

DOCTOR OF PHILOSOPHY

The experience of living with age related  
macular degeneration

*A longitudinal study into the impact of age related macular degeneration on  
quality of life*

Amy Burton

2013

Aston University

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# THE EXPERIENCE OF LIVING WITH AGE RELATED MACULAR DEGENERATION

A Longitudinal Study into the Impact of Age Related Macular  
Degeneration on Quality of Life

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Doctor of Philosophy

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## **Abstract**

In this thesis I contribute to the understanding of the experience of living with Age-Related Macular Degeneration (AMD) and its impact on quality of life through the use of a pragmatically guided mixed methods approach. AMD is a condition resulting in the loss of central vision in old age which can have a huge impact on the lives of patients. This thesis includes: literature reviewing; qualitative meta-synthesis; surveys and descriptive statistics; observation; and analysis of in-depth interviewing, in order to build a picture of what it is like for older people to live with AMD. I present the findings from six separate studies each designed to answer specific research questions. I begin with a mixed methods study to determine how well the most commonly used measure of quality of life for AMD patients' represents patient experiences. I then go on to investigate the experiences of patients with AMD through a meta-synthesis of qualitative research and finally present four of my own empirical studies three of which investigate the experiences of patients with different types of AMD: early dry AMD, treatable wet AMD and advanced wet AMD and the final study investigates what it is like for a couple living together with AMD. Throughout the qualitative studies I use Interpretative Phenomenological Analysis (IPA) to develop an understanding of the experiences and life contexts of patients with AMD. Through rigorous analysis, I identify a range of themes which highlight the shared and divergent experiences of individuals with AMD and the need to acknowledge patients' past, present and potential future life contexts and experiences when providing services to older people with AMD. I relate the findings of the six studies to the wider psychological literature on chronic illness and make recommendations for services for patients with AMD to be provided holistically within a lifeworld-led health care model.

**Key Words:** Age-related Macular Degeneration, Mixed methods, Quality of life, Phenomenology

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## Publications

Parts of this thesis have been published, presented at conferences, or are undergoing review for publication.

### Journal publications

Bennion, A. E., Shaw, R.L., Gibson, J. M. (2012). What do we know about the experience of living with macular degeneration? A systematic review and meta-synthesis. *Social Science and Medicine*, 75, 976-985.

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**Burton, A. E., Shaw, R. L., Gibson, J. M. (Under Review with Journal of Vision Impairment and Blindness)**. "I'd like to know what causes it, you know, anything I've done?": Are we meeting the information and support needs of patients with early dry macular degeneration?.

**Burton, A. E., Shaw, R. L., Gibson, J. M. (Under review with British Journal of Vision Impairment)**. Experiences of patients with age-related macular degeneration receiving anti-vascular endothelial growth factor therapy: A qualitative study.

### Conference presentations

'The experience of age-related macular degeneration: A case study' A. E. Bennion, R. L. Shaw & J. M. Gibson. British Society of Gerontology 40<sup>th</sup> Annual Conference, Plymouth University, Plymouth, July 2011.

'Living together with age related macular degeneration: an interpretative phenomenological analysis' A. E. Bennion, R. L. Shaw, J. M. Gibson & E. Peel. British Society of Gerontology 41st Annual Conference, Keele University, Keele, July 2012.

### Conference posters

'Using mixed methods to investigate the impact of age-related macular degeneration on quality of life' (Poster) A. E. Bennion. British Society of Gerontology 39<sup>th</sup> Annual Conference, Brunel University, London, July 2010.

"Communicating with patients: Experiences of patients with wet age related macular degeneration (AMD)". (Poster) A. E. Bennion, R.L. Shaw, J.M. Gibson & E. Peel. Qualitative Methods in Psychology Conference, London, April 2012

"Changing bodies and minds: Impacts of age related macular degeneration". (Poster). A. E. Bennion, R.L. Shaw, J.M. Gibson & E. Peel. Qualitative Methods in Psychology Conference, London, April 2012

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# **Chapter 1: Introduction and Literature Review**

## **1.1 Introduction**

This thesis presents a series of studies designed to investigate the impact of Age Related Macular Degeneration (AMD; a disease causing central vision loss in old age) on quality of life (QoL) and explores the experience of living with AMD, a condition which is becoming increasingly prevalent in the UK.

As a result of improved health care and living conditions the population in the United Kingdom (UK) and other developed countries is ageing. Between 1983 and 2008 the number of people aged 65 and over in the UK increased by around 1.5 million; the greatest increase being in the oldest old with the number of individuals aged over 85 doubling in the same time frame (Office for National Statistics, 2009a). It is expected that by 2033 the number of individuals aged over 85 will double, reaching around 3.2 million or 5% of the total population (Office for National Statistics, 2009a). With this increase in life expectancy comes a new burden on health care; rising life span leads to increasing numbers of age-related illnesses. In the UK 69% of people aged over 85 and 48% of people over 75 have a disability or limiting long standing illness (Department for Work and Pensions, 2009; Office for National Statistics, 2009b).

## **1.2 Age Related Macular Degeneration**

### **1.2.1 Types of AMD**

Age Related Macular Degeneration is the most common cause of vision loss in older people (Bamashmus, Matlhaga, & Dutton, 2004; Bunce & Wormald, 2006). The Royal College of Ophthalmologists (2009) defines AMD as ageing changes (without any obvious cause) that occur in the central area of the retina (macula) in people aged 50 years and above. The macula lutea (commonly referred to as the macula) is the central part of the retina, which allows individuals to see fine detail and the loss of the light sensitive cells in this area leads to a deterioration in central vision. The Royal College of Ophthalmologists (2009) suggests the condition can be classified into two main types early, and late.

Early AMD (often referred to as 'dry') is characterised by the appearance of small drusen (yellow or white accumulations of extracellular material that build up in Bruch's membrane, which is the retinal basement membrane under the retina) and changes in the retinal pigment epithelium (an important layer of cells in the retina), which can be identified when scans of the eye are taken in clinic. These changes affect the metabolism of the rods and cones ('seeing cells') in the macula, leading to a gradual deterioration in fine detailed and central vision.

Late AMD is used to describe the condition when geographic atrophy and/or exudative disease develop. Geographic atrophy is the advanced form of dry AMD and occurs when the deterioration of the retina has spread to the deepest level and visual impairment is severe. Wet AMD (also known as neovascular and exudative AMD) occurs if the patient develops choroidal neovascularisation (CNV). CNV is the growth of abnormal blood vessels from the tiny blood vessels in the choroid. These blood vessels can break through Bruch's membrane and into the macular part of the retina (where they may leak blood and other fluids), damaging the central vision and eventually leading to scarring of the macula. Wet AMD is likely to cause severe vision loss in a short space of time if treatment is not provided.

### **1.2.2 Prevalence of AMD**

AMD is the leading cause of registerable blindness in many developed countries including the UK. In 2010 608,213 people were estimated to be living with AMD with this number expected to increase to 755,867 by the end of the decade (Minassian, Reidy, Lightstone & Desari, 2011). Dry AMD is the most common form of the condition (Klein, Klein, & Linton, 1992) and estimates have suggested that dry AMD accounts for between 80-90% of cases while wet AMD accounts for between 10 and 20% (Bonastre, Le Pen, Andersen et al., 2002; Bourla & Young, 2006). Prevalence studies have shown that cases of AMD increase dramatically with age (Bonastre et al., 2002). One recent study found late stage AMD, the most disabling form of the condition, to be present in 4.8% of the over 65's, and 12.2% of the over 80's (Owen, Jarrar, Wormald et al. 2011).

The prevalence of AMD differs by racial group, with a generally higher prevalence in white European-descended populations (Cook, Patel, & Tufail, 2008). Black populations are less likely to develop sight threatening AMD than white populations (Friedman, O'Colmain, Tomany et al., 2004) and various mechanisms (such as genetic predisposition) have been postulated to explain this (Bressler, Munoz, & Solomon, 2008). Studies in the United States have indicated that Hispanic and Latin American populations also have a lower incidence of neovascular AMD than European descended white populations (Klein, Klein, Jensen, et al., 1999; Varma, Fraser-Bell, Tan et al., 2004).

### **1.2.3 Treatment**

Treatments are available for wet AMD and given that the condition can progress very quickly it is important that individuals are diagnosed early and that treatment takes place as soon after diagnosis as possible. Evidence suggests that a delay in treatment for wet AMD may lead to a significant reduction in visual acuity. For example, in a study assessing treatment delays in Spanish neovascular AMD patients, it was found that an average wait of 2.3 months

between diagnosis and treatment resulted in a significant decrease in visual acuity (Arias, Armada, Donate et al., 2009).

Anti-vascular endothelial growth factor therapy (anti-VEGF) is the most common treatment for wet AMD and involves an injection of anti-VEGF drugs directly into the eye. The drug blocks the growth factors which lead to the development of new blood vessels in order to slow down the progress of vision loss. The most effective known therapies are Ranibizumab (Lucentis) and Bevacizumab (Avastin). In the UK Ranibizumab was approved for use in wet AMD by the National Institute for Health and Clinical Excellence (NICE) in 2007 and is therefore funded for use in the National Health Service (NHS). Ranibizumab has transformed the visual outlook in patients receiving it as treatment, with 40% gaining some improvement in vision and 90% maintaining their current vision level (Brown, Michels, Kaiser, et al., 2009). The ANCHOR randomized controlled trial (RCT) found a 12 month reduction in visual acuity loss in addition to visual acuity improvement in 37.5% of patients treated with 0.3mg of Ranibizumab when compared to photodynamic therapy (PDT) (a previously used treatment for AMD) (Brown, Kaiser, Michels et al., 2006). Treatment with Ranibizumab has been reported to result in greater improvements in visual function over a 24 month period when compared with other treatments including PDT, verteporfin, or sham when assessed with the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ) (Bressler, Chang, Fine et al., 2009; Chang, Bressler, Fine et al., 2007).

Dry AMD is currently untreatable medically, however there is increasing evidence that there may be a potential protective effect of some micronutrients and vitamins (Age-Related Eye Disease Study Research Group, 2001). In addition patients with dry AMD should be assessed for low vision optical aids and lighting advice which can give considerable benefit (Lamoureux, Pallant, Pesudovs et al., 2007).

#### **1.2.4 Low Vision Rehabilitation**

Low Vision Rehabilitation (LVR) involves the provision of technologies or training designed to enhance residual vision in patients with visual loss. Functional models of LVR are based on the provision of optical and non-optical aids while holistic models attempt to incorporate a wider range of services (i.e. counselling) (Binns, Bunce, Dickinson, et al., 2012). Regardless of model, LVR services have been shown to improve the functional abilities of patients. For example Scott, Smiddy, Schiffman, Feuer, and Pappas (1999) reported that patients attending low vision clinics have self-reported improvements in functional status, satisfaction, and general, near, distance and peripheral vision following service provision.

Multidisciplinary low vision services, where the rehabilitation is tailored around the individual and includes regular monitoring and a variety of services (in addition to the provision of low vision aids) have been reported to result in significant improvements in emotional wellbeing and the ability to read and access information (Lamoureux, et al., 2007). However, a recent systematic review of LVR evaluation studies has suggested that there is little difference in outcomes for optometric and multidisciplinary models of LVR (Binns et al., 2012). For example, Reeves, Harper and Russell (2004) conducted a randomised controlled trial comparing three models of LVR for patients with AMD: enhanced LVR including supplementary home based LVR; conventional LVR based in a hospital clinic; and conventional LVR with home visits which did not include rehabilitation (control). Participants were assessed prior to LVR and at 12 months post LVR on a variety of assessments including: Vision Specific QoL (VCM1); general health related QoL (SF-36); psychological adjustment to loss (Nottingham adjustment scale); a reading task (use by dates on two supermarket products); and self-rated restriction in everyday activities due to visual impairment and the use of low vision aids. The authors reported no significant differences between groups in any outcome measures other than the mental and physical component scores of the SF-36 and recommend that enhanced LVR should not be implemented without firstly assessing its effectiveness.

Whilst LVR had been shown to improve visual function the impact of LVR on QoL and wellbeing is unclear due to contrasting reports of success (de Boer, Twisk, Moll, et al., 2006; Reeves et al., 2004). One reason for this is the failure to discriminate between visual function and vision related QoL in most evaluations (Binns et al., 2012). For example, the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ) is the most widely used outcome measure when evaluating LVR and includes questions about function in addition to more general QoL items. Evidence suggests that it is the items related to function rather than the more general QoL items that show the greatest sensitivity to interventions (Binns et al., 2012).

Self-management programmes and educational interventions are the only forms of LVR which have been reported to have the potential to improve QoL in patients with low vision (Binns et al., 2012). These interventions may therefore be key to helping older individuals manage vision impairment on a day-to-day basis. Brody, Roch-Levecq, Gamst et al. (2002) conducted a RCT of an AMD self-management programme. Patients were assigned either to a 12 hour AMD self-management programme covering behavioural (i.e. skills training and behaviour modelling) and cognitive components (i.e. providing information about biological processes and available aids), 12 hours of tape recorded education, or a waiting list. When control groups were combined the study found significant improvements in mood and function in the

self-management programme group. In addition, those who were depressed at baseline showed significantly greater improvements than those that were not depressed at baseline. Further research into this programme found a sustained improvement in mood and function after six months. An unexpected finding was that those who received the programme were less likely to become depressed in the six months following the intervention (Brody, Roch-Levecq, Thomas, Kaplan, & Brown, 2005).

Birk, Hickl, Wahl et al. (2004) have also provided support for the positive impact of education based intervention programmes for patients with AMD in Germany. The authors designed a six module programme aimed at improving psychosocial outcomes (emotional and behavioural) covering topics including: progressive muscle relaxation; exchange of disease related experiences; understanding the connections among thought emotion and behaviour; description of, and emphasis on, the use of available resources; improvement of general problem-solving skills; and information exchange of treatments and rehabilitation options. The participants in the programme showed improvements in five out of the six outcome measures (decreased negative affect; increased perceived autonomy; improved activities of daily living; increased active problem orientation; and decreased depression) only the measure of positive affect failed to show any improvement. Positive and negative affect were measured using a German version of the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). The reason for changes in negative affect only could be due to the intervention working to improve negative affect while positive affect remained stable. This is similar to the finding of Brody et al. (2002) discussed above in which patients with higher levels of depression benefitted most substantially from the intervention.

Dahlin-Ivanoff, Klepp & Sjostrand (1998) ran and evaluated a health education programme for AMD patients based on the Health Belief Model (HBM; which proposes that a person's decisions about taking health-related action are determined by their perceptions of; susceptibility to disease, severity or seriousness of disease, benefits of health action, and barriers to performing action). In this study the HBM was slightly modified, firstly self-efficacy was included, and secondly, as the participants had already been diagnosed, perceived susceptibility was replaced with acceptance of diagnoses. A sample of 45 older people with AMD took part in the intervention which consisted of two to three hour weekly meetings held over eight weeks. The programme covered information and skills training in the areas of: self-care, meals, communication, orientation and mobility, food preparation, shopping, financial management and cleaning. Focus groups were employed to evaluate the intervention which indicated improved or maintained security in daily occupations for the participants. Despite reported improvements there were some indications that participants did not understand all

the information given and participants highlighted the need to consider the amount of variation in visual acuity within the programme groups. Positive aspects of the programme discussed by the participants were social support, regained hope and the opportunity to meet others with the same disease. It could be that these elements of the programme were more effective than the content of the intervention itself. The reference to regained hope highlights that patients need more than just information to improve their experience with the condition. There is a clear need for research that goes deeper than the prescriptive content areas provided within models such as the HBM, this research highlights that the experiences of patients are important when understanding the ways in which older people make sense of and adjust to their lives with vision impairment.

The evidence discussed has indicated that group based LVR interventions may be more effective than individual interventions for older patients. One explanation for this may be that the skills acquired during group interventions enable participants to continue to meet new challenges as their vision deteriorates (Binn et al. 2012). In addition, other aspects of group programmes which may be beneficial for patients include the social support aspect of the interventions, for example having supportive friends and relatives and being involved in support services and social activities have all been suggested as factors which enhance QoL in older people with vision impairment (Wong, Guymer, Hassell, & Keeffe, 2004). Qualitative in-depth experiential research would help to understand the experiences of patients and the aspects of interventions which are of most value to the patients themselves and could also help to understand the key reasons why these types of intervention fail with some individuals (i.e., presence of co morbidities, access problems, etc.)

### **1.2.5 Impacts of AMD**

Quantitative research has indicated that individuals with AMD suffer from: decreased QoL; decreased levels of well-being; increased psychological distress (including depression); and health related disability (Augustin, Sahel, Bandello et al., 2007; Berdeaux, Nordman, Colin & Arnould, 2005; Brody, Gamst, Williams et al., 2001; Chia, Wang, Rochtchina et al., 2004; Esteban, Martinez, Navalon et al., 2008; Williams, Brody, Thomas et al., 1998); these findings are comparable with individuals with other serious illnesses such as arthritis, chronic obstructive pulmonary disease, cancer and stroke (Williams, et al., 1998)

Functional limitations are frequent in patients with AMD. For example, reading is a common hobby for many older people and ability to read has been highlighted as one of the major problems for individuals with AMD (Hazel, Petre, Armstrong, Benson & Frost 2000). In addition, Hazel et al. (2000) reported that text reading speed has been found to correlate highly with concern about vision. Reading is often more than a pastime and plays an

important role in day-to-day life, for example, reading plays a key role managing medications, preparing meals, carry out shopping etc. Another commonly reported functional limitation is the ability to drive; for example research using self-report questionnaires has found that individuals with AMD report more difficulty on driving subscales of health related QoL measures (Berdeaux, et al., 2005; Clemons, Chew, Bressler & McBee 2003). Qualitative research has suggested that this reduction in the ability to drive may also lead to individuals feeling that they are losing their independence (Owsley, McGwin, Scilley et al. 2006). More research could be done to investigate the impact of loss of function on patients' day-to-day lives and how this may change over time. For example, adaptation to vision impairment could play an important role in patients' understanding of these experiences and the way in which they impact on QoL.

Dissatisfaction with ability to engage in valued daily activities is likely to lead to depression in patients with AMD (Rovner, Casten, Hegel, Hauck & Tasman 2007). Prevalence of depression in AMD patients has been suggested to be around twice that of other community dwelling adults (Brody et al., 2001) and nearly a third of patients with AMD are likely to be depressed (Brody et al., 2001; Rovner and Casten, 2002). Rates of depression may differ depending on the type of AMD diagnosed, for example, patients with wet AMD have been reported to have significantly more depression symptoms than elderly controls without AMD and with no other ocular pathology (Cruess, Zlateva, Xu et al., 2007) and higher levels of depression appear to be associated with poorer visual acuity (Augustin et al., 2007). Little research reports depression rates of patients with early AMD, however as visual acuity is likely to be closer than those with no AMD patients with early dry AMD may be less affected. Interestingly some research has indicated that individuals with severe vision loss in both eyes exhibit less emotional distress than those with vision loss in only one eye. This may indicate the possibility of adaptation to blindness in some patients (Williams et al., 1998). Depression has also been found to predict cognitive decline and dementia in patients with AMD (Rovner, Casten and Leiby, 2009) and depressed individuals with visual impairment are at risk of health decline and further disablement without early interventions being put in place (Jones, Rovner, Crews et al., 2009). Worryingly, visual impairment in elderly people has also been found to be a risk factor for suicide (Waern, Rubenowitz, Runeson et al., 2002). Depression is therefore an important element of the experience of AMD for many patients and while much is known about the prevalence of the condition less is known about the day-to-day impact. In-depth qualitative research may be able to investigate this further and shed light on the ways patients may be able to manage and adapt to vision impairment and in turn avoid depression.

A common and distressing side effect of AMD is called Charles Bonnet Syndrome (CBS) (Jackson and Ferencz, 2009). Individuals with CBS experience visual hallucinations which are unrelated to underlying pathology (Menon, 2005). Most commonly observed images are of adults or children and are described as detailed and clear compared to their blurred images of the real world (Menon, 2005). Prevalence is estimated to be between 10-38% in older individuals with visual impairment (Jackson, Bassett, Nirmalan et al., 2007) with one study reporting prevalence to be as high as 63% (Menon, 2005). The condition frequently goes unrecognised in clinical practice as many patients are unwilling to admit to hallucinations due to fear of being stigmatized or labelled as mentally unstable (Menon, 2005; Vojnokovic, Radeljak, Dessardo et al., 2010) despite having insight into the unreality of their visions (Menon, 2005). For example, one study has reported that participants were reluctant to volunteer information about visual hallucinations without direct questioning on the subject (Menon, 2005). There is a lack of awareness by HCPs regarding the condition (Vojnokovic et al., 2010) despite evidence that, by recognising reports of these hallucinations as symptoms of visual impairment, it is possible to avoid misdiagnosis of psychosis, cognitive decline, and medication side effects and avoid possible mismanagement (Jackson, et al., 2007). It is important to be aware of this potential co morbidity of AMD as elderly patients with visual impairment may be considerably distressed by their visions and may be comforted by reassurance that their symptoms do not represent any sinister pathology (i.e., mental health problems or the development of dementia) (Menon, Jayakrishna, Rahman et al., 2003).

#### ***1.2.5.1 Impacts on wellbeing and quality of life***

Given the functional and emotional impacts of AMD discussed above it is clear that the condition has the ability to impact drastically on an individual's QoL. However, It has been reported that HCPs and members of the general public may greatly under-estimate the impact of AMD on health related QoL when compared to ratings made by patients themselves (Stein, Brown, Brown, et al., 2003).

Disease severity may play an important role in mediating the impact of AMD on QoL, for example visual acuity in the better eye may be a major determinant of QoL (Berdeaux, et al., 2005; Leys, Zlateva, Shah, Patel, & Ocular, 2008). Berdeaux et al, (2005) reported a specific impact of worst eye visual acuity on some dimensions of QoL: mental health; colour vision; dependency; and distance activities. Therefore treatment of the worst eye may be vital to ensure good vision related QoL in AMD patients. However, contradictions regarding the impact of bilateral and unilateral impairment on QoL have been reported. For example, qualitative research has indicated that AMD can have less impact on QoL when unilateral (Wong, et al., 2004) while quantitative research has suggested bilateral impairment causes

less emotional distress than unilateral, indicating the possibility of adaptation to blindness in some patients (Williams, et al., 1998). Reasons for these contradictions may lie in the methods of data collection used in these studies and the individual life contexts of the participants involved. It is evident that more research is needed to explore the possible differences between patients with differing levels of vision impairment resulting from AMD.

Many studies have investigated the impact of a variety of treatments on QoL in AMD. One study which evaluated the impact of photodynamic therapy (PDT: a previously used treatment for AMD) on QoL found that at one year follow up there were significant decreases in some QoL items and patients were also significantly less anxious and more independent outdoors (Armbrecht, Aspinall and Dhillon, 2004). In addition, macular translocation (another potential AMD treatment) has been found to improve self ratings of QoL when measured by the NEI-VFQ pre and post surgery (Cahill, Stinnett, Banks et al., 2005). Interestingly it has also been reported that after macular translocation patients may report improved visual function despite no significant improvement in visual acuity (Nguyen, Besch, Bartz-Schmidt et al., 2007) though this may be a reflection of the unvalidated nine item measure used to rate visual function rather than a major change in patient experience. A weakness of these quantitative designs is that they are unable to suggest the possible reasons for improvements such as this. The employment of qualitative methods alongside this study may have been able to improve understanding of this finding.

Little research has investigated the effects of treatable compared to untreatable AMD on QoL. While research into visual impairment has indicated that individuals with non-correctable impairment have lower SF-36 (a health survey including physical and mental health summary measures) scores than individuals with correctable visual impairment, and that increasing severity of impairment is associated with significantly lower SF-36 scores in physical and mental domains (Chia, et al., 2004), the reasons for these differences are unclear. There is a gap in the literature around the relationship between the possibility of treatment for AMD and its impact on QoL. In-depth research in this area would provide a greater understanding of the impact of the disease as well as potentially helping to develop relevant support for those diagnosed with both forms of AMD.

### **1.3 Psychological research into health and illness**

Traditionally biomedical approaches have been taken to the study of health and illness. These approaches aim to understand the pathophysiology of the body and discover mechanisms for clinical treatment. In particular, medical research seeks to find ways to reverse illness and return the body to “normal” functioning or, if this is not possible, to control symptoms in order to minimise the impact on the body (Wellard, 1998). This approach to health and illness views

the mechanisms of disease as physical entities within the body which can be objectively studied. Taking direction from the natural sciences, medical research is therefore based on a positivist epistemology and is conducted in search of a single “true” account of reality.

In 1977 Engel sought to critique the medical model suggesting that it did not adequately reflect human experience. Engel proposed a holistic approach acknowledging that physical changes in the body did not occur in isolation. This biopsychosocial model argued that health and illness should be viewed as a consequence of physical, psychological and cultural variables, and has been the basis for much health psychology research. Health psychology is concerned with “the promotion and maintenance of health, the prevention and treatment of illness, the identification of etiologic and diagnostic correlated of health, illness and related dysfunction, and the analysis and improvement of the health care system and health policy information” (Matarazzo, 1980, p. 808). Health psychology has tended to adopt positivist epistemological assumptions and methods used by mainstream psychology and other health related disciplines, such as medicine, in order to gain recognition and respect within the wider scientific community (Murray & Chamberlain, 1999). Psychological research into health and illness has therefore mainly been conducted through attempts at objective measurement and the identification of statistical associations between psychological variables (Murray & Chamberlain, 1999).

Some psychologists have criticised traditional health psychology for readily accepting medical ideology, uncritically adopting medical concepts and focusing on individualistic views of health and illness (Lyons & Chamberlain, 2006). Critical health psychologists wish to develop research methods which seek to understand and explain social phenomena from a more naturalistic, contextual and holistic view point. This movement was led by human science approaches including a focus on discourse, narrative, and social representations. These approaches do not argue for a single fixed reality or ‘truth’ and instead assert that there are multiple truths represented by each individual’s perception and meaning making. An example of this is social constructionism which has played a key role in understanding narratives of health and illness by proposing that all research is historically, socially and culturally located. For social constructionists all talk or ‘text’ is produced to serve a purpose and is constrained within the context within which it is constructed, for example, the interaction between the participant and the researcher (Chamberlain, 2004). A famous example of this is the statement that there is “nothing beyond the text” (Edwards & Potter, 1992). The social constructionist perspective has been criticised by many authors who have argued that by purely focusing on language, the approach fails to adequately consider the role of embodiment, materiality and power in experience (Nightingale & Cromby, 1999). For

example, Burr (1999) argued that by asserting that all experience is constructed through language social constructionism is ignoring the status of personal experience and the role of embodiment as well as failing to allow for personal agency. Burr proposed that, rather than being controlled by the societal structures in which an individual lives, individuals are able to draw upon or resist these positions through discourse.

An alternative critical approach is phenomenological psychology which has embraced the role of personal experiences when attempting to understand health and illness. Phenomenological psychology has roots in the work of existential philosophers (e.g. Heidegger, 1962; Husserl, 1970). The central focus of this approach is the *lifeworld* (Husserl, 1970) which includes all aspects of experience within our everyday lives (i.e., objects, relationships, the body) and can be defined as a world “that appears meaningfully to consciousness in its qualitative, flowing given-ness; not an objective world ‘out there’, but a humanly relational world, full of meanings” (Todres Galvin, and Dahlberg, 2007, p.55).

A lifeworld-led approach to health care takes the perspective that the lives of individuals are key to understanding health and illness because the quality of human life cannot be quantitatively measured or defined (Todres et al., 2007). Therefore, all ‘objective science’ is viewed as a second-order knowledge system dependent upon individuals’ first-order personal experiences or *lifeworlds* (Husserl, 1970). Lifeworld theory takes a holistic view of experience in which everything is related; every moment, event or experience is always part of a bigger picture and related to other aspects of that picture (i.e. near is related to far, seen is related to hidden, and self is related to other) (Todres et al., 2007). Lifeworld-led health care is more than the patient-centred care emphasised within current NHS policy (i.e. DoH, 2005) which aims to involve the patient in decisions about care and give them ‘choice’ and agency. This approach to care has been criticised for taking the meaning of health, illness, suffering and wellbeing for granted and painting patients as simple ‘consumers’ of care (Dahlberg, Todres, and Galvin, 2009). Lifeworld-led health care instead conceptualises health and wellbeing as more than the absence of illness and acknowledges the ‘situated freedom’ (Heidegger, 1962) of patients. For many patients the meaning of health represents the ability ‘to be able to’, for example to carry out major and minor life projects and the presence of illness may represent a challenge to this aim (Smith & Lloyd, 2006) However, human beings can find possibilities for wellbeing and a good life despite the presence of illness, for example through coming to terms with the current possibilities and limitations placed on them within their own *lifeworld* (Dahlberg et al., 2009). Therefore in order to treat ‘illness’, health care professionals (HCPs) need to move away from the current ‘medical model’ which is focused on treating

'abnormalities' in the body towards a more holistic understanding of what health and illness means to patients and how the presence of illness may be impacting on patients' *lifeworlds*.

Phenomenological methods are one way of gaining in-depth information about the *lifeworld* which help develop understanding of both the possible shared dimensions of experience and the unique contextualised experiences of individuals. The study of individual *lifeworlds* can bring us closer to fully understanding the experience of health and illness and there is an expanding body of evidence in this area (i.e. Smith, Flowers and Larkin, 2009).

#### **1.4 Health psychology and chronic illness**

Health psychology has played a key role in research into chronic illness. For example health psychologists have conducted research into compliance or adherence to medical regimens, adjustment to illness and the assessment of quality of life (Wellard, 1998).

Compliance refers to the degree to which a patient follows medical recommendations (Wellard, 1998). It has been estimated that 50-75% of patients do not comply with medical advice (Wertheimer & Santella, 2003). Social cognition models have frequently been used by psychologists in order to attempt to explain compliance to recommended health behaviours. For example, the Health Belief Model (HBM: Rosenstock, 1966) was originally designed in order to explain compliance with medical recommendations (Becker and Mainman, 1975). The HBM proposes that a person's decisions about taking health-related action are determined by their perceptions of; susceptibility to disease, severity or seriousness of disease, benefits of health action, and barriers to performing action. This model takes a positivist approach to understanding compliance and fails to acknowledge the fluid nature of a patient's *lifeworld* within which adherence occurs. In terms of chronic illness the need to engage in health behaviours can be ongoing and ability to continue with these behaviours occurs within a person's constantly changing life context. Compliance to recommendations made by health care professionals is vital to ensure AMD patients preserve their remaining vision for as long as possible. For example, the use of vitamin supplements may slow the progression of the condition, while monitoring with the Amsler grid can help to ensure patients receive treatment for wet AMD at the earliest possible opportunity.

Another important area of research in relation to compliance is doctor-patient communication. Communication has been reported to be the least satisfying aspect of the doctor-patient encounter for patients (Ley, 1982). One reason for this in an ophthalmology setting is that the dialogue in consultations is frequently physician-centred rather than patient-centred (i.e., consultations are led entirely by the physician and comprising mainly of closed ended questions (Friedman, Hahn, Quigley et al., 2009). Good patient-provider communication can

result in: greater patient satisfaction, increased patient adherence to treatment, decreased patient anxiety and distress, improved mental health in doctors, and improvements in health promotion (Marks, Murray, Evans, et al., 2005). Communication between HCPs and older patients can be particularly problematic. Reasons for this include; lower levels of health literacy in older adults (Zamora & Clingerman, 2011), increased prevalence of sensory impairment, and reported ageism within the health care system.

For many years ageism has been prevalent in western society in which older people are often perceived as having low value and a high economic burden (Bowling, 2007). Despite the agreement of the government to make ageism in the health service illegal evidence of ageist practice is still being reported and it has been suggested that the move has been more of a political gesture than a commitment to improving services (Fitzpatrick, 2009). Ageism in the health service is evident in a variety of areas; HCPs may discount or trivialize medical problems of older people, inappropriately attributing their problems to the "natural processes" of aging (Greene, Hoffman, Charon et al., 1987), HCPs may be less likely to suggest offer certain services to older patients (Age Concern England, 2001; Greenfield et al., 1987), and HCPs may consider elderly patients more "difficult" to deal with than younger patients (Adelman, Greene, & Charon, 1991). Ageism such as this can affect the behaviour of health care professions resulting in poor care for older people, for example the Care Quality Commission (2011) report has highlighted that, in hospitals, staff members often fail to respect the privacy and dignity of patients and speak to patients in a condescending and dismissive way. Ageism may not only be found in the behaviours of HCPs but also in older people themselves. Levy (2001) suggested that a lifetime of exposure to implicit stereotypical attitudes in society can lead to older people directing stereotypes onto themselves. This 'implicit ageism' (Levy and Banaji, 2002) may operate on an unconscious level in which ageist assumptions are directed toward the self. For example, one major source of information regarding the levels of chronic illness and disability in the UK is the British General Household Survey (GHS). The GHS employs a single question to assess the prevalence of chronic health problems: "Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time". This question is problematic in the case of older people who often do not report conditions in response to this question as they see the acquisition of chronic illness as a 'normal' part of ageing (Martin, Meltzer, & Elliot, 1988; Sanders, Donovan, & Diepper, 2002). One way to combat this may be to encourage the involvement of patients in their own care, which is often important to individuals with chronic conditions (Bodenheimer, Lorig, Holman, and Grumbach, 2002). International qualitative research has indicated that many older people have a desire to be involved in their own care and a key facilitator to this

involvement is good communication from health care professionals (i.e. spending time with the patient and showing interest, giving clear information, being trustworthy and supportive) (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007).

Health psychologists have also attempted to understand psychological processes involved in the adaptation to chronic illness. However, the term adaptation has been ill-defined in the psychological literature (Schilling, Wahl, Horowitz et al., 2011). Traditionally research in this area has been based on cognitive models of stress such the transactional model proposed by Lazarus and Folkman (1984). In this model psychological stress occurs when the relationship between a person and their environment is experienced as taxing, exceeding their resources, and endangering wellbeing (Lazarus and Folkman, 1984). Therefore when a chronic illness is experienced the individual initially appraises whether the condition is non-threatening, potentially harmful, threatening to self-esteem, or challenging (primary appraisal), and then assesses their ability to cope with this threat or challenge with the resources available to them (secondary appraisal). This model would therefore argue that if an individual perceives that they have ability to cope with the stressors resulting from chronic illness then they will be able to successfully adapt. This association between 'coping' and adaptation in chronic illness has been criticised for implying that the individual plays an active role in adjusting to condition. It has been argued that adaptation in this context may also be achieved through a passive process of coping (Diener, Suh, Lucas, & Smith, 1999). This argument has been used to explain paradox effects reported in the health literature, such as disabled individuals reporting better well-being than expected (Lacey, Fagerlin, Loewenstein et al., 2008) and incidences of improved wellbeing when adapting to permanent rather than temporary disability (Smith, Loewenstein, Jankovic, & Ubel, 2009)

Despite fitting with health psychology's definition of health and illness, historically much of the in-depth and qualitative research into the experience of chronic illness has been conducted within medical sociology (Nettleton, 1995). For example, the theory of Biographical Disruption (Bury, 1982) illuminated the way in which being diagnosed with a disabling condition can have a disruptive impact on an individual's life. Symptoms resulting from disabling conditions can "disrupt the normal flow of everyday life and introduce a growing sense of uncertainty into it" (Bury, 1997, p. 124). Biographical disruption has three main factors: "the disruption of taken-for-granted assumptions and behaviours", "the fundamental rethinking of the person's biography and self-concept, and "the response to disruption involving the mobilisation of resources, in facing an altered situation" (Bury, 1982, p.169-170). Another example is the work of Charmaz (1983) who proposed that by seeking meaning in chronic illness patients' attempt to make sense of the feeling of a 'loss of self'. When a person

acquires a long standing illness the experience clashes with taken-for-granted notions of: the physical body, the individuals' sense of "normality"; and valued elements of the self and social relationships (Charmaz, 1983). Perceptions of 'normality' and challenges to 'normality' are therefore key to understanding many older peoples' perceptions of chronic illness.

### **1.5 Quality of Life and wellbeing in older age**

In health and health care research quality of life (QoL) is frequently used as the outcome measure for intervention evaluations and clinical trials; however the concept itself is frequently left undefined. Lack of consensus and ambiguity about the meaning of QoL (Bowling & Windsor, 2001) has led to difficulties in measurement and identifying the components of the multi-dimensional concept (Holmes, 2005). When definitions are provided, the concept is most commonly defined in terms of a functionalist perspective based on individuals' abilities to complete daily activities or fulfil expected social roles.

Holmes (2005) discussed the history of the term "quality of life", proposing that the term first entered the vocabulary after World War Two when it referred to "the good life" which was dependent on more than material wealth and included a wide variety of factors (employment, housing, environment, visual arts and health). Since then a variety of multidimensional models have been proposed which attempt to define the concepts relevant to QoL (i.e. Aaronson 1988; Lawton, 1983). More recently McCormick, Clifton, Sachrajda et al., (2009) have reviewed the evidence around the main factors influencing wellbeing and QoL in older people in the United Kingdom. This review reported that, after the age of 75, elements of wellbeing (physical and mental health, levels of poverty, risks for depression and levels of participation) are likely to begin to deteriorate. Based on a framework developed by Nazaroo, Greenwadi, Bajekal and Lewis (2005) the authors identified five 'essential elements' for ensuring wellbeing in later life: resilience (i.e. the ability to cope with stress and adversity); independence; health; income and wealth; and having a role and time to fulfil this role.

Much of the previous research into QoL has used a medical model which assumes the identification of risk factors can help predict future behaviours and therefore by developing interventions to modify risk factors we can treat ailments, improve QoL, and extend lifespan. These studies have mainly used quantitative methods and have frequently focused on negative outcomes (mortality, functional decline, etc.) and the risk factors for those outcomes (age, gender, co morbidities, etc.). Often health economists have used these outcome measures in order to make calculations about the quality of people's lives, for example through the production of a QALY (quality-adjusted life years). The QALY measure stresses four aspects of life quality: physical mobility, capacity for self-care, freedom from pain and distress, and social adjustment, and is intended to allow comparison of treatments for

different conditions (Culyer, Lavers and Williams, 1972). These measures are used by medical professionals to justify the withdrawal of treatment from individuals who need or want them if they believe they are not in the patient's best interests (Barnes and Mercer, 2010). Barnes and Mercer (2010) have highlighted the failings of these methods of decision making by describing an example of a patient living with a degenerative condition which leads to the loss of all physical abilities while remaining entirely cognitively aware. The patient was concerned that doctors would decide to withdraw artificial nutrition and hydration resulting in him experiencing dehydration while fully conscious. He therefore took the doctors to court to challenge their right to withdraw treatment. Initially the court ruled in the patient's favour, but this was later overturned by the General Medical Council. This enabled doctors to make all decisions about the patient's care and meant that even if a patient wished for treatment, the doctors could not be made to offer it (McLean & Williamson, 2007). Another example of a utility measure used to calculate the value of health care interventions is TTO (Time Trade Off). TTO is a method in which the patients are asked how many years in perfect health they would consider equivalent to their remaining life expectancy in the current health state. The National Institute of Clinical Excellence (NICE) have recommended the use of TTO methods for assessing the value of health care interventions (NICE, 2004). However, the reliability and validity of these measures, particularly with older patients, have been criticised for a variety of reasons such as the timing of administration (when participants are feeling most vulnerable during appointments) and the questions being particularly difficult for older participants given their shorter life expectancies.

Gabriel and Bowling (2004) recommended that in order to achieve a better understanding of QoL in older individuals, research must move beyond health and functional status to a broader definition based on concepts derived from the older people themselves. The authors conducted a national survey looking at QoL for older people in the United Kingdom. Quantitative and qualitative data were collected from 999 respondents. The key areas identified as being important for QoL in this sample included: social comparisons and expectations; personality and psychological factors (including the constructs of optimism and pessimism); health and functional status; individual social capital (including social activities); social contacts and prevention of loneliness; and wider social capital (in this study this related to the individuals perceptions of the quality of their surrounding neighbourhood) including the provision of services and the feeling of safety. Bryant, Corbett & Kutner, 2001 have also criticised traditional positivist models for too frequently focusing on function and failing to acknowledge the dynamic nature of ageing. Bryant et al. (2001) proposed a model of healthy ageing which highlights the dynamic nature of ageing as a process rather than a static entity to be observed at a single point in time (as many survey studies assume). From

conversations with older people Bryant et al. (2001) proposed that to age healthily requires the ability for older people to 'go and do' meaningful activity. The four factors which enable older people to achieve this goal include having: something worthwhile and desirable to do, the ability to accomplish the activity, the resources to support the activity, and sufficient will or positive attitude. This focus on 'going and doing' moves the definition of healthy ageing and QoL away from functional factors and the absence of disabilities towards the importance of older people's lived experiences and the ability to engage meaningfully in everyday life.

Research to promote healthy ageing needs to move away from a focus on illness towards a more holistic approach which aims to optimise older adults' life contexts and improve wellbeing. In addition, as the passage of time and fluidity of life contexts are important aspects of life experience (which quantitative methods often fail to address due to the prescriptive and predetermined categories used in this type of research), an approach to QoL and healthy ageing research is needed which is able to recognise and investigate non static and contextual elements of human existence and address longitudinal changes in health and wellbeing.

#### **1.6 Best Practice with AMD patients**

AMD has a high societal cost burden as patients report substantial health related problems and health resource utilisation. These include an increased risk of falling, provision of vision enhancing equipment, depression/anxiety treatment, and needing assistance with activities of daily living, all of which have associated medical costs (Cruess, Zlateva, Xu et al., 2008). The societal cost for the average health authority in the UK for the care of Wet AMD patients has been suggested to be around £7.4 million compared to only £1 million for equivalent patients without neovascular AMD (Lotery, Xu, Zlatave, & Loftus, 2007). In addition, research has suggested that neovascular AMD leads to a reduction in life expectancy by approximately two years (Bandello, Lafuma, & Berdeaux, 2007). It is therefore vital that patients receive the best possible care based on the best available evidence to reduce the impact of the condition on patients' lives and the financial cost to the health care system.

Two sets of guidelines are available regarding best practice when treating patients with AMD. The most recent guidelines written by the Royal College of Ophthalmologists were published in 2009 and a review of these guidelines is due to be completed in summer 2012. These guidelines have been produced to encourage best practice in the NHS and private sector, to inform the education of ophthalmology professionals, as a resource for patients and carers, and to help guide the commissioning of services. The guide covers information about the procedures for the diagnosis, treatment, and management of patients with AMD. In addition

NICE (2008) has published guidelines for the use of anti-VEGF treatments for patients with wet AMD.

Ranubizumab (also known as Lucentis) is recommended for the treatment of wet AMD (NICE, 2008). The criteria for treatment require the patient to have: vision between 6/12 and 6/96 (with normal visual acuity being 6/6) in the eye to be treated, no permanent structural damage to the central fovea, and evidence of presumed disease progression (such as blood vessel growth or recent changes in visual acuity). Initially the Lucentis was provided to the NHS in a cost-sharing programme, whereby the drug was provided free after 14 injections. However since May 2012 there has been a new agreement by which the price has been reduced and the cost-sharing scheme discontinued (NICE, 2012).

Ranibizumab treatment is administered as a 0.5mg dose which is injected directly into the eye during outpatient clinic appointments. Patients are initially given a loading dose of three injections over three months. After this patients are monitored on a monthly basis in clinic. If a patient exhibits a loss of five letters on the ETDRS scale (The treatment of diabetic retinopathy scale) or one Snellen line of vision (one line on a typical chart used by optometrists when testing vision; letters decreasing in size from top to bottom of the chart) this indicates a need for an additional dose. Prior to the cost reduction in 2012 the treatment costs were approximately £761.20 per injection before tax, this resulted in an approximate two year cost of £10,700 per eye treated (based on eight injections in year one and six injections in year two) or £18,300 per eye treated (based on twelve injections each year) (NICE, 2008). It is recommended that treatment should be continued if a patient meets the following criteria: there is persistent evidence of lesion activity, the lesions continue to respond to repeated treatment, and there are no contra-indications to continuing treatment (Royal College of Ophthalmologists, 2009).

At present there is no clear protocol for the discontinuation of treatment in patients who have a loss of adequate response to therapy and NICE (2008) recommend that this be developed. In addition, NICE have recommended further research be carried out in the long term effect of Ranibizumab treatment in patients with AMD, in particular in the areas of visual acuity, anatomical damage to the macular, adverse events, and QoL (NICE, 2008). While clinics are expected to monitor the clinical signs of AMD through tests of visual acuity (such as Snellen ratings) and the use of eye scanning equipment such as optical coherence tomography (OCT) and fundus fluorescein angiography (FFA), there are no guidelines for the monitoring of non-clinical issues relating to AMD. The Royal College of Ophthalmology (2009) guidelines specifically state:

*“The collection of quality of life data does not need to be undertaken routinely on patients’ receiving treatment for AMD. Quality of life data will be necessary to estimate cost effectiveness of treatment. Quality of life data may need to be collected as part of commissioning arrangements for patients receiving treatment”*

If this is the case it is therefore vital that the measures used to indicate patient QoL in these trials accurately represent the experiences of patients.

The Royal College of Ophthalmology (2009) makes specific recommendations for the management of chronic and long standing vision loss. They recommend that care is taken in the process of diagnosing patients, for example they state that patients frequently report failing to take in any further information after being given bad news. The guide therefore emphasises the need to provide information to patients and in particular recommends giving the patient both verbal and written information about the condition, available rehabilitation, and possible contacts for further information or services. They also highlight the danger of immediate discharge for patients who cannot be treated and the use of phrases such as “nothing more can be done” which can be unhelpful and distressing for patients. In addition, the guide recommends patients are offered rehabilitation and low vision services at the earliest possible point to enable patients the best support possible. Summaries of the management information included in the guide can be found in Table 1 and Table 2.

Prior to the existence of these guidelines it was evident that best practice was not always received by patients with AMD. In 2002, Mitchell, Bradley, Anderson et al., investigated the perceptions of health care services for patients with macular disease who were members of the Macular Disease Society (MDS). In response to a postal survey participants reported a variety of issues with the service received from their eye specialist and general practitioners (GPs). Dissatisfaction was common with individuals reporting that they felt HCPs were not interested in them as a person. In addition, the clinician’s attitude was most commonly cited as the cause of patient dissatisfaction. Many patients felt that they were not given enough information about the disease at diagnosis and some patients who approached their GPs, also found that the GPs were poorly informed about the condition. When GPs did have knowledge about the condition this was positively correlated with perceived helpfulness and supportiveness of the GP by the patient. Therefore the education of GPs in addition to patients is vital for improving the patient experience. Many participants reported being told “nothing can be done to help with your macular disease” (p. 779) and failed to be informed of available rehabilitation services, low vision aid provision, and training. This resulted in resignation, depression, and in some cases suicidal feelings in patients. While this study focused on patients with all kinds of macular disease, patients all shared negative experiences of health care services, and the majority of respondents were participants with

AMD. The authors proposed that a greater awareness of anxieties and a better provision of information by HCPs could improve this experience for patients. Even after the report of this study there were further reports of problems with the health care service provided to patients with AMD. For example, one study reported a need for more accurate information and education for AMD patients as well as a greater level of sensitivity shown by HCPs (Wong, et al., 2004). In addition, shock at diagnosis and a lack of information and support to cope with this was commonly reported by patients (Mitchell & Bradley, 2006).

No research could be found to address whether the implementation of the RCOphth and NICE guidelines had improved AMD patient experience in the UK. However, some survey evidence with regards to smoking cessation in an American clinic suggested that providers rarely asked about smoking status or offered cessation advice to their patients, and felt they needed more training to assist patients with stopping smoking (Caban-Martinez, Davila, Lam et al., 2011). In addition, this study suggested that very few of the patients were aware that smoking increased the risk of AMD or had been advised to quit by their HCPs (Caban-Martinez et al., 2011). Another American study reported that, despite evidence from the Age-Related Eye Disease Study Research Group (2001) which reported substantial benefits of the use of some vitamin supplements for some patients with AMD, many eligible patients were not taking the supplements. The study found that of 64 patients surveyed, 63% met the criteria for AREDS supplement recommendation, but only 43% were taking vitamins in the recommended doses. The most common reason for non-use of the vitamin supplements in this study was that patients reported never having been recommended to take the supplements by HCPs (Hochstetler, Scott, Kunselman et al., 2010). This study used self-report measures and it is possible that patients surveyed responded with what they thought the researcher wanted to hear and therefore this may overestimate the level of supplement use. In addition, some patients may have been using supplements but not at the recommended dose; the impact of this is unknown but may be beneficial when compared with no supplements at all. These studies illustrate that despite the availability of evidence, the recommendations often do not find their way into clinical practice. Communication between HCPs and patients appears to be poor, while advice may be given to patients in clinic it is clear that more research is needed to investigate patients understanding of this information and to ascertain reasons for potential non-adherence to recommendations made by HCPs. This information would be vital for developing new ways for HCPs to present recommended health related actions to patients.

**Table 1: Recommendations for diagnosis adapted from: The Royal College of Ophthalmologists (2009). *Age Related Macular Degeneration Guidelines for Management*. London: Royal College of Ophthalmologists.**

	<b>Observation made by RCOphth</b>	<b>Action to be taken in clinic</b>
<b>Breaking bad news</b>	Patients report that after receiving news that their eye condition is not treatable, they tend not to hear further information during the consultation.	Important that patients are given written information at the end of the consultation concerning their eye condition, available rehabilitation services and useful contact numbers.
<b>Avoid 'diagnose and immediate discharge</b>	Patients with macular disease who have lesions which are not treatable with current therapies are often seen only once in the eye clinic and then discharged. They can be unaware of what to expect in the future or where they can obtain relevant information or how to find their way through the maze of services and organisations.	Although there may seem little advantage in seeing the patient a second time, because most are not able to take in information after receiving bad news, a follow up visit is of benefit to receive further information and ask questions. They must be given contact details of someone they can come back and talk to. This may be an Eye Clinic Liaison Officer (ECLO).
<b>The clinic experience at time of diagnosis</b>	Patients frequently report that the diagnosis was given in an uncaring manner.	A good initial experience at the hospital will almost certainly help the patient's future outlook, expectations and achievements. A satisfactory patient experience can only be achieved by good training.
<b>Importance of signposting</b>	Receiving a diagnosis without the follow up information required regarding support services leaves patients feeling lost and isolated and not knowing where to find help.	Provide information about services such as visual rehabilitation officers, social services, local help groups such as the RNIB, and Macular Disease Society
<b>Provide literature in the clinic</b>	Patients appreciate being given information regarding their condition that can be read at leisure.	It should be the responsibility of staff in the clinic to make information leaflets available and ensure that patients are offered them before leaving.
<b>Staff Training</b>	Empathetic handling of a new diagnosis for a patient is a responsibility for the whole unit	Continuous staff training is needed. All staff in a unit should be aware of the impact of diagnosis on patients.

**Table 2: Information needs of patients adapted from: The Royal College of Ophthalmologists (2009). *Age Related Macular Degeneration Guidelines for Management*. London: Royal College of Ophthalmologists.**

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**Information needs of patients at diagnosis recommended by RCOphth:**

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**a. Clear diagnosis.**

- Patients should know the name of the condition causing their sight loss and whether they have early AMD or late AMD or a combination of these, preferably in writing as well as verbally.
- This means that when they are ready to seek further advice and information they are armed with this vital knowledge.
- A vague description such as 'you have an eye condition to do with ageing' is not acceptable.

**b. Vision prognosis**

- Patients should be told the outlook for their vision, whether it may develop in the second eye and if it is 'dry' whether it could become 'wet'?
- Education regarding the second eye must be given. Patients must be informed that if they develop distortion or blurring in their second eye then they need to know how to get back in the system for urgent review.

**c. Treatment options if they exist.**

- All eye department staff need to be aware that even if treatment is not appropriate for a patient with sight loss, individuals can be helped by a range of non-medical supportive measures.
- Eye Departments wherever they are located need to be aware of what is currently available to treat AMD, and if not able to offer one of the current treatments they must make patients aware of the full range of treatments available both on the NHS and privately.
- Phrases such as "nothing more can be done" in a medical sense should be avoided as this terminology can be devastating and unhelpful.
- Interventions which can help the individual come to terms with their sight loss, retain their independence, and improve their function and quality life include information about the condition and prognosis, emotional support, counselling, a low vision assessment and practical input such as rehabilitation covering daily living skills, mobility and the benefits of lighting, colour and contrast in maximising the use of residual sight.
- All staff and the patients need to be aware of the need to treat exudative AMD urgently. Patients should be told to contact the clinic if they have not received an appointment for treatment or further assessment within 2 weeks.

**d. Hallucinations -Charles Bonnet Syndrome (CBS).**

- Patients may become severely distressed by the thought that CBS symptoms may mean they could be developing a serious mental illness.
- Anxiety is more damaging than the hallucinations themselves.
- Patients should be alerted to the possibility of CBS which typically improves by 18 months but can last many years.

**e. Risk and improvement factors.** Patients should be alerted to the risk factors:

- Smoking** is a recognised risk factor for both dry and wet AMD. All patients with macular degeneration
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should be advised to stop smoking.

**-Diet and nutrition.**

- Patients should be advised to eat a diet rich in fruit and vegetables (sources of antioxidant vitamins), include oily fish (source of omega-3 fatty acids) and sources of lutein/zeaxanthin (fruit and vegetables and eggs).

- Patients can also be advised about nutritional supplements: There are now many a vast number of different nutritional supplements for eye health available. Only the AREDS formula is proven to be beneficial in people with intermediate and advanced AMD.

**- Bright sunlight**

-patients with AMD are severely affected by the glare of sunlight and therefore good quality anti-glare lenses are essential.

**f. Continuing ocular exams**

- The importance of ongoing regular eye examinations must be clearly explained to the patient, especially if they are likely to be discharged from the hospital system.

- Individuals should be advised to attend their optician at least every two years or more frequently if relevant.

**g. Date of next appointment**

-Patients should know if they are discharged or still on the books

**h. Change of vision.**

-Patients must be advised what they should do if they experiences a sudden change in vision.

- The eye department staff must be aware of the need for this group of patients to be seen urgently.

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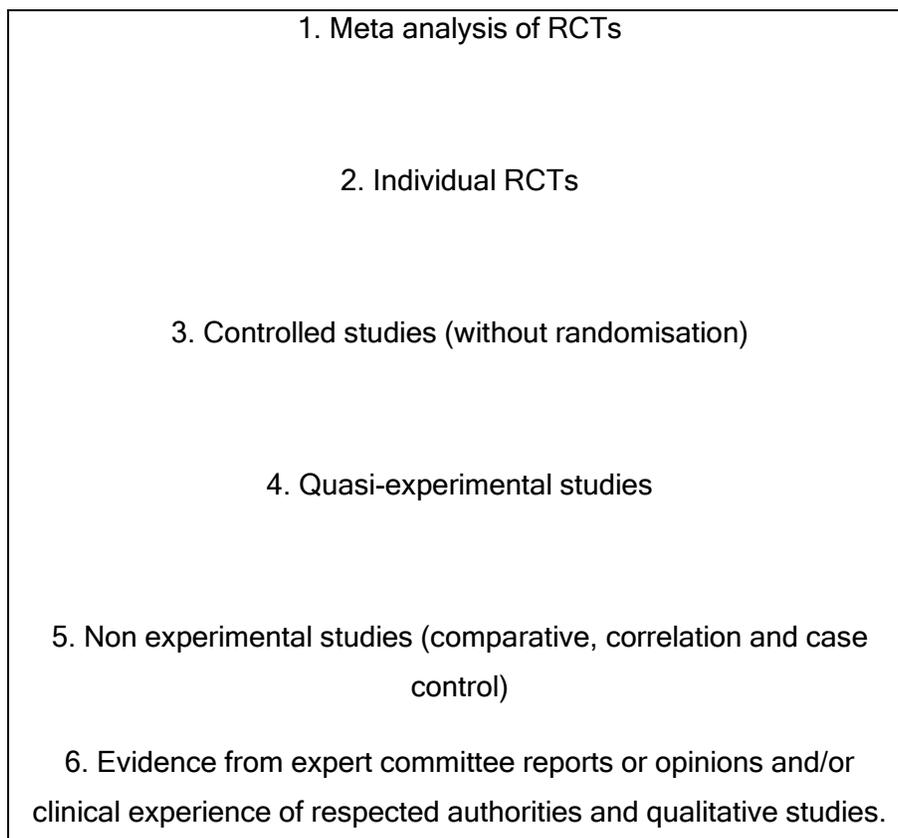
## **1.7 Evidence Based Practice**

The discussion above has indicated that, while guidelines exist for the management of patients with AMD, often the recommended information and guidance does not get through to the patients themselves and does not translate into changes in patient behaviour. One of the reasons for this may be that only certain types of evidence get through to HCPs and patients. Recommendations for practice in the UK are disseminated via reviews conducted by organisations such as the National Institute of Clinical Excellence and the Cochrane Collaboration. These guides are informed by Evidence Based Practice (EBP) which has evolved from Evidence Based Medicine (EBM) and argues for the use of current best evidence in making decisions about the care of individual patients through the integration of clinical expertise with the best available systematic clinical research (Sackett, Rosenburg, Grey et al., 1996).

EBP has developed dependent on the positivist medical model which follows the assumptions of the natural sciences and argues that research can be a value free process whereby

objective knowledge ('truth') can be gained through empirical methods such as direct observation and measurement. Positivism therefore asserts that there is a single reality or world which exists independently from individual perception of it. This epistemological stance privileges certain types of evidence over others, for example RCTs are placed at the top of the NICE hierarchy of evidence (Figure 1).

Figure 1: NICE Hierarchy of evidence



Reliance solely on the methods of the natural sciences is problematic as “the epistemological, ontological and methodological assumptions considered appropriate for clinical medicine may be inappropriate for non-biomedical health and social care” (Marks, 2002 p. 7). Many evidence based practitioners have begun to acknowledge that randomised controlled trials are unable to answer many of the questions necessary for improving interventions and practice (i.e. Sackett & Wennberg, 1997) and it is becoming increasingly accepted that other forms of evidence can and should contribute to the knowledge base (Shaw, 2012).

One major flaw in the reliance on a positivist epistemology in work related to the human sciences is the assumption that objectivity is possible. Even when attempts to remain objective in research are made, it is generally accepted that observations and descriptions are selective and dependant on the researcher’s interests (Willig, 2008). All evidence is

therefore a product of a long line of assumptions made by the researcher including choices about epistemology, theory, methodology, and methods (Crotty, 1998). The impossibility of true objectivity means that in order to inform practice and policy a pragmatic approach to research is needed. Pragmatism provides a philosophical basis for research which is not committed to any specific theory about reality and holds the following assumptions: researchers are free to choose techniques which best meet their needs and purposes; the world is not an absolute unity; truth is what works at the time; research occurs in social, historical, cultural and political contexts; and that there is an external world independent of the mind as well as lodged within the mind (Creswell, 2009). Pragmatism's central thesis is that knowledge is functional and that methods for achieving it are not set within a hierarchical structure with one method superior to others. Success and quality of pragmatic research is therefore judged in terms of whether the methods used were successful in answering the question set.

The literature review above has indicated that questions related to health and illness and the care of patients need to explore more than the use of RCTs alone will allow. Detailed in-depth research about the understandings and meanings given by patients to their experiences is needed in order educate both HCPs and patients to ensure the best possible care. As has been explained, EBP advocates the combination of the best available evidence with clinical experience, therefore experiential knowledge is already playing a key role in decisions about the management and treatment of chronic illness. At present clinicians rely solely on their own immediate clinical experience which may not be the best evidence for each individual patient. By incorporating in-depth, transparent, and systematic qualitative work into the knowledge base it is possible to take this further to include patient's experiential knowledge.

A key strength of the phenomenological approach is that it champions the human individual as the starting point for human science (Todres, 2003). This in turn ensures that practice and policy are informed by an empathic understanding of what people go through and that interpretations are grounded in the *lifeworld* of actual experiences (Todres et al., 2007). Therefore, in addition to evidence provided by RCTs, the incorporation of focused experiential research into EBP guidelines would expand HCPs experiential knowledge beyond that of their own immediate experience and in turn improve the quality of practice for patients.

### **1.8 The argument for mixed methods AMD research**

Improving the care of patients with AMD requires research answering a range of complex questions relating to QoL and the experience of living with a long term and deteriorating condition. Taking a pragmatic approach and utilising methods most suitable for individual research questions posed will ensure that improvements to EBP guidelines can be made. In

particular the inclusion of health psychology methods which acknowledge the physical, psychological, and contextual nature of AMD are vital for informing EBP and helping to develop services and information that will improve the QoL of patients living with AMD. Despite the presence of holistic frameworks such as the biopsychosocial model (Engel, 1977) within health psychology, the adoption of medical science methods and reliance on quantitative measures means that research is often conducted in isolation from real world life contexts and life worlds. These approaches do not fully reflect individuals' experiences of illness and health care environments (Crossley, 2000). Therefore, the incorporation of qualitative and quantitative methods is required in order to answer a wide ranging research questions regarding AMD and ensure that practice and policy is based on the best available evidence.

### **1.9 Statement of epistemological stance**

Throughout this thesis a pragmatic approach to knowledge is taken. Practical consequences are key to pragmatic approaches, and theories are therefore 'true' to differing degrees dependent on how well they 'work' to address the research question or problem posed (Dures, Rumsey, & Morris, 2010). Pragmatism is able to address the concerns of both quantitative and qualitative researchers as "all human inquiry involves imagination and interpretation" (Yardley and Bishop, 2008: p. 355) and intentions and values must be "grounded in empirical, embodied experience" (p. 355). Using pragmatism as the base for developing mixed methods gives researchers the flexibility to conduct investigations using the tools needed to answer specific research questions. By conducting research pragmatically and combining aspects of both qualitative and quantitative methods in order to answer specific research questions it is possible to gain a more complete understanding of what it is like to live with conditions such as AMD. No single method is viewed as inherently superior to another as there are multiple ways of making sense of the world and multiple standpoints on what is important or valuable (Green, 2008). Pragmatic approaches are therefore able to acknowledge the complex nature of the social world which includes both 'interpretivist' and 'positivist' phenomena (Sale, Lohfeld, & Brazil, 2002) and highlight the need to develop a holistic understanding of phenomena based on the varying dimensions of which it is comprised.

### **1.10 Rationale for This Thesis**

The objective of this project was to explore the experience of living with AMD and the ways in which the condition may impact on QoL over time. This project aimed to fill the gaps in the literature on the experience of living with AMD and its impact on QoL by using a variety of methods. A total of six studies which take a longitudinal mixed methods and pragmatic

approach to answering the overarching research questions are presented in order to provide a fuller picture on the nature of living with AMD. Data collected and analysed include literature reviews, questionnaire responses, and in-depth qualitative interviewing. Little qualitative research has been conducted in the area and in particular there is a dearth of research employing a longitudinal design. This type of research is vital to developing a greater understanding of the experience of living with AMD and its impact on QoL.

By choosing to use a longitudinal mixed methods design this research is able to add to the existing literature in a way which has been rarely used in the past. Most research into AMD has focused on either qualitative or quantitative methods in order to answer research questions. The adoption of mixed methods enables this research to explore novel research questions such as the applicability of QoL questionnaire measures for assessing the impact of treatment on AMD. Questions such as these would not be able to be explored with the use of a single method.

The design of the overall project uses both qualitative and quantitative methods, however the balance of these two methods is not split equally. The project is more heavily focused on the qualitative methodology in order to develop an experiential understanding of living with AMD. This is due to the inability of quantitative methods to capture the intricacies of patient experiences. Qualitative methodologies are more suitable for answering many of the research questions raised during the progression of this thesis and ensure the research takes a *lifeworld* led approach to understanding the experience of living with AMD.

### **1.10.1 Overarching research questions**

There are several overarching research questions that this project aimed to answer in addition to more focused questions at each stage of the research. The overarching research questions were as follows:

What is it like to live with age related macular degeneration?

How might living with age related macular degeneration impact on quality of life?

Does the experience of living with macular degeneration change over time?

In what ways might the experience of living with macular degeneration be different for individuals with treatable or untreatable forms of the condition?

## Chapter 2: Methodology

### 2.1 Introduction

Given the wide ranging nature of this research project, it was necessary to develop a methodology with the flexibility to answer the developing research questions. This section provides a justification for the use of mixed methods and a pragmatic approach as the guide for this research.

#### 2.1.1 Mixed methods research

As discussed in the previous chapter, evidence based health care needs to utilise the methods best suited to acquiring the knowledge needed to inform health care practice. Quality of life (QoL) is a difficult concept to define and as a result the use of purely quantitative or purely qualitative methodologies may be insufficient for understanding the full experience of AMD and its impact on QoL. Mixed methods may be a more appropriate approach to this research as it has been proposed that mixed methods designs have numerous benefits including: the ability to answer research questions which single approach designs cannot; the provision of better or stronger inferences from research findings; and the opportunity to present a greater diversity of views within a single study (Tashakkori & Teddlie, 2003).

Mixed methods research is a relatively new development in psychology and health sciences. Traditionally a dualism has been evident, portraying qualitative and quantitative research as representing two incompatible paradigms (Kuhn, 1970). Todd, Nerlich and McKeown (2004) discuss in their introductory chapter to 'Mixing Methods in Psychology: The integration of qualitative and quantitative methods in theory and practice' the longstanding debate between the two methods;

*'Whereas qualitative researchers accuse quantitative ones of positivism, reductionism, determinism and objectivism, quantitative researchers accuse qualitative ones of fuzziness and subjectivity' (p. 5).*

It has been argued that qualitative and quantitative research hold different paradigmatic assumptions regarding; reality (ontology), what we can know about that reality (epistemology), and how we can know about that reality (methodology) (Sale, Lohfeld & Brazil, 2002). This 'incompatibility thesis' (Howe, 1988) has advocated that qualitative and quantitative research methods could not, and should not, be mixed. However, many researchers have contested this arguing that quantitative and qualitative research methods may have more similarities than differences (however epistemological differences do make it

difficult to reconcile some differences, for example, the use of survey methods with discourse analysis) (Bryman, 1992; Onwuegbuzie & Leech, 2005; Yardley & Bishop, 2008).

It has been argued that combining methods within the same study enables researchers to develop a more holistic understanding of phenomena and may uncover conclusions which purist methodologies would be unable to access (Jick, 1979). Traditionally 'triangulation' has been a key concept in the use of mixed methods and involves "the combination of methodologies in the study of the same phenomena" (Denzin, 1978 p. 291). Originally triangulation was argued to be able to highlight the flaws and biases in measurement through the comparison of the findings of different methods (Frost & Bowen, 2011). This use of triangulation supports the positivist assumption that research is able to identify a single "truth" which can be validated through agreement between methods. In contrast more critical approaches, which acknowledge the complex and multi-faceted nature of individual *lifeworlds*, argue that triangulation serves a different purpose. For example through 'integration' the different paradigmatic assumptions inherent in different methods can work synergistically to produce a whole which is greater than the sum of its parts (Moran-Ellis, Cronan, Dickinson et al., 2006). This approach acknowledges the differences in the ontological and epistemological claims of different paradigms and asserts that these inherent differences prevent the results of one method being claimed as validation for the other. Instead the combination of the differing epistemological claims can be used to develop multi-dimensional understandings of phenomenon which exist within a multi-faceted and complex social world (Frost & Bowen, 2011).

The value of utilising both qualitative and quantitative approaches is becoming more accepted and there is an argument to find ways to combine the methods rather than separate them. One way to combine methods is through the use of a pragmatic theoretical perspective which has played an important role in the development of mixed methods research (Creswell, 2009; Howe, 1988; Tashakkori & Teddlie, 2003; Todd, et al., 2004; Yardley, 2001; Yardley & Bishop, 2008).

## **2.2 The case for pragmatism**

Pragmatism stems from the work of the philosophers John Dewey, George Herbert Mead, and William James (Johnson & Onwuegbuzie, 2004) and provides a philosophical basis for research which is not committed to any specific theory about reality. Pragmatism holds the assumptions that: researchers are free to choose techniques which best meet their needs and purposes; the world is not an absolute unity; truth is what works at the time; research occurs in social, historical, cultural and political contexts; and that there is an external world independent of the mind as well as lodged within the mind (Creswell, 2009). Practical

consequences are key to pragmatic approaches, and theories are therefore “true” to differing degrees dependent on how well they ‘work’ to address the research question or problem posed (Dures, Rumsey, & Morris, 2010). Yardley and Bishop (2008) proposed that pragmatism is able to address the concerns of both quantitative and qualitative researchers as “all human inquiry involves imagination and interpretation” (p. 355) and intentions and values must be “grounded in empirical, embodied experience” (p. 355). Using pragmatism as the base for developing mixed methods gives researchers the flexibility to conduct investigations using the tools needed to answer specific research questions. It also allows researchers to pay attention to data which would be unwanted and ignored in single methods research (i.e. scribbled explanations to answers given in multiple choice questionnaires).

By conducting research pragmatically and combining aspects of both qualitative and quantitative methods in order to answer specific research questions it is possible to gain a more complete understanding of what it is like to live with conditions such as AMD. A pragmatic stance ensures that no single method is viewed as inherently superior to another and acknowledges that there are multiple ways of making sense of the world and multiple standpoints on what is important or valuable (Green, 2008). Pragmatic approaches are therefore able to acknowledge the complex nature of the social world which includes both ‘interpretivist’ and ‘positivist’ phenomena (Sale, Lohfeld, & Brazil, 2002) and highlight the need to develop a holistic understanding of phenomena based on the varying dimensions of which it is comprised. Phenomenological methods can facilitate this aim by developing in depth experiential understandings of health and illness in order to understand different ways individuals make sense of phenomena.

### **2.2.1 Phenomenology**

Phenomenological approaches to analysis are committed to developing an understanding of individuals’ points of view and attributions of meaning. Phenomenology subscribes to the view that there is a ‘real’ world which exists independently of our consciousness and that we can gain direct access to this world via our senses. However, our experiences of the world are dependent on our interpretation of the information gleaned by our senses and therefore represent interpretations of ‘phenomena’ rather than direct experience of the thing itself as it exists independent of our consciousness of it. The way individuals make sense of the world is dependent upon the interaction between the ‘real’ world as it exists and our cognitive interpretations and appraisals of the ‘thing’ of which we are conscious. Husserl (1927) used the term ‘intentionality’ to explain the way in which consciousness is always consciousness of something (e.g. an object, a memory, an imagination) and consequently bound to the real

world. Therefore, the task of the researcher is to examine the process of 'sense making' by individuals as this is key to understanding human behaviour (Giorgi, 1995).

Phenomenology has developed in distinct directions and there have been two key phases: transcendental, and existential. Descriptive phenomenological approaches (i.e. Giorgi & Giorgi, 2003) have been heavily influenced by Husserl's (1927) transcendental phenomenology which is concerned with utilising a process of methodological 'reduction' in order to identify the essential core structures of experience or 'essences'. The term transcendental relates to the requirement to 'transcend' everyday assumptions. In order to achieve this aim researchers are required to 'bracket' prior assumptions and engage with the universal essence of phenomena as they present themselves to consciousness. By stepping outside of this 'natural attitude' the researcher is able to take on a 'phenomenological attitude' which involves a move from focusing on objects in the real world to reflexively analysing our perception of those objects. Husserl asserted that science is a second-order knowledge system which is unable to exist without access to the first-order taken-for-granted everyday personal experiences or *lifeworld* of individuals.

Later phenomenological writings developed with a focus on an existential as opposed to a transcendental approach (i.e. Heidegger and Merleau-Ponty). Existential phenomenology argues that 'bracketing' and 'transcending' everyday assumptions can never be fully achieved as our observations are always made from somewhere and therefore focus on understanding 'existence' as lived. This is of particular interest in the area of chronic illness research as diagnosis with chronic illness can fundamentally alter a persons' understanding of their existence (e.g. Bury, 1982; Osborn & Smith, 1998). One example is the way that chronic illness can have important implications for the way in which individuals view their own bodies. This was discussed by Merleau-Ponty (1962) who stressed the importance of context in understanding experience and focused on the way in which experiences are always embodied. Merleau-Ponty's work highlighted individuals as 'body-subjects' whereby the body is not an object in the world but instead a means of communicating with the world and proposed that while we can observe others and feel empathy towards them we can never entirely understand or share their experience as it is dependent on their own embodied position within the world. An understanding of the ways in which patients view and understand their bodies is vital in research investigating the impact of chronic illness, for example patients with multiple sclerosis have described the way in which illness can impact on not only the body but also the relationships between body, self and others (Finlay, 2003a).

In addition to the importance of the body existential phenomenology has also highlighted the importance of life history and human development in understanding and making sense of

experiences (Heidegger, 1962; Sartre 1956/1943). According to Sartre (1956/1943) the self is not a pre-existing entity which can be discovered through research but is instead an ever changing project of the individual. For example, patients are often required to renegotiate their sense of self following the onset of chronic illness (e.g. Charmaz, 1983). The occurrence of AMD in older people may have a particularly great impact on an individual's sense of self when considered within a patient's life history as a 'sighted' individual and the wider ageing process (Mogk, 2008).

Heidegger's (1962) main focus was on the ontological question of existence itself and the way in which existence becomes meaningful. Heidegger used the word 'Dasein' (there-being) to describe the situated quality of being and proposed that individuals are inextricably linked with the world (being-in-the-world). 'Dasein' has a number of key features which are fundamental to human existence (Langdrige, 2007). The first feature is "temporality", or our experience of time. Time is a fundamental part of our existence and our understanding of present experiences is also informed by our past and the projection of our future. Langdrige (2007) explains this in terms of our constant attempts at 'selving', whereby throughout our existence we are attempting to make sense of ourselves and others. However this attempt at "selving" is limited by our "facticity" (the way in which 'Dasein' is thrown into an already existing world of objects, language and culture) and therefore while we are attempting to create ourselves we are also limited by the physical, psychological and social factors of the world in which we live. Heidegger (1962) also argued that, as we are always linked with the world, our quest to find meaning in our lives is therefore inherently social in nature. We are inextricably linked with the lives of other people and are therefore constantly being-in-the-world-with-others. This is particularly relevant to older people with AMD as past research (discussed in the introductory chapter to this thesis) has suggested that the most valued aspects of interventions for AMD patients include social support, hope, and experience sharing (i.e. Dahlin-Ivanoff et al. 1998; Wong et al. 2004). There is scope for experiential research to develop a greater understanding of the importance of being-with-others in the experiences of patients with AMD.

Heidegger (1962) also suggested we are subject to our knowledge of the ultimate limit to existence (the inevitability of death), therefore we are always being-towards-death. For most of our existence we do not consider this inevitability, however, often when our lives become disrupted in some way (such as the acquisition of a disability like AMD) our mortality comes into focus and this can lead to anxiety. An example of research in the health field which draws on concepts similar to Heidegger's being-towards-death is biographical disruption (Bury, 1997). For example, many women diagnosed with chronic fatigue syndrome and fibromyalgia experience the condition as a radical disruption within their lives which impacts

on elements such as work and social life and results in a renegotiation of identity (Asbring, 2001). Other researchers have argued that biographical disruption is not inevitable after the sudden onset of illness and have illustrated that, in the case of stroke, successful renegotiation of identity can be mediated by social factors such as age, other health conditions, and previous knowledge of the illness experience (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004). AMD can either result in a sudden change in vision (wet) or a slower progressive deterioration (dry), these distinct differences in illness experiences could result in different impacts on patients self and identity. Phenomenological research focused on the different types of AMD can help to illuminate this aspect of the condition.

In the introduction I highlighted the importance of context for understanding impacts QoL in the lives of older people, by taking an existential phenomenological approach to learning about AMD patient experiences it is possible to gather 'rich' data regarding the impact of the condition on the self within the context of ageing lives.

### **2.2.2 Hermeneutics**

Hermeneutics is the theory of interpretation, and the way in which we see meaning in the world around us is through interpretation of our experiences. Heidegger (1962/1927) asserted that whenever something is interpreted the interpretation made will be based on fore-conceptions (i.e. prior experiences, assumptions, and knowledge) and we cannot help but interpret experience in light of these. In addition Heidegger stressed that we are 'thrown' into the world and therefore cannot stop ourselves from seeing it from our own perspective. For Heidegger, elements of experience 'appear' to us in our consciousness and as they appear they may have visible or hidden meanings and therefore contradicts Husserl's arguments about 'bracketing' prior experience as we can never fully escape from our fore-conceptions. However, Heidegger also explained that our interpretations of new experiences may be a way for us to become aware of and reflect upon our relevant fore-conceptions, and as a result interpretation is a cyclical process of interpretation and reflexivity.

### **2.2.3 Reflexivity**

As researchers it is important to be continually reflexive about the research process as it is impossible to avoid own fore-understandings and prejudgements becoming part of the research (Finlay, 2003b). Sartre (1956) described the multi-layered nature of consciousness comprising of: un-reflective consciousness (consciousness which is absorbed in living in the moment), reflective consciousness (when experience becomes the object of reflection), and self-reflective consciousness (when the self becomes the aim of reflection). Reflexivity in

research is vital as neither the researcher nor the participants have privileged access to the 'reality' of lived experience.

It is important to acknowledge that data collection takes place within a specific context. For example, an interview is a formalised process which in most cases is structured and led by the researcher who is responsible for choosing the topic of the interview and the interview schedule (Kvale & Brinkman, 2009). However, the data produced by the interview represents a co-construction of meanings and this can be better understood by considering Gadamer's (1975) 'horizons'. All individuals have pre-conceptions, beliefs, and past experiences which make up their 'horizon' of understanding and are therefore only able to make sense of and interpret the world within these 'horizons'. As researchers we engage with the 'horizons' of our participants, and if these 'horizons' overlap it is possible for the researcher to understand the participant and the participant to understand the researcher. No two people have the same horizons and therefore it is important to pro-actively explore our own horizons before we can make sense of those of our participants. This can be achieved by clarifying our fore-understandings at the start of the research in order to help us use the interpretations by others to help us make sense of and challenge our pre-conceptions and make sense of the phenomena in a new light. It is therefore important to acknowledge that any narration (either by participant or researcher) of experience provided in this thesis is an interpretation, and that the interpretation is provided in a way which makes sense within the context it is given (Finlay, 2003b).

### **2.3 Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA) has been chosen as the analysis method for the qualitative element of this research as it enables me to embrace an existential phenomenological approach which draws on the theory of hermeneutics. IPA is an idiographic qualitative analysis method which aims to "explore in detail how participants are making sense of their personal and social world" (Smith, Jarman, & Osborn, 1999, p 51) and is particularly useful in the context of understanding experiences of ill health (Brocki & Wearden, 2006). Reflexivity is important to IPA which acknowledges that analyses are shaped by the researcher's own personal interpretations and experiences. IPA involves a double hermeneutic in which 'the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world' (Smith & Osborn, 2008, p. 53).

While most quantitative research is concerned with the 'nomothetic' and making general claims about the population as a whole, IPA takes an idiographic approach and is committed to understanding the particular.

*“The particular eternally underlies the general; the general eternally has to comply with the particular”*

The quote from Goethe (quoted in Hermans, 1988: p. 785) above exemplifies the importance of understanding the experience of the individual when attempting to develop an understanding of phenomena. Meaning can be interpreted on a number of levels which relate to one another and provide a variety of perspectives on which an understanding of the whole is based. This ‘hermeneutic circle’ is highlighted by all of the hermeneutic philosophers and refers to the way in which the part is related to the whole while the whole is related to each of its component parts. For example, a single word can make sense in isolation, however the word is given meaning within the whole sentence, and without each individual word, the meaning of the whole sentence is lost. Therefore an understanding of individual experiences AMD can help to build a ‘whole’ picture of the condition.

In terms of evidence based practice (discussed in the introductory chapter to this thesis) it is necessary to include both nomothetic and idiographic research questions in order for us to develop a holistic understanding of different phenomena within health and illness. Mixed method approaches are required in order to generate a holistic understanding of AMD and make recommendations for practice.

#### **2.4 Personal reflexivity**

Given the importance of reflexivity in phenomenological research I feel it is necessary to identify my own pre-conceptions and assumptions with regards to the research topic. This was my starting point and I anticipated my prior-knowledge to both inform and be challenged by the interpretations uncovered during the qualitative element of this research.



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<sup>1</sup> . Bennion, A. E., & Forshaw, M. J. (2012). Insights from the experiences of older people with hearing impairment in the United Kingdom: recommendations for nurse-led rehabilitation, *International Journal of Older People Nursing*, doi: 10.1111/j.1748-3743.2012.00318.x.



Illustration removed for copyright restrictions

By outlining these pre-conceptions I hope to be transparent in the way my interpretations have developed. Throughout my research I continued to reflect on my thoughts about my

participants and the impact their stories had on my pre-conceived ideas about AMD and will come back to these thoughts again at the end of my thesis.

## **2.5 Summary**

The decision to take a pragmatic approach to this research has been based on the need to collect data in a variety of methods in order to develop a greater understanding of the complex concept of QoL in relation to experiences with AMD. By taking a pragmatic stance to data collection and analysis it is feasible to utilise the methods deemed most suitable for answering specific research questions. IPA is a method of qualitative analysis which draws upon phenomenology, hermeneutics and idiography and can add to the development of a holistic understanding of the condition. Phenomena within the world are complex and multi-faceted therefore both quantitative and qualitative methods can add to the understanding of QoL for patients with AMD.

## **Chapter 3: A mixed methods study of the impact of AMD on the quality of life of treatable wet AMD patients**

### **3.1 Introduction**

As discussed in chapter one wet age related macular degeneration (AMD) is currently the only treatable form of AMD and anti-vascular endothelial growth factor (anti-VEGF) therapy is the most common treatment and involves an injection of anti-VEGF drugs directly into the eye. Recommendations for drug treatments are often based on clinical measures, however more recently it has been accepted that visual acuity measurements alone are unable to assess the impact of treatments for AMD on quality of life (QoL) and that the combination of visual acuity and self-report QoL measures may help researchers to understand the impacts (Slakter & Stur, 2005).

Mitchell and Bradley (2006) reviewed 28 measures used for assessing the QoL of AMD patients. The authors concluded that generic health status measures such as the Short Form Health Survey (SF-36: Ware & Sherbourne, 1992) are of little relevance in vision research as most participants do not consider their eyesight when asked about their health. In addition, they reported that disease specific and visual function measures have been better validated in AMD populations. The authors therefore recommend visual function measures such as the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ: Mangione, Lee, and Guitierrez et al., 2001), and disease specific measures, such as the Macular Disease Quality of Life Questionnaire (MacDQoL: Mitchell & Bradley, 2004), for use in AMD research. A second review of 58 psychometric QoL measures conducted by Finger, Fleckstein, Holz and Scholl (2008) lends support to this recommendation. The authors evaluated the available measures developed since 1990 and concluded that the NEI-VFQ was the most commonly used (29% of studies) and the best validated measure available.

The NEI-VFQ assesses both factors relating to visual function as well as psychological factors such as social health, mental health and dependency. And various studies have reported the reliability of the NEI-VFQ for use with patients with AMD (Finger et al., 2008; Mangione, Lee, Pitts et al., 1998; Miskala, Hawkins, Mangione et al., 2003). Treatment with Ranibizumab has been assessed using the NEI-VFQ and it has been reported that Ranibizumab treatment results in greater improvements in visual function over a 24 month period when compared with other previously prescribed treatments (Bressler et al., 2009; Chang et al., 2007). In addition, reductions of ten points in the overall or subscale scores of the NEI-VFQ have been reported to be associated with clinically significant changes in vision in AMD patients (Lindblad & Clemons, 2005). Validation for measures such as the NEI-VFQ is usually based

on the scale's correlation with other measures of QoL and its relationship to clinical measures such as visual acuity. Some researchers have criticised the NEI-VFQ as being little more than a measure of visual function arguing that the measure should not be reported as an indicator of QoL (Mitchell & Bradley, 2006). In addition, Gooberman-Hill, Ayis & Ebrahim (2003) found that when older people are asked about long-standing illnesses they may give different answers during surveys and interviews. This study highlighted the way that the complex answers provided in interviews illustrated the importance of themes such as control, health service provision, time and ageing, in older peoples understanding of their health status which could not be identified using questionnaires. It is therefore useful to view responses to formal surveys as 'elements of people's wider narratives about themselves' (Gooberman-Hill et al., 2003, p.2562)

What is lacking in evaluations of the NEI-VFQ is an assessment of the results of the survey alongside data which represents the in-depth experiences of individuals living with AMD.

### **3.2 Aims**

The aim of this study was to determine how well the NEI-VFQ reflects patients' experiences. This was achieved through a comparison of NEI-VFQ survey data with qualitative data collected through in-depth interviews. There were five main research questions:

- How suitable is the NEI-VFQ as an outcome measure in studies assessing the success of AMD treatments?
- Which NEI-VFQ subscales suggest the greatest changes and warrant further investigation?
- How may NEI-VFQ ratings and QoL change over time in treated AMD patients?
- Do different participants experience different NEI-VFQ scores? If so, what are the potential reasons for differing scores between interview participants and changing scores within participants over time?
- Can we learn about other elements of patient experience by using the NEI-VFQ alongside exploratory qualitative research methods?

### **3.3 Method**

#### **3.3.1 Design**

This pilot study utilised a mixed methods approach with two strands. One strand of the study was a postal survey using the NEI-VFQ within a longitudinal design with repeated measures. Survey data were collected at three time points; (1) prior to treatment, (2) three months following initial treatment, and (3) nine months following initial treatment. In addition to the

postal survey in-depth qualitative interviews and face-to-face completion of the NEI-VFQ with treated patients was completed at two time points; (1) immediately following diagnosis, (2) nine months after initial treatment. The findings of the in-depth interviews are used to illuminate the findings of the exploratory analysis of the survey data.

### **3.3.2 Quantitative measures**

The NEI-VFQ was used in both the postal survey and face-to-face interviews. The measure is reported to be the most frequently used in AMD population studies and clinical research (Finger et al. 2008; Revicki, Rentz, Harnam et al. 2010). A short form version of the measure was used in this pilot study to limit the burden on participants' time. The NEI-VFQ-25 includes a variety of subscales including: general health (1 item); general vision (1 item); ocular discomfort (2 items); near activities (6 items); distance activities (6 items); vision-specific social functioning (3 items); vision-specific mental health (5 items); vision-specific expectations; vision-specific role difficulties (4 items); vision-specific dependency (4 items); driving (3 items); colour vision (1 item); and peripheral vision (1 item) (full details of the questions for each subscale can be seen in table 3). These subscales are scored on a zero to 100 point scale in which 100 indicates the best possible score and zero indicates the worst possible score. It has been reported that a 4-6 point change on the NEI-VFQ is associated with the equivalent of a 15 letter change in best corrected visual acuity; suggesting it is a sensitive measure of visual function in patients with wet AMD (Suner, Kokame, Yu et al., 2009). The subscales of the NEI-VFQ have been found to have relatively high internal consistency when used with patients with age related eye diseases with Cronbach's alphas between 0.58 and 0.94 (Clemons et al. 2003; Mangione et al., 1998). Interclass correlations reported by Mangione et al., (1998) have also shown the NEI-VFQ to have good test retest reliability for all subscales ( $r = 0.68-0.91$ ). The NEI-VFQ has been reported to have good subscale (exceeding  $r=0.70$  for all bar one subscales) and total score ( $r=0.96$ ) reliability in AMD patients. In addition to completion of the NEI-VFQ participants were required to provide demographic information about gender and date of birth. Information about specific diagnosis and visual acuity status at baseline were accessed via patients' medical records.

### **3.3.3 Ethics**

Ethical approval was obtained from the NHS Research Ethics Committee (REC) (Evidence of this can be seen in appendix 4) and from Aston University REC. Research and development (R&D) approval was also obtained from the Heart of England and Sandwell and West Birmingham NHS Foundation Trusts. In order to preserve anonymity survey data sets were through the use of unique identifier codes for each participant (written at the top of the distributed questionnaires). For interview participants pseudonyms were used to replace all

personal identifiers; and when the accuracy of transcripts had been verified, the original recordings were destroyed.

**Table 3: NEI-VFQ subscale questions**

Subscale	Questions
General Health	-In general, how would you say your overall health is? (excellent, very good, good, fair or poor)
General Vision	-At the present time, how would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is? (Excellent, good, fair, poor, very poor, or completely blind.)
Ocular discomfort	-How much pain or discomfort have you had in and around your eyes (for example, burning, itching, or aching)? -How much does pain or discomfort in or -around your eyes, for example, burning, itching, or aching, keep you from doing what you'd like to be doing?
Near Activities	-How much difficulty do you have reading ordinary print in newspapers? -How much difficulty do you have doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing things around the house, or using hand tools? -Because of your eyesight, how much difficulty do you have finding something on a crowded shelf?
Distance Activities	-How much difficulty do you have reading street signs or the names of stores? -Because of your eyesight, how much difficulty do you have going down steps, stairs, or curbs in dim light or at night? -Because of your eyesight, how much difficulty do you have going out to see movies, plays, or sports events?
Vision Specific Social Functioning	-Because of your eyesight, how much difficulty do you have seeing how people react to things you say? -Because of your eyesight, how much difficulty do you have visiting with people in their homes, at parties, or in restaurants?
Vision Specific Mental Health	-How much of the time do you worry about your eyesight? -I feel frustrated a lot of the time because of my eyesight? -I have much less control over what I do, because of my eyesight? -I worry about doing things that will embarrass myself or others, because of my eyesight?
Vision Specific Role Difficulties	-Do you accomplish less than you would like because of your vision? -Are you limited in how long you can work or do other activities because of your vision?
Vision Specific Dependency	-I stay home most of the time because of my eyesight. -Because of my eyesight, I have to rely too much on what other people tell me. -I need a lot of help from others because of my eyesight
Driving	-IF CURRENTLY DRIVING: How much difficulty do you have driving during the daytime in familiar places? -How much difficulty do you have driving at night? Would you say you have: -How much difficulty do you have driving in difficult conditions, such as in bad weather, during rush hour, on the motorway, or in city traffic?
Colour Vision	-Because of your eyesight, how much difficulty do you have picking out and matching your own clothes?
Peripheral Vision	-Because of your eyesight, how much difficulty do you have noticing objects off to the side while you are walking along?

### **3.3.4 Recruitment**

#### ***3.3.4.1 Postal survey***

Recruitment for the postal survey was conducted by administration staff at two Birmingham hospitals. Postal survey participants were identified as any individual diagnosed with wet AMD and offered appointments for Ranibizumab treatment. Letters introducing the research and inviting participation were sent to 120 patients eligible for Ranibizumab treatment between June and September 2010 along with their initial appointment letters for treatment. These letters included a consent form, NEI-VFQ questionnaire, and a personal details form (see Appendix 1 p. 243) which participants were invited to complete and return within two weeks of receiving the letter.

#### ***3.3.4.2 Face-to-face interviews***

Interview participants were recruited face-to-face in the clinic. I observed macular clinics at two hospitals between May and July 2010. Clinic ophthalmologists identified new patients who were to be treated with Ranibuzumab and asked them whether they would be happy to discuss the research. I took these patients to a quiet room and described the study. At the end of this discussion patients were asked if they had any questions and whether they were happy to be contacted regarding taking part. The patients supplied their contact details and I agreed to contact them in two days' time. Patients were given information about the study to take away and read before being contacted by phone. Two days later I contacted the patients and asked if they had had enough time to consider the study and whether they would agree to take part. During this phone call I arranged the first interview with patients who wished to participate. I contacted participants again by phone at nine months to arrange the second interviews.

### **3.3.5 Participants**

#### ***3.3.5.1 Postal Survey***

The survey strand of the research recruited 25 participants who returned questionnaires at each time point. Following the initial data collection period 36 questionnaires were returned representing a 30% return rate. At three months 28 of the 36 questionnaires were returned (an overall 23% return rate). At nine months 25 of the 28 questionnaires were returned (overall a 21% return rate from time one to time three). Participant ages ranged from 60-91 (mean age 79) and there was a gender split of 10 men, 14 women and one participant for which the gender was not indicated. After accessing the patients' medical records it was found that only 16 of the 25 had received treatment, therefore only the scores from these 16 participants could be included in the analysis. There are various reasons why patients may

have chosen not to respond to this survey (i.e., time, lack of interest, difficulties reading the questionnaire), Due to the small sample it should not be assumed that the participants included are representative of the patient group as a whole.

### ***3.3.5.2 Face-to-face Interviews***

A total of seven interview participants receiving treatment were recruited; two men and five women. The ages of the interview participants ranged from 75 to 89 (mean age 82). Most participants were being treated for AMD in one eye and two participants (Alison and Jordan) were being treated for AMD in both eyes.

### ***3.3.5.3 Overall Sample***

The overall sample including both interview and postal survey respondents consisted of 23 participants with a gender split of 14 women and 9 men. The ages of the participants ranged from 60 to 90 (mean age 79.7). The participants' visual acuity as measured using the Snellen scale ranged from 6/12 to hand movements only in the worst seeing eye and 6/6 to 6/60 in the best seeing eye. Snellen visual acuity ratings are achieved in order from good vision to poor; 6/5; 6/6; 6/7.5; 6/9; 6/12; 6/18; 6/24; 6/36; 6/60; 3/60; 6/96; count fingers (CF); hand movements (HM); Perception of light (PL).

## **3.3.6 Procedures**

### ***3.3.6.1 Postal survey data collection***

Questionnaires were distributed initially prior to treatment, at three months (when patients would have begun treatment) and at 9 months (when treatment is likely to have had an effect). All participants who returned the first set of questionnaires were followed up at three months. At this time point participants were again sent information about the study, a copy of the NEI VFQ (all in large print), and postage paid return envelope. Participants were requested to return the questionnaires within two weeks. For the postal survey participants the three month questionnaires acted as a prompt to remind participants about the research in the hope that this may result in a higher return rate at nine months. Three time points were included to enable this pilot study to assess the feasibility of using postal surveys with participants with AMD by assessing the return rate of the questionnaires at each time point. It was assumed that participants who failed to return postal questionnaires at any of the time points no longer consented to take part in the research and therefore were not contacted again. All participants who returned questionnaires at three months post initial treatment were sent a final postal survey at nine months after initial treatment and again requested to return the questionnaire within two weeks. Due to the sensitive nature of the participants' diagnosis

and treatment, in order to limit the burden placed on participants, and to ensure participants were consenting to take part rather than being coerced no reminders were sent.

### **3.3.6.2 Interview data collection**

In-depth interviews were repeated with seven participants immediately following diagnosis and at nine months post diagnosis. Cornwell (1984) has distinguished between “public” and “private” accounts given by participants in a research context. In her research into the accounts of health and illness provided by men and women in East London, Cornwell found that through repeated interviewing it was possible to build up a rapport with participants in order to encourage them to describe their private accounts. Both of these types of account are important as they are able to reveal the wide variety of factors governing individuals’ beliefs, behaviour, and sense making. Repeated interviews help to build up a rapport with the participants and develop more detailed information about both public and private accounts. In this research interviews with participants included the completion of standardised questionnaires as well as open ended in-depth interview questions.

Prior to the interviews I completed the NEI-VFQ with the participant by reading out the questions and available answers and recording responses given in order to trial the administration of the NEI-VFQ via face-to-face interview. The whole session was audio-recorded with the participants’ consent. The NEI-VFQ was completed first with the participant and then I moved on to more open ended questions using a semi-structured interview schedule. Had the questionnaire been completed after the interview the issues discussed during the interview may have influenced the participants’ responses to the questionnaire. As data were to be combined from the surveys completed during interviews and postal surveys it was necessary to limit the number of confounding variables as far as possible. The interviews conducted with the participants may have acted like an ‘intervention’ for this sample and could therefore have altered their responses if the questionnaire was delivered following the interview.

Following completion of the questionnaire I began an in-depth interview. The initial interview began with an open question “tell me about your AMD- how did you come to be diagnosed?”. I allowed the participant to lead the discussion adding prompt questions such as “can you tell me more about that?”, “how did that make you feel” when deemed necessary. I proceeded to ask open questions around a variety of topics; day to day life with AMD, support from friends and family, interaction with the hospital, thoughts about the future with AMD. The second interview proceeded in the same manner with the opening question being “how have things been since the last time we met”. At the end of each interview the participants were given the

opportunity to add anything they felt had not been covered in the interview and ask any questions they may have about the research.

### **3.4 Methods of analysis**

#### **3.4.1 Statistical analysis of survey data**

Given the small sample size in this study an exploratory statistical analysis was conducted. The data were not normally distributed therefore non parametric tests were used for all analyses. Mann-Whitney U tests were employed to assess any significant differences between the two types of survey administration. Wilcoxon's signed rank tests were used to investigate differences in the subscales between baseline and nine months and were completed for the total NEI-VFQ score and each subscale

Further descriptive statistical analysis was conducted focusing on the survey scores for the interview participants only. Individual interview participant NEI-VFQ scores were explored descriptively by using subscale scores to produce graphs for each participant. These graphs were used to compare similarities and differences between the individual interview participants.

#### **3.4.2 Thematic analysis of the interview data**

For the purposes of this study the qualitative data were analysed thematically in order to explore the ways in which they may add depth to the responses to the NEI-VFQ. More in-depth analyses are presented in the later chapters of this thesis. Deductive thematic analysis informed by the guidance of Braun and Clarke (2006) was employed. Thematic analysis is a qualitative method which seeks to go beyond the identification of theme prevalence to explore meaning in depth (Braun and Clarke, 2006). The most important aspect of this type of analysis is that the themes identified capture issues of analytic importance with regards to the research questions. In line with this transcribed interviews were coded according to the NEI-VFQ subscales to explore the way in which the interview data may illuminate the specific survey subscales. Quotes relating to each of the subscales were extracted and recorded in an excel spreadsheet including subscale, participant, interview number, and line numbers. Quotes which helped to explain any similarities and differences and add detail to the participants' experiences of each subscale were included in the results.

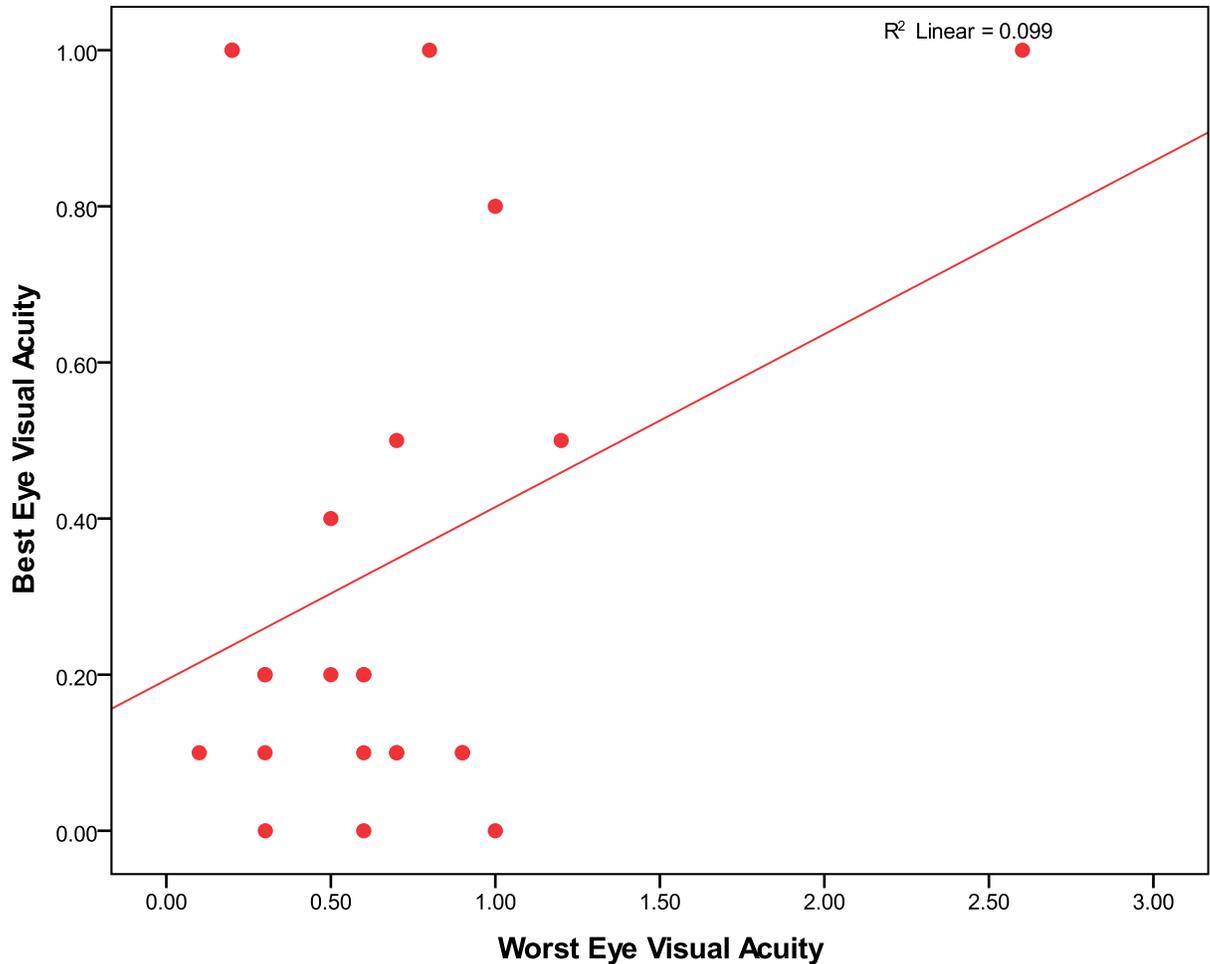
### **3.5 Results**

#### **3.5.1 Visual acuity**

Snellen visual acuity ratings were transformed into LogMar visual acuity scores to create a graphical representation of the participants' visual acuity. Higher scores on the LogMar scale

represent poorer visual acuity. Visual acuity data for the sample can be seen in Figure 2. The graph suggests that individuals with poorer best eye visual acuity also tended to have poorer worst eye visual acuity.

Figure 2: Best and Worst Eye Logmar Visual Acuity for the Sample and Line of Best Fit



### 3.5.2 Methods of survey administration

There were no significant differences at zero months or nine months post diagnosis for the NEI-VFQ or any of its subscales between participants who completed the survey by post and those who completed the survey face-to-face (Table 4). In addition, there was no significant difference at baseline for best eye ( $U(23)= 48.5, Z= -.513, p=.608$ ) and worst eye ( $U(23)= 39, Z= -1.142, p=.253$ ) visual acuity between the participants for each type of survey administration. Therefore it was feasible to include both face-to-face and postal survey data as a single sample in further exploratory analysis

**Table 4: Comparison of postal and face-to-face survey responses**

Subscale	Baseline			9 Months		
	Mann-Whitney U	Z Score	Sig.	Mann-Whitney U	Z Score	Sig.
General Health	32	-1.713	.087	43	-.1668	.091
General Vision	53	-.215	.830	49	-.509	.611
Ocular discomfort	41.5	-.995	.320	39.5	-1.139	.255
Near Activities	47	-.607	.554	39	-1.143	.253
Distance Activities	51.5	-.303	.762	38.5	-1.177	.239
Social Functioning	50.5	-.386	.699	43.5	-.876	.381
Mental Health	48	-.544	.587	53.5	-.168	.867
Role Difficulties	52.5	-.242	.808	43	-.899	.369
Dependency	56	.000	1.0	52.5	-.248	.804
Driving	55	-.079	.937	55.5	-.039	.696
Colour Vision	30	-1.853	.064	35.5	-.1478	.139
Peripheral Vision	51	-.350	.727	42	-.951	.342
Total VFQ Score	46	-.668	.504	46.5	-.635	.525

### 3.5.3 Descriptive statistics

Descriptive statistics relating to percentiles and median scores for each of the subscales were calculated and are reported in Table 5 for both postal and face-to-face survey responses (all N=23; except for driving subscale N=8).

**Table 5: Table showing percentiles and median for subscales of the NEI VFQ**

Subscale*	0 Months		9 Months	
	Median	(UQ,LQ)	Median	(UQ,LQ)
General Health	50	(25, 50)	50	(25, 50)
General Vision	60	(60, 80)	60	(60, 80)
Ocular discomfort	75	(62.5,87.5)	75	(62.5, 87.5)
Near Activities	58.3	(41.8, 75)	66.8	(50, 83.3)
Distance Activities	66.8	(43.7, 83.3)	75	(33.3, 83.3)
Social Functioning	87.5	(50, 100)	87.5	(75, 100)
Mental Health	68.8	(25, 87.5)	62.5	(37.5, 87.5)
Role Difficulties	75	(37.5, 75)	75	(50, 87.5)
Dependency	91.7	(50, 100)	100	(47.9, 100)
Driving (N=8)	83.3	(66.7, 89.5)	87.5	(77.1, 100)
Colour Vision	75	(50, 100)	75	(75, 100)
Peripheral Vision	75	(50, 100)	75	(55, 75)
Total VFQ Score	78.3	(48.6, 85.7)	74.1	(52.6, 84.5)

\* Possible score range for all subscales was 0-100.

Differences in the scores between baseline and nine months for total NEI-VFQ scores and each subscale (N=23; except for driving N=8) were calculated and can be seen in Table 6.

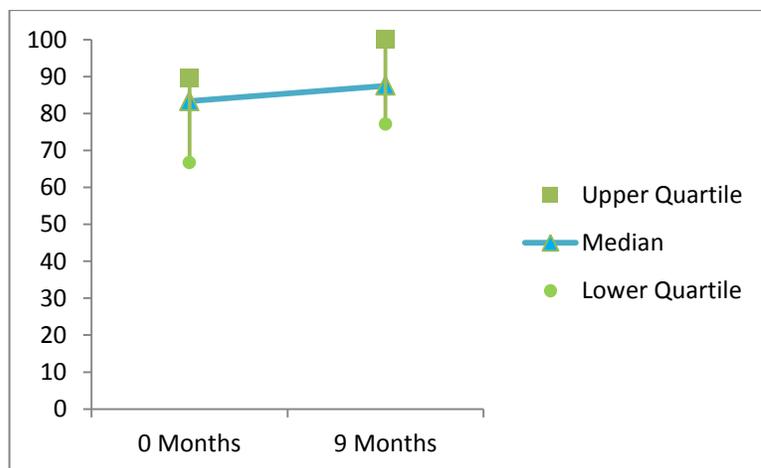
**Table 6: signed rank tests comparing NEI-VFQ subscales at zero and nine months post diagnosis**

Subscale	Z	P (two-tailed)
General Health	-1 <sup>a</sup>	.317
General Vision	-.333 <sup>a</sup>	.739
Ocular discomfort	-.613 <sup>a</sup>	.540
Near Activities	-.950 <sup>b</sup>	.342
Distance Activities	-.259 <sup>b</sup>	.796
Social Functioning	-.638 <sup>b</sup>	.523
Mental Health	-.380 <sup>b</sup>	.704
Role Difficulties	-.287 <sup>b</sup>	.774
Dependency	-.868 <sup>b</sup>	.386
Driving (N=8)	-1.782 <sup>b</sup>	.075
Colour Vision	-1.930 <sup>b</sup>	.054
Peripheral Vision	-1.071 <sup>a</sup>	.284
Total VFQ Score	-.571 <sup>b</sup>	.605

(<sup>a</sup> based on positive ranks, <sup>b</sup> based on negative ranks)

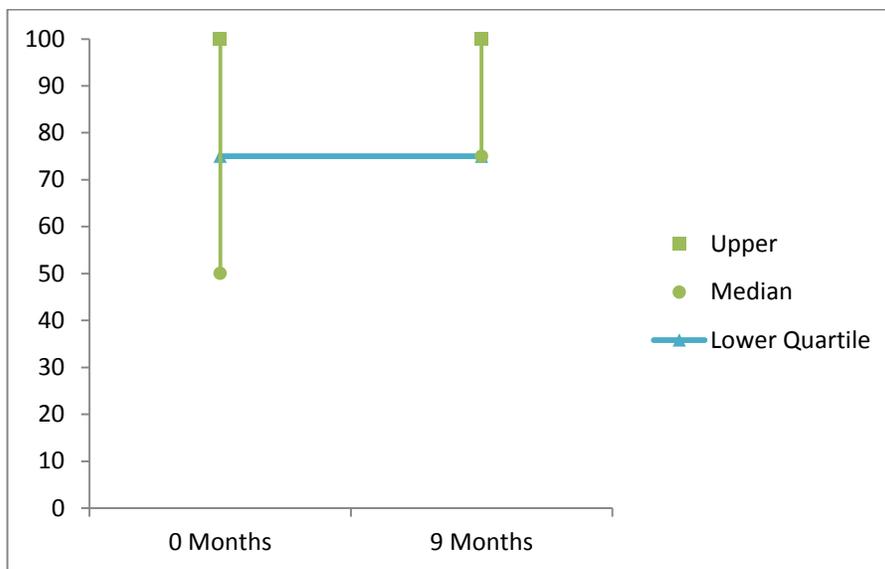
There were no significant differences for either the NEI-VFQ total score or any of its subscales between zero and nine months post diagnosis. The subscales which came closest to a significant difference (driving and colour vision) were explored by presenting the data graphically. The graph for the driving subscale can be found in Figure 3. This graph suggests that the participants may have experienced a slight increase in driving ability between baseline and nine months. However this is based on a very small sample (N=8) and therefore cannot be used to make any firm conclusions about the relationship between treatment and driving ability.

**Figure 3: Graph comparing driving subscale scores at baseline and nine months**

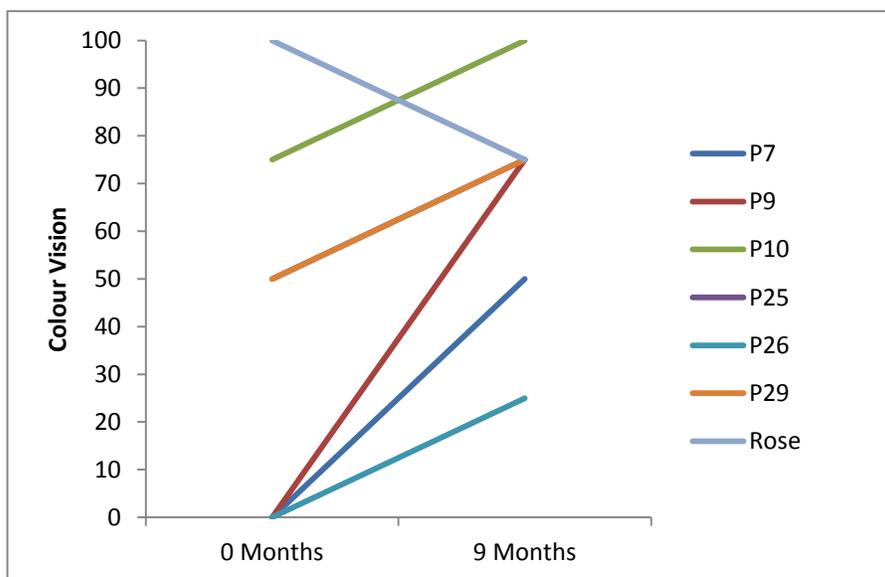


The graph for the colour vision subscale can be found in Figure 4. A closer look at the data for participants who experienced a change in colour vision between baseline and nine months can be seen in Figure 5. This data suggests that nearly all participants showed an improvement in colour vision at nine months. It is possible that these improvements in colour vision may have resulted from undergoing AMD treatment and this finding would be worthy of further exploration using a larger sample.

**Figure 4: Graph comparing colour vision subscale scores at baseline and nine months**



**Figure 5: Graph exploring the changes in participants' colour vision from baseline to nine months**



### 3.5.4 Interview participant demographics

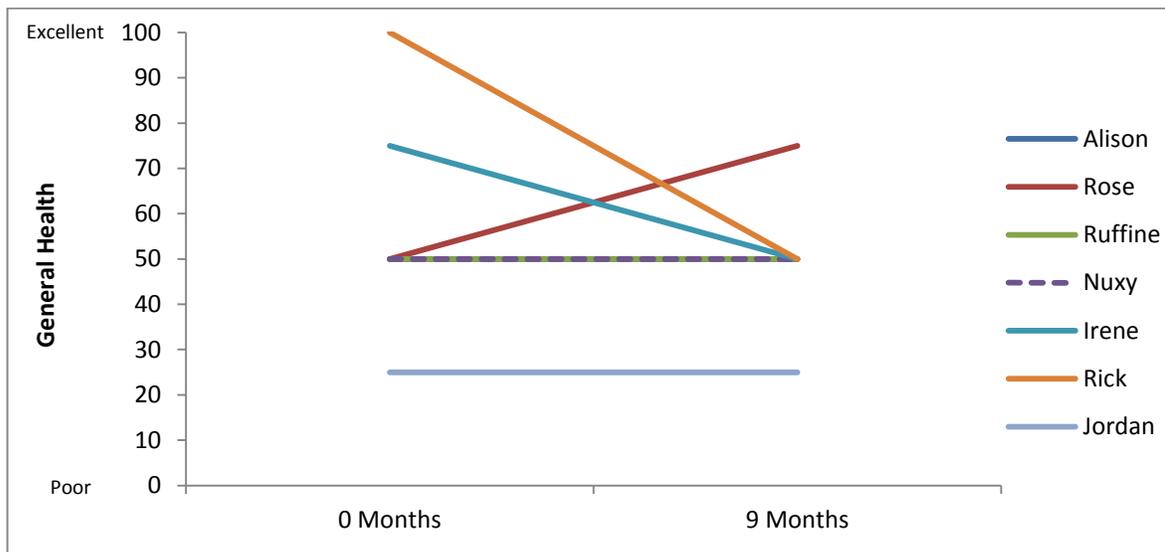
Demographic information relating to the interview participants can be found in Table 7.

**Table 7: Interview participant demographics**

Participant	Gender	Age	Diagnosis	Left Eye VA	Right Eye VA
Alison	Female	85	Wet AMD both eyes	6/12 (mild impairment)	6/9 (mild impairment)
Rose	Female	89	Wet AMD one eye	6/12 (mild impairment)	6/9 (mild impairment)
Ruffine	Female	82	Wet AMD one eye	6/6 (mild impairment)	6/24 (mild impairment)
Jordan	Female	75	Wet AMD both eyes	6/60 (moderate)	6/36 (moderate)
Irene	Female	86	One wet one dry	6/30 (moderate)	6/7.5 (mild impairment)
Rick	Male	82	Wet AMD one eye	6/9 (Mild impairment)	6/19 (mild impairment)
Nuxy	Male	78	Wet AMD one eye	6/7 (Mild impairment)	6/12 (mild impairment)

### 3.5.5 General Health

Figure 6 shows the starting level of general health varied across the interview participants. Most described either a decrease in general health, or that their general health had remained the same between zero and nine months post diagnosis. Rose was the only participant to indicate an increase in her perceived general health at nine months.



**Figure 6: Graph showing general health ratings for interview participants**

While Rose’s response to the NEI-VFQ question about general health suggested an improvement in her general health over time, her discussion of her health during the interview seemed to contradict this. At the first interview Rose acknowledged some problems with her foot but felt her health was good when considered in relation to her age:

*Well I suppose I’m very good actually for my age! 90 this year! ((laughs...))And I’ve got trouble with my foot, I’m having to, they want me to have a new knee and ...so I’m having to wear this inside my shoes for 6 months to try and straighten my foot*

*up...Well it's healing and my knee after, if I'm not walking straight it's not going to heal properly is it?...*

*Rose interview 1, line 31-45*

Rose's response illustrates her expectation that her body may deteriorate with age and that the experience of failing limbs (such as problems with her feet and knees) was not perceived by Rose as "health" in the same way that illnesses (for example, kidney disease or diabetes) might be perceived as ill health. Rose was therefore normalising the process of deterioration as a result of the ageing process. It is possible that the close proximity of Rose's 90<sup>th</sup> birthday may have prompted her to consider her age when making a judgement about her general health. The excitement of this approaching milestone meant she overlooked her general health problems in the light of successfully reaching 90 years. By Rose's second interview the novelty of her 90<sup>th</sup> birthday may have worn off and she gave an indication of recent changes in her health. For example, when asked how often Rose woke feeling fresh and rested she explained:

*Just lately I can't get out of bed in the morning so I'm not sure that I wake up feeling fresh and rested.*

*Rose interview 2, line 244-246*

Despite this Rose gave a response of "very good" when asked about her general health on the NEI-VFQ suggesting a contradiction between her day-to-day health experiences and her perceived health at the moment of questioning.

Rick's perceived general health showed the greatest decrease between the two interviews. At the first interview Rick described his health as excellent despite various health issues. For example, Rick described the problems he had walking:

*I'm not a walker. That's my only fault. I'm terrible. I need a new knee joint but he won't put me in for the operation. He doesn't recommend it. He doesn't recommend it.... Whether it's my heart or my age or what, I don't know.*

*Rick interview 1, line 538-543*

Rick had a knee problem which was being left untreated. While Rick was uncertain about the reason for his doctor deciding against treatment he felt a recent unexpected heart attack may be the explanation. This change in physical health was having implications not only for his ability to walk, but also to engage in his hobby of gardening:

*I love what bit [of gardening] I can. I used to be in it all the time. Growing plants and that, tomatoes and that. But I can't bend down now like I could do. I can but I start to ache. I did, the lad cut the edging and I was just doing, pulling the what's its name. Ooo my back when I got up next morning, my back was killing me because it hurts your legs as well as your back.*

*Rick interview 2, line 944-951*

It is possible that this combination of health problems and the impact it appeared to be having on Rick's ability to engage in his hobbies may have resulted in his perceived decrease in general health.

Ruffine and Nuxy described their health as good in both interviews; despite this they highlighted elements of ill health. For example, Nuxy explained the way he felt his body was deteriorating as he aged:

*I've had a good life, a happy life and I ain't got a lot of complaints really ... but when your, when your health starts to go and I, I take my tablets and I think, 'oh why, why me?' and it doesn't worry me that much, but then you think well, I'm 78 years old and things, you know? You ain't gonna be 25 all the rest of your life, things have got to start to, deteriorate in your body, so yeah. You've got to accept it basically I think.*

*Nuxy interview 1, line 434-443*

For many of the participants deteriorating health was an inevitable outcome of old age. While HCP's have access to epidemiological data and clinical experience on which to build a perception of 'normal' ageing older people themselves rely on knowledge of their own social circle and family experiences as a reference point for what 'normal' ageing represents. For these older people assessment of general health seemed to be a global assessment rather than one attributed to physical deterioration. If the participants felt able to continue to get on with their lives then their rating of their perceived general health remained good.

Despite the positive ratings of general health given by most of the participants it seemed that these ratings may be context dependent. Many spoke of the way in which their perceived health was constantly fluctuating:

*it's all according to health wise how I feel, you know, sometimes your joints ache, and you, and some days I feel as right as rain.*

*Nuxy interview 2, line 148-150*

*Well sometimes you feel a bit active some days and some you don't.*

*Irene interview 1, line 280-281*

This fluctuating perception of general health suggests that responses to perceived general health ratings should not be taken out of the context in which they are given. For example, a

participant who rates their health as excellent one morning may only give a rating of good the next if they experienced a poor night's sleep in between. This illustrates the experiential context of perception which is overlooked in traditional questionnaire research.

### 3.5.6 General Vision

Figure 7 shows that most participants' vision remained the same. Only Nuxy described deterioration in vision and only Rick described an improvement in vision at nine months post diagnosis. Most of the interview participants responded to this question with either good or fair. Only Jordan described her vision as poor. Jordan had the lowest visual acuity rating of all of the participants; it is therefore understandable that her general vision rating was lower than the other participants.

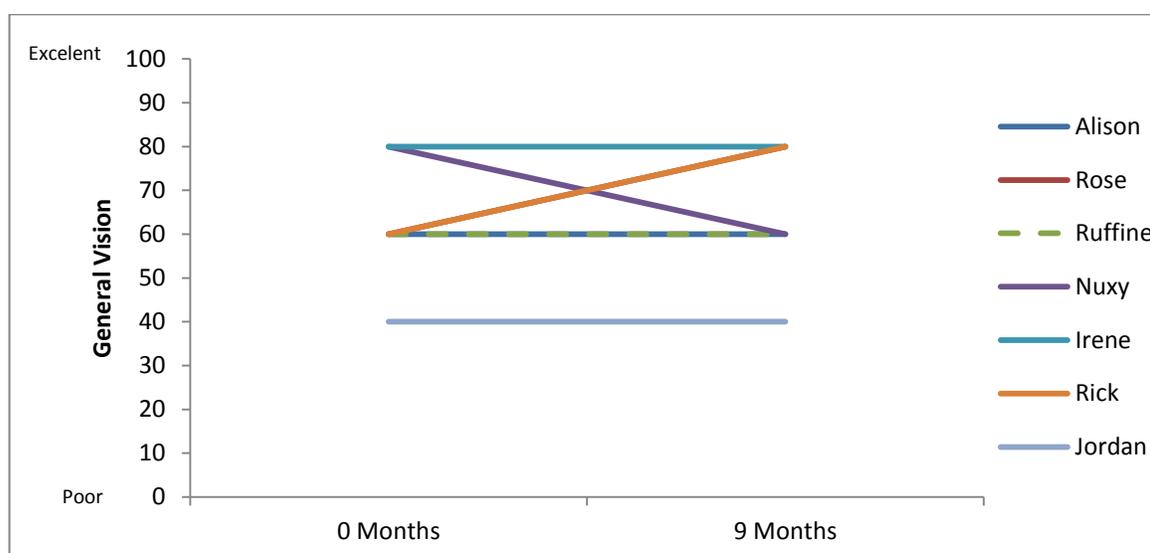


Figure 7: Graph showing general vision ratings for interview participants

Rick's changing perceptions about his vision may be explained by his interaction with the hospital clinic and his opticians. At the first interview Rick described his vision as fair:

*I've always had good eyesight. But the, it's only the last 12 months now, it's around about 6 months ago when I was going with my eyes, I can see quite well without spectacles on.*

*Rick interview 1, line 412-415*

Rick's evaluation of his general vision as fair rather than good may be a result of his need to attend the hospital. While he had always perceived his vision as good, and still experienced good vision, his need to attend the hospital recently may have led him to base his rating on his need for treatment. For example, had he given a 'good' rating for his vision, his need to attend the hospital for treatment may no longer make sense to him. By Rick's second

interview his rating of general vision had improved from 'fair' to 'good', this again may be a result of his interaction with the hospital:

*I went down there and had the eyes, the injection in the eye, and my sight was, my sight were better, there were no doubt about it my sight were better, but other than that no difference really.*

*Rick interview 2, line 396-400*

Following Rick's injection treatment it had been suggested to him that his vision had improved; while he had no evidence of this in his own experience it legitimated his evaluation of his general vision as "good". This use of his experiences with the hospital for providing ratings of his general vision is explained by Rick in his second interview:

*Well, actually to me [my eyes] they seem good to me, but obviously they think not, the right eye has been getting weaker, my left eye is still good, it's just my right eye that's slightly weaker like you know? I mean I've got no, tunnel, I can see right and left, I've got no tunnel vision or anything like that, now to me, it, it, I would have, if I hadn't been sent the hospital and they'd notified me, I wouldn't actually have realised my eyes were getting worse would I?*

*Rick interview 2, line 523-531*

Rick wondered if he was only aware of the deterioration in his vision because he had been referred to the hospital for assessment and treatment as he wasn't sure that his own experiences of his vision had given him any cause for concern about his eyesight. In Rick's ending statement he seemed to be questioning whether he would have experienced deterioration in his vision had he not been diagnosed at the hospital. There appeared to be a lack of certainty about what Rick's experience should be, leaving him unable to make a satisfactory judgement in his own mind about whether his vision had actually changed. It is perhaps disappointing to learn that only Rick experienced improvements in his vision following treatment. It is important to remember that patients perceptions of treatment success may be due to an assumption that treatment should result in improvements, while clinicians may assign treatment success to maintenance of current vision. It is therefore vital to ensure patients have realistic expectations about the results of treatment to reduce any disappointment if improvement is not experienced.

Nuxy was the only participant to describe a decrease in general vision despite having had treatment for his AMD. At his first interview he described his vision as 'good', and explained the importance of maintaining his vision to enable him to get on with his life:

*Well, I say, as long as I can, the thing that is keeping me going basically, as long as I can keep my sight in the one eye and partial sight in the other, it's not going to worry me a lot, because I've got the peripheral vision and the vision in the left eye, so it's gonna affect me a little bit, but not that it's going to stop me doing anything, so you know, that's the only thing that's, but if anything goes wrong with my left eye I am going to be in trouble and that's when I'm going to start to worry basically.*

*Nuxy interview 1, line 638-649*

By the second interview Nuxy's rating of his vision had dropped to 'fair'. Nuxy had been attending the hospital for injection treatment and had been told that the blister which had formed in the eye with AMD had dispersed. Despite this apparent 'success' of treatment, Nuxy had not noticed any change in his vision during his day-to-day life. Nuxy had been told by the hospital that the treatment was to maintain rather than improve his vision and he had accepted this. Despite the aim of the treatment to maintain his vision Nuxy had begun to notice he was struggling more with activities such as reading (discussed further in near activities p.70) and this was beginning to worry him (see later section on vision specific mental health for further discussion, p 78). It is likely that this worry and increasing difficulty with near activities explains Nuxy's change in general vision rating from 'good' to 'fair'.

As with ratings of general health given by the participants, ratings of general vision were frequently explained in terms of expectations in relation to the participant's age, for example Rose explained:

*I never used to wear my glasses half the time, I never used to need to, I used to be able to read and see small print and see fairly long distance and everything you know? So my eyes weren't that bad years ago, it's, just that they've got old with me.*

*Rose interview 1, line 1145-1150*

Rose rated her general health and general vision based on her expectations given her age. Rose perceived her body had deteriorated as she aged and her eyes had too and felt she needed to accept this as a part of old age. Similarly, Alison felt that her visual deterioration needed to be accepted:

*I suppose on the whole and it would have been nice if my eyesight had stayed ok, but I can't do anything about it, so, eventually you, well I don't know whether you grow to accept it, but you learn that it can't be, and you can never accept it because you think why me? It's only human, and you say why me? But that's it, that's life.*

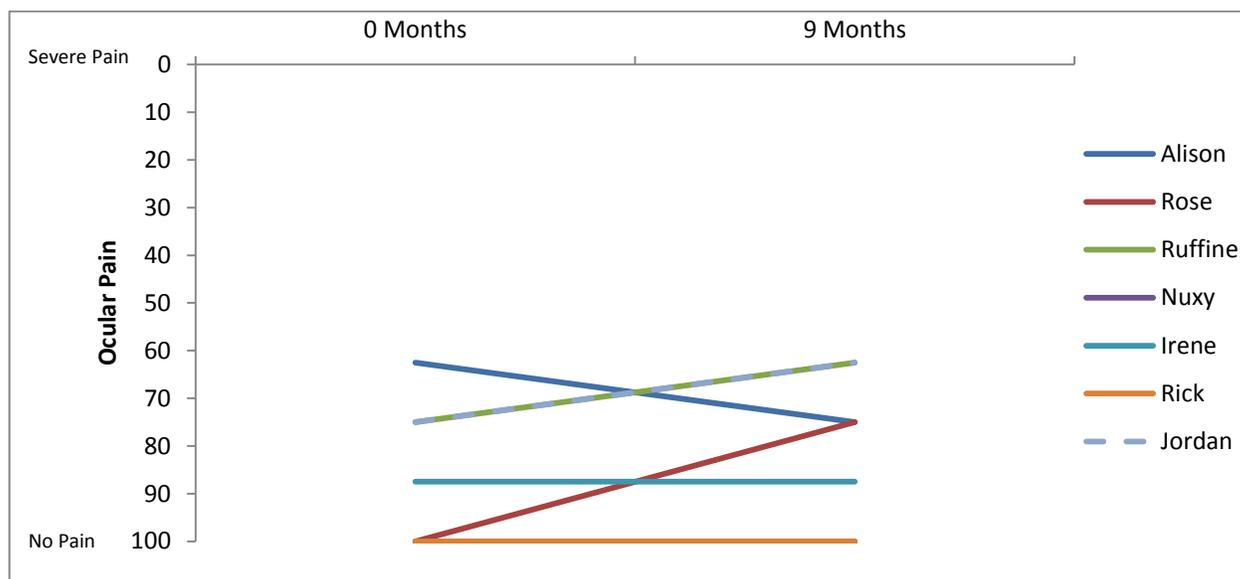
*Alison interview 2, line 1180-1187*

Ratings about general vision were based on the participants' expectations of their vision. These expectations were based on a variety of factors; stereotypes of ageing, experiences of

friends and family members, and their visual deterioration in relation to other physical deterioration.

### 3.5.7 Ocular discomfort

Figure 8 suggests that some participants reported a greater impact of ocular discomfort at the second interview. Some of the participants highlighted itching and aching resulting from treatments for AMD and other conditions such as glaucoma. A couple of the participants suggested their eyes began to ache if they used them for too long with high concentration activities such as reading.



**Figure 8: Graph showing ocular discomfort ratings for interview participants**

Only Alison reported that her level of ocular discomfort had decreased from zero to nine months. While Alison reported that the pain was mild at both occasions she had felt that the pain was keeping her from doing things ‘some of the time’ at zero months and only ‘a little of the time’ at nine months. At the first interview Alison suggested that ‘discomfort’ prevented her from doing things some of the time “*obviously you don’t want to start aching*” (interview 1, line 411-412). At the second interview Alison was making more focused choices to preserve her eyesight and these choices were impacting on the hobbies she was able to pursue “*I used to like reading books and my eyes would ache if I started to [read]*” (interview 2, line 117-118).

Jordan, Ruffine and Rose all reported an increase in ocular discomfort at nine months. Rose’s account was particularly interesting as she reported ‘no pain’ at the first interview, however at the second interview she reported ‘mild pain’ which prevented her from doing things she wanted to ‘a little of the time’. Despite initially saying she experienced no pain in the first interview, Rose went on to explain:

*it's mild, very mild, the only time I did have some [pain] was I have to have a drop in my eye every day...And I had some from the chemist and they sent on my prescription and they were fine and then they suddenly changed the make I think it was, and it made my eyes ache and itch and I went back with them and I said I couldn't use them so I still, I had the same drops without any additives in there and they seemed to be [ok].*

*Rose interview 1, line 114-124*

Rose reported that drops she believed were for AMD had caused discomfort in her eyes when she had been given a different brand. This suggests that her initial answer of 'no pain' did not fully represent her experience as Rose was experiencing ocular discomfort in some circumstances at the first interview. At the second interview the ocular discomfort had become itching, again caused by drops:

*I do get itching round my eyes, but I have got drops that I put in, I presume it's caused from dry eyes, I put drops in it you know? It doesn't stop me from doing anything.*

*Rose interview 2, line 173-176*

Despite explaining that she had been given new drops to replace those that had caused her discomfort, she still reported problems at the second interview. What is interesting here is that when directly questioned about whether ocular pain or discomfort stopped her from doing things Rose wanted to be doing she responded with "a little of the time", however in the quote above Rose stated "*it doesn't stop me from doing anything*". This suggests that sometimes Rose was unable to do things she wanted to, however AMD did not stop her doing things altogether as she was perhaps able to get things done when she was not experiencing any pain. It seemed to be difficult for Rose to attribute aspects of her experience to the condition or to treatment for the condition because her understanding of what experiencing AMD should be like was unclear.

### **3.5.8 Near Activities**

Near vision activity ability seemed to change between zero and nine months and most participants showed an increase in near activity abilities between the first and second interviews (figure 9). Given that these patients were receiving treatment for AMD it is expected that their visual acuity should remain stable or increase and this may explain the improvements in near vision abilities.

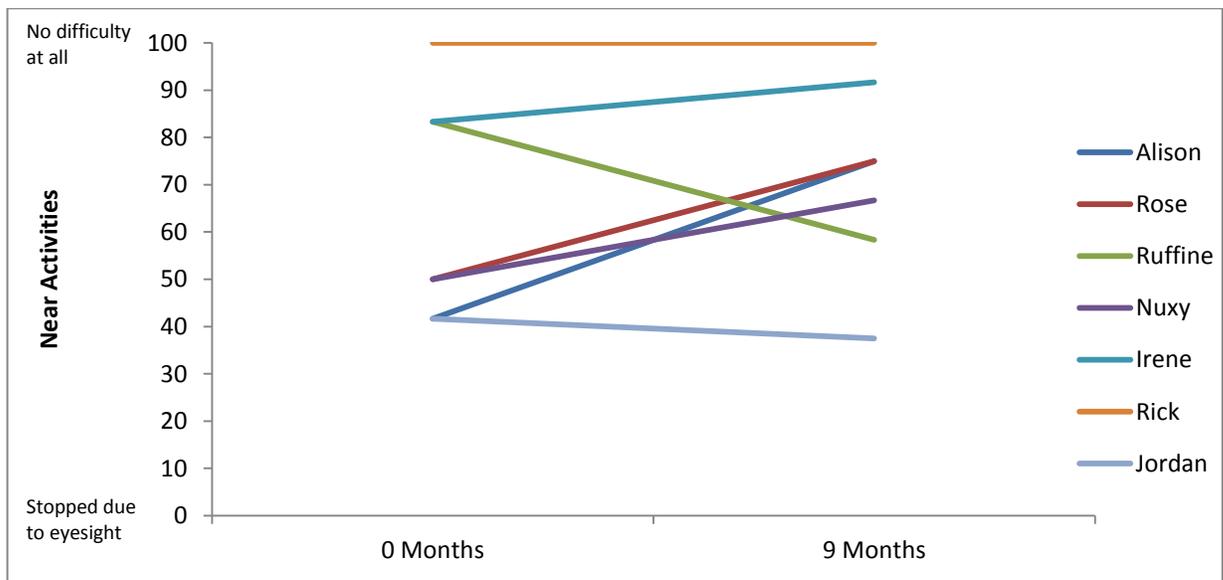


Figure 9: Graph showing near activity ratings for interview participants

Ruffine reported the greatest drop in near vision activity ratings. Ruffine’s ability to read newspapers remained the same; however her difficulty with finding things on a crowded shelf increased from ‘none of the time’ to ‘a little of the time’, and her difficulty with close up hobbies increased from ‘no difficulty’ to ‘moderate difficulty’. During the first interview Ruffine explained how she adapted to any difficulties she may have when reading:

*some books are, quite plain, others are very very small, well I tend not, I tend to, when I check when I’m buying a book, I don’t use my glasses and check to see, if I can see them fairly plainly I know I’ll read them with glasses, if I can’t I don’t buy them...You know? And I, I don’t want to go into these books where you’ve got to have the big print, I don’t think I’m, they are that bad yet, but if the other eye becomes more clearer then I won’t have to bother whether the print is very small.*

*Ruffine interview 1, Line 984-987*

In order to avoid being unable to read Ruffine made sure she only chose books in a suitable size of print, this strategy meant that she did not experience being unable to read. At the second interview the experience of being unable to read was becoming unavoidable:

*I can read but I can’t read small print. Such as when you are looking on, when I try to see how many calories are on a thing, with my glasses which needs changing, but I can’t until it’s done, I can’t read very well, so that makes it difficult, you know? When you are in a, sort of when I come back here and I look at the carton I think how long has it got to be in the oven, how long has it got to be in the microwave, I can’t see it very well.*

*Ruffine interview 2, Line 260-269*

At the second interview Ruffine’s reading difficulties extended beyond reading the newspaper and were affecting other aspects of her life. Ruffine assigned her increasing difficulties to over

use of her eyes and as a result she was avoiding activities which may wear her vision out in the hope that this would preserve the vision she still had:

*I've got one of the CDs where you sit and plug it in, I'm trying to do that more, I'm trying not to read too much, or watch the TV too much, I'm trying to ease it off a bit...To try and rest my eyes more...You know, I thought, well don't try and wear them out... Too much, until you've had them done [treated].*

*Ruffine interview 1, line 795-806*

The fear of overusing the eyes was not only present in Ruffine's account. Alison also described avoiding enjoyable activities for fear of wearing her eyes out:

*I would have the painting out, and I'd be doing something, which I haven't and I keep sort of thinking oh I will do and I think no, I sort of put a limit on how much I use my eyes a lot, does this make sense to you?*

*Alison interview 2, Line 625-629*

Both participants were unclear about the risk some activities may pose to their eyesight and were making adjustments to their day-to-day activities based on lay theory. As a result the participants were limiting the variety of their lives and giving up activities which had given them enjoyment. These assumptions and lay theories may result from the approach to consultations used by the HCPs. If a HCP is unclear at the time of diagnosis about what the risks to vision are for the patient then the patient will not have enough information to make informed decisions about what activities should or should not be pursued.

At the first interview Alison and Jordan reported the same level of difficulty with near activities, however by the second interview Alison's level of difficulty had drastically decreased while Jordan was experiencing increased difficulty with near activities. When talking about her near vision abilities at Alison mentioned very similar things at both interviews, i.e. had she been able to see better she would have been doing more reading and painting. Despite these slight problems she maintained that she still had useful near vision which was amplified when she used magnifiers:

*I do crosswords in the local paper, occasionally, depending on how small I do have to use that [magnifier]*

*Alison interview 2, line 522-524*

In contrast Jordan's ratings of near vision activities were poor at both interviews and even the use of magnifiers was unable to provide assistance:

*I've bought one of those spy glasses. Oh, our kiddies did laugh, the size of it. Wait till you see the size of it (gets magnifying glass) and I still can't see with that.... Well*

*I've tried to read and I've to write.... I don't think it's a very good one or it's my eyes.*

*Jordan interview 1, line 461-468*

Even with a high magnification aid Jordan was unable to see to read or write. Her experience of visual impairment was very different to Alison and she reported difficulty with a wider variety of issues. For example, food shopping could be difficult:

*If I buy sausage or bacon, I'm frightened in case it goes out, not in date. It's like I bought milk the other day, I had a little stroll up the road there, only just up the corner there, come back, I hadn't got no milk, make a cup of coffee, and it was all bitty on the top, and it was out of bloomin date, my daughter come at half past 12, I said this milk is out of date, she said, 'give it here' she took it back. You see I couldn't see the date on it*

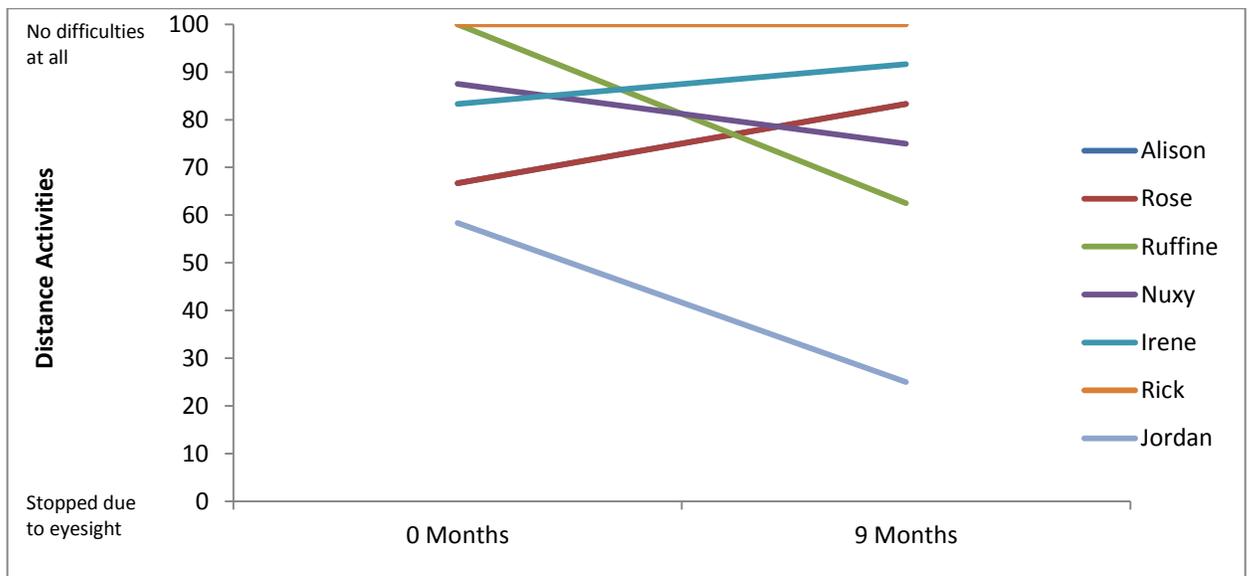
*Jordan interview 2, 797-806*

As a result of Jordan's problems she found herself highly dependent on her children (see dependence section for further discussion p.82).

The questions about near activities in the survey did not seem to cover the full extent of the activities that AMD was having an effect upon. As a result the survey may not be giving a clear picture of the impact of AMD on near activities. In addition to reading newspapers the participants mentioned many other types of reading: reading food packets and sell by dates, reading books, reading prices when shopping, reading menus in restaurants, and reading subtitles. While many participants reported difficulties with close up activities and hobbies in the survey the interviews revealed what kinds of activities these were: doing cross words, sewing, cooking, looking at photographs, fishing (setting up floats and hooks), do-it-yourself activities, and jigsaws and games. Many near activities described by the participants were not covered by any of the near activity survey questions: seeing the line when hanging out washing, using mobile phones, using cash points, and identifying denominations of notes and coins when shopping. This clearly illustrates that the questions included in the measure did not accurately reflect the experiences of many patients.

### **3.5.9 Distance Activities**

Figure 10 shows that the participants' reports of their distance vision varied in terms of increasing and decreasing abilities. Ruffine, Nuxy and Jordan all described a decrease in distance vision abilities while Rose and Irene reported improvements. The participants who reported a decrease in distance vision abilities all reported at the second interview that they had 'stopped going out to plays, movies and sports events for reasons other than vision loss'; therefore this question had little impact on their overall scores. Rick reported no problems with distance activities at either interview.



**Figure 10: Graph showing distance activity ratings for interview participants**

Some participants elaborated on their abilities to see street signs, walk down steps in the dark, or go and see plays, movies and sports events. When these activities were mentioned problems tended to be caused by factors other than AMD. For example, Rose discussed going to the cinema and theatre with her niece and explained that the biggest problem was not with seeing the screen or stage but with the layout of the venue:

*I did go to the cinema not too long ago with my niece, again she took me to [Town] and that wasn't too bad that time, but I went, used to go to [Town name] theatre with her and I, it was so close between the seats my knees used to be cramped up. When I come to stand up to walk out, you were right on some steps and I used to be scared to death going down those steps. So, if there's, if there's no steps there, like when I went to the cinema we were right in the front row and you could stretch your legs and there was nothing there it was fine, but I don't often go now because I've stopped going to the theatre with her for that because of that reason.*

*Rose interview 1, Line 330-345*

Rose explained that she had no problem seeing people on stage at the theatre or seeing the cinema screen. It appears that the problems experienced were indirectly related to vision and were a combination of other mobility related health problems and the layout and number of steps in venues. Feeling unsteady on her feet and not being confident with her ability to see the steps resulted in Rose being too afraid to attend the cinema or theatre. In addition, Rose relied on her niece to take her to these activities as a result there appeared to be a link between the participant's abilities and their dependence on their families (see dependency section for further discussion, p. 82). Many of the participants highlighted that they were unable to get to activities outside of their home without transport provided by family members.

Rather than discussing walking down steps and stairs in the dark (covered in the survey) participants' highlighted problems walking and getting around in the day time. For example Jordan explained that her AMD made walking in public places much more difficult:

*When I go out it's like treading on eggshells when I'm walking, I'm frightened; I'm just looking on the floor all the while.*

*Jordan interview 2, line 110-113*

Jordan explained that her fear of tripping on uneven surfaces meant that often she chose to stay at home to avoid the stress of walking outside. This was particularly difficult for Jordan to come to terms with as she had previously been a keen walker. The fear Jordan experienced was very significant and likely to represent the experience of many older people with vision impairment. This fear of walking may indicate the start of reduced mobility which with increasing frailty and the risk of falling could relate to a whole host of other problems and a general decline in health. It is important to understand the challenges to normal social activities faced by patients (such as walking down the pavement) in order to holistically understand their experience of conditions such as AMD.

Another distance vision activity which affected mobility and getting out of the house was the ability to read bus numbers:

*I used to be able to see something long distance at one time, but I can't see that so much now, it's, I know at one time I couldn't see the bus until it was right on top of me and I say to people, what number bus is coming up and I used to feel such a fool. ((laughs))*

*Rose interview 2, line 1129-1135*

A few of the participants talked about their struggles to read bus numbers and Jordan even recounted a story where she had taken the wrong bus and ended up in an unfamiliar part of town. The need to ask others to tell them the bus numbers often resulted in embarrassment for the participants to the point that that some avoided using buses to prevent the embarrassment caused.

One of the most commonly discussed distance vision activities was the ability to watch television; however this was not covered by the survey. Ruffine, who reported the greatest decrease in distance vision abilities, explained her experiences of watching the television:

*I don't use my glasses for TV, I found I didn't need them, and err, if I close one I can see it perfect, if I close the other eye, I can still see it, but I can't see the faces, not clearly.*

*Ruffine interview 1, line 726-730*

At the time of the first interview Ruffine felt that her vision was at a sufficient level to enable her to watch television unaided, however she acknowledged that if she were only relying on her eye with AMD she would have some difficulties. Ruffine felt her good eye was compensating for the problems she was experiencing in the eye with AMD. During the second interview Ruffine reiterated what she had said in the first interview:

*I don't need my glasses for the TV, in fact I don't read a lot now because I can tell I need stronger glasses. But when I look at the TV without my glasses, if I close the bad eye I can see perfectly, if I close the good eye, I can see to a certain extent but I can't distinguish the features, the faces.*

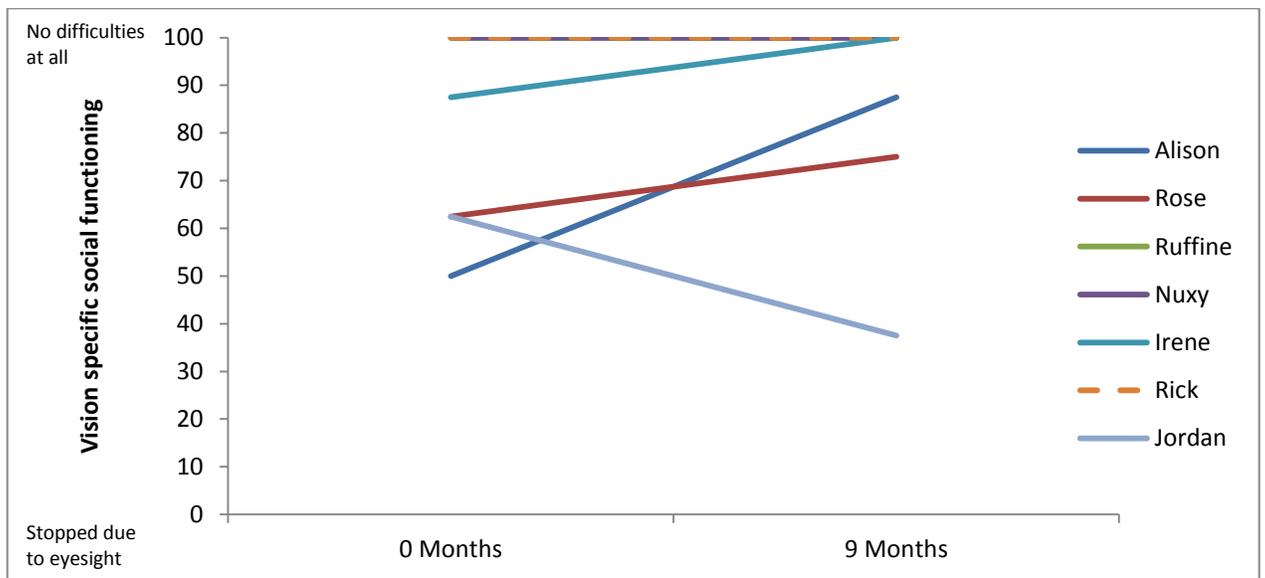
*Ruffine Interview 2, line 694-700*

The difference in the second interview was that Ruffine had reported becoming aware that her current glasses were no longer suitable for some activities. This difficulty was limited to reading; however her description suggested that Ruffine was aware of the deterioration in her vision.

Many of the distance activities reported by participants in the interviews were unrelated to the survey questions. For example some activities mentioned included: looking at objects on the sideboard, reading bus numbers, walking down stairs during the day, watching television, fishing (watching the float), reading clocks, looking at photographs in frames, looking outside through windows, recognising faces, walking in public places, missing the cup when pouring drinks, and seeing pan handles when cooking. Like the near activities subscale discussed previously these missed experiences illustrate that the NEI-VFQ is not sensitive to many of the issues important to older people with vision impairment.

#### **3.5.10 Vision Specific Social Functioning**

Vision specific social functioning in the survey included the ability to see people's reactions during conversation and the ability of participants to get out of their home to visit others. Figure 11 shows that both Rick and Ruffine indicated no problems with social functioning resulting from their vision. Alison, Rose and Irene reported improvements in vision specific social functioning over time and Jordan reported a decrease in vision specific social functioning.



**Figure 11: Graph showing vision specific social functioning ratings for interview participants**

For some of the participants the ability to be socially engaged was dependent on assistance from family members. For example, Alison was a member of a variety of groups and societies but her attendance needed to be co-ordinated around her daughter’s availability to drive her to events:

*I belong to WI, and all those sort of things, but usually my daughter takes me, and I mean one of the members drops me back. So, but I still do that, I’ve been a member of WI for 38 years so, and it’s quite interesting, it keeps this ((points to brain))*

*Alison interview 2, line 705-709*

Assistance from others gave Alison opportunities to remain socially engaged. In addition to this she felt the societies she attended were a great way to remain mentally active. Rose also suggested that her visits to friends and relatives were dependent on having someone to take her:

*I don’t visit unless I’m picked up and taken.*

*Rose interview 1, line 310-311*

In comparison to Alison who lived with her daughter, Rose lived alone, as a result she felt less able to be socially engaged and explained “*I don’t do much social life actually*”. For both of these women social engagement was dependent on assistance from others rather than visual limitations, however, for Rose this help was less readily available. While the participants explained that help from others could get them to social events they also both mentioned difficulties with using buses due to their vision, this may suggest that there is an indirect link between visual impairment and ability to remain socially engaged.

The survey asked about participants' abilities to see how others reacted to the things that they said and most gave little thought to this question suggesting that this was not usually a problem for them. However, some did suggest that facial recognition was a problem, for example Alison explained that she had met a lady at the hospital who recommended a support group she could attend, when she attended the group the lady had been present but she had not recognised her:

*I'd sat side-on to the lady [when I met her], and I couldn't recognise her because I'd only seen her side-on. And when I got there [to the support group], she didn't know me either, and apart from side-on, it was only when my daughter came and picked me up, she said, 'that's the lady you spoke to', I said, 'Is it?', I hadn't a clue! So I did go and speak to her, she said 'yes that's right' she said, 'but I didn't know you either' she didn't know me, because we only sat side-on.*

*Alison interview 2, Line 1291-1300*

At the second interview Alison had responded to the question about how often she had problems seeing others' reactions to what she had said with 'none of the time'. The quote above suggests that facial recognition could be a problem for Alison and act as a barrier to social engagement; however this was not in the way that the survey question had suggested. Alison's ability to recognise the faces of others was dependent on context as when she saw the lady from the hospital in a different context she was unable to recognise her, just as the lady had been unable to recognise Alison. Alison had wanted to engage with other people at the group meeting, but her visual disability had been a barrier to this.

Jordan showed the greatest decrease in this subscale. Jordan described one particular event when she had been stood outside her house when a neighbour had passed by on a bicycle:

*I mean when he come down, [neighbour] come down and I never acknowledged him, and that's when you feel awful, people wave to you and you kind of think, who's that? And I said to her, 'don't think I'm being ignorant' she said, 'no I don't think that' but I have to go right up to them, you know? To see them.*

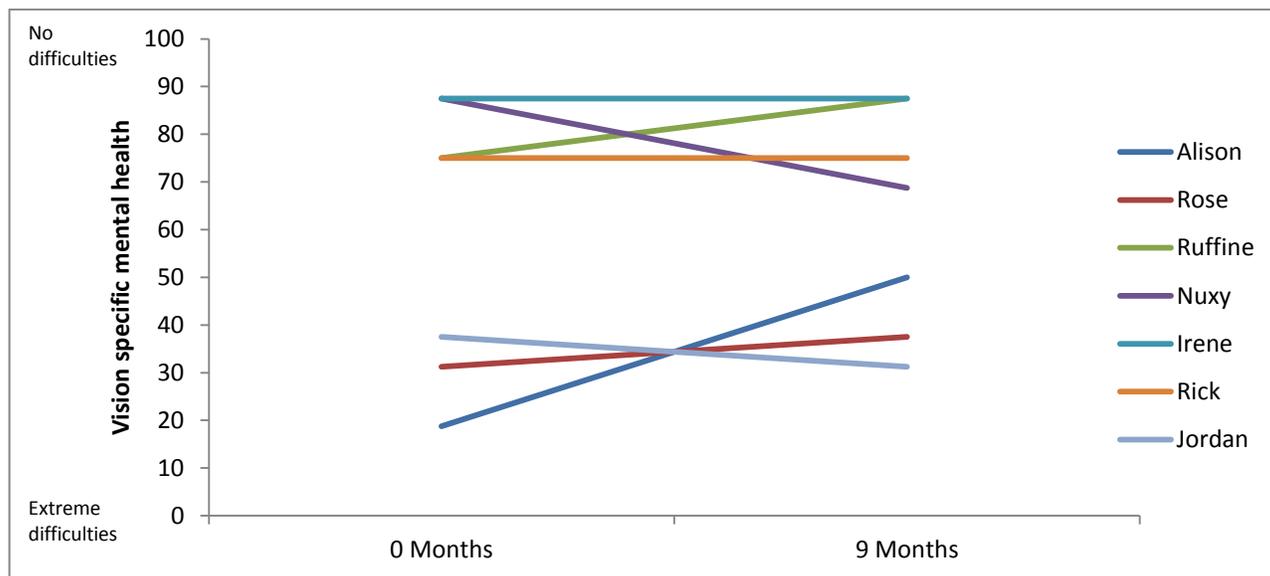
*Jordan interview 2, line 1225-1232*

Jordan's experience highlights the impact her visual deterioration was having on her self-concept. She worried how she was perceived by others and in particular she was concerned that neighbours may think she was deliberately choosing not to speak to them. This experience illustrated both the isolating nature of the condition for Jordan and the psychological distress this could cause.

### **3.5.11 Vision Specific Mental Health**

Figure 12 illustrates the changes in vision specific mental health between the first and second interviews with the participants. There appears to be two distinct groups; Alison, Rose and

Jordan who give generally lower vision specific mental health ratings, and Irene, Ruffine, Rick and Nuxy who give generally higher vision specific mental health ratings. Ruffine, Alison and Rose showed improvements in vision specific mental health, Jordan and Nuxy showed decreases in vision specific mental health, and Rick and Irene’s vision specific mental health remained the same between the two interviews.



**Figure 12: Graph showing vision specific mental health ratings for interview participants**

Ratings for vision specific mental health in the survey were based on feelings of frustration, control, worry and embarrassment. No participant rated themselves as having perfect vision specific mental health and all of the participants expressed examples of at least one of these emotions during the interviews. The participants reported worrying about a wide variety of things including: crossing the road, what their eyesight would be like in the future, being a nuisance or a burden, having treatment, and losing their driving licence. The participants reported frustration with doing every day activities (such as household chores or DIY), reading and wearing glasses. The participants reported being embarrassed by; asking for help, being dependent on others, and doing things wrong.

Nuxy’s responses suggested the greatest decrease in vision specific mental health. It was evident from his interviews that he was gradually becoming more concerned about his vision, at his first interview he was satisfied that if his vision remained constant he would have no need to worry. Nuxy’s knowledge that he would retain his peripheral vision made him feel confident that he would still be able to get by despite the deterioration due to AMD; at this point his only concern was that the vision in his other eye may also deteriorate. By the second interview Nuxy was becoming more concerned:

*I suppose yeah, the only worry part, you do worry, deep down you do worry in case it gets worse so it seems to be alright at the moment, I've had it 12 months so, it hasn't got any worse so... Yes it is deep down yeah, occasionally it comes up you know? Especially if you are having difficulty reading or whatever you are doing and then you, then you start to worry but normally I don't, I don't worry at all.*

*Nuxy interview 2, line 691-702*

By the second interview Nuxy's worry was beginning more frequent and these concerns were especially prominent at the times when he began to struggle with his usual activities such as reading.

Jordan also reported a decrease in vision specific mental health between the two interviews. It was evident in the second interview that her continuing decline in vision was becoming more and more restricting leaving her feeling hopeless and less interested in getting on with her life:

*I don't feel as if I want to go visiting like I used to, I used to love to go visiting, as I say in the morning I'm alright until I've done everything, and I'm sitting there and I think, 'I can't do that because I can't bloomin' see to do it' you know? ...I know it's not me, it's not me, but I just don't know. I don't feel, now how can I put it, I don't feel so nice in myself as I used to, I used to get up and have a shower, bath, a shower we used to have in the other house, shower and I used to like to dress up nice, put make up on. I never used to go out without make up, never, but now I just don't bother, I haven't wore make up for the last 12 months, not even lipstick, at one time I wouldn't even go out the door without lipstick on, but not now, I can't be bothered, I haven't let myself go like dirty or, not changing clothes, not that way, but I've let myself go*

*Jordan interview 2, line 1147-1169*

This extract illustrates the way in which Jordan's vision specific mental health and social functioning and general vision were intertwined. Once Jordan had completed her daily chores she was left with nothing else to do as all of her hobbies required better near vision than she currently experienced and she felt afraid to go out of her home as she needed to constantly watch the floor to ensure she didn't fall. These factors combined had an impact on who she perceived herself to be. As Jordan was unable to continue with activities she once did she no longer felt like herself and this was not only a feeling but by no longer wearing make-up she also externally presented herself as a different person.

Rose's ratings of her vision specific mental health were also linked to her concerns about being dependent. Rose was embarrassed by the level of help she needed from others:

*I feel embarrassed sometimes because people help me more, you know? They, when I go out with my niece, it worries me more that embarrasses me because they help me, you know, apart from the not being able to walk properly it's because I can't see properly either and all the while they are saying to you, 'are*

*you alright?, are you alright? Can you see that, are you alright?' and ((laughs)) and you get embarrassed because they worry about you, that's what it is.... I worry because I don't want to be a nuisance.*

*Rose interview 1, 1420-1433*

Rose explained that she was experiencing multiple health problems related to both her mobility and her vision and as a result felt others perceived her as in need of help. Rose was embarrassed by the help offered by others and the way in which she was being perceived. Rose didn't want to impact on other people's lives and when they offered assistance she felt she was becoming a burden to them.

Irene's answers to the survey questions suggested that AMD had little impact on her vision specific mental health. It is clear from the graph that the survey indicated Irene's vision specific mental health to be the best of all the participants, and this was consistent across both interviews. When asked whether she was ever frustrated by her vision she responded with 'definitely false' on both occasions; however during Irene's first interview she appeared to directly contradict this statement:

*It does get a bit frustrating at times. You know, to think, 'Oh I wish I could see a bit more'*

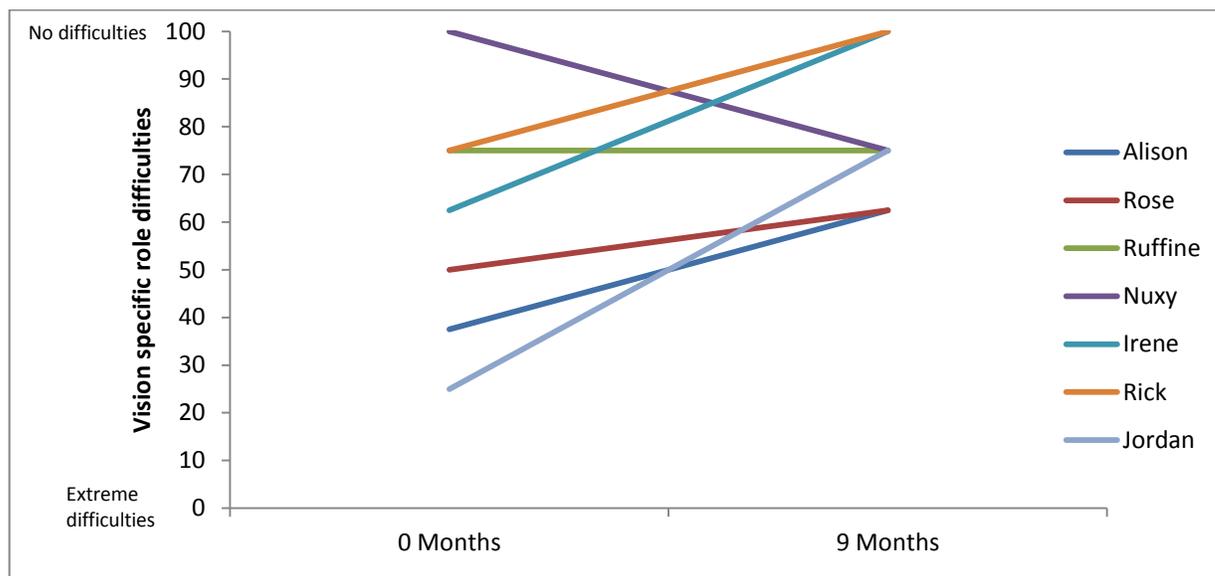
*Irene interview 1, line 788-790*

Irene explained that she often became frustrated when she was unable to see something. For example she described her vision as hazy and gave examples of activities such as looking at the clock or at photographs on her mantelpiece which she was struggling with. Irene had recently undergone an operation to remove a cataract and following the operation she expected an improvement in her vision but instead found her eyesight to be hazy. Irene explained that when she reported this haze to the hospital she had been diagnosed with AMD. It was when Irene's vision expectations were not met following the operation that she decided to contact the hospital. By the time of the second interview Irene had undergone treatment for AMD and explained that the haze had mostly disappeared. In the second interview Irene made no reference to her vision causing frustration suggesting that treatment had improved this aspect of her experience. Irene's answers to the survey did not illustrate this change; it was perhaps only when she began to discuss her experiences that she became aware of the frustration her vision had caused.

### **3.5.12 Vision Specific Role Difficulties**

The survey attributed role difficulties to limitations in being able to do work and accomplish activities. Almost all of the participants reported an increase in their ability to fulfil roles over

the two interviews; only Nuxy described a decrease in role specific abilities, while Ruffine's rating remained the same at both interviews (figure 13).



**Figure 13: Graph showing vision specific role difficulty ratings for interview participants**

Nuxy reported a decrease in vision specific role abilities between the first and second interview. He gave the same response ('none of the time') when asked how limited he was in how long he could do work or other activities because of vision at both interviews. Therefore the change in score was based on his response to the question about how much his vision stopped him accomplishing things he wanted to be doing. At the first interview Nuxy reported that he accomplished less 'none of the time' and at the second interview he reported that he accomplished less 'some of the time'.

None of the participants talked specifically about their role difficulties in the interviews. However many did discuss increasing dependence on others in order to get on with things they wanted to do. The increase in role abilities suggested by the survey therefore conflicts with the increasing levels of dependence discussed by participants. When compared with the graph for vision specific dependency both graphs seem to suggest findings at odds with the participants' interview data (see vision specific dependency for further discussion p. 82).

### 3.5.13 Vision Specific Dependency

Figure 14 illustrates that Nuxy, Irene, Rick and Ruffine all reported no vision specific dependency at either interview, while Alison, Jordan and Rose all reported fairly high levels of vision specific dependency at the first interview but these ratings fell by the second interview. This is an interesting finding as it directly contrasts to the findings from the in-depth interviews conducted for this study. All of the participants, except for Ruffine, mentioned dependency in

some form in at least one of their interviews. The differences between the survey and interview findings suggest the survey questions may not be sensitive to the types of dependency experienced by the participants.

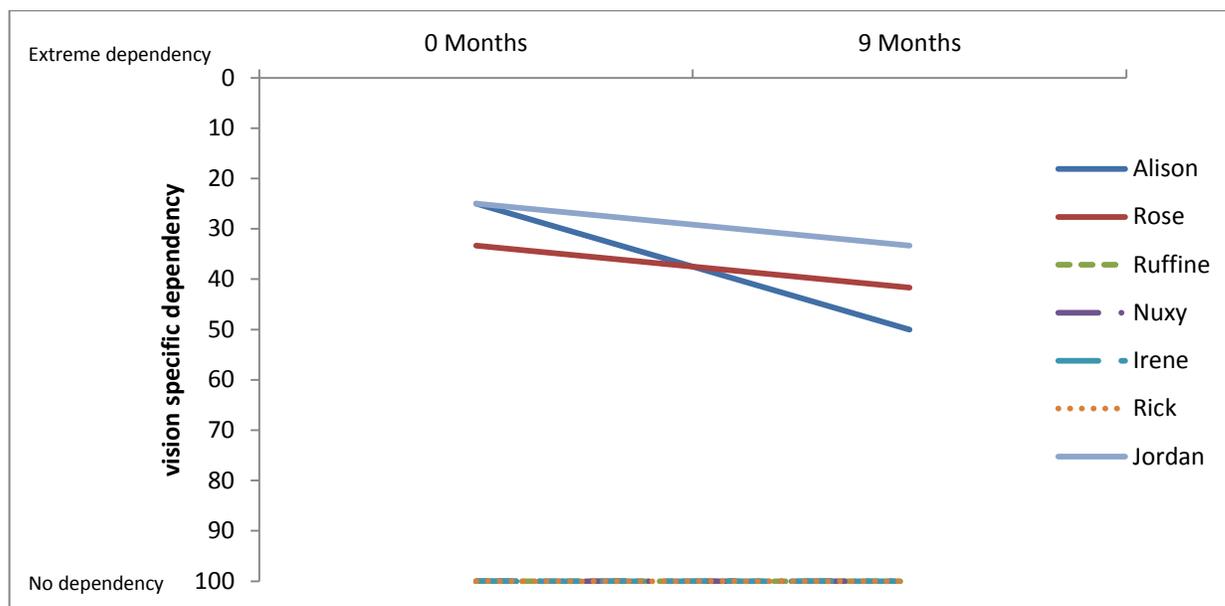


Figure 14: Graph showing vision specific dependency ratings for interview participants

Nuxy’s discussion of dependency fitted with his report that he experienced no vision specific dependency. His interview discussions focused on his need to remain independent rather than on any form of increasing dependency he was experiencing:

*I should hate for people to and I know it sounds, but doing everything from washing you to doing cleaning you up after you’ve been to the toilet, now oh, that, that would send me round the twist. I mean I know it’s silly things and you notice it when I had a small break in my wrist and I had a you know, I’d only got one arm I couldn’t and I tell you what I found it that difficult. Because you normally have two hands to whatever you are doing but doing your button, doing your tie up, doing your shoe, and when you’ve only got one hand, so if you can’t do anything for yourself it must be terrible, yeah I seem to. And as I say, the fact that I drive, I get out, throw my gear in the back and go fishing, you can’t do that when you can’t drive, you’ve got to rely on other people, that’s I don’t like that, I like to be doing things for myself and while I can I will, that’s yeah.*

*Nuxy interview 2, line 664-682*

The interview data suggested that Nuxy was not experiencing any vision related dependency at the time of the interview but he did express concern that this may change in the future. Nuxy associated real dependency with being physically unable to do things and his own brief experience of dependency due to a broken arm reaffirmed his desire to remain independent for as long as possible. Nuxy reported being able to drive which meant he had the means to do all of the activities he wanted to, however he did express fears about becoming more

dependent in the future if he was no longer able to drive (see driving subscale for further discussion p.86). Irene also suggested that she had no vision related dependency. However, Irene did explain that she relied on her family to take her to hospital appointments:

*the last time that [daughter] came and we went to [the hospital]. It's a bit awkward really when you keep asking. And I mean, the thing is, they've got to keep having time off work, from work.*

*Irene interview 1, line 974-978*

This dependency was indirectly related to her AMD. Irene needed to attend the hospital at least once a month for monitoring and treatment and believed she was becoming a burden to her daughter who needed to keep taking time off work in order to take her to the hospital. This problem resulted from a combination of Irene's AMD diagnosis and Irene's husband's deteriorating physical health which meant he was no longer able to drive the car. While one of the survey questions asked about needing help from others due to vision Irene did not interpret this to include being taken to the hospital and therefore answered 'definitely false' on both occasions. This is an example of an occasion where the survey missed an important element of the experience for Irene.

Rick was another participant who reported no vision specific dependency, but he did discuss dependency during the in-depth interviews. Like Irene, Rick reported that his family took him to hospital appointments (Rick was able to drive but could not drive himself to ophthalmology appointments). Rick suggested that increasing dependency seemed to be being forced on him by his family:

*They won't let me do anything, I mean I used to do my own decorating and everything, I have been always handy. Can't do it now like. The kids come down if I go away. They start, .. I'm waiting for them now. When I go away in September, they strip my house down and redecorate.*

*Rick interview 1, Line 160-163*

Rick reported physical health problems in addition to vision impairment. He had lived in his home for many years and had kept it as it was when his wife had died a few years ago. Rick's family expressed concern about him living in the house alone and frequently attempted to persuade him to move elsewhere. Rick was happy in his home and was determined to remain independent despite increasing mobility difficulties ("*My daughter keeps on I'm too independent... Too independent, I like to be independent*" Rick interview 1, line 153-155). Rick's forced dependency was related to his mobility and physical health rather than his vision, however his family's concern about his vision problems may have been adding to their desire to take care of Rick.

Rose, Jordan and Alison all reported a decrease in dependency between the first and second interviews based on the survey data. However, Rose's account seemed to suggest her level of dependence had increased by the second interview. During the first interview Rose asserted her independence:

*I never ask for help, I would never ask for help, no. I'm too independent for that... I'm independent as much as I go out shopping, I do my own shopping, if I want to find out anything, I find it out, I ring around and find out what I want to know you know? I get by, whatever I want getting done I'll get by.*

*Rose interview 1, line 909-919*

However, during the same interview she also discussed some situations in which she was dependent on others:

*I can't see to put screws in anything, or I have to get somebody to do everything for me where as one time I'd have a go and do it myself.*

*Rose interview 1, line 398-401*

By the second interview Rose's assertions of dependence had gone and Rose was starting to admit that she has become more dependent on others:

*Well I can't do it myself I have to get somebody in to do it, yes, no and whatever I want doing I have to find somebody to do it for me....[it makes me feel] frustrated ((laughs)) and especially the garden is, well I used to love gardening, but of course I can't do that now, so I have to pay somebody else to do it.*

*Rose interview 2, line 824-832*

The time between the first and second interviews seemed to be a transitional period for Rose. Rose began by asserting independence and identifying with her past self who was capable of getting things done. By the second interview Rose's independent self was beginning to be lost and this was difficult for Rose to accept and deal with and led to her being frustrated and upset that she could no longer do the things she once did. While this change is clearly reflected in the interviews, Rose's responses to the survey seem to suggest the opposite (a decrease in dependency). A closer look at Rose's survey responses indicates that the change is dependent on a single item (I need a lot of help from others because of my eyesight) which Rose answered as 'definitely true' in the first interview and 'mostly true' in the second interview. This single question was not sufficient to highlight the full extent of dependency changes for Rose.

Jordan's survey responses also contradicted the interview discussions. Jordan reported a substantial decrease in dependency on one question (needing a lot of help from others) altering her response from 'mostly true' to 'mostly false', and a slight increase in another

survey question (rely too much on what other people tell me) from 'mostly true' to 'definitely true'. While both of these questions were measures of dependency Jordan had interpreted them differently at the two interviews. At both interviews Jordan related 'relying on what others told her' to her need for her daughters to read letters; *"I have to depend on the kiddies doing a lot. They come to read my letters or they come to look at different things for me."* (Jordan Interview 1, line 897-899). This question was immediately followed in the survey by the question about needing help; at the first interview Jordan related the two questions and answered the second questions with "*mostly true again*" suggesting that she was considering the same issues when thinking about the question. Jordan's first interview took place on the morning of her first treatment and she repeatedly referred to her concern and about what the treatment may be like. This may explain her negative view of her situation on that day and help to explain her associating the two questions. The stress she was experiencing as the survey was administered may have been preventing her from taking time to consider each question.

By the second interview Jordan had undergone many treatments and was no longer concerned about this. When asked the questions again Jordan did not relate needing help from others to activities such as reading letters; she instead talked about being able to do her own housework and chores:

*I'll have a go at ironing, have I got the creases out you know? And things like that, washing machine I can turn that on, electric scale I'm alright with.*

*Jordan interview 2, line 547-549*

At the second interview Jordan did not relate the two questions and took time to consider each question individually. Jordan described feeling independent as she was capable of maintaining her home and doing her chores. Jordan's biggest problems were with hobbies and entertainment activities (as discussed in near activities p.70) and she therefore did not associate her AMD with needing help from others.

#### **3.5.14 Driving**

Only two of the participants were driving at the time of the interviews (Nuxy and Rick) and neither participant reported any change in driving ability between the first and second interview. Alison had stopped driving shortly before her first interview and discussed the loss that this had been for her. Driving was an important part of these participant's lives as it enabled them freedom to get out of their homes and engage in activities they wanted to do:

*To me [driving] is the thing absolutely, because it's your freedom.*

*Alison interview 1, line 1183-1184*

*If I get in the mood, I just buzz off. I like my driving and, if I can't drive, I can't get out. I should never be out of the house like, you know.*

*Rick interview 1, line 433-437*

Both Rick and Nuxy highlighted the negative impact that no longer being able to drive would have on their lives. Rick talked about not being able to get out of the house, while Nuxy highlighted the more emotional impacts the loss of driving may have for him:

*I think it would make me a bit depressed to be quite honest because, I mean I drive, I drive most places wherever I go and the fact that I've got the bus pass now, err, two or three times a week me and the Mrs go out, I've got a thing, but the only way you can get down to the North station is to drive, so I drive down there, then we jump up on the train and we do our trips all around the midlands, because it don't cost you nothing and it's great you know? It's nice to get out, but the driving bit, that's the one, that's the bit that worries me, it really worries me that does, that I wouldn't be able to drive.*

*Nuxy interview 1, line 534-543*

Not being able to drive was the main concern that having AMD had caused for Nuxy. By the second interview this concern had become even more serious with the suggestion that no longer being able to drive may “kill” him or the sense of self he was holding on to:

*I'll tell you what, when I have to stop driving that'll kill me that will, I tell you. I've been driving since I was 16, now that's a long time and I love driving, yes. Yes so, if I stopped carrying on, I'm still going, I don't think I'm dangerous anyway, I've been driving too long to be dangerous so.*

*Nuxy interview 2, line 486-492*

If Nuxy became unable to drive he would need to restructure the way he saw himself in order to adjust to the changes in his independence which would be forced on him by the loss of his car. For all three participants driving ability was heavily linked to their abilities to remain independent. The survey questions for the driving subscale focused specifically on driving ability rather than the impact either driving or not driving would have on the participants' lives. This is an important element of the experience of AMD which is not sufficiently addressed by the survey alone.

The combined postal and interview survey data suggested a significant improvement in driving ability between zero and nine months post diagnosis. It may be possible that for those still driving at the start of treatment the improvements experienced as a result of treatment may have a positive effect on driving ability. Nuxy and Rick both discussed a fear of what their lives may be like if they were required to stop driving, however their survey responses indicated no decline in driving ability between the two time points.

### 3.5.15 Colour Vision

Colour vision was measured in the survey using a single item which asked about picking out the colours of clothes. Figure 15 shows that Three of the participants (Rick, Irene and Ruffine) reported no problems with picking out and matching clothes at either interview. Jordan and Alison both reported 'a little difficulty' with picking out and matching clothes at both interviews. Rose was the only participant to experience an increase in difficulty matching clothes as she reported 'no problem' at the first interview and 'a little difficulty' at the second.

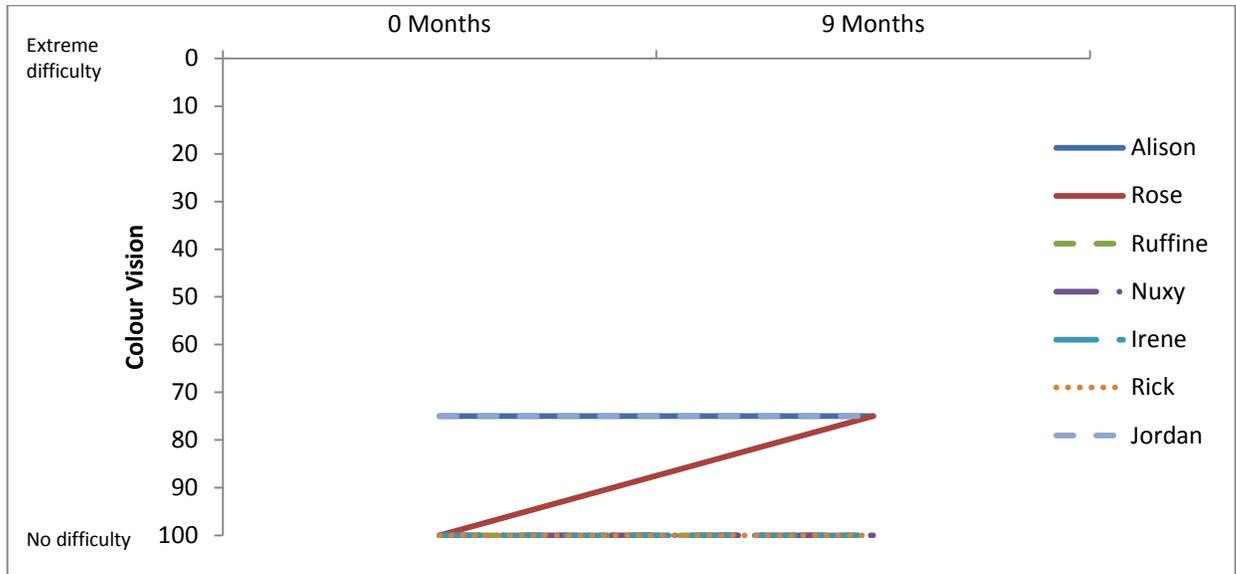


Figure 15: Graph showing colour vision ratings for interview participants

Only a few of the participants expanded on their colour vision in the interviews. Alison's explanation for matching colours suggests she may have attributed the question to a matter of 'style' and being able to co-ordinate colours rather than to a visual difficulty:

*I've been good with colours anyway with painting so that hasn't really been a problem.*

*Alison interview 2, line 70-72*

Rose recognised that colours sometimes did not always appear the same in different contexts; however she attributed this to external factors such as the lighting when shopping rather than to a decline in her colour vision.

*I have difficulty sometimes with the colours in a shop, because the electric light always seems to change the colours doesn't it, but, really speaking I don't suppose it's difficulty, I can see the colours of things, I'm not colour blind or anything you know?*

*Rose interview 2, line 121-126*

Nuxy felt the colour vision question did not apply to him as he took little interest in the colours of his clothing:

*I'm not that really into clothes you know? Whatever is at the top of the drawer you know, I just pick it up and put it on, you know? As long as it's been washed and ironed, that's alright with that.*

*Nuxy interview 1, line 104-108*

This single item was perhaps unsuitable for assessing the impact of AMD on colour vision for some of the participants due to the context of the question being irrelevant or unimportant to some.

### 3.5.16 Peripheral Vision

Most of the participants reported the same level of difficulty with peripheral vision at both interviews (figure 16). Rick, Irene and Ruffine all reported 'no difficulty' with peripheral vision at both interviews. Jordan and Rose reported 'moderate difficulty' with peripheral vision at both interviews. Alison reported a decrease in difficulty from 'moderate' to 'a little difficulty' between the two interviews and Nuxy reported an increase in difficulty from 'a little' to 'moderate' between the two interviews.

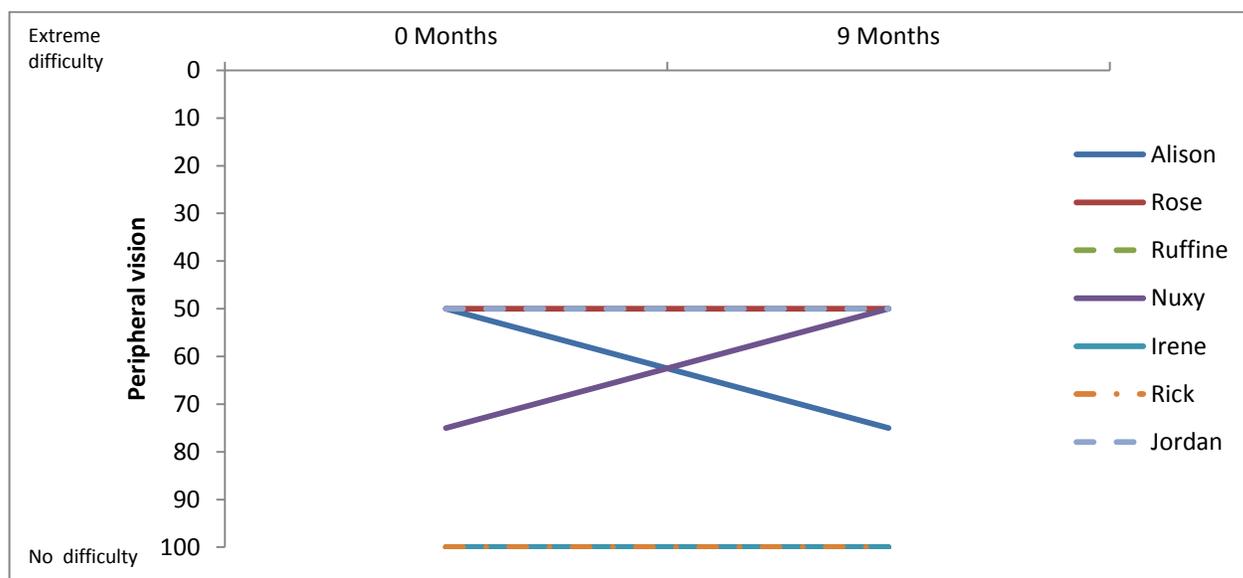


Figure 16: Graph showing peripheral vision ratings for interview participants

Rose was the only participant to elaborate on her peripheral vision during the interviews:

*When you've got a hearing aid as well, it doesn't always, the sound doesn't always seem to be where it's coming from really. So it is difficult when there is anything coming up the side of you.*

*Rose interview 1, line 245-249*

Rose's judgement of her peripheral vision was based on a combination of hearing and vision loss. It may be possible that without hearing loss Rose would report a less severe impact on her peripheral vision.

### **3.6 Results summary**

The objective of this chapter was to explore how well the NEI-VFQ reflects the experiences of patients

#### **3.6.1 How suitable is the NEI-VFQ as an outcome measure in studies assessing the success of AMD treatments?**

The survey showed no significant changes in the NEI-VFQ total score or subscales between zero and nine months in patients treated for wet AMD. With a larger sample size it is possible that significant changes may have been found as has been reported in other studies (Bressler et al. 2009; Chang et al. 2007). Looking more closely at the interview data highlighted potential changes in subscales which were not found to be significant in the survey data. Improvements and declines varied depending on the context of each of the participants' experiences. It is therefore possible that the postal survey did not detect changes across the whole sample as, for individuals, changes may occur in different directions. While this may be evened out in a larger sample it does illustrate the way that questionnaire research can minimize the importance of differences in individual life contexts and experiences for the patients themselves. This exemplifies the importance of the experiential context of participants' perceptions when judging health and supports the work of Gooberman-Hill, Ayis, and Ebrahim (2003). While surveys like the NEI-VFQ often show agreement when compared with other quantitative measures there seems to be poor agreement between these measures and the meaning the individual prescribes to their health status. Where some researchers committed to quantitative methods may stress this to illustrate the unreliability of self-report measures, the use of a mixed-methods research approach enabled an exploration of the variability and nuances evident in older peoples sense-making regarding ill health. This illustrates the need for in-depth approaches to understanding the experiences of patients with AMD in order to fully understand the impact of the condition on QoL.

#### **3.6.2 Which NEI-VFQ subscales suggest the greatest potential changes and warrant further investigation?**

While the statistical analysis of the NEI-VFQ subscales suggested trend level differences in driving ability and colour vision over time, the small sample size of this study does not enable any firm conclusions to be drawn.

Nearly all participants in the postal survey showed an improvement in colour vision at nine months and it is possible that these improvements in colour vision may have resulted from undergoing AMD treatment. This finding would therefore be worthy of further exploration using a larger sample. However, in the interview subsample this improvement in colour vision over time was not replicated. The colour vision subscale was based on a single item relating to judging and matching the colour of clothing, and as a result some of the interview participants failed to see any relevance of this question to their lives. Therefore this subscale question may not be particularly sensitive to AMD patients potential changes in colour vision.

In terms of the driving subscale the additional detail provided within the qualitative data highlighted the way that this activity represented freedom and independence for participants and was therefore an important aspect in their lives. Participants highlighted fears about their future driving abilities which were linked to their need to maintain their independence. While the survey may be capable of assessing functional driving ability it overlooked the emotional impact threats to driving ability may have on the participants. The interviews suggested that experiences related to many of the subscales were intertwined with each other as well as with the context of the participants lives. Driving is an example where without this ability the participants expected to experience increased dependence and reduced social functioning as well as more mental health problems (for example Nuxy reported that he'd feel depressed if he could no longer drive).

### **3.6.3 How may NEI-VFQ ratings and QoL change over time in treated AMD patients?**

The sample size in this pilot study was insufficient to make any firm conclusions about the way in which NEI-VFQ and QoL may change over time. However, when combined with the interview data it was evident that changes in experience did occur for many patients. Further evidence of these changes is discussed below.

### **3.6.4 Do different participants experience different NEI-VFQ scores? If so what are the potential reasons for differing scores between interview participants and changing scores within participants over time?**

Although the survey data indicated no significant changes in many of the subscales over time the qualitative data highlighted examples of change in specific individuals. The in-depth interviews highlighted important factors relating to the subscales which were not covered by the survey questions. For example, a closer look at the interview participants' responses to the questionnaire suggested an improvement in near vision activities for some but not all of the participants. It is possible that patients may only experience difficulty with a few of the specific issues covered in the questionnaire and this lack of sensitivity in the survey was highlighted

in all of the interviews when participants spoke of difficulties with near vision activities not covered by the questionnaire. This illustrates that the NEI-VFQ subscales are not sensitive to all of the issues experienced by AMD patients.

Another example of the lack of sensitivity in the NEI-VFQ was evident in the distance vision subscale. The interview data highlighted that participants experienced difficulty with a wide variety of distance vision activities which were not addressed by the NEI-VFQ survey. In addition, when considering the questions for the distance activity subscale some of the participants related their experiences to other factors which prevented them doing the activities. For example, Rose no longer attended plays due to a combination of difficulties with the physical layout of the venue and needing to be driven to the events by family members. Rose was limited by the survey options to explain this experience and therefore the scores may fail to accurately represent her experience. Again the social functioning subscale, which asked participants about their ability to see other peoples reactions and their ability to attend social events, appeared insensitive to participants experiences. Most interview participants reported an improvement in this subscale between zero and nine months (with the exception of Jordan) and many of the participants related these activities to other important factors in their lives. For example, an inability to attend social events was linked to troubles using public transport and a reliance on friends and family members to provide transport. The ability to see the reactions of others seemed particularly problematic, while most participants reported little difficulty with this some of the participants went on to explain difficulties with recognising the faces of people they passed in the street. This was an issue which not only reduced their opportunities for being socially involved but created stress and concern about others perceiving the participants to be ignoring them.

### **3.6.5 Can we learn about other elements of patient experience by using the NEI-VFQ alongside exploratory qualitative research methods?**

The discussion regarding the research question above illustrates that additional qualitative data can add context to the interpretation of NEI-VFQ survey data. In addition, each of the methods seemed to be strengthened by the presence of the other. For example, the findings of the postal survey were enhanced by analysing the qualitative data and survey data from the interview participants. While initial interviews tended to include discussion based around information which would be acceptable in a public context (and within the confines of the questionnaire), in later interviews participants revealed more private and more deviant accounts which would not be accessed by the use of the questionnaire alone. In addition, during data collection the participants regularly added additional information when answering the questionnaire and survey questions frequently acted as prompts for further discussion

about specific QoL issues relevant to the qualitative data (i.e. when asked about general health, the participants often proceeded to detail any health problems they were experiencing).

### **3.7 Discussion**

#### **3.7.1 Implications for the use of the NEI-VFQ**

Some of the subscales included in the NEI-VFQ may not be particularly relevant for AMD patients. For example, ocular discomfort was not reported to be a symptom of AMD. When participants reported ocular discomfort in the interviews it was frequently related to drops and medications which in some cases were prescribed for conditions other than AMD (such as glaucoma). Peripheral vision was another subscale which seemed to have little relevance for AMD participants. AMD is a condition which mainly affects central vision, as a result patients may experience little impact on their peripheral vision abilities. Only one of the participants mentioned peripheral vision issues during the interviews, this participant highlighted difficulties in relation to the combination of AMD and hearing impairment. Dual disabilities are common in older people and can have combined effects on patient experiences of day-to-day life. When answering questions about one condition it is likely to be difficult for participants to make judgements on the condition in isolation; instead participants may use contextual information about other aspects of their lives in order to determine their answers.

Some of the participants changed responses to the questions based on what they were experiencing in the specific moment in time in which they were asked. Key examples of this include Jordan who was awaiting to be given treatment on the afternoon of the interview, and Ruffine who was experiencing severe problems with her legs at the time of her first interview. These experiences are likely to have had some impact on the participants responses to the questions. This illustrates that participants survey responses are intertwined with their life contexts and may be greatly influenced by other factors going on in their lives at the time of survey completion.

The general health subscale is not included when calculating the overall score for visual function, however it is important to note that participants' ratings of general health were heavily influenced by their expectations of health in relation to their age and the health issues of their peers. Despite some participants reporting what would be perceived by HCPs as fairly major health problems (such as mobility problems and recent heart attacks) many still rated their health as good in consideration of their age. The relevance of survey items such as these for the description or definition of health has become of increasing interest to researchers (e.g. Blaxter 1990; Macintyre, Ford, & Hunt 1999; Mallinson, 2002). Validity tends

to be questioned on the basis that surveys constrain the answers given by participants and fail to explore subjective interpretations of the questions and personal life contexts (Donovan, Frankel & Eyles, 1993; Eyles & Donovan, 1990). It has been widely accepted that participants may use differing 'frames of reference' when interpreting global health and quality of life questions. For example, some patients would interpret the questions within their knowledge of the experiences of family and friends, while others might have knowledge of clinical and epidemiological data and therefore use this. In addition, these frames of reference may change over time resulting in shifts in responses to the same question (Robertson, Langston, Stapley et al. 2009). This finding was also mirrored in the participants' ratings of their general vision. Despite having AMD and reporting difficulties with many vision related activities, most participants (with the exception of Jordan) rated their vision relatively highly. There is a widely held view that older people take a stoical approach to reporting clinical pain (Portenoy and Farkash 1988; Hofland 1992) and this may translate into older people's reluctance to complain about issues which they feel are expected of their age group. As a result the participants may be over-reporting their levels of vision.

While quantitative and statistical assessments as discussed in the introduction to this chapter have reported the validity of measures such as the NEI-VFQ, these assessments have been based on the measures level of agreement with other 'objective' measures of visual function. This study has questioned this validity by illustrating that the NEI-VFQ is at odds with the way older people themselves interpret their experiences with AMD.

### **3.7.2 Reflections on the feasibility of mixed methods research with AMD patients**

It would be feasible to conduct this study on a larger scale including a greater number of participants in both the quantitative and qualitative elements of the study as the findings suggest that the NEI-VFQ survey may indicate some improvements in the visual functioning of treated AMD patients' over time. It is possible that this improvement reflected improvements in visual acuity resulting from treatment. However, closer inspection of individual participants' experiences highlighted that changes in the subscales occurred differently for individual patients and were frequently related to contextual factors which were not covered by the NEI-VFQ. Therefore it is necessary to pay closer attention to the in-depth individual experiences of patients in order to gain a greater understanding of the interplay of factors involved in changes in QoL over time.

Both quantitative and qualitative methods have limitations. While quantitative research misses the depth of individual experiences, qualitative work lacks the ability to quantify and generalise results to a wider population. The overall aim of this thesis is to better understand the experience of living with AMD and its impact on wellbeing and QoL. Given the findings of

this preliminary study it seems that a detailed understanding of QoL issues cannot be achieved with quantitative methods alone. Many studies already exist which have used questionnaires and surveys to assess the impact of AMD on QoL, however little research has looked at the in-depth experiences of patients.

### **3.8 Limitations**

There are numerous limitations to this study. The sample size was too small to have the power to detect and significant changes or differences within the sample and was therefore unable to sufficiently answer some of the quantitative research questions posed. However, a variety of barriers existed which resulted in the limited sample size recruited for this study. Recruitment for the postal survey took place in busy clinics placing an additional load on hospital administration staff. In addition, given the participants visual impairment it is likely that the completion of questionnaires was not an easy task for these participants (even in large print). Given that for the postal survey questionnaires were self completed there is a possibility that questionnaires may have been completed by family members rather than by the participants themselves.

It is important to note the differences in administration of the questionnaire between the postal survey and interview participants. While there were no statistical differences found between the responses of the two types of administration it is possible that my presence and the rapport I built up with the interview participants may have affected their responses. In addition, as the qualitative data were collected from participants who were not involved in the postal survey the experiences they report may not have relevance for the postal survey participants.

### **3.9 Summary**

This chapter has highlighted the need to investigate subjective experiences when attempting to understand the impact of AMD and it's treatments on the lives of patients living with AMD. The following chapter develops a greater understanding of the literature relating to the subjective experiences of living with AMD through a literature review and meta-synthesis of qualitative research investigating the experiences of patients with AMD.

## **Chapter 4: What do we know about the experience of age-related macular degeneration? A systematic review and meta-synthesis of qualitative research<sup>2</sup>**

### **4.1 Introduction**

The objective of this chapter is to explore and synthesise the qualitative research relating to the experience of living with AMD. The study presented here has been completed based on the outcomes of the mixed methods study in the previous chapter which highlighted the need to pay closer attention to the subjective experiences of individuals with AMD. While methodological innovation has meant the value of qualitative and mixed-methods research has been recognised (Mulrow, Langhorne, & Grimshaw, 1997), the methodology for including it in evidence synthesis has proved difficult to integrate despite understanding the significance of the social determinants of health alongside the biomedical evidence reported in RCTs (Kelly, Stewart, Morgan et al., 2009). Meta-synthesis represents a possible method for including qualitative evidence in guidelines for practice by systematically reviewing the evidence reporting the needs and experiences of patients with AMD.

### **4.2 Research Question**

This study aimed to explore the qualitative research relating to the experience of living with AMD in order to investigate what we have learnt so far from qualitative research in this area.

### **4.3 Method**

The meta-synthesis of qualitative evidence is a relatively new technique developed in the health and social sciences (e.g. Campbell, Pound, Pope et al., 2003, Malpass, Shaw, Sharp et al., 2009). It is modelled on primary qualitative techniques involving interpretative activity rather than the aggregative techniques in meta-analysis. The goal is to synthesise findings from primary studies to generate a new theoretical understanding of a phenomenon that is 'greater than the sum of parts' (Campbell et al., 2003. p. 672). This involves critical reflection during synthesis and requires a rigorous process to assess the quality of qualitative evidence included (Rycroft-Malone, Seers, Titchen et al., 2004, Dixon-Woods, Fitzpatrick, & Roberts, 2001), a persistent area of debate (Spencer & Ritchie, 2012). Some researchers reject the creation of quality appraisal tools for qualitative research, which by design are not

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<sup>2</sup> Now published: Bennion, A. E., Shaw, R.L., Gibson, J. M. (2012). What do we know about the experience of living with macular degeneration? A systematic review and meta-synthesis. *Social Science and Medicine*, 75, 976-985

prescriptive, while some demand different criteria for different methods (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). In practice the criteria employed by meta-synthesists tend to aim for a 'paradigm neutral' approach. After comparing Critical Appraisal Skills Programme (CASP; a critical appraisal checklist of 10 questions to guide researchers through the review process), Quality Framework (QF; a tool developed by the UK Cabinet Office), and intuitive judgement (unprompted judgements based on expert opinion), Dixon-Woods, Sutton, Shaw et al., (2007) concluded that prompts relating to appropriateness and transparency would be fit for purpose due to their accessibility and generic application. In this chapter I present a meta-synthesis guided by this ethos both in terms of appraising included original studies and in ensuring quality in the conduct of the review.

#### **4.4 Procedure**

This meta-synthesis proceeded in four stages. A systematic search strategy was developed; records retrieved were screened for relevance, appraised and then synthesized.

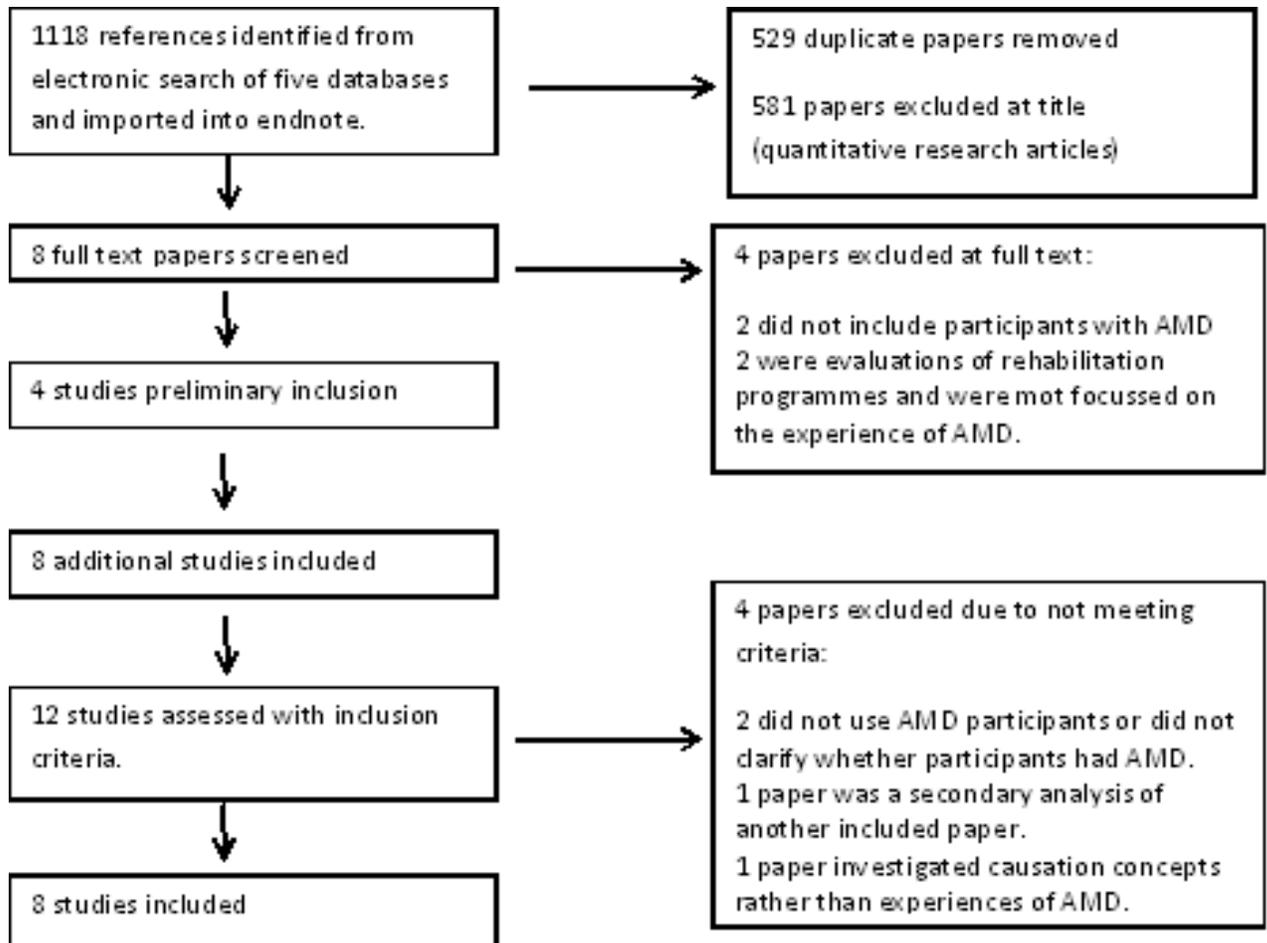
##### **4.4.1 Systematic Search and screening**

Searches of four major databases (Web of Knowledge, Pubmed, Science Direct and Psycarticles) were conducted in October 2010 and updated in October 2011. Keywords included: older people, old age, macular degeneration, AMD, qualitative, focus group(s), and interview(s). Terms were selected to include "who" (older people), "what" (macular degeneration) and "how" (qualitative methods). Inclusion criteria were (a) qualitative research; (b) investigating experiences of AMD (see figure 17 for a flow chart of this search process).

##### **4.4.1.1 Critical appraisal**

Quality was assessed initially using prompts developed by Dixon-Woods et al. (2004) which are designed to encourage critical assessment whilst remaining methodologically neutral (Table 8). Papers were then rated using the coding: KP (key paper which is conceptually rich); SAT (satisfactory paper); IRR (irrelevant paper); or FF (fatally flawed methodology) (Dixon-Woods et al., 2007; Malpass et al., 2009).

Figure 17: Flow chart of systematic search process



#### 4.4.1.2 Synthesis of the studies

The synthesis involved interpretative analysis following the principles of meta-synthesis (Figure 18). Articles were read, re-read and details of the studies recorded (Table 9). Data extraction forms (see appendix example data extraction form) were used to record details of findings coded as first and second order constructs (Malpass et al. 2009) (see appendix for full theme table matrix): first order constructs are study participants' interpretations of their experience (direct quotes from participants); second order constructs are study authors' interpretations of the participants' accounts.

Thematic coding began with data extraction forms of key papers and continued through all eight studies. Synthesis was a cyclical process; when a new theme was identified I returned to the other papers to check for occurrence of the theme. A matrix of shared themes was produced including illustrative quotes from each theme. This matrix was used to complete the analytic process and develop third order constructs, i.e. higher order themes (Malpass et al., 2009). This was achieved by taking the first and second order constructs as data and

analysing them thematically following Braun and Clarke's (2006) principles. The findings presented are organised by themes.

## **4.5 Results**

The review yielded 589 reports excluding duplicates. Titles and abstracts were screened against the inclusion criteria. Reasons for exclusion included: quantitative research (581), qualitative papers that did not include participants with AMD (2) and evaluations of rehabilitation programmes (2). Reference chaining and an additional search of Google Scholar was completed using the same search terms, this yielded a further eight articles (See appendix 12.2.1 for flow chart illustrating search process).

Twelve articles were identified and full copies obtained. Following assessment of the full text, two (Brouwer, Sadlow, Winding, & Hanneman, 2005; Rudman, Huot, Klinger et al., 2010) were rejected because AMD status of the participants was unclear. One (Moore & Miller, 2005) was found to be a second analysis of data from another included article and was excluded. One was rejected as it investigated ideas about cause of AMD rather than experiences of living with AMD (Crossland, Helman, Feeley et al., 2007). The final review is based on the findings of the eight remaining articles (Table 9).

### **4.5.1 Quality appraisal**

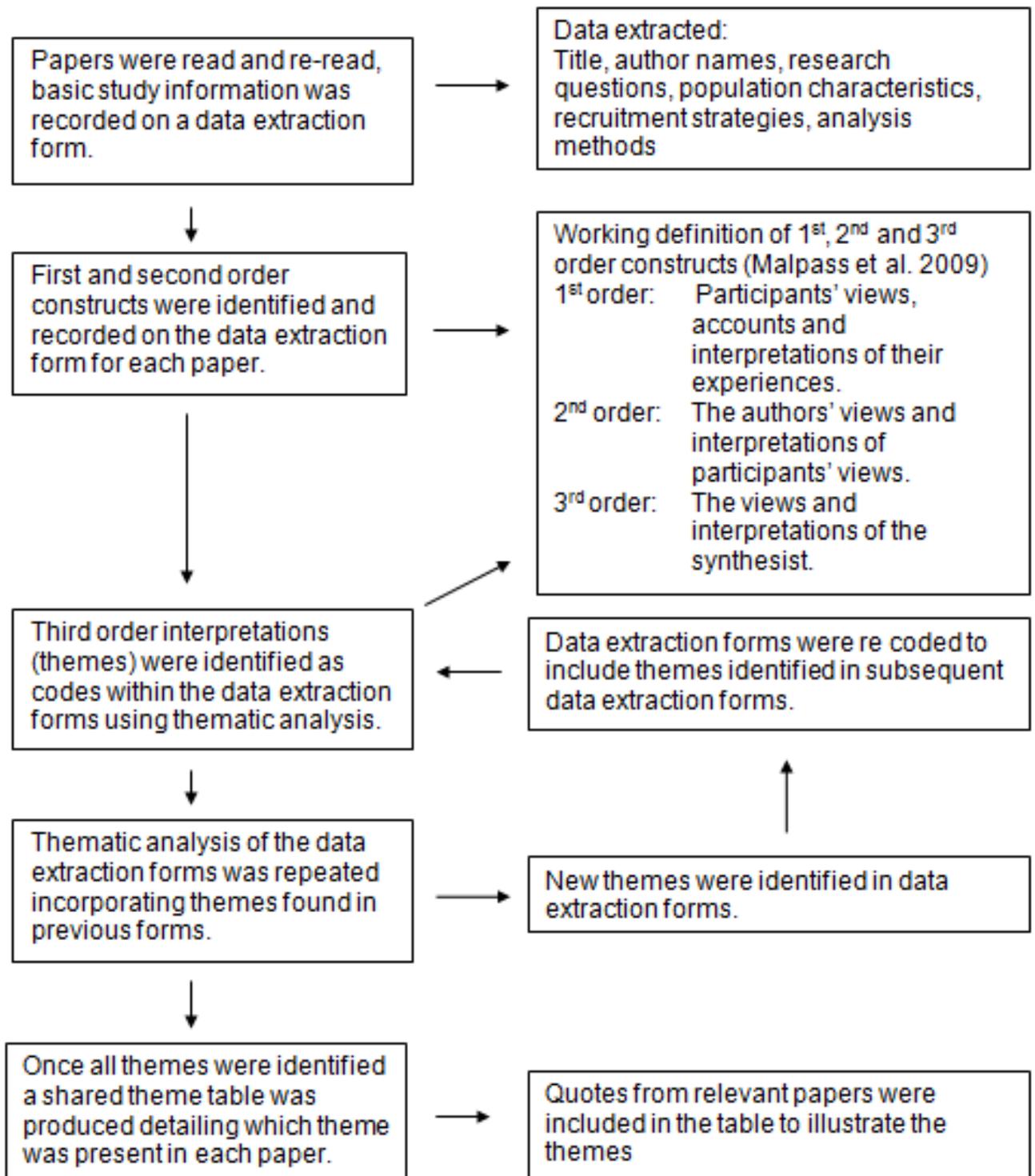
The papers reviewed were judged to be of generally good quality. However, only four of the eight papers were found to provide adequate information to satisfy each of the quality prompt questions (Table 8). Common weaknesses included the lack of a clear description of analytic method, insufficient raw data to support interpretations, and limited contextual information about participants. However, it is acknowledged that restrictions in journal word limits may have caused problems for authors (Walsh & Downe, 2004). Contextual information regarding the sample is needed to ensure transferability, i.e. whether the findings are applicable to other populations. Transparency is essential to achieve trustworthiness, i.e. whether methods are sufficiently rigorous for findings to be used to inform practice or policy. No papers were excluded on the basis of critical appraisal; appraisal was completed not as a basis for exclusion but to highlight potential limitations with individual papers and the sample overall. It was felt that synthesising findings from a variety of studies may allow for the limitations in some studies to be offset by the strengths in others (Dixon-Woods et al., 2006).

Table 8: Assessment of quality based on prompts approach Dixon-Woods, Shaw, Agarwal & Smith (2004)



\*KP (key paper which is conceptually rich); SAT (satisfactory paper); IRR (irrelevant paper); FF (fatally flawed methodology)

Figure 18: Flow chart outlining the synthesis process



**Table 9: Details extracted from reviewed articles (n=8)**

Study	Aim	Country	Participants					Data Collection		Analysis	Results and Themes
			Sampling Method	Age	No. and Sex	AMD Type	Length of time with AMD	Type	duration		
Ivanoff et al 1996	Perceptions of AMD and impact on activities of daily living	Sweden	Purposive	68-91	25 (M=10 F=15)	-	-	5 focus groups	> 2 hours	Krueger's method	Problems performing ADL: functional limitations (difficulty reading recognising people or products and seeing if task is completed); feelings experienced in connection with ADL (insecurity, stupidity, loss of independence). ADL strategies: changing methods, assistive devices, avoidance, asking for help
Moore et al (2000)	Women's experience of AMD	USA	Purposive	63-85	8 F	Bilateral	6 months-20 years	Non-directive unstructured interviews	1-2 hours	Giorgi method	Realistic awareness of vision loss and positivism; losing abilities and discovering abilities; loss of freedom and dependence on others; importance of connections with others; constant fears and changing meanings; creating new ways to live with vision loss.
Moore & Miller (2003)	Men's experience of AMD	USA	Purposive	68-87	8 M	Bilateral	6 months-25 years	Non-directive unstructured interviews	1-2 hours	1 Giorgi method	Abilities and inabilities; cherishing independence; creating strategies; acknowledging progression of visual impairment; confronting uncertainties and fears; persisting with hope and optimism.
Wong et al (2004)	Impact of AMD on QoL	Australia	Theoretical sampling/cross sectional	60-85	15 (M= 7 F= 8)	Various	6 months-7 years	In-depth semi structured interviews	30-80 mins	Grounded Theory	Limitations dependant on degree of visual loss; understanding AMD; difficulty with activities of daily living; driving; loss of independence; social isolation; asking for help; coping and acceptance; rehabilitation.
Owsley et al (2006)	Content areas of emotional issues for AMD patients	USA	Purposive	-	53 (F=28 M=25)	Mixed	-	6 focus groups (6-13 participants)	30-45 mins	Content analysis	Twice as many negative emotional comments (frustration, fear, sadness, anxiety) than positive (gratitude and hope).
Feely et al (2007)	Extend Wong et al's findings; subjective assessment of eccentric viewing	UK	Purposive	62-83	7 (gender unknown)	Bilateral	1-30 months	2 interviews pre and post eccentric viewing training	40 mins	Interpretative phenomenological analysis	Initial shock of diagnosis; societies lack of awareness; frustration, irritation and boredom; asking for help; fear about unpredictability of vision loss; rehabilitation; social support; independence; coping.
Mogk (2008)	AMD from a sociocultural perspective	USA	Purposive	78-92	12 (gender unknown)	Mixed	-	Semi-structured interviews	1-3 hours	Sociocultural – social constructivist	Sighted identity: blindness as the complete absence of sight; AMD as a functional challenge not an identity challenge; vision loss as part of getting older rather than disability. Threat of losing independence: vision compensates for other sensory loss; fear of being placed in nursing homes by family. Desire to be normal; vision loss as an abnormality.
Standford et al (2009)	Longitudinal assessment of psychosocial adjustment to AMD	UK	Subsample from randomised controlled trial.	73-92	37 (F=20 M=17)	-	-	Weekly semi-structured self completed diaries	1 year	Grounded theory	Safety, loss of independence, isolation, support mechanisms, mood, effects of the media and psychosocial adjustment. There was little evidence in the diaries of psychosocial adjustment to visual loss.

#### **4.5.2 Theoretical standpoints**

The studies used a variety of theoretical frameworks and methods: phenomenological methods (Feely, Vetere, and Myers, 2007; Moore, 2000; Moore and Miller, 2003); grounded theory (Stanford, Waterman, Russell, and Harper, 2009; Wong, Guymer, Hassell, and Keefe, 2004); a theoretical framework shaped by social constructionist theory (Mogk, 2008); content analysis (Owsley, Mcgwin, Scilley et al., 2006); and “Krueger’s method” (description and interpretation as a way of understanding meaning within focus group data) (Dahlin-Ivanoff, Sjostrand, Klepp et al., 1996). Some researchers have argued that the synthesis of research with different epistemological standpoints is not desirable as each individual study is theoretically and conceptually unique (Sandelowski, Docherty, and Emden 1997). Finfgeld (2003) has argued that these concerns are unwarranted and that the combination of findings from multiple approaches can enhance the ‘truth value’ of the synthesis. In the spirit of Pragmatism, proposed by Yardley and Bishop (2008) as a means of overcoming epistemological differences to work with different methodologies, I included studies with a variety of research methods and different epistemological frameworks. This enabled the exploration of all findings reported to date, which given the paucity of qualitative research was perfectly feasible.

#### **4.6 Synthesis findings**

The themes presented are: emotional impacts; functional limitations, adaptation and independence; the future with vision impairment; social engagement; disclosure; and interaction with health services.

##### **4.6.1 Emotional Impacts**

Shock was commonly reported as participants’ first reaction to diagnosis, however, there were contradictions regarding how patients went on to cope with AMD. Some made a conscious decision to remain positive and accept that their vision would not be restored (Moore, 2000; Moore & Miller, 2003). In contrast, Wong et al. (2004) reported findings from both ends of the spectrum indicating that some participants reacted with feelings of powerlessness and despair while others reported acceptance; one 75 year old woman explained, “I am not depressed about it [AMD], I just accept it. I mean, I am 75 years old. Goodness gracious me, I have done very well, I think, to be where I am. But then again, it really does upset your life” (p.645)

Moore’s studies suggest an overall theme of hope and optimism (Moore, 2000; Moore & Miller, 2003). In direct contrast, Owsley et al., (2006) found that AMD patients were more likely to make negative emotional comments about their experiences than positive ones.

While positive comments in the study revealed themes of gratitude and hope, the negative themes of frustration, fear, and sadness, were reported twice as often as positive statements (Owsley et al., 2006).

One of the most relevant outcomes of the synthesis for clinical practice was the reports of depressive symptoms. Wong et al., (2004) described some participants as having “fallen victim” to AMD; these participants had become isolated and seemed unable to cope. Stanford et al.’s (2009) participants described living in a sad and lonely world; “I find myself sleeping during the day as I have “no leisure for pleasure” “I live in a sad world of my own” (p. 136). Owsley et al. (2006) reported that negative experiences were not confined to those with the most severe AMD suggesting that “negative emotional burden of the disease is not synonymous with disease severity as defined” (p. 27). Most important of all were the thoughts of suicide expressed; “some days I think, well, suicide is far better than going through this” (participant, Wong et al. 2004: p. 646). Given that negative feelings can occur at any stage and severity of AMD the danger of suicide evident in some patients’ accounts indicates a dire need for support services for these patients as these needs are not currently being met.

#### **4.6.2 Functional limitations, adaptation and independence**

Visual impairment has a huge impact on day-to-day tasks and all of the studies highlighted some areas of functional limitation resulting from AMD. Participants reported difficulties with food and drink preparation (Dahlin-Ivanoff et al. 1996, Stanford et al. 2009, Moore & Miller, 2003); shopping (Dahlin-Ivanoff et al. 1996); and hobbies such as reading (Mogk, 2008), sewing (Moore, 2000) and DIY (Moore and Miller, 2003). One study highlighted that these functional limitations had the biggest impact on individuals with AMD in both eyes:

*For those participants with bilateral AMD, these simple daily activities required concentration, planning, recall capabilities, and the coordination of sensory modalities like hearing and touching. Every task was challenging and constantly reminded them of their limitations. (Wong et al., 2004: p. 639)*

Most participants “attempted to carry on and live their lives as normal regardless of their visual impairment” (Stanford et al. 2009: p. 135). Many participants had adapted to their condition in order to continue with activities. For example, participants the studies conducted by Moore (2000) and Feely et al., (2007) reported the use of other senses to make up for their vision loss. One man in Standford et al.’s (2009) study was determined to continue with his trips to church: “I go to church every Sunday, and each time I sit in a different place so I can work out how to get the best view of the altar.” (Participant, Stanford et al., 2009: p. 139).

As is evidenced by the man’s experiences in church, daily activities with AMD require additional concentration and planning (Wong et al., 2004). Dahlin-Ivanoff et al., (1996)

suggested that patients used four main strategies to adapt to difficulties with activities of daily living: changing how the activity was performed; using assistive devices (i.e., magnifiers); avoidance; and asking for help. Other strategies reported included: using other senses; memory; and vision training (training designed to enable patients to make best use of their remaining vision) (Moore, 2000).

The use of rehabilitation devices provided by social services, such as magnifiers to help with daily activities, was frequently discussed. While some studies reported that participants found these invaluable (Feely et al., 2007); other studies suggested that the devices provided were difficult and impractical (Wong et al., 2004, Stanford et al., 2009). Some participants spoke very highly of the social services support they had received, with evidence of staff taking time to ensure that participants' needs were being met: "I was very impressed that the man from social services came back to try crossing the main road at teatime (the busiest time of the day) to find me a safe place to cross!" (Stanford et al., 2009: p.137). Other participants within the same study reported disappointment with their social services care: "I am very disappointed at the wait from social services" (p. 137). Stanford concluded that the techniques given to patients were not encompassing, and under some circumstances, they were insufficient and limited.

In many of the studies participants feared losing their independence and becoming a burden to their families. For instance, one participant stated, "being independent for a long time, most of your life, you feel as if you are putting your carer to an unnecessary burden at times" (participant, Wong et al., 2004: p. 643). Participants in Wong's study also found it difficult asking for help from friends and relatives as they were reluctant to "trouble", "burden" or "get in the way". Potential dependency resulted in fears such as worries about families placing them in nursing homes before they were ready (Mogk, 2008).

One of the main threats to independence was the loss of the ability to drive (Moore & Miller, 2005). This was one of the key factors leading to dependence on others and the risk of isolation (Moore, 2000; Wong et al., 2004). In Moore and Miller's (2003) study driving was mentioned by almost all of the men interviewed, in addition, women in Moore's earlier study reported the loss of driving as the loss of activity which gave them pleasure (Moore, 2000). Moore and Miller (2005) conducted a second analysis of their data with a specific focus on driving, an important finding was that participants were willing to go to great lengths and risks to continue driving and maintain their independence.

### **4.6.3 The future with vision impairment**

For those with good vision AMD seemed to have little impact; despite this many participants highlighted fears about the future and potential vision deterioration. In Moore's studies women reported fear about the potential psychological impact of their vision loss (Moore, 2000), while men discussed fears about potential injuries to themselves and others and the danger of financial errors (Moore and Miller, 2003). Dahlin-Ivanoff et al., (1996) did not directly report fear expressed by their participants, however, they did highlight participants' desire for more information about the disease to help them prepare for the future.

Thoughts about the future were not all negative; there was also evidence of hope. Hope was often related to thoughts about treatment (Moore, 2000, Stanford et al., 2009), for example one participant in Stanford's study stated "I hear on the radio news that there is a cure - now I have hope" (p. 139). It is possible that this "cure" which patients believed could be coming was more likely to be a treatment for wet AMD, a potential indication of false hope in some participants. Hope was most commonly shown for the idea that vision would not deteriorate further, "I try not to dwell on it... Just one day at a time, and I am hoping, please, God, that this [good eye] will last." (Participant, Wong et al., 2004: p 637).

Participants often acknowledged that AMD was unlikely to improve in terms of their acceptance of their condition and whatever future that may bring; "When you lose your centre vision, it's just like your virginity; once it's gone, it's gone." (Participant, Moore, 2000: p 578). Moore's studies suggested that this acceptance was part of the positivity shown by participants as they "grew to recognize that nothing could be carried out to improve their vision or stop the progression of visual loss" (Moore and Miller, 2003: p 14).

### **4.6.4 Social Engagement**

AMD has a huge impact on opportunities for social engagement and can be an isolating disease, "It [AMD] cuts your social life by about 99.5%. It doesn't matter what you do." (Participant, Wong et al., 2004: p. 641). Stanford et al. (2009) reported that some participants had no social contact during their day, and many reported isolation i.e., 'I live in a sad world of my own' (p. 136). Spontaneous participation was impossible for many participants (Wong et al., 2004) and some actively chose to avoid social situations (Owsley et al., 2006). One commonly reported barrier to social engagement was participants' inability to recognise faces and the embarrassment this caused (Dahlin-Ivanoff et al., 1996; Feely et al., 2007; Owsley et al., 2006; Stanford, 2009).

Reduced participation in social activities and increased isolation can result from a lack of independence and transport difficulties (Wong et al., 2004). This can lead to frustration

(Owsley et al., 2006) and a detrimental effect on AMD patients' well-being. There are potential benefits of social engagement, for example the men interviewed by Moore and Miller (2003) emphasised the importance of maintaining connections with others as a coping strategy allowing them to maintain their independence, "You have to keep up with what's going on in the world. That's why I take classes...there is a lot of companionship in taking classes" (Participant, Moore & Miller., 2003: p. 14).

Unfortunately public knowledge of AMD appears to be limited. Participants reported feeling patronised by their family members (Feely et al., 2007), and finding family members to be unsympathetic and lacking understanding (Wong et al., 2004). Without social support patients expressed fear of being labelled as a fraud (Mogk, 2008; Wong et al., 2004); however, the diagnosis of legal blindness gave some the affirmation they needed and alleviated this concern (Wong et al., 2004).

#### **4.6.5 Disclosure**

Despite the affirmation experienced by some patients when being diagnosed as legally blind, some participants showed a reluctance to label themselves as 'blind' (Mogk 2008; Wong et al., 2004). Mogk (2008) reported that AMD patients view blindness itself as the complete absence of sight and therefore do not feel that they should accept the identity of being blind due to their remaining peripheral vision. Mogk also discussed the concept of blindness in old age as being an 'invisible disability' (p. 585). They suggested that society may see the vision loss caused by AMD as a symptom of growing old rather than an outcome of a disease; this may leave AMD patients open to the risk of being subjected to negative stereotypes of ageing. In comparison, the participants themselves saw their vision loss as a contradiction to their beliefs about normal ageing and therefore struggled to incorporate the disease into their identities. Vision loss caused by AMD is both a symptom of old age and a disability leading to eligibility for blindness registration, therefore some individuals may be comforted by the legitimisation provided by their AMD diagnosis.

Participants expressed concerns about being viewed as a "fraud" due to their "invisible disability" (Mogk, 2008). Despite being registered as severely sight impaired (legally blind) one participant explained "Well, I told them [friends] that I am legally blind; I can't see them. They said jokingly, 'Well, I wouldn't like to drop a \$10 bill out in front of you to see if you pick it up' ... I feel that people that I have seen many times and told them that I am blind, legally blind, they don't believe it" (Participant, Wong et al., 2004: p. 643). Wong et al., (2004) concluded that "whilst participants did not "blame" others for not understanding their condition, they did resent others' unintentional insensitivity toward it" (p. 645). As a result some participants

made active decisions to conceal their AMD, in some circumstances declining equipment given to assist them.

Some participants were reluctant to use equipment which may be seen by others (such as a white cane); they saw these as symbols of disability which they wanted to avoid, again suggesting a reluctance to take on a 'blind' identity (Moore 2000; Wong et al., 2004). Wong et al. (2004) suggest white canes are a symbol of "blindness, disabilities and weakness" as a result "white canes were often found at the bottom of a drawer or in the corner of a room" (p. 642). One participant explained; "You don't want anybody to give you pity, and you think everyone is going to pity you; carrying the white stick or wearing the dark glasses, it's like a symbol, "Look at me, I am blind!" (Participant, Wong et al., 2004: p. 642). Dahlin-Ivanoff et al., (1996) reported that participants were happier with the expression 'visually impaired' rather than 'blind' as a way of describing their disability.

In Moore's (2000) study participants made choices about whether to reveal or hide their vision loss. In cases where they chose to hide it the women reported the worry of appearing snobbish and aloof if they failed to recognise an acquaintance passing them. Despite this, the women continued to hide their vision loss in order to avoid unwanted sympathy; one participant explained, "The less said the better. They end up feeling sorry for me" (p. 581), suggesting that she would rather hide her condition than receive sympathy from others.

#### **4.6.6 Interaction with Health services**

While the health service offers opportunities for treatment for some participants, there was also evidence of disappointment and frustration. Some were hopeful about the possibility of treatment only to feel let down; "I was called for an appointment only to be informed that I was to be registered blind. I feel let down by the NHS" (Participant, Stanford et al., 2009: p. 137).

There was evidence of distrust of the health services, some believing that procedures carried out by health care professionals had caused their AMD; "I was very fearsome of the angiogram—not of the body but of the eyes.... I was resistant to the angiogram because I felt that the angiogram might have brought on the [AMD]." (Participant, Wong et al., 2004: p. 638). The experiences of these participants highlight patients' perceptions of serious failures in terms of communication; it is a fair assumption that these negative views of health services could impact on their future engagement with them.

Other lay theories expressed by participants related to potential causes of AMD were unrelated to their hospital encounters. Many viewed AMD as a normal part of the ageing process. Dahlin-Ivanoff et al. (1996) suggested that patients feel that "[AMD] merely means

that you are getting older and that it is a part of the normal ageing process. Some people believe that nothing can be done about it, except accepting that one is getting older” (p. 518). However, within the same article participants referred to a wide variety of potential external causes for AMD unrelated to age:

*Several potential causes are mentioned: heredity, occupations in which vision is exposed, such as working with computers, fire extinguishing and welding, other diseases, including circulation diseases, and medications they have been taking, such as for asthma and cancer, chemical substances as well as violent sports such as boxing and ball games... reading and watching TV a lot and looking at the eclipse of the sun or moon (Dahlin-Ivanoff et al., 1996: p. 519).*

Dahlin-Ivanoff et al., (1996) suggest that problematic behaviour may arise if patients are uncertain about issues regarding their disease, and it is therefore vital to provide information that participants will understand and remember. These multiple theories about cause suggests that at present patients are struggling to attribute meanings and explanations to their diagnoses, therefore information needs to be provided within a frame of reference which works for and makes sense to the patients within the context of their own lives. Research from other chronic conditions, such as diabetes, has also highlighted that causation accounts are influenced by individual experiences (Lawton et al., 2008). More specifically, Lawton et al. (2008) suggest that the way that patients talk about past experiences and theories of causation is likely to shift over time may help patients to justify or explain present experiences and positions.

#### **4.7 Discussion**

A key outcome of this meta-synthesis was the highlighted emotional impacts and associated dangers of depression in older adults with AMD. Research exploring professionals' perceptions of depression in older people suggests that GPs and nurses may struggle to identify depression in older patients (Murray, Bajeree, Byng et al., 2006). Murray et al, (2006) have also highlighted the potential stigma associated with depression for older people and that family may be the main source of both support and distress in the population. Given the potential isolating impact of AMD and decisions not to disclose their condition to others there is evidently a need for support aimed at alleviating the stigma associated with AMD, enhancing social engagement, and fostering family support for patients in order to avoid potential depression.

Given the day-to-day difficulties experienced by AMD patients and in order to prevent emotional impacts of the condition; there is a need to develop services to help individuals adapt. Owsley et al., (2006) argued for incorporating mental health services into AMD management. While this is necessary for extreme cases, services aimed at the prevention of

stress and mental health issues may be more beneficial long-term. For example, the provision of intervention services aimed at influencing cognitive appraisals of coping through enhanced social support and personal social resources may improve perceptions of mastery, self-efficacy and self-esteem and in turn reduce the discrepancies between idealised self-expectations and the limitations imposed by disabling conditions (Penninx, Tillberg, Kreigsmann et al., 1997). Older people with fewer psychological resources are at increased risk of developing disability (Kempen, van Heuvelen, Van Sonderen et al., 1999) therefore interventions aimed at improving the psychological resources for older people with AMD may help to limit its impact.

An important aspect of older people's perceptions of their lives, regardless of social and cultural background, is the ability to get on with life and maintain physical and social functioning (Cartwright, 2007). The disabling effects of AMD may be a barrier to older people's ability to achieve this goal. Wong et al. (2004) highlighted that rehabilitation may help to reduce emotional distress, overcome barriers to daily routines, and encourage participants to maintain a positive outlook in order to increase their QoL. Dahlin-Ivanoff et al. (1996) recommended that it would be beneficial for these services to include health education designed to improve patients' function in activities of daily living, which could include the provision of information, teaching of strategies to continue with daily activities, support, and problem solving techniques. In the long term, Stanford et al. (2009) reported that adjustment remains similar or may even decline over 12 months. They suggested that current service provision does not meet needs in terms of cognitive, emotional and practical support again highlighting the need for improved support services for AMD patients.

#### **4.8 Limitation of the current literature**

While the qualitative evidence synthesised has highlighted some important areas of interest there are some limitations to the studies undertaken. Firstly many of the papers did not adequately describe the analytic methods used nor provide sufficient raw data to back up their claims. It is vital for qualitative evidence to detail this information to allow findings to be assessed for suitability to be applied to wider populations. Most of the studies employed one-off data collection methods which are only able to provide information from a single time point, comparing different age cohorts, or largely retrospective data. One possibility for expanding the insights gained within qualitative research is to collect longitudinal data. Longitudinal qualitative methods have been used in health research to investigate a variety of long term diseases and disorders (e.g. HIV: Baumgartner, 2007, diabetes: Peel, Douglas, & Lawton, 2007, Chronic Fatigue Syndrome: Whitehead, 2006). A benefit of longitudinal designs is that

analysis may be able to highlight changes in experience over time (Lawton, Rankin, Peel, & Douglas, 2009).

Another limitation is the variability within samples. The length of time participants had been living with AMD varied both within and between studies. By under-reporting the details and context of the participants' experiences studies are failing to meet the level of transparency (Yardley, 2000) necessary for the production of good quality research. The length of time an individual has been living with AMD may have important implications for their perceptions or experience of the disease. Reports about reactions to diagnosis were frequently based on retrospective data with the earliest data collection being between one to 30 months post diagnosis (Wong et al., 2004), therefore we only learn about perceptions of diagnosis once participants have had time to reflect on their condition. Given the potential speed of disease progression, 30 months is a long time in which the experience of AMD may have changed substantially. Research which focuses on groups of participants with smaller variation in time since diagnosis may provide more detailed information about individual experience at specific time points over the course of the disease.

A further issue is the type of AMD with which participants had been diagnosed. Most of the studies recruited participants with AMD ranging from early (dry) to advanced (wet). Patients with wet AMD may be eligible for treatment while this is not possible for dry. The differences in treatment options could result in very different experiences of the disease; this is an important area which has been overlooked. Research is needed which addresses the differences between experiences for treatable and untreatable AMD in order to tailor support to the needs of individuals. Research has mainly investigated the experience of patients with bilateral vision loss, with the exception of Wong et al. (2004) who briefly discussed some of the differences between bilateral and unilateral impairment. Longitudinal research on individual experiences which focuses on specific types of AMD would help to improve understanding of the experience and management of AMD.

#### **4.9 Summary**

This study aimed to synthesise the qualitative literature relating to experiences of living with AMD. The synthesis identified common themes relating to: functional limitations, adaptation and independence; feelings about the future with vision impairment; interaction with the health service, social engagement, disclosure, and the emotional impacts of living with AMD.

Understanding experiences is vital in order to "give voice" (Larkin, Watts and Clifton, 2006) to the concerns and every day experiences of individuals. This meta-synthesis has highlighted that AMD can impact on multiple areas of individuals' lives and can cause major changes

within reports of everyday experiences. It is only through a greater understanding of experiences that we can develop methods to ensure that AMD is only a minimal intrusion on patients' lives. It is also important to be aware of the contradictory findings in some studies. Context and cultural factors are vital to the understanding of individuals' experiences with AMD. Quantitative evidence and survey research is unable to help us understand the nuances of patient experiences. There is a need for diverse evidence to ensure we can understand and prepare for the psychosocial, economic vectors alongside the biomedical and treat the person as well as the disease to improve QoL and in order to ensure patients receive the care they are due. Qualitative evidence is therefore vital to improve understanding in order to ensure that policy and practice are informed by the best available evidence.

The following chapters will begin to take this further by examining the experiences of patients with AMD in context. The chapters will pay close attention to the experiences of specific groups of patients with AMD (early dry AMD, treatable wet AMD, advanced Wet AMD, living together with AMD) and chart the experiences of these participants over time. The next chapter details the background information for the participants included in each study and the subsequent chapters present in-depth accounts of participants' experiences.

## **Chapter 5: Method for the phenomenological work**

### **5.1 Introduction**

Based on the findings of the pilot mixed methods study described in chapter 3 and the meta-synthesis presented in chapter 4 it is evident that further in-depth qualitative work is needed to understand the lifeworld and contextualised experiences of patients with a variety of types of AMD. The metasynthesis in Chapter 4 illustrated that experiences of AMD may be different for different groups of patients and the subsequent chapters address this through in-depth analysis of patients in different AMD groups (early, treatable and late). The objective of this chapter is to introduce the participants who took part in phenomenological work, explain the recruitment strategy, and provide background information about the participants. The final part of the chapter introduces a matrix of themes for the participants which will be discussed in detail for each subgroup of patients in the following chapters.

### **5.2 Research questions**

The overarching research questions for the phenomenological work are:

What is it like to live with age related macular degeneration?

In what ways might the experience of living with macular degeneration be different for individuals with treatable or untreatable forms of the condition?

How might living with age related macular degeneration impact on quality of life?

How might the experience of living with macular degeneration change over time?

### **5.3 Recruitment**

Interview participants were recruited face-to-face within two macular disease clinics in Birmingham. I observed the macular clinics at two hospitals between May and July 2010. Clinic ophthalmologists identified new patients who were diagnosed with AMD and asked them whether they would be happy to discuss the research with me. I took patients to a quiet room and described the study; at the end of this discussion patients were asked if they had any questions and whether they were happy to be contacted regarding taking part. Consenting patients supplied me with their contact details and I agreed to contact them in two days. The participants were given information (see appendix 12.3) about the study to take away and read before being contacted by phone. Two days later I contacted the patients and asked if they had had enough time to consider the study and whether they would agree to take part. During this phone call I arranged the first of the three interviews with patients who agreed to participate. The participants were contacted by phone at nine and eighteen months post diagnosis to arrange the second and third interviews. At the time of the first interview the participants were invited to choose their own pseudonym by which they would be known

throughout the research. It was felt that by choosing their own pseudonym the participants would then be able to recognise references to them in the summary they received at the end of the research.

#### **5.4 Ethics**

Ethical approval was obtained from the NHS Research Ethics Committee (REC) (evidence of this can be seen in appendix 4) and from Aston University REC. Research and development (R&D) approval was also obtained from the Heart of England and Sandwell and West Birmingham NHS Foundation Trusts.

The main ethical issues in this project related to the vulnerability of the older people taking part. I ensured that all participants fully understood the purpose of the research and what was involved before taking part. In addition, all information was provided in large print due to the visual impairment of the participants. As I was visiting older people in their homes I also provided a full CRB disclosure check. I was in constant contact with my supervisory team in order to raise any concerns about the wellbeing of the participants.

#### **5.5 Measures**

##### **5.5.1 Demographics**

Once written informed consent had been obtained the hospital provided me with the participants' diagnosis, name, age, address and contact number, date of birth, treatment status, and visual acuity scores for the day the participants were recruited. It was assumed that all participants had capacity to provide consent.

#### **5.6 Interviews**

Individual semi-structured interviews were conducted. The interviews took place: as soon after diagnosis as possible, 9 months following diagnosis and 18 months following diagnosis. Each interview investigated what it was like to live with AMD. The initial interviews were based around an interview schedule which included: history and diagnosis of AMD, impacts of AMD on day-to-day life, friends and family, support received, and feelings about the future (the interview guide can be found in the appendix). This schedule was used flexibly in order to gain in-depth knowledge about the elements of experience which were most important to the participants. The second and third interviews with participants were more flexible, they began with the question, 'how have things been since the last time we met?' and prompts were based on the original schedule and topics which had been raised by the participants in the previous interviews. The recorded interviews were transcribed verbatim and served as the corpus of data for interpretative phenomenological analysis.

## **5.7 Transcription conventions**

Interviews were transcribed verbatim. In the extracts presented double round brackets (( )) indicate an action by the participant, empty square brackets [] indicate some text has been omitted, square brackets containing text [health care professional] indicated text I have added to clarify the meaning of the quote.

## **5.8 Analysis**

An Interpretative Phenomenological Analysis (IPA) (Smith, et al. 1999) approach was taken to data analysis. Transcripts were analysed one by one and analysis was completed for one participant in the sub group (early AMD, treatable wet AMD, advanced AMD) before moving on to the next. All analysis was completed for one subgroup before moving on to the next. Firstly one transcript was read several times in order to develop a holistic understanding of the participant's experience. Following this the transcript was annotated with unfocused notes relating to elements of the text which appeared to be interesting or of significance. Next a table with two columns was created alongside the transcript and the text was read in small sections (or meaning-units; Langdridge 2007), 5-10 lines at a time and descriptive summaries were noted in the first column for each section (see appendix 11.3.3 for examples of how the analysis was conducted). Once descriptive summaries were completed these were read along with the original text and initial unfocused notes and then theme ideas were noted in the second column of the table. These themes were listed on a second sheet and clustered under conceptual headings (which were overarching titles which encompassed the key elements of the themes contained within them). During this process attention was paid to the original transcript to ensure that the developing themes were representative of the participant's accounts. A document was produced including all relevant data extracts for each of the themes. This process was repeated for the first and second interviews for each participant. Much of the information reported in the final interviews had already been discussed previously, therefore the final interview was read and elements of the interview which represented new information or changes in experience were highlighted and notes made. An overall document including themes from all of the interviews was completed for each participant. These documents were compared and contrasted between participants to highlight shared and divergent experiences and create conceptual themes which highlighted the important elements of the experience for all participants. Analysis was an iterative and cyclical process whereby there was a constant movement back and forth between the levels of analysis (Shin, Kim and Chung, 2009). A narrative account of the participants' experiences in each subgroup was then produced based on overall conceptual themes. Validation took the form of in-depth discussion of the developing themes during supervisory meetings.

## **5.9 Reflexivity**

I agree with the Heidegger's (1962) argument that it is impossible to bracket your fore-conceptions and prevent them from impacting on developing analysis. I therefore kept a research diary throughout the process to record my changing perceptions and ideas. This included my reflections completed immediately after each interview (including the setting of the interview, any observed changes in the participants mood or health status, my overall impression of the interview and any emotional reactions I had to what had been discussed, and any elements of the interview I felt were particularly important). These reflections were useful when I was attempting to make sense of the participants' experiences and helped to ensure that the themes I developed were tied to the data rather than to my own assumptions. In addition to these notes I also kept a diary of my own developing thoughts and ideas which developed as I undertook analysis and read the literature relating to IPA, AMD and QoL in older people. It is important to remember that the researcher plays an interpretative role in the analytic process and therefore by setting my own assumptions out throughout the analysis I was able to attend to the way that these thoughts and feelings may be shaping my findings.

I had frequent meetings with Rachel Shaw (associate IPA supervisor) and Jon Gibson (Clinical supervisor) to discuss my developing analysis. These meetings helped me focus my thoughts and drew attention to relevant literature, theory, and clinical implications reflected in my analysis which I may have been unaware of. These meetings helped me to question my analysis and enabled me to strengthen my interpretations based on existing literature. In this way the literature was not the starting point for my interpretations but instead was drawn into my developing analysis as a result of my initial notes and developing themes. By approaching the analysis in this way I was able to make sure my developing analysis was grounded in the participants' experiences.

## **5.10 Sample**

Fifteen participants (5 male, 10 female) were initially recruited (data from the patients with wet AMD has also been discussed in chapter 3). During the course of the research there was some participant attrition: one participant was unable to be contacted after the first interview (Amna); three participants declined further involvement after the second interview stating health reasons (Mary, Eric, and Rowans); and three participants were unable to be contacted when arranging the third interviews (Cathleen, Irene, Rose). Amna was unable to speak fluent English and Eric had dementia, as a result their interview data were unsuitable for analysis and has not been included. The first two interviews conducted with Rowans, Mary, Cathleen, Irene, and Rose were included in the analysis and the remaining 8 participants completed all three interviews. Details of all the participants included in the analysis can be seen in Table

10. Participant ages ranged from 75-89 with a mean age of 81.5. Best eye visual acuity ranged from 6/6 to 6/30 while worst eye visual acuity ranged from 6/9.5 to hand movements only. Seven of the participants were eligible for treatment and six of the participants were unable to be treated (two due to having dry AMD and three having wet AMD which was too advanced for treatment). Many of the participants reported other vision related conditions including cataracts and glaucoma.

## **5.11 Pen Portraits**

### **5.11.1 Early dry AMD**

#### ***Rowans***

Rowans was a 77 year old man who was recently married to his second wife following the death of his first wife. Rowans' wife had recently been treated for cataracts at the time of the first interview. Rowans had been recently diagnosed with dry AMD in both eyes, he had mild visual impairment; his visual acuity was 6/12 in his right eye and 6/9 in his left eye. By the third interview Rowans had on-going heart problems which meant regular attendance at hospital and he felt he no longer had time to fit in a third interview. Rowans' wife was present at the second interview and added some comments while the interview was taking place.

#### ***Cathleen***

Cathleen was an 80 year old woman who was widowed and lived alone in her own home. Cathleen was originally diagnosed with dry AMD around 5 years prior to her first interview, however she was recruited following an appointment during which she was told her vision had deteriorated slightly. Cathleen had mild visual impairment; her visual acuity was 6/9.5 in her right eye and 6/7.5 in her left eye. Cathleen had a history of glaucoma for which she had received treatment and took drops. Cathleen completed the first two interviews but was unable to be contacted at the time of the third interview after numerous attempts.

### **5.11.2 Treatable wet AMD**

#### ***Alison***

Alison was an 85 year old woman who had been widowed for over 20 years. Alison lived with her adult daughter in a suburb of Birmingham. Alison had begun treatment for AMD in one eye and was soon diagnosed with wet AMD in her second eye. At the time of the first interview Alison had only mild impairment in both eyes with visual acuity of 6/9 in her right eye and 6/12 in her left eye. Alison's treatment was on-going throughout all three interviews. Alison had needed to stop driving as a result of AMD and now relied on her daughter to take her to appointments. Alison took part in all three interviews.

**Table 10: Participant characteristics**

Pseudonym	Age	Gender	Diagnosis	Treatable?	Visual Acuity*	
					Best Eye	Worst Eye
Rowans	77	Male	Dry AMD both eyes	No	6/9	6/12
Cathleen	80	Female	Dry AMD both eyes	No	6/7.5	6/9.5
Alison	85	Female	Wet AMD both eyes	Yes	6/9	6/12
Irene	86	Female	Wet AMD one eye, dry AMD other eye	Yes	6/7.5	6/30
Rose	89	Female	Wet AMD one eye, dry AMD other eye	Yes	6/9	6/12
Nuxy	78	Male	Wet AMD one eye, dry AMD other eye	Yes	6/7.5	6/12
Ruffine	82	Female	Wet AMD one eye, no AMD other eye	Yes	6/6	6/24
Jordan	75	Female	Wet AMD both eyes	Yes	6/36	6/60
Rick	82	Male	Wet AMD one eye, no AMD other eye	Yes	6/9.5	6/19
Hermione	80	Female	Dry AMD and wet disconform scar	No	6/15	CF
Jessie	87	Female	Dry AMD and wet disconform scar	No	6/24	6/120
Mary	82	Female	Advanced wet AMD, other eye unknown	No	6/9.5	HM
Jack + Sally	82	Male		No	6/30	CF
	77	Female		No	Unknown	

\* Snellen visual acuity. In order from good vision to poor: 6/5; 6/6; 6/7.5; 6/9; 6/12; 6/18, 6/24, 6/36, 6/60, 6/60;; 6/96, CF: count fingers, HM: hand movements, PL: Perception of light

### ***Irene***

Irene was an 86 year old woman who lived with her husband in a bungalow on the outskirts of Birmingham. Irene had been diagnosed with AMD following a cataract operation when her vision had not been as clear as expected. Irene was being treated for wet AMD in her right eye which had mild impairment at the point of first interview (6/7.5); she also had dry AMD in her left eye with mild impairment (6/30). Irene's husband had recently had a fall and damaged his leg which resulted in him no longer being able to drive. Irene relied on family members to take her to appointments. Irene completed the first two interviews but was unable to be contacted at the time of the third interview after numerous attempts.

### ***Rose***

Rose was an 89 year old woman who was widowed and lived alone. She had health problems which restricted her mobility, used a stair lift in her home, and relied on her niece to take her shopping. Rose was being treated for wet AMD in one eye which had mild impairment (6/12), her other eye was also mildly impaired (6/9). Rose sometimes used the ring and ride service to attend appointments. Rose completed the first two interviews but was unable to be contacted at the time of the third interview after numerous attempts.

### ***Nuxy***

Nuxy was a 79 year old man who lived with his wife. Nuxy had been diagnosed with dry AMD in the left eye with mild impairment (6/7.5). Nuxy was also being treated for wet AMD in his right eye which had mild impairment (6/12). At his first consultation Nuxy had been told that he had a large blister which had formed on his retina as a result of AMD, this blister later dispersed enabling the hospital to go ahead with Lucentis treatment. Nuxy still had sufficient vision to continue driving. Nuxy had a family history of glaucoma but did not have glaucoma himself. Nuxy completed all three interviews; however by the third interview his health had rapidly deteriorated after an operation to remove one of his lungs due to lung cancer.

### ***Ruffine***

Ruffine was an 82 year old woman who lived alone in a block of retirement flats. She had no family close by as she had moved to Birmingham from Guernsey during the war and the rest of her family remained there. Ruffine was receiving treatment for wet AMD in her left eye which has mild visual impairment (6/24) and had good vision (6/6) and no problems in her right eye. At the time of diagnosis with AMD Ruffine was also experiencing some problems with her legs and mobility which meant she was confined to her flat for much of the time, however by the second interview this situation had improved. Ruffine took part in all three

interviews, however by the third interview her leg problems had resurfaced and she was again mainly confined to her flat.

### ***Jordan***

Jordan was a 75 year old woman who was widowed and lived alone. Jordan had seven children who visited on a regular basis and lived nearby. Jordan was diagnosed with wet AMD in both eyes with moderate vision loss (6/60 and 6/36) following numerous visits to her optician. Jordan was receiving treatment in both eyes and relied on family members to take her to appointments. Jordan took part in all three interviews.

### ***Rick***

Rick was an 82 year old man who was widowed and lived alone in the house he had bought with his wife. Rick was diagnosed with wet AMD in one eye with mild vision loss (6/19) and dry AMD in the other also with mild vision loss (6/9.5). Rick had family members who lived nearby, visited regularly and drove him to hospital appointments. Rick was continuing to drive but now wore specific glasses for driving. Rick was also being treated with drops for glaucoma. Rick took part in all three interviews.

## **5.11.3 Advanced untreatable wet AMD**

### ***Hermione***

Hermione was an 80 year old woman who lived with her husband in a bungalow in a suburb of Birmingham. Hermione was diagnosed with macular scarring in one eye caused by wet AMD about 7 years ago. She was recruited following an appointment which found dry AMD in her second eye which was beginning to cause deterioration in vision. Hermione had been discharged from the hospital but made yearly visits to her optician for monitoring. Hermione had severe visual impairment in her left eye with only the ability to count fingers; her right eye was mildly impaired with acuity of 6/15, she was also developing a cataract in her left eye. Hermione took part in all three interviews.

### ***Jessie***

Jessie was an 87 year old woman who was widowed and lived alone in warden monitored flats. Jessie was diagnosed with wet AMD in one eye a few years prior to the interview and underwent laser treatment; this had progressed to untreatable macular scarring. Jessie had severe visual impairment in her right eye which had macular scarring (6/120) and moderate visual impairment in her left eye which had dry AMD (6/24). Jessie also had a cataract in her left eye and was being treated for glaucoma. Jessie took part in all three interviews.

### ***Mary***

Mary was an 82 year old woman who was widowed and lived alone as a tenant in a council owned property. Mary had been diagnosed with a large haemorrhage which burst and led to macular scarring in her left eye with severe vision loss and only the ability to see hand movements in front of her left eye. At the time of recruitment the diagnosis of Mary's right eye was unknown but she had only mild visual impairment in this eye (6/9.5). Mary took part in the first and second interviews, when contacted regarding the third interviews she mentioned she was feeling very depressed and did not want a third interview. She explained that her vision was still very poor and she was struggling to manage.

#### **5.11.4 Couple with AMD**

### ***Jack and Sally***

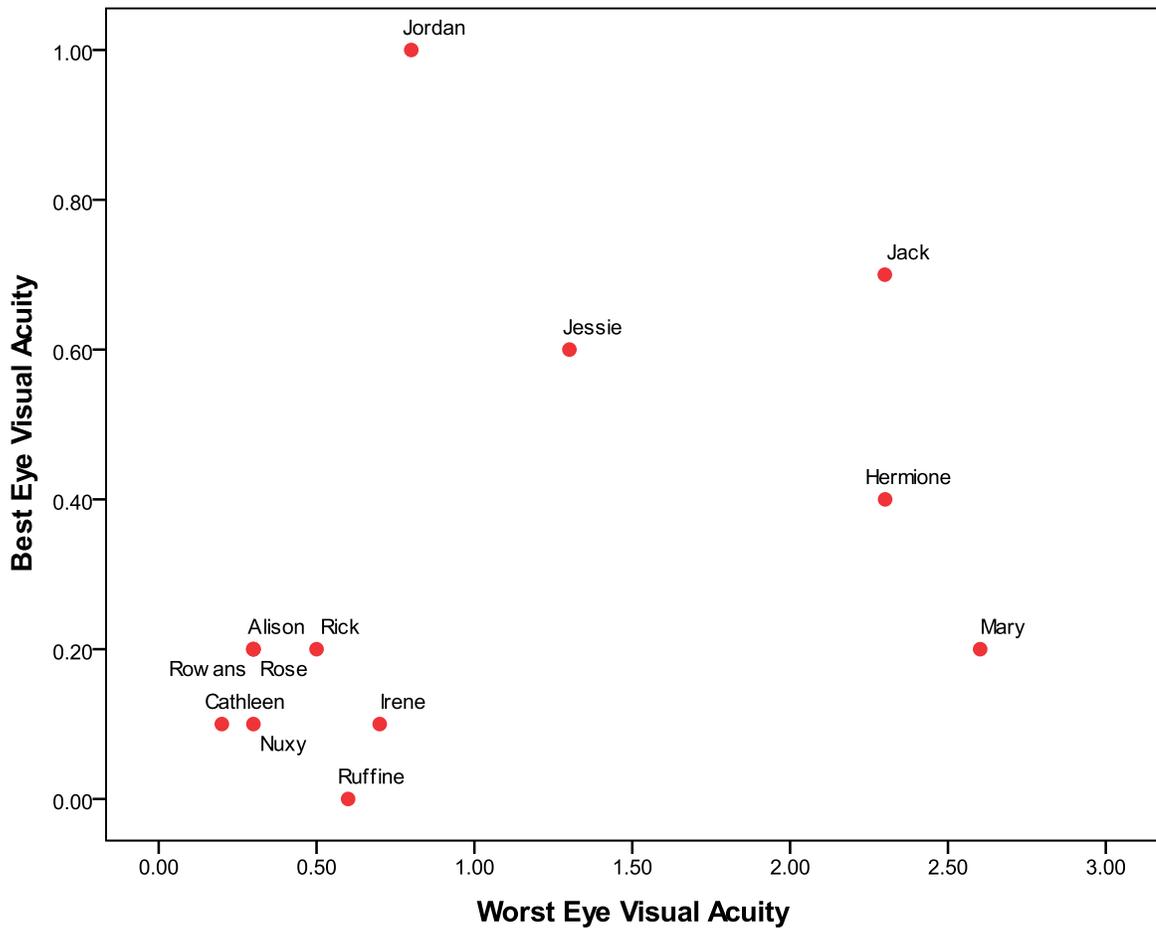
Jack was an 82 year old man with severe visual impairment in both eyes. He had advanced dry AMD in one eye (6/30) and a disconform scar resulting from wet AMD in the other eye (counting fingers). Jack's wet AMD was too advanced for treatment and Jack had been warned that his advanced dry AMD may become wet. Jack lived with his wife Sally, a 77 year old woman, in a block of flats. Sally also had AMD and was diagnosed with dry AMD in both eyes when she was in her 50's. Sally also had mobility problems relating to arthritis which limited her ability to leave the flat. Jack and Sally had a daughter who also lived in the flats. Further details about Jack and Sally will be provided in Chapter 9 "Living together with AMD". Jack and Sally took part in all three interviews.

#### **5.12 Visual Acuity**

Visual acuity of the better eye and worse eye were obtained during hospital appointments using the Snellen chart. Metric Snellen ratings were then converted to the logarithm of the minimum angle of resolution (LogMAR) scale. On the LogMAR scale an increase of 1 point represents a 10-fold drop in vision on the Snellen scale. Using the LogMAR scale, a measurement of 0.0 represents normal vision and 1.0 represents legal blindness. Vision levels classified as counting fingers, hand motion, light perception, and no light perception were assigned visual acuity (LogMAR) 2.301, 2.602, 2.903, and 3.204, respectively.

The graph in Figure 19 illustrates that Ruffine had the highest level of best eye visual acuity and Jordan had the lowest, while Mary had the lowest level of worst eye visual acuity and Cathleen had the highest.

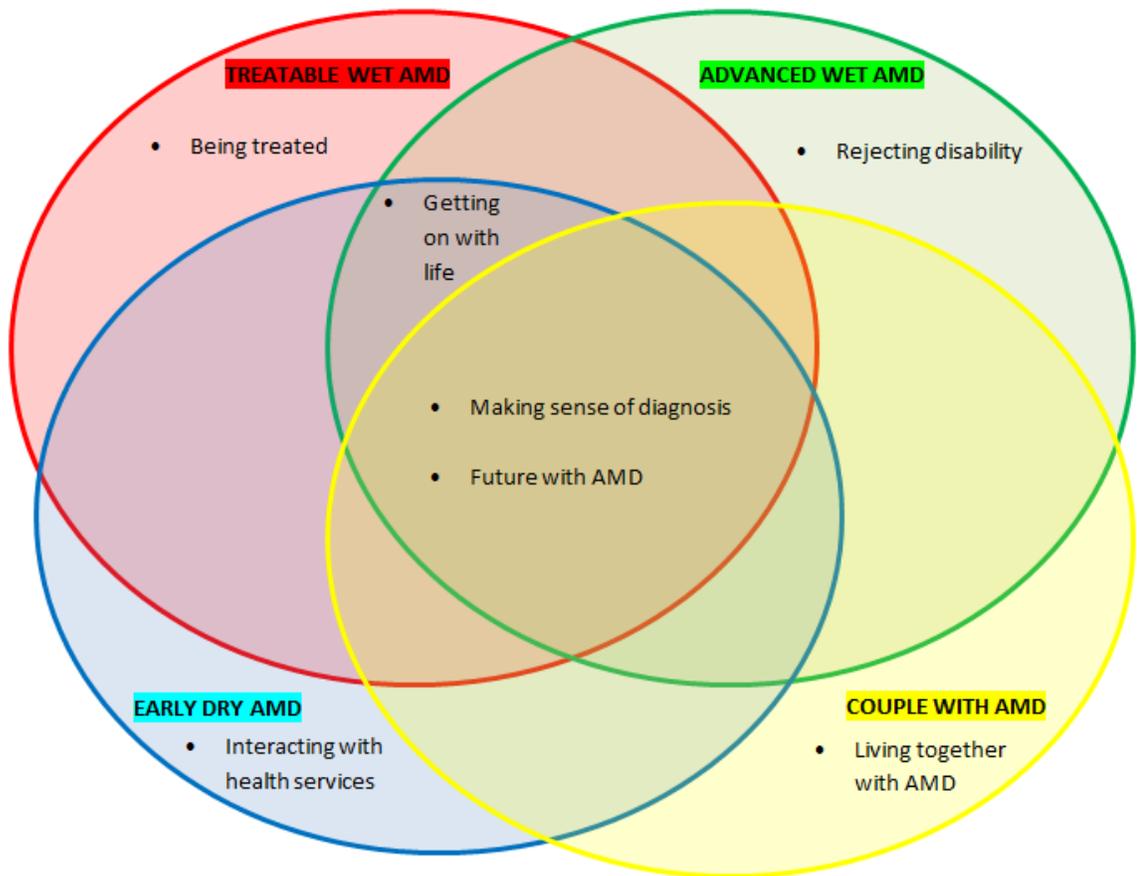
Figure 19: Visual Acuity for Best and Worst Eye for the Participants



### 5.13 Matrix of themes

The next four chapters present the interview data in detail for each of the participant groups in addition to a case study of a couple with AMD (Jack and Sally). The diagram in **Error! Reference source not found.** provides a visual overview of the themes for the entire sample. Following the diagram I explain each of the sections represented and the subsequent four chapters will explore each of the sectors in detail.

Figure 20: Overview of themes for the sub-samples



Two themes “making sense of diagnosis” and “future with AMD” were evident across the entire sample; however each individual had a nuanced experience of these themes. One theme “getting on with life” was evident in three of the sub-samples (early dry, treatable wet, and advanced wet) while for the couple with AMD this theme was less individualised and focused on “living together with AMD”. While all of the participants were interacting with the health service, this interaction had particular salience for two of the subgroups. The early dry AMD participants talked in detail about “interacting with the health service” while for the treatable participants a similar theme focussed specifically on “being treated”. For the advanced AMD patients a unique theme was “rejecting disabilities”. These themes are discussed in detail in the following four chapters.

## Chapter 6: Early Stage Dry AMD

### 6.1 Introduction

In this chapter I present the experiences of two participants with early stage dry AMD. As was discussed in the first chapter of this thesis, early dry AMD is the most common form of the condition. At the early stages vision impairment is minimal; however the condition is progressive and within about 10-15 years of diagnosis patients' vision is likely to deteriorate to the point of meeting the criteria for being registered as severely visually impaired.

### 6.2 Research Question

What is it like to live with early stage dry AMD?

### 6.3 Method

The method for the data collection and analysis for this chapter has been described in chapter 5.

### 6.4 Themes

Table 11 below provides an overview of the four key themes discussed in this chapter.

Table 11: Early Dry AMD Theme Table

Theme	Example
Making sense of diagnosis	<i>She said it might be diabetes or it might be macular degeneration. Well, I was aware of macular degeneration with my sister. I'm aware of diabetes with friends, and I thought that I don't know which one I want, you know. (Cathleen, Interview 1)</i>
	<i>Well as I said I was diagnosed as glucose intolerant, due to lack of energy, I had a blood test on that account, and it was then that was the first time that I was told that I was borderline for driving on the one hand, that I had dry macular degeneration, what's it called, macular degeneration? (Rowans, Interview 1)</i>
Getting on with life	<i>It hasn't, it hasn't stopped me doing anything. Because, you know, I still feel that my eyesight is very good. (Cathleen, Interview 1)</i>
Interaction with health services and appointment experience.	<i>You know, she's just said when everyday objects start getting all out of shape, then come back. And I thought I want to come back before then. I want to know the minute it starts, it turns into a wet macular. And I don't know if I shall. (Cathleen, Interview 1)</i>
	<i>It just in the way the relationship functions they (health care professionals) can either make you think you matter or not and I think (Rowans, Interview 2)</i>
Future with AMD	<i>A very limited life, no television, no reading, a very limited life. That's what, you know, the future looks like for me, if it does progress. (Cathleen, Interview 1)</i>

## 6.5 Making sense of diagnosis

Understandings of AMD diagnosis can be influenced by many aspects of patients' lives. For example, Cathleen spoke of the shock of her diagnoses which occurred during a traumatic time following the loss of her husband:

*The appointment came a month after my husband's death when I was feeling very fragile. And I was absolutely stunned when [the HCP] said to me, virtually in these words, he said, well its macular degeneration. He said 'there's no treatment, there's no cure and you'll go blind'...And I was absolutely devastated having just lost my husband, you know, and I just came home, I walked home, and, you know, what else is life going to throw at me?*

*Cathleen interview 1, line 277-282*

Cathleen's narrative about her diagnosis appointment was interwoven with her bereavement experience. The distress from one event affected coming to terms with the other and vice versa. Rowans also made sense of his diagnosis in terms of his life context. For example, other health problems diagnosed around the same time as AMD were seen as more serious and took priority:

*I was diagnosed as glucose intolerant, due to lack of energy, I had a blood test on that account, and it was then that was the first time that I was told that I was borderline for driving on the one hand, that I had dry macular degeneration, what's it called, macular degeneration?... so that was all new to me. I'd had reading glasses for some time, but that's all..*

*Rowans interview 1, line 73-77*

Rowan described his most prominent concern following diagnosis as his potential to develop diabetes. Rowans followed advice regarding this condition and modified his diet in order to reduce the risk of diabetes, however even once this risk had been diminished AMD did not take priority as a major concern. Rowans was guided by his knowledge of his parents' good health and vision long into old age and seemed to understand dry AMD to be a less serious condition than wet AMD. As a result he did not see himself at risk of any major deterioration in vision and was perhaps able to create a false sense of security:

*Well I've got my head in the sand really about it I suppose, I tend to assume too readily that I've always been fit and I'll always continue to be fit, because my parents were pretty fit, so my hope is that it's not going to be very serious, but at the back of my mind I would think it could turn into wet for all I know and that could be much more serious...but I think a lot of people get it through ageing don't they? Without it necessarily getting to very serious proportions and I suppose I'm hoping to be in that category.*

*Rowans interview 2, line 721-732*

This extract illustrates a rare occasion where Rowans acknowledged that he may be at risk of developing wet AMD and that he realised that this would be more serious than his current condition. It is common for older people to be unable to separate their experience of 'normal' ageing from the development of chronic conditions. Due to Rowans' assumptions about vision loss in old age being "normal" he was not actively attempting to monitor his vision for further deterioration or preserve his remaining vision. In comparison Cathleen described actively attempting to monitor and retain her vision. For example Cathleen used the information she was given at appointments in order to try and understand what her future might be like. Confusion arose for Cathleen when her experiences contradicted the expectations she had developed based on the information she felt she had been given at diagnosis:

*[my diagnosis] was very very harsh. You know? I think he could have put it in a more gentle way you know? But it had no treatment, no cure and you'll go blind. Those were his very words. I nearly had a fit...To be told so boldly like that, I thought, well not if I can help it! Not if I can help it. I've been surprised at the length of time. You know, that was four years ago that, you know my eyesight hasn't deteriorated. Because I've expected it to deteriorate, but I'm beginning to wonder if now it's the start of it and you just don't know, don't know what to do. You know and then I'm taking the supplements, you know, doing my best.*

*Cathleen interview 1, line 816-824*

Cathleen had been distressed and made to feel powerless by her diagnosis experience and lived constantly expecting her vision to deteriorate. Cathleen's explanation that she was 'boldly' given her diagnosis evokes images of fight and resistance and throughout the interviews Cathleen seemed determined to find ways to fight her condition. Examples of Cathleen's fight included the taking of supplements recommended by her doctor and spending her time since diagnosis researching and teaching herself about AMD. By collecting information and learning about her condition Cathleen made attempts to re-balance the power relationship with the health care professionals as well as with AMD itself:

*I've got all this lot [of information], various things. What is it, new surgery, yes oh yes, I'm, you know? Telescope technique, I've got all this stored up to tell them what I want done. Laser light, yes. Here we are, all this lot, anything I find.*

*Cathleen interview 1, line 651-655*

Cathleen hoped she may be able to use this information to instruct the NHS about the treatments she wanted if it came to the point of her needing treatment. In this way the information gave Cathleen the confidence to be assertive in her relationships with health care professionals. Despite all of her research and theories Cathleen remained uncertain about the cause of her AMD. Research and prior knowledge of AMD had provided her with a variety of theories about cause including: glaucoma turning into AMD, previous treatment for glaucoma

causing AMD, genetics, AMD as a build up of waste material which may be washed away by tears, over use of the eyes watching TV and computer screens, and getting shampoo in her eyes:

*I'd like to know what causes it, you know, anything I've done? I mean, I think there's going to be a lot of problems with eyes, the way people do you know, work with these little things, and television and people watching screens, I mean I've not done that. Or any very close work for hours at a time. What does cause it?*

*Cathleen interview 2, line 535-539*

Cathleen struggled to identify a clear causal pathway for her condition and was confused about the role she may have played in the development of AMD. Cathleen is likely to have been aware of other illnesses in which neglecting the body could exacerbate health issues (such as, being overweight leading to a wide variety of health problems including, diabetes, CHD etc) and therefore considered the role of 'strain' and over use of the eyes in the development of the condition. This causation theory may have been fostered by patients commonly being told that AMD resulted from 'wear and tear' in the eyes. This description may not be the best for the patient as it may be perceived as implying personal blame, as Cathleen seems to assume, resulting in the patient feeling guilty about the development of the condition.

## **6.6 Getting on with life**

The participants highlighted minor inconveniences resulting from vision loss. For example, Cathleen explained that she sometimes struggled with small detailed activities but had adapted to this through the use of magnifying glasses and Rowans discussed reading cricket captions on television:

*If I'm sewing you know? If I've got the machine, trying to thread the needle, a little there, sometimes I have got some magnifying clip on glasses which I do use if I'm doing something very complicated or working with black cotton on black material.*

*Cathleen interview 2, line 20-24*

*I watch cricket [on television] you see and the score is up there [in the corner of the screen] the whole time and if you can't quite see it properly there's fidgeting where you are trying to interfere and find out*

*Rowans interview 2, line 645-648*

By experiencing problems "at times" in activities which were once never a problem, it may indicate a need for patients to prepare for the potential deterioration caused by AMD. For patients with early AMD the knowledge of having a progressive condition and the experience of small difficulties may result in a constant fear of further vision loss which is just on the horizon and could soon begin to impact more severely on life. This potential deterioration was

experienced by Rowans between the first and second interview and warning signs of changing vision (such as struggling with small print; “I read the bible, there are very different sized prints of bibles as you probably know and it made a difference when I got something bigger rather than one of the small ones.”, Rowans interview 2, line 633-635) had made the problems caused by AMD more salient.

The biggest threat AMD posed to both participants was regarding the ability to drive:

*It is just the awful thought that, if it gets any worse, for me I'm not going to be able to drive. And my lifeline, really, for getting out is being able to drive to one of these three stations and I get on the train .... You know? And that's my lifeline at the moment, on my own. Being able to get in the car and go out. And if I can't drive, I shall go barmy.*

*Cathleen interview 1, line 415-419*

Losing the ability to drive would have a huge impact on almost every aspect of Cathleen's daily life as the ability to drive was linked to her ability to maintain her independence and freedom. Cathleen's reference to being driven 'barmy' emphasises this as it conjures images of being trapped and unable to live her life without the use of her car. Rowans also valued his driving ability:

*I mean I just found it difficult to accept that I was border line for driving. I think, other people have to be told to get off the road sometimes, or something dreadful has to happen to make you alert to that need, so I think I've seen sense, but to begin with I was a bit resentful of that idea... I knew that I wasn't ready to drive in the near future, I drive 200 miles to Kent to see my son without any bother and back again the same day sometimes, so I really don't quite see why I'm not fit to drive.*

*Rowans interview 1, line 102-108*

Like Cathleen, Rowans felt his life would not be complete without the ability to drive as it would remove one of the factors which enabled him to live life in the way that he had become accustomed to. Prior to diagnosis Rowans felt he had experienced no warning signs that there may be a threat to his ability to drive and this had therefore been a sudden and confusing disruption in his life. Rowans seemed to attempt to resist and rationalize this change by explaining that he did not see why he was unfit to continue with this activity. An example of this is the way in which, immediately after diagnosis, Rowans chose to ignore warnings from doctors and continue with his driving as he had previously done. However, by the second interview his deterioration in vision resulted in Rowans needing distance glasses for driving and the realisation of the effects of AMD were becoming unavoidable:

*[The optician] said that I ought to be having spectacles when I drove because I've never had specs on except for reading before you see? So I've got some which I*

*put in the car, because that's the only time I want to use them, and I hardly ever remember to use them frankly.*

*Rowans interview 2, line 45-47*

Even at this point Rowans chose to give this evidence about his ability to drive in order to justify his driving and re-instate his authority over his life. By choosing not to use driving glasses and avoiding accidents Rowans was proving to himself and others that he was still a capable driver. Each time he made a trip without using his glasses he was reaffirming his driving ability to himself but unfortunately at the same time he was risking becoming one of those people he referred to in his first interview who need to be told to “get off the road” before something “dreadful” happened. This realisation was difficult for Rowans and like Cathleen his actions illustrated his attempts to put up a fight against the impacts AMD was having on his life.

### **6.7 Interaction with health services and appointment experience**

Both participants had been discharged from hospital and instructed to monitor their vision using the Amsler grid (a series of lines in a grid with a dot in the centre; if when looking at the grid the lines appear wavy the patient should contact the hospital as this may indicate a progression in the condition). Given that Rowans did not see AMD as a serious condition it was understandable that he described his use of the Amsler grid as infrequent:

*There is one [line] near to the middle [of the Amsler grid] which has always been slightly, very very slightly wavy ever since I've looked at it, so I thought well that was par for the course and it's never going to be any worse than that so...I've not worried about that rightly or wrongly, but I haven't looked at it very regularly and it's good to be reminded to do that sometimes, but no there is nothing in the way of a major change that I've seen so far.*

*Rowans interview 2, line 935-945*

Rowans explained that he had always seen the lines on the grid as being slightly wavy and therefore assumed that seeing wavy lines was “part of the course” of AMD and did not anticipate any further changes. However, uncertainty about this resolve is evident in Rowans doubt about whether his lack of concern or action was the right thing to do. In contrast, Cathleen had regularly used the Amsler grid and had returned to the hospital when she witnessed wavy lines. However, the reaction from the hospital was not what Cathleen expected as she believed she was told that the distortion was not enough to indicate the development of wet AMD or a need for treatment:

*It's going, just at the top [of the Amsler grid], on the right hand side, it's going wavy. And [the doctor] said 'well don't worry about that too much'. Well I thought that was the actual thing that I'd got to worry about. You know, she's just said when everyday objects start getting all out of shape, then come back. And I*

*thought I want to come back before then. I want to know the minute it starts, it turns into a wet macular. And I don't know if I shall.*

*Cathleen interview 1, line 379-383*

Neither of the participants had any certainty about the right action to take and reacted in very different ways. While Rowans chose to ignore the condition and 'bury' his head in the sand, Cathleen appeared to be being overly cautious about apparent changes in vision. The way Cathleen was given information about her condition at diagnosis led to her being very afraid of what could happen in the future and her over cautious reaction is therefore not surprising. Cathleen's main concern was that her AMD would become wet and she would not be treated until it was too late. Cathleen was attempting to be a 'good patient' and follow the advice given to her regarding the potential rapidity of deterioration however it seemed Cathleen felt that the hospital was not providing any clear indication of what she should expect and she was therefore confused and unable to prepare for the future. Another frustrating and confusing experience was evident when Cathleen described seeking advice about supplements:

*I got about five different lots [of supplements] which I took up [to the hospital]. I plonked them down and said now tell me which are the best ones. [the doctor] said, 'I-Caps'. And I thought. 'I can't win'.*

*Cathleen interview 1, line 692-693*

Cathleen felt that her efforts to source the best tablets were undermined by the doctor's apparent lack of interest. Cathleen was striving to help herself, be a good patient, and take advice, but felt no recognition for her efforts. Cathleen's experience suggested she felt ignored; living in limbo waiting for her vision to deteriorate. On numerous occasions Cathleen referred to how busy the hospital appeared when she attended appointments and her feelings of guilt at the thought of wasting HCPs time:

*I felt awful having been [to the hospital] in March when I went again, you know when, you know, I thought they'll think 'what on earth is she playing at?' You know, coming up here again, she's only just had all this done, but they did do the angiogram which was something different. I expected to get a telling off actually when I came up to the hospital. They think what are you doing here again?*

*Cathleen interview 1, line 595-601*

Cathleen seemed to want to please the doctors, however her search for meaning and cause for her condition was at odds with this and this left her feeling guilty about potentially wasting the doctors' time. Cathleen was making an effort to self monitor and therefore expected the HCPs to reciprocate this effort by giving her clear instructions on how to interpret her symptoms to enable her to prepare for the future. While Rowans reported being unconcerned

about his discharge from the hospital and happy with his regular optician check-ups, Cathleen found her lack of monitoring more difficult to accept as she had prior knowledge of her sister who she perceived to have been too late to receive treatment for wet AMD. Cathleen was therefore desperate to be monitored to ensure she could receive treatment as soon as it was needed and avoid her sisters' fate.

Like Cathleen, Rowans was required to contact the hospital if he noticed any major changes in his vision, however he had very little contact with the hospital other than his original diagnosis. Despite this Rowans had various experiences of opticians' appointments:

*It was a good thing actually that I did as badly as I did in the [sight] test on the wall because if it hadn't been for that I might again have thought that this person doesn't know what they are talking about... when I find that I'm not reading those letters anywhere near so well as I did the last time I did it ...then that brings home to me probably things are more advanced than I realise.*

*Rowans interview 2, line 850-861*

This extract highlights Rowans sense of cynicism and distrust regarding the information provided by HCPs and that Rowans placed responsibility with the HCPs for issues regarding his condition. In comparison, Cathleen appeared to take blame and responsibility for AMD upon herself. Research into locus of control may help to explain this finding. For example, a study looking at chronic pain by Buckelew, Shutty, Hewett et al. (1990) has suggested that women are more likely to attribute ill health to internal causes and to use coping strategies involving self-blame, information seeking, and threat minimization. In addition, younger men are more likely to attribute ill health to internal factors, while older men placed more emphasis on chance and powerful other factors. The experiences of Rowans and Cathleen seem to add evidence to these findings.

Rowans' mistrust meant he was reluctant to accept medical opinion without evidence based on his own experiences. One possibility for this mistrust was due to Rowans' perceptions of the HCPs based on appointment experiences:

*I think the danger is that you react personally to them and, your judgments then might be disproportionate ... I remembered the man who had done [the tests] before, who for whatever reason he was rather off hand and it made me, less willing to trust what he said actually, probably without any justification but that was my human reaction [...] in the way the relationship functions they can either make you think you matter or not, and I think, you know she was trying, you know I didn't think I particularly mattered to her, I was just the next in line I think... Whereas some of the other people who did the sight [tests] and things like that were sort of middle aged woman type, they were more motherly and they, they probably made you feel comfortable*

*Rowans interview 2, line 546-551*

Rowans highlighted factors which he felt were important for building trusting relationships with HCPs and he felt were necessary in order to feel respected and cared for rather than just “next in line”. A patient’s perceptions of HCPs has a huge impact on whether they trust them, therefore the interpersonal skills of HCPs plays a crucial role in helping patients understand, monitor, and adapt to their condition.

## 6.8 Future with AMD

The participants were asked about their anticipated future with AMD. Cathleen’s ideas were bleak and based on her knowledge of the experiences of others around her who had been diagnosed with the condition:

*I've got a sister who has gone blind with [AMD]. But she didn't realise until the one eye had gone completely, but well, I mean, as you know, it's not completely blind. [...] And it does worry me and I do think about this because, I do, being on my own, I do not want to be in the situation that she is in.*

*Cathleen interview 1, line 21-26*

Cathleen believed her sister had been diagnosed with wet AMD too late to be treated resulting in a high level of dependence. Cathleen feared this fate for herself which helps to explain her desire for regular monitoring from the hospital. Cathleen seemed to struggle with her understanding of ‘blindness’ and acknowledged that people with AMD did not become “completely blind”. This understanding based on the information provided by HCPs was at odds with her experiential knowledge of her sister’s circumstances and therefore seemed of little comfort to her. Cathleen seemed to assume that if her condition progressed to wet AMD and she could be treated then she would feel more confident about her future. However this was also uncertain as her knowledge of contradicting evidence suggested that her future was at risk regardless of the status of her AMD:

*C: It is really frightening, because I know somebody at one of my groups...who says she's got dry macular, but she's, she can't write her name, she- she's virtually blind, so it isn't just with the wet macular that you can go blind, it's with the dry as well isn't it?*

*A: So, it's frightening to think that that could happen to you at some point?*

*C: Yes, yes it is, it's very frightening, particularly as you get older, you know you think, well what on earth is going to happen to you?*

*Cathleen interview 2, line 365-370*

Cathleen was uncertain about the different types of AMD and her rhetorical question about the impacts of wet and dry illustrates her concern about the potential for her own vision to deteriorate to the level of her sisters. The confusion that contrasting explanations and advice caused for Cathleen resulted in fear and distress regarding the uncertainty of her future.

Living alone was central to Cathleen's life and she struggled to make sense of what level of threat AMD posed to her continuing to live in this way:

*A very limited life, no television, no reading, a very limited life. That's what, you know, the future looks like for me, if it does progress. So this is why I want to know the minute it starts getting worse and I can have something done.*

*Cathleen interview 1, line 783-785*

Cathleen's emphasis on the need for speedy action came from her perception of her sisters' failure to seek help quick enough in addition to advice she had gleaned from her HCP who explained that without treatment vision loss caused by wet AMD could occur very quickly. It seemed that it was not the AMD itself that was causing Cathleen distress, but the confusion and uncertainty about what her future may hold.

Rowans also had experiential knowledge of individuals who he believed had lost much of their vision to AMD. However, he assumed that these people had wet as opposed to dry AMD and therefore did not associate this with his own possible future:

*Well [the man he thinks has wet AMD] couldn't read you see, he would need to blow something up huge if he was going to read it and it would be very slow, and he was still in business so I would read his correspondence for him and he couldn't order to some extent, and I drove him to appointments and that was it really. I ought to know [what kind of AMD he had] shouldn't I? It's very severe, he is registered blind and I would think probably he is the wet kind.*

*Rowans Interview 1, line 227-232*

Rowans had firsthand experience of what the life of someone he believed had wet AMD could be like, however he did not see this in his own future as he associated blindness with wet AMD which he did not have. As discussed earlier Rowans was aware that his AMD could become wet but was reassured by the good health of his parents into old age that wet AMD was unlikely to happen to him. However there was evidence that Rowans was confused about the different kinds of AMD and the 'Chinese whisper's' phenomenon which gave him information about others with the condition also added to this confusion.

## **6.9 Summary**

This chapter analysed the experience of two participants with early dry AMD. This sub-sample of participants illustrates the shared and divergent experiences of individuals with early dry AMD who still have much of their vision and found that AMD affected day to day life very little. It has highlighted four key themes: making sense of diagnosis; getting on with life; interacting with the health service; and the future with AMD. Across all of these themes there was evidence of the participants attempting to get on with their lives despite the uncertainty of their future and the sense of looming loss due to potential further visual deterioration just on the

horizon. These participants were living on the edge of being visually disabled and were trying to make sense of the changes this may mean for their lives. The next chapter presents the experiences of participants with treatable wet AMD.

## Chapter 7: Treatable Wet AMD

### 7.1 Introduction

In this chapter I present the experiences of patients with treatable wet AMD. Wet AMD has the potential to result in a high level of vision loss in a short space of time. However, if diagnosed early a patient will be offered treatment for the condition which usually results in either maintenance of vision or an improvement in vision. This chapter presents the experiences of seven participants (Rose, Ruffine, Alison, Jordan, Irene, Nuxy, and Rick) with treatable wet AMD who were also discussed in chapter 3. These participants all experienced injection treatment for AMD which was an experience unique to this sub-sample.

### 7.2 Research Question

What is it like to live with treatable wet AMD?

### 7.3 Method

The method for the data collection and analysis for this chapter has been described in chapter 5.

### 7.4 Themes

Table 12 provides an overview of the themes which will be discussed in this chapter.

Table 12: Treatable Wet AMD Theme Table

Theme	Subtheme	Example
Making sense of diagnosis	Realisation	<i>I could, suddenly see that I had to move my head to make sure the float was in my vision and that's what started me seeing this shadow on my eye. (Nuxy Interview 1)</i>
	Cause	<i>I use my eyes an awful lot, I don't, I've never given them a rest. (Ruffine Interview 2)</i>
Getting on with life	Encountering difficulties	<i>I can't see to sew, especially if it's dark (Rose Interview 1)</i>
	Driving	<i>I'll tell you what, when I have to stop driving that'll kill me that will, I tell you. (Nuxy Interview 2)</i>
Treatment experience	Preparing for treatment	<i>I don't know how I'm going to cope when I have my needle! ((laughs)). (Rose Interview 1)</i>
	The treatment process	<i>it is a bit of a sensation, but other than that, no pain, just a sensation of having it done like you know? (Rick Interview 2)</i>
	Information and communication	<i>I was just thinking, 'I wonder how many more...how long now' (Irene Interview 2)</i>
	Results of treatment	<i>Well, my eyes have got bad, I've had five injections in my eyes now. (Rose Interview 2)</i>

<b>The future with AMD</b>	Hope	<i>Well I don't really know, I hope that it's going to be better (Rose Interview 2)</i>
	Changing thoughts about the future	<i>If you worry it makes it worse to be quite honest....so look on the bright side. (Nuxy Interview 2)</i>

## 7.5 Making sense of diagnosis

Like the participants with early dry AMD in the previous chapter the participants with treatable wet AMD attempted to make sense of the changes AMD meant for their lives. Like Rowans and Cathleen these participant's discussed their search for a cause, however in contrast while the participants in the previous chapter experienced a slow deterioration of vision these participants' vision tended to deteriorate suddenly. This meant a salient aspect of the experience for these participants was their moments of realisation which made them aware of their condition.

### 7.5.1 Realisation

Moments of realisation about visual deterioration took place when participants noticed discontinuity and sudden changes in their usually taken for granted daily experiences. For example Nuxy identified subtle changes to his experience of fishing:

*N: ... I do a lot of fishing and when you, you've got your eyes focused on, the float which is, as you know is part of fishing, and I could, suddenly see that I had to move my head to make sure the float was in my vision and that's what started me seeing this shadow on my eye.*

*A: So is it like a blind spot?*

*N: Yes, it is, well a blurred spot, not necessarily blind... It's a blurred spot. I can see through the shadow, but it's it's, it's all, it's all blurred so it's yeah.*

*Nuxy interview 1, line 306-322*

Nuxy's AMD drew his attention to bodily movements which would have usually been taken for granted and therefore altered his experience of fishing. Interestingly Nuxy was defensive about my referral to the shadow as a 'blind spot' and was reluctant to use the label 'blind', perhaps because he was uncomfortable with the associations blindness carried. As will be discussed later, driving was very important for Nuxy and if he were to become blind then this would be threat to this activity and his identity as a driver. Instead Nuxy used the term 'blurred' to refer to the shadow this appeared to be a less threatening label which enabled him to maintain his identity as a sighted person.

The description of a 'shadow' was highlighted by many of the participants including Irene (who described being unable to see her grandchildren's faces on photographs) and Ruffine:

*If I'm reading a book ... I have to sort of, if I'm reading this ((holds up book)) ... I have to sort of move [the book] over, so that eye, the good eye is more on it than the other eye.*

*Ruffine interview 1, line 770-777*

In some activities, such as when watching television, Ruffine's described her 'perfect' eye as able to counter the deterioration in the eye with AMD. However when reading Ruffine needed to make adjustments to see the words on the page. The adjustments required to enable these participants to engage in enjoyable hobbies felt strange and unnatural and this feeling of being alienated within their own bodies played a key role in the realisation process.

Jordan's realisation was less sudden and she described repeatedly visiting her optician with concerns about the suitability of her glasses:

*I had these other glasses and they're not a bit of good. And yet when I had them tested, I went to the one up [town] first, up there, the opticians. And then he kept saying, can't do nothing, can't do nothing. And I thought this is silly, can't do nothing? So, I thought well I'm going to change it, so I went to the one up by [town]. And I went up there, and he told me exactly the same as that one did. But I thought it's not right saying that my eyes were deteriorating that quick. And that's when he referred me to the clinic. So the clinic took some photos of my eyes and he said I'll refer you to the hospital. Which they did. And that's the story of my life.*

*Jordan interview 1, line 594-608*

Despite Jordan's vision deteriorating quickly in both eyes she felt it had taken a long time for her to be referred to the hospital. Jordan tended to report the most difficulty in day-to-day life of all the participants. It is possible that Jordan assigned the blame for these difficulties to her delayed referral as she suggested it was her persistence with the optician which eventually resulted in a hospital appointment. Jordan seemed angry and let down by the need to take responsibility for her treatment. She felt that the qualified HCPs had failed her when she had tried all that she felt was in her power to address the problems she was experiencing.

At the time of the first interview Alison had already been receiving treatment for AMD in one of her eyes and her realisation experience was based on the development of wet AMD in her second eye:

*... I was due to go for the routine scan and check up that you go, and, prior to that, about a fortnight before, I thought, 'my sight isn't so good' and then it seemed to snowball ... I thought I'd got the cataract coming in this eye, that's what I thought had come, snowballed, but of course it wasn't and, so that's when, they said, oh, you know? [you have AMD]*

*Alison interview 1, line 809-820*

Alison was being regularly monitored by the hospital but despite this she felt the deterioration in her second eye came on suddenly and soon began to spiral out of control. Alison believed she had no warning that her second eye was going to deteriorate and this therefore came as a shock for her. Understandably Alison's first assumption was that she was developing another cataract as this is what had been the cause of the initial deterioration in her first eye. It is likely that the deterioration in her second eye was highly distressing as Alison had portrayed her ability to manage as being a result of good vision in one eye making up for the loss in the other. Alison had only just had time to come to terms with the diagnosis in her first eye when the second began to deteriorate giving her little time to consider and make sense of her situation.

### 7.5.2 Cause

While some participants assigned the condition to old age, others drew on wider issues and previous experiences. At the first interview both Irene and Rose concluded that their AMD had been caused by old age. For example Rose explained;

A: *So what do you think caused your macular degeneration?*

R: *Old age I suppose, ((laughs))*

A: *Old age?*

R: *((laughs)) It is what it is, I can't think of anything else that caused it.*

*Rose interview 1, line 782-787*

The participants' explanations reflected their appointment experiences which were likely to have been fresh in their minds at the first interview. Both participants were diagnosed in and recruited from the same clinic in which I witnessed the phrase "wear and tear" being frequently used to describe the condition to patients. This had led to Rose and Irene to understand their condition as part of a standard ageing process in which their bodies were gradually deteriorating. Visual deterioration is a common occurrence in old age, with most people needing glasses as they get older. However, AMD is not part of this ageing process for everyone. It is evident from Rose's quote that she seemed uncertain about 'old age' as the explanation for her condition but she had no other available explanation with which to make sense of her experience.

Participants frequently referred to "abuse" of their vision as a potential reason for their AMD. While this was alluded to as a potential cause of the problem most could not pin point examples of when they themselves had 'abused' their vision. Nuxy, for example, was keen to stress that he had been taking good care of his vision due to knowledge that both his mother and aunt had become visually impaired with glaucoma. While he was aware that glaucoma

was a genetic condition, knowledge about the cause of AMD was less certain as Nuxy had no family members with AMD. Nuxy used his past experiences to make sense of the condition and initially considered trauma to his eyes when he was younger as a potential cause:

*funny enough it's, let's get it right, pretty well 60 years ago this year, when I was, I was just 18 and wherever, I worked at the firm I worked for and I'm grinding on the stone and a piece shot in my eye, a piece of metal, I left it for two or three days and it's given me some pain, so then I went to the eye hospital which was in town at the time, and I found out I'd got some, a bit of steel in my eye and it had started to go rusty I think the optician said at the time, now I had to stop in there for a week in town...[]...And they, they took the eye, the bit of steel out and they injected my eye for some reason, I don't know if it was to cut the pain out or what, and then, and then I, and that's the only thing I've had, basically anything you know? Happened to my eyes...[]...That's the only thing as I say that I can think of that, nothing else eyes, well eye wise I've never had anything untoward on my eye sight you know?*

*Nuxy interview 1, line 300-406*

This was the only experiential knowledge available to Nuxy on which he could base his understanding of AMD. When describing the incident Nuxy drifted into the use of present tense as if reliving the memory of the incident and whether this traumatic event may have been a catalyst for the development of his AMD. This explanation did not fit with any information he felt he had been given at the hospital, but without access to any other explanation this was the only event that Nuxy had available to consider as a potential cause of his condition. The parallels between this past experience and Nuxy's current experience with AMD added strength to his causation theory. Firstly in this past experience Nuxy was unsure what the problem with his eye was and it was only after visiting the hospital was he felt he had become aware of the metal in his eyes, and secondly he remembered needing to undergo an injection in his eye as part of his treatment. Both events were out of Nuxy's control and he therefore allocated no responsibility for the issues to himself. By the second interview Nuxy had begun to consider whether something he had done may have played a role in the development of his condition and reassessed his causation theories:

*I don't know [what caused my AMD], I've never abused my eyesight in any way, I've always tried to look after my eyes, I've been wearing glasses for, about twenty years now, but I can't tell you, I can't tell you why, you know? It's, I know it, the glaucoma runs in the family, but the blister at the back of my eye I just can't understand what that... I've thought it was just age, age related, so you know as I say, at my age you've got to expect it if its age related the illness is so yeah.*

*Nuxy interview 2, line 427-442*

When asked about what the hospital had suggested may be the cause Nuxy seemed to be reminded of the advice given to him at the hospital that AMD was age-related. However, this explanation had not been sufficient for Nuxy to understand his diagnosis, hence his attempt to

make sense of his diagnosis in terms of both the trauma incident he experienced and the possible genetic causes of AMD.

Ruffine was also given the explanation that her AMD resulted from 'wear and tear' and old age and made sense of this differently to the other participants. Rather than associate the condition with a natural part of the ageing process Ruffine instead immediately considered that there may be an element of self blame:

A: *So what do you think caused your macular degeneration?*

R: *Age*

A: *Age? Can you expand on that?*

R: *I probably, use them too much, use my eyes too much. I've always been an avid reader, book reader, I've always been very very keen on writing letters, I use my eyes an awful lot, I don't, I've never given them a rest. I'm doing more so now, because I tend to be more tired. I mean if I'm watching a programme in the afternoon and say I've been out shopping in the morning or been for a walk in the morning and I come back and have my lunch. And then I'll put the tele on and I'll sit back, put my chair up and I'm asleep. I'm sleeping more now than I've ever done. Which is perhaps a good thing for my eyes, but I think I've used my eyes too much, and that, that's probably the reason. I don't sit and listen to music as I should do, instead of always reading or writing. Which I've eased up quite a lot on the reading, whether I'll ease up on the writing I don't know, as long as people write to me I'll answer them. You know?*

*Ruffine interview 2, line 657-684*

Ruffine saw her vision as a commodity which she only had a limited amount of and by overusing this commodity in the past she had put herself at risk of a future without her eyesight. Ruffine's description is littered with a sense of guilt and responsibility for her AMD as she felt that by pursuing enjoyable activities throughout her life she had threatened her future vision and 'used up' her eyes. This has connotations of 'greed' and 'morality' which seem to have prompted Ruffine to take steps to preserve her remaining vision (sleeping more and easing up on reading), however she seemed to fear that this may be too little too late. Ruffine's love of writing was greater than her fear of losing her eyesight as writing had been a major part of her life and had been important to her ability to remain socially engaged with friends and relatives. This may also relate to issues of morality and guilt regarding Ruffine's choice not to return to Guernsey and her family after she had been relocated during the war. While her husband was alive she had been comfortable in Birmingham but after the death of her husband she had begun to feel isolated and alone and perhaps guilty about leaving her family behind. Ruffine did not have the funds to return to Guernsey and when she spoke about visiting family she referred to these holidays as trips 'home'. Writing was the main form

of communication between herself and her family (as it had been during the war) and therefore was given a higher value than the need to retain her vision. In order to justify this, Ruffine had placed her choice to continue writing as out of her control, 'as long as people write to me I'll answer them' and this enabled her to defend her choice despite the perceived risks to her vision. Ruffine was not the only participant to fear overusing their eyes as Alison was also concerned by this. Alison explained that she was choosing not to paint or watch television as she felt these activities may strain her vision and cause them to deteriorate more quickly. This lay belief was having important implications for the lives of the participants. Both of these women were sacrificing activities they enjoyed in order to take control of their deterioration and preserve their vision for the future.

## **7.6 Getting on with life**

AMD represented difficulties and challenges for the participants which needed to be overcome in order to allow them to get on with life.

### **7.6.1 Encountering difficulties**

Many of the participants found activities which were once part of their routine or taken for granted had become more difficult and in some cases impossible with the onset of AMD:

*I can't see to sew, especially if it's dark, I tried to turn some trousers up and I made a right mess of them, because they were dark, and I thought I'd be able to see in the daylight but I couldn't so I had to send them and have them done. But apart from reading what's on books, on the packets and things, when you are cooking you know? I managed all right. ((laughs))*

*Rose interview 1, line 157-167*

Rose's beliefs about what she was capable of proved to be at odds with her experience of what she was actually able to achieve. It seemed that Rose was unable to identify with the person who struggled to cook and sew and instead referred to herself as someone who was 'managing'. However, her examples of difficulties undermined this and illustrated the possibility that she actually doubted her ability to manage. Rose explained that there were many activities which she came across and was unable to do. When she found an activity like this she would ask others for help. However when help was offered without Rose's request she became embarrassed as this contradicted her belief that she was able to 'manage':

*I feel embarrassed sometimes because people help me more, you know? They, when I go out with my niece, it worries me more that embarrasses me because they help me, you know, apart from the not being able to walk properly it's because I can't see properly either and all the while they are saying to you, 'are you alright?', are you alright? Can you see that, are you alright?' and ((laughs)) and you get embarrassed because they worry about you, that's what it is.*

*Rose interview 1, line 1420-1430*

Rose was struggling to come to terms with the ways in which her life had changed. While she was happy to ask for and receive help with some activities (DIY, shopping, travelling), other activities, like the example above, were more difficult incorporate into her view of herself as independent and managing. Rose did not like that her family now seemed to be treating her differently and felt embarrassed by the ways she was intruding on other people's lives and becoming a nuisance to them. Rose also gave an example where she was 'plugged in' in the car by her niece as she was unable to see to fasten her seatbelt. This experience made Rose feel embarrassed and treated like a child and she was frustrated that she could no longer do simple activities for herself. Rose wanted to feel independent and capable but felt she was being forced into dependence by health circumstances which were out of her control.

Jordan reported the most difficulties as a result of AMD. These difficulties were more than functional and appeared to be impacting on her emotional wellbeing:

*If I sit and think about it, I do get upset. So, I just totter about and do something. Look in drawers or tidy drawers. Something like that. And that's how it gets me. But I say, it's when I sit in here and I can't see the tele properly. I have to sit right over there and I can just see the outlines of them. But it's things like that. In the daytime, I don't mind because I say, I can potter around doing something. Ironing, I have no trouble with, put my washing machine on, just hang it out, and then iron it. I've just got to potter about in the daytime. It's at night when I can't, I think I'm in bed at 8 o'clock... So, it does get me down because I've always been active.*

*Jordan interview 1, line 423-534*

Jordan became very tearful and upset at times during the interview as she felt her condition was out of her control and there was no way she could regain her past life and activities she enjoyed. AMD was preventing her doing many of her hobbies, such as looking at old photos, playing games with her grandson and watching countdown. It was in the times when Jordan had no distractions that she began to think about her situation and all of the activities she was no longer to engage in. The impacts for Jordan were more than just functional as the condition prevented her from living her life in the way she had been accustomed. As a result the condition was impacting on Jordan's sense of self:

*I don't know. I know it's not me, it's not me, but I just don't know. I don't feel, now how can I put it, I don't feel so nice in myself as I used to, I used to get up and*

*have a shower [...] and I used to like to dress up nice, put make up on. I never used to go out without make up, never, but now I just don't bother, I haven't wore make up for the last 12 months, not even lipstick, at one time I wouldn't even go out the door without lipstick on, but not now, I can't be bothered, I haven't let myself go like dirty or, not changing clothes, not that way, but I've let myself go in, I don't know, like to look nice, go out and put make up on and go here, go there, and because our kids say, you know? Come visit me Mum, and I just can't be bothered.*

*Jordan interview 2, line 1162-1172*

Developing and living with AMD was more than just a loss of vision: changes in circumstances affected Jordan's whole life, altering her perspective on her sense of self. Jordan felt AMD was causing her to be increasingly withdrawn and emotionally affected. During the third interview Jordan described being visited and provided with equipment to help her with day-to-day activities:

*A: OK, so in general how have things been since the last time I was here?*

*J: Not too bad because I've had help off people like you, because they've bought me a radio, and then I've had talking books, I said I didn't want the papers they are too depressing ((laughs)). So I said I'd like talking books and I've had the radio and they've given me a little thing to put on the cup when I make a cup of tea, and if it gets to so far it makes a noise where I've got to stop, so they've been very helpful so it's not been too bad.*

*Jordan interview 3, line 213-221*

These additions to Jordan's life gave her a greater feeling of control as she was once again able to do simple things for herself and enabled her to regain some sense of her past self. Jordan spoke excitedly about looking forward to getting talking books and being able to listen to them during the day as an alternative to watching the television (which continued to cause frustration as she was unable to see the screen clearly). These possibilities would once again give her distractions from thinking about her condition. It was these small changes that gave Jordan some sense of hope about her immediate future. However thoughts of the upcoming Christmas still resulted in Jordan feeling down about her abilities:

*But I just get a bit fed up that I can't do anything myself. You know? I mean, Christmas coming up you know? And I've just got no interest this year. But otherwise I'm alright ((laughs)) When you go up the hospital and you see people worse off than yourself you think well at least I can see a bit well, that's how I feel.*

*Jordan interview 3, line 230-235*

Christmas reminded Jordan of past happy occasions spent with her family when she could enjoy a drink and be 'herself'. This year the prospect of Christmas no longer filled her with joy

and it was only thoughts about others who were in worse situations than herself that prevented her inabilities from overwhelming her.

### 7.6.2 Driving

Another issue which affected the participants' independence was the loss of the ability to drive. Driving served a variety of purposes: it was functional, allowing the participants to get around and do shopping; it was an escape from their homes and a source of freedom; and it was a symbol of independence.

Prior to her diagnosis and treatment for AMD Alison had been able to drive to the many groups and clubs that she was involved in. However, the deterioration in her vision meant she was no longer able to drive. This loss had been a major disappointment for Alison:

A: *Yes, absolutely, [driving] is, to me it is **the thing** absolutely, because it's your freedom.*

*Alison interview 1, line 1183-1184*

It was not only the loss of the ability to drive itself that was the issue for Alison but the feeling of restriction that coincided with it. Not being able to 'jump in the car' resulted in Alison relying more on her daughter and other people:

*I do have to ask for lifts now, which I don't like doing. But, it's, it's essential that I still belong to these things to meet people. Well I've been a member of the WI for 38 years so I don't want to just stop that and [the] Guild and of course art societies I go to*

*Alison interview 1, line 1168-1174*

Attending groups and clubs was an 'essential' part of maintaining continuity in Alison's life. The necessity to ask for help challenged this taken for granted aspect of Alison's day-to-day existence. Alison's loss of independence had become a strain on her relationship with her daughter as all of her activities now needed to be structured around her daughter's diary as well as her own and Alison resented the loss of freedom that this caused. Elsewhere in the interview Alison spoke of hope that the treatment may at some point restore her vision to the point where she would be able to drive again and take back control of her day-to-day activities. Stopping attending the groups was not an option for Alison who had been involved in them for many years and she felt that being a member of these groups was part of who she was and was not ready to consider who she would become without them. The hope that her loss of independence would only be a temporary experience enabled Alison to come to terms with her reliance on her daughter.

Nuxy remained able to drive, but spoke of the risk to driving that his deteriorating vision posed:

*... I suppose I could get a lift off him [son-in-law] or me grandson, but you, you can't please yourself then, you've got to rely on them when they, when they are available for fishing. I've got a bit of freedom, I can say to the Mrs, we'll do the shopping tomorrow and I'm going fishing, just like that, but if I've got to rely on somebody else, I've got to wait until they are ready, so, that's what, that's what really, doesn't upset me, but that's what, that's the things I think about when I can't drive.*

*Nuxy interview 1, line 575-583*

Nuxy used the car for a variety of activities, one of which was to enable him to pursue his hobby of fishing which he did two to three times a week. Like Alison, Nuxy highlighted the freedom that being able to drive gave him; enabling him to make his own decisions about what he wanted to do and when he wanted to do it. Nuxy also talked about the potential dependence that could result if he were no longer able to drive and the emotional impact these thoughts had on him. Elsewhere in the interview Nuxy suggested that he might become depressed if he were no longer able to drive. He explained that driving was important to enable himself and his wife to get out of the house and do their shopping and without it they would be trapped at home. Nuxy's final statement "the things I think about when I can't drive" suggests that these worries may have been playing on his mind. Nuxy had been comparing his life now to what it may be like if his vision deteriorated and was becoming distressed by the potential impact visual deterioration may have. By the second interview Nuxy had been dwelling further on the potential loss of his driving ability and the perceived impacts had become more serious:

*A: Are you still driving, you are still driving aren't you?*

*N: Yes, yeah, that's the, ah I'll tell you what, when I have to stop driving that'll kill me that will, I tell you. I've been driving since I was 16, now that's a long time and I love driving, yes. Yes so, if I stopped carrying on, I'm still going, I don't think I'm dangerous anyway, I've been driving too long to be dangerous so.*

*Nuxy interview 2, line 484-492*

Driving was part of Nuxy's identity and it had been a major source of enjoyment in both his work and personal life from a young age. Nuxy had worked driving vans and lorries across Europe and looked back on these experiences fondly. Nuxy now felt that not being able to drive had the potential to 'kill' him. It is unclear whether Nuxy felt this literally or whether he was referring to the death of the man he once was. Without his ability to drive Nuxy would no longer be able to engage in the activities that made him who he was and in this extract Nuxy

was holding on; he was 'still going'. Nuxy provided justification for his continuing to drive and this illustrated that he had considered the potential risks of continuing to drive with his visual deterioration. Nuxy felt his vast experience as a driver was able to outweigh the potential risks and compensate for his visual deterioration. By the time of the third interview other substantial health problems relating to the removal of a lung due to lung cancer meant Nuxy no longer had the physical capability to drive:

N: *[having a lung removed means] you are stuck in the house, I can't drive I can't get out you know, it's, it affects your mobility and I've always been mobile all my life always been a driver since I was 17 so, yes it really affected me that did. But I'm getting over it now it's, yes. ((long pause))*

A: *So what does your week involve now?*

N: *Sitting here mostly.*

A: *OK*

N: *Sleeping mostly, I sleep downstairs I don't sleep upstairs now. I can walk about but I'm getting, I get out of breath very quickly. I might sit in the back kitchen for an hour or two in the day but it's mostly sitting here. Occasionally the wife comes and takes me out but, I've got a wheelchair she folds that up and puts that in the back of the car and we might go out for a drive to one of the shopping centers but not very often yeah. Well I can't expect the Mrs to push me about I mean she's only about 8 stone my Mrs, mind you I ain't much more now the weight I've lost. But no, I don't get out a lot now at all.*

*Nuxy interview 3, line 77-98*

Other life factors meant that Nuxy had become the dependent man who was unable to drive that he had feared becoming in earlier interviews. Nuxy's health had clearly deteriorated at the time of the third interview and he did not have the same enthusiasm for his hobbies like driving and fishing which he had discussed in his earlier interviews as he was no longer capable of these. The combination of other health problems and the limitations these had posed forced Nuxy to renegotiate who he was and the level of importance he prescribed to driving.

### **7.7 Treatment Experience**

Treatment was a major part of experiencing AMD for all the participants in this subsample. Most had been warned that their vision would potentially deteriorate further if they did not have treatment. Therefore, despite being confused by much of the information provided, the participants were keen to go ahead with treatment in order to avoid a potential future with 'blindness'.

### 7.7.1 Preparing for treatment

At the first interview Rose was preparing to undergo treatment for the first time, “*I don’t know how I’m going to cope when I have my needle! ((laughs))*” (Rose interview 1, line 585-586). Rose was aware that treatment involved an injection into the eye and this understandably resulted in anxiety, fear and uncertainty. By the second interview Rose had been to the hospital for treatment several times:

*Well, it never worried me at all when I went the first time you know? Because you didn’t know what you’d got to come, but it worries you a little but, you know? You are a little bit apprehensive, but I can’t say that it’s- I’m not a nervous disposition so, you know? People would say, ‘oh, I couldn’t do that, I should be frightened to death!’ but I’m not a nervous disposition so, it doesn’t, doesn’t you know? Upset me that much ((laughs)).*

*Rose interview 2, line 517-524*

Rose explained that she had not found the treatments as distressing as she had originally feared and as a result no longer looked back on her first treatments as an anxious time. Rose’s experiences illustrate the way in which her imagination of treatment was more distressing than the reality. This is an important issue as patients may decline AMD treatment due to fear. Rose’s shift from fear to bravery is illuminated by the way she talks about her sense of self. By describing herself as someone who is ‘not a nervous disposition’ Rose was able to talk herself out of the fear and this enabled Rose to manage her emotional response to treatment. Like Rose, Rick felt more confident about treatment as time went on:

*Rick: I went last time, and the last one I had on the last treatment, and there was a, well I say older lady, I was probably older than she was probably, she was there with her husband and she was like that like you know, obviously [inaudible] and there’s a lady there and they said ‘he’ll tell ya’ and they said, ‘what’s it like’, and I said, ‘your first one?’ like you know, I’d had two or three, and I said, ‘no, there’s no pain’ I said, ‘it’s a funny sensation, and you feel a bit squeezy when you go in and you see the chair there, and you see them with the masks on’, that’s what frightens-frightens people I think. I said, ‘there’s a funny sensation, just a funny sensation’ and ‘I said there’s no need to worry, no pain, definitely no pain’ and it’s, she went in before me and when she come out her husband went, ‘thanks’, I said ‘it’s alright, it’s no problem’, and you know, I’m glad I could have put somebody at ease, I had nobody to tell me that ((laughs)) I was the only one there that night, funny that, I was the only one in the waiting room that night.*

*Amy: So how did you feel being there on your own?*

*Rick: I, you know, obviously, you know, what I was the same as that lady, a needle in my eye! You know?*

*Rick interview 2, line 588-600*

When Rick went for his first treatment he had no one to ease his concerns and therefore sat alone and worried in the waiting room. However, at a later appointment, Rick was able to use his prior knowledge and experience of treatment to ease the concerns of another patient. This example illustrates the way in which sharing information with patients may help to ease their concern about treatment and reduce unnecessary distress.

### 7.7.2 The treatment process

All of the participants described a fairly uniform process of treatment appointments:

*it's like the operating table which you, you have a cap on and so you obviously lie down and they put the sides up and, then she appears, oh and you nearly always have another drops in your eye, and she sort of, if you, if you visualise it feels like a clamp which your eyelids are clamped open and then they bring the big light over the operating table on to there, which sort of makes you think well, I wish I could shut my eyes ... and then of course she puts the needles in, which you do feel and you can also feel, see the liquid when it's coming, go across your eye, you see the liquid go across, and of course it's essential that you've usually got a nurse either side of you because you've got to put your arms down in case you suddenly put your hand up and so there, and, then the consultant usually says, when it's over, 'can you see the fingers' and then, can you see, often, three fingers or two fingers, you tell them, OK. Then obviously, then you sit up gingerly and, one of the nurses takes you back because you are a bit sort of unsteady to the day ward place*

*Alison interview 1, line 873-885*

For those familiar with it, Alison's account evokes the psychological torture scene from Stanley Kubrick's film, 'A Clockwork Orange', in which the protagonist is injected with a nausea inducing drug, his eyes are clamped open, and he is forced to watch graphically violent films. In this film the protagonist has no choice and is restricted and while he wishes to look away he can't, just as Alison was unable to shut her eyes to escape the bright light. In the absence of embodied knowledge we can only draw on images (which may for some be like this scene from A Clockwork Orange) within our experience to make sense of what may happen to us. This may help to explain why Rose and Rick found the anticipation of being treated more anxiety provoking than the actuality. Despite sounding like torture Alison was keen to continue with her treatment which illustrated that the results experienced and the threat of a future without vision were worth the inconvenience and serious discomfort.

One of the ways the participants were able to manage the distress treatment caused was by building up relationships with the nurses:

*It is scary going in to hospital, it is, so when you get to know all the staff and the staff know you, and it is, and they are all, I don't know how many people who's hand I've held, because they all do that, and I might tell you, it is very very good, because when the initial thing goes, the needle is there, you do, and you grip you*

*know? And so it mightn't sound much when the nurses do it, but it is very important, very important, because you do grab the hand, I mean, it doesn't last for long but it's quite scary.*

*Alison interview 2, line 220-226*

Treatment was a scary necessity for Alison which included both psychological and physical fear. Holding the hands of the nurses was reassuring physical contact as well as performing the function of keeping hands away from her eyes whilst being treated. The care offered by nurses was in direct contrast to the role of restricting Alison that they also fulfilled. Getting to know the nurses and portraying them as friends rather than strangers could be Alison's method of self-comfort. As Alison could not have real friends or family with her in the treatment room the presence of 'friends' which are nurses helped to reduce her fear. Ruffine also described attempts to build relationships with the hospital staff:

*It doesn't worry me at all. I'm not, in fact, whether it's nerves or not I don't know, but I joke. I joke a lot with the nurse in case, in fact one of them said, 'oh, it's her the jokey foreigner again' ((laughs)) and that's what they call me ((laughs)) ...I joke with them, so it passes, it doesn't worry me one bit.*

*Ruffine interview 2, line 302-318*

Ruffine's jokes acted as self-calming strategies which made her laugh and served to distract her from the treatment procedure. This strategy reduced the amount of anxiety Ruffine would otherwise experience if her full attention was focused on the treatment. In addition, Ruffine was able to take on the persona of a 'jokey foreigner' (a reference to her move from Guernsey during the war) when she attended the hospital for treatment and this was facilitated by the hospital staff. This may have enabled Ruffine to distance herself from the treatment as she was there playing a character and acting out a part of being the nurses 'friend' rather than being there as herself, again limiting her level of anxiety. These examples illustrate that patients feel that positive and friendly relationships with HCPs play an important role in helping them to cope with and manage the anxious feelings related to treatment.

### **7.7.3 Health care professional-patient communication**

In addition to playing a comforting role there was evidence that relationships with HCPs could be improved and utilised to reduce the confusion experienced at hospital appointments (involving multiple tests and interactions with various members of medical staff). Examples of this confusion were evident in participants' descriptions of undergoing tests and scans with no knowledge of their purpose:

*I didn't see the reason why there were so many different people that I had to go and see individually, I mean the same nurse could have come and done, put the in, the thing, the injection in my arm, she could have come and took it out...you*

*were, you were going from one place to another, and you waited, another place to another, then you waited, another place to another, then you waited, and then there was one, one you lady she came, when I asked, for someone to come and take this out at the end, one young lady came and she took my blood pressure, I'd finished then, and I said 'are you going to take this?', 'no you'll have to wait for a nurse'.*

*Ruffine interview 1, line 571-581*

This description resembles a production line in which the patient goes through the motions of the appointment and is passed from one member of staff to another with little understanding of what each aspect of the appointment is for. Ruffine felt undervalued by those who were treating her and did not feel treated like a person as even basic introductions were overlooked. This is a stark contrast to the positive relationships with the treatment nurses that Ruffine portrayed in the previous section. A lack of suitable information and communication with patients could exacerbate the confusion experienced by patients; therefore a more personal relationship with HCPs may help to combat this. Another example of this was Rick's attempts at friendly communication with hospital staff:

*It seemed like they were photographing my eyes, there was a flash, I presume that was it. Because jokingly, I said what was that and I said well you could have said smile like you know and she looked at me as if I'm barmy....But then I went to, I think it was about 4 or 5 different places, which, well they know what they're doing. It's no use me arguing about it is it?*

*Rick interview 1, line 365-379*

It is evident that Rick did not have enough information to provide informed consent for this procedure. His lack of knowledge left him powerless and his only option was to adopt the role of submissive patient and go through with the tests. Rick attempted to make light of his confusion by joking with the hospital staff but the reaction Rick received only served to add to his anxiety and left Rick continuing to feel confused. Rick attempted to communicate with the hospital staff as part of a natural conversation attempting to turn the doctor-patient relationship into that of a friendship in order to even out the power imbalance he was experiencing. Elsewhere in the interviews Rick described an interaction from many years ago in which his doctor had advised him to take up smoking a pipe rather than cigarettes. He presented this relationship as one in which both parties were equal and his doctor was giving him advice which he could choose to take or not take. This is a stark contrast to Rick's relationship with the staff at the eye hospital in which he felt powerless as decisions about treatment were made for him rather than as part of a mutual discussion.

Despite the problems with appointments and communication there were some examples of more positive appointment experiences:

*[the ophthalmologist said] 'my name is Mr so and so, I'm pleased to meet you'. I said, 'well I'm not pleased to see you', like you know? And he laughed and we went in... He asked, 'are you taking your drugs?' And I said 'yes', I said 'morning and night', and he said, 'the morning ones' he said, you can take that twice', he said, and I said 'it says on the...', he says 'yes its quite all right, I know what it means', he said, 'it says morning and the other one is night time', he said 'well you can take it mid afternoon or within two hours of taking the night one', he said 'it won't do you any harm', and I said, 'oh', which is what I do now... but he was the only one that asked me if I was taking the drops funnily enough*

*Rick interview 2, line 812-834*

Rick felt more comfortable with this interaction as it felt more like his relationship with his old doctor (discussed above). Patients preferred appointments which exemplified balanced relationships, mutual respect, and professional friendship, leaving them empowered about decisions they could make about treatment.

#### **7.7.4 Information and communication**

It seemed that confusion could develop over time and communication with patients was sometimes slow resulting in unnecessary anxiety:

*... all I want = now is some contact from the hospital to say what's happening next, I mean that's, because I say it's, oh God, well last Monday, so it's been five days basically and I haven't heard a word yet from, from the [hospital][...]I mean there could be things they could be doing now to, to make sure that it doesn't deteriorate too quickly, but I don't know nothing, I don't know nothing apart from, we'll get in touch with you, that's all I know basically.*

*Nuxy interview 1, line 817-822*

As time passed Nuxy had experienced increasing anxiety as he realised he lacked information about what was happening within his own body. Nuxy dwelled on his situation and thought about the potential impact on his future. Knowledge was the only possible source of power and Nuxy's search and desire for information represented his attempt to regain control in a time of uncertainty.

Communication could also be affected by other age related factors. For example, hearing loss is a common occurrence in old age and can dramatically affect doctor-patient communication (Barnett, 2003). Rick's experiences highlighted the emotional impact this could have:

*I couldn't understand that doctor ... I couldn't understand her properly 'cause she's speaks too quick for me... I'm slightly hard of hearing in this ear and I must be slow at picking it up like that...I kept having to say, "Sorry could you repeat that". I don't like keep doing that to people. I think it's rude, well it's not rude, I can't help it. But I don't like doing that like you know, and she was getting annoyed with me. Wasn't she?*

*Rick interview 1, line 399-403*

Rick found himself in an uncomfortable situation where he desired information but at the same time did not want to create a nuisance of himself. Rick's embarrassment and perceived stigma affected his interpretation of his experience as he believed himself to be a bad patient who was frustrating his doctor.

Confusion often began prior to the first appointment as many of the participants commented on problems with hospital appointment letter. The letters gave little information about what each appointment was for and what the participant should expect. Each participant would undergo a scan every month to check if further Lucentis injections were required and would receive a letter inviting them to the scan and, if needed, a second letter inviting them for treatment. On many occasions these letters were sent together:

*when I read all this [in the letters]... I thought they've sent me all these [appointments] all at once, have they slipped up? Which one am I supposed to have? ... Because I know they do slip up at hospitals because at the orthopedic hospital, they sent me a, the follow up of what the scans going to be before I had and appointment for the scan! ((laughs))... I thought well this is ridiculous!*

*Ruffine interview 1, line 842-845*

Ruffine was confused by the number of appointment letters she received. Based on past experiences of hospital mistakes she had assumed this may also be a mistake. Ruffine was able to read these letters for herself; however other participants with poorer vision needed to rely on family members to relay the information. For example, Jordan relied on her daughters to read her letters, suggesting that this form of communication may not be the most suitable way to ensure information gets directly to patients.

#### **7.7.5 Results of treatment**

Treatment was ongoing for all of the participants and none suggested that they were aware of when their treatment cycle was likely to end. Treatment had become part of the routine of the participants' lives and they began to accept that more and more injections may be needed. Ruffine had been testing her eyes in order to assess the effects of treatment:

*I can't really say it's improved a lot, because when I look at the TV, I don't need my glasses for the TV, in fact I don't read a lot now because I can tell I need stronger glasses. But when I look at the TV without my glasses, if I close the bad eye I can see perfectly, if I close the good eye, I can see to a certain extent but I can't distinguish the features, the faces. So I know that I'll probably need more injections yes.*

*Ruffine interview 2, line 293-301*

Ruffine's testing indicated to her that her vision may be continuing to deteriorate. However, most participants reported some positive results of treatment. Irene seemed to experience the greatest improvements:

*the vision and everything, has gone a bit, quite a bit better you know? Quite good I've been quite pleased with it. The last fortnight I think there was [an appointment], and [the ophthalmologist] said,...'come and have a look at this now [Irene]', she'd got it on the laptop, and there was a line going down and there was a bump across, sort of enlarged bump like that, and she said, 'that's before and after', and there was just a slight little bump, and she said, 'we are very pleased with the way it's, you've responded to the treatment'. So I was very pleased with that, I could see that myself, and she was quite pleased with how its, 'you've responded to it, responded quite well', I said, 'yes I'm pleased with it as well'*

*Irene interview 2, line 297-313*

In comparison Jordan appeared to experience the least improvement following treatment:

*They gave me the injections like to get rid of that lump at the back of my eye. Which they have done, they said it's gone now, so you don't have to have no more treatment, and that's what I thought, if I've got to have no more treatment why didn't they put me straight onto glasses?*

*Jordan interview 2, line 688-692*

The most important aspects of AMD for patients were the day-to-day impacts of their condition and the improvements treatment may make to this. During their hospital appointments many were given indications of the clinical improvements treatment was having for them. Both Irene and Jordan had been told that the "lump" resulting from AMD had been reduced by treatment. Irene's daily experiences fitted well with the clinical changes that were described to her by her doctors. Irene had noticed slight changes in her day-to-day life, for example she could now see faces on photographs, read the clock on her mantle piece, and see the flowers in a neighbour's garden. The reduction of the lump on the scan therefore made sense to Irene as a visual indication of her improvements. Jordan's experiences were very different as the doctors seemed pleased that she had shown clinical improvements to the point where she was no longer to have further treatment. However, Jordan had not experienced these improvements in her day-to-day life and struggled to understand how her treatment could have been a "success". Jordan concluded that her failure to experience the success herself must be a result of incorrectly prescribed glasses. Jordan continued to be frustrated and confused by whether the prescription was the responsibility of the hospital or her high street optician.

## 7.8 The future with AMD

The participants were asked to discuss their thoughts about the future. All of the participants highlighted a sense of uncertainty and some described fear of further deterioration and the loss of activities they enjoyed. Others spoke of hope that treatment may improve their vision and approached thoughts about the future with attempts to accept their circumstances.

### 7.8.1 Hope

At the time of the first interview Rose spoke about hope that she would see improvements in her vision following treatment:

*Amy: So what do you think you're eyesight will be like in the future? Do you think things will change?*

*Rose: Well I'm hoping so because [the ophthalmologist] said that they should go back to what they were normally so I'm hoping.*

*Rose interview 1, line 1113-1118*

However, by the second interview Rose had not experienced the improvements she had hoped for and this increased the uncertainty she felt about her future. In order to make sense of and cope with this Rose reassessed her priorities and instead focused her hopes on maintaining the vision she had:

*Amy: ... what do you think your vision is going to be like in the future?*

*Rose: Well, I don't really know, I hope that it's going to be better, but I can't see that, but as long as they are giving me the injections and that's supposed to stop you from going blind, so I'm hoping that it's going to be all right.*

*Rose interview 2, line 653-657*

For Rose vision impairment seems to be a 'black and white' construct in which you are either sighted or go blind. In reality, vision impairment works on a continuum from perfect vision to complete blindness. It seems that Rose may assume that if the injections fail then there will be nothing preventing her from complete blindness. This again illustrates the need for clearer communication with patients to enable them to develop realistic expectations about their prognosis and avoid unnecessary distress.

### 7.8.2 Acceptance

Other participants made sense of their future by accepting their visual impairment as part of life and the ageing process:

*we all want something that we can't have, so I suppose on the whole and it would have been nice if my eyesight had stayed ok, but I can't do anything about it, so, eventually you, well I don't know whether you grow to accept it, but you learn that it*

*can't be, and you can never accept it because you think why me? It's only human, and you say why me? But that's it, that's life.*

*Alison interview 2, line 1179-1187*

Alison looked at her situation as something she was powerless to change and while she could question it and become upset about it she could not resolve it. In this sense, Alison drew on the perception of humans as fallible imperfect creatures in order to justify her disappointment about her situation. As everyone ages they come across challenges and changes that are out of their control and they can either dwell on them or accept them. Alison had already dealt with the most difficult change in her life when she lost her husband and frequently referred to a wish that he was still with her. In comparison to the loss of her husband, her diagnosis with AMD was just another part of life that she needed to accept. This highlights the ability of in-depth data like this to put experiences into perspective within entire life contexts.

Rick was also accepting of his condition and made sense of it in terms of the progression of his life. Rick focused on his past experience as achieving life goals which could be ticked off his list. Having met all of his goals Rick seemed to have come to terms with his mortality and any deteriorating health which came with old age:

*I'm not a pessimist and I'm not an optimist, with my age, come on, with my age every day is a bonus isn't it? ...to be quite frank if the Dr come and said, 'sorry, you won't be here tomorrow night', I'd say, 'it's a bit of bad luck but I've had a good life and that's it'. I've had a good life and I've worked hard all my life and I've had a good wife and I've got a good family and I don't owe anybody a penny so, you know?*

*Rick interview 2, line 848-862*

Rick drew on the 'good innings' metaphor in order to make sense of his experience with AMD. He felt he had achieved all the goals he needed to have had a 'good life' and was therefore ready for death when the time came. The issue of mortality was highlighted again in Rick's third interview when he offered advice about treatment:

*Just don't worry about it and accept the treatment because if you don't you are not going to get any better are you? There is nothing you can do about it is there like that? Nothing you can do about it, same as death if you are ready to go you are ready to go, I know I'm morbid, if you are ready to go you are ready to go*

*Rick interview 3, line 697-702*

Rick was happy about the way treatment had allowed him to maintain his vision and make the most of the years he had left. Rick's knowledge about his past experiences and his impending death gave him perspective on his life. Rick was happy with how his life had progressed and all he had achieved. For example, elsewhere in the interview Rick described his past

experiences of winning international dancing competitions with his wife and, like Alison; he felt he had already lost the most important element of his life when his wife died. The best days of Rick's life had been in his younger years when he was married, working, and caring for his children and now that these days were over and he was experiencing increasing mobility problems and ill health he seemed content with coming to the end of his life.

### 7.8.3 Changing thoughts about the future

Nuxy was the most willing to discuss the potential for further deterioration and his approach to this seemed to change across the interviews. In the first interview Nuxy seemed to be mentally preparing himself for the possibility that his vision would get worse 'I can't see it getting better, no, not the way it is now' (Interview 1). When Nuxy was diagnosed he remembered being made aware of the nature of the condition and during his first interview was attempting to come to terms with this. By the second interview Nuxy seemed to re-assess his future and was keen to be grateful for the health he still had and the life he had left:

*It isn't going to bother me, it won't bother me now. Very little grumbles me, ((laughs)) I think that's the way to think, you worry about, worrying about what the future is. There's I'll give you an example, there's a woman comes, she's the president of our club, and she's had one or two little problems in the last 6 months, she had a slight stroke, which, I've had a heart attack, I had two heart attacks, and she had a problem with summit on her heart, that's to me it was just part of like. And Monday night she said to her husband, 'I'm going to bed, I feel a bit tired' and never woke up, 63, you know so? Worrying about next year, you don't do that I don't anyway I just worry about tomorrow... I think if you worry, it makes it worse to be quite honest, you start to go down and so look on the bright side ((laughs))*

Nuxy interview 2, line 595-612

The experience of the sudden death of a friend had caused Nuxy to reassess his priorities and prompted Nuxy to consider his own mortality. The woman had no warning other than earlier heart attacks (which Nuxy himself has experienced) and her death was therefore very sudden. Nuxy had a responsibility to make the most of the life he had left and AMD no longer seemed to be a major concern. By focusing on one day at a time Nuxy developed a life strategy to remain positive and not dwell on his future. In this way Nuxy was working out how to live in the context of being faced with his own mortality and his body breaking down, but his increasing difficulties with co morbidities often challenged this resolve:

*you do worry, deep down you do worry in case it gets worse so it seems to be all right at the moment, I've had it 12 months so, it hasn't got any worse so... deep down yeah, occasionally it comes up you know? Especially if you are having difficulty reading or whatever you are doing and then you, then you start to worry but normally I don't, I don't worry at all.*

Nuxy interview 2, line 691-702

Despite being determined to value the time he had left in life latent worries occasionally surfaced. When usual taken for granted activities posed difficulties, Nuxy was reminded of his condition and the potential deterioration it posed. Without vision Nuxy's ability to value his existence would be much more challenging and this caused ongoing concern. By the third interview Nuxy's health had deteriorated and AMD was no longer his primary health concern. Nuxy had reprioritised and instead worried about his ability to breathe:

*[the future] wouldn't worry you so much if that was all you'd got to worry about my eyesight, but, I can cope with that, it's the breathing and the mobility bit that really annoys me sometimes, yeah.*

*Nuxy interview 3, line 814-816*

Alongside living with AMD all of the participants were trying to come to terms with their ageing bodies and in some cases deteriorating health. The participants talked about physical and mobility problems, feeling tired and reduced independence resulting from their ageing bodies. It was these ageing bodies that often posed the greatest challenge to the participants' perceptions of their future.

## **7.9 Summary**

These themes have highlighted the experiences of older people with treatable wet AMD. It is evident that the participants drew on a variety of factors in order to make sense of their experiences. The participants frequently tried to understand their experiences in terms of the context of their past, present and potential future lives. The realisation of visual impairment was experienced alongside other factors relating to the ageing bodies of the participants and many struggled to maintain the continuity that their lives once had in the face of new difficulties. As a result this frequently challenged their sense of self. While for some the prospect of treatment represented hope and improvement in vision, for others treatment was an unwelcome intrusion in their lives which failed to improve their quality of life. Treatment and interactions with the hospital could be an anxiety provoking and distressing time for the participants, the stress of which was often heightened by the perception of poor communication and information provision by health care professionals. Treatment commitments and increasing difficulties with day-to-day tasks also represented a source of increasing dependence on others which many of the participants struggled to come to terms with. The next chapter introduces patients whose AMD has developed past the point of treatment. These patients have been living for longer with AMD and have no prospect for their vision improving in the future.

## Chapter 8: Advanced Untreatable AMD

### 8.1 Introduction

This chapter discusses the experiences of three participants who were all living with advanced wet AMD. These participants had been living with AMD for the longest amount of time, had the greatest level of visual deterioration and were unable to be treated for the condition.

### 8.2 Research Question

What is it like to live with advanced untreatable AMD?

### 8.3 Method

The method for the data collection and analysis for this chapter has been described in chapter 5.

### 8.4 Themes

The table below provides an overview of the four key themes to be discussed in this chapter.

Table 13: Advanced Wet AMD Theme Table

Theme	Example
Making sense of diagnosis	<i>...the next day I bought the paper, and I couldn't read it!</i> (Jessie interview 1)
	<i>I've also got cataracts developing, I don't think they are at a very far stage and the thought is, and I agree with that, leave well alone at the moment</i> (Hermione interview 1)
	<i>I thought it, I thought it was cancer at first and I wouldn't say the word. I said tell me it's not, what do you think it is.... They just looked at me and said nothing.</i> (Mary interview 1)
	<i>I asked my optician last time, and I did say what specifically does this big change mean? Because it's very difficult to do, for an ordinary person to know.</i> (Hermione interview 2)
Getting on with life	<i>I am conscious of where I'm walking, curbs and things like that,</i> (Jessie interview 2)
	<i>I've got a fairly tidy mind and very untidy hands.</i> (Hermione interview 1)
	<i>I try and go out I think that's, that will keep me going more than you know?</i> (Jessie interview 1)
	<i>It's a nuisance, but I wish I didn't have it, but it's there, and I've got to deal with it.</i> (Hermione interview 3)
Rejecting disability	<i>She [lady from social services] said to me, she said, 'well', she said, 'I'd like to measure you, standing up, for your white stick', and I said 'I don't want a white stick!'</i> (Jessie interview 2)

**The future with AMD**

*It made me feel better to know that [I wouldn't become blind], because you know I could tolerate this, I don't think you ever get used to it... (Mary interview 2)*

## 8.5 Making sense of diagnosis

Diagnosis with AMD can be a confusing experience. This theme highlights the ways in which the participants, like those in the previous chapters, struggled to make sense of their diagnosis.

### 8.5.1 Realisation

Like the participants with treatable wet AMD these three women highlighted moments of realisation which led them to acknowledge that their vision had deteriorated. Jessie and Mary describe these as sudden, bewildering and confusing experiences. For example, Jessie described an incident when her ability to read seemed to have deteriorated from one day to the next:

*I always used to remember, I was at the dance club, and the thing, they was having a do like, [inaudible speech] menu, and I read it, and I thought 'oh, that's alright' and as a matter of fact the lady next to me said, 'oh you are better than me', she said, 'I can't see it' you know? And I read it and I thought, 'oh' and I was alright, but the next day I bought the paper, and I couldn't read it!*

*Jessie interview 1, line 393-398*

Jessie's mixed up account, with quick short and sharp speech (including the inaudible section) suggests she was continuing to struggle to piece together and make sense of her sudden deterioration. Jessie's shocked tone (evident in her exclamation of "oh") suggested that it was taking time to come to terms with her condition and suggests that she was still surprised at the sudden and unexpected changes she had experienced. Mary's visual impairment was also described as coming on very suddenly:

*Yes, I say about three weeks ago, yes. I was sitting watching [TV] one night and I felt this haze come over my eye and I was cleaning my glasses and it persisted and that's when I decided, "oh I need new glasses", that's the trouble. And I went, on spec, I didn't intend to go, I kept putting it off going, you know, about three weeks. And I thought I was going on the day, my daughter said "well you go and do it", and when I got out at [neighbourhood], by [street], you don't know it in [town] do you? No, no, it's a big main street, and I thought I will go. And I went round the corner and booked a, went in and seen them and they seen to my eyes and they sent me straight to the hospital.*

*Mary interview 1, line 1047-1059*

Mary described hesitance about making an appointment with her optician and there are two possible reasons for this. Firstly, as an older person, attending the optician and being prescribed new glasses was probably part of Mary's routine and therefore a change in vision

alone was not enough to prompt her to seek emergency assistance. Secondly, the haze was an unusual physical sensation which Mary had not experienced before; it is possible that she was putting off an appointment for fear that this unexpected change may be something more serious than the need for a new prescription. For Mary personal experience was not enough and it was only after a prompt from her daughter that she took action. This may be the case for many older people experiencing AMD who may attribute their changing vision to a 'normal' part of ageing and therefore leaving them at risk of further deterioration due to not seeking help soon enough. Had Mary been more aware of the risk of the condition she may have had a higher motivation to attend her optician and be diagnosed; in turn resulting in earlier treatment and slower progression of visual deterioration.

In comparison, Hermione's moment of realisation came some time after she had already begun to make adjustments due to her deteriorating vision. Hermione described an incident where her husband was able to see things which she could not:

*It was really brought home to me one day we were out [driving] and [husband] said, 'oh horses!' and I said, 'I can't see any horses!' and it was a day much like this, a little bit less than this and there were a couple of riders riding side by side, which was naughty, and the rumps of the horses, I just couldn't see, they faded into the distance, and I [thought], 'oh heavens' and I had stopped driving then but I realised somehow how limited it is really.*

*Hermione interview 2, line 972-980*

Hermione explained that, at the time of the incident, she had already been wearing glasses for many years and had chosen to stop driving. Unlike Mary, small changes in Hermione's day-to-day experience had therefore been enough to prompt action and behaviour change to some extent. However these changes were perhaps unconscious until Hermione's concrete experience in which she was unable to see the horses. This experience helped Hermione reflect on the build up of small difficulties she had experienced and help her to make sense of and realise the full the extent of her visual limitations. This moment seemed to be a turning point for Hermione which confirmed and legitimated her decision to stop driving but also reminded her of the risk she would have been in had she continued to drive. It is only clear memories of incidents like this that made Hermione fully conscious of the level of her impairment. Had the horses not been pointed out to her, knowledge of her deterioration, like the horses rumps could have faded into the background.

This realisation of vision loss may have been less bewildering for Hermione than for the other participants (for example when compared with the confusion experienced by Jessie when she suddenly discovered that she was unable to read something she had been able to read the day before) due to Hermione's knowledge of her mother's experience with vision loss:

*You don't know how you are going to be like that I only know how my mum was, she managed wonderfully well but reading she couldn't do but she did love, sewing she couldn't do, so you know, it's following that pattern so, but otherwise she did manage but then she didn't go out very much and I'd still like to go out quite a bit so I might have to rely on people bit more or I might have to be content to be not out so much, so until it happens I don't really know.*

*Hermione Interview 3, line 350-360*

Hermione's memory of her mother's experiences became her frame of reference for her own future with AMD. This may have been particularly important as her moments of realisation seemed to mirror the changes she had witnessed in her mother. Hermione's memories of her mother perhaps provided motivation for the way she conducted her own life. For example she remembered her mother as being content to stay at home while Hermione herself chose to get out of her home and remain active. Hermione's recollections of her mother's limited lifestyle perhaps heightened the level of value she saw in her own vision and these clear expectations about how her AMD might progress enabled her to make daily decisions about how to conduct her life. However, Hermione was aware of the progressive nature of her condition and presented her future as less certain. Concerns about how she would manage further deterioration when it occurred were a constant shadow over her. Hermione's comments about struggling to complete activities she had previously been able to manage, for example spilling tea when pouring it into her cup, were concrete examples of her vision beginning to deteriorate further. In the immediate moment Hermione expected to be able to complete these activities easily but when she took time to reflect on these difficulties her struggles with simple tasks perhaps represented warning signals about a future in which she would be no longer able to manage with her vision impairment.

### **8.5.2 Co-morbidities**

The women experienced other health problems alongside their AMD. Jessie and Hermione had both been diagnosed with cataracts and considered the ways in which this may have affected their vision. For example, Hermione explained her diagnosis:

*This one went wet immediately, I understand from [the ophthalmologist], and so I have a little peripheral vision in this one, and over the time this one has deteriorated, it's remained dry so far, but I've also got cataracts developing, I don't think they are at a very far stage and the thought is, and I agree with that, leave well alone at the moment, because of the, although it's a very common op nowadays and people don't think two things about it, they've always got a risk and I don't want to lose what I still have in this one, I've got a little peripheral in that, and I could probably blunder about the house ok, but doing anything close, I'd have great difficulty.*

*Hermione interview 1, line 106-102*

Hermione had lived with wet AMD for many years and her 'good' eye also had dry AMD and a developing cataract. Hermione had witnessed her mother being given cataract operations which she perceived to have made no difference to her Mother's vision and it is likely that this helped her to accept the advice given by her ophthalmologist to avoid the operation. Jessie was also prepared to trust the ophthalmologist who suggested that the risks of the operation outweighed the potential benefits, '*I said, 'well, I'll go with your advice', he said, 'leave well alone', he said, 'you've got enough to manage' you know? 'You're managing'*' (Jessie T2, Line 502-505). Both women described building up a trusting relationship with their ophthalmologist and spoke highly of health care professionals, often praising the care they had received. These positive relationships meant the women appeared happy to draw on the information given in appointments in order to make sense of their diagnosis and treatment decisions. Both women seemed content that they could manage with their current level of impairment and the operation represented a potential threat to be avoided. Hermione was aware of the progressive nature of both AMD and cataracts, and this perhaps challenged her resolve to remain independent and highlighted the possibility of becoming the 'blundering' woman she described. Her allusion to the cataract being not at a far stage at present suggests she had perhaps been considering what her life may be like if her cataract progressed. In comparison, Jessie seemed less aware of the potential deterioration she may face in the future and was living in the present. Jessie was content as long as she was able to manage and was happy to leave things as they were and passively place herself in the hands of the hospital staff.

### **8.5.3 Information Exchange**

Consultations between health care professionals and the participants took the form of an information exchange. Participants gave information in terms of vision tests, scans, and medical histories and in return they were given information about their diagnosis and treatment. Although the information given to patients was likely to have been very similar for each participant the way in which this information was understood and made sense of differed depending on each individuals' circumstances. Mary's interaction with her opticians and the hospital staff at the time of diagnosis was an example of the confusion which could occur as a result of poorly communicated information:

*I thought it, I thought it was cancer at first and I wouldn't say the word. I said "tell me its not--, what do you think it is?" This was to the three opticians and they wouldn't answer. They just looked at me and said nothing. And I felt, but when I said to this doctor I could tell... he must have knew, I was so frightened and he knew what I was thinking because he said it's not what you're thinking. And I was pleased about that.*

*Mary interview 1, line 1165-1173*

The assumption about cancer is understandable given the numerous experiences with cancer Mary had faced (her husband, sister and daughter had all had cancer). The silence of the three opticians served to add to her concerns and this seemingly unprofessional behaviour highlights the possible need for improved training for opticians when dealing with patients receiving emergency referrals as Mary's interpretations of the opticians' behaviour increased her level of distress. Mary's fear was exemplified in her struggle to articulate the word 'cancer', perhaps believing that by saying the word out loud cancer would suddenly become real and overwhelm her. Even during the interviews with me Mary avoided the word 'cancer', only when prompted did she refer to it directly by name. It seemed reassurances from HCP's had done little to relieve Mary's fears about cancer and this intense fear had shaped her interpretations of the interaction with the HCPs at the hospital. Mary did not say the HCPs had mentioned cancer, but their suggestion that it was "not what you think" had been interpreted by her to mean that they had understood her fear. It is far more likely that the HCPs had assumed Mary had been fearful of losing her sight altogether. This situation indicates a need for clear unambiguous communication between patients and HCPs. Even after the consultation Mary remained fearful and uncertain about what was happening to her and this became increasingly evident at her second interview in which Mary explained the three months of hell she went through following her initial diagnosis:

*The [first] three months was hell until I went again, because I thought that I'd had a brain hemorrhage. You know because it was, it must have been massive for it to go across, from what the Dr said. It was absolutely massive, they've got a way of dissolving and it did but it's done the damage, you know with the eye so?*

*Mary interview 2, line 359-365*

By the second interview the blood clot (haemorrhage) which had been detected by the opticians and doctors at her first appointment had dispersed leaving her with macular scarring and no improvement in vision. Mary's understanding of the size of the clot had played an important role in shaping her understanding of the severity of the condition and resulted in her experiencing a living hell and each day fearing that she would have a brain haemorrhage. Mary's experience of being rushed into the hospital accident and emergency had left her with the belief that the condition she had was very serious and could potentially kill her (she had repeatedly asked in the first interview if her condition was serious and whether it was 'a killer'). It seemed the unexpected dispersal of the haemorrhage by her second interview eased these concerns. And had she known at diagnosis that these clots had a 'habit' of dispersing and that she was not facing a threat to her life perhaps she would not have felt she had lived through hell for three months.

Perceptions of information provision seemed to vary across the participants accounts. While all described being given information verbally some also referred to the provision of information leaflets:

*H: I'm trying to think about all the various things I've had done, it's, it's the seeing part of the iris isn't it? What did? How did [the ophthalmologist] describe it to me? And I've seen photographs of it... And it looks really like a black blob, the blood vessels seem to be increased and it takes the sight. I'm not absolutely sure but I have got some leaflets, I haven't read them for ages ((laughs))*

*A: ((Laughs))*

*H: I'm just trying to get on with it and not worry about it.*

*Hermione interview 1, line 162-170*

Hermione drew together her appointment experience and the medical information available to her in order to construct her description of the condition. This understanding was based on past experience which she had not recently sought to revise and her final statement about getting on and not worrying perhaps explains why she had not read the leaflets recently. The leaflets were likely to highlight the progressive nature of the condition and perhaps hinted at the future deterioration and potential dependence. Consideration of this information could cause distress and by choosing to avoid this information Hermione was able to protect herself from this. It is concerning that patients are given information leaflets when the nature of their condition means that information in this format may be difficult for patients to access. Information leaflets require a conscious effort to sit down, perhaps with a magnifier, and attend to the information. Various barriers to this behaviour are likely to exist including lack of time, poor lighting, poor literacy, etc. Reading may also represent a frustrating experience which reminded patients of activities they could no longer pursue. For example, Jessie had not taken the time to sit down and look at the information leaflets which had been provided by the hospital and collected for her by her granddaughter as she had begun reading as hobby following retirement but was soon unable to read due to visual deterioration. These experiences reflect an imbalance in the information exchange between health care professionals and patients which may be addressed by finding new ways to provide information about AMD in order to help to manage patients' fears and uncertainty about the future.

#### **8.5.4 The 'big change'**

Uncertainty about changes in vision prevailed in the accounts of all three women. This was enhanced by the knowledge of clinical changes in their condition which were evident to the HCPs but not felt by the participants in their own bodily experiences. One example of this was

explained by Mary who had been told that the blood clot behind her retina had dissolved between the first and second interview:

*... the next time I went, it'd gone, it'd dissolved, but I thought, well why didn't I feel it dissolve? So I was wondering about that you know? I suppose it just, it's badly scarred they said, it's very badly scarred underneath, I know I'll never be able, but at least I can see a bit, some people can't anyway.*

*Mary interview 2, line 1007-1016*

Mary had a life's worth of embodied knowledge and felt that she should know it better than anyone else. Therefore, Mary felt she should have the skills to detect major changes in her body but explained that the doctors were able to tell her things that were happening in her body which she had no physical sensation of. For example, Mary seemed unaware that it was possible for the clot to dissolve and struggled to understand why there had been no physical sensation of the clot dissolving as there had been of it forming (the haze). It is understandable that Mary was unable to detect these changes but to her it felt like she had lost touch with her body. Any potential positivity Mary may have felt about the dispersal of the clot was tainted by the scarring it left behind. Mary attempted to raise her spirits by being grateful for her remaining vision and used social comparison as a form of defence strategy to make her feel better about her situation, however this attempt did not appear to be successful suggesting she may have been attempting to externally present herself as being positive while internally she was struggling.

The women believed they were expected to take responsibility for recognising 'big changes' in their vision which may indicate any serious progression of their condition. This responsibility caused anxiety for the women who were uncertain that they would be able to recognise any 'big change':

*A: You said, you, had a number to call if you notice any big change. What kind of big change do they mean?*

*H: Well, this is right, this is what puzzles me very much, and then [the ophthalmologist] said you would very soon know if anything changes, so I asked my optician last time, and I did say what specifically does this big change mean? Because it's very difficult to do, for an ordinary person to know, and he said for one thing your reading would go very quickly, that would happen, and I know you've got to, you've got about three weeks or something haven't you to do something about this drastic change. But you know, this is what I wonder, would you know quickly enough? And you can't sort of, when ring somebody and say, I think it's not very good today, what do I do? ((laughs)) So I did ask that specific question again last time I saw him.*

*A: So you don't know exactly?*

H: *I don't know exactly no, no, not at all. I mean it's fine isn't it, for someone to say to you, well you would notice a change because= but you can't be sure.*

A: *No.*

H: *I'm not sure what I'm looking for! I mean obviously if I suddenly couldn't see or some dramatic change, but would it be as dramatic as that? You know, you ask yourself the question. So we will see, I hope not ((laughs))*

*Hermione interview 2, line 790-814*

Hermione saw herself as an 'ordinary person' in relation to the ophthalmologists who were the experts. However, when she sought expert advice to prepare herself for the 'big change', she found the explanations did not give her the information she needed. Hermione trusted the advice of the ophthalmologists and was keen to be a good patient (i.e. she did not want to make a nuisance of herself by ringing the help line each time she witnessed a small change), but at the same time she did not want to miss the 'three week' window for treatment. This is similar to the experiences of Cathleen presented in chapter 5. Given the loss of vision in her first eye as a result of not seeking help quickly enough Hermione was understandably anxious about missing the signs of deterioration in her second eye. By the time of the 'dramatic change' (she described seeing 'distorted lampposts' which alerted her to this) in her first eye Hermione's vision was already unsalvageable and she was clearly struggling to reconcile this issue. Hermione did not know what to look for in her changing vision and became increasingly emotional about this uncertainty, building up to the exclamation 'I'm not sure what I'm looking for!'. Following this potentially cathartic outburst Hermione returned to her accepting and stoical approach ('we will see') again accepting her powerlessness and avoiding distressing herself by dwelling on what may happen in the future. While identifying a 'big change' may seem a simple instruction for ophthalmologists to give to patients the reality of identifying this 'big change' may be extremely difficult. Patients, like Hermione, are expected to take control of their diagnosis and be confident in their identification of this 'big change'. However they may not be confident in their abilities to identify these types of changes in vision and this type of direction by ophthalmologists may be unknowingly placing too much responsibility on patients.

## **8.6 Getting on with life**

### **8.6.1 Encountering difficulties**

All three women described some parts of their lives which had become increasingly difficult with the onset of AMD. For example, they described difficulties with sewing, gardening, facial recognition, and mobility. Jessie and Hermione both described their experiences of shopping

and highlighted ways in which an activity which was once regarded as a hobby had become a functional necessity:

*... what I do find difficulty in, if I'm in somewhere like M&S or wherever, one of the bigger stores, [is] seeing sizes clearly. But matching, I can match colours reasonably well, I find on the whole, and I can generally speaking carry a colour reasonably well in my mind so that's not too bad, and at home I know what I've got so I know what goes with what ((laughs)) I don't get the same, I can't go on looking for clothes as I used to be able to at one time, you know, I've done a bit of shopping and that's enough.*

*Hermione interview 1, line 608-614*

*... the pleasure's gone, the pleasure has gone out of that, the pleasure has gone out of clothes shopping, yeah.*

*Jessie interview 1, line 8833-835*

Both women struggled to read sizes and pricing and as a result the activity of shopping required much more concentration and effort than it had previously. These are examples of the way in which an activity which was enjoyable had now become purely functional. Hermione attempted to adapt to this change by altering her perception of her identity from someone who enjoyed shopping to someone who was happier doing a short shop and taking things home to try on. One behaviour change which facilitated this adaptation was memorising the colours of the clothing she owned and choosing items she felt would match. Jessie was more direct in describing her experience and explained that shopping was a hobby from which the “pleasure” had been lost as a result of AMD. Rather than finding new ways to continue with shopping, as Hermione had done, Jessie had instead adapted by choosing to stop clothes shopping and avoid the frustrations (such as the inability to read the prices and sizes on labels) it brought. Changes in the experience of shopping represent an indirect loss which had resulted from visual deterioration. Both women were physically capable of going on a shopping trip but their deterioration in vision meant the frustration resulting from their shopping experiences meant they had to change the way they approached this activity.

Another difficulty acknowledged was related to mobility. All three women discussed mobility difficulties experienced when in unfamiliar surroundings such as walking in public streets or in cafes:

*... I was out for a coffee somewhere in a public place and they had, it was so funny, they had a change of carpet part way through and there was a big broad band in the carpet and I had no idea that it wasn't a step so walking through across the carpet of course I was sort of [mimes attempting to climb a step] and it is the silly things, things like that, then you realise, 'oh gosh this is a nuisance'*

*Hermione interview 1, line 498-504*

AMD only affects the central vision which means individuals are still able to get around using peripheral vision but may be unaware of obstacles in front of them. In this example Hermione was attempting to climb a step which was not there which was a problem that Hermione had not yet been able to actively adapt to. In the absence of making adaptations Hermione used humour in her presentation of the experience. By making light of these 'silly things' she found an alternative way to cope with the impact they were having on her day-to-day life. How she was viewed by others was very important to Hermione (discussed further later) and as this incident occurred in a public place outside of her home Hermione would have been conscious of other people being able to see her attempts to climb the 'step'. Humour was a strategy that Hermione could use to deal with the embarrassment of these experiences while maintaining her 'public image' and sense of self.

Jessie and Mary both described experiences which had already caused them to be cautious when walking around in public places. Jessie had experienced a serious fall while running for a bus which resulted in a long stay in hospital while Mary had been knocked down by a car when crossing the road. For these participants AMD represented an additional risk factor to an already anxiety provoking activity. Both Jessie and Mary explained that they spent much of the time watching the ground to ensure they didn't fall and all three women expressed concerns about crossing the road:

*...I've never realised my eyes are so precious but it's made me more careful if I go out now.*

*Mary interview 1, line 9 - 10*

*I don't go walking out like I used to. I am conscious of where I'm walking, curbs and things like that, that's the main thing, and little man holes and things like that, that, as I walk along I'm sort of, you are part looking on the floor all the time*

*Jessie interview 2, line 255-259*

The development of AMD combined with past experiences of falls and accidents had altered the way in which these women made sense of their surroundings; the outside world no longer represented freedom and a chance to explore but was instead a world of hazards and potential dangers.

## 8.6.2 Discrepancies between body and mind

Getting on with life was a challenge and the women discussed situations in which they felt that their body was unable to keep up with the capabilities of their mind. For example, Hermione felt that everything was “slowing down” as a result of her mind working faster than her eyes:

*I think I'm slow at doing everything, because when I am looking around my sight doesn't seem to be, move as fast as I do, do you know what I mean, and I've got a fairly tidy mind and very untidy hands, so I can put things down anywhere when I am working and finding them is a bind, whereas you could go into a room you know? Our rooms are quite small, you glance round and you'd see whatever you were looking for, I go in and I have to look in detail now, so things like that, that it impacts on everything, in the kitchen I keep a magnifying glass, so that if I'm cooking or reading a you know? Pack of anything, my magnifying glass is to hand, and I do find that, although I've got these ordinary reading glasses I do find the magnifier you know? Quickens up what I'm doing, otherwise, you know squinting.*

*Hermione interview 1, line 175-180*

Hermione experienced a disparity between the capabilities of her mind and the physical abilities of her body. We experience the world we live in through our bodies and while Hermione was keen to get things done quickly her body had become a barrier to her achieving her goals. Hermione's body had become separated from her “self” and seemed alien to her, as was evident in the suggestion that her mind was tidy while her hands were not. This is an example of a previously taken for granted bodily experience becoming something which now required conscious consideration. As Hermione's vision was unable to keep up with her mind, in turn her body was unable to keep up with her vision. Similar reports of dissonance between body and mind and the need to consciously consider previously taken for granted actions can be found in the literature for other degenerative conditions. In particular this issue has been highlighted for individuals with Parkinson's disease (Bramley and Eatough, 2007) and the way in which individuals make sense of this dissonance can have important implications for their ongoing management of and ability to cope with the impacts of the condition.

Discrepancies between body and mind are examples of the way in which these women were no longer able to trust their vision in the way they once had. Deterioration resulted in their visual perceptions of the world often being distorted and untrustworthy. The most extreme example of this is the experience of Charles Bonnet Syndrome (CBS; a side effect of AMD where a patient sees things, i.e. furniture or people, which aren't really there). Mary was the only one of the three women to describe experiencing CBS:

*M: Sometimes, Amy, I imagine I can see things, but I read that about it, that sometimes that you imagine, I would say it's like me sometimes, I've thought I've seen a piece of furniture there and when I've looked again it's not, it's just it's, imagination or your eyes or what.*

*A: So what do you think when you see things like that?*

*M: What can I say to that Amy? In the, you look again and you are alright, because you look twice and it's gone, it's just this, I get, I suppose it comes, but you are imagining things and [inaudible] I've looked over there and thought it was a piece of furniture and it isn't ((laughs)) and I looked again at it. But I suppose I've got to put up with this now for the rest of my life. I don't think it's a killing thing this is it Amy?*

*Mary interview 1, line 341-358*

Mary's experiences of CBS were confusing for her, in particular when her experiences meant she could not trust her own eyesight. Mary was unsure whether the images were caused by her imagination, her eyes, or 'what'. Visions such as these may be particularly concerning for an older person as they may be misconstrued by others as a symptom of dementia or other causes of mental decline. Following her statement about imagining she could see things Mary was quick to point out that she had read about this experience in others and make a link between the visions and her AMD in addition to asserting that she was aware of the imaginary nature of these images. Mary may have been concerned that I would not be aware of CBS and therefore may judge her negatively for her admission of seeing things that weren't there. Mary was understandably fearful of the world given that she was no longer able to trust her visual perceptions, and this fits with the fearful persona she presented throughout her interviews. In this instance, to counter the distress that this thought may cause, Mary returned to a more comforting element of her understanding that AMD was not a killer. Mary's question at the end of this extract hinted that she still had concerns that AMD may be life threatening. Mary seemed prepared to live with the inconvenience of CBS in exchange for continuing to live her life.

These women were not experiencing AMD in isolation and many of the changes they were coming to terms with were also related to their ageing bodies. Hermione and Jessie both referred to the ways in which their bodies were slowing down and assigned many of the changes they were experiencing to their ageing bodies rather than to and restrictions resulting from AMD;

*I find it really in the main, much the same as always but slower. But that you know, I really can't put that all down if I'm honest to Macular-D, I think it's just being that little bit older, and having a bit of pain you know with various bits and bobs, but against that, I look at it overall and you know and look all the way round at different people my age and era and I think well on the whole I'm fairly lucky. And I find thinking like that helps you along no end really, and I'm lucky enough, I've got a*

*lovely husband and I think you've got to think of all of these things and accept this as part of me now really, annoying, but a part of me really.*

*Hermione interview 2, line 569-584*

*Well, I don't say I'm limited in time doing things around the house, you know, because I've always been here, there, and everywhere. Obviously with my age I have to slow down, but I don't find in my own mind that I've got any difficulty.*

*Jessie interview 2, line 72-75*

Hermione and Jessie found it easier to incorporate some of these changes into a narrative of ageing rather than one of 'disease' associated with AMD. By associating these changes with old age these women may be able to 'normalise' their experiences and reduce the distress they caused. In current western society young people are often caught up in busy lives filled with responsibilities such as work and with retirement individuals are usually given the opportunity to relax and take life at a slower pace. While this slower pace may at first be a choice, when the body begins to deteriorate it becomes more of a necessity. Older people are often forced to slow down even on occasions when this may not be what they actually want to do. By finding a new way to make sense of these changes these women may be able to adapt more easily to incorporating them into the sense of 'self'. In this way rather than being someone suffering from a 'disease' they are instead experiencing natural changes of women who are getting older. If issues and difficulties are associated with shared changes with their peers this helps the women to retain a sense of who they are as proud and independent women. In discussions with me, as a younger woman, the participants may have felt the need to remind me of their capabilities to remain independent and therefore chose to reiterate that they did not have any difficulties which were preventing them from living their life. These assertions may also be attempts to retain independence. The loss of this physical independence which had always been taken for granted would be devastating. In particular Jessie's assertion that difficulties had not yet taken hold in her 'own mind' may have helped her to maintain a sense of this independence.

### **8.6.3 Adaptation**

In some circumstances the women described attempts to adapt to problems in order to continue getting on with life. For example a common problem seemed to be the frustration associated with being unable to recognise the faces of friends and acquaintances. Hermione presented some strategies she used when attending parties:

*... in a party atmosphere of course, you can't see people until you get near to them so I've got to be (.) walk across if I think it's someone, if I know them well I can tell if they are moving or if they are walking, I can tell that, friends coming along towards me up the road, I know because of the way they walk, and otherwise I*

*can't see their face until they are close to me, so I haven't found any difficulty in that, but I certainly haven't stopped going! [Laughs]*

*Hermione interview 1, line 20-25*

Hermione described active strategies to remain socially engaged (i.e. moving closer to people at parties or focussing on body movements rather than facial features in order to recognise friends) and presented these adaptations not as a choice she had made but as something she had “got to be”. While there was an element of difficulty in these activities, the adaptations Hermione had made enabled her to feel confident enough to continue going to parties. Jessie described a different strategy to deal with her inability to recognise faces:

*J: ...what's frustrating a lot is when you are walking along the road and you don't recognise somebody... you can't see their features and, I have said to a couple of my friends up at the shop I say, 'don't let me pass you', no I didn't know until last week, I happened to see somebody but I hadn't, this was one of my neighbours and I had passed her... []*

*A: And how do you feel about knowing that you are possibly missing people?*

*J: Oh of course it's upsetting that is, you know? You, well you think to yourself I hope they don't think I'm being= well you say you hope that if you do see them you'll explain why you have passed them, you know, before. That is frustrating.*

*Jessie interview 1, line 663-669*

Jessie was clearly frustrated and upset by her experiences as her comments in the extract above illustrate. Following an incident where she had not recognised one of her friends Jessie described her attempt to adapt by asking friends to speak to her first. Jessie felt unable to meet the social requirements of a mutual ‘friendship’ and her choice of adaptation strategy (placing responsibility on the other person in the friendship) may have helped to justify the guilt that the knowledge of missing people caused for her when she was unable to initiate encounters. However, this strategy had been unsuccessful on a practical level and Jessie had become aware that she was still missing opportunities to be socially engaged. As a result the guilt about failing to live up to the social expectations inherent in friendships meant she continued to be distressed. Jessie seemed to attempt to justify this again by explaining how the situation was out of her control and how she would behave if her vision were better (upon seeing her friends she would explain why she had missed them). Jessie was trapped in a cycle of missing friends and rarely getting the opportunity to explain to them why she didn't talk to them in order to instruct them to talk to her first and this resulted in ongoing unavoidable guilt and frustration. Jessie's strategy was more passive than Hermione's and relied on others altering their behaviours; unfortunately others had not been adapting to

Jessie's needs. Jessie also explained that she feared others would assume she was purposefully being rude and to support this gave examples where individuals had questioned her level of visual impairment. For example, Jessie lived in a block of warden controlled flats, and described an incident in which a member of staff had questioned her ability to do her own shopping if she could not see. This experience resulted in Jessie worrying that others may be suspicious of the severity of her visual impairment given how well she was managing. This seemed to be an irresolvable issue as Jessie was determined to remain independent, but also needed others to be aware of her limitations in order to ensure their perceptions of her remained positive.

Knitting and sewing were two activities which Hermione and Jessie referred to in their interviews. For Hermione these activities were viewed as chores or necessities, but for Jessie they were hobbies which had been lost. Hermione had chosen to limit her sewing to times when it was completely necessary and Jessie had been forced to give up sewing entirely:

*J: Well, it's going out more than anything, you know? I can't do my knitting and sewing and things like that.*

*A: Are those things you used to do?*

*J: Yeah. But I try and go out I think that's, that will keep me going more than you know?*

*A: So rather than hobbies you used to do, you get out and do things.*

*J: Yeah, I've lost them hobbies, yes I've lost those hobbies yes, but, umm.*

*Jessie interview 1, line 717-722*

Sewing was a 'lost' hobby for Jessie and in order to overcome this loss she had replaced these activities with getting out of the house and getting on with life. By giving herself new goals and activities Jessie had been able to maintain a sense of independence and achievement which she would otherwise have lost. However, this aim had not been entirely successful:

*I do miss my knitting and sewing, now if there is anything I want doing like, say you just want to alter something, it's a bind to try and alter that, and I've give all my wool away, so there is no, I've given it to one person at the church is having the big balls, and that lady at the top does a lot of craft work and I've give her all the, because I thought if I can't use it I don't want it there to remind me that I can't use it so it's gone... I'm getting used to it now but it hurt at the beginning, and I tried, and I got my knitting out and I tried and I thought, If I struggle to do that, it's not my knitting, because I've always been prided on my knitting, I've done a hell of a lot in the past, you know? And I thought, if I drop a stitch I couldn't see to pick it up, and I thought, no, it's not my knitting I can't drop my standard, yes. And there's some time, years ago when [granddaughter] was at, probably at school or college, I can't remember now, and she bought a coat from the erm, from, it was reduced and she*

*said to the woman, oh, 'what's it reduced?' and apparently the coat hanger had got caught in the pocket and pulled it down, so she said, the woman said to her, she said, 'it could be mended, have you got a machine' she said, 'no, but I've got a nanny!' ((laughs)) And nanny had to do it and I made quite a good job of it, but I couldn't do anything like it now, and we always laugh about that, she said, 'no I haven't got a machine, but I've got a nanny!' ((laughs)) and it's so all those things I have to not think about now... I've got rid of the stuff that would have reminded me and that, say, and you tend to find that where that would have filled a lot of time up, when like, such as the snow was on the ground, it wasn't there, it wasn't there to do it.*

*Jessie interview 2, line 942-961*

Four main issues were raised relating to Jessie's experience of losing a hobby she previously enjoyed. Firstly, coming to terms with the loss had been a slow and difficult process which was still ongoing. Dropping standards of needle craft didn't fit with Jessie's perception of 'self' and to make sense of this she distanced herself from the things she had produced ('it's not my knitting'). Rather than accepting the change and altering her identity to become someone who was not a good seamstress Jessie instead took steps to ensure she kept her view of herself as someone good at these activities. Hermione also described giving up the activities to avoid reminding herself that sewing and knitting were things she was no longer able to do. In these circumstances avoidance acted as a defence mechanism enabling the women to avoid anxiety resulting from these threats to their self-concept. Self-concept also played an important role in the second issue raised in the extract relating to the way in which Jessie made sense of her changing circumstances in terms of her memories of being a good seamstress. For example, Jessie told a story about her granddaughter who purchased a damaged coat and looked back on this experience with pride at both being able to make a good job of the coat and to be a good grandmother. Jessie's ability was not only good, but better than having a machine, and this was how Jessie wanted her abilities to be remembered. Jessie acknowledged that she could still knit and sew, but what she produced would be at a low standard and she would not see it as hers and so took active steps to distance herself from knitting and sewing she saw as below standard (the third issue in the extract). The wool and sewing equipment that Jessie owned was a constant reminder of a hobby she was no longer able to pursue. Rather than dwell on her loss Jessie gave these reminders away to others who would get joy from her wool. This act of charity was beneficial in two ways, firstly it removed the source of sadness and prevented her dwelling on her loss and secondly the act of charity made Jessie feel good about donating to others and therefore eased the pain of her lost hobby.

The final issue Jessie talked about in this extract was how things were for her now. Sewing and knitting were hobbies that took up much of her time in the past and were important

elements of her self-concept. Without these hobbies Jessie felt lost and left in a situation where she was considering who she was and how she should be spending her time. Jessie didn't want to dwell on her losses but had been left with an emptiness which would have once been filled by her hobby. When the weather was good Jessie could distract herself by getting out of the house, however when the weather was poor (such as during the heavy snow which proceeded the interview) Jessie's sewing and knitting were no longer there to turn to; not only because she had given away the equipment she needed, but also because if she had attempted the activity the product would not have been 'hers' anyway. Jessie was still struggling to make sense of this change. All of these issues illustrate Jessie's attempts to take ownership of her changing self. Jessie saw her knitting as 'hers'; she took ownership of it and felt that if it were no longer up to her standards then that ownership would be lost. Jessie therefore created a 'self' who used to be a good seamstress rather than a 'self' who was a poor seamstress. In this way Jessie was able to limit the distress this new self caused to her and take ownership of the self she was becoming by looking back fondly on her past achievements.

Hermione and Jessie both tended to provide pro-active examples of adaptation strategies. In contrast Mary seemed more apathetic and less motivated to adapt to her changing circumstances. For example, Mary explained how she had previously enjoyed reading the paper and keeping up with news and current affairs but the 'haze' over her vision was preventing this pastime:

*M: It's just the same that haze in front of the eyes and straining this one, I actually do strain with that one, you know, and I can't hardly read. I have this spy glass on there just a little bit and it gets on my nerves so I put it down.*

*A: So, do you not do reading anymore?*

*M: No, no, I love, I used to love a paper. I love a paper better than a book, the news, you know.*

*A: So, how do you feel about not being able to read the paper anymore?*

*M: Well, I read a little bit, I can read the headlines. Like if I go into a shop, I can see the headlines on the front page but I can't, couldn't see through, mind you, to be truthful, Amy, if I've got a paper I miss half of it, I only see certain pages. You know, the news of the day without sports or things like that, you know, kind of thing. So that's that, it's lazy, I think, oh I've got it again all day, to sit with it all day again.*

*Mary interview 1, line 1493-1512*

Mary presented the 'haze' as a central feature in her life which interfered with her daily activities and had become a strain and a source of frustration. The haze was not only

preventing her from completing activities she enjoyed but had also become a barrier to her engagement with the outside world. Mary's experiences were very different to those of Jessie and Hermione who actively worked to find alternative ways to get on with life. Alternative ways to keep up with the news such as listening to the radio or getting audio books were possible but Mary did not have the knowledge or motivation to pursue these and it seemed that she had chosen to give in to her AMD. Mary's description of sitting with her AMD all day 'again' creates a powerful image of Mary living each day with the burden of AMD. Mary's lack of proactive adaptation to her circumstances may be explained by her overall apathetic attitude to life. During the first interview Mary did give some examples of attempts to get on with life, but by the second interview these attempts seemed to have ceased. The clearest examples of this change are in the ways Mary discussed life without her husband:

*I wake up every day and I think "oh, another day on your own". I'm missing my husband more than ever now. I'm missing him, he died of cancer. And I say, 'Oh, [husband], why aren't you here'. Because I know he'll be looking after me properly, you know, but I'm having a try anyhow, I'm trying.*

*Mary interview 1, line 943-948*

Living alone was a significant factor in Mary's attitude to life. In the first interview Mary discussed the sadness of waking up and living each day alone without her husband. What is interesting here is the present tense Mary used to talk about her husband. By suggesting that 'he'll' be looking after her properly Mary created a sense that her husband was still with her and looking after her. After living life as part of a couple the shock of living alone was still understandably difficult for Mary to adapt to and she seemed to be reminiscing of happier times when her husband was still with her. In contrast to Hermione who was supported by her husband, Mary no longer had this support. By the second interview Mary seemed much more depressed and less prepared to keep 'trying':

*I think you exist, you just exist when you lose your partner, sometimes you feel you want to be with them, you do get out and one day we'll be back together, when I talk to [friend] her husband is I think, he lost his wife when I wasn't very old, before I lost my [husband] and that's been 24 years, it's always, I said I want to be with him to my sister and I've got that comfort of knowing he's gone to her now he's with her, he's at peace with her you know? The grief he's left behind with his two sons as well but, oh dear.*

*Mary interview 2, line 683-693*

Mary no longer felt she was 'living' her life; she just 'exists'. This extract is very emotional as despite it being 24 years since her husband's death Mary still longed to be with him. These thoughts may have been particularly prevalent as Mary's sister had recently died and Mary recalled talking with her sister about wanting to be with her husband. It seems Mary was

going through the motions of life and waiting for death which would be a happier time for her, as she would rejoin her sister and husband. Mary's experiences relate strongly to Heidegger's (1927, 1962) concept of being-towards-death; the prospect of death is, non-relational, certain, indefinite and not to be outstripped. Death is an experience that is inevitable and Mary had accepted this, she knew it was something she would go through alone but was 'existing' in the uncertainty of when death would come. Mary was preparing herself for the ending of her life which was the inevitable final experience and for Mary this would be the moment at which she transcended to extended existence. Mary was a devout Catholic and believed that she would be reunited with her husband and sister in heaven when she died and seemed comforted knowing that her sister and husband were together and knowing that one day she would join them. However, Mary also seemed to feel guilt at her hopes for death as she had seen firsthand the grief left behind when a person died, and knew that when she died she would leave the same for her own family. As Mary viewed herself as only 'existing' she now felt depressed much of the time:

*I get really depressed, and I'll tell you the truth Amy, I'm getting lazy, I was never lazy in my life, it had to be just so, but now I've gone so depressed that I don't seem to care, I think "oh so and so wants doing, so and so wants doing" and I think, I'll leave it. And that's not me, if I see anything, you know, I just forget about it, maybe that's how I am, and getting older sweetheart you know?*

*Mary interview 2, line 25-33*

Mary's feelings of 'laziness' brought up moral issues regarding taking responsibility for herself. She didn't view herself as a lazy person, and she knew that in the past she was able to do things for herself. It seemed like Mary was shutting down and preparing for the end of her life and no longer saw the importance of completing 'trivial' daily tasks. Elsewhere in the interview Mary spoke about her past self as 'house proud' (she would always make sure her kitchen was clean and the rest of her home was tidy) but she no longer felt pleasure from this. The feeling of waiting for life to end had important implications for Mary's perceptions of her AMD. Mary was giving in to the additional difficulties resulting from her vision impairment as she no longer felt the motivation needed to attempt to get on with her life.

#### **8.6.4 Acceptance**

Hermione and Jessie were not preparing for death in the way that Mary was and both of these women seemed determined to continue living their lives despite the difficulties they faced. AMD therefore represented a challenge that needed to be overcome and in order to manage the changes and challenges posed the women were prepared to renegotiate their lives and priorities. For example, Hermione made sense of her condition by asserting that the future was out of her control:

*I might still be going strong or other things might happen, something else might happen to take me off in the near future. How do you know? You don't know, you can't plan and if you think about them too much it still doesn't make any difference. So that's it, you have to make plans for self sufficiency if you can, as much as you can. And hope ((laughs)) so you know, yes, that's the philosophy anyway at the moment...It is out of your control, providing you don't do daft things anything can happen really, you don't know, you can't see into the future can you? So you only know as of this one moment, and then it's beyond your control. It's a nuisance, but I wish I didn't have it, but it's there, and I've got to deal with it.*

*Hermione interview 3, line 367-384*

The future and old age are unpredictable and with increasing old age individuals are at risk of more serious health complications. Hermione's philosophy was to live each day as it came and avoid thoughts about the future as this could cause her to feel "in the dumps". Hermione therefore avoided these thoughts as a defence strategy against anxiety caused by events which were out of her control. By focusing on the present Hermione was able to negotiate her way through her day-to-day activities and get on with living her life. Hermione was unable to change what the future may bring but she was able to negotiate her present experiences to ensure that she was making the most of the abilities and opportunities she had. Hermione spoke proudly about her abilities to attend groups with friends, make trips to the theatre, read for the talking newspaper and go out alone at night and viewed all of these things as positive achievements in comparison to other older people who she felt were far less capable than her. Jessie also stressed the importance of being grateful for what she had and not letting AMD rule her life. When asked what advice she would give to someone recently diagnosed with her condition Jessie explained:

*Well for one I'd say, "don't let it rule you life", that's the main thing, you know you've got to, it isn't a case of fighting it, you've got to accept it, you can't do anything about, you can't make it better, it won't get better, you know, some people, like such as here they'll say how's your eye's may are they any better? I say, "they won't get better", I've just got to accept it, it takes quite a bit of doing at first, but you can't let it ruin your life and there's a lot of people much worse than you, you know, if you are able to get about then do so, and it's no good weeping about it.*

*Jessie Interview 3, line 506-517*

Jessie stressed that in order to get on with her life she needed to make sure AMD did not control her. In comparison to other older people who lived in the surrounding flats Jessie made sure she continued to be engaged in a wide variety of activities and refused to remain confined to her home. Jessie had taken time to accept her condition and acknowledge that it would not improve and had needed to put work in to get to the point where she accepted her situation. Upon reaching this point she was determined to remain positive and on top of things and not allow her situation to get her down. Jessie seemed proud of her ability to maintain her

independence. For example, during her third interview Jessie explained that her GP had said to her that he wished more of his older patients were like Jessie. Jessie recounted experiences of three previous heart operations and described these operations as chances at life. As a result Jessie felt morally obliged to make the most of the opportunity for life she had been given.

Both Hermione and Jessie were determined to get on with life and make the most of what they had and described themselves as being 'grateful for small mercies' (Jessie interview 3). These women valued everything good that happened to them even when they didn't have everything they wanted. As long as they were able to continue with the activities which were important to them then they did not portray AMD as having a huge impact on their quality of life. In comparison Mary was prepared to give in to AMD as she had reached the point where she no longer felt motivated to get on with her life and was instead preparing herself for the inevitability of death.

### 8.7 Rejecting disability

Despite the advanced nature of these women's AMD both Hermione and Jessie expressed desires to reject being perceived as disabled by others. This issue was discussed by both women in terms of the way in which they felt they may be perceived by strangers. Both women explained that the biggest issue was when they came to the check out while shopping:

*...on the whole the check out is the one I dislike most, it's all happening isn't it quickly, and I find that putting things into a bag at the same time as I'm trying to pay my money, and being slow with the money, I hate it, in fact what I don't want to do is to put my hand out to the cashier and let her take bits and bobs because it's what many old people will have to do and I don't want to do that, so I try very hard to look as if I'm fine and I'm getting it right, really, but I do find pound notes and 10p's oddly enough, although they don't feel the same, I don't feel I want to give myself time to feel the coins, so I often offer a note which means by the time I get home I've got a purse full of small change. That sort of thing but it's all part of it isn't it?*

*Hermione interview 2, line 407-430*

*the silver is difficult, I usually, if I'm sorting any money out at all before I go out, I'll sit on the bed because it's you get the light just round the corner there and I sit on the bed and put it on the bed, yes I can see that, but that is difficult yes*

*Jessie interview 2, line 1035-1040*

Hermione was keen to preserve her image as a capable and independent woman and was reluctant to become one of the 'old women' who needed to allow the cashier to take the money directly from their hands. Hermione attempted to consciously adapt to this by feeling

the coins carefully if she had time, or alternatively handing over notes in the place of coins. While these strategies enabled Hermione to manage her embarrassment at the immediate moment of the transaction, the knowledge of her purse full of coins when she returned home reminded Hermione of her difficulties. Hermione was trying to manage her outward persona and avoid becoming a 'bumbling old woman'; however her difficulties challenged this perception of herself. Jessie chose to arrange her money before going out so she knew where in her purse each type of coin could be found, this was a strategy that Hermione also mentioned but suggested she was not yet ready to take that step. By arranging her coins in this way Jessie was able to manage others' perception of her and ensure that she appeared as if she was able to see the coins clearly.

Jessie was very determined to manage the way in which she was perceived by others and another clear example of a desire to reject disability was evident in Jessie's determination to reject the offer of a white stick. During the first interview Jessie explained how others had suggested that she should have a white stick:

*As I say, when I've said to people, [inaudible] you've got to be assessed again and that, 'oh you'll have to get a white stick', and I shiver a bit. But do you think that is necessary?*

*Jessie interview 1, line 876-880*

Clearly Jessie was concerned about being given the stick, when pressed about her reasons for this Jessie simply said 'pride'. The suggestion of using a white stick was so uncomfortable for Jessie that she felt her body physically shiver in addition to the serious emotional response she felt when imagining herself using the stick. This physical response to the suggestion is interesting; it highlights the link between Jessie's bodily sensations, emotional reactions and her experiences. The idea of using a white stick is more than simply an emotional response it also prompts a physical reaction. This perhaps links back to Jessie's childhood experiences of wearing glasses when the glasses may have been a symbol to other children that Jessie was in some way different to them and by using a white stick Jessie would again be giving others a symbol that she had a disability and was in some way 'different'. Jessie was experiencing 'felt' stigma as no actual stigmatising had taken place but she feared the discrimination which may occur. At the second interview Jessie had been visited by social services who had recommended she have a white stick. Again Jessie had rejected the stick outright, but after some persuasion she had agreed to take a fold up cane to be kept in her hand bag:

*She [lady from social services] said to me, she said, 'well', she said, 'I'd like to measure you, standing up, for your white stick', and I said 'I don't want a white*

*stick!* and she was oh, quite, she said 'and why not?!' very sharp, 'why not!', I said, 'pride', and I said, 'I've got my own stick', I'll show it to you [gets stick]... Well I, I said, 'I don't need it as people need it for arthritis and things like that luckily, but it does make me conscious of where I'm walking and what I'm doing', I said, 'but I don't want a white stick!'. She wasn't very pleased, she said, 'we'll I'll tell you what she said, 'have a white cane', she said 'put this in your handbag'.

*Jessie interview 2, line 427-437*

Jessie described being offered a variety of aids (magnifiers, writing aids etc) which she had accepted, but when it came to the offer of a white stick she became very uncomfortable. The aids Jessie was happy with were those that she would use in her own home out of the sight of others. However, the white stick would be used when she was outside her home and could be seen by friends and strangers. Jessie had accepted her walking stick as an aid to make her walk more carefully and watch what she was doing, however the white stick represented a symbol to others that she had a disability and it was this that Jessie struggled to come to terms with. The walking stick could be justified as it had a dual function, it both symbolised her disability in terms of walking, but also made her consciously walk more carefully to avoid falling. In contrast, the white stick had a single function; to make others aware of her visual disability. Jessie attempted to use her walking stick as a bargaining tool, suggesting that it was enough and there was no need for the white stick. The possibility of hiding the stick appealed to Jessie who insisted she had too much pride to allow others to see her with it. Without using the white stick Jessie blended in as any other person in the street and her visual disability was hidden from others, however the white stick was a symbol which told other people she had a visual disability. The main use Jessie had for the white stick was crossing the road:

*J: Well I use it as I say, I just, for crossing mainly that road there, and I tend to put it back in my bag again.*

*A: Yes, you still don't want to be seen with it?*

*J: No, no, I mean, it's being independent yes. But I wouldn't like a white stick.*

*A: No.*

*J: No, there the, you know? I think, in my opinion of course, I think people could pity on you with that.*

*Jessie interview 2, line 575-582*

Jessie rejected the idea of a white stick that she would hold constantly, choosing to only use it for crossing the road in order to minimise the chance of others seeing her with it and pitying her. Pity is a powerful word which paints the individual as a victim and Jessie did not wish to be seen in this way. Rejecting the white stick was a form of psychological protection for

Jessie; the symbol of the white stick was so powerful that Jessie viewed giving in to it as giving up. Jessie was able to manage the perceptions of others and hold onto her independence and control by choosing when it was acceptable to use the white stick and when it was not needed. Jessie's difficulties coming to terms with the perceptions of others were not limited to the perceptions of strangers:

*most times I go on holiday with them [family], now when I went on holiday with them last couple of times, I said to my daughter, I said, 'do your mind your mother having a stick?', she said, 'don't be so daft' ((laughs)). I minded it at the time you know?*

*Jessie interview 1, line 591-602*

While the stick was something Jessie had to come to terms with personally, it seems her family had no concerns about her use of the stick; however her daughter's abrupt response may have been no comfort to Jessie. Jessie viewed herself as an independent capable woman and she seemed uncomfortable with the mothering she experienced from her daughter and family and the way in which they perceived her as an elderly person in need of their support. On numerous occasions throughout the interviews Jessie referred to times when her family had helped her in some way and while she was grateful for this support, she also seemed to be battling with the idea that this made her dependent on her family. Jessie struggled to come to terms with the significant shift in roles in the mother/child relationship as she had gone from a carer to someone being cared for. Jessie viewed herself as independent, but she felt her family viewed her as dependent and this was something she was struggling to make sense of.

In direct contrast to both Jessie and Hermione, Mary seemed willing to accept dependence and portray her vulnerability to others. Mary's relationship with her children was also changing and she felt lucky that she had children to care for her. Mary did not want to be a burden to her children but each time her daughter helped her she was given the opportunity to avoid doing things for herself. When Mary took these opportunities she became angry about becoming a 'lazy' person she didn't recognise:

*The cooking, cooking is getting a bit hopeless, but my daughter is very good, she, she spends days cooking different things for me and she'll bring them all in one lot, and they'll last me, because I'm getting very very lazy, I'm getting lazy Amy and it's making me lazy, and I, and you enjoy it better when it's cooked for you*

*Mary interview 2, line 192-198*

Mary was beginning to find activities such as cooking much more difficult and "hopeless". Mary's relationship with her daughter was becoming reversed with Mary changing from Mother to dependent and was choosing not to fight this change in status. Mary felt guilt at

becoming 'lazy', but attempted to ease this guilt by reframing the help her daughter gave her from being a burden to being a positive experience for her daughter as she spoke about the way that her daughter enjoyed cooking. Mary seemed less motivated to fight to remain the independent woman she once had been and it seemed she was slowly giving in to her disability. The feelings of laziness are faint reminders of who she felt she once was but as she was gradually being overwhelmed by her AMD she was giving in to the new dependent self she was becoming. In other circumstances Mary found being mothered comforting:

*Well, do you know what frightened me, Amy, the photography, I thought it was never going to end. And it was every 8 minutes he was coming in and your back was killing you in the high chair and my arm. And every 8 minutes and he did one side to the other but he did say at the end that you've been a good girl. He took me by the hand, you know, I was frightened because he was discussing it and it seemed as if they didn't know, you know, the way they was talking, they've probably got an idea...*

*Mary interview 1, line 486-500*

The diagnostic photography took a long time and resulted in both physical and mental discomfort for Mary. Mary's fear was often overwhelming and she clung to offers of care and support which eased her fear and made her feel like a 'good girl'. Mary frequently spoke about others taking her by the hand and supporting and comforting her and her vulnerability seemed like that of a scared child in need of an adult to care for her. The decision about treatment was made for Mary by the Doctors and she did not try to actively involve herself in it. Mary's experiences in this respect are very different to those of Hermione and Jessie as she was happy to be vulnerable and dependent. Mary's fear seemed to have taken full control of her and she seemed almost paralysed by it. Mary frequently explained that she had been a nervous person for most of her life. However with the loss of family members and gradually increasing ill health Mary seemed no longer able to manage this fear for herself. Throughout the interviews Mary brought up memories of her love for her Mother who had been very important to her. She spoke fondly of her mother as someone who had cared for her and made her feel safe. Mary had been recently bereaved by the loss of a sister, and another sister was very ill and therefore all the ties to her mother seemed to be gradually being lost. It's possible that Mary was attempting to re-create the feeling of safety her Mother gave her through her relationships with others and this may explain her changing relationship with her daughter and vulnerability with health care professionals.

## **8.8 The future with AMD**

All three women expressed fears about their future with AMD. Hermione's main concern was becoming dependent on and a burden to others. Hermione attempted to ensure she had reciprocal relationships with others, however with her developing AMD this had become more

challenging. For example, being unable to drive had altered her relationships with friends as she was unable to give back to them in the same way that they gave to her:

*I find too that I have lifts with groups of friends if we are doing something with one of the groups, but I feel I can't repay them, and one of the things I sometimes like to do is go to a friend, 'oh, how's about we go out for whatever' and I don't think I can do that because they drive and they would feel obliged to drive.*

*Hermione interview 1, line 295-299*

Hermione's friendships were at one time entirely reciprocal as she was able to offer things to her friends and they would offer things in return. By no longer being able to drive there had been a shift in these relationships for Hermione and she felt guilt about not being able to return favours. Hermione was able to manage these difficulties and accept that her life and relationships had changed and she felt there was no point worrying about them as there was nothing she could do to change them. Her ability to take this stance may be helped by the relationship she had with her husband. However, Hermione acknowledged that in the future things may change:

*A: So how do you feel about the things that, the way things have changed, things take longer for you now and?*

*H: Well, I just find I have to accept them, because there is no point, I mean I get, sometimes I get, I say, 'oh goodness [Hermione], stop it!' ((laughs)) it sounds ridiculous but there is no point really Amy, I've got to find ways through it, and this is the easy stage, later on it will be much more difficult.*

*A: So what do you, what do you anticipate will be different in the future?*

*H: I think dependence on someone else for more things, and that I dread, I mean something else might carry me off before then, so I'm not to worry about it, I'm very lucky to have a wonderful husband at the moment, but who knows what might happen, one of my fears is that if [husband] was really poorly or something like that I wouldn't be able to care for him in the same, in the way I'd like to, but there is no point in thinking about something like that because you can't organise it, you can't reorganise it can you?*

*Hermione interview 1, line 228-239*

Again Hermione referred to relationships and here she spoke about the support she received from her husband. Elsewhere in the interviews she spoke about her husband driving her to places, but that she was also able to get out by herself by walking. Hermione feared a change in this relationship and felt that if her husband were ill she would be unable to care for him in the way he cared for her and there would no longer be balance in their relationship. Nothing seemed certain for Hermione and she was being forced to adapt to her constantly changing life and relationships. Hermione wanted to take control of her life but found that dependency

was slowly creeping in and Hermione was trying to come to terms with this. Hermione attempted to manage by being determined not to dwell on her AMD ('I've got to find ways through it'). Giving in to AMD was not an option for her and she had to keep going and make the most of her situation. Hermione had mentioned elsewhere in the interview that she used social comparison and compared herself to other people her age and felt very lucky to be in the situation she was in. Hermione's future was uncertain as she may live to develop very poor vision, or 'something else might carry me off before then'. Hermione made sense of this by accepting that she couldn't predict what would happen to her and was not able to 'organise' or 'reorganise' what might happen so there was no point dwelling or becoming worried about her future. Despite presenting this bravery and acceptance on the surface Hermione also felt powerless to change the future and unconsciously it seemed the worry was always there:

*... I wouldn't say I don't exactly worry, I worry about it a little bit because of the dependency later on, I do find just occasionally in the night I wake, and I find I'm worrying about it... And worrying about what might happen later on... Otherwise when I'm sort of fully conscience, conscious, I don't do, I don't worry about it, but then I do and that is quite a little panicky time and then I sort of have to give myself a good telling off or go and make a cup of tea or something.*

*Hermione interview 1, line 409-416*

While Hermione was sleeping her fears surfaced and she woke in a panic, in order to cope with this she found distractions as a way to take control of her worries. Hermione felt lucky that she was still able to do so many things, but there was a constant fear that she would one day become dependent. While Hermione was awake she was able to manage this fear by distracting herself with other tasks, however when she was asleep she had no control over her fears. This fear of dependency may be explained by her knowledge of her own mother's experiences with visual impairment. Hermione's mother lost much of her vision in her 40's; at this time she also lost her husband and was left to manage alone with her visual impairment:

*H: Not being able to do things yourself, simple things and what was I going to say? Intruding on people's lives, and I would hate it, absolutely hate it if my daughter or son had to look after me and I know this happens doesn't it in life, but I always hope that never happens really because of my sight when the rest of me might be able to cope and my sight wouldn't be there.*

*A: Yeah, I see what you mean, so while you feel in yourself able to do things*

*H: While I feel reasonable*

*A: It's your eyes that are causing problems*

*H: That's right yes. I mean my mother was quite content and she accepted that there was lots of things she couldn't do and latterly she was very,*

*because my dad died in his 50's so she was younger, but she, I suppose made herself content in a life that wasn't out and about that much, she would come and stay here for a fortnight during the school holidays when I was at home, she would come and stay happily, but she sort of made herself cope with it I think so, I hope I will do the same for as long as I could.*

*Hermione interview 1, line 426-438*

Hermione's mother was an embodied example of Hermione's own future. In the first interview Hermione talked about providing support for her mother, describing her as content with a life that was restricted to the home and visits to her family. Hermione struggled with the idea of being dependent on any family member and worried about the impact on her relationships. Witnessing a family member becoming dependent is a common experience for many people, but this is particularly salient for Hermione given her own visual impairment. While her mother made herself cope, Hermione could only hope that she would manage in the same way. Hermione hated the idea that her body may let her down and the thought that while in herself she would be able to cope, her body would not be capable of coping. This is another example of dissonance between body and mind in which Hermione is being forced to confront the potential dependent changes she fears in her future. In the second interview Hermione spoke further about her mother's experiences, she explained that she was aware that her mother's vision deteriorated as she aged and she also acknowledged the difficulties her mother faced. At this point Hermione had experienced a slight deterioration in her own vision since the first interview and was also living with a developing cataract. Again this is particularly salient for Hermione's experiences as there are many parallels between her own experience and that of her mothers. Like Hermione, little could be done to improve her mother's vision and Hermione fears the dependence her mother had. Hermione was afraid of becoming dependent in the way she had witnessed in her mother. Like Hermione, Mary attempted to avoid thoughts about her future:

*I try not to think of that, you know I try not to think of the future because you never know what it's going to bring, what's going to happen do you? You don't know.*

*Mary interview 2, line 885-87*

Both women emphasized the uncertainty that the future held and their helplessness in terms of altering what their future might be like. However, while Hermione had the memory of her dependent mother as a warning about what her future may hold, Mary had no similar past experiences to draw on. The future was a blank canvas for Mary who could only imagine a future much the same as her current situation:

*M: It made me feel better to know that [I wouldn't become blind], because you know I could tolerate this, I don't think you ever get used to it, you*

*know kind of thing, and I'm glad I can, I'm glad I can see the television better, not that it, not so good today as it, as it's a bad day, no two days seem alike.*

*Mary interview 2, line 982-989*

Mary took each day as it came as she was unable to predict what the future would hold. Mary would go through the rest of her life needing to 'tolerate' the condition she would never get used to. AMD was a constant part of her existence and there was never a time when she felt she would be herself without AMD again and AMD had become part of her. While there were occasions, or good days, when Mary's vision seemed slightly better she knew that perhaps tomorrow it would be worse again. Mary was living a life of uncertainty, each morning she woke up and did not know if it would be a 'good day' or a 'bad day'.

Jessie spoke less frequently about what she expected the future to be like and like Mary, seemed to have no clear picture of her future. When directly questioned she did hint that things may become more difficult for her:

*A: If I did not have MD my feelings about the future would be*

*J: I should say much better because I would say that at 87 years of age ((laughs)) I can't have much future in front of me but I still feel like I can go on forever, which I know I can't!*

*Jessie interview 2, line 281-284*

Jessie chose not to think about her future as given her age she didn't see that she had much future ahead of her ("I still feel like I can go on forever, which I know I can't!"). Rather than thinking about the future Jessie lived each day at a time. Jessie felt she was managing well with her situation as she lived independently, volunteered in a church shop and gave church tours, attended church groups and keep fit classes and was able to do her own shopping. However she was aware of her age and the inevitability of deteriorating health. Jessie had become accustomed to her current situation and faced the future with hope that deterioration may not happen:

*J: Well, I'm hoping that they stop like they are, because I'm getting accustomed to it*

*Jessie interview 2, line 831-833*

Jessie felt she was managing as she was at present but there was a hint of fear which she portrayed throughout her interviews when making assumptions about the future that she may not be able to cope if further deterioration happened. Jessie had taken a realistic view of her condition and accepted that no improvement would occur, and as with other areas of her life

she was committed to getting on with life and making the most of vision she still had, but there was a continual concern that one day she would not be able to continue getting on with life.

### **8.9 Summary**

The themes discussed have highlighted the many ways in which these women have tried to understand their diagnosis with AMD and make sense of their experiences. The diagnosis of AMD had been a challenge for these women and a barrier to them getting on with their lives as they once had. AMD challenged the women's sense of independence and forced them to adapt to and control the new ways in which they were perceived by others. In addition, AMD not only affected their present experiences but also their interpretations of what their futures may be like. In particular regardless of whether they had ideas about what the future may be like, or whether the future represented the unknown, there were fears of what the future may bring. Unlike the participants in the previous chapters these participants had been living with vision impairment for many years, as a result it seemed they had attempted to develop coping strategies to enable them to continue with their lives despite their condition. The next chapter presents a unique case study of a couple who were living together with AMD.

## Chapter 9: Living Together With AMD

### 9.1 Introduction

This chapter presents the experiences of a couple who were living together after both being diagnosed with AMD and investigates the impact of this coupledness on their experiences. Coupledness in old age can fulfil a variety of functions for the individual including friendship, intimacy, love, emotional support and mutual help (De Jong Gierveld, 2002). There are also a number of benefits associated with marriage in later life including support, ongoing companionship and emotional attachment (Bradbury, Fincham & Beach, 2000; Xu & Burleson, 2004). Older married adults tend to report better health and quality of life (QoL) when compared to those not married (e.g. Bookwala & Fekete, 2009; Kim & Mckenry, 2002). In particular, better quality marriage (defined as a satisfying relationship with supportive behaviours and spending recreational time together) has been shown to help buffer the negative impact of later life stressors on QoL (Bookwala, 2011).

Dyadic relationships are present in the lives of many older people; however few qualitative studies have focused on the dyad as a unit of study (Koren, 2011; Shepperd, Coyle & Heggarty, 2010). Dyadic relationships are an important contextual factor in the lives of older people, and it is therefore useful to capture the lived experience of individuals who are living as part of a couple (Koren, 2011, Eisikovits & Koren, 2010). Phenomena, such as vision loss, are part of shared experiences and interactions involving multiple perspectives, such as the interaction between spouses. Research has indicated that depression resulting from the vision impairment of one partner can negatively impact on the depression levels of a spouse (Goodman & Shippy, 2002). In addition, longitudinal research has demonstrated negative impacts of vision impairment in one partner on the spouse's health and wellbeing irrespective of their own level of vision impairment (Strawbridge, Wallhagen and Shema, 2007).

Traditionally the medical model has focused on the individual alone and paid little attention to the social contexts of the patients' *lifeworld*. Koren (2011) highlighted the "we-ness" or togetherness experienced by couples in old age and suggested that, by identifying the overlap and contrasts in the descriptions of couples' experiences, we can gain an understanding of phenomena which are more than the sum of two individual versions. The experience of vision impairment caused by AMD is an under researched area and no research exists which investigates the experiences of couples in which both partners are living with the condition. This chapter aims to develop an understanding of the ways in which a couple, living together with AMD, make sense of their experiences with the condition. I have chosen to present this

couple as a case study in their own right to highlight the importance of 'couplehood' (Koren, 2011) in the experiences of these two participants.

### **9.1.1 Research question**

What is the experience of 'living-together' with AMD?

## **9.2 Participants**

The participants in this case study were a white, British, heterosexual, couple who had been married for 60 years. Jack was an 82 year old man who had been recruited at an eye hospital in the UK. At the time of the first interview Jack introduced me to his wife Sally who was also registered with the eye hospital, at this time Sally was also recruited to take part in the research. Sally was a 77 year old woman who had been diagnosed with dry AMD when she was 55. Sally had numerous other health problems including osteoporosis, diabetes, and glaucoma and was restricted to the home as her mobility was severely limited. Jack had been diagnosed with advanced dry AMD in one eye and wet AMD in his other eye which had become a scar. Jack had severe vision impairment in both eyes. Jack and Sally represent a unique case study as both members of the couple were living with AMD.

## **9.3 Method**

### **9.3.1 Interviews**

Joint interviewing is one possible method of data collection (Allan, 1980; Morris, 2001) however the authenticity of this method has been questioned (Taylor & De Vocht, 2011). Most research into the perspectives of couples has employed separate individual interviews with each partner in order to access each individual's interpretation of the experience being researched. Many researchers believe the presence of the other partner may result in the 'concealment' of some aspects of the experience, however joint interviewing may also enhance disclosure through supplementation of each other stories, probing, challenging, introducing new themes for discussion, and reminding the partner of elements of the experience which may have been forgotten (Taylor & De Vocht, 2011). The interpretative phenomenological approach taken in this thesis advocates that multiple 'truths' are possible and acknowledges that all presentations of experience involve interpretations. Therefore joint interviews enable participants to both present their own perspectives and blend their experiences to represent themselves as concurrent partners in a relationship (Hertz, 1995; Morris, 2001).

According to Heidegger's phenomenological theory (discussed in the methods chapter of this thesis) an individual is inextricably linked to the world around them and the other individuals in

the world and therefore a person is always 'being-in-the-world-with-others'. Married couples represent a system that consists of two mutually influencing partners and the aim of joint interviewing is not to distinguish between descriptions but to learn from the collective and shared meanings attributed to the couple's experiences (Taylor & De Vocht, 2011). In this way joint interviewing can provide access to the couples 'fusion of horizons' (Gadamer, 1975).

Three joint interviews were conducted with the couple in their own home over a period of 18 months: immediately following Jack's recruitment (when Jack had been diagnosed with advancing dry AMD in one eye in addition to an existing macular scar in the other eye); 9 months after recruitment; and 18 months after recruitment. Both members of the couple were present at each interview which lasted between 1 and 2.5 hours.

### 9.3.2 Data Analysis

Interpretative phenomenological analysis (IPA: Smith et al., 1999) was employed using the dyad as the unit of analysis to produce a thematic account of the couples shared and divergent experiences. Dyadic analysis is particularly useful when the topic under study is a shared experience (Eisikovits & Koren, 2010). Other studies using dyadic analysis have been conducted using both individual and joint interviews (e.g., de Visser & McDonald, 2007; Hodgson, 2004; Ungar et al., 2006).

## 9.4 Themes

The table below provides an overview of the themes which will be covered in this chapter.

Table 14: Theme table for couple living together with AMD

Theme	Subtheme	Example
<b>Living together with AMD</b>	Sharing the load	<i>S: We work between us don't we?</i> (Interview 2)
	Living half a life	<i>it chops your life in half really</i> (Jack, Interview 3)
	Relationship strains	<i>S: Well we get irritable with one another</i> <i>J: Yeah we are shouting at each other all the time now.</i> (Interview 3)
<b>Making sense of diagnosis</b>	Conflicting experiences	<i>I know that if it's the dry that nothing- it is the dry that nothing can be done, isn't it? But, if he has got the wet, why aren't they doing anything?</i> (Sally, Interview 1)
	Confusion about cause	<i>A: So what do you think caused your macular degeneration?</i> <i>J: old age I suppose, wear and tear! That's what they said to me.</i> (Interview 2)
	Registering as partially sighted	<i>We are both on the partially blind register now</i> (Sally, Interview 3)

<b>The future with AMD</b>	Other health problems	<i>I think before this gets a lot worse, I think something else would happen. Most of the people that we know that was in very good health, they've just had one thing wrong and they're dead. (Sally, Interview 1)</i>
	Living alone	<i>S: When one of us dies, I think it will, when you're the two of you together, but I should hate to be without [Jack] and I think he'd hate to be without me wouldn't you?</i>

## 9.5 Results

### 9.5.1 Living Together with AMD

#### 9.5.1.1 Sharing the load

When Jack and Sally first retired they were able to pursue enjoyable activities together. They were sociable and spent time out visiting others and enjoyed the early years of their retirement:

*S: I mean we'd go out every day at one time when you were first retired didn't we?*

*J: Yes, we were used to going out and mixing with people, and talking you know?*

*Interview 3*

Jack and Sally started their retirement with reasonable health. They spent time shopping and dividing the weekly chores and responsibilities:

*When he first retired it wasn't too bad. He'd do the shopping in the morning and I would get the dinner early and we'd be out every afternoon.*

*Sally, Interview 1*

The couple presented themselves working in unison throughout their 60 years of marriage in order to complete activities, each fulfilling the responsibilities they were able to complete and creating a sense of continuity between their initial retirement and current experiences:

*S: We work between us don't we?*

*J: Yes, when I get up in the morning like, I put the, all the main things out for the breakfast.*

*S: Which we only have cereal and fruit.*

*J: Yes and what I do then is-- I pick so many grapes out and put them in like a colander thing and leave them swilling under the tap while I take the night clothes out and put them into the appropriate places.*

*Interview 2*

The couple presented themselves as sharing responsibilities and when Sally's vision began to deteriorate Jack had taken responsibility for activities she struggled with due to AMD and other health issues. However, when Jack's vision also began to deteriorate the couple found it increasingly difficult to share the load of household chores and responsibilities. The couple's changing vision forced them to renegotiate their roles within the household:

*J: Sally does all the administration work, I mean I did write cheques at one point [...]*

*S: He only started to write the cheques because I couldn't write them*

### *Interview 3*

In the interviews Sally explained that she had previously worked in accounts and had enjoyed keeping a hand written book of accounts for the couple's expenditure. When Jack became unable to read cheques, Sally's past administration experience meant she was best placed to fulfill this role, however her own visual deterioration made this difficult. The changes in vision experienced by the couple had meant their roles were constantly fluctuating. For example, Jack temporarily took responsibility for the finances when his vision was better suited to the role, but with Jack's deteriorating vision he allocated this responsibility to Sally once again. The changing health context of the couple's lives resulted in them needing to find new ways to fulfill the roles expected of them within the relationship. For example, Sally discussed increasingly rely on her daughter to enable her to meet her financial responsibilities "I can't write my cheques, my daughter does those" (Sally Interview 3).

Sally's physical deterioration restricted her ability to complete physical chores. For example, the couple needed to employ a cleaner to help them with house work. To counter the loss of previous responsibilities Sally attempted to develop new responsibilities such as writing the shopping list:

*S: I've always done all the paper work until these last few years. It's got a lot worse, and you've always had to write the cheques haven't you Jack? And I do try and 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-*

*J: And a thing to tick them off. I'm like an octopus ((laughs))*

### *Interview 2*

Sally's input into the shopping became pointless as the combination of her poor vision limiting her ability to write and Jack's poor vision limiting his ability to read resulted in further difficulties. Jack's physical abilities enabled him to get out of the house to visit the shops and

this became his responsibility within the relationship when previously they had enjoyed shopping together. Jack often struggled with this responsibility:

*J: But if you had got a bottle there, at one time, you just pick it up and you'd read the ingredients, and the sell-by date and everything. You can't even see what it is. (laughs)*

*S: When he comes in with shopping, I get it all out and I'm with the magnifying glass going,*

*J: And I keep thinking she's going to find something wrong.*

*S: Out of date.*

*J: Like a detective.*

#### *Interview 1*

The couple renegotiated this activity and found new ways to share the responsibility of shopping. When Jack returned home Sally took responsibility for checking the dates of the items he had bought. The couple expressed a wish to remain independent in terms of providing for themselves and helping each other and working as a team enabled them to achieve this.

#### **9.5.1.2 Living half a life**

AMD and its associated disabilities had resulted in a severe curtailment of Jack's activities and he explained that "it chops your life in half really" (Jack, Interview 3). Jack compared his past life with the life he was currently experiencing and found a wide variety of activities more difficult than he had previously. For example, Jack described struggling with cooking (judging measurements and reading the temperature on the cooker), walking down stairs, watching the television, reading letters, putting batteries in electrical items (such as magnifiers), using his mobile phone, hanging pictures, and seeing peoples facial features. In addition, due to the location of their home Jack sometimes needed to cross busy roads and found this difficult as he was unable to see the cars coming:

*When I worked in the city, I would jump over the top of cars. I used to cross all in and out of the traffic, it didn't bother me. But I wouldn't do anything like that now (laughs).*

#### *Jack, Interview 1*

Both Jack and Sally highlighted the frustration that difficulties with activities such as these could cause:

*I think frustration is one of the biggest things, isn't it? You get really mad at yourself, you know. That you can't do these things.*

*Sally, Interview 1*

The couple struggled to identify with the older people they had become in their old age. In their youth they had been able to remain independent but now, even simple activities took time and resulted in frustration. Not identifying with their difficulties resulted in anger directed inwards at the self. Jack and Sally talked about internal continuity with their past selves, however their bodies were betraying them and preventing them from continuing to live life in the way they once had. Sally had never imagined a life like the one she was now living:

*When you are younger you don't think that this is ever going to happen to you. The time goes quickly though, that's one thing, it doesn't drag, and you find as you get older that time does go quickly. I think what it is, you have to do something and then you have a little sit down before you start off again, whereas you'd have done it more quickly years ago.*

*Sally, Interview 2*

Sally highlighted the temporal changes resulting for advancing age and deteriorating health. Sally felt her life was quickly passing her by despite the fact that daily chores now took longer to complete. The meaning of time seems to change within this quote; at first 'time' represents Sally's lifespan and moves on to discuss time passing in terms of completing daily chores. Perhaps due to things taking longer Sally felt that her hours were full, whereas in the past she would have been more productive and quickly completed her daily chores.

### **9.5.1.3 Relationship strains**

Throughout all three interviews the couple touched upon the strains AMD placed on their relationship. In particular they seemed concerned by arguments resulting from the difficulties they experienced:

*S: Well we get irritable with one another*

*J: Yeah we are shouting at each other all the time now.*

*A: Ok, what kind of things do you argue about?*

*S: Well he does make a bit of a mess*

*J: The mess I make sometimes yes.*

*S: I mean I know he can't help it and he'll say well I can't see and I'll say well I can't*

*J: We can't get used to that you see*

*S: When I'm in the kitchen, well I've got used to, mine's been so much slower than his, I just put my fingers over the kitchen table and I can feel whether it's clean or not but he doesn't think to do that.*

*J: I'm not used to it see*

### *Interview 3*

Jack and Sally experienced deteriorating vision within their own individual life-worlds and the subtle differences of these prevented them from fully understanding each other's experiences. This perhaps relates to their gendered roles within the household, for example in the past Sally may have fulfilled the traditional 'wife' role in relation to cleaning and this kind of activity may have become instinctual, in comparison Jack is less likely to have carried out this type of activity and therefore may not be used to cleaning up after himself (*'I'm not used to it you see'*). Sally made sense of these differences in terms of the length of time they had each had to come to terms with their AMD:

*Mine's been since I was 55, and I'm 78 now so that's been 20 odd years, but his has come on like over 2 years hasn't it? very quickly, so mine being slowly, I mean I didn't notice mine at all until I was told, and even so when they had told me it was a long long time before I noticed it was very gradual, and I think that's why I was able to cope with it better because it was so gradual.*

### *Sally, Interview 3*

While Sally had many years to come to terms with her gradual visual deterioration Jack's sudden reduction in vision meant he needed to adjust more quickly in order to help him cope. Jack was less used to completing activities such as cleaning the table and this combined with his visual deterioration meant he continued these activities as he always had; only cleaning when he saw the need. This inability to understand each other led to frustration and arguments which were frequently discussed throughout the interviews. However, the couple tended to make light of these arguments, both frequently joking about their frustration with the other.

## **9.5.2 Making Sense of Diagnosis**

### **9.5.2.1 *Conflicting experiences***

Jack and Sally had different types of AMD, however having been diagnosed with the same overall condition it was evident that they were frustrated and confused by their conflicting experiences. These conflicting experiences highlight the idiosyncrasies experienced by patients with differing forms of AMD. The couple worked as a team to piece together the information they had gleaned from their appointments:

- J: But I got, two, two things, like two different eye, things wrong with my eyes. One eye is wet and one eye is dry. Well I thought either one or the other they could do something. Because what did they tell you if they'd have been something else that they could have done something?*
- S: I've forgotten now.*
- J: They did say something though didn't they? About this wet and dry?*
- S: Oh yes, I think I've got the one they can't do anything for, but you always thought you've got one eye's got one type and one eye's got the other.*
- J: Yes, that's right. That's what it said in the report wasn't it?... But they haven't bothered about the one eye ((laughs))*

*Interview 2*

It seemed that the couple did not understand the difference between the two types of the condition and found it to be particularly confusing that despite Jack having both types of AMD (one in each eye) he was not being given any form of treatment from the hospital. This was due to Jack's wet AMD being past the point of treatment, but it seemed that this had not been made clear to Jack. Due to a perceived lack of information Jack and Sally both struggled to make sense of this:

*I know that if it's the dry that nothing- it is the dry that nothing can be done, isn't it? But, if he has got the wet, why aren't they doing anything?*

*Sally, Interview 1*

Jack and Sally had very different diagnosis experiences. While Sally's AMD had been identified by her optician prior to her noticing deterioration in vision, Jack had visited his doctor when he noticed his vision was deteriorating:

*I told the doctor that I thought my eyes were deteriorating. You know, and they made an appointment for the eye hospital. The trouble is, at the eye hospital they examined my eyes and everything but they don't give me a follow-up.*

*Jack, Interview 1*

Jack's appointments frequently left him with no additional information about his condition. He recounted that he had been advised to visit the Emergency Department if he noticed any problems and was not given automatic follow up appointments. However, Jack was reluctant to visit the emergency department as: he didn't know what changes he needed to identify; he felt he wouldn't be sure he would see someone who knew about his condition; and he was concerned about wasting money on travel if the appointment was not needed. In comparison, Sally felt that it had been made clear to her that nothing could be done to help and despite this she was provided with regular follow up appointments to monitor her vision:

*I mean they told me straight, they can't do anything, but I think you feel a bit better knowing that you are going there and they are still looking at your eyes, because there's not just macular degeneration, there's other things isn't there?*

*Sally, Interview 2*

Sally believed that her follow up appointments were related to her glaucoma and diabetes in addition to her AMD. As Jack did not have these conditions she felt this may be why he was being treated differently. However this did little to alleviate Jack's own concerns and he explained that lack of attention from the health services "gets you down" (Interview 2). This lack of attention left Jack feeling like he had been written off by the medical profession:

*J: It- it, you know, you don't like the feeling that they are writing you off because you are a certain age really, you don't want that kind of feeling really.*

*A: Is that how you feel?*

*Both: Yes.*

*J: Oh yes well, I don't say it grieves me, but I still think that-*

*S: But I mean it's mostly old people, that have trouble with their eyes though isn't it.*

*Interview 2*

Both Jack and Sally felt that they were being written off due to their age. Jack tried to be accepting of this considering it as a normal part of getting older while Sally referred directly to the relationship between getting older and deteriorating vision.

#### **9.5.2.2 Confusion about cause**

Jack and Sally's inability to pinpoint the cause of their condition was exacerbated by their different experiences in the development of AMD. When asked "What do you think caused your AMD" the couple tended to speak for the both of them ('we') and worked together to co-construct an account of the cause of their condition:

*We don't really know what's caused it. I mean, we eat well. Don't we? [...] We don't do anything to bring it on. I don't smoke or drink or anything.*

*Jack, Interview 1*

During the first interview Jack referred to a variety of known risk factors for AMD (diet, smoking, alcohol); it is possible that these risk factors had been pointed out in the information given to Jack immediately following his diagnosis. Based on Jack's knowledge of risk factors he seemed to assume that an element of their behaviour must have caused the condition ("*We don't do anything to bring it on*"). By the second interview the risk factors considered at the first interview seemed to no longer be a concern:

- A: *So what do you think caused your macular degeneration?*
- J: *Old age I suppose, wear and tear! That's what they said to me.*
- S: *Well yes, but it wasn't, I mean mine started when I was about 55, well that's not old is it?*

#### *Interview 2*

At the second interview Jack portrayed the cause of AMD as part of the ageing process. It seemed that Jack related “wear and tear” to the bodily decline typically associated with old age. However, Sally’s experience of being diagnosed when she was 55 directly contrasted with this suggestion. Sally did not perceive 55 as old age and struggled to understand why she had developed the condition so early. This conflicting evidence combined with the differing experiences of the couple perhaps exacerbated their continuing confusion with their diagnosis. During the third interview the couple again referred to “wear and tear”:

- J: *Wear and tear they [health care professionals] said*
- A: *what does wear and tear mean?*
- J: *Just an ageing thing*
- S: *Just age, I think it's always been there, you know? They've always said old people can't see very well and I think that's just it*

#### *Interview 3*

By the third interview Sally no longer attempted to challenge the assumption that AMD may be related to the ageing process and instead embraced this suggestion. This interview was conducted (at least) 18 months following Jack’s diagnosis and the couple had had time to come to terms with their shared condition. It is possible that over time AMD had been incorporated into their sense of identity and the couple had moved on from trying to ascertain the reasons for their condition to a passive acceptance of AMD as part of the ageing process. This willingness to draw on the stereotypical image of an older person with poor vision was perhaps related to the couples registration as partially sighted which represented an official acknowledgement of their condition.

#### **9.5.2.3 Registering as partially sighted**

When asked about becoming registered as partially sighted at the first interview the couple were aware of this possibility but neither had become registered:

- A: *Are either of you registered as partially-sighted?*
- J: *No. They did talk to me about it, you know.*
- S: *They did to me as well.*

*J: They said you could be registered as part sighted.*

*S: For what reason?*

*J: They didn't do anything about it at that. Yes. But he said that you could be registered as part-sighted. Well what does that mean? What does it do? Does it open the door for different things?*

*Interview 1*

The couple was unaware of any benefits associated with registering. This lack of incentive to become registered was a barrier that the couple was reluctant to cross. Registration perhaps represented an acceptance of 'becoming old' and being labeled as such as this represented a further step on their life journey towards death. During the third interview Sally spontaneously explained that they had both become registered as partially sighted:

*We are both on the partially blind register now. [...] they asked me a long time ago to be registered, and I said 'well is there any point?' and they said 'no', but since he was registered he's been, they've helped him, given him a white stick and they've give him a watch he can see and he's got a code to ring [telephone provider] unless we can't see to get a number.*

*Sally, Interview 3*

Jack seemed to be more amenable than Sally, therefore when the recommendation to become registered arose he took it despite not expecting to receive any personal benefit. This perhaps relates to Jack's desire for attention from medical professionals (mentioned earlier). The provision of new equipment and services was an unexpected benefit which prompted Sally to also register. Once made aware of the value of registration the couple was willing to take this next life step together.

### **9.5.3 The future with AMD**

#### **9.5.3.1 Other health problems**

Throughout the interviews Jack and Sally tended to joke about the future, however at times they did highlight concerns about their ability to cope. Jack was conscious of the need to fulfil important day-to-day roles to ensure the couple could continue to live independently and feared that his combined health problems may prevent them from achieving this goal in the future:

*I won't always be able to do the shopping. I don't really know regards whether we will always be able to manage ourselves in the flat. We hope so. But if we get to the stage where I can't do the shopping, it might not just be because of my eyes though. I also have COA (chronic obstructive pulmonary disease)*

*Jack, Interview 1*

Whilst accepting that the future was likely to change, Jack clung to the hope that even with deteriorating health the couple would be able to continue to live together co-dependently in the flat in which they had lived for their entire married life (60 years). Jack felt he was managing well even with poor eyesight; however the threat of spiraling health problems which he could not predict was ever present. Like Jack, Sally was hopeful about their ability to continue to manage in the future. Sally's 'hope' was guided by the health professionals' suggestions about her prognosis:

*[the optician] did say and I'm hoping that is right, he said, 'you should be able to get round your flat, even if you can't get out, you'll be alright in situations where you know where you are'. I think before this gets a lot worse, I think something else would happen. Most of the people that we know that was in very good health, they've just had one thing wrong and they're dead.*

*Sally, Interview 1*

Sally felt reassured by her optician that AMD would never result in a complete loss of independence. However, Sally lived with a wide variety of other health problems which represented a greater threat than AMD. The couple gave many examples throughout the interviews of other older people who had suddenly and unexpectedly died and this knowledge seemed to leave them with a constant fear that they may lose their partner. The couple struggled with the uncertainty of not knowing when they may need to attempt to cope alone and how they would achieve this when the time came.

#### **9.5.3.2 Living alone**

As has been highlighted throughout this analysis Jack and Sally relied on each other to continue getting on with their lives. The 60 years of married life the couple had shared meant that their histories were inter-twined and life without their partner was unimaginable:

*S: When one of us dies, I think it will, when you're the two of you together, but I should hate to be without [Jack] and I think he'd hate to be without me wouldn't you?*

*J: Not worried about you the pension will go!*

*S: ((laughs))*

*J: ((laughs)) That's what you've got to keep living to draw your [pension]*

*S: Hang about, we should miss one another's company I mean, I mean we've been married 60 years this year, so and it's a long time.*

*J: Yes, I suppose it's a bit of a mistake in a way, but we've never really gone anywhere separate have we?*

*Interview 2*

It seems the consideration of the devastating event of bereavement may have been too threatening for Jack to consider and he instead made light of the situation by referring to the loss of Sally's pension. There were many occasions during the interviews where Jack used humor when faced with threatening thoughts about the future. The couple had mentioned that they were always able to laugh together, and this is perhaps one aspect of their relationship that helped them stick together through difficult situations. Some research examining examples of painful self-disclosure by older people, such as bereavement, suggested that these narratives are frequently accompanied by humor as a method for individuals to shift the narrative and convert painful life events into everyday matters which can be discussed easily and laughed about (Matsumoto, 2009).

Jack and Sally struggled to imagine a life without the one another and Jack wondered whether in some ways becoming so intertwined in each others' lives may have set themselves up for a difficult time when bereavement inevitably occurred. As is mentioned above the couple had seen many other couples separated by the death of a partner and this made their own mortality much more salient. Jack and Sally were aware of the possibility of the loss of their partner but were determined to continue "living together with AMD" for as long as their health allowed.

## **9.6 Summary**

Very few studies have looked at dyadic relationships and their relevance to the experience of disability. This exploratory qualitative case study has highlighted the importance of context when understanding experiences of older people living with vision loss caused by AMD. In particular, it lends support to claims that understanding dyadic relationships and the togetherness or 'we-ness' experienced is vital when considering the experiences of older couples (Esikovits & Koren, 2010; Koren 2009).

Jack and Sally lived together with developing AMD. Their past, present and future relationship was an important part of their experiences with the condition and they helped each other through living with the condition. Like the other participants they struggled to make sense of the cause of their condition and to get on with living their lives. Unlike the other participants, Jack and Sally had access to their shared and contrasting experiences in order to attempt to make sense of their own lived experience of AMD. Jack and Sally are a clear example of the need for the provision of holistic health care services which take into account patients' entire life contexts.

## **Chapter 10: Discussion**

### **10.1 Introduction**

The main research questions for this thesis were:

- What is it like to live with age related macular degeneration?
- How does living with age related macular degeneration impact on quality of life?
- Does the experience of living with macular degeneration change over time?
- In what ways is the experience of living with macular degeneration different for individuals with treatable or untreatable forms of the condition?

Throughout the studies presented in chapters 3, 4, 6, 7, 8 and 9, I have aimed to answer these research questions using a pragmatic mixed methods approach. The aim of this chapter is to consider the thesis as a whole and its implications for the development of theory and practice. Firstly I will summarise the key findings from each of the chapters. I will then go on to explain the ways in which these findings can contribute to health psychology theory and the use of mixed methods to inform evidence based practice. Next I will discuss some of the practical implications that come out of this research, possible limitations of the thesis, and reflexively consider my own role in the research process. Finally I will introduce possible avenues for further research.

### **10.2 Summary of findings**

The first study (chapter 3) aimed to explore how well the NEI-VFQ captured the experiences of patients. The study highlighted that surveys such as the NEI-VFQ (the most commonly used measure for assessing the improvements in QoL resulting from treatment and interventions with AMD patients) may underestimate the ongoing impact of vision impairment caused by AMD on patients' lives. For example, some of the NEI-VFQ subscales seemed insufficient for assessing changes for AMD patients as many of the issues discussed in the in-depth interviews were not addressed by the survey. In addition, many of the survey items were intertwined and in some cases indirectly related to visual impairment and therefore not picked up by the survey. Choices to provide treatment for AMD may be based on the results of improvements found on surveys such as the NEI-VFQ in addition to clinical improvements in visual acuity. This study concluded that evaluations of the impact of treatment on QoL for AMD patients needs to pay closer attention to qualitative data and the individual experiences of patients in order to understand the complexity and contexts of patients' lives.

The second study (chapter 4) aimed to build on the conclusions from the pilot study and develop a greater understanding of the qualitative literature into AMD. The meta-synthesis

presented has important implications for understanding the experience of AMD and the provision of services and support for patients. The review highlighted themes relating to: functional limitations, adaptation and independence; feelings about the future with vision impairment; interaction with the health services; social engagement; disclosure; and the emotional impacts of living with AMD. This study concluded that attention to the experience of living with AMD can help us to better understand the needs of patients. In addition the meta-synthesis study highlighted some gaps within the existing qualitative research into AMD. These gaps included; the need to investigate the different types of AMD separately, the need for longitudinal research, and the need to compare treatable and untreatable AMD. These issues have been further investigated in chapters 6, 7, 8, and 9.

The third study (Chapter 6) focused on Cathleen and Rowans, two participants with early dry AMD. The chapter presented four themes which were evident in the participants' accounts which were: making sense of AMD, getting on with life, interacting with the health services and the future with AMD. These themes were evident within the following three studies (with the exception of getting on with life which became living together with AMD for the final case study); however individual differences in experiences were evident. A key element of the experience of living with AMD for the participants with early AMD was the uncertainty about the future. Cathleen and Rowans both experienced some slight difficulties with daily activities, and while they were managing these at the time of the interviews they both hinted at the possibility of future deterioration and increasing difficulty. Early dry AMD is the first stage of the condition for many older people, some may not realise they have had early dry AMD as their first contact with the hospital will be when treatable wet AMD begins to develop. There is no certainty of progression to wet AMD, and for many individuals this does not happen. However, deterioration of vision is ongoing and out of the participants control; and it is that uncertainty and looming loss which seems to have the biggest potential to impact on QoL.

Study four (Chapter 7) analysed seven participants with treatable wet AMD. Like the participants in the first study these participants discussed: making sense of diagnosis; getting on with life; interaction with the health services; and the future with AMD. The most salient issue for these participants was their experiences of treatment. Treatment was a scary but necessary part of their journey through living with AMD. Almost all asserted that treatment was worth any distress or inconvenience it may cause and urged others diagnosed with AMD to go ahead with treatment if it was offered. Treatment represented the possibility, and for some the actuality, of improved vision and with it changes to QoL.

Study 5 (Chapter 8) explored the experiences of three participants (Hermione, Mary and Jessie) who were all living with advanced untreatable wet AMD. As with the previous studies

the participants discussed making sense of diagnosis; getting on with life; interacting with the health services; and the future with AMD. However, these participants also highlighted the challenges of disability and their attempts to reject this disability. Having lived with vision loss for many years these participants had had time to begin to accept and adjust to their vision impairment and suggested many coping strategies they used to continue to get on with their lives. However, increasing disability and the provision of symbols of disability in the form of aids challenged these participants' resolve to continue to get on with their lives as they always had and represented a new problem along their AMD journey.

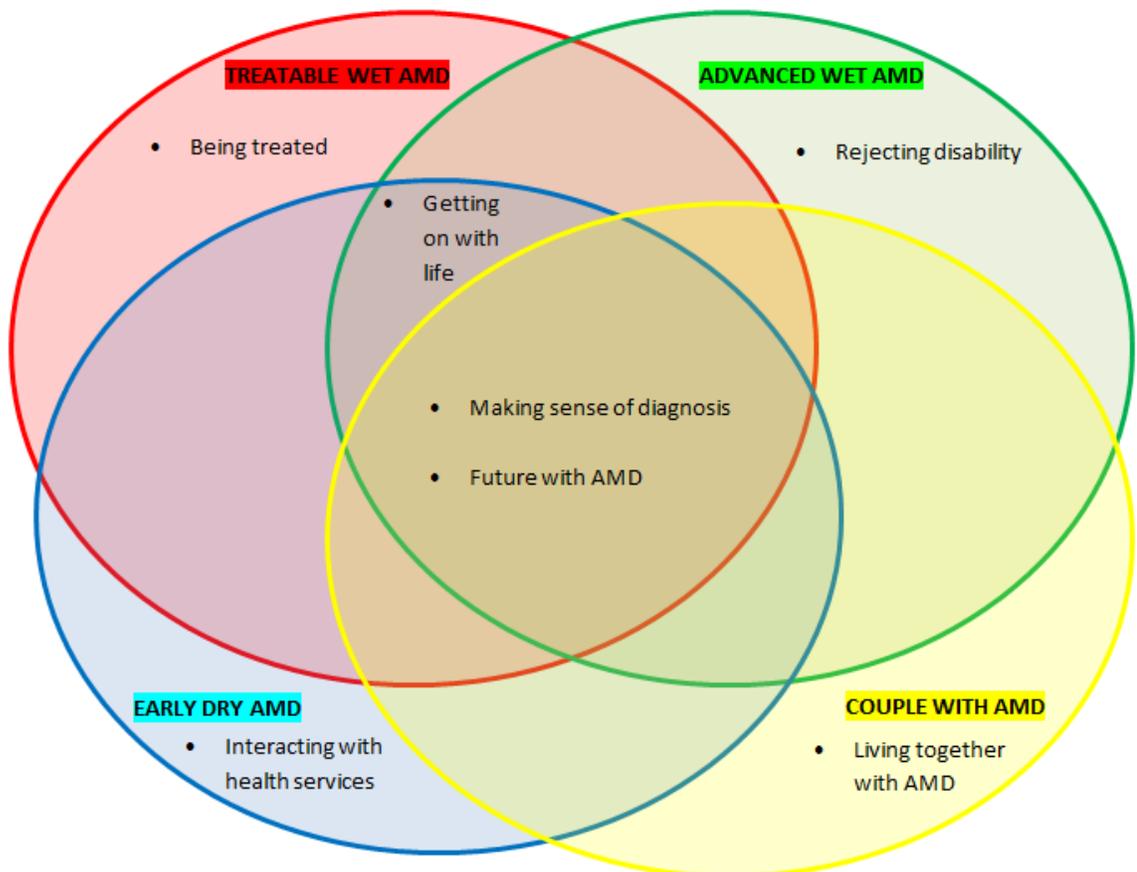
Study 6 (chapter 9) focused on Jack and Sally, a married couple living together with AMD. Sally had lived with dry AMD for many years while Jack had quickly developed advanced wet AMD over a short space of time. Like the other participants Jack and Sally talked about making sense of diagnosis, interacting with the health services, and the future with AMD. However, for this couple, getting on with life was an interaction as they were 'living together with AMD'. The couple's shared and contrasting experiences across their AMD journey had important implications for their understanding of their own condition. While in some respects the partners understood each other's lives with AMD, in others they were challenged by the apparent differences in experiences. Jack and Sally worked together in order to live their lives and each used the abilities they had to fulfil important daily activities. Jack summed up the couple's experience when he explained that AMD "chops your life in half". Most research investigating QoL has focused on individuals and has failed to address the importance of shared lives and spousal relationships.

Chapter 9 highlighted the importance of spousal relationships and shared experiences in old age which can be key determinants in individuals' QoL. Recently interest has begun to develop in the interrelatedness of couple hood in old age and health. For example, one longitudinal study (Hoppman, Gerstoff, & Hibbert, 2011) reported a link between functional limitations and depression in older married couples. In particular it was highlighted that functional limitations or depression in one partner can impact upon the functional limitations and depression of their spouse. In another study, collaborative coping (for example spouses pooling resources and engaging in joint problem solving) appeared to be associated with better mood and improved perceptions of the ability to manage stressful situations in couples where one partner was living with prostate cancer (Berg Weibe, Butner et al. 2008). Jack and Sally exemplify the importance of acknowledging the context of individuals' lives, including spousal relationships, when designing services for older people with AMD.

### 10.3 Shared and divergent experiences

It is evident that the participants experiences explored in this thesis exhibited elements of both shared and divergent experiences. As figure 20 (originally discussed in chapter 5 and replicated here) illustrates, the participants all discussed issues regarding making sense of diagnosis and their futures with AMD. Getting on with life was also important to the participants sense of wellbeing and quality of life, and for the couple living with AMD this included the ability to get on with life as a couple. In addition, each of the participant groups described elements of experience which were of unique importance to the subgroup. These differing experiences highlight the need to tailor support to individual circumstances rather than taking a blanket approach to caring for and treating patients with AMD. The importance of these shared and divergent experiences will be discussed further in the later sections of this chapter.

Figure 21: Overview of themes for the sub-samples



## **10.4 Contributions to health psychology theory**

Throughout this thesis I have drawn attention to the importance of attending to context and the *lifeworld* when understanding the experience of chronic illnesses such as AMD. Health and illness have traditionally been understood from the biomedical model (Wellard, 1998) and this thesis has challenged concepts based on individualistic and biomedical frameworks by illustrating the relevance of other elements of the *lifeworld* to patients' understanding and experience of their condition.

### **10.4.1 Contributions to knowledge about the experience of chronic illness**

The themes discussed in the phenomenological work illustrate the issues faced by individuals diagnosed with a long term degenerative condition. There was evidence of underlying shared themes within these chapters which can be related to existing sociological and psychological research into the experience of chronic illness.

#### ***10.4.1.1 Causation accounts***

Each participant was asked what they felt was the cause of their condition at each interview they participated in. A wide variety of potential causes were suggested by the patients (e.g., age, wear and tear, over use of the eyes, trauma to the eyes, cataract surgery, etc). Previous research has suggested that accounts of causation may change over time (Lawton, Peel, Parry, & Douglas, 2008) and this was highlighted across the interviews in this study. In the theme 'making sense of diagnoses' it was evident that some of the participants reported subtle changes in causation theories over time. For example, Nuxy at first assigns his AMD to experiencing a trauma to his eye in his 20s and later considered whether he had at some point abused his eyesight, Jack initially seemed unsure of the cause of AMD and later related the cause to 'wear and tear' and old age, and Cathleen spent time continually searching for a cause for her condition. This evidence of changing causation accounts over time indicates possible problems with the use of social cognition theories to explain compliance to clinical recommendations. In addition, other evidence has suggested that people may embrace particular causation accounts in order to justify certain behaviours (Hunt, Jordan, & Irwin, 1989). This argument was also supported within this thesis, for example Ruffine referred to her assumption that over use of the eyes caused AMD when explaining her decision to reduce the time she spent reading and watching television. The health belief model assumes that beliefs precede behaviour, however if beliefs are constantly changing then interventions based on the assumption of static beliefs about cause may not improve compliance. Health care professionals need to be aware that patients' *lifeworlds* are not static and individuals' perceptions of their condition are therefore informed and influenced by their personal experience (Lawton et al., 2008). In addition, understandings of how a patient makes sense of

their condition (their illness representations) is important as evidence suggests a predictable relationship between illness cognitions, coping and other outcomes (Hagger & Orbell, 2003).

AMD was most commonly assigned to 'age' by the participants. While AMD is an age related condition this attribution may also indicate the risk of older people experiencing symptoms of AMD and not seeking the health care assistance they require as they assume it is a 'normal' part of the ageing process. Many of the participants explained that they had been unaware of their condition until being informed by an optician or other health care professional despite having experienced evidence of their deteriorating vision in their day-to-day lives. This finding illustrates the presence of internalised 'implicit ageism' (Levy and Banaji, 2002) and the assumption that many chronic illness experiences are a 'normal' part of ageing.

#### ***10.4.1.2 Biographical disruption***

The experiences of the participants have illustrated the way in which AMD can disrupt usual ways of being-in-the-world (Heidegger, 1927/1962) and it was evident that many of the experiences described by the participants reflected the theory of 'biographical disruption' (Bury, 1982). Bury (1982) suggests that biographical disruption can impact upon every aspect of an individual's life including; disrupting relationships and increasing dependency, causing the need to re-examine thoughts and ideas about the future, and bringing the worlds of pain and suffering and the possibility of death into focus rather than merely distant possibilities. The symptoms resulting from disabling conditions can "disrupt the normal flow of everyday life and introduce a growing sense of uncertainty into it" (Bury, 1997, p. 124). This uncertainty relates to Heidegger's concept of being-towards-death and the anxiety resulting from being conscious of our inevitable mortality. This had clearly been the case for these participants who were trying to get on with their lives despite their diagnosis and other illnesses and were left with disrupted relationships, increasing dependency, and a sense of uncertainty about their futures.

According to Bury (1982) biographical disruption is likely to begin with the "disruption of taken-for-granted assumptions and behaviours" (p. 169) which brings usually unconscious bodily states into focus and consciousness. This relates to the work of the philosopher Merleau-Ponty (1962) who described people as 'body-subjects' and argued that we know the world only through our own embodied position within it. The participants in this thesis had come to know the world around them through their bodies. Changes in bodily capabilities brought about through the loss of vision transformed usually taken for granted experiences into issues which needed conscious consideration. As a result the participants needed to make sense of and come to terms with new ways of experiencing the world. These new ways of experiencing the world were often interpreted as a discrepancy between 'body' and 'mind'. Corbin and

Strauss (1991) have argued that “to be disabled means your body has failed you” (p. 138) and this is how many of the participants spoke about their AMD. For example, many of the participants described incidents in which they became frustrated when they struggled with previously taken for granted activities such as walking down the street, making a cup of tea, or reading the paper. The mind and the body are linked within the *lifeworld* and this is evident in the psychological impacts of the condition on patients. It is evident that there is a need for holistic services which incorporate more than just a focus on ‘the body’ and incorporate a wide range of support to assist patients to adapt to the impact of the condition.

The second element of biographical disruption described by Bury (1982) is the “fundamental rethinking of the person’s biography and self-concept” (p. 169). This relates to Heidegger’s “temporality” and helps to address one of the key research questions within this thesis; whether the experience of AMD changed over time. It is evident from looking at the thesis as a whole that the participants’ experiences showed some evidence of change over time (i.e. accounts about cause, adjusting to treatment), in addition those with early AMD illustrated subtle differences in experience to those with late AMD (i.e. looming loss, and adapting to the condition) suggesting possible changes in experience across the course of the condition. An important issue highlighted by this thesis is the impact of the passing of time on experiences of AMD. Heidegger talks about the way in which individuals are situated within the passage of time (being-in-time) and are inextricably linked to the world in which they are situated (being-in-the-world). A key aspect of this is the way in which our past, present and future are interlinked and interact with one another to create possible selves.

The third element of biographical disruption is “the response to disruption involving the mobilisation of resources, in facing an altered situation” (Bury, 1982, p.169-170). Many of the participants in this study refused to be passive victims limited by the disabling effects of AMD. For example many participants were determined to remain independent and used resources such as equipment, friends and family members, and other senses, in order to manage and get on with their lives despite the difficulties they faced. In comparison, a few participants such as Mary (Chapter 9) seemed to give in to their circumstances and used resources in other ways by accepting assistance from others including health care professionals and family members and accepted increasing dependence. This adaptation is also related to the individuals’ re-thinking of their self-concept or identities during attempts to find new meaning in their lives. Most participants seemed determined to hold on to their past self-concept as independent people despite the changes in their bodily experience while a few adjusted their self-concept to become a ‘dependent’.

These changes were forced upon the participants with AMD and while in some ways the participants were managing to adapt to their changing experience they also gave frequent examples of distress and frustration. In order to manage the impacts of identity changes there were instances when the participants with all types of AMD described difficulties as part of 'normal' biographical transition from youth to old age. This narrative of ageing has also been reported in older people with stroke or arthritis and prevents the need for a qualitative shift in self-identity (Pound, Gompertz and Ebrahim, 1998; Sanders et al., 2002). The participants seemed to be attempting to reconcile the contrasting 'selves' they were experiencing as a result of biographical disruption. In one respect they still felt they were the stable identities of the younger people they had once been and were determined to continue to get on with their lives and that they were just getting older. However, they were also battling with their identities of being older people with AMD whose bodies were letting them down. This battle was reflected in the way the participants often told stories of difficulties and embarrassing situations alongside the presentation of cheerful stoicism. In this way the participants were negotiating their identities by providing both 'public' and 'private' accounts (Cornwell, 1984). The public presentation of 'cheerful stoicism' and 'mustn't grumble' attitudes is common in older people and contrasts with Cornwell's (1984) suggested 'private' accounts which are more sensitive to negative bodily experiences. The participants seemed to repeatedly change between public and private accounts during the interviews in their attempts to manage and take control of their conflicting identities. Accounts of co-existing stable and disrupted identities have been reported in older people suffering from conditions such as arthritis (Sanders, et al., 2002) and so may reflect a common part of the ageing experience. This is an interesting finding which suggests that attempts to change and retain self are fluid and dependent on the context the individual is in. This is something worthy of further research and exemplifies the need to understand the experience of ageing more fully.

Biographical disruption leaves individuals with a sense of uncertainty about their lives and future biography. This is related to Heidegger's concept of being-towards-death experienced when the inevitability of mortality is made conscious. This was clearly the case for the participants in this thesis who were not only uncertain about their long term future but faced uncertainty about their abilities on a day-to-day basis. This was particularly salient for the participants with early AMD (chapter 7) whose diagnosis with AMD left them with a looming sense of loss and uncertainty about their futures. The participants attempted to make sense of their experiences within the context of their own lives and each participant's interpretations were based on their own individual experiences. However, no past or current experiences could prepare them for the potential uncertainty of their futures.

### ***10.4.1.3 Stigma***

Stigma is a common issue within chronic illness research (i.e. Goffman, 1963). Many of the participants were attempting to come to terms with their bodily changes and the associated stigma of having a disabling condition. Human beings cannot avoid being 'thrown' (Heidegger, 1927/1968) into a world where difference is often discriminated against. Goffman (1963) described stigma as something which reduces the bearer "from a whole and usual person to a tainted, discounted one" (p. 3) and distinguished between two types of 'spoiled identity' which result from the acquisition of disability; 'discredited' and 'discreditable'. While individuals who are 'discredited' have an externally perceivable source of stigma (perhaps a wheelchair), those who are 'discreditable' have an invisible source of stigma. Individuals with AMD could be labelled as 'discreditable' as their visual impairment is only perceived by others if they make it so (i.e. by using a magnifier or holding a white cane). Goffman (1963) suggested that these 'discreditable' individuals are likely to be preoccupied with managing the way in which they are perceived by 'normal' others. 'Discreditable' individuals are constantly making choices about whether "to display or not display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case to whom, how, when and where" (p. 42). We can see these choices mirrored in the experiences of many of the participants throughout this thesis. This was particularly relevant for the participants with advanced untreatable AMD as each woman was making choices in order to manage the information available to others and the ways in which they were perceived. An example of this is the way that Jessie's choices about when and how to use her white cane enabled her to manage when and how individuals were made aware of her condition. The idea of 'discreditable' identities relates closely to the issue of felt stigma which has been widely discussed in the epilepsy literature (e.g. Jacoby, 1994, Sankar, Cho, Wolpe, & Schairer, 2006). Enacted stigma refers to actual discrimination whilst felt stigma is the fear of such discrimination (Scambler, 1998). These women did not speak of enacted stigma, whereby they experienced direct discrimination as a result of their condition, instead they talked about the fear of potential stigma or "felt stigma" which they may experience if others became aware of their condition. As suggested by Goffman (1963), these women were making decisions about when and how to share information about their condition as a result of "felt stigma" resulting from their potentially 'discreditable' identities.

### ***10.4.1.4 Compliance and doctor-patient communication***

The introductory chapter to this thesis discussed the way in which social cognitive models such as the Health Belief Model (Rosenstock, 1966) have been traditionally used to explain patient compliance. The findings of this thesis illustrate that there is more to decisions about compliance than this model advocates (i.e. perceptions of; susceptibility to disease, severity or seriousness of disease, benefits of health action, and barriers to performing action) as

patients live within their own *lifeworlds* and all aspects of this *lifeworld* can have implications for compliance to medical recommendations. For example, the model overlooks the impact of social relationships and relationships with health care professionals (HCPs). It has been reported that perceptions of HCP's behaviour and comments can influence patients' views regarding the severity of their condition (Troughton, Jarvis & Skinner, 2008). This was found in the case of Mary who became increasingly distressed (to the point of believing she may have cancer) as a result of her perceptions of the HCPs behaviour. In addition, Rowans discussed the importance of 'trusting' the HCP and the way his perceptions of their behaviour influenced the choices he made regarding the advice given. Trusting relationships with HCPs can both promote and constrain health related behaviours. For example, in the case of early dry AMD the acceptance of the HCP's medical authority meant that patients like Rowans may not see monitoring vision (via the Amsler grid) as something they should be responsible for and instead may rely solely on opticians and HCPs. Patients' reliance on their HCPs judgements raises questions regarding informed consent. Often patients accept HCPs decisions regarding their health as they are perceived to be the 'experts' (Goyder, Carlisle, Lawton, & Peters, 2009). This is a failing of the traditional medical model of health care which positions patients as 'passive' recipients of care and may indicate commonly held beliefs in older people who have lived much of their lives receiving this model of health care. More recently the 'patient-centred' approach to health care (DOH, 2005) has gone some way to change this by empowering patients and giving them an element of 'choice' in their care. However this could be taken further by acknowledging that patients and HCPs have different types of 'expertise' as the HCP has clinical and technical knowledge while the patient has experiential knowledge of what it is like for them to live with the condition (Dahlberg, Todres, & Galvin, 2009).

#### **10.4.2 Contributions to the use of mixed methods to inform Evidence Based Practice**

In the past evidence based practice (EBP) has been mainly informed by quantitative research (particularly RCTs and reviews of RCTs) which have tended to group patients into those with AMD and those without and failed to acknowledge the inherent differences in experience across the spectrum of the condition. My pilot mixed methods study illustrated that questionnaire data is unable to fully understand the meaning of AMD to patients while my meta-synthesis has highlighted limitations in qualitative studies conducted to date which has overlooked the different 'types' of AMD and the importance of the *lifeworld*.

Current guidelines for practice with patients with AMD are particularly focused on decisions regarding anti-VEGF treatment and fail to adequately address the needs of patients at other 'stages' within the disease continuum. The NICE (2008) treatment guidelines use objective

clinical measures (such as visual acuity) as the basis for decisions about treatment, however it is evident that the patients themselves may make different treatment decisions based on their daily experience with the condition. For example, Jordan did not experience any of the clinical benefit of her treatment and therefore was severely emotionally affected by the experience. As there are no guidelines with regards to assisting patients with the emotional impacts of the condition these experiences are likely to continue to affect quality of life. While the guidelines produced by the Royal College of Ophthalmologists (2009) have tried to go some way to improving the experience of all patients in terms of communication between HCPs and patients, they are based on the clinical experience of 'experts' in the field who have used their own observations to develop the practice recommendations. In light of the experiences presented by the participants in this thesis it appears that the recommendations are insufficient in terms of the experiences of patients themselves. For example, there appears to be an over reliance on leaflets and written information within the recommendations. Based on the experiences of the participants in this research it would seem these methods are not suitable for many patients who find reading difficult due to their vision loss. This is an example of where 'expert' opinion and patient experience differ and highlights the need for the incorporation of experiential patient data when developing guidelines for practice.

In addition, it would seem that much of the 'advised' information in the Royal College of Ophthalmology guidelines is not getting through to patients. For example, few of the participants were aware of the specific benefits of vitamin supplements, the risk of smoking, their prognosis and what to look for to identify AMD progression, the possible side effects (such as CBS), or whether there were non-medical treatment options (such as counselling) available. All of these are listed as recommended information to be given to patients at diagnosis within the guidelines. More work is clearly needed into assessing HCPs perceptions and use of guidelines and the ways in which guidelines may be utilised in order to make a bigger impact on practice. Experiential work into the use of the guidelines by HCPs may help to illuminate why the required information is not adequately being passed on to patients.

By including chapters dedicated to subsamples of participants with AMD I have been able to take an idiographic approach to exploring the research question: 'What are the differences in experiences between the types of AMD?'. My thesis has highlighted there are many shared elements of the experience of living with AMD regardless of the type and availability of treatment, however, chapters 6-8 have illustrated elements of the experience which are particularly salient for certain groups of participants at specific stages of AMD progression which should be taken into account when developing practice guidelines.

For individuals with early dry AMD there is a feeling of being on the edge of disability. These participants are still able to continue with their lives in much the same way as they had been used to as early AMD had little impact on their day-to-day lives. The finding that early AMD has significantly less impact on visual functioning and day-to-day life than late AMD has been reported in both clinic and population based quantitative studies (Lamoureux, Mitchell, Rees et al., 2011; Mangione et al 1999). What was important to the experience of these participants with early AMD was the way in which subtle changes in day-to-day experience and the threat of increasing disability were a constant shadow hanging over their lives. This realisation would not have been available through the use of quantitative measures and highlights the value of experiential research in understanding the experiences of patients.

For individuals with wet treatable AMD the treatment experience was understandably the most salient element of their experience. Treatment was an unpleasant but necessary experience which began as a source of anxiety but once participants had opportunity to reflect on the experience and consider the impacts of treatment for their futures it was incorporated into the routine of day-to-day life. This has been the first study to investigate in detail the experiences of patients undergoing Anti-VEGF treatment for AMD and has highlighted some important elements of the experience. Treatment takes place within the context of a patients' whole life, past experiences, 'horizons' etc and therefore quantitative measures of QoL only go part way to understanding this.

The participants with advanced wet AMD had reached a stage where they were coming to terms with irreversible vision loss and attempting to renegotiate their identities in light of this. In particular, they were attempting to avoid stigma and create continuity within their sense of self through the rejection of disability. For these participants to make sense of their existence priorities were rearranged to emphasise the importance of getting on with life. These patients may be left abandoned by the health service as they are no longer eligible for treatment. However, this research has highlighted that even at this stage of the disease process it is vital to continue to support patients. By offering support and assistance to patients at the earliest possible stage of the condition it may help patients to adjust and adapt to changing circumstances more easily and achieve the goal of 'getting on with life'.

#### **10.4.3 Relevance to quality of life literature**

By looking at the experiences of participants with AMD this thesis has attempted to address the research question: What is the impact of AMD on quality of life? The literature review in chapter one highlighted the way in which much of the research into QoL is focused on functional decline. This study attempted to take a wider holistic view of QoL based on the experiences of older people themselves as has been recommended by Gabriel and Bowling

(2004). The studies presented in this thesis suggest that the participants took a more global view of QoL. For example, the pilot study illustrated that considerations of health and QoL were made based on more than functional ability; some participants rated health and QoL highly regardless of poor physical health or functional ability. The discussions about QoL with these participants seemed to lend support to Bryant et al.'s (2001) model of healthy ageing in older people which proposes that being healthy is related to the ability to 'go and do' meaningful activities. Many of the participants within this research highlighted the need to achieve meaningful activities (such as shopping, meeting with friends, volunteering, and doing household chores) in order to feel they were getting on with their lives and that their lives had 'quality'. As was discussed in the pilot study the participants' interviews tended to associate 'health' with more than functional abilities and the absence or presence of illness. Health also related to how well they were getting on with their lives. It was only at times when getting on with life was restricted in some way (such as restricted mobility) that the participants believed that there had been deterioration in their health and QoL. For example, Ruffine explained that when her mobility was restricted by leg problems and she could not get out of her flat as she usually would she felt her health was poor. This again supports the need for acknowledging the *lifeworld* of patients when providing care and designing services. From a phenomenological perspective health often means 'to be able to', or in other words being satisfied with your ability to carry out minor and major life projects (Smith & Lloyd, 2006). The presence of illness often disrupts this ability 'to be able to do' and health care needs to find ways to assist patients to come to terms with this and re-enable them 'to be able to' do activities which make their lives meaningful. Bryant et al suggest four key features of healthy ageing; having something worthwhile and desirable to do, possessing the required abilities to meet perceived challenges, obtaining the necessary resources, and having the will to go and do. All of these elements need to be considered when providing services for older people. These needs will be explored further in the practical implications section that follows.

## **10.5 Practical implications: Recommendations for providing health services to patients with AMD**

This next section draws together some of the practical and clinical implications which have been raised throughout this research and makes suggestions for further research which may expand upon the issues highlighted in order to provide concrete recommendations for practice.

### **10.5.1 Evaluations of interventions, treatments, and the impact of services**

Most clinical studies rely on quantitative measures of QoL in order to justify and make decisions about interventions and treatments. QoL measures such as NEI-VFQ may miss

important elements of experience (as discussed in the pilot study). Ratings on the scales may change in different directions dependent on individuals' experiences. This finding has been exemplified in phenomenological work in this thesis which has shown that the way in which individuals interpret their diagnosis and the cause of their condition may have important implications for their QoL. For example participants may change activities based on these understandings (i.e. giving up reading to ensure they don't "use up" remaining eyesight).

The evident varying experiences of patients with treatable AMD suggest that clinical measures alone may be insufficient to address the impact of AMD. Patients therefore need more than clinical treatment in order to come to terms with the condition. One possible source of support highlighted in this thesis would be support groups and meetings in which the participants have shared experiences of AMD. These groups can act as a source of support, advice, and social comparison which help AMD patients cope with their experiences. In addition, AMD restricts opportunities for social engagement in a variety of ways, recognising faces, losing driving ability, mobility problems and problems with public transport. These factors can restrict individuals with AMD and in turn impact on QoL. Supporting patients to remain socially engaged is vital to ensure their long term QoL.

#### **10.5.2 Information provision, communication and empowerment**

A systematic review of the health information needs of patients with visual impairments has illustrated the paucity of research in the area of information and communication with visually impaired patients (Beverley, Bath & Booth, 2003). The experiences of the participants in this research suggest that patients may be left bewildered and confused following diagnosis with AMD. For patients who are not eligible to receive treatment there is no prospect of improvement in their visual abilities and it is evident that patients may struggle to come to terms with the uncertainty and inevitable deterioration. The distress caused by diagnosis with AMD may be in some way reduced by ensuring that patients understand the information they are given about the condition and ensuring that they know what to expect with regards to visual changes.

It is clear that during appointments many of the participants did not feel empowered to ask questions and clarify information with HCPs. For example, Rick saw the HCPs as the 'experts' with whom he was unable to argue and therefore had a passive role in his care. Another example is Cathleen who felt unable to ask for information directly from the professionals in clinic for fear of being a burden, she therefore collected information elsewhere, leaving her at risk of misunderstanding important information regarding her condition. More needs to be done to improve communication between HCPs and patients and even the balance in the power relationship between the two. An example of unsuitable information provision was that

AMD patients in this research were given leaflets as a source of information about their condition. Leaflets are often not based on any form of theory or research evidence (Abraham, Krahe, Dominic and Fritsche, 2002), and for individuals with visual impairment leaflets may not be the most suitable medium for the delivery of information forcing individuals to seek information elsewhere (Beverley, Bath, & Barber, 2011). A clear example of this can be seen in Jessie's experiences as she was given leaflets and written information but avoided reading them due to the difficulties she experienced when reading. In addition to information leaflets, patients also recounted troubles reading letters regarding their condition. This has important implications for patient confidentiality and feelings of independence as individuals may be forced to rely on friends or family members to read letters and other information.

Another issue raised in this thesis is the problems encountered by patients with AMD when reading small print. In particular patients may struggle to read information provided with medication, therefore leaving them at risk of incorrect dosage or administration. Alternative methods of administering this information may go some way to addressing this issue (Raynor & Yerassimou, 1997). Letters were a major source of confusion and frustration for many of the participants as they did not understand what appointments were for, or were unable to read the letter themselves and had to rely on the help of family members. Even practitioners acknowledge that letters may be unsuitable for many patients as even when comprehensive information is provided the dense text and difficult concepts described may be problematic for the patients to understand (Goyder, Carlisle, Lawton, & Peters, 2009). Alternatives such as telephone help lines may be an easily and relatively inexpensive means of providing access to this information (Goyder et al., 2009; Raynor, 1994).

The most important issue highlighted in this thesis is that AMD patients have different information needs depending on a variety of factors such as their diagnosis type, stage of disease, prior knowledge of the condition, availability of treatment, life history and context. Visually impaired people are a heterogeneous group (Beverley, Bath & Booth, 2003), and this should be taken into account when designing information formats and providing information to patients.

### **10.5.3 Low Vision Rehabilitation (LVR)**

All of the participants mentioned the provision of LVR, this was usually in the form of the provision of optical aids such as magnifying glasses and non optical aids such as "bump ons" (small tactile bumps placed on kitchen equipment such as ovens to mark specific temperatures). Despite the value of LVR for improving visual function (highlighted in the literature review in chapter 1) some participants felt they waited a long time for this support to be provided (only at the 18 month interviews was full support given to Jack and Jordan). Once

this support was given these participants talked about the benefits of these services. For example, Jordan enjoyed listening to her new radio with large clear buttons and made use of this on a daily basis. This gave Jordan something to do in times when, in the past, she would have sat and begun to dwell on her condition.

As was highlighted in the literature review in chapter one, the provision of low vision aids and lighting advice can give considerable benefit to patients (Lamoureux et al. 2007). This research has suggested that there may be scope to provide these services at an earlier time point in order to help older people with AMD maintain their QoL. Reeves et al (2004) reported that advanced LVR resulted in little improvement in QoL; however the provision of standard LVR did have more benefits than no LVR. However, this thesis has also highlighted that some participants are not ready for LVR, for example Rowans saw no need for support as he felt his vision was good, and Hermione did not feel ready to take the next step towards seeking aids for her vision. Therefore care needs to be taken when introducing the possibility of assistance and acknowledgement that patients need to maintain independence is required in order to maximise the uptake of these services.

The participants in this research did not mention many opportunities for group support and education. The literature review in chapter one highlighted the benefits of these types of service and therefore this seems to have been under used in this sample. Many of the participants expressed a desire to remain socially engaged and the use of social comparison as a coping strategy to deal with their own limitations. In addition, some participants expressed surprise when they learned many other older people shared their condition (for example when they witnessed the number of patients in the waiting room at hospital appointments). This suggests that the development of group support and interventions may have been beneficial for the participants' in this sample as an opportunity to discuss their experiences with others in the same situation as themselves. Group support has been shown to be both attractive to and beneficial for patients with other conditions (i.e., Hegelson, Cohen, Schulz and Yasko, 2000).

#### **10.5.4 Self management interventions and support groups**

As is discussed above none of the participants reported being involved in self-management interventions despite evidence that these programmes can improve mood and function and reduce depression (Birk et al., 2004; Brody et al., 2002). It seems that these types of programmes were not perceived to be available for the participants despite the possibility of involvement in support groups, the Macular Degeneration Society, and monthly meetings to discuss AMD with others. It seems the elements of social support and the opportunity to meet others with the same condition (which became a source of social comparison often

highlighted as a coping strategy by the participants) could help participants to make sense of living with AMD. This supports the findings of previous research which has suggested that the elements of interventions providing the most support to patients were the opportunity for social comparison and the support of meeting others with shared experiences (Birk et al. 2004; Dahlin-Ivanoff et al. 1998). These elements of support provide meaningful activities for older people to 'go and do' and may provide the resources needed to facilitate the achievement of goals. Self management interventions and group support are therefore great opportunities for 'healthy ageing' as defined in Bryant et al's (2001) model.

#### **10.5.5 *Lifeworld- led healthcare***

Throughout this research I have attempted to portray the need to take a more lifeworld-led approach to health care. The current medical focus on treatment of the eyes and improvement of visual function is insufficient for reconciling the internal conflict experienced when living with AMD which fundamentally challenges patients taken for granted ways of being-in-the-world. Interaction with health services was an important aspect of the experience of living with AMD and improvements in this area could lead to overall improvements in the quality of life of patients.

Early intervention in the form of emotional support and referral to other organisations such as social services would help to provide a more holistic service and may overcome some of problems resulting from visual impairment (Norwell and Hiles, 2005). Time and funding restraints experienced by ophthalmologists and other HCPs are likely to prevent in-depth discussion and recognition of a patient's *lifeworld* within routine appointments. However, the provision of dedicated staff members who act as 'lead workers' and co-ordinate services holistically would ensure that all the needs within a patients' *lifeworld* are addressed. This would attend to many of the issues discussed above and in turn improve the long term quality of life of patients' reducing the need for more costly services at a later date. This service has existed to some extent within NHS clinics through the Royal National Institute of Blind People funded provision of Eye Clinic Liaison Officers (ECLO). No standard job description exists for ECLOs however the key responsibilities for this role are the provision of: advice about registration and certification, information on eye conditions, access to emotional support, referral to other agencies (such as social care), a bridge between clinical and social services, and support for the family (Subramanian, Conway, & Gillespie-Gallery, 2011). At present this service is not provided consistently within clinics across the UK and variability is evident in a wide variety of areas (e.g. the role title, qualifications, appointment system, availability in clinic, consistency of referral, etc.) (Subramanian et al., 2011). Despite support for the service from the Royal College of Ophthalmologists, funding for roles such as the ECLO are at risk in

some Primary Care Trusts (Macular Disease Society, 2012). The evidence presented in this thesis highlights the need for tailored support services such as the ECLO to be provided within all NHS eye clinics. In order for these to be most effective they should be based on a lifeworld-led health care model which incorporates all aspects of patients' *lifeworlds*. Solihull hospital eye clinic provide a unique service using this model which is funded by the NHS. Patients diagnosed with a condition causing vision impairment are referred to a service which includes a two hour holistic interview and needs assessment which incorporates all aspects of a patients' life context (e.g. living situation, mobility needs, diet, smoking behaviour, daily activities etc) (Personal Communication, 2012). While the national statistics for the register of blind people suggest a decrease in the number of new registrations between 2008 and 2011 (NHS, 2011) the Solihull clinic have reported a steady increase in the number of registered patients (Personal Communication, 2012). As the number of registered patients is used as an indicator for the need for service provisions this disparity suggests that there may be a nationwide underestimation of the level of funding required for supporting patients with vision impairment, therefore putting roles such as the ECLO at even higher levels of risk.

#### **10.6 Limitations of this thesis**

The initial study presented in chapter three was largely limited due to sample size. As a result no firm conclusions could be drawn from the quantitative data presented in this chapter. In addition, given the findings regarding the use of written information with AMD patients, the use of self-completed paper questionnaires was a key limitation of this study. Uptake in the study and the amount of data obtained may have been improved through the use of questionnaires administered via telephone and this should be considered in future research.

A limitation of the qualitative studies presented is the inclusion of only white British older people. As is mentioned in the introduction AMD has a much higher prevalence rate in Caucasians than in other races (Cook, et al., 2008). One South Asian participant was recruited at the beginning of the research however language barriers resulted in her data being unsuitable for the purpose of this research (and she was also unable to be contacted at the time of the second interviews). Older people from minority groups living in the UK with AMD are an under researched population. It seems that no research to date has been conducted looking at the experiences of these older people, and this information would be invaluable when designing support services.

Another limitation is the qualitative chapters of the thesis present data from small samples. However this is a necessity for IPA which required small homogenous groups of participants (Smith et al., 1999). Homogeneity in the groups was not entirely possible (though the groups did all share the type of vision impairment experienced) and therefore care has been taken to

provide contextual information about the participants to assist with generalisation where possible. In addition, the level of detail provided by these examples may be transferrable across settings and populations (Yardley, 2000). For example it has highlighted the need to know about older peoples' life context and significant others in order to understand how well they may be able to adapt to new situations such as progressive disability.

### **10.7 Future Research**

Future research could add to the findings of this research in a wide variety of ways. Firstly within research into AMD itself it is evident that there is a need to evaluate the outcomes and feasibility and costs of providing holistic lifeworld-led care (such as within the ECLO service). Evaluation of these services could lead to recommendations for standard practice to be incorporated across the health service. In addition new methods of providing information to patients should be developed and evaluated to ascertain the best way to ensure patients are adequately informed about their condition. I would also suggest that in-depth experiential research with the providers of ophthalmology services could help to understand the facilitators and barriers to providing information and holistic care to patients.

This research has highlighted the strength of using a pragmatic approach to mixing methods in order to inform evidence based practice. More research needs to be done into the ways in which different research methods can be incorporated into the guidance for practice and the uptake and clinical use of this information by health care professionals.

### **10.8 Reflexivity**

It is important to acknowledge my own impact on this research and how my involvement as a researcher, interviewer, and analyst has shaped the outcomes of this thesis. Throughout my time interviewing it became evident that I was building rapport with my participants. They seemed to see me as a potential source of information due to their knowledge of my discussions with other people who shared their condition. I was asked a wide variety of questions about treatments, causes, what AMD may be like for them in the future which are likely to have been key to my focus on these issues within the thesis. I believe that as these were the areas I was asked about it was also clear that these issues were important for the participants themselves.

Given the proximity of my age to the ages of the participants' grandchildren I felt many of the participants seemed to treat me in some ways as a surrogate grandchild. Reflecting on my knowledge at the start of this thesis I may also have been seeing my participants as surrogate grandparents and comparing their experiences with my knowledge of my Nan's experiences with AMD. The interviews were led by me but I was aware that my participants were (probably

unconsciously) challenging this as they asked me questions about myself, my personal life, and what I planned to do in the future and the participants were also keen for me to stay in touch with them at the end of the research. This brought up important ethical questions for me regarding my relationship with my participants and I continually attempted to make it clear that I would contact the participants with a summary of my findings at a later date. I did complete this summary and a few of my participants contacted me once again to thank me for the information. This gave me a feeling of pride as they appeared to have understood the information I provided and I hoped in some way it had helped them make sense of their own experiences.

I also became invested in some of the lives of my participants. In some instances I raised concerns with my supervisors about problems the participants were facing, which may have prompted these participants to receive further attention from the health care professionals. For example, Mary was very distressed about her condition and concerned about her future, she had explained to me she felt depressed. I asked my clinical supervisor (Jon Gibson) to contact this participant and Mary later mentioned this contact as a pleasant experience which helped to put her mind at rest. These elements of my experience with the participants highlighted the value my participants tended to place on personalised care and building relationships with those providing care and services.

My determination to ensure my analysis would make sense to my participants meant that I avoided engaging with the phenomenological literature as far as possible within the results chapters. I instead chose to bring this literature in to highlight salient aspects of my findings during my discussion. I deliberately took this approach as I feel that sometimes research can become overwhelmed with 'theoretical language'. I believe that one of the barriers to the incorporation of qualitative research into EBP may stem from the inaccessible way in which some qualitative research can be presented. By ensuring my research avoided this 'flowery' language I feel that it is much more accessible to participants and HCPs alike who may be unfamiliar with the background epistemological and phenomenological theory behind my chosen research methods.

### **10.9 Concluding comments**

This thesis is an important step towards understanding the experience of age related macular degeneration and the potential for the condition to impact on the quality of life of older people. The use of a mixed methods pragmatic approach to research has allowed me to develop an understanding of the experience of living with AMD for patients with different types of the condition. I have been able to highlight shared and divergent experiences and the need to acknowledge individuals' life contexts, prior knowledge and histories when making decisions

about care and service provision for AMD patients. A holistic approach to care for AMD patients is required which acknowledges the context of individual patients' *lifeworlds* and incorporates clinical, psychological, and health and social care services in order to improve the quality of life and wellbeing of patients.

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## Appendices

### 11.1 Appendix 1: Mixed methods pilot study supplementary material

#### 11.1.1 Postal survey patient information sheet



Aston Triangle  
Birmingham B4 7ET

Tel: +44(0)121 204 3000

[www.aston.ac.uk](http://www.aston.ac.uk)

Dear Patient,

My name is Amy Bennion, I am a PhD student being supervised by Professor Jon Gibson. I am conducting some research into people's experiences of age-related macular degeneration, and would be grateful if you could spare a few minutes to complete the enclosed questionnaires (Visual Functioning Questionnaire and Well-being Questionnaire) and consent form.

Participation in this research is entirely voluntary and will in no way effect the treatment you are receiving for your age-related macular degeneration. I have enclosed some further information about the research which you can read before deciding to take part. If you are happy to be involved in the research please complete the questionnaires and consent form and bring them with you to your next eye clinic appointment at Solihull Hospital in the envelope provided. If you agree to take part I will be contacting you on two further occasions over the next 18 months to fill in questionnaires which I will send to you by post, you can choose to withdraw from this research at any time by contacting me on the details below.

If you have any queries about this research or why you have been asked to take part please do not hesitate to contact me.

Yours sincerely,

Amy Bennion  
PhD Researcher  
Life and Health Sciences  
Aston University  
[bennioae@aston.ac.uk](mailto:bennioae@aston.ac.uk)  
Telephone: 07725221379

## Participant Information Sheet

### **Project Title:** Quality of Life and Wellbeing in Older Patients with Macular Degeneration

You are invited to take part in a research project being led by Amy Bennion from Aston University, Birmingham.

#### Why you have been chosen

Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the information. Please ask questions if there is anything you are unsure of or if you need any more information.

You have been invited to take part as you have been diagnosed with age-related macular degeneration. Your participation is entirely voluntary and prior to participation your permission and informed consent will be sought.

#### What will happen if you take part?

You will be asked to complete 2 sets of questionnaires over the next 18 months. These questionnaires will enquire about your experience of macular degeneration.

#### Example question:

If I did not have macular degeneration my experience of shopping would be (please choose one):

- Very much better
- Much better
- A little better
- The same
- Worse

Macular degeneration is a personal issue and if you feel you will be uncomfortable discussing any issues relating to your condition you may choose not to participate.

You will not be required to give your name to take part in the study, instead you will be given a false name which will be used to identify you in academic papers. You will remain completely anonymous and will not be able to be identified.

#### Use of the research findings

The results of this research will be used as part of my PhD thesis. Results may be used to illustrate both my thesis and academic papers.

Little is known about the long term impact of macular degeneration. We cannot promise that this research will help you individually, however it is hoped that the information collected in this study will help develop a greater understanding of the long-term experience of the condition. This type of information may be used to inform services and rehabilitation, and give advice, for those diagnosed with macular degeneration in the future

#### Contact details

Your participation in this research is completely voluntary and you may choose to withdraw from the research at any time by contacting me on the details below.

Amy Bennion

Life and Health Sciences

Aston University

Birmingham

B4 7ET

Email: [bennioae@aston.ac.uk](mailto:bennioae@aston.ac.uk)

Telephone: 01212043914



#### Advice and support:

If you wish to obtain any independent advice about taking part in this research you can contact the Patient Advice and Liaison Service on the numbers below.

Heartlands Hospital: 0121 424 0929

Solihull Hospital: 0121 424 4499

For advice and support with dealing with your macular degeneration you can contact the Macular Disease Society helpline using the contact details below.

Telephone: 0845 241 2041

Email: [counselling@maculardisease.org](mailto:counselling@maculardisease.org)

**INFORMED CONSENT**

**Project Title:** Quality of Life and Wellbeing in Older Patients with Macular Degeneration

**Name of researcher:** Amy Bennion

**Please tick to confirm**

I confirm that I have read and understand the information sheet dated 9<sup>th</sup> June 2010 for the above named study

I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, or legal rights being affected.

I understand that relevant sections of any of my notes and data collected during the study, and medical notes relating to my macular degeneration diagnosis may be looked at by the research team from Aston University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

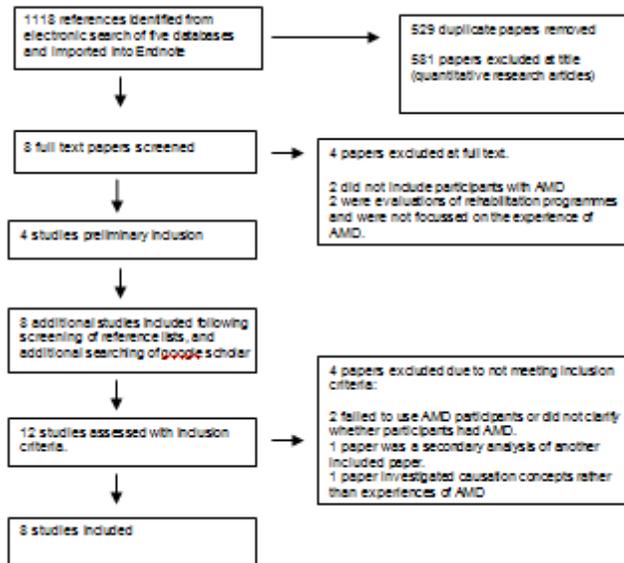
I agree to allow any verbal interviews to be audio taped by the researcher (*not applicable for postal survey*)

I agree to take part in the above research study

Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature
<u>Amy Bennion</u>	<u>9<sup>th</sup> June 2010</u>	<u>A. Bennion</u>

## 11.2 Appendix 2: Meta-synthesis process supplementary material

### 11.2.1 Flow chart illustrating search process



### 11.2.2 Example data extraction form

Study Details			
Authors			
Title			
Reference			
Location			
Research Question/ Objectives			
Participants			
Population			
Age	Mean:	Range:	
Gender	N	M	F
Ethnicity			
Recruitment			
Intervention			
Data Collection			

Method (eg. survey, focus group, interviews)		
Validation (eg. is survey tool validated; are interviews transcribed and is respondent validation used?)		
Analysis		
Method (eg. descriptive statistics (% reported only; analysis of transcripts employing a stated method)		
Findings (data must be verbatim quotes or authors' statements clearly based on data)		
How are results presented?		
Theme 1	First order	Second order
Theme 2	First order	Second order

Theme 3	First order	Second order
Authors Conclusions		
Comments		
Limitations, reviewer comments, etc.		
References		
Possible new includes		
Background papers		

### 11.2.3 Metasynthesis Theme Table

Future	Hope	Wong 2004	“When faced with this progressively deteriorating condition, the participants often felt powerless, despair, and incapacitated.”	“I try not to dwell on it.... Just one day at a time, and I am hoping, please, God, that this [good eye] will last.” “So long as I am not totally blind, I will cope. But I will find it very hard if I am totally blind.... I just pray that I am never... gonna be blind!”
		Moore 2003	While the men acknowledged the progression of their visual loss, they continued to hold hope that a successful treatment could be discovered, making comments such as, ‘But there is something that comes out new everyday’ and ‘I’m looking for the doctors and the scientists to come up with some eyes to see with.’	‘I don’t know what the future holds’ and ‘Maybe you can go the rest of your life without going blind, totally, who knows?’
		Moore 2000		“I just pray it don’t, as I say, I just pray it don’t get worse. If it stays the way it is, I can live with it. It’s aggravating, but the thought of it getting worse would be more, more terrifying.”
		Stanford 2009		“I hear on the radio news that there is a cure - now I have hope”
	Acceptance	Moore 2003	These men grew to recognize that nothing could be carried out to improve their vision or	You better do the best you can with it. And do what you want to do now because it’s not going to get better, it’s going to get

			stop the progression of visual loss	worse.
		Moore 2000	awareness that visual loss was a reality and that lost vision would not be restored	“it’s not going to get any better” “When you lose your centre vision, it’s just like your virginity; once it’s gone, it’s gone.”
		Feeley 2007	relief that they would not become totally blind, since peripheral vision would remain.	
		Dahlin- Ivanoff 1996		“You get used to it, you get used to it with a little bit of time”
	Negativity and Fear	Owsley 2006		“fear other eye will become impaired” “worry worsening vision will stop driving” “Afraid because I only have peripheral vision”
		Moore 2003	Although the men recognized that their visual loss would progress, fears and uncertainties about the future were evident.	But there ain’t a damn thing they can do for you right now. They can tell you it’s staying the same or getting worse, it’s not going to get better. I don’t think, unless it’s a miracle.
		Mogk 2008		Q: Do you see yourself as having anything in common with younger people who lose vision? A: Yes, I do because I feel younger. I don’t feel like an old person, and when I see old people, I’m sorry for them. I guess when I lose my [remaining] vision, I will be old. Q: So losing vision actually means

				becoming old? A: Yes, indeed.
		Feeley 2007	participants felt a real fear of the future and the unpredictability of vision loss and their ability to cope	
		Dahlin-Ivanoff 1996		They express a need to know what is going to happen in the future, if the condition is getting worse and how fast.  They all want to have a chance to prepare for the future by having all the information available.
Third order constructs (themes)	Sub Theme	Paper	Second order constructs	First order constructs
Interaction with the health service	Lay theories and concerns	Wong 2004	Once the ARMD was diagnosed, they were often told by their ophthalmologists that “there’s nothing for you”; “you can’t do anything about it”; or “it is too far gone, there’s nothing we can do.” Although many understood ARMD as “a haemorrhage,” “bleeding,” “a	My simple mind deduced that perhaps in the surgery [an excision on the cheek for skin cancer], perhaps a rush of blood to repair the damage, the rush of blood must have caused the leak. That’s been discounted, I think, but nonetheless that’s my theory. “I was very fearsome of the angiogram—not of the body but of the eyes.... I was

			leak in the back of the eye,” or “a drusen,” some participants were still searching for an <i>answer</i> .	resistant to the angiogram because I felt that the angiogram might have brought on the [AMD].”
		Moore 2003	Comments indicated that the men had uncertainties and scepticism about their diagnosis and treatment	<p>‘I could see wavy lines and he (the physician) said, “Well you’re O.K. If it gets worse come back”. He didn’t diagnose it. I went to a second doctor and he diagnosed it.’</p> <p>I think he (the physician) went too far with the laser. Because the day he did it, he had somebody else in there with him and he was showing them how they do it. And I think he got a little carried away.</p> <p>When they treated my eyes with laser, which I won’t recommend to anybody...they put lasers in your eyes you might as well forget about it.</p> <p>My eyes probably wouldn’t have been like this if I had stayed with Dr. D. Every time we went down there we saw a different doctor.</p>
		Dahlin-Ivanoff 1996	There is an idea that age related degeneration merely means that you are getting older and their it is a part of the normal ageing process, Some people believe that nothing can be done about it, except	“But this is a new disease isn’t it, so I think I should criticize science a little, is it really that new? Could we have got this disease from chemicals?”

			<p>accepting that one is getting older.</p> <p>Appear to think no research is currently being conducted on macular degeneration.</p> <p>Question whether the disease is really that common considering they had never heard about the disease.</p> <p>Several potential causes are mentioned: heredity, occupations in which vision is exposed, such as working with computers, fire extinguishing and welding, other diseases, including circulation diseases, and medications they have been taking, such as for asthma and cancer, chemical substances as well as violent sports such as boxing and ball games. Reading and watching TV a lot and looking at the eclipse of the sun or moon are also discussed as potential causes.</p> <p>they find it odd and cannot understand why spectacles seldom help.</p>	
Frustration and disappointment with appointments	Stanford 2009	Hospital appointments appeared to present an element of support which is possibly why waiting	<p>“I went to the hospital, but I am not very happy now as they can’t help much”</p> <p>“I was looking forward to my appointment</p>	

			<p>times for appointments were reported to be very frustrating.</p> <p>The participants looked forward to their hospital appointments, anticipating that their visual loss could be restored and appeared dejected by the outcome of the visit.</p>	<p>at the hospital. When I was there I had the sad news that there was nothing more that they could do. Instead they discharged me with an appointment to see someone about LVAs”</p> <p>“I was shocked to be told nothing more could be done”</p> <p>“I was called for an appointment only to be informed that I was to be registered blind. I feel let down by the NHS”</p> <p>“I was happy to hear of a cure, but told I would be discharged at my next visit”</p> <p>“I hear on the radio news that there is a cure - now I have hope”</p>
		Owsley 2006		<p>“Mad with doctor because he waiting so long to tell me about my vision condition”</p> <p>“Depressing going to the doctor”</p>
	Shock of diagnosis	Feeley 2007	initial shock of discovering AMD revealed that the participants took time to understand the chronic progressive effects of their illness and did not make full use of low vision devices, such as white canes and magnifiers.	
Third order constructs (themes)	Sub Theme	Paper	Second order constructs	First order constructs
Independence	Functional limitations	Wong 2004	Because of their progressively deteriorating visual function,	<p>“I’m half the man I used to be”</p> <p>When I get a letter, I can’t read it. I can</p>

			<p>many of the optical aids and adaptive devices that the participants had used had been rendered useless. For the participants with intact visual function, pouring a cup of tea, opening a can of soup, shopping in a supermarket, reading a bank statement, watching television, or crossing a street were easy, undemanding tasks that they performed many times a day.</p> <p>“for those participants with bilateral ARMD, these simple daily activities required concentration, planning, recall capabilities, and the coordination of sensory modalities like hearing and touching. Every task was challenging and constantly reminded them of their limitations.”</p>	<p>get a bill, gas, light bill, you know, like mundane things, and I will go and try to look at it with the glasses, but I can't do that. And they are the sort of things that keep hitting you all the time; they come back to you to remind you, you can't see.(76 F, bilateral AMD)</p> <p>I have dropped a lot of things, thinking that I am on the bench, but I am not on it. And I have dropped cups, plates, and mugs. Well, it's trial and error. You have to learn instead of just plonking your things down; you have to get to the edge with one hand and then place it with another. (66 F divorcee)</p> <p>“Simple things like crossing the street. I can't cross the street wherever I want to; I must go to the light and wait and listen to the clicker because I have had a couple of incidents when I thought it was clear [but it was not], and that was very devastating, I can tell you, very frightening.” (76 F)</p>
		Stanford 2009	<p>The vulnerability of participants was evident as, in the process of living life as they had before their vision deteriorated, they appeared to place themselves in considerable danger as they went about their daily lives.</p>	<p>Attempt to continue gardening “I fell down some steps”  “I walked into a dustbin left on the street” (F)  “I can't cross the road anymore since I was nearly knocked down” (M)  “I badly cut my finger chopping</p>

			Others regretted that they could not continue hobbies such as sewing or reading independently without 'cumbersome' low visual aids (LVA).	<p>vegetables”</p> <p>“I scolded my hand making a cup of tea”</p> <p>“I have become clumsy. I knocked a cup of tea over myself while I was cleaning up in the kitchen”</p> <p>“I cannot distinguish labels on tins of food or the prices very well”</p> <p>LVA's are “cumbersome”</p> <p>“Preparing meals is a challenge”</p>
		Moore 2003		<p>I just can't do shop projects like I used to... it's just pitiful...I am the most laughable thing you ever seen if I try to drive a nail. Because, I hit the board four times and maybe miss the nail five times. So I don't try to do that anymore. I don't try to use any power equipment.</p> <p>'I'm used to reading manuals, blueprints, stuff like that, and you just can't pick certain things to look at. You've got to look at the whole picture'.</p> <p>'I can still write cheques and pay bills', another commented 'I have difficulty keeping my chequebook up'</p>
		Moore 2000	<p>The women detailed the multiple losses that circumscribed their lives as a result of visual deficits. A visual deficit resulted in the loss of many abilities, but they all detailed other abilities that remained.</p> <p>All eight of the women</p>	<p>I can't drive anymore. . . . I can't read the paper. I can't [socialize]. What can I do out there? I can't knit, I can't sew, I can't [do] embroidery anymore. Sew, or read, or knit or do any of the things that I used to love to do.</p> <p>I, uh, comb my hair, I brush it out and kind of place it. So far as seeing what it looks</p>

			emphasized their inability to drive; to recognize people; and to read recipes, their mail, newspapers, menus, and other important information. Shopping alone and reading price tags was a difficulty specifically expressed by five of the participants. Other lost abilities included ascertaining traffic lights, writing checks, and determining coins and the monetary value of paper money	<p>like, I can't. I can't see to put makeup on. I can't do personal things like shaving your legs. Things like that you just can't do. You can't see enough to do it. And I can't see to put nail polish on or anything like that.</p> <p>I was so overwhelmed by all the traffic and the noise, it's like, it made me think of that, uh, in the <i>Wizard of Oz</i>, where Judy Garland says, "Lions and tigers and bears. Oh my!" I was thinking, "Cars, and trucks, and buses, oh my!"</p>
		Mogk 2008	<p>vision loss is not a single blow to a particular sensory capacity, but a systemic blow to a complex system of adaptations that an individual has developed to compensate for multiple losses, whether visible or not.</p> <p>Their narratives suggest that they essentially continued to see themselves as sighted people—just without sight—which is a striking articulation of their lived experience. As a result, their narratives focused consistently on actually doing, not on identity terms like blind, low vision, or disabled.</p>	
		Dahlin	Factors contributing to	"Not being able to read is a problem"

	Ivanoff 1996	<p>problems in the different areas of ADL can be categorized as: (a) functional limitations and (b) the feelings experienced in connection with performing ADL.</p> <p>Functional limitations are perceived by the participants in three different ways; difficulty in reading, difficulty in distinguishing or recognizing people or products, and difficulty in seeing if the task is completed.</p>	<p>"It's a problem not being able to read, do needlework and take care of daily activities. I wasn't to be able to bake, and yes, I want to do it all by myself.</p>
	Feeley 2007	<p>The giving up of tasks that proved too difficult, such as reading and hobbies, led to frustration, irritation, and boredom.</p>	<p>As one participant noted: "You lose your confidence with cooking. My son helps me a lot with that. In fact, I don't enjoy cooking now like I used to; now I think it's just a chore."</p>
	Mogk 2008	<p>The participants perceived vision loss as a functional challenge that affected one's ability to complete tasks, not as an identity challenge that affected one's ability to be sighted.</p>	
Dependency	Stanford 2009	<p>The quotes mentioned previously illustrate how the man with AMD could not go out alone, but neither could his wife (who did not suffer from the disease) as she could not leave</p>	<p>"If It wasn't for my sight I would be fine, but it makes you feel quite vulnerable and dependent on others"          "My wife needs to accompany me at all times"          The wife of one participant wrote: 'I can't</p>

			<p>her husband alone. The wife therefore became co-dependent as a consequence of AMD.</p> <p>Other themes arising from the diaries, such as isolation and low mood, may result from losing independence as people became reliant on others to function in their daily lives.</p>	<p>leave him in the house on his own as I am frightened at what he may get up to when I am away.'</p> <p>"I was disappointed that I could not choose my own Birthday card for my granddaughter. I had to rely on my daughter to do this for me"</p>
		Wong 2004		"Being independent for a long time, most of your life, you feel as if you are putting your carer to an unnecessary burden at times."
		Owsley 2006		<p>"Bothers me to think about depending on others"</p> <p>"Biggest fear is losing my independence"</p> <p>"fear coping with life after my husband's death because he helps me"</p> <p>"get depressed sometimes because of having to depend on others"</p>
		Moore 2003	Their stories reflected a cherishing of independence as they struggled with growing dependence on others	Often reluctant to ask others for assistance, and one commented, 'I've been a doer myself all my life...I never asked nobody things that I could do. I hate to ask anybody to do anything'.
		Moore 2000		<p>"I don't have any freedom"</p> <p>"I can't do what I want to do when I want to do it"</p> <p>To begin with, you lose all independence. I was a very independent person. I</p>

				<p>worked all my life, I was, ah, self-supporting. I made all my own decisions. I went where I wanted to go, when I wanted to go. Now, if I want to go to the drugstore, I have to ask someone to take me. . . . You have no more independence. Because there is always something that somebody must do for you.</p> <p>If Robert [participant's husband] goes shopping with me, I get in the store, if he turns loose of me to go look at something over here and I look at something over here, and I turn around he's not there, I'm lost. And I panic. And I'll freeze. It's a terrible feeling. You feel like you look around and you don't recognize anything, like "where am I?" and "what if he [participant's husband] doesn't come back?" I can imagine what it must be like, what a child feels like when they get lost, separated from their parent when they are out shopping . . . I can imagine what that must feel like. It must be terrifying for them. Because it is terrifying.</p>
		Mogk 2008	<p>Several participants expressed the fear that their adult children would decide that they, the participants, were no longer competent to run their own homes as a result of vision loss and would attempt to relocate them to a senior housing facility, which they saw as</p>	<p>: I don't know what will happen when [my vision] gets worse. . . . My children think I should go to a senior home.</p> <p>Q: You say that with such a great look on your face. Like you're going to be very polite about it, but you'd like to shoot somebody.</p> <p>A: We do argue about it. . . . I have a friend who also has macular</p>

		<p>tantamount to or a step toward going to a nursing home</p> <p>The participants in this set of interviews, however, articulated the relationship between vision loss and death differently. For them, the ultimate threat of vision loss from AMD is its capacity to dismantle one's ability to function independently without affecting vitality or longevity; the challenge of AMD is that it is unrelated to death.</p> <p>AMD does threaten to land them in nursing homes while they are still fully vital and fully cognizant of their surroundings. Moreover, they perceived this threat as present and frighteningly possible, regardless of their own overall health.</p> <p>participants also seemed highly aware of the ways in which vision loss may exacerbate existing medical conditions, possibly disastrously. The most common example was the realistic fear that the combination of vision loss, mild age-related balance deficits, and osteoporosis would result in a fall leading to a hip fracture.</p>	<p>degeneration. . . . She did go into a very nice senior home, St. Thomas Towers. She hates it. . . . I can sympathize with her so strongly because she's always been her own person. Even though they say you still can be [one] there, it's not the same. Just not the same. . . . It's a different way of looking at yourself . . . . You're going in, and that's going to be it. It's all downhill from there. Any changes will be because you go into the assisted-living part and then go into the hospital part. But you don't come out.</p> <p>Q: But you live in an apartment building here, too. That would be an apartment building that offers more services. I mean, St. Thomas Towers isn't a nursing home.</p> <p>A: That's what my children tell me. But who lives there? Old people.</p> <p>Now, they tell me that she [a 90- year-old former neighbour] is really blind—she can't see anything. She can't do anything for herself. She's a little old lady. I think they have her in a home</p> <p>I guess [my vision] can get worse, .but] I can walk and everything] . . .</p> <p>Now, I wouldn't like a nursing . . . home. To me, all they do in there is sit and wait to die. . . . Now, I think if you didn't want to live and you had to live like [that], they should give you a shot and put you to</p>
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				<p>sleep. . . . You have to go sooner or later, so what's the difference? . . . . There I would be miserable. So I hope I never get there.</p> <p>"My son tries to tell me that I'm old, and I'm always telling him that I'm middle-aged."</p>
Maintaining independence	Stanford 2009	The narratives demonstrate that, despite the difficulties they were faced with, the participants attempted to carry on and live their lives as normal regardless of their visual impairment.		
	Moore 2003	These older men quickly described how their visual capabilities and limitations strongly influenced what they could and could not do in their daily lives. However, not willing to be defined by their limitations, they seemed compelled to emphasize their capabilities.	<p>One man stated, 'I am the chief cook and bottle washer here', while another commented, 'I've got lots of tools and there's always things to fix it seems'. Others stated: 'I still serve on boards', 'I can see the slot machines', and 'I handle twenty-nine (financial) accounts. I do investing'.</p> <p>A desire to maintain independence and control in the financial aspect of their lives was apparent in comments such as 'I still want to manage my finances' and 'I don't want any one of my kids to see how much money I've got in the bank'.</p>	
	Moore 2000	still many things they could do with their remaining vision. women spoke about continuing	<p>"I do everything I did before as far as keeping the house."</p> <p>"I still try to do my own cooking, I burn a</p>	

			to cook, to do housecleaning, and to do the laundry	good many onions [laughter], but I still try.”  “But we still play cards, we still go dancing, of course dancing, you don’t have to see.”
		Dahlin Ivanoff 1996	The general opinion is that being independent and able to manage on your own is important.	Asking others for help and explaining that they have bad eyesight is a necessary strategy, but some feel embarrassed having to do this.
Driving		Wong 2004	the biggest difficulty that the participants experienced was losing their ability to drive and hence their independence. The participants had to rely on family members and friends or public transportation to commute to and from places	“It’s quite a big thing giving up your car. You just can’t hop into it and go anywhere.”  “You don’t want anybody to give you pity, and you think everyone is going to pity you; carrying the white stick or wearing the dark glasses, it’s like a symbol, “Look at me, I am blind!”
		Owsley 2006		“embarrassed because ran off the road when driving at night”
		Moore 2003		‘I guess driving is the biggest thing, biggest loss’. Others stated: ‘I’ve lost my truck because I can’t see well enough to drive’ and ‘my driving has been impacted by my sight’ ‘I can’t drive, legally’ and ‘I still had a driver’s license...but I, ah, reached the point where I thought I’d better get myself off the road, which I did.’ A link between driving and independence was evidenced by statements such as ‘If

				you don't have your car to go do those things yourself, it's really hard,' and '...if I can drive, I can do anything I want to do'.
		Moore 2000		I can't drive anymore. . . . I can't read the paper. I can't [socialize]. What can I do out there? I can't knit, I can't sew, I can't [do] embroidery anymore. Sew, or read, or knit or do any of the things that I used to love to do.
Third order constructs (themes)	Sub Theme	Paper	Second order constructs	First order constructs
Social engagement	Isolation	Wong 2004	As a result of this loss of independence and self autonomy, some participants had become isolated in their homes. They were unable to engage in social activities like meeting friends for afternoon tea or going to a dance without transportation by others. Spontaneous participation in activities was no longer possible, and for many, it had a negative impact on their social health. The participants needed to accommodate to the disabling responses from the wider social network and arrange their lives around their visual impairments.	<p>“It [ARMD] cuts your social life by about 99.5%. It doesn't matter what you do.”</p> <p>“Well, funny as it may seem, all my friends have sort of dropped off. I find that very hard to understand.... They have just completely dropped [me] since they knew that I was losing my eyesight.”</p> <p>An 83-year-old Italian woman, who previously enjoyed teaching foreign languages at a university and going ballroom dancing with friends, said: “I have to think my eyes cut off everything.... Before it [life] was full of energy; now it is full of nothing.”</p>

		Stanford 2009	Some participants had little contact outside of their home and due to lack of independence all social interaction was lost. There were instances where participants did not document any visitors in their diary other than, for example, the milkman. In the absence of visitors calling at their home, some participants recorded the man in the post office or the shopkeeper in the greengrocers as the only people that they had spoken to that day. It was also apparent that unless a participant had regular contact with a friend or relative for visits outside the home, many were made effectively housebound by their circumstances.	Some people did not seek contact. One woman wrote: 'I'm fed up with coming and goings and just want time to myself.' A man commented: 'I find myself sleeping during the day as I have "no leisure for pleasure".' Another man, reflecting on his life, commented: 'I live in a sad world of my own.'
		Owsley 2006		"Bothers me to stay home from social events" "Avoid social functions because of my vision"
	Benefits of social engagement	Wong 2004	participants who engaged continuously in social activities conducted by Vision Australia Foundation or other local organizations tended to remain	

			active, to be less distressed by their physical limitations, to have a positive outlook on life, and to be in better overall psychosocial health. However, despite the benefits found in 7 participants, 2 urban participants failed to attend the social groups because they were “too far away,” and another 2 had stopped attending following their initial participation.	
		Moore 2003	Ways of remaining connected with others included spending time with family, serving on community boards, attending church, and talking on citizen band radio.	You have to keep up with what’s going on in the world. That’s why I take classes...there is a lot of companionship in taking classes’. ‘There are two luncheon groups that are very interesting that I attend’, while another stated, ‘I am one of those who has to be doing something, helping somebody’
		Owsley 2006		“Wonderful and encouraging just to be able to go out to social activities” “Blessing to have daughter cook nightly”
		Stanford 2009		Visitors and telephone calls were eagerly awaited “A phone call from my daughter is the highlight of my day” (F)
		Moore	Although they struggled with the	“I lead an active life, um, I like to stay

		2000	loss of personal freedoms and strove to remain independent from others, at the same time, participants discovered the importance of maintaining connections with others.	busy, I am a people person, and I like to be involved with people.” “I-I talk on the phone, that helps a great deal. The telephone is my lifeline.”
	Embarrassment	Stanford 2009		“I have difficulty recognising people in the street”
		Owsley 2006		“Embarrassed about not being able to recognise people” “intimidating to tell co workers about my vision problems” “Feel awkward not recognizing friends and family”
		Feeley 2007	<i>Social support from family and friends.</i> Two participants found the extra attention they were receiving from family members since the onset of their AMD to be patronizing. They reported that they did not like their arms being held and led, and thought that if they could overcome the difficulties of their vision loss, they should be allowed to cope independently.	

		Dahlin Ivanoff 1996	Difficult recognising people and facial expressions- worried how they would be perceived.	
Third order constructs (themes)	Sub Theme	Paper	Second order constructs	First order constructs
Disclosure	Rejecting symbols of disability and negative stereotypes	Wong 2004	Although many participants had profound visual impairment and had been prescribed white canes by orientation and mobility instructors for daily activities, their white canes were often found at the bottom of a drawer or in the corner of a room. None of the participants actually wanted to be seen with a white cane. For them, the white cane was a symbol of blindness, disabilities, and weakness. It may have also represented self-pity and self-insufficiency.	One unmarried 76-year-old woman stated: "You don't want anybody to give you pity, and you think everyone is going to pity you; carrying the white stick or wearing the dark glasses, it's like a symbol, "Look at me, I am blind!"  Q: Do you think of yourself as someone who has a disability? A: No. Absolutely not. Not yet. Q: And why not? A: When I'm with people who are either old or disabled, I feel so much more in control. I feel so much younger, abler, all of these things. ,No, I don't have disabilities . . . except when I board the plane, and then I'm a little old lady [laughs]. And I suppose I'm wrong. But it's odd; it's the way I want to be wrong. I want to think of myself as a whole person. When you're disabled, you're not a whole person.
		Mogk 2008	The inquiry found a strong tendency among the participants to describe themselves as "not blind." Participants' responses	I guess I never thought of it much as a part of aging. You wear glasses now [and you're in your 30s]. . . . There's a woman who works [with a friend of mine] who has macular degeneration. She either

		<p>reflected an awareness that when older adults lose vision from AMD, their impairment is often perceived globally; that is, they are not seen primarily as blind or as having low vision, but as older.</p> <p>This understanding that vision loss renders one old, rather than blind, likely occurs not only because impaired older adults are often perceived globally as aged, regardless of their discrete disability, but because AMD does not generally affect the appearance of the eye, nor, in most cases, does it severely affect a person's ability to make or approximate eye contact with others.</p> <p>Ultimately, the participants' narratives suggest that older persons with AMD are at an immediate risk of being subject to negative stereotypes not of blindness, but of aging</p> <p>The association of abnormal with a host of negative traits, culminating in the notion of being somehow less than a whole human being, continues to underlie common</p>	<p>developed it when she was 50 or she is 50 now, and that's quite young.</p> <p>I never, never dreamed that . . . I was going to have this. I never dreamed that.</p> <p>I fought [AMD] until the blob came. That convinced me. I think of it as a living creature. So the blob came, and then I knew it was happening. . . . It's hard to believe it could happen that way, but it does. . . . This isn't me—I mean, I'm a very visual person</p>
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			<p>conceptions of impairment and disability, although the disability rights movement has fought hard to counter this legacy. This heritage may be a factor in the responses of older adults to vision loss and visual rehabilitation, regardless of their understanding of blindness in particular</p> <p>AMD was not considered by the participants to be a normative experience of ageing. While vision loss renders one older, it is nevertheless abnormal. The participants perceived AMD itself as an unexpected misfortune, an alien affliction, that was incongruent with their sense of themselves at any age.</p>	
		Moore 2000	<p>As the women discovered the importance of maintaining connections with others, they also discovered ways to nurture those connections by either disclosing or failing to disclose the extent of their visual loss to others. All of the participants spoke of times when they either revealed or concealed their</p>	<p>“You know, they [others] don’t know I got problems with my eyes and I have to tell them sorry, I didn’t know who you were.” At a later point in her story, this participant told of how she concealed her visual loss, stating, “The less said the better. They end up feeling sorry for me.”</p>

			visual loss as they related to others. Many of the women worried that others would think they were snobbish or aloof. In actuality, the women just could not see well enough to recognize others. At these times, the women often chose to disclose their visual loss.	
		Dahlin-Ivanoff 1996	They imply that visual impairment is something one does not talk about, and that there is very little understanding for disability in general. They want to make people aware that they have a vision impairment but it is important to show that they are not totally blind. When the word "blind" is discussed the opinion emerges that the expression "visually impaired" is a better way of describing the disability.	
	Legal blindness and being a "fraud"	Wong 2004	Not only did legal blindness give them access to the blindness pension and half-priced public transportation, it provided them with the affirmation they needed. The participants needed the official confirmation that although they	Well, I told them [friends] that I am legally blind; I can't see them. They said jokingly, "Well, I wouldn't like to drop a \$10 bill out in front of you to see if you pick it up."... I feel that people that I have seen many times and told them that I am blind, legally blind, they don't believe it. (78 M)

			<p>had intact peripheral vision, they did suffer from visual impairment and were not what others might think, “a fraud.”</p> <p>It was these unsympathetic and somewhat demeaning responses from others that often provoked emotional disturbance and irritation in the participants. Such responses threatened their integrity and undermined their efforts to maintain their autonomy. Although the participants did not “blame” others for not understanding their condition, they did resent others’ unintentional insensitivity toward it. Understanding and acceptance by family members and friends were crucial to their ability to accept and cope with ARMD.</p>	
		Mogk 2008	<p>Although the participants expressed typical sighted reactions to blindness, including sympathy (especially for children who are blind) or admiration (for professionals who are blind), they could not recall any specific negative cultural images of blindness,</p>	<p>Q: How would you describe your vision loss? Would you describe yourself as having “bad vision” or “low vision”?</p> <p>A: Oh, it’s worse than that. It was low in the beginning, but it’s zilch now.</p> <p>“oh I use the term legally blind to my income tax people... but I don’t go around</p>

		<p>even when prompted. Instead, they expressed bewilderment at the relevance of the topic, as if their experiences were unrelated to those of people who are blind</p> <p>The participants shared the widespread sighted understanding of blindness as the absolute absence of sight</p> <p>calling oneself “blind,” despite residual vision, would be claiming a hardship that one is not actually experiencing, which they considered fraudulent or self-indulgent. Those who agreed that they were “legally blind” understood this to be a tax term or a synonym for “low vision,” not as a designation of identity like “blind.- attempt by older people to avoid stigmatization however did now identify as blind as this would mean complete absence of sight, functional not identity challenge, global perceived identity “older”</p>	<p>and say it. I don’t do that. Now if people ask me, like these ladies that I go to the coffee concert with- they’re all so helpful- and they do want to do this and do that, and the other thing. And I did tell them. I say ‘now, I cannot see. I’m legally blind’ because it just happened last year. And they always want you to go here and there”</p> <p>Q: Would you use the word disabled to describe yourself?</p> <p>A: No, not really. One of the things I miss—OK, for instance, a word. You’re talking about a word. I had been in the habit of anytime that I ran across a word I wasn’t familiar with, I’d look it up in the dictionary. I have a dictionary in the drawer there. I’d look it up in the dictionary to find the meaning of it. I miss that. I’m interested in knowing what the word is and what its meaning is, and I miss it because I can’t go to the dictionary like I used to.</p>
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Third order constructs (themes)	Sub Theme	Paper	Second order constructs	First order constructs
Emotional Impacts	Depression and low mood	Wong 2004	<p>Others who were socially isolated often found it extremely difficult to comprehend their misfortune, fell short of developing coping strategies, and had fallen victim to ARMD.</p> <p>Some participants never stopped asking themselves, "why me?" especially during little mishaps, stressful events, and changes in their environment. Questioning why they had ARMD and their inability to accept it were destructive to their psychosocial well-being. Attempts to forget about ARMD and reduce its impact on life were only partially successful. There were times when they could cope better with it than at others. However, anxiety, frustration, and powerlessness prevailed in their lives.</p>	In an extreme case, one 66-year-old woman, who became distanced from her family members after she separated from her husband, said: "Some days I think, well, suicide is far better than going through this."
		Stanford 2009	<p>Feelings indicative of low mood were apparent from the data. Loss of hope had consequences on feelings of</p>	<p>"I find myself seeping during the day as I have "no leisure for pleasure"            "I live in a sad world of my own"            Desperation - "everyday feels the same"</p>

			well-being. There were expressions of low mood and a lack of positive outlook.	Loss of hope - "i'm trapped in a grey world" "going to bed is a nightmare... I lie awake, my only thoughts being the state of my eyes" "I am in a state where there is no way out" "I have many health problems but the state of my eyes bothers me most" "I can't be bothered doing things because of my eyesight". "I look forward to sunny days to cheer me up, bad weather only makes me feel worse" "It's a sunny day - my sight is better when the sun shines"
		Owsley 2006	Negative comments in the focus groups were not confined to those persons with advanced disease; rather, negative comments were common among those in the early and intermediate stages of disease as well, indicating that the negative emotional burden of the disease is not synonymous with disease severity as defined	"Angry because of my vision" "Feel sad about my vision" "Devastated about my vision" "Depressing to focus on my visual condition" "My first reaction to my vision impairment was sadness" "Cried all the time when I learned of my problem"
		Dahlin-Ivanoff, 1996	"Then you're very worried, you worry all the time"	
	Positivity	Moore 2003		'I have just real happy days,' 'I love life,' 'I don't sit around crying in my beer,' and 'I'm awfully thankful for any sunrise that I wake up to'

		Moore 2000	still many things they could do with their remaining vision.  being blessed with some remaining vision, expressing thankfulness for peripheral visual capabilities	“I see the world through rose coloured glasses. Life is to be lived, not cried about.” “I’m not blind and I guess I have a lot to be thankful for, because I still can see some things pretty good.” many other individuals were experiencing worse things than visual loss “But I thank God, see I think there’s always somebody that’s in worse shape than you or me.”
		Wong 2004		am not depressed about it [ARMD], I just accept it. I mean, I am 75 years old. Goodness gracious me, I have done very well, I think, to be where I am. But then again, it really does upset your life. (75 M early Alzheimer’s)”
Third order constructs (themes)	Sub Theme	Paper	Second order constructs	First order constructs
Coping and adaptation	Social services and equipment negatives	Wong 2004	Given equipment to assist and taught techniques some found them difficult to use.	“If I sit right up close and turn my head to look outside [to try and see the television screen].... It’s very hard to try and watch television looking at the side of your eye.”
		Stanford 2009	They received optical assistance, such as magnifiers and closed-circuit televisions, but, as we mentioned earlier, many found them to be impractical and difficult to use	For example, a 78-year-old man who was able to maintain his own garden found it difficult to use the techniques. As he put it: “If I sit right up close and turn my head to look outside [to try and see the television screen].... It’s very hard to try

			<p>with the presence of only peripheral vision.</p> <p>Many participants had used techniques, such as tactile markings, audiotapes, and colour codings, to help them perform daily activities and found that these techniques alleviated many of their anxieties. However, these techniques were not encompassing, and under some circumstances, they were insufficient and limited.</p> <p>The patients were studied over a 12-month period, but the extent, if any, of psychosocial adjustment was not evident from the diaries.</p>	<p>and watch television looking at the side of your eye.”</p> <p>“It’s a great strain to use a magnifier”</p> <p>“I am very disappointed at the wait from social services”</p> <p>“Exasperated, I have written to the secretary of health to complain about my management”</p>
	Social services and equipment positives	Stanford 2009	Using low visual aids is indicative of attempts to adjust and some were hopeful about the positive change that these may make to their lives.	<p>“I was very impressed that the man from social services came back to try crossing the main road at teatime (the busiest time of the day) to find me a safe place to cross!</p> <p>“I was thrilled to be shown how to enlarge the sheet music so I can play the piano”</p> <p>“the week ended well with a visit from social services providing helpful aids”</p>

		Feeley 2007	<i>Standard rehabilitation: Using magnifiers.</i> Four participants found their magnifiers to be invaluable when needed for "spot" reading	"The magnifiers have certainly made life possible. Without them, I would find it very difficult.
	Adaptation	Stanford 2009		<p>There were some examples of adaptation. For example, one woman commented she felt 'under the weather' due to her visual problems but: 'I was still able to enjoy my grandson's birthday.' Another woman stated: 'Preparing meals is a challenge', highlighting the difficulties but indicating she is not being defeated by this task.</p> <p>One man in particular went to great lengths to adapt to the problems caused by his vision. He remarked: 'I go to church every Sunday, and each time I sit in a different place so I can work out how to get the best view of the altar.'</p>
		Moore 2000	<p>A wide variety of strategies for living with a visual loss were devised by these women as a means of accomplishing the activities of everyday life. Some women used their other senses and memory strategies to integrate visual loss into their lives.</p> <p>All of the women used visual assistive devices, aids, and training. Two of the women</p>	"Another thing, a new thing that I'm trying to do now, is to try and find ways around doing something without using your sight."

			were involved in the talking book program, and one used the reading radio service, in which the daily newspaper is read. One participant stated that talking books were a "godsend." Four of the women rode the access bus, a bus service available to those with disabilities, to appointments and activities.	
		Feeley 2007	<p><i>Daily tasks and role change.</i> The participants needed to use their other senses, such as sound and touch, to perform daily tasks. They all explained that tasks had to be broken down into smaller stages, but that they had to allow much more time to complete the tasks. Four participants reported losing their confidence to continue with some activities in the home, which led to a change of roles within their families.</p> <p>participants realized that to expedite daily tasks quickly, it was easier to ask for help</p>	I . . . still do read, kind of extensively, poetry, prose, you name it. I also do crosswords; therefore, my brain is working in a sort of way. . . . So when I'm reading a sentence, I know what I'm reading. I know what to expect, in a sense. I mean, I might be running along, and there may be a word there; my brain will now take over and say what that word should be in the context of the text. Do you see what I mean?
		Dahlin-Ivanoff	Changing the way an activity is performed is one strategy	"you learn to live with your disability using the vision that is left"

		1996	The domestic environment can be modified by the use of specialized equipment and assistive devices. Compensation for the loss of vision is yet another strategy; such people use other senses. Avoidance is also a strategy: participants avoid activities which make them feel insecure.	"I find short cuts, new ways of doing things that never crossed my mind before"
Positive attitude		Owsley 2006		"being able to have peripheral vision is encouraging" "have stopped worrying" "hopeful about maintaining current level of vision" "Have accepted vision impairment" "No longer bothered by having others help" "Thank God for current vision" "feel thankful for current vision" "Feel like left eye is in good condition" "Glad not to be blind after cataract surgery on right eye" "lucky that it happened later in life" "Thankful to have worked so long"
		Moore 2003	Despite fears, hope and optimism prevailed in the older men's lives and their comments reflected an acceptance of their visual loss and positive overall attitude	'If the good Lord is willing for me to see again, I'll see'.  ...and it's just going to become part of my life as I go along, and uh, I'll accept it, what happens, will happen.

				<p>Their statements suggested that their positive attitudes were conscious choices. One stated, 'God forbid that I should start feeling sorry for myself, that would be ridiculous,' while another commented, 'I don't let it bother me. I'm not going to. I'm going to live...So I do have hopes'.</p>
		Moore 2000	<p>As the older women chose to be realistically aware of their visual loss, they also chose to view life from a steadfastly positive perspective being blessed with some remaining vision, expressing thankfulness for peripheral visual capabilities</p>	<p>"I see the world through rose coloured glasses. Life is to be lived, not cried about."          "I'm not blind and I guess I have a lot to be thankful for, because I still can see some things pretty good."          But I thank God, see I think there's always somebody that's in worse shape than you or me."          "Some days I don't even, uh, some days my sight don't bother me at all . . . but um, then other days, 'Why can't I see?'"</p>
		Feeley 2007		<p>I'm a more balanced person. I'm a lot more empathic when dealing with other people, and I've developed a better sense of humor than I had before; it's usually targeted at myself. I haven't got sulky or negative in my feelings.</p>

## **11.3 Appendix 3: Qualitative studies supplementary material**

### **11.3.1 Interview Participant Information Sheet**

#### Participant Information Sheet

**Project Title:** Quality of Life and Wellbeing in Older Patients with Macular Degeneration

You are invited to take part in a research project being led by Amy Bennion from Aston University, Birmingham.

Why you have been chosen

Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the information. Please ask questions if there is anything you are unsure of or if you need any more information.

You have been invited to take part as you have been diagnosed with age-related macular degeneration. Your participation is entirely voluntary and prior to participation your permission and informed consent will be sought.

What will happen if you take part?

You will be invited to take part in 3 one to one interviews over the next 18 months. During these interviews you will be invited to discuss your experience of macular degeneration.

These interviews can take place in your own home, or another comfortable location chosen by you at a time convenient for you. It is anticipated that these sessions will last between 60 and 90 minutes, some interviews may go on longer, however, you will be able to end the interview at any point and take breaks if needed.

Macular degeneration is a personal issue and if you feel you will be uncomfortable discussing any issues relating to your condition you may choose not to participate.

You will not be required to give your name to take part in the study, instead you will be asked to provide a false name which will be used to identify you in any quotations used in academic papers. You will remain completely anonymous and will not be able to be identified by these quotations.

Use of the research findings

The results of this research will be used as part of my PhD thesis. Results from the interviews may be used to illustrate both my thesis and academic papers.

Little is known about the long term impact of macular degeneration. We cannot promise that this research will help you individually, however it is hoped that the information collected in this study will help develop a greater understanding of the long-term experience of the condition. This type of information may be used to inform services and rehabilitation, and give advice, for those diagnosed with macular degeneration in the future.

#### Contact details

Your participation in this research is completely voluntary and you may choose to withdraw from the research at any time by contacting me on the details below.

Amy Bennion

Life and Health Sciences

Aston University

Birmingham

B4 7ET

Email: [bennioae@aston.ac.uk](mailto:bennioae@aston.ac.uk)

Telephone: 01212043914



#### Advice and support:

If you wish to obtain any independent advice about taking part in this research you can contact the Patient Advice and Liaison Service on the numbers below.

Heartlands Hospital: 0121 424 0929

Solihull Hospital: 0121 424 4499

For advice and support with dealing with your macular degeneration you can contact the Macular Disease Society helpline using the contact details below.

Telephone: **0845 241 2041**

Email: [counselling@maculardeisease.org](mailto:counselling@maculardeisease.org)

### 11.3.2 Interview Questions

1. Tell me about the history of your AMD - How did you come to be diagnosed?
  - Who referred you? Why were you referred?
  - How did you find out you had AMD?
  - Is one or both eyes involved?
  - What do you think caused your AMD?
  
2. In what ways does AMD affect your day to day life?
  - What is your daily/weekly routine?
  - What are your hobbies? What do you like to spend your time doing?
  - How often do you leave the house? What do you do when you go out?
  - Are any things difficult? Is anything easier? Are things different to how they were before you were diagnosed?
  
3. How supportive do you feel friends and family are?
  - Do they know you have AMD?
  - How did they react to your AMD diagnosis?
  
4. What support are you receiving for your AMD?
  - Are you receiving any treatment?
  - Have you accessed any low vision services?
  - Have these things helped? In what way?
  
5. What do you think living with AMD will be like for you in the future?
  - Do you think anything will change?
  - How might things be improved?
  - What support would you like to receive?
  
6. Is there anything else you would like to talk about which you feel is important?

### 11.3.3 Example of iterative qualitative analysis (IPA) process

#### 11.3.3.1 Examples of initial unfocused coding and notes for Hermione Interview 1

TRANSCRIPT	EXPLORATORY COMMENTS
<p>Amy: Ok, so you have the questionnaire, and which bits do you have confusion with?</p> <p>Hermione: As we go along, you see, one or two I haven't done but some, the thing about visiting friends, you know, not going because, and I wasn't sure whether, quite what you meant by that, because there is another one about embarrassment further on. Let me have a look and then get [husband] to make me a coffee. ((Looks through questionnaire)). Just one or two I haven't done (.) Where is it? Where is it? (.) No the majority of them I have.</p> <p>Amy: You mentioned this one, number 11, because of your eyesight, how much difficulty do you have seeing people react to things you say?</p> <p>Hermione: I've never really thought about that you know, I don't think I do have any difficulty, just people often react with their voice anyway, you can hear it can't you, and I haven't really considered that. And I don't think, I don't</p>	<p>Visiting friends and embarrassment link.</p> <p>Using other senses.</p> <p>Never thought about it before being asked in questionnaire.</p>

<p>think I have any difficulty in that, it never occurred to me.</p> <p>Amy: OK. And what else ((looks for missing answers in questionnaire))</p> <p>Hermione: Oh, because of your eye sight how much difficulty do you have in visiting people's homes, at parties or in restaurants? Is that because I might be embarrassed, or?</p> <p>Amy: I think It's open to your interpretation, I would assume it's, to do with=</p> <p>Hermione: =seeing people and dealing with people?= I haven't found this difficult, I, the difficulty I do have is seeing faces at a distance for instance, now with my glasses on I think I could probably see what you look like. But I have to get ((takes of reading glasses and puts on other glasses)) Yes I can quite clearly. But I have to get, but in a party atmosphere of course, you can't see people until you get near to them so I've got to be (.) walk across if I think it's someone, if I know them well I can tell if they are moving or if they are walking, I can tell that, friends coming along towards me up the road, I know because of the way they walk, and</p>	<p>Facial recognition.</p> <p>Engaging in groups. Difficulty seeing faces at a distance.</p> <p>Recognise people through body movements.</p> <p>Still goes to parties despite difficulties.</p> <p>Preparing self for different experience. Accepting different experience.</p>
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<p>otherwise I can't see their face until they are close to me, so I haven't found any difficulty in that, but I certainly haven't stopped going! ((Laughs))</p>	
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**11.3.3.2 Example of description and interpretation process (descriptive summaries) for Hermione Interview 1**

Original Text	Description	Interpretation
<p>A: You mentioned this one, number 11, because of your eyesight, how much difficulty do you have seeing people react to things you say?</p> <p>H: I've never really thought about that you know, I don't think I do have any difficulty, just people often react with their voice anyway, you can hear it can't you, and I haven't really considered that. And I don't think, I don't think I have any difficulty in that, it never occurred to me.</p> <p>A: OK. And what else ((looks for missing answers in questionnaire))</p>	<p>Hasn't thought about whether she can see people react to what she says. People react with their voices. Doesn't think she has difficulty seeing people react, has never considered if she does.</p>	<p>Hasn't needed to think about whether she can see people's reactions as she has adapted and listens to voices instead.</p> <p>Adaptation.</p>

<p>H: Oh, because of your eye sight how much difficulty do you have in visiting people's homes, at parties or in restaurants? Is that because I might be embarrassed, or?</p> <p>A: I think It's open to your interpretation, I would assume it's, to do with=</p> <p>H: =seeing people and dealing with people?= A: Yeah.</p> <p>H: I haven't found this difficult, I, the difficulty I do have is seeing faces at a distance for instance, now with my glasses on I think I could probably see what you look like. But I have to get ((takes of reading glasses and puts on other glasses)) Yes I can quite clearly. But I have to get, but in a party atmosphere of course, you can't see people until you get near to them so I've got to be (.) walk across if I think it's someone, if I know them well I can tell if they are moving or if they are walking, I can tell that, friends coming along towards me up the road, I</p>	<p>Doesn't have difficulty visiting people. Has difficulty recognising faces from a distance. Could see my face clearly with glasses on. In a party atmosphere she would need to walk over to someone if she thought she knew them to see them. She can recognise friends by the way they walk, but can't see their faces until they are close. Doesn't have difficulty with parties and hasn't stopped going to them if she</p>	<p>Barriers to social engagement. Ability to recognise faces is different in different situations. Harder in busy places. Hermione needs to adapt in some situations in order to recognise people. Making adaptations means she hasn't stopped going to parties- remaining socially engaged.</p>
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<p>know because of the way they walk, and otherwise I can't see their face until they are close to me, so I haven't found any difficulty in that, but I certainly haven't stopped going! ((Laughs))</p> <p>A: OK.</p> <p>H: If anybody invites me I'll go ((laughs))</p> <p>A: ((laughs)) I guess the next one is quite similar, because of your eyesight how much difficulty do you have going out to the movies=</p> <p>H: Yes, there is difficulty in I don't go to cinema, cinema is not my scene, plays yes I go to, and you have to go being aware that you are not going to see it.</p> <p>A: Yes.</p> <p>H: As you normally see it, so, I'd just put a little difficulty.</p>	<p>is invited.</p> <p>Doesn't go to the cinema, it's not her thing. Goes to plays, but you have to be aware you are not going to see it as you normally see it.</p>	<p>Maintaining activities. Acceptance/ Still able to do activities she used to enjoy but has to accept they won't be the same. She won't be able to see at the theatre.</p>
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### 11.3.3.3 Example of code grouping and theme development for Hermione Interview 1

#### An active mind vs. a limited body: adapting to the constraints of AMD and functional limitations

Hermione feels that AMD is slowing her down causing a dissonance between her body and mind. Hermione's mind is active but her body is limited which impacts on various elements of Hermione's life. Despite Hermione's attempts to cope with the constraints placed upon her by her AMD she still describes some activities which she finds difficult as a result of her AMD. Hermione is no longer able to drive, has difficulty shopping and her mobility is impaired in unfamiliar surroundings.

*H: ...I do find too, talking about eating out and that sort of thing, it isn't a bother, you don't see the food quite so easily on your plate glancing down.*

*A: Oh right. Yes.*

*H: And occasionally they are, at home, [husband] will suddenly take my knife and turn it over and I've picked it up and I've got it the wrong way round ((laughs))*

*A: ((laughs))*

*H: Things like that.*

*A: Yes.*

*H: But no, it's not difficult. I'm slower eating, so I think that's a good thing ((Laughs)).*

Line 509-517

*I think I'm slow at doing everything, because when I am looking around my sight doesn't seem to be, move as fast as I do, do you know what I mean, and I'm got a fairly tidy mind and very untidy hands, so I can put things down anywhere when I am working and finding them is a bind, whereas you could go into a room you know? Our rooms are quite small, you glance round and you'd see whatever you were looking for, I go in and I have to look in detail now, so things like that, that it impacts on everything, in the kitchen I keep a magnifying glass, so that if I'm cooking or reading a you know? Pack of anything, my magnifying glass is to hand, and I do find that, although I've got these ordinary reading glasses I do find the magnifier you know? Quickens up what I'm doing, otherwise, you know squinting. Outside I find if I am, say I'm in Solihull walking along the high street I find that can be a little bit confusing because there are people everywhere coming and whilst I can see Ok, I can't judge distances as well so it does impact on that and distances of cars from me, coming along, I can't judge that as exactly as could and that's another reason for stopping driving.*

Line 175-187

*H: ...I was never a long distance driver, you know? It was usually short distances, it was convenient when I was working, and it's the evenings, I mean [husband] is wonderful, he'll drive me and take me anywhere, but he has his own*

*busy things he does and I'd like to be independent while I can, but it's things in, so I want to go up to the village up to a meeting or a play or something like that that they do, we hope to go to, Friday evening, we'll go to there, and there are things that I like to do in the evening, which you know? If you've no buses around much in the evenings, so it does stop me doing that, or going to friends in the evening on my own with some of the girls together, we'll have a get together and going in the evening on my own isn't so easy, so that sort of thing I miss, but otherwise, it makes me walk more, it makes me walk in the village, where as I think, 'oh gosh I'm running short of time I'll go in the car'*

A: *Yeah ((laughs))*

H: *and walking which is good for the back.*

A: *it's good yeah.*

H: *Yes, so that sort of thing, and shopping, we do a big shop together now, and shop as little as possible in between, shopping was useful to do that sort of thing, and carrying, but it's that sort of thing mainly or going, I don't have many family now, but when my mum was alive she lived about 30-40 miles away so that was very very handy then and that sort of thing I would miss, but sadly my sister isn't around either now, or several friends, so you know from that point of view I don't have to go those journeys and [husband] loves driving still, so he will and we'll go round and about but he does all the driving.*

**Line 274-293**

### Inevitable vision loss: imagining the future with AMD

Hermione worries about her inevitable deterioration of vision and how she will cope. She fears potential dependency on others which causes extreme anxiety, in order to cope she attempts to repress her feelings about her AMD. Hermione does not see herself as at the stage of AMD where she needs help, but acknowledges that this is likely to change in the future. Hermione's vision of her future is shaped by the parallels she sees between her own visual impairment and her mother's vision loss.

A: *So how do you feel about the things that, the way things have changed, things take longer for you now and?*

H: *Well, I just find I have to accept them, because there is no point, I mean I get, sometimes I get, I say, 'oh goodness [Hermione], stop it!' ((laughs)) it sounds ridiculous but there is no point really Amy, I've got to find ways through it, and this is the easy stage, later on it will be much more difficult.*

A: *So what do you, what do you anticipate will be different in the future?*

H: *I think dependence on someone else for more things, and that I dread, I mean something else might carry me off before then, so I'm not to worry about it, I'm very lucky to have a wonderful husband at the moment, but who knows what might happen, one of my fears is that if [husband] was really poorly or something like that I wouldn't be able to care for him in the same, in the way I'd like to ,but*

*there is no point in thinking about something like that because you can't organise it, you can't reorganise it can you?*

**Line 228-239**

*H: Err, I wouldn't say I don't exactly worry, I worry about it a little bit because of the dependency later on, I do find just occasionally in the night I wake, and I find I'm worrying about it.*

*A: Oh.*

*H: And worrying about what might happen later on.*

*A: Yeah.*

*H: Otherwise when I'm sort of fully conscience, conscious, I don't do, I don't worry about it, but then I do and that is quite a little panicky time and then I sort of have to give myself a good telling off or go and make a cup of tea or something.*

*A: So you worry about it when you are not actually thinking about it.*

*H: Yes, yes, I wake up thinking just occasionally and it's quite a frightening thing really, but it's not very often.*

*A: And you are worrying about potentially what things are like in the future not=*

*H: Not now no, not now. No I think how lucky I am at the moment, and but I do wonder, I do have a fear of being dependant really. Which really does, really does frighten me.*

**Line 409-422**

*A: So how do you feel about the things that, the way things have changed, things take longer for you now and?*

*H: Well, I just find I have to accept them, because there is no point, I mean I get, sometimes I get, I say, 'oh goodness [Hermione], stop it!' ((laughs)) it sounds ridiculous but there is no point really Amy, I've got to find ways through it, and this is the easy stage, later on it will be much more difficult.*

*A: So what do you, what do you anticipate will be different in the future?*

*H: I think dependence on someone else for more things, and that I dread, I mean something else might carry me off before then, so I'm not to worry about it, I'm very lucky to have a wonderful husband at the moment, but who knows what might happen, one of my fears is that if [husband] was really poorly or something like that I wouldn't be able to care for him in the same, in the way I'd like to ,but there is no point in thinking about something like that because you can't organise it, you can't reorganise it can you?*

**Line 228-239**

## Interaction with the health service, monitoring and maintaining vision

Hermione's AMD was well developed when she was diagnosed. Various barriers presented themselves before she could be diagnosed and Hermione failed to recognise the seriousness of her condition until it was too late. Hermione now only attends appointments when she feels she needs to, she is responsible for maintaining her own vision which includes taking vitamin supplements.

*H: Yes it was, I had had reading glasses for a short time, but otherwise I'd had no real problems, and this particular time [husband] had had a knee done so we were just busier and you know? And what have you, I didn't think about eyes very much at all, and I was thinking, oh, it's about time I went to the dentist again, oh dentist, umm optician again, I probably need to change my reading glasses and this went on and I didn't do it, and then I realised when I was walking our little dog one morning that the lampposts were all curly and that really frightened me, but I wasn't sure what it was, then I thought, well I will make an appointment and I'd made my appointment and unfortunately I had a little spell in hospital, most you know? I wasn't expecting it and suddenly I was, so I had to put that one off and by the time that finished then I went and had my eye appointment and this is when I discovered what I had and so, by that time, most of the sight in this one had gone without me realising really, except obviously a little bit of peripheral vision, so that is how it is at the moment.*

**Line 94-104**

*H: This one went wet immediately, I understand from Mr Gibson, and so I have a little peripheral vision in this one, and over the time this one has deteriorated, it's remained dry so far, but I've also got cataracts developing, I don't think they are at a very far stage and the thought is, and I agree with that, leave well alone at the moment, because of the, although it's a very common op nowadays and people don't think two things about it, they've always got a risk and I don't want to lose what I still have in this one, I've got a little peripheral in that, and I could probably blunder about the house ok, but doing anything close, I'd have great difficulty.*

*A: Ok, so how long ago were you diagnosed?*

*H: I think it must be, now I'm trying to work back, I think it's 5 to 6 years ago.*

*A: Ok.*

*H: So you know, I've been hanging on to this one for quite a time, although I saw Mr. Gibson a fortnight ago and it had deteriorated a little bit and of course the cataract as well makes it a bit more fussy.*

**Line 106-118**

*A check up yes, I hadn't been to the hospital in very long, right earlier on, I went to the clinic in Grove Road to start with and saw someone there, and then I went to the hospital later, but eventually of course there was nothing the hospital could do, and I think I had a number for an emergency should I need it and I thought it was going on and it was getting less, I knew it had deteriorated a bit and I thought*

*I wonder if I would be eligible to go to the hospital again. I enjoyed seeing Mr Gibson and I toyed whether to go back to the clinic or not, I could afford to go, but it is very expensive every 6 months or so, so I thought I wonder if I could go to the hospital and just piece of mind really, so I was able to go and I was very lucky, and it was just the usual things and thought it had deteriorated from last time, so now I'm just decide if I want to go along to the clinic I will do, but the hospital of course I can't do anything about now.*

*Line 120-129*

## 11.4 Appendix 4: Evidence of NHS Ethical Approval

  
**Birmingham, East, North and Solihull Research Ethics Committee**  
REC Offices  
Osprey House  
Albert Street  
Redditch  
B97 4DE  
Telephone: 01527 587688  
Facsimile: 01527 587501

30 March 2010

Miss Amy Bennion  
PhD Researcher  
Aston University  
Life and Health Sciences  
Aston University  
Aston Triangle, Birmingham  
B4 7ET

Dear Miss Bennion

**Study Title:** Quality of Life and Wellbeing in Older Patients with Macular Degeneration: A Longitudinal Mixed Methods Study  
**REC reference number:** 10/H1206/17  
**Protocol number:** 5

Thank you for your letter of 22 March 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		09 February 2010
REC application		09 February 2010
Protocol	5	03 February 2010
Investigator CV		
Evidence of insurance or indemnity		03 June 2007
Summary/Synopsis	1	09 February 2010
Interview Schedules/Topic Guides	2	19 January 2010
Questionnaire: NEI-VFQ 25		
Questionnaire: WBQ12		
Academic Supervisor CV		
Participant Information Sheet: Quantitative	3	22 March 2010
Participant Information Sheet: Qualitative	5	22 March 2010
Participant Consent Form	2	22 March 2010
Response to Request for Further Information		22 March 2010

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports

- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

10/H1206/17

Please quote this number on all correspondence

Yours sincerely



**Dr Rex J Polson**  
Chair

Email: [jenny.tyers@westmidlands.nhs.uk](mailto:jenny.tyers@westmidlands.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Nichola Seare  
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B4 7ET

Miss Elizabeth Adey, Heart of England NHS Foundation Trust