnormal (Foucault, 1983) bound up within both. In the case of constructions of AMD as unexpected and unknown, participants construct AMD as a fundamentally abnormal event, disrupting their hitherto normal, healthy state; in contrast, constructions of AMD as natural – located within a biomedical discourse of ageing as decline (Phelan, 2018) – equate it with being a normal, expected part of chronological ageing. Both constructions thus arguably converge in affording a subjectivity of normalcy, in a world where impairment or illness is often stigmatised and othered.

Furthermore, both constructions arguably position the subject with AMD as the unsuspecting, passive recipient of a condition beyond their control, potentially helping avoid feelings of guilt or self-blame. This subjectivity could be understood against the backdrop of moralistic discourses surrounding many chronic illnesses with multifactorial (i.e. interacting genetic and environmental) determinants, that often place heavy responsibility on the individual for lifestyle modifications (see e.g. Peel (2014), on discourses of the aetiology of dementia). Interestingly, such discourse around individual responsibility for prevention was absent in the included extracts on AMD. Therefore – with the caveat that lifestyle factors (such as smoking exposure and access to a healthy diet) are socioeconomically and structurally determined rather than purely individual choices (Everest et al., 2022) – it could be noted that the constructions represented here overlook the fact that risk of AMD may be determined by more than purely ageing and, implicitly, genetics. (While AMD is largely genetically determined, changes to smoking and diet in particular may reduce AMD risk for those with an elevated genetic risk (e.g. Colijn et al., 2021).)

3.3.2. Constructing AMD as a total loss of independence

A recurrent interpretative repertoire across studies was the idea of 'losing independence' due to AMD, with independence constructed as an all-or-nothing, binary phenomenon, linked above all to continuation with functional activities (see Appendix 4, Table 2 for quotations Q11–Q13). For example, a participant in McCloud et al. (2014) stated:

> "I was independent all my life, I've done everything by myself, and now I have to depend on someone … it's [vision loss] taken away my ability to perform a normal functional life, because I now have to rely on other people to help in many, many ways."

The construction of independence as a binary in included studies was reinforced through the use of extreme case formulations (Pomerantz, 1986), intensifying words which take participants' claims to extremes; for example, in the extract above, "I was independent *all my life*", "I've done *everything* by myself" (italics added for emphasis). Specifically, independence was largely constructed as inseparable from the notion of "doing things" (Q13), physically acting on the world. In particular, driving was constructed as an essential element of independence, and giving up driving due to AMD was constructed as a loss of freedom and self-reliance (Q14, Q15), aligning with other studies where older adults construct cessation of driving as a critical turning point towards dependence (Rudman et al., 2006; Sanford et al., 2019). Arguably, this reflects a cultural preoccupation in industrialised societies with the car; as Kleege writes:

> The inability to drive sets them apart, reinforcing their status as abnormal. Because in America today, and increasingly in the rest of the industrialised world as well, *normal* means not only to see, hear, walk, talk and possess an average IQ and income, but also to drive. (Kleege, 1999, p.30)

Indeed, while using a car represents its own form of dependence on an object, car use becomes overwhelmingly constructed as a means of independence due to the driver's sense of apparent total control over where and when they travel (Hagman, 2003).

In more biomedical research on age-related eye disease, ‘functional independence’ (the notion of performing – mostly physical – daily activities) tends to be valorised as a taken-for-granted positive goal of treatment and rehabilitation. However, more critical perspectives suggest that discourses of positive, successful ageing can obfuscate the very real potential for ill health and disabilities to “make independence an untenable goal” (Trentham, 2019, p.199). Conceivably, the excessive valorisation of independence may create distress or self-blame for people with AMD, if independence becomes internalised as a key marker for success which is challenging to achieve in reality (McGrath et al., 2017). Perspectives from disability studies may encourage us to take a more expansive view of independence, whereby independence is “not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it” (Brisenden, 1989, p. 9, cited in Morris, 2004). Accordingly, independence is not necessarily about self-sufficiency, in terms of physically managing on one's own or doing everything for oneself, but more about being in a position to make one's own decisions and access appropriate support (Beresford, 2012). From this perspective, social or material support from others can strengthen wellbeing and empowerment, rather than being a marker of dependence (McLaughlin, 2020).

Such a discourse of *interdependence*, recognising that people with AMD may rely on but also be relied upon by others in a complex web of relational ties, is certainly underrepresented in the included studies when compared to discourses centred around a binary of dependence versus independence. This is not to deny the lived experience of many people with AMD, who may see maintenance of independence as a crucial prerequisite for living well; but more to highlight that alternative ways to configure in(ter)dependence do not generally find their way into discourse about AMD within these qualitative studies. Indeed, where a dependence on others is discussed, it tended to be presented in at best a neutral sense (*e.g.* “She [participant's wife] now reads to me, she knows that it gets so arduous for me” (Participant: Moore & Miller, 2003)); or at worst as a source of great loss or disappointment (Q16, Q17, e.g. “All the plans that I had for our family have all gone and it's now all reliant solely on [my wife] … I hide in the background”). In the latter extract, agency is constructed as being transferred from the participant to a family member, reminiscent of the ‘all or nothing’ independence–dependence binary discussed above. There is little sense of collaboration or shared decision-making, but rather the speaker deferring entirely to their relative, with the participant consequently becoming “hid[den] in the background” .

It is noteworthy that strong dichotomies of dependence versus independence are a common feature in research and policy spheres considering ageing more generally. Many dominant models of ‘successful ageing’ are concerned with “independence, avoidance of disability, and individual responsibility” (Martinson & Berridge, 2015), while fears of becoming ‘dependent’ may underpin hegemonic ideologies which see ageing and disability as states to be feared (Stone, 2003). However, a more critical perspective helpfully directs attention to the complex social, structural, relational and environmental factors which shape possibilities for independence (Priestley & Rabiee, 2002). Indeed, it is noteworthy that in a study exploring how a couple experience living with AMD together (Burton et al., 2015), the participants co-constructed a more nuanced, dialectical and dynamic view of in/dependence:

> “[Sally]: And I do try to write things, but when we've written things down we can't see what we've wrote! I write the shopping list, but he has to take the magnifying glass, that means when he goes around the supermarket he's got the supermarket trolley, the shopping trolley, the shopping list and the magnifying glass…
>
> [Jack]: And a thing to tick them off (*Sally laughs*) I'm like an octopus (*laughs*).”

The participants – both living with AMD – construct a division of labour within the dyad, where each partner uniquely contributes within their collective unit. This construction of a harmonious, humorous interdependence arises in a specific interview context, involving two partners living together with AMD. This contrasts with the other studies, where the constructions generally reinforce a rigid demarcation between the now-‘dependent’ person with AMD, and either their ‘independent’ pre-AMD self, or the rest of their family or social group.

Closely bound up with discursive constructions of (in)dependence is the metaphor of ‘burden’, either constructed as an imaginary state to be feared or as one currently experienced (Q18, Q19). AMD was often constructed as precipitating a shift from being an independent, fully functioning person to an implicitly dehumanised ‘burden’ position, bound up with feelings of guilt, passivity and worthlessness. In their critical ethnography of older adults living with vision loss in Canada, McGrath et al. (2016) note the preponderance of participants describing themselves using terms such as ‘burden’ and ‘nuisance’, out-of-place in a world seemingly populated by efficient, independent agents. More broadly, McLaughlin's (2013) exploration of ‘burden fixation’ in the context of families affected by disability demonstrates how this pervasive framing can obscure the full and valued role of disabled people within their families and communities. Furthermore, the burden metaphor has political and socioeconomic implications, with disability scholars linking the discourse of burden with the privatisation of care in many societies. For if care for people with chronic conditions and disabilities becomes discursively configured as an individual or familial ‘burden’, it may become a private, hidden activity that absolves public services of their responsibilities. In tandem, if community or public services do not provide appropriate forms of support, individuals then become more likely to require more material help and care within the private domain, and this may itself reinforce a sense of inconveniencing others (Soldatic & Meekosha, 2012).

3.3.3. Constructing AMD as grievous loss

Consistently across studies, participants constructed the experience of AMD as one of deep loss and grief, either in the participant's present or envisaged in the future. (For quotations, see Appendix 4, Table 3.) From a critical perspective in disability studies, many of the extracts can be considered examples of what Oliver refers to as “disability as personal tragedy” (Oliver, 1986). For example, extracts from a diary study based in the United Kingdom (UK) (Stanford et al., 2009) included entries such as “I live in a sad world of my own” or “I'm in a state where there is no way out”. These comments vividly construct a sense of despair, loneliness and claustrophobia. An associated interpretative repertoire is ‘AMD as a prison’ (Appendix 4, Table 3, Q20–Q22), with participants constructing themselves as “imprisoned” or “cut off”. Such metaphors of entrapment, of a world closing in around the participant, have a concrete, physical quality.

One feature common to these accounts is a sense of dread, drawing on the interpretative repertoire of life with AMD as a site of ‘no future’ (Q23, Q24), a common construction in many dominant, culturally-entrenched representations of disability (Kafer, 2013; Rice et al., 2017). Indeed, with AMD being a progressive disease, the construction of decline over time was a common discursive feature across accounts; for example, one participant in Moore and Miller (2003) stated: “And do what you want to do now because it's not going to get better, it's going to get worse.” This constructs a sense of ‘living on borrowed time’ and a diminished future that awaits, where opportunities and possibilities will become restricted.

Underpinning these constructions is a sense of what Alison Kafer identifies as:

> “the ‘before disability’ self and the ‘after disability’ self (as if the distinction were always so clear, always so binary). Compulsory nostalgia is at work here, with a cultural expectation that the relation between these two selves is always one of loss, and of loss that moves in only one direction.” (Kafer, 2013, p.42)

In line with Kafer's notion of ‘compulsory nostalgia’, and the idea of the ‘before disability’ and ‘after disability’ self, there were several examples of participants constructing themselves as a fundamentally different person to who they were before the onset of AMD, an interpretative repertoire I termed the ‘before AMD and after AMD self’. For example, a participant in Mogk (2008) stated starkly: “This isn't me – I mean, I'm a very visual person.” As an element of this interpretative repertoire, I identified constructions of a dichotomy between pre-AMD success and post-AMD failure with reference to functional activities. These constructions were frequently deployed in talk about inability to perform daily functional activities, concentrated around frequent use and emphatic repetition of the term “can't” (Q28–Q30, e.g. “I can't read the paper. I can't [socialise]. What can I do out there?”). In the latter quote, the participant positions themselves as isolated from the activity-rich world outside and excluded from functional activities. It is noteworthy that difficulties with functional daily activities are a predominant theme in the qualitative literature on everyday life with AMD. From a social constructionist perspective, a focus on ‘activities of daily living’ can itself be considered a discourse that codifies ‘normal’ and ‘abnormal’ functioning within a body. This risks “reducing a life to functional limitation in instrumental or daily care acts” (Richardson & Abrams, 2020, p.43), and reproducing restrictive normative limits for what it means to function and age well with AMD. Such discourse creates parameters for a “normal functional life” (Q12), which if unattainable, may result in a subjective experience of failure.

Another common discursive construction within this theme is the repertoire of vision loss due to AMD as a ‘fate worse than death’ (Q31–Q33), with one participant in Wong et al. (2004) stating: “Suicide is far better than going through this.” Such constructions of AMD as a fate worse than death are arguably drawn upon by participants to emphasise how they could not accept or imagine a future without sight. This trope of ‘better off dead than disabled’ is widespread, as disability scholars have noted (e.g. Shakespeare, 2013), reflecting the negative valuation of impairment in many contemporary societies, and rooted in a discourse of disability as personal tragedy (Oliver, 1986). As Kleege states, regarding the portrayal of vision loss in the 1992 film *Scent of a Woman*, “Darkness might as well be death; life without sight is hardly living” (Kleege, 1999, p.47). Profound fear of blindness, often constructed as the ultimate negative destination of AMD, permeates this discursive construction of life with vision loss as unliveable and unacceptable (e.g. “I just hope I don't live too long if I go completely blind”; Participant in McCloud et al., 2014). Notable here is the construction of ‘blindness’ as an imagined, anticipated state rather than an experienced reality. This aligns with the argument that extreme hypothetical imaginaries of visual impairment as catastrophe can drown out the complex, more nuanced perspectives of individuals living with visual impairment (Schillmeier, 2006). Additionally, on a practical level, such discourses that position blindness as the catastrophic endpoint of AMD underline potential for eye care professionals to raise awareness that AMD rarely leads to total loss of vision (Crossland et al., 2007).

3.3.4. Constructing AMD as a condition to be stoically accepted

In contrast to the constructions of AMD as a catastrophe or source of loss and grief discussed above, the extracts also included examples of participants taking up a more stoical subject position and drawing on constructions of perseverance (for quotations, see Appendix 4, Table 4). Often this stoic position was made available by drawing on constructions of carrying on as before and accepting AMD (Q34–Q40, e.g. “I'll accept it, what happens will happen”; Participant in Moore & Miller, 2003). Alternatively, participants drew on constructions of acceptance that were more gradual and phased in their nature, involving initial shock and then depicting acceptance as an eventual restoration of equilibrium (Q36). Some participants adopted a stronger position of stoicism (e.g. Q39, “It doesn't affect me at all"). However, participants' stoical constructions also presented unconcern about AMD as an effortful, wilful process (e.g. Q40, "I don't let it bother me. I'm not going to"), an outlook to be cultivated rather than emerging naturally.

A common discursive strategy was the use of comparisons with imagined or real others in more difficult situations, an interpretative repertoire termed 'there's always someone worse off' (Q41–Q43), which has been noted in several studies of age-related vision loss (e.g. McGrath & Corrado, 2019). Such downward comparisons can set up a kind of "hierarchy of impairment" (Deal, 2003), a continuum of more- or less-desirable health states, that may communicate a sense of gratitude and acceptance even as this creates a distance from those positioned as 'worse off'. An additional discursive strategy that emerged across extracts to set up positions of persevering in spite of AMD was the construction of AMD as a 'critical juncture' (Q44–Q46), a fork-in-the-road presenting a choice between becoming stuck in self-pity versus adopting a resolute, forward-looking attitude (e.g. "You either get up and go or you sit in your chair and die, and I think I'd rather get up and go"; Participant in Lane et al., 2019). These constructions set up the subject position of the agentic individual, summoning their willpower, control and determination to choose to 'get up and go'.

Indeed, in common with discourses surrounding other chronic conditions, metaphors of 'fighting' AMD were drawn upon, which configure the body as a battleground and put the onus on individuals with a chronic condition not to give up the fight (Willig, 2011). It is notable that AMD was constructed as a kind of 'encroaching enemy' by one participant (e.g. "I think of it as a living creature"; Participant in Mogk, 2008), which the individual has to fight to keep at bay (Q47, Q48). This discourse of fighting AMD is employed to convey a desired resilience to the effects of AMD: a sense that even if vision loss attributable to AMD becomes more advanced, the speaker will not allow the condition to erode their quality of life. As has been highlighted elsewhere, such discourse affords positions that are often typified by their "relentless and unforgiving individualism" (Willig, 2011, p.902), in terms of the individual's responsibility to 'stay strong'.

However, one extract from Moore et al. (2000) provided a counterpoint to this individualistic position, with the participant discussing the value of audiobooks and an access bus for people with disabilities: "I'd fight to the death anybody that decides to take those books away from me, or that bus.” Here the participant positions themselves in a fight to retain vital resources such as accessible audiobooks or transport for themselves, but which could also be congruent with the social model of disability (by recognising the essential role of such community resources in supporting wellbeing). In this way, we see an alternative construction of a “fight” to expand or protect collective rights and resources, an endeavour whose effects could have implications beyond the individual.

3.3.5. Constructing AMD as an opportunity for discovery

In a small number of extracts, participants’ talk went beyond a stoical acceptance of AMD to draw on constructions of new discoveries and growth since diagnosis (Appendix 4, Table 5, Q49, Q50). In these extracts, AMD was constructed as a journey or ‘quest’ with a focus on “what can be reclaimed of life” (thus resonating with what is referred to as the “quest narrative” in Frank, 1998, p.204), for example in terms of meaningful changes to their way-of-being (Q49, “I'm a more balanced person”) or a sense of curiosity and playfulness, e.g. treating a buffet as a “treasure hunt” (Q50).

Several participants – when describing how they had adapted to AMD – drew on constructions of compensating by using other faculties and skills, setting up the subject position of the person with AMD as an innovator who ‘lives and learns’ (Q51-Q54). These constructions, of innovation, effort and learning, challenge the idea of ‘compensatory powers’ (Jernigan, 1974; Makepeace, 2021), a common trope in narratives of vision loss, suggesting that visually impaired people have extraordinary abilities that ‘compensate’ for low vision.[17] Indeed, this trope discounts the time, practice and effort that people with visual impairment may expend in order to adapt to vision loss, as illustrated in one included extract with its emphasis on “trial and error” (Q52).

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[17] Georgina Kleege (1999, p.220) also reflects on “the familiar myth of compensation” in *Sight Unseen*, as an “attempt to console the sighted with the promise that lost sight will be repaid in some way or another”.

3.4. Discussion

In sum, the dominant discourses around AMD, as drawn upon by participants quoted in peer-reviewed qualitative studies, appear largely – though not exclusively – to be shaped by biomedical logics that construct AMD as a tragedy and a threat to independence. The constructions of AMD identified are also inherently tied to biomedical discourses of ageing which configure ageing as bodily decline and, echoing the analysis of McGrath et al. (2016), frame the functional and psychological response to AMD largely as a question of individual responsibility. Constructions of the aetiology of AMD in the included studies (Section 3.3.1) tended to position the participant with AMD as an unsuspecting, passive recipient of a condition constructed overwhelmingly as a consequence of physiological ageing, potentially helping avoid subjective experiences of guilt and self-blame. The emphasis on age as the fundamental cause of AMD runs counter to healthist discourses of individual responsibility for managing disease risk that dominate in many other chronic conditions (Gibson et al., 2015; Peel, 2014). This suggests there may be value in a public health approach to addressing some of the modifiable factors partially contributing to risk of AMD, particularly smoking and diet; while accepting that such 'risk factors' are socioeconomically and environmentally patterned, and so avoiding a potentially moralising discourse of individual risk management.

Approaching the analysis with the social model of disability in mind, extracts where participants saw the challenges of living with AMD and visual impairment as a social, collective, political or economic issue were notable in their scarcity. AMD was generally constructed as an individualised experience of shock, a loss of function and independence, and a source of deep distress (even as a 'fate worse than death' – Section 3.3.3), that could generally only be overcome through individual effort (Section 3.3.4). Such constructions of AMD as personal tragedy arguably function to legitimate the subjective experience of suffering caused by vision loss, in a society set up for sighted people where individuals are "subjected to a daily diet of the personal tragedy model of visual impairment" (French & Swain, 2004, p.35).

It is important to note that the majority of the included studies were conducted in English, in high-income country contexts. However, two of the included studies were conducted in China (Bian et al., 2018, 2019). These studies both explicitly attest to the importance of family support, as well as concern about how AMD may impact both the individual and their wider family; not only emotionally, but also financially in a context where patients formerly paid for injection treatments for wet AMD, prior to 2019 when medical insurance was extended to cover wet AMD treatment in China (Lu et al., 2021). In this context, constructions of loss of independence and the person with AMD as a 'burden' may be informed not only by societal discourses but also by more material, economic concerns. The only other included study from a non-English-speaking context was conducted in Sweden (Dahlin-Ivanoff et al., 1996), but this only included limited published extracts. The quotations published verbatim were most relevant to Theme 5 (Q53-54), within the repertoire of 'You live and learn', although the study also focused prominently on problems and limitations linked to AMD. Therefore, on the basis of relatively limited data, I would argue that talk within these three studies conducted in non-English-speaking contexts broadly aligned with the overall constructions identified in English-speaking contexts.

The present study's findings largely align with the call of McGrath et al. (2017) to incorporate critical disability perspectives into research on age-related vision loss, in order to question or nuance ideological notions of independence and normalcy. Indeed, it is striking in the analysis how frequently, and uniformly across countries, that the experience of AMD was constructed as a total loss of independence (Section 3.3.2), framed within an 'all or nothing' polarity. The analysis also identified a similar, though perhaps less strikingly uniform polarity, in the construction of AMD across studies as a 'critical juncture' or 'fork-in-the-road' (Section 3.3.4), presenting a stark binary choice between exercising willpower to keep living well or withdrawing into oblivion. Such a binary arguably reproduces moralistic discourses common in Western, industrialised societies that emphasise individual will and self-reliance in achieving health and success (Kittay, 2015); and this concurrently downplays the ways in which, for example, features of the physical, social, economic or political environment around the person may influence how they respond to and live with AMD and vision loss. To draw on Baars and Phillipson's (2013) typology of 'existential' and 'contingent' limitations linked to ageing, the discourses and repertoires mobilised by participants generally tended to configure AMD solely as a source of inherent, 'existential' problems within the individual, rather than problems stemming from societal, structural or environmental barriers which are arguably 'contingent' or modifiable. Indeed, the polarities and extremities often evidenced in the included extracts, such as the construction of losing all independence or vision loss as a fate worse than death, arguably close down the potential for life with AMD to be (for at least some individuals) “mundane, a mere matter of seeking practical solutions to everyday inconveniences” (Kleege, 1999, p.228).

The concept of “ideological dilemmas” (Billig et al., 1988) can help to make sense of the disparity between critical thought about disability and ageing (which suggests that many dominant, naturalised discourses are in fact socially and historically ‘contingent’), and participants’ talk (which constructs many of the effects of AMD as ‘existential’ and unavoidable).[18] Critical thought from gerontology and disability studies could be considered “intellectual ideology” (defined as “a system of political, religious or philosophical thinking” (Billig, 1988, p.27)), a theoretical position that valuably seeks to reconfigure society's understanding of ageing and impairment. In contrast, participants' discourse is generally situated in the “lived ideology” – “what passes for common sense within a society” (Billig et al., 1988, p.27); namely, biomedical understandings of illness, impairment and ageing, which shape mainstream, common-sense ideas around vision loss. From the ideological dilemmas perspective, there is a dialectic between the “intellectual ideology” and the “lived ideology”. How these ideologies are deployed in discourse will change depending on social and argumentative context, rather than existing at polar opposite ends of a binary. From this viewpoint, research on AMD tends to be a context for focusing on understanding and addressing ‘problems’, especially as much of the research is conducted within the clinical worlds of ophthalmology and optometry. (There were a small number of exceptions to this more biomedical framing, where an expressly critical or sociocultural approach was adopted (e.g. McGrath et al., 2016; Mogk, 2008).) Indeed, Tanner and colleagues’ review considering the “loss focus” in AMD research concluded that “negative expectations and attitudes reflected in research questions and the outcomes reported may contribute to negative outcomes” (Tanner et al., 2020). Such a “loss focus” may explain why more dilemmatic,

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[18] The ideological dilemmas concept acknowledges that our common-sense thinking in everyday life is inherently ‘dilemmatic’, often drawing on contrasting, even contradictory discourses and repertoires. A good example is in the cultural currency of seemingly incompatible maxims and proverbs – the proverb ‘many hands make light work’ exists in tandem with, and yet contradicts, the proverb ‘too many cooks spoil the broth’. Neither maxim predominates common-sense thinking, nor is one inherently more valid than the other; and the same individual may draw on each proverb but in different social and rhetorical contexts for different ends.

everyday aspects of living with AMD are less salient in the included extracts. Extending Tanner et al.'s (2020) notion of the "loss focus", it could also be argued that many of the published research studies on AMD also subscribe to – and reproduce - a kind of "dependence focus"; whereby it is assumed that the ceasing of specific physical, functional activities due to vision loss inevitably equates to a problematic state of dependence. Arguably, qualitative research in AMD may call for less dualist and more "both/and" thinking (Spinelli, 2014, p.14), which recognises that individuals in their everyday life may move between, and find meaning in, both a more "intellectual ideology" of interdependence and a "lived ideology" of independence, for instance. In line with McGrath et al. (2017), the present study's findings point to the value of an approach drawing on critical disability studies and critical gerontology, which could shift the emphasis towards a focus on how societies and environments produce (and can therefore also *re*duce) disability for people living with AMD.

3.4.1. Limitations

This secondary analysis sought to attend to the discursive features of participant accounts of AMD within previously published qualitative studies. A particular limitation inherent in this approach was the decontextualisation of the included extracts, removed from their accompanying context, commentary or qualifiers. This lack of context can be a problem arising in secondary analyses of qualitative data generally (Wästerfors et al., 2014), but particularly when using discourse analysis. Using this approach, there was no way to explore the different positions adopted by the same participant, and consider the consistency or variability in how they draw upon discursive resources and repertoires within an interactional context. Because the extracts were decontextualised, I could not trace how the same participant might have taken up different positions within the interview conversation, and how they might have been positioned in specific ways in interactions immediately before the talk that is quoted in the extract. Furthermore, in the case of studies conducted in non-English-speaking countries (Bian et al., 2018, 2019; Dahlin-Ivanoff et al., 1996), the interviews and focus group were conducted, respectively, in Mandarin Chinese and Swedish. This creates a potential issue in terms of equivalence of meaning between the original and translated text, especially considering the notion of the translator's subjectivity

(Munday, 2014), which introduces an additional level of interpretation, and thus creates additional distance between the participants' original words and my analysis.

This secondary analysis focused on decontextualised, published text rather than raw data from individuals' accounts. However, this does not preclude ethical issues arising from the analysis (Thorne, 1998), a second key area of limitations. A potential ethical issue with this analysis is that participants never provided consent for their talk to be analysed in this way from this particular epistemological standpoint; the included research studies generally assume a realist epistemology, rather than the social constructionist epistemology underpinning discourse analysis. While we do not anticipate risks to participant confidentiality, there is arguably an ethical issue of sensitivity and fidelity to participants' perspectives. Drawing on the hermeneutics of faith and suspicion, as theorised by Ricoeur (see Section 2.5, p.47-48), we can consider that the vast majority of the (largely) realist research articles included in this analysis operate using a hermeneutic of faith. The articles implicitly or explicitly adopt an empathic attitude towards participants of “care or concern … That concern, as we know, presents itself as a “neutral” wish to describe and not to reduce” (Ricoeur, 1970, p.28). Discourse analysis does not imply a lack of “care or concern” or empathy for participants; however, it does to some extent involve using a hermeneutic of suspicion, a “tearing off of masks” (Ricoeur, 1970, p.30). This hermeneutic of suspicion entails a kind of questioning or deconstruction that looks beyond the face value of talk, described as an interest in “the sense beneath the sense” (Tomkins & Eatough, 2018, p.194). Subsequently, as attempted in my analysis, it is possible to re-engage with a hermeneutic of faith when tentatively considering the implications of discourse for subjective experience. In the present analysis, adopting a hermeneutic of suspicion often involved working with theory from critical fields such as disability studies and gerontology. Much of this could be considered opaque and abstracted from participants’ experience, an “intellectual ideology” seemingly divorced from (and potentially even seen as invalidating of) their “lived ideology”.[19] Participants in the original studies could, for example, validly critique the present study’s critique of biomedical discourse, given that advances in biomedical science

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[19] In their discussion of discourse analysis in mental health research, Challenor et al. (2021, p.130) similarly note that “participants themselves may not recognise the claims that are being made on their behalf’, meaning that researchers must “remain acutely reflexive and alive to the potential for the abuse of power that lies with their own role”.

hold out hopes of slowing their vision loss. Indeed, for reasons that may lie in participants' identities, politics, life histories or self-concepts, many people with AMD may not identify with the more social or political dimension of disability discussed in this analysis (Grue, 2017; Kafer, 2013; McGrath et al., 2017; Mogk, 2008). Therefore, there is a fundamental tension that this secondary analysis proposes interpretations which could be problematic to the original research participants. This underscores a need for awareness that I, as an analyst, am shaped and bounded by my own interests (particularly in critical gerontology and disability studies perspectives); and that a multiplicity of other valid complementary or divergent interpretations could be made on the basis of the same extracts.[xiv]

I return to consider implications of this chapter in the overall Discussion of substantive findings at thesis level in Chapter 7, and in Chapter 8 I consider how the FDA fits alongside the interpretative phenomenological stance adopted in the rest of the thesis.

Chapter 4: Interpretative Phenomenological Analysis findings (Participants 1-8)

4.1. Introduction

This chapter presents the findings of an interpretative phenomenological analysis study of eight participants' experiences of AMD within their personal, social and relational contexts. This marks a shift in epistemological stance following the FDA of Chapter 3, grounded in a social constructionist epistemology. The studies discussed in the following three chapters (Chapters 4-6) were all undertaken from an interpretative phenomenological stance. The research question guiding the IPA study of this chapter was: how do people experience AMD within their personal, social and relational contexts?[20]

4.2. Methodology

In terms of the overarching study design, I conducted a full interpretative phenomenological analysis of the interview transcripts of an initial eight participants who formed the 'core' sample. (I then analysed the remaining eight participants in the subsequent chapter, Chapter 5, using template analysis.)

The decision around how to determine which participants would form the core sample was a challenging one. Dennis et al. (2013), whose study combined a first stage hermeneutic phenomenological approach with template analysis, selected the core eight interviews based on those closest to median length. As an approach that might add an element of randomness, I considered analysing the initial eight transcripts, but as a novice IPA researcher, the disadvantage was that I felt that the quality of interviews improved on aggregate as I progressed with the interviews. Conversely, choosing the last eight transcripts was not a practical option because I had already started analysing certain earlier interviews (such as Ruby's and Andrew's accounts) and engaging with the data using the IPA steps before all interviews were completed. (This was at the time when I foresaw involving fewer

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[20] This study has not yet been written up for publication, although I have presented aspects of the results in poster presentations at two conferences – shown in Appendix 5 and 6.

participants - before amending the protocol in summer 2020 - and was therefore planning to use IPA to analyse all transcripts.) Larkin (2022a) suggests that additional potential options include selecting the most homogeneous, the most heterogeneous, or the richest transcripts, provided that the chosen dimension is appropriate in light of the study context and research question. My selection process arguably fell in-between choosing the most heterogeneous and richest transcripts, as I wanted to aim for both breadth (heterogeneity) and depth (richness) in order to feel most confident that the analysis of eight would imbue the initial template with a depth of insight and, as far as is possible in IPA, a sense of comprehensiveness. This logic was by no means foolproof. For example, Howard's experience of and relationship to AMD was complex because this experience was overshadowed by also living with tinnitus and intense caring responsibilities for his wife. I wanted to include a participant like Howard who had only lived with AMD for a short time, and thought that exploring his AMD in light of these other challenges he was facing would be illuminating. However in hindsight, Marianne's account, analysed with template analysis, could perhaps have been a better choice as she went into significantly more depth about her experience of AMD and perspectives on the future, which was a significant theme of the analysis (see Theme 1.2 (Section 4.3.1.2) on temporalities). This highlights a potential tension, in that selecting the core sample is a relatively irreversible process compared to the rest of IPA, where recursive processes of returning to revisit data or themes are generally a key part of iteratively deepening one's understanding of the phenomenon. Inevitably, the core sample had to be chosen pre-analysis, because this approach was chosen as a practical means of managing the larger sample size. Yet the full richness and complexity of participants' accounts could only be fully appreciated retrospectively, once deeply embroiled in in-depth analysis.

For the core sample of eight participants, the cross-case analysis was underpinned by an initial idiographic focus on the eight participants. Summaries showing the superordinate themes developed for each participant are included in Appendix 7.

The description of data collection methods below applies to all sixteen participants recruited; however, the data analysis section in this chapter is only relevant to the full interpretative phenomenological analysis of the core sample of eight participants. Table 3 in the Participant Characteristics section clarifies the participants whose data was analysed in the full IPA, the focus of the present chapter, and those whose data was subsequently analysed using Template Analysis (Chapter 5).

4.2.1. Recruitment of participants

Interview participants were recruited through a number of different means, using a purposive sampling strategy to recruit participants who had been living with AMD for enough time to make sense of their experience of the condition. Firstly, a small number of participants (N=3) were recruited by word of mouth through the City, University of London Optometry department and City Sight, an eye care clinic based at City University. One further participant was recruited through word-of-mouth as she was a friend of a previous participant. The remaining participants were recruited through different channels of the Macular Society, the UK's leading charity supporting people with AMD, specifically: through a tweet I sent which was then retweeted by the Macular Society's main account (N=3); an email circulated by the London Macular Society network (N=1); and *Sideview,* the quarterly magazine published by the Macular Society (N=10).

Participants were deemed to be eligible to participate in the study if they were:

- Aged 55 or over;
- Had had a diagnosis of age-related macular degeneration for at least two years at the time of the interview (in at least one eye);
- Did not have a diagnosed or known hearing impairment;
- Were willing to have a detailed discussion about their communication, interactions and relationships with other people, understanding that this topic could be personal or sensitive.

The age range was chosen on the basis that I was interested in the lived experience of older adults with AMD, and AMD is usually seen in individuals over 55 (Coleman et al., 2008). The time of two years was chosen as a period that would allow participants more time to reflect on changes since diagnosis, compared to those more recently diagnosed.[21] The experience of being diagnosed could have been explored as a phenomenon of interest in its own right,

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[21] It is important to note that for many individuals with AMD, there may be some awareness of their vision changing but this is not always attributed to AMD, and a diagnosis may only be sought when the visual changes interfere with key daily activities (Parfitt et al., 2019).

but I was more interested in how individuals make sense of AMD once they have settled into awareness of the condition and begun to integrate it into their life. Indeed, longitudinal research suggests that positive mood declines particularly sharply immediately following diagnosis and then ceases to decline around 24 months from this point (Schilling & Wahl, 2006). This provides an additional ethical rationale for the inclusion criterion of having lived with AMD for at least 2 years, in seeking to recruit participants who had passed this initial stage of shock and emotional upheaval. However, AMD progresses heterogeneously for different individuals, and so inevitably participants' experiences as shared during the interview represented a snapshot in time, amid an ongoing process of meaning-making about an evolving phenomenon. The lack of hearing impairment was specified because of the study's initial, narrower interest in how people with AMD experience communication and social interaction with others (hence also the final eligibility criterion). In this context, I envisaged that for those with dual sensory impairment affecting vision and hearing, hearing impairment might significantly affect patterns of communication and interaction more than eye disease. As discussed in the Introduction (1.7.1), the phenomenon of interest subsequently became somewhat broader, although an interest in communication and relationship patterns with others still remained.

The ethical protocol for the study, as approved in January 2020, initially involved face-to-face interviews at the university, and some brief, non-invasive tests of visual function to establish a baseline understanding of the participant's visual symptoms. However, due to the COVID-19 pandemic and distancing measures introduced in the UK in March 2020, and after consultation with my supervisors I decided to move to telephone interviews. (Further reflections on this transition from the face-to-face to telephone interviews are discussed in Chapter 8, and also in our reflective article on telephone interviewing (Enoch et al., 2023; Appendix 2). Once participants expressed an interest, by getting in touch with me either by telephone or email, I called participants to explain the study and participants had the opportunity to ask questions about the study and the topics we would likely cover. At the end of this call, I asked if participants were happy to take part. If so, I sent them a copy of the Participant Information Sheet (PIS; Appendix 8) to consider. I agreed to call participants one week later, and if they were still happy to participate, I subsequently sent them the consent form (Appendix 9) to sign and return to me either by email, or in a pre-addressed envelope. Once participants consented to take part, we arranged a time for the interview. Participants were offered the opportunity for a telephone or videoconferencing (e.g. Skype, Zoom) interview, but all participants opted for the telephone. We went through the consent form again verbally on the phone before beginning the interview.[22]

4.2.2. Participant characteristics

Eighteen participants were recruited for the study. Select demographic and clinical characteristics of the participants are displayed in Table 3 below, while Table 4 provides more contextual biographical information about their experience of AMD and living situation.

Table 3. Select participant demographics and clinical characteristics relevant to AMD/vision loss (correct at time of interview). Participants shaded in blue represent the core sample of eight participants whose accounts were analysed with IPA, the focus of the present chapter.

Pseudonym	**Time of interview**	**Age**	**Gender**	**Type of AMD**	**Eye(s) affected by AMD**	**Years living with AMD**	**Level of certified sight impairment**[23]
Ruby	April 2020	96	F	Wet	Both	26	Severely sight impaired (blind)
Andrew	May 2020	72	M	Dry	Both	7	Severely sight impaired (blind)
Ralph	August 2020	67	M	Dry	Both	20	Severely sight impaired (blind)
Sylvia	October 2020	88	F	Wet	Both	15	Not certified
Rose	October 2020	79	F	Wet	Both	6	Not certified
Denise	October 2020	77	F	Wet	Both	4	Not certified
Howard	October 2020	79	M	Wet	Both	3	Not certified
Sandra	October 2020	75	F	Wet	Both	5	Sight impaired (partially sighted)
Patricia	March 2020	91	F	Both	Both	2	Not certified

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[22] We submitted an Ethics amendment allowing for certain participants to consent verbally if they found engaging with the written consent form challenging due to their vision loss. This is discussed further in the Ethical Considerations section below.

[23] This refers to the categories used for legally certifying visual impairment in the UK (RNIB, n.d.). Being sight impaired (previously known as 'partially sighted') like Sandra refers to a visual acuity of 6/60 to 3/60 with a full field of vision; Crossland (2024) notes this level is approximately 10-20 times poorer than good vision. Being severely sight impaired (previously known as 'legally blind') like Ruby, Andrew and Ralph refers to visual acuity worse than 3/60. If a participant is "not certified", this does not necessarily mean that they do not have visual impairment; either their vision may not be sufficiently low to meet the criteria for certification, or they may not want to be certified and registered, as certification is a voluntary process.

Kate	July 2020	72	F	Wet	Both	28	Severely sight impaired (blind)
Pearl	July 2020	97	F	Dry	Both	19	Severely sight impaired (blind)
Nicola	September 2020	69	F	Dry	Both	7	Not certified
Louis	September 2020	91	M	Dry	Both	12	Sight impaired (partially sighted)
Marianne	September 2020	68	F	Dry	Both	2.5	Not certified
Hannah	September 2020	84	F	Dry	Both	10	Not certified
Victoria	October 2020	87	F	Both	Both - Right (wet), left (dry)	2.5	Not certified
Julie	October 2020	92	F	Both	Both	4	Severely sight impaired (blind)
Suzanne	October 2020	84	F	Dry	One eye	3	Not certified

Table 4. Brief participant biographies with contextual information for participants in the core sample (N=8)

Table redacted from online published version to protect participant confidentiality.

Table redacted from online published version to protect participant confidentiality.

4.2.3. Sampling strategy

I initially intended to recruit a sample of around 10 participants, given the emphasis in IPA on recruiting small samples to allow for detailed, in-depth case-by-case analysis, among a relatively homogeneous group who share the experience of the phenomenon under investigation (Smith et al., 2021). The sample would arguably have been more homogeneous and uniform in the initial protocol when interviews were due to take place in person in the London area; as it would have necessarily limited participants to those willing and able to travel to the university in central London. Transferring interviews to the telephone diversified the sample, by allowing us to recruit a more geographically dispersed range of participants, including in rural areas where the geographical environment interacted with the participant's vision loss to shape their daily life. However, homogeneity was retained in terms of their experience of the phenomenon. I did not pre-specify any socio-demographic characteristics such as gender, race or ethnicity, or social class, since there was no rationale to presuppose from previous phenomenological work on AMD (e.g. Burton, 2013; Burton et al., 2015) that experiences would significantly differ depending on these factors. Were systematic divergences in experiences to emerge from analysis of the interviews, then that would represent a future avenue for enquiry.

Although I offered in the original 'pre-COVID' protocol an option for meeting face-to-face near the participant's home, in hindsight this original protocol was implicitly setting up a "normative mode of participation" (Mitchell & Snyder, 2015) of attending the interview in-person at the university, from which people with more severe visual impairment and/or reduced mobility might have felt excluded. Thus the telephone interviews helped to recruit a broader range of participants from different geographies and, most likely, with a broader range of visual impairment than if interviews had taken place in person. From an IPA perspective, this represented a move away from sample homogeneity; but one which supported the objectives of the research, to understand how people with AMD experience the condition within their diverse personal, relational and social contexts. However, , this increased level of heterogeneity creates its own challenges – in addition to those typically encountered in IPA - in terms of theoretical transferability of the findings (discussed in Chapter 8).

The recruitment of 18 participants when I had initially specified a sample of 10 participants can be explained amid the uncertainties and disruption caused by COVID-19 and changing the format of the interviews to take place by telephone. At this time, in mid-2020, we were planning to involve all the IPA participants in a second phase of research, which were later reconfigured as home-tour interview case studies (Chapter 6). However, it was unknown how long the pandemic and the associated distancing regulations would last (especially when interacting with older adults), given that this was long before the successful development of COVID vaccines. We therefore expected to be conducting home tour interviews with object elicitation remotely, and imagined this would not appeal to many participants; therefore, expecting attrition, we submitted an Ethics amendment to increase the sample size from 10 to 15. It also happened that once the Macular Society *Sideview* September 2020 edition was published, there was an overwhelming response to the advert, with around 40 individuals getting in touch at once over the course of a week. This was a marked contrast to the previous six months, over which time I had only managed to recruit six participants. In an ideal world, I might have wished to work with one interested potential participant at a time, going through the process of initial expression of interest to consenting (which took at least a week) one-by-one. However, in reality, these conversations with interested participants were taking place in parallel and I wanted participants to know I welcomed their interest and enthusiasm about taking part; I also expected some attrition once we began discussing the PIS in more detail and specifying the inclusion/exclusion criteria. Therefore, pursuing many of these conversations in parallel, I ended up slightly 'over-recruiting', as it would have felt potentially unfair to then exclude the last three participants from the study when they were already in the process of considering the PIS and invested in taking part. My supervisors and I later decided to shift the envisaged second phase of the research (the home tour interviews, discussed in Chapter 6) to a more exploratory case study approach, and so in the end this larger sample was not strictly needed. However, we also became interested as a team in new approaches in IPA to working with larger samples, for example conducting IPA on a core sample of transcripts and then extending the analysis using template analysis (Chapter 5). It therefore became the case that this larger sample afforded an opportunity to try something new methodologically.

The preceding paragraph illustrates how COVID necessitated a more flexible approach, and led to many changes away from our initially more linear, straightforward protocol. Making such changes was unsettling and often led me to question whether they were compromising the rigour of the study; however the changes also allowed new lines of enquiry to emerge organically. This in turn pushed me to take a more deliberately reflexive approach considering how the interview context – at the micro-level of the interaction through to the macro-level of events going on in the world at large – shapes the kind of knowledge qualitative research may produce (see Chapter 8).

Finally, it is also important to note that two of the 18 participants' data (Patricia and Nicola's accounts) were not deemed to be suitable for interpretative phenomenological analysis, as they lent themselves to a more discursive reading which was outside the purview of the analysis. The way I handled this data is discussed in Chapter 8 (Section 8.2.2).

4.2.4. Data collection procedure

In line with many IPA studies conducted in health psychology, I used semi-structured, in-depth, one-to-one interviews to collect data, by telephone due to COVID-19 restrictions. As suggested by Smith, Flowers and Larkin (2021), the aim of the interview is to provide a space for the participant to discuss experiences and concerns relevant for them, and as far as possible to enter into their lifeworld.[xv]

At the start of the interview, I sought to set participants' expectations about the interview being less a pure information-gathering exercise, and more focused on the participant's own experience of AMD; and I encouraged them to speak at length and respond with whatever came to mind on the relevant topic. As opposed to structured interviews or questionnaires, semi-structured interviews for IPA studies position the participant as the expert-by-experience or storyteller, and include the flexibility to explore issues the researcher may not have considered in advance. In discussing the procedure with participants, I explained that this kind of interview might be somewhat less structured and directive than interviews (or questionnaires) they may have previously participated in, or (if new to research participation) how they perhaps imagined interviews to be. Indeed, several participants were puzzled about how this kind of "conversation with purpose" - as Smith, Flowers and Larkin (2021) describe the qualitative research interview - could constitute research. This may partly stem from the overwhelming preponderance of biomedical, scientific discourse within the AMD research ecosystem (see Chapter 3), setting up participant expectations of a more positivist-empiricist approach to research which I sought to dispel.[24]

The interview schedule (Appendix 10) was used as a guide, to help map out in advance the kind of topics I aimed to cover in the interview, rather than as a rigid, prescriptive instrument. The interview schedule included some initial scene-setting questions, in terms of how participants were feeling in general on that day, and more specifically their feelings about the forthcoming interview. Although not formally written into the interview schedule, discussion of how the participant was coping with the COVID-19 pandemic was also inevitably discussed as this was such a salient, immediate feature of experience in 2020. The interview schedule then led with more open-ended questions (e.g. "Could you please give me a brief history of your experience of living with AMD?") in order to encourage participants to discuss aspects of their experience of AMD they considered most meaningful. There was then a gradual "funnelling" (Smith & Osborn, 2008) towards a more granular focus on communication, social interaction and relationships. The interview schedule was iterated over time, reflecting a broadening out from the theme of communication and social interaction to a growing interest in how the person's unique context and living situation – especially in terms of the people and places around them –

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[24] It is also possible that participants often had these expectations because they were recruited through the Macular Society, which generally tends to publicise more biomedical or quantitative research.

shaped their experience of AMD. This interest was further cemented by the secondary FDA analysis (Chapter 3), which encouraged me to be more curious about some of the concepts that both the participant and I might at first take for granted. For example, if participants discussed feeling as though they had lost their independence, following the FDA study I became even more interested in exploring what independence meant for them, how they defined it, and the importance they attached to it.

The evolution of the interview schedule to focus more on the participant's interactions with the people and places around them also stemmed from the difficulties of asking about communication and relationships head-on. Particularly if I moved towards asking participants about any difficulties communicating, it was often challenging for them to answer such questions in the abstract. Smith, Flowers and Larkin (2021) note that the interviewer may have to come at the research question 'sideways'; namely that the interviewer has to elicit discussion of topics relevant to the research question, and it is then through the analysis - rather than direct 'answers' from the participant - that the research question can begin to be answered. Indeed, while not renouncing the focus on communication and social interaction, I accepted that this theme would have to be explored with reference to concrete experiences rather than in an abstract, macro-level way. Relatedly, because of moving the interview to the telephone, we invited participants to reflect at the end of the interview on their experience of participating by phone rather than face-to-face; this in turn yielded interesting insights discussed further in Chapter 8.

At the end of the interview, a debrief took place with participants, inviting them to share any feedback on the interview and if they had any questions or concerns arising from the interview or about my PhD research more broadly. I talked the participant through, and subsequently sent them, a debrief sheet (Appendix 11). This included our research team's contact details, as well as a list of relevant mental health and sight loss organisations, in case they wished to later seek support or discuss any issues which may have arisen during the interview.

4.2.5. Ethical considerations

Ethical approval for the study was granted by the City, University of London Psychology Research Ethics Committee (REC) on 3 January 2020 (reference ETH1920-0318).

Participants were offered a £10 voucher or charity donation as a token of thanks for their time; all ultimately opted for charity donations. This amount was chosen to recognise the contribution of the participant to the research, while being a reasonable amount that was unlikely to be coercive.

When interviews moved to the telephone from March 2020 onwards, this necessitated changes to the research protocol and an amendment to the study was subsequently approved by the Psychology REC on 31 March 2020. The amendment stipulated that a small number of interviews (2-3) would be conducted, since at this stage it was not clear for how long COVID-19 and the physical distancing measures would be in place. As discussed in Chapter 8, we believed that telephone interviews were an inferior substitute for face-to-face interviews; indeed, in one email to my supervisor I wrote "*I'm aware that this [telephone interviewing] does not sit well with IPA*". This is despite Sweet's (2002) justification of the phone interview in phenomenological research, and a rich, high-quality IPA study exploring treatment experiences of people living with ileostomies where interviews were carried out by phone or Skype (Spiers et al., 2016). However, at the time of submitting the ethics amendment, I had not come across these latter papers and believed it was inevitable that – especially being an early-career qualitative researcher – an IPA study conducted by telephone or videoconferencing would yield lower-quality data, and so believed that phone interviews should only be an interim solution. By summer 2020, it was clear that working with an older adult group, the original protocol with interviews conducted in-person at the university was unlikely to be viable in the longer-term, and would potentially discourage or exclude many otherwise willing participants. We therefore submitted another amendment to the Psychology REC (ETH2021-0299), to conduct all interviews by telephone, which was approved on 5 October, 2020. This reflected our appraisal as a research team that the telephone interviews were yielding rich data and that, with no way of predicting when the pandemic and associated measures would end, it was preferable to carry on collecting data than wait to resume face-to-face interviews.

The transition from face-to-face to telephone interviews shaped aspects of the study's ethical considerations. Some of these were more procedural; for example, while we retained a preference for collecting signed copies of the consent forms, a small number of participants with more severe visual impairment preferred the form to be read to them and to provide their consent verbally rather than navigating the written form. This is in keeping with the City, University of London policy that verbally-recorded (oral) consent is acceptable and valid in specific circumstances (City University of London, 2024), and this change was approved in the October 2020 amendment.[25]

In a broader sense, certain new ethical questions arose when conducting the interviews by phone. While there was a reduced physical risk because of potentially vulnerable participants travelling to the university, there were risks associated with not being in each other's presence for the interview, for example due to the lack of non-verbal communication and gestural information on the phone. When conducting phenomenological research, Finlay (2006, p.23) suggests that attending to movements and non-verbal communication is a fundamental element of listening and enables "experiencing the whole" of the participant's embodied presence. Without such information, we reasoned it could be more challenging not only to build rapport but also to attend to potential non-verbal signs of discomfort. Therefore, more explicit verbal 'checking in' was required throughout the interview. For example, with certain more sensitive questions I was particularly tentative, or explicitly emphasised the optionality of answering the question or alternatively discussing other topics. I of course may have adopted such strategies in person, but arguably they became more necessary on the telephone. My approach was in line with Dewing's (2008) notion of consent as a dynamic, ongoing process, requiring continual renegotiation throughout the study in a way that continually reminds participants of their role as a volunteer and their right to withdraw at any point (or to move on to another discussion topic). At the same time, I sought to balance this care and responsibility towards participants with recognising them as autonomous agents and avoiding presuppositions of apparent "vulnerability" (Poland & Birt, 2018). I became somewhat more confident finding this balance, following reflective discussions with my supervisor reflecting on the initial interviews. I also sought to remain attuned to the boundary-setting or "don't go there" messages (Sinding & Aronson, 2003) conveyed explicitly or implicitly (e.g. through a change

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[25] There are precedents in the literature for obtaining consent verbally when undertaking research with people with visual impairment (e.g. Trujillo Tanner et al., 2018).

in tone of voice) by participants; while also accepting that participants make active choices in what they decide to disclose (or not).

Ethical considerations were also relevant at the stage of data analysis and interpretation, and I sought to remain cautious and tentative about claims being made on the basis of participants' accounts. This process is discussed more fully in the Data Analysis (4.2.7) and Reflexivity (4.2.8) sections below.

4.2.6. Transcription of interviews

The audio-recorded interviews were transcribed verbatim, adopting an 'overt' or naturalised approach to transcription which aims to represent as much of the participant's original utterance (e.g. repetitions, hesitations, stutters, pauses, breaths, laughter) as possible. (This contrasts with a 'covert' or 'denaturalised' approach to transcription which is largely focused on the content alone (Willig, 2012).) In IPA, and several other qualitative methodologies, transcription is itself a "form of interpretative activity" (Smith et al., 2021, p.69). Arguably, decision-making by the researcher about how to transcribe itself constitutes a process of active construction, even when the researcher is seeking to faithfully reproduce and capture the participant's talk (Hammersley, 2010). For this reason, even if transcription was conducted before beginning formal analysis, transcription represented a key stage in engaging with the data and involved beginning to make some exploratory notes (thus overlapping with the first stage in the data analysis procedure, outlined below).

In the transcripts themselves, and quotations included in the Results section, the following notations are used:

- … = a brief pause
- […] = omission of intervening, unnecessary text
- *Italicised text* = a word/phrase that the participant emphasised
- -- = a 'false start' before the participant interrupted themselves and changed tack
- [Text in square brackets] = Word/phrase added to provide missing context, in order to make meaning clearer and more explicit e.g. "It [AMD] is not, 'What is', it's what you imagine it to be." This formulation can also denote where potentially identifying details have been redacted, e.g. "We're lucky having the hospital in [town]."

- [*Italicised text in square brackets*] = Non-verbal action or aspect of intonation e.g. "[*short laugh*]" "[*speaking faster*]"

In the Results section, when analysing the quotes, **bold text** was sometimes used to draw attention to a specific word/phrase spoken by the participant that was particularly relevant to the point being discussed.

4.2.7. Data analysis

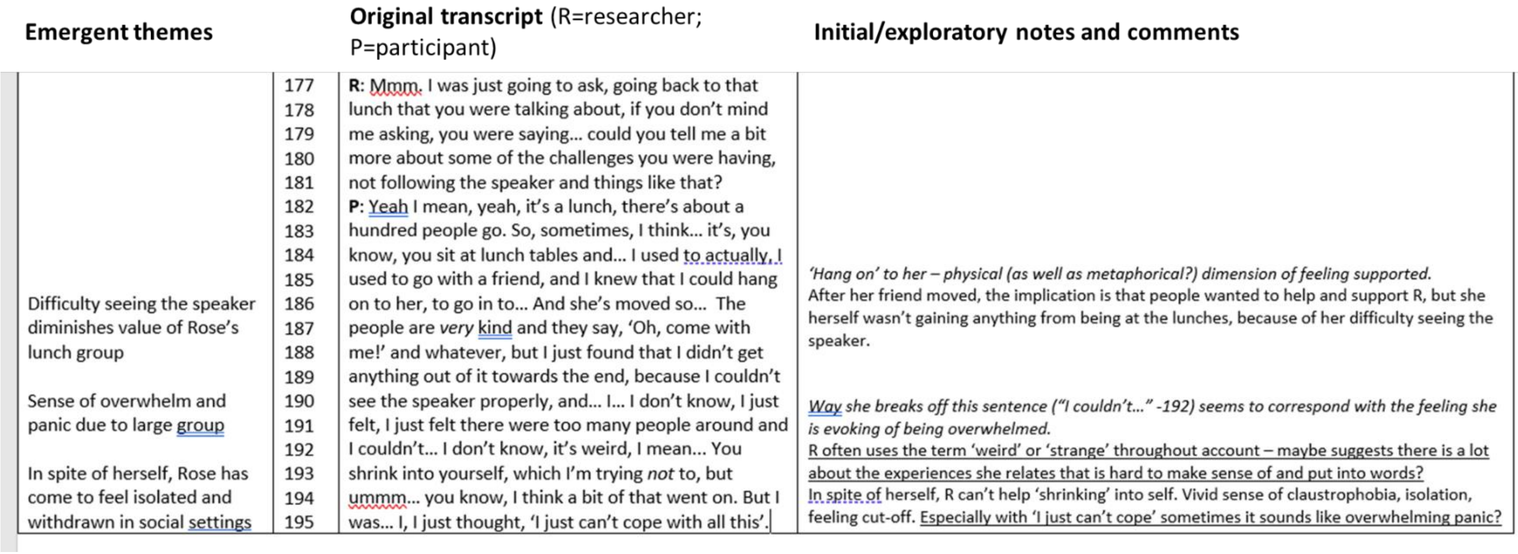
The eight transcripts were analysed using the steps outlined in detail below, as discussed by Smith et al (2009). It is important to note that in the second edition of Smith et al.'s guide to IPA, published in late 2021, there was a change in terminology (e.g. away from "emergent themes" towards "experiential statements"). I began analysing interviews in early 2021 before the new edition was published, and therefore was already using the first edition (2009) terminology. However, the second edition (2021) and the new terminology it introduced inevitably influenced my thinking at different stages, as discussed below.

(NB. Stages 1-4 were carried out on each transcript in turn. Stage 5 then took place once each of the eight transcripts had been analysed using Stages 1-4.)

- Stage 1 – Reading and re-reading: This first stage of the analysis following transcription involved immersion in the data through repeated readings of the transcript. I would listen to the recording alongside the first transcript reading, to help bring the transcript to life, since hearing the participant's voice and intonation, and the emotions these conveyed, helped with immersion in their 'lifeworld'. Some brief, often reflexive notes were made as comments in the margin when I was particularly struck by particularly salient, meaningful or complex aspects of the participant's account.
- Stage 2 – Initial noting: This stage involved writing detailed notes on interesting features of the participant's account with regards to their lived experience of AMD. The kind of comments recorded at this stage were descriptive, linguistic and conceptual. Descriptive comments tended to focus on synthesising the participant's

experiences and concerns, and exploring their meaning for the participant, particularly relating to their experience of AMD. Linguistic comments included commentary on particular word choice or figurative language such as imagery, similes or metaphors, and features of tone and prosody such as patterns of stress/emphasis, changes of pitch or speed, repetition or hesitation, and non-verbal features such as laughter. Conceptual comments aimed to go beyond the more explicit, surface meanings expressed by participants towards a deeper level of interpretation, "opening up of a range of provisional meanings" (Smith et al., 2009, p.89). Such conceptual comments were also sometimes more reflexive, encapsulating aspects of my encounter with the text. Smith et al. (2009) suggest such reflections can be seen as part of a Gadamerian dialogue between the analyst's 'top-down' pre-conceptions (which are inevitably present, however much there is an attempt to bracket these) and the more 'bottom up' understandings emerging from the encounter with the participant's lifeworld. Frequently, the conceptual comments were framed as questions, tentative ideas or possible interpretations that might further crystallise or develop in a different direction once other parts of the transcript were analysed (as per the hermeneutic circle). Examples of the initial, exploratory notes for participant Rose are shown in Figure 4, in the right-hand column; descriptive comments are shown in plain text, linguistic comments in *italic text,* and conceptual comments in underlined text.

Figure 4. Example of initial noting (Stage 2 – right-hand column) and emergent themes development (Stage 3 – left-hand column) for participant Rose

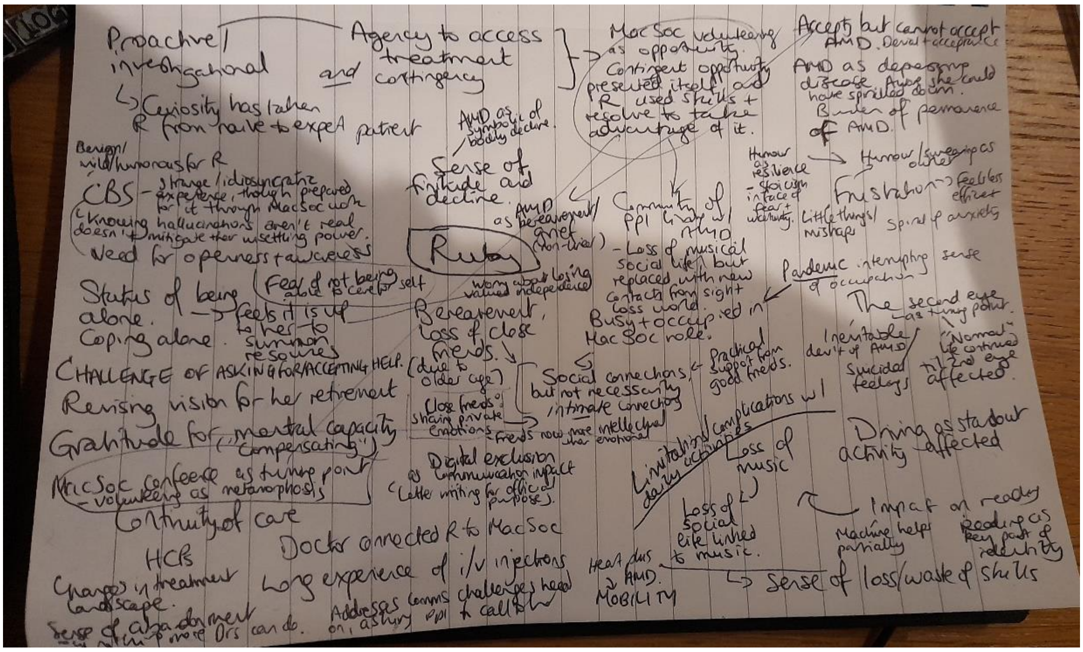


Emergent themes		**Original transcript** (R=researcher; P=participant)	**Initial/exploratory notes and comments**
	177	**R**: Mmm. I was just going to ask, going back to that	
	178	lunch that you were talking about, if you don't mind	
	179	me asking, you were saying... could you tell me a bit	
	180	more about some of the challenges you were having,	
	181	not following the speaker and things like that?	
	182	**P**: Yeah I mean, yeah, it's a lunch, there's about a	
	183	hundred people go. So, sometimes, I think... it's, you	
	184	know, you sit at lunch tables and... I used to actually, I	
	185	used to go with a friend, and I knew that I could hang	*'Hang on' to her – physical (as well as metaphorical?) dimension of feeling supported.*
Difficulty seeing the speaker diminishes value of Rose's lunch group	186	on to her, to go in to... And she's moved so... The	After her friend moved, the implication is that people wanted to help and support R, but she herself wasn't gaining anything from being at the lunches, because of her difficulty seeing the speaker.
	187	people are *very* kind and they say, 'Oh, come with	
	188	me!' and whatever, but I just found that I didn't get	
	189	anything out of it towards the end, because I couldn't	
Sense of overwhelm and panic due to large group	190	see the speaker properly, and... I... I don't know, I just	*Way she breaks off this sentence ("I couldn't..." -192) seems to correspond with the feeling she is evoking of being overwhelmed.*
	191	felt, I just felt there were too many people around and	
	192	I couldn't... I don't know, it's weird, I mean... You	R often uses the term 'weird' or 'strange' throughout account – maybe suggests there is a lot about the experiences she relates that is hard to make sense of and put into words?
In spite of herself, Rose has come to feel isolated and withdrawn in social settings	193	shrink into yourself, which I'm trying *not* to, but	
	194	ummm... you know, I think a bit of that went on. But I	In spite of herself, R can't help 'shrinking' into self. Vivid sense of claustrophobia, isolation, feeling cut-off. Especially with 'I just can't cope' sometimes it sounds like overwhelming panic?
	195	was... I, I just thought, 'I just can't cope with all this'.	

- Stage 3 – Developing emergent themes: This third stage involved working from the transcript and the exploratory notes of Stage 2, to develop “emergent themes”, concise statements of the phenomenological, experiential meaning of a relevant section of the transcript. In the second edition of Smith et al. (2021), the term “experiential statements” is used instead of emergent themes, to emphasise that the statements should relate directly to participants’ experiences. It is instructive to compare the example emergent themes in the first edition - e.g. “The questioning self”; “Lost self”; “Time period” (Smith et al., 2009, p.93) - with experiential statements in the second edition - e.g. “Best friendship is marked by the passage of time and sharing of experience”. These examples illustrate that experiential statements are more granular and specific than emergent themes, and more grounded in the idiosyncrasies of the individual participant’s experience (even if the example experiential statement is starting to move to stating something more broadly applicable about “best friendship”). The example emergent themes, by contrast, are somewhat more abstract and distanced from the participant’s experience. For this reason, while I continued to broadly stick to the former IPA steps and terminology, my emergent themes were arguably closer in character to experiential statements than to the kinds of emergent themes profiled in the 2009 first edition. Examples of the emergent themes are shown in the left-hand column in Figure 4.

- Stage 4 – Searching for connections across emergent themes, in order to develop superordinate themes (at the level of the individual): This stage of the analysis involved taking the list of emergent themes from the left-hand margin of the transcript, ordered chronologically, and purposefully randomising these, in order to look for new unexpected connections between themes, and to begin considering where and how the emergent themes potentially clustered together. I adopted two strategies at this point. Firstly, I would import all themes into a Microsoft Excel spreadsheet, and move these around into different columns when they seemed to cluster together in some way, in terms of overlapping experiential concerns and patterns of meaning, but also where the emergent themes represented opposite ends of an experiential spectrum (e.g. hope and hopelessness). Secondly, I would take the clusters in development and create mind-maps that might help further look for and pinpoint connections across themes. An example mindmap for participant Ruby is shown in Figure 5. This mindmapping process in turn helped with establishing the salient patterns and areas of overlap, and eventually abstracting and/or subsuming a large number of emergent themes into a small number of superordinate themes. For example, the 162 emergent themes developed from Ruby's transcript were eventually developed into four superordinate themes, with titles such as "AMD as a 'depressing disease': experiencing bodily decline and cumulative frustrations". As in Stage 3, although I used the procedure and terminology of the IPA first edition, I was influenced by the second edition and sought to preserve the experiential texture of the account, often by drawing on verbatim phrases of the participant which encapsulated the theme's core meaning. The superordinate themes for each of the eight participants in turn are shown in Appendix 7. (Note that in the new terminology, these superordinate themes are termed 'Personal Experiential Themes' (PETs), which makes explicit that the themes are located at the level of the particular person whose account is being analysed, and is directly related to their experiences. An example PET from Smith et al. (2021) is "The specialness of a best friendship" (p.95).)

Figure 5. Mindmap of emergent themes, aiding in the development of superordinate themes for participant Ruby (stage 4)



- Stage 5 (after all transcripts individually analysed) – Looking for patterns across cases, to develop a master table of themes (at the level of the group)[26]: After developing personal superordinate themes for each individual participant in turn, superordinate themes were developed at the level of the group by making connections across the superordinate themes of the eight participants. An example of how the group-level superordinate theme "The intensive effort of learning to live with AMD" was developed is displayed below in Figure 6. This was an iterative and recursive process, which began by surveying all the individual analyses at participant level and considering either where certain personal superordinate themes or sub-themes overlapped between at least two participants; or where a personal theme was so central or salient – even if only expressed by one participant - that I felt it needed to be preserved in the final analysis (where it then eventually became integrated with other participants' personal themes once the analysis moved to a higher level of abstraction). These candidate group-level themes were then sorted into clusters, producing an initial master table of group-level themes and sub-themes. This became the 'prototype' version of the template which was used in the Template Analysis discussed in Chapter 5 (see Appendix 12). A subsequent analysis then involved considering how these clusters of salient group-level themes could be refined into more coherent, higher-level group subordinate and superordinate themes, which would each be rich and substantive enough to encapsulate convergences and divergences in participants' experiences. At this point of developing the group-level subordinate and superordinate themes, I was mindful of Smith et al.'s (2009, p.107) suggestion that superordinate themes can be considered recurrent across the group if they are represented in at least a third, or ideally half, of participants. While important to be aware of and to indicate the recurrence of themes across participants (Nizza et al., 2021), equally it is important to encapsulate divergence and idiosyncrasy in participants' experiences, and integrating experiences which are not highly prevalent across the sample (but sometimes may even function as a kind of

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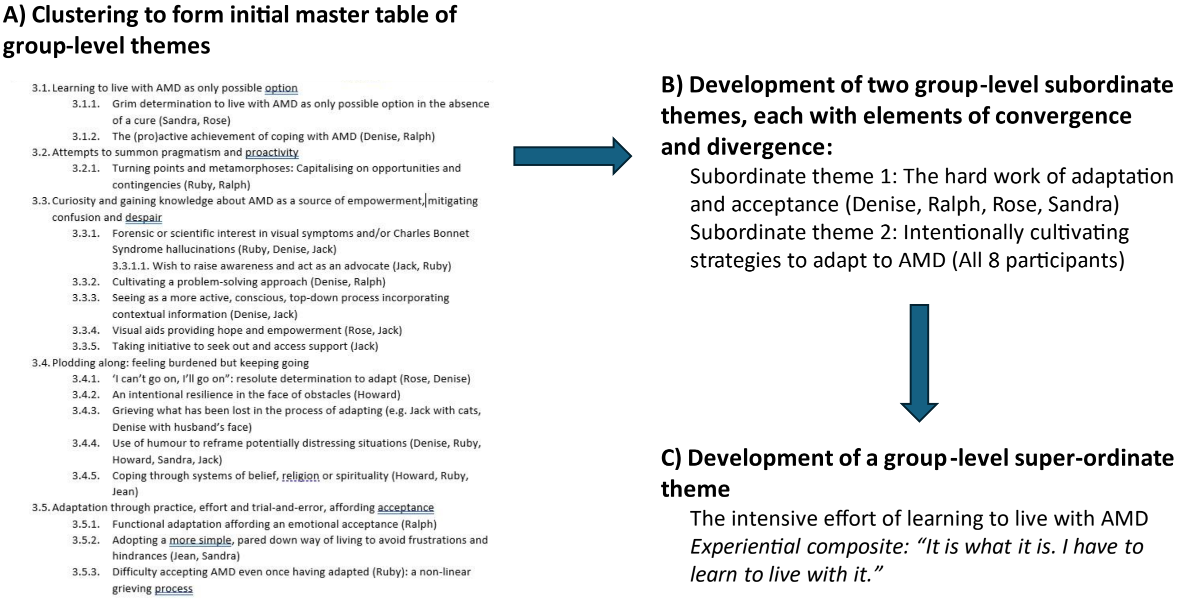
[26] In the new terminology, these are termed Group Experiential Themes (e.g. "There is a specialness to best friendship" – (Smith et al. 2021, p.102)), contrasted with the Personal Experiential Themes at the level of one individual participant. Again, while using the overall framework of the first IPA edition (Smith et al., 2009), in the description of Stage 5 I adopt the 'personal' versus 'group' terminology as a useful distinction for clarity.

‘exception which proves the rule’). Considering this recurrence criterion as a general, if not absolute, rule-of-thumb, I felt comfortable developing a **sub-**ordinate theme at group level if at least two participants spoke to this concern in some way (especially when knowing that there was still a higher level of more macro-level thematising I would subsequently have to undertake in order to develop the group **super-**ordinate themes). The group-level superordinate themes were then developed by clustering the group-level subordinate themes. This then organically meant that in the group superordinate themes, operating at a higher level of abstraction, at least half of, and normally most, participants were represented at some point within each superordinate theme (even if there was considerable divergence in participants’ experiences within these high-level superordinate themes). For some of the group-level superordinate themes, a kind of composite quote was formulated, that was not necessarily a direct verbatim quotation from a participant but which encapsulated the experiential flavour of the theme. The final master table of group superordinate themes (and the constituent group subordinate themes) is shown below in the Results (Table 5).

Figure 6. Example process of formulating theme clusters, subordinate themes, and superordinate themes at the group level (stage 5), for superordinate theme 2 (“The intensive effort of learning to live with AMD”; Section 4.3.2)



A) Clustering to form initial master table of group-level themes

- 3.1. Learning to live with AMD as only possible option
  - 3.1.1. Grim determination to live with AMD as only possible option in the absence of a cure (Sandra, Rose)
  - 3.1.2. The (pro)active achievement of coping with AMD (Denise, Ralph)
- 3.2. Attempts to summon pragmatism and proactivity
  - 3.2.1. Turning points and metamorphoses: Capitalising on opportunities and contingencies (Ruby, Ralph)
- 3.3. Curiosity and gaining knowledge about AMD as a source of empowerment, mitigating confusion and despair
  - 3.3.1. Forensic or scientific interest in visual symptoms and/or Charles Bonnet Syndrome hallucinations (Ruby, Denise, Jack)
    - 3.3.1.1. Wish to raise awareness and act as an advocate (Jack, Ruby)
  - 3.3.2. Cultivating a problem-solving approach (Denise, Ralph)
  - 3.3.3. Seeing as a more active, conscious, top-down process incorporating contextual information (Denise, Jack)
  - 3.3.4. Visual aids providing hope and empowerment (Rose, Jack)
  - 3.3.5. Taking initiative to seek out and access support (Jack)
- 3.4. Plodding along: feeling burdened but keeping going
  - 3.4.1. ‘I can’t go on, I’ll go on”: resolute determination to adapt (Rose, Denise)
  - 3.4.2. An intentional resilience in the face of obstacles (Howard)
  - 3.4.3. Grieving what has been lost in the process of adapting (e.g. Jack with cats, Denise with husband’s face)
  - 3.4.4. Use of humour to reframe potentially distressing situations (Denise, Ruby, Howard, Sandra, Jack)
  - 3.4.5. Coping through systems of belief, religion or spirituality (Howard, Ruby, Jean)
- 3.5. Adaptation through practice, effort and trial-and-error, affording acceptance
  - 3.5.1. Functional adaptation affording an emotional acceptance (Ralph)
  - 3.5.2. Adopting a more simple, pared down way of living to avoid frustrations and hindrances (Jean, Sandra)
  - 3.5.3. Difficulty accepting AMD even once having adapted (Ruby): a non-linear grieving process

B) Development of two group-level subordinate themes, each with elements of convergence and divergence:

Subordinate theme 1: The hard work of adaptation and acceptance (Denise, Ralph, Rose, Sandra)
Subordinate theme 2: Intentionally cultivating strategies to adapt to AMD (All 8 participants)

C) Development of a group-level super-ordinate theme

The intensive effort of learning to live with AMD
Experiential composite: “It is what it is. I have to learn to live with it.”

Although not a formal part of the analysis procedure *per se*, in writing up the themes, further refinement of the analysis inevitably took place when moving between the write-up, the tables of themes and the transcripts themselves. For example, certain emergent themes that had not necessarily been included at the later stages of the analysis process were sometimes re-included, or ended up being integrated into a different super- or-sub-ordinate theme than initially envisaged. In this way, the writing itself involved a process of continually moving back and forth between the group-thematic level and a more idiographic focus on participants' transcripts. As such, the writing-up could be seen as a final stage of the recursive analytic process.

4.2.8. Researcher reflexivity during data collection and analysis

A fuller discussion of reflexivity within the context of the overall PhD is included in Chapter 2 and Chapter 8. However, it is important to acknowledge the need for reflexivity to be embedded throughout the data collection and analysis processes, especially given the role of interpretation in IPA and its theoretical underpinning in hermeneutics. Indeed, the notion of the double hermeneutic posits that the researcher is involved in an active process of interpreting the participant's interpretation of their experience (Smith & Fieldsend, 2021). As an additional dimension of the double hermeneutic, Smith et al (2021, p.30) advocate combining a hermeneutic of empathy with hermeneutic of questioning (Ricoeur, 1970, as cited in Eatough & Smith, 2017); the former may be considered more affirming and taking the participant at their word, while the latter may seek to probe beneath the surface meanings and tentatively explore more latent aspects of the participant's account. These interpretative processes aim to bring possible new meanings to light; as per the Gadamerian dialogue referenced earlier, interpretation involves a fusing between our horizon of understanding as a researcher and the participant's horizon of understanding (Finlay, 2003; Shaw, 2010). However, in the dialogic process between previous understandings and the new understandings emerging, the researcher needs to be alert to and self-aware of their own preconceptions and fore-understandings, in order to be ready to embrace new understandings through the encounter with the participant's text. For example, I was careful about how far to discuss my father's AMD experience with participants, and whether to disclose this at all (and if so, at what point in the interview). While I was not a direct 'insider' in terms of first-hand experience of AMD, I often found it was positive disclosing my personal connection to AMD to participants during interviews. For example, I reflected after one interview that this disclosure “caused a shift to a more confessional rather than ‘information-providing’ mode from the participant” (extract from my PhD journal). However, at the analysis stage, I sometimes found myself having to take care to not overly privilege the more optimistic or hopeful aspects of the experience because of my personal leaning towards a strengths-based approach that is likely inspired by my familial connection. To guard against this, I sought to remain particularly close to the idiographic specificities of the eight participants, for example regularly returning to the individual participant analyses (Appendix 7) throughout the group-thematising process.

4.3. Results (write-up of themes)

Table 5. Table displaying group-level superordinate themes and subordinate themes

Superordinate theme	**Subordinate themes**
1. Reconfiguring a destabilised identity and struggling to find a new place in the world	• AMD as a frustrating condition that imposes new limitations • AMD shifting over time between the foreground and background of experience • Who am I now? Re-evaluating identity and self-concept with vision loss • An incongruence between the inner lifeworld and regard of others • “You shrink into yourself”: Isolation and the struggle to find belonging
2. The intensive effort of learning to live with AMD	• The hard work of adaptation and acceptance • Intentionally cultivating strategies to adapt to AMD
3. Navigating the hope-despair continuum	• Experiencing loss without losing it: Maintaining a precarious equilibrium between hope and despair • Metamorphosis: Emerging from the abyss of despair
4. Negotiating one’s place in the world	• Alone but not alone: the role of relationships in the experience of AMD • The power of support groups and sharing AMD experiences to foster a sense of belonging • Rootedness in place • Navigating independence and interdependence: Negotiations to remain included in a sighted world

4.3.1. SUPERORDINATE THEME 1: Reconfiguring a destabilised identity and struggling to find a new place in the world

“Who am I now, what is happening to me, who will I become, and where do I belong?”

This superordinate theme aims to encapsulate the questions of a destabilised identity and self-concept, and unsettled notions of the future, following the onset of AMD and vision loss.[27] Participants spoke of a feeling of incongruence between their inner

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[27] As will be discussed later, it is important to note that *diagnosis* with AMD and the *onset* of visual symptoms are – from an experiential point of view – two related but distinct phenomena. As Ralph states (in Theme 1.2), the future that an AMD diagnosis seems to herald can itself create a feeling of fear and doom for certain individuals even before they experience any significant visual symptoms first-hand. This temporal dimension is more centrally explored in the subsequent sub-theme, 1.2 (Section 4.3.1.2).

lifeworld and new sense of themselves, and how they were seen and understood by other people in their lives. In this way, AMD sometimes held a deeper meaning for participants beyond simply affecting their vision, bringing about a more existential reckoning with who they are and what they stand for. This superordinate theme encompasses existential doubts and questions participants implicitly or explicitly voiced, such as ‘Who am I now?’, ‘What is happening to me?’, ‘Who will I become?’ and ‘Where do I belong?’.

4.3.1.1. AMD as a frustrating condition that imposes new limitations

This subordinate theme encapsulates the varying degrees of frustration discussed by all participants regarding feeling newly limited and having everyday tasks and activities curtailed or becoming more difficult due to AMD relative to their life before. Frustration was explicitly mentioned by five participants as the recurring emotion characterising their everyday life with AMD. Denise characterised a “rough day” with AMD as “jolly frustrating”; Sandra stated, “It’s frustrating sometimes, it really is”; while Sylvia stated that when difficulties with everyday vision-related activities arise, it is “very frustrating”. When discussing the effects of AMD on her everyday life, Ruby described feeling overwhelmingly “frustrated”, stating,

> “… the main thing [is] *frustration*, because I cannot work as I once could.” (Ruby)

Here Ruby voiced feeling like a more limited and less efficient version of her former self; and following this quotation, she immediately went on to discuss her use of a reading machine, a low vision aid that magnifies text to aid with reading. The side-by-side juxtaposition of these two experiences suggests Ruby views her eyes (and by extension her body) like a machine that is no longer working at maximum capacity, needing to be supplemented with external physical aids. For Ruby, the mounting physical frustrations entailed by AMD – including ceasing driving, mishaps or accidents, or taking more time to undertake certain everyday tasks - seemed to be bound up with the status of AMD as a symbol of broader bodily decline and finitude:

> “The dry [AMD] is always there and… will cause deterioration, just like other parts of the body… all… deteriorate.” (Ruby)

Ruby's quotation, with its repetition of "deterioration" in a slow, hesitant tone, starkly illustrates how she perceives AMD and vision loss as a marker of a more global, existential sense of increasing physical limitation in the context of growing older and the passage of time. Ralph was somewhat more oblique on this point, but similarly discussed how the physical frustrations and accidents that may occur with AMD can trigger a greater emotional response than the event itself would ordinarily warrant:

> "I've done this before, I thought there's a table there and I put a cup of coffee down and there isn't a table there, I just dropped it on the floor! […] It has a hugely disproportionate crushing effect on you." (Ralph)

While Ralph did not elaborate further on this point, he described this scenario soon after discussing the longing many people with AMD often experience for things to be "as they were"; this would suggest he perhaps sees such accidents as reifying the effects of vision loss, providing a starkly physical illustration of the new limitations and mishaps that may accrue as AMD progresses.

Rose also discussed the wide range of activities she has had to give up because of AMD, conveying an overwhelming sense of feeling increasingly limited:

> "I can't go out on my own … because I can't even walk. Well I can *walk*, but I mean I can't walk out on my own […] so I can't… I can't do anything spontaneously, the way I used to." (Rose)

Rose begins the quote by saying she cannot even walk, but qualifies this to explain it is more that she cannot walk out on her own and be spontaneous. Thus it is not so much the case that she absolutely cannot do things, but instead she seems to be emphasizing the fact that an activity like walking has now lost the features that once made it enjoyable and meaningful. On an experiential level, it seems she cannot fully access the activity and find fulfilment in it as before, now that she feels more limited and less spontaneous. Ruby similarly related the frustration she experienced with the fatigue and laboriousness of using the reading machine to help read printed text, presenting a stark contrast to her former professional identity in which reading was a core element:

> "I was a lecturer in a college of education, and my main thing was teaching of reading. […] And now of course I'm stuck with this awful thing of reading word by word almost, which is another thing that frustrates me". (Ruby)

Ruby here illustrates the frustration of feeling limited in comparison to her life before AMD, and the sense of loss at finding herself now shut out from an activity in which she was once highly expert.

4.3.1.2. AMD shifting over time between the foreground and background of experience

This subordinate theme aims to encapsulate the strongly temporal element of all participants' accounts, encompassing the ways in which they experienced the effects of AMD as an event which brought into relief their past, present and future sense-of-selves and identities in the context of ageing. Participants' reflection on their past, present and future with AMD served to highlight how, as one phenomenon within the broader context of ageing and (frequently) co-occurring chronic illnesses, AMD was variously a more or less salient phenomenon at different points within their time living with the disease.

Participants Sandra and Denise both linked aspects of their daily life becoming more limited or frustrating to older age alongside AMD; for example, Sandra stated:

> "It's not only the eyesight, it's my age. Cos when I was young I'd do everything! […] I used to ski and everything. But I think it's my age more than the eyesight to be truthful … Because when you get older, you don't do things really... I did go with my friend to a social club, but it wasn't me, do you know what I mean?" (Sandra)

In this extract, Sandra suggests that not only because of her eyesight but also older age, "you don't do things really", with this sudden transition from adventurous activities like skiing towards a quiet life made to sound like a universal truism attributable to growing older. Indeed, Sandra's sense that the social club "wasn't me" perhaps suggests this older version of herself is not experienced as her 'true self' (which links to the feelings of incongruence between one's own subjective experience and the regard or expectations of others, discussed in Section 4.3.1.4). While in some instances, "do you know what I mean?" might seem to be a linguistic filler, at this point in Sandra's account it perhaps more concretely represented an appeal to an imaginary archetype of a social club for older people, within which Sandra did not see herself fitting. This might suggest AMD poses two interweaving threats to Sandra's identity, not only directly through the visual symptoms and their consequences for activities such as driving, but also because the condition is bound up, in terms of naming and aetiology, with biological ageing and so carries a label of 'older age' which feels somewhat incongruent. Denise spoke similarly about how age and eyesight might combine to affect her day-to-day activities:

> "And the other thing is, Jamie, you have to remember my age [*laugh*]. AMD does come with older people… I do have to say to myself, 'Oh for goodness sake, it's not your eyes, it's really, you know, you're just-- well I won't say I'm doddery, I'm nowhere near that, but you have to realise that some of these things are because you're slowing down. So, yes, it's a bit difficult to actually separate some of these things really." (Denise)

Here Denise suggested that the frustrations of sight loss can be hard to disentangle from other changes associated with ageing. As in other parts of her account, Denise hesitated over which word to use, for example disclaiming being "doddery", a word evoking stereotypes of infirm old age, but concluding that ageing as much as the vision loss she has experienced has entailed a "slowing down".

For some participants, AMD was one of many challenges they were facing in (later) life, such that it often existed more in the background of their everyday experience. This was particularly the case with Howard, who was living with tinnitus alongside AMD. On the two occasions when Howard had become particularly distressed about AMD, he attributed much of this feeling to his tinnitus:

> "It could be that my tinnitus had a major role to play in those two episodes where I went down, a bit depressed with the macular, with my sight. So I don't know. But I consider, I mean, my tinnitus is my… is my biggest problem." (Howard)

With his tentative language in this quote ("it could be..", "I don't know"), Howard alludes to the difficulty of parsing the "depressing" nature of AMD from the tinnitus. The tinnitus has always felt more threatening, overwhelming and constant, whereas AMD has only caused Howard particular distress on two specific occasions when he was already struggling due to tinnitus.

While Howard discussed the distress he experienced due to AMD as limited to two points in time, other participants living with AMD for longer discussed more synoptically how their experiences of AMD and sense-making around the condition had transformed over time. For example, in Sylvia's case, it was only once she developed wet AMD and began eye injection treatments that the condition became an intrusion on her daily life:

> "It [AMD] was quite mild to begin with and didn't really affect me. You sort of get used to having bad vision really. And then it really started when it turned into wet macular on one eye, I still had the dry on the other. That was, sort of, full on with injections and things like that." (Sylvia)

This quote suggests that for a long time, Sylvia became accustomed to "bad vision" but it was only when she developed wet AMD that the condition's effects became more "full on". As Sylvia's account continued, it became clear that AMD had tended to bring about periods of upheaval and distress very much in conjunction with other shocks in her life:

> "Really, I don't find it's a problem to me now. I suppose I've just adapted to it. […] But when the other eye went, I must admit, it did shake me. […] Because when the one eye went, I could still drive. But when the other eye went, the optician said, 'Oh you'll have to give up [driving]', and I realised I would. So it's a bit life-changing. And we moved from a house. My husband died. And we moved from a house to this flat, over the road. And I hated it to begin with. I mean that was quite a difficult time for me, with the eye problem, because it was a lot to take in. Going to a retirement flat, not driving, um… I didn't like the flat. And that was when I rang for the Macular [Society], for somebody to listen to me about it. It's like I needed somebody to talk to then. But now I've adapted to it, do you know what I mean." (Sylvia)

This extract demonstrates how Sylvia has eventually become "adapted" to AMD after an intense period of "life-changing" upheaval, when stopping driving due to AMD coincided with the loss of her husband and moving home. In contrast with her current positive appraisal of her home and living situation, the intensity with which she "hated" life in her retirement flat initially emphasises the profound sadness Sylvia felt at this time.

Participants' awareness that shocks that may accompany the ageing process – in terms of bereavements or other chronic health conditions – can complicate the course of AMD arguably intensified the future-oriented despair that many participants voiced. As Ralph stated:

> “It’s hard because… it [AMD] is not, ‘What is’, it’s what you imagine it to be.” (Ralph)

This succinctly encapsulates that the imagined future with AMD, and its eventual effects, can be a fundamental emotional challenge alongside the present, embodied effects of the condition. Ruby similarly discussed AMD as a “depressing” disease, with its incurable, progressive nature creating a sense of foreboding about the future:

> “You can’t see any future in it, because there’s no cure, is there? [...] So in a way, it’s a depressing disease. Cos you know that there’s no, probably – certainly in my lifetime – there’s no light at the end of the tunnel, really.” (Ruby)

The metaphor of the tunnel implies a spatial sense of claustrophobia, but there is arguably also a temporal aspect to the metaphor; Ruby implies that even as she has learnt to live with AMD after 26 years, without a cure there is a persistent sense of going deeper into the “tunnel” as time goes on, rather than at some point emerging into the light. The implication is that AMD for Ruby is particularly depressing because it does not follow the kind of typical, normative pattern for curable diseases where the individual receives treatment for the condition and then recovers, thereby emerging on the far side of the tunnel. Instead, the temporal experience of AMD for Ruby is remarkably non-linear, managing well with AMD in many ways while simultaneously continuing to experience AMD as a depressing condition. Both the anticipated and experienced effects of AMD have at certain points led Ruby to a point where she felt hopeless and had suicidal feelings, especially after her second eye was affected by severe vision loss. She summarised the doubts and questioning that accompanied these feelings:

> “And then you start to get very… not exactly depressed, but you start getting terrific anxiety. ‘What am I gonna do? Who’s going to look after me? Where am I gonna go?’, and so on.” (Ruby)

The rhetorical questions express Ruby’s sense of being at a loss for ideas and options, and her profound feelings of desperation and panic about a fundamentally unpredictable future. Casting forwards in time, Denise expressed very similar concerns about where she might end up:

> "The thought always comes to mind, is it going to… be fairly stable or will it eventually mean that… both eyes go. […] I mean, obviously I'm frightened as to where it's going to lead to." (Denise)

This quote illustrates Denise's apprehension about how far her vision will become affected, encapsulating that amid other uncertainties about the future, there is the added complexity that AMD can progress at very different rates for each person. Stating that she is "obviously" frightened imbues her feelings with a universal quality, suggesting that anxiety or fear is an entirely natural response in the face of potential vision loss.

In conjunction with this future-oriented perspective, there was also a pervasive sense of gradual loss and accruing limitations relative to the past self. For example, Denise stated, about finding it harder to recognise faces due to vision loss, "It's just a reminder that things aren't as good as they used to be." Tying together the past, present and future, Ralph (who has lived for 20 years with AMD) put himself in the shoes of other people early in the AMD course, discussing how their despair may stem from a feeling of becoming unmoored from their pre-AMD past alongside fears of the future:

> "You want things to be as they are, were, um you might feel angry, resentment, 'Why is it happening to me?'. And also not understanding what's happening, that's the big thing. The number of times I've been on calls and people say… 'I don't know what I'm going to be able to do. The doctor says it's going to get worse. Are the lights gonna go out? How am I gonna do this? How am I gonna do that?' And people start to get really really worried about it. And - I can remember this - it's sort of like, is the world closing in around you? The world, your world, is getting smaller." (Ralph)

This extract encapsulates the sense of claustrophobia, and the consecutive questions appear to demonstrate the uncertainties and fears for the future that might overwhelm someone contemplating the progression of their AMD. The "I can remember this" bridges between Ralph's experience of listening to other people with AMD confronting these fears in the present with his own past experience that was defined by a sense of the world closing in around him. Alongside the fearful regard for the future, there is also a painful desire for things to "be as they are, were"; the rapid pivoting between tenses here could imply yearning not only to return to a pre-AMD past, but also to stay rooted in the present, in the knowledge that the future holds possibilities of further AMD progression and vision loss.

4.3.1.3. Who am I now? Re-evaluating identity and self-concept with vision loss

Relating to the previous sub-theme of temporality, almost all participants – either explicitly or implicitly - discussed AMD as unsettling their previously taken-for-granted sense of identity and self-concept. Often their identity was initially destabilised by AMD when functional activities became disrupted due to vision loss. However, as time went on, this disruption sometimes brought into relief participants' more essential characteristics that remained intact, or that arguably became more salient and pronounced as they learnt to live with the condition.

Sandra, for example, suggested that the negative thoughts and feelings she experienced soon after diagnosis, regarding her future trajectory, felt entirely out of keeping with her previous sense-of-self:

> "In the beginning, I had really bad thoughts, to be truthful […] And I've never felt like that in all my life, I've never felt like that, ever, never... I'm quite an outgoing person." (Sandra)

Sandra emphasised the "really bad thoughts" she experienced when first diagnosed with AMD, which jarred with her sense of identity and self-concept, believing that as an "outgoing person" she could never experience such "bad" and negative thoughts. Ruby more implicitly voiced this sense of struggling to integrate the changes precipitated by vision loss with her overall sense-of-self, as a highly independent, self-reliant individual:

> "I'm not very good at asking people for help, that's one of the big problems of having lived on your own all your life, you think you can do everything, and you're very very independent, and it's a little difficult to contact people and say, 'I need help'. This is something that I've not yet learned to do." (Ruby)

This extract shows how asking for help with daily activities fundamentally challenges the independent, self-reliant identity Ruby has developed throughout her life, especially as someone who has always lived alone.

Howard's account also framed AMD as a threat to his identity, as someone who aspires to handle the shocks of life gracefully and stoically. This sense of AMD as a potential threat to his coherent sense of identity came across when Howard described attending a local Macular Society group:

> "And I am registered with the local [Macular Society] group up in [town name] but in fact I've only been to one meeting which was a relevant meeting, about macular degeneration. […] It's a lot of sort of very elderly people, you know, talking about my difficulty with seeing. Or where they're gonna have the next meeting." (Howard)

This extract suggests that Howard sees the other attendees as very different to himself, as "very elderly people" with whom Howard does not identify. It is noteworthy that Howard accepts that the group discussions do have direct relevance to him, since the group members "are talking about **my** difficulty with seeing", but even so he clearly does not experience a sense of belonging there. Given the multiple stresses he is managing from tinnitus and his caring responsibilities, it may be that voicing and dwelling on the vulnerability he feels due to AMD is not a helpful strategy for him while its impacts on his life remain relatively limited and contained, in contrast to the more salient problems he is experiencing in the here-and-now. Drawing together these extracts from Sandra, Ruby and Howard's accounts, there was a sense that the new objective realities of their life with AMD – such as no longer being able to drive, or asking for help with certain tasks - felt deeply incongruent with, or threatening to, their subjective sense of who they feel they are.

There was a sense among some participants that pre-existing, essential aspects of their identity could be initially undermined by AMD, through the loss of certain functional activities, but in fact came to be deeply affirmed as life with vision loss unfolded. Andrew had worked as a taxi driver earlier in life, and his identity as someone 'in the driver's seat' had continued to be affirmed throughout his time with vision loss. For example, he discussed his inherent, lifelong tendency to "get involved with things", a pattern that has now extended to his leadership role in several sight loss support groups:

> "I still keep involved in things and I know what's going on, I know the people that are in the [group forum], I know all the people who go to the meetings and things. All through my life I've always been involved with some sort of a committee or another, even when I could see." (Andrew)

Even as Andrew's vision has deteriorated, there has been continuity in this aspect of his identity, with a sense of belonging and leadership within groups clearly being important and meaningful for him. Somewhat in parallel to Andrew's account, Sylvia explained how her professional identity as an artist had evolved with vision loss, discussing how she had proactively changed her style of painting since the onset of AMD:

> "I belong to an art group. I was an- I'm an artist. And um, I had changed my way of painting. […] I've just recently done a painting in resin… where you can sort of just put the paints on and chase it around with a hot gun, …a sort of drier thing. And it's really good, I'm really quite pleased with how it's turned out… I used to sell my paintings, I think I could sell this one actually. But I don't want to, I quite like it myself!" (Sylvia)

Here Sylvia's happiness about her painting demonstrates a sense of confidence in her abilities, and her enthusiasm for the new approach to painting she has taken up. The joke about (not) selling her painting underlines that for Sylvia, this painting is on a par with her previous work, rather than representing any kind of decline. It is also interesting to see the change in tense at the start of the extract from "I was" to "I'm an artist", suggesting that being an artist remains a core part of her identity and sense of herself. Indeed, by changing her way of painting by using resin, this adaptation means she is able to continue practising her craft, and remain an artist not only in her identity but also as an active producer of art. Later in Sylvia's account, she suggested that the work she is producing now is more congruent with her authentic preferences:

> "I wasn't very detailed. I used to be detailed with eyes and doing portraits, I could do all that. But my main aim is sort of very loose painting. I don't like fiddling things, it's sort of, very wet onto wet and all done quite quickly, once I've done the face." (Sylvia)

Here, Sylvia suggests that while she used to produce portraits and more detailed paintings, her truer calling has always been towards a looser, more spontaneous and free style of painting. Therefore, it appears that the changes she has made in response to AMD and vision loss have to some extent affirmed her artistic identity and reoriented her towards the kind of work she always sought to produce.

4.3.1.4. An incongruence between the inner lifeworld and regard of others

The previous subordinate theme considered how identity could be both unsettled and affirmed over the *temporal* trajectory of AMD. Equally, participants frequently voiced challenges with how to identify as a person with vision loss, depending on the relational, social or environmental context in which they found themselves.

Often these challenges negotiating living with AMD in the presence of sighted others were attributable to the non-visible nature of AMD. For example, Denise stated:

> “There are some days when you go from the beginning to the end and you think, that’s been a really good day. I haven’t got cross with anything, I haven’t got frustrated… […] I do then think, I feel a fraud, because it’s gone so smoothly. And then I say to myself, ‘But there is something wrong with your eyes’. […] It sounds a bit bizarre, but I just feel that when they’re really smooth days, well I suppose I’m not thinking about it, so the sight’s not hanging over me.” (Denise)

This extract highlights the seeming mismatch between Denise’s day-to-day experience when her visual symptoms are not causing her any functional issues, and her overall awareness of herself as a person experiencing AMD and vision loss. This creates a sense of incongruence or “feeling a fraud”, a term which alludes to potential feelings of guilt or shame when she is not struggling. Part of the challenge also arguably stemmed from putting the complex, fluctuating visual symptoms of AMD into words. For example, Denise described the visual hallucinations she experienced due to Charles Bonnet Syndrome[28]:

> “I only see a bright coloured area, multi-coloured, and strangely enough, it always seems to appear as a sk-- – for want of a better explanation – a skirt, so it doesn’t matter if it’s a man or a woman, they have a panel across them as a skirt.” (Denise)

Denise’s account here alludes to the abstract, technicolour nature of the hallucination, with “for want of a better explanation” implying the challenge of faithfully conveying the essence of the hallucination in language. This is an additional dimension of the sense of incongruence individuals with AMD may feel, as it is challenging to communicate the visual experience in words in a way that allows for genuine understanding from others.

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[28] Charles Bonnet Syndrome (CBS) refers to visual hallucinations commonly experienced by individuals with vision loss. These hallucinations may range from ‘simple hallucinations’ such as flashes of light through to ‘complex hallucinations’ such as faces, animals or vivid scenery or landscapes. With CBS, the individual is aware that what they are observing does not have a material reality (Jones et al., 2021).

Rose highlighted a similar complexity, and the incongruence between how she appears to others to be functioning well and the often difficult, overwhelming feelings she experiences privately. Indeed, similarly to Denise, she spoke of the challenges linked to the non-visible nature of AMD:

> "I think the worst thing is that it's not obvious that there's anything wrong with you. […] It's a weird thing, because [people] look at you as if you're strange and say, 'Well you look alright, so, you know, you should be doing the things that you used to do.' That's kind of a challenge, shall we say." (Rose)

Here Rose evokes a feeling of being judged and invalidated by others, who do not understand the internal changes she is experiencing due to vision loss, changes which mean she cannot simply "do the things [she] used to do". At the same time, she felt that if she were to fully divulge her difficult experiences to others, it would either take her down the road of self-pity, or that other people would still not be able to truly understand and empathise with how she feels:

> "Cos people know that I've got it and I was going for injections, [and they ask me] 'How are your eyes?'… You just sort of say, 'Oh fine'. You can't explain, even my husband can't understand (or I'm sure he can't - he doesn't say) what I can't see. Of course I can see quite a lot especially when close to him. In the house I'm alright. So it's difficult saying to people what I can and can't do. I used to go on at length, but if people asked me now… Oh my god, I'm just boring them to tears, and so you just sort of say, 'Oh I'm fine, you know, I'm coping'." (Rose)

Here Rose explains that when other people ask about her eyes, she replies to say that everything is fine, because even the closest people to her like her husband cannot understand, and that if she were to explain everything in detail she feels like she would be "boring [people] to tears". Therefore, being pessimistic about the possibilities that other people will understand or take an interest, she consequently feels like the only alternative is to adopt a mask of coping for the sake of others. Like Denise in the previous paragraph, Rose suggests that it is challenging to put into words what she can or cannot do, and even when she does explain – in order to try to bridge the gulf between her own experience and how others perceive it - she feels as if other people cannot understand. This in turn may compound the sense of incongruence, this gap she feels between how she comes across to others and truly feels; and it seems for Rose that the gap feels impossible to close because of the challenge of expressing her changing visual symptoms, which fluctuate depending on the context.

Sandra also illustrated this sense of being in limbo, and the dilemma about how far to identify with and disclose her vision loss, when discussing situations where people have been rude towards her on the basis of assuming she has good vision:

> "Really I should get myself a white stick, I think, to show that I am… I'm not blind, but I can't see very well. I don't know if that would help me. I don't know. Perhaps it would. I don't know." (Sandra)

Here Sandra presents an ongoing dilemma that she is grappling with in 'real time' (highlighted by the repetition of "I don't know"), regarding whether to use a white stick to signal to others that she is sight impaired. Sandra conveys being in a liminal state where she does not necessarily know where she stands. While she admittedly cannot "see very well", using a white stick and thereby seeming to adopt the identity of being "blind" does not feel right for her either, creating a sense of being in limbo. Arguably, using the white stick could engender a feeling of incongruence between the image other people might have of her as "blind", and her own sense of still being the same person internally who just happens to see less well than previously.

4.3.1.5. "You shrink into yourself": Isolation and the struggle to feel included

One emotional consequence of this incongruence for certain participants was a sense of loneliness and isolation, in part due to perceiving a widening gulf in experience between themselves and sighted others. For example, Rose discussed feeling overwhelmed in group settings since the onset of her AMD, which prevented her from engaging in social activities and groups she once valued. She communicated feeling simultaneously isolated and overwhelmed in social settings:

> "I used to go with a friend [to a group]. But I just found that I didn't get anything out of it towards the end, because I couldn't see the speaker properly. I just felt there were too many people around and I couldn't… It's weird, I mean... You shrink into yourself , which I'm trying not to, but I think a bit of that went on. I just thought, 'I just can't cope with all this'." (Rose)

The way she describes “shrinking into herself” gives a sense of becoming a shadow of her former self, increasingly at a remove from others, despite challenging herself to resist becoming isolated. In this specific situation, these feelings appear to be directly related to the challenge of seeing the speaker amid the crowd of other people, with the entire experience becoming overwhelming. This theme of the loneliness attributable to AMD for Rose was further emphasised when she discussed the impacts of the COVID-19 lockdown:

> “It’s strange really, cos they put everybody in lockdown, and nobody could really do anything… So everybody’s in the same boat as you, so it was a strange thing… Really you weren’t being deprived of much because everybody else was in the same situation. And also, there was no pressure to go anywhere or turn up for things. So it certainly didn’t make things worse… It almost kind of lowered my anxiety. Which is a… bit odd. Everybody else was getting more anxious.” (Rose)

This quote suggests that once “everyone was in the same boat”, Rose felt a sense of belonging, in a context where her feelings of isolation no longer seemed unique. As Rose says, there was no longer pressure to go anywhere, and she therefore felt less uniquely isolated and could relax into her safe and familiar daily routine in her home, as opposed to the world outside that already felt threatening and overwhelming for Rose before the pandemic. This shines a spotlight on what is at issue for Rose with her AMD, namely that so much of her suffering is about feeling fundamentally different from sighted others, as if she were on her own on a different planet.

For certain participants, this potentially isolating feeling of feeling misunderstood and excluded from the world of sighted others had more of a dual quality; sometimes, other people’s failure to be considerate of their vision loss could entail simultaneous frustration and relief, highlighting the importance of context in determining how far they wanted their vision loss taken into account. Ralph summarised this tension:

> “So people who know you do appreciate that you have a difficulty. The nice thing is though that sometimes they forget you’ve got the difficulty, and just treat you like anybody else, and then at some point, I’ll say, ‘Hey guys, I can’t do that!’. So … it’s a two way thing, sometimes you think, ‘Bloody hell, they should know I can’t see that’, but on the other hand thinking that, ‘Oh no, they’re just treating me like anybody else!’” (Ralph)

Here, Ralph illustrated the seeming paradox of appreciating both when others are mindful and also forgetful of their (non-visible) vision loss in social situations. Ralph considered this process as a "two way thing", a dialectic where the positive sensation of being treated "like anybody else" can co-exist with a frustration that others "should know" better. Denise voiced a similar mix of frustration and appreciation:

> "I have over the years told people I have a problem, and quite a lot of them will say something and then say, 'Oh yes of course, you won't see it so well'. Like someone trying to show me a photograph on their mobile phone of their grandchildren or something, and you think, 'No I can't see that at all. I can't make any sense of it'. That's what I feel a bit uncomfortable about telling people, you know *[laughing],* you're wasting your time showing me this. But I do just say, 'I'm sorry but I really can't see it very easily'. Then they tend, you know, not to get the phone out really. I think… most of them know, but they don't fuss around me, I don't like fuss anyway." (Denise)

The start of this quotation implies that even when Denise has shared her vision loss with others, they will not necessarily consider her sight loss until a specific instance arises where Denise cannot easily participate, such as viewing a photo on a smartphone. Denise provides an insight into her inner monologue here, wanting to tell her interlocutor in a blunt, humorous way that they are "wasting their time", but in fact stating plainly and politely that she cannot see, which sends a clear message (because "then they tend not to get the phone out really"). This interaction demonstrates the social challenge and "uncomfortable" effort of continually having to disclose vision loss to others, but equally Denise wants to be clear that she does not want "fuss". Like Ralph, this implies she might be troubled by excessive focus on her vision loss, but this coexists with a frustration regarding others' lack of awareness. Indeed, certain participants discussed the paradox that other people might forget about their vision loss precisely because they had adapted well to the condition; as Sylvia stated, "Well I suppose because I've had it a long time, um, people don't… they forget that I've got it really. I've adapted to it, and people don't notice there's a problem, quite frankly."

This illustrates how identity as a person with vision loss due to the non-visible condition of AMD is in flux and highly contextual, rather than fixed, often emerging only when specific situations arise. Participants suggested that other people's understanding and consideration of the visual difficulties they faced could often help them feel more included and involved, but this coexisted with the wish in other situations to be treated no differently than pre-AMD.

4.3.2. SUPERORDINATE THEME 2: The intensive effort of learning to live with AMD

"It is what it is. I have to learn to live with it."

This superordinate theme aimed to encapsulate the effort, practice and intentionality that underpins adapting to AMD, with most participants expressing a stoical, pragmatic sense of finding AMD occasionally or frequently unbearable but feeling they have no choice but to learn to live with it. The superordinate theme also considers the different strategies and practices that participants put into place to either work round or through the practical and emotional challenges presented by vision loss.

4.3.2.1. The hard work of adaptation and acceptance

Five of the eight participants spoke explicitly of the importance of "learning" how to live with AMD, implying a dual process of both functional and emotional adjustment. Part of the impetus for learning to live with AMD stemmed from the incurable nature of the condition, which necessarily forced a stoical outlook on these participants. For example, Rose stated:

> "At the moment, it's a battle [*short laugh*], I'm battling every day, and every day is a challenge, let's say. […] It's not going to get any different so I've got to learn. You've got to learn ways round it." (Rose)

Rose's use of a battle metaphor firmly suggests this is her personal, lonely 'cross to bear', illustrating the intense struggle she faces to keep going. Later in the quote, the movement between "I've" and the generic "you've" perhaps implies the challenge Rose faces, of personally internalising what she more generically or abstractly perceives to be the most logical, pragmatic strategy to adopt. Just as Rose spoke of "ways round it", Denise similarly spoke of the need to "get round" the problems and obstacles presented by vision loss.

Like Rose, Sandra referenced the lack of a cure for AMD as a fundamental stimulus towards accepting AMD as part of her life. Sandra's emphasis on "learning to live with AMD" was particularly focused on the emotional and mental labour of learning to live with something that fundamentally feels deeply unbearable:

> "Well the thing is to learn to live with, cos at the moment there's not a cure, there's not a thing in the world I can do, and I think, well, some people are worse off than me. Some people are literally blind… A friend's daughter's got a little girl, she's gone blind, she's seventeen now, and I think that's terrible, that's so shocking… So I've had to learn to live with it. Sometimes, I don't-- I don't wanna live with it, I think, 'Oh no, I can't cope with this', but I have to. There's not a lot I can do." (Sandra)

Sandra's reasoning here encapsulated the tension between the seemingly intolerable nature of AMD and vision loss and the imperative to learn to live with the condition, starkly stating that there are times when she does not want to live with the condition but it is her only choice. The comparative reference to those who are "literally blind" and a friend's granddaughter who has developed visual impairment at a younger age reminds her she is not alone in experiencing a distressing and "shocking" event that she cannot redress. Sandra thus appeared to differentiate between her lack of control with regards to AMD, with no possible restitution in the form of a cure, and her capacity to determinedly learn to cope with her new reality. Her logic here called to my mind the paradox encapsulated by Samuel Beckett, 'I can't go on, I'll go on' (Beckett, 1953). Like Sandra, Rose alluded to the continual internal effort and struggle to learn to live with AMD, only possible through what she summarised as "sheer determination". Ralph also stated that in order to adapt to vision loss, "the trick is to work out what the method is that works for you", but he emphasised the sheer effort required to do so:

> "The older that you get, the less energy you've got to put into things. You don't necessarily want to *learn* to do new things." (Ralph)

Here, Ralph suggests that AMD and vision loss necessitates a learning process at a time of life when this may take up a greater share of the individual's energy.

Other participants were somewhat more muted and euphemistic, but analysis of their accounts attested to the considerable effort involved in summoning their pragmatism and proactivity to adapt to life with vision loss. For example, Denise, like Sandra, was clear but subdued about the distressing consequences of AMD, while reinforcing the necessity of learning to live with the condition:

> "Sometimes it upsets me when I sit opposite my husband and I can't always make out his features. That's strange. But it's one of those things that you just-- well you have to get used to them don't you, so, I just… just get used to them. I suppose it's just adjusting to it really and trying to accept that's what happened." (Denise)

Here, Denise presented adjusting to and accepting her new reality as the only possible option, with this very stark formulation of "you have to get used to them, so I get used to them". For Denise, becoming "used to" the changes wrought by AMD does not negate the sense of loss this process can entail; however, it is noteworthy that this process of accommodation to the changes is an effortful one, that involves "trying" to accept the situation. Indeed, towards the end of her account, Denise stated:

> "I think it's just a case of plodding along and seeing what turns up." (Denise)

At first, the process of "plodding along" could sound quite vague and almost passive. However, in Denise's case this is clearly a very active, intentional process involving sustained hard work and effort. We can therefore see Denise's stoical outlook as hard-earned and very active, even though sometimes the language used to allude to this process can be euphemistic. In both the latter two quotes, she often qualifies her experience with *"it's just a case of"*, an understated formulation that belies the profound emotional and cognitive efforts she seems to be making to adapt.

4.3.2.2. Intentionally cultivating strategies to adapt to AMD

All participants spoke of the practical work of learning to live with AMD and the initiatives they had taken which helped them to manage and, to different degrees, accept the frustrations and limitations they experienced.

For some participants, scientific curiosity and gaining knowledge about AMD could function as a source of empowerment or reassurance, mitigating confusion and despair. In a very direct illustration of how curiosity could help participants learn to live with AMD, Ruby discussed proactively investigating and accessing injection treatments for AMD when these were first becoming available in the mid-/late-2000s:

> "I had been doing a bit of research on my own about macular degeneration, and I'd heard about a possible treatment." (Ruby)

This is a clear illustration of how Ruby applied her sense of agency, curiosity and proactivity to capitalise on opportunities to undergo treatment, that has in turn made it easier for her to live with AMD. As another example, Denise adopted an almost forensic, scientific interest in her symptoms, which more indirectly appeared to help her to cope. This particularly came across when Denise discussed the visual hallucinations from Charles Bonnet Syndrome (CBS):

> "I learnt it was called hallucinations, or referred to as hallucinations. […] We just laugh, the postman's got a flower-coloured skirt on or something when I see him [*laughing slightly*]. It doesn't last for very long but it certainly wasn't something that concerned me, just fascinated me… I suppose I have a bit of a curiosity about some of these things, so it helps in a way." (Denise)

Denise emphasised at several points that these hallucinations do not concern her but just fascinate her. She appeared to attribute this fascination to her fundamental sense of curiosity about the world, but we may also interpret this curiosity as an active, conscious, intentional coping strategy that Denise adopts, knowing, as she says, that "it helps in a way". Her curiosity about the visual symptoms also appears to cohere with her more global sense of self outside AMD, having "always been quite observant with detail. So that helps me". Her vision may have changed but her identity is consistent, and she possesses a self-knowledge and analytical curiosity that she can proactively mobilise in the face of what can clearly often be a mystifying and unsettling constellation of symptoms. Similarly, regarding visual hallucinations from CBS, Andrew recounted moving from a place of incomprehension about what he was experiencing, to eventually understanding CBS and supporting others experiencing the phenomenon:

> "It's very strange, the first time I was trying to step over all these little chairs, I was trying not to tread on them, cos one I didn't wanna break them, and two I didn't wanna trip over! It is a weird experience, I've never had any other experience like it in my life. I can't explain it. Knowing that I think they're there, and they were really very very real to me." (Andrew)

Here Andrew captures the surreal nature of the experience, and the challenge of putting into words the discontinuity between the seeming material reality of the chairs and his subsequent awareness of having experienced a hallucination. Now informed about the aetiology of CBS, Andrew has become keen to reassure other people experiencing visual hallucinations:

> “Some of the old ladies at the Macular and the other clubs, they think they’re going mad when they see these things. They think it’s a sort of madness, it’s their brain. They don’t realise that it’s the message coming from their eyes that… the brain doesn’t understand. Even when they know about it, they still think they’re going mad. But I always tell them, ‘Don’t worry, it will go. It will disappear. It may come back in a different form, but it’s not anything to worry about. I don’t worry about it’.” (Andrew)

Andrew has therefore sought to use his experience of hallucinations to reassure others, illustrating his belief that knowledge about the source of the hallucinations (“the message coming from their eyes that the brain doesn’t understand”) can reduce the fear CBS may inspire.

Active, conscious processes of planning and organisation in daily life were referenced by all participants as ways to feel more hopeful and empowered in living with AMD, although for some it still remained a struggle to contain the frustrations of feeling limited by vision loss. For example, Rose was highly positive about embracing visual aids to help her with daily activities such as using specific glasses to watch television, and when discussing these there was a notable shift – at least initially - towards a more optimistic tone:

> “The glasses they sent have been brilliant. […] I mean, they’re like a telescope, um you know, it’s just amazing. So at least I can watch a bit more television. And the magnifier is good but it’s only a small one. […] They’re sort of helpful, but everything seems such a lot of trouble to find the right person, and… now they’ve got my notes, and then they haven’t got my notes, and sometimes [*short laugh*] you get exhau-- Everything, to be honest, everything seems exhausting, to do. But, anyway, it’s how it is.” (Rose)

Here, she describes the glasses that help with watching television as “brilliant” and “amazing” (while elsewhere in her account describes audiobooks as “an absolute godsend” and the iPad as her “saviour”). However, she then moves on to discuss how much effort and “trouble” it takes to find the right person and the right resource, an “exhausting” process.

This leaves Rose feeling equivocal as to whether the benefits of low vision aids justify the tiring efforts to access support. The cadence of the quote above illustrates a broader feature of Rose's account, which often brought to mind the image of a pair of old-fashioned weighing scales; sometimes there was a burgeoning sense of hope and empowerment, but this always risked tipping back towards despair and isolation. There was the sense that Rose is moving towards wanting to accept and embrace her new reality with AMD, and that she is sometimes able to access a more positive and empowered way of thinking about things, but overall still finds the experience incredibly lonely and difficult. In contrast, Ralph – who had lived with vision loss for almost twenty years and significantly longer than Rose – recounted how there are now only "four things" he cannot do, including driving and cycling alone (so he now rides on a tandem bicycle), but "apart from that, I can do everything else." Ralph discussed using visual aids like magnifiers and YouTube on his adapted computer, in combination with his memory, to find new ways to repair his bicycle, which illustrated:

> "the sort of lengths… that you go to… the care and attention that you have to do […] It might take me an hour to adjust the brake? Which would take a normal sighted person five or ten minutes." (Ralph)

This highlights the painstaking skill, concentration, effort and time involved in adapting his activities, involving trial-and-error and learning from what works and does not work:

> "The trick is to work out what the method is that works for you. And a lot of that is by… trial and error… You know, you learn by your mistakes". (Ralph)

Ralph's words here highlight the need for each individual to find workarounds and methods through "trial and error" that are specifically suitable for them. Somewhat like Ralph, Denise discussed recognising people's faces as a form of problem-solving, using contextual information in a top-down fashion to cope with the challenges presented by vision loss:

> "When I go out and I meet people, I often can't see people as such or recognise them until they're right up to me, going by their face. Their face is just quite blurry until really they're quite near and then I realise who they are. However, I realise that if you use body language, you know people how they walk, things like that… This doesn't apply all the time, but if you see people regularly, it's surprising how often they wear the same clothes, the same colour coat… So I've taken more notice of that by looking at people coming towards me… So that works." (Denise)

Denise's account here illustrates the intellectual problem solving that goes into recognising people now that her ability to recognise faces visually has diminished. It is an intensive process, noticing other people's body language, and piecing this together with her memory of their specific clothes, a kind of puzzle she works hard to solve. Despite differences in how far Rose, Ralph and Denise felt they had managed to adapt to AMD, all attested to the substantial effort required in the process. By contrast, Andrew was the only participant who overtly seemed to frame practical adaptation as a smooth and easy process, for example when he discussed adapting to using a white stick:

> "Well, I seem to have taken to it like a duck to water. As soon as I had the white stick, I just went out and I just carry it, it's just like normal for me now. I didn't have a sort of… transition period where I felt strange with it." (Andrew)

Comparing himself to a "duck to water" suggests the seamlessness of his adaptation to using the white stick, implying everything is working exactly as it should. Yet while his depiction of life with AMD appeared to be one with few hiccups, in this extract there is the hint that he has cultivated this ability to work at things and arrive at a pragmatic, proactive position. Saying that using the white stick "is just like normal for me **now**" implies that there was still a period where the cane was *not* normal and required some getting used to, even though he states there was not a significant transition period. Similarly, even when Andrew discussed accessing support from statutory Council services easily, as if it was merely a case of asking for support which quickly materialised, there was still a sense that this was made possible through proactive, conscious effort:

> "There's a lot [of support] out there but you've got to go and find it, it's not going to come and knock on your door! And I say that to a lot of people, that if you want to find out about something, you've got to go and find out. You're not going to get people knocking on your door saying have you heard about a radio station?! It just doesn't happen." (Andrew)

Andrew contrasted himself throughout his account with less proactive others, seemingly possessing a natural ability to be proactive but one which, looking beneath the surface, he has in fact worked to cultivate.

While these examples illustrate how participants found ways round daily hindrances, there were also examples of participants proactively paring back and simplifying aspects of their life in order to avoid situations where frustrations and feelings of limitation could arise. This was particularly the case for Sylvia and Sandra. Sylvia described how she now aims to keep life very simple and contained, and that this approach helps her to avoid frustration and feel more in control:

> "I would try anything at one stage, but I'm quite reticent putting myself into difficulties, I'm a bit more careful what I do... And I suppose age comes into that as well. […] I don't put myself into difficulties, let's say [*slight laugh*]. I keep life very simple, like with the television, I got rid of all the recording things so it's just on-off… Otherwise it's so frustrating trying to sort of see what you're doing. So I don't want to go down that one. And I keep things quite simple. It's a small flat, so I have not many cups and saucers, I know where everything is. I don't want to have to have frustration like that. […] I don't want to put myself into difficulties. I just keep things very simple… otherwise it's very frustrating. And I try to avoid that, because it's my life, do you know what I mean? I don't want to go down that one." (Sylvia)

In this quote, Sylvia suggested she structures her life and environment to be simple, in order to minimise situations where difficulties may emerge. Her language in the quote suggests awareness of other ways she could hypothetically choose to be living (perhaps the way she lived before the onset of AMD), but adamantly repeats, "I don't want to go down that one", as a more complicated life could overwhelm her, potentially opening up a Pandora's box of difficulty and frustrations. Instead, the emphasis is on everything being in its place to avoid frustrating situations. Stating "it's my life" towards the end of the quote emphasises her perspective that this adopting of simplicity and avoiding frustrations is what works for her (even if, it is implied, others might take a very different view of or be critical of this approach). Alongside Sylvia's proactive cultivation of order and simplicity, at other points in her account Sylvia also voiced a stoic fearlessness, two positions which may at first seem to be in tension:

> "You've got to have spirit as well. You can't just sit down on this thing [AMD]. You've got to, you know, go for it really". (Sylvia)

The fact that Sylvia holds this perspective in tandem with an emphasis on simplifying and paring down her life serves to highlight that this process of cultivating a simple life and routine has emerged from a position of pragmatism and intentionality, rather than avoidance. For Sylvia, it seems that simplifying her life is itself a form of proactivity and "go[ing] for it". Sandra also discussed how her life had become more simplified, but this had occurred in a somewhat more organic fashion when she moved back to the UK from abroad to have eye injection treatment for AMD:

> "It's only a little house I've got, like I say I've had bigger houses. […] I'm quite contented with having a little house and everything, it doesn't bother me. […] Now I'm not interested in material things, I'm more interested in my health. And that's what people don't realise, these people who have material-- they don't think of their health, they think everything's fine, until something happens, and that's it." (Sandra)

Here, Sandra suggested she has renounced a more materialistic way of life and finds herself "quite contented" with living in a smaller house which also seems to symbolise a simpler, less expansive life than she had previously lived when abroad. She thus suggests a reordering of her priorities since the onset of AMD; while she does not necessarily frame the simplifying of her life as an intentional, proactive act in the way that Sylvia does, it appears that Sandra is encouraging herself to find contentment in this simplified life as a way to live well with AMD.

A final key strategy that participants cultivated to sustain resilience and cope with the emotional consequences of AMD, particularly the frustrations, was by summoning internal resources, such as their sense of humour or religious faith. With regards to humour, all participants at some point in their account framed aspects of their experience with AMD as either straightforwardly or somewhat more 'darkly' humorous. Ruby's account was frequently humorous in a way that conveyed a stoical, resilient form of perspective-taking, for example discussing her approach to managing frustrations:

> "I have to be very careful, but I've got a very good store of swear words [*short laugh*] that come out when I'm alone – which I am mostly now - and this is the way I sort of get rid of it [the frustration] really." (Ruby)

Arguably, related to Ruby's sense of humour and capacity to reframe these potentially distressing situations as something funny, she also suggested that her mental sharpness has allowed her to "compensate" for many of the limitations imposed on her by AMD:

> "Everything has its limitations now, which before I didn't… [*trails off*] Thank goodness I've still got my mind -- at nearly ninety-seven I've still got my mind, and I'm able still to be active and

> contribute to the Macular Society… and so on. So that is a sort of, should I say, compensation [*laughs*] but, you know, that's it really." (Ruby)

Thus while Ruby voices in a matter-of-fact way that she is now fundamentally physically limited in ways that she was not before, she expresses (somewhat ironically) appreciation of the lack of mental limitations which allow her to make a "contribution". Andrew also focused on the humorous side when others described him as "blind":

> "I often joke with my wife that sometimes I'm walking along, and somebody will walk round me and I'll hear women saying to their little kids, 'Be careful, mind the blind man'. And I think to myself, well I'm not blind. But they don't know that, and I'm not prepared to stop and tell them, 'I can see you a bit but I can't see very well', so I just ignore it. [*Laughing*] I find it quite funny 'Mind the blind man', and I'm not blind. But I can't see them clearly." (Andrew)

In this quote, Andrew alludes to the incongruence between appraisal by others as blind, versus his own sense of himself being visually impaired but not 'blind'. The humour Andrew finds in this situation suggests his reaction to being read by others as blind is more one of absurdity, rather than offense or upset, for even though he cannot see well he still has some vision. Indeed, this fact that AMD rarely leads to total vision loss is something Andrew discussed holding onto as a source of reassurance, having been informed of this by the second ophthalmologist he saw (after the first erroneously told him he would go 'blind'). Alongside humour, certain participants' faith or spirituality helped them to cultivate a sense of acceptance and stoicism in the face of challenges posed by AMD. In Howard's case this was in the form of organised religion as a "committed Christian"; for Ruby, this was a more independent, agnostic form of spirituality, which impelled her to want to make something productive of her experience of AMD:

> "I've studied a particular person, and I have ways of thinking about the Earth, and how we've got to… work for the Earth, and that involves working for other people. And that I suppose is how I probably came to get so involved with the Macular Society… realising that we've gotta work, we've got to work to find a cure, we just have to." (Ruby)

Here, there is a real sense of zeal and mission in how Ruby discusses her work with the Macular Society, as being informed by her deep-seated belief system about the need to work for something larger than herself, and demonstrates how this keeps her motivated in the face of difficulties.

4.3.3. SUPERORDINATE THEME 3: Navigating the hope-despair continuum

While many participants discussed achieving a degree of adaptation to the effects of AMD and vision loss, this process was often in tension with the struggle to accept AMD at a more fundamental level; with participants often navigating a dynamic continuum between feelings of hope and despair, or loss and acceptance. Within this theme, the metaphor often came to mind of an abyss, with participants' description of different phases of their life with AMD implying that at times they were either teetering on the edge of the abyss, or had entered the abyss to emerge out of it, either temporarily or more definitively.

Notably, the same participant sometimes expressed finding or having previously found themselves in both these situations (i.e. either teetering on the edge of the 'abyss', or having emerged from it) at different points in their accounts of life with AMD.

4.3.3.1. Experiencing loss without losing it: Maintaining a precarious equilibrium between hope and despair

Denise's account particularly exemplified the tension between hope and despair, as she was managing to stay hopeful and prevent drastic consequences from AMD in the present but also aware that the future could become significantly more difficult. This tension came across when seeking to articulate the sense of loss she has experienced due to AMD:

> "Obviously I apologise if I don't recognise [people] straight away. […] But that's… not embarrassing cos I've got used to it now, but it is a bit sort of um… it is upsetting a bit, but it's not that drastic." (Denise)

Here, Denise seemed to be struggling to find the right words to use to illustrate the emotional impact AMD can frequently have on her, without overstating it (saying it is "upsetting a bit but not that drastic"). Indeed, throughout her account, there was a tension between Denise managing to prevent drastic consequences from AMD in the present and her awareness that in a different time and place, the experience could become a lot more difficult (for example stating at another point in her account, "Obviously I'm frightened as to where it's going to lead to"). Metaphorically, it is as though Denise were hovering on the edge of a precipice, glimpsing into an abyss where things are more "drastic", and where she could perhaps end up, were it not for her proactive management strategies of adapting and compensating. This notion of being on the edge of a potentially more “drastic” experience was further confirmed when Denise discussed how the ophthalmologist told her, with regard to her visual hallucinations, that she was “on the edge” of Charles Bonnet syndrome (CBS), and the outcome could go either way. As Denise stated, “It [the CBS] might get worse, or it might disappear”. Here again, Denise’s account conveyed a sense of being on the borderline of an experience that could potentially become more catastrophic. She is fully aware of the potential for things to change, but so far, her active coping and curiosity has pulled her back from tipping over into catastrophe.

While Denise’s account brought to mind the image of someone looking down into the abyss of despair but drawing herself back, other participants’ accounts often evoked a precarious equilibrium, where they might move in and out of states of profound despair, or where despair oscillated or coexisted with a more positive sense of hope and resilience. For example, Sandra referenced the “really bad thoughts” she had early on in AMD, but moved on to explain:

> “But it has got better… Sometimes I wake up in the night thinking, ‘Oh my god, my eyesight’. You know, I’m never gonna stop doing that, never. But I don’t have terrible thoughts like I did at the beginning.” (Sandra)

Sandra was clear in this quote that the particularly negative, “terrible” thoughts had receded, but that anxiety and trepidation about the future trajectory of her eyesight would always be a consistent feature that would “never” (emphatically repeated) stop worrying her. However, there was a sense here that these anxious thoughts in the present feel qualitatively distinct, and represent a positive evolution, from the more overwhelming and all-encompassing negative thoughts early on about how she could not carry on and live a life with AMD. Sandra’s account thus suggested the potential to enter into the abyss of despair, but then to later arrive at a point where despair was no longer so acute. Ruby’s account mirrored aspects of Sandra’s in some ways, although Ruby explicitly named the thoughts and feelings she experienced when her second eye was affected as suicidal:

> “When my second eye went… the first thing was, I won’t be able to… look after myself any more. That was my first thought. And… I’m not ashamed to say, I felt a bit suicidal… And because… I thought… I’m not going into a [care] home.” (Ruby)

Ruby here suggested that it was particularly fears of no longer being able to look after herself and live independently in her own home that were linked to her suicidal feelings of utter hopelessness and despair. Shortly following this extract, Ruby stated:

> "But, of course, injections came along, and everything wasn't as bad as I thought it was gonna be." (Ruby)

This abrupt, unforeseen development was reflected in Ruby's account by an instant, more upbeat change in her tone when she discussed how these injections to stabilise her vision loss prevented her worst fears from materialising.

This kind of dialectic between hope and despair was a consistent feature of Ruby's account, particularly with regards to discussing coping with vision loss as akin to the grieving process. On the one hand, she drew parallels between adjusting to AMD with grief following a bereavement:

> "When someone realises they've got macular, it's really the same sort of stages you go through as when you've had a bereavement. At first, you think it hasn't happened. You know, [you think] it will go away." (Ruby)

Ruby discussed bereavement extensively throughout her account, with reference to having lost many close, intimate friends, and also more implicitly to a loss of her identity as a keen sight-reading musician due to sight loss. In the quotation immediately above, she depicted adjustment to AMD as a staged process of grief which begins with a feeling that AMD will be temporary and will pass (akin to the 'denial' stage in the famous Kubler-Ross model).[29] However, at other points in her account, Ruby was clear that the process of grieving that comes with adapting to AMD and vision loss is often in fact less linear, when suggesting that she was still living with grief even despite developing resilience and coping strategies:

> "Shall I say, after twenty-six years, I've never really come to terms with losing my sight. I've never really been able to accept that this has happened to me. I'm still… trying to behave as though… it hadn't happened." (Ruby)

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[29] The Kübler-Ross model (Kübler-Ross & Kessler, 2014) refers to a model of moving through and finding meaning in grief and loss in five stages (denial, anger, bargaining, depression and acceptance). Organisations supporting people with visual impairment often include refer to this model in their support/education materials, e.g. https://www.rnib.org.uk/your-eyes/navigating-sight-loss/resources-for-mental-wellbeing/guides-to-good-mental-health/good-mental-health-sight-loss-five-stages-grief/

Even though Ruby generally discussed adjusting to and coping well with AMD on a practical level, this quotation suggests that on a more existential level, vision loss remains something that she cannot come to terms with and believe has actually happened to her. (To consider the Kubler-Ross grief model, she suggests that even after twenty-six years, she is still somewhat embroiled in the initial denial phase.) This may help to further explain why the effects of AMD on the second eye drove her into such an acutely intense, suicidal state of despair, because it brought home the permanence of her vision loss and took away any possibility of this new reality being transitory. Ruby stated: "When my second eye went, of course it was much worse. I knew it wouldn't go away." This stage of grief for Ruby was characterised by feelings of anger, guilt and self-blame:

> "And I got very angry. And I started feeling… guilty, about things. This seems to be a pattern that people go through. You feel guilty. 'Why did I do this? Why did I smoke when I was a student? Why didn't the doctors pick it up sooner?'" (Ruby)

In this quotation, Ruby sees these emotions as emblematic of a more universal grieving "pattern" that many people would relate to. Thus it seems that it helps Ruby to make sense of her despairing feelings as part and parcel of the grieving process; but her account also suggests that this is not a process she has been able to move through linearly, but one where many of the traditional emotions associated with grief remain in the mix, and make themselves felt in unpredictable and non-linear ways. Therefore grief and loss (at the despair end of the continuum) still characterise Ruby's experience of AMD, even while these feelings co-exist with a sense of resilience and acceptance (at the hope end of the continuum).

4.3.3.2. Metamorphosis: Emerging from the abyss of despair

While the sub-ordinate theme above highlighted the tensions between coexisting hope and despair in participants' accounts, there were also instances in participants' accounts where there were distinct turning points, a marked juncture where the despair subsided and a sense of hope and optimism was – either permanently or temporarily - restored. This was particularly the case for participants Ruby and Ralph who had each lived with AMD for at least twenty years. For example, for Ruby, the most painful, acute state of grief she entered into did not persist, in particular when she switched her focus to becoming an expert on AMD who could help others:

> “From there I went on and I trained as a trainer for eccentric viewing, and now I also befriend people with Charles Bonnet. in all that time then, of course I was finding out more about the disease, and that… began to occupy most-- a bit of my time. […] Otherwise, I think I would have just gone down and down and down. And become, well I don’t know, morose and… maybe, horrible.” (Ruby)

This quotation illustrates how Ruby could envisage herself potentially sliding “down and down and down”, in a spiral that risked not only making her “morose” but also negatively affecting her way of relating to other people (making her “horrible”, implying a sense of bitterness). However, there came a point where she was able to find a way out of this state, impelled by curiosity and a sense of mission to become an advocate for people with AMD. Indeed, this was conveyed most vividly when Ruby was offered the chance to become a volunteer speaker for the Macular Society, which she described as:

> “my saving grace. And that turned my life around, and made… then… my great liability into something constructive.” (Ruby)

The quasi-religious language of “saving grace” implies that Ruby experienced this volunteering opportunity almost like a divinely ordained stroke of luck. However, this volunteer speaking role allowed Ruby to draw on her experience of public speaking from her occupation as a college lecturer, and it was clear that she ultimately viewed herself as the central agent in undertaking this metamorphosis, stating: “And now I’ve actually turned my life around.” Indeed, the unusual first-person phrasing of “**I’ve**… turned my life around” (as opposed to the earlier phrasing of “**that** turned my life around” in the quotation above) places Ruby at the centre of this transformation, and conveys the sense of empowerment she has found in bringing her energy and skillset to her Macular Society volunteering. Interestingly, Ruby’s mindset of capitalising on what can be reclaimed from AMD continues to inform her volunteer work helping people with AMD to maximise their remaining capacity to read (a technique called ‘eccentric viewing’[30]):

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[30] Eccentric viewing refers to looking at objects or text off-centre, to the side, in order to make use of intact areas of vision (often involving the peripheral vision which is much less affected by AMD than central vision).

> "There is this way of reading. And trying to make them feel that they too can make something constructive out of… what they've got". (Ruby)

This confirms the central importance for Ruby of people with AMD like herself feeling that with effort and proactivity, there are avenues to forge something constructive out of the difficulties caused by AMD. The language implies a sense of generativity, with Ruby using her skills and experiences from throughout her life, and the long period of time that she has lived with AMD, to nurture and support others.

Ruby's account had strong parallels, both thematically and linguistically, with Ralph's account of experiencing – in his words - a "metamorphosis, if you want to call it that…". Ralph had reached the lowest point in his AMD journey after about ten years, when AMD came to represent "the end of the world" for him. It was precisely the story of a GP on one informational video Ralph received from the Macular Society that encouraged him to get involved with the charity, because he identified so strongly with the experience and mindset of the GP:

> "One of these was from a guy who was a GP, who'd got Macular, and his story was very similar to mine. He reached a point where he thought, 'Crumbs, my sight's getting that bad that I can't drive, I can't do what I normally want to do, I can't work as a GP'. And so, he says, 'I made the mistake of, sort of, retiring prematurely'. And he says, 'It was only after a period of time', he says, 'that I started to make adjustments and realised, I could do most of the things that I could do before!' And I thought, bloody hell, that's me! [*exhilarated tone*] That's really me!" (Ralph)

This extract demonstrates Ralph's strong identification with the GP, and the sense of hope and energy that the GP's story imbued in him, specifically relating to the fact that changes and adaptations to functional activities suddenly seemed possible. Ralph presented this episode as a turning point, and the hope engendered by his identification with the GP enabled Ralph to undertake the hard work of adapting to AMD. Indeed at the time of the interview, Ralph presented his adaptation to AMD as a *fait accompli*, with a secure, clear self-knowledge in terms of the functional activities he can and cannot do. He discussed his "metamorphosis", occasioned by contact with the Macular Society, as one characterised above all by practical adaptations:

> “And then bit by bit, I started to adapt my lifestyle, to the point that now, the only things that I can’t do that I would have done before is… drive… [and] to ride a bike by myself, so I have a tandem now. Er there’s three things, oh, four things… There’s watching live sport, as… I can’t see-- I can’t go to a football match, cos I can’t see the players… and play racket or ball games. So apart from that, I can do everything else.” (Ralph)

The extract illustrates Ralph’s precision in terms of quantifying the number of activities vision loss now precludes, stating that across all other domains of life he has learned to adapt to the changes. This is a synoptic, birds-eye view of the process of adaptation, which sounds very neat and seamless, but at other points in his account he described the grief he felt at different stages of his journey:

> “And then I realised what was possible and how it would be possible for me to live a fairly normal life. There’s no magic formula to it… I describe it as very much like if you look at the seven stages of the grieving process. When you lose your sight, it feels very much like you’ve lost… Well you have lost something valuable and precious that you love, and… you know, you do go through the process of getting angry, you know, being in denial, bargaining, saying ‘Well if I do this, if I live this way, can I do that?’… Um, negotiating with yourself and with others, and then looking for different options, choosing an option and then, you start to adapt your life and then accept it. And that took, two, three years something like that, maybe longer than that, I don’t know, I’ve never really analysed it!” (Ralph)

In this extract, Ralph like Ruby equated adapting to sight loss with the staged Kubler-Ross model of grief, movingly comparing losing sight to losing someone you love, because of how valuable and precious sight is for him. For Ralph, it was the uncertainty about how he could continue to live functionally that was at the heart of his grief and distress caused by AMD, and once he felt he had adapted practically and functionally, this gave him a more secure sense of acceptance. Towards the end of the interview, he stated:

> “As I say, it’s like somebody who’s died… How am I ever going to get over the loss of this… but you do. It… it’s not just the passage of time, it’s also your state of mind changes, and you make it change because you… you want to find ways of moving on, of getting on, of maintaining as good a quality of life as you possibly can, given the limitations of central vision loss.” (Ralph)

This extract clearly encapsulates Ralph's view that the sense of loss that early on in AMD may feel insurmountable can in fact be overcome, once inherent limitations are accepted and the person pragmatically finds ways to adapt. He is very clear that this is a very active, intentional process, whereby the person has to change their state of mind rather than assuming that time will passively work its "magic formula". This therefore echoes Ruby's account when she stated, "And now I've actually turned my life around." While both Ruby and Ralph acknowledge elements of happenstance and support from others, they also positioned themselves as engaged and proactive agents, who had to make considerable efforts to make practical changes and thereby extricate themselves from despair.

4.3.4. SUPERORDINATE THEME 4: Negotiating one's place in the world

This superordinate theme considers how participants experienced AMD within their relational, social and physical environments, and the ways in which sight loss had changed their ways of relating to the people in their lives and the wider world around them. There was a sense that AMD had changed the horizons and scope of both their physical/material and relational/social worlds, and navigating through these changes involved "negotiating" different physical, relational and social obstacles and challenges. Participants discussed both explicitly and implicitly how the people and environments surrounding them could create challenges in their everyday lives with sight loss, but could also provide forms of support and a safety net that cushioned them from certain forms of difficulty.

4.3.4.1. Alone but not alone: the role of close relationships in the experience of AMD

This subordinate theme focuses on participants' consideration of their significant relationships, and how they navigated the continuum of feeling alone but also not alone in their experience of AMD and sight loss. Even participants supported by a loved one such as a spouse to whom they felt close often still discussed the processes of coping with and adapting to AMD as something they went through alone.

There were several instances in which the participants referred to their spouse or partner in a way that fused themselves and their loved one, encapsulating the effects of

AMD on them as a pair, as a “we” or “us”. For example, Howard described himself and his wife Susan (who herself was living with chronic illness) as an inseparable but in some ways isolated unit, who could not necessarily count on family or social support from outside but depended heavily on each other:

> “Unfortunately we have a very very bad relationship with our family, so that we have very very little to do with them, or it’s more true to say they have very little to do with us. Which is one of the great sadnesses. It’s probably the biggest sadness of our life actually. So the answer is actually, no I don’t share it with the family at all. For me, you know my lifeline really is Susan. And I can share anything with, with her. She’s… she’s not well and so we sort of work on the basis of two halves making a whole [*short laugh*]. Two damaged halves, but nevertheless, making a whole.” (Howard)

In this extract, Howard encapsulates the sadness about his and Susan’s estrangement from their family, and highlights that he and Susan are entirely interdependent, as “two damaged halves… making a whole”, working together in the face of chronic health problems with limited outside support. Denise referred throughout her account to her “exceptionally supportive husband”, with whom she can discuss anything:

> “I’m very fortunate, because my husband and I can talk about anything, so if something weird-- well not weird, but if I misinterpret anything visually, I would say, you know, that looks like so-and-so, but now I know it isn’t.” (Denise)

Here Denise suggests that she and her husband can discuss the more profound emotional challenges of AMD, but her husband can also help in instances in daily life if she “misinterprets anything visually”, implying a dual role for her husband in providing both practical and emotional support. For Denise, it appeared that relationships with her husband but also with friends and other family members helped to buffer her from some of the worst impacts of AMD and stop things tipping over into catastrophe (as discussed in Theme 3.1 (Section 4.3.3.1) above). She also stated:

> “We’re lucky having the hospital in [town] which is more like a cottage hospital. […] And it also means that people don’t have to go too far. For us, it’s only twenty minutes away. So that’s another blessing, you know, it’s not a day’s outing, so that’s another good thing. But I can see how if you’re on your own and… what have you, it could be very frightening. Very frightening.” (Denise)

In this quote, it is noteworthy that Denise began talking about the hospital by saying “**we**’re lucky”. That could seem like a generic “we”, referring to people in the area, but then it becomes clearer that this “we” refers to Denise and her husband specifically, with the “for us”, and then with a sudden shift to thinking about how frightening it would be to go through the experience alone. The language here really brings home how Denise and her husband experience AMD as a conjoined “we”. With Andrew, the strength of his connection with his wife and the way that they experienced AMD jointly as a pair came across more implicitly, through the ‘process’ as much as the ‘content’ of the interview. It emerged halfway through the interview that Andrew’s wife had been present throughout, and the extent of their interdependence came across at many different points in Andrew’s account. Andrew’s wife would sometimes interject during the interview to provide additional details, or laugh along or confirm the details of anecdotes Andrew was recounting. Their seamless sense of working as a team came across clearly when Andrew discussed his treasurer role at one of his groups for people with vision loss:

> “I’m the treasurer for that group. My wife helps me quite a lot with the… I keep a record of what money’s arriving and what’s paid out. And my wife writes it all in the bookkeeping ledger. So she does all the writing, but I keep the accounts in my head.” (Andrew)

This quote neatly summarises the clear division of labour, with Andrew and his wife each playing to their strengths and having their own domain where each takes ownership. At points in the interview, Andrew talked about himself and his wife as one person, to the extent that he stated (when discussing having previously had cats), “We have never been a dog person”. Indeed, the close bond between Andrew and his wife came across non-verbally throughout the interview, with Andrew’s wife often inputting into the conversation in a way that demonstrated how intertwined their lives are. At the same time, while Andrew clearly highlighted his wife’s sensitivity and consideration of his needs (e.g. “my wife is always very very careful not to put things on the floor anywhere”), he also discussed how aspects of his AMD and vision loss can also still pass her by:

> “And even my wife-- we’ve been married nearly fifty years. And several times I’ve said something to her, and then I think why isn’t she answering me, and then she’ll look round and say, ‘Oh I’m sorry, I shook my head’. She shook her head. So even after living with me

> with this AMD for seven years, she'll still sometimes forget or she'll shrug or nod her head, and she sometimes sort of forgets that I can't see her!" (Andrew)

This extract demonstrates that despite the closeness of bond between Andrew and his wife, and their sense of almost constant companionship, Andrew's wife can still forget he cannot always pick up on non-verbal gestures like a shake of the head. This arguably alludes to the continuum or paradox of being alone and not alone with a condition like AMD; while Andrew is very strongly supported by his wife, such a fusing of horizons between the person with AMD and their loved one, in terms of fully sharing in their visual experience, can inevitably never be absolute. Andrew's wife being present in the interview acted as a vivid, embodied illustration of their closeness. By contrast, other participants voiced being close to their spouses or partners but often discussed their relationship in more instrumental terms. For example, Ralph stated:

> "If I was living by myself when I got this, I could see social isolation being a real problem. But my wife acts as, you know, my carer and supporter. So things like in the kitchen, where I put things down on the side of the worktop because I haven't judged where the worktop is compared to where I put the plate and… she just walks past and pushes the plate up." (Ralph)

This vignette of Ralph and his wife in the kitchen seems to highlight the seamlessness of her support for him, subtly rearranging things to help. He also stated: "I tend not to drift very far from my wife when I'm away on holiday", which underscores her anchoring presence. There was little discussion of the more internal dynamics of their relationship, but instead Ralph focussed on the pragmatic, everyday support provided by his wife which clearly gave him a sense of security and assurance.

While humour was previously discussed in this analysis as a resource that participants intentionally cultivated as part of their adaptation to AMD (Theme 2.2, Section 4.3.2.2), many of the participants discussed humorous interpersonal interactions centring around the effects of AMD and sight loss. Indeed, the same limitations that were a source of frustration or distress for participants could at other points in their account be transformed into something humorous, often through interpersonal interactions with loved ones. This pivoting from the challenges of AMD to finding humour in the situation was particularly clearly illustrated by Sandra:

> “And when I write now, I don’t write straight, I write crooked, like a child [*ironical laugh*]. It’s your eyesight that does it, you know, you’re lookin-- I think I’m writing straight but I’m not. And my other half, he goes, ‘You’ve written this like a drunk person’, I went, ‘Ooo next time I’ll have a drink’ [*laughing*].” (Sandra)

In this extract, Sandra began by recounting how sight loss has affected her writing, comparing her writing now to that of a “child”, implying that the challenges with certain functional tasks caused by AMD symbolise a kind of deskilling or regression to childhood. Sandra then described her partner injecting humour into the situation, suggesting her writing looks like the work of a “drunk person”. The notion of being drunk and having a drink implicitly presents an alternative to the idea of the crooked writing as a childlike regression, and signals a more upbeat and empowered tone compared to the start of the extract where Sandra had been speaking in a more downcast tone. This darker humour, finding laughter in the face of challenges, also came across when Sylvia discussed the sense of mutual support between herself and her deaf partner:

> “We laugh, my partner and I… He’s got a flat downstairs, and we sit outside when it’s been sunny, and if somebody’s coming down the path, I’ll go, ‘Who’s that you see?’ And he tells me. And he’s deaf, so [*laugh*]… I have to tell him what people are saying, so we have a bit of a laugh about it.” (Sylvia)

Sylvia’s laughter here (both expressed while she was speaking and also in the episode she recounted) demonstrates the humour she is able to access in certain situations, sharing a sense of camaraderie with her partner. Sylvia describes her and her partner finding the humorous side in their situation, conveying a sense of mutual support and solidarity as they each help each other to see or hear things respectively. Andrew and his wife also discussed finding a shared joy and humour in aspects of his AMD and vision loss:

> “You’ll find this funny, she’s just put two fingers up to me [*Andrew’s wife laughing in the background*]. Often I can’t tell if she’s putting one finger up or two fingers up, this is the joke we have… I can’t tell how many fingers she’s putting up so I don’t know how bad I’m being [*long laugh*].” (Andrew)

This extract highlighted the humour co-created between Andrew and his wife, conveying a degree of joy and silliness in vision loss and its consequences, arguably bolstering the sense that this is something with which they can cope together.[31]

It is important to note that there were participants who appraised their close relationships in different and arguably less positive ways, in terms of how their relationships affected and were affected by their experience of AMD. As Rose stated (discussed in Theme 1.4, Section 4.3.1.4):

> "You can't explain, even my husband can't understand (or I'm sure he can't - he doesn't say) what I can't see. Of course I can see quite a lot especially when close to him." (Rose)

Pertinent to the present theme is the fact that Rose described her husband as being supportive in many ways, but a gap in understanding nonetheless remained between them. Rose also discussed a sense of guilt towards her husband, feeling like she was letting him down and that her vision loss had derailed the vision they shared for retirement:

> "I think one thing is, it does affect your relationship with your husband, or wife, or… I don't know if other people find this. I mean, my husband's really really good, he'll shop, he'll do anything, but in a way, he's lost *me*… you know, as the partner who they used to be that-- […] We wanted to do the big holiday – we've done *a lot* of big holidays, so I don't miss them, but… he still wants to do the big holidays, and he's very active and wants to sort of still be out there, whereas I'm… suddenly not interested, so I do feel it's affected him, and I feel sorry for that. You know, he's had to curb a lot of his plans, let's say, because of me. So that's one of the worst aspects of it, I suppose. I mean he's very good, he shops, drives. As I say, we do go out together. So it's fine. But it does change the dynamics, I suppose, of the things we expected to do. Because obviously now we're retired. He's got great plans for whatever we were going to do, and now I'm just not interested, because I know I wouldn't enjoy it and I can't see it properly, so you kind of… are a bit of a wet blanket, let's say." (Rose)

At the start of the extract, Rose began by pointing out generally how AMD may change relationships with the person's "husband or wife", before moving to discuss how her own

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[31] It is also noteworthy that Andrew invited me to join in on the joke too (inviting me to see the humour when he said, "You'll find this funny"). As a reflexive note, this was the point when I realised that Andrew's wife had been present throughout our whole phone interview. Therefore as opposed to laughing, I was in fact feeling nervous about the methodological and ethical implications of her presence in the interview. I discuss this point further in the reflective paper on the telephone interviews (Enoch et al., 2023; Appendix 2).

identity as a "partner" now feels different, with a sense that this is no longer a partnership of equals, with Rose feeling like she has become "lost" to her husband as the partner he would recognise. There is a sense of deep regret and sadness that Rose feels she cannot join in the plans with her husband as she would have liked, which comes across with full force when she describes herself as "a bit of a wet blanket". It is notable that Rose suggests her husband has never explicitly voiced any disappointment or negative reactions about how their life has changed; but instead she describes herself as somewhat fading out of aspects of their relationship, becoming an absence and hindering their shared plans. Thus even while her husband's observable behaviour speaks to his support for Rose, she assumes that she is somehow dragging him down, reflecting a negative view of herself. Relevant also to Section 4.3.4.3 below, there is a sense of Rose's geographical space becoming very closed down with AMD, in the opposite direction to her husband who still has the "grand plans" and hope for "the big holidays" in their retirement. Discussing how they manage this challenge together, Rose stated:

> "Sometimes he [Rose's husband] says, 'You'll be alright when you get there'. At the beginning, he used to keep saying, 'Oh you'll get better, you know, you'll get better', cos he didn't really understand. Ummm… I suppose we plod along, is what I'd say for that one. I do try, and I do do things that I, you know, wouldn't be bothered to do, but… he's very very fit, and you know, he would like to do a lot more than we do. So it's just a matter of acceptance really." (Rose)

This extract underscores Rose's feeling that her husband never quite keeps up with understanding what she is going through, but it also somewhat redresses the balance between them when compared with the previous quote. In this latter quote, there is a sense that Rose and her husband meet each other halfway, in that she feels like he would like to be doing more, but at the same time she is doing things she otherwise "wouldn't be bothered to do" for his sake. Here "we plod along", a term used by Denise earlier, sounds euphemistic, but as Rose divulges here, there are very challenging and effortful processes involved in maintaining this uneasy form of equilibrium. Interestingly, Rose's firsthand experience of this relational challenge was somewhat echoed by Ruby talking second-hand about the difficulties couples might experience due to AMD. Ruby herself was single and had never married, and felt things to be more difficult for those with a partner, although in a different way to that discussed by Rose:

> "I find it's more difficult if they [other people with AMD] have got a spouse. […] And I've found this more than once. When someone has got a husband or wife, they overprotect them quite often, and don't allow them to… take a bit of risk, really, in trying to do things." (Ruby)

Ruby is speaking from her experience of volunteering and meeting other people with macular disease, in particular one episode witnessing an overprotective husband who made assumptions that his wife would not be able to make decisions about her own capabilities. In many ways, this represents the opposite to the challenge experienced by Rose, whose husband was encouraging her to do things which she felt were beyond her. However, Ruby's observation could speak to the broader difficulties that couples may go through when the person with AMD and their partner cannot fully 'meet' and establish a shared understanding of the AMD experience.

Beyond couple relationships, participants often mentioned friends as sources of support but went into very different levels of detail about the ways in which friendships featured within their experience of AMD and vision loss; some made more generalised statements about their friendships or social life, while others spoke in depth about certain specific friendships. In the first category, Denise, for example, stated:

> "All my friends are very supportive. Obviously I'm not a bad case if you know what I mean, I don't really need too much help. But I would be able to ask them for help if needed. And going across the road I don't need any help, but I really have to concentrate on that and be aware of it. Um… I can discuss things with my friends. I don't, I haven't had any need to discuss anything like depression or anything with them." (Denise)

In this extract, Denise clarifies that her friends are generally supportive, but suggests she does not heavily rely on them. When discussing crossing the road, the implication is that doing so without help from others demands a heightened level of concentration and awareness on her part. This shows that she chooses to 'go it alone' as much as she can without taking up offers from friends, while aware that this option of support from friends is potentially available. While Denise always seems to be aware that things could be worse in future, in the present she guards against reliance on her friends, in part because (as she stated following this extract) it is above all with her husband that she can talk about anything. Howard somewhat similarly suggested that he felt able to be more open about his experience of AMD than tinnitus, but nonetheless in practice did not necessarily discuss his experience with people beyond his wife: “I don’t share my um er… visual problems with [friends] at all. I don’t talk about it”. For some participants, bereavements meant that there were not necessarily close friends at hand with whom they could discuss the experience of AMD even if they might want to. For example, Ruby stated:

> “I mean I really haven’t got any, what I would call, ‘close friends’ any more... […] A close friend as in someone with whom you feel quite comfortable in, you know… talking and expressing maybe private things, you know, feelings and emotions.” (Ruby)

Ruby here defines close friendship as an experience of profound comfort and openness, where any more private, intimate feelings can be shared. Indeed, while Ruby discussed extensively how she engages with friends, neighbours and acquaintances, who provide practical support (“people who offer me a lift. Um, very good friends”), it is clear that she saw this as a distinct phenomenon from genuine close friendship (despite describing these people who give her lifts as “very good friends”). With many of the individuals she socialises with now, such as through her philosophy group, she stated that the engagement is “more on an intellectual level”. While she clearly relishes this kind of intellectual discussion, this represented a marked change from discussion of “feelings and emotions” that formerly took place with close friends. AMD had also restricted her circle of friends because much of her social life revolved around playing in music groups, which she had to give up when she could no longer sight-read music. However, through her engagement with macular disease and vision loss groups, she had also gained new social contacts:

> “I’ve lost contact with people that I would have been with had I still got my sight, I suppose. But I’ve gained, in a way, because I’m now involved in our local blind society…” (Ruby)

This extract echoes other segments of Ruby’s account where she discussed her contribution to groups like the Macular Society as a kind of “compensation”, with a sense in this present extract that despite the losses there are new connections she has gained through her engagement with sight loss groups. At the same time, the tone with which she recounted this sense of balancing was somewhat ironical and resigned; this hints at the deep existential challenge of no longer having close friends in later life, even if there are still many positive and supportive – if somewhat less profound and enduring – connections in her life who equip her to cope with some of the challenges of AMD. Like Ruby losing contact with her friends from music, Rose had also experienced a feeling of her social life shrinking, with vision loss making certain group activities overwhelming for her:

> "It diminishes, I suppose, relationships with friends. I used to do coffee with a big group… I don't do that now. […] I used to do an aerobics class once a week. And there was a big group of us, that were… we were good friends-- you know, not friends, as in-- just acquaintances when you meet people like that. I just don't see that group of people now. And I used to do an art class, and I don't see that group of people now." (Rose)

In this extract, Rose - like Ruby - differentiated between acquaintances and friends, although her hesitancy here about how to define and label the other members of the groups ("not friends, as in, just acquaintances") perhaps underscores the challenge of verbalising what these people and membership in these groups previously meant to her. She clearly feels the absence of these social groups, and it seems that even though she did not necessarily feel close to the constituent individuals, there was something meaningful about her involvement in these groups, symbolic of her more dynamic social life before sight loss. Indeed, she highlighted that friendships outside groups, on a more one-to-one basis, had also become more challenging since stopping driving due to vision loss:

> "Family life is fine, cos we've got a very close-knit family, and we meet up when we can. […] Friends, it's more difficult, cos… your spontaneity goes. […] It's all wrapped up in Covid as well, but before Covid, because I couldn't drive … I wasn't driving if my husband wasn't here. You know, you're kind of trapped. I couldn't just ring someone and say, 'Oh let's go for a coffee' … the spontaneity goes, so, you know… so it kind of loses its appeal. And, you know, I have a couple of good friends that understand and I arrange with them, but… it has affected the relations with friends, but not family, definitely not family." (Rose)

In this extract, Rose recounted how she felt "kind of trapped" because of no longer being able to drive, reducing the potential for more spontaneous socialising, which Rose suggests is part of the "appeal". She suggests that she has retrenched to a smaller group of "a couple of good friends that understand"; notably, she has felt able to open up to a friend living with AMD and other health issues as well:

> “Yeah, I’ve got a friend and she has got it [AMD], but […] she’s a friend who’s had a lot of health issues as well, who I feel like I’ve… supported. So we kind of support each other, as far as the mental aspects of it. […] She’s one that I can, you know, go through all the frustrations and things like that [with]… but there aren’t a lot of people you can be that open with. […] They [other people] don’t know what to say-- they can’t say anything because they don’t understand it. I’m not saying people are cruel, not at all. People are very kind. But you know, they can’t say anything, so it’s no good going on about it.” (Rose)

In this extract, Rose highlights the mutually supportive nature of this friendship, being clear that with this friend she feels able to be fully open about the “mental aspects” and “frustrations” of life with AMD. The contrast is made with other people who may be very kind and well-intentioned but still lack first-hand understanding and insight of how it feels to live with AMD. Rose notably includes her husband and family in this latter category, stating:

> “We’re a very close family, it keeps me going. But then I don’t think they really understand what I’m going through, let’s say, internally, cos I don’t put too much on them. They do help you to cope, but you need somebody who really understands what it is… to be able to open up to them. It is a difficult thing for people to understand I think.” (Rose)

Thus for Rose, her closeness with her family does not necessarily align with the feeling of being understood and the ability to be truly open about the experience of sight loss, highlighting the importance of connecting with friends with comparable experiences. It also implies a kind of fundamental boundary, in that no matter how supportive Rose’s partner or family members may be, a gap in understanding will remain that can only be bridged through relating to a peer with parallel experiences. Like Rose, Ralph spoke extensively about particular friendships and their value in helping him come to terms with vision loss. In his account, he suggested that part of his ability to adapt to AMD within his social world had stemmed from having people close to him whom he could ask for help:

> “Unless you’ve got some sort of network of support around you, I can see quite how easily I could get into the situation of thinking, ‘Oh that’s too difficult to do. I don’t want to bother… other people’. I mean… a good example is this… my pal who - he was a work colleague, but we’ve been going out cycling together for nearly thirty years –and when I said I couldn’t go cycling, he says, ‘Well’, he says, ‘Have you thought about a tandem?’. And I says, ‘Yeah, but you wanna go out by yourself, you wanna go out with the lads’. He says, ‘No I tell you what. If

> you get a tandem, I'll pilot it and you go behind'. And we've had it for… seven, eight years, we go out every week on it, we go all over the place." (Ralph)

In this extract, Ralph discusses the importance of having caring, supportive people around which has enabled him to try new things, rather than becoming more limited by fears of tasks being too difficult or worries about bothering other people (as Rose described happening). Ralph initially thought that his friend would not want to keep cycling with him, because Ralph would slow him down; but it is clear that Ralph's friend was supportive and was the one who proactively proposed the tandem. At the same time, Ralph is clear that there is a virtuous circle between having supportive people around, and the person with AMD feeling able to ask for help, and these factors combining to create a sense of feeling valued and understood:

> "What I'm getting at Jamie, is if you don't have that [supportive people around you], you don't ask, and if you don't ask, then people don't understand… […] So, yeah, I've no problem with that, but some people one, might have a problem to ask other people, and two, might not have other people to ask". (Ralph)

Here, Ralph encapsulated the vital importance of – and expressed gratitude for - having supportive people around and having the ability to ask for help, the two mutually-reinforcing preconditions in his view for feeling well supported and understood.

4.3.4.2. The power of support groups and sharing AMD experiences to foster a sense of belonging

Two participants, Ralph and Andrew, were particularly deeply embedded in macular disease and/or sight loss groups, and Ralph recounted in detail how crucial a role group support from peers with AMD had played in his "metamorphosis". Ralph suggested that his transition to a mindset focussed on future possibilities with AMD was very much due to learning from the experiences of others:

> "That [acceptance] was not through some sort of self-enlightenment - there is an element of that - but what it was through was through talking to others who'd experienced, who were experiencing something like myself." (Ralph)

Ralph suggested it was less about the changes to his own mindset as an individual (although these did play a role) and more about being exposed to the stories of others, which propelled him on his journey towards acceptance. He describes his first Macular Society group meeting as feeling like,

> "…being immersed in a warm bath […] because it was the very very first time – and I'd lived with this for the best part of ten years – where I'd actually met any other people who'd, one: who'd got not necessarily the exactly the same as me, but they'd got central vision loss. And two: where, when we were talking, everyone understands what you're talking about and how it feels. That is hugely, hugely powerful, hugely powerful". (Ralph)

The comparison of the group to a warm bath encapsulates the sense of homely comfort and relaxation he felt on joining the group and discovering that other people were living with comparable experiences. The repetition of "hugely powerful" at the end of the extract reinforces how meaningful it was for Ralph to connect with others with a shared experience of central vision loss. The groups also clearly appeal to Ralph as someone who is eager to keep learning about, and to share his tips on, how to live well with macular disease:

> "I mean to start with it's interesting, because you're learning things from other people… and of course, you realise that you can impart some knowledge, or hopefully a gem of… 'Have you tried doing this?', to people. 'Ooh yeah that's a good idea!' So it's a two-way street." (Ralph)

This attests to the importance of mutual support and exchange of knowledge within the groups, with the word "gem" implying that a small tip could end up being potentially transformative for someone's adaptation to AMD. Although Rose had only attended three Macular Society group meetings at the time of the interview, she also valued this function of the groups:

> "I've joined the local group, but of course with Covid that can't meet… So I'm looking forward to that getting back actually. Because I think you get more information from other people who've got the disease and then you can… swap notes." (Rose)

Here Rose explicitly makes clear that much of the value of these groups is learning from other people with AMD and exchanging ideas. In parallel, Andrew spoke of the central role sight loss groups play in his life, but by contrast with other participants he often tended to focus more on the logistics and composition of the groups. Nonetheless, as someone with a lifelong tendency to "get involved with things" it was clear that membership in the group was a way for him to find common ground with others:

> "Yeah, I do feel quite an affinity with *all* of the groups. I feel that I understand some of their problems the people that-- Some people that I've met who have been blind since birth. I can't really *imagine* living my life not having been able to see." (Andrew)

Here Andrew evokes a shared bond and understanding among people in the groups, even with the group members visually impaired from birth whose experiences Andrew acknowledges to be highly distinct from his own.

There were however divergent experiences of such groups, and it was not a given that a specific group would be the right fit for each individual with AMD, depending on their personal history and their journey. As discussed in Theme 1.3 (Section 4.3.1.3), Howard did not necessarily identify with other members of the Macular Society group he attended, and more generally expressed finding excessive focus on symptoms and problems (especially for his tinnitus, but also AMD) unhelpful. While Ralph had forged a close bond with members of his Macular Society group, he recounted the experience of a younger woman (with vision loss from a form of macular degeneration affecting younger individuals, known as Stargardt's disease) to illustrate the challenge certain people may face when joining a group for the first time. As Ralph stated:

> "She was at the start of her journey. We were all part way through ours, at various stages, which we needed to be to join the group. She wasn't ready to join the group. […] [There is a lot] of gallows humour, you know, cos we're talking about walking into bus stops and that sort of stuff. And then there are people falling about laughing even more. So, people coming up with the daft things happening to them you see, which we've all had, and we're all trying to outdo each other. And she just couldn't cope with it, because as I say, she hadn't gone-- and as I was saying to you, her vision loss might have been very similar to mine. But her approach to how she was dealing with it, and mine, might have been very different." (Ralph)

In this extract, Ralph illustrates the ways in which the in-group bonding and dark humour about dealing with the day-to-day consequences of vision loss might be overwhelming for someone attending the group for the first time without having already developed some degree of coping and acceptance. Ralph subsequently went on to make the point that soon after diagnosis, individuals are not ready “to laugh and joke about it”, and instead are looking to find “routes… to be able to lead a normal life”. He acknowledged that other group meetings on a different day might have been more suitable for this new member, and he is clear that he and other group members tried hard to support her, to help her “understand that we understand what she was feeling like, because… that is the biggest thing”, highlighting the value of these group meetings for fostering a sense of belonging and mutual understanding. Ralph clarified that “understanding” is not only about supporting each other with the emotional challenges of the condition, but also more pragmatic and instrumental given the low levels of awareness around macular disease:

> “Until I joined the Macular Society, I thought I was the only one person in the world who had it! Or understood about it! I’d never met anybody who had macular disease.” (Ralph)

This quote could imply that some of the loneliness of living with AMD may stem in part from it feeling like an unfamiliar, unknown condition, such that when people like Ralph are diagnosed they are not aware of how many other people are living with the condition and going through similar experiences.

While clear from these extracts that sharing experiences with other people with AMD was particularly beneficial, Sylvia reflected on coming across a local spiritual group, rather than a group specific to AMD, which helped her through her lowest ebb:

> “**Jamie:** … What do you think helped you to adjust in the end?
>
> **Sylvia:** I think it was time, really. And I did different things. I did things that were local, that I could walk to. I belong to the spiritualist church. They’re not open now, but that was a life changer actually. Because they did hands-on healing, and… when [my husband] died, I noticed this advert, and that was within walking distance, so I thought, ‘Oh, I’ll pop in there’. And they were all so lovely, and I thought, yes, I felt quite at home there, with the hands-on healing. They taught you [that] you could talk about anything.” (Sylvia)

Here, Sylvia highlights the role of spiritual support in her recovery from the multiple losses she experienced, and the importance of a support network rooted in the immediate local area. Sylvia conveys a sense of community and compassion in this church, and suggests they helped her feel more able to open up and to “talk about anything”. Her account also implies the importance of these groups and networks being “local” and close by, which might make it easier to explore and try out a group, in order to see if the individual feels a sense of belonging there.

4.3.4.3. Rootedness in place

This sub-ordinate theme aims to encapsulate a phenomenon described by all participants to varying degrees, in terms of feeling like their environment, their geographical world, had become less expansive since the onset of vision loss, particularly – but not solely – due to stopping driving.

At the most fundamental, micro level of the individual, only one participant Ralph explicitly discussed the claustrophobia entailed by living with vision loss and feeling like the world was "closing in" (discussed in Section 4.3.1.2). More commonly, the sense of becoming somewhat closed off from a wider world was discussed by participants with reference to ceasing driving. Unanimously, participants discussed stopping driving as a major change in their life attributable to vision loss, and on a practical level it represented a loss of convenience and spontaneity (for example, as discussed by Rose in Section 4.3.4.1, where she talked about no longer driving as an impediment to spontaneous arrangements with friends). For some participants, particularly Sandra, driving cessation was felt to symbolise a deeper loss of agency, freedom and independence. Sandra recounted how she had previously driven alone when abroad and now, being partially sighted and no longer driving, has to rely on others. She stated:

> "Driving was everything to me, everything… everything. You'd go out, get in the car and go! But I can't go on my own, now I can't do it. I sometimes go by bus shopping, but I don't like it very much to be truthful. Actually I… I don't, I don't like it. That's the only thing that really got me was the car... That's the real thing… it's independence isn't it. You can do exactly what you wanna do, you haven't got to rely on someone else to take you. But they [relatives] have been good, I can't say they've not… They've been really good." (Sandra)

This extract encapsulates the treasured central place of driving in Sandra's life, with the very emphatic repetition of "everything" at the start of the extract conveying the overwhelming sense of loss and change relative to her life before AMD. She then disclosed, at first tentatively and then much more decisively, that she does not like using public transport. For

Sandra, the car represented independence and spontaneity, a way for her to instantly act on her wishes and decisions, to be an agentic subject in a way which no longer feels available to her. Even though her family are supportive, they cannot make up for this deep personal loss. Similarly, Sylvia described stopping driving as “a bit life-changing”, with giving up driving precipitating a particularly distressing period for her. Both Sylvia and Rose highlighted the way in which it was only when their second eye was affected by AMD that they had to stop driving:

> “I was able to sort of carry on until I got it in the other eye, and then I had to sell my car and give up driving. So now, I’m sort of very dependent on other people.” (Rose)

In this way, stopping driving marked a major turning point in their AMD journey, with Rose in this extract suggesting a sudden transition to becoming “very dependent” on other people after ceasing to drive. Sylvia similarly recounted how, on a practical level, driving was a means of engaging in a variety of meaningful activities. Therefore, giving up driving meant having to stop attending her art class and visiting certain friends who were only accessible by car:

> “[Giving up driving] meant… I used to go to an art group that I couldn’t possibly get to by bus. I liked the tutor, I liked what she did, so there was giving up that. It was like a bereavement, in some respects. Cos I couldn’t do that. I couldn’t visit my friend at [name of town], I used to go there on the [motorway], I used to love… going further afield, do you know what I mean? That was all different. I couldn’t do that, and she [Sylvia’s friend] didn’t drive, so I couldn’t see her. And it was a lot of adjustment like that… So it did take time to get over that. It was like a bereavement really.” (Sylvia)

Bookending this extract with the emphasis on giving up driving as a bereavement highlights the grief and loss Sylvia experienced when stopping driving and then having to cease certain activities. Like Sandra and Rose, driving had been emblematic of Sylvia’s sense of independence:

> “I was quite independent… and got there on my own, which I couldn’t any more. I don’t really like being reliant on people. So my-- so your independence goes a bit.” (Sylvia)

It is interesting in this quote that Sylvia suggests some activities are now off limits (“I couldn’t any more”), but she does not suggest that she has undergone a binary transformation from independence to dependence. Indeed, her language is more qualified, stating she was “quite independent” and “your independence goes a bit”. Therefore there is not an automatic equivalence drawn between driving and independence; arguably, this may relate to Sylvia’s ability to continue feeling self-reliant because of her living situation where so much is still accessible on her doorstep and she feels connected to other people in her immediate surroundings. Furthermore, Sylvia discussed how she also missed driving as an activity in its own right, that made her feel free and empowered:

> “I used to love my little cars as well… I really enjoyed that. My husband went abroad as well quite a bit with his job. So it was quite nice because I was quite independent with my car, I could go here there and everywhere while he was away.” (Sylvia)

This quote demonstrates clearly how Sylvia’s grief about giving up driving is also about grieving the loss of the intrinsic joy driving brought her, with the line about “lov[ing] my little cars” conveying an affectionate, tender fondness towards the cars she formerly drove. The extract also conveys the sense of freedom and joy afforded by driving, implying that while Sylvia’s husband was abroad, driving enabled her to enjoy a similar sense of adventure. Sylvia mentioned several times that she had “got over” not driving, but these extracts also illustrated how she missed the activity. Similarly, Ralph’s discussions around stopping driving demonstrated how a sense of acceptance about this new status quo can coexist with a sense of loss:

> “I’ve accepted it. I feel regret that I can’t drive, but I don’t feel jealous, I don’t feel that I’m missing out. I know I am missing out but I don’t feel-- If it was sort of feeling a bit jealous, ‘I wish I could do that’, I’d be forever thinking about it. Then I just accept it’s something I can’t do, sort of like… It’s a physical limitation that I cannot overcome, through… because sheer force of gravity won’t let me do it, whatever. So I don’t think about ‘what if’…” (Ralph)

In this extract, Ralph was more hesitant than at other points in his account, expressing the duality of his emotional response to no longer driving, with acceptance coexisting alongside regret, and also working to keep any potentially nascent feelings of “jealousy” in check. He emphasises a distinction between “know[ing]” and “feeling” in the second line of the extract; intellectually knowing he is missing out on what was once a valued activity but refusing to entertain the associated, potentially jealous and bitter feelings of missing out, instead pragmatically accepting as a fact-of-life – like the “sheer force of gravity” – that driving is now unequivocally off-limits.

Similarly, Andrew reflected on the loss of convenience that ceasing driving had entailed but somewhat uniquely, he did not necessarily equate stopping driving with a reduction in independence. In contrast to Sandra for example, Andrew saw public transport in his well-connected local area as liberating and enabling rather than a burdensome cross to bear, for example when he discussed using public transport to attend group meetings:

> “I’m able to get to most of these meetings on my own, I go on the bus. And some of them are taken in Council transport, but I can get to most of them on my own. And I can still see enough to go out and get on buses and even trains.” (Andrew)

It is noteworthy in this quote that Andrew sees using public transport as a marker of his independence, repeating how he uses it to attend meetings “on my own”, rather than depicting use of public transport as a form of dependence. At the same time, he did reflect on the loss of convenience that ceasing driving has entailed:

> “Well, it was the convenience. If I wanted to go to the local supermarket, or to one of the groups, I could just get in the car, drive there, park, and then go to whatever meeting or whatever was there. Once I gave up driving, I had to get to a bus stop, get the buses and wait around for buses. It was the convenience of the car that I really liked. That’s what I miss the most. But now, as I say, although for the last couple of months I haven’t been able to go out, usually I get to all the meetings without a problem.” (Andrew)

Andrew voices missing the loss of “convenience”, with the implication that using public transport can be a more cumbersome and less time-efficient process involving “waiting around”, even if it does still enable him to attend group meetings. However, the emphasis is – in contrast to other participants – more squarely on the practicality of driving, rather than on driving as more symbolic of independence or self-reliance. When Andrew highlights driving as the main activity with which AMD has interfered, there was the sense that he misses the act of driving (like Sylvia), partly because of his professional life as a taxi driver:

> “Well I’ve always driven a lot. I used to be a cab driver, years ago, so I’ve driven 40 or 50,000 miles a year for 20 years. And that is the one thing I really do miss, the driving. Although, as I say, I gave up five or six years ago, and I don’t miss it so much now, because the transport

> links around [local area] are very good. So there are plenty of buses I can get, and there's the train, and it's not too far to the underground station. I can use trains, I've got my freedom pass now that I'm over 65, so I can get about ok without it. Without the car." (Andrew)

In the first lines of this quote, Andrew reflected on both how he does and does not miss driving because of his local area being well set-up in terms of transport links. While he misses the essence of driving as an activity, Andrew clearly does not feel isolated or cut-off by the effect of AMD on his ability to drive as other participants might who live in more rural areas. Like Andrew, Sylvia was clear that in many ways she had adapted to the new reality of not driving, with her emotional experience of adaptation aided by the practicalities of her geographical location, being close to the centre of her town and to the shops:

> "But now I've adapted to it, do you know what I mean. I've got over not driving. The thing is, you've got to be in the centre of things really. I'm in the centre of [town] here, and it's really a nice little flat, it's round the corner, it only takes me five minutes to get to the shops. So I can walk there, I'm on a good bus route as well. But I think this is essential." (Sylvia)

This highlights the importance of being geographically well connected for remaining socially connected and part of a community, and creating a feeling of being "in the centre of things". From a different temporal perspective, Howard (the only participant still driving at the time of interview) was already anticipating the time when he could no longer drive and making necessary preparations for himself and his wife when this eventually transpired. Howard was concerned about the seemingly inevitable likelihood of soon having to stop driving, especially in his role as a carer for his wife Susan:

> "Us not having a driving license is of, you know, of great consequence. But we know it will happen." (Howard)

While Howard was clear that AMD was not his principal health concern, he suggested that his worries about AMD chiefly related to driving:

> "[AMD]'s not something I'm upset about, you know … I think because it's a while-- Susan and I are working towards when the time comes that I can't drive. So we have just bought a second mobility scooter. We're not far from a bus stop and it's one [a scooter] that, you know, you push the button and it automatically folds up. So you can get it on a bus very, very easily and we're just increasingly beginning to use that. We've been on a couple of bus trips… so we're just trying to work our way round it." (Howard)

In this quote, Howard recounted how he and his wife are making active preparations for what feels like an inevitable future where driving is no longer an option, pre-emptively navigating public transport in their area using mobility scooters in order to mitigate the impact of no longer driving. It is clear that they are proactively trying to adapt now before further sight loss, “working towards” a solution. This conveys a sense of living in the shadow of ceasing driving, but also arguably trying to reduce the ‘weight’ of that shadow through proactive, realistic planning. In the quote, Howard and his wife appear to be approaching this strategy as a shared work-in-progress, attempting a workaround in partnership that will hopefully cushion against the shock of Howard eventually ceasing driving.

4.3.4.4. Navigating independence and interdependence: Negotiations to remain included in a sighted world

A key relational and social dynamic within their AMD experience discussed by five of the eight participants concerned navigating the changing nature of their independence and/or interdependence, and how to ask for help from other people. For example, Ruby was clear that as someone who had never been married and lived alone, she had no choice but to remain fully self-reliant during her life with AMD, stating:

> “For me, ‘course, there was nobody, so I’ve gotta… sink or swim.” (Ruby)

Nonetheless, Ruby also understood the value of help and support from others, discussing how – precipitated by the COVID-19 pandemic - she has recognised the need to become more comfortable asking for and accepting help from others:

> “I’m not very good at asking people for help, that’s one of the big problems of having lived on your own all your life, you think you can do everything, and you’re very very independent, and it’s a little difficult to contact people and say, ‘I need help’. This is something that I’ve not yet learned to do.” (Ruby)

This expresses the challenge of asking for help that comes with Ruby’s strong embrace of an independent, self-reliant identity. Indeed, she voiced the existence of a feeling of discomfort linked to asking for help, which she found hard to put into words:

> "It's just… this thing of… I don't know what it is. This sort of, almost, barrier. 'Oh they won't bring me the right stuff, you know, it won't be as good as if I go [shopping] myself'. I don't know if that creeps in." (Ruby)

This quotation illustrates the discomfort of feeling that if she does accept help, and surrender some control, the outcome will predictably fall short in some way compared to if she were to undertake the task herself. However, the pandemic also increased Ruby's awareness of the inevitable need to rely on others, accepting that this can involve a slight diminution of autonomy but is ultimately key to continuing to "survive" and adapt to this unprecedented situation:

> "I've just got somehow to accept that, in this period that we're going through, that it's not possible for me to do these things, and… if I want to survive, I've gotta rely a bit more on other people." (Ruby)

In this extract, the context of the COVID-19 pandemic and lockdown at the time of the interview with Ruby (April 2020) looms large; Ruby shows a self-awareness that relying on other people has become crucial and non-negotiable during this time of intense vulnerability, when in the absence of COVID-19 vaccines or treatments, avoiding crowded places could indeed be a matter of "survival". However, it is clear from other parts of Ruby's account, as discussed above, that she was already grappling with the dilemma of asking others for help in the context of vision loss; although it was the pandemic that brought this issue starkly into relief.

Like Ruby, Ralph had also come to the realisation that "getting on" in a world that caters for sighted people fundamentally involves what he termed elsewhere as "negotiating with yourself and others". As he stated:

> "To be able to function normally – and most people that I know now who've had the condition for some time have come to that knowledge and understanding – there needs to be a transaction with other people. For a lot of things, you can't just simply do it yourself." (Ralph)

For Ralph here, the key to functioning "normally" is accepting what he cannot do alone and the need to engage with other people - in a kind of "transaction" - in order to achieve certain tasks. Ralph notably never used the language of (in)dependence at any point in his account, contrasting with other participants. Indeed, many aspects of his account display an enacted inter-dependence with others that was configured neutrally, and presented dispassionately as a fact-of-life in light of having certain non-negotiable physical limitations. Andrew was similarly matter-of-fact in his discussion of the importance of asking for help from others, although he diverged from other participants with a focus on the ways in which people do (or do not) seek help from statutory or charity services (rather than from other individuals). For example, he voiced frustration at several points in his account towards individuals who - although aware that help was available - would not take it up. The way in which he described other people refusing to reach out for help contrasted with his own resourcefulness and efforts to access aids and supports that have helped him to cope with the impacts of AMD. For example, he recounted a conversation with a woman he met on a cruise who was also living with AMD:

> "I said, 'But surely you can get help? There's help for these things! Get in touch with your local council, [my local] Council has got a sensory team who will come and explain things to you. I had someone come and explain to me about the white stick when I first had AMD.' 'Oh no,' she said, 'No I'm not going to get any help'. She wouldn't go to get any help." (Andrew)

Here, Andrew communicates a disbelief and almost exasperation towards her and other people with AMD he mentions throughout his account who seem set against making adaptations. Arguably, this communicates the strength of Andrew's desire to encourage others to take steps to proactively manage AMD, knowing how much these actions can help. This frustration came across more strongly in another extract with a similarly rhetorical tone:

> "There's a couple that I used to see regularly on the local bus, the man's got macular degeneration and his wife is always with him. He doesn't go out on his own, and… I've told him about the sensory department at the council, he won't get in touch with them. I've told him about the Macular Society self-help group, the local group, he won't get in touch with them. I've told them about [local vision loss charity], he won't get in touch with them… I don't understand why. It can open up a lot of different things, you don't have to do everything." (Andrew)

There is a contrast here between Andrew and this man he describes, who (unlike Andrew) does not move around independently and refuses to engage with statutory and charity services. The repetition of "he won't get in touch with them" serves to emphasise the fact that this man refuses to consider Andrew's advice, despite the multiplicity of options on offer. On an experiential level, it appears Andrew cannot understand why some people refuse to be helped, and he ends the extract succinctly by stating that getting in touch with these services can be a route to opening up new possibilities, without any obligation or commitment "to do everything". Arguably, Andrew's frustration served to further underscore the transformative effects these services and groups had had on his life, and perhaps the way in which promptly seeking help had resulted in his continuing to live autonomously and engage in a wide range of meaningful activities.

Denise did not discuss in significant detail the challenges of asking for help, but as discussed in Section 4.3.4.1, she described how she does not necessarily need to ask friends for much help in light of the support she receives from her husband. She also discussed the difficulty she finds with asking for help depending on the situation at hand:

> "I mean if I needed help, I could ask someone, one of my friends helped me with my knitting, that sort of thing. But… it hasn't, no I don't think it has affected any relationships at all, really. They're not embarrassed by it. My friend, I used to drive to see her, she's quite happy to come and drive. I don't like getting on buses on my own, I have difficulty seeing the number at the front. But at the same time, I could always ask the bus driver, or someone around, but I don't feel over-comfortable, but I guess I'm fortunate that I don't have to use public transport very often. So… I don't have any bad experiences there." (Denise)

This extract illustrates the ways in which the context may determine the ease Denise feels in asking for help, and her ambivalence in doing so. She suggests it is easy to ask for help from her friends, and it is interesting that Denise highlights how "they're not embarrassed by it" (arguably with the implication being that in different circumstances, some level of embarrassment might be expected). As things stand however, there is the suggestion that friends might be providing more instrumental support, helping Denise with knitting or driving to see her, although she does not feel this changes the essential quality of their friendship. The latter part of the extract then suggests that by contrast, she does not feel "over-comfortable" asking for help on public transport; this contrasts with the implied simplicity of asking for help from people such as her friends and husband. Sylvia expressed a similar selectivity in terms of whom she might ask for help, with familiarity making the process easier:

> “Well I pick and choose who I ask [for help], do you know what I mean. I usually use the same local shops. So I don’t mind asking staff in there to look for things for me. And there’s a deaf girl in there, and she’s really really good. I’m sort of blind and she’s deaf [*laughing*] so she will always look for things for me… There’s a little Sainsbury round the corner where I live in [name of town]. Everybody’s very good and they’re very helpful really.” (Sylvia)

Here, Sylvia described regularly visiting the same local shops and becoming familiar with staff working there, which she suggests makes it easier and more comfortable to request help looking for items. In particular, she implies a strong connection with the deaf staff member in one of the local shops, which may stem from their common experience of sensory loss. The description of how she “pick[s] and choose[s]” whom she asks for help has echoes of Andrew’s statement about asking for help from services and groups (“you don’t have to do everything”), making clear that depending on context, certain sources of help and support will inevitably feel more personally appropriate and valuable than others.

Ralph went into a particularly granular level of detail about the challenges of asking for help from others with everyday tasks. Ralph discussed feeling embarrassment asking other people for help in the earlier years of his life with AMD, before transitioning to no longer feeling awkward or self-conscious. This had partly come about through near mishaps which functioned for Ralph as “hard earned… lessons” and also what he called “aversion therapy. If you keep exposing yourself to it, a little bit at a time, you get used to it, it becomes normal.” He recounted an incident where he ended up on the wrong train, and adopted a new strategy to ensure this would not happen again:

> “I would look at the boards then stand underneath the boards facing the crowd […] And I’d go to someone and say, ‘Excuse me, can you tell me what train is to [station name]? I can’t see the board’. I must have done that a hundred times with a hundred per cent success rate. It was sort of overcoming the… embarrassment, or hesitancy… You know, I’d tell myself, ‘Well people could just turn round and say, ‘No’, or ‘I don’t speak English’ or whatever.” (Ralph)

This extract demonstrates the kind of ‘negotiating’ Ralph engages in, overcoming the initial embarrassment and hesitancy by considering the potential ‘worst case scenario’, and realising that even if this were to materialise then he would still be able to cope with the outcome. At the same time, Ralph is clear that asking for help from other people can be challenging to accept, as it implies ceding control to other people:

> "Nobody wants to be seen to not be able to do anything. You always want to do things for yourself. To give over that degree of control, or a degree of control, or to be in a position of weakness, or apparent weakness, is sometimes quite difficult to overcome." (Ralph)

Here Ralph highlighted concerns (that he frames as being somewhat universal, rather than specifically unique to his experience) about having to surrender some degree of control to other people in order to perform functional tasks, echoing Ruby's perspective discussed above. In the quotation above, it is noteworthy that much of the issue is about how this 'giving over' of control may appear to others ("be **seen** to be able to can't do anything"; "**apparent** weakness"). This implies that it is not only distress intrinsically linked to not being able to undertake certain tasks, but also a more socially contingent sense of shame, with concerns about being perceived by others as incapable. However, in Ralph's case, he has come to accept this surrender of control as a way of exerting agency and remaining included in his sighted social world; thus a reliance on others has become a means of safeguarding his autonomy and independence. For example, Ralph recounted frequently struggling to find his friends in the pub when they met for pub quizzes, and how he has now encouraged them to make their presence known to him:

> "And I've now trained them all that when they see me - everyone around us thinks we're daft! – they all turn around to face me and all start waving their arms! Like, you know, they're in a football crowd. So what I do is see the movement, and then thumbs up, yep, I can see you, you're over there." (Ralph)

The word "trained" that Ralph uses alludes to the intentionality (and arguably, emotional labour) required to inculcate these new practices among his friends; but the implication is that they are now on board and wave to Ralph enthusiastically. There is an acknowledgement that this behaviour may look strange to others, but the implication seems to be that this habituation process has required some his friends to become more comfortable resisting certain social norms and standing out. The comparison with a football crowd is noteworthy, as within a football-spectating context, such enthusiastic gestures may constitute more accepted, valorised behaviour than in a typical social setting; the comparison thus implies that his friends are not so much breaking social norms as transferring them from one context where this expressive behaviour may be more accepted and expected. In contrast, Andrew had not necessarily 'trained' the people around him, but in common with Ralph, he pragmatically located the responsibility to be included in social situations with other people rather than taking on any feelings of being excluded. For example, Andrew like Ralph discussed navigating conversations in the pub:

> "Because I can't see them looking at me, I don't realise they're talking to me. And Wendy will say to me, 'Andrew! They're talking to ya' *[Wendy laughing in the background]*. And then I sort of take note, and pay attention." (Andrew)

Andrew characterised this feeling of unawareness that he is being addressed in conversation as "zon[ing] out… and go[ing] off into a sort of, like, dream world", and it appeared to stem in part from being excluded from conversations because of his sight loss:

> "And another thing that I do find, it doesn't upset me or anything, but… people will come up and ask my wife a question, about me, and I think, well I'm quite capable. If they ask me the question, I'm quite capable of answering it. But they sort of treat me as though, because I can't see, I don't know what they're talking about." (Andrew)

Ultimately, his response to these occurrences is to address it head on and ask people if they are addressing him:

> "Yeah, I'm straightforward, I say to them, 'Are you talking to me?' It doesn't bother *me* in any way, whether it bothers them I don't know." (Andrew)

He also subsequently stated:

> "If they want to make sure that I'm hearing, they need to tell me that they're talking to me". (Andrew)

It is clear from these quotes that Andrew locates the responsibility with other people to engage him clearly and explicitly in conversation, rather than framing this challenge with conversations as a fundamental limitation that is rooted in his vision loss. This illustrates Andrew's awareness of the ways in which the people and environment surrounding him have a responsibility and role to play in helping him to feel included.

The relationship of these findings to previous literature, and implications for practice, are discussed in Chapter 7. (A concise summary of the IPA themes is included in Endnote xvi, Appendix 22.)

Chapter 5: Template Analysis, extending the findings of the IPA study

5.1. Introduction

Chapter 4 was focused on an interpretative phenomenological analysis (IPA) of the accounts of the core sample of eight participants living with AMD. This chapter considers how I extended the IPA with template analysis (TeA) of eight further accounts, in line with Smith, Flowers and Larkin's (2021) suggestion that this combination of methods can help manage analysis of larger samples. Smith et al. (2021) state that while both framework analysis and TeA can combine well with IPA, "template analysis is the more obvious partner out of the two, because it has roots in experiential psychology too" (Smith et al., 2021, p.124). Brooks et al. (2015) acknowledge that there are many similarities between TeA and framework analysis, in that both approaches involve using some initial data to generate an *a priori* thematic structure applied across the whole dataset. However, TeA places greater emphasis on the iterative, recursive development of the thematic coding structure; arguably this process has parallels with the iterative, recursive development of personal and group-level sub-themes and super-ordinate themes in IPA. Furthermore, while framework analysis has particular relevance to health services and policy research (Gale et al., 2013), TeA has been used extensively in more "experientially focused studies" (Brooks et al., 2015, p.206) in health psychology (e.g. King et al., 2002; McGarry et al., 2020; Thompson et al., 2010). These considerations led me to choose TeA (rather than framework analysis) as a means of extending the findings from the IPA conducted on the core sample (Chapter 4), and using TeA to consider how the experiential themes might be substantiated, developed further, or nuanced by the remaining eight participants' accounts.

As discussed in Chapter 2, template analysis can be considered a particular style of thematic analysis (Brooks et al., 2015). At its core, it involves the generation of a coding template on the basis of a subset of data, which is then used to analyse further data items and iteratively (re)developed and refined in the process. Crucially, the template is a tool to aid in the process of analysis rather than an end-goal in itself. The template is structured and organised using a hierarchy of themes and codes (discussed in more detail in the Methods, Section 5.2). While the template is highly structured, equally it constitutes a flexible tool that can be adapted according to requirements of the particular study, for example in terms of the detail or granularity of the theme/code hierarchy, or whether the themes/codes are more descriptive or interpretative. Like thematic analysis, template analysis does not pre-specify a particular epistemological orientation, and can be conducted from stances ranging from realist to critical realist (within which my interpretative phenomenological approach would sit) to constructionist.

In this chapter, I report on the use of template analysis (TeA) to take the themes and sub-themes developed in the IPA of Chapter 4 and develop these further by analysing the accounts of eight subsequent participants. The IPA themes and sub-themes became the basis for an initial template, which was then refined and redeveloped after analysing the eight participants' accounts. I introduce previous literature combining TeA and phenomenological approaches, before specifying the methods and procedure, discussing the new insights developed, and reflecting on the advantages and challenges of the TeA process.

5.1.1. Conducting template analysis with a phenomenological approach

There is relatively limited guidance in the literature regarding how to combine IPA with TeA, and there are a number of different approaches researchers have taken that combine phenomenological approaches with template analysis. Based on a (non-systematic) literature search using Google Scholar (with search terms including "IPA OR phenomenolog*" AND "template analysis"), it appeared that authors have taken three overlapping but somewhat distinct approaches to combining phenomenology and TeA, discussed in the subsequent paragraphs:

1. **Conducting TeA from a phenomenological underpinning:** This may not necessarily be considered a 'combination' of methods *per se*, given that template analysis – like other methods within the overall family of thematic analysis, such as reflexive thematic analysis or framework analysis – is flexible and does not pre-specify a given epistemological approach (Brooks et al., 2015, p.205). Therefore, undertaking TeA with a phenomenological orientation does not strictly constitute a 'mixed-method'. However, in

order to inform my own TeA approach, I found it helpful to understand how TeA with a phenomenological orientation may be conducted. My search suggested a large number of studies use template analysis as the 'single-stage' method throughout, informed and underpinned by a hermeneutic or interpretative phenomenological approach or position (e.g. Kelly et al., 2020; Lewis et al., 2016; McGarry et al., 2020; McLaughlin et al., 2021; Sandy et al., 2022; Simons et al., 2018; Yates & Skinner, 2021). While some of these studies involved smaller numbers of participants akin to an IPA study (e.g. eight participants in Lewis et al. (2016), in other studies, template analysis allowed for the involvement of much larger sample sizes (e.g. 43 participants in Simons et al. (2018)).

Such studies describe aspects of their process in ways that have overlap with IPA, with an epistemological underpinning in phenomenology and hermeneutics (even if - especially in the larger studies - there is less emphasis on idiographic, within-case analysis and concurrently a greater focus on cross-case analysis (Brooks et al., 2015)). For example, Lewis et al. (2016) discuss having compiled an initial template based on their *a priori,* expected areas of interest; this template became a reflexive tool to concretely identify their presuppositions and assumptions. They then incorporated themes generated from their analysis of the two first transcripts into that initial template and compared these with the *a priori* areas of interest they had defined. Meanwhile, Kelly et al. (2020) discuss their reflexive process, working through their pre-judgements in line with the idea of the hermeneutic circle and using the template as a "tool to think with" as they gradually developed tentative and then more finalised interpretations. These examples suggest that while there at first might seem to be a sense of jarring or discontinuity between IPA (which seeks to enter the participant's lifeworld and avoid pre-assuming aspects of their experience) and a method like TeA (which involves approaching data with *a priori* themes), this is not necessarily the case. The researcher may still adopt a reflexive approach and remain mindful that the "whole" of the template is only ever a work-in-progress, and at any point can be radically re-developed through engagement with a "part" (e.g. a single interview transcript) which challenges the hitherto-developed coding scheme. Indeed, as Nigel King, who has used TeA with a phenomenological orientation extensively (King et al., 2008), states:

> "It is important to note that these *a priori* themes must always be seen as provisional and tentative and should be held open to modification or even

> deletion as the coding template is developed from its initial form to its final version. They are emphatically not rigid, predefined coding categories of the kind utilized in quantitative content analysis." (King et al., 2002, p.334)

As an example of a particularly iterative approach to phenomenological TeA, Emma Turley's work, discussed in Brooks et al. (2015), involved initially conducting a descriptive phenomenological analysis on accounts from four individuals. Turley and colleagues then conducted a second-stage project using template analysis; here, findings from the descriptive phenomenological study were used to develop *a priori* themes for the template that were used to analyse the accounts of nine participants (four of whom took part in the first-stage, descriptive phenomenological study, while five were new to the research). These template themes were initially kept broad, in keeping with a phenomenological stance and in order to remain open to new, significant thematic concerns. However, Turley recounts that while the intention was to develop the template from the stage one findings, "the author became increasingly concerned that using only this data would make it more difficult to approach the remaining transcripts with a truly open phenomenological attitude" (Brooks et al., 2015, p.215). Indeed, Turley notes that an open, phenomenological perspective was vital, but this made the use of more top-down *a priori* thematising somewhat contentious. This concern led Turley to conduct a preliminary round of coding of the entire dataset as a means of developing the template, which was much more comprehensive and detailed than initially envisaged. This template became even more detailed when Turley returned with the template to code each transcript, with the template iteratively adapted in response to the reorganisation and reclassification of themes. As a helpful reflexive point, Turley identifies a core tension, in that the more detailed the initial template (with the detail aiming to represent the unique individual experiences of all nine participants), the more the analyst may feel wedded to its structure and unwilling to modify it. This necessitates the cultivation of "an open attitude of discovery towards emerging themes" (Brooks et al., 2015, p.217) to avoid setting the template in stone too early in the analytic process. Indeed, this aligns with the concluding advice of Brooks et al. (2015, p.218), namely to avoid an overly narrow focus on developing the template as a final end-product, and instead to consider the template development above all as a means of making sense of the data.

2. **Conducting initial IPA on a sub-sample of accounts, and then extending the findings through TeA:** Most closely connected with the approach I have opted to take, my search found a small number of studies where authors conducted an initial IPA analysis, working with a core sample of transcripts, and then extended the findings through TeA. Largely, such papers provided relatively limited detail about the precise procedural steps of the methodology. One example in this vein provided by Smith et al. (2021) is a study by Dennis et al. (2013), where the authors drew on a two-stage hermeneutic phenomenological approach to explore the complex experiences of participants living with fibromyalgia. Conducting IPA with their core sample of eight participants whose transcripts were closest to median length, they developed a structure of experiential themes and sub-themes; their sub-themes were then the basis for the "main features" of the template they produced to analyse the remaining 12 transcripts. The authors state that their TeA not only aimed to "extend the reach of our initial analysis", but also to "fine tune" it, and allow for the integration of new material not previously included in the IPA (Dennis et al., 2013, p.767).

   Another study in this vein was conducted by Merriel et al. (2018), who sought to understand the working life experiences of maternity staff in hospitals in Malawi. Nine (out of 31) of the interviews, with the richest experiential data, were analysed using IPA; the emerging themes were then used as the basis of a template used for the second phase of the analysis. They suggest that this approach allowed "the analysis to be grounded in the lived experience, but also to cope with the volume of data collected" (Merriel et al., 2018, p.3), allowing for a balance between a depth of understanding and diversity of participants.

   Bond et al. (2023) conducted an IPA analysis of interviews with five individuals living with psychosis, who took part in a virtual reality therapy intervention to address agoraphobia symptoms. Bond and colleagues then used the initial IPA themes as the basis for a preliminary template, to analyse the accounts of the remaining 15 participants. They conducted the TeA in batches, with participants allocated to sub-groups based on their responses to the intervention, and the template was updated following each sub-group analysis.

In another study with a more complex design, Tour et al. (2022) conducted IPA on transcripts of four email interviews with individuals living with long-term, visible skin conditions who write online blogs about their experiences. They then used the preliminary thematic findings from the IPA to create a template, and used TeA to subsequently analyse the content of the participants’ first five and most recent five blog posts. The study highlights differences between IPA-analysed interviews and TeA-analysed blog content, noting that themes such as "Defeat and discontent" were represented in interviews but were absent from blogs; suggesting participants intentionally framed their blogs more positively to align with social expectations and to avoid appearing negative or hopeless. While the article does not explicitly reflect on the strengths and limitations of combining IPA and TeA, it implicitly makes a convincing case for combining the two. The IPA helped to illuminate participants’ private, complex experiences of blogging about their condition, while the TeA allowed for analysis of public-facing material that, produced with an online audience in mind, would not necessarily be suitable for IPA. By combining these two approaches, the innovative analysis thereby brings to light some of the tensions, convergences and divergences between the same individual’s private and publicly-shared experiences of their condition.

3. **Conducting both IPA and TeA in parallel:** A final domain identified in the literature search consisted of articles using a simultaneous fusion of IPA and TeA (as opposed to initial IPA, consequently extended through TeA). One recent example is a study on spinal cord rehabilitation by Weber et al. (2021), who conducted IPA on fourteen transcripts, but reported using TeA to facilitate cross-case analysis. They state that once they reached the point of looking for patterns across cases, “a final hierarchical template was designed to ensure full inclusion of meaningful entities from the original dataset” (Weber et al., 2021, p.338). With otherwise limited detail about the methods, I interpret this to mean that the template operated as a kind of organisational crutch at the later, cross-case IPA stages, allowing the authors to hierarchically structure their themes and sub-themes and ensure they were doing justice to the full range of the significant, meaningful content. (Following this interpretation, such a template would essentially be

similar to the initial master table of themes - or table of group experiential themes in the new IPA terminology – at the cross-case analysis stage of IPA.)

A reflexive, comparative account of using both IPA and TeA to analyse different datasets is provided by Reynolds (2003), who used TeA with a theoretically-derived template to analyse the written narratives of women with chronic illness discussing the meaning of artistic occupation. In a second study, Reynolds then used IPA to analyse in-depth interviews on the same topic. Reynolds reflects on the ways in which the template, derived from a specific cognitive-behavioural perspective on coping with chronic illness (Moos & Schaefer, 1984), inescapably limited deeper and more wide-ranging interpretation of the participants' unique, personal relationship to arts within their specific family, social or cultural context. Reynolds also notes that the TeA approach tended to "fragment the data, destroying its coherent phenomenological quality" (Reynolds, 2003, p.554); furthermore, TeA encouraged focus on the *content* of data but somewhat overlooked the structure and linguistic features of the narratives. Taking these points together, this implies that it may be beneficial to adopt an idiographic approach that attends to participants' accounts as an integrated whole – attending not only to *what* is said but *how* it is said – alongside the steps of TeA.[32]

5.1.2. Defining my interpretative phenomenological approach to TeA

Based on this survey of the literature, a number of potential 'lessons learned' emerged, of which I aimed to be mindful while undertaking TeA with an interpretative phenomenological stance:

- I aimed to make a conscious effort to attend to the idiographic, within-participant experience during analysis, even as the template may inescapably push the analyst towards a more cross-case focus. This aligns with the notion of the hermeneutic circle, in that deeper immersion within one participant's account may help to

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[32] Reynolds' template was derived from the specific theory of Moos and Schaefer (1984), and Reynolds reflects on how structuring the template deductively, using categories derived from their theory, risked neglecting the social and cultural dynamics at play. Therefore, Reynolds' comparison of IPA and TeA is arguably also bound up with broader questions regarding the relative merits of a more inductive versus deductive approach to qualitative analysis.

illuminate the central concepts of, or connections between, particular group-level themes or sub-themes.

- Following on from the above, coding accounts using the template may naturally direct attention to the more plainly-stated, manifest content of participants' accounts. Thus it was important to remain engaged in interpretation of the more latent features of participants' accounts; for example, what was conveyed in their language, tone and the overall flow and structure of their narrative. I found that listening back to participants' accounts while analysing the transcript helped to remain rooted in the participant's language and tone, which also helped retain a sense of immersion in their lifeworld (even if not undertaking the depth of analysis that IPA would entail).
- I aimed to remain attuned to the unique experiential, phenomenological and existential concerns of participants even as the hierarchical structure of the template could potentially lead the analyst into what Braun and Clarke (in the context of thematic analysis) term 'domain summaries' (Braun & Clarke, 2019), whereby a theme is equated to a straightforward topic summary, rather than a story about patterns of meaning.
- While I was focused on systematically tracking changes to the template, I aimed to balance this with a more creative and free approach, seeing the template as a "tool to think with" (Coffey and Atkinson, 1996, as cited in Kelly et al., 2020) and facilitating further interpretation and nuancing of the data, rather than fixating on the template as the end-goal in itself. This helped to avoid treating the template too early as a fixed entity, and to remain open to new themes (or relationships between themes) developing and thus amending the provisional template structure.

With this last point in mind, the Results section of this chapter does not present the full findings of the analysis of all 16 participants. Instead, it presents a summary of the new thematic insights that were developed during the TeA process (and had not arisen in the IPA), with a reflexive focus on how the TeA process brought these new insights and connections to light. Beforehand, I describe the specific methods of compiling and iterating the template, and the steps of the analytic procedure.

5.2. Methods

While the Introduction above included reflections on key considerations when conducting TeA with a phenomenological orientation, this section outlines the more granular procedural steps used to conduct the TeA, based on the method presented by Brooks and King (2014). The participant recruitment, characteristics and methods of data collection are described in the Methods section of Chapter 4. Therefore, the present section specifically focuses on the steps of data analysis.

In line with several of the studies mentioned above using IPA and then extending the analysis through TeA (e.g. Bond et al., 2023; Dennis et al., 2013; Merriel et al., 2018), the themes and sub-themes developed from the IPA were loosely used as the basis of the initial template (Appendix 12). Essentially, I therefore transformed the interim IPA themes and sub-themes into the *a priori* themes,[33] as described in TeA guidance (e.g. Brooks & King, 2014), formulating the initial template as a tool for further coding. Brooks and King suggest such *a priori* themes should only ever be tentative, and that to avoid becoming too "blinkered" and restricted by the template, they suggest only using a small number of themes and codes.[34,35] However, there are examples (e.g. Turley, writing in Brooks et al. (2015), about her work using TeA from a phenomenological stance) where templates are somewhat more detailed and comprehensive. In the paper by Merriel et al. (2018), who conducted an initial IPA study with 9 participants and then extended the findings to include all 31 participants, the initial template based on the IPA is reproduced in a detailed form. Interestingly, the superordinate

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[33] The themes/sub-themes were "interim" because I started the template analysis in March 2023, but the IPA themes were only finalised in February 2024. I was looking forward to starting on the template analysis, but additionally was unsure whether the TeA approach would work. Therefore, I wanted to start on the TeA sooner rather than later - in case a rethink of the approach might be required - and so ended up starting the TeA before the IPA was finalised (see also Footnote 36).

[34] Codes in TeA are defined by Brooks and King (2014, p.4) as "labels to index [themes]". If one considers the codes in a template as labels indexing or linking to aspects of a richer, more experiential theme, then it may be somewhat inevitable that certain codes will read like a "domain summary", rather than having the linguistic richness of an experiential theme in IPA.

[35] In terms of terminology of themes/codes in this chapter, I interpreted TeA themes to be akin to the superordinate themes of IPA; TeA sub-themes to be one level lower than themes in the template hierarchy, i.e. akin to the sub-themes of IPA; and codes to be one level lower than sub-themes in the template hierarchy, i.e. an individual component adding to a sub-theme, akin to emergent themes in IPA. When conducting the TeA, broadly speaking, a new code was added to the template when this was a meaningful experiential concern discussed by one participant, or where it was a specific new angle on a pre-existing sub-theme. By contrast, a new sub-theme (at a higher hierarchical level than codes) reflected a significantly more novel area of experiential concerns, and shared by at least two participants.

theme names in Merriel and colleagues' template are relatively experiential (e.g. "Being a healthcare worker is hectic but good outcomes are enjoyable"), but many of the code names (e.g. "Feedback from patients") arguably resemble a 'domain summary'. This observation resonated with concerns about certain codes in my initial template being too akin to a 'bucket' of topics or a 'domain summary', for example code 1.2.2. "AMD interacting with other shocks: health conditions, disabilities, COVID-19, bereavement". I realised that this was not so much about a shared pattern of experience among the participants, but more a shared reference across the accounts that might in fact conceal highly divergent experiences; for example, for some participants (e.g. Ruby), the COVID-19 lockdown compounded their sense of isolation linked to AMD, while conversely for others (e.g. Rose) lockdown assuaged their sense of loneliness and alienation. This illustrates how, unlike in IPA where one is purposefully attending to convergence and divergence, the codes I developed for the template did not always provide an indication of the intensity or the directionality of the experience.

I began compiling the template before the IPA themes and sub-themes were finalised. Therefore, the initial template does not reflect decisions taken during the final stages of IPA analysis and writing-up to modify certain themes or to subsume or combine certain themes. In hindsight, I would likely have produced a more concise and coherent template after the IPA themes had been finalised and I had greater confidence in the richness and aptness of the themes. However, the practicalities of my PhD necessitated starting on the template before the IPA was written up.[36] This meant that I was very keen to ensure the diverse experiences of the initial eight participants were preserved in the template themes and codes, which arguably led to an overly detailed and comprehensive template. As such, it was particularly important to bear in mind the advice of Brooks and King (2014) to avoid becoming "blinkered" and overly wedded to or constrained by the template.

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[36] I started conducting the Template Analysis before the IPA themes were concluded and written up, because of concerns around how this would work (it being a relatively experimental approach) and also to fit with the schedule of supervisions where I would bring discussion of individual participants' accounts. There were eight accounts to analyse for the Template Analysis, as for the IPA, and my supervisor and I would meet approximately once per month to discuss the analysis. Therefore it would have been infeasible within the time-frame of the PhD to only begin the Template Analysis once the IPA was fully complete and written-up.

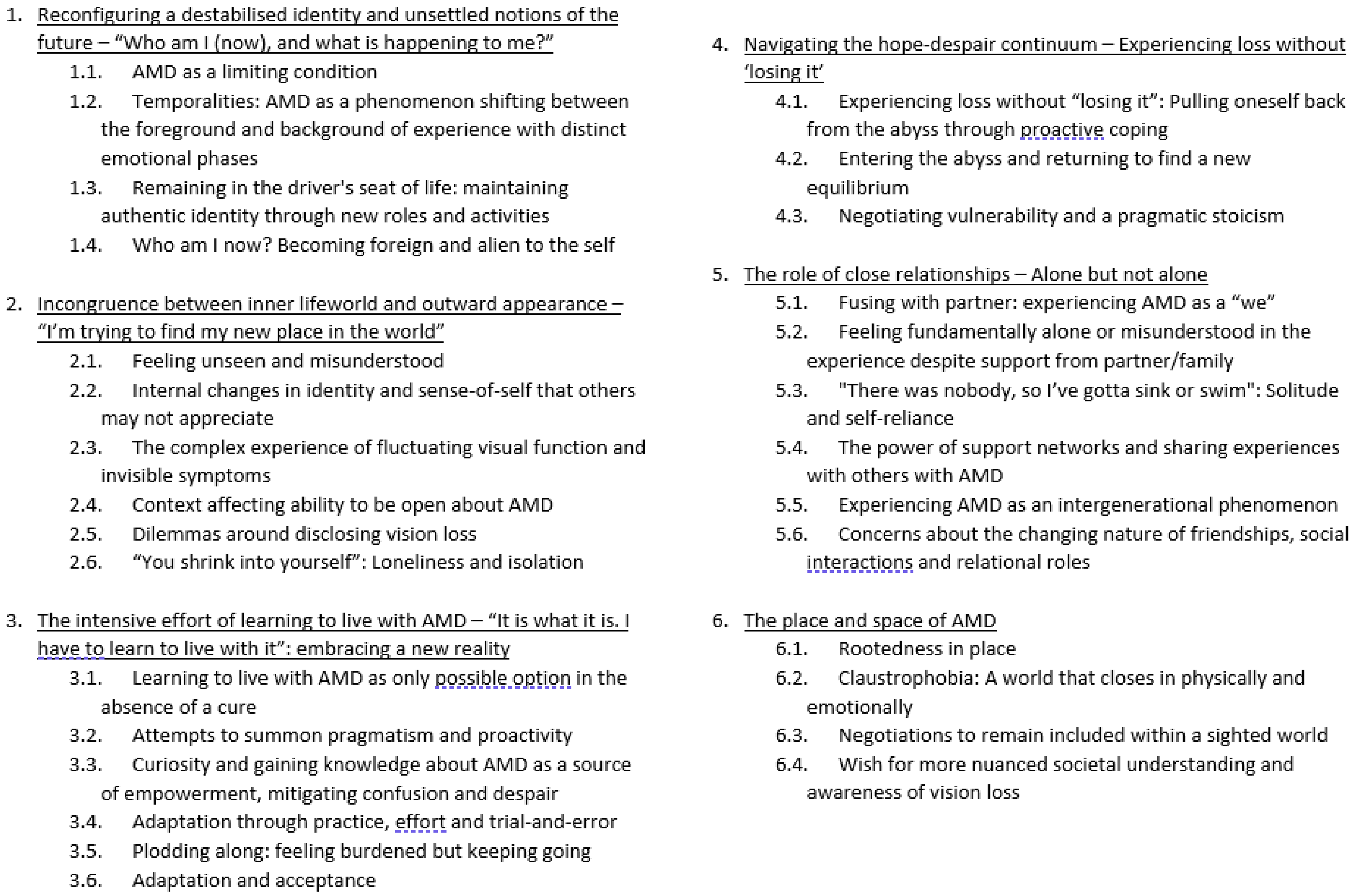
Taking the initial template, I worked through the transcripts of the remaining 8 participants whose accounts were not analysed in the IPA. (Because I conceived of the TeA as a means of extending the IPA findings, I did not return to the IPA transcripts with the template.) I went through each transcript in turn on Microsoft Word, with a copy of the most recent iteration of the template before me, and highlighted text segments that fitted into the existing themes and codes, noting in a Comment box the theme/code with which the text segment aligned (see Appendix 13 for an example of a coded transcript). When participants discussed an experience or concern not yet represented in the template, I modified the template using TrackChanges; generally, this meant *adding to* the existing themes and codes of the template - when I interpreted new thematic concerns in a participant's account – rather than collapsing, removing or combining themes. On the one hand, this focus on adding material from new accounts – rather than subsuming or combining - may suggest I was too wedded to the initial template. However, because this initial template was based on the close analysis of the 8 initial participants' accounts with an idiographic lens, it felt important to retain the existing themes, while also remaining open to adding to these further. (Eventually, once all eight of the remaining transcripts were analysed with TeA, it was possible to move away from this purely additive focus towards combining or reducing down themes and codes, especially where these were seen to be repetitious.) With each new transcript analysed, a new iteration of the template was developed and saved. For each participant, I also listened back to their interview to retain a holistic focus on the content, structure, tone and communication style of the participant, and alongside the template modifications, I made notes on what seemed to be the key concerns and central experiences for each participant from a phenomenological point-of-view. (See Appendix 14 for an example of these reflective notes.) This strategy to some extent allayed some of my concerns about the 'cross-case' focus of the template overwhelming a more idiographic, person-centred, 'within-case' lens.

5.3. Results

The full final template is displayed in Appendix 15, which includes the newly developed codes. In Figure 7 below, as per Brooks and King (2014), I present a simplified version of the final template, including only the top-level headings (themes) and second-level headings (sub-themes). Codes, which I conceptualised as being one (or more) hierarchical level more granular than sub-themes (see Footnote 35, p.164), are therefore not included in Figure 7.

In this Results section, I focus on the new insights that were developed during the TeA process. I felt that the most intuitive way to do this was to compare the initial and final template, and discuss notable new insights developed through the TeA under each of the six template theme names. However, as mentioned above, when describing these new thematic concerns I also aim to provide some idiographic exploration of some of the participants' experiences. Table 6 below provides a summary of the sub-themes (ST) and codes (C) that were amended or newly developed during the TeA, and are therefore the focus of discussion in the Results section.

Figure 7. Simplified version of final template



1. Reconfiguring a destabilised identity and unsettled notions of the future – “Who am I (now), and what is happening to me?”
    1.1. AMD as a limiting condition
    1.2. Temporalities: AMD as a phenomenon shifting between the foreground and background of experience with distinct emotional phases
    1.3. Remaining in the driver's seat of life: maintaining authentic identity through new roles and activities
    1.4. Who am I now? Becoming foreign and alien to the self

2. Incongruence between inner lifeworld and outward appearance – “I’m trying to find my new place in the world”
    2.1. Feeling unseen and misunderstood
    2.2. Internal changes in identity and sense-of-self that others may not appreciate
    2.3. The complex experience of fluctuating visual function and invisible symptoms
    2.4. Context affecting ability to be open about AMD
    2.5. Dilemmas around disclosing vision loss
    2.6. “You shrink into yourself”: Loneliness and isolation

3. The intensive effort of learning to live with AMD – “It is what it is. I have to learn to live with it”: embracing a new reality
    3.1. Learning to live with AMD as only possible option in the absence of a cure
    3.2. Attempts to summon pragmatism and proactivity
    3.3. Curiosity and gaining knowledge about AMD as a source of empowerment, mitigating confusion and despair
    3.4. Adaptation through practice, effort and trial-and-error
    3.5. Plodding along: feeling burdened but keeping going
    3.6. Adaptation and acceptance

4. Navigating the hope-despair continuum – Experiencing loss without ‘losing it’
    4.1. Experiencing loss without “losing it”: Pulling oneself back from the abyss through proactive coping
    4.2. Entering the abyss and returning to find a new equilibrium
    4.3. Negotiating vulnerability and a pragmatic stoicism

5. The role of close relationships – Alone but not alone
    5.1. Fusing with partner: experiencing AMD as a “we”
    5.2. Feeling fundamentally alone or misunderstood in the experience despite support from partner/family
    5.3. "There was nobody, so I’ve gotta sink or swim": Solitude and self-reliance
    5.4. The power of support networks and sharing experiences with others with AMD
    5.5. Experiencing AMD as an intergenerational phenomenon
    5.6. Concerns about the changing nature of friendships, social interactions and relational roles

6. The place and space of AMD
    6.1. Rootedness in place
    6.2. Claustrophobia: A world that closes in physically and emotionally
    6.3. Negotiations to remain included within a sighted world
    6.4. Wish for more nuanced societal understanding and awareness of vision loss

Table 6. Summary of new sub-themes/codes developed through the TeA and discussed in Results

Name of theme	**New or altered sub-theme (ST) or code (C) developed through the TeA**
1. Reconfiguring a destabilised identity and unsettled notions of the future – “Who am I (now), and what is happening to me?”	• **ST 1.1: “**AMD as a “depressing”, frustrating condition” changed to “AMD as a limiting condition” • **C 1.2.6:** “Vigilant trepidation/apprehension at early stage, amid uncertainty about how future life with AMD will be” • **ST 1.4:** “Who am I now? Becoming foreign and alien to the self”
2. Incongruence between inner lifeworld and outward appearance – “I’m trying to find my new place in the world”	• **C 2.2.1**: “Where’s my place within the world of people with AMD? Looking at the central phenomenon of vision loss from the periphery” • **C 2.3.3:** “The challenge of putting the visual experience of AMD into words” • **ST 2.4:** “Context affecting ability to be open about AMD”
3. The intensive effort of learning to live with AMD – “It is what it is. I have to learn to live with it”: embracing a new reality	• **C 3.3.7:** “Wish for the world at-large to be made more accessible for people with vision loss” • **C 3.6.3:** “Comparison with others’ experiences as a source of inspiration, motivation and reassurance”

4. Navigating the hope-despair continuum	- **C 4.1.2:** "Letting despair in, while resisting the pull of catastrophic thoughts of the future"
5. The role of close relationships – Alone but not alone	- **ST 5.5:** "Experiencing AMD as an intergenerational phenomenon" - **ST 5.6:** "Concerns about the changing nature of friendships, social interactions and relational roles"
6. The place and space of AMD	- **ST 6.4:** "Wish for more nuanced societal understanding and awareness of vision loss"

5.3.1. Reconfiguring a destabilised identity and unsettled notions of the future – "Who am I (now), and what is happening to me?"

One notable change between the initial version of the template based on the IPA themes and the final template was the change of sub-theme 1.1 from "AMD as a "depressing", frustrating condition" to "AMD as a limiting condition" (which in turn informed the naming of this sub-theme in the final IPA write-up as "AMD as a frustrating condition that imposes new limitations"). This change was made in response to analysis of Pearl's account with TeA. Pearl's account repeatedly conveyed the sense that she was to some extent managing to get by, but whatever strategies she used to cope never felt quite sufficient to truly remedy the sensation of feeling limited by vision loss. This was illustrated when Pearl discussed listening to talking books:

> "I'm getting talking books from RNIB, but I find them so lonely… I haven't finished one yet, I just find it so lonely, sitting here, listening to the talking…" (Pearl).

While other participants in the IPA, such as Andrew and Rose, spoke highly of talking books as a lifeline, Pearl's perspective conveyed a sense of limitation and loss that ultimately felt irremediable. This also came across when she discussed sitting close to the television and turning her head to the side to discern faces:

> "It's certainly not the same way as recognising in the normal central vision. I have to turn my face at right angles, and just look out through the corner of my eye, and I might see what someone's face looks like. But it… it doesn't *mean* as much as when I see it with my central vision. That's a way of putting it." (Pearl)

This extract illustrates that while Pearl may have found a way round to adapt to her changing vision, there is a fundamental sense that seeing faces using her peripheral vision "doesn't *mean* as much". The way that she then states "That's a way of putting it" implies the challenge of putting the sensation into words, but she still conveys - in a resigned, matter-of-fact way - the newfound limitations she is having to contend with. Thus the change of sub-theme title aimed to encapsulate more neutrally that AMD imposes new limitations, from which may stem feelings of depression, frustration, or alternatively a sense of acceptance that may run the gamut from more serene and positive (e.g. in the case of someone like Andrew) to more resigned and flattened (as in Pearl's case).

Novel insights were also gleaned within the "Temporalities" sub-theme (1.2), with regard to participants' sense-making around the future with AMD. A new code was developed within Temporalities, "Vigilant trepidation/apprehension at early stage, amid uncertainty about how future life with AMD will be" (1.2.6). Marianne, Suzanne and Victoria - whose interviews took place between 2.5 and 3 years following their AMD diagnosis – particularly spoke to this concern, perhaps reflecting a greater predominance of participants with earlier-stage AMD among the TeA participants (see Table 3, p.78). In different degrees of explicitness and depth, these three participants all voiced a sense of vigilant trepidation amid the uncertainty of their future AMD trajectory. For example, Marianne explained that her father had lived with macular disease for 20 years, and so even before her diagnosis, she "half-suspected the macular". She never explicitly stated she was worried about the future of her vision, but a sense of apprehension and trepidation came across more implicitly:

> "It is getting worse, slightly, you know, and it is still dry and I do the Amsler grid test every week, just to check… But how much of it is macular, how much of it is cataracts, I don't know. But I suspect with my left eye it is particularly macular. It does seem to be central vision with that." (Marianne)

Marianne's use of the Amsler grid[37] each week "just to check" illustrates her sense of being in a state of watchful anticipation, alert to any changes, highly mindful perhaps in part because of her consciousness of her father's experience. Strengthening the interpretation that much of Marianne's experience of AMD is defined by watching for what is coming in the future, she stated at the end of the interview:

> "I've heard it described as, you sort of go along and you're sort of doing alright and then you hit a barrier. And… then you go down a bit when you hit that barrier. […] But the first time I

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[37] The Amsler Grid is a grid of small squares with a small dot (fixation-point) at the centre, which is printed onto a sheet of card and used at home by a person with dry AMD to monitor visual changes (e.g. distortions) that might signal the development of wet AMD.

> can't actually read something, even with a struggle and even getting tired, the first time that I don't recognise someone reasonably close, that is going to be more of a problem. And whether, or how well, I will cope with that, I don't know. I will just have to hope I can learn from all these wonderful people that have taught me so much so far." (Marianne)

In comparison to the more latent sense of foreboding in the earlier quoted extract, in this later extract Marianne is explicit in voicing her fear about the extent to which further visual deterioration will take place, and the uncertainty surrounding her future ability to cope. Although not a metaphor used by Marianne herself, her account brought to my mind the image of someone watching a wave far out at sea on the horizon, knowing that the wave will inevitably arrive but unsure how powerful it will be when it reaches the shore. Indeed, this complex experience of being at the early stage of AMD and unsure of the trajectory ahead also came across when Marianne discussed how she might respond to friends who ask about her eyes:

> "They [my eyes] are not as good as they were this time last year. What will probably happen this time next year will be that they won't be as good as they are now. Unless I'm one of these unfortunate people who has a sudden change - and there are people I've spoken to who have had a sudden change - unless that happened, there probably won't be much change. It will just be gradual, and so I think I may hit more barriers when there comes a time when I can no longer see small print easily, if I find it tiring. When I can no longer do whatever, you know, I think that will be more of a… And at the moment I don't have problems going out and about and things. Whereas I know people who have lost confidence in going out and about." (Marianne)

Here Marianne again refers to the difficulty that may come if she "hits barriers" in future, and it is noteworthy that after beginning the sentence starting "When I can no longer do whatever", she cannot specify what that will feel like; the ellipsis in the third-to-last line of the extract denotes a pause as Marianne breaks off the sentence to refocus on how she currently faces no problems. While this abrupt rerouting of her train-of-thought should not be overinterpreted, it is possible to suggest that part of Marianne's experience involves wanting to turn away from a focus on the later-stage consequences of AMD. She seems to move between an analytical awareness of the range of possible future outcomes from AMD (for example, when she hastens to add that "there are people I've spoken to who have, you know, had a sudden change"), and a determination to keep this apprehension about the future on the periphery and avoid catastrophising, arguably because it is painful to face the (highly uncertain) worst-case scenario. Quite a similar formulation was evidenced by Suzanne, who voiced this awareness that things could become more difficult, but also reoriented herself away from dwelling on the potential worst-case scenario:

> “I can walk and I can go to get my paper, and all that sort of thing. So… I just hope it doesn’t get too much worse. But I suppose it probably will. I mean I don’t know how good-- do you know anything about Macushield, have you talked to people and heard what they think about it?” (Suzanne)

Here, Suzanne juxtaposes her hope that her vision will not get worse with a more intellectual awareness that it probably will, before quickly rerouting to discuss Macushield, a supplement she has been recommended to take in order to slow progression of AMD. As with Marianne, Suzanne’s experience combines a perceptive understanding of where she could theoretically end up with AMD with a strategy of turning away from facing this head-on; it is also notable that she reorients towards pragmatic action she can undertake in the present (using Macushield supplements) to potentially slow AMD progression. At the same time, like Marianne describing hitting barriers, Suzanne voiced a similar perspective on how different activities can become affected, and was aware that challenges could continue to accrue:

> “I suppose I’m just fighting a rear-guard action really, and [*laugh*] trying very hard to keep going with the things I like doing… And then suddenly, you suddenly realise it’s no good to go on fighting, you can’t do that any more.” (Suzanne)

In this extract drawing on military metaphors, Suzanne’s reference to a “rear-guard action” implies the effort of trying to adapt to AMD and “keep going” but eventually having to accept that new limitations are making certain activities impossible. “Rear-guard action” is defined by the Oxford English Dictionary as “A defensive stand made by the rearguard of a retreating army”, implying a somewhat desperate struggle to keep doing what she can in the face of the encroaching, potentially overwhelming force of AMD. Like Marianne, Suzanne thus encapsulates the experience of making the preparations and adaptations that she can, while very much aware that amid the uncertainty of how AMD may progress in the future, all these carefully laid adaptive plans and procedures may no longer be fit for purpose.

Within this first theme, an additional sub-theme added was “Who am I now? Becoming foreign and alien to the self” (sub-theme 1.4). “Who am I now?” was included within the composite quote for the IPA theme, but it truly crystallised as a central thematic interest when analysing the TeA transcripts. While participants in the IPA such as Ruby and Sandra voiced feeling that certain fundamental aspects of their identity felt challenged, in terms of their self-sufficient and outgoing natures respectively, TeA participants Hannah and Julie gave voice more overtly to the experience of coming to feel somewhat foreign or alien to themselves and to the fear of becoming the kind of person they never wanted to be. For example, Hannah stated:

> “[I get] slightly irritated with other people that can do everything when they’re complaining. Now this is probably my nature, but I think, ‘Oh my goodness, please don’t complain. You know, you’re able to work, you’re able to see well, you’ve got a job or you’re happily married or whatever.’ I think maybe… you’re not as patient to allow other people to be who they are. Now, I think that’s me. You know, you become a grumpy old lady in other words, if you’re not careful.” (Hannah)

This extract suggests Hannah feels she could end up going down a slippery slope towards becoming “a grumpy old lady”, becoming embittered and less “patient” of others, who – in this more “grumpy” state of mind Hannah is conveying – are taking their good fortunes for granted. Hannah’s perspective here suggests an ability to step outside herself and observe herself; this ability to be self-aware and see herself through other people’s eyes may arguably help her be “careful” to avoid becoming “a grumpy old lady”, but it could also conceivably lead her to internalise the presumed negative views of others, and thereby reject or blame herself. This dynamic also came across when Hannah discussed using public transport:

> “[On the train] it isn’t easy. […] You’re wobbling about and you’re frightened you’ll fall. You know, none of these thoughts were in your head seven years ago. […] And if you have a bag, which usually I have round my neck anyway, I strap it round, and… and a stick, and… You look like one of these bag ladies who fumble about and you used to get very irritated with when you could do everything yourself! And so, you can understand people being terribly pedantic. My brother has wet AMD, and he’s terribly deliberate. And I used to think, ‘Oh come on brother, you’re so slow now!’. But… I know why he’s slow. He’s slow so that he doesn’t make a mistake.” (Hannah)

Here Hannah seems to voice the foreignness of the embodied feelings of physical vulnerability she feels, which were never "in [her] head seven years ago". Hannah then goes on to compare herself to "one of these bag ladies" with whom she had previously got irritated and she has now become. While this has led her to greater understanding and empathy for the "pedantic", "deliberate" and "slow" manner of her brother, there is perhaps a latent sense that she does not extend this empathy to herself but instead believes that other people will judge her, just as she previously judged slower-moving passengers. Perhaps because public transport was central in Andrew's account, I perceived a notable contrast between Hannah's judgement of herself and Andrew's lack of judgement towards himself, instead believing that others should accommodate and cater to him. Thus Hannah's account illustrates how AMD, and the new limitations and vulnerabilities the condition may entail, could potentially lead individuals to adopt an attitude of self-loathing. Arguably, individuals like Hannah are negotiating a newfound sense of embodied vulnerability, while living in a social world where vulnerability is stigmatised, a stigma they may then internalise and turn against themselves.

Julie's experience also spoke to the theme of "Who am I?", feeling a sense of no longer recognising herself. Like Ruby speaking about how AMD had affected her reading ability, Julie - as a former architect - felt deeply that a central, defining core part of her identity had been lost due to AMD:

> "I trained as an architect, I qualified as an architect. And I felt that the macular degeneration had robbed me of my identity. I felt that very strongly. Because of course, architecture's a very *visual* thing to do. […] I can't put it into words really. It [AMD] changed my life, I think it changed my outlook. But most of all, I felt I'd lost my identity. Architecture was who I was and what I was, and the ability to actually do it any more, and assess the character of villages and all that sort of thing I did in planning… I really felt I was missing out on things. […] And architecture being a bit of a perfectionist's career, I think it made me feel a bit *inferior* at first. And I had to sort of talk myself out of that." (Julie)

Very vividly, Julie conveys feeling that AMD has "robbed" her of her identity, causing her to lose her ability to engage in architecture which was "who I was and what I was" because of it being such a visual, sight-focused occupation. It is noteworthy that Julie – somewhat like Hannah fearing going down the road of becoming a "grumpy old lady" – experienced herself potentially falling into a state of feeling “inferior”, that she then had to talk herself out of (like Hannah warning herself to be “careful” not to become grumpy). Indeed both participants’ accounts demonstrate the mental effort involved in resisting the feelings of self-blame and a negative view of themselves that may easily come to the fore as a result of AMD unsettling the coherence of one’s identity and sense-of-self.

5.3.2. Incongruence between inner lifeworld and outward appearance – “I’m trying to find my new place in the world”

Within this theme (which came to be subsumed, along with the previous theme, into Theme 1 in the IPA write-up – “Reconfiguring a destabilised identity and struggling to find a new place in the world”), a small number of new codes were developed during the template analysis. These codes reflected new insights developed from the transcripts and helped shed further light on the manifold, diverse ways in which the theme was manifested among the new set of eight participants.

One such code was “Where’s my place within the world of people with AMD? Looking at the central phenomenon of vision loss from the periphery” (2.2.1), discussed by Marianne in particular when she recounted volunteering with a Macular Society group. Living with early-stage AMD and not yet experiencing advanced symptoms, Marianne would undertake tasks like making coffee or helping attendees with more advanced AMD to fill out forms. She stated:

> “I felt partly I was there under false pretences at first, but, you know, it’s interesting to hear other people’s experiences.” (Marianne)

Stating that she felt like she was attending the group under “false pretences” illustrates the lack of clarity Marianne feels about where she belongs within the category of people with AMD; this also has parallels with the oscillation (discussed in the previous theme on p.170-171) between experiencing herself as facing relatively few challenges in the present but apprehensively aware that these may accumulate in the future. This lack of clarity regarding where Marianne belongs in the AMD world was echoed when she discussed her ambivalence about disclosing her diagnosis of AMD when giving talks about the condition as a volunteer:

> "I think it's useful to say at some point when I'm giving a talk, but I don't want to announce it too early on, you know, 'this is why I'm doing it', 'I've got it', type of thing. You don't want that. But I don't want them to think I'm speaking in total isolation from it." (Marianne)

This misgiving about announcing her AMD too early seems to be linked to Marianne's wariness to be seen only to be speaking from her lived experience, when she is at an early stage. However, this concern is balanced out by wanting to reassure the audience that she is not "speaking in total isolation" from understanding of the realities of the condition (perhaps implicitly because of her father's experience of AMD as well as her own).

An additional code developed during the template analysis was "The challenge of putting the visual experience of AMD into words" (code 2.3.3), something noted in the IPA when Denise was discussing symptoms of Charles Bonnet Syndrome (p.107 in Chapter 4). However, this challenge was evidenced among the eight TeA participants specifically in terms of articulating the phenomenology of the visual symptoms of AMD. For example, Suzanne stated:

> "It's quite different with these letters all getting-- numbers getting muddled up, and letters doing strange things like… climbing steps as you go along the line. Very odd. And it's difficult to explain that to anyone." (Suzanne)

Here, Suzanne was trying to explain the difference between many of her relatives' experiences of short-sightedness and her AMD symptoms. Suzanne illustrates the sometimes profoundly surreal nature of the visual experience for her, with letters and numbers becoming jumbled within lines of text. She links this uncanny experience to the challenge of explaining the visual phenomenology to others and allowing them to understand ("it's difficult to explain that to anyone"). Suzanne also discussed feeling like her perception of colour had changed, but again voiced struggling to find the most appropriate words to convey the phenomenon:

> "Some colours are very difficult to see. I've obviously lost my… But it's not like colour blindness. […] Blue is the colour that is bad. I noticed, we had a flower festival in our church last year, and, we had some beautiful flower arrangements, and somebody said to me, 'Oh aren't those delphiniums just beautiful?' And I said, 'Where? I can't see delphiniums'. And she said, 'Well there, in those arrangements over the windows'. And I could not see the blue. I could see the other colours but I could not see the blue. And then when the sun came out,

> through the church windows, and shone brightly, I could see them. But I had lost the blue completely. It's very odd, I don't know whether everyone has the same problem. […] Perhaps that's just a normal thing, maybe anyone who's got short sight can't see blue very well either. You know, ordinary short sight. I don't know." (Suzanne)

This extract illustrates Suzanne grappling with how to define her changing perception of colour; she breaks off from saying "I've obviously lost my…" before categorically stating that what she experiences is not colour blindness *per se*. Continuing, her experience of being unable to see the blue delphiniums implies a near-total absence of visual information in blue, rather than (as might be the case in colour blindness) being unable to distinguish the colour blue or tell it apart from other colours. Towards the end of the extract, and aware that there may not be a definitive answer, she reflects speculatively on whether other people with AMD would have a similar visual experience, or indeed if that is something that extends to anyone with "short sight". This extract helps to clarify the link discussed in the IPA chapter (p.108-110) between the challenge of articulating the visual experience and a potential sense of isolation, as Suzanne is grappling with the question of whether other individuals with vision loss share in this confusing, "very odd" experience and if anyone else would understand. Pearl also alluded to this challenge of finding the right language to convey how her vision was changing with AMD (and in her case, with glaucoma)[38]:

> "My right eye doesn't seem to change. But I can't really see a lot. There may be a bit of peripheral vision, but not a lot. And with my other one, I had a glaucoma operation, because of the peripheral vision I would need when the central vision goes. But because my eyes seem to be sinking back into my head with old age, I am losing the peripheral vision. At least that's what it seems like to me." (Pearl)

Not only does Pearl imply the difficulty of parsing what's due to eye disease like AMD or glaucoma versus "old age", but also the image of her "eyes sinking back into my head" arguably conveys the unusual and confusing nature of her visual experience. Kate provided a slightly divergent perspective on the challenge of articulating the visual phenomenology of

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[38] Glaucoma is a group of eye conditions that cause damage to the optic nerve. In addition to AMD, Pearl was living with chronic open-angle glaucoma, which causes a gradual deterioration of peripheral vision (Weinreb & Khaw, 2004), in contrast to AMD which affects central vision.

AMD, because over time it may become the person's norm and they might naturally cease to focus on it as a specific phenomenon:

> "Yeah, and a lot of times, people don't want to talk about [AMD] because it's there all the time, they want to get *away* from it, almost. […] If you're concentrating [on other things], your brain sort of switches off to it. […] You do start to sort of think about other things and not notice it so much." (Kate)

This implies that the actual visual symptoms of AMD may be something individuals end up relegating to the background of their experience, either deliberately seeking to "get *away* from it" or more organically when the focus shifts to "concentrating" on other things so that the "brain switches off to it". Kate's perspective might help to explain why trying to put the visual phenomenology into words is difficult, if it is something the person has been actively trying to push to the back of their mind and finds challenging to face head-on, or alternatively if over time, it has organically become the everyday backdrop to their visual experience. Hannah voiced how the effects of AMD on her vision in some ways remain a mystery to herself, let alone when trying to explain it to others:

> "But the other thing I find with this sight loss, thinking about it, is that… you cannot explain to people why you can see one day and you can't see the next. And… that is a puzzle to me, never mind anybody else that doesn't have the condition. […] And that is very hard for the person as well as those who you live around." (Hannah)

As with other participants, including Denise and Rose from the IPA, Hannah links the variable nature of visual symptoms, depending on the specific day or background context, with the challenge of inculcating an understanding among others regarding what she can and cannot see. Similarly, Julie articulated the discontinuity between how AMD might be spoken about and how it is actually experienced first-hand:

> "I think it's fairly difficult for either of them [Julie's sons] to realise just… what a serious change it is, to have macular. I mean, you think, 'Oh dear, the poor person can't see very well anymore'. But until you actually experience it yourself, you don't realise quite what impact it's going to have." (Julie)

Julie's quotation illustrates the fundamental, seemingly immutable reality that true realisation of the effects that AMD has on the person – beyond a vague awareness that they "can't see very well anymore" - can only be gleaned through direct experience.

Another code developed in the TeA, somewhat related to this challenge of articulating what having AMD means in terms of the visual experience, was "Context affecting ability to be open about AMD" (2.4). This arguably complemented a neighbouring sub-theme in the original template, "Dilemmas around disclosing vision loss" (2.5), exemplified in the IPA by Sandra's deliberations about whether to use a white stick (Chapter 4, p.109). However, in four of the TeA participants' cases, they voiced a clear sense that the place, time and social context differentially affect their ability to open up about life with AMD, with this often being a continuum, from feeling able to be very open about their AMD while others experienced it as something very private. Louis, at arguably the more open end of this continuum, stated:

> "I let it be pretty well known, I'm not ashamed of saying I've got macular degeneration, and I just say to people, that's it and I'll do my best…" (Louis)

This extract illustrates Louis' highly matter-of-fact, problem-solving approach to AMD, and (later in his account) he suggested that his ease and comfort disclosing AMD - as demonstrated here - also then made it easier to ask others for help with everyday tasks. Marianne clearly articulated how her willingness to be open changes depending on the interactional context, stating:

> "It depends who it's with. Sometimes you think, 'Oh it's not worth mentioning here, because we're only going to be here with these people for a short time'. […] Unless somebody mentions macular, you know, if we were just talking generally, I wouldn't have brought it up." (Marianne)

This seems to suggest that there may be times when Marianne feels an initial impulse to divulge her experience, but concludes that in the end "it's not worth mentioning" if she will not be with the interlocutor long enough, implying the importance of discussing it in a careful and purposeful way. Julie also stated, when reflecting on how she found the interview experience, that "I don't suppose I talk about it [AMD] with other people very much"; and she suggested her limited inclination to discuss AMD may be linked to being more broadly reserved about talking about herself:

> "I've never been someone who-- If somebody says how are you, I don't go into great detail about how I am, I don't say, 'Oh I've got macular!' [*laughing*]. So yes it's a difficult thing to deal with, isn't it." (Julie)

Here, Julie identifies herself as the kind of person who in quite a stoical and reserved fashion would be unlikely to discuss her health and wellbeing extensively if someone asked her how she was, and AMD also fits within this category of topics she would be unlikely to divulge in great depth. At the same time, she voiced an awareness that a lack of avenues to talk about AMD with others compounds the difficulties the condition presents. Pearl seemed to feel similarly, and contrasted her reticence to talk about AMD with people she knows with the opportunity to focus on it in the research interview:

> "Having this talk, and answering your questions, I think will help me. Because I don't want to discuss my eyes getting a bit worse every day with anyone I know. I'd rather not do that. And yet, I feel I would want to. So perhaps this has helped me as well Jamie." (Pearl)

Pearl's reflection here also called to mind Rose's assertion that taking part in the interview was "liberating":

> "[It's] very liberating really…. And up to a point it normalises it. You don't feel… so unique, like a one-off. You are part of a community of people that have got the same thing." (Rose)

Pearl and Rose's quotes taken together illustrate the paradox that many individuals may feel reluctant or ashamed to discuss AMD with people in their lives, but clearly feel a wish to share the experience with someone, clearly illustrated by Pearl saying she would "rather not" discuss AMD and yet simultaneously "I feel I would want to".

5.3.3. The intensive effort of learning to live with AMD – "It is what it is. I have to learn to live with it": embracing a new reality

Perhaps more than any of the other themes, many of the TeA participants' experiences fitted neatly into the sub-themes and codes of this theme derived from the IPA, and there was often striking consistency between the language used by the TeA and IPA participants. For example, just as Rose spoke of “learn[ing] ways round” AMD (p.112), Marianne stated:

> “I am looking at hobbies that will perhaps need less good sight, […] that perhaps won’t require the fine sight. So I am sort of looking at other ways around certain things.” (Marianne)

While not necessarily warranting a new code in itself, one notable, unique experiential aspect discussed only by Marianne was the idea of almost ‘rationing’ her vision, strategically treating it as a finite resource, for example with reading which had become tiring for her:

> “I am an absolutely avid talking book listener now [*short laugh*]. I still read a little, but I try and keep the reading to things I’m not going to be able to get on talking book, and that I can read in shorter bursts.” (Marianne)

As with participants in the IPA, Marianne’s strategy here attests to some of the mental and organisational effort involved in adapting to life with AMD.

Two more novel codes were developed within this theme on the basis of the TeA. While it did not fit into a specific place in the template as seamlessly as certain other codes, a code “Wish for the world at-large to be made more accessible for people with vision loss” (3.3.7) was developed from Louis and Suzanne’s accounts, in a way that was voiced explicitly where it had been far more implicit in the IPA. I decided to place this code within sub-theme 3.3, “Curiosity and gaining knowledge about AMD as a source of empowerment, mitigating confusion and despair”, because both participants had clear knowledge of what was necessary to make aspects of their environment more accessible, and – especially in Louis’ case – clearly articulated how improving accessibility would make it easier for him to live well with AMD and remain included in the world. Louis made this very clear at the end of the interview when he summarised the three key aspects of his experience he had wanted to highlight in his account:

> “The problems that come with macular degeneration; the way in which you deal with it; and the sort of help that you could, and perhaps should, expect from the world out there.” (Louis)

Notable in this, as Louis reflected on his experience of the interview, was naming clearly that the “world out there” should be accommodating to the person with AMD, alongside his own individual efforts to “deal with it”. Both Louis and Suzanne focused in on the issue of legible text in official documentation:

> “[It is important that] councils recognise that the small print size is totally useless for those who have even 50% macular degeneration. They need to be able to get large print easily. They don’t have to fill in forms and all that sort of stuff, they ought to be able to ring up. There should be a number where people with macular degeneration can just dial and say, “You’ve sent me some documentation today, I can’t see what it is. Will you send me some in large print?” That’s what you should be able to do.” (Louis)

While Louis is speaking here more generically about what he would like to see change, rather than the specificities of his own experience, his forthrightness on this point was arguably based on his own hard-earned experience of being excluded from accessing print materials:

> “I do see quite a lot of adverts, in the paper, and the… board or something, and it’s no good me reading it, because I can’t see what it’s all about!” (Louis)

This was echoed very closely by Suzanne, who stated:

> “I mean, those small notices that you read on a wall or something, you just can’t read it and that’s very trying.” (Suzanne)

Although these quotations may appear somewhat tangential to understanding the lifeworld of people with AMD, they demonstrate an elementary but important point that the intensive effort of learning to live with AMD - which many participants discussed taking on themselves as a personal endeavour - is of course highly intensified by the many exclusionary and inaccessible obstacles in (what Louis terms) “the world out there”.

The second novel code developed through the TeA within this theme was “Comparison with others’ experiences as a source of inspiration, motivation and reassurance” (C 3.6.3), within the “Adaptation and acceptance” sub-theme. In experiential terms, comparisons were expressed in two main ways: sometimes participants felt a sense of stoic gratitude when considering what had befallen others in their lives or what could have befallen them; at other times, participants looked to others living with AMD or similar conditions as potential role models who imbued them with hope and inspiration. Participants in the IPA touched upon this issue; for example, Sandra compared herself with people who are “literally blind”, and Ralph discussed his identification with the GP in a Macular Society video whom he described as instrumental in his “metamorphosis”. However, this thematic concern crystallised in the process of the TeA as a phenomenon that warranted my specific attention and representation within the formal structure of the analysis. Suzanne for example spoke of her late husband’s colour-blindness, which then caused her to reflect on how sight loss compared to the possibility of losing other senses such as her hearing:

> “It’s like really losing your hearing... Losing your sight is, I think, not as bad as losing your hearing. […] If you have heard, and you now can’t hear… well you just have to write everything down I suppose, and that must be very trying. So there are lots of other problems. You know, mine isn’t the worst. Sorry I’m waffling on [*laughs*].” (Suzanne)

Suzanne here illustrated how she might compare herself to people with other conditions such as hearing loss, and other problems more generally, but then became concerned she was “waffling”; this perhaps implies some self-consciousness about this kind of formulation, arguably since this comparison with others is ultimately speculative, rather than based on first-hand knowledge gleaned through her own experience. However, the extract also illustrates that Suzanne is able to step back from her own experience, and take a more birds-eye view that puts AMD into perspective with other people’s experiences. While Suzanne’s reflection was more generalised, as she compared herself living with AMD to people with “other problems”, Marianne compared herself more specifically to other people she had met with more advanced AMD or visual impairment:

> “I mean I’ve met people in their late nineties, still on their own and managing! [*Imitating people she has talked to*] ‘I’m having difficulties threading a needle now!’ you know, [*laughing*] Golly! I mean, absolutely inspiring people. That helps… you know, what have I got to grumble about? It’s been great, a great help.” (Marianne)

Here Marianne makes clear that meeting people who might be a lot older with more advanced AMD has given her a palpable sense of hope, which also came across through her laughter and animated tone of her account here. Given that much of Marianne’s account was dominated by an apprehensive uncertainty about where AMD could lead, it appears that calling to mind the image of these “absolutely inspiring” people provides a concrete example of one possible, more positive path she may take through the condition. The statement “what have I got to grumble about” suggests Marianne may be thinking about how these people may be in objectively much more difficult circumstances with more advanced AMD, but in her eyes they are symbols of a remarkable resilience, who inspire her to try to cultivate the same optimistic and pragmatic mindset. While Marianne drew on inspiration from looking ahead to those who potentially represented a possible future, Hannah arrived at a similar conclusion by looking back into her past and her mother’s experience of chronic illness. When I asked Hannah what helped her to - as Hannah stated - “learn to live with what you’ve got, accept it [AMD], and just get on with it really”, she then responded:

> “My mum would say, “Don’t worry, it’s the nature of the beast”. And I think it’s the way you’re brought up, partly, and my mum had chronic illnesses. […] I think… my mum was stoic. And you are influenced by what you see and what you live with. And she was amazing! I mean she couldn’t see at all. And… she lived alone, and I’m sure she had… many lonely hours, but when you were with her, she never grumbled. She grumbled about her pain, arthritic pain, but she didn’t *grumble* grumble.” (Hannah)

Here Hannah evokes her mother as a key influence throughout her life, who was “stoic” and did not “*grumble* grumble”; arguably the “nature of the beast”[39] evokes the sense of “it is what it is”, incorporated into the composite quote for superordinate theme in the IPA (“It is what it is. I have to learn to live with it.”). Hannah voices clear admiration for her mother, about how “amazing” she was, and seemingly resilient and stoic in the face of multiple challenges; this clearly provides an inspiration for her, but it is worth also recalling Hannah’s fear of becoming a “grumpy old lady” discussed earlier in this chapter. Thus it seems that part of her experience of trying to cope with AMD is orientating herself towards examples like her mother, while all too aware of the latent, insidious possibility of becoming “grumpy”, and clearly working hard to resist going down that path. The description of how her mother “didn’t *grumble* grumble” implies that Hannah perceives there to be an acceptable level of grumbling, a perimeter that she would like to remain within, as her mother did. This hints at the intense efforts Hannah may be making to manage her emotions and maintain a kind of

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[39] Defined by the Oxford English Dictionary as “the (usually undesirable) inherent or essential quality or character of a person, event, circumstance”.

equilibrium, to acknowledge the difficulties of her situation without tipping over into what she would characterise as excessive “grumbling”.

5.3.4. Navigating the hope-despair continuum

Within this theme, concerned with the emotional dynamics of participants’ AMD experiences, shifting on a continuum between states of hope and despair, a small number of codes were developed based on analysis of the TeA participants’ accounts.

While it was not necessarily an entirely new thematic concern, analysis of Hannah’s account (somewhat complemented by Suzanne’s account) led to development of a new code “Letting despair in, while resisting the pull of catastrophic thoughts of the future” (4.1.2), nested within the sub-theme “Experiencing loss without ‘losing it’: Pulling oneself back from the abyss through proactive coping” (4.1). While interpretation of Denise’s account led to the development of this sub-theme in the IPA, Hannah and Suzanne voiced somewhat more explicitly the psychic ‘tug-of-war’ involved in managing their emotional states, trying to limit the inevitable thoughts of catastrophe (and the feelings of despair these could entail) and actively, intentionally move towards the cultivation of hope. For example, Hannah articulated the mental effort involved in trying to pull herself back from fear or despair about how severe her vision loss might become:

> “I don’t let my mind go there too often, but I hope I do not go… blind. I don’t know what I would do. You don’t have choices, so you can’t say what if this-and-this [happens], but I don’t think I’d be [*laughing*] as happy as I am at the minute. I think I would struggle terribly. But I don’t… don’t let that come in too often, because it’s not necessary. Because it *could* never happen. It *could,* it doesn’t have to. And it wouldn’t be good to ponder on all that could happen in life, you know. But to be not able to see is quite hard for just daily living.” (Hannah)

Perhaps more explicitly than Denise, whose account was most central to developing this sub-theme in the IPA, Hannah here points to the very active efforts she is making not to tip into despair, and not to picture the worst-case scenario of severe vision loss which she imagines would be highly distressing and cause her to “struggle terribly”. The language here, with Hannah stating “I don’t let my mind go there” or “I don’t let that come in too often” implies a vigilance on her part, alert to when these negative thoughts about the future are bubbling up and firmly resisting giving into them. She encapsulates the clash here between knowing intellectually that thinking ahead is an unnecessary thing to do (when the exact visual outcomes of AMD are uncertain), while simultaneously unable to avoid thinking ahead, considering for example how "to be not able to see is quite hard for just daily living".[40] It is as though there is a tussle between the more pre-reflective, emotional response Hannah has when thoughts of the future creep in, and her rational, logical side which is determined and working hard to keep such thoughts in-check and thus avoid falling into despair. Indeed, Hannah described becoming practised at learning to reappraise frustrating, difficult situations that might occasion despair, and instead to adopt a more hopeful and compassionate self-talk:

> "I'm just starting to get into that stage now where I do make mistakes, especially over numbers and words… I miss a whole word out. And it becomes very annoying. And then afterwards, you laugh and you think, 'Can I be so stupid to miss that? Why didn't I just turn my head and look at it properly?'. You do turn it around, but it takes time, to train yourself to do it. And I think that happens with all aspects of life. You know, you either go under and be a misery to yourself and everybody else, or you attempt to be better at your last… stage of your journey." (Hannah)

This extract illustrates clearly how Hannah does feel frustration when reading and missing numbers or words, but later reappraises the situation to laugh and find humour in it. This reappraisal of the situation seems to have parallels with the broader process Hannah is alluding to here, of sometimes by default, more pre-reflectively, finding herself moving towards becoming "a misery to yourself and everybody else" (recalling the "grumpy old lady" image), but intentionally, proactively cultivating a positive, pragmatic approach ("attempt to be better"), to avoid going down the path of despair. Interestingly, while it was Marianne's account that brought to mind the image of the wave of possible future catastrophe linked to AMD, Hannah's language here also introduces a water-based metaphor, of potentially drowning in despair when she speaks of "go[ing] under", a possible scenario she is intentionally seeking to keep at bay. Suzanne also echoed this thought

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[40] Hannah's formulation here has similarities with Marianne's discussion on p.171 (within the Temporalities sub-theme of Theme 1) about the uncertainty of where she will end up and how she would cope with more advanced vision loss.

process, and like Hannah she explained it with reference to AMD, but also saw it as emblematic of the kind of processing required to respond to shocks in life more generally:

> "It never occurred to me I would have something like this wretched macular degeneration, and I do sometimes get a little bit bitter about it, but not too much. There's no point… You can't do that. I mean I've had-- Sorry, this is not really relevant, but my first husband died in an awful accident […] So that was a bit sort of fraught. And I could have got very bitter about that, but I didn't, and I think I'm lucky that I'm somebody who doesn't get bitter. You just have to get on with life. And I think that's really how I'm trying to regard this. You know, even if I can't do all the things I want to do, I'm going to do something. So if I can help you in any way, that's a good thing." (Suzanne)

Suzanne here admits that she sometimes feels "a little bit bitter" about AMD, but ultimately seems to see that bitterness as futile ("There's no point… You can't do that"). While she disclaims it as irrelevant, she refers to the traumatic death of her first husband and the potential to have spiralled down into "a very bitter" state, but instead chose to "get on what life". Notably, Suzanne does not deny the reality of feeling more limited ("even if I can't do all the things I want to do"), but is determined to stay as engaged and proactive as she can ("I'm going to do something"). Linking Suzanne and Hannah's accounts (and also reminiscent of Ruby's account in the IPA, p.125-126), both participants admitted openly to feeling difficult, unsettling feelings, for example of bitterness, frustration and grumpiness. However, their accounts also illustrated an awareness that these states are matters of degree existing on a continuum, and so they are actively guarding themselves from slipping further along this continuum towards the despairing end, intentionally and resourcefully finding ways to remain oriented towards a state of hope and pragmatism.

5.3.5. The role of close relationships – Alone but not alone

Within the superordinate theme focusing on how AMD shapes interpersonal relationships, three new codes were developed.

Firstly, certain participants in the TeA explored "experiencing AMD as an intergenerational phenomenon" (ST 5.5). This manifested in two main ways: firstly, in terms of participants' experiences being influenced by ideas and expectations based on family members' experiences of vision loss; and secondly, in terms of concern about their children or grandchildren also having an elevated risk of experiencing AMD. Hannah and Marianne in particular spoke to the first manifestation of this phenomenon. Hannah's mother and grandfather had both experienced visual impairment, recounting:

> "When I was first diagnosed, I was actually quite anxious because my mother had sight impairment and my paternal grandfather was blind with a different condition. And so the thought of living alone, with sight loss, was not something I looked forward to." (Hannah)

In this extract, Hannah relates feeling anxious particularly because of her family members' experiences of sight loss, implying these set up a kind of foreshadowing or precedent for where she might end up "living alone, with sight loss". Marianne also used a similar formulation, discussing how her father's experience of AMD set up certain expectations for her own, when discussing trying to read smaller print text:

> "I do find the print a struggle, and I'm sure that will alter in the future, looking at what happened to dad. I suspect that it's not going to improve, let's put it like that [*soft laugh*]." (Marianne)

Like Hannah, Marianne alludes to the decline of vision that she sees as likely based on her father's experience, although is somewhat euphemistic about this future ("it's not going to improve"), like Hannah stating the future "was not something I looked forward to". However, as noted above under Theme 3 (p.184), Hannah's mother has also provided her with a positive role model to follow, in terms of her stoical, pragmatic outlook in response to visual impairment and her other chronic health problems. This also came across when Hannah invoked some of her mother's coping strategies, for example to try and maximise use of her intact peripheral vision:

> "'Look like a chicken' is the answer my mum had to everything, 'Just look like a chicken!'. And it's true, because you have your periphery vision, not your central vision, and you see a little bit more if you look like a chicken, with its head on the side. If you see a chicken looking for food, it stands with one eye looking [*laughing*]." (Hannah)

This extract, similarly to Hannah recounting her mum using the phrase "the nature of the beast", vividly demonstrates how some of her mother's strategies in response to vision loss have taken deep root and remain accessible to Hannah, as a source of humour and inspiration in the face of challenges posed by vision loss. When Hannah states, "and it's true", this attests to the ways in which her first-hand experience of vision loss has confirmed the aptness of her mother's chicken comparison. This sense of achieving a kind of intersubjectivity or 'meeting-of-minds' with her mother also came across when Hannah discussed experiencing visual hallucinations from Charles Bonnet Syndrome (CBS):

> "And my mum had it, with a child. She saw a child putting the washing out on the line. And she described her. She had an old-fashioned apron on, and she was about twelve, and this and this… I said, 'Mother, there's nobody there!' And it wasn't recognised in her day. So we just thought, 'Oh mother's losing the plot'. But she wasn't, she was very alert mentally. But now… I couldn't believe it cos I have a fireplace, and I gather papers and drop them beside my chair. And this little kitten was sitting on these things. And it was so plain! I put my hand down and there was nothing." (Hannah)

Here, Hannah compares her hallucination of a kitten with her mother's hallucination of a child, and Hannah's first-hand experience of a hallucination seems to bring her closer to better understanding her mother's experience. Hannah implies that her deeper understanding of what her mother was experiencing is due not only to Hannah's first-hand experience of hallucinations, but also to the increase in awareness of CBS (which "wasn't recognised in her day") that has retrospectively dispelled the notion that her mother was "losing the plot". Marianne also discussed coming to understand her father's experience better, once she learnt more about AMD and the preservation of peripheral vision:

> "I mean I've been able to see with my dad, he's spotted a plane in the sky, he's spotted a snail on the ground, he doesn't recognise me. And you think [*laughing*], "Oh, you know, he can see that snail, he can't see me!" But he couldn't see me to recognise. When I thought about it, I realised exactly why. Because the snail was in his peripheral vision, but he was looking straight at me. It's that sort of thing that I think is so easy to do. You know, I knew all about macular, as a relative, I knew all about it! But still, I found it hard to… work out how he could see the snail and not me. So you know, if that's me, how much harder for somebody who doesn't know much about it." (Marianne)

This extract attests to the challenge of translating abstract knowledge about the effects AMD can have into an experiential understanding, with Marianne discussing her process (presumably before she started experiencing AMD herself) of putting herself into her father's shoes and seeking to understand why a plane in the sky or snail on the ground might be visible through his peripheral vision even if he could not recognise Marianne using his central vision.

Suzanne spoke to the other, future-oriented manifestation of AMD as an intergenerational phenomenon, stating:

> "I'll tell you what I am concerned about are the genetic problems, whether I'm likely to have passed it on to my children. […] Cos people always ask me do you have it in the family sort of thing. […] I can't really tell whether any of my relations have had it, I just don't know. But I would hate to pass it on to any of my children, if there's a way of avoiding it." (Suzanne)

This extract shows that for Suzanne, worries about where AMD will culminate in her own life also extend to considering whether her children may be at heightened risk, and whether they might be able to take preventative action to reduce the risk. Thus the experience of AMD as an intergenerational phenomenon involved both looking back and forward, and cemented the sense of a dynamic interplay between being alone and not alone; for example, for both Hannah and Marianne, the experiences of their parents with vision loss were present and palpable throughout the accounts, acting as a kind of internal reference point in relation to which they evaluated their own experiences. Meanwhile, Suzanne was acutely aware that her AMD experience could be one shared by her children, although she expressed hope that they would not be affected.

The second new sub-theme developed from the TeA encompassed "concerns about the changing nature of friendships, social interactions and relational roles" (ST 5.6). While this notion was implicit or latent in certain other accounts, Suzanne explicitly voiced concern about becoming a "nuisance", in the specific social context of playing bridge:

> "We all played bridge in the evenings, and I realised more and more what a nuisan[ce]-- You know, people are very kind, but it's a nuisance for them to have to keep telling me what the card is when I can't see it. So I shall hesitate a bit about playing with anyone good." (Suzanne)

It is noteworthy here that Suzanne initially hesitates to label herself as a "nuisance", but then uses the term to describe the inconvenience for other bridge players to have to tell her the cards. She stated before this extract that she perceives bridge as "a social thing that I am going to lose", but at least in the present, her solution has been to play with individuals whom she considers “aren’t very good”, rather than to give up altogether. Suzanne’s experience points to how certain social groups structured around vision-related activities such as particular sports, games or crafts, may present particular challenges for a person with AMD who still wishes to participate but is grappling with newfound limitations. Kate also voiced struggling with the social implications of vision loss, and having to resist the impulse to withdraw from certain social situations:

> “I think I’ve been my own OT [occupational therapist] really. But there are areas of mixing with people which I know I get wrong sometimes. And I think that’s been one of my biggest problems, from being a real sociable sort of person… It is quite easy to actually want to become a recluse, you know, changing completely. And I will jump out of my wanting to do that, because again I have a very supportive husband… But I think friendships and interactions with people is one of the biggest problems really.” (Kate)

Here, Kate clearly illustrates the temptation to “become a recluse”, which feels out of keeping with her self-concept as a “sociable sort of person”. She voices the need to “jump out of my wanting to do that”, almost as if she has to snap herself out from a kind of creeping tendency towards isolating herself in order to avoid potentially distressing social situations (for example, not recognising people in public and their assuming that she is being rude – discussed directly below within Theme 6).

5.3.6. The place and space of AMD

Within this theme, a significant new sub-theme was developed, regarding participants’ “wish for more nuanced societal understanding and awareness of vision loss” (ST 6.4), particularly based on Kate and Louis’ accounts. Kate spoke extensively about how vision loss made it challenging for her to appreciate the subtleties of non-verbal communication, and her concern about how difficulties recognising people when out-and-about might lead her to be perceived as potentially rude or standoffish:

> “People sometimes have said to [my husband] that I was a bit rude and stand-offish. But they don’t realise I can’t see. […] I’ve lost all that, all the subtleties of, if you’re in a meeting, you know, and someone will look at somebody and they’ll know when the next one wants to speak… I can’t do any of that, so I always mess it up without meaning to mess it up.” (Kate)

Kate's extract here illustrates how much of daily social interaction is predicated on the assumption that people can pick up on non-verbal cues in all their "subtleties"; and the ways in which difficulties doing so are often misinterpreted as "rude or stand-offish", a moral judgement which feels at odds with Kate's experience of simply no longer having this capacity to interpret non-verbal cues. Indeed, she is very clear that she "mess[es] it up without meaning to mess it up". This implies the dual challenge people with visual impairment may face in social situations, of not only finding it difficult to read subtle non-verbal cues but also then potentially being negatively judged or shamed for this. Kate also stated:

> "The main thing I wanted to get over to you really was the lack of being able to communicate with people at a distance, and so, you know, people think I'm just snubbing them. Cos all this business of facial expressions… someone will smile at you and you just look… blank at them. So they forget that you can't see them smiling." (Kate)

Again, this quotation illustrates how people with vision loss may be shut out from the non-verbal signalling that is often taken-for-granted as a mode of communication, and may be misinterpreted as Kate "snubbing them". Louis discussed an almost identical experience, and relayed the embarrassment that difficulties recognising people caused him:

> "I don't find it easy to recognise people, until they are very close to me. In other words, until they get to about three, four feet away from me, I can't genuinely see who they are. That's my biggest loss of performance. […] It's a bit embarrassing when you're walking towards someone and you get right up to three feet before you say, 'Oh hello', you know, it's a bit… They think I'm being rude, but I'm not. I can't recognise them." (Louis)

Here Louis voices his concern that other people think he is being rude when in fact he is in fact simply unable to discern who they are. The way he states "I can't genuinely see who they are" implies, like in Kate's account above, that it is not a matter of will or moral agency, which is insinuated by the judgement of being rude; instead, it is simply a fact-of-life and limitation that he cannot himself change. Having said that, both Louis and Kate (somewhat like Andrew in the IPA) suggested the need for education and wider awareness of the effects of vision loss in order to help change sighted people's perceptions. Kate stated:

> "When you've watched television, for example, how often do you see something that involves people with poor vision or that are blind? Not very often. If you're watching a film

> on Netflix, how often do you see somebody that's blind on that? So I think education of *people*, well maybe education of children, going into schools. […] Cos people just don't think. You know, I could walk round with a sort of placard on my front or something, saying I can't see you [*laughing]…* I don't know, but I think there's just very little awareness about it." (Kate)

Kate here suggests that people with visual impairment are rarely featured in films and culture (indeed, later elsewhere in the account, she explicitly referred to people with visual impairment as a "hidden bunch"). She argued that education should start in schools to encourage people to be more aware of visual impairment, suggesting that short of wearing a "placard… saying I can't see you", people will inevitably not consider the possibility of visual impairment. Louis similarly suggested that, in the context of individuals organising events, "the organiser [should] keep in mind that some people will have difficulties".

5.4. Reflections on the Template Analysis process

Overall, using TeA to extend the interpretative phenomenological analysis of the original eight accounts allowed for the development of specific new insights. It could be argued that the possibility of assigning aspects of the participants' account to the *a priori* themes and sub-themes then freed up attention to focus on the more novel experiential features of the accounts, or concerns or experiences that seemed to present as unique or anomalous and had not previously been encapsulated in the template. Furthermore, when part of a TeA participant's account neatly fitted with existing sub-themes/codes, this also bolstered a sense that the themes developed through the IPA were expressing some notion of a shared experience of AMD, which strengthened my confidence in the IPA themes possessing some degree of generalisability.

One notable observation was that communication and social interaction, the central interest of the PhD study as originally conceived, was discussed more explicitly in some of the interviews analysed with TeA than in the IPA. It could also be argued that issues of exclusion and accessibility, more macro-level concerns, were discussed more by the TeA participants, particularly participants Kate and Louis. Such concerns may in some ways be less compatible with IPA, because identifying barriers involves discussing events happening outside the person. While it is possible to focus on the experience of exclusion itself, talking about and identifying a barrier in the physical and social environment may not necessarily prompt deeper sense-making or further experiential reflections. This was particularly the case in the analysis of Louis' account, who focused less on the feeling of being excluded (although this did come through, indirectly) and more on the practical obstacles, intensified by inaccessibility and ableism in the built and social environment, that he had to navigate in daily life. Even though the TeA was still underpinned by a phenomenological epistemology, the more flexible form of the analysis in this chapter (allowing more scope for following potential lines-of-enquiry less centrally related to lived experience) seemed to allow for a greater possibility to attend to these less squarely experiential aspects of Louis' account.

On a more procedural level, the TeA was often challenging in terms of developing, subsuming or refining new or updated codes into coherent sub-themes or codes that warranted attention in the Results write-up section. For example, sometimes I added a new code into the template while analysing one of the TeA participant's accounts, but later realised that this was arguably just a variation on a sub-theme already discussed in the IPA. As one illustration of this, a new code "Finding 'ways round': making changes and adaptations to valued activities and hobbies" (C 3.3.6) was developed within the theme on "the intensive effort of learning to live with AMD". However, when actually embarking on writing about this code and how participants illustrated this, I realised that this was another way of illustrating a phenomenon already discussed in the IPA (vividly demonstrated, for instance, by Sylvia discussing her changing style of painting as her vision loss progressed). The TeA participants provided further striking examples of this experience in different domains of life; for example, Suzanne discussed moving to a different section of the choir where she would no longer need to be able to read the sheet music. However, I did not necessarily know whether this experience felt distinct enough to warrant focus as a new thematic concern. This was particularly the case in the theme on "the role of close relationships" (Theme 5 in the template); many of the TeA participants spoke eloquently and movingly of how AMD had affected their close relationships, and also how close relationships potentially supported and/or problematised their ability to cope with AMD. Sometimes the unique features of the TeA participants' relationships with others led me to begin developing a new code, for example 'generativity through acts of generosity' from Hannah's account, when she discussed seeking new ways to support her friends since her social life had changed after stopping driving. This felt like a rich and meaningful insight; but because it was unique to Hannah, and in some ways did not necessarily feel so different to Ruby discussing her volunteering in the IPA (under Theme 3.2 in the IPA, p.126), I hesitated about how far to represent these person-level insights in the TeA write-up. This in turn demonstrates the ways in which the TeA process makes large amounts of data manageable, but inevitably involves some omission of individual-level experiences, despite the intention to attend closely to the idiographic. Additionally, if even more manifest, semantic content feels like it may be excluded through the process of TeA, this was even more the case with the latent, tonal aspects of participants' accounts. Nonetheless, such a limitation arguably also applies within IPA; for at the point of moving from idiographic, case-by-case analysis to developing superordinate themes applicable across cases, this more profound sense of the person's lifeworld as an individual may become somewhat diluted. However, and as discussed in the subsequent paragraph, often standing back to consider the whole person would itself trigger re-interpretation (and subsequent re-naming or re-organisation) of certain themes and sub-themes, demonstrating – in keeping with the hermeneutic circle – how an understanding of the individual participants' lifeworld can feed into the process of cross-case thematising.

Because I was conducting analysis of the TeA participants' accounts at the same time as writing up the IPA, the analysis processes were often complementary or mutually reinforcing. Yet if more concerned with rigour in a narrow sense (without the concerns of timing and practicality discussed in Footnote 36, p.165), one might advise keeping these processes more separate. Nonetheless, I would argue that if one is seeking to use the dual process of IPA and TeA to deepen understanding of the central phenomenon, and one accepts the overall qualitative analysis as an iterative, recursive process, then this is arguably less of a concern. Sometimes when analysing a TeA participant's account, I was reminded of something latent in the IPA participants' accounts, a feature that I had not necessarily alighted upon as being so meaningful when conducting the IPA. A good example of this was the sub-theme "Who am I now?" (IPA theme 1.3, and discussed above in the TeA under Theme 1), which only crystallised as a key thematic concern when analysing the TeA participant Hannah's account. Hannah's very vivid description of coming to feel alien to herself, worrying about becoming an unfamiliar version of herself - such as a "grumpy old lady" or "one of these bag ladies" who is overly slow and deliberate - helped to subsequently approach the analysis of accounts of IPA participants such as Ruby or Sandra in a new light. This may be seen as a somewhat high-level manifestation of the hermeneutic circle, whereby an insight prompted in the TeA deepened understanding of what was really at stake for participants in the IPA, an issue that I was tentatively moving towards identifying as experientially significant but had as yet struggled to truly pinpoint.

A final issue relates to the process of using TeA to extend or develop the IPA findings, which – at least in this write-up – has privileged novelty of content over rich illustrations of existing themes. This reflection emerged most strikingly when analysing Suzanne's account, when she compared the process of coming up against new limitations to getting stuck halfway when going over a step stile[41]:

> "You can't believe that you can't do something that you've always been able to do. It's like climbing over a stile, and you suddenly realise your leg won't go over. It's… very hard to give up your independence, you know, just your… your ability to do anything! I think, getting old, it's not easy to accept."

This simile of getting stuck halfway over a stile was striking in conveying Suzanne's shock of very suddenly finding herself unable to do something that had always been taken-for-granted, and thus encapsulated the insidious, unexpected nature of the new limitations that accumulate with AMD. While a linguistically and conceptually rich description, this did not dramatically alter understanding of the phenomenon of participants experiencing AMD as a limiting condition. However it occurred to me that if this had been analysed within the IPA, such a description may perhaps have been considered a "gem", defined by Smith as "the relatively rare utterance that is especially resonant and offers potent analytical leverage to a study" (Smith, 2011, p.6). Suzanne's account was not only analysed with TeA, but was also analysed as the final account, when the IPA themes had already crystallised into a relatively finalised form. This made me aware of how Suzanne's simile, which could have perhaps been a central ingredient in developing the theme in IPA, had somewhat less 'status' in the TeA,

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[41] Stiles are commonly found in the UK countryside, and are defined by the Oxford English Dictionary as "an arrangement of steps, rungs, or the like, contrived to allow passage over or through a fence to one person at a time, while forming a barrier to the passage of sheep or cattle".

because it simply confirmed an already-developed theme, albeit in a particularly striking and powerful way.

Ultimately however, it is important to state that while the TeA process was documented in this stand-alone chapter, separately from the IPA (Chapter 4), in reality another analysis that was less focused on transparently showcasing the methodology could more organically incorporate meaningful elements of the TeA participants' accounts into existing IPA themes. Thus such a demarcation in this thesis between the IPA and TeA processes, in order to focus on the different methodologies, is inevitably more artificial than would be the case in a more content-focused presentation, where there would be flexibility to straightforwardly incorporate potential 'gems' like Suzanne's simile of the stile into the IPA write-up. Yet the description of the TeA process in this chapter has aimed to illustrate what the method can afford in terms of new insights developed and practical expediency, as well as the challenges of remaining rooted in the idiographic and considering at what point an idiosyncratic concern warrants attention as its own sub-theme or code. In Chapter 8, I discuss these methodological issues further.

Chapter 6: Home tour interview case studies

6.1. Introduction

As noted in the Methodological Overview (Chapter 2), this phase of the PhD aimed to explore more centrally how the physical, relational and social environments in which participants are situated may shape their experiences of AMD. Moreover, a key aim was to situate the research process within the participants' everyday environment, by conducting interviews combined with a home tour at two participants' homes. An additional hope was that this interview combined with a home tour might allow for more fresh, in-the-moment reflection and meaning-making to develop (see the Background and Rationale section, Section 6.1.1).

This phase of the research was conceived as a case-study design with only a small number of participants, for several reasons. Firstly, there were practical constraints, including time considerations in terms of the PhD timeline, and logistical limitations; participants for the IPA interviews were recruited from across the UK, and it would have entailed significant time and expense to reach certain participants especially living in rural areas. Secondly, as discussed under ethical and safety considerations below, I had some concerns that the home-tour methods could be experienced as intrusive or unsettling for some participants. Thirdly, having conducted long, in-depth interviews for the IPA study, I was unsure how far this next phase, conducted 3 years after the IPA interviews, would generate particularly new data or insights.[42]

6.1.1. Background and rationale for the methods

6.1.1.1. Extending IPA's focus on the person-in context

Interpretative phenomenological analysis (IPA), the methodology used in Chapter 4, attends to the experiences of a person-in-context, recognising that "the physical, social and cultural world has an existence which precedes us, and which constrains what we can do, be and claim" (Smith et al., 2021, p.140). Todorova (2011) encourages IPA researchers to be mindful "to include socio-cultural situatedness... to deepen the embeddedness of the

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[42] At the same time, there was an awareness that changes in the participants' vision or other life circumstances between the timepoints of the two interviews (Summer 2020, versus Autumn 2023) might generate certain specific new insights.

analyses in cultural, political, historical 'local worlds'." Indeed, an overall concern of this PhD is to consider how a person's immediate context and environments, but also how social norms and cultural values – particularly concerning ageing and disability – may influence and be bound up with an individual's psychological experience of AMD.

The home-tour approach discussed in this chapter aimed to attend to how embodiment and materiality shape the experiences of people living with AMD. This is in response to certain critiques that IPA may privilege a "cognitivist" approach (e.g. Murray & Holmes, 2014), potentially neglecting how experiences arise within a living body "that exists in a spatiotemporal relation with others and with its environment or place" (Murray & Holmes, 2014, p.20). Indeed, Merleau-Ponty (1962), whose ideas inform IPA's emphasis on embodiment, conceived of human beings as "body-subjects", whereby our bodies are intertwined with and fundamentally engaged in communication with the world around us. Merleau-Ponty differentiated between *parole parlée* (spoken speech) and *parole parlante* (speaking speech); the first may be considered stock speech and familiar scripts, while the second is more active and pre-reflective, "language that has not yet been fixed or sedimented by the usual conventions" (Murray & Holmes, 2014, p.25). Arguably, IPA can seek to tap into aspects of this more embodied *parole parlante,* this real-time attempt to verbally make sense of embodied experiences which may not be straightforwardly explicable. Accordingly, alternative methods – whereby participants do not simply tell the researcher about their experience, but also communicate through objects, drawings or photos, for example – may help to tap into aspects of experience or "felt sense" (Gendlin, 1997, as cited in Boden & Eatough, 2014) that may be implicit, taken-for-granted and challenging to verbalise.

6.1.1.2. Exploring individuals' experiences within their socio-environmental context

Alongside this focus on more embodied, pre-reflective experiences, the home tour interviews also aimed to shine a light on the interrelationships between individuals' sense-making around AMD and their socio-ecological environment. Bronfenbrenner's bioecological systems theory is highly relevant here, highlighting an "evolving interaction" between an individual and the environment in which they are embedded, an environment composed of “a set of nested structures, each inside the next, like a set of Russian dolls” (Bronfenbrenner, 1979). Within this conceptualisation, the “Russian dolls” can be considered to be a person’s:

- Microsystem – the immediate context of their home, family and friends.
- Mesosystem – the intersection of microsystems, such as interactions between the person’s family member with a healthcare provider.
- Exosystem – contexts which may include members of the individual’s microsystems, but do not include the individual themselves. An example might be if a relative who provides informal care for the person with AMD is working, and how this might affect the person with AMD at the centre.
- Macrosystem – the broader social and structural forces (a “societal blueprint” in Bronfenbrenner’s words) and context within which individuals’ lives are lived, including broader value systems, norms and discourses.
- Chronosystem – changes over time and life transitions.

The structure of these overlapping systems within which a person is embedded and developing are illustrated in Figure 8.

Figure 8. Illustration of Bronfenbrenner’s bioecological systems theory

Figure removed due to copyright restrictions.

Particularly relevant to exploring experiences of AMD, Bronfenbrenner’s theory recognises how individuals’ psychological experiences and sense-making in response to shocks like AMD both shape and are shaped by their environment (Greenfield, 2012). For example, our interviews in the IPA study suggested that individuals with a strong sense of proactivity and optimism may feel more confident and empowered to embrace adaptations in their environment, such as using low vision aids. Such individuals thus may feel more able to “maximize the congruity between [their] needs and the offerings of the environment”

(Lawton, 1974, p. 258, as cited in Greenfield, 2012). Equally, those whose environments are already set up to meet their needs may then experience AMD as less disruptive or catastrophic. For example, individuals living in contexts where amenities are accessible and close-at-hand, or with good public transport options, may feel more confident about going out and less limited in their options for socialising or leisure, and therefore remain better connected and engaged in meaningful activities.

6.1.1.3. Engaging with embodiment and materiality through home tours

Paying attention to the environmental and socio-ecological context of experience aligns with a turn towards the material in qualitative social research (Woodward, 2016), and using materials as a means to elicit talk about people's relationships with the natural and physical environment around them. In the case of the present study, the 'material' located within the person's microsystem was their home and the significant objects within it. I aimed to use the material environment of the home as a starting point, to ground my exploration of the experience of AMD in context through interviews structured around a 'home tour'.

There have been moves in qualitative research in psychology towards eliciting data that extends beyond the linguistic/verbal domain, for example with visual methods becoming more commonly used, whereby participants may be invited to express aspects of their embodied and/or spatial experiences through photographs, films or drawings (Reavey, 2020). Yet the home tour described in this chapter arguably has a more established tradition in disciplines drawing on ethnographic approaches (Pink, 2015), such as anthropology, sociology or geography, than in psychology. Home tours can help to illuminate individuals' engagement with their material and environmental surroundings (Gillon & Gibson, 2018; Tolia-Kelly, 2004), and illustrate how they relate and give meaning to their home space and objects within it. As an example, home tours have been used to explore what home means to people with dementia, in the context of their relational and social networks in their local area (Clark et al., 2020; Odzakovic et al., 2021).

Arguably, the home tour interview that I conducted contained elements of other methodologies concerned with materiality and embodiment, such as object elicitation and walking interviews. Although not an extensive field, there is a history within psychology of considering how individuals relate to meaningful significant objects (e.g. Csikszentmihalyi &

Halton, 1981; Rubinstein, 1987). For example, Rubinstein's study (1987, p.231) of the significance older adults attach to objects in the home highlights that objects are:

> "…sacred within a personal meaning system and its concomitant sense of order, and as such they may serve to structure space within the home, may aid in giving meaning to that space, and more important, may act as living embodiments that help support, bolster, or authenticate personal ideological systems."

Rubinstein's research found that such objects were especially representative of salient meaningful relationships, variously representing the timelessness or transitions in key relationships within the participants' lives. In a study exploring the relationships of people living with dementia in a care home to significant objects, Lee and Bartlett (2021) proposed the notion of "material citizenship", emphasising the role that access to objects can play in identity and agency, as they enable individuals to "live the life they want to live". Furthermore, it could be argued that in the context of progressive conditions such as AMD, objects help to anchor a sense-of-self despite the changes taking place. In their study using object elicitation with people living with schizophrenia, Romano and colleagues (2012) suggest that objects may represent the enduring sense of self, which has been reshaped, but not swept away, by mental illness. In this vein, the rootedness of home tour interviews in material objects and surroundings could represent an anchor, helping participants to think about both changes and continuities in their sense-of-self.

In recent research in qualitative psychology, Willig (2017b) used object elicitation as a means of encouraging "in the moment" meaning-making among people living with advanced cancer, as opposed to potentially more rehearsed narratives that may have been generated through more typical semi-structured interviews. Willig's reflections on object elicitation highlight how the process of selecting objects in advance of the interview "offers research participants an active role in setting the agenda" (Willig, 2017b, p.212). I therefore hoped that the home tour set-up could perhaps confer a similar benefit, in that – in the absence of a more traditional interview agenda - the participant would be able to decide what they chose to highlight as salient to their AMD experiences during the home tour.

6.1.2. Study objectives

The aim of the home tour interview study was therefore to:

- Extend the analysis of the IPA study, aiming to explore participants' embodied experience of AMD within the context of their home environment and social/relational network.
- Consider how the home-tour interview method may help to gain access to the social and relational dimensions of participants' AMD experiences, for example considering how participants share the material space of their home or local area with other people (such as Andrew with his wife, or Sylvia with her partner).
- Reflexively consider the opportunities and challenges afforded by the home tour interview methodology, alongside the IPA accounts in Chapter 4.

The research question guiding the study was: How do people with AMD experience the condition within the specific relational, social and environmental context of 'home' [*including their local area*]? Alongside, there was a more reflexive, methodological interest in how far the home tour interview elicited new insights and meaning-making around AMD beyond the findings of the IPA (Chapter 4).

6.2. Methods

6.2.1. Developing the interview schedule

The interview schedule development was guided by similar principles to the interview schedule for the IPA study in Chapter 4, using open-ended questions and being responsive to the experiences and concerns voiced by the participants. Because the aim of the home-tour interview was to allow for more unrehearsed, spontaneous, in-the-moment meaning-making, linked to the features of the home that they chose to show me, there were relatively few direct questions posed to participants, in comparison to a more traditional interview format. Furthermore, many of the questions were tailored to the specific situations or experiences of participants discussed in the previous interview for the IPA study.

The initial opening questions were developed based on discussions with my supervisor, as well as what I perceived to be logical follow-up questions based on the previous IPA interviews. For example, there were questions around changes to participants' experience of AMD in the intervening three years since the initial interview, questions about where in the home they felt more or less comfortable or more or less affected by AMD, as well as more reflexive questions about how they experienced the home tour interview.

The initial and final versions of the interview schedule, illustrating the changes made based on patient and public involvement discussed below, are shown in Appendix 16.

6.2.2. Patient and public involvement

While planning and setting up the study, I consulted with a small number of “experts-by-experience” to understand their perspectives on the home tour interview procedure. This consultation exercise was carried out in advance of applying for ethics approval, in line with the NHS Health Research Authority guidance stating that ethical approval is not required to involve patients/members of the public in the research planning or design stage (Health Research Authority, 2020). Given my dad’s experience of AMD, I invited him and my mum to provide feedback on the concept and details of the interview, and also consulted with one individual, (pseudonym) Mary, who had volunteered to take part in the IPA interviews after we had already reached our recruitment target. Mary had consented for her contact details to be kept on file for contacting about future research opportunities.

In this consultation, the aim was for these experts-by-experience to contribute their views on the proposed methods for the home tour interview; and by encouraging them to reflect on how they themselves might hypothetically find the experience of a home tour, to consider possible changes and improvements to the methodology. The information provided to the experts and questions asked of them are displayed in Appendix 17.

Before this consultation exercise, I was concerned that the study would be seen as too unfocused, and hard to explain to participants who may often expect research conducted in a more positivist, empiricist vein within the medical model. In general, both my parents and Mary who gave their feedback on the interview procedure and questions suggested that everything was generally clear, which boosted my confidence in the home tour interview fundamentally ‘making sense’. They made valuable suggestions for improvement at a more granular level of detail, especially in terms of refining the wording of the participant information sheet and the interview schedule. For example, in the participant information sheet used to explain the study to the participants, my mum suggested emphasising the option for participants to be accompanied by a partner, spouse or friend if that would make them feel more comfortable. Mary commented in detail on the wording of the questions, particularly in terms of suggesting that instead of mentioning "AMD" in the questions, it would be better to frame the questions in terms of "sight loss" or "reduced sight", as this better reflects the person's experiential reality. The interview schedule was re-drafted on the basis of such feedback, and the final version of the interview schedule is shown in Appendix 18.

6.2.3. Participants

The participants recruited for the home tour interview study were two participants from the IPA study, Andrew and Sylvia, who had agreed in 2020 to be contacted again for a future interview. My supervisors and I believed that there were elements of their accounts in particular that would benefit from further exploration using this methodology that aimed to centre the participant's embodied experience within their material and social environment. In the case of Andrew, it was felt that his account of his experience of AMD, while rich and in-depth, very much centred around the "doing" of activities, rather than directly considering the emotional dimensions of his experience, and we thought that the home tour interview might help to tap into these. Meanwhile, in Sylvia's case, much of her account focused on her experience of being a visual artist, and discussing how her style of painting had changed since the onset of AMD. We therefore considered that this would make a home tour that took in her paintings particularly fitting.

The characteristics of the two participants are shown in Table 3, Chapter 4 (p.78). However it is worth noting that both participants discussed their circumstances as having changed since the interview for the IPA study.[43] Andrew recounted being told by his eyecare team that his vision had not changed significantly in the intervening three and a half years, but he believed his sight had got worse during this time. More significantly, he had experienced three falls which had made him less mobile, to the point where he had given up

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[43] Andrew's interview for the IPA study was conducted in May 2020, and Sylvia's interview for the IPA study was conducted in October 2020. The home tour interviews for both participants were conducted in November 2023.

certain activities such as blind bowls. Sylvia's circumstances had not changed as significantly, although like Andrew she felt that her sight "isn't so good as it was".

6.2.4. Data collection procedure

Ethical approval for the study was granted by the City, University of London Psychology Research Ethics Committee (ETH2223-1962). I initially contacted participants by email to arrange a telephone call to explain the new study to them. When we spoke on the telephone, I then discussed the participant information sheet (PIS – Appendix 19) with them, and responded to any queries they had. I then emailed the PIS to the participant, and invited them to consider the information (and discuss it with relatives or friends if they wished). I then contacted the participants one week after sending the PIS to see if the participants had any queries or wanted to discuss any aspects further. During this second call, we went through the consent form (Appendix 20) verbally, and if they were willing to take part, we scheduled an interview for as soon as possible after the call.

After arriving at the participant's home, we went over the structure of the interview again and discussed the PIS. I then went through the printed copy of the consent form with participants, which they signed, thereby providing informed written consent to participate. The interviews unfolded organically (using the interview schedule flexibly), and I invited the participant to show me and discuss spaces and objects in the home that felt meaningful in the context of their AMD. With the participant's consent, the interview was audio-recorded.

Following the interview, the participant and I briefly reflected on the interview process. I left a debrief sheet containing my and my supervisors' contact details for any follow-up questions, as well as contact details for support organisations such as the Macular Society, RNIB and Mind. After leaving the participant, I made contact with my supervisor to confirm that all went well.[44]

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[44] To guarantee my safety as a researcher, I gave my supervisor Carla a sealed envelope with the address and contact details of the participant beforehand, to open only if she did not hear from me following the interview. This was to be shredded and discarded in the (highly probable) event that the interview went smoothly.

6.2.5. Ethical and safety considerations

There were particular ethical issues that had to be taken into account when using this home tour data collection method.

Firstly, I was conscious of issues that could arise from a health and safety perspective in terms of the potential physical hazards and risks. In ethnographic research, a distinction may be made between ‘ambient’ and ‘situational’ risks (Lee, 1995), with ambient risk referring to risks inherent in the fieldwork setting, while situational risks arise more directly from the research activity. For example, low lighting in the participant’s home that could increase the risk of falling (Kesler et al., 2005) may be considered an ambient risk; however, entering a seldom-used, cluttered storage room with trip hazards during the home tour could be considered a situational risk, directly attributable to the research activity. Given that there was potential for both kinds of risk to arise, I emphasised to the participants when discussing the PIS that they should feel comfortable and confident walking round their home with me, and during the home tour itself I regularly checked in with the participant that they were happy to proceed.

Secondly, there were also ethical concerns arising from the potential emotional impact on participants of the home tour, as a method that I believed might elicit potentially more fresh, unexpected ‘in-the-moment’ reflections from participants compared to more established narratives. In line with Willig's (2017b) recommendations when employing object elicitation, I regularly checked that participants were happy to proceed during the interview itself, employing the notion of “process consent” (Dewing, 2008) and remaining alert to any subtle signs of discomfort.

Bashir (2018) highlights that accordance with health and safety policies and procedures cannot fully prepare the researcher for the unpredictability of real life situations in home-based research; and emphasises the importance of researcher reflexivity, to be considerate and self-aware of how the participant may make sense of the researcher’s behaviour when visiting the participant’s home. I was particularly conscious of the dynamic of being a guest in the participant’s home throughout the home tour interview. This made me determined to make the interview a positive experience for the participant; however, on reflection, this may have limited the extent to which I felt able to probe more deeply into some of the participants’ experiences (as discussed in the Reflections, Section 6.4).

6.2.6. Data transcription

Following the interviews, I transcribed the audio-recorded home tour interview data, using the same transcription conventions outlined in Chapter 4 (p.87). In contrast to the telephone interviews, there was a challenge in sometimes conveying the sense of place and materiality of the home when transcribing. For example, participants would sometimes be speaking with reference to a specific object, and I felt that simply transcribing their words with a comment such as [*demonstrating the audiobook player*] represented a loss of quality of the in-person interaction. Both participants allowed me to take photos for my own records, so that I could retain a visual impression of the objects or spaces they discussed; however, I had not sought ethical approval to publish these. In any case, I believe it would be challenging, particularly in the case of Sylvia and her paintings, to publish these without risking identifying the participant.

6.2.7. Data analysis

6.2.7.1. Rationale for reflexive thematic analysis

I had initially intended to analyse the home tour interviews using IPA, for consistency with the first round of interviews. However, following the first of the two home tour interviews (with Andrew), I began reconsidering, and ended up taking the decision to analyse the home tour interview data with reflexive thematic analysis (RTA) (Braun & Clarke, 2022) from a phenomenological, experiential perspective, for three main reasons outlined in turn.

Firstly, the home tour interview – in contrast to the telephone interviews for the IPA study – went beyond an account of personal experience, because so much of the discussion focused on more prosaic realities of the home environment.[45] RTA, even when carried out from a phenomenological perspective as here, provided more flexibility, in that I was able to code and analyse aspects of the research data that contributed to the research question (for example, when Andrew discussed local Council services, or architectural features of his

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[45] Braun and Clarke (2021, p.6) note that RTA may be more appropriate than IPA when “the research question is focused on something other than (just) personal experience and sense-making”.

home) even if these aspects would not necessarily have contributed towards development of experiential themes in IPA.

Secondly, a key interest in this analysis concerned how the participants' AMD experiences were situated within their broader sociocultural and environmental context.[46] While noted in this chapter's introduction that IPA considers individuals' experiences as embodied and situated in the world around them, from an analysis perspective RTA provided more freedom to (tentatively) go further with analysing how the environment and culture surrounding the participant shaped their experiences. Indeed, my approach to RTA – being conducted from an experiential stance – generally involved more inductive analysis, with analysis driven primarily by the interview data rather than external theory. However, being somewhat more flexible, I felt that RTA allowed me to draw more explicit comparisons (when it felt particularly pertinent) between the insights generated from the home tour interviews and other areas of knowledge developed during the PhD from the broader literature.

Thirdly, the flexibility of RTA allowed for the perspective of Wendy, Andrew's wife, to be incorporated into the interview analysis in a way that may have been challenging in an IPA. IPA has been used in interviews with dyads, with moves towards more multi-perspectival designs that aim to explore the same phenomenon from different experiential perspectives (Larkin et al., 2019); specifically in AMD research, Burton et al. (2015) considered how members of a couple, both living with AMD, make sense of the condition. However, in the present study's case, the couple experience *per se* was not the primary interest; instead, Wendy tended to reflect back or provide a conduit to aspects of Andrew's experiences, largely sharing aspects of Andrew's experience rather than disclosing her own. Although they seemed to approach life together as a team, it would not necessarily be coherent with an IPA approach to assume that Wendy's perception of Andrew's experience was a straightforward reflection or facsimile of his own. For example, sometimes she would interject in response to a question that would then take Andrew's discussion of his experience in a new direction, in a way that would not have occurred without her presence at the interview. I felt that the flexibility of RTA allowed me to incorporate and allow for

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[46] Braun and Clarke (2021, p.6) note that RTA may be more appropriate than IPA when "the analytic interest is on how personal experiences are located within wider socio-cultural contexts."

(cautious) analysis of Wendy's perspective on Andrew's experiences, in a way that might have felt potentially incoherent with the epistemology and methodology of IPA.

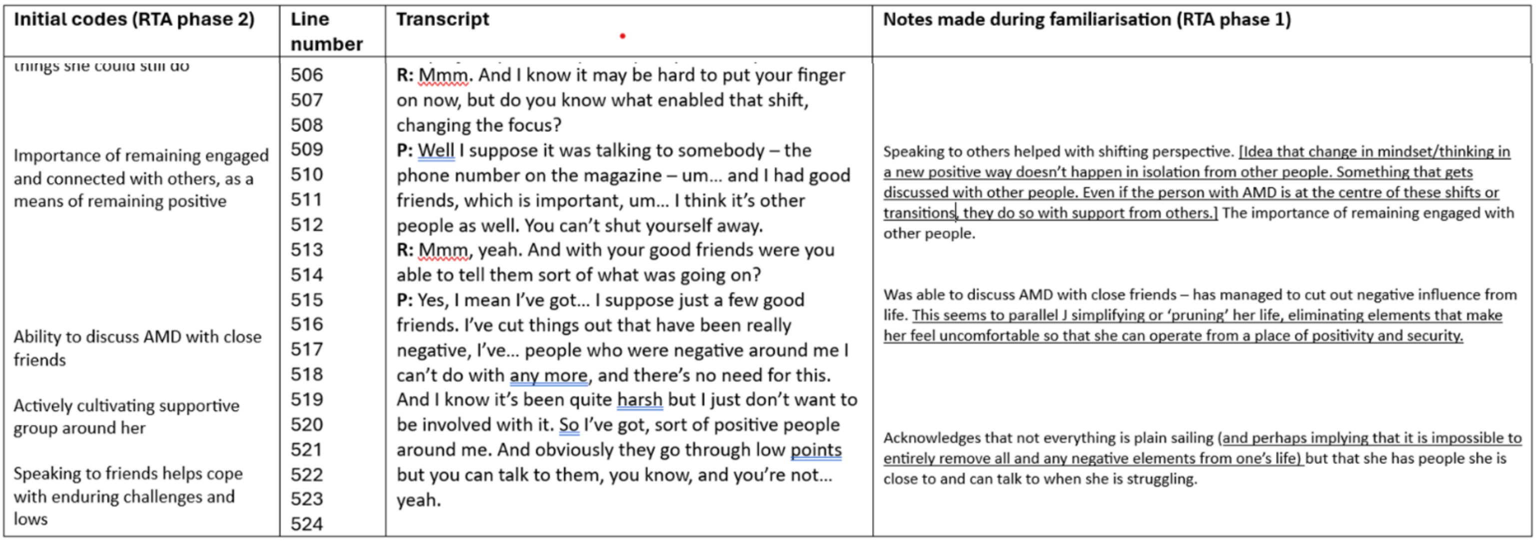
The rationale for an RTA is arguably challenged by the fact that there were only two participants in the study, when IPA would generally be favoured with small samples and RTA would be more appropriate when the sample is large (generally larger than N = 10) (Braun and Clarke, 2021). However, Braun and Clarke (2022) point out that RTA has been used in case study research, for example in a study exploring physical activity among two men living with Alzheimer's disease and their wives (Cedervall & Åberg, 2010). This assuaged my concerns about conducting RTA using only two participants' accounts.

6.2.7.2. Steps of data analysis

The home tour interview data were analysed using Braun and Clarke's (2022) approach to reflexive thematic analysis. Below I outline the six phases, and my approach and decision-making within each. As in IPA, it is important to note that these phases are recursive, with movement back and forth between the phases, and I returned back to earlier phases as the analysis developed.

- <u>Phase 1 - Familiarisation with the dataset:</u> This phase involved immersion in the data, through listening back to the audio recording and conducting multiple re-readings. While reading/listening, I made notes in terms of any thoughts and observations on the data that sprung to mind. In doing so, I found it helpful to use the approach recommended by Smith et al. (2009), to write descriptive comments in plain text, linguistic comments in *italics*, and more conceptual or reflexive comments in <u>underlined text.</u> (I drew on Smith et al.'s guidance (2009) here because I was accustomed to this method of noting from the IPA study in Chapter 4 (p.89) and found it helpful, and I considered this noting system to be compatible with RTA.) In practical terms, as with the IPA, I set up a word document with the transcript in the middle column, a column on the right for notes made during this familiarisation phase (as well as a column on the left for initial codes made during phase 2 – see Figure 9). A challenge I reflected on in the familiarisation phase was that much of the data already felt 'familiar', because the participant's narrative often adhered closely to what they had previously shared in the IPA interview. Therefore it was sometimes a challenge to take a ‘beginner’s mindset’ when considering the data, staying open to new meanings in the data in keeping with an inductive approach,[47] rather than simply reproducing analytic observations from the IPA. A consequence was that I was sometimes more drawn to focusing on the novel elements of the accounts; therefore, I sought to bear in mind Braun and Clarke’s advice to “giv[e] full and equal attention to each data item” (Braun & Clarke, 2006, p.89).

Figure 9. Example showing familiarisation notes (RTA phase 1) and initial codes (phase 2)



Initial codes (RTA phase 2)	Line number	Transcript	Notes made during familiarisation (RTA phase 1)
things she could still do	506 507 508	R: Mmm. And I know it may be hard to put your finger on now, but do you know what enabled that shift, changing the focus?	
Importance of remaining engaged and connected with others, as a means of remaining positive	509 510 511 512	P: Well I suppose it was talking to somebody – the phone number on the magazine – um… and I had good friends, which is important, um… I think it’s other people as well. You can’t shut yourself away.	Speaking to others helped with shifting perspective. [Idea that change in mindset/thinking in a new positive way doesn’t happen in isolation from other people. Something that gets discussed with other people. Even if the person with AMD is at the centre of these shifts or transitions, they do so with support from others.] The importance of remaining engaged with other people.
	513 514	R: Mmm, yeah. And with your good friends were you able to tell them sort of what was going on?	
Ability to discuss AMD with close friends Actively cultivating supportive group around her Speaking to friends helps cope with enduring challenges and lows	515 516 517 518 519 520 521 522 523 524	P: Yes, I mean I’ve got… I suppose just a few good friends. I’ve cut things out that have been really negative, I’ve… people who were negative around me I can’t do with any more, and there’s no need for this. And I know it’s been quite harsh but I just don’t want to be involved with it. So I’ve got, sort of positive people around me. And obviously they go through low points but you can talk to them, you know, and you’re not… yeah.	Was able to discuss AMD with close friends – has managed to cut out negative influence from life. This seems to parallel J simplifying or ‘pruning’ her life, eliminating elements that make her feel uncomfortable so that she can operate from a place of positivity and security. Acknowledges that not everything is plain sailing (and perhaps implying that it is impossible to entirely remove all and any negative elements from one’s life) but that she has people she is close to and can talk to when she is struggling.

- Phase 2 - Coding: This phase involved working through the accounts, and developing initial codes, insights gleaned through my analytic engagement with, and interpretation of, the data and the familiarisation notes from Phase 1. In contrast to IPA, Braun and Clarke (2022, p.53) do not advocate line-by-line coding, and instead suggest coding data that is relevant (in a broad sense) to the research question. Crucially, these codes are always provisional ‘works-in-progress’ that can evolve throughout the analysis phases. Braun and Clarke suggest that codes can sit on a continuum from semantic to latent, whereby semantic codes are more descriptive, and stay closer to the overt meaning and manifest content of the data; while latent codes are somewhat more interpretative, and encapsulate more implicit and/or conceptual meanings. I sought to code at both levels, but arguably stayed somewhat closer to the semantic end of the continuum, as this felt more coherent with the more phenomenological and inductive approach I was seeking to adopt. As an

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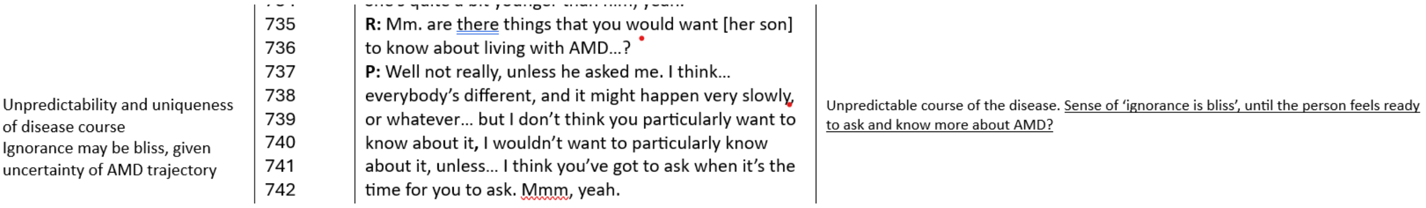
[47] It is worth noting that from a “big Q” perspective, even when we adopt a broadly inductive approach, we can never be purely, fully inductive, “because of what we bring to the data analytic process, as theoretically embedded and socially positioned researchers” (Braun & Clarke, 2022b, p.56).

example of the two levels of coding, there was a passage where Sylvia discussed not wanting to talk to her son (who had recently been diagnosed with AMD) about the condition, because of the uncertainty regarding how it might progress. The text, with notes and codes, is shown below in Figure 10. I coded this segment firstly with a more semantic code, “unpredictability and uniqueness of the disease course”, and then a more latent code “ignorance may be bliss, given uncertainty of AMD trajectory”. Sylvia herself was hesitant during this segment, and did not state anything as categorically or as strongly as “ignorance is bliss”, but I interpreted that as the underlying essence of what she was communicating.

Figure 10. Extract from Sylvia’s transcript, showing a semantic and latent code



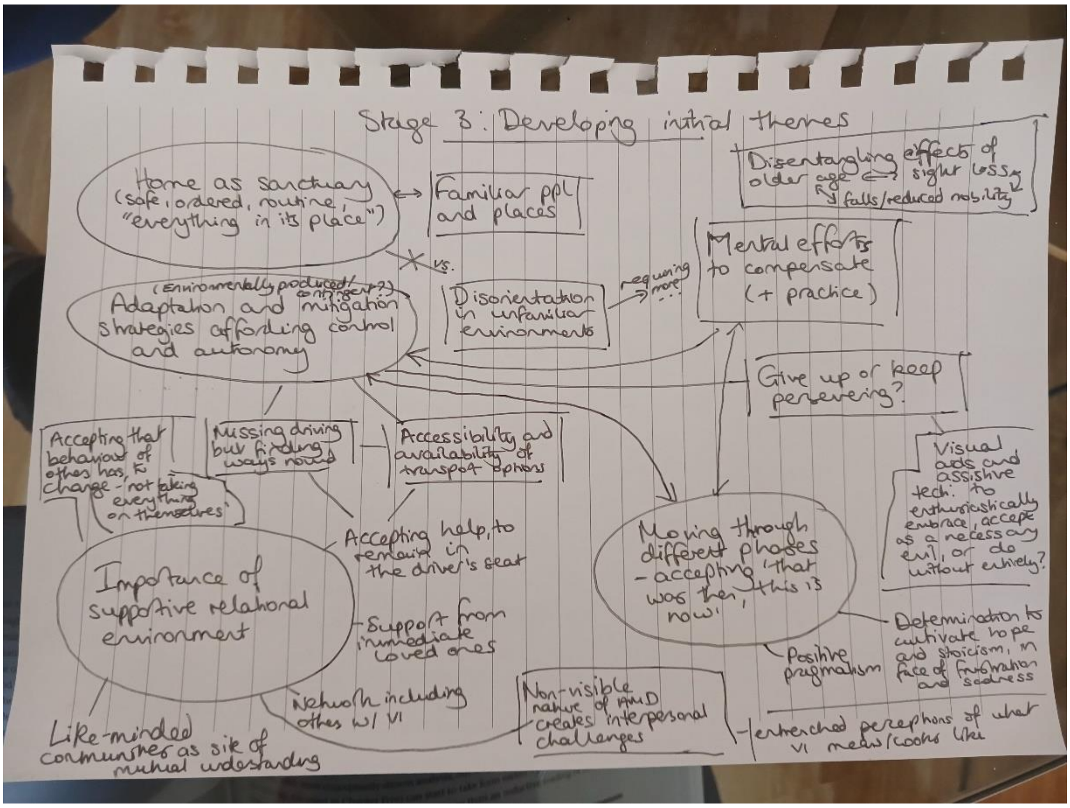
Unpredictability and uniqueness of disease course
Ignorance may be bliss, given uncertainty of AMD trajectory

R: Mm. are there things that you would want [her son] to know about living with AMD...?
P: Well not really, unless he asked me. I think... everybody’s different, and it might happen very slowly, or whatever... but I don’t think you particularly want to know about it, I wouldn’t want to particularly know about it, unless... I think you’ve got to ask when it’s the time for you to ask. Mmm, yeah.

Unpredictable course of the disease. Sense of ‘ignorance is bliss’, until the person feels ready to ask and know more about AMD?

- Phase 3 – Generating initial themes: Working from the codes developed in Phase 2, in this phase I aimed to consider where codes seemed to cluster together to generate initial themes, defined by Braun and Clarke (2022, p.77) as “a pattern of shared meaning organised around a central concept”. At this stage, as with IPA, a key concern was not to get too attached to the initial candidate themes, remaining aware that these were provisional and would likely change in future phases of analysis. In order to begin exploring shared patterns of meaning across the accounts, I undertook two parallel processes. Firstly, I copied all the codes from both transcript into an Excel spreadsheet and moved these round in different configurations to help consider where there were potential clusters relevant to the research question. Secondly, and somewhat in tandem, I developed a number of thematic maps to help consider where clusters of codes seemed to coalesce into something beginning to resemble a theme. An initial mapping of the patterns is shown in Figure 11. Terry et al. (2017) suggest that high quality themes should be distinctive, without too much overlap, even though it is important to also consider relationships between distinct themes. However, in the initial mindmap (Figure 11), many of the clusters seemed to relate to each other which suggested the boundaries of the clusters were not particularly distinct. This was not a problem *per se*, but pointed to the need to redefine the themes in Phases 4 and 5.

Figure 11. Initial mapping of patterns across the two accounts



- <u>Phase 4 – Developing and reviewing themes:</u> This phase involved developing the initial themes from Phase 3 by returning to the coded data extracts (and the dataset as a whole) to consider the viability of the clusters developed in Phase 3, and consider whether the candidate themes could be refined and enriched. During this process, I was particularly focused on clarifying the central organising concepts of the candidate themes and reconsidering the theme boundaries. I found it helpful to think about the 'story' being told by each theme, how well it told "a distinctive and meaningful story that answers the research question" (Terry et al., 2017). In practical terms, I re-engaged with the coded extracts by taking the four initial clusters I developed during Phase 3 (shown in Table 7 below), and copying the different codes, and source data extracts, under these headings.

Table 7. Initial clusters developed by the end of Phase 3/at start of Phase 4

Cluster 1	**Cluster 2**	**Cluster 3**	**Cluster 4**

Home as a sanctuary affording familiarity and order	Importance of supportive relational environment	Adaptation and mitigation strategies affording control and autonomy	Moving through different phases: accepting 'that was then, this is now'

At the end of this process, I noted in my research journal that "*I'm still not exactly sure what the theme titles should be, but the clusters generally work; though there are quite a few important points that don't quite fit*". My concerns about this last point, of disparate meanings that did not "fit" into the clusters, were somewhat allayed by Braun and Clarke's (2022, p.99) assertion that themes should convey something *important,* rather than what is most common or prevalent in the data. This helped me move beyond an initial mindset of trying to make themes comprehensive, so that they would encompass all the codes, and instead accept that certain codes would not be incorporated into the final analysis. By the end of this phase, I was broadly happy with the thematic clustering but had several potential names for each theme. For example, the working title for cluster 2 developed in Phase 3 ("Importance of supportive relational environment") was essentially a topic summary rather than a theme, but I could not decide at this point on a better name, although provisional options included: ""A relational environment that protects and enables", "A relational environment that maximises the embrace of new possibilities", and "A relational environment that expands the boundaries of what is possible".

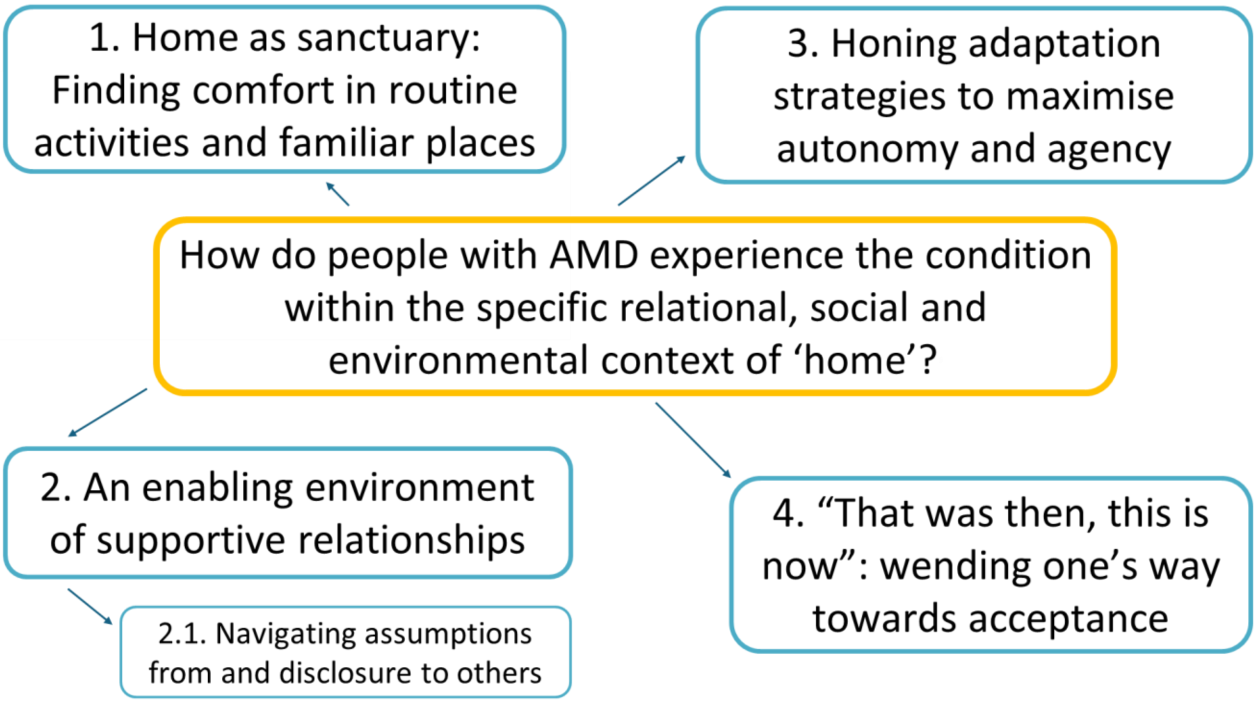
- <u>Phase 5 – Refining, defining and naming themes:</u> The key task at this stage of analysis was to define the themes, with a few sentences to distil the essence of each theme. I found that writing this kind of "abstract" for a theme (Braun and Clarke, 2022, p.108) helped me to then name each theme with a greater degree of confidence. The process of defining the theme allowed for a check on the balance between a theme being too 'thin', lacking depth and detail, or at the other end of the spectrum being overly complex. At this stage, I also considered the viability of potential sub-themes; I had generally eschewed these, in line with Braun and Clarke's view that sub-themes ought to be used sparingly because with too many, the "analysis will likely start to feel fragmented and thin, and lacking in analytic depth" (Braun and Clarke, 2022, p.88). However, I felt that a sub-theme ("Navigating assumptions from and disclosure to others") was viable within Theme 2 ("An enabling environment of supportive relationships"), to illustrate how assumptions from and disclosure to others about vision loss was a key interpersonal dynamic that could facilitate or limit their everyday living with vision loss. A final thematic map was developed at this stage, shown below in Figure 12.

- Phase 6 – Writing up: This phase involved producing the report, and as in IPA, further refinement of the themes was still possible while writing. In RTA, it is important to write an analytic narrative that includes examples from the data and interpretation of these data extracts. As a contrast to IPA, Braun and Clarke advocate connecting data to the research question "*and to* the scholarly fields your work is situated within" (Braun and Clarke, 2022, p.129). As such, even while taking an inductive, experiential approach in this analysis, I drew some parallels with the existing research or theory where a finding resonated with existing literature I have come across during the PhD. As Braun and Clarke acknowledge, in a doctoral thesis like this, there is a more general discussion chapter (Chapter 7) where such interpretation can be deepened and nuanced; but even here, in the presentation of the analysis, they still advocate some contextualising of the analysis in relation to the existing literature.

6.3. Analysis

Four themes were developed through the reflexive thematic analysis, which are displayed in a thematic map in Figure 12.

Figure 12. Thematic map providing overview of themes (with research question at the centre)



6.3.1. Home as sanctuary: Finding comfort in routine activities and familiar places

This theme explores a central experience voiced by both participants, with both finding comfort and a sense of security in familiarity, order and routine. Under such circumstances, their vision loss from AMD presented far fewer obstacles in terms of their day-to-day functioning, and helped keep in check the difficult feelings of frustration and exclusion that could come with negotiating unfamiliar tasks or places. Indeed, both participants attested to the sense of disorientation they could feel in less familiar environments, where their visual difficulties became more salient. While this comfort in familiar settings applied to both places in their home and local area, their home in particular was portrayed as a kind of sanctuary where everything was ordered and in its place, thereby limiting the challenges posed by AMD. To some extent, familiar places in their local area represented an extension of the home, with the sense of safety, predictability and familiarity affording a similar feeling of 'sanctuary'.

Both participants voiced the importance of everything being in its place, and this enabling them to feel comfortable in the home environment:

> “I’m used to where everything is, do you know what I mean? I mean, I love my home. I see my partner every day, I go down there at… I suppose half past four and come back at seven, and I just love to come back!” (Sylvia)

> “**Wendy**: ….and he keeps things in boxes, cos you find it easier don’t you…
> **Andrew**: I know where everything is over there.
> **Wendy**: …I mean I really hate that corner but… it suits him so…
> **Jamie**: Is it kind of your system?
> **Andrew**: Yeah. I know where everything is…”

In both extracts, Andrew and Sylvia emphasised the importance of being “used to where everything is” or “know[ing] where everything is”. Notably, the systems Sylvia and Andrew use in the organisation of their home are highly personal and idiosyncratic; Sylvia was clear that she enjoys time with her partner as part of her daily routine, but equally conveyed a sense of joy and delight about coming back home. In Andrew’s account, it became clear that Wendy was averse to Andrew’s system of organising but accepted this (“it suits him”) as a way for him to keep track of his items. Andrew voiced a sense of confidence and ease when in his home environment, for example when he stated:

> “Everywhere at home I’m ok… I’m very comfortable everywhere at home, I never ever use my stick at home, even in the garden I don’t take my stick, I can get around the garden.” (Andrew)

Even though Andrew generally felt comfortable using mobility aids such as his white stick and walking stick, he clarified here that these are unnecessary given the comfort he feels in his home environment. Indeed, both participants voiced a sense of ‘fitting’ in with their home environment, a place where they felt confident amid a sense of order and routine. Sylvia for example stated:

> “I think as you get older, you don’t really want all these things. I used to sort of have a house, that had this and that, and always changing things, but you don’t want that now, no. Just keep it simple.” (Sylvia)

In this extract, Sylvia evokes her previous home life as busy and dynamic (“always changing things”), but now suggests that with older age she just wants to “keep it simple”. Although Sylvia talks of having a house in the past (“I used to have a house”) presumably to differentiate it to living in a flat, there is perhaps also a sense here that the home itself as a material, external reality becomes less important.[48] Instead, Sylvia seemed to now regard her home as a more neutral space that, in its simplicity, supports her daily functioning. In this way, like Andrew with his sense of seamless functioning within the home, both participants appear to form a kind of “assemblage”[49] (Deleuze & Guattari, 1987) with the objects and space of their home that provided comfort and also appeared to insulate or buffer them from feeling limited by their vision loss.

This ease in routine, familiar environments and situations extended to familiar places in the local area, and was contrasted with unfamiliar spaces in which AMD might “kick in”, as Sylvia stated. In Sylvia’s account, there was often a contrast made between a familiar situation, where she managed well, and unfamiliar situations in which she might feel suddenly overwhelmed:

> “I usually go over to Sainsbury’s, which is quite small, over the road, and I more or less know where things are. But if I went to a big sort of supermarket, I’d panic a bit in there, because honestly it’s a struggle to see where things are. It’s really familiarity, really. […] I know it well over there. And although I don’t have so much choice, I’m not bothered, I don’t really want lots of choices, cos I can’t really see [*slight, rueful laugh*] what it’s all about.” (Sylvia)
>
> “I’m ok in my home but if I’m going to bowls and I’m in different teams, I do panic a bit, because I can’t see where my team is, cos quite a few teams are playing, and I… I can’t see where they’re sitting and I… get a little bit agitated with that. I’m ok but it’s one of things where I think, oh, where are they sitting.” (Sylvia)

In these extracts, Sylvia referred to how she might “panic[s] a bit” in a large supermarket where she would struggle to see things; similarly she described going to bowls tournaments

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[48] This may also be compared with Sandra in the IPA study (Chapter 4, p.120) stating: “It’s only a little house I’ve got, like I say I’ve had bigger houses. [...] I’m quite contented with having a little house and everything, it doesn’t bother me. [...] Now I’m not interested in material things, I’m more interested in my health.” (Sandra)

[49] Drawing on Deleuze and Guattari’s work, the concept of “assemblages” has become a cornerstone of post-qualitative inquiry (e.g. St. Pierre, 2018), and emphasises the manifold ways in which human and non-human entities are entangled or bound up with each other and come to function as a whole. This perspective in turn destabilises the notion of humans as fixed essences and instead encourages attention to how different contexts create ever-shifting *possibilities* for humans “to act and affect”(Monforte et al., 2020, p.1250) in relation to (human and non-human) others. As a concrete example of employing the concept of assemblages in research, Monforte et al. (2021) explored how a man who had experienced spinal cord injury lives in an assemblage not only with his wheelchair, but also with other material features of his environment such as assistive devices, as well as with personal stories and narratives, and broader discourses (for example around disability).

and struggling to see where her team was, causing her to "panic a bit". Both these formulations conveyed the sudden feeling of overwhelm and anxiety that result from being unable to see and consequently to orient herself. Notably, in both these situations, Sylvia was alone; in contrast, Andrew's account conveyed the ways in which supportive others could help to maximise the comfort and familiarity of an environment that under different circumstances might be challenging to navigate:

> "I tend to walk along, reaching out to hold on to Wendy if I don't know where I am. But like at the pub, I can get up from the table, walk through the bar, go to the loo, come back again… Everybody there usually knows that I'm blind. It's like the Red Sea parting [*Wendy laughing*], you know, they all part and let me go… I can sort of see that they're moving to give me a clear run. And people we know like those, they are very good, they're good to us." (Andrew)

In this extract, Andrew conveyed his appreciation for the responsiveness and understanding of other people who, knowing him well, "know that I'm blind" and who "move to give me a clear run"; this clarifies that the responses of other people - who are portrayed by Andrew as parting dramatically to give him a "clear run" through the pub – help to support his easy, smooth movement around the space. In line with the principles of the Social Model of Disability (Oliver, 2004), this demonstrates how the behaviour of others can play a role in constructing an environment that enables people with visual impairment, by removing disabling social barriers. Andrew noted that in these kinds of social environment, he feels at ease and supported to the extent that other people do not perceive him as blind; for example, he stated:

> "I had two people the other week say to me, I didn't know you were blind. Because I'm so at home in the bingo hall, I know where I'm going". (Andrew)

This demonstrates how (non-visible) sight loss can be forgotten by others when he is managing well in a familiar environment. Andrew's account attested to the process of previously unfamiliar spaces coming familiar, through a more top-down process of learning and concentration that allowed him to become habituated to and confident in a previously unfamiliar space:

> "**Wendy**: But most places you are comfortable, at normal places.
> **Andrew**: I'm comfortable at all the places like [clubs].

> **Wendy:** Also we still do go on cruises if we can. Andrew gets comfortable, very comfortable, in a couple of days on the ship, he can even find his way round.
> **Andrew**: I find my way round because as soon as we get out of a lift, I can see how many doors we pass and I know our cabin's this door or whatever, and I can easily get to and from the cabin, or wherever I need to go."

This extract provides an insight into Andrew's internal cognitive processes and mental efforts involved in navigating his way around a cruise ship, with this becoming a more 'top down' process in the absence of visual information. Alongside this seeming sense of mastery of his environment, Andrew however did also voice awareness that circumstances could change:

> "Well I've still got a fair bit of peripheral vision, but er… I presume that's gonna get less over the next few years, I mean… I'm not as confident outside as I used to be." (Andrew)

In this extract, Andrew simultaneously anticipates his sight loss potentially getting worse (while also acknowledging through the reference to his peripheral vision that he will retain some sight). He skips ahead from reflecting on the progression of his vision loss to feeling less confident outside his home than previously, which points to the link between advancing vision loss and a reduced sense of confidence in navigating the world outside the home.

6.3.2. An enabling environment of supportive relationships

Both participants expressed the importance of a social environment of close relationships and understanding from others that facilitated daily life with AMD. For example, Sylvia expressed the importance of supportive, close relationships in helping her to cope with the changes linked to her AMD, when she stated:

> "I think… it's personal really but I think it's support with me and people around me. […] Some people are quite good on their own. I'm not bad on my own, I like my own space. But I do like to sort of [*laugh*] have company, yes." (Sylvia)

As discussed in the previous theme, Sylvia had previously voiced her sense of comfort in her own company at home which was reaffirmed in this extract; however this was balanced against her appreciation of having the company of others. She differentiates herself from those who are "quite good on their own", stating she's "not bad" on her own but values company and support from others. The importance of supportive relationships also came across when I asked her what helped her emerge from a previously difficult phase:

> **Jamie:** What do you think helped you out of that phase?
> **Sylvia:** I suppose I'm luckily quite strong. I had to sort of talk myself out of it really. And sort of look on things that I could do… yes.
> **Jamie:** Mmm. And I know it may be hard to put your finger on now, but do you know what enabled that shift… changing the focus?
> **Sylvia:** Well I suppose it was talking to somebody – the phone number on the [Macular Society] magazine… And I had good friends, which is important… I think it's other people as well. You can't shut yourself away.

In this exchange, Sylvia initially accounts for the kind of turnaround she experienced as a result of her mental strength, and by encouraging herself to shift her focus on to things that she could still do. However, particularly pertinent to the present theme, she goes on to suggest that this was not a process that occurred at a purely individual level in isolation, but through talking to others, such as the Macular Society counselling service and her friend. This hints at the fact that even if the person with AMD takes the initiative in 'turning their life around', they do so with support from and in relation to others. Andrew in particular believed that much of his ability to accept AMD was linked to his strong relationship with his wife:

> "**Jamie:** [Discussing accepting the transition from print books to talking books] What do you think has helped *you* to accept it?
> **Andrew**: I think… being two of us, having Wendy, who looks up a lot of stuff on Google. She's very good at research and things. She's found out about so much that I never would have found out about on my own. So people who are on their own, they don't like to… ask their children to do too much, or… I don't know."

Andrew clarifies that it is "being two of us", this sense of being in a team with Wendy, that has been crucial to his adaptation to AMD. He suggests there is a practical dimension here, since Wendy is skilled at finding out about services and resources available. He goes on to draw a contrast between his situation and those living with AMD on their own, who may face a kind of dilemma if asking others, such as their children, for help; the contrast suggests that with Wendy he does not experience this dilemma, because in a sense it is presented as a given that they work through challenges together. Nonetheless, Andrew showed an awareness of limits in terms of how much he can rely on Wendy, and described having to find an equilibrium between staying busy and engaged in his activities but avoiding taking on too much:

> "**Andrew**: There's lots of other things I could do to raise funds [for the vision loss groups], but… I would need certainly a lot of help from Wendy and I don't like to…
> **Wendy**: …[*laughing*] overstretch her!
> **Andrew**: …overstep the mark."

In this extract, Andrew and Wendy spoke over each other to arrive at the same conclusion of not wanting to "overstretch" Wendy or "overstep the mark", conveying – with humour - the mutual awareness of an implicit boundary within their supportive relationship.

Sylvia's experience suggested that the process of cultivating an enabling. nurturing support system was a highly proactive and intentional one. For example, she stated:

> "Yes, I mean I've got… I suppose just a few good friends. I've cut things out that have been really negative, people who were negative around me I can't do with any more, and there's no need for this. And I know it's been quite harsh but I just don't want to be involved with it. So I've got, sort of positive people around me. And obviously they go through low points but you can talk to them. I suppose I shifted a bit… I thought, I can't do with people I don't understand any more." (Sylvia)

This sense of cutting down her friendships to exclude those who are "really negative", and only to include "a few good friends" that Sylvia can "understand" has parallels with the process of simplifying her home life that Sylvia discussed within Theme 1 (p.217). In each case, there is the sense of curating both a social life and a home life that caters to her needs and minimises shocks and disruptions (of the kind that she experienced when her husband died, and she had to cease driving and move flat). While Sylvia discussed the sense of loss and inconvenience she felt since ceasing driving, she also had friends in her network who responded in a way that mitigated the negative impact of her ceasing driving on the maintenance of their friendship. For instance, she stated:

> "I've got a very good friend… and she comes up, and picks me up and takes me back. She's doing that at the end of the month… for a couple of nights, and things like that." (Sylvia)

While Sylvia went on to suggest that this was not necessarily an ideal situation (saying, "It's… not quite the same, but you get used to a sort of a situation"), it was also clear that she valued this effort made by her friend to sustain the friendship across a large distance, beyond solely relying on telephone calls.

Close relationships with significant others were part of this support system, but so were connections with friends or group members within like-minded communities, whether vision-loss-related or not. Andrew in particular described himself as having a fundamentally outgoing nature:

> "I love meeting new people, it's something I've always done, and I do enjoy meeting new people, finding out about them…" (Andrew)

This demonstrates Andrew's self-concept as a sociable and curious person, an identity that has continued to be affirmed through his membership in vision loss groups. More implicitly than manifestly, Andrew tended to contrast the quality and variety of his social connections with the relative social isolation of other people he met through his vision loss groups:

> "…and the only time they come out, some of them, is for the [vision loss group], because a bus comes round, picks them up and takes them there and takes them back again. They just don't get out any other time." (Andrew)

This paints a picture of many of the other group members with vision loss living in isolation, which Andrew perceived as a contrast to his own life rich in social ties and activities. On the one hand, Andrew and Wendy saw this in certain cases as a matter of individual disposition (for example, Wendy stated, "I feel some of these people have given up, if you know what I mean. 'Oh I'm blind, that's it, it's over.' […] And they're not all really old, and a lot of them are fitter than Andrew, physically…"). However, elsewhere in his account, Andrew acknowledged the good fortune that he enjoys in terms of his local environment and the abundance of groups:

> "I thought it might be that they've just not asked or not found out. But they've all got a Macular Society, a local macular society same as me, but they all have about six people, five, four, even three in one case, three people. And they meet in somebody's house! Whereas we get about twenty to thirty, used to get fifty people! And we meet in a hall… They've got very few other people to talk to about their experiences, and their life. Whereas we've got… lots of people we can talk to. I've said to them, ring your council, and when I get back to them

> they say, 'Well I rang the council and they said, no there isn't anything, there's no blind clubs…'" (Andrew)

In contrast to the first interview I conducted with Andrew, where he often emphasised other people's unwillingness to be proactive or to seek out support, in this extract he drew attention to the systemic disparities in the local availability of support groups. His reasoning here, with an emphasis on the small number of individuals in other groups in contrast to his own, underlines the value he places on having a large, wide network of people with visual impairment with whom to discuss his experiences.

6.3.2.1. Navigating assumptions from and disclosure to others

Both participants discussed how the non-visible nature of AMD creates interpersonal challenges, in terms of other people often lacking understanding and awareness about vision loss. These assumptions from others about vision loss, and dilemmas around disclosing AMD to others, were a commonplace feature of the participants' everyday interpersonal interactions, which could variously have enabling or disabling effects on their relationships and social life.

Both participants discussed how other people made assumptions about their ability to see, based on preconceived stereotypes of what people with vision loss would look like and how they might act:

> "But if I meet somebody new and I tell them that I can't see, they often say, 'You don't look blind'. What should we have, or wear, that makes us look blind? I think blind people should have, I dunno, t-shirts or something [*laughing*] saying, 'I'm blind'!" (Andrew)

> "Well they say, you always look quite normal, as if… [*laughing*] Well not exactly those words, do you know what I mean, but 'you don't look as if…'." (Sylvia)

It is noteworthy here that Andrew and Sylvia are describing similar experiences in divergent ways; Andrew's extract includes frequent repetition of the word "blind", while Sylvia instead tails off and takes it as understood that she is referring to AMD or visual impairment, which in her formulation is implicitly positioned as the antithesis of being "quite normal". Similarly demonstrating how other people presume they have good vision, Sylvia and Andrew described near-identical occurrences of being greeted by others with a non-verbal signal, such as a wave, that they could not perceive:

> "But you'd be surprised by the times I'm walking down the road, or along the street, and someone will go toot toot and wave at me from a car. I don't know, I'll never know who they were. I've even had people who know I'm blind say to me, 'I walked past you on the street the other day, I waved!'... I don't see them! Some of them, they just don't appreciate what being blind means. 'I waved to you'… Well, you can wave all you like and I'm never gonna see you!" (Andrew)

> "We went out for a meal the other day, and this lady who lives here with her husband, she said, 'We were waving at you Sylvia, and you weren't replying', and I said, 'Well you know I can't see that far!'" (Sylvia)

In both cases, the participants are clear that the people waving know they have vision loss and, while humorous, Andrew and Sylvia's responses in these scenarios implicitly convey a sense of exasperation both feel about the lack of understanding of vision loss. There were however some differences in their responses to such situations. Sylvia stated:

> "It's quite difficult – sometimes – because they have coffee mornings, and if someone's opposite me on the sofa, I'm not sure whether they're talking to me because I can't see whether they're looking at me. And I have to sort of say, 'Are you talking to me?', you know, and they forget that I can't really see…" (Sylvia)

While there was understatement in Sylvia's description of these interactions ("*quite* difficult"; "sometimes"), Sylvia here conveys the awkwardness of these encounters where she feels the responsibility falls to her to clarify whether she is being addressed. By comparison, Andrew was somewhat more direct about the fact that it is incumbent on other people to address him and give their name:

> "I do use my stick to walk over there, but I know my way around the ground… I still know a lot of people, I say to people, if I walk past you, I'm not ignoring you, just tell me who you are and I shall know." (Andrew)

While Andrew conveyed bemusement and frustration at other people who apparently knew about his vision loss forgetting about it on occasion, Sylvia was somewhat more muted and equivocal, stating:

> "Well I don't mind, because it looks as if you're quite normal! [*laugh*] But in some ways you want them to know because you don't want them to think you're ignoring them, so… So when I'm shopping or something, I tend not to look up, because I'm frightened that I might

> pass somebody and they think I'm ignoring them. So I tend to look on the ground a bit. Yes, they usually say… something. Unless they want to ignore me!." (Sylvia)

Here Sylvia suggests a duality between appreciating others being mindful of her vision loss, but also feeling gratified when they forget because then "it looks as if you're quite normal", which implicitly equates good vision with a status of normality (Bolt, 2005). Sylvia states this initially with a laugh, as if potentially self-conscious about it being a flippant remark, but then returns to address the point in detail and states more reflectively that she does in fact want others to be mindful so that they do not perceive her as rude. Moreover, her strategy of looking down at the ground, in order to avoid potentially awkward social encounters where others might erroneously perceive her as rude, then puts the responsibility on others to address her. The fact that Sylvia can both appreciate being perceived as "normal" in the eyes of others, but also from a pragmatic point-of-view wants them to be aware of her vision loss and then respond accordingly, demonstrates the challenge - entailed by the non-visible nature of AMD - in navigating this ambivalent sense of fitting in with sighted society. Indeed, soon after this extract, Sylvia confirmed that ultimately she did want to be open about her AMD:

> "Well I don't find I want it to be a secret… It's just one of those things. Probably other people have… bad legs or whatever. It's just another sort of… thing that's a problem." (Sylvia)

It is striking here that Sylvia alights on the comparison of AMD to "bad legs" as a condition that is configured not only as more potentially visible to others, but also as more normalised and run-of-the-mill. It seems that for Sylvia in this extract, comparing AMD to a physical, more visible symptom that sits squarely within the realm of the body, makes it seem more legitimate and less shameful to disclose. This in turn hints at the dilemmas and potential feelings of embarrassment and shame that can accompany a non-visible condition such as AMD. Alternatively, the desired comparison to "bad legs" could also imply a wish for AMD to be considered as somewhat more incidental ("another sort of… thing that's a problem"), rather than something like AMD that is arguably more unusual or stigmatised, and thus risks potentially becoming a defining, totalising feature of her identity.

The dilemma that Sylvia voiced here about disclosure of her AMD was thrown into relief by Andrew's discussion of using a white stick, an act which unambiguously drew others' attention to his status as sight impaired. Andrew discussed using his white stick as a tool that mitigated against others' knee-jerk responses of impatience and judgement:

> "**Andrew**: Yeah cos [when] I used to get off the bus, you'd have people saying, 'Come on, get on with it!'
> **Wendy**: Yeah, and this was ten years ago and he looked younger then, and they'd say, 'Get on with it mate, get a move on!'.
> **Andrew**: …so get a white stick and then they'll know that you can't see. So a white stick does help in that way." (Andrew)

Andrew and Wendy's description here suggests that other passengers could often be hostile and impatient when he was taking time to alight the bus, and a white stick is framed as the solution; demonstrating how an unambiguous marker of impairment is seen as a helpful tool in legitimating non-normative behaviour. However, Andrew and Wendy also drew attention to how openness about vision loss may in certain situations create more vulnerability:

> "I think… there should be something that… I don't know, a wristband (but people don't always see wristbands) that tells people you can't see. Although there could be a disadvantage to that, people could take advantage of that… I walk along and people don't know I'm blind. If they did know I was blind, they might try to, I dunno, stick hands in my pockets, take things away, I don't know. So there would be disadvantages to that. I don't know what the answer is." (Andrew)

Because Andrew was now using a walking stick that was also a white stick, but looked more like a standard walking stick rather than the long cane that is commonly used by people with vision loss, here in this extract he was reckoning with the dilemma of how far to broadcast his vision loss. While he was generally positive throughout the interview about the idea of being identifiable as vision impaired, his reticence here stemmed from concerns about becoming more vulnerable and susceptible to being "taken advantage of". He ends by stating "I don't know what the answer is", essentially leaving this as an open question. This perhaps suggests that the precise social context may determine whether it feels safe and advantageous to disclose vision loss or not, with this process being a continual negotiation between the person with vision loss and the outside social world.

6.3.3. Honing adaptation strategies to maximise autonomy and agency

This theme explored the ways in which both participants worked hard to embrace mitigation and adaptation strategies that could maximise their sense of autonomy and agency. This often involved swapping one activity or way of doing a task for another, sometimes using visual aids or assistive devices (perhaps more enthusiastically in Andrew's than Sylvia's case). It is noteworthy that adopting these mitigation and adaptation strategies was a process of 'honing' over time, in the sense that there were dilemmas and hesitations about shifting activities in this way, and the novelty of such changes took some getting used to.

In Sylvia's case, having worked as a visual artist, she discussed her transition from more detailed portrait painting to working with resin, and she showed me examples of her work during the home tour. She associated her transition to beginning to work with resin to the time when both eyes were affected by AMD, which made detailed painting impossible:

> "Obviously I had that, but to begin with, it's not too bad, if one eye's ok. But now I would find it quite difficult with details. So what I do now – with the last thing I did – this is resin, so it's sort of like you just *[laughing]* chuck it on. And you chase it around with a hot gun." (Sylvia)

The language Sylvia uses to describe painting with resin makes it out to be a very organic, liberating process, laughing as she described "chuck[ing] it on" with a sense of abandon. When I asked Sylvia about how she experienced this new form of artistic expression, she stated:

> "I did what I was able to do. I suppose that's the only answer to that one. I realised I could do that, I wouldn't tackle something that I couldn't do… I still might have a go at a portrait, but it would probably be a profile maybe, I might be able to manage that. [Partner's name] downstairs, he's very detailed, he would draw it out for me, but I would never normally have people drawing that out for me. I would do my own. But that helps me if I wanted to do a portrait now, yes." (Sylvia)

Sylvia here shows a strong sense of self-knowledge in terms of what is and is not within her grasp as a practising artist. She does not rule out "hav[ing] a go at a portrait" but would not seriously tackle something she believes to be beyond her capabilities. This in turn demonstrates the strategies Sylvia uses to continue to affirm her identity as an artist while also choosing not to engage in work where the effects of AMD would potentially be more pronounced. It is also noteworthy that she mentions the possibility of her partner drawing the outline for her, a practical example of the support they provide for each other. However, at other points in her account, the strategies Sylvia described using to preserve her sense of agency and control arguably involved a kind of curtailment or restriction of meaningful activities;[50] this came across explicitly when she stated:

> “I loved driving, and going to different places under my own steam. And it was giving up a lot of my independence and what I could do. Things I did, I couldn’t get there any more, and I didn’t really want to ask people to take me, it’s not the same. So I had to sort of… change then, the things I did.” (Sylvia)

Sylvia here suggests that even if there were other people available to take her to places, “it’s not the same” and she preferred to change the things she did. The language used in this extract is definitive in terms of the negative effect of ceasing driving on her activities (“I **had** to… change the things I did”), but notably her description of “giving up a lot of my independence” differs from constructions of the total loss of independence drawn upon in much of the published literature on AMD (see Chapter 3). Indeed, she went on to state that in many ways she remained quite independent, in the context of getting to bowls.

> “I’m quite independent, you know… My partner, though he still drives, I don’t like depending on him. I get [local charity transport], to go under my own steam. […] You can’t drive yourself, so this is really the second best.” (Sylvia)

This extract demonstrates how using transport provided by a local charity helps Sylvia to continue feeling autonomous and in control, and to avoid feeling like she is depending on her partner; in many ways this is in line with ideas from the social model of disability, demonstrating how these kind of services can empower and preserve a person’s sense of dignity and self-determination (Keyes et al., 2015) even in the face of physical limitations.

For Andrew, his enthusiastic embrace of different visual aids and assistive technologies played a key role in helping him adapt to vision loss and to feel autonomous and agentic. There was a palpable sense of enthusiasm and pride as Andrew showed me different devices in his home. It was also noteworthy that when I asked him what the

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[50] This aligns with findings of McGrath et al. (2016), who found that some individuals with AMD may give up on valued activities, rather than accept help with these, in the pursuit of remaining independent.

significant changes had been at home since the onset of vision loss, he alighted on specific devices that he found useful:

> "**Jamie**: And I was going to ask, what have been the most significant changes at home since vision loss?
> **Andrew**: Changes since I got AMD… well one is that scanner on the table over there, that enables me to read certain things. The talking books and talking newspapers I get every week…. What other significant things do I do. Well I've got a gadget to make cups of tea, I can make a cup of tea without anyone else… I've got a talking alarm clock by the side of my bed which hasn't got any hands. This is a speaking watch [*Andrew demonstrated it*]. That gives you the time… it gives you the date. That only does the time and date, but the one upstairs is an alarm clock."

Both Andrew's tone, and the range of devices he discussed using, conveyed a sense of enthusiasm about his "gadgets" and the assistance they can provide in everyday tasks. For Andrew, the central end-goal of these gadgets was to preserve his sense of independence:

> "**Jamie**: It [*the talking alarm clock*] is great. I mean how do you feel using these gadgets, does it--?
> **Andrew**: Well it makes me feel independent, being able to set an alarm, and, you know, if I'm wandering around wondering what time is it, I just press the button and it tells me. Yeah it does give me a bit of independence. And when Wendy's out, like on Thursday she's going to a club, I can make myself cups of tea whenever I want."

In this extract, Andrew illustrates how the use of these gadgets helps, particularly when his wife Wendy is out of the house. The specific example he provides of making himself cups of tea whenever he wants illustrates what is often at stake for people in terms of "feeling independent", namely the ability to act on one's own wants and needs without this being mediated through another person. It is noteworthy that Andrew clearly feels empowered by his use of assistive devices here, describing the seamless processes by which the assistive devices allow him to achieve tasks. His zeal for these assistive devices also came across when he mentioned discussing them with his vision loss groups, and often being disappointed to find that others did not want to use them. For example, at the end of the interview he said he would have liked to record the home tour and show it to his groups, hoping that this might overcome some of the apathy he sees among the other group participants in terms of taking advantage of assistive devices:

> "I've enjoyed your visit. I just wish that somebody could have taken a video of what we've done today. And I could show it at [sight loss group] so that people can see it. Because when… I took my USB player two weeks ago into [the local vision loss group] and showed it to people. And there were two or three – I mean it's 20 people there – two or three who came up and had a look but the rest don't want to know. They didn't want to know." (Andrew)

Indeed, Andrew was clear that he found the simplicity and ease afforded by assistive technologies appealing, in response to others who felt a sense of resistance to using devices like talking books:

> "Well I think that's the trouble at my clubs, you say to people about talking books and they say, well I used to like reading but I can't get on with talking books. But they've never listened to one. But it's so simple, all you've got to do is pop it in there…" (Andrew)

Some of the assistive devices he discussed were used more as a response to reduced mobility after his falls rather than AMD *per se*. Andrew recognised such items had co-benefits, but he made a clear distinction between what had been installed in response to AMD versus his falls:

> "That was after my fall but it does help for AMD as well. It gives me something to grip onto going up and down the stairs. And the grab rail up here, I can grab onto it if I feel I'm gonna fall. But that's not really an AMD thing. That was put in because of the fall." (Andrew)

Particularly relevant to the notion of "honing" adaptation strategies introduced in the theme title, Andrew suggested that these devices in the home – to differing degrees – were associated with a kind of learning curve, suggesting that arriving at a position of ease with and accommodation to the devices could take time, and that the devices were not always initially embraced particularly enthusiastically:

> "**Andrew**: To be honest with you, when they said we'll put this [*a grab rail in the bed*] in there I said, 'I don't need it', but I don't half use it every day! To get out of bed I do use it.
> **Jamie**: Yeah. How come you were initially hesitant, do you think?
> **Andrew**: I dunno, I felt like I should be able to get out of bed on my own."

While Andrew was clear that this rail in the bed was installed in response to the fall, rather than AMD, it demonstrates the kind of self-talk that might accompany initial use of assistive devices required for AMD as well as for other reasons. Andrew initially felt he "should" be able to get out of bed on his own, demonstrating that at this point the grab rail was not so much considered part of an 'assemblage' (see Theme 1, p.218) with his body, but something that represented a kind of external crutch that made concrete his inability to accomplish a basic task by himself. This therefore suggests that Andrew not only becoming accustomed to using such assistive devices, but doing so enthusiastically, has clearly involved working through some of these initial preconceptions, rather than being an instantaneous process.[51]

6.3.4. "That was then, this is now": wending one's way towards acceptance

While both participants showed flexibility in their ability to adapt to AMD, there was a clear sense of experiencing challenging, phased transitions over time, moving through different phases to arrive at different points on the dynamic continuum of acceptance. Both attested to the challenges and sadness of giving up certain activities, especially driving and specific hobbies, and no longer seeing certain individuals who could only be reached by car. Acceptance was a dynamic process for both that appeared to be a product of a positive pragmatism and a determination to choose the path of hope and stoicism in the face of frustration and sadness. It was also noteworthy how supports in the social-relational domain (such as close relationships) and in the environment (such as public transport) could cushion against drastic negative changes and a sense of loss, which then helped in the continuous, effortful task of acceptance.

Sylvia's account provided a clear sense of the different emotional experiences across time as her AMD and vision loss progressed:

> "I suppose you have to stay positive with it. You could get [*rueful laugh*] quite depressed wondering what's going to happen. But I just feel you've got to live each day as it comes, really… I was very upset when my other eye went, because I had to give up driving, and we

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[51] For both Andrew and Sylvia, I had the mental image while writing this theme of taking to a new activity like "a duck to water", a phrase used by Andrew in our first interview (for the IPA study) when discussing taking up the white cane. It may be a trite comparison but I was often thinking about the duck appearing calm and at ease above water, at a more manifest, observable level, and the feet paddling fast and effortfully below, more implicitly and latently, as a metaphor encapsulating both participants' hard work to remain stoic and pragmatic.

> moved to a flat, and it was all too much really. It was all-- giving up too much all together. But I did ring a number that they had in the magazine there, and they would help me to talk it through. I found that quite good." (Sylvia)

In this extract, Sylvia suddenly shifted tense from the present, in which she exhorts the importance of "staying positive" and living in the moment to avoid ruminating about the future, to the past. Simultaneously, there is a switch from a more generic second-person "you" (e.g. "you have to stay positive with it"), to the "I" of her own experience. There is arguably a tension here between the more abstract, generic imperative to think positively and her own concrete experience of despair (from which she was gradually able to emerge with support from others). This could be interpreted to underline the difficulty of individually seeking to come to terms with AMD without outside support. Alternatively, it could be the case that Sylvia's experience when her second eye was affected by AMD, and the sense of utter overwhelm and despair this caused her, has taught her these salutary lessons about the need to think positively. In this scenario, it may be that her experience of emerging from this particularly difficult phase has equipped her with the confidence to know that such periods will not last forever; and in this case, her conclusion to "live each day as it comes" is not a generic cliché but more a belief based on first-hand experiential knowledge, aware of the potential for her emotional responses to AMD to shift with time and support.

While Andrew did not describe experiencing a comparable low-point to Sylvia, he used strikingly similar language to the quote from Sylvia above when he discussed his concerns for the future. He stated:

> "Well I admit, I've admitted to myself that I'll never get my sight back, I know I'm never gonna drive a car again, I know my eyes are gonna get worse. But the time's gonna come where – like my mum – I'm gonna be indoors all the time and not go out. But I wanna do the going out while I can. There's a saying, 'live every day as if it's your last' and who knows, one day it will be [*laughing*]." (Andrew)

Here Andrew voices facing a future where his eyesight could get worse (although elsewhere in the account, he described feeling reassured "that I will not go completely blind, I'll always have some sense of vision"), and compared the future he envisaged to the experience of his mother (who also had AMD), typified by being restricted to staying indoors. While this is in many ways a pessimistic view of the future, with staying indoors described as a kind of inevitable end-stage state, Andrew remains pragmatic and determined - like Sylvia – to take life day-by-day and make the most of the current state of his vision.

Crucially, the stoical, hopeful pragmatism that Sylvia and Andrew seemed to share - despite their different trajectories - did not negate the very real sense of loss that both voiced experiencing. This particularly came through when Sylvia discussed stopping attending her art class:

> “**Sylvia:** I've given up my art class, cos that was a bit frustrating. Though… I don't know, at the moment [*laugh*].
> **Jamie**: Mm. So what led you to give up the art class?
> **Sylvia**: Well… I couldn't really do what I normally did, do you know what I mean? I miss the company, but I'm still in touch, they ask me to their parties, things like that. I just didn't… feel… Cos they're quite clever a lot of them, I couldn't… [*hesitating*] I don't know, I didn't enjoy going any more. I don't know. Because I couldn't do what I normally did.”

This extract illustrates, both in Sylvia's words themselves and the quiet, faltering tone with which they were expressed, the sadness of no longer being able to “do what I normally did”, which sapped the enjoyment from the activity even in the presence of the other supportive, friendly group members. In particular, in referring to how “they're quite clever a lot of them”, Sylvia perhaps hinted at feeling that she could not keep up with the class, and this comparison of her current abilities not only to her artistic capabilities before AMD, but also to those of others in the class, became difficult to bear. At another point in her account, Sylvia was clear that the group would have welcomed and supported her to stay, but this was very much a decision she took based on her personal feelings:

> “I could have stayed, they [other art group members] would have been happy for me to stay. But it's my decision, you know, it's how you feel about things.” (Sylvia)

This extract illustrates how even in spite of the highly accommodating environment, Sylvia felt fundamentally unwilling to stay in the group when she felt no longer able to engage in the class in the way that she once could. The sense of sadness and finality Sylvia conveys, of a door irrevocably closing on a meaningful area of life (even while keeping a door open to art through her work with resin), found a parallel in Andrew's account where he discussed no longer being able to have cats in the home:

> "**Andrew:** Over on the china cabinet, we've got a couple of photographs of cats we used to have. We've always had cats… but when the last cat died, must be ten years ago now about that time, the time I was first diagnosed. When that cat died, we knew I had the macular and we decided not to get another cat because… they sit where they like and I might sit on them or trip over them.
> **Wendy:** So that is a decision totally made because of his eyesight. Totally made. And we both like cats."

While Andrew and Wendy discussed no longer having cats in a somewhat more matter-of-fact tone than Sylvia describing giving up her art class, there was still a stark sense of sadness for what had been, especially when pointing to the photographs on the cabinet. It was notable that this was one change in their lives that had been impelled purely by AMD and sight loss, rather than the more intertwined effects of sight loss, ageing and falls which dominated Andrew's account.

For both Sylvia and Andrew, the very real losses they had experienced were somewhat cushioned by a strand of more 'top-down' pragmatic and stoical thinking that allowed them to put the losses in perspective. In both cases, they suggested that the ability to adopt this mindset could be a more fundamental personality trait. For example, Sylvia stated the following about the importance of proactivity in adapting to AMD, while acknowledging that others might function well by adapting a divergent approach:

> "Yes, you've got to adapt! It's really sink or swim isn't it, you're either going to sit here, and do nothing... You've got to… Well, everybody's so different. I mean one of the ladies here, she's got a sight problem as well. She seems to be quite happy 'in', and I think oh dear, but she seems to… be quite happy on her own. It's people with different personalities, really."
> (Sylvia)

Sylvia's language here had strong parallels not only with Ruby's discussion in the IPA of the need to "sink or swim" (Chapter 4, p.149), but it also echoed – when she discussed the binary choice between adapting and "sit[ting] here… do[ing] nothing" - one of the constructions in the discourse analysis (AMD as a condition to be stoically accepted) (Chapter 3, p.65). Interestingly, Sylvia moves in this extract from framing this 'fork-in-the-road' type choice between adapting versus sinking into oblivion as a universal truism (using the second-person, generic "you" pronoun), to a more specific contrast between this more agentic philosophy that she subscribes to and the contentment of her fellow resident with sight loss who seems to enjoy time indoors in her own company. The extract therefore concludes with an acknowledgement – in contrast to the seeming universal truth about the need to stay active and agentic in response to AMD - that there is in fact no single, linear path towards adaptation; and the somewhat more solitary and resigned approach of her neighbour may also be a valid response. In Andrew's case, when we discussed the aspects of his personality that equipped him to adapt successfully to AMD, he and Wendy alighted firstly on his stubbornness as an advantageous trait (aligning somewhat with the agentic, plucky spirit alluded to by Sylvia with her language of "sink or swim"). This extract followed on from Andrew and Wendy comparing his proactiveness with the relative passivity of other members of the groups to which Andrew belonged:

> "**Wendy:** I think he's just a stubborn old wotsit! [*laughing*]
> **Andrew**: I'm a stubborn old wotsit, I don't deny that! I am stubborn. But to me it's just another phase of my life. I played football, I played cricket, I played squash, I played badminton, I played golf, at different times… you know, if I couldn't play football any more I played golf. If I couldn't play golf any more I played snooker. I've always done something to occupy my time. So now, I read books mostly and do things at home. It's just another phase of my life, to me. You know, I'd love to be able to play football, I'd love to play cricket, I'd love to play golf!"

While being "a stubborn old wotsit" helped, what also came across in this extract was the extent of Andrew's flexibility and his ability to let go of old activities, and then wholeheartedly and determinedly embrace the activities and opportunities available to him in the next phase of life. This ability to transition gracefully between different phases of life did not negate a continuing sense of loss or regret (which came across when Andrew voiced his wish to "be able to play football… cricket… golf"). Andrew's perspective here brought to my mind a phenomenological study conducted in the Netherlands among older adults who – by contrast - felt their life was completed and no longer worth living. The study authors concluded that this phenomenon under investigation stemmed fundamentally from "'a tangle of inability and unwillingness to connect to one's actual life'" (Van Wijngaarden et al., 2015). In that study, the participants felt unable to live in the present and stay connected to themselves and others when their current life felt so incompatible with their expectations and self-concept. Andrew's description of his ability to "occupy [his] time" as best he can, and treating AMD as "just another phase of my life", seemed to represent the opposite of what Van Wijngaarden and colleagues (2015) termed this ‘inability and unwillingness to connect to one’s actual life’. Andrew not only seemed to have the confidence and self-efficacy to connect with others and engage in meaningful activities, but also a sense of commitment to make the most of whatever phase of life he found himself in. It is also noteworthy that one might expect that defining life as a series of distinct phases, characterised above all by the constituent activities, might at first seem to make the loss of such activities more salient. However, in Andrew’s case it seemed that the ability to replace one activity with another helped with accepting the losses, which were sometimes discussed with humour:

> “**Andrew:** It’s a new phase of my life. I mean, I used to play cards, cribbage… I used to play darts.
> **Wendy**: Ha! [*laughing*] Just imagining…
> **Andrew**: …yeah I wouldn’t risk darts now! I don’t think anyone would play with me! But no, you’ve got to laugh about it, because it is funny in a way.” (Andrew)

This ability to accept life stoically as a progression of discrete phases – acknowledging the losses, with humour - appeared to be a feature quite central to his personality, but also facilitated by his support from Wendy and the environment in which he found himself. This came across particularly when discussing his initial sadness at no longer driving, which has somewhat been alleviated through the availability and accessibility of public transport in his local area. Andrew stated:

> “**Andrew:** Yeah I really missed driving when I couldn’t drive but I don’t miss it any more, I must admit… […]
> **Jamie**: About the driving, you told me last time you were a taxi driver as well. I think some people never get over the loss of driving… what do you think helped you move through that?
> **Andrew**: I think the fact that here, we’ve got so many different bus routes, and we’ve got the overground station, we’ve got the tube station, so I can a bus to the station, get a train to…
> **Wendy:** …we can get a bus from this little crossroads… that will take us to the station, to the same line that you…
> **Andrew:** …and then we’re on the tube… I think the fact that we can get around so well, helped me. I wouldn’t have liked it if I couldn’t go out at the time when I couldn’t drive any more. That I wouldn’t have liked.”

This extract demonstrates that driving was initially a loss Andrew had to come to terms with, but public transport allowed him to remain connected and on the move. At the end of the extract, he was emphatic that he "wouldn't have liked it" had ceasing driving limited his ability to stay mobile and get around. This example illustrates how much of Andrew's ability to adapt stoically to AMD may be innate, but the enabling environment around him also plays a key role in supporting his wellbeing and connectedness in this new phase of life with AMD.

6.4. Reflections on the home tour interview and analysis process

Full, more substantive discussion of the content of the findings is covered in Chapter 7. In this present section, I briefly reflect on the process of conducting the home tour interviews and analysis. (More overarching reflections about using RTA alongside the other methods of the PhD are covered in Chapter 8.)

Beyond answering the research question, a secondary objective of this study was to 'reflexively consider the opportunities and challenges afforded by the home tour interview methodology, alongside the IPA accounts in Chapter 4.' I enjoyed the interviews with both participants, and equally both participants were positive about the experience.[52] Being located in their homes helped shed more light on the participants' everyday lives and routines. Interestingly, this sometimes had the effect of 'decentring' AMD, as it became just one aspect of their overall lifeworld at home; whereas when discussing their experience of AMD by phone, the experience of AMD remained front and centre. Arguably the home tour process helped to see how participants like Andrew and Sylvia integrate AMD and vision loss into their lives, in a way that runs counter to the kind of "loss focus" paradigm in AMD research discussed by Tanner et al. (2020); since being in their homes provided more insight into the sum total of their daily lives, within which AMD played an important but not overwhelming part. This meant that at certain points during analysis of the interviews, I questioned the effectiveness of the home tour methodology in tapping into more pre-

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[52] Sylvia for example stated "I quite like being face to face... You get the whole personality of someone", while Andrew stated, "I've enjoyed your visit. I just wish that somebody could have taken a video of what we've done today. And I could show it at [sight loss group] so that people can see it."

reflective, embodied aspects of the participants' experience of AMD, since I felt we had often delved more deeply into their AMD experiences during the first telephone interview.

This discrepancy between the first interview (conducted by telephone) and the home tour interview could potentially be explained in several ways. For instance, it may be the case that both the participants and I approached the home tour interview appreciating that they had already relayed the different phases of their emotional experience with AMD in-depth in the first interview; and so, given my focus on their home life, this interview was framed more as a chance to focus on the corporeal, physical practicalities of their home activities and routines. It may also have been the case that, conscious of my place as a guest in the participant's home, I wanted the interview to be a positive experience; and so my desire to be polite, agreeable and reassuring perhaps meant that the interview often defaulted more to "small talk" than one might expect in a research interview. Hämäläinen & Rautio (2013, p.19) discuss how in research interviews in families' homes, participants may feel "they have to put on a good face", and this could have applied in my interviews. Furthermore, my desire to keep the interview positive may have interacted with any tendency on the part of participants to want to keep the conversation more at surface level. This may lend credence to the argument postulated by Spiers et al. (2016) that telephone interviews, by providing a greater sense of anonymity or confidentiality, can in fact afford deeper sharing of sensitive emotional experiences. In spite of this, there were arguably moments where the participants reflected more deeply on their experience, for example when Andrew shared his perspective on treating his experience of AMD as "a new phase of life". Yet overall, I did not feel that the discussion of objects and places in the home was itself a route to unlocking such deeper reflections. Instead, it felt more as though we would discuss the objects and places in quite practical terms, and this would be interspersed with more of an experiential, existential perspective on AMD (which often overlapped significantly with what was shared during the IPA interview). Given that the reasons why this dynamic might have developed are essentially conjecture, it may be helpful to think about the IPA telephone interviews and home tour interviews as potentially complementary rather than trying to define points of relative superiority or inferiority. (The relative merits of the interview modalities are further discussed in Chapter 8.)

Reflecting on the process of reflexive thematic analysis, I believe it worked effectively in helping to continue exploration of participants' lived experiences while also providing more latitude to analyse actualities of the participant's home and local environment alongside their more experiential, existential reflections. I also appreciated the encouragement of Braun and Clarke, as discussed for example in their RTA reporting guidelines (Braun & Clarke, 2024), to incorporate existing research and theory into the analysis write-up to set my interpretation of the data within the broader scholarly context. That said, I sometimes struggled with whether this affected the coherence of the analysis, introducing a 'top-down' perspective that I was concerned potentially clashed with the more bottom-up, inductive, experiential approach with which I embarked on the analysis. Indeed, some of this discomfort perhaps stemmed from my experience of IPA, where the emphasis is on remaining rooted in the participants' lifeworld, and therefore where it would be rare to integrate top-down theoretical perspectives or literature into the analysis. Yet arguably, all inductive analysis – particularly at a more interpretative level - is shaped by the researcher's broader understandings of the world. However, I felt that when conducting IPA, interpretation was above all underpinned by the hermeneutic circle, seeking evidence for interpretation of one part of the account in another part and thus helping to further development of a more holistic interpretation. The RTA felt in some ways more intellectually exciting and dynamic, by feeling I had licence to more intentionally draw on different external perspectives from theory and literature; but it also potentially felt more 'chaotic', in the sense that depending on the idiosyncratic connections I made between the data and existing literature, the analysis could then potentially unfold in a number of different directions. However, in the big Q tradition of RTA, this confidence to (reflexively) apply a top-down perspective is arguably part and parcel of becoming what Braun and Clarke (2023, p.1) term a "knowing researcher" and one who "strives to 'own' their perspectives".

The home tour interview findings are discussed more holistically in Chapter 7, and I reflect further on the different data collection and analysis methods in the PhD as a whole in Chapter 8.

Chapter 7 – Discussion of substantive findings

This chapter presents a discussion of the thesis findings, contextualised within broader theory and literature, and considering the thesis' implications for practice. I look across the four substantive studies that are the focus of Chapters 3-6 inclusive; and consider holistically how the studies help respond to the research questions posed at the start of the thesis, which were:

- How do people experience AMD within their (unique and shared) relational and social worlds?
- How do individuals experience AMD differently, within their relational, social and environmental context?

I discuss the findings in terms of how individuals in the study experienced AMD as an embodied, existential phenomenon, and then consider AMD in the context of the participants' relational and social life, before moving to consider how AMD is experienced in the 'socio-material'[53] environmental context. I conclude the chapter by exploring implications for practice and future research.

7.1. Summary of findings

The secondary discourse analysis in Chapter 3 used Foucauldian Discourse Analysis (FDA) to analyse how AMD was discursively constructed in 25 published qualitative studies, in order to map the discursive terrain of talk about AMD in qualitative research. I suggest there were five distinct ways in which research participants constructed AMD:

1. AMD as a mysterious affliction, linked to biological ageing;
2. AMD as a total loss of independence;
3. AMD as grievous loss;
4. AMD as a condition to be stoically accepted;
5. AMD as an opportunity for discovery. (It is worth noting that this latter set of constructions was less salient than the preceding four.)

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[53] I consider a 'socio-material' perspective to be attending to the interplay between "complex social, economic, material, spatial and affective factors and agents" (Lupton, 2022).

There was a particularly striking construction of independence as an ‘all-or-nothing’, binary phenomenon, with AMD often constructed as signalling an end to independent life (itself constructed as the self-sufficient physical undertaking of daily activities). In the fourth set of constructions, I was particularly struck by talk illustrating the imperative to take charge as an individual, and to muster one’s own willpower to live with AMD or else to sink into oblivion. To draw on Baars and Phillipson's (2013) helpful typology of ‘existential’ and ‘contingent’ limitations linked to ageing, the discourses and repertoires mobilised by participants generally tended to configure AMD solely as a source of inherent, ‘existential’ problems within the individual; rather than problems stemming from societal, structural or environmental barriers which are arguably ‘contingent’ or modifiable. The FDA findings thus align with the argument that much – though not all – of the research on quality-of-life and wellbeing in AMD has been rooted in a loss-focused paradigm (Tanner et al., 2020), often taking-for-granted notions such as “independence” and “normalcy” without considering how these are produced in particular social and environmental contexts (McGrath et al., 2017). Conducting the FDA involved engaging with literature from critical gerontology and disability studies, which encouraged me to look beyond how AMD is lived in the body to also consider the discourses, norms and practices that shape the social and environmental context in which AMD is experienced. To draw on Thomas' social-relational theory of disability (Thomas, 2004), this means attending to both *impairment effects* – the embodied, sensory experience of living with AMD and vision loss – and *disablism* – avoidable oppression caused by institutions, physical and social structures, and discriminatory attitudes.

Turning to the findings of the interpretative phenomenological studies, Chapter 4 presented a full IPA study based on the accounts of eight participants, while Chapter 5 presented a template analysis on the basis of eight further participants’ accounts, extending and further developing the Chapter 4 IPA findings. Chapter 6 then used reflexive thematic analysis (RTA) to analyse home tour interviews undertaken with two participants from the IPA study.

Four themes were developed in the IPA study (Chapter 4), namely:

- Reconfiguring a destabilised identity and struggling to find a new place in the world

- The intensive effort of learning to live with AMD
- Navigating the hope-despair continuum
- Negotiating one’s place in the world.

In the template analysis (TeA) in Chapter 5, these findings were further nuanced through the development of further sub-themes and codes, although the overall thematic structure of the IPA of Chapter 4 was not fundamentally altered. The TeA yielded new insights; this list is not comprehensive, but the following insights were most salient, adding significantly ‘new’ understanding beyond the IPA of Chapter 4:

- Vigilant trepidation at an early stage of AMD, amid uncertainty about the future
- A sense of becoming foreign and alien to the self due to AMD
- Experiencing AMD as an intergenerational phenomenon
- The gulf between the self and others when seeking to disclose or verbalise the complex, dynamic experience of AMD
- Wishing for a more accessible and understanding society.

The RTA presented in Chapter 6 led to the development of four themes, namely:

- Home as sanctuary: Finding comfort in routine activities and familiar places
- An enabling environment of supportive relationships
- Honing adaptation strategies to maximise autonomy and agency
- “That was then, this is now”: wending one’s way towards acceptance.

In the RTA, parts of the latter two themes aligned with Theme 2 in the IPA (“The intensive effort of learning to live with AMD”), while the RTA theme around the “Enabling environment of supportive relationships” had echoes of Theme 4 in the IPA (“Negotiating one’s place in the world”). However, the greater attention in the home tour interviews to participants’ situated context suggested that supports in the social-relational domain, such as close relationships, and in the environment, such as public transport, could cushion against drastic negative changes and a sense of loss, which then supported participants’ continuous, effortful task of acceptance.

In the following sections, I consider the findings as a whole in relation to prior research and theory, to consider the shared and idiosyncratic experiences of AMD in context.

7.2. AMD as an embodied, existential phenomenon

7.2.1. An intertwined disruption of sense of body and sense of self

Looking across the three interpretative phenomenological studies, experiences of AMD for many participants included sadness regarding the embodied changes to their vision, and frustrations and limitations with everyday activities. Arguably however, for certain participants, AMD was more than the sum of its functional effects and represented a kind of existential reckoning or crisis point. Certain participants, such as Hannah, Julie and Sandra, voiced how the condition had destabilised their identity and self-concept. AMD and its impacts caused them to question their sense-of-themselves; for example, Sandra had always considered herself an “outgoing person” who would never have expected to experience suicidal thoughts after her diagnosis, while Julie as a former architect felt “robbed of [her] identity”. Hannah voiced the foreign, alien nature of feeling more physically vulnerable due to vision loss, and her worries about potentially becoming embittered and being positioned by others as a “grumpy old lady”. As also discussed by Burton (2013), where one participant stated that AMD “chops your life in half”, such experiences would appear to align closely with Bury's (1982) notion of biographical disruption, especially when defined as the “fundamental re-thinking of the person’s biography and self-concept” (Bury, 1982, p.169). They also align with Charmaz’s argument that chronic illness and impairment “erodes taken-for-granted preferred identities as well as their health”, and entails physical losses that cause individuals to reassess “who they are and who they can become” (Charmaz, 1995, p.660).

As also noted by Burton (2013), participants in my study perceived changes in their embodied experience, such as limitations undertaking physical tasks, to be intertwined with broader changes in their identity and self-concept. For example, Ruby had been an academic expert on reading, which made her struggle to read using assistive devices particularly frustrating and challenging to bear. This illustrates Carel's (2013, p.352) assertion, drawing on both Merleau-Ponty (1962) and her personal experience of chronic lung disease, that chronic illness or impairment represents a:

> “…conflict between the biological body and life projects. Whilst the individual person’s ‘‘personal life’ is engaged in a project, the biological body obstructs it.”

The findings from my interpretative phenomenological studies vividly illustrated the sudden, shocking realisations of this ‘conflict’ between the body and one’s sense-of-self, for example when Suzanne compared the disbelief “that you can’t do something that you’ve always been able to do” to getting stuck halfway over a stile. This can be seen as an illustration of Paterson and Hughes' (1999, p.603) description of “the impaired body […] stunned into its own recognition by its presence-as-alien-being-in-the-world”, a stark contrast to the ways in which the consciousness of the body (specifically in this case, sight) might often be phenomenologically “absent” when healthy or unimpaired (Leder, 1990). In his work on the phenomenology of illness, Leder (1990) used the term “dys-appearance” to encapsulate this feeling of bodily alienation and incoherence, whereby illness or impairment causes the previously pre-reflective “absent” body, harmoniously integrated with our will and consciousness as a “body-subject” (Merleau-Ponty, 1962), to become alien and other.[54] This also aligns with Svenaeus' (2011) argument, drawing on Heidegger, that chronic illness entails a feeling of “unhomelike” being-in-the-world. Such a perspective may help with understanding why seemingly trivial accidents or mishaps had, in Ralph’s words, a “hugely disproportionate crushing effect”. For in addition to the immediate inconvenience or frustration, such events also represented stark reminders of the accruing bodily limitations, and a contrast to the previous sense of ease in the body, “revealing finitude, inability, and alienation from one’s body” (Carel, 2013, p.347). As Toombs (1995, p.19) suggests, these daily frustrations do not only reinforce a sense of loss of ability, but can bring a shameful sense of feeling diminished, no longer able to do things the person feels they “should be able to do for [themselves]”.

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[54] Relevant to this discussion, Leder in fact draws on the example of seeing with the eye to exemplify how, in the absence of illness and impairment, we use the body to seamlessly act on our decisions rather than focusing on the “corporeal means of accomplishment” of a task. Leder states that “In seeing, we physically act from the eye; we attend from it to the objects of its gaze; and this vision rests on an unknown and unproblematic ‘I can’” (Leder, 1990, p.20), a seamless process which a condition such as AMD patently disrupts.

7.2.2. Projecting forwards and looking backwards: temporal oscillations in AMD experience

The PhD findings thus illustrate a stark sense of disruption and unsettling of the sense-of-self caused by AMD, consistent with previous phenomenological research on chronic illness and impairment. Perhaps more unique to AMD was the way in which certain participants perceived the condition as bound up with the broader ageing process and, in the case of Ruby particularly, with a sense of finitude, as she described how her eye would continue to "deteriorate, just like other parts of the body… all… deteriorate." Arguably this represents the embodied dimension of the interpretative repertoire identified in the FDA which constructed AMD as a consequence of biological age, and a harbinger of decline. This equivalence between ageing and being-towards-death was never made explicit, but was indicated – especially if adopting a more 'suspicious' interpretation - by participants like Denise discussing how she struggled to know what daily challenges were attributable to AMD specifically or ageing more generally, in the context of an overall feeling of "slowing down". Furthermore, for participants such as Ruby, the incurable nature of AMD meant that the "chronicity" (Andersen et al., 2021) of the condition loomed large, when she reflected on the lack of a "light at the end of the tunnel", the absence of any promise of restitution (Frank, 1998). By contrast, in response to the inherent uncertainty of AMD progression amid other experiences of ageing, some participants exhorted the need to "live every day as if it's your last" (Andrew) or "live each day as it comes" (Sylvia), a stoic and in many ways optimistic mentality, but one that also implicitly echoes Beauvoir's (1970) idea of "the closure of the futural horizon" (Heinämaa, 2014, p.180) amid the process of ageing.

The way in which participants contextualised AMD within the broader temporal structure of ageing exemplified how their experiences and meaning-making around AMD were constantly in dialogue with their pasts and their imagined futures. As Toombs (1990, p.238) states, drawing on Husserl to analyse the temporality of chronic illness:

> "The present 'fact' of illness represents not so much an isolated instant along a given time-line as it does a present-now, which must be considered against the horizons of past and future."

Indeed, Ralph emphasised the significance of these 'horizons' of the future when he stated, "It's hard because… [AMD] is not, 'What is', it's what you imagine it to be." The complex interweaving of temporal perspectives was perhaps most clearly illustrated by Marianne, whose father had lived with AMD for two decades and who was herself living with early-stage AMD, and discussed AMD as an intergenerational phenomenon. Marianne's father's experience represented a potential blueprint of what she expected might happen to her, for example when discussing how she would likely begin to struggle with small print in future. In her account, there was a dual sense that she was simultaneously apprehensive and on alert for changes, but also trying hard to avoid focusing on potential future possibilities in light of the unpredictable, highly individualised disease course in AMD. Not only did Marianne voice uncertainties about her future vision, but also regarding "whether, or how well, I will cope" with the practical changes. At the same time, she drew hope and reassurance from the experiences of others she knew who lived with AMD, demonstrating how her past encounters with the condition helped provide positive exemplars for her future being-in-the-world with AMD. Therefore, for a participant like Marianne, AMD was not the "site of no future" (Kafer, 2013, p.3) that often featured in constructions of AMD identified in the FDA. For other participants, such as Ruby and Sandra, AMD had sometimes seemed to presage "no future" and caused them to have "terrible", and in Ruby's case explicitly suicidal, thoughts about what could happen to them. However, for both Ruby and Sandra, these feelings had shifted with time, as both struggled to accept life with AMD even though they had simultaneously learned to live with the condition in the absence of any alternative. Yet often these experiential shifts at a more 'bird's eye' level, that the participant could analyse as distinct phases of their response to AMD, ran in parallel to more frequent oscillations in mood over time at the day-to-day level (discussed in Section 7.2.4 below with regards to the 'hope-despair continuum').

7.2.3. Embodied and socially contingent limitations to activities

As Burton found (e.g. 2013, p.167), not only did AMD cause certain activities to become off limits but also changed the nature of other activities, which were still doable, but no longer enjoyable, meaningful or satisfying in the same way. This came across strikingly when Rose stated that she "can't even walk", then immediately correcting herself to say, "Well I can *walk,* but I mean I can't walk out on my own […] so I can't do anything spontaneously". Rose's discussion of challenges with walking was a stark illustration of what

Lourens and Swartz (2016, p.243) refer to as the “narrowing of possibilities that changes one’s being-in-the-world” when one is unable to access activities as before; in line with Merleau-Ponty's (1962, p.188) notion that the body affords a “whole field of possibilities” for human experience which may “collapse” in some cases of impairment. To some extent, Rose’s perspective, with its emphasis on her preference to “walk out on my own” aligns with participants in McGrath et al.'s (2016) study, who tended to restrict their activities if they would need to ‘depend’ on others to continue accessing an activity. At a more embodied, phenomenological level of analysis however, it was clear that Rose missed the very feeling of being able to instantly act on her whims and go for walks whenever she wanted to.

This phenomenological perspective contrasts with the FDA, where I critiqued the literature’s emphasis on what the body with AMD can and cannot ‘do’, often conceived in a purely physical, functional sense. Indeed, Richardson and Abrams (2020) critique the discursive construction of ‘activities of daily living’, as reproducing a restrictive, normative and overwhelmingly functional conceptualisation of wellbeing in daily life. Certain participants were implicitly aware of the socially contingent rather than inherent, given nature of their difficulties, locating the problem in society rather than in their “body-gone-wrong” (Michalko, 2002); for example, when Louis, Marianne and Suzanne discussed issues with reading small print. Nonetheless, participants clearly voiced that in progressive vision loss, there can be a particularly painful, embodied sense of experiencing their vision changing and deteriorating. This came across when Denise discussed her increasing difficulties discerning her husband’s facial features, or recognising the faces of acquaintances, both of which upset her and also served as “a reminder that things aren’t as good as they used to be”. Furthermore, Pearl discussed trying to recognise faces on the television by turning her head and using her peripheral vision, but concluded that “it doesn’t *mean* as much as when I see it with my central vision”. Therefore, while participants found manifold ways around challenges, certain limitations remained fundamentally irremediable, an example of how “illnesses come between the body and the world” (Bergoffen, 2014, p.133), undermining what was previously a more direct embodied engagement. Specifically in the case of vision loss, it may feel as though a distance opens up between the person and their environment, an environment which was previously immediately accessible through sight. A person with vision loss may instead have to make more intentional efforts to “go to the environment in order to ‘see it’” (Michalko, 2002, p.124), and this may fundamentally alter the meaning and texture of experiences.

Thus overall, the participants recognised that some of their difficulties stemmed from inaccessible practices and norms in the world, but there were also profoundly upsetting or troubling embodied experiences of limitation that were much more purely attributable to their changing sight. These findings strongly support the relevance of a critical disability studies approach (e.g. Crow, 1996), which recognises the need for removal of disabling barriers at a societal and structural level, but also acknowledges the suffering attributable to the bodily experience of impairment.

7.2.4. Learning to live with AMD and navigating the hope-despair continuum

In line with the repertoire identified in the FDA of “you live and learn” (e.g. in Dahlin-Ivanoff et al., 1996), a common shared experience among the participants was the determination to learn to live with AMD. In line with the differing temporal horizons of the participants, living with AMD for varying periods of time, this experience could be more past-oriented, such as Ralph and Ruby reflecting back on the process of learning to adapt to AMD over decades; or more future-oriented, in the case of participants like Rose and Sandra who were still experiencing many difficulties and had significant worries about future vision loss, but felt that learning to “find ways round” in daily life was the only option in the absence of a cure. This ongoing, evolving process of finding alternative ways to complete daily tasks as the body changes has been noted in other studies of chronic illness and impairment, such as Toombs’ phenomenological exploration of loss of mobility in multiple sclerosis, where “one has to learn *and relearn* how to negotiate the surrounding world on an ongoing basis” (Toombs, 1995, p.13). Aligning with Toombs’ perspective that “‘I can do it again’ can never be taken-for-granted”, among participants in the present study, the work and effort to adapt was often unceasing. There were few examples of dramatic epiphanies or metamorphoses,[55] and more often a hard-earned process requiring determined, resolute and protracted effort (“plodding along” in Denise’s words, or “sink or swim” in the words of both Sylvia and Ruby). Indeed, even participants such as Ruby, who voiced having “turned

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[55] Ralph was an exception, who did term the turning point in his journey a “metamorphosis, if you want to call it that...”

her life around" when she started volunteering for the Macular Society still simultaneously voiced "never really coming to terms with losing my sight" after 26 years living with AMD, demonstrating a kind of fundamentally irresolvable tension between acceptance and struggling. Interestingly, despite this tension and the non-linear trajectory of her experience, Ruby (among other participants) compared the emotional response to AMD with the five-stage Kübler-Ross model of grieving and arriving at acceptance (Kübler-Ross & Kessler, 2014). Alongside accounts of difficult events or emotional states, participants also used humour to reframe or diffuse potentially painful experiences, a form of stoical "troubles resistance"[56] (Jefferson, 1984, p.351) that has been noted in other narratives of vision loss (Burton et al., 2015; Stampp et al., 2024) and ageing more broadly (Matsumoto, 2009).

Linking to the issue of temporalities discussed above, participants' experiences of AMD emerged as highly non-linear, which meant there was rarely a pure sense of the "loss of self" described by Charmaz (1983) or narratives entirely defined by chaos (Frank, 1998).[xvii] Instead, there were strong echoes of Ferrey et al.'s (2024, p.6) findings that adaptation to visual impairment is often a non-linear process, and that "complete adaptation may take some time, and may not ever be completely achieved". Ferrey and colleagues also reflect how the progressive and fluctuating nature of vision loss complicates the process of 'coming to terms with' a new identity; this tendency was borne out among participants in my study who could experience dramatic day-to-day changes in their vision and functioning. Ferrey and colleagues draw on Yoshida's (1993) metaphor of the pendulum of the self, to express the sense of dynamic, constantly shifting movement between a disabled and non-disabled identity depending on time and context.

Somewhat analogous to the metaphor of the pendulum, I interpreted certain participants' experiences as oscillating dynamically between a sense of hope and despair, often picturing in my mind an old-fashioned balance scale that was in constant, subtle motion. Yoshida's (1993) pendulum metaphor applied to the process of reconstructing identity following traumatic spinal cord injury; in contrast, the hope-despair continuum that I interpreted to be a significant feature of many of the participants' accounts related more to

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[56] "Troubles resistance" is defined by Jefferson, in the context of conversation analysis, as deployment of humour or laughter when discussing difficult situations, which functions to show that "although there is this trouble, it is not getting the better" of the speaker, who is "managing... in good spirits and in a position to take the trouble lightly" (Jefferson, 1984, p.351).

the dynamic of ‘mood’ among participants, rather than identity, with regards to their daily lived experience of AMD. ‘Mood’ here not only refers to the emotional quality of the experiences, but also has a Heideggerian sense (*Stimmung*) (Withy, 2021), in terms of thinking about what participants chose to ‘tune into’ and how this affected the way in which they interpreted their experiences. A good example was in Hannah’s discussion of initially finding it “very annoying” when she misses or misinterprets words and numbers when reading, but then finding a way to laugh about it: she stated “you do turn it around, but it takes time, to train yourself to do it”. This exemplified the way in which participants like Hannah were constantly moving between varied emotional states over short intervals of time, depending on the combination of events they were experiencing and the perspective they adopted in response. In Hannah’s example, part of the learning to live with AMD involved making the mental effort to reappraise frustrating, difficult situations (that could potentially draw her into rumination and despair), and instead adopting a more hopeful, humorous or self-compassionate approach.

Considering the hope end of the continuum, the existentialist philosopher Gabriel Marcel described hope as “the act by which this temptation [to despair] is actively or victoriously overcome” (Marcel, 1951, p.36). Hope for Marcel is a way of being-in-the-world, a disposition towards finding something worthwhile in our reality and other people, and - relevant to the discussion of temporality - a refusal to see the future as inextricably dictated by the circumstances of one’s past and present (Stratton-Lake, 1998). Marcel’s conceptualisation of hope aligns with the emphasis shared by Hannah and other participants on actively directing their attention and efforts to avoid falling into despair, whether through sheer practicality and pragmatism, humour, or faith and spiritual beliefs. Furthermore, Ruby’s emphasis on “working for the Earth, working for other people” and her volunteering with the Macular Society as a way to contribute to that mission reflects Marcel’s argument that hope is constituted intersubjectively in concert with others, “through a we and for a we” (Marcel, 1973, p.143). There was a sense among several participants that navigating this hope-despair continuum, often in the presence of supportive others who helped provide a form of safety net, could be imagined as a kind of walk along the edge of a precipice, with participants able to catch glimpses of the abyss beneath, but proactively drawing themselves back from the edge through active coping strategies and avoiding rumination about the fundamentally uncertain trajectory of future vision loss.

7.2.5. Fostering an intentional commitment to a new phase of life

It is challenging to generalise about the overall emotional journey participants underwent, with significant inter-individual differences in their response to AMD but also *intra*-individual differences, often oscillating dynamically between different emotional responses. However, if seeking to tentatively generalise about what helped participants actively inhabit a place of hope and turn away from despair, there appeared to be a sense of empowerment in first accepting the irremediable limitations of AMD, and then defining projects and strategies over which they retained control. To some extent, this fits with an existentialist emphasis on working within the limitations of one's 'facticity', the unchangeable givens of one's condition, but within those limits embracing the available freedom to make choices and pursue one's own meaningful projects (Cooper, 2015, p.117). Andrew, Sylvia, Ralph and Suzanne explicitly voiced their commitment to this mindset in different ways, united by a tendency to matter-of-factly face up to the painful losses entailed by AMD and to pursue what remained within their reach. As a particularly precise example, Ralph could identify four specific activities he was no longer able to do since developing vision impairment; while he had made changes to certain activities (such as using a tandem bicycle, and needing more time to undertake certain activities like bicycle repairs)[57], these allowed for continuation of the activities in a way that continued to affirm his sense-of-self. A parallel was also evident in Sylvia adapting her style of painting from detailed portraiture to using resin, which felt organic and liberating even as it entailed accepting loss. This change felt congruent with Sylvia's identity as an artist, and represented a notable counterpoint to the binary construction of a 'before versus after AMD self' identified in the FDA. In comparison to quotes such as "This isn't me… I'm a very visual person" (Mogk, 2008, p.588),

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[57] Scholars exploring the phenomenology of disability discuss how the experience of time changes for people with disabilities, for example with previously mundane tasks coming to require "an untoward amount of time" (Toombs, 1995, p.19). Scholars such as Kafer (2013, p.26) use the term "crip time" to encapsulate the way in which the facts of one's body but also ableist barriers in the environment may come together to slow down the time it takes disabled people to accomplish a task or get somewhere. Importantly, crip time is also "a challenge to normative and normalizing expectations of pace and scheduling" (2013, p.27).

Sylvia implied a sadness at no longer being able to pursue certain artistic pursuits, such as her art group, but still continued to affirm her identity as an artist by finding a new medium. Andrew similarly voiced missing the sports that had been an important part of his life before vision loss, but treated AMD as a “new phase of life”, whereby he resolutely replaced activities that he had had to give up with other pastimes (aligning with the ‘getting on with life’ theme developed in Burton’s (2013) IPA study).

These latter participants’ perspectives arguably provide a concrete example of navigating the existential tension between the unalterable limitations engendered by AMD, and the freedom and possibilities remaining available to them which provided a route for continuing to live in a way that felt congruent and authentic. Drawing on Karl Jaspers, Van Deurzen (2009, p.49) writes, “I become authentic in as much as I am willing to face up to my freedom and possibility as well as to my limitations and my loneliness”, and several participants illustrated this tendency to accept what was now ‘off-limits’ and then devote their energies to the possibilities that remained. Notably, participants generally voiced taking time to arrive at this stance, often after experiencing intense emotional upheavals, and several participants were conscious that this was not a mode they could immediately access, amid the anxiety following diagnosis or significant setbacks (such as stopping driving). To consider Arthur Frank’s typology of illness narratives, such a stance arguably aligns with the quest narrative, accepting what has been lost and looking “not to restitution, but rather to what can be reclaimed of life” (1998, p.204).[58] Aspects of the quest narrative in the accounts of certain participants such as Sylvia and Ralph - who had experienced deep despair but now arrived at a position of greater equanimity - somewhat echoed the process of “post-traumatic growth” that has been explored in adapting to AMD (Tanner et al., 2022). Tanner and colleagues suggest that the process of “intrusive rumination”, associated with depressive symptoms (akin to being in the ‘abyss’ discussed above), can eventually pave the way to a process of “deliberate rumination”, a calmer process that is linked to a focus on making positive changes. Participants in my study were largely euphemistic, and never dramatised or simplified the difficult, hard-earned, often frustrating and onerous process of adaptation, nor explicitly framed the process as one of personal ‘growth’ or ‘transformation’.

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[58] Notably, among the participants in the present study, chaos and quest narratives often co-existed or oscillated dynamically, rather than being fixed or all-encompassing modes of sense-making.

Yet they did make clear that facing the facts of their limitations, and intentionally working to focus on what remained possible and available to them, helped them in coming to terms with vision loss.

7.3. AMD in relational and social life

This section considers the findings regarding how people with AMD experienced the condition within the context of their relationships with others and broader social life, aiming to consider the ways in which AMD shapes being-with-others as an inseparable dimension of being-in-the-world. Participants often moved along a continuum of feeling "alone but not alone" in their journey of adapting to AMD. They could feel supported and accompanied in their AMD experience, whilst also feeling fundamentally alone in it at a more embodied and affective level. In line with the 'alone but not alone' IPA sub-theme (4.1), many participants voiced having to summon their own resources to avoid falling into despair, but also acknowledged that relatives and friends could act as a kind of safety net, a buffer between themselves and the abyss of despair.

I was particularly interested throughout the thesis in how AMD might shape, and be shaped by, the dynamics of close relationships, in response to this being an understudied area in qualitative research on age-related vision loss (Lehane et al., 2017). However, participants discussed how AMD changed their patterns of 'relating' in a broader sense, beyond partners and families to also discuss how AMD affected their way of engaging with other people in society at large. Here, the findings from the FDA also have relevance, in considering how certain normative discourses around ageing, disability and vision might have implications for the subjectivity of the participants.

7.3.1. Moving between independence, dependence and interdependence

The FDA illustrated how research participants in previous qualitative studies largely constructed AMD as the end of or the total loss of independence.[59] Although I did not

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[59] Burton et al.'s (2015) case study involving a couple where both members were living with AMD is one of the few qualitative studies in AMD that explicitly recognises the possibility of maintaining a level of autonomy in terms of decision-making even while being physically and emotionally (inter-)dependent on others.

analyse my interview data with a discourse analytic approach, it is worth noting that such a construction was occasionally echoed by participants in my study, such as Suzanne stating, “It’s very hard to give up your… independence, your, you know, just your… your ability to do anything”. As in the FDA, Suzanne’s phrasing constructs independence as an all-or-nothing phenomenon, suggesting that as soon as there are constraints on one’s physical, functional “ability to do anything” then independence is “given up”. From a critical perspective, we can consider the extreme valorisation of independence (defined in narrow functional terms) above values such as interdependence and connectedness to others as socially constructed. Furthermore, as McGrath et al. (2016) convincingly argue, in certain cases the very pursuit of independence (and avoidance of scenarios potentially threatening ‘dependence’) may limit the activities and social participation of people with AMD. In contrast, in the interpretative phenomenological studies, it was rare for participants to frame independence as an all-or-nothing phenomenon.[60] A good example was Ruby asserting her continued identity as a “very, very independent” person; while also accepting that, especially in the context of the COVID-19 pandemic, “I’ve gotta rely a bit more on other people” and learn to ask for help. Ralph similarly understood, and had previously experienced, feelings of frustration and shame at being unable to achieve certain tasks alone, and accepted the need to “give over a degree of control to others”, seeing this process as a kind of social negotiation or “transaction”.[xviii]

Participants voiced an existential tension between wishing for the freedom to act fully self-sufficiently, and the inevitable limitations arising from both the body and society which might then make help from others necessary. The challenge of accepting limitations on freedom arguably came across most strongly when participants such as Sandra and Sylvia discussed giving up driving; both evoked the sheer joy they felt in the activity itself, but above all the sense of freedom to, in Sandra’s words, “do exactly what you wanna do” and not “rely on someone else to take you”. Sandra explicitly equated the car with “independence”, and a strong sense of the loss associated with stopping driving permeated Sandra’s account, even though she had supportive relatives. This grief felt profound and real

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[60] It may be that these more extreme, binary constructions of independence as an ‘all-or-nothing’ phenomenon were particularly stark in the decontextualised extracts. In contrast, in the IPA, I had the full context of the participant’s overall account which allowed for more nuanced exploration of meaning-making around independence in all its complexity.

to me during our interview and the analysis, even while I was holding in my mind notions from the FDA of the social construction of the car as the guarantor of self-reliance and freedom (Hagman, 2003). So even as one can regard the valorisation of independence as a potentially limiting, counterproductive social construct for people with AMD, one can also hold space for the participants' profound feelings of loss at the limitation of no longer driving, feeling that their freedom to act had become somewhat compromised by reliance on others.

While driving seemed to represent a normative, objective marker of 'independence', how participants experienced and enacted in/dependence in other domains of everyday life was highly idiosyncratic within their specific relational or environmental context. For example, Sylvia and Andrew's experience when discussing their home and local area attested to the independence they felt thanks to public transport or rideshares provided by a local charity, which allowed them to pursue their activities "under [their] own steam" as Sylvia stated. However, Sylvia felt that relying on her partner to drive her would equate to "depending on him". In contrast, for participants like Denise and Andrew who seemed to experience AMD as a "we" together with their spouse, there was not necessarily a sense that accepting help from their spouse equated to 'dependence'. Here, the experiences of Andrew and Denise may be considered a form of "relational autonomy" (Mackenzie & Stoljar, 2000) in action, moving away from binary notions of dependence and independence. A relational autonomy perspective recognises that "our practical identities and value commitments are constituted in and by our interpersonal relationships and social environment" (Mackenzie, 2008, p.519), and therefore that relationships and social structures variously enable - or place limits on - the exercise of an individual's autonomy. The concept also makes space for recognising that self-determination, agency and freedom to make choices, while never truly limitless, can still be exercised while depending physically on others; thus allowing for autonomy while "accepting welcome assistance and acknowledging interdependence" (Stephens & Breheny, 2018, p.119).[xix] Therefore, this view suggests not only that all individuals are fundamentally in relation to and enmeshed with each other, but also that possibilities for self-determination may be influenced more by relational and social conditions than by physical, functional self-sufficiency (Kittay, 2011). Ralph in particular demonstrated the relevance of relational autonomy when describing asking people for help to read the train times on the displays at train stations, or encouraging his friends to wave enthusiastically when he enters the pub. By “negotiating”, as he expressed it, with others for help, he continued to be able to access and be included in meaningful everyday activities. Similarly, relational autonomy makes space for experiences such as Howard’s, who perceived himself and his wife (herself living with chronic illness) as bringing different contributions to a partnership of care, as “two damaged halves… making a whole”.

Despite the theoretical value of a relational autonomy lens, the study findings suggest that it may be highly challenging for people with AMD to cope with the perceived loss of independence and the consequent need to (re-)negotiate autonomy, after living most of their lives subject to prevailing discourses that valorise narrow ideals of physical independence and self-sufficiency. Indeed, the FDA highlighted how deeply discourses of independence are embedded within notions of living and ageing well across contexts. Furthermore, in the UK context, this global tendency may interact with the hegemony of the stoical, self-reliant “stiff upper lip” approach to life that dominated British society and culture in the first half of the twentieth century (Capstick & Clegg, 2013), when almost all the participants were born. Such discourses arguably worked to compound the existential challenge the participants in my interviews faced with accepting that their independence in the physical, embodied sense had changed, even as they simultaneously accepted help from others and enacted forms of interdependence.

7.3.2. The challenge of intersubjectivity, connectedness and feeling understood

While the sub-section above (7.3.1) considered how AMD may shape processes of interdependence with others, this sub-section considers the findings around how AMD influenced participants’ feelings of connection and intersubjectivity with others, and conversely the feelings of loneliness and isolation that some participants attributed to AMD. Participants could experience both these states at different times and in different contexts. At the most fundamental corporeal level, vision loss from AMD could impede recognising or discerning the facial expressions and features of loved ones, or picking up on the normative, non-verbal cues of social interaction. Certain participants, particularly Kate, echoed concerns voiced by participants in other studies (Burton, 2013; Lane et al., 2019) about being perceived as rude or standoffish by acquaintances; and Kate voiced the temptation “to actually want to become a recluse" which she was actively working to stave off. To varying degrees, participants voiced challenges caused by vision loss in accessing certain activities that were integral to their social life. As found by Rudman et al. (2016) in their study of Canadian older adults with vision loss, certain modifiable factors – such as lack of accessible public transport options – seemed to also affect the decision-making of participants in my study regarding whether to continue attending certain social groups. However, arguably more salient in participants' accounts was the sense that the activity would not feel the same as it did before, even if they could still attend; for example, when Rose discussed not being able to see the speaker at her lunch group, or Sylvia struggling to see the teacher's demonstration in her art class. When these challenges arose, both participants evoked an emerging gulf between themselves and the other attendees – Rose strikingly discussing "shrink[ing] into [her]self" – that no extrinsic help or accommodations could necessarily remedy. While certain participants perceived ceasing certain social activities altogether as the most viable option, others like Suzanne discussed a kind of "scaling back" (Rudman et al., 2016), for example trying to avoid playing against difficult opponents in bridge and thereby avoid becoming a potential "nuisance" to her bridge partner.

For many participants, close relationships and friendships were a vital element of the safety net that cushioned them from falling into a state of irremediable despair and isolation. That said, for other participants, a palpable sense of loneliness emerged from the gulf they perceived to exist between their own first-hand experience of AMD and others' attempts to understand it. This brought to mind the existential tension between our *being-with* others (Mitsein) and each individual's fundamental aloneness, encapsulated by Cooper (2015, p.172):

> "However empathic or intuitive we may be, there is never the possibility of fully experiencing the experiencing of the other – it will always lie beyond our grasp."

This gulf was most keenly evoked in Rose's account, discussing how her husband, although patient and supportive, could not truly comprehend what she can and cannot see. This compounded her sense of loneliness, and feeling fundamentally separate from others. Rose was perhaps the only participant whose experiences aligned with the stark sense of loneliness evoked by participants with AMD in the diary study by Stanford et al. (2009), which included statements such as “I live in a sad world of my own”.[61] This painful, embodied sense of feeling fundamentally separate and othered exists in a disablist social context, whereby impairments such as vision loss are configured as a departure from the ‘world of the normal’, where the non-impaired biology represents the only legitimate way of being in the world” (Michalko, 2002, p.61). Michalko argues that a lifetime’s exposure to the biomedical discourse of impairment as “the body-gone-wrong” compounds the individual’s sense of suffering in isolation, and which then makes it harder to “experience suffering as a collective or intersubjective matter” (ibid).

Indeed, participants both in the FDA and the IPA study framed AMD as unfamiliar and unknown when compared to other eye conditions, and Ralph voiced feeling at one stage as if he were “the only one person in the world who had it”. In contrast, Ralph compared later finding the right group to “being immersed in a warm bath”, evoking a sense of finding a “homelike” place and helping to remedy the sense of “unhomelikeness” (Svenaeus, 2011) initially occasioned by AMD. There was a relative consensus among participants that speaking with other people who had experienced AMD or other sight loss conditions first-hand was crucial to overcome this sense of alienation, as well as to receive practical information and tips on coping with sight loss. That said, there was an implicit sense from certain participants – aligning with Michalko’s argument above that disablism can impede intersubjectivity – that they did not necessarily want to connect with others whom they perceived to be in a worse state and as potentially foreshadowing their future trajectory, as documented in Taylor et al.'s (2020) study on experiences of people with dry AMD. This further underlines the challenge in forging a collective sense of identity among people with AMD: not only as a condition that develops late in life among people who have previously been sighted and thus “subjected to a daily diet of the personal tragedy model of visual impairment” (French & Swain, 2004, p.35); but also as a condition that progresses heterogeneously with considerable divergence in the extent of sight loss and the individual’s response (McCloud et al., 2014).

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[61] It is important to note that Stanford et al. (2009) recruited participants who had been newly referred to an NHS Low Vision Clinic. In contrast, participants in my study were recruited through the Macular Society, and many of them had lived with AMD for a long time, both factors that might mean participants in my study had had more exposure to other people living with AMD, that might have lessened their sense of loneliness and alienation. Recruitment issues are considered in more detail in Chapter 8, p.314.

The IPA findings also suggest that a key contributing factor to the challenge of being understood by others was the difficulty of putting their embodied experience of AMD into words, an underexplored issue in the existing literature. The elusive, shifting nature of participants' everyday visual symptoms and experiences appeared to add to the challenge of being understood by others, such that the experience could be intersubjectively shared. Sometimes this came across when participants were describing their visual difficulties, with short phrases such as "that's a way of putting it" or "for want of a better explanation" implying that language could only go so far to capture the sensory experience of their changing vision. For some participants such as Suzanne, the uncanny, "very odd" nature of certain visual experiences – such as difficulties seeing the colour blue - implicitly seemed to be linked to a potential feeling of isolation and feeling like the 'odd-one-out'; especially when visual symptoms extended beyond central vision loss, the hallmark of AMD. Clinical research has helped to establish that AMD results in a much larger array of symptoms than simply reduced central vision (Taylor et al., 2018), to encompass blurring, distortion, "shimmering", specks, and difficulties with colour vision. Therefore, the already challenging task (from an interpretative phenomenological perspective) of articulating one's embodied experiences and broader lifeworld in language (Todres & Galvin, 2008) arguably entails an additional level of complication in the case of AMD. Participants noted the temporal and contextual variation in their visual experience, with factors such as the time of day, the relative un/familiarity of their surroundings or the task, or their energy levels, affecting what they could and could not see. Indeed, clinical research demonstrates that earlier-stage AMD may hardly affect vision in good lighting conditions, but the symptoms become pronounced in low lighting conditions (Terheyden et al., 2023). This contextual or temporal variation in participants' visual experience could make it difficult for others to understand what might be visually challenging or not. As Hannah expressed it, discussing the day-to-day variation in her vision, "That is a puzzle to me, never mind anybody else that doesn't have the condition." It was therefore sometimes challenging for participants to firmly categorise, in their own mind and to others, what visual activities were still possible versus off-limits. In line with Gadamer's (1960/1990) notion that language discloses and mediates our being-in-the-world, negotiating the effects of AMD in the social world and achieving understanding from others required extensive, ongoing dialogue. Such a dialogue required effort on the part of the person with AMD to disclose an often confusing, shifting reality, but could also be the site of new understandings and humour, in line with Gadamer's notion that it is when language breaks down and "words fail" that new interpretations of experience can begin (Risser, 2019). Denise's experience was a good example of the ways in which these uncanny experiences could come to be shared with others, when talking about her visual hallucinations of the postman wearing a technicolour skirt and stating that "**we** just laugh" about it, signalling that her husband – although he cannot directly access the experience – is included in the joke.

Alongside these changes in relating to others that were directly attributable to AMD, certain participants, particularly Ruby and Pearl, implied that AMD interacted with a broader sense of "existential loneliness" (Carr & Fang, 2023), in the broader context of ageing, other comorbid health conditions, and the COVID-19 pandemic. Such existential loneliness, a distinct feeling of separateness and isolation from others, was particularly linked to bereavements that participants had suffered, as well as to the COVID-19 lockdown for certain participants. The idiosyncratic and highly contextual nature of loneliness was illustrated in how participants discussed the pandemic: for Pearl, it compounded her sense of loneliness; while by contrast, Rose came to feel that others were now "in the same boat" as her. Rose's perspective aligns with qualitative findings suggesting that older adults already experiencing loneliness pre-pandemic imbued their loneliness during the lockdown with new meaning, as responsible, necessary and a shared experience with others (Bundy et al., 2021). There were also notable individual differences regarding how the same activity could be a route to connectedness or, on the contrary, compound loneliness further. For example, Andrew discussed enjoying listening to talking books alongside his wife Wendy, while Pearl voiced finding the experience of listening to talking books, "so lonely", and suggested that the talking book voice only intensified awareness of her isolation. The participants' divergent experiences reinforce the importance of acknowledging the potential loneliness and loss of connection that may accompany ageing and impairment, even as one seeks to avoid the *a priori* assumption these experiences as inherently negative or tragic (Gilleard, 2018).

7.3.3. Moving between subjectivity and objectification: the gaze, stigma and disclosure

The thesis findings at points illustrated the stigma surrounding age-related vision loss, which Burton (2013) discussed extensively, drawing on Goffman's (1963) concept of spoiled identities. Participants in Burton’s (2013) study were often negotiating whether, when and how to disclose their potentially “discreditable” identity as visually impaired, which (given the non-visible nature of AMD-related sight loss) may only be perceived by others if actively revealed through, for example, the use of a white cane. Andrew and Sandra both attested to rude or impatient behaviour they had experienced in public when others assumed they had good vision; although Andrew noted that when he carried a white cane, other people were far more patient. At the time of the interview, Sandra appeared to be grappling with the question of whether to use a white cane to signify to others that “I’m not blind, but I can’t see very well”. This sense of being in a liminal state between binary poles of healthy versus impaired, and the consequent dilemma around disclosing vision loss, aligns with Garland-Thomson's (2017, p.114) argument that the experience of disability often involves “classification dilemmas [and] ambiguous status […] Within this liminal space, the disabled person must constitute something akin to identity”. Similarly, Ferrey et al.'s (2024) study involving participants of different ages and different forms of visual impairment described the phenomenon of “self-presentation work” in which participants were engaged, often seeking to ‘pass’ as having good vision and noting the effort this requires. Relevant to Sandra’s experience of rude and impatient behaviour from others in public spaces, Reeve (2019) notes that ‘passing’ as non-impaired means conforming to the conventional norms of behaviour, time-efficiency (see Footnote 57, p.252) and stamina, which could clearly be challenging for participants in my study such as when negotiating public transport. Hughes (2012, p.28) suggests that the “tyranny of normalcy” and ableism in society encourages concealment of non-visible disabilities. Hughes also suggests that the “ontological bluff” (ibid.) of passing can be profoundly precarious, carrying not only the constant ‘risk’ of disability status being revealed (Reeve, 2019) but also the risk of internalisation of feelings of shame around disability.[xx] Indeed, Andrew’s frustration with people refusing assistive devices so that they could ‘pass’ as sighted implied his belief that their reluctance to seek support was denying them the help that had enabled him—and could potentially enable them—to live well with vision loss.

Nonetheless, the findings suggested that participants like Ralph and Sylvia, who used visual aids and were open with others about their vision loss, could still see vision loss as a stigmatised identity. Even though it could be inconvenient when others forgot about their vision loss, they sometimes appreciated being perceived by others as ‘normal’, aligning with Michalko's (2002, p.81) description of experiencing the “seduction of the ‘normal world’ […] its lure of ordinary life”. Indeed, when discussing her willingness to be open about AMD, Sylvia compared it to having “bad legs or whatever”, equating AMD to a common and squarely physical form of impairment, that arguably contrasts with the non-visible, perception-altering phenomenon of vision loss. Although vision loss has been shown to be among one of the less stigmatised health conditions (Deal, 2003), it may be the case that Sylvia sees vision loss as a more stigmatised state than bad legs which might be seen to be a feature of ‘typical’ ageing, the kind of impairment that is “institutionalised [within] the standard model of the lifecourse” (Grenier et al., 2016). Indeed, the well-documented fears that sighted people feel around vision loss could theoretically add to the sense of stigma, as individuals want to distance themselves from association with what Hunt (1966, p.158) refers to in the context of disability stigma as “the shadow side of life”. This points to the value of raising awareness of real, nuanced experiences of vision loss, which do not deny the challenges, but also avoid reproducing distorted and fearmongering social representations of vision loss and disability more broadly (Shakespeare, 2013).

Even while dilemmas around disclosure of vision loss appeared to be influenced by negative discourses and social representations of disability and ageing, participants also attested to the difficult embodied experience of becoming objectified by others due to their visual impairment. For some participants such as Sandra, this feeling of being configured as an object rather than subject seemed to be linked to her self-perception of being physically dependent on others, for example when being driven around by others, which felt akin to a relinquishing of agency. Meanwhile, Hannah’s experience attested to how the experience of “dys-appearing” (Leder, 1990) and objectifying one’s suddenly foreign, alien and vulnerable body was also bound up with concerns about being objectified by others. Her self-conscious description of herself “looking like one of these bag ladies who fumble about” suggested the potential for some people with AMD like Hannah to turn the (presumed) stigmatising, objectifying gaze of others against the self. This example affirms Reeve's (2019) argument that those who acquire impairment in later life may have to deal with a complicated internal shift from ‘normal’ to ‘Other’, requiring the person to work through internalised stereotypes, and potentially dealing with the guilt of how they might have perceived such individuals previously.[xxi] Hannah’s experience encapsulated the intense discomfort that can come with being caught up in other people’s assumptions and stereotypes, particularly in her case around ageing. As previously noted (p.18-19), existentialist philosophers including Beauvoir (1970/1977) and Sartre (1946/1989) have considered how the “Look” or “gaze” of others is always threatening to turn us into an object (Cooper, 2015, p.192).[xxii] Furthermore, in the context of ageing (and one might also apply this to vision loss), Beauvoir discussed the layered process that may occur, of becoming both other to oneself and also othered by society (Gilleard, 2022). Notably, participants could have this experience of “being-for-the-Other” (Sartre, 1943), the object of an othering gaze, through seemingly ‘positive’ attributions which were rooted in stereotypes of what vision loss ‘should’ look like, such as when told by others that they “looked normal”. This exemplifies “the disbelieving gaze” (Samuels, 2003) of others in response to non-visible disabilities like vision loss, particularly when symptoms may fluctuate over time and depending on context. Such incidences further signal the need for improving awareness of the complex spectrum of effects that vision loss can entail, moving away from dominant, binary framings of vision loss or ‘blindness’ as the polar opposite of sightedness (Bolt, 2005).

7.4. AMD in the socio-material environment

The section above focused on how AMD shapes dynamics of close relationships and social interactions. This next section turns to consider the ways in which the broader social and material environment around the person may shape their experience of AMD.

7.4.1. Differences in socio-material circumstances shaping experience

The focus on the lifeworlds of people with AMD that predominated in this thesis did not necessary allow for detailed study of the participants’ demographic and socioeconomic conditions. However, there were implicit suggestions that the material (economic) and socio-demographic (e.g. marital status, living situation, urban versus rural) circumstances in which participants found themselves differentially affected their response to AMD. Kleinschmidt's

(1999) study of participants who perceived themselves to have successfully adapted to AMD noted the importance of what could be summarised as social capital – a robust network of personal support from relatives and friends, as well as healthcare professionals – in adaptation. Both theoretically speaking and as illustrated by my data, there is a clear interplay between participants' subjective experience of AMD, and their material and/or socio-demographic conditions. Charmaz (1995, p.670) notes that in the face of chronic illness, "money and help" fundamentally open up more freedom of choice in the activities individuals pursue, which in turn feed back positively into their sense of identity and self-concept. In *The Coming of Age,* Beauvoir (1970/1972) also emphasised that the possibility of "flourishing" in older age is contingent not only on bodily conditions, but also crucially on "worldly conditions" including wealth and social capital (Svenaeus, 2023). Participants in my study came from varied class and professional backgrounds, and tended to note the good fortune or challenge of their material circumstances in specific, idiosyncratic ways. For example, availability of public transport, or mobility assistance, allowed participants like Andrew and Sylvia to remain engaged in leisure and social activities beyond the more immediate surroundings of their local area. Especially in Andrew's case, there was a sense of empowerment and pride that came through in the negotiation of public transport, alongside its more instrumental value as a means of mobility. Yet for certain participants like Hannah and Denise, public transport could also be a site of vulnerability and "dys-appearance" (Leder, 1990), where the effects of their physical limitations (such as seeing the bus number, or struggling to alight) were brought home amid the potentially objectifying gaze of others. Interacting with the availability and accessibility of transport options were the amenities in the participants' local area, that made them feel "fortunate", such as Denise describing the high quality of care at the local hospital near her, or Sylvia appreciating living in the centre of town. These examples clearly illustrate the ways in which the environment can influence the wellbeing and participation of people with AMD, as noted by McGrath, Rudman, Spafford, et al. (2017). However, the present study findings also suggest that such features can become part of a kind of psychological 'safety net' that may hold out a sense of hope and possibility, and thereby help buffer the person with AMD from the despair of feeling that their options have become restricted or closed off.

7.4.2. The human, material and ‘more than human’ in AMD experiences

Chapter 6 introduced Deleuze and Guattari's (1987) notion of ‘assemblages’, when discussing Sylvia and particularly Andrew being entangled with material, non-human entities in the environment. The assemblages concept also has relevance to other participants who discussed their use of visual aids, assistive devices and technologies, such as Ralph using his adapted computer and magnifier, which enabled him to persevere with the majority of his pre-AMD activities. As noted by Liu et al. (2022) and Toombs (1995), the right kind of assistive devices and aids can afford freedom and autonomy when living with chronic illness or disability, and this sense of empowerment and possibility came through strongly in many participants’ accounts, especially in Andrew’s enthusiasm for his “gadgets” which allowed him to feel independent. Furthermore, even a participant like Rose, who was struggling with the effects of AMD, described her iPad as a “saviour” and audiobooks as “an absolute godsend”. At the same time, Ruby’s frustrating and tiring experiences with her reading machine, and Pearl’s feelings of loneliness listening to audiobooks, illustrated the variation in the sense of satisfaction experienced between different individuals with their assistive devices.

The concept of ‘assemblages’ can be considered a post-humanist notion, moving away from humanist ideas of the individual as a bounded, autonomous agent who acts on their environment in a ‘top-down’ fashion, and towards the idea of agency as a complex phenomenon that emerges from the assemblage between human and non-human (e.g. natural or material) entities (Monforte et al., 2021). Arguably there are parallels between the concept of the assemblage and Carel’s analysis, drawing on Merleau-Ponty, that “external props such as a walking stick can become an integral part of one’s lived body” (Carel, 2007, p.108); this quotation brings to mind Andrew’s discussion of taking to his white stick like a ‘duck to water’. Similarly, Toombs (1995, p.21) notes that that aids will only be effective if the person has an accepting affective response towards them, and the importance of “accept[ing] such objects as extensions of bodily space, rather than as symbols of disability, before they can effectively incorporate them into the lived body.”

Where the assemblage concept arguably goes further than existential-phenomenological conceptions of embodied being-in-the-world is in drawing attention to how, at any point in time, a person with AMD may face challenges that emerge from a complex, interlocking web or ‘rhizome’ of heterogeneous elements. Such elements can belong to different “orders of existence” traditionally considered, and analysed, as highly separate or oppositional (Feely, 2016). Furthermore, from this perspective no single one of these “orders of existence”, as a causative or explanatory factor, can be definitively separated out and privileged over any other. If using the assemblages concept to account for an obstacle faced by a person with AMD, the obstacle may be considered to emerge from a myriad combination of elements including: the biology of the body; the person’s affect, sensations and emotional responses; their relationships; the materiality of the environment; encounters with technology; laws, policies and funding; and societal discourses and ideologies (Feely, 2016). Thus, if using the concept of assemblages to account for Andrew’s willingness to use aids like a white stick for instance, we might consider the fusing of different elements, including: his pragmatic mindset; support from his wife Wendy to find out about services and accompany him; social services provision in his local area; familiarity with his neighbourhood; and an ability to see the white stick as a positive tool for inviting understanding and awareness from others, as well as a seeming sense of resilience against the potentially ‘othering’ gaze and disablist societal discourses. It is important to note that phenomenological studies of illness and impairment already engage holistically with the body’s complex changing relations to other people and the material environment (e.g. Carel & Kidd, 2020; Lourens & Swartz, 2016; Toombs, 1995). For example, Toombs speaks of the “global sense of disorder that permeates the patient's everyday life” (1995, p.20), and suggests that illness simultaneously changes one’s experience of surrounding space, the parameters of time, interactions with objects in the material environment, one’s own bodily identity, relationships with others, and awareness of societal attitudes and prejudices. Therefore one may question the extent to which the assemblages concept is adding radically new understanding. That said, I find the concept a useful reminder to engage intentionally with participants’ material realities, without reverting to ‘essentialism’ (Feely, 2016), and considering how participants’ embodied experiences are fundamentally intertwined with the material, social, economic, cultural and political environment around them. This arguably provides a further rationale for a pluralistic approach to qualitative research. A pluralistic approach may still not allow the continually evolving and dynamic character of such assemblages to be definitively ‘grasped’, but it can help to better attend to the full complexity of experiences of and responses to AMD.

7.4.3. Fitting and misfitting amid disablist social norms

As noted previously, participants could experience AMD as a feeling of alienation and “unhomelikeness” in the body. Furthermore, if considering participants’ experiences in line with the assemblages concept discussed in Section 7.4.2, it also appeared that this “unhomelike” feeling was intensified when participants faced barriers and exclusion in the social and/or material world that gave rise to a sense of their body not ‘fitting’ into the world. Rosemarie Garland-Thomson draws on new materialist philosophy (which underpins the concept of assemblages discussed above) in her conceptualisation of “misfitting”, a dynamic process shifting over space and time which “occurs when the environment does not sustain the shape and function of the body that enters it” (Garland-Thomson, 2011, p.594). Hughes similarly notes that the world is a “home” for non-disabled bodies, and that even the standardised norms of movement and timing that structure everyday interactions are based on the “carnal and emotional needs of non-disabled people” (Hughes, 2004, p.59). This perspective helps us to understand the affective, emotional response that could take place when participants like Denise were unable to see photos her friends showed her on their smartphones, or when Rose was unable to see the speaker at the lunches she previously attended. In such instances, the whole material/social environment became a space in which they no longer felt like they ‘fitted’, aligning with Lourens and Swartz's (2016, p.243) description of inaccessible spaces or unusable objects consequently making “the entire environment… hostile and uninviting”. In contrast, participants’ experiences in my study, particularly during the home tours, illustrated how home was often configured as a kind of sanctuary in part because they could control the sense of ‘fit’ with their environment, and their visual difficulties thereby became less salient. Meanwhile, in unfamiliar settings, participants might have not only a primary experience of struggling to navigate the environment, but also a secondary, more self-conscious experience of themselves as ‘misfitting’ in their bodies and in the world.

Nonetheless, it is also important to note Garland-Thomson’s (2011) emphasis on the potential for innovation, resourcefulness and generativity inherent within the dynamic, spatially- and temporally-contingent process of ‘misfitting’. For example, not being able to see her audience during public speaking engagements helped Kate to feel uninhibited, becoming the “life and soul of the party”; while Sylvia was proud of her resin paintings that she had taken up in response to detailed portraiture no longer being possible. Such a focus on generativity does not deny the losses and challenges of AMD, but allows for honouring the adaptability, resourcefulness and joy participants could sometimes access as a direct consequence of, rather than in spite of, their condition. Such vignettes might help to nuance and chip away at the hegemony of the “personal tragedy” discourses, as illuminated in the FDA; especially if we shift a focus towards the myriad ways in which society and the material environment compound (and so, equally, could alleviate) the challenges that AMD and sight loss may occasion. Indeed, while no participant explicitly named practices as (dis)ableist or ageist, every participant at some point made clear that the intertwined social and/or material environment presented barriers and obstacles in their everyday life. Often participants saw these barriers as something they ‘should’ be able to work through or around, and thus risked blaming themselves. Equally however, there were examples of participants recognising that it was incumbent upon other people to change their behaviours. This came across strongly in Andrew’s account, who saw it as others’ responsibility to include him in conversation by addressing him clearly and unambiguously, rather than taking-for-granted that he would pick up on non-verbal conversational cues. At a more societal level, Kate and Louis were particularly outspoken about their hopes for public awareness and understanding of vision loss to improve. They emphasised the non-visible nature of AMD, and the contextual flux of visual symptoms depending on the relative level of (mis)fit with the environment, pointing to the need for more nuanced understanding from sighted others. Arguably, the implications go beyond AMD to other non-visible conditions, towards the notion of universal access and inclusion; for, as Hirschmann (2015, p.222) suggests, “If we considered the invisibly disabled body as the norm, this would take us further because we cannot know what that body can and cannot do.”

7.5. Implications for practice and further research

7.5.1. From dichotomies to dialectics?

The pluralistic approach of the PhD, using FDA and interpretative phenomenology, generated opportunities for thinking about the experience of AMD from different epistemological perspectives. However, in demarcating the social constructionist approach of the FDA (Chapter 3) from the interpretative phenomenological stance of Chapters 4-6, it has been a challenge not to reproduce simplistic dualisms between these epistemologies. Furthermore, the dualism of social constructionist versus phenomenological can in turn pull other potential dualisms into its orbit, such as discourse versus experience, the social versus the corporeal, the object versus the subject, and the external world versus the inner 'life-world'. In introducing the notion of assemblages and Garland-Thomson's (2011) helpful notion of mis/fitting, I hope to convey – in line with existential-phenomenological notions of being-in-the-world and being-with-others - how the individual experiences AMD in constant, dynamic relation to their own pasts and futures, the other people in their families and communities, the material environment, and predominant social norms, discourses and representations. This dynamic, assemblage perspective arguably has some commonality with Spinelli's (2014, p.31) argument that existential phenomenology allows for "'hold[ing] the tension' between apparently contrasting, separate and contradictory concerns"; and for considering being-in-the-world as "relationally attuned", inter-dependent and always in relation to others. Spinelli suggests that moving away from the dominant dualisms in psychology opens up a space for a "both/and" perspective, accepting that seeming polarities can coexist and mutually influence each other, such as the body and mind coming together as a unified "bodymind" (Price, 2015).[xxiii]

Embracing a 'both/and' perspective helps with reconciling the considerable variation both between and within participants' experiences, if we envisage participants dynamically negotiating tensions or moving along continua. These continua encompass the differing levels of functional vision *between* participants, ranging from early-stage AMD to significant visual impairment, but also *within* participants themselves, depending on the context in which they found themselves interacting with the world around them. The 'hope-despair' continuum is another example, with certain participants not only moving between these states over defined periods of time in their overall AMD 'journey', but also sometimes poised in a constantly oscillating equilibrium between these states in daily life. This PhD suggests that further research on experiences of AMD – and arguably of age-related vision loss more generally – could arguably do more to move beyond the "big divides" (Schillmeier, 2006, p.482) that dominate in modern epistemology (e.g. between agency versus social structure, or nature versus culture) in order to honour the full richness and heterogeneity of experiences of vision loss. Indeed, considering the “both/and” in AMD experiences also has implications for practice, in opening up space to consider how the world around the person – the relational, social, and environmental context – could be modified to support the adaptation and wellbeing of people with AMD; while also recognising that much can be done to support individuals to cope with and navigate a world that, as it stands, is poorly set up for those living with vision loss.

7.5.2. Reconfiguring talk around AMD: Making space for loss without assuming a “loss focus”

A ‘both/and’, assemblages-influenced perspective aligns with the dual perspective frequently voiced by participants; they often found life with AMD and vision loss to be extremely challenging, but also sometimes a source of humour, connection to others and meaningful experiences. As critical disability scholars have noted, it is possible to simultaneously want to dismantle notions of disability as tragic or undesirable, without rejecting the value of biomedical ‘restitution’ or denying feelings of loss (e.g. Kafer, 2013, p.4; Price, 2015, p.276). This perspective also comes through in autobiographical writing on visual impairment; in *Life Unseen*, Selina Mills (2023) discusses the need to fight against negative stereotypes and representations of blindness, while acknowledging the fear and loss it entails at an experiential level. As Mills (2023, p.110) states, “Not seeing in a very seeing world is hard and involves a great deal of adaptation”. Mills suggests the value of reconfiguring our notions of blindness and vision loss, to “simply just a different way of being on this planet”; and similarly, Georgina Kleege in *Sight Unseen* advocates a “blander and more mundane” image of vision loss, ”a matter of seeking practical solutions to everyday inconveniences” (Kleege, 1999, p.228). These perspectives imply a rejection of grand narratives, weighed down by negative stereotypes of blindness, and a pragmatic reorientation towards the nuanced lived experiences of people living with vision loss. This aligns with Burton’s (2013) call for a holistic “lifeworld-led healthcare model” in AMD that takes into account how AMD changes the person’s taken-for-granted ways of being-in-the-world. Notably, a perspective engaging closely with participants’ experiential and socio-material realities can acknowledge the value of biomedical interventions and treatments (such as injections for wet AMD, which can halt or even somewhat reverse vision loss). At the same time, it can acknowledge that the medical model offers limited understanding of what AMD means to the person in their everyday context; and that a narrow medical lens can overlook the social, political, cultural and environmental processes that could be modified to improve the wellbeing of people with AMD in the here-and-now (Kafer, 2013, p.5).

On the basis of bringing together FDA and IPA findings, it could also be argued that many participants, upon diagnosis with AMD, are susceptible to being negatively positioned within discourses that overwhelmingly frame the condition as one of tragedy and loss. What became clear through the IPA was that many participants were able to work through states of initial despair to arrive at a position where hope and positivity came through, even if despair sometimes still made itself felt. This process seemed to occur through a dynamic interplay between learning to find ways around and adapt on a very individual level, but also arguably because their own mixed, nuanced experiences proved a corrective to the totalising discourses that had held sway over their earlier premonitions of their future. For example, several participants voiced reappraising prior beliefs that AMD would lead to total "blindness", finding reassurance in coming to understand that some level of peripheral vision would remain, aligning with Feely et al. (2007) where participants experienced relief in knowing they would retain some peripheral vision. Participants' talk sometimes suggested, especially earlier on in the condition, that they conceived of 'blindness' or even vision 'loss' as equating to complete loss of vision, with no light perception, aligning with the common stereotype that "blind people saw nothing, only darkness" (Whitburn & Goodley, 2022, p.6). When a doctor told Andrew he would go "blind", it could be the case that the doctor was employing the term to denote the legal visual impairment threshold, but it was implicit in my study – and in others, including Burton (2013, p.154) - that individuals will commonly assume blindness is akin to no light perception, rather than perceiving of vision loss as a spectrum. Furthermore, as the study findings showed, the visual, embodied experience of AMD is less often a progressive transition from light to dark, and more often a constellation of unusual, fluctuating visual symptoms. This aligns with Mills' (2023, p.15) assertion that "So much of the experience of blindness is not binary – black or white – nor total all-encompassing darkness. Most of the time it's a strange ambiguity of murkiness or blankness – it just is not seeing".

Similarly, participants often went on journeys from seeing AMD as a “site of no future” (Kafer, 2013) to understanding through experience the possibilities that remained open to them. Such trajectories, although not universally evidenced among the participants, align with research demonstrating that people appraise *imagined* quality-of-life with disability more negatively than the quality-of-life *experienced* by those living with disability (Mackenzie & Scully, 2007; Shakespeare, 2013). In particular, this thesis suggests that one particular discursive spectre that overshadows the subjectivity of people with AMD is fear of becoming ‘dependent’, in the context of ageing in the modern, Western world where such a subject position is perhaps particularly feared. Although speculative, the findings suggest that it may also be helpful for policymakers and researchers to ensure nuance when discussing notions of independence, to avoid perpetuating what we could call a “dependence focus” (after the “loss focus” of Tanner et al., 2020) in discussing AMD, since this risks reproducing simplistic assumptions that the challenges AMD poses to physical self-sufficiency equate to an overall loss of autonomy.

Therefore, when communicating about AMD in research and healthcare settings, analysis of the findings together with the literature suggests considering the following:

- To avoid valorisation of narrow ideals of independence in AMD research and care practice, and framings that equate requiring help from others with daily tasks as a state of ‘dependence’ (McGrath et al., 2017). As argued in Section 7.3.1., it may be helpful to shift focus towards how the autonomy of people with AMD can be fostered - in concert with support from other people, organisations or technologies - even when their physical self-sufficiency is affected.
- To move away from reproducing fearful and stigmatising representations of AMD and age-related vision loss, that preclude continuing possibilities for joy, meaning and autonomy when living with vision loss. Campaigns and efforts by the NHS, professional bodies and voluntary organisations to promote eye health, or detect AMD earlier, can valuably help to prevent visual impairment and acknowledge the challenges of sight loss conditions, without resorting to (and further fuelling) unnuanced, overly bleak imaginaries of life with sight loss (Bolt, 2016; Shakespeare, 2013).

- To raise public awareness that AMD does not lead to total blindness (Feely et al., 2007), and that AMD may be experienced phenomenologically as a constellation of visual symptoms beyond the hallmark symptom of central vision loss (Taylor et al., 2018). The thesis demonstrates that the array of AMD symptoms may be challenging to convey verbally, hence requiring patience and understanding from eye care professionals, and relatives and friends.
- More generally, the thesis suggests value in raising awareness among the sighted public of the realities of living with vision loss, for example understanding that a person with a white cane still may have some preserved vision, but also that anyone may be living with a non-visible form of vision loss and may therefore require accommodations. More nuanced and faithful representation of visually impaired people's diverse experiences in media and culture could also be helpful, to fight presumptions that vision loss is a "site of no future" (Kafer, 2013, p.3). As Mills states (2023, p.249),

  > "We need to hear more stories, whether those who talk about how bereft of the world they feel because they cannot see, as well as people who found new courage and new life in their sightlessness. There is no judgement either way. We need to hear all these voices – in all their diversity – so as to manage our own experiences and expectations."

7.5.3. Supporting people with AMD through an existential juncture

Certain participants, especially those who were somewhat more private within their social lives about their AMD experiences, seemed to find value in the space to talk, finding it "liberating". Rose implied that the research interview helped her to feel like part of a community of people with the condition, in a way that normalised AMD, and made her feel like one-of-many rather than the odd-one-out. Hodge et al.'s (2013) evaluation of an emotional support and counselling service for people with visual impairment similarly suggested that this normalisation of experience, through the process of being listened to by an impartial listener, was perceived by participants as one of the most helpful elements of the intervention. The importance of a space for participants to tell their story echoes Willig's (2015) observation, in a phenomenological exploration of living with advanced cancer, about the importance of hearing and witnessing participants' 'chaos narratives' (Frank, 1998); this process potentially allows "new meaning to emerge, if only initially through the meaning that resides within the act of claiming the right to tell a chaos story" (Willig, 2015, p.423). While there is an existing infrastructure in the UK for emotional support and counselling for people with sight loss (Pybis et al., 2016), such support can be scarce or uneven, and may not be responsive to clients' changing needs as their experience of sight loss evolves (Thetford et al., 2011; Trott et al., 2023). Thurston suggests that counselling for people with sight loss could be based around a model that considers five stages of sight loss, that do not necessarily progress in a linear fashion, including: the diagnosis; hiding the sight loss; the point of impact, when losses occur; coming out as a visually impaired person; and establishing a 'new normal' (Thurston, 2024; Thurston et al., 2013). Thurston argues that counselling may be particularly helpful during the third stage, the 'point of impact', when the losses are being felt most keenly and to help avoid individuals becoming stuck in this phase. At the same time, the present study noted the significant differences between individuals in how their perspective towards AMD changed over time, making it challenging to predict *a priori* when and for whom support will be helpful. Indeed, this fits with Carel et al.'s (2016, p.1152) description of chronic conditions as "existentially transformative", not necessarily implying *positive* transformation, but instead suggesting that a person can never know in advance how they will experience a condition like AMD and be changed by the experience. Indeed, as Ralph stated, there was no "magic formula" to pre-specify how one might arrive at a sense of a 'new normal' (Thurston, 2024), this being a non-linear process also arguably tied up with the heterogeneous physiological trajectory of sight loss in AMD.

This in turn points to the importance of non-pathologising, person-centred forms of therapy and counselling that can support people with AMD to arrive at a position where they can accept and integrate it into their lives in their own time (Leder & Aho, 2024). As noted in the Introduction, psychological interventions evaluated among people with AMD have tended to be more rooted in a cognitive-behavioural therapeutic modality (Senra et al., 2019). However, the findings of the present study suggest a potential complementary role for psychotherapeutic or counselling approaches rooted in the existential-phenomenological tradition, that can respond to the idiosyncrasy of experiences and meaning-making around AMD. Interventions informed by existential-phenomenological perspectives could create a space for individuals to discuss how AMD interacts with their broader concerns about identity, loneliness, the ageing process, and finitude and mortality. Crucially, as argued throughout, existential-phenomenological approaches also acknowledge that being-with-others in society (*Mitsein*) is bound up with being-in-the-world (*Dasein)*, and so would also permit consideration of how socio-cultural norms around ageing, disability and modern society's privileging of the visual mode frame individuals' experiences of vision loss. Therapeutic interventions grounded in existential-phenomenological principles do not lend themselves to positivist, empirical evaluation, given their rejection of essentialism and embrace of individuals' unique subjectivity (Vos, 2019). Nonetheless, certain more pluralistic modes of intervention incorporating existential perspectives, such as meaning-centred therapies, have been clinically evaluated, and show promise in reducing distress and improving quality of life, precisely by explicitly addressing and enhancing clients' sense of meaning-in-life (Vos, 2019; Vos et al., 2015). Vos (2016) therefore suggests that many individuals with chronic conditions would benefit from a therapeutic practice that aims to respond to the question of "How can I live a meaningful and satisfying life despite the physical, psychological, social and existential limitations of my disease?". I would argue that the findings of the present study underscore the value of Vos' approach for those facing a turning point or moment of 'crisis' in their AMD experience, and could help them to reorient their focus towards what remains possible and in their control. This could help to respond to the feeling of being 'stuck' that many participants evoked – either presently or retrospectively – and the concomitant feelings of loss, loneliness and fears of the future.

7.5.4. Learning from the hard-earned, pragmatic wisdom of the participants

While the above paragraph introduced a more 'top-down' perspective, in terms of how existential-phenomenological or meaning-based therapies may support people with AMD, it is also worth considering from a more 'bottom-up' perspective what had worked for participants to find their way towards coping with AMD. With the caveat of there being no one-size-fits-all "magic formula", awareness of the array of strategies used by the study participants could nonetheless provide avenues for future research; which could in turn feed into informing the psychosocial interventions offered by low vision services and voluntary organisations in the UK. For example, at the end of the home tour interview, Andrew reflected that he would have liked to make a video of the tour and the demonstration of his assistive devices, which he suggested could demystify and normalise the use of such technologies. Considering that Ralph largely attributed his metamorphosis to watching a Macular Society informational video (where a GP explained his adaptations to macular disease), Andrew's proposed video could equally be an empowering and hopeful resource for someone else living with AMD. Thus future research could consider co-design of accessible multimedia resources with people affected by AMD, that focus on the adaptations that can be made. This could provide a welcome counterpoint to the 'loss focus' in AMD research (Tanner et al., 2020), and often highly negative, stigmatising media portrayals of sight loss (Bolt, 2016; Fuchigami et al., 2022). Such a video could also be explored as an elicitation tool in action research involving people with AMD, considering how they perceive and make sense of these kinds of adaptations, and what they might wish to change within their own unique circumstances.

An additional key point of wisdom gleaned from participants pertained to the ability to embrace new activities or 'projects', even when certain other activities were no longer available to them. Certain participants had a strong sense of what limitations in their life were non-modifiable (or "existential", in Baars and Phillipson's (2013) terms), versus what was "contingent", and therefore modifiable, through workarounds, or with some degree of help from others or from statutory or voluntary services. Additionally, several participants had embraced new 'projects', such as Sylvia with her resin painting, or Ruby and Kate with volunteering. As Svenaeus (2023) notes, such projects can be modest and simple rather than radical, and still add to a sense of purpose and finding meaning; recalling, for example, how Ruby described her volunteering with the Macular Society as "[making] my great liability into… something constructive."

Alongside the importance of projects that provide a sense of purpose and meaning, several participants advocated as far as possible staying grounded in the present moment and trying to avoid ruminating about how far sight loss could progress. They acknowledged that some level of worry about the future was a natural response to an AMD diagnosis, but had come to realise the importance of finding workarounds in the here-and-now, especially in light of the unpredictable disease course of AMD. This aligns with Carel's suggestion, based on her own experience of chronic illness, that "focusing on present abilities, joys and experiences instead of worrying about a no-longer-existing past and a not-yet-existing future, is a way of avoiding some of the suffering caused by illness" (Carel, 2008, p.134). Certain meaning-centred therapies, discussed above, contain elements of mindfulness meditation which as a practice could help to cultivate a non-judgemental awareness of and attunement to the flow of present experience. Indeed, exploratory studies involving participants with vision impairment suggest the promise and value of mindfulness in coping with stressful situations (Lyngroth & Gammelsæter, 2023) and fostering a sense of spiritual wellbeing (Marquès-Brocksopp, 2014). While Carel's (2008) invitation to remain firmly rooted in the present resonated with many participants' perspectives, it is also important to note that for some participants the past could constitute a helpful resource, for example by drawing strength from memories of loved ones, or from memories of previous occupational or leisure pursuits that bolstered their identity and sense-of-self. Therefore, even while an orientation towards the present may be a helpful strategy, it is important to avoid the assumption (interwoven into certain strands of existential thought) that the past is a barren, lifeless "desert" (Svenaeus, 2023). The richness of the past as a resource came across particularly when participants recalled their parents' approach to living with AMD, and it was clear that the memories of their parents' past words, aphorisms and perspectives in the face of AMD continued to guide participants' present-day sense-making.

Furthermore, the findings support the value of participation in group settings, which could include peer support groups or group therapy interventions. Several participants explicitly or implicitly noted the importance of finding a group that felt "homelike" and the right fit. Therefore, for certain individuals with AMD, it may take time to settle upon the appropriate group environment. For some participants who were more private about their AMD, there also appeared to be value in approaches such as befriending or one-to-one peer support with other people living with AMD. Regardless of the extent to which participants felt more private or open about AMD, almost all participants attested to experiencing a sense of belonging and reassurance when they felt understood by others. As discussed, it was often challenging for participants to verbally convey the precise impacts of AMD to others without the experience; therefore, achieving a feeling of mutual understanding and intersubjectivity with others felt particularly valuable. Other qualitative studies involving people with AMD attest to the value of group support (Burton, 2013; Dahlin-Ivanoff et al., 1998; Taylor et al., 2020). These authors disagree in terms of the nuances of whether it is helpful to have a group of heterogeneous vision levels; Dahlin-Ivanoff et al. (1998) suggest that heterogeneity could allow group participants to serve as models for each other, although Taylor et al. (2020) recommend more stratified groups to avoid the risk that those with early-stage AMD become distressed seeing how vision loss could progress. While the idiographic nature of my study cannot definitively endorse or reject either of these arguments, the participants' perspectives inevitably varied; for example, Marianne drew inspiration seeing how well people with advanced vision loss had adapted to their conditions, while others like Howard felt like he did not fit into the group he attended, where he perceived the majority of participants to be older with more advanced visual symptoms. The groups to which participants belonged tended to be support groups run by the Macular Society or other vision loss charities, where participants exchanged practical tips or emotional support. An avenue for future research could be to explore the value of group therapy interventions among people with AMD, given the findings in this thesis about the challenges of 'being-for-others' and disclosing their AMD experiences. The kinds of meaning-centred therapy discussed above (p.276) are often delivered in groups, and group therapeutic approaches also align with the emphasis in existential thought on being-with-others (Cooper et al., 2019). There is some evidence that group therapy can support people through existential crisis points, such as metastatic breast cancer (Beatty et al., 2018, as cited in Tantam, 2019), and as Tantam (2019) suggests, such groups may exert their positive effect through helping participants to find intersubjectivity and a 'meeting of minds' with others. In light of this point, and given the heterogeneous preferences of participants in my study, it is also important to explore whether formal group therapeutic support would offer additional benefits beyond peer-support groups such as those run by the Macular Society, or groups that cluster around shared interests. As an example of the latter, an IPA study exploring experiences of older adults with sight loss participating in an audiobook group concluded that the friendship and sense of belonging nurtured through group participation was as valuable and meaningful for participants as the actual book discussion (Lang & Brooks, 2015). Therefore from a practical perspective, it is important to bear in mind the individual's unique preferences and outlook, and to be able to personalise the form of individual or group support that might be most helpful and resonate with them.

The discussion of findings above must be considered in line with the thesis limitations, which are discussed in the next chapter on methodological reflections.

Chapter 8– Methodological reflections

In Chapter 7, I discussed the substantive findings of the PhD. This chapter reflects on methodological and epistemological issues that arose during the research, considering the advantages and challenges of taking a pluralistic qualitative approach at the overarching level of the thesis. I also reflect on some of the data collection challenges, consider limitations of the research in light of evaluation criteria, and explore potential methodological 'lessons-learned' on the basis of my research experiences.

8.1. Reflections on pluralism at thesis level

As discussed in Chapter 2, there was an interest throughout my PhD in considering the viability of a pluralistic approach to exploring AMD experiences. The research question guiding this focus, from a methodological perspective, was: "How far does the use of multiple methodologies allow for an integrated exploration of AMD as an experience both rooted in the person and rooted in context?"

The Foucauldian Discourse Analysis (FDA) was not initially a project I envisaged when I embarked on the PhD. I intended to use a variety of data collection methods within an overall interpretative phenomenological epistemology (i.e. combining more conventional semi-structured interviews, analysed using IPA, with more embodied, pre-reflective elicitation techniques, such as the home tour interviews). However, I had not initially foreseen introducing a social constructionist epistemological lens into the thesis. Thus, a research thesis project originally conceived – to draw on Frost and Bailey-Rodriguez (2020) – as subscribing to "methodological pluralism" also ended up involving a layer of "analytical pluralism", in light of adopting a social constructionist epistemology for the FDA and then interpretative phenomenology for the remaining studies. I first reflect on the "analytical pluralism" in my thesis, and then turn to the elements of "methodological pluralism".

8.1.1. Analytical pluralism

It is important to note that analytical pluralism generally refers to the application of different qualitative methodologies (often with different epistemological commitments) to the *same* dataset (Clarke et al., 2015; Frost & Bailey-Rodriguez, 2020). This was not the case in my thesis, where different methodologies and epistemologies were drawn upon but applied to different datasets. Therefore I use the term "analytical pluralism" here in a broad sense, at the overarching thesis level, to refer to using different methodologies (and epistemologies) for the FDA (Chapter 3) versus the interpretative phenomenological studies (Chapters 4-6).

I had envisaged the PhD as rooted in interpretative phenomenology and not initially foreseen a 'foray' into social constructionism. However, the FDA study developed relatively organically, growing out of my increasing interest in the broader critical literature on disability and ageing, considering how this might problematise certain taken-for-granted perspectives in the qualitative literature on AMD. I also undertook the FDA partly in response to the unexpected events of the COVID-19 pandemic, given my concerns that data collection for the interpretative phenomenological studies would not be viable for the foreseeable future. I found that conducting the FDA on published qualitative extracts gave me a sense of the discursive landscape and resources that have dominated talk about AMD within previous qualitative research studies. Furthermore, I came to the FDA having never conducted discourse analytic research, and found it a fascinating conduit into a rich critical literature on disability, ageing and socio-cultural representations of vision. Such literature could feasibly have remained more peripheral to the thesis, had I stayed within my initially-envisaged interpretative phenomenological stance.

As discussed in Chapter 2 (p.42), the layers of knowledge gleaned through pluralistic approaches, drawing on potentially clashing epistemological stances such as FDA and IPA, can sit side-by-side. This strategy can be an alternative to seeking to integrate potentially incompatible or incommensurate findings (Black & Riley, 2018; Willig, 2021). In this thesis, I perceived the epistemologically-distinct layer of knowledge that was developed through the FDA as, in Burr's terms, establishing a "conceptual backcloth" (Burr, 2015, p.78). The FDA allowed me to map some of the prevailing discursive resources to talk about AMD and to critically analyse these with theory (mainly critical theory from disability studies and gerontology). Additionally, developing a sense of this 'backcloth' in the qualitative AMD literature provided two key benefits for the thesis as a whole. Firstly, it prompted immersion in more critical literature on disability and ageing, which itself became part of the broader backcloth informing my eventual interpretation of the thesis findings. Secondly, conducting the FDA was, in hindsight, a valuable practical step to support the bracketing of taken-for-granted preconceptions in the IPA data collection. For example, I think that before undertaking the FDA, I subscribed to more of a ‘loss focus’ (Tanner et al., 2020) mentality, making the *a priori* assumption that AMD would be a difficult experience for all. Similarly, I might have used seemingly neutral, but ultimately value-laden, terminology around the importance of ‘maintaining independence’; without considering that I myself was further reproducing a dominant discourse that valorises narrow, often unattainable ideals of independence (Trentham, 2019). Yet conversely, I had to take care when analysing the interpretative phenomenological data, to avoid potentially ‘over-interpreting’ experiences which I hoped could present a fresh, novel kind of “counter-frame” (Goethals et al., 2022) to hegemonic or negative representations of ageing, disability and vision loss.[62]

I ultimately came to see a complementary kind of ‘figure-ground’ relationship between the IPA and FDA (Giguere, 2021),[xxiv] with FDA illuminating the sociocultural ‘ground’ (the discursive context of age-related vision loss), and IPA illuminating the ‘figure’ (of participants’ lived experiences). While the ‘figure’ of lived experience was the foregrounded phenomenon throughout my PhD, I perceived a degree of dynamic interaction between the layers of the lived experience ‘figure’ and the discursive ‘ground’. When IPA participants shared their experiences of AMD through language, some of this overlapped closely with the FDA discursive backcloth, weighed down with cultural and socio-historical baggage and engrained representations of vision loss, ageing and disability. However, in the interpretative phenomenological studies, close attention to participants’ interpretation of their experiences in their full complexity and contradictions allowed for new nuanced understandings to develop. The development of such understandings can be explained in my view by the hermeneutic circle so central to interpretative phenomenological enquiry, compared to the analysis of decontextualised extracts in the FDA. For example, in the FDA, I suggested AMD was often constructed as a kind of critical juncture, a fork-in-the-road presenting a binary choice between individualistic summoning of willpower to persevere stoically, or sinking into oblivion. However, in the IPA, with access to the participant’s full

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[62] One example was remaining attuned to feelings of loss within the data, both when conducting the interviews and during analysis. As discussed in the Introduction, I intended my research to be open-ended and avoid assuming a ‘loss focus’. However, experiences of loss and grief were at the heart of many participants’ accounts. I therefore had to take care that my desire to challenge a ‘loss-focused’ paradigm did not risk under-representing or disavowing the full extent of such experiences.

account, I perceived that what could seem to be simplistic declarations of stoicism were in fact deeply-rooted beliefs based on first-hand personal knowledge gleaned from their past and current experiences. This also explains why the FDA remained more in the 'background' of the thesis; for the lack of insight into participants' full accounts and the hermeneutic of suspicion together combined to make the knowledge gleaned from the FDA feel somewhat more partial or ephemeral. In contrast, I felt more grounded and rooted in the data when conducting the interpretative phenomenological work, with the hermeneutically circular processes helping me to continually develop and strengthen interpretations from the bottom-up (rather than through the more top-down, theory-informed approach of the FDA). Yet because the FDA involved working with such a different form of data when compared to the interpretative phenomenological studies, in a sense I cannot compare like with like. Therefore, it could be interesting in future research to consider how far the 'ground' of discourse about AMD and the 'figure' of lived experience of AMD might converge or diverge if analysing the same dataset with the two different methodologies (e.g. Baboulene & Willig, 2023; Dewe & Coyle, 2014). Applying FDA and IPA in this kind of dual focus methodology could help to understand how the individual's situated, contextual discursive 'ground' (rather than the more abstracted, macro-level 'ground' explored in my FDA study) may shape the 'figure' of their lived experience of AMD.[xxv]

8.1.2. Methodological pluralism

I now turn to reflect on the affordances and challenges of using different data collection methods within the thesis studies that employed an interpretative phenomenological epistemology. Key details are briefly summarised in Table 8 for context.

Table 8. Key details of interpretative phenomenological studies (Chapters 4-6)

Chapter	Method of data collection	Participants (N)	Method of analysis
4	Semi-structured telephone interviews	8	Interpretative Phenomenological Analysis (IPA)
5	Semi-structured telephone interviews	8	Template Analysis (TeA)

6	Home tour interviews	2 (previously interviewed for the IPA in Chapter 4)	Reflexive Thematic Analysis (RTA)

Considering firstly how the TeA in Chapter 5 functioned as a way of extending the IPA findings of Chapter 4, I would argue that the TeA was a practical means of working with a larger sample, but as I reflect in Chapter 5 itself, the separation of these two studies for the purposes of the thesis was somewhat artificial. If presenting findings at a somewhat less granular level of detail, for example in a journal article, it would of course be possible to integrate the new codes/sub-themes developed through template analysis into the overall IPA write-up. Certain key insights shared by the participants in the TeA could have sat at the heart of the IPA themes of Chapter 4, and inevitably would have caused these themes to develop slightly differently. There was also a struggle to know at what point the idiosyncratic nuances of an experience discussed by one of the TeA participants were sufficiently distinct from the existing IPA content to warrant new code or sub-theme development. Nonetheless, in the case of both the TeA and the RTA of the home tour interviews, I personally appreciated the flexibility to analyse participant experiences that felt somewhat on the margins of being experiential concerns, and would perhaps have been omitted amid the experiential theme development process of IPA. For example, issues around exclusionary, inaccessible environments were discussed in Chapters 5 and 6, especially by participants such as Kate and Louis. One could argue that, at least implicitly, an important element of their AMD experience related to finding themselves confronted by barriers in the world around them. However, if analysing their accounts using the stages of IPA, I am unsure whether discussion of these material barriers - for example around large print, or inaccessible pavements - would necessarily have crystallised into core thematic concerns at the personal, experiential level. Thus I felt that the TeA and RTA allowed for easier integration of these features of participants' "local worlds" (Todorova, 2011) into the analysis. As I reflect in the RTA (Chapter 6), I also welcomed the opportunity to introduce a more top-down lens when my reading of the data seemed to resonate with previous theory or empirical literature. That said, in both the TeA and RTA, I always aimed for the primary mode of engagement to be more bottom-up, inductive, and rooted in the lived realities of the participants' experiences.

As noted in Section 6.4, I did not find that my home-tour interviews provided a conduit to more pre-reflective, in-the-moment meaning making, of the kind I had initially expected. Arguably because we had discussed Andrew's and Sylvia's experiences in such detail in our first interview, the home-tour interview came to feel more like an information-gathering, fact-finding exercise detailing the features of their socio-material environments. Inevitably, discussion of these features did unlock certain new experiential insights, beyond what had already been gleaned from the IPA interviews. Yet I had perhaps entered into the home tour interviews expecting that this data collection modality could help tap into participants' pre-linguistic "felt sense" (Gendlin, 1997). One could argue that if this were the objective, it could perhaps be more effective to use elicitation methods such as emotional mapping of the home (Sallay et al., 2019), which focuses squarely on participants' emotional experiences linked to different areas of their home. Arguably, by simply inviting the participants to show me different salient features of their home environment, the participant and I ended up more attuned to the environment's materiality rather than to its experiential, emotional texture (although of course these intertwined somewhat). That said, I do think the home-tour modality combined with a more conventional IPA interview can play a useful role, in responding to the relative neglect of focus on how environmental context enables or disables people living with age-related vision loss (McGrath et al., 2017). I would argue that the home-tour study took me back to thinking more critically about the ways in which societal and environmental context shapes AMD experience, but perhaps at the expense of generating additional insight into more personal and relational dimensions. To go further in understanding the influence of this more macro-level environmental context on AMD experiences, one productive avenue for future research could be to conduct walking interviews (e.g. Iared & Oliveira, 2017; Kinney, 2017; Odzakovic et al., 2020) to explore how individuals' experiences relate to their local neighbourhood environment. Such interviews could be ethically challenging in the context of AMD, particularly for participants with mobility issues or more severe visual impairment, although potential mitigations could include using transport rather than walking, or involving a relative or friend in the interview. As demonstrated by the participation of Wendy in Andrew's home-tour interview, the presence of a spouse, relative or close friend – while potentially limiting certain disclosures – would not necessarily be an impediment if the focus is on the material context.

Furthermore, one might argue that such an interview in the presence of a loved one more faithfully and naturalistically represents the lived, relational reality of their daily experience.

8.2. Data collection challenges

In this section, I reflect briefly on challenges that arose during the conduct of my interviews when collecting data for the interpretative phenomenological studies of the PhD, organised around two salient issues: firstly, undertaking the interviews for the IPA and TeA by telephone; and secondly, the question of how to handle data that was unsuitable for analysis with IPA.

8.2.1. “If I don’t like it, I’ll just pop the phone down!” (Victoria): Reflecting on participant and researcher experiences of telephone interviews conducted during the COVID-19 pandemic

I reflect in detail on the process of changing the interview protocol for the IPA/TeA study, to conduct interviews by phone instead of face-to-face, in a reflective paper published in *SSM - Qualitative Research in Health* (Enoch et al., 2023; Appendix 2). This paper argues that moving interviews to the telephone in early 2020 was a practical, expedient response to the suspension of face-to-face data collection in the context of distancing measures to limit the spread of COVID-19. While telephone interviews have been used effectively in previous phenomenological studies (e.g. Spiers et al., 2016; Sweet, 2002), I initially had concerns that telephone interviews would generate poorer-quality data, especially in light of a challenging first interview. Yet ultimately it felt as though telephone interviews were the only viable option, since the alternative was to stop interviewing altogether, in the context of the first wave of the pandemic when there were uncertainties regarding how long distancing measures would remain in place. A helpful step was to incorporate reflexive questions into the interview schedule, and I asked participants before concluding the interview how they had found the interview experience, and how they thought it might have compared to a hypothetical face-to-face interview. My initial concerns that the telephone modality was somehow ‘lesser than’ thereby encouraged a more intentional focus on the interactional context of the interview, which led to insightful reflections from participants about how it felt to talk about their experience of AMD. Their responses, together with my own reflections following each interview, helped in establishing a sense of the advantages and challenges of the telephone modality in different domains, including:

- **Practicalities:** Telephone interviewing opened up the possibility of interview participation to participants based outside the London area. While videoconferencing was also an option offered to participants, they all expressed a preference for telephone interviewing, and once this had become my "new normal" for data collection I was inclined to keep this consistent across participants. Evidently, conducting the telephone interviews allowed for data collection to continue in the real-time context of the pandemic, thus allowing insights to be gleaned in terms of participants' experiences of AMD during this atypical time period.
- **Interview quality:** Some participants voiced concerns about the clarity of the communication, sometimes struggling to hear me clearly, although this was generally remediable by repeating questions or, for example, phoning a landline number rather than a mobile phone. Some participants regretted the lack of face-to-face contact as a way to formulate more of a natural rapport. However, others suggested that the telephone modality could in some ways be liberating and allow for a greater sense of openness. This aligns with the reflection of Spiers et al. (2016), who conducted an IPA using telephone interviews and suggest that the phone afforded participants a greater sense of confidentiality and anonymity.
- **Embodiment:** Given the focus of the study on aspects of embodied experience, there was arguably an irony in using the 'disembodied' medium of the telephone for data collection. Both the participants and I were aware of the lack of body language and non-verbal cues, and could feel at times a sense of something missing. For example, I reflected in my journal that because of not being able to see and visualise the participant, the phone interview "may lead to less prejudgement, but equally it perhaps obscures certain aspects of participants' experience". It is impossible to know how a face-to-face interview would have compared, but perhaps I was more able to suspend preconceptions about participants' physical condition and surroundings because of the phone interview, which potentially led me to ask more open questions. At the same time, meeting in person could have allowed for certain talking points to emerge organically in context, for example if the participant was

using visual aids during a face-to-face interview. I argue in the paper (Appendix 2) that it was still possible to attend closely to the physicality of participants' embodied experiences even when not physically in the participants' presence. I was encouraged in this by an article by Parton et al. (2016), who explored women's constructions of embodiment after cancer. Parton and colleagues conducted face-to-face interviews with certain participants and telephone interviews with others, and found that the telephone interviews elicited richer, more detailed description of bodily changes, potentially as participants compensated for the very lack of "visual embodied communication".

- **Agency and power:** I suggest that telephone interviews allowed for greater accessibility and inclusion, compared to the original face-to-face interview protocol which would have required participants to travel to the university. This was especially pertinent given that several participants lived with other health conditions or mobility issues which could have complicated travel. Hence the telephone modality allowed for recruitment of a more diverse range of participants in terms of physical health and level of visual impairment. Participants also noted the greater flexibility and degree of control in a telephone interview, which arguably helped to reduce certain power imbalances between the participant and myself as the researcher. Indeed, one participant, Victoria, stated that she had less apprehension about the interview over the phone relative to face-to-face, because if she were not enjoying the interview, she could simply "pop the phone down".

On the basis of these points, the paper recommends that there may be value in a kind of methodological pluralism that gives participants more choice as to the modality they would prefer, calibrating the data collection modality with accessibility for the participant. This would move away from somewhat positivist concerns about a standardised protocol towards recognising each research encounter, in the words of Demuth (2015, p.212), as providing insights into a "unique experience in irreversible time [that] can neither be replicated nor generalized". My experience of conducting the interviews by phone encouraged a sharper focus on the specific context of the "social event that is the research interview" (Shaw, 2010, p.238), a unique relational encounter between the researcher and participant with its own specific dynamic. This further substantiates Holt's (2010) argument for encouraging participants to reflect on their interview experience, as a means of understanding the ways in which the unique interview context may influence the way they disclose their experience of the phenomenon of interest. This is a practice I plan to carry forward in future qualitative research, whether conducted by telephone or face-to-face, and remaining attentive to how aspects of the interview context may shape the nature of the data collected.

8.2.2. Handling data that does not fit with an interpretative phenomenological approach

On certain occasions, when collecting and analysing data for the IPA/TeA studies, I came up against data that did not appear to fit with an interpretative phenomenological epistemology. As short-hand, I would think about this data as not being ‘IPA-compatible’. In discussion with my supervisor Carla, we concluded that two whole interviews out of the 18 conducted were not IPA-compatible. The first of these, with Patricia, was the first interview I undertook, and I reflect in depth on this experience in the telephone interviewing reflective paper (Enoch et al., 2023; Appendix 2). Considering Patricia’s account, my supervisor Carla and I concluded that the data would have lent itself better to discourse analysis, because even while I sought to embrace a hermeneutic of empathy, it was hard to let go of a more suspicious hermeneutic that saw Patricia undertaking a kind of “‘identity work” (Björk et al., 2019; Cassell, 2005) of constructing herself as resilient and invulnerable. At the same time, we did consider that from a different perspective, one could feasibly embrace a hermeneutic of empathy and explore Patricia’s experience of constructing her experience in this invulnerable way. However, this would be a topic distinct from the experience of AMD *per se,* and could be the topic of a future research study or reflection.

In the second of these two non-IPA-compatible interviews, with Nicola, there was a short period of the interview where she reflected on her experiences and those of her father who had also lived with AMD. However, she had very early-stage AMD and was heavily involved in Macular Society volunteering; so ultimately, the interview became much more focused on the experiences of the people with more advanced AMD, whom Nicola supported as a volunteer. Nicola had told me in our initial conversation when discussing the study that AMD had not yet had much of an effect in her life, beyond needing more light to see. However, at that time, I thought that it was important to represent the full spectrum of AMD experiences; Nicola was eligible under my pre-specified inclusion criteria, as was Patricia who was also living with early-stage AMD, and so I believed that it was important for this experience of 'not being particularly affected' to also be honoured. This in turn raises some questions around the thorny notion of homogeneity of the sample in IPA, especially in a progressive condition such as AMD where there is such a wide spectrum of physiological and functional effects. In hindsight, I perhaps could have made more specific inclusion criteria, for example only including participants with certified sight impairment or severe sight impairment, or drawing on the Beckman classification of early, intermediate and late AMD (Ferris et al., 2013). At the same time, recruiting participants through the voluntary sector, I was not sure if participants themselves would necessarily know their stage, especially when these classifications of AMD have not been universally accepted and adopted (Guymer, 2022). At the stage when Nicola reached out to participate, I had received limited interest in the study and so thought that amid the uncertainty of recruiting participants during COVID-19, it would still be worthwhile conducting an interview. Furthermore, reflecting back on the interview transcript, there were missed opportunities for more phenomenological exploration; for example, at points where Nicola voiced awareness that she was speaking more about others' than her own experience, I could have done more to reorient the interview to discuss her own experiences. I think that amid my concern to make the interview a positive experience, and to treat each participant as an expert on their experiences, I ended up sometimes relinquishing assertiveness and slightly lost my focus on treating the interview as a "conversation with a purpose" (Smith et al., 2021, p.54) centred around the specific research questions.

This question of how to handle data from an interview such as Nicola's, which mostly encompassed second-hand rather than her own experiences, also raised questions about how to handle parts of other participants' accounts where they spoke more in terms of the generalities of AMD experiences rather than their own personal experience. This was often signalled by the use of generic "you" pronouns, which Malone (2013) terms the indefinite second person pronoun. I found this was particularly noticeable in Ralph's account, interweaving a candid account of his own experience with more generalised statements of what “you” (i.e. ‘one’) might experience when living with AMD. As Malone (2013) notes, there is an ambiguity in the range of reference of the ‘you’, in terms of whether it might refer to a more limited group, or constitute a fundamental truism at a more abstract level. This points to the need to interpret the expression of such generalities in context (in line with the hermeneutic circle), rather than pre-assuming, as I initially did, that participants perhaps wanted to create a sense of distance from more challenging aspects of their own experiences. In Ralph’s case, he had lived through a long period of despair with AMD. In this context, I think his use of these “you” statements came across as expressing his deeply-rooted belief that so much of one’s experience of AMD is experienced similarly by others, even if it can feel so uniquely difficult and alienating. In this way, his use of aphorisms mobilising this generic “you” pronoun illustrated the importance he attached to encouraging solidarity and a meeting of minds among people with AMD. Thus, Ralph’s discussion of the experiences of others or these kinds of general truisms helped to shed light on his more personal, experiential concerns and beliefs.

8.3. Limitations of the thesis

Some limitations of the methodological approach have been considered within the individual chapters, as part of the reflections on the less ‘orthodox’ methodologies used in Chapters 3, 5 and 6. In the present section, I reflect on broader limitations of the research processes at a more macro-level. To structure discussion of the limitations, I have drawn on Yardley's (2000) broad principles for assessing the quality of qualitative research. These were chosen because of their applicability across different epistemologies and methods, and Yardley illustrates the relevance of the criteria in the context of both phenomenological and discursive qualitative research. Yardley’s (2000) quality criteria for qualitative research, considered below in turn, are: Sensitivity to context; Commitment and rigour; Transparency and coherence; Impact and importance.

Yardley suggests that sensitivity to context can include “awareness of the participants’ perspectives and setting, [and] the sociocultural and linguistic context of the research” (Yardley, 2017, p.295). If considering this definition, there were a number of challenges in my thesis. Firstly, as noted in Section 8.2.1 above, conducting interviews by telephone perhaps somewhat clouded my awareness of participants’ material setting, which by contrast I was able to access in the home tour interviews of Chapter 6. Secondly, in the interpretative phenomenological studies, I did not collect any formal demographic data from participants other than their age (since this was an inclusion criterion), and relied on the interview data itself to reveal any demographic markers that were pertinent in the context of participants' accounts. I was perhaps – in hindsight, unduly - concerned that asking for more detailed demographic information at the time of the interview (such as ethnicity, or education level) could potentially cause participants to feel judged, or concerned that I would view them through a certain lens. That said, there is a strong argument for recording these demographic details as a precondition of sensitivity to context; especially since psychological research has often framed experiences of white, affluent individuals from westernised countries as the universal norm (Braun & Clarke, 2022, p.211). One approach for future research could therefore be to ask participants to complete a short demographic questionnaire at the end of the interview, to ensure these details are documented while avoiding any influence on the interview rapport.

Yardley's (2000) criterion of commitment and rigour encompasses the "depth/breadth" and "resulting completeness" of the data collection and analysis. On this point, there are two limitations to consider in the context of my thesis.

Firstly, as noted in Chapter 3, the FDA drew on decontextualised data extracts from published qualitative studies on AMD. Given that my intention was to ground participants' experiences within available discursive resources, I perhaps could have additionally or alternatively analysed discursive constructions of AMD within materials more likely to be consumed by participants themselves in their daily lives, such as perspectives on AMD within newspapers or Macular Society magazines. In hindsight, such an approach might have tapped into configuring a discursive landscape that was somewhat more proximal to participants' sense-making around AMD. The decision to undertake a secondary discourse analysis of extracts in published qualitative studies was motivated by my interest in how AMD is constructed specifically within the context of previous qualitative research. Yet this arguably provided insight into a discursive landscape that was somewhat more distant from the IPA study participants' everyday discursive context.

Secondly, it is important to note that all participants were recruited through networks of the Macular Society, the largest UK charity supporting people with AMD. Those who contacted me about the study, and the eventual participants, all had varying experiences and levels of knowledge about the condition. However, they arguably all had a certain baseline understanding that there was a form of support out there which they could access through the Macular Society. Thus future research might seek other avenues to engage people with AMD (for example through NHS clinics), which might help to understand the experiences of potentially more underrepresented demographic groups less well-connected to support services.

Yardley's third criterion of transparency and coherence relates to the clarity and power of the account, and encourages a detailed and reflexive approach to presenting findings, in such a way that the reader can understand how conclusions were drawn. While I feel that my approach throughout the PhD has been highly detailed, and I have aimed for both personal and epistemological reflexivity, a lingering concern relates to the clarity of the narrative, especially when moving from specific, contextual understandings of AMD experiences to a more generalised, macro-level. This issue also relates to Yardley's fourth criterion on "impact and importance", which – in the pursuit of enriching our understanding and having practical relevance – implies that the research has generated transferable knowledge. Notions of generalisability in the kind of 'Big Q' (Kidder & Fine, 1987) qualitative research presented in this thesis steer clear of the statistical generalisation entrenched in quantitative research, which would take issue with the small sample size in this thesis. Nonetheless, as noted by Willig (2021, p.27), if we see participants' experiences as at least partially socially constituted, then this means that one individual's experiential account, drawing in part on socially available ways of conveying meaning, does potentially tell us something about the more general character of such experiences. Even IPA, with its emphasis on the unique idiosyncracy of individuals' experiences, would treat the individual as embedded within linguistic, relational and social contexts; and so certain experiences will likely be intersubjectively shared rather than entirely atomised phenomena. (This recalls Schleiermacher's maxim that "everyone carries a minimum of everyone else within themself" (Schleiermacher, 1998, p.93).) Therefore, I see the thesis findings, even though based on a relatively small number of participants' experiences, as having theoretical (or analytical) generalisability (Demuth, 2018). Theoretical generalisability suggests that a rich, detailed analysis of a person's experiences situated within their precise context can provide more generalised understanding of such experiences within comparable contexts. While I subscribe to this perspective, I did face challenges in the IPA of Chapter 4 when moving from the idiographic (case-by-case) to cross-case analysis, and considering at what point two inevitably unique but somewhat related experiences overlapped, to be suitable for inclusion within the same higher-order theme. It is somewhat inevitable that this process of considering concerns across the IPA sample meant collapsing some of the nuanced variations in individuals' experiences. However, I kept the idiographic analyses (Appendix 7) of the participants to-hand, returning to these throughout the cross-case analysis, to ensure that the unique experiences they shared were represented. Nizza et al. (2021) recommend that IPA researchers attend to "convergence and divergence", and my hope is that there was enough detail about individuals' specific context and circumstances to help illustrate how such idiosyncrasies may have shaped their experiences.

8.4. Methodological implications for future research

The limitations and issues discussed in the present chapter give rise to considerations for future research.

Firstly, the discussion above suggests the potential for future research to adopt an analytically pluralist approach 'within participants', using a dual focus approach to analyse the same participants' discourse and lived experience within their own particular discursive context (e.g. Baboulene & Willig, 2023; Colahan et al., 2012). This would respond to the issue discussed previously: that the FDA I conducted on the discursive constructions of AMD in previous qualitative research felt somewhat decontextualised and distant from participants' more specific discursive terrain. Secondly, I would suggest that future research could seek to explore the influence of the neighbourhood environment, as well as the home environment, on shaping experiences of AMD, particularly understanding situations where challenges or inaccessibility arise and how these could be alleviated. Thirdly, the thesis suggests that more novel, embodied methods such as the home tour interview hold promise, but may be more of a route into understanding the participants' socio-material context rather than their lived experience *per se*. It could therefore be beneficial to explore whether certain elicitation techniques suited to people with age-related vision loss might help to further explore more pre-reflective dimensions of experience, such as an emotional mapping (Sallay et al., 2019) or experience mapping approach (Sallay et al., 2024). As a further example, I believe that activities such as participants creating time-lines (e.g. Rossi-Harries et al., 2024) of their AMD experiences could be particularly interesting given the progressive and dynamic nature of the condition and the participants’ consequent emotional responses.

In the final chapter, I include a brief conclusion and overall reflection on the thesis findings.

Chapter 9: Final reflections and conclusions

Throughout the five years of this thesis, I have been asked by multiple family members and friends what I have ‘found’ in my PhD research. This engaged and well-meaning question can feel surprisingly, and frustratingly, difficult to answer. Fundamentally, the simultaneous breadth and idiosyncracy of the findings from the FDA and the 16 participants’ perspectives – all with very different life histories, AMD trajectories, and relational and socio-material circumstances - makes it challenging to settle on the most salient summary points. The very individual differences in experiencing and responding to AMD that have made it a meaningful, complex and nuanced area to explore hinder a kind of ‘elevator pitch’ response. Above all, people are often interested in the ‘why’: how to explain why some individuals seem to take AMD in their stride, while for others it represents a catastrophic existential crisis? The potential explanations are myriad and elude easy summation given my idiographic focus. Indeed my research has been more centrally engaged in *how* individuals experience AMD within their context, and has only been able to make tentative claims as to *why* the individual may experience AMD in specific ways.

However, as discussed in the findings of Chapter 7, and in keeping with the discussion of generalisability in Chapter 8, there are still certain common threads in the experiences of AMD explored in this thesis. At the personal level of the individual, many participants struggled with the frustrating imposition of new limitations, some of which were socially- or environmentally-constituted, but many of which were also experienced more directly within the body. Certain tasks or activities no longer being achievable could foreclose a sense of having future possibilities, compounding a potential sense of finitude within the broader context of ageing. Participants’ experiences were highly dynamic over time, and some had experienced deep despair but emerged from this to find varying new degrees of equilibrium and purpose. By contrast, for others, there was a more continual process of navigating the ‘hope-despair’ continuum and consistently working hard to “plod along” and sidestep despair. Intentionality, a lack of self-stigma, an ability to remain grounded in the present, and a supportive safety net of relationships appeared to underpin the perspectives of participants who voiced arriving at a greater degree of accommodation to AMD. Arguably common to many experiences of chronic illness, hard work – involving pragmatism, proactivity, practice, and intense mental and physical efforts – appeared to underpin the adaptation trajectories of all participants. At the same time, coming to terms with AMD was often framed as a (non-linear, often ongoing) grieving process, and for many participants it took significant time to feel open to embracing possibilities still available to them and cultivating a hopeful, pragmatic outlook. I suggest that therapeutic interventions moving beyond the biomedical model, perhaps drawing on existential-phenomenological theories, could create a helpful space for acknowledging and processing the distress that may be triggered by an AMD diagnosis, often experienced alongside other health or psychosocial challenges relating to ageing. Such interventions may help to foster a sense of hope, pragmatism, confidence and meaning.

The thesis has argued that these personal experiences of adapting to AMD are inherently rooted in the person's relational, social and environmental world. The findings illustrate how societal stigma around vision loss, ageing and disability, and material and environmental barriers facing people with vision loss, loom large for people with AMD. Such stigma and barriers interact with the bodily symptoms of AMD to make it a psychological experience that is about much more than solely changes to vision. After a lifetime with sight, AMD can make the person feel 'unhomelike' not only in their own body, but also in a world that valorises narrow ideals of independence, efficiency and normalcy. The both/and perspective taken throughout the thesis allows for acknowledging the deep frustrations and distress that may come from the feelings of foreignness, limitation, 'dys-appearance' in the body, or the longing for things to be as they were before; while also noting how deeply disablism and ageism are embedded within the norms and ideologies that shape dominant societal imaginaries of what it means to live and age with vision loss. I argue that at least some of the sense of loss in AMD could be remedied through greater awareness of, and tangible support for, the practical adaptations that can be made to age-related vision loss; including by finding workarounds, and using assistive devices and/or visual aids where appropriate. Furthermore, stories about the real, nuanced, mixed, mundane, humorous lived experiences of people with AMD may be a powerful counterpoint to the negative, tragedy- and panic-infused narratives of age-related vision loss deeply embedded in modern, western culture. Perhaps because the experienced effects of AMD contrast starkly with prevailing social representations of vision loss, participants found that meeting other people with AMD with whom they identified or experienced a ‘meeting of minds’ could be a powerful corrective to feelings of despair and alienation.

I therefore believe that both research and care for people with AMD could do much to help foster a sense of accommodation to the visual changes at an existential level; while also seeking to create accessible, inclusive and actively welcoming environments, so that people with AMD can feel a greater sense of hope and belonging in the world at large.

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