Patients' and caregivers' experiences of living with a macular condition.

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Doctor of Philosophy.

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Declaration of Authorship for Co-Authored Work

If you are presenting partly co-authored work, please indicate below your individual contribution to the thesis.

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I confirm that specific aspects of the research reported in the thesis that I am presenting has been co-authored with:

Clare Bradley and Winfried Amoaku

Within this partly co-authored work, I declare that the following contributions are entirely my own work:

(Here you should indicate, in précis style, the datasets that you gathered, interpreted and discussed; methods that you developed; complete first drafts that you wrote; content that is entirely your own work; etc. It is often appropriate to organise this statement by chapter)

Content from this thesis have been published in the following publications (all papers were drafted by the author with supervisory input from Professor Clare Bradley, and with input from Winfried Amoaku for the 2017 paper published in BMJ Open):

Boxell, E.M., Amoaku, W.M. & Bradley, C. (2017). Healthcare experiences of patients with age-related macular degeneration: have things improved? Cross-sectional survey responses of Macular Society members in 2013 compared with 1999. *BMJ Open. 7.*

Updates on the research project were published in the Macular Society's journal, *Digest*:

Boxell, E.M. & Bradley, C. (2016). The experiences of caregivers and recipients of support and assistance for AMD. *Digest, Journal of the Macular Disease Society. 81-83.*

Boxell, E.M. & Bradley, C. (2015). Increase in patient satisfaction within diagnostic consultations: the Macular Society survey 2013. *Digest, Journal of the Macular Disease Society. 64-65.*

Boxell, E.M. & Bradley, C. (2014). Understanding the experiences of people with macular conditions. *Digest, Journal of the Macular Disease Society. 78-79.*

The Macular Society 2013 survey described in Chapter 2 was designed by the author and Professor Clare Bradley with valuable input from Winfried Amoaku. The author managed data collection and preparation of the Macular Society 2013 survey data. The author and Professor Clare Bradley planned the statistical analysis of the 2013 survey data. The author carried out the statistical analysis. The results and discussion for the following sections in Chapter 3 were drafted by the author into the manuscript published in *BMJ Open*: Experiences in the diagnostic consultation: 1999 vs 2013 samples, Impact of 2002 publication of MDSQ (the 1999 survey) results and 2009 RCOphth guidelines on healthcare experiences, Experiences with general practitioners (GPs) around the time of diagnosis. This manuscript was revised and approved by Professor Clare Bradley and Winfried Amoaku. The remaining results and discussion that appear in Chapter 3 are the author's sole work.
The results which appear in Chapter 4 are from the Macular Society 2013 survey dataset. The author carried out the statistical analysis, interpreted the results, discussed the results and wrote this Chapter alone (with study supervision from Professor Clare Bradley).

The work that appears in Chapters 6 to 9 is entirely the author's own. Chapters 1 and 5 are literature reviews written by the author. Study supervision was provided by Professor Clare Bradley (for all thesis Chapters) and Dr Marco Cinnirella (for Chapters 5 to 8).
Where I have consulted the work of others, this is always clearly stated.

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Abstract

The Macular Society 2013 survey (MSQ 2013) formed study 1 of the thesis. This nationwide survey was sent to 4000 members of the Macular Society. The main purpose was to investigate the healthcare experiences of people with macular conditions and determine whether a previous survey and Royal College of Ophthalmologist (RCOphth) management guidelines brought improvements. Results showed that patients diagnosed with age-related macular degeneration (AMD) since the previous 1999 survey reported better experiences at diagnostic consultation. Overall satisfaction with the diagnostic consultation improved following publication of the RCOphth guidelines. However information and support provision at diagnosis remained low.

Of the MSQ 2013 respondents, 53% reported receiving care from family or friends because of their AMD. Respondents who received care reported poorer quality of life and well-being than those who didn't receive care, despite controlling for degree of visual impairment. Reasons for the relationship between poor well-being and receiving care were investigated using a mixed-methods approach. Two studies explored the impact of receiving and providing support for wet and/or dry AMD using a dyadic perspective (i.e. including both person with AMD and their caregiver). Previous research has often neglected to take into account the close relationship between caregiver/s and person/people with AMD (pwAMD). This mixed-methods study filled this gap. Quantitative study 2 investigated 72 such dyads using structural equation modelling to examine predictors of well-being in the pwAMD and caregiver, caregiver general health and caregiver reactions towards providing support. Qualitative study 3 reports interviews with eight dyads exploring experiences in greater depth. This research provides information to enhance our understanding of how pwAMD and their caregivers adapt to living with AMD. It highlights the similarities and differences between pwAMD/caregiver pairs where the caregiver was the spouse of the pwAMD, and those where the caregiver was the adult-offspring of the pwAMD.

Dissemination of Findings

Publications

Boxell, E.M., Amoaku, W.M. & Bradley, C. (2017). Healthcare experiences of patients with age-related macular degeneration: have things improved? Cross-sectional survey responses of Macular Society members in 2013 compared with 1999. *BMJ Open. 7.*

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Invited talks

Bradley, C., Boxell, E.M. & Amoaku, W.M. (2016). *Healthcare experiences of patients with age-related macular degeneration in the UK*. Oral presentation at The Elizabeth Thomas seminar for Macular Disease, Nottingham, UK. Royal College of Ophthalmologists. 28th October 2016.

Boxell, E.M. & Bradley, C. (2014). *Your experiences: results of the patient experience survey*. Oral presentation at the Macular Society 2014 annual conference, London. 27th September 2014.

Poster presentation

Boxell, E.M. & Bradley, C. (2014). *Perceived quality of health care for patients with macular conditions: where are we now?* Royal College of Ophthalmology annual conference, Birmingham, UK. May 2014.

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The Macular Society funded the PhD studentship that supported this research. They reviewed and commented on the Macular Society 2013 survey leading to the addition of one item which will be reported elsewhere and has not been reported in this thesis. They were responsible for printing and posting the Macular Society 2013 survey. However they did not play a role in the study design, data analysis, interpretation of the data or the study write up.

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Abbreviations/ Acronyms

AMD	Age-related macular degeneration
AREDS	Age-related eye disease study
CBS	Charles Bonnet Syndrome
CNV	Choroidal Neovascularisation
CRA	Caregiver Reaction Assessment
DLTV	Daily Living Tasks Dependent on Vision
ECP	Eye-care professional
FIML	Full information maximum likelihood
GP	General practitioner
HCP	Healthcare professional
IADL	Instrumental activities of daily living
LVC	Low-vision clinic
LVR	Low-vision rehabilitation
MCAR	Missing completely at random
MDSQ 1999	Macular Disease Society Questionnaire 1999
MSQ 2013	Macular Society 2013 survey
NHS	National Health Service
NICE	National Institute for Health and Care excellence
PRO	Patient-reported outcome
pwAMD	Person with AMD/ People with AMD (according to context)
QoL	Quality of life
RCOphth	Royal College of Ophthalmologists
RCT	Randomised controlled trial
RNIB	Royal National Institute of Blind people
RPE	Retinal Pigment Epithelium
SEM	Structural Equation Model
SI	Sight impaired
SSI	Severely sight impaired
VEGF	Vascular Endothelial growth factor
VI	Visual impairment
VIF	Variance Inflation Factor

W-BQ 12	Well-being Questionnaire (12-item)
W-BQ 16	Well-being Questionnaire (16-item)
WHO	World Health Organisation

Chapter 1: Introduction and Literature review

INTRODUCTION

This thesis presents a series of studies which investigate the information and support received by people with age-related macular degeneration (AMD) from health and social care services, the voluntary sector, and friends and family. It includes the first study to examine the impact of receiving and providing care for AMD both from the perspective of people with AMD (pwAMD) and their caregivers. Chapter 1 provides background information on AMD including a critical review of the literature on the experience of living with AMD, and what is known about the help and support reported to be received by pwAMD. A review of the research on receiving care because of vision loss, and on caregivers of pwAMD is presented in Chapter 5.

LITERATURE REVIEW

Age-related macular degeneration (AMD) is a progressive chronic eye condition affecting people aged 50 years and above (RCOphth, 2009). AMD is one of many eye conditions affecting the macular. The macular is the central part of the retina used for activities requiring fine vision (e.g. reading, writing and recognising faces). Central vision deteriorates while peripheral vision is usually retained. Other types of macular condition include (for example): juvenile macular dystrophies, myopic maculopathy, macular hole, diabetic macular oedema, and retinal vein occlusion.

AMD is the leading cause of blindness in developed countries (Bourne et al., 2014). There were approximately 513,000 people living with late AMD in the UK in 2012, and numbers are expected to grow by a third by 2020 with the increasing age of the population (Owen et al., 2012).

Types of AMD

In the early stages of the condition, drusen (yellow or white extracellular deposits) form between the retinal pigment epithelium (RPE) and Bruch's membrane (Ratnapriya & Chew, 2013). There may also be areas of hypopigmentation of the RPE, and/or hyperpigmentation in the outer retina or choroid associated with drusen. AMD may be asymptomatic in the early stages.

Late or advanced stage AMD can be ‘wet’ or ‘dry’. Exudative or neovascular AMD (also known as wet AMD) usually involves choroidal neovascularisation (CNV). This is where new blood vessels have formed in the choroid and may be leaking blood or fluid into the retina leading to fibrous scarring. Geographic atrophy or non-neovascular AMD (also known as dry AMD) is characterised by the progressive atrophy of the RPE, choriocapillaris and photoreceptors (Lim, Mitchell, Seddon, Holz, & Wong, 2012). Dry AMD can convert to, or be associated with, wet AMD in the same or contralateral eye. Advanced AMD is more likely to cause more pronounced central vision loss (Lim et al., 2012). Dry AMD accounts for 80-85% of cases of AMD, whilst wet AMD accounts for 15-20% (Bonastre et al., 2002).

Symptoms of AMD

Geographic atrophy (dry AMD) may not produce noticeable symptoms at first and is usually detected during a routine fundus examination. When geographic atrophy is bilateral (involving both eyes), a deterioration in central vision is more noticeable. Patients may have difficulty reading small print, and later on, large print (RCOphth, 2013).

Symptoms typical of onset of exudative (wet) AMD include central vision blurring and distortion. Straight lines may appear crooked or wavy. Vision loss caused by a haemorrhage or fluid accumulation secondary to CNV may produce sudden and profound vision loss (Jager , Mieler , & Miller 2008). Other symptoms typical of wet AMD include a dark central patch in the visual field (scotoma) (Mitchell, Annemans, White, Gallagher, & Thomas, 2011; RCOphth, 2013).

Charles Bonnet Syndrome

PwAMD may experience a common side effect of vision loss known as Charles Bonnet Syndrome (CBS). CBS is the experience of visual hallucinations which can take the form of, for example: people, trees, plants, patterns, animals or objects.

Visual hallucinations may not be reported for fear of being labelled as having a serious mental illness (Menon, 2005). The experience of hallucinations has been linked to poorer well-being (Mitchell, 2003), higher emotional distress and decreased functional ability (Scott, Schein, Feuer, & Folstein, 2001). Although there is currently no cure for hallucinations, informing patients that hallucinations are usually benign has been shown to ease distress (Menon, 2005).

A large-scale nationwide survey sent to members of the Macular Society found a 39% prevalence of CBS in people who reported diagnosis of a macular condition (Cox & ffytche, 2014). Of those experiencing hallucinations, 75% had had CBS for 5 years or more (Cox & ffytche, 2014). Respondents who reported that hallucinations had a negative effect on their lives were more likely to report more frequent hallucinations, hallucination episodes of longer duration, fear-inducing hallucinations, hallucinations which affected daily activities, having attributed hallucinations to mental illness and not knowing about CBS at the onset of symptoms (Cox & ffytche, 2014). Whilst 47% had spoken to a healthcare professional about their hallucinations, 7% had not spoken to anyone about their hallucinations (Cox & ffytche, 2014). Thus suggesting that many people experiencing CBS are not being given information on them (either at diagnosis or later on) and that this might affect their reactions to the hallucinations.

Prevalence of AMD

Several epidemiological studies have investigated the incidence and prevalence of AMD. In the UK, overall prevalence of late stage AMD in those aged over 50 was 2.4% which is equivalent to 513,000 cases (Owen et al., 2012). Prevalence rates increased with age. Estimated prevalence of AMD in people aged over 65 years was 4.8%, increasing to 12.2% in those aged over 80 (Owen et al., 2012). The authors estimated an increase of 71,200 new cases of late AMD per year.

A recent meta-analysis combining global data from population-based studies of AMD patients estimated pooled prevalence rates of: early AMD (8.01%, 95% credible intervals (Crl), 3.98%-15.49%), late AMD (0.37%, 95% Crl, 0.18%-0.77%) and any AMD (8.69%, 95% Crl, 4.26%-17.40%). The projected number of pwAMD worldwide in 2020 is 196 million (95% Crl, 140-261), increasing to 288 million in 2040 (95% Crl, 205-399) (Wong et al., 2014).

Risk factors

The exact causes of AMD are still being investigated (Ratnapriya & Chew, 2013). Both genetic and non-genetic factors are thought to play a role in causing AMD. Non-genetic risk factors such as smoking and older age are consistently linked with increased risk for any form of AMD (e.g. Chakravarthy et al., 2010; Klein, Klein, Tomany, Meuer, & Huang, 2002; Smith et al., 2001; Thornton et al., 2005). A review by Chakravarthy et al. (2010) found no significant association between gender and AMD risk.

Chakravarthy et al. (2010) noted inconsistent associations between risk of AMD and both cardiovascular factors (e.g. hypertension and hyperlipidaemia) and greater Body Mass Index.

There is mixed evidence to suggest an increased prevalence of AMD in white compared to other ethnic groups (e.g. Chakravarthy et al., 2010; Klein et al., 2013). A recent meta-analysis of global data from patients with AMD found higher prevalence of early stage AMD in people with European ancestry than in those with Asian ancestry, but rates of late stage AMD were similar (Wong et al., 2014). Both early and late AMD were more prevalent in those with European ancestry than African ancestry (Wong et al., 2014).

Family history of AMD is inconsistently associated with risk of AMD (Chakravarthy et al., 2010). Research is on-going into the identification of genes linked to susceptibility to AMD (Ratnapriya & Chew, 2013).

There has been inconsistent evidence for an association between lighter iris pigmentation (i.e. blue vs brown eyes) and development of late AMD (Chakravarthy et al., 2010). Eye-related risk factors with consistent associations with late AMD include previous cataract surgery (Chakravarthy et al., 2010) and clinical signs such as drusen and pigmentary irregularities (Age-Related Eye Disease Study Research, 2005).

Knowledge of macular conditions

A US study found one third of a sample taken from the general population (i.e. including people either at high or low risk of developing AMD) had never heard of AMD (Cimarolli, Laban-Baker, Hamilton, & Stuen, 2012). Of those who had heard of AMD before, most reported becoming aware of AMD through knowing someone with the condition. Knowledge of AMD risk factors and perceived risk of AMD was low (Cimarolli et al., 2012). Just over a third of those at high risk of developing AMD (due to older age, having smoked and white ethnicity) believed they had a small risk of developing AMD (Cimarolli et al., 2012).

Cimarolli et al. (2012) suggested that people may not go for eye tests if they are unaware of AMD and their potential risk of AMD. A UK study investigated reasons why older adults do not go for eye tests and found poor knowledge of eye disease (Shickle & Griffin, 2014). Respondents were unaware of the purpose of different elements of the eye examination. Eye tests were perceived to be predominantly for correcting for refractive error and assessing the need for spectacles. Other barriers included: feeling vulnerable about getting their answers to the tests 'wrong' and looking foolish, the perception that wearing spectacles made them look old and frail, fear of being told that they would lose their driving license or being told that they would go blind, and having previously experienced 'hard sell' in opticians (Shickle & Griffin, 2014). Improving awareness of the need for eye tests to test for other causes of preventable sight loss might improve attendance at screening, but other factors such as informing patients about the need for different tests and explaining the procedure may also be important.

There is evidence to show that timely treatment given at the onset of CNV secondary to AMD with anti-vascular endothelial growth factor (VEGF) injections leads to better visual outcomes (e.g. Real et al., 2013). Thus early detection, diagnosis and treatment may prevent unnecessary sight loss. Despite this, an international survey sent to people who had experienced symptoms of wet AMD found that a quarter of respondents waited more than a month to seek help for their symptom(s) (Varano et al., 2015). The main reason for delaying seeking help was due to thinking that the symptom(s) would resolve itself (themselves). The authors suggested that this may be due to a lack of awareness about eye health and the impact of a delayed diagnosis.

Medical and surgical treatment

At present, there is no cure for AMD. There are no proven treatments for dry AMD to date although progression may be reduced with the Age-Related Eye Disease Study 2 (AREDS 2) formula nutritional supplements (Age-Related Eye Disease Study 2 Research, 2013; Age-Related Eye Disease Study Research, 2001). Significant advances have been made in treatment for wet AMD with intravitreal injections of anti-VEGF drugs.

Ranibizumab (Lucentis, Genentech/Novartis) was approved for use in the UK by the National Institute for Health and Care Excellence (NICE) in August 2008 (NICE, 2008), and has been successful in preventing vision loss (Brown et al., 2006; Brown et al., 2009; Martin, 2011; Rosenfeld et al., 2006). More recently, aflibercept (Eylea, Regeneron/Bayer), was approved by NICE in July 2013 (NICE, 2013). In addition, the off-license use of bevacizumab (Avastin, Roche/Genentech) has been advocated by some specialists for the same indication since 2006 (Amoaku, 2008) and has been found to have similar efficacy to Ranibizumab (Chakravarthy et al., 2013).

Estimates suggest there may be 26, 000 people with wet AMD now eligible for treatment in the UK each year (NICE, 2008). Evidence suggests that the number of patients eligible for blindness certification has decreased since the introduction of anti-VEGF injections (e.g. Bloch, Larsen, & Munch, 2012).

Anti-VEGF treatment is injected directly into the eye and works to inhibit the production of vascular endothelial growth factor (VEGF); a secreted endothelial-specific mitogen which plays a key role in promoting neovascularisation in wet AMD. Patients receiving injections usually start with a ‘loading phase’ of one injection per month for three months. At which point they are either monitored through monthly visits to assess the need for re-treatment (for Ranibizumab), or receive injections every two months for a year followed by monitoring (for aflibercept). The introduction of anti-VEGF treatment has led to financial and service capacity pressures on the NHS, with some clinics struggling to provide monthly treatment reviews where applicable (Amoaku et al., 2012).

Laser treatment and photodynamic therapy are other treatments available for wet AMD but are only used in a minority of cases where patients present with particular clinical factors, e.g. laser treatment may be given to patients with lesions far away from the fovea (RCOphth, 2013). Submacular surgery, macular translocation and radiotherapy treatment have been provided in the past however they are no longer recommended by the Royal College of Ophthalmologists (RCOphth, 2013).

Anti-VEGF treatment has revolutionised the treatment of wet AMD however no effective therapy exists to treat those with dry AMD which accounts for the majority of cases of AMD. Nevertheless, new understandings of AMD and recent technological breakthroughs have led to new clinical trials aiming to find a cure for AMD (e.g. stem cell-based therapy involving regenerating RPE cells in geographic atrophy (Hanus, Zhao, & Wang, 2016)).

The impact of anti-VEGF treatment on patients

A recent study found that 12% of patients receiving treatment for wet AMD reported clinical levels of depression, and 17% reported symptoms of anxiety (Senra, Balaskas, Mahmoodi, & Aslam, 2017). The majority were not receiving appropriate psychological or psychiatric treatment (Senra et al., 2017). Clinical levels of depression were higher in patients who were in the early stages of receiving treatment, however the authors suggested this may be due to these patients being recently diagnosed with wet AMD and subsequent concern about their prognosis rather than being due to treatment specifically. Anxiety was caused by fear of going blind because of the injections (e.g. the needle doing damage to the eye), concern about treatment effectiveness, and anticipatory anxiety (waiting in the waiting room) rather than due to treatment-related pain (Senra et al., 2017).

It has been argued that patient experiences of receiving treatment should be taken into account when creating guidelines to improve ophthalmology practice (Burton, Shaw, & Gibson, 2013). There have been several qualitative studies investigating patients' experiences of receiving anti-VEGF treatment (e.g. Henriksen & Adhami, 2010; McCloud, Khadka, Gilhotra, & Pesudovs, 2014; Thetford, Hodge, Harding, Taylor, & Knox, 2013). Similar to the findings reported above from Senra et al. (2017), Thetford et al. (2013) found that patients reported "anxiety and fear of the unknown" and were apprehensive about receiving injections. Anxiety about and discomfort from having the injections have been reported for various aspects of the treatment including the application of eye drops, the use of surgical drapes and needle entry, long waiting times, fear of losing their sight, fear of side effects and prior experiences of pain when receiving previous injections (Senra, Ali, Balaskas, & Aslam, 2016; Thetford et al., 2013).

Despite the anxiety related to treatment, patients report that receiving anti-VEGF treatment is worth the initial distress so that future vision loss can be prevented, and would recommend the treatment to others (Burton et al., 2013; Thetford et al., 2013).

Burton et al. (2013) reported that patients described building relationships with nurses to help manage distress. Holding hands with the nurse during the procedure was considered a physical reassurance. Others reported using humour as a distraction. Making sure patients are adequately informed may help to ease their concerns and reduce unnecessary worry prior to treatment. Many patients reported not receiving explanations for tests and scans (Burton et al., 2013). This lack of information provision raises questions about the adequacy of informed consent for the procedure. Clearer communication with patients is needed to help them to develop realistic expectations about prognosis following treatment. Some patients reported difficulty understanding hospital appointment letters and information leaflets (Burton et al., 2013). Subsequently, it has been recommended that information about the procedure should be delivered verbally (as well as in written format), and that explanatory videos or peer support may help to ease pre-treatment anxiety (Burton et al., 2013; Thetford et al., 2013).

An international survey conducted in nine countries (Australia, Brazil, Canada, France, Germany, Italy, Japan, Spain and the UK) found that, for respondents receiving treatment for wet AMD and who had a caregiver, 60% of these caregivers always attended appointments with the person with AMD (Varano et al., 2015). Many caregivers reported that frequent appointments were inconvenient. However for many patients, treatment resulted in a temporary improvement or stabilisation in their vision, and caregivers reported this enabled them to reduce the level of domestic assistance provided. The majority of patients attended every clinic appointment (84%). The main reason for non-attendance was due to their caregiver being unable to take them, followed by fear of having the injection and patient illness.

(Further research findings on the impact of providing care for someone with AMD, including caregiver burden associated with anti-VEGF treatment, are presented in Chapter 5.)

Monitoring vision

There is evidence to suggest that people diagnosed with an untreatable eye condition such as dry AMD and who are discharged from the eye clinic with the message that nothing more can be done for them, stop attending routine eye tests in the future

(Thetford, Robinson, Knox, Mehta, & Wong, 2009). A lack of information in the diagnostic consultation meant that people often had little understanding of their condition and the importance of continuing to get their eyes tested to monitor for deterioration (Thetford et al., 2009). The RCOphth guidelines (RCOphth, 2013) recommended that patients should be advised to go for eye tests at least every two years and to monitor their AMD at home using an Amsler Grid (a square arrangement of vertical and horizontal lines that helps to assess a person's central visual field by identifying if there are any gaps, waviness or missing portions of the lines in the grid). Early detection of changes and timely treatment may lead to better visual outcomes.

Recently, there has been interest in moving the monitoring of treatable wet AMD away from eye clinics and into community settings (with a referral back to the hospital for treatment if needed). The primary aim is to reduce the pressure on hospital eye clinics. Trials are currently being carried out to assess feasibility and acceptability of this new model. (For an example, see the Effectiveness of Community vs Hospital Eye Service (ECHoES) trial (Taylor et al., 2016; Townsend et al., 2015)). Additionally, to help meet service demands for the number of people requiring treatment, there have been trials to train nurse practitioners in delivering anti-VEGF injections. This has been shown to be safe and effective (Hasler et al., 2015; Li, Greenberg, & Krzystolik, 2015; Simcock, Kingett, Mann, Reddy, & Park, 2014). Therefore, in the near future there may be major changes to the way people with AMD are seen for diagnosis and treatment.

Impact of AMD

First, when reviewing the literature on the impact of AMD, it is important to be vigilant in noting the measures used in research studies so that appropriate conclusions are drawn from the study findings. For instance, a variety of different measures have been referred to as measures of quality of life (QoL) including measures of anxiety and depression (e.g. Hospital Anxiety and Depression Scale, HADS, Zigmond and Snaith (1983)), life satisfaction (e.g. Life satisfaction index, James, Davies, and Ananthakopan (1986)), health status (e.g. SF-36, Ware, Snow, Kosinski, and Gandek (1993)), functional status (e.g. Instrumental Activities of Daily Living, IADL, Williams, Brody, Thomas, Kaplan, and Brown (1998)) and vision-specific functional status measures (e.g. National Eye Institute Vision Function Questionnaire, NEI-VFQ, Mangione et al. (1998)). These measure phenomena that may be related to QoL but are not in themselves measures of QoL (Mitchell & Bradley, 2006). QoL has been defined as how good or bad an individual feels his or her life to be (Joyce, 1994; McGee, O'Boyle, Hickey, O'Malley, & Joyce, 1991). It is a subjective perception that means different things to different people. Mitchell and Bradley (2006) argued that in order to be relevant to pwAMD, measures of QoL should include aspects of life impacted by AMD and allow patients to rate the importance of these aspects of life for their QoL. For instance, the NEI-VFQ measure has vision-specific items which enables the measurement of the impact of AMD on activities that may be affected by vision (e.g. ability to play card games), however it does not measure the importance or relevance of these items to the person's QoL. For people who regularly play card games, AMD would impact on their QoL in this respect but there would be no such impact on someone who does not play card games. This difference in importance would not be picked up by measures of visual function alone (Covert, Berdeaux, Mitchell, Bradley, & Barnes, 2007).

If measures of health status are used as if they are measures of QoL, the results can be misleading. Health may be good while QoL may be greatly affected by vision loss and worry about future visual impairment. Additionally, the EuroQoL (EQ-5D, Brooks (1996)), a commonly-used 6-item measure of health status, contains items that may not be relevant to AMD (e.g. overall health, pain, mobility) (Mitchell, 2007).

The MacDQoL (Mitchell & Bradley, 2004) has been developed as an individualised measure of the impact of macular conditions on QoL. It contains two overview items: generic 'present QoL' and MD-specific 'impact of MD on QoL', plus a further 23 items identified as affected by MD and of importance to the QoL of many people with macular conditions (e.g. difficulties with household tasks). Respondents are asked to rate the impact of AMD on these domains as well as the importance of that domain for their QoL. Using this measure, Mitchell et al. (2005) found the domains most impacted by AMD were independence, leisure activities, dealing with personal affairs and getting out and about. The negative impact of AMD increased with more severe vision loss (Mitchell et al., 2008).

Current guidelines focus on the use of objective measures (e.g. visual acuity) to guide treatment decisions (e.g. NICE, 2008). However Burton et al. (2013) argued that patients may make different treatment decisions based on their daily experiences (i.e. whether they are able to see to do hobbies that are important to them). Thus it is important to consider patient experiences when guiding treatment decisions. The use of individualised measures of QoL are becoming more commonplace (e.g. the MacDQoL, used in the Inhibit VEGF in Age-related choroidal Neovascularisation (IVAN) trial to compare efficacy of Ranibizumab and Bevacizumab treatment (e.g. Chakravarthy et al. (2013)), is now linguistically validated into 25 languages as well as English for the UK).

Medical decision makers such as NICE currently rely on the EQ-5D health status tool (often wrongly referred to as a QoL measure) to calculate utility values. Techniques such as Time Trade Off (TTO) are used to elicit preferences for different health states measured by the EQ-5D or similar tools and in turn are used to calculate Quality Adjusted Life Years (QALYs). The cost of a QALY gained from treatment is used to make decisions about which treatments to provide on the National Health Service (NHS). TTO measures have been criticised for being too hypothetical, ridiculous, and objectionable due to religious reasons (Brown et al., 2006). TTO questions ask patients to consider how much of their remaining life they would be willing to give up in return for normal vision. This has been criticised as elderly people may find this difficult to answer due to their limited life expectancy and indeed some question whether it is even ethical to ask such a question (Mitchell, 2007). Additionally the data sets used to calculate utility values are often collected from members of the general public who are given descriptions of the health condition being assessed but have no personal experience of the condition. Studies have shown that the general public tend to underestimate the impact of AMD on QoL (Stein, Brown, Brown, Hollands, & Sharma, 2003). Thus treatments for AMD may be found to be less cost-effective in comparison, because of the public's underestimation of the impact of AMD on QoL (Mitchell & Bradley, 2006).

Functional limitations

Visual impairment can impact on the day-to-day lives of pwAMD. Hochberg et al. (2012) found AMD patients experienced difficulty preparing meals, doing food shopping and travelling. These became more difficult with more severe vision loss.

Studies suggest that between 39-45% of AMD patients require help with at least one activity of daily living (e.g. Taylor, Hobby, Binns, & Crabb, 2016). Experiencing falls is twice as common in the population with wet AMD compared to elderly controls and people with wet AMD have a quadrupled need for assistance with daily activities (Soubrane et al., 2007). Vision-specific functioning has been found to be significantly worse in people with late AMD than early AMD (Lamoureux et al., 2011), and in people with both eyes affected as opposed to one eye (Dong et al., 2004; Marback, Maia Junior, Morais, & Takahashi, 2007).

Whilst most research uses quantitative measures to examine the impact of AMD on non-vision specific functioning such as the Activities of Daily Living scale (ADL) and Instrumental activities of daily living (IADL), or vision-specific functioning such as the National Eye Institute-Vision Function Questionnaire (NEI-VFQ), other research has used qualitative methods. For instance, Bennion, Shaw, and Gibson (2012) reported a meta-synthesis of qualitative research on the experience of living with AMD. Whilst qualitative research can be used to confirm quantitative study findings (e.g. this review also found that pwAMD reported difficulties with everyday tasks such as cooking), it can provide a more complete picture of how people cope with these changes emotionally and the means by which they have adapted, which might not be picked up by using quantitative measures. For instance, many pwAMD reported that difficulties carrying out tasks and loss of ability to drive led them to fear losing their independence and increased worry about becoming a burden to family and friends. Indeed, loss of the ability to drive due to AMD has been cited as one of the main threats to independence (Weaver Moore & Miller, 2003).

Psychological impact

AMD has a considerable impact on psychological aspects of life. It has been linked to an increased risk for depression (e.g.Brody et al., 2001; Dawson, Mallen, Gouldstone, Yarham, & Mansell, 2014; Mathew et al., 2011; Soubrane et al., 2007), anxiety (e.g. Soubrane et al., 2007), poor quality of life (e.g. Mitchell & Bradley, 2006), poor psychosocial adjustment (e.g. Stanford, Waterman, Russell, & Harper, 2009), poor life satisfaction (e.g. Davis, Loviekitchin, & Thompson, 1995) and emotional distress (e.g. Williams et al., 1998). People with VI have a higher risk of committing suicide compared to elderly controls (Johnson, Rovner, & Haller, 2014; Waern et al., 2002). People with vision loss were more likely than those without vision loss to be diagnosed with agoraphobia and social phobia, suggesting that anxiety may arise from the impact of vision loss on functioning related to specific places or social situations such as being on a bus or eating at a restaurant (van der Aa, Comijs, Penninx, van Rens, & van Nispen, 2015). Indeed, symptoms of depression have been found to be associated with loss of vision-specific functioning, independent of level of visual acuity (e.g. Banerjee, Kumar, Kulhara, & Gupta, 2008; Rovner & Casten, 2001, 2002). AMD patients who reported they were dissatisfied with performance of valued activities were 2.5 times more likely to become depressed than those satisfied with their ability to carry out valued activities (Rovner, Casten, Hegel, Hauck, & Tasman, 2007).

The qualitative literature highlights individual differences in patients' experiences with some reacting more positively to an AMD diagnosis than others (Bennion et al., 2012). Those who had not experienced much vision loss reported that AMD had little impact, however there was concern about future vision loss (Bennion et al., 2012). A variety of reactions to AMD have been reported including negative reactions such as uncertainty and fear about the future, frustration, sadness and inadequacy as well as positive ones such as hope, optimism (for the development of a cure for AMD or that vision would not deteriorate further) and an enthusiasm to hold onto independence (Owsley et al., 2006; Weaver Moore & Miller, 2003).

There is conflicting evidence on the impact of unilateral or bilateral AMD on emotional health. Some results suggest a greater impact when both eyes are affected (e.g. Mitchell, 2003; Wong, Guymer, Hassell, & Keeffe, 2004). This may be due to poor visual acuity leading to difficulties carrying out vision-specific tasks, resulting in poorer psychological health. Others suggest poorer psychological health when only one eye is affected (e.g. Williams et al., 1998); perhaps due to fear of losing sight in the second eye (Slakter & Stur, 2005). Other factors associated with depression in AMD patients include neuroticism (Rovner & Casten, 2001), and time since diagnosis with more recently diagnosed patients reporting higher levels of emotional distress (Williams et al., 1998).

Social impact

A meta-synthesis of the qualitative literature on the impact of AMD found that vision loss caused by AMD can lead to feelings of isolation (Bennion et al., 2012). People with AMD report barriers to social engagement including; feeling embarrassed because they are unable to see and recognise faces, and difficulty getting to places to see friends and family. In addition, public knowledge of AMD appears to be limited, and this led participants to feel that some family and friends lacked an understanding of their condition and were consequently unaware of their needs. Some participants were concerned that they would be labelled as a fraud due to their 'invisible disability'. Whilst certification as SI or SSI gave some affirmation of their vision loss, some participants remained reluctant to disclose their sight loss to others. The decision to conceal their AMD led some people to refuse low-vision aids. Sometimes, concealment of AMD from friends and family was to avoid unwanted sympathy (Bennion et al., 2012).

(A comprehensive review of the impact that AMD has on people who provide support to someone with AMD is presented in Chapter 5.)

Support for living with AMD

Registration as severely sight impaired (blind) or sight impaired (partially sighted)

In England and Wales, registration as sight impaired (SI) or severely sight impaired (SSI) is initiated with certification from a consultant ophthalmologist at the consent of the patient (Bunce, Xing, & Wormald, 2010). Data from April 2007 to March 2008 estimate that AMD accounts for over half of all registrations as SI or SSI in the UK (Bunce et al., 2010). This may be an underrepresentation of the true number of people eligible for registration. Thetford et al. (2009) reported that some patients eligible for registration may not be registered. People already registered as SI and who have experienced a deterioration in sight since registration may also experience barriers and delays to registration as SSI including: having to be referred to see an ophthalmologist and other health conditions taking precedence (Hodge, Thetford, Knox, & Robinson, 2015).

When sight loss has deteriorated to a point where patients can receive a Certificate of Visual Impairment from an ophthalmologist, the council will receive a copy of the certificate. They should then contact the patient to ask if they would like to be registered and if they would like a vision rehabilitation needs assessment. Otherwise, people with VI can contact their council directly and ask for an assessment. Referral can also be via another organisation or service.

Low-vision rehabilitation services

Given the impact of AMD, what support is available to help pwAMD manage the changes associated with vision loss? All councils in England should offer vision rehabilitation services to people with VI (RNIB, 2016b). This may either be provided by the council or the council may contract a sight loss charity or organisation to provide this service. Vision rehabilitation provides training and advice to help people learn daily living skills to maintain independence. This may include, for example: tips, advice and training on how to cook, clean and maintain the home safely, advice on lighting, and mobility training (e.g. building confidence to move around safely both inside and outside the home).

Excluding financial support, most services are available to people with VI regardless of registration status. The latest Royal College of Ophthalmologist guidelines (RCOphth, 2013) recommend that eye-care professionals should not wait to refer a patient to low-vision services until all treatment options have been exhausted or until a patient’s vision has deteriorated to the point when registration becomes appropriate. It may be easier to make changes that may help activities of daily living when a patient’s vision is still good. However there is evidence to suggest that many people do not receive support until after registration, and even then, support may be limited (Hodge et al., 2015; Thetford et al., 2009). People with VI reported being seen for an initial assessment, but were then left to contact services for further help if needed (Hodge et al., 2015). However many reported barriers to accessing this help, such as not knowing who to contact (Thetford et al., 2009). Others were unaware of what support was available or did not know what help to ask for (Thetford et al., 2009). Additionally, offers of help soon after diagnosis or registration may be rejected if people with VI are unable to accept support at a time when they are still coming to terms with their diagnosis (Thetford et al., 2009). The Royal National Institute of Blind People (RNIB) report that many people with vision loss are unaware that vision rehabilitation services are available and that these services can be used at any point; they are not restricted to people who have just been diagnosed or registered, or have experienced recent vision loss (RNIB, 2016b) . Thus people with VI should be made aware of the ongoing availability of these services and who to contact for help (RNIB, 2016b).

Vision rehabilitation support is provided free-of-charge, however a financial assessment is usually required if social care is needed (e.g. having someone to help with domestic tasks). Minor aids and adaptations, up to the value of £1000, are also provided for free. If the person with VI has an unpaid carer who helps to meet some of their needs, they have the right to request a carer’s assessment. Following this, carers may receive help from the council, such as equipment to help with caring duties or being offered support (e.g. respite breaks). They may also be eligible for specific benefits (e.g. Carer’s Allowance).

A freedom of information request found that, in England, just under half of people registered as SI or SSI and who are in contact with their council have not received a vision rehabilitation assessment for their support needs (RNIB, 2016a). Of those who did receive an assessment, many felt they did not receive an assessment sensitive to their particular needs (RNIB, 2016a). Similarly, the Network 1000 survey found that half of the survey respondents had never been to a low-vision clinic despite being registered as SI or SSI (Douglas, Pavey, Corcoran, & Eperjesi, 2010). Referral to vision rehabilitation varied widely across comparable local authorities in England (RNIB, 2016a). The variable distribution of low-vision services across the UK have been reported elsewhere (Culham et al., 2002). For instance, eye clinic liaison officers (ECLOs) provide patients with much-needed information about their eye condition, the services available in eye clinics and the community, emotional support and referral to social services. They are said to bridge the gap between health and social care (RNIB, 2015). However this service has not been widely-implemented. It is thought that only around 30% of eye clinics in the UK have an ECLO (RNIB, 2015). There is wide variation on how this role is set up; some clinics employ someone full-time to fill this position, whilst in other clinics the role is undertaken by volunteers. The role has not been established as a statutory element of eye health care, despite evidence suggesting that the service can provide health and social care budgets with a financial return of £10.57 for every one pound invested (Sital Singh, 2013).

Dickinson et al. (2011) suggested a template model of a comprehensive low-vision service would include ophthalmological care (diagnosis, treatment and monitoring), social care needs (review of the home environment, self-care and benefits), low-vision aids (optical aids, lighting), and emotional support (counselling). The LOVSME project (LOw-Vision Service Model Evaluation) profiled seven UK low-vision services. No standard model of delivery existed in the UK. The seven services profiled had different formats for how they provided low-vision services (Dickinson et al., 2011). The services were multi-disciplinary but none fulfilled all the components of the comprehensive ‘template’ model (Dickinson et al., 2011). Only one of the seven services performed clinical audits of effectiveness in the form of QoL evaluations, but these data had not been published at the time of the evaluation, and it was unclear how the results were used. Thus low-vision services provided in the UK vary across the country and their effectiveness has not yet been shown in published studies.

Binns et al., (2012) conducted a systematic review of low-vision rehabilitation (LVR) evaluations from around the world. Fifty eight articles reporting the results of 52 studies met the inclusion criteria of having included people with a visual impairment in a rehabilitation service, and with the study design including a comparison (between groups or over time). Only 7 studies were RCTs. The authors examined potential sources of bias including the robustness of the study design (e.g. RCT vs before and after), whether the study included a wait list control, whether details were provided on randomisation and masking procedures (if relevant to the study design), the use of validated outcome measures, whether the outcome data were collected by someone independent of the providers running the service and the detail of the results provided (e.g. reporting of data to allow effect sizes to be calculated). Only studies that included over ten participants were included in the review. The synthesis of the evidence provided in the studies found provision of LVR improved functional outcomes (e.g. in ADLs) in people with VI but the evidence for effects on mood, QoL and health status were conflicting (Binns et al., 2012). A variety of measures were used to assess QoL. Many studies included in the review stated an increase in vision-related QoL after the intervention, however upon closer inspection, Binns and colleagues suggest that these results were due to improvements in the items from these measures that assess *functional* abilities, and that these showed greater sensitivity to the intervention.

The lack of consensus of the impact of LVR on symptoms of depression may be due to selection bias. Patients with depression have been found to be less likely to use low-vision services (Tolman, Hill, Kleinschmidt, & Gregg, 2005). Thus it may be difficult to detect the effect of these services on depression.

According to Binns and colleagues, the studies on LVR to date were poorly designed (e.g. few studies included a comparison group). There were difficulties making between-study comparisons as there was seemingly a lack of consensus on the best outcome measures to use for evaluation (the authors reported that 47 different outcome measures were used). Lack of follow-up made it difficult to establish the long-term effectiveness of interventions (Binns et al., 2012). The evidence included in the review was not sufficient to provide recommendations on what type of service produces the best outcomes for people with VI. More high-quality RCTs of LVR are needed, plus a clearer focus on the cost-effectiveness of interventions (Binns et al., 2012). More research is needed to ascertain the benefits of LVR on the QoL of pwAMD.

Several barriers to LVR uptake have been reported. These include difficulty accepting vision loss, a reluctance to use services that were perceived as being geared towards the SSI, a lack of information about low-vision services from eye specialists, fear of being stereotyped and difficulty travelling to the clinic (Pollard, Simpson, Lamoureux, & Keeffe, 2003; Southall & Wittich, 2012).

Many clinics in the UK do not routinely provide emotional support to people with VI despite the psychological impact of AMD (Gillespie-Gallery, Conway, & Subramanian, 2012). Cimarolli et al. (2016) suggested that rehabilitation professionals should refer patients to specialist mental health services if depression and anxiety symptoms do not respond to rehabilitation. Furthermore, more needs to be done to encourage patients who are depressed to attend LVR.

In conclusion, the development of an evidence-based intervention that can be used within existing care systems has been hindered by a lack of research into the cost-effectiveness of interventions. Additionally the use of a variety of components in interventions (e.g. teaching problem-solving skills, LVA provision) and the variety of outcome measures used in evaluation have prevented between-study comparisons.

Many people with VI receive information and support from sight loss voluntary and charitable organisations. Indeed Hodge et al. (2015) reported that people with VI were more likely to receive support from the voluntary sector than the statutory sector (although this may be due to the method of recruitment used and area from which their participants were recruited: participants were recruited through a voluntary organisation which played a significant role in the area in which the participants lived). Services provided by the RNIB and the Macular Society include, for instance, emotional support and provision of information on eye conditions and treatments available. These services can be received over the phone or internet and thus may be more accessible than locally provided services run at the hospital or social services if patients have difficulty getting to these places.

If people with VI are able to get out and about, local support groups may provide additional support. An evaluation was run on one of the many peer support groups run by members of a UK charity (the Macular Society), for patients newly diagnosed with AMD (Bradley, Mitchell, & Bradley, 2005). The peer support programme consisted of six weekly discussion groups. Participants also received leaflets on the topics discussed in the sessions. Using the Well-being questionnaire (W-BQ12), participants who reported poorer negative well-being at baseline experienced greater improvements in well-being post-intervention than those who reported better well-being at baseline. A course evaluation form designed for the study found that participants thought the leaflets were informative, and that the aims of the programme had been met (to provide information about MD, to provide friendship and support, and to promote adjustment to MD). Attendance rates were high suggesting acceptance of the programme.

Information and support provision to patients with AMD

The diagnostic consultation is, for many people, the first opportunity to receive information, support and advice on their macular condition and ways of managing their condition. If there is no treatment available for the patient's AMD, they are often discharged and this consultation may be the only time that patients are seen in clinic unless they experience a deterioration in vision or are referred for registration as SI or SSI.

The first study presented in this thesis follows a previous survey carried out in 1999 by Dr Mitchell and Professor Bradley at Royal Holloway, University of London, in collaboration with the Macular Society (previously called the Macular Disease Society). This study formed part of the PhD thesis by Dr Jan Mitchell (Mitchell, 2003). The Macular Society is a British charitable organisation who support people with a macular condition. The Macular Disease Society Questionnaire (henceforth referred to as "MDSQ 1999") used in the survey was designed in response to reports of unsatisfactory healthcare experiences from members of the Leicester local group of the Society, chaired by Peggy Bradley who undertook an initial pilot study. The subsequent postal survey was sent to 2000 randomly selected members of the Macular Society in 1999, and received a 71% response rate (1421 completed questionnaires were returned). The majority of respondents reported having AMD however the data included respondents with other macular conditions including 23 with macular dystrophy, 15 with macular hole, 8 with pseudoxanthoma elasticum and 3 with diabetic macular retinopathy.

Results of the MDSQ 1999 were published in the *British Journal of Ophthalmology* (Mitchell, Bradley, Anderson, Ffytche, & Bradley, 2002), and Jan Mitchell's thesis (Mitchell, 2003). Key findings from the survey included: over 50% of respondents thought that the eye specialist who first diagnosed their macular condition was not interested in them as a person, and 41% reported being dissatisfied with the diagnostic consultation. Respondents were asked to give their reasons for dissatisfaction. The most common reason was the attitude of the eye specialist; they were commonly seen as being dismissive, patronising, brusque or unfeeling. The second most cited reason for dissatisfaction was lack of information provision to patients about their condition and/ or what further help was available.

Experiences with general practitioners (GPs) were not much better. Twice as many respondents reported that their GP was "not at all well-informed" about their macular condition compared with those who said their GP was "very well-informed". About equal numbers reported that their GP was "very helpful and supportive" about their macular condition, or "not at all helpful and supportive". There was a significant correlation between perceived GP knowledge and perceived GP supportiveness (Mitchell et al., 2002). This is important because early consultations with healthcare professionals may affect future help-seeking. Unsatisfactory experiences with GPs may result in patients being reluctant to consult GPs when further help and support is needed (e.g. referral to an ophthalmologist for registration).

The survey also found that 1247 respondents were told that nothing could be done to help with their macular disease (Mitchell et al., 2002). Understandably this provoked an emotional reaction. The most commonly cited reactions were anxiety and / or depression (60.7%) and resignation (60.3%). Worryingly, as many as 54 respondents (4.3%) reported feeling suicidal. Other research has found that people with VI who were discharged with the message that ‘nothing can be done’ were less likely to go for eye tests (Thetford et al., 2009). Continual monitoring of eyesight is important in case dry AMD turns to treatable wet AMD, or if wet AMD develops in the second eye. Early detection and treatment is likely to lead to better visual outcomes. In addition, although it may be the case that nothing can be done in terms of medical treatment for the macular condition, there are ways in which pwAMD can be supported such as through low-vision aid provision and training that can help patients to manage their condition. Patients should be made aware of the availability of such support and that they have not been left to manage their condition alone. However previous research suggests they are not given information about further support available (Mitchell et al., 2002; Thetford et al., 2009; Thetford, Robinson, Knox, Mehta, & Wong, 2011).

The majority of respondents to the 1999 survey reported experiencing visual changes since the onset of their macular condition, such as blurred vision, flashing lights or difficulty seeing at night (n=1111, 78.2%) (Mitchell et al., 2002). Of these respondents, a quarter reported experiencing visual hallucinations as a result of their macular condition (n=282, 25.4%). Only 122 (43.3%) had talked about these hallucinations with a healthcare professional (HCP), and of these, only 59 had been given a cause for the hallucinations (48.4%). The explanations given were not always accurate or reassuring. They included being due to age (n=3), stress (n=2), brain confusion (n=1), the environment (n=1), having nothing to do with their macular condition (n=1) or being due to psychological reasons (n=1). Mitchell et al. (2002) suggested that lack of information provision about visual hallucinations may lead to hallucinations being attributed to a serious mental illness such as dementia. Indeed not knowing about CBS at the onset of symptoms and having attributed symptoms to mental illness were associated with people reporting that CBS had a negative effect on their lives (Cox & ffytche, 2014). Thus lack of information provision or information that is delivered in an unhelpful manner, may affect pwAMDs' understanding of their condition, their well-being and future help-seeking behaviour.

Leventhal's Self-regulation model of illness (e.g. Leventhal et al., 1997) suggested that patients form cognitive and emotional representations of their illness by comparing their own ideas about their illness with the information they receive. Misconceptions about their illness and inappropriate information provision may lead to maladaptive response to the illness. For instance, believing that one's illness is uncontrollable leads to more passive coping (Moss-Morris, Petrie, & Weinman, 1996). In AMD, this may lead to patients not adopting behaviours that could prevent further deterioration such as protecting eyes from bright sunlight, taking AREDS 2 nutritional supplements and stopping smoking. Believing that one is to blame for their condition can lead to emotional distress (e.g. Newsom, Knapp, & Schulz, 1996). PwAMD have reported incorrect causes for their AMD including 'wear and tear' due to having watched 'too much TV' or reading (Burton, Shaw, & Gibson, 2013). If these incorrect causes are not addressed, this may lead to poorer emotional outcomes and unnecessary avoidance of previously-enjoyed activities.

Patient satisfaction has been consistently associated with better patient outcomes. Stewart (1995) reviewed the literature and found that the quality of physician-patient communication in the history taking segment of the consultation and during discussion of the management plan, was found to influence patient health outcomes including emotional health, symptom resolution, function, physiologic measures (e.g. blood pressure and blood sugar level) and pain control. A more recent review found consistent links between patient experience, clinical effectiveness and patient safety (Doyle, Lennox, & Bell, 2013). Positive patient experiences were associated with better self-rated and objectively measured health, adherence to recommended treatment and medication, preventative care (such as use of screening services and immunisations) and healthcare resource use (Doyle et al., 2013).

Patient experiences are an important indicator of quality of healthcare and are routinely collected in the NHS using large-scale surveys, e.g. General Practice Patient

Survey (https://gp-patient.co.uk/), Care Quality Commission national patient experience surveys (http://www.nhssurveys.org/), National Cancer Patient Experience survey (https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey).

Best practice guidelines

Following the publication of the 1999 survey results, the Royal College of Ophthalmologists (RCOphth) produced guidelines for management of AMD. Whereas initial guidance focussed on possible treatment options (Amoaku, 2008; RCOphth, 2000), the guidelines first published in February 2009 (RCOphth, 2009) (updated September 2013, RCOphth, 2013), set standards for best practice and included recommendations about information to be communicated to patients within the diagnostic consultation. The steering group involved in writing the guidelines included a Macular Society representative who used the MDSQ 1999 survey results and the Mitchell et al. (2002) paper to assist the development of the recommendations.

The RCOphth 2009 guidelines stated that all patients require: a clear diagnosis (ensuring patients know the name of their condition), the prognosis and what to do if vision deteriorates, written information for patient and relatives, and signposting to other organisations such as the Macular Society for further help and support. The guidelines also highlighted the importance of an awareness of the impact of a diagnosis of this progressive eye condition, and the need to show empathy with patients. Moreover, the guidelines emphasised that patients require information about the possibility of experiencing visual hallucinations (Charles Bonnet Syndrome [CBS]) in order to avoid distress resulting from incorrectly attributing the cause of these hallucinations to, for example, dementia (RCOphth, 2009).

There has yet to be an investigation of whether healthcare experiences have improved for pwAMD following the introduction of the 2009 RCOphth guidelines and the publication of the 1999 survey results in 2002 (Mitchell et al., 2002). A recent qualitative study found gaps in information provision to pwAMD (Burton et al., 2013). These included the benefits of registering as SI or SSI and details of how to register, causes of AMD, reasons for, and explanations of, medical processes and eye procedures, how to monitor eyes for changes in vision and the impact of smoking, healthy diet and vitamin supplements on eye health. The most common source of information provided was verbal information given in hospital appointments however participants reported difficulty in understanding what was being said, and trouble recalling the information (Burton et al., 2013). It was also noted that many participants had not heard of AMD before diagnosis and as a result, diagnosis came as a shock. This lack of prior knowledge meant that participants lacked a frame of reference which they could use to make sense of their condition, and thus the information provided in consultations was all the more important in terms of helping participants understand their condition (Burton et al., 2013). A large-scale quantitative study may be able to establish whether information and support issues for pwAMD are widespread.

Whilst information provision in the diagnostic consultation may be key, it is recognised that diagnosis of a condition causing vision loss can be a shock (Beverley, Bath, & Barber, 2007; Hodge, Barr, Bowen, Leeven, & Knox, 2013; Thurston, Thurston, & McLeod, 2010). Information may be difficult to take in at the time of diagnosis and this points to the need for ongoing support and information provision (Beverley et al., 2007). Thus the first study presented in this thesis will also examine sources of information and support after the initial diagnostic consultation.

Statement of epistemological stance

Crotty (1998) argued that in order to justify the use of specific methods and methodologies in research, researchers must be clear on the assumptions they bring to their work. This includes the philosophical assumptions they bring to the research and their resulting worldview.

Briefly, a post-positivist worldview argues that research can be a value-free process where objective knowledge (the ‘truth’) can be gained through empirical methods such as direct observation and measurement, and that the world exists independently from the individual’s perception of it. This worldview is typically associated with quantitative research. In contrast, the constructivist worldview, which is typically associated with qualitative approaches, uses individuals’ views and perspectives to inform the understanding or meaning of a phenomenon.

Throughout this thesis, a pragmatic approach is taken. Pragmatism provides a philosophical basis for research which is not committed to a specific theory about reality and acknowledges that there are many different ways of making sense of the world. This might mean combining both deductive and inductive thinking, typically associated with post-positivism and constructivism, respectively (Creswell & Plano Clark, 2011).

In pragmatism, the focus is on using the most suitable methods for answering the research question/s. This means that it can advocate the use of multiple methods of data collection to inform the problem/s under study; if this is the best way to answer the research question. Its epistemology is focused on practicality; the researcher collects data using a ‘what works’ approach to answering the research question.

Literature review search strategy

The purpose of the literature reviews reported in this Chapter and in Chapter 5 were to give a comprehensive overview of the current state of knowledge on the topic and identify gaps in the research in order to help define the research questions. Thus a narrative review was chosen over a more in-depth systematic review methodology which is used to answer a specific research question. Systematic reviews should provide enough information about the search strategy used to enable replication. Whilst this is not normally reported for a narrative review, an overview of the search strategy used in Chapter 1 is presented in Appendix 1, and in Appendix 8 for Chapter 5, for information.

Overarching research questions of the thesis

1. To investigate whether healthcare experiences of patients with age-related macular degeneration have improved since the first survey in 1999. To determine whether significant improvements have been made since publication of the 1999 survey results in 2002, and/ or the Royal College of Ophthalmologists (RCOphth, 2009) management guidelines in 2009. (Methods in Chapter 2, results and discussion are in Chapter 3.)
2. To examine other sources of information and support used by people with AMD (pwAMD) after the diagnostic consultation, in particular support from friends and family. (Methods in Chapter 2, results and discussion in Chapters 3 and 4.)

3. To explore the impact of receiving and providing care for AMD from the perspectives of pwAMD and their caregivers. (Literature reviewed in Chapter 5, methods in Chapter 6, results and discussion in Chapters 7 (quantitative study) and 8 (qualitative study).)

Chapter 2: The Macular Society 2013 survey: Methodology.

AIMS AND OBJECTIVES

The main aim of the first study presented in this thesis was to establish whether healthcare experiences have changed for people diagnosed with macular conditions since a similar survey was carried out in 1999 (see Mitchell et al., 2002). A summary of the findings from the 1999 survey appear in Chapter 1.

Following publication of the 1999 survey results in 2002, the Royal College of Ophthalmologists (RCOphth) produced guidelines for the management of age-related macular degeneration (AMD) (RCOphth, 2009). The guidelines published in February 2009 (updated September 2013) set standards for best practice and included recommendations about information to be communicated within the diagnostic consultation to people with AMD (RCOphth, 2009, 2013). (See Chapter 1 for a summary of these recommendations.) This study aimed to investigate whether significant improvements in information and support provision in the diagnostic consultation had been made since publication of the 1999 survey results in 2002, and/or the RCOphth AMD guidelines in 2009.

An additional objective of this study was to investigate sources of information and support for people with macular conditions after the diagnostic consultation, e.g. from eye-care professionals (ECPs), low-vision clinics (LVCs) and friends and family.

METHOD

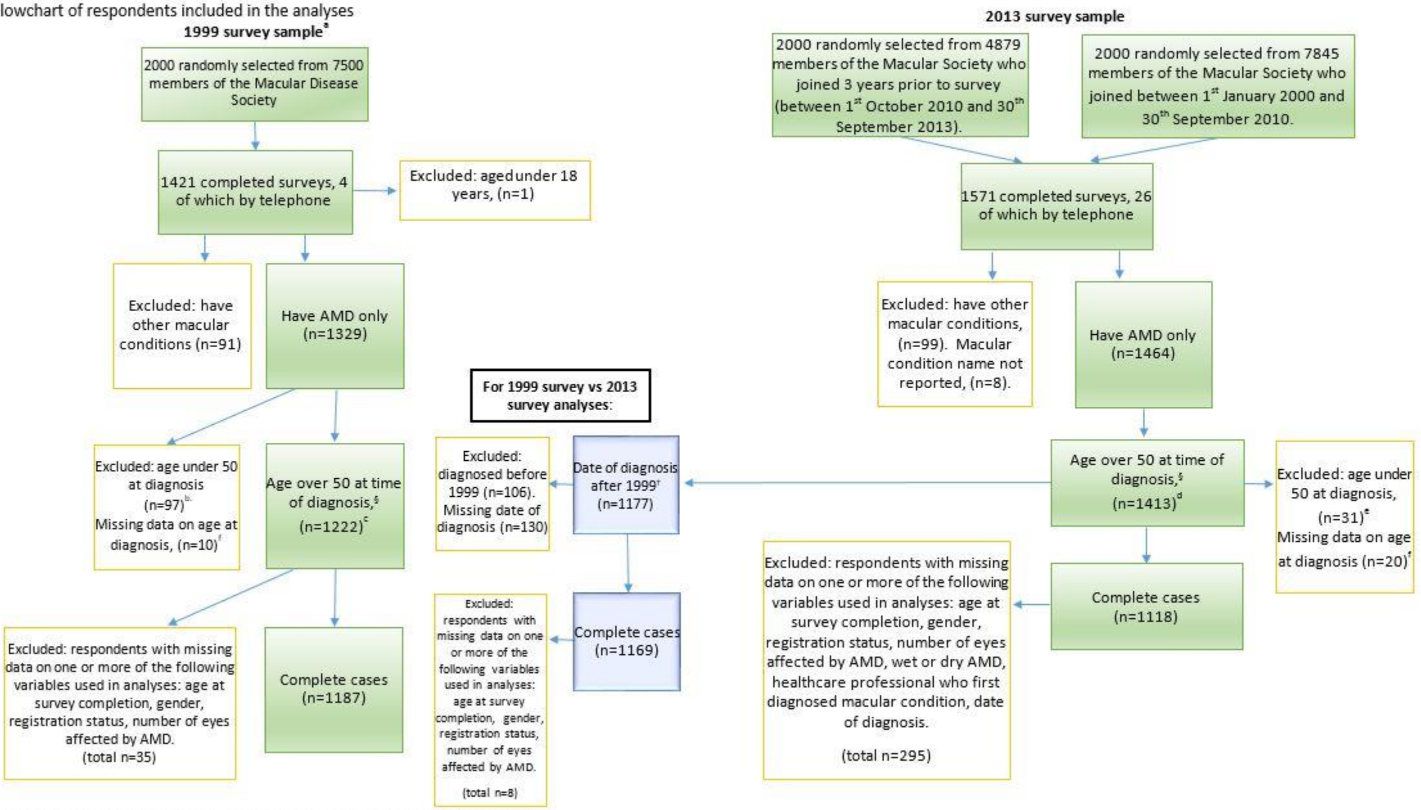
Research design

The present study used survey methodology in order to make direct comparisons with responses from the 1999 Macular Disease Society Questionnaire (MDSQ 1999). Using cross-sectional survey methodology is a time- and resource- efficient way to collect data from a large sample. Many people with macular conditions experience difficulties with reading and writing, hence telephone survey completion with the researcher was offered.

Participants

A total of 4000 members of the Macular Society who joined after 1st January 2000 were selected from the membership database using campaign management software (NFP CARE, Advance Computer Software Group). In order to achieve an adequate sample size to investigate the impact of the RCOphth guidelines, the sample was stratified based on date of joining the Macular Society (as a proxy for date of diagnosis). Two thousand of the total 4000 members sampled were randomly selected from a total sample of 4879 members who had joined within three years prior to the 2013 survey being undertaken (i.e. between the 1st October 2010 and 30th September 2013) (referred to as ‘recently joined’). A further 2000 members were randomly selected from the 7845 members who had joined the Society between 1st January 2000 and 30th September 2010. Further selection criteria and the number of respondents included/excluded are summarised in Figure 2.1.

Figure 1. Flowchart of respondents included in the analyses



[a] The 1999 survey dataset from the Mitchell et al., (2002) paper was re-analysed for use in this paper.

[b] This includes: n=94 who reported their age at first diagnosis, and n= 3 whose missing age at first diagnosis was imputed using data on age at survey completion where provided; using single regression and expectation maximisation methods. (The correlation between age at survey completion and age at diagnosis was r_s=0.81, p<0.001, for 1999 sample; r_s=0.79, p<0.01, for 2013 sample.) Where data imputation methods agreed they were over 50 at diagnosis, these respondents were included in the analyses. (Imputation for this variable was used for sample selection as per this flowchart, and not for use in analyses.)

[c] This includes: n=1097 who reported their age at first diagnosis, and n=125 whose missing age at diagnosis was imputed (using methods described above[b]).

[d] This includes: n= 1282 who reported their age at diagnosis, and n=131 whose age at diagnosis was imputed (using methods described above[b]). N.B. of the respondents for whom there were missing data for age at diagnosis that were imputed and included in this step, these participants were then removed in a later step as they didn't report their date of diagnosis which was needed for the main analysis.

[e] These were all original data.

[f] There were no data on age at survey completion for this n with missing data on age at diagnosis, so these data could not be imputed.

[§] As the RCOphth guidelines are specific to AMD, the present report focuses on data from people with AMD and hence only those respondents diagnosed age 50 or above.

[†] To avoid overlap in experiences at diagnosis, the 2013 survey respondents diagnosed prior to 1999 (but who joined the Society from 2000 onwards) were excluded from the analyses comparing 1999 and 2013 samples, but included in the analyses involving only the 2013 respondents.

Figure 2.1. Flowchart of respondents included in the analyses.

The MDSQ 1999 (following pilot testing and clarification as required) was sent to 2000 randomly selected members of the Macular Society in 1999, and 1421 completed surveys were received (71% response rate). The Macular Society has since sent other surveys to its members, and response rates have fallen (e.g. Cox & ffytche, 2014 obtained a response rate of 31%, n=1254). A total of four thousand 2013 surveys were mailed in order to achieve a comparable sample size with the MDSQ 1999.

The inclusion criteria were that participants must be over the age of 18, be currently residing in the UK, have been diagnosed with a macular condition, were not a professional member of the society nor a supporter of someone with a macular condition, and must be able to read, write and understand the English language[1]. In order to investigate the impact of the RCOphth 2009 guidelines which focus on AMD, only respondents who were diagnosed with AMD were selected for analysis. Other macular conditions have different prognoses and treatments available, thus respondents with these conditions may have significantly different healthcare experiences. AMD is the most common macular condition and participants with AMD formed the majority of the sample. For continuity, the results presented in this thesis are from respondents who were diagnosed with AMD.

Materials

Updating the Macular Disease Society Questionnaire 1999 (MDSQ 1999)

In response to reports of unsatisfactory experiences with healthcare professionals (HCPs) among members of the Macular Society, members of the Leicester local Macular Society group instigated the design and piloting of the MDSQ 1999. This survey included questions derived from the literature whilst others were newly-designed and were based on experiences with HCPs at the time of diagnosis and thereafter. A copy of the MDSQ 1999 is provided in Appendix 2.

Updating the 1999 survey involved collaboration between the author, Prof Clare Bradley (CB), Dr Jan Mitchell (who managed the MDSQ 1999), Helen Jackman (the

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[1] Participants were asked if English was their first language and if not, to rate their level of English comprehension on a 7-point scale (with 7 being 'very fluent'). All respondents whose first language was not English self-rated their fluency as 5 or above. The author checked the hard copy survey responses of respondents with scores of 5 or 6, and concluded that they were able to understand and respond to the survey questions without difficulty. Thus all respondents were included in analysis.

Chief Executive Officer (CEO) of the Macular Society at the time), and Cathy Yelf (the Head of External Relations at the Macular Society at the time, now CEO). This involved careful consideration, discussion and compromise across all parties to include questions that would investigate the aims of the study and that were of importance to stakeholders including the Macular Society, HCPs, researchers and members of the Macular Society.

A copy of the Macular Society 2013 survey (MSQ 2013) is provided in Appendix 3. Table 1 in Appendix 4 provides details of the survey questions including: the MDSQ 1999 questions which were omitted from the MSQ 2013, changes to the wording of questions replicated from the MDSQ 1999, and the newly-designed questions for the MSQ 2013. The results presented in Chapter 3 focus on information and support provision in the diagnostic consultation and thereafter. Chapter 4 presents findings on support received for AMD from family and friends. Details of question design for these topics are presented below. Details of questions from the MSQ 2013 that are not reported in this thesis are provided in Table 1, Appendix 4, for information.

Three key questions on experiences in the diagnostic consultation from the MDSQ 1999 were replicated to enable comparison over time. These asked respondents whether they were given the name of their macular condition at the time of diagnosis, if they felt the HCP who diagnosed them was interested in them as a person, and their overall satisfaction with the diagnostic consultation. In the MDSQ 1999, respondents were asked to provide reasons for dissatisfaction with the consultation only. The MSQ 2013 used a modified version of this question which asked respondents to provide reasons for dissatisfaction or satisfaction with the diagnostic consultation. The wording of the questions were changed from experiences with the ‘eye specialist’ (in the 1999 survey) to ‘healthcare professional’ (in the 2013 survey) to reflect the fact that optometrists can now diagnose macular conditions (whereas in 1999 this was not the case).

Seven new questions were designed to assess the incorporation of the RCOphth guidelines into practice, and focus on information and support provision around the time of diagnosis (see rows 16-21 of Table 1, Appendix 4). Respondents were asked which HCP they considered as the first to diagnose their macular condition.

Two questions on experiences with GPs were replicated from the 1999 survey. These asked about respondents' perception of their GPs' knowledge of their condition and how supportive they felt their GP was about their condition. Responses were made on a Likert scale of 0 (not at all) to 3 (very). In the 1999 survey, missing data on responses to the two GP questions were considerable. Many wrote on the survey that they had not seen their GP about their macular condition (Mitchell et al., 2002). A "not applicable" option was therefore added in the 2013 survey to investigate how many had not visited their GP about their AMD.

In order to investigate help and support received after the diagnostic consultation, several questions were replicated from the MDSQ 1999 to enable comparison over time. This included questions on whether or not respondents had experienced visual hallucinations and whether they had spoken to a HCP about them (see row 53 of Table 1, Appendix 4), attendance at a low-vision clinic (LVC) (see rows 41-43 of Table 1, Appendix 4), and membership of a local group for people with macular conditions (see row 39 of Table 1, Appendix 4). A newly-designed question investigated whether respondents had received psychological support for AMD since diagnosis and if not, whether they would have liked to have received this support now or at the time of diagnosis. A new question was designed to assess whether respondents had recently seen an eye-care professional (ECP), and if not, whether they felt they had needed to. If respondents had ticked that they had not seen a ECP but had needed to, they were asked to provide reason/s why.

A new question was designed to investigate how many respondents received unpaid care, support or assistance for their macular condition, who provides this support and how much support they receive per week.

The MSQ 2013 included the 16-item Well-Being questionnaire (W-BQ16). This contains four subscales: negative well-being, positive well-being, energy, and stress. For all scales/ subscales, higher scores represent more of the type of well-being indicated by the name of the scale/ subscale. Scores for the total scale range from 0-48. The MDSQ 1999 included the 12-item Well-Being questionnaire (see row 32 of Table 1, Appendix 4). The W-BQ12 but not the W-BQ16, has been psychometrically evaluated with a sample of people with macular conditions (Mitchell & Bradley, 2001). The W-BQ16 was included to enable psychometric evaluation of this longer version.

Quality of life was measured using two overview items from the MacDQoL (Mitchell et al., 2005). One item assessed general quality of life (QoL) and was measured on a 7-point scale (excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad). The other assessed the impact of MD on their QoL. It was measured on a 5-point scale scored from -3 which indicates their QoL would be 'very much better' (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be 'worse'). Higher scores indicate better quality of life. The MDSQ 1999 contained the same two QoL questions, with some differences to the response options for the MD-specific QoL item and stem for the general QoL item (see row 31 of Table 1, Appendix 4). In a previous version of the MacDQoL used in the MDSQ 1999, there were three positive response options for the MD-specific QoL item ('*a little worse', 'much worse'* and '*very much worse'*). This was reduced to one option ('*worse*'). This change was made because few people use this end of the scale, as it would indicate benefits of having a macular condition, which are usually perceived as being few if any (see Mitchell & Bradley, 2004).

Socio-demographic information (age, gender, living circumstances (alone or with other/s)) were collected. Eye-related information (wet or dry AMD, registration status, AMD in one or both eyes, date of first diagnosis, self-assessed change in vision since diagnosis) were also gathered. A single-item was used to measure self-rated health status (see row 75 of Table 1, Appendix 4).

Questionnaire package presentation

Similar to the MDSQ 1999, the 2013 survey was designed for self-completion by people with a macular condition and pilot tested.

Macular conditions are characterised by central vision loss. Central vision is used to process fine details, therefore many participants would have difficulty reading a regular paper survey. Prof Clare Bradley and other researchers at the Health Psychology Research Unit have considerable experience in formatting questionnaires for people with macular conditions, and the Macular Society have a knowledge base of acceptable fonts and layouts that they use in their publications.

Based on this expertise, the following design principles were followed:

- Use of size 16 Arial font.
- Text was justified to the left to give a strong vertical line down the page to make the questions easier to follow. (Questions are more likely to be missed by people with vision loss if they start mid-page or are indented.)
- The use of upper case letters was avoided except where dictated by grammar. Words formed of lower case letters are differentiated more easily than those with upper case letters. They also give the reader a better indication of word shape which helps visually impaired people to anticipate, to some extent, what the word might be.
- Response boxes were placed immediately after the end of a question, where possible. Where response boxes where placed away from the question, a heavily dotted line guided the reader to the boxes.
- Boxes with solid black lines were provided for free-text responses. People with macular conditions may find it difficult to write along lines, as these lines can appear wavy. Therefore writing in boxes may be less difficult.
- Where a question had a yes/ no answer that led to a different pathway of responses, a solid black arrow from the yes/ no tickbox indicated the pathway for respondents to take. This was included to make it easier for respondents to follow the question.
- Careful consideration was taken to ensure that questions weren’t split across pages.
- The anchors for the W-BQ16 and questions on experiences with GPs were specified in the instructions as well as at the top of the scale, as the anchors above the scale could not be left-justified and might be missed by someone with a visual impairment.

The questionnaire booklet, including a single-page consent form, consisted of 31 pages. Questions were printed double-sided on A3 sheets and stapled down the middle to create a booklet. Please see Appendices 3, 5 and 6 for all materials sent to participants. The survey packs included (in the following order): a covering letter (designed by Helen Jackman, former CEO of the Macular Society, checked by the author), a participant information sheet, the survey booklet (containing the consent form, the MSQ 2013, a contact details sheet, a sheet requesting the contact details of the participant's caregiver, and blank pages for continuation of survey responses), a sheet asking participants to provide their reason/s for not taking part (if applicable) and a freepost envelope addressed to the author. The contact details sheet asked participants to provide their name, telephone number, postal and email address if they agreed to be contacted by the researcher for clarification of their responses (if needed). This sheet also asked respondents if they would be interested in taking part in future research. A 'yes' or 'no' tickbox response was provided. The second study presented in this thesis investigates the impact of receiving and providing support for AMD from the perspective of people with AMD and their caregivers. Thus, in the MSQ 2013 questionnaire booklet, respondents were asked to provide the contact details (name, telephone number, postal and/or email address) if they knew a caregiver who they felt might be interested in taking part in this research. (It was stated that they would be under no obligation to take part.)

The researchers' (EB and CB) contact details (telephone number, email and postal addresses) were provided for enquiries about the research.

Seven hundred and twenty-four of the 4000 members selected to take part had opted to receive information from the Macular Society on audio CD. The Macular Society recorded the information from the cover letter and information sheet (including the author's contact details), onto an audio CD. This was included in the questionnaire pack for the members who had opted to receive information on audio CD.

Ethics

Ethical approval was obtained from the ethics committee of Royal Holloway, University of London (Ref: 05-13). The committee requested that we make an attempt to debrief the participants prior to publishing material in a publication. The costs of creating and sending a debriefing newsletter (and audio CD) to all the participants that were sent the survey were estimated to be £1404.57. These costs were not budgeted for in the project grant. We put forward this explanation to the ethics committee and suggested a summary of the results in the Macular Society's journal, Digest, (which is sent to members of the society) would be sufficient in informing participants of the results of the survey. The ethics committee agreed to this. A summary of the results appeared in Digest 2015 (Boxell & Bradley, 2015).

To preserve the Macular Society members' confidentiality, the surveys were sent from the Macular Society. The researchers did not have access to participants' personal details unless they were provided by the participant (either by requesting telephone completion of the survey or by writing their contact details on the relevant page of the survey). To preserve anonymity, when surveys were received by the author, the consent form and contact details forms were removed from the completed survey. These details were put into a password-protected computer file. A unique identifier code was written at the top of the completed survey, the contact details sheet and the consent form. These were stored in locked cabinets separately. Hard copies of the data will be kept for up to five years. Electronic copies of the database will be stored for longer (max 15 years) to allow for long-term follow up if needed. Hard copies of the completed surveys will be disposed of as confidential waste. A similar protocol was used for participants who completed the survey over the phone with the researcher (they were assigned a unique identifier code). The audio-recordings were used to write the respondents' answers onto a paper copy of the survey. As they also included the respondents' consent to take part, the recordings are being kept until a year after full publication of the project, at which point they will be destroyed. We did not ask participant's permission for data sharing, thus the data are only accessible to the author and CB.

Procedure

The Macular Society sent the postal surveys to members in November 2013. Both the 1999 and 2013 surveys provided freepost return envelopes. Adverts informing members that the surveys would be sent to randomly-selected members of the Macular Society appeared in SideView (the membership magazine).

Twenty six respondents requested telephone survey completion: all were conducted by the author. Verbal consent was taken. All telephone interviews were audio-recorded.

No reminders were sent for either the 1999 or 2013 survey. Preserving confidentiality was the main reason for this as well as the cost. It was also to minimise any confusion that may result from members who had already completed the survey being sent a reminder to fill in the survey (if we had sent out a blanket reminder to everyone selected to take part in the survey).

Data entry

Data entry was initially conducted by the author and seven undergraduate Psychology students as part of the Royal Holloway Passport Award scheme. This scheme enables students to gain recognition for taking part in work placements. Data entry and checking took longer than anticipated, thus the author sought funding for a specialist company to continue with data entry. Dajon Data Management were selected and employed to enter closed tick-box response data. Three of the seven placement students were employed on a temporary basis to complete free-text data entry from the remaining surveys, and conduct checks on the closed tick-box response data entered by Dajon Data Management. Data were entered into an SPSS file designed by the author before data entry began. All those responsible for data entry were given guidelines for data entry produced by the author, and signed a confidentiality agreement before being given access to the completed questionnaires.

All data entries were double-checked by either the author or a student. The author was on hand to answer queries regarding data entry. Any recurrent problems with data entry were discussed with all those involved in data entry until the issue was resolved.

Participant identifying information (including contact details) were removed before anyone other than the author and her supervisor had access to the surveys, and were stored in a separate database to which only the author and her supervisor had access.

Data analysis

Experiences in the diagnostic consultation

To explore the impact of the RCOphth guidelines published in February 2009 and the publication of the MDSQ 1999 results in July 2002, a new variable was created based on the 2013 survey respondents' date of diagnosis (before or after each of these dates). Socio-demographic differences between these three groups within the 2013 survey data and between the 1999 and 2013 samples, were explored using Pearson Chi-squared analyses (χ^2), one-way independent ANOVA'S or *t* tests (or the non-parametric equivalent, Mann Whitney test, where required). Significant results were followed up with post-hoc evaluation of results (e.g. examining adjusted residuals for χ^2 analyses). Effect sizes are reported for significant results.

The outcome variables of interest were the ten questions (3 replicated and 7 new) on healthcare experiences relating to the diagnostic consultation (e.g. "overall, did you feel that the diagnostic consultation with this healthcare professional was satisfactory?"). Responses were always binary ('yes'/'no'). First, differences on these outcomes were explored using χ^2 analyses; between the 1999 and 2013 samples (for the 3 replicated questions), and across the three sub-groups within the 2013 survey sample (for all ten questions). Then binary logistic regressions were used to assess factors associated with satisfactory healthcare experiences. Separate logistic regressions were carried out for each healthcare-experience question. Independent variables were the socio-demographic data, information on the respondent's eye condition, and the main variable of interest – the survey groups (1999 vs 2013 samples for the three replicated questions, or the three sub-groups of the 2013 survey sample for all 10 questions). Separate unadjusted logistic regressions explored the relationship between each predictor and the outcomes; then multivariable analyses with all predictors entered were conducted. The sample size fulfilled the requirement of >10 respondents for the lesser reported outcome event (i.e. satisfaction or dissatisfaction) per predictor variable for multivariable logistic regression analyses (i.e. events per predictor variable) (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996).

Preliminary analyses indicated a general trend of increasing satisfaction with healthcare experiences over time. In order to assess the impact of the interventions, this increasing trend was controlled for by creating a continuous variable that ranked the respondents' year of diagnosis (e.g. the first year of diagnosis in the dataset was 1980 and was coded as 1, and the last was 2013 and coded as 30). This variable was entered into the logistic regression analyses. It is referred to in Chapter 3 as the 'year rank' variable.

No problems with multicollinearity or linearity of the logit were observed.

Reasons for satisfaction or dissatisfaction with the diagnostic consultation (free-text responses)

Respondents were asked to give reasons why they were satisfied or dissatisfied with the diagnostic consultation, in their own words. The responses were coded using content analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005), and were quantified. A coding framework was designed by the author and refined with the help of a research assistant. Both completed the coding of responses. Where multiple reasons were given, multiple codes were allocated. The ten reasons for dissatisfaction from the 1999 survey were used as codes in the coding framework. New codes were developed for responses which were not represented in the 1999 survey coding framework. In particular, the 1999 survey question asked respondents to provide reasons for dissatisfaction with the diagnostic consultation only. Therefore new codes were developed to reflect the reasons for satisfaction reported in the 2013 survey. See Appendix 7 for coding framework.

Visual hallucinations (Charles Bonnet syndrome)

Respondents were asked if they had experienced visual hallucinations since diagnosis of AMD. A brief description of Charles Bonnet syndrome (CBS) was provided. Respondents could tick either “yes” or “no” and if yes, they were asked to provide a description of their experience. These descriptions were checked to exclude any responses that were clearly not CBS. Descriptions were included if they described simple repeated patterns including shapes, grids, dots of colour or straight lines, or more complex hallucinations such as detailed picture/s of people, animals, insects, landscapes and buildings. Where there was any uncertainty, descriptions were checked with an ophthalmologist.

The number of respondents who had experienced hallucinations are reported, along with the type of hallucination reported (either simple/ complex/ both simple and complex hallucination/s). Pearson Chi-squared analyses (χ^2) compared responses from the 1999 and 2013 samples on the number of respondents who had spoken to a HCP about their hallucinations, and whether respondents were given a cause for hallucination/s. The latter were coded and quantified and compared with the causes reported in the 1999 survey.

Within the 2013 sample, χ^2 analyses explored differences in socio-demographic and eye-related factors between respondents who had experienced hallucinations and those who hadn't. Mann-Whitney tests explored differences in quality of life (both MD-specific and general) and well-being between those who had experienced hallucinations and those who hadn't.

χ^2 analyses explored associations between information provision on hallucinations around the time of diagnosis and experiencing hallucinations later on. χ^2 analyses were used to see if there was an association between receiving information on hallucinations around the time of diagnosis and whether respondents later spoke to a HCP about their hallucinations.

Mann-Whitney tests were used to investigate associations between information provision on hallucinations around the time of diagnosis and QoL and well-being at the time of survey completion. These analyses were conducted separately for people who had experienced hallucinations and those who hadn't. Mann-Whitney tests were also used to explore associations between talking to a HCP about hallucinations after their onset and QoL and well-being at survey completion (conducted separately for those who were told around the time of diagnosis about hallucinations and those who weren't).

For bivariate analysis, non-parametric tests were used due to significant skewness (at $p<0.001$) for the variables of MD-specific QoL, general QoL and well-being. The MD-specific QoL and general QoL items also showed significant kurtosis.

Information and support after the diagnostic consultation

Mann-Whitney tests or χ^2 analyses were used to explore differences between the 1999 and 2013 sample groups in experiences with GPs, attendance at a low-vision clinic, membership of a local support group for people with a macular condition, and whether respondents received more information about their macular condition post-diagnosis.

Frequencies are reported for the 2013 survey respondents who had been to see an ECP within the past year, and if they hadn't, whether they had needed to. The reasons why they hadn't been but had needed to, were coded and quantified. The number of respondents who reported being offered psychological support for their macular condition, or who would have liked to have received/ currently receive psychological support, are also reported. Frequencies are reported for the 2013 survey respondents who had attended a LVC and rated their level of satisfaction with the LVC on a 5-point scale (satisfied, slightly satisfied, neither satisfied nor dissatisfied, slightly dissatisfied, dissatisfied). The number of respondents who had not attended a LVC but who reported that they would have liked to are stated along with those who indicated they did not need to attend a LVC.

All analyses were conducted in SPSS version 21.0.

Correcting for the use of multiple testing in the same sample

It has been argued that experiment-wise error correction should be used in such cases of multiple testing to correct for the increased risk of type I error (i.e. concluding that a significant difference is present when it is not) (Dunn, 1961). A commonly used method to correct for this error is the use of Bonferroni correction. In practice, this involves using an adjusted significance level of α / T (where α = the critical p level, and T= the number of tests performed). However there have been several criticisms of this method, most notably that the probability of a type I error cannot be decreased without increasing the risk of type II error, such that real differences may not be detected (Perneger, 1998).

It has been recommended that where analyses are to be carried out in an exploratory context with an aim to see what findings might be worthy of further study, a correction should not be applied to avoid the possibility of type II error. However when it is imperative to avoid type I error or when a large number of tests are being carried out without a pre-planned hypothesis in an attempt to establish if any results are significant, then corrections should be applied (Armstrong, 2014).

On a practical level, there is no guidance on what constitutes the population of tests for which the correction should be applied. For example, should corrections be applied to all tests in an article (or in this case, this thesis) or a subset of them, tests performed but not included in the article (thesis), or tests of the same data that are included in other reports (Perneger, 1998). The analysis of data presented in this thesis required use of multiple different tests (Mann Whitney, Kruskal Wallis, chi-square, etc). It has been suggested that applying corrections to multiple tests that use different statistical procedures based on different statistical models may result in conflicting conclusions from the same data (Armstrong, 2014).

The author chose not to apply corrections to the tests presented in this thesis to be able to investigate potential relationships between variables where they existed (i.e. to reduce the chance of type II error). However one must be wary that this may increase the risk of type I error when making firm conclusions from the results. The exact p values are reported throughout the thesis for transparency.

Missing data and variables

There was a total of 289 respondents from the 1999 and 2013 surveys with missing data for age at first diagnosis (10.3%). The analyses reported in this thesis focus on AMD, therefore only those who were over the age of 50 at diagnosis and who had a diagnosis of AMD were included. Figure 2.1 explains how missing data were imputed to aid sample selection.

In the 1999 survey, 709 respondents (58%) had missing data on whether they had wet or dry AMD. There were no questions with responses that correlated highly with this variable from the 1999 survey, so these data were not imputed, and this variable was not used as a predictor in the analyses comparing the healthcare experiences of the 1999 and 2013 samples. Additionally, there was no question in the 1999 MDSQ on which HCP had first diagnosed the AMD, so this variable was not entered into the analyses comparing experiences at diagnosis for the 1999 and 2013 samples.

There were varying amounts of missing data on other independent variables, the greatest being for date of diagnosis (missing n=300, 11.4%). There were no suitable variables to allow imputation of these missing values.

Analyses comparing the 1999 and 2013 datasets are for those respondents with complete data on all the independent variables included in the analysis of experiences in the diagnostic consultation: 1187 from 1999-, and 1169 from 2013-survey respondents (see Figure 2.1). For continuity, only these respondents were selected for the analyses used in the rest of the thesis.

Sample size for each analysis will vary slightly depending on item non-response and missing data on additional independent variables included in the particular analysis. For example, the questions on experiences in the diagnostic consultation for the 2013-survey-only analyses- which included additional independent variables (some with missing data)- left 1118 respondents (see Figure 2.1). Further information on missing data for each analysis is provided either in the relevant results tables or in the text alongside the results.

Additional information on the hallucinations analyses

There were 119 respondents who wrote descriptions that were not consistent with visual hallucinations but were consistent with symptoms of AMD such as wavy lines, or objects being distorted. These participants were removed from the analysis of responses on hallucinations. Thirty nine respondents left the answer missing in the 2013 survey. The 1999 survey asked whether respondents had experienced any visual changes generally and not hallucinations specifically. Two hundred and thirty-nine respondents reported having experienced visual changes but did not specify what type (i.e. hallucination, flashing lights, blurred vision), thus they were coded as missing. This left 1011 respondents for analysis in the 2013 sample, and 948 respondents in the 1999 sample.

Conclusion

The present chapter describes the design and development of the Macular Society 2013 survey that was used to investigate the experiences of people with macular conditions for comparison with the 1999 survey. Chapter 3 presents the results and discussion of experiences of information and support provision in the diagnostic consultation and thereafter. Chapter 4 reports the impact of receiving unpaid care, support or assistance for AMD.

Chapter 3:

The Macular Society 2013 survey: Experiences in the healthcare system and thereafter, for people with age-related macular degeneration. Results and discussion.

RESULTS

Sample characteristics

Completed postal surveys were returned by 1545 respondents out of the 4000. Telephone completions by 26 gave a total sample size of 1571 for the 2013 sample (a 39% response rate). A further 267 uncompleted surveys were returned, with reasons for non-completion, giving a gross response rate of 46%. The most common reason given for non-completion was ‘old age’, followed by ‘ill health’. The MDSQ 1999 had been completed and returned by 1421 participants, including four telephone interviews (71% response rate).

For characteristics of the 1999 and 2013 survey samples, see Table 3.1. Respondents to the 2013 survey were significantly older and less likely to be registered as either sight impaired (SI) or severely sight impaired (SSI) than the 1999 survey respondents. The two samples did not differ in gender, whether one or both eyes were affected by AMD or the time between diagnosis and survey completion.

Table 3.1. Respondent characteristics in the 1999 and 2013 survey groups. Values are frequencies (valid percentage %) unless otherwise stated.

Variables		**1999 sample (n= 1187)**	**2013 sample (n= 1169)[b]**	**Statistic, p value, effect size and n.**
Gender	Male	368 (31.0%)	358 (30.6%)	χ^2 (1)=0.04, p=0.84: n=2356.
	Female	819 (69.0%)	811 (69.4%)	
Age at survey completion (years)	Mean (SD)	78.34 (7.10)	80.15 (7.99)	*t* (2313.83)= -5.79, p<0.001***: r= - 0.02, n=2356.
	Median	78.66	81.00	
Registration status	Not registered	469 (39.5%)	790 (67.6%)	χ^2 (2)=206.53, p<0.001***: Cramer's V= 0.30, n=2356.
	Registered sight impaired (SI)/ partially sighted	379 (31.9%)	256 (21.9%)	
	Registered severely sight impaired (SSI)/ blind	339 (28.6%)	123 (10.5%)	
Number of eyes affected	One eye	223 (18.8%)	226 (19.3%)	χ^2 (1)=0.11, p=0.74: n=2356.
	Both eyes	964 (81.2%)	943 (80.7%)	
Years since diagnosis[a]	Mean (SD)	5.91 (4.92)	5.55 (3.77)	U=635, 839.00, z= 0.30, p=0.77: n=2249.
	Median	5.00	5.00	

[a]For information. Not included in further analyses. [b]The majority of the 2013 survey respondents self-reported their ethnicity as "white" (99.5%). No question on ethnicity was included in the 1999 survey. *p<0.05, **p<0.01, ***p<0.001.

To explore the impact of the RCOphth guidelines published in February 2009, and the publication of the MDSQ 1999 results in July 2002, a new variable was created based on the 2013 survey respondents’ date of diagnosis (before or after each of these dates). Within these 2013 survey sub-groups, respondents diagnosed after the 2009 RCOphth publication were younger, less likely to be registered, less likely to have both eyes affected by AMD, and more likely to have been first diagnosed by an optometrist (Table 3.2). Those diagnosed before the publication of the 2002 paper were more likely to have dry AMD and less likely to have wet AMD. Those diagnosed after the publication of the 2009 RCOphth guidelines were more likely to have wet AMD. There were no differences in gender balance within the 2013 sub-groups.

Table 3.2. Respondent characteristics in the 2013 survey sub-groups. Values are frequencies (valid percentage %) unless otherwise stated.

Variables		Before MDSQ 1999 paper results publication (July 2002) (n=194)	Between 2002 and 2009 (n=448)	After RCOphth publication (February 2009) (n=476)	Statistic, p value: effect size.
Gender	Male	72 (37.1%)	135 (30.1%)	153 (32.1%)	χ^2 (2)=3.02, p=0.22.
	Female	122 (62.9%)	313 (69.9%)	323 (67.9%)	
Age at survey completion (years)	Mean (SD)	82.12 (7.26)	80.56 (7.68)	79.37 (8.16)	F (2, 1115)= 8.86, p<0.001***: ω^2=0.01†.
	Median	83.00	82.00	80.00	
Registration status	Not registered	87 (44.8%)	269 (60.0%)	390 (81.9%)	χ^2 (4)=108.67, p<0.001***: Cramer's V=0.22.
	Registered sight impaired (SI)/ partially sighted	62 (32.0%)	117 (26.1%)	67 (14.1%)	
	Registered severely sight impaired (SSI)/ blind	45 (23.2%)	62 (13.8%)	19 (4.0%)	
Number of eyes affected	One eye	19 (9.8%)	61 (13.6%)	132 (27.7%)	χ^2 (2)=42.76, p<0.001***: Cramer's V=0.20.
	Both eyes	175 (90.2%)	387 (86.4%)	344 (72.3%)	
Wet AMD only v dry AMD only v mixed wet and dry AMD	Wet AMD only	43 (22.2%)	175 (39.1%)	195 (41.0%)	χ^2 (4)=26.22, p<0.001***: Cramer's V=0.11.
	Dry AMD only	108 (55.7%)	176 (39.3%)	201 (42.2%)	
	Both wet and dry AMD	43 (22.2%)	97 (21.7%)	80 (16.8%)	
HCP who first diagnosed AMD	Hospital eye specialist	131 (67.5%)	258 (57.6%)	230 (48.3%)	χ^2 (2)=22.07, p<0.001***: Cramer's V=0.14.
	Optometrist	63 (32.5%)	190 (42.4%)	246 (51.7%)	

[†] $\omega^2=0.01$ represents a small effect size, 0.06 a medium effect size and 0.14 a large effect size.
$^{*}p<0.05$, $^{**}p<0.01$, $^{***}p<0.001$.

Experiences in the diagnostic consultation: 1999 vs 2013 samples

Respondents from the 2013 survey were significantly more likely than the 1999 survey respondents to report feeling that the HCP who diagnosed their condition was interested in them as a person (71% compared with 47%- see Table 3.3). They were also more likely to report being given the name of their condition at diagnosis (91% v 78%) and being generally more satisfied with the diagnostic consultation (76% v 61%).

Table 3.3. Comparison of responses to questions on experiences within the diagnostic consultation across survey sample groups. Values are frequencies of 'yes' responses (valid percentage %) unless otherwise stated.

	1999 survey sample	**2013 survey sample**	**χ^2 , p-value: effect size and n.**	**2013 survey sample sub-groups**			**χ^2, p-value: effect size and n.**
				Before MDSQ 1999 paper results publication (July 2002)	**Between 2002 and 2009**	**After RCOphth guidelines publication (February 2009)**	
Interested in you as a person?[a]	537 (46.9%)	805 (71.2%)	χ^2 (1)= 138.58, p<0.001***: phi= 0.25, n=2276.	126 (67.0%)	302 (70.1%)	351 (74.8%)	χ^2 (2)= 4.86, p=0.09: n=1088.
Given the name of your condition?[b]	906 (77.6%)	1045 (91.0%)	χ^2 (1)= 78.34, p<0.001***: phi= 0.18, n=2315.	165 (86.4%)	401 (91.1%)	435 (92.6%)	χ^2 (2)= 6.30, p=0.04*: Cramer's V= 0.08, n=1101.
Generally satisfied with diagnostic consultation? [c]	698 (61.0%)	856 (75.8%)	χ^2 (1)= 57.59, p<0.001***: phi= 0.16, n=2273.	129 (70.1%)	320 (73.7%)	382 (82.0%)	χ^2 (2)= 13.85, p=0.01*: Cramer's V= 0.11, n=1084.
Given written information?[d]	-	-	-	34 (17.7%)	133 (30.4%)	193 (41.9%)	χ^2 (2)= 37.98, p<0.001***:

							Cramer’s V= 0.19, n=1090.
Given appropriate support, help or advice?[e]	-	-	-	86 (45.7%)	229 (52.2%)	302 (64.1%)	χ^2 (2)= 23.25, p<0.001***: Cramer’s V= 0.15, n=1098.
Information about the Macular Society?[f]	-	-	-	28 (15.1%)	106 (24.0%)	150 (31.9%)	χ^2 (2)= 21.07, p<0.001***: Cramer’s V= 0.14, n=1097.
Information on action if sudden deterioration in your vision?[g]	-	-	-	80 (42.3%)	227 (51.4%)	262 (56.3%)	χ^2 (2)= 10.67, p=0.005**: Cramer’s V= 0.10, n=1096.
Given information about likely progress of macular condition?[h]	-	-	-	84 (43.5%)	203 (46.2%)	190 (40.6%)	χ^2 (2)= 2.94, p=0.23: n=1100.
Other contacts for help and support?[i]	-	-	-	29 (15.4%)	75 (17.1%)	90 (19.5%)	χ^2 (2)= 1.75, p=0.42: n=1088.

Told about visual hallucinations?[j]	-	-	-	26 (13.5%)	66 (15.4%)	80 (17.2%)	χ^2 (2)= 1.47, p=0.48: n=1085.

[a] “Did you feel that this healthcare professional (who first diagnosed your macular condition), was interested in you as a person?” (Response ‘Yes’ or ‘No’ here and to all questions listed below.)

[b] “Were you given the name of your condition at the time of diagnosis?” (This question was included in the MDSQ 1999 but the responses were not reported in the 2002 paper.)

[c] “Overall, did you feel that the diagnostic consultation with this healthcare professional was satisfactory?”

[d] “Were you given any written information about your macular condition at the time of diagnosis?”

[e] “Do you feel you were given appropriate support, help or advice at the time of diagnosis?”

[f] “Were you given information about the Macular Society (or the Macular Disease Society, as it was previously called) at the time of diagnosis?”

[g] “Were you given any information around the time of diagnosis about what to do if you were to have a sudden deterioration in your vision?”

[h] “Around the time of diagnosis, were you given information about the likely progress of your macular condition?”

[i] “Were you given any other contacts for help and support at the time of diagnosis?”

[j] “Were you told by a healthcare professional, around the time of diagnosis, of the possibility of experiencing visual hallucinations as a side effect of sight loss?”

*p<0.05, **p<0.01, ***p<0.001.

Binary logistic regressions controlling for differences in socio-demographic and eye-related factors, confirmed that being a 2013 survey respondent was a significant predictor of satisfaction with these aspects of healthcare (see Table 3.4 for Odds Ratios).

Table 3.4. Predictors of healthcare experiences in comparable questions from the 1999 and 2013 surveys; unadjusted (univariable analyses) and multivariable analysis adjusting for all other predictors.

		Interested in you as a person?[a] (n=2276)		**Given name of condition?[b] (n=2315)**		**Overall satisfaction?[c] (n=2273)**	
Predictor		**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**
Sample (1999 or 2013)	1999	1.00	1.00	1.00	1.00	1.00	1.00
	2013	2.80 (2.35 to 3.33)***	2.75 (2.28 to 3.31)***	2.92 (2.29 to 3.73)***	2.78 (2.14 to 3.61)***	2.00 (1.67 to 2.40)***	1.90 (1.56 to 2.31)***
Gender	Male	1.00	1.00	1.00	1.00	1.00	1.00
	Female	0.73 (0.61 to 0.87)**	0.71 (0.59 to 0.86)***	0.80 (0.63 to 1.03)	0.77 (0.60 to 1.00)*	0.68 (0.55 to 0.82)***	0.67 (0.55 to 0.82)***
[§]Age at survey completion		1.02 (1.01 to 1.03)**	1.01 (1.00 to 1.02)	0.99 (0.97 to 1.00)	0.98 (0.97 to 1.00)*	1.03 (1.01 to 1.04)***	1.02 (1.01 to 1.04)***
Registration status							
Contrast 1	Not registered	1.00	1.00	1.00	1.00	1.00	1.00
	Registered as SI or SSI	0.50 (0.36 to 0.70)***	0.95 (0.64 to 1.42)	0.30 (0.19 to 0.47)***	0.60 (0.36 to 1.02)	0.62 (0.44 to 0.89)**	0.89 (0.59 to 1.35)

Contrast 2	Registered SI	1.00	1.00	1.00	1.00	1.00	1.00
	Registered as SSI	0.87 (0.68 to 1.10)	0.97 (0.75 to 1.25)	0.65 (0.48 to 0.88)**	0.72 (0.53 to 0.97)*	0.70 (0.55 to 0.91)**	0.74 (0.57 to 0.96)
Number of eyes affected	one eye affected	1.00	1.00	1.00	1.00	1.00	1.00
	both eyes affected	0.78 (0.63 to 0.97)*	0.77 (0.60 to 0.97)*	0.78 (0.58 to 1.06)	0.92 (0.66 to 1.28)	0.78 (0.62 to 0.99)*	0.74 (0.58 to 0.96)*
Adjusted Model statistics		-	χ^2 (6)= 160.91, $p<0.001$***.	-	χ^2 (6)= 100.80, $p<0.001$***.	-	χ^2(6)=97.05, $p<0.001$***.
[†]Adjusted Model Nagelkerke’s R^2		-	0.09	-	0.07	-	0.06

Abbreviations: OR= Odds ratio; CI= confidence interval.

[a] “Did you feel that this healthcare professional (who first diagnosed your macular condition), was interested in you as a person?” (Response was yes=1, no=0 for this and all questions below.)

[b] “Were you given the name of your condition at the time of diagnosis?”

[c] “Overall, did you feel that the diagnostic consultation with this healthcare professional was satisfactory?”

[§]In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases).

[†]Nagelkerke’s R^2 is a measure of model fit, where 0 indicates the predictors poorly predict the outcome and 1 is where the model predicts the outcome perfectly.

*$p<0.05$, **$p<0.01$, ***$p<0.001$.

Impact of 2002 publication of MDSQ (the 1999 survey) results and 2009 RCOphth guidelines on healthcare experiences

Within the 2013 sample, a general pattern of increase in information provision and satisfaction with the diagnostic consultation was observed over the three time periods studied (pre-publication of the 1999 survey results in 2002, between 2002 and when the RCOphth guidelines were published in 2009, and post-2009 RCOphth guidelines) for all aspects of the consultation, apart from provision of information on the likely progress of the macular condition (see percentages in Table 3.3). Unadjusted logistic regressions using the 'year rank' variable found an increasing trend in information and support provision across time for six of the ten aspects of healthcare experiences (see Table 3.5). These were for being given: the name of the macular condition, written information on the condition, Macular Society information, information on what to do if they experienced a sudden deterioration in vision, receiving appropriate help and support at the time of diagnosis, and overall satisfaction with the diagnostic consultation. Further unadjusted analyses using the 2013 survey sub-groups found significant increases in the same six aspects of information and support provision after the 2002 paper publication compared with pre-publication in 2002 (indicative of a combined effect of both interventions; see Table 3.5). However, there were significant improvements made after the 2009 RCOphth guidelines publication only for four of these namely: information on the Macular Society ($p<0.01$), provision of written information ($p<0.001$), receiving appropriate support, help or advice at the time of diagnosis ($p<0.001$), and overall satisfaction with the diagnostic consultation ($p<0.01$).

Table 3.5. Unadjusted odds ratios from binary logistic regressions investigating changes in information and support provision since the 2002 publication of the 1999 survey results and the 2009 RCOphth guidelines.

	Interest as a person? OR (95% CI) n=1088	**Overall satisfact^{n}?** OR (95% CI) n=1084	**Name of condition?** OR (95% CI) n=1101	**Written informat^{n}?** OR (95% CI) n=1090	**Info on deterior-ation?** OR (95% CI) n=1096	**Help & support?** OR (95% CI) n=1098	**Macular Society contact?** OR (95% CI) n=1097	**Other contacts?** OR (95% CI) n=1088	**Likely progress?** OR (95% CI) n=1100	**Hallucin-ation?** OR (95% CI) n=1085
Socio-demographic										
Gender										
Male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Female	0.73 (0.54 to 0.97)*	0.67 (0.49 to 0.91)*	0.99 (0.64 to 1.54)	0.79 (0.60 to 1.03)	0.78 (0.61 to 1.01)	0.68 (0.52 to 0.88)**	1.05 (0.79 to 1.40)	0.90 (0.65 to 1.25)	0.63 (0.49 to 0.81)***	0.98 (0.70 to 1.39)
Age at survey completion§	1.01 (1.00 to 1.03)	1.03 (1.01 to 1.05)**	0.96 (0.93 to 0.98)**	0.98 (0.96 to 0.99)**	0.97 (0.95 to 0.98)***	1.01 (1.00 to 1.03)	0.99 (0.97 to 1.01)	1.01 (0.99 to 1.03)	1.00 (0.99 to 1.02)	1.03 (1.00 to 1.05)*
Eye-related variables										

Number of eyes affected										
One eye	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Both eyes	0.58 (0.40 to 0.83)**	0.57 (0.38 to 0.85)**	0.87 (0.50 to 1.50)	0.60 (0.44 to 0.81)**	0.77 (0.57 to 1.04)	0.58 (0.42 to 0.80)**	0.55 (0.40 to 0.75)***	0.93 (0.63 to 1.38)	0.82 (0.61 to 1.11)	0.89 (0.60 to 1.33)
Registration status										
Contrast 1										
Not registered	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Registered as SI or SSI	0.52 (0.30 to 0.92)*	0.65 (0.36 to 1.19)	0.16 (0.07 to 0.38)***	0.58 (0.33 to 1.02)	0.29 (0.17 to 0.49)***	0.31 (0.18 to 0.53)***	0.89 (0.49 to 1.62)	4.13 (2.16 to 7.91)***	0.82 (0.48 to 1.38)	2.92 (1.14 to 4.61)*
Contrast 2										
Registered as SI	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Registered as SSI	1.11 (0.69 to 1.76)	0.63 (0.38 to 1.03)	0.48 (0.26 to 0.87)*	0.86 (0.53 to 1.40)	0.93 (0.60 to 1.44)	0.55 (0.35 to 0.85)**	1.15 (0.70 to 1.90)	1.11 (0.67 to 1.83)	1.05 (0.68 to 1.63)	0.82 (0.47 to 1.44)
wet or dry AMD										
Contrast 1										

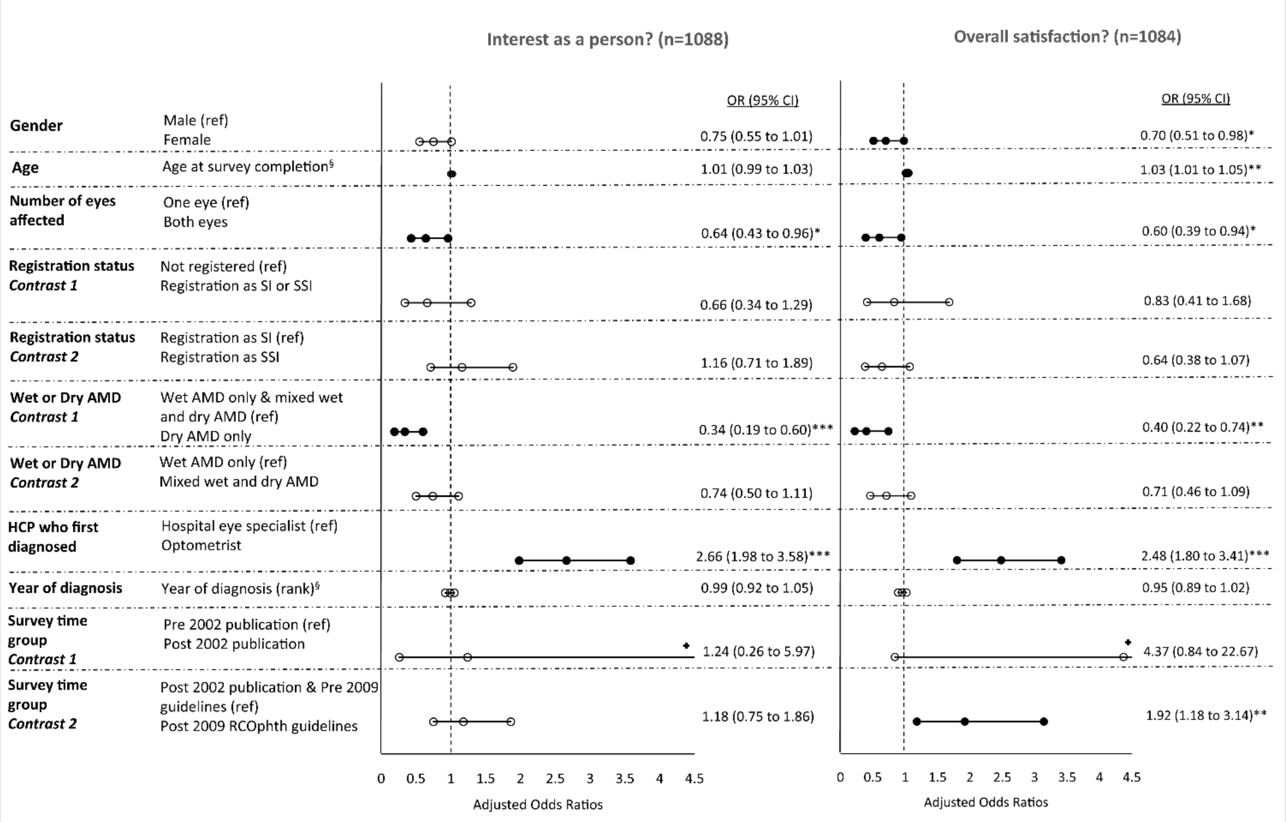
Wet AMD only and mixed wet and dry AMD	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
dry AMD only	0.44 (0.26 to 0.75)**	0.48 (0.27 to 0.84)*	2.27 (0.94 to 5.51)	0.59 (0.35 to 1.01)	0.57 (0.35 to 0.92)*	0.29 (0.17 to 0.47)***	0.65 (0.37 to 1.15)	0.67 (0.35 to 1.28)	0.59 (0.36 to 0.97)*	0.44 (0.22 to 0.89)*
Contrast 2										
Wet AMD only	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Mixed wet and dry AMD	0.67 (0.46 to 0.98)*	0.60 (0.40 to 0.90)*	1.17 (0.68 to 2.03)	0.76 (0.54 to 1.09)	0.82 (0.59 to 1.14)	0.62 (0.44 to 0.87)**	0.84 (0.58 to 1.22)	0.85 (0.56 to 1.31)	0.98 (0.71 to 1.37)	0.88 (0.57 to 1.36)
Healthcare-related variables										
HCP who first diagnosed										
Hospital eye specialist	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	n/a[a]
Optometrist	2.49 (1.88 to 3.30)***	2.40 (1.77 to 3.26)***	0.63 (0.42 to 0.96)*	0.73 (0.57 to 0.95)*	0.86 (0.68 to 1.10)	1.28 (1.01 to 1.63)*	0.94 (0.71 to 1.23)	0.91 (0.67 to 1.25)	1.11 (0.88 to 1.42)	n/a[a]

Year of diagnosis (rank) §	1.02 (1.00 to 1.05)	1.03 (1.01 to 1.06)*	1.06 (1.03 to 1.10)**	1.10 (1.07 to 1.14)***	1.04 (1.02 to 1.07)***	1.07 (1.04 to 1.09)***	1.08 (1.05 to 1.11)***	1.02 (0.98 to 1.05)	0.99 (0.97 to 1.01)	1.02 (0.99 to 1.06)
Survey time group										
Contrast 1										
Before July 2002 publicatⁿ of MDSQ 1999 results	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
After the 2002 publicatⁿ (combined intervention effect)	1.58 (0.80 to 3.14)	2.24 (1.10 to 4.59)*	3.47 (1.33 to 9.02)*	7.31 (3.25 to 16.42)***	2.58 (1.36 to 4.91)**	2.84 (1.50 to 5.38)**	4.74 (1.99 to 11.29)***	1.37 (0.58 to 3.25)	0.96 (0.51 to 1.81)	1.41 (0.57 to 3.48)
Contrast 2										
Time between the 2002 paper publicatⁿ - 2009 RCOphth guidelines publicatⁿ	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00

After RCOphth guidelines publicat^{n} (February 2009)	1.29 (0.96 to 1.72)	1.63 (1.19 to 2.24)**	1.19 (0.74 to 1.92)	1.64 (1.25 to 2.16)***	1.22 (0.94 to 1.59)	1.63 (1.25 to 2.13)***	1.49 (1.11 to 1.99)**	1.19 (0.85 to 1.67)	0.80 (0.62 to 1.04)	1.16 (0.81 to 1.65)

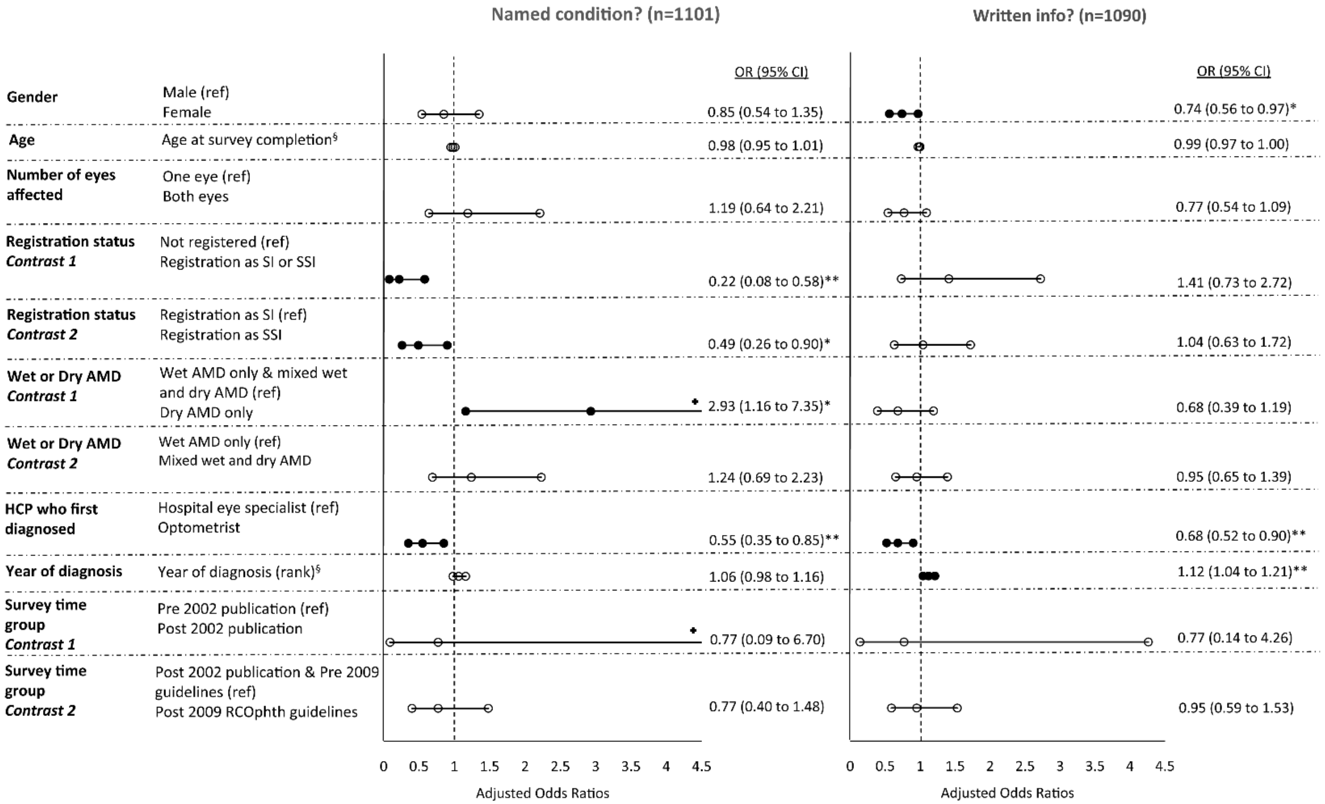
[§] In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases). [a] This question was not specific to the diagnostic consultation, but asked if they were told “around the time of diagnosis”. *p<0.05. **p<0.01. ***p<0.001.

Figures 3.1a-j below show the adjusted odds ratios for logistic regressions controlling for the impact of socio-demographic, eye-related and healthcare-related variables.



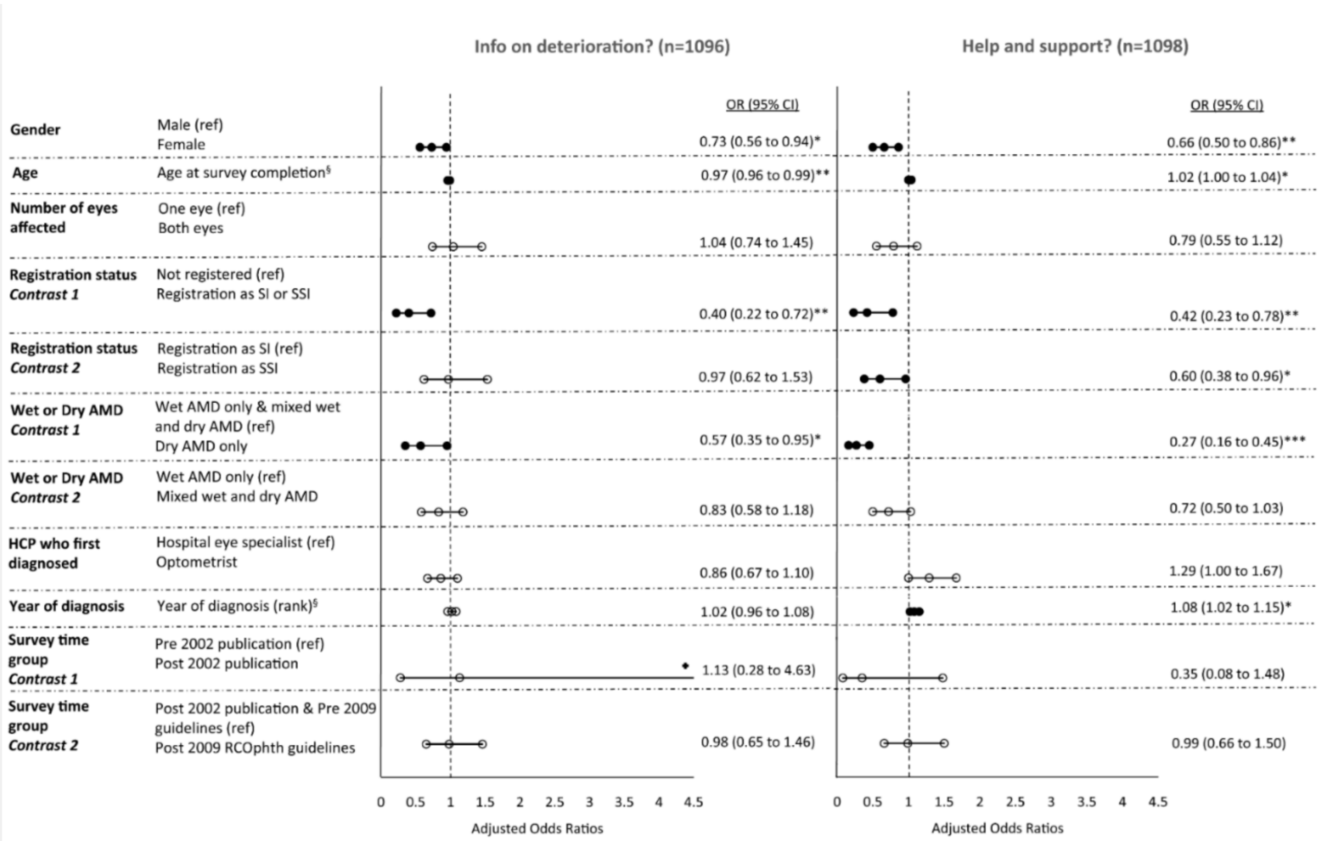
§ In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases). Final model statistics: 'interest as a person,' χ^2 (11)= 80.31, $p<0.001$; final model Nagelkerke's R^2= 0.10. 'Overall satisfaction', χ^2 (11)= 86.67, $p<0.001$; final model Nagelkerke's R^2= 0.12. Markers are shown for variables included in each model. Filled markers indicate statistical significance ($p<0.05$). *$p<0.05$. **$p<0.01$. ***$p<0.001$. Error bars indicate 95% confidence intervals. '+' indicates odds ratio and/or upper bound of confidence interval exceeds the 4.5 maximum that could be fitted on the figure.

Figure 3.1a and 3.1b. Adjusted odds ratios for binary logistic regressions of satisfaction with healthcare experiences for respondents' reports of whether 'the HCP who diagnosed them was interested in them as a person' and 'overall satisfaction with the diagnostic consultation'.



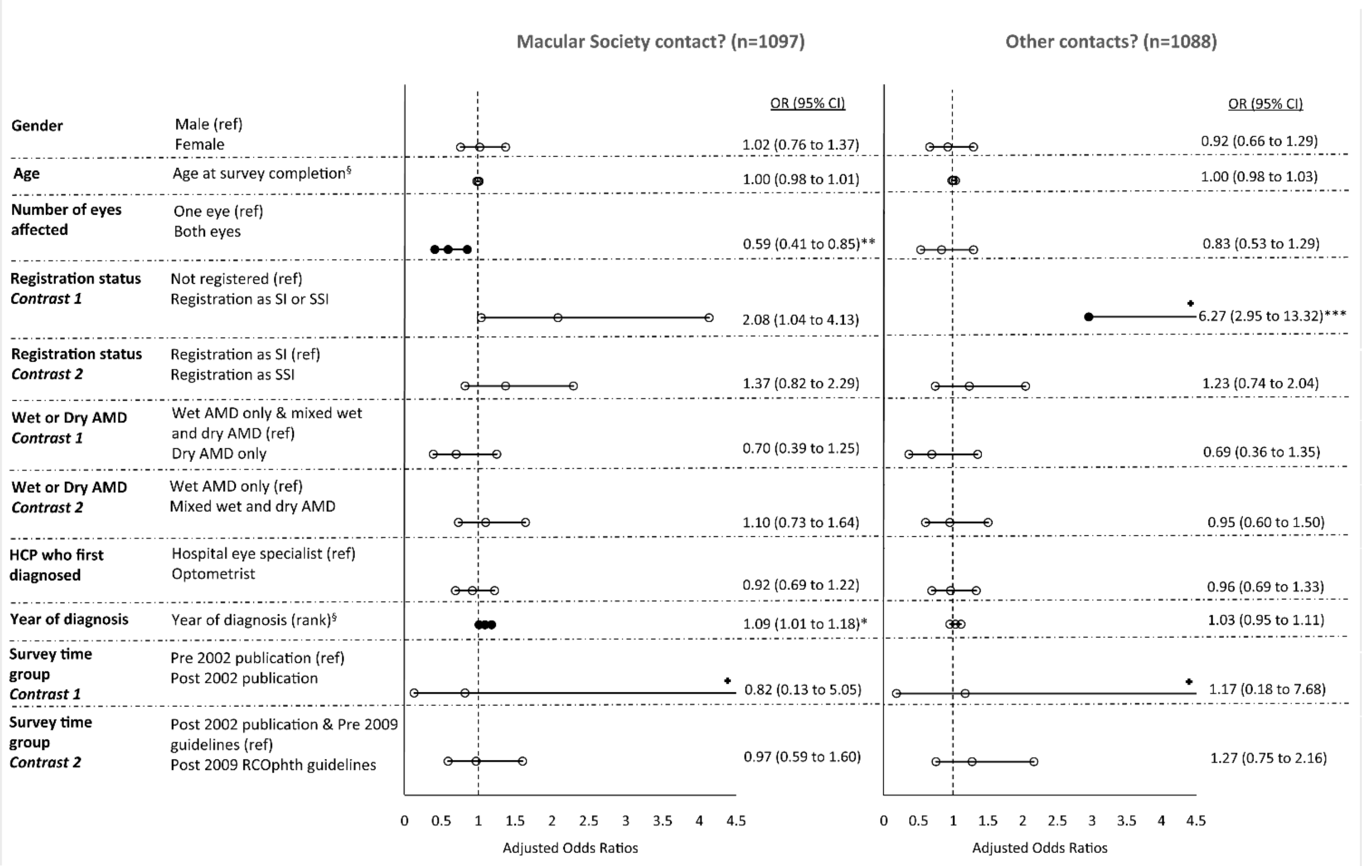
§ In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases).
Final model statistics: 'named condition,' χ^2 (11)= 43.29, p<0.001; final model Nagelkerke's R^2= 0.09. 'Written information', χ^2 (11)= 73.21, p<0.001; final model Nagelkerke's R^2= 0.09. Markers are shown for variables included in each model. Filled markers indicate statistical significance (p<0.05). *p<0.05. **p<0.01. ***p<0.001. Error bars indicate 95% confidence intervals. '+' indicates odds ratio and/or upper bound of confidence interval exceeds the 4.5 maximum that could be fitted on the figure.

Figure 3.1c and 3.1d. Adjusted odds ratios for binary logistic regressions of satisfaction with healthcare experiences for respondents' reports of whether they were given 'the name of their macular condition' and 'written information about their macular condition' at the time of diagnosis.



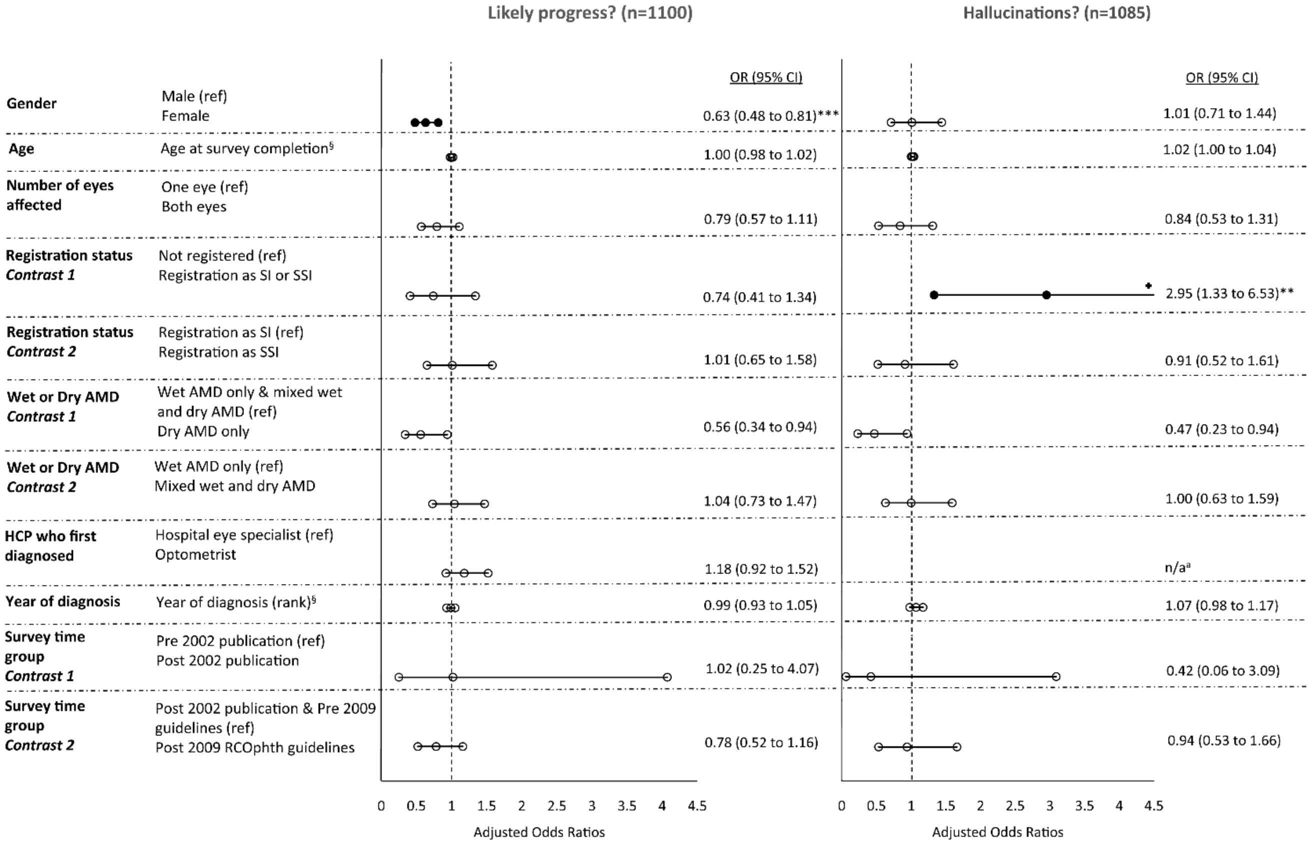
§ In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases).
Final model statistics: 'info on deterioration,' χ^2 (11)= 50.88, p<0.001; final model Nagelkerke's R^2= 0.06. 'Help and support', χ^2 (11)= 98.81, p<0.001; final model Nagelkerke's R^2= 0.12.
Markers are shown for variables included in each model. Filled markers indicate statistical significance (p<0.05). *p<0.05. **p<0.01. ***p<0.001. Error bars indicate 95% confidence intervals. '+' indicates odds ratio and/or upper bound of confidence interval exceeds the 4.5 maximum that could be fitted on the figure.

Figure 3.1e and 3.1f. Adjusted odds ratios for binary logistic regressions of satisfaction with healthcare experiences for respondents' reports of whether they were given 'information on what to do if they were to have a sudden deterioration in vision' and 'appropriate help, support and advice' at the time of diagnosis.



§ In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases).
Final model statistics: 'Macular Society contact,' χ^2 (11)= 40.31, p<0.001; final model Nagelkerke's R^2= 0.05. 'Other contacts', χ^2 (11)= 29.77, p<0.01; final model Nagelkerke's R^2= 0.04.
Markers are shown for variables included in each model. Filled markers indicate statistical significance (p<0.05). *p<0.05. **p<0.01. ***p<0.001. Error bars indicate 95% confidence intervals. '+' indicates odds ratio and/or upper bound of confidence interval exceeds the 4.5 maximum that could be fitted on the figure.

Figure 3.1g and 3.1h. Adjusted odds ratios for binary logistic regressions of satisfaction with healthcare experiences for respondents' reports of whether they were given 'information about the Macular Society' and 'other contacts for help and support' at the time of diagnosis.



§ In logistic regression, for continuous variables such as age at survey completion, an odds ratio over 1 indicates increasing likelihood of the outcome as the predictor increases (i.e. as age increases). [a] This question was not specific to the diagnostic consultation, but asked if they were told "around the time of diagnosis". Final model statistics: 'Likely progress,' χ^2 (11)= 25.78, $p<0.01$; final model Nagelkerke's R^2= 0.03. 'Hallucinations,' χ^2 (10)= 22.34, $p<0.05$; final model Nagelkerke's R^2= 0.04. Markers are shown for variables included in each model. Filled markers indicate statistical significance ($p<0.05$). *$p<0.05$. **$p<0.01$. ***$p<0.001$. Error bars indicate 95% confidence intervals. '+' indicates odds ratio and/or upper bound of confidence interval exceeds the 4.5 maximum that could be fitted on the figure.

Figure 3.1i and 3.1j. Adjusted odds ratios for binary logistic regressions of satisfaction with healthcare experiences for respondents' reports of whether they were given information around the time of diagnosis on the 'likely progress of their macular condition' and on 'the possibility of experiencing visual hallucinations as a side effect of sight loss'.

In the multivariable analyses presented in Figures 3.1a-j, the trend for increasing satisfaction with healthcare experiences across time remained significant for the following three aspects of healthcare: provision of written information ($p<0.01$), information about the Macular Society ($p<0.05$), and being given appropriate support, help or advice at the time of diagnosis ($p<0.05$). Once this trend was adjusted for, of the ten aspects of care, only overall satisfaction with the diagnostic consultation significantly improved, and only after the 2009 RCOphth guidelines publication ($p<0.01$). There were no significant improvements associated with the 2002 publication of the MDSQ 1999 results (ps>0.05).

Women were less likely than men to report receiving information and support on five aspects of care: provision of written information, information on what to do if they have a sudden deterioration in vision, receiving appropriate help, support and advice at diagnosis, information on the likely progress of their macular condition and overall satisfaction with the diagnostic consultation (see Figures 3.1b, d, e, f and i). Older respondents were more likely to report overall satisfaction with the diagnostic consultation ($p<0.01$), and receiving appropriate help, support and advice at diagnosis ($p<0.05$), but were less likely than younger respondents to report receiving information on what to do if they have a sudden deterioration in their vision ($p<0.01$). Respondents who were registered as sight impaired (SI) or severely sight impaired (SSI) were less likely than those not registered to report being told the name of their condition at diagnosis, being given information on what to do if they experience a sudden deterioration in vision, and report receiving appropriate help and support at diagnosis (ps<0.01). However they were more likely to report being given other contacts for help and support ($p<0.001$), and information on visual hallucinations ($p<0.01$). Respondents who were first diagnosed by an optometrist were more likely than those diagnosed by an eye specialist to report feeling that the HCP who diagnosed them was interested in them as a person and overall satisfaction with the consultation (ps<0.001). Whereas, those first diagnosed by an eye specialist were more likely to report being given the name of their condition at diagnosis and written information on the condition (ps<0.01). There were no significant differences between eye specialists and optometrists on the other five aspects of information and support provision studied. (See Figures 3.1a-j.)

Reasons for satisfaction or dissatisfaction with the diagnostic consultation (free-text responses)

Table 3.6 shows a comparison between the 1999 and 2013 survey samples' responses for the ten most commonly cited reasons for dissatisfaction with the diagnostic consultation from the 1999 survey. For a detailed descriptions of codes, see Appendix 7 for the coding framework.

Table 3.6. A comparison of the number of 1999 and 2013 survey respondents reporting the same reasons for dissatisfaction with the diagnostic consultation (percentages are of those who reported being dissatisfied with the consultation within each survey group).

Reason for dissatisfaction[b]	**1999 responses** (n=446)[a]	**2013 responses** (n=273)[a]	**χ^2**
	Yes (valid %)	Yes (valid %)	
Specialist's attitude (seen as dismissive, patronising, brusque, unfeeling, uninterested in patient/ condition, used jargon, talked to colleagues whilst ignoring the patient, made patient feel of no consequence because of their age)	196 (45.4%)	74 (28.6%)	χ^2 (1)=19.20, p<0.001***, phi= -0.17, n=691.
Lack of information or advice (about condition, prognosis, adjustment, low vision aids, self-help groups, counselling), lack of written information.	193 (44.7%)	120 (46.3%)	χ^2 (1)=0.18, p=0.67, phi=0.02, n=691.
Told nothing could be done	61 (14.1%)	60 (23.2%)	χ^2 (1)=9.17, p<0.01**, phi=0.12, n=691.

Problems with management (delay in getting appointments, paperwork/ correspondence lost, seeing different doctors)	45 (10.4%)	65 (25.1%)	χ^2 (1)=26.07, p<0.001***, phi=0.19, n=691.
Shocked by what they were told	33 (7.7%)	13 (5.0%)	χ^2 (1)=1.83, p=0.18, phi= -0.05, n=689.
Lack of time with the consultant	31 (7.2%)	13 (5.0%)	χ^2 (1)=1.31, p=0.25, phi = -0.04, n=688.
Discharged after consultation	28 (6.5%)	21 (8.1%)	χ^2 (1)=.65, p=0.42, phi=0.03, n=691.
Condition not named	21 (4.9%)	35 (13.5%)	χ^2 (1)=16.28, p<0.001***, phi=0.15, n=691.
No opportunity for questions	17 (3.9%)	8 (3.1%)	χ^2 (1)=.33, p=0.56, phi= -0.02, n=691.
Wanted second opinion	8 (1.9%)	10 (3.9%)	χ^2 (1)=2.58, p=0.11, phi=0.06, n=691.

[a] There were 14 participants in each the 1999 and 2013 surveys who reported being dissatisfied with the diagnostic consultation but did not provide a reason why.[b] Reasons for dissatisfaction were coded using codes stated in the paper publishing the results of the 1999 survey (Mitchell et al., 2002). *p<0.05, **p<0.01, ***p<0.001.

The 2013 survey respondents’ top ten reasons for satisfaction or dissatisfaction with the diagnostic consultation are provided in Table 3.7.

Table 3.7. The ten most cited reasons for satisfaction or dissatisfaction with the diagnostic consultation by the 2013 survey respondents.

Reason for satisfaction	Yes (valid %) (total n=831)[a]	Example quote:	**Reason for dissatisfaction**	Yes (valid %) (total n=253)[b]	Example quote:
Information was provided	163 (33.6%)	"The consultant explained everything"	**Lack of information or advice** †	111 (45.7%)	"…I was not given any information about [the] condition and had to ask several times before I felt I understood what was happening- and that I wasn't going to go blind!"
Referred to or within a hospital	150 (30.9%)	"Referred me to eye specialist"	**Healthcare professional attitude** †	70 (28.8%)	"Made no attempt to reassure me…very curt and abrupt"
Prevention of delay	130 (26.8%)	"Optician sent me straight to an eye centre"	**Problems with management** †	62 (25.5%)	"Whole clinic experience was cold and staff omitted to always introduce themselves and explain each step of the process"

Healthcare professional's attitude	96 (19.8%)	"He took an interest in me"	**Told nothing could be done** †	57 (23.5%)	"I was told that I would go completely blind in that eye and nothing could be done"
Treatment received or information on treatment	76 (15.7%)	"Receiving Lucentis Injections"	**Delay to diagnosis**	29 (11.9%)	"He made an urgent plea for me to be seen by a hospital consultant, but I had to chase this up repeatedly to obtain an appointment & it was more than a month before I was successful!"
Examination was thorough	61 (12.6%)	"Thorough examination included laser scans"	**Macular condition not named** †	28 (11.5%)	"Did not give a name to my condition"
Competence of healthcare professional (good)	42 (8.7%)	"She was an expert in the area"	**Negative comment on treatment received**	26 (10.7%)	"It was in the early days of treatment and it wasn't available on the NHS"

Referred to GP[c]	35 (7.2%)	"She referred me to GP"	**Caused a delay to receiving treatment**	24 (9.9%)	"I saw XXX at XXX who said it was far too late to treat my AMD. Optician should have bypassed GP."
Diagnosis made or confirmed	31 (6.4%)	"Pleased something being done, I had not imagined it"	**Discharged after consultation** [†]	18 (7.4%)	"No follow-up given"
Follow up received/ offered	30 (6.2%)	"I had a six month repeat consultation"	**Competence of healthcare professional (poor)**	18 (7.4%)	"[Optician] Told me not to worry don't need to see consultant. I went to doctor of my own volition and left eye was already wet so glad I did as then able to offer treatment."

[a] There were 346 respondents who didn't write a reason for satisfaction. [b] There were 10 respondents who didn't write a reason for dissatisfaction. [c] Please note that although some respondents viewed referral to a GP as positive, in practice it is unnecessary and may have delayed receipt of appropriate treatment. [†] Indicates reasons for dissatisfaction reported in the paper publishing the MDSQ 1999 results.

For the 2013 survey respondents, the most common cause of *satisfaction* with the consultation was due to information provision within the consultation. The most common cause of *dissatisfaction* with the consultation was due to lack of information provision. Six of the top ten reasons for dissatisfaction with the consultation cited by the 1999 sample were cited in the top ten reasons for dissatisfaction by the 2013 sample. The four reasons cited in the top ten reasons by the 1999 sample, but not in the top ten of the 2013 sample, were: being shocked by what they were told in the consultation, lack of time in the consultation, no opportunity given to ask questions, and the respondent wanting a second opinion. Nevertheless, they were still cited as reasons for dissatisfaction by the 2013 survey respondents (Table 3.6). The attitude of the healthcare professional who diagnosed them was the second most commonly cited reason for dissatisfaction (Table 3.7). A comparison of the proportion of 1999 and 2013 survey respondents providing this reason in their free-text responses found that fewer 2013 respondents reported the healthcare professional's attitude as a reason for dissatisfaction (Table 3.6). There was no significant difference in the proportion of 1999 and 2013 survey respondents reporting a lack of information provision at diagnosis (Table 3.6). In both samples, nearly half of the respondents who were dissatisfied with the consultation reported this as a reason for dissatisfaction.

The 2013 survey respondents were more likely than the 1999 respondents to cite the following reasons for dissatisfaction: being told that nothing could be done to help with their macular condition, problems with management (e.g. delay getting appointments, correspondence lost), and not receiving the name of their condition at diagnosis (Table 3.6). The reason for this may be partly explained by the HCP who diagnosed the condition. Optometrists are now able to diagnose AMD whereas in 1999 only ophthalmologists were entitled to give this diagnosis. The 2013 survey asked respondents to state which HCP had first diagnosed them. Table 3.8 shows the reasons for dissatisfaction split between those diagnosed by an eye specialist and those diagnosed by an optometrist.

Table 3.8. Comparison of reasons for dissatisfaction by those first diagnosed by a hospital eye specialist or an optometrist from the 2013 sample (only the ten most commonly cited reasons are included here).

Reason for dissatisfaction	**Hospital eye specialist** (n=180) Frequency of yes responses (valid %)	**Optometrist** (n=73) Frequency of yes responses (valid %)	**Statistic, p value**.
Caused a delay to receiving treatment	17 (9.8%)	7 (10.0%)	χ^2 (1)=0.002, p=0.97, phi=0.003, n=243.
Delay to diagnosis	20 (11.6%)	9 (12.9%)	χ^2 (1)=0.08, p=0.78, phi= 0.02, n=243.
Competence of healthcare professional	13 (7.5%)	5 (7.1%)	χ^2 (1)=0.01, p=0.92, phi= -0.01, n=243.
Lack of information or advice [a]	81 (46.8%)	30 (42.9%)	χ^2 (1)=0.32, p=0.57, phi= -0.04, n=243.
Healthcare professional attitude [a]	55 (31.8%)	15 (21.4%)	χ^2 (1)=2.61, p=0.11, phi= -0.10, n=243.
Told nothing could be done [a]	49 (28.3%)	8 (11.4%)**	χ^2 (1)=7.92, p=0.01**, phi= -0.18, n=243.
Discharged after consultation [a]	14 (8.1%)	4 (5.7%)	χ^2 (1)=0.41, p=0.52, phi= -0.04, n=243.
Condition not named [a]	14 (8.1%)	14 (20.0%)**	χ^2 (1)=6.93, p=0.01**, phi= 0.17, n=243.
Management problems [a]	41 (23.7%)	21 (30.0%)	χ^2 (1)=1.04, p=0.31, phi= 0.07, n=243.
Negative comment on treatment received	21 (12.1%)	5 (7.1%)	χ^2 (1)=1.30, p=0.25, phi= -0.07, n=243.

[a] Indicates reasons for dissatisfaction reported in the paper publishing the MDSQ 1999 results. These were compared between Healthcare professional type. *p<0.05, **p<0.01, ***p<0.001.

Although there were no significant differences between those diagnosed by an eye specialist and those diagnosed by an optometrist in the proportion of respondents reporting problems with management, the results show that more respondents diagnosed by an optometrist stated dissatisfaction due to not being told the name of their condition, and that more respondents diagnosed by an eye specialist reported dissatisfaction due to being told that nothing could be done for their macular condition.

There were several new reasons for dissatisfaction provided in the free-text responses by the 2013 survey respondents and that had not been given as reasons by the 1999 survey respondents. Two reasons were a perceived ‘delay to diagnosis’ and ‘delay to receiving treatment’ (mentioned by 12% and 10% of the survey respondents who were dissatisfied, respectively; see Table 3.7). Other reasons include ‘negative comments made on the (medical) treatment received’ and ‘poor competence of the HCP’. There were no significant differences in the proportion of respondents reporting these as reasons for dissatisfaction by those diagnosed by an optometrist or an eye specialist (Table 3.8).

The most commonly cited reason for satisfaction with the diagnostic consultation was having received information and advice (Table 3.7). Table 3.9 shows the reasons for satisfaction split between those diagnosed by an eye specialist and those diagnosed by an optometrist.

Table 3.9. Comparison of reasons for satisfaction by those first diagnosed by a hospital eye specialist or an optometrist (only the ten most commonly cited reasons are included here).

Reason for satisfaction	**Hospital eye specialist** (n=421)[a] Frequency of yes responses (valid %)	**Optometrist** (n=410)[b] Frequency of yes responses (valid %)	**Statistic, p value.**
Information was provided	93 (38.9%)	70 (28.5%)*	χ^2 (1)=5.94, p=0.02*, phi= -0.11, n=485.
Referred to or within a hospital	41 (17.2%)	109 (44.3%)***	χ^2 (1)=41.84, p<0.001***, phi= 0.29, n=485.
Prevention of delay	51 (21.3%)	79 (32.1%)**	χ^2 (1)=7.17, p=0.01**, phi= 0.12, n=485.
Healthcare professional’s attitude	55 (23.0%)	41 (16.7%)	χ^2 (1)=3.08, p=0.08, phi= -0.08, n=485.
Treatment received or received information on treatment	57 (23.8%)	19 (7.7%)***	χ^2 (1)=23.86, p<0.001***, phi= -0.22, n=485.
Examination was thorough	34 (14.2%)	27 (11.0%)	χ^2 (1)=1.17, p=0.28, phi= -0.05, n=485.
HCP competent	19 (7.9%)	23 (9.3%)	χ^2 (1)=0.30, p=0.58, phi= 0.03, n=485.
Referred to GP [c]	0 (0%)	31 (12.6%)***	χ^2 (1)=21.62, p<0.001***, phi= 0.21, n=485.
Diagnosis made or confirmed	14 (5.9%)	17 (6.9%)	χ^2 (1)=0.23, p=0.64, phi= 0.02, n=485.
Follow up received/offered	17 (7.1%)	13 (5.3%)	χ^2 (1)=0.70, p=0.40, phi= -0.04, n=485.

[a] 182 respondents did not provide a reason for satisfaction with the consultation with the hospital eye specialist. [b] 164 respondents did not provide a reason for satisfaction with the consultation with the optometrist. [c] Please note that although some respondents viewed referral to a GP as positive, in practice it is unnecessary and may have delayed receipt of appropriate treatment. *p<0.05. **p<0.01. ***p<0.001.

Satisfaction due to information provision was reported by a greater proportion of respondents first diagnosed by an eye specialist than those diagnosed by an optometrist (Table 3.9). The healthcare professional's attitude was the fourth most commonly stated reason for satisfaction, reported by nearly a fifth of those satisfied with the diagnostic consultation (Table 3.7). There was no significant difference in the proportion of respondents first diagnosed by an eye specialist or an optometrist who reported this as a reason for satisfaction (Table 3.9). Other reasons for satisfaction included: being offered a follow-up consultation, having the diagnosis made or confirmed, the competence of the healthcare professional (good), and having received a thorough examination. There were no significant differences between respondents diagnosed by an eye specialist or an optometrist on these reasons. The second most commonly cited reason for satisfaction was receiving a referral to the hospital or within a hospital that led to the diagnosis being confirmed (Table 3.7). Significantly more of the respondents who were first diagnosed by an optometrist stated this as a reason for satisfaction (Table 3.9). As expected, only respondents who were first diagnosed by an optometrist reported satisfaction due to being referred to a GP.

A 'prevention of delay' was the third most common reason for satisfaction. This was reported by significantly more respondents first diagnosed by an optometrist than an eye specialist. Seventy six respondents reported satisfaction due to having received treatment for their condition or receiving information on treatment. This was, as expected, mentioned by more respondents first diagnosed by an eye specialist than an optometrist.

Experiences with general practitioners (GPs) around the time of diagnosis

Figures 3.2 and 3.3 show a comparison of the 1999 and 2013 survey responses on respondents' views of GP knowledge about AMD, and help and support received from GPs in relation to their macular condition.

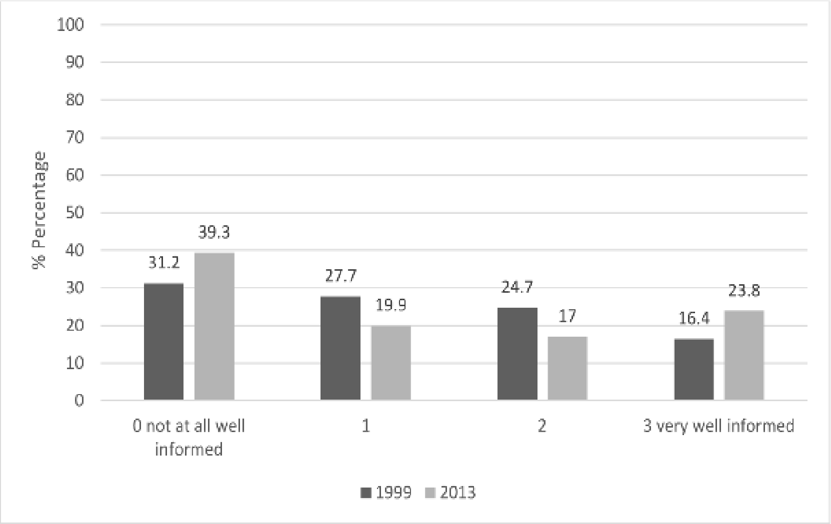


Figure 3.2. Comparison of the 1999 and 2013 survey responses to the question "Around the time you were first diagnosed with your macular condition, to what extent was your GP well-informed about your condition?"[a]

[a] "not applicable" responses are excluded. The responses of the remaining 684 respondents in the 2013 survey group and 957 in the 1999 survey are reported here.

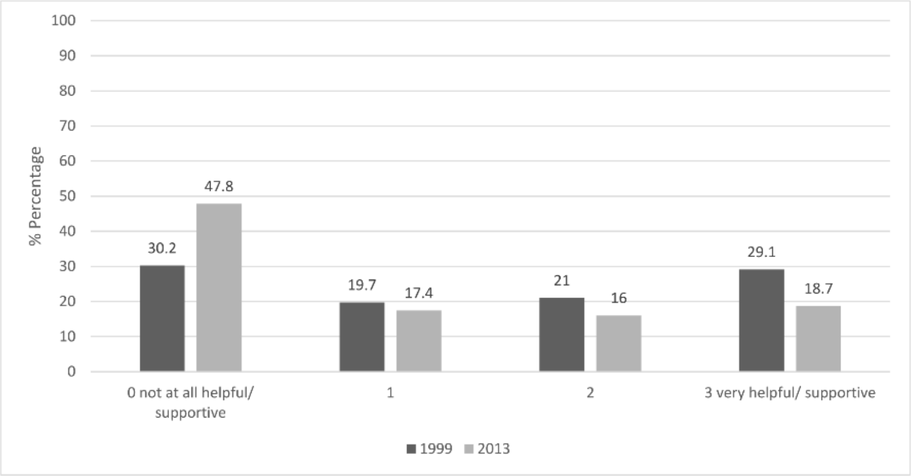


Figure 3.3. Comparison of the 1999 and 2013 survey responses to the question "To what extent has your GP been helpful and supportive about your macular condition?"[a]

[a] "not applicable" responses are excluded. The responses of the remaining 742 respondents in the 2013 sample and 1064 in the 1999 sample are reported here.

In the 2013 survey, 163 respondents felt that their GP was “very well-informed” about their condition (23.8% of responses). However, many more said that their GP was “not at all well-informed” (n=269, 39.3%). Additionally, only 139 respondents (18.7%) reported that their GP was “very helpful and supportive” about their AMD, and almost half of the survey respondents (47.8%) reported that their GP was “not at all helpful/supportive” (n=355).

Mann-Whitney tests found no significant differences between the 1999 and 2013 samples in reported GP knowledge of AMD (U= 321, 207.00, z= -0.67, p=0.50, n=1641), but there was a significant difference in reports of GP supportiveness. Respondents from the 2013 survey were more dissatisfied with the support provided by GPs (U= 314, 740.00, z= -7.66, p<0.001, n=1806).

Experiences of visual hallucinations (Charles Bonnet Syndrome)

Comparing the 1999 vs 2013 survey responses

Visual hallucinations were reported by 225 respondents (22.3%) from the 2013 sample. A similar number reported experiencing visual hallucinations in the 1999 sample (n=244, 25.7%). The figures do not differ significantly between the surveys, (χ^2 (1)= 3.26, p= 0.07, n=1959). Of the hallucinations described by the 2013 survey respondents, 49 reported having hallucinations of simple repeated patterns and 110 reported more complex hallucinations e.g. of figures, plants or animals. Sixty two respondents reported descriptions consistent with both types of hallucinations. Four respondents provided descriptions of their hallucinations for which it was difficult to determine whether they were simple or complex hallucinations. Among those reporting visual hallucinations, only 76 (33.8%) reported talking to a HCP about them. A significantly smaller proportion of the 2013 survey respondents talked to a HCP about hallucinations than the 1999 survey respondents (n in 2013 sample=76, 33.8% vs n in 1999 sample=106, 43.4%; χ^2 (1)= 5.62, p=0.02, n=461; Cramer’s v= 0.11). Of the respondents who spoke to a HCP about hallucinations, 45 of the respondents from the 2013 survey (59.2%) reported receiving an explanation for the visual hallucinations, compared to 42 respondents (39.6%) from the 1999 survey. This difference is significant; a greater proportion of the 2013 survey respondents were given a cause for the hallucinations (χ^2 (1)= 6.51, p= 0.01. n=173; Cramer’s v= 0.19). The causes given to respondents from the 1999 survey included being due to age (n=3), stress (n=2), psychological reasons (n=1), brain confusion (n = 1), having nothing to do with AMD (n = 1), or being attributed to the environment (n = 1). In the 2013 survey, the majority of respondents reported being given an accurate explanation for the hallucinations. These explanations included simply being told they were due to CBS (n=4), or were a side effect of AMD (n=12), and 23 reported receiving more detailed explanations such as it is “the brain compensating for lack of vision”. However one participant noted, “a total dismissal when discussed with health officials, as though they had never heard of it”. Despite being told that the hallucinations were due to AMD, some respondents did not feel this was an adequate explanation of the cause of CBS, e.g. one respondent wrote, “I was told it happens to us VIPs [visually impaired persons] not the cause”.

Factors associated with experiencing hallucinations

The 2013 survey respondents who reported having experienced hallucinations were more likely to be living alone, be registered as SI or SSI, have both eyes affected by AMD, have a caregiver, be older and have been diagnosed longer ago (see Table 3.10).

There were no differences between those who had or had not experienced hallucinations for type of AMD (wet AMD, dry AMD or both wet and dry AMD), and sex.

Table 3.10. Factors associated with experiencing hallucinations. Values are frequencies (valid percentage %) unless otherwise stated. Adjusted standardised residuals are shown in square brackets[†].

Variables		**Respondents reporting hallucinations (n= 225)**	**Respondents who haven't experienced hallucinations (n= 786)**	**statistic, p value, effect size.**
Gender	Male	59 (26.2%) [-1.6]	250 (31.8%) [1.6]	χ^2 (1)=2.57, p=0.11: phi= 0.05; n=1011.
	Female	166 (73.8%) [1.6]	536 (68.2%) [-1.6]	
Age at survey completion (years)	Mean (SD)	83.56 (7.01)	79.12 (8.03)	U=117, 572.00, z= 7.55, p<0.001***; n=1011.
	Median	84.00	80.00	
Registration status	Not registered	85 (37.8%) [-11.6]	614 (78.1%) [11.6]	χ^2 (2)=138.32, p<0.001***: Cramer's V= 0.37; n=1011.
	Registered sight impaired (SI)/ partially sighted	88 (39.1%) [7.5]	125 (15.9%) [-7.5]	
	Registered severely sight impaired (SSI)/ blind	52 (23.1%) [7.6]	47 (6.0%) [-7.6]	
Number of eyes	One eye	19 (8.4%) [-4.9]	183 (23.3%) [4.9]	χ^2 (1)=24.09, p<0.001***:
	Both eyes	206 (91.6%)	603 (76.7%)	

affected by AMD		[4.9]	[-4.9]	phi= 0.15; n=1011.
Receipt of care for AMD	Have caregiver	174 (79.1%) [8.7]	355 (46.0%) [-8.7]	χ^2 (1)=75.11, p<0.001***: phi= 0.28; n=991.
	No caregiver	46 (20.9%) [-8.7]	416 (54.0%) [8.7]	
Wet, dry or both wet and dry AMD	Wet AMD	73 (35.4%) [-1.3]	301 (40.3%) [1.3]	χ^2 (2)=3.25, p=0.20; n=952.
	Dry AMD	86 (41.7%) [-0.1]	313 (42.0%) [0.1]	
	Wet and dry AMD	47 (22.8%) [1.7]	132 (17.7%) [-1.7]	
Live alone?	No	112 (50.7%) [-2.0]	454 (58.4%) [2.0]	χ^2 (1)=4.13, p<0.05*: phi= -0.06; n=999.
	Yes	109 (49.3%) [2.0]	324 (41.6%) [-2.0]	
Years since diagnosis	Mean (SD)	6.68 (3.73)	5.10 (3.65)	U=110, 676.50, z= 5.79, p<0.001***; n=1011.
	Median	7.00	4.00	

[†] Adjusted standardised residuals over 2 show where expected frequencies are significantly different from their observed frequencies and therefore indicate which cells are non-independent of each other (i.e. the variables are significantly related to each other). Negative residuals indicate a lower observed frequency than expected given the null hypothesis of independence. Positive residuals indicate a higher observed frequency than expected. *p<0.05, **p<0.01, ***p<0.001.

Associations between experiencing hallucinations and QoL and well-being

The 2013 survey respondents who reported having had experienced hallucinations since diagnosis were more likely to report poorer QoL (both general and MD-specific) and well-being at the time of survey completion (ps<0.001; Table 3.11).

Table 3.11. Comparison of QoL and well-being for the 2013 survey respondents reporting hallucinations vs no hallucinations (n=1011).

Variables		Reported experienced hallucinations	Reported not experienced hallucinations	Statistics, p value
General quality of life[a]	Mean (SD)	0.62 (1.17)	1.24 (1.04)	U=60, 450.50, z= -7.26, p<0.001***: n=1004.
	Median	1.00	1.00	
MD-specific quality of life[b]	Mean (SD)	-2.44 (0.74)	-1.82 (1.06)	U=58, 905.00, z= -7.84, p<0.001***: n=1005.
	Median	-3.00	-2.00	
Well-being[c]	Mean (SD)	28.35 (9.63)	33.16 (8.67)	U=51, 360.50, z= -6.41, p<0.001***: n=914.
	Median	30.00	35.00	

[a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD-specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). [c] General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being. *p<0.05, **p<0.01, ***p<0.001.

Associations between information provision on hallucinations around the time of diagnosis and experiencing hallucinations

Overall, respondents who had experienced hallucinations were significantly more likely to report having received information on them around the time of diagnosis than those who hadn’t experienced hallucinations (χ^2 (1)= 20.99, p< 0.001; n=986; phi= 0.15). Examination of the adjusted standardised residuals indicate that of the 2013 survey respondents who reported having had experienced hallucination/s, they were more likely to report not having received information on hallucinations around the time of diagnosis (n=162, 74%) than having received this information (n=56, 26%). Those who hadn’t experienced hallucinations were also more likely to report that they hadn’t received information on them around the time of diagnosis (n=669, 87%) than having received this information (n=99, 13%).

Associations between information provision on hallucinations around the time of diagnosis and talking to a HCP about their hallucinations later on (for people who had experienced hallucinations)

Of the 2013 survey respondents who had experienced hallucination/s, there was a significant association between having received information on hallucinations around the time of diagnosis and talking to a HCP about their hallucinations later on (χ^2 (1)= 6.22, p= 0.01; n=217; phi= 0.17). Those who had received information on hallucinations around the time of diagnosis were more likely to see a HCP about them later on.

Associations between information provision on hallucinations around the time of diagnosis and QoL and well-being

For the 2013 survey respondents who had experienced hallucinations, there were no significant differences between respondents who were given information on hallucinations around the time of diagnosis and those who weren’t given this information in their QoL, MD-specific QoL and well-being at the time of survey completion (see bottom half of Table 3.12). For the respondents who hadn’t reported hallucinations, there were no significant differences in QoL, MD-specific QoL and well-being between respondents who were given this information around the time of diagnosis and those who weren’t (see top part of Table 3.12).

Table 3.12. Quality of Life and well-being of the 2013 survey respondents who were or were not given information on hallucinations around the time of diagnosis (split by those who reported later experiencing hallucinations and those who didn't).

Variables		**Told about hallucinations around the time of diagnosis**	**Not told about hallucinations around the time of diagnosis**	**Statistics, p value**
Respondents not reporting hallucinations				
General quality of life[a]	Mean (SD)	1.39 (1.00)	1.22 (1.04)	U=36, 230.50, z= 1.66, p=0.096: n=765.
	Median	1.00	1.00	
MD-specific quality of life[b]	Mean (SD)	-1.97 (1.01)	-1.80 (1.07)	U=29, 868.00, z= -1.46, p=0.15: n=766.
	Median	-2.00	-2.00	
Well-being[c]	Mean (SD)	33.90 (9.17)	33.09 (8.61)	U=28, 574.50, z= 1.03, p=0.30: n=696.
	Median	36.00	34.42	
Respondents reporting hallucinations				
General quality of life[a]	Mean (SD)	0.50 (1.19)	0.67 (1.16)	U= 4, 224.00, z= -0.73, p=0.46: n=217.
	Median	1.00	1.00	
MD-specific quality of life[b]	Mean (SD)	-2.48 (0.76)	-2.41 (0.74)	U=4, 225.50, z= -0.86, p=0.39: n=218.

	Median	-3.00	-3.00	
Well-being[c]	Mean (SD)	27.50 (9.25)	28.51 (9.88)	U=3, 465.50, z= -0.87, p=0.38: n=199.
	Median	27.00	30.00	

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[a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD-specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). [c] General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being.

Associations between QoL and well-being and talking to a HCP about hallucinations after their onset

For respondents not told about hallucinations around the time of diagnosis, there were no significant differences in QoL, MD-specific QoL and well-being between those who later spoke to a HCP about their hallucinations and those who didn’t (see top part of Table 3.13). Of those who spoke to a HCP about their hallucinations, there were no significant differences between respondents who were and were not given a cause for the hallucinations in QoL, MD-specific QoL and well-being (U=192.00, z= -1.31, p=0.19: n=45; U=264.00, z= .45, p=0.66: n=45; U=240.50, z= 1.08, p=0.28: n=41, respectively).

Table 3.13. Quality of Life and well-being of the 2013 survey respondents who did or didn't talk to a HCP about hallucinations after their onset (split by those who were told or not told about hallucinations around the time of diagnosis).

Variables		**Spoke to a HCP about hallucination/s after onset**	**Didn't speak to HCP about hallucination/s after onset**	**Statistics, p value**
Respondents not told about hallucinations around the time of diagnosis				
General quality of life[a]	**Mean (SD)**	0.65 (1.44)	0.68 (1.03)	U=2, 784.50, z= 0.38, p=0.71: n=160.
	Median	1.00	1.00	
MD-specific quality of life[b]	**Mean (SD)**	-2.48 (0.71)	-2.39 (0.75)	U=2, 534.00, z= -0.74, p=0.46: n=161.
	Median	-3.00	-3.00	
Well-being[c]	**Mean (SD)**	27.68 (11.02)	28.84 (9.44)	U=2, 170.50, z= -0.40, p=0.69: n=147.
	Median	29.50	30.00	
Respondents told about hallucinations around the time of diagnosis				
General quality of life[a]	**Mean (SD)**	0.07 (1.21)	0.90 (1.05)	U= 235.50, z= -2.67, p=0.008**: n=56.
	Median	0.00	1.00	
MD-specific quality of life[b]	**Mean (SD)**	-2.48 (0.85)	-2.48 (0.69)	U=374.50, z= -0.32, p=0.75: n=56.
	Median	-3.00	-3.00	
Well-being[c]	**Mean (SD)**	22.83 (8.16)	32.36 (7.80)	U= 128.00, z= -3.72, p<0.001***: n=51.

Median	21.00	33.67

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[a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD-specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). [c] General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being. *p<0.05, **p<0.01, ***p<0.001.

For respondents who reported being given information on hallucinations around the time of diagnosis and who also later spoke to a HCP about their hallucinations, they were more likely to have poorer QoL and well-being than those who didn't speak to a HCP about them, but not poorer MD-specific QoL (see Table 3.13). Those who talked to a HCP about their hallucinations and were told a cause for them did not have significantly different QoL, MD-specific QoL and well-being to those not given a cause (U=78.50, z= -0.14, p=0.90: n=27; U=58.50, z= -1.36, p=0.25: n=27; U=76.50, z= 0.25, p=0.81: n=26, respectively).

Further information and support

A number of questions were included in the 2013 survey to establish whether respondents sought further support after diagnosis, or if they felt further help was needed but not received.

Recent experience with eye care professionals (ECPs)

The majority of respondents reported having seen an eye specialist or optometrist about their macular condition in the past 12 months (n=946, 81%). Two hundred people reported not seeing anyone (17.1%), and no response was given for 23 people. Of those who had not seen an ECP, 175 (87.5%) did not feel the need to see anyone, whilst 25 did want to see an eye specialist or optometrist. Of the 25 who had not seen an ECP but felt they needed to, some were waiting for booked appointments. Others had been to see their GP or optometrist but were waiting for a referral to an eye specialist. Of note, there were two respondents who had noticed a deterioration in their vision, had been to see their GP and were awaiting referral.

Two respondents reported barriers to getting appointments. One of these respondents reported feeling that they "needed to see someone, but no-one can be of help or are interested enough to help". This suggests this respondent experienced two barriers to seeking help- the perception that nothing can be done to help, with the added perception that ECPs aren't "interested enough" to help. The other respondent felt that their doctor had "blocked- but not clearly refused" a referral to the eye specialist.

Four respondents specified that they had noticed a deterioration in vision which precipitated their need to seek help. Another four respondents hadn’t noticed a change in vision but felt that they ‘needed’ to see their ECP for reassurance that their sight hadn’t become worse, for instance one respondent wrote, “I am only checked for glaucoma. It would be reassuring to know how my MD was.” One respondent stated ill health was the reason for not seeking help with their macular condition when needed.

Information on AMD received after diagnosis

Both the 1999 and 2013 survey respondents were asked if they received information about their macular condition after diagnosis, and where this information came from. A similar proportion of respondents from the 1999 survey (n=949, 79.9%) and the 2013 survey (n=931, 79.6%) reported receiving information elsewhere. The number of respondents reporting not having received further information had only reduced very slightly (n=193, 16.5% of the 2013 survey respondents who reported not receiving any information on their macular condition since diagnosis compared to the number in the 1999 survey, n=208, 17.5%).

Local group membership

Just over 40% of the 2013 survey respondents reported membership to a local group for people with a macular condition (n=483, 41.3%). This was significantly more than the proportion of respondents reporting local group membership in the 1999 survey (n=360, 30.3%; χ^2 (1)= 30.19, p<0.001, phi=0.11, n=2324).

Low-vision clinic (LVC) attendance

Around 36% of the 2013 survey respondents reported having attended a low-vision clinic (LVC, n=415). Most respondents had not been to a LVC (n=717, 61%). Others had missing data (n=37, 3%). Significantly more of the 1999 survey respondents had been to a LVC (n=628, 53%; χ^2 (1)= 67.88, p<0.001, phi= -0.17, n=2300). This may be partly explained by a greater proportion of the 1999 survey respondents being registered as SI or SSI (n=718, 60.5%) than the 2013 survey respondents (n=379, 32.4%). Registration status was significantly associated with LVC attendance in both samples. Those who were registered were more likely to have been to a LVC in both the 1999 sample (χ^2 (2)= 337.77, p<0.001, Cramer's V= 0.54, n=1168) and the 2013 sample (χ^2 (2)= 256.81, p<0.001, Cramer's V= 0.48, n=1132).

Of the 2013 survey respondents who hadn't been to a LVC, 227 respondents reported that they would like to attend a LVC (33.5%). 451 respondents reported not having been to a LVC nor wanting to attend one (66.5%).

For those who had been to a LVC, satisfaction was generally high. The majority reported being 'satisfied' (n=267, 63.4%), or were 'slightly satisfied' (n=59, 14%). However 54 respondents reported being 'neither satisfied nor dissatisfied' and 40 respondents reported being 'slightly dissatisfied' or 'dissatisfied' (9.7%).

Psychological support

The 2013 survey respondents were asked if they had ever been offered any psychological support from the hospital or eye clinic. The majority of respondents answered 'no' (n=1120, 95.8%). Only 26 respondents reported being offered psychological support (2.2%). (There were missing data on this question for 23 respondents.) Just over 30% of respondents reported that they would have liked to have been offered psychological support at the time of diagnosis of their AMD (n=289). There were 96 respondents who reported they would have liked to have been offered psychological support at the time of the 2013 survey completion (9.7%).

DISCUSSION

Information and support provision in the diagnostic consultation and with GPs

Patient experiences are an important indicator of quality of healthcare. The Macular Society 2013 survey of people with AMD (pwAMD) found significant improvements since the 1999 survey in patients being given the name of their macular condition at diagnosis, feeling that the HCP who first diagnosed them was interested in them as a person and overall satisfaction with the diagnostic consultation. Of two interventions that might have influenced this increase in satisfaction (the publication of the 1999 survey results and the 2009 publication of RCOphth recommendations for information and support provision to AMD patients) only the latter was associated with significant improvements and this was only for overall satisfaction with the diagnostic consultation. Satisfaction with the three aspects of care measured in both surveys was high initially, reducing the scope for improvements which were nevertheless apparent over time.

The 2013 survey included seven newly-designed questions based on RCOphth recommendations for information and support provision at diagnosis. Only three recommendations showed a significant trend of improvement over time (for written information on the macular condition, information on the Macular Society and for receiving appropriate help, support and advice at diagnosis). However there were no additional improvements, over and above this general trend, following publication of the 2009 guidelines. The proportion of respondents reporting provision of this information and support remains low. For instance, receiving written information on the macular condition was reported by 18% of respondents diagnosed before the publication of the 1999 survey results, 30% diagnosed after their publication, and 42% in those diagnosed after publication of the RCOphth guidelines- showing that despite the increase in this information provision, 58% of those diagnosed after the RCOphth guidelines were still reporting not receiving written information. This pattern of low information provision is similar across other areas. For instance, after the publication of the RCOphth guidelines, only 32% of the survey respondents reported receiving information about the Macular Society and 20% reported receiving other contacts for help and support.

This is the first large-scale survey to examine whether improvements in practice followed interventions designed to improve AMD patients' experiences in the healthcare system. The survey is also unique in examining whether respondents felt they were receiving adequate support from their GPs for AMD. The multivariable analysis of experiences in the diagnostic consultation included several important socio-demographic, eye-related and healthcare factors which were found to be linked to patients' experiences. Of particular note is the association between registration as SI or SSI and lack of information provision at diagnosis on what patients need to do if they experience a sudden deterioration in vision. Although such an association in a cross-sectional study is not necessarily indicative of a causal relationship, this finding may suggest that lack of this information may cause subsequent sight loss sufficient to warrant registration. Respondents with dry AMD were less likely than those with wet AMD to be given information at diagnosis on what to do if they experience a sudden deterioration in vision. This is despite current knowledge that if dry AMD turns to wet AMD, it is important that patients should seek help quickly as treatment is available that may prevent unnecessary sight loss.

Previous research has consistently found that older patients tend to be more satisfied with their healthcare experiences (Croker et al., 2013; Heje, Vedsted, Sokolowski, & Olesen, 2008; Voutilainen, Pitkäaho, Vehviläinen-Julkunen, & Sherwood, 2015). There is some evidence also of women being less satisfied than men, although this finding has been less consistent (e.g.Heje et al., 2008). The results presented in this chapter show some similar findings and some differences. Women were less likely than men to report receiving information and support on five aspects of care. Older respondents were more likely to report overall satisfaction with the diagnostic consultation and receiving appropriate help, support and advice at diagnosis, but were less likely than younger respondents to report receiving information on what to do if they have a sudden deterioration in their vision. The present study did not investigate the cause of differences in reports of information and support provision, for example, whether they were due to differences in patient characteristics (e.g. expectations) or differential treatment from HCPs providing less information and support to women than men, and less information but more help, support and advice to older people than younger people. Nevertheless an awareness of these differences should prompt HCPs to check these particular 'at risk' groups have received and understood important information.

It has been suggested that the gender differences found in the present study may be due to men bringing their female partners with them to diagnostic consultations, and that the women ask questions on their partner's behalf (personal communication with W. Amoaku, 28th October 2016). Indeed there is evidence that women are more likely to receive information in GP consultations because they are more likely to ask for this information (Pendleton & Bochner, 1980). Nguyen Thi, Briançon, Empereur, and Guillemin (2002) suggested that women make the decisions about healthcare in the household for their children, spouse, and parents. Women tend to use more health services (Owens, 2008), and thus they may be more experienced or rehearsed in asking questions. That women were less likely to receive some aspects of information and support may be due to them being too shocked to ask questions when it comes to their own diagnostic consultations, and their male partners are less likely to elicit information on their behalf.

Another explanation may be due to gender differences in expectations of healthcare. Analysis of free-text responses of reasons for dissatisfaction with inpatient hospital stays indicated that male patients' responses were more likely to reflect a need to be taken care of whereas womens' responses reflected a need to be respected and taken seriously (Foss & Hofoss, 2004). For instance, men were more likely to report dissatisfaction relating to maltreatment (e.g. staff incompetence, mistakes made during diagnosis/ treatment, long waiting times), and women described negative experiences due to poor staff attitude (feeling that they had not been listened to or regarded as important). In the present study however, there were no significant gender differences in whether respondents felt that the HCP seemed interested in them as a person, which might reflect perceptions of staff attitude. However women were more likely to report not receiving "appropriate support, help or advice at the time of diagnosis".

Thus there may be complex reasons for gender differences including differences in expectations and needs as well as the patient's behaviour, such as eliciting information for themselves or on another's behalf. It may be that there are different expectations and needs for information and support in different healthcare settings (e.g. GP consultations, diagnostic consultations in a hospital vs at an optometrists), and for different health conditions. The reasons for gender differences for some, but not all aspects of information and support provision in diagnostic consultations for AMD are beyond the scope of this study and could be investigated in future research.

The 2013 survey respondents were more likely than the 1999 sample to report that their GP had not been helpful and supportive about their macular condition, and reported GP knowledge of AMD remains low. In contrast to the 1999 survey, the 2013 survey included a 'not applicable' response for the questions on experiences with GPs. It could be argued that having this response option reduces the reliability of the comparison between the 1999 and 2013 survey responses because it may have changed the likelihood of non-response. A high number of the 2013 survey respondents used the ‘not applicable’ option. For the question that asked for their opinion of their GPs knowledge of AMD, only 38 respondents left this answer blank and a large number used the ‘not applicable’ option (n=447). In comparison, 230 respondents to the 1999 survey left their answer blank to this question. Respondents were told in both surveys that they could leave survey questions blank if they wished. That 38 of the 2013 survey respondents still left their answer blank suggests there may be other reasons for item non-response and respondents exercised their right to leave their answer blank if they wished.

The large number of responders who used the ‘not applicable’ option in the 2013 survey might be explained by the more recent removal of the need to refer patients with suspected AMD via their GP. The introduction of anti-VEGF injections in 2008 may also mean that more patients are being seen in the eye clinic and thus there may be fewer patients seeing their GP about AMD than in the 1999 survey. Therefore it was felt that including the ‘not applicable’ option would more accurately investigate patients’ experiences given the reduction in the need for pwAMD to see their GP.
It is important to note that the results reported here demonstrate changes in information and support provision that occurred around the time of the interventions (the publication of the 2002 paper and 2009 RCOphth guidelines): they do not demonstrate direct cause and effect. It would have been difficult to create control questions based on information and support provision outside of the guidelines, as the guidelines cover many aspects of information and support. Creating control questions that would be comparable to the recommendations in importance would have been difficult and subjective. If the questions were less important, then this may itself be a reason for differences in results and thus could not be used as a control. The inclusion of the questions on experiences with GPs (who are unlikely to have read the RCOphth guidelines) could be seen to act as a control to test whether patient experiences would have improved across time regardless of the RCOphth guidelines. The lack of improvement in reports of experiences with GPs lends weight to the view that the RCOphth guidelines may well have had a positive influence on ECPs which in turn may have improved overall patient satisfaction with the diagnostic consultation. Additionally, the multivariable analysis controlled for trends of improving satisfaction across time where they existed.

Anti-VEGF injections were approved by NICE in August 2008. It cannot be excluded that the improvement in patients' overall satisfaction with the diagnostic consultation found after the RCOphth 2009 guidelines introduction may be due, directly or indirectly, to the introduction of anti-VEGF, and that ECPs may be more engaged with a condition, when one form of the condition is treatable. GPs would also be aware of the introduction of anti-VEGF injections but not the RCOphth guidelines; patient satisfaction with GPs did not show the same improvements found for ophthalmologists and optometrists.

It should be noted that the adjusted r-squared values for the multivariable logistic regression analyses examining experiences in the diagnostic consultation were small, ranging from 0.03 to 0.12 (where 0 indicates a poorly fitting model and 1 indicates a perfectly fitting model). However the purpose of these analyses was to establish which variables had significant relationships with the healthcare experience variables, rather than determine a model that might perfectly explain differences in healthcare experiences.

It will be important to investigate HCPs' responses and explanations for the findings reported here on the lack of information and support provision to pwAMD in and around the time of diagnosis. Perhaps the introduction of anti-VEGF injections for wet AMD has meant eye specialists are hard-pushed to find the time to provide adequate information and support in their diagnostic consultations. Perhaps ECPs don't currently feel confident in providing the information recommended e.g. on the likely progress of macular conditions. Rates of diagnosis of AMD are expected to increase in the future, putting more pressure on eye clinics. High quality written information for pwAMD, pertinent to the RCOphth guidelines, is provided to eye clinics free of charge by the Macular Society, but appears to be underused. This information might usefully be provided in community and primary care settings. Indeed the results indicate that 45% of respondents considered that it was their optometrist who first diagnosed their AMD, and many reported seeing their GP about their macular condition. Some eye clinics in the UK have volunteers or eye clinic liaison officers available to provide support to pwAMD and who could hand pwAMD this leaflet. Crucially, staff and volunteers need to highlight and emphasise important points in the booklet (e.g. what to do if pwAMD experience a sudden deterioration in vision).

Reasons for satisfaction or dissatisfaction with the diagnostic consultation

What do the free-text responses add to the closed tick-box responses reported above? Respondents were asked to write their reasons for satisfaction or dissatisfaction with the diagnostic consultation in their own words. Patient satisfaction and experiences are subjective and it could be argued that free-text responses may more closely reflect the respondents' perceptions of the consultation than the closed tick-box responses. That the most common reason for satisfaction and dissatisfaction was the provision or lack of provision of information and advice, reflects that patients regard this as important and supports the findings from the closed tick-box responses. The healthcare professional's attitude was the second most commonly cited reason for dissatisfaction with the diagnostic consultation. The comparison of the 1999 and 2013 survey responses suggested a decrease in respondents reporting the healthcare professional's attitude as a reason for dissatisfaction in the free-text response, and this is also reflected in the closed tick-box question which found an increase in the number of respondents reporting that the healthcare professional who diagnosed them appeared interested in them as a person.

Initial evidence from a recent systematic review found that in primary care consultations, affective reassurance through verbal and non-verbal communication, for example, showing empathy, and recognising and responding to patient distress, was associated with the short-term outcome of higher patient satisfaction, but poorer longer-term outcomes including poorer recovery and higher symptom burden (Pincus et al., 2013). The review included studies where patients had conditions causing pain and discomfort, where the cause is poorly understood and where further tests and investigations are not indicated (e.g. irritable bowel syndrome, low back pain). However it should be noted that the results of the review are limited by the duration of follow-up; the majority of studies included in the review followed participants up to a maximum of four months. In addition, only a few high quality studies could be found. AMD is also a condition for which the exact cause is unknown and treatment is not available for people with dry AMD or untreatable wet AMD. However AMD does not tend to be associated with symptoms of pain and discomfort. There is currently no research which has investigated the impact of giving affective reassurance to people diagnosed with AMD. It is possible that being comforted and receiving sympathy from a HCP for a diagnosis of a condition that may cause significant vision loss, might lead pwAMD to feel more worried and negative about their future with AMD. These negative perceptions could impact on the individual's beliefs about what they can and cannot do (their self-efficacy), their functioning and ultimately their well-being. Building a rapport with patients could be seen as distressing for people with untreatable AMD who are only seen once in the diagnostic consultation and are then discharged. However it must be noted that for many people being diagnosed with AMD comes as a shock (Beverley et al., 2007; Hodge et al., 2013; Thurston et al., 2010). Thus pwAMD are likely to benefit from seeing a HCP who is attentive to their emotional and information needs. The interaction between cognitive reassurance (giving information and checking patient's understanding of the information) and affective reassurance is poorly understood (Pincus et al., 2013). It may be that showing empathy for the patient's concerns as well as providing information on the likely progress of their macular condition and what they can do to prevent further deterioration, may be associated with high patient satisfaction and positive long-term outcomes such as better visual acuity and functioning.

Compared to the 1999 survey responses, more 2013 survey respondents reported being told that nothing could be done to help with their macular condition and not being told the name of their macular condition. However, when prompted using the closed tick-box question, more 2013 survey respondents reported being given the name of their macular condition than the 1999 survey respondents. Further examination of the free-text responses indicated that those first diagnosed by an eye specialist were more likely to report that they had been told that nothing could be done to help with their macular condition compared with those diagnosed by an optometrist. Those first diagnosed by an optometrist were more likely to state that they had not been told the name of their macular condition. Some of these findings are supported by the results from the closed tick-box responses. Optometrists were less likely to give the name of the macular condition than hospital eye specialists. Optometrists may spot the signs of AMD but refer on to a hospital eye specialist for confirmation of diagnosis, and therefore be reluctant to name the condition. Once confirmed by a hospital eye specialist, the specialist will have the equipment to be able to confirm the type of AMD and determine whether medical treatment is available for the condition. They are in a position to be able to inform patients that there is no medical treatment available for the patient's type of AMD. Thus the responses are in line with the roles of these ECPs. Mitchell et al. (2002) report patients' emotional reactions to being told that "nothing can be done". Fifty four respondents to the 1999 MDSQ reported feeling suicidal after being told this. It is worth noting that although medical treatment may be unavailable for some types of AMD, there are other types of resources that can be used to help adjustment to sight loss, including low-vision aid provision and training. Being given information on how to access low-vision services might prevent patients from leaving the consultation without hope or control over their future with AMD. Additionally, being told that "nothing can be done" may cause a delay to help-seeking for people who notice changes in their vision that might be associated with untreatable dry AMD changing to treatable wet AMD. Thetford et al. (2009) report that people who were told that there was nothing that could be done for their sight loss were less likely to go to future eye tests as it was assumed that there was no reason to go to the tests. Indeed the 2009 RCOphth guidelines recommend avoiding using the phrase "nothing can be done" in consultations.

The 2013 survey respondents reported similar reasons for dissatisfaction with the diagnostic consultation as those surveyed 14 years before. The reasons why ECPs still appear not to be providing information and support remain to be investigated. Some of the new reasons for satisfaction and dissatisfaction found in the 2013 survey may reflect the introduction of anti-VEGF treatment for some types of wet AMD. Respondents reported being dissatisfied due to delays to diagnosis or starting treatment, thus they may be aware of the urgency of receiving a diagnosis so that medical treatment, if available, can begin as soon as possible to reduce sight loss. The third most commonly cited reason for satisfaction was the prevention of delay. These findings suggest that patients appreciate their condition being taken seriously. There was no indication that urgency increased anxiety or worry. Although some respondents reported satisfaction due to being referred to a GP, it is possible that patients are unaware that this is an unnecessary step in referral for confirmation of diagnosis and causes delays that may result in serious sight loss. Clearly there is still a need to inform optometrists that such a referral to a GP is no longer necessary and may cause dangerous delays that threaten sight. It may also be beneficial to inform patients and the general public so that they are empowered to contest referral back to their GP if their optometrist suggests this is required for diagnosis.

One reason for dissatisfaction provided in both the 1999 and 2013 surveys was the lack of a follow-up consultation. The RCOphth 2009 guidelines recommend that ophthalmologists avoid ‘diagnose and immediate discharge’. Some of the 2013 survey respondents reported satisfaction due to being offered a follow-up consultation. The responses do not provide information on whether these follow-up appointments were offered for treatment, but it is clear that respondents were pleased that this had been offered to them. Now that there is treatment available for some forms of AMD, patients may be wary of deterioration in sight and understand the need to monitor their sight for changes. A follow-up consultation may help to reassure patients that their sight will be monitored and may also provide the opportunity to ask for further information post-diagnosis. The surveys did not ask respondents directly if they had received a follow-up appointment following diagnosis. It is possible that respondents received important information and support in this second consultation, and that the results reported here are an underestimation of the information provided by ECPs.

There has yet to be a study which examines the psychological impact of diagnosis of early AMD. Evidence exists to show that patients diagnosed with treatable wet AMD are more likely to have better visual outcomes if treated earlier on (Ying, Huang, Jaffe et al., 2013; Rauch, Weingessel, Maca et al., 2012), and thus spotting wet AMD at an earlier stage is likely to lead to better visual outcomes. There is currently no evidence to show the benefit of early diagnosis for dry or untreatable wet AMD. However, as discussed, providing information and support both at diagnosis and after diagnosis may help patients to implement behaviours that could help maintain vision (stopping smoking, taking AREDS 2 supplements) and ADLs (by being referred early to low-vision services), as well as being educated in how to monitor for changes in vision so that they can detect deterioration and seek medical treatment quickly if necessary. Whether the benefits of this outweigh possible negative psychological impacts (increased worry about whether they will go blind) have yet to be investigated, but it is likely that information and support will help patients with early AMD to feel more in control and able to manage their condition. Evidence from the present study suggests that pwAMD valued early detection as they appreciated the speed with which they were referred for diagnosis and thus establishing whether AMD is treatable with anti-VEGF may be paramount.

A greater proportion of respondents who were satisfied with the diagnostic consultation than those who were dissatisfied left the free-text response for reasons for satisfaction or dissatisfaction missing. Whilst the 1999 survey asked for reasons for dissatisfaction only, the 2013 survey asked for reasons for satisfaction as well as dissatisfaction and this question was added to explore causes of satisfaction. The lack of written reasons for satisfaction may show that respondents did not have a particular reason for satisfaction, but there was nothing in particular that caused them to be dissatisfied with the consultation. It may be easier to leave a response blank when one might not be required- reporting being dissatisfied might be perceived as needing justification whereas satisfaction may not. It is possible that adding this response option may have caused some participants who remember being dissatisfied with the consultation but could not think of a particular reason why, to change their response to reporting satisfaction with the diagnostic consultation. Thus there may be a falsely high number of people reporting satisfaction in the 2013 survey. That there was a high number of respondents reporting not receiving information and support in the closed tick-box responses suggests that when prompted, respondents can recall aspects of the consultation that are linked to reasons for dissatisfaction.

The comparisons between the 1999 and 2013 samples or within the 2013 sample between those diagnosed by an optometrist or hospital eye specialist, must be interpreted with caution since these were free-text box responses and respondents were unprompted for specific reasons for satisfaction or dissatisfaction with the consultation. The closed tick-box responses may provide a more valid comparison between these groups.

A further note of caution to make in the comparisons between the 1999 and 2013 survey responses: the survey responses were coded by different coders and it is possible that the coders may have had different interpretations of the responses. The free-text responses from the 1999 survey were unfortunately not available for checking that similar responses would be coded similarly; only the codes representing how the responses had been coded were available.

Hallucinations

The publication of the RCOphth guidelines in 2009 were not associated with an increase in pwAMD being informed, around the time of diagnosis, about the possibility of experiencing visual hallucinations as a side effect of sight loss. Of respondents who experienced hallucinations, 74% reported not having received information about hallucinations around the time of diagnosis. Against expectations, the respondents who weren't given information on hallucinations around the time of diagnosis and who later experienced hallucinations, were less likely to have talked to a HCP about their hallucinations than those who had received information about them around the time of diagnosis. Perhaps respondents who had previously discussed hallucinations with a HCP felt more comfortable raising the issue with them at a later point. Concern that the cause of the hallucination/s may be due to a serious mental illness (e.g. dementia) may be a barrier to people with CBS seeking help (Menon, 2005). Alternatively it may be that respondents who had unsatisfactory experiences with HCPs and who didn't receive information from them around the time of diagnosis were less likely to seek information and support from them later on.

Many researchers have found that people experiencing hallucinations derive reassurance from being told about CBS and its cause (e.g.Abbott, Connor, Artes, & Abadi, 2007; Cox & ffytche, 2014; Menon, 2005; Teunisse, Cruysberg, Hoefnagels, Verbeek, & Zitman, 1996), and indeed the RCOphth guidelines recommend that information on hallucinations should be provided to patients with AMD. In the present study, respondents who experienced hallucinations and who were given information on them around the time of diagnosis were not more likely to report better general QoL, MD-specific QoL, or well-being at the time of survey completion, than those who didn't receive this information. Thus information provision about hallucinations around the time of diagnosis may not make a difference to these patient-reported outcomes (PROs) an average of six years later. Of the respondents who didn't receive information on hallucinations at diagnosis, those who later spoke to a HCP about them were also not more likely to have better QoL or well-being than respondents who didn’t speak to a HCP about their hallucination/s. This suggests that information provision around the time of experiencing hallucinations may also not be beneficial. Further investigation to see if receiving a cause for the hallucination affected QoL or well-being also found no difference between those given and those not given a cause.

Given that the research described above found that people tend to be reassured by receiving information on CBS, it is a surprising finding from this study that respondents who reported receiving information on hallucinations around the time of diagnosis and who also later spoke to a HCP about them, were more likely to report poorer QoL and well-being than those who didn’t speak to a HCP about them later. Those who spoke to a HCP about hallucinations were not more likely to have better QoL or well-being if they were given a cause for the hallucinations. Thus the information provided in the consultation may not be the cause of the difference in QoL and well-being between those who spoke to a HCP about their hallucinations and those who didn’t.

That the respondents who spoke to a HCP about their hallucinations even after being told about hallucinations at diagnosis, had poorer QoL and well-being than those who didn’t seek further help might be due to these respondents experiencing hallucinations which were having a more negative impact on their life. Indeed Cox and ffytche (2014) found that respondents who reported that hallucinations had a negative effect on their life were more likely to seek support. That there were no significant differences in MD-specific QoL between those who saw a HCP later on and those who didn’t may be due to them experiencing hallucinations that were causing poorer MD-specific QoL which improved after seeing the HCP, whereas the PROs that were not MD-specific were not able to show this improvement. Alternatively, it may be that poorer general health drove the appointment to see a HCP in which hallucinations happened to be discussed. Poorer general health may be linked to poorer well-being and quality of life, but not MD-specific QoL, but it was not controlled for in the analyses reported here.

The reasons for the findings reported here may be complex and warrant further study. Present QoL, MD-specific QoL and well-being were the main PROs used in this study. Perhaps more specific measures assessing changes in anxiety about hallucinations or adjustment to coping with sight loss may be more sensitive to detect the impact of information provision.

In this cross-sectional study it is impossible to determine cause and effect. One should be aware of the problems of making causal assumptions. Perhaps the information provided, or the interaction with the HCP led to poorer QoL and well-being. Perhaps the finding that those who were told by a HCP about the possibility of experiencing hallucinations were more likely to talk to a HCP about them later when experiencing hallucinations themselves, may be due to not having initially received a satisfactory explanation for them, and this is the cause of poorer QoL and well-being. For the respondents who later spoke to a HCP about the hallucinations, almost all causes for hallucinations given were accurate and one might hypothesise that receiving an accurate explanation for the hallucinations would lead to better PROs. However there were no significant differences in QoL or well-being between respondents who stated they received an explanation and those who didn't. Perhaps those who didn't receive an explanation from a HCP were more likely to seek information elsewhere, however this was not measured in the current study. The source of the information may therefore be an important indicator of how patients cope with CBS. As mentioned above, we only measured PROs at the time of survey completion. Assessing changes in PROs before and after information seeking may provide a clearer picture of how discussions on hallucinations with HCPs impact on patient's understanding and adjustment to experiencing hallucinations.

A strength of this study is the inclusion of pwAMD who hadn't experienced hallucinations and being able to see the effect of information provision on those not yet affected by personal experience of hallucinations. Of respondents who hadn't reported hallucinations, those who were informed about them around the time of diagnosis did not have significantly different QoL or well-being at the time of survey completion than those not informed about them. Therefore, although the results suggest that information provision on hallucinations around the time of diagnosis may not have beneficial long-term effects on QoL and well-being, the results may also provide evidence that provision of this information does not lead to negative effects in those who haven't yet experienced them, such as increased worry or anxiety about hallucinations.

There are limitations that require noting. The survey respondents were Macular Society members and had sought out the society for further help and support after diagnosis. They may be more proactive in seeking further information than the general AMD population or have read about CBS in Macular Society publications, and thus be more informed about them. The survey did not measure respondent's knowledge of CBS and if they received information on them from elsewhere. Thus we do not know if respondents received accurate information on CBS from other sources after diagnosis. Those who sought and/or received accurate information on hallucinations may be reassured and this may have impacted on the PROs.

There are other factors that may have influenced information seeking or the PROs and that weren't controlled for in the analysis. In addition to the factors mentioned above (i.e. experiencing more distressing hallucinations linked to information seeking, poorer general health), the analyses did not take into account the severity of sight loss, which may be associated with the likelihood of experiencing hallucinations, QoL and well-being.

Similar to Cox and ffytche (2014), the survey method used here asked respondents to self-report whether they experienced hallucinations. Respondents provided descriptions of their hallucinations which were reviewed by the author who consulted an ophthalmologist about the range of manifestations of CBS. Respondents whose descriptions were not consistent with CBS were filtered out of the analyses, and this was determined, in part, by the choice of words used by the respondent to describe their CBS. Thus there may have been some respondents who experienced hallucinations but were removed from the analyses. ECPs may face a similar problem in their consultations. At present, there is no formal criteria available to help ECPs to recognise and formally diagnose CBS (personal communication with W. Amoaku, 20th March 2017). Diagnosis is based on the patient's description and the ECP's knowledge of CBS. This point shows the similarities between the method used in the survey and practice in real-life consultations. It helps to highlight how the language used to describe hallucinations in a consultation may determine HCPs recognition of CBS and how they discuss it thereafter.

The self-report survey method meant that the cause of the hallucinations may not have been confirmed by a HCP as being due to CBS. Hallucinations may instead be due to other causes, such as dementia.

The present study found that respondents who lived alone were more likely to report CBS. This supports previous findings that those who live alone are more predisposed to hallucinations, and this has been explained by low levels of arousal and sensory deprivation being a trigger for CBS (e.g.Teunisse et al., 1996). The present study was the first to find that respondents who reported having a caregiver were more likely to report hallucinations. Perhaps respondents who experience hallucinations and are distressed by them are more likely to ask for or receive support from friends and family. A cautionary note, however, that it may be that registration status is associated with both hallucinations and receiving care for AMD and this wasn't adjusted for in the analysis of the results reported here.

Previous research suggests that people may be reluctant to admit experiencing visual hallucinations for fear of being labelled as 'insane' or 'psychiatrically unstable' (e.g.Menon, 2005; Mosimann et al., 2008). Despite assurance of the anonymity of the surveys, some respondents may have been reluctant to admit having experienced hallucinations. Thus there may be under-reporting of hallucinations in the results presented here.

Fewer of the 2013 survey respondents than the 1999 respondents spoke to a HCP about hallucinations and this finding may suggest that the more recent survey respondents are more informed about hallucinations. This seems unlikely to be due to HCPs providing information about them as the results show no significant increases in provision of this information around the time of diagnosis, since the 2002 paper or 2009 RCOphth guidelines. As mentioned above, the sample were Macular Society members who may have found out about hallucinations from membership magazines, local support groups and/or the national conference and may therefore have not needed to seek information from a HCP. However there may be other reasons why fewer of the 2013 survey respondents than the 1999 sample spoke to a HCP about hallucinations. The 2013 sample were, on average, older than the 1999 sample. Dementia is associated with older age (van der Flier & Scheltens, 2005). It is possible that the 2013 sample may have been more concerned about the cause of visual hallucinations being due to dementia and were worried about receiving a diagnosis of dementia if they sought medical help. Alternatively it could be that greater pressure on eye clinics since the introduction of anti-VEGF injections in 2008 meant that patients were reluctant to seek help from ECPs, for example, because of worry about taking up their time.

The present study did not ask which HCP the respondent had seen about hallucinations, and this may have affected whether respondents were given a cause for the hallucinations and the accuracy of the explanation given. For example, ophthalmologists who may have read the RCOphth 2009 guidelines and are aware of CBS, may be in a position to recognise hallucinations when they occur and provide an accurate explanation for them as well as reassurance as to their benign cause. On the other hand, GPs may not have heard of CBS and thus may not have been able to give an accurate and reassuring explanation.

The survey did not ask if the explanations provided for hallucinations were satisfactory. This might be inferred from one respondent's response, who wrote, "I was told it happens to us VIP's [visually impaired persons] not the cause". Whether respondents received a satisfactory explanation for the hallucination/s may impact on their adjustment to them, leading to better QoL and well-being. Future research might usefully examine how information on hallucinations is discussed in consultations to see if HCPs are able to diagnose CBS accurately and give information in a way that is acceptable to patients.

Further information and support

The majority of the results reported above were for experiences in or around the time of the diagnostic consultation. Many patients may not be offered a follow-up appointment after the initial diagnostic consultation, particularly if no medical or surgical treatment is available for their macular condition. Thus it was important to investigate if patients are receiving further information and support, the sources of this support, and whether this support met their needs. There were some positive findings. Ninety six percent of respondents reported having seen a ECP about their macular condition in the past year, or not having a need to see one. A greater proportion of 2013 survey respondents than the 1999 respondents, reported membership of a local group for people with macular conditions. The benefits of membership of a peer support group have been reported elsewhere (e.g.Bradley et al., 2005).

However there is still room for improvement for many aspects of help and support for pwAMD post-diagnosis. Some respondents reported barriers to seeking help from a ECP about their macular condition. This included feeling that ECPs were not interested in their condition or that nothing could be done to help. Some reported having to wait for a referral from the GP to access the eye clinic. Some respondents stated specifically that they would like reassurance from a ECP who continued to monitor their sight. Previous research has also found that AMD patients expressed a desire for regular monitoring by HCPs (Burton et al., 2013). Knowing that they were under the care of a hospital may give a sense of security that their sight is being monitored, and perhaps indicates patients' lack of confidence in noticing changes in their vision.

Although a high proportion of respondents reported receiving further information about their macular condition after diagnosis, there were still 17% of respondents who did not receive any information on their condition. This is despite these respondents being members of the Macular Society. This may indicate that these respondents aren't receiving information and support to meet their needs.

Around 60% of the 2013 survey respondents had not been to a LVC. This may be due in part to a low proportion of the respondents being registered as SI or SSI. Registration triggers an assessment of needs from the local social services. However it is advised that HCPs should not wait until an individual's sight has deteriorated enough to warrant registration before referring to low-vision and rehabilitation services (RCOphth, 2009). Two hundred and twenty-seven respondents reported that they would like to attend a LVC. The reasons why respondents had not been to a LVC were not investigated in this study. Perhaps individuals did not know about the low- vision services available to them, or they do not know how to access these services. Perhaps they had tried to access the services but they were unavailable. The majority of respondents who had been to a LVC reported being 'satisfied' or 'slightly satisfied' with the clinic. This may suggest that these respondents' needs were met by this service, and that those who reported wanting to go to a LVC could also benefit from this service. The reasons why 40 respondents felt dissatisfied with the LVC remain to be examined, and suggest there may be some room for improvement in the service provided.

Around 96% of respondents reported that they had never been offered psychological support from the hospital or eye clinic. This is despite many pwAMD reporting being shocked and worried after a diagnosis of AMD (Hodge et al., 2013). Indeed, just over 30% of respondents reported that would have liked to have received psychological support at the time of diagnosis, and this emphasises the impact of diagnosis of AMD on mental health. There were considerably fewer respondents who reported having liked to have received psychological support at the time of survey completion (10%), however this is still a considerable number of people and shows the longer-term effects of AMD. It is possible that these figures reflect an under-reporting of the actual number of respondents needing psychological support. Some respondents may have been completing the questionnaire with a friend or family member and may not have wanted them to be aware of their need for psychological support. The availability of formal services that provide emotional support for people with low-vision are not generally provided in a hospital eye clinic, but may be available through low-vision services. Ophthalmologists, optometrists and GPs should be in a position to inform their patients about how to contact these services if the need arises.

General methodological points on the survey

The response rate to the 2013 survey was low, but was not dissimilar to that of other surveys including the last nationwide General Practice patient survey (35.7% for 2015,Ipsos, 2016) and the Macular Society's survey the previous year (31% response rate, Cox & ffytche, 2014). One might question the representativeness of the survey sample. Individuals may have joined the Macular Society because they had unsatisfactory experiences in their diagnostic consultations and sought information and support elsewhere. Conversely, this sample may have received information about the Macular Society in the diagnostic consultation more often than the general AMD population and thus be more satisfied. Members may have higher expectations of information and support than the general AMD population and be more likely to request information at diagnosis, if it is not offered. There has yet to be a large, geographically representative population study of AMD in the UK that could be used to estimate the representativeness of the sample. Additionally, no socio-demographic information was available on the non-responders to the survey to help estimate the representativeness of the final sample. As the most common reason stated by the 'non-responders' who returned paperwork was 'old age', followed by 'ill health', it is possible that those younger and in better general health are over-represented in the 2013 survey. However the 2013 sample were on average older than the 1999 sample, and thus there seems not to be an over-representation of younger people in this sample. In comparison, non-responders to the 1999 survey cited 'ill health' or 'visual impairment' as the most common reasons for non-response. There were significantly fewer respondents registered as SI or SSI in the 2013 sample compared to the 1999 sample, perhaps due to the introduction of treatment for some forms of AMD in 2008 leading to better visual outcomes. Consequently, age and registration status were controlled for in the multivariable analyses comparing responses from the 1999 and 2013 samples.

Respondents were asked to reflect on their experiences at diagnosis and this may be subject to recall bias. The use of survey methodology retrospectively to investigate patient experiences in consultations has been previously reported (Douglas et al., 2010). Being diagnosed with a condition that could lead to sight loss was shown in the telephone survey completion interviews to be a particularly memorable event for most people. The literature on autobiographical memory suggests that women recall more details than men (Grysman, Fivush, Merrill, & Graci, 2016). In this study however, men were more likely to report receiving several aspects of information and support provision than were women. This suggests that recall bias was not the main problem here but, rather, women may have received less information and support than men. The information that patients recall from their diagnostic consultation, even if asked years later, may still be relevant and important particularly for AMD where only a small minority of patients are seen repeatedly – those receiving, or being monitored for anti-VEGF treatment for wet AMD.

Summary

The Macular Society 2013 survey results showed that patients diagnosed with AMD since the previous 1999 survey reported better experiences at diagnostic consultation. Overall satisfaction with the diagnostic consultation improved following publication of the RCOphth guidelines. However information and support provision at diagnosis remained low. There were also no significant improvements in information and support provision associated with the publication of the 1999 survey results. In free-text responses, the top two reasons for dissatisfaction with the diagnostic consultation reported by the 1999 sample remained the same for the 2013 sample. Reasons for dissatisfaction included a lack of information or advice given (about condition, prognosis, further help) and poor HCP attitude (seen as dismissive, patronising, unfeeling). The top reason for satisfaction with the consultation was having received information on the condition, demonstrating the importance that pwAMD place on receiving information and support to help them manage their AMD.

There were notable sex and age differences in provision of information and support. Women reported receiving less information and support than men, and older respondents reported receiving less information but more help and support, and were more likely to report overall satisfaction with the consultation. Importantly, a lack of information provision on what to do if one experiences a sudden deterioration in vision was associated with being registered as SI or SSI. This demonstrates the need for this information to be given to pwAMD.

Experiences with GPs were not much better. Reports of GP knowledge of AMD remain low, and the 2013 survey respondents reported receiving lower levels of help and support from GPs than the 1999 sample. This chapter reports on several other areas where information and support provision to pwAMD could be improved after diagnosis, e.g. referral to psychological support or to a LVC. Thus the results reported in this chapter highlight the lack of information and support provided to pwAMD during and after the diagnostic consultation, and provide suggestions for how this could be improved. The next chapter investigates support received from other sources; pwAMDs' family and friends.

Chapter 4

Receiving support for AMD: results from the Macular Society 2013 survey.

Introduction

There has been very little research examining the receipt of informal care and support in people with AMD (pwAMD). Several questions in the Macular Society 2013 survey were designed to explore this. In particular, this study aimed to investigate how many pwAMD receive support for AMD, who provides this support, the amount of support received and the relationship between receiving this support and the patient-reported outcomes of general and MD-specific quality of life (QoL) and well-being. Chapter 2 provides a description of the study methods including details of the survey design and procedure. Chapter 3 provides the 2013 survey respondent characteristics. The results from the 2013 survey on support received for AMD from family and friends are reported in this chapter.

Data analysis

Frequencies, means and medians were used to describe the socio-demographic, eye- and health-related characteristics, and support-related characteristics of the sample. Descriptive statistics were analysed for living circumstances (living alone or with other/s), age, gender, registration status (objective VI), self-assessed change in vision since diagnosis (better/ stayed the same/ worse, henceforth 'subjective VI'), general health status, whether respondents received care or not and if so, who provided this care and the amount of care they received. The patient-reported outcome variables of interest were well-being and generic and MD-specific QoL. First I explored differences in respondent characteristics between respondents who reported receiving care with those who didn't, and of the former we also examined differences between respondents who reported receiving different amounts of care. Then each independent variable was assessed to see if it was significantly associated with QoL and well-being. These analyses were run using Pearson Chi-squared analyses (χ^2), Mann-Whitney, Kruskal-Wallis tests and Spearman's or point-biserial correlations, as appropriate. Effect sizes are reported for significant results. Post-hoc tests were carried out to evaluate significant results.

A hierarchical multiple regression was conducted to test the hypothesis that the socio-demographic, health- and eye-related variables were associated with QoL and well-being. This analysis assessed the unique contribution that having a caregiver made to the QoL and well-being outcome variables, after covariates had been controlled for. The variables were entered in blocks, so that each block of variables could be examined for their additional contribution to the variance. First, separate regressions were carried out for each dependent variable (well-being, generic QoL and MD-specific QoL) to see if having a caregiver was associated with each dependent variable. Then those who reported receiving care were selected and entered into regressions to see if the amount of care received was associated with the three dependent variables. These analyses controlled for the relationship of the caregiver to the pwAMD (i.e. spouse, adult-offspring or 'other' type of relationship to the pwAMD). A multivariate analysis of covariance (MANCOVA), which would include the three dependent variables in one analysis and would control for type I familywise error, could not have been used since the independent variables were not independent of each other.

The usual rule of thumb for multiple regression is a minimum of 15 cases per 'predictor' (i.e. independent variable). A sufficient sample size is needed to have enough power to detect small effect sizes. The multiple regression with the largest number of variables had nine independent variables and thus would require a sample size of at least 135 participants.

All analyses were conducted in SPSS version 21.0.

Missing data

For continuity with the results presented in Chapter 3, this study included only the 2013 survey respondents who were diagnosed with AMD and were aged over 50 at the time of diagnosis. The same data imputation methods were used to assist the selection of respondents, as shown in Figure 2.1 in Chapter 2.

First, there were missing data from 39 respondents (2.8%) for whether or not they had a caregiver. Twenty eight respondents had left this question and the following questions on the details of the caregiver completely blank. It was considered inappropriate to impute data for this variable as there were no other variables that could be used to predict the missing data reliably. Eleven (0.8%) had chosen not to tick a response but wrote an answer instead. Of the 770 participants who reported receiving care, there were 86 (11.2%) with missing data on how much care they receive. Forty seven of these had left their answer blank. Twenty nine respondents instead chose to write an answer. This included receiving help ‘when necessary’, ‘occasionally’, ‘variable’ or ‘don’t know’. Ten wrote ‘not applicable’ despite having ticked the box to say that they receive care. Perhaps this was due to difficulty distinguishing support from care, for instance one participant wrote ‘*All my friends & family are very supportive & helpful, but I have no designated carer*.’ Imputation of missing data was considered to be guesswork. Since the sample size was sufficiently powered for the analysis, it was decided to avoid this guesswork and remove these participants from the analyses.

The ‘self-assessed change in vision since diagnosis’ variable (subjective VI) had missing data for 75 (5.3%) respondents. A dummy variable was constructed, assigning a value of 1 to those data that were missing and a value of 0 to those not missing. Mann-Whitney tests found no significant differences on the dependent variables of well-being and QoL between those participants with and without missing data for subjective VI. Therefore missingness was not related to the dependent variables and decisions on how to proceed are not so critical (Tabachnick & Fidell, 2014). There was a significant relationship between the ‘change in vision since diagnosis’ and ‘registration status’ variables ($r_s = 0.29$, $p<0.001$) however this was not strong enough to assist with imputation of missing values. Since there were no appropriate variables to help predict values for imputation of missing data, those participants with missing data for the ‘change in vision since diagnosis’ variable were removed from the analyses.

The W-BQ16 had the largest amount of missing data. The guidelines for the treatment of missing scores were followed (Mitchell & Bradley, 2001). If only one item was missing from a subscale, then this was imputed using the average score from the other scores in the subscale. If more than one score was missing, then the score and that subscale were left blank. Nevertheless there was still a large amount of missing data, the greatest being for the ‘energy’ subscale for which 107 participants had missing scores. There were smaller but still significant amounts of missing data for the ‘negative well-being’ subscale (n=93), the ‘stress’ subscale (n=87) and the ‘positive well-being’ subscale (n=72). In order that the reliability of the scale does not drop below an acceptable level, the guidelines suggest that a total well-being score should not be computed if participants have more than one subscale with an estimated score, or more than one item missing so that a subscale score cannot be computed. There were 158 (11.2%) participants with missing total well-being scores. There were no other variables that could be used to predict missing scores reliably.

A dummy variable was constructed to see if those who had missing total well-being scores were different from those who had these scores. Those with missing scores were more likely to be older, be registered as sight impaired and be female. There were no significant differences on the other socio-demographic, eye- and health-related variables. There was no significant difference in whether or not these respondents were more or less likely to report receiving care, the amount of care received or who provided the support. Bivariate analysis of the impact of the independent variables on the dependent variables was run with and without the respondents with missing data on well-being, generic QoL and MD-specific QoL. There were no differences in the results, and running the multivariate analysis with and without the respondents with missing data also showed no differences in the results.

Respondents were asked to state their relationship with their caregiver (if applicable). There were missing data for 9 respondents. Respondents could identify more than one caregiver, in which case the first response stated was taken as the primary (main) person who provides care.

There were small amounts of missing data for other variables, as follows: general health (n=11,0.8%), gender (n=2,0.1%), living circumstances (n=16,1.1%), and registration status (n=9, 0.6%). There were small amounts of missing data on the outcome variables of generic QoL (n=9, 0.6%) and MD-specific QoL (n=9, 0.6%) (both are single-item measures).

The analyses included respondents who had data for all variables, which left 1067 respondents for use in analysis.

Data screening

For bivariate analysis, non-parametric tests were used due to significant skewness (at $p<0.001$) for the variables of age at survey completion (standardised skewness score=-5.67) and the dependent variables of MD-specific QoL, general QoL and well-being (standardised skewness scores= 8.27, -6.21 and -8.39, respectively). The MD-specific QoL and general QoL items also showed significant kurtosis (standardised kurtosis scores of -5.40 and 3.27, respectively).

Evaluation of the assumptions of multiple regression were tested through residual analysis.

There were no correlations between independent variables that were over 0.7. There were no issues of multicollinearity as indicated by no variance inflation factors (VIF values) over 10 (scores ranged from 1.04 to 3.26), and no tolerance values under 0.1 (scores ranged from 0.31 to 0.96). There were no indications of singularity.

Partial regression plots and a plot of studentised residuals against the predicted values revealed no problems of nonlinearity. There was independence of residuals, as assessed by the Durbin-Watson statistic of around 2 for all analyses. Visual inspection of plots of studentised residuals against unstandardised predicted values showed homoscedasticity. The assumption of normality was met for the majority of analyses, as assessed by the aforementioned plots plus Q-Q plots of studentised residuals. The MD-specific QoL item showed positive skewness. Multivariate analyses were repeated with this variable transformed (using logarithmic, square root and inverse transformations), however this did not improve the model. No transformation improved both skewness and kurtosis values. Therefore the results presented below are for the MD-specific QoL item in its original form.

Fewer than 1% of standardised residuals had standard deviations greater than ±3.3. These were checked for accuracy of data entry and it was concluded that scores were legitimate. In a large sample there are more likely to be a few outliers (Tabachnick & Fidell, 2014). These respondents were included in the analysis since no Cook's distance values were above 1 indicating that no respondents were exerting a disproportionately large influence on the model.

RESULTS

Sample characteristics

Completed surveys were returned by 1545 respondents out of the 4000. Telephone completions by 26 gave a total sample size of 1571 for the 2013 sample (a 39% response rate). A further 267 uncompleted surveys were returned, with reasons for non-completion, giving a gross response rate of 46%. The most common reason given for non-completion was ‘old age’, followed by ‘ill health’.

Descriptive results

The majority of respondents reported receiving unpaid care, support or assistance for AMD (n= 558, 52.3%). For characteristics of the respondents who reported receiving care and those who didn’t, see Table 4.1. Large adjusted standardised residuals (over 2) indicate where cells deviate from independence and provide evidence against the null hypothesis (see Beasley & Schumacker, 1995).

Table 4.1. Respondent characteristics for those who reported receiving care and those who didn't. Values are frequencies (valid percentage %) unless otherwise stated. Adjusted standardised residuals are shown in square brackets†.

Variables		**Respondents who don't receive care (n= 509)**	**Respondents who receive care (n= 558)**	**statistic, p value, effect size.**
Gender	Male	149 (29.3%) [-2.0]	195 (34.9%) [2.0]	χ^2 (1)=3.92, p=0.048*: phi= -0.06.
	Female	360 (70.7%) [2.0]	363 (65.1%) [-2.0]	
Age at survey completion (years)	Mean (SD)	77.83 (8.32)	81.87 (7.23)	*U*=183,005.00, z= 8.16, p<0.001***.
	Median	78.00	83.00	
Registration status	Not registered	454 (89.2%) [14.5]	265 (47.5%) [-14.5]	χ^2 (2)=214.25, p<0.001***: Cramer's V= 0.45.
	Registered sight impaired (SI)/ partially sighted	45 (8.8%) [-9.8]	187 (33.5%) [9.8]	
	Registered severely sight impaired (SSI)/ blind	10 (2.0%) [-8.9]	106 (19.0%) [8.9]	
Self-assessed change in vision since diagnosis	Better	62 (12.2%) [-0.3]	71 (12.7%) [0.3]	χ^2 (2)=69.32, p<0.001***: Cramer's V= 0.26.
	Stayed the same	215 (42.2%) [8.1]	108 (19.4%) [-8.1]	
	Worse	232 (45.6%) [-7.4]	379 (67.9%) [7.4]	
	Mean (SD)	2.72 (1.03)	3.10 (1.11)	

General health status[≠]	Median	3.00	3.00	*U*=169,055.50, z= 5.60, p<0.001***.
Living circumstances	Live with other/s	255 (50.1%) [-4.1]	349 (62.5%) [4.1]	χ^2 (1)=16.79, p<0.001***: phi= -0.13.
	Live alone	254 (49.9%) [4.1]	209 (37.5%) [-4.1]	

*p<0.05, **p<0.01, ***p<0.001. [†] Adjusted standardised residuals over 2 show where expected frequencies are significantly different from their observed frequencies and therefore indicate which cells are non-independent of each other (i.e. the variables are significantly related to each other). Negative residuals indicate a lower observed frequency than expected given the null hypothesis of independence. Positive residuals indicate a higher observed frequency than expected. [≠] Higher scores indicate poorer self-rated health.

Respondents who reported receiving care were more likely to be registered as SI or SSI than those not receiving care. Of the respondents who received care, 379 reported their sight was ‘worse’ since diagnosis compared to the expected count of 320 if the null hypothesis was true (that change in vision was unrelated to receiving care). They were more likely to report their sight had become ‘worse’ since diagnosis and were less likely to report it had stayed ‘the same’ than those not receiving care. Male respondents were more likely than expected to report receiving care for AMD. Older respondents and those who were living with someone else were more likely to report receiving care. Those who received care for AMD were more likely than those not receiving care to report poorer general health.

Of those respondents who reported receiving care, the majority reported receiving ‘fewer than 7 hours per week’ of care (n=262, 47%). Almost half as many reported receiving ‘more than 35 hours of care per week’ (n=128). One hundred and twenty-seven respondents reported receiving ‘7 to 14 hours a week’, whilst only 41 respondents reported receiving ’15 to 35 hours’ of care a week.

Table 4.2 shows the characteristics of the respondents who reported receiving different amounts of care for AMD. The adjusted standardised residuals indicate where the significant differences lie (i.e. where there are associations between the two variables that contribute to the significant chi-square result).

Table 4.2. Comparison of respondent characteristics between each group reporting receiving different amounts of care for AMD. Values are frequencies (valid percentage %) unless otherwise stated. Adjusted standardised residuals are shown in square brackets[†].

Variables		**Fewer than 7 hours per week (n=262)**	**7 to 14 hours (n=127)**	**15 to 35 hours (n=41)**	**More than 35 hours per week (n=128)**	**Statistic, p value: effect size.**
Gender	Male	75 (28.6%) [-2.9]	45 (35.4%) [0.1]	18 (43.9%) [1.2]	57 (44.5%) [2.6]	χ^2 (3)=11.24, p=0.01*. Cramer's V=0.14.
	Female	187 (71.4%) [2.9]	82 (64.6%) [-0.1]	23 (56.1%) [-1.2]	71 (55.5%) [-2.6]	
Age at survey completion (years)	Mean (SD)	82.01 (7.39)	82.48 (7.05)	81.37 (7.66)	81.12 (6.92)	*H* (3)= 3.55, *p*=0.31.
	Median	83.00	84.00	83.00	82.00	
Registration status	Not registered	162 (61.8%) [6.4]	46 (36.2%) [-2.9]	9 (22.0%) [-3.4]	48 (37.5%) [-2.6]	χ^2 (6)=44.58, p<0.001***: Cramer's V=0.20.
	Registered sight impaired (SI)/ partially sighted	64 (24.4%) [-4.3]	54 (42.5%) [2.4]	20 (48.8%) [2.2]	49 (38.3%) [1.3]	

	Registered severely sight impaired (SSI)/ blind	36 (13.7%) [-3.0]	27 (21.3%) [0.7]	12 (29.3%) [1.7]	31 (24.2%) [1.7]	
Self-assessed change in vision since diagnosis	Better	51 (19.5%) [4.5]	8 (6.3%) [-2.5]	1 (2.4%) [-2.1]	11 (8.6%) [-1.6]	χ^2 (6)=26.68, p<0.001***: Cramer's V=0.16.
	Stayed the same	54 (20.6%) [0.7]	26 (20.5%) [0.4]	4 (9.8%) [-1.6]	24 (18.8%) [-0.2]	
	Worse	157 (59.9%) [-3.8]	93 (73.2%) [1.5]	36 (87.8%) [2.8]	93 (72.7%) [1.3]	
General health status≠	Mean (SD)	2.95 (1.09)	3.09 (1.12)	3.41 (1.20)	3.34 (1.04)	*H* (3)= 16.81, *p*=0.001**. *J*= 59,748.00, *z*= 3.86, *p*<0.001***.
	Median	3.00	3.00	3.00	3.00	
Living circumstances	Live with other/s	126 (48.1%) [-6.6]	71 (55.9%) [-1.8]	29 (70.7%) [1.1]	123 (96.1%) [8.9]	χ^2 (3)=88.42, p<0.001***: Cramer's V=0.40.
	Live alone	136 (51.9%) [6.6]	56 (44.1%) [1.8]	12 (29.3%) [-1.1]	5 (3.9%) [-8.9]	

Relationship of caregiver to the respondent	Spouse	109 (41.6%) [-5.4]	58 (45.7%) [-2.1]	27 (65.9%) [1.6]	106 (82.8%) [7.5]	χ^2 (6)=73.24, p<0.001***: Cramer's V=0.26.
	Adult-offspring	96 (36.6%) [2.3]	53 (41.7%) [2.8]	13 (31.7%) [0.0]	15 (11.7%) [-5.5]	
	Other (including friend, neighbour, sibling etc)	57 (21.8%) [4.6]	16 (12.6%) [-0.7]	1 (2.4%) [-2.3]	7 (5.5%) [-3.3]	

*p<0.05, **p<0.01, ***p<0.001. † Adjusted standardised residuals over 2 show where expected frequencies are significantly different from their observed frequencies and therefore indicate which cells are non-independent of each other (i.e. the variables are significantly related to each other). Negative residuals indicate a lower observed frequency than expected given the null hypothesis of independence. Positive residuals indicate a higher observed frequency than expected. ≠ Higher scores indicate poorer self-rated health.

There was a significant association between the amount of care received and registration status, self-assessed change in vision since diagnosis, gender, living circumstances, and general health. There was no significant difference in respondents' age across the hours of care groups.

The majority of respondents reported that their caregiver was their spouse (n= 300, 53.8%). One hundred and seventy-seven reported their caregiver was their offspring, and 81 reported 'other' types of relationships to their caregiver (e.g. friend, neighbour, or other family member such as their sibling). There was a significant association between the pwAMD/caregiver relationship type and the amount of care received (see Table 4.2). Those whose spouse was their caregiver were more likely to report receiving 'more than 35 hours per week' of care than people whose adult-offspring were supporting them or those with 'other' types of relationships to their caregiver. Those with 'other' types of pwAMD/ caregiver relationships were more likely to report receiving 'fewer than 7 hours per week' of care.

The support-related variables were not independent of the socio-demographic, eye- and health-related variables and hence multiple regression was used to adjust for these variables in order to see the unique impact that the support-related variables had on the dependent variables. All variables included in the multivariate analysis were significantly associated with the dependent variables. The exceptions were for the relationship between living circumstances and MD-specific QoL, gender and MD-specific QoL and the type of pwAMD/ caregiver relationship and MD-specific QoL (see Table 4.3). The bivariate results for the main variables of interest (whether or not respondents reported having a caregiver and how much care they received) are described below. The results for the other independent variables are presented in Table 4.3.

Table 4.3. Bivariate analysis of the relationships between the independent variables and quality of life and well-being outcomes (n=1067).

		General quality of life^a			**MD- specific quality of life^b**			**Well-being^c**		
Predictor		**Mean (SD)**	**Median**	**statistic, p value, effect size.**	**Mean (SD)**	**Median**	**statistic, p value, effect size.**	**Mean (SD)**	**Median**	**statistic, p value, effect size.**
Gender	Male	1.21 (1.10)	1.00	U=112,184.00, z= -2.69, p=0.01**.	-1.95 (1.02)	-2.00	U=121,184.00, z= -0.71, p=0.50.	33.97 (8.15)	35.00	U=101,332.50, z= -4.90, p<0.001***.
	Female	1.04 (1.12)	1.00		-1.99 (1.04)	-2.00		30.98 (9.23)	32.00	
				r_{pb} =-.07, p=0.02*.			r_{pb} =-.02, p=0.56.			r_{pb} = -.16, p<0.001***.
Age at survey completion				r_s = -.25, p<0.001***.			r_s = -.22, p<0.001***.			r_s = -.10, p<0.01**.
Living circumstances	Live alone	0.94 (1.08)	1.00	U=120,223.00, z= -4.09, p<0.001***.	-2.03 (1.03)	-2.00	U=132,184.50, z= -1.61, p=0.11.	31.05 (9.18)	32.00	U=125,820.50, z= -2.81, p=0.005**.
	Live with other/s	1.21 (1.13)	1.00		-1.94 (1.04)	-2.00		32.62 (8.82)	34.00	

				$r_{pb} = -.12$, $p<0.001$***.			$r_{pb} = -.05$, $p=0.13$.			$r_{pb} = -.09$, $p=0.005$**.
Registration status	Not registered	1.30 (1.03)	1.00	H (2)= 77.31, p<0.001***. J= 97,777.00, z= -8.84, p<0.001***.	-1.70 (1.04)	-2.00	H (2)= 171.39, p<0.001***. J= 79,784.00, z= -12.89, p<0.001***.	33.12 (8.61)	34.00	H (2)= 37.95, p<0.001***. J= 108,773.00, z= -6.21, p<0.001***.
	Registered as SI	0.73 (1.08)	1.00		-2.54 (0.76)	-3.00		30.04 (8.87)	32.00	
	Registered as SSI	0.53 (1.27)	1.00		-2.57 (0.70)	-3.00		28.45 (10.13)	29.00	
Self-assessed change in vision since diagnosis	Better	1.52 (0.97)	2.00	H (2)= 108.45, p<0.001***. J= 110,684.00, z= -10.14, p<0.001***.	-1.71 (1.03)	-2.00	H (2)= 88.74, p<0.001***. J= 117,573.00, z= -8.85, p<0.001***.	34.88 (8.61)	36.33	H (2)= 57.50, p<0.001***. J= 121,946.00, z= -7.56, p<0.001***.
	Stayed the same	1.50 (0.99)	2.00		-1.59 (1.13)	-2.00		34.09 (8.19)	35.00	
	Worse	0.79 (1.11)	1.00		-2.24 (0.89)	-2.00		30.17 (9.09)	31.00	
General health status $^{\neq}$				$r_s = -.60$, $p<0.001$***.			$r_s = -.16$, $p<0.001$***.			$r_s = -.54$, $p<0.001$***.

Relationship of caregiver to person with AMD	Spouse	0.96 (1.06)	1.00	*H* (2)= 18.54, *p*<0.001***. *J*= 37,694.00, *z*= -4.30, *p*<0.001***.n=558.	-2.38 (0.75)	-3.00	*H* (2)= 1.49, p=0.47. *J*= 43,725.00, *z*= -1.22, p=0.22. n=558.	31.37 (8.55)	32.00	*H* (2)= 7.23, *p*=0.03*. *J*= 40,603.50, *z*= -2.66, *p*=0.008**. n=558.
	Adult-offspring	0.64 (1.14)	1.00		-2.44 (0.78)	-3.00		29.33 (9.28)	30.67	
	Other	0.41 (1.14)	0.00		-2.40 (0.90)	-3.00		28.67 (9.78)	29.00	

[a] Quality of life (QoL) is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD- specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [c] General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being. [≠] Higher scores indicate poorer self-rated health.

Previous research has found that subjective and objective vision impairment (VI) affect outcomes differently. For instance, Brennan et al. (2011) found that objective and subjective assessments of VI were independent predictors of the social support received in older adults with AMD. In the present study we used registration status as an objective assessment of VI, and self-assessed change in VI since diagnosis as a subjective assessment of VI. We hypothesised that they may have different effects on the need for care, thus controlling for both would provide a better indication of the additional impact that receiving care had on the QoL and well-being outcomes, over and above the need for care.

Receiving care vs not receiving care

Bivariate analyses found that respondents who reported receiving care for AMD were more likely to report poorer well-being (U = 109, 912.00, z = -6.39, p<0.001), general QoL (U = 94, 515.00, z = -9.83, p<0.001) and MD-specific QoL (U = 76, 485.50, z = -13.72, p<0.001) than those not receiving care (see Table 4.4 for descriptive statistics).

Table 4.4. Descriptive statistics of outcome variables for respondents who reported receiving care and those who didn't (n=1067).

	Respondents who don't receive care		**Respondents who receive care**	
	Mean (SD)	**Median**	**Mean (SD)**	**Median**
General quality of life[a]	1.44 (1.01)	1.00	0.78 (1.11)	1.00
MD- specific quality of life[b]	-1.51 (1.08)	-2.00	-2.40 (0.78)	-3.00
Well-being[c]	33.71 (8.65)	35.00	30.33 (9.02)	31.00

[a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD-specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be 'very much better' (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be 'worse'). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [c] General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being.

The variables were entered into the multiple regression analyses in blocks so that each block of variables could be examined for their additional contribution to the variance. Independent variables were entered in the order suggested by Cohen and Cohen (1983), where variables that occur chronologically or temporally prior should go in the first step (such as socio-demographic variables). These are then followed by chronologically later variables such as vision and health-related variables (e.g. subjective and objective VI, and general health status.) Receipt of care was entered in the third and final step. (See Table 4.5.)

Table 4.5. Summary of Hierarchical Regression Analysis for the unique contribution of the *receipt of care* for AMD on quality of life (general and MD-specific) and well-being.

	General quality of life[a]			**MD-specific quality of life[b]**			**Well-being[c]**		
Step and variable	B	SE B	β	B	SE B	β	B	SE B	β
Step 1									
Age	-0.03	0.004	-.23***	-0.03	0.004	-.25***	-0.10	0.04	-.09**
Gender[Ψ]	-0.20	0.08	-.09**	-0.11	0.07	-.05	-3.05	0.61	-.16***
Living circumstances [§]	-0.06	0.07	-.03	0.08	0.07	.04	-0.33	0.60	-.02
Step 2									
Age	-0.01	0.004	-.09***	-0.02	0.004	-.14***	0.03	0.03	.03
Gender[Ψ]	-0.05	0.06	-.02	-0.04	0.07	-.02	-1.98	0.51	-.10***
Living circumstances [§]	-0.03	0.06	-.02	0.08	0.06	.04	-0.11	0.50	-.01
Subjective VI[α]	-0.27	0.04	-.17***	-0.23	0.04	-.16***	-1.49	0.33	-.12***
Objective VI[¥]	-0.18	0.04	-.11***	-0.40	0.05	-.27***	-1.18	0.36	-.09**
General health status[≠]	-0.56	0.02	-.55***	-0.08	0.03	-.09**	-4.27	0.21	-.52***
Step 3									
Age	-0.01	0.004	-.06*	-0.01	0.004	-.07*	0.05	0.03	.04
Gender[Ψ]	-0.05	0.06	-.02	-0.04	0.06	-.02	-1.98	0.51	-.10***
Living circumstances [§]	-0.11	0.06	-.05	-0.07	0.06	-.03	-0.42	0.51	-.02
Subjective VI[α]	-0.26	0.04	-.16***	-0.22	0.04	-.15***	-1.46	0.33	-.11***
Objective VI[¥]	-0.09	0.04	-.06*	-0.23	0.05	-.15***	-0.81	0.38	-.06*
General health status[≠]	-0.55	0.02	-.53***	-0.05	0.03	-.05	-4.20	0.21	-.51***
Whether or not receive care[±]	-0.33	0.06	-.15***	-0.66	0.06	-.32***	-1.35	0.52	-.08*

SE: standard error. R^2 is the proportion of variance explained by the model. ΔR^2 is the change in R^2 at each step as new variables are entered into the model, and the level of significance of R^2 is assessed using the F- ratio. [a] R^2= .06*** for step 1; ΔR^2= .37*** for step 2; ΔR^2= .02*** for step 3. [b] R^2= .05 for step 1***; ΔR^2= .12 for step 2***; ΔR^2= .08*** for step 3. [c] R^2= .03*** for step 1; ΔR^2= .31*** for step 2; ΔR^2= .004* for step 3. *p<.05. ** p<.01.*** p<.001. n=1067. [a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD- specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be 'very much better' (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be 'worse'). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [c]General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being. [Ψ] Gender variable coded, 0=male, 1=female. [§] Living circumstances variable coded, 0= live with other/s, 1=live alone. [α]Subjective VI measured by self-assessed change in vision since diagnosis. Coded as, 1= better, 2= the same, 3= worse. [¥] Objective VI measured using registration status. This was coded as, 1= not registered, 2= registered as sight impaired, 3= registered as severely sight impaired. [≠] Higher scores indicate poorer self-rated health. [±] Receipt of care. Coded as, 0= respondent does not receive informal care, 1= respondent receives informal care.

Quality of life

Age, gender, living circumstances, subjective and objective VI, and general health status explained 43.3% of the variance in QoL. After the receipt of care variable was entered, the total variance explained by the model as a whole was 44.8%, (F(7, 1059)= 124.75, p<0.001, R^2 =.45 , Adj R^2 =.45). The receipt of care variable was significantly associated with QoL over and above the other independent variables, and explained an additional 1.6% of variance in QoL (F_{inc} (1, 1059)=30.83, p<0.001). In the final model, age, general health status, objective VI, subjective VI and the receipt of care were significantly associated with QoL (see Table 4.5). General health status recorded the highest beta value (standardised regression coefficient), followed by subjective VI, the receipt of care, age and objective VI. Those who were older, in poorer health, who were more likely to report that their vision was worse since diagnosis, who were registered as SI or SSI, and were receiving care for AMD were more likely to report poorer QoL.

MD-specific Quality of Life

The independent variables accounted for 25% of the variance in MD-specific QoL, (F (7,1059)= 51.69, p<0.001, R^2=.26, Adj R^2= .25). The receipt of care variable explained an additional 7.5% of the variance in MD-specific QoL after controlling for the other independent variables, (F_{inc} (1, 1059) = 106.98, p<0.001). In the final model, older age, a greater perceived deterioration in vision since diagnosis, registration as SI or SSI, and receiving care for AMD were all significantly associated with poorer MD-specific QoL. The receipt of care recorded the highest beta weight.

Well-being

The regression of well-being on the independent variables accounted for 34% of the variance, (F (7,1059) = 79.45, p<0.001, R^2=.34, Adj R^2= .34). The receipt of care variable contributed an additional 0.4% of the variance in well-being after controlling for the other independent variables, (F_{inc} (1, 1059)= 6.70, p=0.01). In the final model, age and living circumstances were not significant variables in the model. The strongest associations with well-being came from (in order of decreasing beta weights): general health status (β = -.51, $p<0.001$), subjective VI (β = -.11, $p<0.001$), gender (β = -.10, $p<0.001$), the receipt of care (β = -.08, $p<0.01$), and objective VI (β = -.06, $p<0.05$).

The amount of care received for AMD

Bivariate analyses found that the amount of care received for AMD was significantly associated with general QoL, MD- specific QoL and well-being (see Table 4.6). Jonckheere's test showed significant trends in the data: in general, those who received more care were more likely to report poorer QoL and well-being.

Table 4.6. Comparison of patient-reported outcome variables for respondents receiving different *amounts of care* for AMD (n=558).

Variables		**Fewer than 7 hours per week**	**7 to 14 hours per week**	**15 to 35 hours per week**	**More than 35 hours per week**	**Statistics, p value**
General quality of life[a]	**Mean (SD)**	0.98 (1.04)	0.65 (1.11)	0.44 (1.03)	0.61 (1.24)	*H* (3)= 17.01, *p*<0.001***. *J*= 44,868.00, *z*= -3.68, *p*<0.001***.
	Median	1.00	1.00	0.00	1.00	
MD-specific quality of life[b]	**Mean (SD)**	-2.24 (0.88)	-2.45 (0.73)	-2.63 (0.54)	-2.60 (0.62)	*H* (3)= 19.50, *p*<0.001***. *J*= 44,123.50, *z*= -4.37, *p*<0.001***.
	Median	-2.00	-3.00	-3.00	-3.00	
Well-being[c]	**Mean (SD)**	31.56 (8.75)	31.21 (8.59)	27.32 (8.94)	27.92 (9.43)	*H* (3)= 19.98, *p*<0.001***. *J*= 44,084.50, *z*= -3.92, *p*<0.001***.
	Median	32.83	32.00	27.00	28.00	

[a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD-specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be 'very much better' (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be 'worse'). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [c]General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being.

Further examination of the means and median scores on the QoL and well-being variables found an exception to this trend (see Table 4.6). The ‘15 to 35 hours of care a week’ group reported lower mean and median QoL and well-being scores plus a lower mean score for MD-specific QoL than the ‘more than 35 hours of care a week’ group. These results prompted further examination of the characteristics of the sample who reported receiving ‘15 to 35 hours of care a week’. This group were not more or less likely to be male or female, or be living alone or with other/s (see Table 4.2). In contrast, the ‘more than 35 hours a week’ group were more likely to be male than female, and report living with someone else vs living alone. The ‘more than 35 hours of care a week’ group were more likely to report their caregiver was their spouse than their offspring or ‘other’ type of relationship. The ‘15 to 35 hours of care a week’ group were not more or less likely to report that their caregiver was their spouse or their offspring, but were less likely to report it was an ‘other’ type of relationship.

In Table 4.2, the adjusted standardised residual for the description of vision as being ‘worse’ since diagnosis was larger for the ‘15 to 35 hours of care a week’ group than for the ‘more than 35 hours of care a week’ group; indicating that more respondents than expected gave this response. Additionally, the residuals indicate that the ‘15 to 35 hours of care a week’ group were less likely to not be registered as SI or SSI and were more likely to be registered as SI. The means also suggest that this group were more likely to report poorer general health than those receiving ‘more than 35 hours of care a week’.

Hierarchical multiple regressions were run for each QoL and well-being dependent variables using the same independent variables included in steps one and two of the analysis above. The pwAMD/caregiver relationship type was added in step three. The amount-of-care-received variable was entered into the fourth and final step. (See Table 4.7.)

Table 4.7. Summary of Hierarchical Regression Analysis for the unique contribution of the *amount of care* received for AMD on quality of life (general and MD-specific) and well-being.

	General quality of life[a]			**MD-specific quality of life**[b]			**Well-being**[c]		
Step and variable	B	SE B	β	B	SE B	β	B	SE B	β
Step 1									
Age	-0.03	0.01	-.16***	-0.01	0.01	-.10*	-0.13	0.06	-.10*
Gender[Ψ]	-0.29	0.10	-.12**	-0.01	0.07	-.003	-3.65	0.84	-.19***
Living circumstances[§]	-0.10	0.11	-.04	0.02	0.08	.01	-0.06	0.88	-.003
Step 2									
Age	-0.01	0.01	-.08*	-0.01	0.01	-.05	-0.04	0.05	-.03
Gender [Ψ]	-0.14	0.09	-.06	0.02	0.07	.01	-2.57	0.73	-.14***
Living circumstances [§]	-0.03	0.09	-.01	0.06	0.08	.03	0.40	0.76	.02
Subjective VI[α]	-0.32	0.06	-.20***	-0.14	0.05	-.13**	-1.58	0.48	-.12**
Objective VI[¥]	-0.09	0.05	-.06	-0.22	0.04	-.21***	-0.56	0.45	-.05
General health status[≠]	-0.50	0.04	-.49***	-0.02	0.03	-.03	-3.81	0.30	-.47***
Step 3									
Age	-0.01	0.01	-.08*	-0.01	0.01	-.06	-0.04	0.05	-.03
Gender [Ψ]	-0.13	0.09	-.05	0.02	0.07	.01	-2.51	0.75	-.13**
Living circumstances [§]	0.07	0.14	.03	0.06	0.08	.03	0.76	1.17	.04
Subjective VI[α]	-0.31	0.06	-.20***	-0.14	0.05	-.13**	-1.58	0.48	-.12**
Objective VI[¥]	-0.09	0.05	-.06	-0.22	0.05	-.21***	-0.55	0.45	-.05
General health status[≠]	-0.50	0.04	-.49***	-0.02	0.03	-.03	-3.80	0.30	-.47***
Adult offspring caregiver (spouse)[#]	-0.06	0.15	-.03	0.05	0.12	.03	-0.37	1.25	-.02

‘Other’ caregiver relationship (spouse)$^{\#}$	-0.28	0.16	-.09	0.09	0.13	.04	-0.71	1.36	-.03
Step 4									
Age	-0.01	0.01	-.08*	-0.01	0.01	-.05	-0.03	0.05	-.02
Gender$^{\Psi}$	-0.13	0.09	-.06	0.004	0.07	.003	-2.58	0.74	-.14**
Living circumstances §	0.01	0.14	.002	-0.09	0.12	-.05	-0.10	1.20	-.01
Subjective VI$^{\alpha}$	-0.30	0.06	-.19***	-0.13	0.05	-.11**	-1.42	0.48	-.11**
Objective VI$^{¥}$	-0.06	0.06	-.04	-0.18	0.05	-.18***	-0.23	0.46	-.02
General health status$^{\neq}$	-0.48	0.04	-.48***	-0.002	0.03	-.003	-3.63	0.30	-.45***
Adult offspring caregiver (spouse)$^{\#}$	-0.07	0.15	-.03	0.03	0.12	.02	-0.51	1.24	-.03
‘Other’ caregiver relationship (spouse)$^{\#}$	-0.30	0.16	-.10	0.05	0.13	.02	-1.08	1.36	-.04
Amount of care received$^{\alpha}$	-0.07	0.04	-.07	-0.10	0.03	-.16**	-0.91	0.31	-.12**

SE: standard error. R^2 is the proportion of variance explained by the model. ΔR^2 is the change in R^2 at each step as new variables are entered into the model, and the level of significance of R^2 is assessed using the *F*- ratio. [a] R^2= .04*** for step 1; ΔR^2= .31*** for step 2; ΔR^2= .005 for step 3; ΔR^2= .004 for step 4. [b] R^2= .003 for step 1; ΔR^2= .08*** for step 2; ΔR^2= .001 for step 3; ΔR^2= .02** for step 4. [c] R^2= .04*** for step 1; ΔR^2= .25*** for step 2; ΔR^2= .00 for step 3; ΔR^2= .01** for step 4. *p<.05. ** p<.01.*** p<.001. n=558. [a] Quality of life is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [b] MD-specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [c]General well-being (W-BQ16) is on a scale of 0 to 48 where higher scores indicate higher well-being. $^{\Psi}$ Gender variable coded, 0=male, 1=female. § Living circumstances variable coded, 0= live with someone else, 1=live alone. $^{\alpha}$Subjective VI measured by self-assessed change in vision since diagnosis. Coded as, 1= better, 2= the same, 3= worse. $^{¥}$ Objective VI measured using registration status. This was coded as, 1= not registered, 2= registered as sight impaired, 3= registered as severely sight impaired. $^{\neq}$ Higher scores indicate poorer self-rated health. $^{\#}$ Relationship of caregiver to the respondent. Nominal variable (caregiver was spouse, adult-offspring or ‘other’ relationship to the respondent) was converted into a set of dichotomous variables using dummy coding. $^{\alpha}$ Amount of care received per week. Coded as, 1= fewer than 7 hours, 2= between 7 and 14 hours, 3= between 15 and 35 hours, 4= more than 35 hours.

Quality of life

Age, gender, living circumstances, subjective and objective VI and general health status explained 35% of the variance in QoL. The addition of the pwAMD/ caregiver relationship type variable did not reliably improve R^2 (F_{inc} (2, 549)=2.09, p=0.13). After the amount-of-care-received variable was entered, the total variance explained by the model as a whole was 35.5%, (F(9, 548)= 35.06, p<0.001, R^2 =.37 , Adj R^2 =.36). The amount-of-care-received variable was not significantly associated with QoL over and above the other variables included in the regression (F_{inc} (1, 548)=3.14, p=0.08). In the final model, age, general health status and subjective VI were significantly associated with QoL (see Table 4.7). General health status recorded the highest beta value, followed by subjective VI, and age. Respondents who were older, in poorer health, and who reported their vision was 'worse' since diagnosis were more likely to report poorer QoL.

MD-specific Quality of Life

The independent variables accounted for 8.9% of the variance in MD-specific QoL, (F (9,548)= 7.05, p<0.001, R^2 =.10, Adj R^2 =.09). The addition of the pwAMD/ caregiver relationship type variable did not significantly improve the model (F_{inc} (2, 549) = 0.22, p=0.80). The amount-of-care-received variable explained an additional 1.8% of the variance in MD-specific QoL after controlling for the other independent variables, (F_{inc} (1, 548) = 10.77, p<0.01). In the final model, socio-demographic variables and general health status were not significant. The vision-related variables (objective and subjective VI) and the amount-of-care-received variable were significantly associated with MD-specific QoL.

Well-being

The regression of well-being on the independent variables accounted for 29.2% of the variance, (F (9,548) = 26.54, p<0.001, R^2 =.30, Adj R^2 =.29). Adding the pwAMD/caregiver relationship type variable did not improve the model (F_{inc} (2,549)= 0.14, p=0.87). The amount-of-care-received variable contributed an additional 1.1% of the variance in well-being after controlling for the other independent variables, (F_{inc} (1,548)= 8.47, p<0.01). In the final model, age, living circumstances and objective VI were not significant variables in the model. The strongest associations with well-being came from (in order of decreasing beta weights): general health status (β= -.45, p<0.001), gender (β = -.14, p<0.001), the amount-of-care-received (β = -.12, p<.01), and subjective VI (β = -.11, p<0.01). Respondents who were in poorer health, were female, who reported their vision was 'worse' since diagnosis and who received higher amounts of care for AMD were more likely to report poorer well-being.

DISCUSSION

This study found that for pwAMD, the receipt of informal care and support received from others was significantly associated with QoL, MD-specific QoL and well-being, over and above socio-demographic variables such as age and gender, and vision- and health-related variables. Those who reported receiving higher amounts of informal care and support from others were more likely to report lower MD-specific QoL and lower well-being, but not lower general QoL.

This study used data from questionnaires sent to a nationwide sample of members of the Macular Society. The analyses were not restricted to people using care-related or rehabilitation services and thus may be more generalisable to pwAMD, however it is possible that participants may have been looking for support when they joined the Macular Society and thus may be receiving less support than non-members of the Macular Society. Nevertheless, this is the first nationwide study to assess the number of pwAMD receiving informal support from others, as well as examining who provides this support and the associations between receiving this support and QoL and well-being.

The study adjusted for socio-demographic, health-, eye- and support- related factors that were associated with the dependent variables (QoL and well-being) and the main independent variables of interest (receipt of care and the amount of care received). In particular, bivariate analyses found the association between the amount-of-care-received variable and the dependent variables to be non-linear. Further investigation found significant associations between the amount-of-care-received variable and socio-demographic, health-, eye- and support- related factors that may account for this non-linear pattern. There were no problems with linearity in the multiple regression, as assessed through residual analysis. Thus including these factors enabled the unique relationship between the amount-of-care-received variable and the patient-reported outcomes to be examined.

Both the receipt of care and the amount of care received were significantly associated with MD-specific QoL. Since the survey question asked about care received for AMD it might be expected that this would be more sensitive to the quality of life question specific to AMD. The vision-related variables (subjective and objective VI) were also significantly associated with MD-specific QoL. The receipt of care accounted for a larger proportion of the variance in MD-specific QoL than the vision-related variables, indicating its importance over the vision-related variables in explaining MD-specific QoL. However when the analysis was refined to assess the importance of the amount-of-care-received in explaining MD-specific QoL, objective VI was more strongly associated with MD-specific QoL. Perhaps this suggests that there are factors other than the amount-of-support-received that are related to receiving support and might account for the relationship between the receipt of support and MD-specific QoL.

The receipt of care was significantly associated with general QoL and well-being, and the amount-of-care-received was significantly associated with well-being, but not general QoL. These outcomes were not specific to AMD, thus showing the relationship between receiving support for AMD and broader patient-reported outcomes. The finding that the amount of care for AMD was not related to general QoL may be due to the broadness of the term ‘QoL’. QoL has been described as ‘a subjective perception’ that ‘means different things to different people’ (p7, Mitchell & Bradley, 2006). In this study, only the overview single-item from the MacDQoL was used to measure general QoL. Well-being was measured used the W-BQ16 which contains specific questions on feeling depressed or anxious, as well as positive well-being items concerned with enthusiasm for life (the energy and positive well-being subscales). As discussed above, the MD-specific QoL item is specific to AMD. Thus more specific or more detailed measures may be more sensitive to detect the impact of the amount of care received or the need for more support.

The ‘change in vision status since diagnosis’ item was used as a subjective measure of VI. In the hierarchical regressions reported here, it was more strongly associated with general QoL and well-being than the objective measure of VI used in the study (registration status). However objective VI was more strongly associated with MD-specific QoL in the regression including the amount-of-care-received variable, and accounted for a similar amount of the variance in the regression when the receipt of care variable was included in the regression for MD-specific QoL. This highlights the difference between these two measures. It is not known why the subjective VI measure is more strongly associated than the objective VI measure with well-being and general QoL, but not MD-specific QoL. The subjective VI measure used in this study assessed a perceived change in vision since diagnosis. This will be dependent on both perceived level of VI at diagnosis and perceived change in vision since diagnosis. Respondents who experienced a bleed at diagnosis, for example, may perceive very poor vision at diagnosis but have an improvement in vision following treatment, and thus report their sight was ‘better’ since diagnosis. Nevertheless they may have experienced deterioration since diagnosis that may not be as bad as the bleed experienced at diagnosis, but may still lead to them being registered by the time of survey completion. It is this actual level of VI (i.e. reflected in their registration status) that may be more likely to reflect their present MD-specific QoL.

The stronger relationship between subjective VI and QoL and well-being may be due to the perception of change in vision being more sensitive to mood; those who feel they have poor QoL or who are more depressed or anxious may be more likely to view their sight as having deteriorated. Whereas registration status, as an objective measure, is independent of differences in mood. The association between subjective and objective VI was small in this study and one might expect a stronger correlation if subjective VI was based on vision. It is important to note that this cross-sectional study was unable to determine causal associations between the variables studied. Whilst it may that subjective VI was a predictor of the patient-reported outcomes, it might be that poorer QoL and well-being predicted one’s perception of change in vision.

Of the socio-demographic, eye-, health- and support- related variables included in the regressions, it was general health status that was most strongly associated with general QoL and well-being; poorer self-rated general health was associated with poorer QoL and well-being. However, general health status wasn’t significantly associated with MD-specific QoL. This supports other researchers’ arguments that health does not reflect the impact of AMD on QoL, and provides support to suggest that health status measures e.g. SF-12, may not pick up on what is important to pwAMDs' QoL (Mitchell & Bradley, 2006).

Receiving more care for AMD was significantly related to poorer patient-reported outcomes over and above the type of relationship the caregiver had with the respondent (i.e. spouse, offspring or 'other'). The type of pwAMD/ caregiver relationship was not significantly associated with QoL or well-being in the regression models. Thus whether care was received from a spouse, offspring or the 'other' types of pwAMD/ caregiver relationships, did not appear to affect the patient-reported outcomes included in this study.

Conclusion

In this study, receiving care for AMD was significantly associated with poorer QoL and well-being. That it was significantly associated with these dependent variables over and above subjective and objective VI shows its unique relationship with these patient-reported outcomes. Receiving higher amounts of support for AMD was linked to poorer patient-reported outcomes. The amount of variance attributed to the amount-of-care variable in the regressions were small but were similar to the variance predicted by the vision-related variables. Perhaps there are other aspects of receiving support that affect QoL and well-being since the regressions including the receipt of care variable accounted for a higher amount of the variance in the patient-reported outcome variables. This will be explored in the remaining studies that form this thesis. A discussion of the relevant literature on support as positive or problematic follows in the next chapter. This is followed by the rationale for the follow-on studies.

Chapter 5:

The impact of providing and receiving support for AMD: Literature review.

The Macular Society 2013 survey results presented in Chapter 4 state that for pwAMD, the receipt of informal care and support from others was significantly associated with poorer general quality of life (QoL), MD-specific QoL and well-being, over and above socio-demographic variables such as age and gender, and vision- and health-related variables. Receiving higher amounts of informal care and support from others was significantly related to poorer MD-specific QoL and lower well-being, but not lower general QoL. The type of relationship between pwAMD and their caregivers (i.e. spouse, adult-offspring/ parent, other) wasn't significantly associated with these patient-reported outcomes.

A literature review found that the majority of research has used an individual rather than a dyadic perspective to investigate the experience of supporting someone living with AMD or vision loss. Research has examined the impact of receiving care from the perspective of the person with vision loss (but none have focused specifically on pwAMD), or the 'burden' caregivers report from supporting someone living with AMD. In the caregiving research literature, there has been very little research exploring the caregiving role in the context of the interactive relationship between the support recipient and provider. I present the relevant research below and argue why the experience of receiving support for AMD should be investigated using a dyadic approach. (Details of the methodology of the review are provided in Appendix 8.)

The impact of receiving support for the person with low vision.

Most of the social support literature suggests that receiving support is considered to have positive effects on well-being (e.g. Wang, 2016), physical health (e.g. Reblin & Uchino, 2008; Spiegel, Kraemer, Bloom, & Gottheil, 1989; Uchino, Cacioppo, & Kiecolt-Glaser, 1996) and mortality (Uchino, 2006). Within the vision impairment (VI) literature, support received from others has been linked to both positive and negative outcomes.

First, it is important to be aware of several definitions:

- Instrumental support-also referred to as tangible support or practical support-is defined as providing assistance with tasks of everyday living or provision of material goods.
- Emotional support (or affective support) involves the verbal and non-verbal communication of caring and concern.
- Informational support is the provision of information and advice.
- Support can be broken down into receipt of support (received support). This might be measured, for example, by asking respondents to state how often over the past month they have received support e.g. with housework (taken from Cimarolli, Reinhardt, & Horowitz, 2006). Perceived support (the perception that support would be available if needed) may also be examined (Helgeson & Cohen, 1996). This may be measured with a question such as: "In times of trouble, can you count on at least some of your family or friends most of the time, some of the time, or hardly ever?" (taken from Sheffler & Sachs-Ericsson, 2016). A more accurate term for this maybe 'perceived availability of support', which clarifies that this refers to the potential for support to be provided or perceived availability of support rather than the participant's perception of whether or not they have received actual support.
- Furthermore, another way of investigating social support is to examine the *size* of the person's social support network.

In a study of working age adults living with VI, instrumental support was the most common type of support received (Cimarolli & Boerner, 2005). Instrumental support may be important to people with VI because the majority have some degree of functional limitation associated with vision loss. Reinhardt, Boerner, and Horowitz (2006) found that greater *receipt* of instrumental support was linked to experiencing more symptoms of depression, but was unrelated to adaptation to vision loss. In contrast, *perceived* instrumental support was linked to better adaptation to vision loss, but unrelated to depressive symptoms. Both *received* and *perceived* emotional support had beneficial effects on adjustment to vision loss. Support was measured using self-report questionnaires commonly used in the social support literature. To measure *received* support, participants were asked to list the persons in their social network who they had received affective and instrumental support from over the past month. *Perceived* support was assessed via a single item with a 4-point scale: ‘have support from family and friends *if needed*: most of the time, some of the time, only occasionally or not at all’. The findings highlight that receiving support for vision loss may not lead to better outcomes. Rather it is the perception that help would be there *if needed* that leads to positive outcomes. It also highlights the importance of emotional as well as instrumental support for people with VI. The results point to the importance of measuring different types of support given their different impact on psychological outcomes.

One type of support that has been studied in detail for people with VI is overprotectiveness. Individuals who perceive the support they receive as overprotective may have the feeling of being helped unnecessarily or being overly restricted by their support providers (Thompson & Sobolew-Shubin, 1993). Some researchers suggest that ‘negative’ support such as overprotection is independent of whether or not support receivers perceive it to stem from the supportive intent of the support providers (e.g. Shiozaki et al., 2011). Therefore although it may not necessarily be perceived as negative support by the recipient, it is generally considered to lead to poorer outcomes.

Overprotection has been argued to be a particularly salient issue for people with VI because of the increased risk of falls and injuries associated with this condition (Cimarolli, Boerner, Reinhardt, & Horowitz, 2013). It is possible that some support providers may have difficulty providing the appropriate balance of instrumental support to enable a person with VI to live as independently as possible. Greater independence may have a knock-on effect on patient-reported outcomes such as well-being. A lack of knowledge of the person’s visual acuity and the impact of this on their functional abilities, as well as concern for their safety, may contribute to overprotection.

In working age adults with VI, overprotection was linked to a greater number of depressive symptoms and higher levels of anxiety, even after controlling for vision loss severity, functional disability and perceived social support (Cimarolli, 2006). In people with age-related vision loss, overprotection was associated with poorer adjustment to vision loss, and lower scores on measures of vision-specific adaptation and environmental mastery (Cimarolli et al., 2006). Results indicated that higher levels of functional disability were related to greater instrumental support received, and both were related to greater perceived overprotection in adults with age-related vision loss. The researchers suggested that further research needs to identify other pathways that contribute to overprotection, such as negative interactions between the support recipient and provider. Cimarolli and colleagues also suggested future research could look at perceived satisfaction with instrumental and emotional support, and include support providers as well as people with VI to determine antecedents to overprotection and the dynamics of perceived overprotection.

Cimarolli et al. (2013) conducted further exploration of the relationship between overprotection and the amount of support received for VI. In a longitudinal study carried out over a year, they found that although perceived overprotection increased over time, it was only related to instrumental support initially. This lends further support to the investigation of other factors influencing the perception of overprotection, other than the amount of support received.

Three models of overprotection were proposed by Thompson, Galbraith, Thomas, Swan, and Vrungos (2002). They hypothesised that overprotective caregiving may result from either: a caregiving style that is overly intrusive and involved but not based on negative attitudes towards the patient (the “involved” model), or that overprotection arises from caregiver resentment and this is expressed through over-controlling care and negative behaviours and attitudes towards the care recipient (the “resentment” model). Alternatively it might be that caregiver’s overprotective style might arise from a reaction to the low level of autonomy and independence of the care recipient (the “patient source” model).

Thompson et al. (2002) tested the three models (involved, resentment and patient source) in patient-caregiver dyads in which the patient had experienced a stroke (henceforth referred to as ‘stroke survivor’). They collected quantitative data from questionnaires and task observations. Some support was found for the ‘resentment’ model; that overprotective caregiving was related to an over-controlling caregiving style and behaviours that resulted from resentment and negative affect toward the stroke survivor. However caregivers' expressions of criticisms and frustration were not related to perceived overprotection. The researchers also investigated equity within the patient-caregiver relationship. Thompson et al. (2002) refer to Exchange theory which suggests that satisfaction in a relationship arises from the perceived balance of resources given and received in the relationship. For instance, if caregivers perceive themselves to be under-benefitting in a relationship, and the patient to be over-benefitting, this may result in caregiver resentment. Thompson et al. (2002) found evidence to support this theory; caregivers who reported under-benefitting from the relationship had higher resentment. Resentment partly mediated the relationship between caregivers' perception of under-benefitting and the stroke survivors' feeling of being overprotected. This further supports their "resentment" model.

Thompson et al. (2002) report that perceptions of being overprotected came from several sources. First from caregiver resentment towards the stroke survivor and towards the caregiving role. Secondly through the dependency of the stroke survivor. In addition, stroke survivors' dependent attitudes were associated with caregiver resentment.

Thompson et al. (2002) findings suggest that it may not be over-helping itself that resulted in the stroke survivors feeling overprotected, but other factors such as negative affect and resentment. The results may suggest that caregiver dissatisfaction with the caregiving role may lead to 'burden' and resentment and this could result in overprotective behaviours towards the stroke survivor. Additionally the dependence of the stroke survivor was associated with overprotection and with caregiver resentment, providing partial support for the "patient source" model. Longitudinal research would need to confirm the pathways to overprotection. These findings are in contrast to Fiske, Coyne, and Smith (1991) who found that overprotection was unrelated to caregiver hostility. This difference in findings may be due to the researchers contrasting definitions of overprotection and the different instruments used to measure overprotection. Arguably the most important difference may be that patient perceptions of overprotectiveness were measured in the Thompson et al. (2002) study whereas spousal perceptions were measured by Fiske et al. (1991) and may not be reflective of patient perceptions.

In the Thompson et al. (2002) study, both physical and mental health functioning of the patient were unrelated to overprotection. The authors suggest future research could explore further causes of caregiver resentment including the quality of the pre-caring relationship and lack of support for the caregiver. These aspects are taken into account in some models of caregiver burden which will be described below (e.g. Pearlin, Mullan, Semple, & Skaff, 1990 stress-process model).

The majority of the social support literature for people with VI has focused on overprotective support as a negative consequence of receiving support, however other types of negative support have been identified. A number of other types of negative support were reported by adults of working age with VI (Cimarolli & Boerner, 2005). These included: their social network underestimating or overestimating their capabilities, their social network not understanding their need for independence, conflict with members of their social network, their support network not being able to provide adequate help, and the perception that their support provider neglects themselves. More symptoms of depression and reduced life satisfaction were more likely in people who reported receiving only negative support or who reported a lack of support. Those who reported receiving both positive and negative support had better psychological health. The social network underestimating their capabilities was the most frequently reported type of negative help received (Cimarolli & Boerner, 2005).

Cimarolli et al. (2006) recommended that future research could explore the receipt of negative support in more detail by including support providers and observing negative interactions within dyads to investigate the causes of negative support. With regards to the study of overprotection in people with VI, longitudinal research is needed to examine the antecedents to overprotection, its association with the dependency of the person with VI and its impact on disability.

Introduction to research on caregivers

Many developed countries have an aging population and a common response is to delay residential care by enabling older people to live in the community for longer. The emphasis is on the community, friends and family of older adults to provide unpaid care and support (Aggar, Ronaldson, & Cameron, 2011). Of the care required to support people at home, 80% is reported to be provided by family caregivers (Parveen & Morrison, 2012).

A caregiver has been defined as someone who provides emotional and physical support for an individual who is experiencing difficulties due to physical, cognitive, or emotional impairments, and often does this without financial compensation (Bridges, 1995). A report by Carers UK (2016) estimated that there are around 6.5 million caregivers in the UK saving the National Health Service (NHS) approximately £132 billion per year. Around 39% of the UK population are estimated to provide unpaid care at some point in their lives (Carmichael & Ercolani, 2016).

Caregiver stress is a strong predictor of an older person entering residential care (Spillman & Long, 2009). There is a need to assess the impact of caregiving in order to create healthcare initiatives and strategies to support caregivers to enable them to stay in their caregiving role.

The impact of caring in the general population

The Carers UK 2014 survey reported that 80% of the 4924 carers surveyed felt caring impacted negatively on their health. Health and well-being were affected in a variety of ways for instance, through a lack of sleep, a reduction in physical activity, and not having enough time to take care of one’s own health; including having a well-balanced diet and making timely health appointments (Carers UK, 2014). Psychological health was also impacted with 82% of caregivers reporting feeling more stressed because of their caregiving role, and 73% feeling more anxious. Half of respondents stated that they were affected by depression after taking on the caregiving role (Carers UK, 2014).

Caregiving affected carers’ employment (Carers UK, 2014). Some carers reported having to cut their working hours, retire early or give up work entirely in order to provide care. This impacted on their income, career prospects and ability to save for pensions or for their own care needs. Caregivers reported having to turn down opportunities for promotion or a better job elsewhere in order to keep working flexibly to fit around their caregiving role. Fifty four percent of the caregivers surveyed reported struggling to pay for household bills or to make ends meet (Carers UK, 2014).

Seventy five percent of caregivers who completed the Carers UK 2014 survey reported difficulties maintaining relationships and social networks, and reported that this was due to other people not understanding the impact of caregiving (Carers UK, 2014).

Similar findings appear elsewhere in the research literature. A review by Oyebode (2003) reports that one-third to one-half of caregivers experience psychological distress . Caregiving can bring direct stresses (e.g. reduced time and energy) as well as indirect stresses (e.g. an indirect effect on social life and work) (Oyebode, 2003).

Given the impact on health, work and social relationships, it is concerning that many caregivers are still reporting struggling to get the support they need from health and social care services, despite the introduction of the Care Act 2014 and Children and Families Act 2014 (Carers UK, 2016). The authors stated, ‘The survey shows evidence of public services creaking under pressure- charging is up, the right services are harder to find and vital support is cut or under threat, leaving many carers anxious about the future and their ability to continue to care’ (p5, Carers UK, 2016).

Models of caregiving

Several models of the impact of caregiving appear in the literature, and include both patient and caregiver determinants of ‘caregiver burden’. Lazarus and Folkman (1984) described the ‘Transactional model of stress and coping’ when conceptualising the experience of caregiving. Within this framework, stress occurs when a person perceives their resources and capabilities to be insufficient to cope with the environment. Cognitive appraisal and coping are critical mediators of stressful person-environment relationships and long-term outcomes (Folkman, Lazarus, Gruen, & Delongis, 1986). This model has been used in caregiving research as it has been found to have good predictive validity when applied to the caregiving situation, and it is applicable when examining both positive and negative caregiver outcomes (Parveen & Morrison, 2012).

Other models build on this approach and apply it to the caregiving role. The stress-process model of Pearlin et al. (1990) was guided by their research with caregivers of people with Alzheimer’s disease (see Figure 5.1). This model distinguishes four domains: background and contextual factors, stressors, mediators of stress, and outcomes. Stressors are divided into three types: primary stressors which are directly connected with providing care (e.g. level of help required for everyday care), secondary role strains such as those caused by the conflicting roles of caring, work and family responsibilities, and secondary 'intra-psychic' strains including the caregiver's level of confidence in their role. Mediators include coping strategies and social support. Finally, outcomes include caregiver physical and mental health, and yielding of the caregiver role.

One issue with the Pearlin et al. (1990) stress process model is the grouping together of objective (e.g. Activities of Daily Living/ ADL) and subjective (e.g. role overload) indicators of burden as primary stressors (Bastawrous, 2013). The Yates, Tennstedt, and Chang (1999) stress model distinguishes between objective ('stressors') and subjective indicators ('appraisals') (see Figure 5.2). In this model, the primary *stressors* (e.g. ADL) predict the primary *appraisal* of care (number of hours spent caregiving) as well as secondary appraisals (burden) and outcomes (well-being). As in the Pearlin et al. (1990) model, perceived social support acts as a mediator in addition to the frequency of getting a break, number of hours of formal care received and caregiver self-esteem.

The common underlying principle of these models is the assumption that caregiving itself may not automatically cause stress; it is the caregiver's appraisal of the 'stressors' that may lead to stress, and that this can be influenced by other factors such as social support.

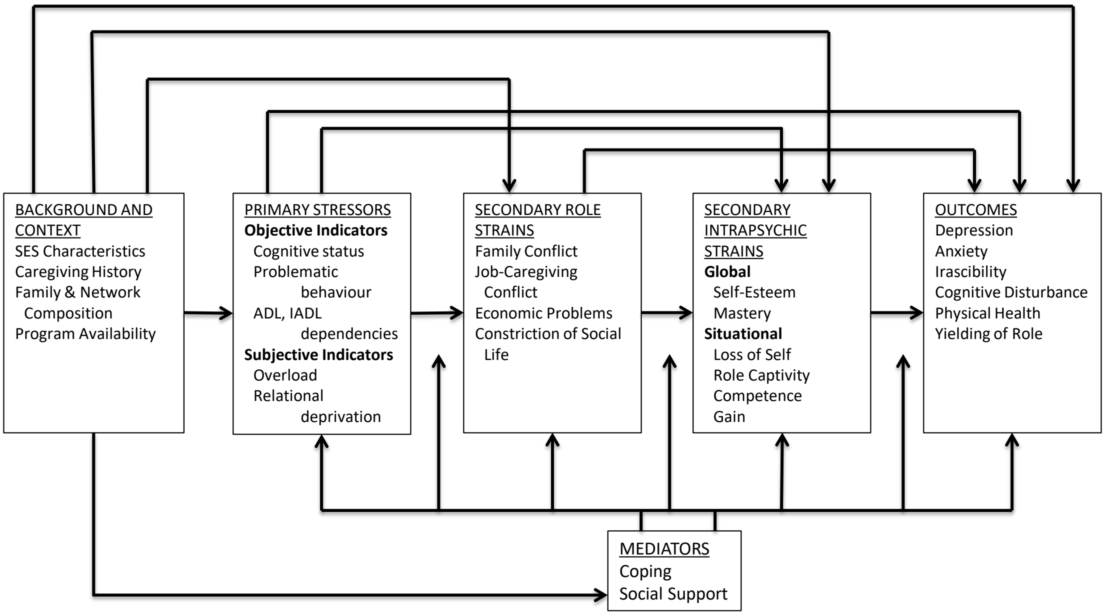

Figure 5.1. Pearlin et al.'s Stress-process model. (Taken from Pearlin et al., 1990, used with permission from the publisher Oxford University Press.)

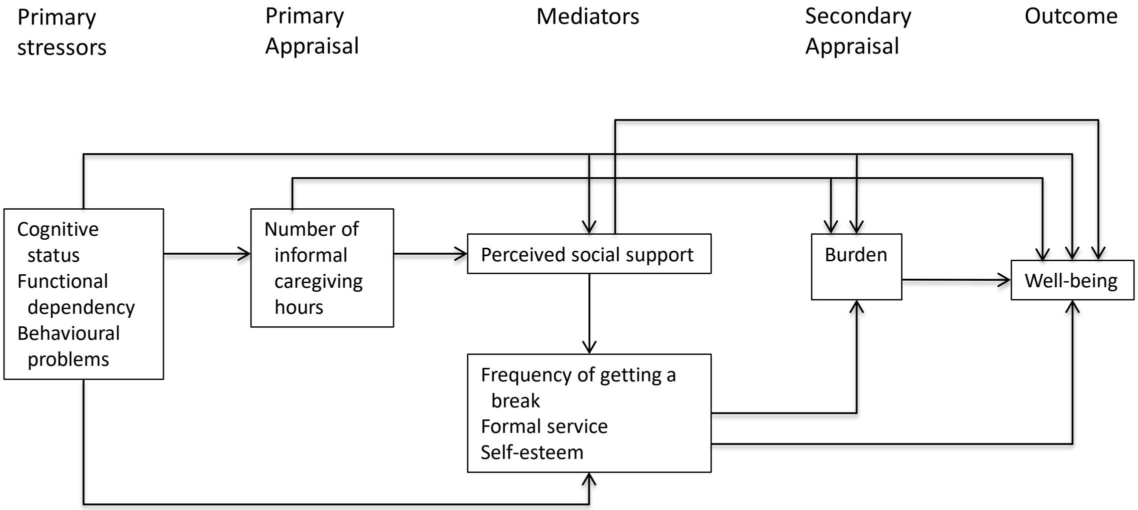

Figure 5.2. Yates et al., (1999) Stress-Process model. (Reproduced from Bastawrous, 2013, used with permission from publishers Elsevier and Oxford University Press.)

Although some stress theories take into account the impact of the caregiving role on the other roles the caregiver undertakes (for instance work or child caring responsibilities), role theory focuses specifically on how the various roles interact and the implications this has for burden, in particular, the impact of role overload and conflict (Biddle, 1986).

Measuring the impact of caregiving

Oyebode (2003) highlighted the importance of distinguishing between objective and subjective burden. Objective burden refers to the additional practical support or assistance that is required. Subjective burden is the emotional and cognitive reaction to caregiving. Thus they are similar to the 'stressors' and 'appraisals' specified in the stress-process models described above. It is important to distinguish between them as two caregivers could perform the same tasks for their patients (i.e. objective burden), but one may feel differently about the impact of this than the other due to their personal interpretation of the situation (i.e. subjective burden). Failure to distinguish between the two has been argued to hinder the understanding about the source of burden which limits the ability to design interventions of benefit to caregivers (Bastawrous, 2013).

The impact of providing support to someone with low-vision

There has been very little research on the experiences of caregivers providing support to people with VI, particularly people with macular conditions. The results of the Macular Society Survey 2013 (herewith '2013 survey') show that 52.3% of members perceive themselves to have a friend or family member who provides unpaid care, support or assistance to them because of their macular condition, yet this population has been relatively understudied.

Other research suggests a high number of caregivers that provide support to people with VI. For example 20% of caregivers in the UK report looking after someone with a sensory impairment (The NHS Information Centre, 2010).

The majority of research into the experiences of providing support to someone with AMD have focused on caregivers who support someone living with *wet* AMD. The Caregiver Reaction Assessment (CRA, Given et al., 1992) measure has been used to assess reactions to supporting someone receiving treatment for wet AMD. Gohil et al. (2015) found caregiver 'burden' was associated with caregiver activities related to treatment (e.g. taking pwAMD to eye clinics) and to disease impact (visual function scores, visual acuity in better eye and the number of injections received). The level of caregiver 'burden' reported by the 250 caregivers studied, was similar to that reported for caregivers of people with atrial fibrillation who required regular hospital appointments for monitoring thromboprophylaxis (see Coleman et al., 2012). Around 70% of caregivers reported attending 10 or more eye clinic appointments in the past year, with around 25% requiring time off work to support the pwAMD with their treatment. Ten percent reported this had led to a loss of income. The majority of caregivers recruited were women (63%). Female caregiver gender was a significant predictor of caregiver burden.

Although validated measures of caregiver or pwAMD psychological health were not included in the Gohil et al. (2015) study, there were indications that caregivers' mental health was affected by caregiving. Caregivers reported specific health problems due to providing care, including anxiety (38.8% of caregivers), tiredness (39.6%) and depression (29.6%). Over half of the caregivers reported they had not received information about wet AMD, its treatment, potential loss of vision, or any further support that might be available to them to help them in their caregiving role.

Similarly, Gopinath, Kifley, Cummins, Heraghty, and Mitchell (2015) focused on caregivers of people with wet AMD, however they designed a bespoke questionnaire instead of using validated measures. They found that caregivers who perceived the pwAMD was 'highly dependent' on them were more likely to report caregiver distress. Other predictors of caregiver distress included the pwAMDs' severity of sight loss, male pwAMD gender and caregivers' own health. More than half of the sample reported a 'negative state of mind' and having to make changes to their lives because of the impact of caregiving, including making changes to their retirement plans as well as their everyday plans. Caregivers who supported someone who was blind, compared to supporting someone with good vision, were more likely to provide daily or constant care, have a negative state of mind and have their lifestyle and retirement plans affected due to providing care. Interestingly, care providers who reported the pwAMD was currently receiving treatment for their eye condition, were less likely to report feeling that the pwAMD was dependent on them. The authors suggested that treatment may maintain the quality of life and independence of pwAMD, thereby potentially reducing the risk of caregiver burden. Alternatively it could be that caregivers are convinced that treatment might prevent the pwAMD experiencing permanent vision loss and this hope could impact on caregiver outcomes. This study therefore adds to the findings of Gohil et al. (2015) who only included caregivers who were supporting pwAMD receiving treatment. The findings of Gopinath et al. (2015) suggest that caregivers of pwAMD not receiving treatment may have poorer caregiver outcomes than those who are looking after pwAMD receiving treatment.

The free-text response questions included in the same survey sent to caregivers in the Gopinath et al. (2015) study were analysed using an 'inductive' grounded theory approach and reported separately (Vukicevic, Heraghty, Cummins, Gopinath, & Mitchell, 2016). The authors argued that the qualitative data provide an understanding of the reasons for caregiver distress that add to the predictors identified by Gopinath et al. (2015). Vukicevic et al. (2016) reported that caregivers were 'compassionate and self-sacrificing', and provided encouragement to the pwAMD whilst taking on the additional responsibility of caregiving. They reported that lack of outside help (either sought or received) had a negative impact on the relationship between the pwAMD and their caregiver. The researchers only analysed data from caregivers. The pwAMD perspective may help to validate the findings. The authors concluded 'It is quite evident that caregivers are very special people and require more support than currently available to them to prevent or ease the known issue of distress experienced as a result of caring' (p421, Vukicevic et al., 2016). They argued that the experience of providing care to someone with AMD doesn't only involve stress and burden (as could be concluded from quantitative studies), as these aspects were not identified by participants as being the most important aspects of providing care. Instead the qualitative data found that altruistic personality traits and compassion, empathy and self-sacrifice were important in providing care.

A global cohort of people with wet AMD and their caregivers took part in a survey in 2012 that spanned nine countries including Australia, Brazil, Canada, France, Germany, Italy, Japan, Spain and the UK. The survey was developed through collaboration between members of an independent steering committee including ophthalmologists. The results have been reported in several papers (Varano et al., 2015, 2016). The respondents were all receiving anti-VEGF injections at the time of recruitment, or had received them recently. The majority of people with wet AMD reported receiving help from a paid or unpaid caregiver (82%). Most caregivers were the child or grandchild of the pwAMD (47%). Sixty three percent of caregivers lived with the pwAMD.

Varano et al. (2016) reported that 31% of caregivers felt providing support to the pwAMD had a negative impact on their lives, however 35% reported a positive impact. Thirty five percent of caregivers reported feeling sad and 24% reported depression. An increase in negative emotions was associated with longer duration of AMD and AMD in both eyes compared to one. The authors reported that the emotional impact of the diagnosis of AMD on the caregiver was similar to that on the pwAMD. However positive aspects of caregiving were also reported; 48% reported that it made them feel ‘useful’.

Caregiving impacted on the caregivers’ schedule; 27% of caregivers rated caregiving as ‘inconvenient’ (Varano et al., 2016). This was linked to missed days of employment or personal obligations. The most frequent type of support provided by the caregiver was help with travelling to appointments. The level of support provided tended to increase with the duration of AMD. Fifty four percent of pwAMD reported being dependent on the person who provides them with care, which is slightly lower than the percentage of caregivers who reported that the pwAMD they provide support to was dependent on them (57%). PwAMD in one eye were more likely to report needing support on an ‘as needed’ basis. Twenty six percent of pwAMD reported a fall in the previous two years due to VI, and just over a third (34%) of these had been hospitalised as a result of the fall. The majority of caregivers always attended treatment appointments with the pwAMD (60%) (Varano et al., 2015). Some reported being able to reduce the amount of domestic assistance provided after starting treatment (30%), with just over half reporting a temporary improvement or stabilisation in the pwAMD’s vision (Varano et al., 2015). Lack of information about the condition was cited as one obstacle to coping with the diagnosis of AMD by 11% of pwAMD and 16% of caregivers. Lack of understanding of AMD was also highlighted as an issue by 25% of caregivers (Varano et al., 2015).

These studies provide some information about the demographic characteristics of caregivers of people who support someone living with wet AMD. They also provide information on the emotional impact of AMD and the types of support provided.

Analyses are mainly descriptive and although some studies recruited pwAMD/ caregiver pairs, these data have not yet been analysed as a dyad within the context of the shared impact of living together with AMD. Some results are suggestive of the dyadic nature of coping with AMD, e.g. Varano et al. (2016) found that caregivers and pwAMD reported similar emotional impact following diagnosis, however only descriptive data were reported. Additionally, validated measures were not used to measure patient-reported outcomes including depression or well-being. The findings reported by Vukicevic et al. (2016) indicate that qualitative research methods may be useful in highlighting both negative and positive aspects of providing support.

Health outcomes in patient-caregiver dyad research

What has been lacking, not just in AMD research, but more generally, is the study of support as a two-way process. Research typically considers the support recipient or provider in isolation and ignores their interactive relationship, leaving us with an incomplete picture. More recently, this has been changing.

One recently proposed method for studying dyadic outcomes that is rising in popularity is the Actor-Partner Interdependence Model (APIM; Cook & Kenny, 2005). This model takes into account the effect of an individual's own influence or characteristics on an outcome (referred to as actor effects), as well as the effect of their partner's (referred to as partner effects). Actor effects are estimated after taking into account partner effects (and vice versa). This method has been used to investigate, for instance, the actor and partner effects of spouse health on marital satisfaction (Korporaal, van Groenou, & van Tilburg, 2013), the impact of chronic cardiovascular disease patients' and their spouses' illness cognitions on psychological symptoms (depression and anxiety), whilst controlling for marital quality (Karademas, 2014), and the relationship between advanced cancer patients' and their caregivers' mental health, physical health and self-efficacy over time (Kershaw et al., 2015).

There has been some research examining the influence of a person with VI's outcomes on their caregiver, however none of which have used the APIM. For instance, Bambara et al. (2009) found 35% of their sample of family caregivers of people with VI were identified as being at risk for depression (using the Center for Epidemiologic Studies-Depression Scale, CES-D). Caregivers' symptoms of depression and their life satisfaction scores were associated with the person with VI's own symptoms of depression.

Strawbridge, Wallhagen, and Shema (2007) summarised three conceptual frameworks that might be appropriate for explaining why the person with VI might affect their caregivers' physical and psychological health outcomes. First, communication theory states that VI may affect communication patterns between pairs. Although people with VI may still be able to interact verbally without problems, non-verbal communication may be affected. Non-verbal cues can indicate emotional content of communication, and so without being able to see these cues, the person with VI may misinterpret the meaning of what is being said (Heine & Browning, 2002). Strawbridge et al. (2007) argued that this could result in a feeling of lack of connectedness within pairs which could negatively affect pair's well-being.

Secondly, affect or emotional contagion refers to a process where an individual's mood spreads to others who are in close contact (Bookwala & Schulz, 1996). According this theory, changes in an individual's mood should be followed in time by similar changes in their partner's mood. Studying this theory would require a longitudinal analysis.

Lastly, Strawbridge et al. (2007) suggested that the stress-process model (Pearlin et al., 1990, as described above) may be a relevant framework for explaining the impact of a person's VI on their partner's or caregiver's outcomes. However, Strawbridge et al. (2007) acknowledged the model was designed for caregivers of people with dementia and so may contain illness-specific aspects not relevant to the study of VI.

Strawbridge et al. (2007) conducted a longitudinal study to investigate the impact of VI within married couples where one has VI. They found that VI negatively impacted spouses' depression, physical functioning, well-being and marital quality. These effects were similar to the impact of VI on the individual with VI's own outcomes. There were gender differences. Husbands' VI impacted more negatively on wives' social involvement, well-being and marital quality than the impact of wives' VI on husbands' outcomes. The results were discussed in relation to each of the above frameworks. Strawbridge et al. suggested their results were in line with communication theory and with the Pearlin et al. (1990) stress-process model, however further work would need to be conducted to confirm this. Nevertheless, this suggests that models of caregiver burden would be appropriate to assess the impact of AMD on both patient and caregiver outcomes.

The only dyadic qualitative research study to explore the impact of AMD was conducted by Burton, Shaw, and Gibson (2015). They reported a longitudinal qualitative case study of a married couple who both had AMD. Three themes were discussed. The first, “the disruption of visual impairment”, described how the couple made ‘sense’ of the impact of AMD including impact on their activities. The second theme, “managing mutual deterioration”, describes the ebb and flow over time of changes in autonomy, dependency and increasing disability. It also refers to each member of the dyad using their partner’s AMD as a frame of reference with which to compare to their understanding of their own AMD. Finally, “resilience through togetherness” describes the joint experience of coping with AMD. The researchers described how the couple’s lives were ‘knitted together’ (p1291) since having spent their adult lives together, and argued for the importance of understanding the experience of living with a long-term condition in old age within a wider context of ‘home life, the interdependence between partners and the impact of co-morbidities’ (p1291) (Burton et al., 2015).

Summary

Research into positive and negative types of social support received for VI paints a complicated picture of the impact of receiving support for VI. *Received* instrumental support is related to negative outcomes such as higher risk for depression. However *perceived* instrumental support is related to better adaptation to VI. Perceived overprotection has been linked to a range of poorer psychological health outcomes for people with VI. The antecedents to overprotection have yet to be confirmed, but one study suggested it might arise from caregiver resentment and negative affect towards the patient (see Thompson et al., 2002), however others have suggested overprotection may be unrelated to hostility (Fiske et al., 1991). Additionally the impact of receiving support have yet to be investigated in pwAMD specifically.

There is a wealth of both qualitative and quantitative research into the experience of caregiver burden for chronic conditions. However there has been much less research on caregivers of pwAMD. Several researchers have highlighted the emotional and physical impact of supporting someone living with AMD. However the majority of studies have focussed on caregivers supporting pwAMD who have received treatment for wet AMD, and have yet to explore the experiences of people supporting someone with dry AMD or untreatable wet AMD. Nevertheless, the reported impact on caregivers indicate that this is an important research topic needed to determine how best to support caregivers of pwAMD.

In the past few years, there has been a gradual increase in studying the dyadic response to illness. This research area benefits from more sophisticated statistical analysis techniques (e.g. the APIM) and the rising popularity of qualitative research. The field of coping with VI or AMD has yet to bring together research into caregiver burden, dyadic coping with illness, social support and overprotection to investigate coping with AMD as a dyadic and dynamic system.

The next step in the research reported in this thesis is to investigate further the reasons why pwAMD who reported receiving care in the Macular Society 2013 survey were more likely to report poorer QoL and well-being even after controlling for degree of VI (using registration status and pwAMD-reported change in vision status since diagnosis). As discussed above, there are theoretical perspectives and models that suggest that patient/ caregiver pairs may affect each other's psychological and physical health. Only one study has examined the impact of AMD using a dyadic approach (Burton et al., 2015), however both individuals were living with AMD and could be argued to have different experiences from people who support someone with AMD who do not themselves have any VI. In order to further the research in this area, both the well-being of the pwAMD and their caregiver will be investigated using a dyadic perspective.

What is the difference between 'providing support' and being there for your loved one whilst they are coping with a chronic condition? Is there one? Evidence from qualitative literature suggests the label of 'caregiver burden' may be rejected by some caregivers (e.g. Greenwood & Mackenzie, 2010). Is there any benefit in perceiving support provided in a relationship to be 'care', with caregivers experiencing 'caregiver burden'? The author believes that research might move forward by taking a holistic view of the impact of living with AMD and using a dyadic perspective.

Chapter 6:

The impact of providing and receiving support for AMD: A mixed methods study of person with AMD/ caregiver dyads: Methodology.

Introduction and rationale for this study

Chapter 4 reported the findings from the Macular Society 2013 survey that suggested that receiving care for AMD was related to poorer well-being and quality of life (QoL), after controlling for degree of visual impairment (VI) using registration status and patient-reported change in vision status since diagnosis. Respondents who reported receiving more hours of care a week for their AMD, were more likely to report poorer well-being, after controlling for other factors including registration status, self-reported vision loss since diagnosis, age, gender, whether they lived alone, general health status and whether their caregiver was their spouse, adult-offspring or 'other' type of pwAMD/caregiver relationship (friend, neighbour or other family member).

The aim of the quantitative second study was to investigate reasons for the relationship between receiving more care for AMD and poorer well-being. The quantitative first study relied on registration status and patient-reported change in vision status since diagnosis as indicators of degree of VI. However previous research indicates that people with VI may not be appropriately registered (Thetford et al., 2009). People with VI whose vision has deteriorated to a point where registration is applicable, may not be registered. Furthermore, people registered as SI who have experienced further vision loss may not be registered as SSI (see Chapter 1 for a discussion). The single-item question designed by the author that was used as a subjective measure to assess respondents' change in vision status since diagnosis (whether vision is better, the same or worse), had a lower than expected correlation with registration status in the results presented in Chapter 4. It was considered that it may not accurately reflect level of VI (as discussed in Chapter 4). Subsequently, the quantitative second study used a validated measure of pwAMD difficulty carrying out vision-dependent tasks as an indicator of level of VI. PwAMD ability to manage activities of daily living was also measured in order to assess the amount of help required. Replicating the first study, data were collected on pwAMDs' perceptions of the amount of help received per week. It was hypothesised that the amount of help required, would predict the amount of help received. The questionnaires used were expected to provide a more detailed picture of the pathways to the well-being and QoL of pwAMD.

A review of the literature reported in Chapter 5 found that there was very little reported research on the experiences of people who provide help, support or assistance to pwAMD, and in particular, for people with dry AMD. The quantitative study to be reported here explores caregiver reactions to providing support for people with dry and wet AMD. It also examines the predictors of reactions to providing support and caregiver well-being and QoL. The Yates et al. (1999) stress model is used as a framework; combining pwAMD and caregiver factors into one model.

The qualitative third study follows the quantitative second study and explores the findings of both quantitative studies in greater detail.

The overall aim of this study was to explore the impact of receiving and providing support for AMD in more detail. A dyadic approach was used for both the quantitative and qualitative studies to take into account the interactive relationship between the support recipient and provider.

Philosophical and methodological framework

Taking a pragmatic approach, this study used a sequential mixed methods design to answer the research questions. The second quantitative study used quantitative research methods to build on the quantitative first study findings. This methodology was chosen given one of the reasons for carrying out the research was to explore the use of other quantitative measures to help explain the first study findings. However using quantitative measures provides a somewhat reductionist view of the impact of providing and receiving support for AMD that might not fully capture the individuals' experiences. So in order to investigate this research aim more comprehensively, a qualitative third study was added to help explain and add to the quantitative study findings. Using more than one method or source of data in the study of social phenomena is referred to as triangulation. Triangulation is typically employed for three main reasons: confirmation, completeness and abductive inspiration (Risjord, Moloney, & Dunbar, 2001). In other words, a mixed methods approach was used in order to maximise reliability and validity through using both qualitative and quantitative approaches to corroborate findings, to build a more comprehensive picture of the phenomena under study and to begin to make inferences about the causal mechanisms that account for the phenomena (Risjord et al., 2001). However Risjord et al. (2001) noted that there is still controversy as to whether quantitative and qualitative methods can together confirm study findings to a greater degree than either method alone.

The quantitative second study was used to facilitate the sampling of participants for the qualitative third study. The two methods are given equal priority in this research study. It was felt that by using both quantitative and qualitative research methods to answer the research aims, one could gain a more complete understanding of the impact of receiving and providing support for AMD.

Theoretical perspective, methodology and methods

As discussed in the literature review in Chapter 5, several different theories have been proposed to explain the impact of providing support, however two theories that have been suggested to be most relevant to the field are stress theory and role theory (Bastawrous, 2013).

Highlighted by several 'stress' theories (e.g. the stress process model of Pearlin et al. (1990) and the stress model of Yates et al. (1999)) is the importance of distinguishing between objective and subjective burden in assessing the impact on the caregiver. Objective burden indicators include the patient's cognitive status, problematic behaviour and difficulties with activities of daily living (ADL) and/or instrumental activities of daily living (IADL). The models differ on the perception of whether subjective burden is perceived as a primary stressor alongside the objective indicators (as stated in the Pearlin et al. (1990) model) or whether subjective burden is seen as part of a secondary appraisal of providing care (Yates et al. (1999)). Whilst the Yates et al. (1999) model views only mental health as a caregiver 'outcome', the Pearlin et al. (1990) model includes several outcomes including both mental and physical health.

The *measures* section in this chapter explains which objective and subjective burden measures were chosen. The model proposed by Yates et al. (1999) was used as a framework given that the ‘primary appraisal’ included in the model was in line with the measure used in the first quantitative study (number of hours of care provided), and this is also included in the second study. Additionally, the hypothesis that objective burden (primary appraisals) would predict subjective burden (secondary appraisals) seemed plausible.

Previous research on the impact of receiving support for VI has mainly focused on the risk of overprotection (e.g. Cimarolli, 2006). However, as described in the literature review, there may be other appraisals of the impact of receiving support that help to explain well-being and QoL. There are currently no validated questionnaires measuring the impact of receiving support for AMD/ VI that could be used in the quantitative study. Therefore both negative and positive appraisals of receiving support were explored in the qualitative study.

Whilst the theories discussed so far have focussed on patient- or caregiver-specific explanations for impacts on well-being or QoL outcomes, there has been less research looking at the experience within the patient-caregiver dyad. Thus the choice of measures of predictors of patient or caregiver outcomes could not be informed by any existing theoretical frameworks.

This research used methods and analysis specific to dyad-based research (as far as possible). They will be described in the relevant sections in this chapter.

QUANTITATIVE STUDY

Aims

The aims of this study were to investigate further the impact of receiving support for AMD, and to assess the impact that providing support for someone with AMD has on their caregiver. The main aims were to confirm the 2013 survey findings, examine the predictors of: pwAMD and caregiver hours of care received/ provided, caregiver reactions to providing support, and pwAMD and caregiver outcomes. The direction of relationships between predictors and outcomes were informed by the stress model of Yates et al. (1999).

Research design

The above aims were investigated in the quantitative strand of the mixed method study used postal questionnaires.

Participants and procedure

At the end of the Macular Society 2013 survey, respondents were asked to provide their own and their caregiver's contact details if they were interested in receiving information about taking part in future research. Of the 1413 respondents to the 2013 survey who had AMD, 137 provided their contact details and those of their caregivers (9.7%). They were sent questionnaire packages in October and November 2015 containing an information sheet explaining both stages of the research study (the quantitative and qualitative parts), a consent form, the questionnaires (detailed in the 'materials' section) and a stamped addressed return envelope. Participants were asked to contact the researcher if they would prefer to go through the questionnaires over the phone. The researcher audio-recorded verbal consent from participants before going through the questionnaires.

Included in the questionnaire pack was a response slip. Participants were asked to complete and return this if they did not want to take part in the research. Participants who had not returned this response slip or a completed questionnaire were contacted once more via email (if they had provided an email address) or by telephone to check they had received the questionnaire pack.

There were some instances where questionnaires were returned with pages uncompleted. It was considered that these pages may have been unintentionally missed out. Photocopies of the blank pages were sent back to participants to ask them to either complete and return these pages using the stamped addressed envelope provided, or to complete and return a reply slip stating they had intentionally left these responses blank. This was done to reduce missing data.

The exclusion/ inclusion criteria were as follows: participants were required to have a good standard of spoken and written English and be over the age of 18. Caregivers needed to be the primary caregiver, and not be formally paid for this role. All participants met these criteria.

Ethics

This study was approved by Royal Holloway, University of London ethics committee (Application number: 04/15).

MEASURES

Questionnaire Package Design

So that the results from the respondents with AMD from this study could be compared with the results from the Macular Society 2013 survey, several of the same measures were used (for more detail on these measures, see Chapter 2). It was important that pwAMD and caregivers completed the same measures for the appraisal of the number of hours of care received/ provided and well-being so that the non-independence of the dyads could be controlled for in multivariate analysis.

Questionnaires sent to pwAMD and their caregivers (these match the measures used in the Macular Society 2013 survey):

- Well-being, using the 16-item Well-Being questionnaire (W-BQ16). This contains four subscales: negative well-being, positive well-being, energy, and stress. For all scales/ subscales, higher scores represent more of the type of well-being indicated by the name of the scale/ subscale. Scores for the total scale range from 0-48.
- Quality of life, using two overview items from the MacDQoL (Mitchell et al., 2005). One item assessed general quality of life (QoL). The other assessed the impact of AMD on their QoL. The latter was adapted for caregivers. Caregivers were asked, ‘If I did not provide care to my friend or relative with a macular condition, my quality of life would be:…’ The response options for this item for the pwAMD were unchanged, and on a 5-point scale (very much better/ much better/ a little better/ the same/ worse). As the adapted question for caregivers had not been tested before, the ‘worse’ option was split into three response options in order to add balance to the scale. These were: ‘a little worse/ much worse/ very much worse’. Higher scores indicate less negative (or more positive) impact of caring for someone with MD on the caregiver’s QoL.

- General health status (single-item self-assessment of their general health). Participants were asked, ‘In general, my health is:’ followed by a 7-point scale scored as: 7=excellent, 6= very good, 5= good, 4= neither good nor bad, 3= bad, 2= very bad, 1= extremely bad. Higher scores indicate better general health.
- Self-reported registration status (for pwAMD only). Response options were ‘not registered/ registered as sight impaired (visually impaired) or registered as severely sight impaired (blind)’.
- Amount of care received/ provided for AMD (‘primary appraisal’ of caregiving). PwAMD were asked to state the person who ‘most often’ provided them with help, support or assistance. Their response was compared with the details of the caregiver we had on record, to check they were their main caregiver. Participants were then asked: ‘Please tick how many hours per week this person spends helping you (on average)’. Caregivers were asked: ‘Please tick how many hours per week you spend helping them (on average)’. Both the questions to the pwAMD and caregiver had the same 4-point ordinal response options: fewer than 7 hours per week/ 7 to 14 hours/ 15 to 35 hours/ more than 35 hours per week. Higher scores indicate that the participant received/ provided more hours of care.

The measures in this study that were not included in the Macular Society 2013 survey are described separately for the pwAMD and caregiver below.

Additional questionnaires sent to pwAMD

Amount and type of help required

A review of the literature found no standardised questionnaire designed to measure the amount and/or type of support received/provided for AMD or for VI generally.

Three different measures were therefore used to assess the amount and type of support that might be required, and to see if these would predict the amount of support received for AMD (the pwAMDs’ primary appraisal), the amount of support provided for AMD (the caregivers’ primary appraisal), caregivers’ reactions to providing support and pwAMD and caregiver outcomes. PwAMD general health status (as described above), difficulties with instrumental tasks of daily living and a vision function measure were used.

Instrumental Activities of Daily Living (IADLs)

Ability to carry out instrumental activities of daily living were assessed using a 8-item measure used in previous research with pwAMD (Hochberg et al., 2012). IADLs included eight activities: preparing meals, grocery shopping, managing one's own money, using a telephone, heavy housework, light housework, getting to places beyond walking distance, and taking medications. Participants were asked to rate each IADL on a 4-item scale, where 1= 'No difficulty', 2= 'with difficulty, but without help', 3= 'with help', 4= 'unable to perform task'. In line with previous research, participants were considered to have a disability regarding a specific IADL if they reported doing the task with help or not doing the task at all (e.g. Hochberg et al., 2012; Shumway-Cook et al., 2007). Therefore scores of 3 or 4 were recoded as 1 (to show an inability to complete this task alone), and scores of 1 or 2 were recoded as 0 (to show they were able to complete this task alone). Individual scores for each IADL were added together to give a total score which ranged from 0 (can perform all IADLs with or without difficulty) to 8 (inability to perform any of the IADLs alone).

Daily Living Tasks Dependent on Vision (DLTV)

The DLTV was included to assess the impact AMD had on vision-related tasks. This measure was developed, designed and tested in pwAMD (Hart, Chakravarthy, Stevenson, & Jamison, 1999). It consists of 24-items. Two items ask respondents to rate their overall distance and near vision on a scale of 1 (poor) to 4 (excellent). These two items are not normally included in the DLTV total score. The remaining 22-items cover a range of aspects of visual function including far distance, intermediate and near vision, binocularity, field of vision, light and dark adaptation and contrast sensitivity. Participants were asked to score each of these to reflect the level of difficulty they have with each task. The scoring reflects the following responses: 4= no difficulty, 3= a little difficulty, 2= a lot of difficulty, 1= cannot see to do. The total DLTV score can range between 22 and 88. Total scores were reverse coded so that higher scores indicated poorer visual function.

The DLTV was found to be able to distinguish between pwAMD and people with cataracts (Hart et al., 1999). It is also able to discriminate between different levels of severity of AMD (Schmier, Halpern, & Covert, 2006). The DLTV has been used in RCTs for subfoveal radiotherapy and shown sensitivity to changes in vision over time (Stevenson et al., 2005).

The NEI-VFQ (Mangione et al., 1998) is more commonly used in AMD population studies and clinical research than the DLTV (Finger, Fleckenstein, Holz, & Scholl, 2008). However this measure was designed for people with vision loss (rather than AMD specifically), meaning that it may not contain items pertinent to pwAMD. It may also contain items not perceived as relevant to pwAMD (e.g. items on ocular discomfort). The DLTV was chosen over other measures of visual function for the following reasons: its appropriateness in measuring the intended construct (the items are more specific to tasks of daily living that might require help, and therefore had 'face validity' for the study aims), it's applicability and relevance to the AMD population, the length of the questionnaire (it is shorter than the NEI-VFQ 25), and its ability to be used as a pen and paper questionnaire.

One aspect of functioning not measured in the DLTV is driving status. It was considered that including a measure of this would be particularly relevant to this research topic given that this may be one of the activities caregivers undertake as part of providing support. Questions on driving status were added to the end of the DLTV.

Participants were asked a series of questions on whether they had ever driven and whether they currently drive. For those who had stopped driving, they were asked whether this was due to their AMD. For those who still drive, they were asked if they felt able to drive under certain conditions: 'to familiar places in daylight/ in the dark', and 'to unfamiliar places in daylight/ in the dark'. Responses were a yes/ no tickbox. Finally they were asked whether or not their caregiver currently drove, and if yes, whether they 'drove them to places'. The above questions were designed to measure the level of pwAMDs' functioning, i.e. whether or not they could drive and their ability to drive under certain conditions. It was also included to ask directly about a caregiver activity.

Additional questions for caregivers of pwAMD

The Caregiver Reaction Assessment Instrument

The Caregiver Reaction Assessment (CRA, Given et al., 1992) was used to assess the impact of providing support for the pwAMD. The CRA was developed and tested in caregivers of elderly people with physical impairments, Alzheimer's disease and cancer. It is a 24-item scale assessing both positive and negative reactions to providing support. It consists of five subscales measuring caregiver esteem, family support for help with caring, and impact on finances, health and the caregiver's schedule.

The CRA has since been used in research with caregivers of people with other conditions (e.g. dementia, cancer, chronic obstructive pulmonary disease, multiple sclerosis) (e.g. Burton et al., 2012; Forbes, While, & Mathes, 2007; Persson, Wennman-Larsen, Sundin, & Gustavsson, 2008). More recently it's been used to assess the impact of supporting someone receiving treatment for wet AMD (Gohil et al., 2015). Deeken, Taylor, Mangan, Yabroff, and Ingham (2003) reviewed and recommended the CRA for use in caregiver research. In the original development paper, the CRA demonstrated good internal consistency (Cronbach's alphas for the five subscales range from 0.80-0.90), construct validity (it correlated as expected with measures of depression and activities of daily living), content validity and stability over time (Given et al., 1992).

The CRA was chosen over a more well-known measure of 'caregiver burden'- the Zarit Burden Interview (ZBI, Zarit, Reever, & Bach-Peterson, 1980). The review by Deeken et al. (2003) stated the ZBI had not yet undergone rigorous psychometric testing (including assessments of reliability). It has also been criticised for being unidimensional and not reflecting the impact of caregiving on multiple aspects of caregivers' lives (Given et al., 1992). The measure has since been validated in diverse samples, undergone testing of its factor structure and been tested in various short-form versions (e.g. Hébert, Bravo, & Préville, 2000; Higginson, Gao, Jackson, Murray, & Harding, 2010). However since the ZBI had been designed for caregivers of people with dementia, some of the items were not thought to be relevant to the caregivers in this study (e.g. 'I feel embarrassed over my spouse's behaviour', 'I feel uncomfortable when I have friends over'). Therefore the CRA measure was used.

In order to establish the applicability of the CRA to caregivers of pwAMD, two questions were added after the CRA. Caregivers were asked ‘Are there any other areas of your life that you feel have been impacted on by providing care for the person with a macular condition that were not asked about in these questionnaires?’ and ‘Were there any questions that you found particularly difficult to answer, or that you felt did not apply to you? If so, which question(s)?’ Text boxes were provided for the participants’ response.

Global indicators of the impact of providing care

Two overview items were designed to assess the impact of caregiving. The first asked about the negative impact: ‘In general, I feel that providing care to my relative or friend with a macular condition, has a negative impact on me and my life’. The other asked about the positive impact: ‘In general, I feel that providing care to my relative or friend with a macular condition, has a positive impact on me and my life’. Both questions had the same response scale, ranging from 1 (strongly disagree) to 6 (strongly agree). These questions were included to see if they correlated with the CRA total or subscale scores.

Additionally, a question on the level of dependency of the pwAMD was included. This question was based on a similar question used in the Gopinath et al. (2015) research study reported in Chapter 5 (the question stem was not included in the study report and thus could not be replicated). In the present work, caregivers were asked: ‘How dependent do you feel the person with the macular condition has been on you since diagnosis?’ Responses were on a 5-point scale: ‘not at all’/ ‘somewhat’/ ‘moderately’/ ‘very’/ ‘extremely’ dependent. This question was included because caregivers’ perceptions of care recipient dependency were related to caregivers’ negative state of mind, changes to their lifestyle, and changes to their retirement plans (Gopinath et al., 2015). An indicator of dependency as an appraisal of providing support is not included in the CRA. Given the potential impact of this on caregiver outcomes, this item was included in the present study.

Socio-demographic, and additional questions on care, and eye- and health-related characteristics

Socio-demographic questions

Participants were asked to complete a short questionnaire which included questions on socio-demographic variables (marital status, employment status, highest qualification obtained). Caregivers were asked to provide their date of birth, gender, ethnic group, whether English was their first language and if not, to rate their level of fluency in English on a scale of 1 (very basic) to 7 (very fluent). PwAMD had already been asked for this information in the Macular Society 2013 survey and so were not asked again. Caregivers were asked if their employment status had changed since they had started providing care for the pwAMD. Response options were (tickbox response): gave up work, reduced work hours, took paid leave, took unpaid leave, or none of the above. An ‘other’ response option was included, with a free-text box response where participants could state any other changes to their employment due to providing care. Caregivers were asked whether they had children, and if so, to state how many they had and their age/s.

Details of caring

Caregivers were asked to state what relationship they had to the pwAMD (i.e. husband, daughter). This was included to check they matched the pwAMD’s response on who was their main caregiver. A question on the length of caring was included: ‘How long have you been providing care/ support/ assistance to the person with a macular condition, because of this condition?’ There were three response options: ‘less than a year’, ‘between 1 and 5 years’ and ‘more than 5 years’. Caregivers were asked if they had provided care to the pwAMD before the diagnosis of AMD (yes/ no response). If they ticked ‘yes’, they were asked to provide details.

Caregivers were asked if they lived with the pwAMD (response was a yes/ no tickbox).

Both pwAMD and their caregivers were asked: ‘Does anyone else provide *you/ them* with assistance (because of *your/ their* macular condition)?’ (Words in italics were used as appropriate.) This was followed by a yes/ no tickbox response. Participants were asked to give the name of the person(s) and their relationship to the pwAMD, if relevant.

Treatment for AMD

PwAMD were asked if they had ever received treatment for their macular condition. This had a yes/ no tickbox response. They were also asked if they were currently receiving treatment for AMD and to state the name of the treatment, if known. These questions were added to explore the impact of receiving treatment.

Comorbid health conditions

PwAMD were asked whether they had any of the following medical conditions: diabetes, stroke, heart attack/ heart disease, kidney disease, asthma/ lung disease. Participants were asked to write down any other 'serious or long-term condition(s)' if they did not appear in this list. This question was included to establish whether participants might be receiving care or treatment for another condition.

See Appendix 9 for the questionnaire package sent to the pwAMD, and Appendix 10 for those sent to their caregiver.

Questionnaire Package Presentation

The same design and presentation guidelines for questionnaires designed for pwAMD were followed as those used in the Macular Society 2013 survey (see guidelines in Chapter 2). These guidelines were applied to the questionnaires for both the pwAMD and their caregivers.

The order in which the questionnaires appeared in the booklet were considered carefully. In order to maximise the response rate, respondent fatigue and the potential impact of the sensitive and emotive nature of some of the questionnaires were taken into account. The potentially sensitive questions and questionnaires asking the pwAMD about their well-being and QoL were placed in the middle of the booklet instead of near the front of the booklet. It was hoped that this would avoid the perception that the entire booklet contained measures of an emotive nature which may have negatively influenced participants' willingness to complete the rest of the questionnaire. Instead the IADL and DLTV measures were put at the front of the questionnaire package as these were perceived to be less sensitive, but still important for data analysis. Since caregivers were not asked to complete the IADL or DLTV, the CRA was placed at the front of their questionnaire booklet. The additional questions on socio-demographic data etc., were placed at the end of the questionnaire as these were considered to be the least important for data analysis (in case respondent fatigue meant participants missed out questions).

The questionnaire booklet, including a 2-page consent form, was 16 pages for the pwAMD, and 15 pages for caregivers. Pages were printed double-sided.

Data analysis

Frequencies and means were used to describe the sample. The characteristics of the sub-sample of 2013 survey respondents who took part in the second study were compared with the larger group of 2013 survey respondents included in the first study (who were included in the analysis of results presented in Chapter 4). Pearson Chi-squared analyses (χ^2), Mann-Whitney tests and Kruskal-Wallis tests were used, as required. Effect sizes are reported for significant results. The guidelines provided by Cohen (1988) were followed for determining the strength of size of correlations: r between 0.1 and 0.3 is a small association, r between 0.3 and 0.5 is a moderate association, and $r>0.5$ is a large or strong correlation. Post-hoc tests were carried out to evaluate significant results.

Socio-demographic, eye- and health-related characteristics and support-related characteristics of the dyads were analysed descriptively. Bivariate analyses explored differences between dyads with different types of pwAMD/caregiver relationships (i.e. between spouse pairs or adult-offspring/parent pairs). Descriptive statistics were analysed for the ‘stressors’ (pwAMD DLTV score, IADL score and general health status), the ‘primary appraisal’ (amount of help provided/ received), the ‘secondary appraisal’ (caregiver reactions to providing support, CRA score) and ‘outcomes’ (well-being and general health). Then relationships were explored between these variables (and other variables of interest) using bivariate analyses. All analyses were conducted in SPSS version 21.0.

Scoring of the CRA subscale and total scores vary between different studies. The present study followed the scoring used by Gohil et al. (2015) to enable comparison of scores. To facilitate comparison of scores with other studies, the author made some changes to scoring (e.g. reverse scoring subscale scores).

Structural equation modelling (SEM) using Mplus (version 7.4, Muthen & Muthen, 1998-2015) investigated various direct and indirect pathways to pwAMD and caregivers' outcomes. This statistical technique has a number of advantages over using ordinary regression analysis, including being able to test more than one equation simultaneously and modelling non-independence between dyads by making the dyad the unit of analysis (Cook & Kenny, 2005). PwAMD and caregiver scores for the 'amount of help received/ provided' and their well-being scores had correlated error terms to account for other sources of non-independence (other than those predictors included in the model). The model tested is shown in Figure 6.1. It is based on the Yates et al. (1999) stress model shown in Figure 5.2 in Chapter 5.

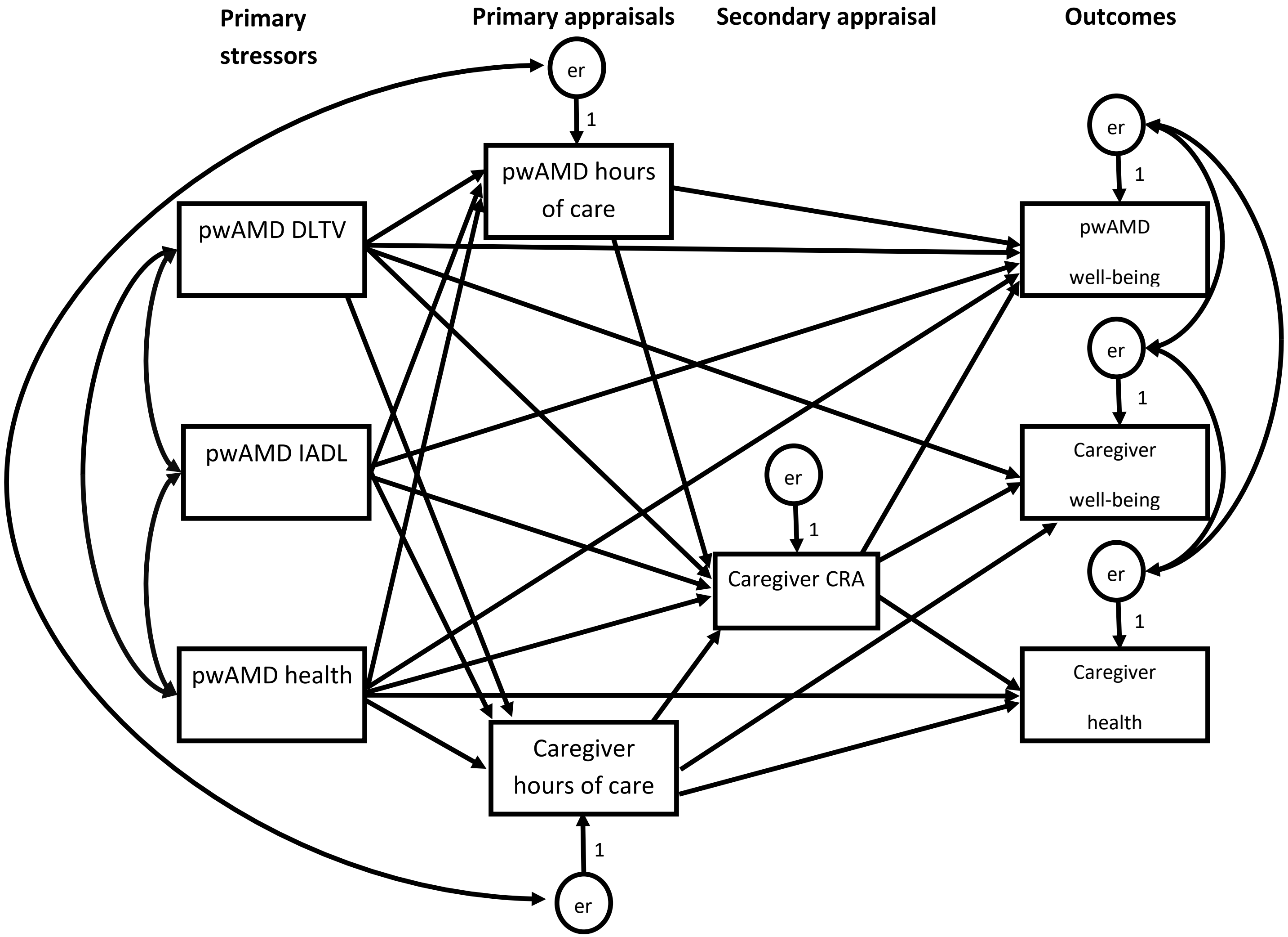

Figure 6.1. Initial path model for the impact of receiving and providing support for age-related macular degeneration. DLTV denotes the Daily Living Tasks dependent on Vision scale. IADL is Instrumental Activities of Daily Living. CRA is the Caregiver Reaction Assessment.

For models which contain only measured variables and not latent variables (as in the present study), the sample size requirements are the same as for ordinary regression analysis (Kenny & Cook, 1999). The usual rule of thumb for multiple regression is a minimum of 15 cases per predictor. The model shown in Figure 6.1 has six predictors (pwAMD IADL score, pwAMD DLTV score, pwAMD general health, pwAMD amount of help received, caregiver amount of help provided, and caregiver CRA score). Using this rule of thumb a sample size of at least 90 dyads would be required. This rule of thumb (as with many others) takes into account the number of predictors in the model. Sufficient sample sizes are needed to have enough power to detect small effect sizes. Since there is little previous research in the field, we had no a priori estimates of the size of the effect we were looking for. Thus in order to have enough power for the analysis, the model contained the minimum number of predictors possible given that the maximum possible sample we could have achieved with the volunteer pool and limits to time and resources was 137 dyads.

Missing data

As noted in the '*Participants and procedures'* section, blank pages were returned to participants with a request for completion or to return a reply slip ticking a box to say they had intentionally left these questions blank.

There were missing data on the IADL measure for seven pwAMD (9.7%). These seven participants had missing data for either one or two items. For the DLTV, there were missing data for nine pwAMD (12.5%). Of these, 4 respondents had only one item missing, and 3 had two items missing. However 2 respondents had five items missing; suggesting there may have been some issues with content validity for these particular respondents. Generally speaking, the items 'difficulty reading newspaper headlines' and 'enjoying the scenery if out for a drive' had the most missing data (three people did not respond to each of these items).

For the DLTV, IADL and CRA total and subscale scores, reliability analyses (Cronbach's alpha) were carried out to calculate how many missing data could be tolerated before the reliability of the scale was reduced to an unacceptable level (a value of $\alpha \geq 0.70$ was considered acceptable). If the reliability remained above this level, then it was considered acceptable to calculate an average score using the answered items to impute missing subscale and total scores. This procedure has been reported using data on the W-BQ 12 (Mitchell & Bradley, 2001).

Cronbach's alpha for the IADL scale with 4 items removed was 0.78. The DLTV could be reduced to a five-item scale which had a Cronbach's alpha of 0.74. Thus average scores were computed despite missing data.

The CRA had the largest amount of missing data. The greatest amount of missing data was for the 'lack of family support' subscale where 6 participants had missing scores. There were smaller amounts of missing data for the 'impact on health' subscale (n=3) and 'impact on finances' subscale (n=2). The 'schedule' and 'esteem' subscales had no missing data. The total score was based on the average of the subscale scores. There were 8 participants with missing total CRA scores as they had too many missing data on the subscales in order for the subscales to be computed using the average score (reliability would have dropped below an acceptable level).

The same procedure was used for caregiver and pwAMD scores on the W-BQ 16. One pwAMD and two caregivers had too many missing items for the total score to be computed.

There were smaller amounts of missing data for other variables, as follows: pwAMD general health (n=1), pwAMD amount of help received (n=4), caregiver amount of help provided (n=4). There were no missing data for caregivers' general health.

The SEM analysis used the full information maximum likelihood (FIML) estimation available in Mplus. This allowed all 72 dyads to be included, which was important given the small sample size. Little's Missing Completely at Random (MCAR) test was used to confirm that data were missing at random (so FIML techniques were valid).

Data screening

Prior to conducting the SEM, the variables that were to be included in the model were examined for accuracy of data entry, missing values and the assumptions of multivariate analysis.

Outliers

Univariate outliers were checked for by looking for very large standardised scores. Scores over 3.29 are indicative of outliers (Tabachnick & Fidell, 2014). There were no scores in excess of 3.29 in the dataset. Multivariate outliers were examined using Mahalanobis distance. None were significant (p<0.001, Tabachnick & Fidell, 2014) so there was no cause for concern.

Multicollinearity

No correlations between independent variables were over 0.7, apart from between pwAMDs' and caregivers' responses for the amount of care they reported receiving/ providing. Chapter 7 explains the reasons why both variables were included in the model tested. Despite this, no VIF values were over 10, and no tolerance values were under 0.1. There were no indications of singularity.

Normality

All variables were checked for normality by visually assessing histograms and examining skewness and kurtosis statistics for each variable. Both caregiver and pwAMD hours of care had kurtosis values that were significant at the $p<0.01$ level (caregiver hours of care kurtosis z-score = -2.69, pwAMD hours of care kurtosis z-score= -2.70). Negative kurtosis is indicative of peaked tails with a relatively flat distribution. The majority of respondents in the sample reported providing/ receiving either the lowest or highest amount of support, resulting in peaked tails. The 'hours of care' variables only have four categories and therefore responses are restricted to a smaller range. These variables were left as they were and not transformed since some kurtosis might be expected for these variables and it was not significant at a higher level (i.e. p<0.001).

All other variables had skewness and kurtosis z-scores below 1.96 (which would be indicative of significant skewness or kurtosis at $p<0.05$).

QUALITATIVE STUDY

Aims

The primary purpose of the qualitative study was to help corroborate, explain and add to the quantitative study findings.

Research design

The qualitative phase used telephone interviews with pwAMD/caregiver pairs.

Since the research study was examining shared experiences of support for AMD, it was important to take into account the impact of the dyad on the research design. It was felt that interviewing pwAMD and their respective caregivers would deepen our understanding of the experience of providing and receiving support, by including both perspectives which could be compared and contrasted. The use of the dyad as the unit of analysis was taken into account in sampling, data collection, analysis and interpretation.

Eisikovits and Koren (2010) identified five modes of dyadic data collection: separate interviews with each member of the dyad (either by one interviewer at separate times, or by two interviewers simultaneously), joint interviews with both members of the dyad, both separate and joint interviews with the same participants, and separate interviews with some dyads and joint interviews with others. Joint interviewing has several benefits including participants being able to prompt each other which could lead to new insights, as well as potentially being quicker to conduct. However separate interviews were considered to be preferable in this study as the research topic meant that sensitive issues would be raised (e.g. impact on relationships, negative aspects of receiving/providing support) that individuals might not feel comfortable discussing in front of their partner. This could be an ethical issue if there is the potential to cause harm to relationships by revealing sensitive information. Separate interviews also allow participants to speak without being inhibited by the presence of their partner. In addition, both individual and joint perspectives can be gained from conducting separate interviews. Norlyk, Haahr, and Hall (2016) argued that the presence of a partner during an interview session might influence data and favour expressions of shared experiences rather than individual experiences. Therefore separate interviews were conducted for ethical and methodological reasons. However it must be noted that there are disadvantages to conducting separate interviews. One of which is the issue of maintaining internal confidentiality. This occurs when there is the potential for one member of a dyad to read and recognise information from the other member, by presenting it alongside information they are able to identify as their own (Ummel & Achille, 2016).

The process of dyadic data analysis from separate interviews is a relatively under-reported topic, however Eisikovits and Koren (2010) provided initial guidelines, derived through ‘trial and error’ (p1645). The guidelines focus on comparing and contrasting the individuals’ perspectives on both descriptive and interpretive levels to move from “I-ness” to “we-ness”. They argued that this leads to ‘various reconstruction of the existing themes and the emergence of unique subthemes’ (p1645). The analysis of overlaps and contrasts between the individuals’ perspectives can indicate differing degrees of ‘togetherness or separateness’ and ‘awareness or unawareness’ (of how their partner thinks and feels) within the relationship. Thereby this process of dyadic analysis can be used to determine the nature of the dyadic relationship. The study of overlaps and contrasts in the interview data within respective pairs was used in this study to focus the analysis and indicate where pairs agreed or disagreed on topics. However the themes themselves were based on the overall content of the data.

Telephone interviews were used instead of face-to-face interviews. Some argue that face-to-face interviews are preferable because they may help to build a rapport between interviewer and interviewee, which is particularly important for research investigating in-depth personal experiences (e.g. Opdenakker, 2006). This difficulty building rapport is partly caused by the lack of visual communication. However the absence of face-to-face contact may be advantageous in cases where interviews may benefit from this ‘anonymity’- particularly if participants feel more comfortable revealing sensitive information over the phone than face-to-face (Opdenakker, 2006; Sturges & Hanrahan, 2004). Vogl (2013) argued that telephone interviews may provide responses that are less socially desirable. The anonymous nature means participants do not ‘lose face’, which may lead to more honest answers. This was thought to be an advantage in this research where respondents might feel uncomfortable revealing negative feelings on the care they receive or provide to their respective partner. There are mixed findings in the literature with regard to whether telephone interviews are as effective in being able to elicit sensitive information (e.g. Tourangeau & Yan, 2007). Some argue that there is actually very little difference between the two modes of interview (e.g. Sturges & Hanrahan, 2004; Vogl, 2013).

Additionally, telephone interviews were thought to provide other advantages. From an ethical viewpoint, it could be argued that the telephone potentially gives a greater sense of control for the interviewee; it is easier to end an interview by terminating a phone call than asking someone to leave their house (Vogl, 2013). Additionally, using a telephone may mean interviewees find it easier to resist talking to their partner if they are present, or it can act as protection from their partner overhearing the conversation, or from their partner interrupting the conversation (Holt, 2010). Telephone interviews were also chosen due to the desire to collect data from a geographically dispersed sample and limits on time and finances meant that travelling to participants’ homes was not feasible.

Ethics

Ethical approval was granted as above.

Participants and procedure

Respondents to the quantitative study were asked to tick a box on the consent form, to show their interest in taking part in telephone interviews. (Details of the qualitative study were included in the Participant Information Sheet sent with the questionnaires.)

Of the 72 pairs who returned completed questionnaires and were eligible to take part, 32 (44.4%) volunteered to take part in the follow-up interviews. The primary aim of the qualitative study was to add to the quantitative study findings, where well-being was used as both a pwAMD and caregiver outcome. With this in mind, in order to collect qualitative data on a range of different peoples' experiences, I selected pairs who had: similar well-being scores (i.e. both had low well-being or high well-being scores), those who had discrepant scores (i.e. one person in the pair had high well-being, and the other had low well-being) and those for whom both the pwAMD and their caregiver had well-being scores around the mean score for the sample. The quantitative analysis found a large correlation between pwAMD and caregiver well-being scores, indicating the majority of pairs had similar well-being scores (r_s =0.54, p<0.001, reported in Chapter 7). The pairs who had discrepant scores may be considered 'outliers', however it was important in this study to investigate a range of different peoples' experiences. With this main selection criterion in mind, I also aimed to select people who had a range of scores on the DLTV and CRA measures and who had different relationships between the pwAMD and the caregiver (i.e. whether they were spouses or adult-offspring of the pwAMD).

Following sample selection, I phoned participants using the contact number they provided, and reminded them of the details of the research study. I asked if they had any questions on the study and whether they were still interested in taking part in the interviews. All participants agreed to take part. I arranged a separate time and date to phone them back for the interview. Of the pairs that lived together, both interviews were arranged with the person who answered this initial phone call. At the beginning of each interview, I reminded participants of the research before asking them again if they would like to take part (this was done primarily to check whether the person who didn't answer the initial phone call was informed of the study and agreed to take part). Participants were asked if they consented to the interview being audio-recorded; all participants agreed. Consent to take part was audio-recorded at the beginning of all interviews. I suggested that individuals might prefer being alone at the time of the interview, so that their responses wouldn't be overhead. Interviews with the pwAMD and their respective caregiver typically took place on the same day, apart from one couple, where the caregiver asked the researcher to complete the interview at a different date. Interviews took place in February and March 2016. They lasted between 25 minutes (participant 120) and 90 minutes (participant 37a).

Recruitment stopped at 16 individuals (8 pwAMD/caregiver pairs). This was because of time and resource constraints. There are no specific guidelines for the optimum number of interviews needed for a good quality thematic analysis. Instead, many researchers describe stopping interviewing when it is considered that no new information could be gained from doing more interviews. This is referred to as reaching ‘saturation’. When saturation is reached however, is a matter of debate (e.g. Francis et al., 2010; Guest, Bunce, & Johnson, 2006), with some researchers suggesting sample size can be determined a priori using methods typically associated with calculating sample sizes in quantitative studies (Fugard & Potts, 2015). It is important that researchers are clear on whether they feel saturation has been reached (Green & Thorogood, 2004; O’Reilly & Parker, 2013). When saturation hasn’t been reached, instead of interpreting findings as invalid, it may simply mean that the phenomenon hasn’t been fully explored yet (Morse, 1995). Indeed, some researchers argue that saturation may never be achieved as there are always new phenomenon to discover (Green & Thorogood, 2004; Wray, Markovic, & Manderson, 2007).

According to Morse (2015), indicators of saturation include: having adequate scope (the data should be comprehensive enough to show breadth and depth of the topic), and be replicable (participants report similar responses in situations which have features in common). For this to happen, the sample should be adequate (large enough for replication) and appropriate (be experts on the topic of interest). Saturation may also be achieved when the researcher’s questions are answered; this requires a circular process where researchers interpret the data and recognise ‘holes’ which can be used to aid further sampling. This process allows the researcher to learn about the phenomenon and develop theory.

Indicators that saturation hasn’t been reached include that there are too few examples in each theme to develop concepts or theory and that results are ‘tentative, obvious, and uninteresting’ (p588, Morse, 2015). The present study took these indicators into consideration during the recruitment and analysis phases.

Recording and transcribing

Digitally recorded interviews were transcribed verbatim by two research administrators and the researcher, using Express Scribe Transcription Software v5.81 (NCH software). All verbal and non-verbal (e.g. coughs) utterances were transcribed so that the transcript reflected the 'true' data. All transcripts were checked for accuracy by the researcher. Data were entered into NVivo v.10 (QSR International), for coding.

MATERIALS

Interview guide

Separate interview guides were created for the pwAMD and their caregiver. They were designed to guide participants towards reflecting on their experiences of receiving or providing support for AMD, and their views on how their partner has coped. The topics in the interview guides for the pwAMD and their caregiver followed a similar pattern: the experience of diagnosis, impact of AMD on their own and their partner's life, specific questions on the support provided including the types of support received, the impact of receiving or providing support (as relevant) including questions on support from others, and QoL. Copies of the interview guides are provided in Appendices 11 and 12.

The interview questions were based on the research aims. The first question asked pwAMD to: 'Tell me about your experience of diagnosis of AMD'. It was hypothesised that participants would give factually based answers (e.g. when they first recognised the symptoms), as well as emotional reflections on diagnosis. This question was asked at the beginning so that participants would have the chance to reflect on the impact of AMD from diagnosis, and it was thought that having this in mind might lead to richer answers later on. Caregivers were also asked to reflect on their memory of diagnosis of AMD, but before this they were asked for details about when they first started providing support for AMD and whether they had ever provided support to the pwAMD for another medical condition.

Following this, there were general questions on the impact of AMD diagnosis on their life as well as their partner's. This was kept broad so that participants could interpret this as they wished, potentially leading to new insights on this research topic. Afterwards there were a series of questions that asked more specifically about the impact of providing or receiving support. These questions were guided by the research aims and the literature review. For instance, both the pwAMD and caregivers were asked about the negative and positive consequences of receiving or providing support. These open-ended questions were included to see if the responses might add to the literature on overprotection (Cimarolli, 2006), or reactions to providing care (e.g. Pearlin et al.,'s (1990) and Yates et al.,'s (1999) Stress process models; Given et al. (1992)), and might be specific to providing support for AMD. These were followed by more specific questions (if not already discussed in answer to the general questions). For instance, pwAMD were asked if they felt they received 'the amount and kind of support or assistance you need from them [the caregiver], when you need it'. For caregivers, they were asked whether they felt the care they provided was 'sufficient or more than sufficient'. These questions were added to help guide participants to talk about the amount of help provided, and it was hoped that this might lead them to bring up the topic of overprotection without using leading questions. The dyadic design is unique in getting both the patient and caregiver's views on this potential issue.

Given that previous research has found caring impacts on the patient-caregiver relationship, and this contributes to caregivers' well-being (e.g. Bastawrous, Gignac, Kapral, & Cameron, 2014), a question was included that asked whether participants felt their relationship had changed since they started receiving or providing support.

The author used the prompt 'was there anything that helped or hindered this?' throughout the interview to investigate facilitators and barriers to coping with AMD. The guide also included a question on whether outside help was used and whether this was perceived as helpful in adjusting to life with AMD. In addition, pwAMD were asked if they felt there was anything that could be done to help their caregiver provide support, and caregivers were asked if there was anything that could be done to help them provide support. This was added to establish need for outside support and provided a direct, tangible way that pwAMD and their caregivers might be assisted.

Other questions were added to help explain the quantitative study findings. For example, in order to investigate differences between the 2013 survey and the second quantitative study findings regarding the relationship between the amount of help received/ provided and other variables (see Chapter 7), we prompted participants with the answer they gave on how much support they received/provided in the second quantitative study and asked them if they remembered having difficulty answering this question. We asked participants about the types of support they provided/received. This was done for two reasons; to add to the quantitative study findings (as this wasn't included as a measure), and to see if this would prompt participants to reconsider their response on how much care they received/provided.

As there is currently no validated measure available to record the amount and type of support provided specifically for AMD, the quantitative study relied on the DLTV, IADL and general health status to provide a proxy of the amount and type of help required. Gopinath et al. (2015) created their own instrument of the activities caregivers of pwAMD provide help with. These activities included: exercise and/or sport, cooking food, cleaning, gardening, making the bed, hanging laundry, reading, hobbies, playing with or caring for their grandchildren, getting dressed, personal grooming, leaving the house, travelling/holidays, using automated teller machines/electronic funds transfer at point of sale (ATMs/EFTPOS), and/or entering PIN number, playing/walking their pet, driving the car, managing their finances, climbing stairs and shopping. In order to assess the types of activities caregivers provide help with, both the pwAMD and their caregiver were asked if they received/ provided help with these activities described in the Gopinath et al. (2015) study. In addition to these activities, the following activities were perceived to be relevant to this research topic and were included: 'booking GP or hospital appointments with them', 'attending GP or hospital appointments with them', 'washing laundry', 'preparing food' and 'providing emotional support'. 'Leaving the house' was broadened to 'getting out and about'. This list was used as a guide to facilitate discussion on the types of activities they receive/provide help with rather than to be used as a quantitative, structured measure.

The interviews were primarily guided by the set interview questions however participants were left free to direct the conversation to topics they felt were relevant to their experience.

Towards the end of the interview guide, there was a question asking participants to rate their current QoL as either ‘excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad’. They were asked if there was anything affecting their QoL at the moment, that hadn’t already been discussed. This was to establish if there were other factors affecting the participants’ current QoL that could have affected their answers or were important to them.

At the end of the interview, the researcher summarised what they understood to be the participants’ experience and invited participants to ‘step in’ if they felt the researcher had misunderstood their responses, or to confirm if they had understood correctly. Half of the sample had experienced vision loss, and so we felt it would be too onerous to ask these participants to check their interview transcripts. This therefore acted as a ‘check-point’ where participants could add to their responses and help aid the researcher’s interpretation of their responses, if required.

ANALYSIS

Thematic analysis

The decision to use thematic analysis was guided by the pragmatic worldview used throughout this thesis. Unlike other qualitative analysis methods (e.g. grounded theory, interpretative discourse analysis), thematic analysis is not tied to a specific epistemology and can be used to answer a variety of research questions (Braun & Clarke, 2006). It has been described as ‘a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data’ (p5, Braun & Clarke, 2006). Importantly, it was felt that this type of analysis would be more likely to provide information in an accessible format to those who may want to use it to inform services or policy for pwAMD and their caregivers.

Thematic analysis is a method for identifying patterns in one's data whilst also going beyond this to a wider interpretation of the data.

Data were coded following the procedure outlined by Braun and Clarke (2006). An inductive, 'bottom-up' approach was taken to analysis where themes were not driven by the researcher's theoretical interest or the literature, but instead were strongly linked to the data. First, I familiarised myself with the data. Finalised transcripts were read whilst listening to the audio-recording of the interview to check interpretations of the meaning applied to the data. Then preliminary notes were made whilst re-reading the transcripts. The next phase involves identifying initial codes. Codes 'identify a feature of the data (semantic content or latent) that appears interesting to the analyst' (p18, Braun & Clarke, 2006). Once a list of codes have been collated, the next phase is to re-focus the analysis to a broader level of themes. This involves sorting the codes into themes. For this stage I created mind-maps to sort the codes visually. The following phase involves the refinement of themes. For instance, some themes identified in the previous phase may be discarded if there is not enough data to support them, or if the codes are too diverse. One might find that two or more themes are similar and these could be combined to form a single theme. For this stage, I took into account the dual criteria for judging categories developed by Patton (1990); themes should have both internal homogeneity (data within themes should cohere together meaningfully) and external heterogeneity (themes should be distinct). The first step involves going back to the dataset to check all coded extracts for each theme form a coherent pattern. Once completed, the next part is stepping back and checking that the themes reflect the meaning in the whole dataset. The entire dataset is then re-read to check that the themes accurately represent the data and to code data that might have been missed previously. The process of refining themes should be stopped when refinements are not adding anything substantial. Once a satisfactory thematic map has been created, themes are then tested by assessing their ability to adequately define the "… 'essence' of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captures" (p22, Braun & Clarke, 2006). This is also the stage where themes are named. The final stage is writing up. Braun and Clarke (2006) suggest that data extracts should illustrate the prevalence of a theme and be easily identifiable as an example of the issue. The analytic narrative that accompanies the extracts should go beyond description of the data, and make an argument in relation to the research question.

One should note that movement through these stages is not linear; it is recursive, where one can move back and forth as needed.

Rigour

A basic requirement for the reporting of research is that it is presented in sufficient detail so that it can be evaluated. Criteria for the assessment of good quality qualitative research exist (e.g. Yardley, 2000), however concerns have been raised about rigid criteria stifling creativity in qualitative research (Elliott, Fischer, & Rennie, 1999), and the validity of such criteria has been questioned given the diverse range of qualitative approaches (Reicher, 2000). Despite this, Elliott et al. (1999) argue that guidelines for qualitative research are necessary to help introduce rigour into qualitative research and to encourage researchers to be self-reflective in their research practices.

For this research I took into account the guidelines for publishing qualitative research studies in psychology and related fields, created by Elliott et al. (1999). These include several judging criteria in common with quantitative approaches. For instance, the research should have clear research questions, the methods chosen should be appropriate, the researcher should collect informed consent from participants and the research should provide a strong contribution to the research field. In addition, Elliott et al. (1999) suggested further criteria specific to qualitative research. These include elements of transparency; the researcher should specify their theoretical orientations and attempt to recognise their thoughts and feelings that are relevant to the research to try to reduce or balance their influence (see '*reflexivity*' and '*personal reflexivity'* sections below). They also suggested the researcher provides information on the participants to aid the reader in making judgements about the suitability of the sample and potential generalisability of the research (see '*table of interview participants' characteristics'* section below). Further suggestions were: including extracts of the data, conducting credibility checks (e.g. 'triangulation' with quantitative data or using multiple qualitative data analysts), reporting analysis in a coherent manner, using methods and samples in line with whether the researchers are aiming to gather data on the general experience of the topic under study or a more specific investigation, acknowledging the limitations to the generalisability of the results, and finally that the report is presented in such a way that the reader can judge it to represent the topic accurately or at least have expanded their appreciation and understanding of the topic.

For assessment criteria specific to thematic analysis, I used guidelines produced by Braun and Clarke (2006). An important decision researchers make during the process of analysis is how they decide on what counts as a theme. According to the Braun and Clarke (2006) guidelines, a theme is 'some level of *patterned* response or meaning within the data set' (p10, italics are in text). Braun and Clarke (2006) argued that prevalence is left up to the researcher's judgement, there are no strict cut-offs for how much presence a theme needs to have in a dataset before it can be labelled as a theme. What is important, Braun and Clarke (2006) argued, is that the theme is important in answering one's research questions. This is the approach used in the analysis reported in the present study. In this research, I chose to provide a rich thematic description of the entire dataset by identifying the themes that were pertinent to answering the research questions.

Reflexivity

It is important that researchers are aware of the potential bias they bring to their research. With this in mind, it is suggested that instead of trying to control one's influence on the research process, one should instead acknowledge it (Ortlipp, 2008). In order to create transparency in qualitative research, one should make their experiences, values, opinions, thoughts and feelings visible and an acknowledged part of the research process (e.g. how these have influenced their research interests and the way they choose to do their research), by keeping a reflective journal or field notes and using them to write up the research (Ortlipp, 2008).

> ‘The process of reflection helps to bring the unconscious into consciousness and thus open for inspection’ (p703, Ortlipp, 2008).

With this in mind, I kept a reflective journal throughout this research and added to it during all stages of the research process. In addition, I included field notes in the reflective journal. For instance, after each interview, I wrote up field notes on reflections and impressions from the interviews. This included notes on observations made during the interview (e.g. indications that the caregiver/pwAMD was in the background) and my interpretations (e.g. noting general impressions about the participant’s well-being). These notes were referred to during the analysis phase, although not always used.

Personal reflexivity

Given the importance of reflexivity and transparency in qualitative research I feel it is important to identify and share with the reader my relevant experiences, thoughts and feelings with regards to this research. First, my own experiences of observing my father provide support to his mother with AMD could be compared to that of the pwAMD/ caregiver pairs in the qualitative study, particularly as the adult-offspring/parent pairs were similar in age to my father and his mother. Secondly, during the process of qualitative analysis of the interview data for this study, my mother was diagnosed with a serious condition for which I became her main caregiver. Throughout the research I continued to reflect on my thoughts related to my pre-conceived ideas of AMD and experiences of providing care by writing in the reflective journal. I hoped that this awareness allowed me to reflect on these preconceptions and base my interpretations as close as possible to the experiences of the pwAMD and caregivers included in this study.

My determination to make sure that the research results made sense to pwAMD, their caregivers, HCPs and other professionals, and charitable bodies influenced the choice of research methods and methods of data analysis used in the study. I was driven by my wish for the research to be understood and incorporated into services. Thus this influenced the choice of a pragmatic approach to this research.

Ethical issues and considerations taken in reporting the results

All identifiable information were removed from the transcripts. Participants were assigned ID numbers in place of their actual name. This is particularly an issue in dyadic research where individuals may be able to recognise their partner's responses (i.e. the issue of 'internal confidentiality'). I have therefore tried to strike a balance between leaving out information to safeguard confidentiality whilst leaving in information that helps to preserve the context of the situation described and analysed. Results are therefore presented at a more general, and therefore less identifiable level (Ummel & Achille, 2016).

It is suggested that in order to preserve anonymity, data on demographic characteristics should not be presented line-by-line as this might enable an interested party to identify an individual (Morse & Coulehan, 2015). The authors suggested that where analysis is related to participants' scores, that these individual scores should not be presented with quotes, but rather a 'group label' (e.g. high or low well-being) should be used. Overall they recommended only reporting data that are necessary to aid interpretation and understanding. A summary of the interviewee characteristics is provided in Table 6.1.

Table 6.1. Table of interview participants' characteristics[ψ].

Participant ID number	**Role**	**Daily Living Tasks Dependent on Vision scale (DLTV score)**[a] (median=61.50)	**Living together?**	**General well-being (W-BQ 16 score)**[b] (pwAMD mean=28.94, caregiver mean= 31.07)	**Caregiver Reaction Assessment score (CRA)**[c] (mean =2.4)	**Self-reported number of hours of care received/ provided for AMD**
Adult offspring/ parent with AMD pairs						
1	Mother with AMD	Below median	no	30 Above mean (although close to mean) (pwAMD and caregiver had *similar* general well-being)	n/a	15-35 hours per week
1a	Daughter of mother with AMD	n/a		28 Below mean (although close to mean)	Below mean	7-14 hours a week
19	Mother with AMD	Above median	yes	26 Below mean (pwAMD had well-being just below the mean, whereas the caregiver had general well-being much above that of the mean and that of the pwAMD)	n/a	More than 35 hours a week
19a	Daughter of mother with AMD	n/a		38 Above mean	Missing data	15 to 35 hours a week

37	Mother with AMD	Above median	no	16 Below mean (pwAMD and caregiver had *similar* general well-being. Both were much below the mean for their respective group.)	n/a	15 to 35 hours a week
37a	Daughter of mother with AMD	n/a		18 Below mean	Above mean	7 to 14 hours a week
120	Mother with AMD	Above median	yes	17 Below mean (pwAMD had much lower general well-being than their caregiver)	n/a	Missing data
120a	Son of mother with AMD	n/a		33 Above mean	Missing data	Missing data
Spouse person with AMD/caregiver pairs						
128	Wife with AMD	Above median	yes	13 Below mean (Both the pwAMD and caregiver had well-being below the mean for their respective group. *PwAMD* had lower well-being than their *caregiver*.)	n/a	15 to 35 hours a week
128a	Husband of Wife with AMD	n/a		23 Below mean	Above mean	7 to 14 hours a week

28	Husband with AMD	Below median	yes	45 Above mean (PwAMD had much higher general well-being than their caregiver)	n/a	15 to 35 hours a week
28a	Wife of husband with AMD	n/a		26 Below mean	Below mean	15 to 35 hours a week
121	Husband with AMD	Above median	yes	26 Below mean (Both the pwAMD and caregiver had well-being below the mean for their respective group. *Caregiver* had lower well-being than *pwAMD*.)	n/a	More than 35 hours a week
121a	Wife of husband with AMD	n/a		16 Below mean	Above mean	More than 35 hours a week
81	Wife with AMD	Above median	yes	39 Above mean (*Both* pwAMD and their caregiver had *high* general well-being)	n/a	More than 35 hours a week
81a	Husband of Wife with AMD	n/a		45 Above mean	Below mean	More than 35 hours a week

Participant ID numbers with ‘a’ indicate the caregiver within the pair. [ψ] Means and median scores shown were calculated based on the 72 pairs who took part in the quantitative study. [a] DLTV was completed by PWAMD only. Possible score range: 22 to 88, lower score indicates better visual function. [b] Score on the W-BQ 16 ranged from: 0-48, higher scores indicate better well-being. [c] Caregiver Reaction Assessment was completed by caregivers only. Possible score range: 1-5, higher scores indicate more negative impact of providing care.

In conclusion, the above chapter describes the methods used in this mixed-methods study examining the impact of receiving and providing support for AMD. The quantitative study results and discussion are presented in Chapter 7. The results of the qualitative data analysis are presented in Chapter 8 with a discussion of how they add to and help explain the quantitative study findings.

Chapter 7:

The impact of providing and receiving support for AMD: Results and discussion from the quantitative study.

Of the 137 person with AMD/ caregiver dyads sent questionnaire packs, 81 caregivers and 83 people with AMD (pwAMD) returned completed surveys. Three pwAMD requested telephone completion of surveys, giving a total of 86 pwAMD who completed the survey. This was a 59% response rate for caregivers and 63% for pwAMD. The results reported in this chapter are for 72 dyads where both the pwAMD and their respective caregiver returned completed questionnaires.

SAMPLE CHARACTERISTICS

Characteristics of the non-responders

Of the 51 pwAMD who did not complete a questionnaire, 19 people provided reasons for not taking part (giving a gross response rate for pwAMD of 77%). Reasons for non-response included poor health (n=8), feeling that the questionnaire was not applicable to them (n=3), or being too busy to take part (n=1). Eight people provided a reason under the 'other' textbox. The majority of 'other' responses were from family or friends who informed the researcher that the pwAMD had died. One person stated that they felt their responses would have been affected by the repercussions of a recent serious accident. One caregiver who was the daughter of the pwAMD replied saying that her mother 'hates talking about her macular experiences'.

Pearson Chi-squared analyses (χ^2) and independent-samples Mann Whitney tests were conducted to examine differences and similarities between those who completed the questionnaires and those who didn't. There were no significant differences between the pwAMD who completed the questionnaire (n=86) and those who didn't take part (n=51), on their MSQ 2013 responses for the following: well-being, general quality of life (QoL), MD-specific QoL, the number of people who provided them with support for AMD, age at time of MSQ 2013 completion, number of eyes affected by AMD, self-assessed change in vision status since diagnosis (better/ stayed the same/ worse), pwAMD/caregiver relationship type (spouse, adult-offspring or 'other' type of caregiver), the amount of support received per week for AMD, registration status, gender and living circumstances (whether they lived alone). However non-responders were more likely to report poorer general health on the MSQ 2013 than responders (non-responders mean general health rating=3.50, responders mean general health rating= 2.95, U = 2721.00, z= 2.59, p <0.05). (On the MSQ 2013, higher general health ratings indicate poorer self-rated health.)

Comparison between the quantitative second study participants and the Macular Society 2013 survey respondents with caregivers

The MSQ 2013 responses between the 72 participants who took part in the second study and whose data are presented with their caregivers in this chapter, were compared with the 2013 survey respondents who had AMD only, were over the age of 50 at diagnosis and who reported having a caregiver (and were included in the results presented in Chapter 4). This was done as a proxy for seeing how the respondents included in this chapter compare with a wider population of pwAMD who have a caregiver, and to investigate significant differences between the two samples included in the analyses presented in these chapters. Caution must be applied when interpreting the results due to differences in sample size between the groups (72 participants for the present study and 558 from the 2013 survey). This occasionally resulted in expected cell counts below 5 for χ^2 analysis.

The analyses found that the participants in the quantitative second study were more likely than the MSQ 2013 respondents with caregivers to: be male, live with someone else (vs living alone), and were more likely to report receiving more support for AMD (measured in hours per week). The 2013 survey respondents who took part in the first study were more likely to report having more supporters (1.66 vs 1.36 supporters). (See Table 7.1.)

Table 7.1. Characteristics of the sub-sample of respondents who took part in the second study vs the comparative sample from the 2013 survey (i.e. 2013 survey respondents who had AMD only, were over age 50 years at the time of diagnosis, and who had a caregiver). Values are frequencies (valid percentage %) unless otherwise stated[a].

Variables		**Second study participants (n=72)[b]**	**Comparative respondents from 2013 survey (n=558)**	**Interpretation of results; statistic, p value, effect size and n.**
Gender of pwAMD	Male	32 (50.8%)	195 (34.9%)	Significant difference between groups; the second study participants were more likely to be men. χ^2 (1)=6.13, p=0.013*: phi= -0.10. n=621.
	Female	31 (49.2%)	363 (65.1%)	
PwAMD Age at survey completion (years)	Mean (SD)	82.30 (6.61)	81.87 (7.23)	No significant difference between groups. U=18,418.50, z= 0.62, p=0.53: n=621.
	Median	83.00	83.00	

PwAMD Registration status	Not registered	20 (31.7%)	265 (47.5%)	No significant difference between groups. χ^2 (2)=5.69, p=0.06: n=621.
	Registered sight impaired (SI)/ partially sighted	28 (44.4%)	187 (33.5%)	
	Registered severely sight impaired (SSI)/ blind	15 (23.8%)	106 (19.0%)	
Self-assessed change in vision since diagnosis	Better	5 (8.5%)	71 (12.7%)	No significant difference between groups. χ^2 (2)=1.80, p=0.41: n=617.
	Stayed the same	9 (15.3%)	108 (19.4%)	
	Worse	45 (76.3%)	379 (67.9%)	
Number of eyes affected	One eye	2 (3.2%)	53 (9.5%)	No significant difference between groups. χ^2 (1)=2.84, p=0.09: n=618.
	Both eyes	61 (96.8%)	502 (90.5%)	
Wet or dry AMD or both	Wet AMD (one or both eyes)	22 (37.3%)	208 (39.9%)	No significant difference between groups. χ^2 (2)=0.24, p=0.89: n=580.
	Dry AMD (one or both eyes)	25 (42.4%)	204 (39.2%)	

	Wet AMD in one eye, dry AMD in the other	12 (20.3%)	109 (20.9%)	
Living circumstances	Live with other/s	52 (82.5%)	349 (62.5%)	Significant; respondents in the second study were more likely to report living with someone else than living alone (at the time of the 2013 survey). χ^2 (1)=9.89, p=0.002**: phi = -0.13. n=621.
	Live alone	11 (17.5%)	209 (37.5%)	
PwAMD general health[c]	Mean	3.03 (1.02)	3.10 (1.11)	No significant difference between groups. U=17,613.50, z= 0.25, p=0.81: n=620.
	Median	3.00	3.00	
Type of pwAMD/caregiver relationship	Spouse	41 (66.1%)	300 (53.8%)	No significant difference between groups. χ^2 (2)=4.53, p=0.10: n=620.
	Adult-offspring	17 (27.4%)	177 (31.7%)	
	Other	4 (6.5%)	81 (14.5%)	
Number of caregivers	Mean (SD)	1.36 (0.95)	1.66 (0.99)	Significant; 2013 survey respondents reported having more caregivers. U=14, 519.50, z= -2.39, p=0.02*: n=620.
	Median	1.00	1.00	
PwAMD hours of care received	Fewer than 7 hours per week	16 (25.4%)	262 (47.0%)	Significant; adjusted residuals indicate that the second study participants were less likely to report

	7 to 14 hours per week	15 (23.8%)	127 (22.8%)	receiving care for fewer than 7 hours per week and more likely to report receiving care for more than 35 hours a week. χ^2 (3)=13.57, p=0.004**: Cramer's V=0.15. n=621.
	15 to 35 hours per week	9 (14.3%)	41 (7.3%)	
	More than 35 hours per week	23 (36.5%)	128 (22.9%)	
PwAMD QoL[d]	Mean (SD)	0.71 (1.16)	0.78 (1.11)	No significant difference between groups. U=18,274.00, z= -0.72, p=0.47: n=627.
	Median	1.00	1.00	
PwAMD MD-specific QoL[e]	Mean (SD)	-2.52 (0.78)	-2.40 (0.78)	No significant difference between groups. U=17, 328.000, z= -1.53, p=0.13: n=627.
	Median	-3.00	-3.00	
PwAMD GENERAL well-being[f]	Mean (SD)	30.32 (8.99)	30.33 (9.02)	No significant difference between the two groups. U=15,017.50, z= -0.90, p=0.37: n=616.
	Median	31.00	31.00	

[a] Responses are from the Macular Society 2013 survey.[b] Sample size for each analysis will vary slightly depending on item non-response for items on the Macular Society 2013 survey. [c]Higher scores indicate poorer self-rated health. [d] Quality of life (QoL) is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [e]MD- specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be 'very much better' (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be 'worse'). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [f]General well-being is on a scale of 0 to 48 where higher scores indicate higher well-being. *p<0.05, **p<0.01, ***p<0.001.

There were no differences between these two groups on: their age at the time of the MSQ 2013 completion, their well-being or general health, registration status, or their generic QoL or MD-specific QoL. There were no differences in the likelihood of them reporting their adult-offspring or spouse as their primary caregiver. There were no significant differences between the two groups in: the number of eyes that were affected by AMD, self-assessed change in vision status since diagnosis (better/ stayed the same/ worse), and whether they had wet AMD, dry AMD or both wet and dry AMD (see Table 7.1).

Socio-demographic characteristics of the 72 pwAMD and their caregivers

The socio-demographic characteristics of the 72 pwAMD and their caregivers whose data are used in the present study are presented in Table 7.2. All but one of the caregivers identified themselves as ‘white British’. The remaining one participant identified themselves as ‘white Irish’. All pwAMD identified themselves as ‘White’.

Table 7.2. Characteristics of the 72 caregivers and people with AMD. Values are frequencies (valid percentage %) unless otherwise stated.

Variables		**Participants with AMD**	**Caregivers**
Gender[b]	Male	35 (48.6%)	22 (30.6%)
	Female	37 (51.4%)	50 (69.4%)
	Missing	0 (0%)	0 (0%)
Age at survey completion (years)	Mean (SD)	84.39 (6.65)	73.46 (10.42)
	Median	85.00	77.00
	Missing	0 (0%)	0 (0%)
Registration status	Not registered	12 (16.7%)	-[a]
	Registered sight impaired (SI)/ partially sighted	26 (36.1%)	-[a]
	Registered severely sight impaired (SSI)/ blind	34 (47.2%)	-[a]
	Missing	0 (0%)	
Number of eyes affected by AMD[b]	One eye	3 (4.2%)	-[a]
	Both eyes	69 (95.8%)	-[a]
	Missing	0 (0%)	-[a]
Wet or dry AMD or both wet and dry AMD[b]	Wet AMD (one or both eyes)	24 (33.3%)	-[a]
	Dry AMD (one or both eyes)	31 (43.1%)	-[a]
	Wet AMD in one eye, dry AMD in the other	12 (16.7%)	-[a]
	Missing	5 (6.9%)	-[a]
Years since diagnosis[b]	Mean (SD)	11.43 (6.36)	-[a]
	Median	10.00	-[a]
	Missing	5	-[a]

Marital status	Married/living with partner	49 (68.1%)	61 (84.7%)
	Widowed	20 (27.8%)	1 (1.4%)
	Divorced	2 (2.8%)	0 (0%)
	Separated	0 (0%)	1 (1.4%)
	Single	1 (1.4%)	9 (12.5%)
	Civil Partnership	0 (0%)	0 (0%)
	Missing	0 (0%)	0 (0%)
Employment status	Employed, full time	0 (0%)	2 (2.8%)
	Employed, part time	0 (0%)	5 (6.9%)
	Self-employed	0 (0%)	2 (2.8%)
	Looking after family and/or home	0 (0%)	1 (1.4%)
	Retired	70 (97.2%)	59 (81.9%)
	Seeking work/ unemployed	0 (0%)	1 (1.4%)
	Disabled or too ill to work	1 (1.4%)	1 (1.4%)
	Student	0 (0%)	0 (0%)
	Other	1 (1.4%)	1 (1.4%)
	Missing	0 (0%)	0 (0%)
Highest qualification	Degree or higher degree	17 (23.6%)	22 (30.6%)
	Higher Education qualification below degree level	16 (22.2%)	9 (12.5%)
	A Levels or equivalent	3 (4.2%)	13 (18.1%)
	O Level or GCSE or equivalent	10 (13.9%)	15 (20.8%)
	Still studying	0 (0%)	0 (0%)
	No formal qualification	18 (25.0%)	13 (18.1%)
	Other	5 (6.9%)[c]	0 (0%)
	Missing	3 (4.2%)	0 (0%)

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[a] Question was only asked to participants with AMD. [b] Responses are from the Macular Society 2013 survey. [c] 'other' qualifications include: nursing qualification, retired midwife and remedial massage, school certificate 1944, secretarial certificates/ qualifications.

The gender split for pwAMD was almost equal (51% were female). The majority of caregivers were women (69%). PwAMD tended to be older than the caregivers included in this study (Table 7.2).

Over two-thirds of the pwAMD were married or living with a partner, whilst almost 28% were widowed. Most caregivers were either married (85%) or single (13%). All but two of the pwAMD reported being retired. The majority of the caregivers also reported being retired. Some were still working whilst others were seeking work. Two reported not being in formal employment as they were looking after the home or were too ill to work. PwAMD most frequently stated they had no formal qualifications. Caregivers most frequently stated they had a degree or a higher degree.

Eye- and health-related characteristics (general health, number of other medical conditions, treatment for AMD)

The majority of pwAMD were registered as SSI (blind), and had both eyes affected by AMD (see Table 7.2). Only three pwAMD had only one eye affected by AMD. Just over 40% of the pwAMD had dry AMD. At the time of MSQ 2013 survey completion, pwAMD had been diagnosed on average 11 years ago.

The number of pwAMD who reported having a medical condition in addition to AMD are reported in Table 7.3.The most common response was the reporting of one other condition (31.9%, n=23), however one participant reported having eleven conditions. The next highest number reported was seven (reported by only one participant).

Table 7.3. Other medical conditions reported by the pwAMD. Values are frequencies of ‘yes’ responses (valid percentage %).

	Participants with AMD (n=72)
Diabetes	11 (15.3%)
Stroke	8 (11.1%)
Heart attack	22 (30.6%)
Kidney disease	6 (8.3%)
Asthma	11 (15.3%)
Other[a]	38 (52.8%)

[a] Participants were asked to write down the name of any other serious or long-term conditions. Responses varied but were mainly physical health conditions, for example: prostate cancer, polymyalgia, arthritis, and Osteoporosis. Four participants reported having a hearing impairment.

There was a moderate-to-large association between caregivers’ ratings of their general health and pwAMDs’ ratings of general health ($r_s = 0.40$, $p<0.01$). The pwAMD had a wider range of scores than caregivers; no caregivers said their general health was either ‘extremely bad’ or ‘very bad’ whereas pwAMD used these options (see Table 7.4). The median general health scores for both pwAMD and caregivers was 3.00 which indicated that on average, respondents felt their general health was ‘good’.

Table 7.4. Self-reported general health status of the caregivers and people with AMD[a]. Values are frequencies (valid percentage %).

General health description[b]	Participants with AMD	Caregivers
Excellent	3 (4.2%)	7 (9.7%)
Very good	17 (23.6%)	17 (23.6%)
Good	22 (30.6%)	19 (26.4%)
Neither good nor bad	17 (23.6%)	20 (27.8%)
Bad	9 (12.5%)	9 (12.5%)
Very bad	2 (2.8%)	0 (0%)
Extremely bad	1 (1.4%)	0 (0%)
Missing	1 (1.4%)	0 (0%)

[a] There was a moderate-to-large association between caregivers' ratings of their general heath and pwAMDs' ratings of general health ($r_s = 0.40$, $p<0.01$).[b] Participants were asked 'In general, my health is:' followed by the following list of responses 'excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad'.

The most common change in registration status was for participants who were registered as SI at the time of the 2013 survey, to be registered as SSI at the time of the second study. This might suggest that those already in the system, were more likely to be assessed to see whether they would qualify for registration as SSI. Thirteen participants who were not registered at the time of the 2013 survey, reported being registered at the time of the second study; eight as SI and five as SSI. This suggests that some of the respondents in the second study may have had a recent deterioration in vision.

Around 57% (n=41) of pwAMD reported that they had received treatment for their AMD. Of these participants, fifteen reported they were currently receiving treatment for AMD. Twelve reported having eye injections. One respondent reported not knowing the name of the drug injected and another did not report the name. Eight participants reported receiving either Eylea injections (n= 6), or Lucentis injections (n=2). One respondent reported having Lucentis in one eye and Eylea in the other. One reported having both Avastin and Lucentis injections but did not report which had been most recent. Two respondents did not report the type of treatment they were receiving. The remaining respondent reported taking nutritional supplements only.

Support-related characteristics

The majority of the caregivers in the second study were the spouse of the pwAMD (68%). The rest were adult-offspring of the pwAMD (29%), and two people were a neighbour or friend of the pwAMD (3%, see Table 7.5). The majority of caregivers were women (69%) (Table 7.2). This is in line with national statistics on the gender of caregivers which reports that 60% of the caregivers in England are women (The NHS Information Centre, 2010).

Table 7.5. Support-related characteristics of the caregivers and people with AMD. Values are frequencies (valid percentage %) unless otherwise stated.

Variables		Participants with AMD	Caregivers
Relationship of caregiver to person with AMD	Wife	[a]	30 (41.7%)
	Husband		17 (23.6%)
	Daughter		18 (25.0%)
	Son		3 (4.2%)
	Friend		1 (1.4%)
	Neighbour		1 (1.4%)
	Partner		2 (2.8%)
Person with AMD/caregiver relationship (combined groups)	Spouse[†]	49 (68.1%)	
	Adult-offspring/ parent[§]	21 (29.2%)	
	Other	2 (2.8%)	
Amount of care received/ provided	Fewer than 7 hours per week	18 (25.0%)	18 (25.0%)
	7 to 14 hours per week	12 (16.7%)	15 (20.8%)

	15 to 35 hours per week	14 (19.4%)	13 (18.1%)
	More than 35 hours per week	24 (33.3%)	22 (30.6%)
	Missing	4 (5.6%)	4 (5.6%)
Duration of caregiving[b]	Less than a year	-	0 (0%)
	Between 1 and 5 years	-	23 (31.9%)
	More than 5 years	-	49 (68.1%)
Provide support for another condition before AMD diagnosis?[b]	Yes	-	24 (33.3%)
	No	-	47 (65.3%)
	Missing	-	1 (1.4%)
PwAMD receive assistance from others for AMD?	Yes	28 (38.9%)	22 (30.6%)
	No	42 (58.3%)	48 (66.7%)
	Missing	2 (2.8%)	2 (2.8%)
Live with the person with AMD?[b]	Yes	-	57 (79.2%)
	No	-	12 (16.7%)
	Missing	-	3 (4.2%)

[a] PwAMD provided the same responses as caregivers. [b] Question was only asked to caregivers. † Combined ‘wives’/ ‘husbands’/ ‘partners’ caregiver groups. § Combined ‘daughter’/ ‘son’ caregiver groups.

Some caregivers reported having to give up work (4.2%, n=3), and reduce their working hours (6.9%, n=5) as a consequence of providing support to the pwAMD. Only one person reported having to take unpaid leave to provide support. No participants reported taking paid leave to provide support. The majority (76.4%) reported having no change in their employment status due to providing support to the pwAMD; perhaps because the majority were already retired when they started providing support. Some caregivers provided comments that suggested they had experienced employment changes related to providing support. For instance, one person said they 'retired early'. Another said they were 'working part-time but had to stop'. Other responses suggested that some respondents had reflected that reducing their working hours had helped them to cope with providing support, for example: 'I did not change [employment status], I find it less stressful since retirement in 2013' and 'It's easier working part-time for self and time to give to mum'.

The majority of caregivers reported having their own children (77.8%, n=56). Of these, the majority said they had two children (41.07%, n= 23), though the number ranged from one (5.36%, n=3) to six children (5.36%, n=3). Only around 31% of caregivers felt that others provided assistance to the pwAMD because of the AMD. The majority reported not receiving help from others. There were some discrepancies with pwAMD reports. 39% of pwAMD reported receiving help from others (see Table 7.5).

Around a third of caregivers reported providing care to the pwAMD before diagnosis of AMD.

We asked pwAMD for their own and their caregiver's contact details at the time of the Macular Society 2013 survey (at the end of 2013/ early 2014), and we would therefore expect that there wouldn't be any caregivers who reported providing support for less than a year. Indeed, no caregivers reported this. Just over two-thirds of caregivers reported having provided support for AMD for 'more than 5 years'. Therefore caregivers and the pwAMD had provided/ received support for AMD for a relatively long period of time.

There was a large, significant association between caregiver and pwAMD perceptions of how much support they provided/received per week ($r_s = 0.81$, $p<0.01$). The most commonly reported amount of care received per week for AMD was ‘more than 35 hours’. This option was the highest possible amount of care. The non-perfect correlation indicates there are some discrepancies. The majority of dyads (n=47, 72%) reported receiving/providing the same amount of care per week (i.e. within each dyad, pwAMD and caregivers both ticked the same response option). However there were eighteen pairs where the pwAMD and caregiver had ticked different options (plus seven pairs had missing data). For seven of the pairs who had reported different responses, the caregiver had reported they provided more care than the pwAMD reported receiving. However for eleven pairs, the pwAMD reported receiving more care than the caregiver said they provided.

Impact of the person with AMD/ caregiver dyad relationship

The sample size of the ‘other’ pwAMD-caregiver relationship group (n=2) was very small and this led to some violations of the assumptions for analysis (e.g. for χ^2 tests, expected frequencies for each group should be greater than five). Therefore significant differences between the two most common pwAMD-caregiver relationship types were tested (for spouse (n=49) and adult-offspring/ parent relationships (n=21)). The results are presented in Table 7.6.

Table 7.6. Characteristics of spouse dyads and adult-offspring/ parent caregiver dyads. Values are frequencies (valid percentage %) unless otherwise stated.

Variables		**Spouse dyads (n=49)**	**Adult-offspring/ parent dyads (n=21)**	**statistic, p value, effect size and n.**
Gender of pwAMD	Male	31 (63.3%)	4 (19.0%)	χ^2 (1)=11.50, p=0.001**: phi=0.41: n=70.
	Female	18 (36.7%)	17 (81.0%)	
	Missing	0	0	
Gender of caregiver	Male	18 (36.7%)	3 (14.3%)	χ^2 (1)=3.53, p=0.09: n=70.
	Female	31 (63.3%)	18 (85.7%)	
	Missing	0	0	
PwAMD age at survey completion (years)	Mean (SD)	79.65 (5.99)	88.05 (3.31)	U=936.00, z= 5.41, p<0.01**: n=70.
	Median	81.00	89.00	
	Missing	0	0	
Caregiver age at survey completion (years)	Mean (SD)	78.92 (6.26)	60.62 (5.84)	U=19.50, z= -6.35, p<0.01**: n=70.
	Median	80.00	62.00	
	Missing	0	0	

PwAMD registration status	Not registered	10 (20.4%)	2 (9.5%)	χ^2 (2)=1.15, p=0.58: n=70.
	Registered sight impaired (SI)/ partially sighted	17 (34.7%)	8 (38.1%)	
	Registered severely sight impaired (SSI)/ blind	22 (44.9%)	11 (52.4%)	
	Missing	0	0	
Number of eyes affected[a]	One eye	2 (4.1%)	1 (4.8%)	χ^2 (1)=0.02, p=0.90: n=70.
	Both eyes	47 (95.9%)	20 (95.2%)	
	Missing	0	0	
Wet or dry AMD or both[a]	Wet AMD (one or both eyes)	19 (40.4%)	5 (26.3%)	χ^2 (2)=1.43, p=0.55: n=66.
	Dry AMD (one or both eyes)	20 (42.6%)	11 (57.9%)	
	Wet AMD in one eye, dry AMD in the other	8 (17.0%)	3 (15.8%)	
	Missing	2	2	
Years since diagnosis[a]	Mean (SD)	10.53 (5.22)	14.56 (8.30)	U=517.000, z= 1.71, p=0.09: n=63.
	Median	10.00	14.00	
	Missing	4	3	

PwAMD marital status	Married/living with partner	49	0	[b]
	Widowed	0	19	
	Divorced	0	2	
	Separated	0	0	
	Single	0	0	
	Civil Partnership	0	0	
	Missing	0	0	
Caregiver marital status	Married/living with partner	48	12	[b]
	Widowed	0	1	
	Divorced	0	0	
	Separated	1	0	
	Single	0	8	
	Civil Partnership	0	0	
	Missing	0	0	
PwAMD employment status	Employed, full time	0	0	[b]
	Employed, part time	0	0	
	Self-employed	0	0	

	Looking after family and/or home	0	0	
	Retired	48	20	
	Seeking work/ unemployed	0	0	
	Disabled or too ill to work	1	0	
	Student	0	0	
	Other	0	1	
	Missing	0	0	
Caregiver employment status	Employed, full time	0	2	[b]
	Employed, part time	2	3	
	Self-employed	0	2	
	Looking after family and/or home	1	0	
	Retired	46	11	
	Seeking work/ unemployed	0	1	
	Disabled or too ill to work	0	1	
	Student	0	0	
	Other	0	1	

	Missing	0	0	
Living together?	Yes	48 (100%)	8 (42.1%)	χ^2 (1)=33.25, p<0.01**: phi = 0.70: n=67.
	No	0 (0%)	11 (57.9%)	
	Missing	1	2	
PwAMD general health[c]	Mean (SD)	4.59 (1.32)	4.81 (1.25)	U=488.50, z= - 0.21, p=0.84: n=69.
	Median	5.00	5.00	
	Missing	1	0	
Caregiver general health[c]	Mean (SD)	4.73 (1.17)	5.38 (1.11)	U=363.50, z= -1.99, p=0.046*: n=70.
	Median	5.00	5.00	
	Missing	0	0	
PwAMD number of other medical conditions	Mean (SD)	1.63 (1.88)	1.86 (1.77)	U=564.50, z= 0.66, p=0.51: n=70.
	Median	1.00	2.00	
	Missing	0	0	
PwAMD reported hours of care received	Fewer than 7 hours per week	15 (32.6%)	3 (15.0%)	χ^2 (3)=4.03, p=0.26: n=66.
	7 to 14 hours per week	6 (13.0%)	5 (25.0%)	
	15 to 35 hours per week	8 (17.4%)	6 (30.0%)	

	More than 35 hours per week	17 (37.0%)	6 (30.0%)	
	Missing	3	1	
Caregiver reported hours of care provided	Fewer than 7 hours per week	15 (31.9%)	2 (10.5%)	χ^2 (3)=5.06, p=0.17: n=66.
	7 to 14 hours per week	8 (17.0%)	7 (36.8%)	
	15 to 35 hours per week	10 (21.3%)	3 (15.8%)	
	More than 35 hours per week	14 (29.8%)	7 (36.8%)	
	Missing	2	2	
Duration of caregiving	Less than a year	0 (0%)	0 (0%)	χ^2 (1)=1.11, p=0.29: n=70.
	Between 1 and 5 years	18 (36.7%)	5 (23.8%)	
	More than 5 years	31 (63.3%)	16 (76.2%)	
PwAMD level of dependency on caregiver (as reported by the caregiver)[d]	Not at all dependent	3 (6.1%)	0 (0%)	U=608.00, z= 1.23, p=0.22: n=70.
	Somewhat dependent	11 (22.4%)	5 (23.8%)	
	Moderately dependent	16 (32.7%)	4 (19.0%)	
	Very dependent	11 (22.4%)	6 (28.6%)	
	Extremely dependent	8 (16.3%)	6 (28.6%)	

	Missing	0	0	
	Mean (SD)	3.20 (1.15)	3.60 (1.16)	
	Median	3.00	4.00	
PwAMD DLTV score [e]	Mean (SD)	59.28 (16.43)	61.41 (14.31)	U=553.00, z= 0.49, p=0.62: n=70.
	Median	59.00	63.00	
	Missing	0	0	
PwAMD IADL score[f]	Mean (SD)	4.30 (2.80)	4.93 (2.27)	U=573.50, z= 0.76, p=0.45: n=70.
	Median	4.00	5.00	
	Missing	0	0	
PwAMD QoL	Excellent	6 (12.2%)	2 (9.5%)	U=435.500, z= -1.04, p=0.30: n=70.
	Very good	12 (24.5%)	3 (14.3%)	
	Good	11 (22.4%)	3 (14.3%)	
	Neither good nor bad	13 (26.5%)	11 (52.4%)	
	Bad	4 (8.2%)	1 (4.8%)	
	Very bad	1 (2.0%)	1 (4.8%)	
	Extremely bad	2 (4.1%)	0 (0%)	
	Missing	0	0	

	Median	1.00 (Good)	0 (Neither good nor bad)	
PwAMD MD-specific QoL [g]	Very much better	32 (65.3%)	17 (81.0%)	U=419.00, z= -1.50, p=0.14: n=70.
	Much better	10 (20.4%)	3 (14.3%)	
	A little better	5 (10.2%)	1 (4.8%)	
	The same	2 (4.1%)	0 (0%)	
	Worse	0 (0%)	0 (0%)	
	Missing	0	0	
	Median	-3.00 (very much better)	-3.00 (very much better)	
PwAMD negative well-being subscale of W-BQ16 [h]	Mean (SD)	2.77 (2.66)	4.07 (3.16)	U=640.50, z= 1.63, p=0.10: n=70.
	Median	2.00	4.00	
	Missing	0	0	
PwAMD energy subscale of W-BQ16 [i]	Mean (SD)	6.30 (2.90)	5.79 (2.14)	U=421.00, z= -1.21, p=0.23: n=70.
	Median	7.00	5.50	
	Missing	0	0	
PwAMD positive well-being subscale of W-BQ16 [h]	Mean (SD)	6.56 (3.41)	6.43 (3.03)	U=475.50, z= -0.37, p=0.71: n=69.
	Median	7.50	6.00	

	Missing	1	0	
PwAMD stress subscale of W-BQ16 [i]	Mean (SD)	4.17 (2.65)	4.26 (2.51)	U=533.50, z= 0.25, p=0.81: n=70.
	Median	4.00	4.50	
	Missing	0	0	
PwAMD GENERAL well-being score (W-BQ16) [j]	Mean (SD)	29.86 (10.14)	27.88 (9.00)	U=428.00, z= -0.99, p=0.32: n=69.
	Median	30.00	26.00	
	Missing	1	0	
Caregiver QoL	Excellent	3 (6.1%)	2 (9.5%)	U=539.00, z= 0.33, p=0.74: n=70.
	Very good	15 (30.6%)	8 (38.1%)	
	Good	19 (38.8%)	4 (19.0%)	
	Neither good nor bad	8 (16.3%)	6 (28.6%)	
	Bad	4 (8.2%)	1 (4.8%)	
	Very bad	0 (0%)	0 (0%)	
	Extremely bad	0 (0%)	0 (0%)	
	Missing	0	0	
	Median	1.00 (Good)	1.00 (Good)	
Caregiver adapted MD-specific QoL item [g]	Very much better	3 (6.1%)	2 (9.5%)	U=450.00, z= -0.57, p=0.57: n=69.
	Much better	6 (12.2%)	3 (14.3%)	

	A little better	21 (42.9%)	8 (38.1%)	
	The same	18 (36.7%)	7 (33.3%)	
	A little worse	0 (0%)	0 (0%)	
	Much worse	1 (2.0%)	0 (0%)	
	Very much worse	0 (0%)	0 (0%)	
	Missing	0	1	
	Median	-1.00	-1.00	
Caregiver appraisal of positive impact [k]	Mean (SD)	3.43 (1.63)	3.42 (1.50)	U=430.00, z= -0.10, p=0.92: n=65.
	Median	3.50	3.00	
	Missing	3	2	
Caregiver appraisal of negative impact [k]	Mean (SD)	3.29 (1.72)	3.19 (1.69)	U=502.00, z= -0.17, p=0.87: n=70.
	Median	4.00	4.00	
	Missing	0	0	
Caregiver negative well-being subscale of W-BQ16 [h]	Mean (SD)	1.96 (2.31)	2.52 (2.91)	U=522.00, z= 0.39, p=0.70: n=68.
	Median	1.00	1.00	
	Missing	2	0	
Caregiver energy subscale of W-BQ16 [i]	Mean (SD)	6.60 (2.67)	6.69 (2.25)	U=517.50, z= 0.18, p=0.86: n=69.
	Median	6.50	7.00	

	Missing	1	0	
Caregiver positive well-being subscale of W-BQ16 [h]	Mean (SD)	6.69 (3.00)	6.67 (2.63)	U=489.00, z= -0.20, p=0.84: n=69.
	Median	6.00	6.00	
	Missing	1	0	
Caregiver stress subscale of W-BQ16 [i]	Mean (SD)	4.08 (3.39)	4.52 (3.11)	U=554.00, z= 0.66, p=0.51: n=69.
	Median	4.00	4.00	
	Missing	1	0	
Caregiver general well-being score (W-BQ16) [j]	Mean (SD)	31.23 (9.03)	30.31 (9.62)	U=462.00, z= -0.42, p=0.68: n=68.
	Median	32.00	32.00	
	Missing	2	0	
CRA total scale score [l]	Mean (SD)	2.31 (0.63)	2.46 (0.72)	U=436.00, z= 0.62, p=0.54: n=62.
	Median	2.25	2.27	
	Missing	5	3	
CRA ‘lack of family support’ subscale [l]	Mean (SD)	2.23 (0.83)	2.51 (1.10)	U=468.50, z= 0.82, p=0.41: n=64.
	Median	2.00	2.00	
	Missing	3	3	
CRA ‘impact on finances’ subscale [l]	Mean (SD)	2.01 (0.77)	2.18 (1.17)	U=482.50, z= 0.03, p=0.97: n=68.
	Median	2.00	2.00	

	Missing	1	1	
CRA ‘impact on schedule’ subscale[l]	Mean (SD)	2.85 (0.97)	3.20 (1.00)	U=610.00, z= 1.23, p=0.22: n=70.
	Median	2.80	3.00	
	Missing	0	0	
CRA ‘impact on health’ subscale[l]	Mean (SD)	2.38 (0.86)	2.29 (0.76)	U=445.50, z= -0.51, p=0.61: n=67.
	Median	2.25	2.00	
	Missing	3	0	
CRA ‘caregiver esteem’ subscale[l]	Mean (SD)	1.96 (0.72)	2.05 (0.59)	U=603.00, z= 1.14, p=0.26: n=70.
	Median	1.86	2.14	
	Missing	0	0	

*p<0.05, **p<0.01, ***p<0.001. [a] Responses are from the Macular Society 2013 survey. [b] Socio-demographic characteristics provided for information only. [c] Participants were asked ‘In general, my health is:’ followed by the following list of responses ‘excellent / very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad’. Higher scores indicate better health. [d] Caregivers were asked: ‘How dependent do you feel the person with the macular condition has been on you since diagnosis?’ Responses were on a 5-point scale where higher scores indicate higher perceived dependency on the caregiver. [e] DLTV is the Daily Living Tasks Dependent on Vision scale. Scale ranges from 22 to 88 where higher scores indicate poorer visual function. [f] IADL is the Instrumental Activities of Daily Living. Scale ranges from 0 (no disability) to 8 (high disability).[g] MD- specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). More negative scores indicate greater perceived negative impact on QoL. [h] The negative and stress well-being subscales are on a scale of 0 to 12 where higher scores indicate poorer well-being. [i] Positive and energy well-being is on a scale of 0 to 12, where higher scores indicate better well-being in these areas. [j] General well-being is on a scale of 0 to 48 where higher scores indicate better well-being. [k] Caregiver appraisals of the positive and negative impact of providing support are on a scale of 1 to 6 where higher scores indicate more positive or negative impact (respectively). [l] CRA is the Caregiver Reaction Assessment. The subscale and total scale ranges from 1 to 5, where higher scores indicate more negative impact of providing support.

There were no significant differences between dyads who were spouses or adult-offspring/parents in: the pwAMDs' general health, pwAMD number of other medical conditions, pwAMDs' reported hours of care received per week, caregiver reported hours of care provided per week, caregiver-reported level of dependence of the pwAMD on them, IADL scores, DLTV scores, pwAMDs' registration status, pwAMDs' time since diagnosis of AMD, pwAMD number of eyes affected by AMD, and whether the pwAMD had wet, dry or both wet and dry AMD. There were also no differences between these types of dyads in caregivers' QoL, caregivers' subscale scores on the W-BQ16, caregiver general W-BQ16 scores, caregivers' CRA total and subscale scores, as well as the single-item measures of their appraisal of the positive and negative impact of caregiving. In line with the multivariable findings from the 2013 survey (presented in Chapter 4), the type of pwAMD/caregiver relationship was not significantly associated with pwAMD QoL (generic or MD-specific) or their well-being.

Spouse caregivers were more likely to have poorer general health and be older than adult-offspring caregivers. Caregivers' general health was significantly associated with their age (r_s= -0.28, p=0.02, n=72), and this might account for the poorer health status of the older spouse caregivers than adult-offspring caregivers.

The pwAMD whose adult-offspring was supporting them, were more likely to be older than pwAMD whose spouse was their caregiver. All spouse caregivers who responded to the question on living status reported they lived with the pwAMD, whereas only 42% of adult-offspring caregivers reported living with the pwAMD. Two adult-offspring caregivers (under 'missing' in the Table 7.6) noted that they had their own homes, but lived with the pwAMD a lot of the time.

The pwAMD whose caregiver was their spouse were more likely to be male, whereas pwAMD in adult-offspring/parent pairs were more likely to be women than men. There were no significant differences in the proportions of male and female caregivers between spouse and adult-offspring/parent pairs. These differences may be accounted for by the trend of women having a longer life expectancy than men (ONS, 2016) and thus being more likely to require support from their children when their male partner has died. It is only to be expected that caregivers who are spouses of the pwAMD are more likely to be older than caregivers who are adult-offspring of the pwAMD.

'Stressors'

The 'stressors' included in the model tested in this study (shown in Figure 6.1) are pwAMD difficulties with vision-dependent tasks (measured using the DLTV), pwAMD difficulties with tasks of everyday living (their IADL score) and pwAMD self-reported rating of their general health. Details of pwAMDs' general health are provided in Table 7.4. Descriptive statistics and internal consistency reliabilities for pwAMDs' DLTV scores and IADL scores are presented in Table 7.7.

Table 7.7. Descriptive characteristics for ‘stressor’ variables (pwAMD responses).

Variables		
IADL (IADL is the Instrumental Activities of Daily Living. Scale ranges from 0 (no disability) to 8 (high disability).)[a]	Mean (SD)	4.55 (2.65)
	Median	4.79
	Minimum	0
	Maximum	8
	Missing	0
DLTV (DLTV is the Daily Living Tasks Dependent on Vision scale. Scale ranges from 22 to 88 where higher scores indicate poorer visual function.)[a]	Mean (SD)	60.43 (15.83)
	Median	61.50
	Minimum	26.00
	Maximum	85.00
	Missing	0
DLTV single item for near vision (Scores range from 1 (poor) to 4 (excellent).)	Mean (SD)	1.26 (0.59)
	Median	1.00
	Minimum	1 (poor)
	Maximum	3 (good)
	Missing	3
DLTV single item for distance vision Scores range from 1 (poor) to 4 (excellent).	Mean (SD)	1.48 (0.68)
	Median	1.00
	Minimum	1 (poor)
	Maximum	4 (excellent)
	Missing	3
Currently drive?	Yes	4
	No	52
	n/a as have never driven	13
	Missing	3
Reason stopped driving	Mainly because of my	43 (82.7%)

	macular condition	
	Partly due to AMD, partly other reasons[b]	5 (9.6%)
	Mainly other reasons[b]	4 (7.7%)
	Missing	0
Caregiver drives for pwAMD?	Yes	54 (75.0%)
	No	4 (5.56%)
	Not applicable as caregiver doesn’t drive	11 (15.28%)
	Missing	3 (4.17%)

[a] Internal consistency was assessed using Cronbach’s alpha. This was 0.96 for the DLTV, and 0.92 for the IADL. [b] Other reasons for stopping driving included being due to ‘age’, other health issues (e.g. a TIA), another member of the family wanting to drive, and lowered confidence in driving ability (unrelated to changes in eyesight).

The correlation matrix in Table 7.8 presents the results of Spearman’s correlations between the ‘stressors’ included in this study. There were moderate-to-large significant correlations between the three ‘stressors’.

There were significant associations between registration status and both IADL scores and DLTV scores (H (2)= 14.62, p=0.001; H (2)= 21.56, p<0.001, respectively). The trend was in the expected direction where more severe registration status was associated with more difficulties with activities of everyday living (IADL) and vision-dependent tasks (DLTV) (ps<0.001).

Table 7.8. Intercorrelations between ‘stressors’, pwAMD and caregiver QoL, well-being and caregiver reactions to providing support.

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1	IADL	-																
2	DLTV	.69***	-															
3	PwAMD general health	-.44***	-.38**	-														
4	Caregiver appraisal of negative impact of caregiving	.39***	.33**	-.43***	-													
5	Caregiver appraisal of positive impact of caregiving	-.05	-.03	.07	-.35**	-												
6	Level of dependency of pwAMD on caregiver	.70***	.63***	-.49***	.58***	-.15	-											
7	PwAMD QoL	-.48***	-.65***	.54***	-.29*	.21	-.51***	-										
8	PwAMD MD-specific QoL	-.45***	-.54***	.19	-.33**	.09	-.41***	.39***	-									
9	Caregiver QoL	-.49***	-.53***	.47***	-.48***	.20	-.53***	.64***	.33**	-								
10	PwAMD General well-being score (W-BQ16)	-.60***	-.64***	.62***	-.41***	.13	-.62***	.76***	.49***	.64***	-							
11	Caregiver General well-being score (W-BQ16)	-.31**	-.37**	.42***	-.51***	.32*	-.50***	.38**	.24*	.69***	.54***	-						
12	CRA ‘lack of family support’ subscale	.31*	.33**	-.41***	.45***	-.20	.42***	-.36**	-.19	-.51***	-.35**	-.56***	-					

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
13	CRA ‘impact on finances’ subscale	.28*	.36**	-.36**	.31**	-.13	.28*	-.39***	-.15	-.47***	-.48***	-.47***	.38**	-				
14	CRA ‘impact on schedule’ subscale	.53***	.47***	-.49***	.55***	-.24	.67***	-.45***	-.29*	-.65***	-.54***	-.74***	.62***	.48***	-			
15	CRA ‘impact on health’ subscale	.42***	.39***	-.37**	.53***	-.20	.49***	-.40***	-.34**	-.73***	-.60***	-.80***	.49***	.52***	.71***	-		
16	CRA ‘caregiver esteem’ subscale	-.09	-.05	-.08	.21	-.31*	.11	-.16	.03	-.09	-.08	-.14	.17	.20	.20	.01	-	
17	CRA total scale score	.46***	.46***	-.55***	.65***	-.33*	.64***	-.50***	-.29*	-.74***	-.60***	-.82***	.78***	.66***	.89***	.78***	.33**	-

*** $p<0.001$, **$p< 0.01$, * $p<0.05$.

Primary appraisal (hours of care variables)

The ‘hours-of-care’ groups were compared to see if there were differences in health-related, and eye-related variables, caregivers’ secondary appraisals of the impact of caregiving and both pwAMD and caregiver psychological health outcomes (well-being and QoL). The results appear in Table 7.9. Descriptive statistics and frequencies are provided for pwAMD reported ‘hours-of-care’. Differences in the socio-demographic and support-related characteristics between the ‘hours-of-care’ groups are at the bottom of Table 7.9.

Table 7.9. Differences between hours-of-care groups (pwAMD-reported) on characteristics of the caregivers and pwAMD. Values are means and medians unless otherwise stated.

Variables		**Fewer than 7 hours per week (n=18)**	**7 to 14 hours per week (n=12)**	**15 to 35 hours per week (n=14)**	**More than 35 hours per week (n=24)**	**Test for differences between pwAMD reported 'hours of care' groups: statistics, and p value$^{\psi}$.**	**Relationship in the expected direction?**	**Does the analysis using the caregiver 'hours-of-care' variable (instead of pwAMD reported hours of care), show a similar pattern of results?**
Instrumental Activities of Daily Living (range 0 to 8)^{a}	Mean (SD)	1.91 (1.94)	3.80 (1.97)	4.91 (2.38)	6.67 (1.79)	*H* (3)= 34.43, *p*<0.001***.	Yes- in the direction of: more difficulties with IADL, the more support received. All pairwise comparisons are significant apart from between the 7-14 hrs vs 15-35 hrs groups.	Yes. (Similar pattern of results.)
	Median	1.50	4.00	5.50	7.00			
	Missing	0	0	0	0			

DLTV score (range 22 to 88)[b]	Mean (SD)	48.00 (14.83)	59.92 (13.32)	57.71 (11.43)	71.13 (13.20)	*H* (3)= 22.12, *p*<0.001***.	Generally In the direction of: poorer VF, associated with more support received. Only two pairwise comparisons are significant: between fewer than 7 hrs vs more than 35 hrs groups. Also between the 15-35 hrs vs more than 35 hrs groups. N.B. The scores appear to follow a non-linear pattern.	Yes. (Similar pattern of results.) In addition to the two comparisons stated in the pwAMD results, another pairwise comparison is significant: between the 7-14 hrs vs more than 35hrs group is significant.
	Median	49.50	61.50	57.50	76.50			
	Missing	0	0	0	0			
DLTV single-item- distance vision (range from 1 (poor) to 4 (excellent))	Mean (SD)	1.94 (0.89)	1.36 (0.51)	1.54 (0.66)	1.17 (0.38)	*H* (3)= 11.77, *p*=0.008**.	Generally In the direction of poorer distance vision, the more support received. Only one significant pairwise comparison: for between the fewer than 7 hrs group vs more than 35hrs group.	Yes. (Similar pattern of results.) In addition, more pairwise comparisons are significant. In addition to the one comparison stated in the pwAMD results, another one pairwise
	Median	2.00	1.00	1.00	1.00			

							N.B. The scores appear to follow a non-linear pattern.	comparison is significant: between the fewer than 7 hrs group vs 7-14hrs groups.
	Missing	1	0	1	0			
DLTV single-item- near vision (range from 1 (poor) to 4 (excellent))	Mean (SD)	1.59 (0.80)	1.36 (0.81)	1.31 (0.48)	1.00 (0.00)	*H* (3)= 11.19, *p*=0.011*.	Generally in the direction of poorer near vision, the more support received. Only two significant pairwise comparisons: between the fewer than 7 hrs vs more than 35hrs groups. Also between the 15-35 hrs vs more than 35hrs groups.	Yes. (Similar overall pattern of results.) However the comparison between the 15-35 hrs vs more than 35 hrs groups is not significant.
	Median	1.00	1.00	1.00	1.00			
	Missing	1	1	1	0			
Registration status (frequencies)	Not registered	8 (44.4%) †	2 (16.7%)	2 (14.3%)	0 (0%) †	χ^2 (6)=16.73, p=0.009**: Cramer's V= 0.35, n=68.	Significant association between registration status and the amount of care	χ^2 (6)=15.83, p=0.013*: Cramer's V= 0.34, n=68.
	Registered as SI	6 (33.3%)	4 (33.3%)	3 (21.4%)	11 (45.8%)			

	Registered as SSI	4 (22.2%) †	6 (50.0%)	9 (64.3%)	13 (54.2%)		received. The † indicates significant adjusted residuals. The fewer than 7 hours per week group were more likely to not be registered, and less likely to be registered as SSI. The more than 35 hrs group were less likely to be not registered.	Same adjusted residuals were significant, indicating same pattern of results as with the pwAMD hours of care variable.
	Missing	0	0	0	0			
PwAMD general health (range 1 to 7)[c]	Mean (SD)	5.28 (0.89)	4.92 (1.24)	4.89 (1.27)	4.08 (1.35)	*H* (3)= 8.95, *p*=0.03*.	Generally in the direction of poorer general health, the more support received. Only one significant pairwise comparison: between the fewer than 7 hrs vs more than 35hrs groups.	Yes- same results as for pwAMD hours of care.
	Median	6.00	5.00	5.00	4.00			
	Missing	0	0	0	0			
PwAMD number of other conditions	Mean (SD)	1.00 (1.03)	1.50 (1.24)	2.14 (2.91)	1.92 (1.77)	*H* (3)= 3.18, *p*=0.37.	Relationship was not statistically significant.	**No.** This was significant: *H* (3)= 8.37, *p*=0.039*. There was an association
	Median	1.00	1.00	1.00	1.00			
	Missing	0	0	0	0			

								between the number of medical conditions the pwAMD had with the amount of care caregivers reported providing. No pairwise comparisons were significant.
Care recipient dependency (range 1 to 5)[d]	Mean (SD)	2.33 (0.77)	3.13 (0.68)	3.43 (1.16)	4.04 (1.08)	H (3)= 23.61, p<0.001***.	Generally in the direction of more pwAMD dependency on the caregiver, the more support received. There were four significant pairwise comparisons – between fewer than 7 hours per week and the other three groups. Plus between 7-14 hrs vs more than 35 hrs a week group.	Yes-similar pattern to pwAMD hours of care. However the pairwise comparison between fewer than 7 hrs per week and 7-14 hours a week groups was not significant.
	Median	2.00	3.00	3.00	4.00			
	Missing	0	0	0	0			

Caregiver overall negative impact of caregiving (range 1 to 6)[e]	Mean (SD)	2.61 (1.79)	2.50 (1.45)	3.07 (1.39)	3.96 (1.73)	*H* (3)= 9.61, *p*=0.022*.	Generally In the direction of more negative impact related to more support received. Only one significant pairwise comparison: between fewer than 7 hrs vs more than 35 hrs per week. N.B. there appears to be a non-linear pattern in the scores.	Yes-similar pattern to pwAMD hours of care.
	Median	2.00	2.50	3.50	4.00			
	Missing	0	0	0	0			
Caregiver overall positive impact of caregiving (range 1 to 6)[e]	Mean (SD)	3.41 (1.66)	4.17 (1.34)	3.31 (1.32)	3.41 (1.68)	*H* (3)= 2.74, *p*=0.433.	Relationship was not statistically significant.	Yes-relationship is not significant.
	Median	3.00	4.50	3.00	4.00			
	Missing	1	0	1	2			
Caregiver impact of caregiving on	Mean (SD)	-0.61 (0.61)	-0.45 (0.69)	-0.86 (1.29)	-1.13 (1.19)	*H* (3)= 5.53, p=0.137.	Relationship was not statistically significant.	Yes-relationship is not significant.
	Median	-1.00	0.00	-1.00	-1.00			

QoL (range 3 to -3)^{f}	*Missing*	0	1	0	0			
CRA 'lack of family support' subscale (range 1 to 5)^{g}	Mean (SD)	1.88 (0.83)	2.27 (0.71)	2.30 (0.78)	2.64 (1.06)	*H* (3)= 8.43, *p*=0.04*.	In the direction of: caregiver perceiving greater lack of family support with more support received. One significant pairwise comparison between: fewer than 7 hrs and more than 35 hrs a week groups.	Yes. An additional pairwise comparison was significant: between: fewer than 7 hrs and 7-14 hrs a week groups.
	Median	1.80	2.10	2.00	2.50			
	Missing	2	0	0	2			
CRA 'impact on finance' subscale (range 1 to 5)^{g}	Mean (SD)	1.76 (0.79)	2.00 (0.90)	1.98 (0.50)	2.41 (1.11)	*H* (3)= 4.97, *p*=0.17.	Relationship is not significant.	**No**. There is a significant relationship (p=0.005); caregivers perceive greater impact on finance from providing more support.
	Median	1.67	2.00	2.00	2.33			
	Missing	0	0	0	1			

								H (3)= 12.85, *p*=0.005***.* There were significant pairwise comparisons between: fewer than 7 hrs vs more than 35 hrs a week. Plus between 15-35 hrs and more than 35 hrs groups.
CRA 'impact on schedule' subscale (range 1 to 5)[g]	Mean (SD)	2.08 (0.77)	2.95 (0.68)	3.20 (0.66)	3.46 (1.06)	*H* (3)= 18.79, *p*<0.001****.*	There was a significant relationship: caregivers perceived greater negative impact on their schedule if the pwAMD reported receiving more care. There were significant pairwise comparisons between:	Yes- the relationship was significant. There was an additional significant pairwise comparison between: fewer than 7 hrs and 7-14 hrs of care a week group.
	Median	2.00	3.10	3.10	3.50			
	Missing	0	0	0	0			

							-fewer than 7 hrs per week vs more than 35 hours -fewer than 7 hrs vs 15-35hrs a week.	
CRA ‘impact on health’ subscale [g]	Mean (SD)	1.92 (0.65)	2.13 (0.69)	2.55 (0.76)	2.67 (0.96)	*H* (3)= 8.30, *p*=0.04*.	There was a significant relationship: caregivers perceived greater impact on their health as a result of caregiving if the pwAMD reported receiving more care. There were no significant pairwise comparisons.	Yes- there was a similar relationship. There was a significant pairwise comparison between: fewer than 7 hrs and more than 35 hrs a week.
	Median	2.00	2.00	2.38	2.50			
	Missing	0	0	0	2			
CRA ‘esteem’ subscale (range 1 to 5)[g]	Mean (SD)	2.13 (0.95)	1.98 (0.46)	2.20 (0.51)	1.79 (0.52)	*H* (3)= 4.43, *p*=0.22.	Relationship wasn’t statistically significant.	Yes- relationship wasn’t significant.
	Median	2.00	2.00	2.23	1.86			

	Missing	0	0	0	0			
CRA total scale score (range 1 to 5)[h]	Mean (SD)	1.92 (0.66)	2.26 (0.42)	2.45 (0.43)	2.67 (0.72)	*H* (3)= 13.33, *p*=0.004**.	There was a significant relationship: caregivers reported more negative impact of providing support with more support received by the pwAMD. There were two significant pairwise comparisons: between fewer than 7 hrs vs 15-35 hrs groups. Plus between Fewer than 7 hrs vs more than 35 hrs groups.	Yes- the relationship was significant. There were two significant pairwise comparisons: Between fewer than 7 hrs vs 7-14 hrs a week. Plus between fewer than 7 hrs per week vs more than 35 hrs.
	Median	1.78	2.24	2.30	2.78			
	Missing	2	0	0	4			
PwAMD overall QoL (range 3 to -3)[i]	Mean (SD)	1.39 (1.15)	0.92 (1.44)	0.79 (1.12)	0.21 (1.59)	*H* (3)= 6.31, *p*=0.098.	Relationship was not significant.	**No.** There was a significant relationship:
	Median	1.00	0.50	0.50	0.00			

	Missing	0	0	0	0			pwAMD who received more care (as reported by the caregiver), had poorer QoL. *H* (3)= 14.44, *p*=0.002**. One pairwise comparison is significant: between fewer than 7 hours of care vs more than 35 hours of care a week group.
PwAMD MD-specific QoL (range -3 to 1)[j]	Mean (SD)	-2.00 (0.97)	-2.33 (0.99)	-2.89 (0.29)	-2.79 (0.51)	*H* (3)= 13.83, *p*=0.003**.	Generally In the direction of poorer MD-specific QoL related to more support received. Two pairwise comparisons were significant: between fewer than 7 hrs vs 15-35 hrs. Plus between fewer than 7 hrs vs	Yes-similar pattern to pwAMD hours of care. There was one additional significant pairwise comparison: between fewer than 7hr vs 7-
	Median	-2.00	-3.00	-3.00	-3.00			
	Missing	0	0	0	0			

							more than 35 hrs groups. N.B. It appears that scores are in a non-linear pattern.	14 hrs a week groups.
Caregiver overall QoL (range 3 to -3)[i]	Mean (SD)	1.67 (0.84)	1.50 (0.80)	1.14 (0.77)	0.67 (1.20)	*H* (3)= 10.61, *p*=0.014*.	Generally In the direction of poorer caregiver QoL related to more support received. One pairwise comparison is significant: between fewer than 7 hrs vs more than 35 hrs groups.	Yes. (Similar pattern of results.) Two pairwise comparisons were significant, between: fewer than 7 hours per week vs more than 35 hours a week, and between fewer than 7 hours per week and 7-14 hours a week.
	Median	2.00	1.50	1.00	0.50			
	Missing	0	0	0	0			
PwAMD negative well-being subscale	Mean (SD)	1.72 (1.67)	1.96 (1.96)	3.61 (3.21)	4.67 (2.96)	*H* (3)= 12.53 *p*=0.006**.	Generally In the direction of greater negative well-being related to more support received.	Yes. (Similar pattern of results.)

score of W-BQ 16 (range 0 to 12)[k]	Median	1.00	1.50	2.50	5.00		One pairwise comparison is significant, between: fewer than 7 hrs vs more than 35 hrs groups.	Only one pairwise comparison was significant- between fewer than 7 hours per week and more than 35 hours per week groups.
	Missing	0	0	0	0			
PwAMD energy subscale score of the W-BQ16 (range 0 to 12)[k]	Mean (SD)	7.87 (2.11)	6.42 (2.43)	6.68 (2.15)	4.42 (2.80)	*H* (3)= 15.27, *p*=0.002**.	Generally in the direction of lower energy related to more support received. Only one significant pairwise comparison: between fewer than 7hrs vs more than 35hrs. However, there was a non-linear trend in scores.	Yes. (Similar results as when used pwAMD hours of care.) However an additional pairwise comparison was significant: between 15-35 hours a week vs more than 35 hours of care a week.
	Median	8.00	6.50	6.50	5.00			
	Missing	0	0	0	0			
PwAMD positive well-being subscale	Mean (SD)	8.44 (2.41)	7.00 (2.80)	6.23 (3.59)	5.50 (3.15)	*H* (3)= 9.02, *p*=0.029*.	Generally In the direction of lower positive WB related to more support received. Only one	Yes. Same findings as with pwAMD
	Median	8.50	6.00	7.00	6.00			

score of the W-BQ16 (range 0 to 12)[k]	*Missing*	0	0	1	0		significant pairwise comparison: between fewer than 7hrs vs more than 35hrs.	hours of care variable.
PwAMD stress subscale score of the W-BQ16 (range 0 to 12)[k]	Mean (SD)	2.94 (2.21)	3.96 (1.94)	4.67 (2.25)	5.00 (3.01)	*H* (3)= 6.84, *p*=0.077.	Relationship was not significant.	**No.** The Kruskal Wallis test was significant. *H* (3)= 8.24, *p*=0.04*. Generally In the direction of higher stress related to more support received. One pairwise comparison was significant: between fewer than 7 hours a week vs more than 35 hours a week groups.
	Median	3.00	3.50	5.00	5.00			
	Missing	0	0	0	0			
PwAMD general well-	Mean (SD)	35.65 (7.14)	31.50 (7.97)	28.31 (9.03)	24.25 (9.82)	*H* (3)= 13.89, *p*=0.003**.	In the direction of lower general WB related to more support received. Only one significant	Yes. Same results as with pwAMD
	Median	36.00	31.50	30.00	26.00			

being (range 0 to 48)[l]	*Missing*	0	0	1	0		pairwise comparison: between fewer than 7hrs vs more than 35hrs groups.	hours of care.
Caregiver negative well-being subscale score of the W-BQ16 (range 0 to 12)[k]	Mean (SD)	0.71 (1.16)	1.50 (2.07)	3.10 (2.74)	2.92 (2.86)	*H* (3)= 11.07, *p*=0.011*.	Generally In the direction of greater negative WB related to more support received. Two significant pairwise comparisons: between fewer than 7hrs vs more than 35hrs groups. Also between the fewer than 7hrs vs 15-35hrs a week groups. N.B. there appears to be a non-linear trend in scores.	Yes. Similar results as with pwAMD hours of care. However only one pairwise comparison was significant: between fewer than 7 hours a week vs more than 35 hours a week groups.
	Median	0.00	1.00	3.50	2.50			
	Missing	1	0	0	0			
Caregiver energy subscale score of the W-BQ16 (range 0 to 12)[k]	Mean (SD)	7.39 (1.82)	6.75 (2.01)	6.89 (1.62)	6.04 (3.34)	*H* (3)= 2.08, *p*=0.556.	Relationship was not statistically significant.	Yes. Results were also not significant using caregiver reported hours of care provided.
	Median	7.50	8.00	7.00	6.50			
	Missing	0	0	0	0			

Caregiver positive well-being subscale score of the W-BQ 16 (range 0 to 12)[k]	Mean (SD)	7.33 (2.85)	7.00 (2.76)	6.57 (2.34)	6.50 (3.12)	*H* (3)= 0.98, *p*=0.81.	Relationship was not statistically significant.	Yes. Results were also not significant using caregiver reported hours of care provided.
	Median	8.00	7.50	6.00	6.00			
	Missing	0	0	0	0			
Caregiver stress subscale score of the W-BQ16 (range 0 to 12)[k]	Mean (SD)	2.56 (2.57)	3.08 (2.47)	4.86 (2.80)	5.63 (3.87)	*H* (3)= 10.23, *p*=0.017*.	Generally In the direction of higher stress related to more support received. One significant pairwise comparison: between fewer than 7hrs vs more than 35hrs a week groups.	Yes. Same results was with pwAMD hours of care variable.
	Median	2.50	3.50	4.50	5.50			
	Missing	0	0	0	0			
Caregiver general well-being (range 0 to 48)[l]	Mean (SD)	35.59 (5.67)	33.17 (7.18)	29.51 (7.88)	28.00 (11.47)	*H* (3)= 7.65, *p*=0.054.	Kruskal Wallis test was not significant, i.e. caregivers' general well-being was **not** significantly associated with pwAMD reported	**No.** The Kruskal Wallis test **was** significant when the caregiver reported hours of care
	Median	35.00	32.50	27.50	26.00			
	Missing	1	0	0	0			

							hours-of-care-received.	variable was used. *H* (3)= 10.88, *p*=0.012*. There was one significant pairwise comparison: between the fewer than 7 hours group vs more than 35 hours a week group.
Caregiver general health (range 1 to 7)[c]	Mean (SD)	5.39 (1.14)	4.92 (1.17)	5.21 (1.05)	4.42 (1.21)	*H* (3)= 7.78, *p*=0.051.	Kruskal Wallis test was **not** significant, i.e. caregivers' general health was not significantly associated with pwAMD reported hours-of-care-received. n.b. there appears to be a	**No.** The Kruskal Wallis test **was** significant when the caregiver reported hours of care variable was used. *H* (3)= 12.24, *p*=0.007**.
	Median	5.50	5.00	5.00	4.00			
	Missing	0	0	0	0			

							non-linear trend in scores across groups.	There was one significant pairwise comparison: between the fewer than 7 hours group vs more than 35 hours a week group.
Person with AMD/caregiver relationship (frequencies)	Spouse	15 (83.3%)	6 (50%)	8 (57.1%)	17 (70.8%)	χ^2 (6)=6.35, p=0.38: n=68.	Relationship was not statistically significant.	Yes (same result as with pwAMD reported hours-of-care-received). χ^2 (6)=6.65, p=0.36: n=68.
	Adult-offspring	3 (16.7%)	5 (41.7%)	6 (42.9%)	6 (25.0%)			
	Other	0 (0%)	1 (8.3%)	0 (0%)	1 (4.2%)			
Gender of pwAMD (frequencies)	Male	8 (44.4%)	4 (33.3%)	8 (57.1%)	12 (50%)	χ^2 (3)=1.61, p=0.64: n=68.	Relationship was not statistically significant.	Yes (same result as with pwAMD reported hours-of-care-received). χ^2 (3)=2.71, p=0.45: n=68.
	Female	10 (55.6%)	8 (66.7%)	6 (42.9%)	12 (50%)			
	Missing	0	0	0	0			

Gender of caregiver (frequencies)	Male	8 (44.4%)	4 (33.3%)	3 (21.4%)	6 (25.0%)	χ^2 (3)=2.50, p=0.50: n=68.	Relationship was not statistically significant.	Yes (same result as with pwAMD reported hours-of-care-received). χ^2 (3)=3.44, p=0.35: n=68.
	Female	10 (55.6%)	8 (66.7%)	11 (78.6%)	18 (75.0%)			
	Missing	0	0	0	0			
Live with the person with AMD? (frequencies)	Yes	14 (82.4%)	7 (58.3%)†	10 (71.4%)	22 (100%)†	χ^2 (3)=10.23, p=0.013*: Cramer's V= 0.40, n=65.	More than expected of those pairs who live together said 'more than 35 hours per week', and less than expected said the '7-14 hours a week' option. Of those who didn't live together, more than expected said the '7-14 hours a week' option and less than expected said the 'more than 35 hours a week' option.	Yes. Similar findings however the adjusted residuals indicated different causes of the significant result (as detailed below). χ^2 (3)=12.57, p=0.004**: Cramer's V= .44. n=65. For caregivers, the cause of the significant result was mainly due to
	No	3 (17.6%)	5 (41.7%)†	4 (28.6%)	0 (0%) †			
	Missing	1	0	0	2			

								more of the pairs who didn’t live together saying they provided ‘7-14 hours of care a week’, and less than expected of the pairs that lived together saying they provided ‘7-14 hours of care a week’.
Length of time provided support for AMD (frequencies)	Less than a year	0 (0%)	0 (0%)	0 (0%)	0 (0%)	χ^2 (3)=3.93, p=0.28: n=68.	Relationship was not statistically significant.	Yes. (Relationship was not significant.) χ^2 (3)=4.28, p=0.24: n=68.
	Between 1 and 5 years	8 (44.4%)	5 (41.7%)	3 (21.4%)	5 (20.8%)			
	More than 5 years	10 (55.6%)	7 (58.3%)	11 (78.6%)	19 (79.2%)			
	Missing	0	0	0	0			
Time since diagnosis	Mean (SD)	11.40 (5.91)	10.46 (6.12)	12.08 (8.47)	12.33 (6.37)	*H* (3)= 0.99, *p*=0.80.	Relationship was not	Yes. (Relationship

	Median	10.00	8.00	11.00	11.00	statistically significant.	was not significant.) *H* (3)= 0.71, *p*=0.87.
	Missing	3	1	1	3		

* is p<0.05, ** is p<0.01, ***p<0.001. [†] Adjusted residuals over 2.0- indicates cause of overall significant χ^2 test result. [ψ]Kruskal Wallis tests were run to examine differences between the hours- of-care groups. Pairwise comparisons were performed using Dunn (1961) procedure with a Bonferroni correction for multiple comparisons.

[a] IADL is the Instrumental Activities of Daily Living scale. Scale ranges from 0 (no disability) to 8 (high disability). [b] DLTV is the Daily Living Tasks Dependent on Vision scale. Scale ranges from 22 to 88 where higher scores indicate poorer visual function. [c] Self-rated health is measured using a single item. Higher scores indicate better health. [d] Caregivers were asked: ‘How dependent do you feel the person with the macular condition has been on you since diagnosis?’ Responses were on a 5-point scale where higher scores indicate higher perceived dependency on the caregiver. [e] Caregiver appraisals of the positive and negative impact of providing support are on a scale of 1 to 6 where higher scores indicate more positive or negative impact (respectively). [f] Higher scores indicated less negative/ more positive impact of caring for someone with MD on the caregiver’s quality of life. [g] Subscales of the Caregiver Reaction Assessment (CRA) are scored so that higher scores indicate more negative impact of caregiving for the topic of the subscale, e.g. higher scores on the ‘impact on finances’ subscale indicate more negative impact of caregiving on finances. [h]CRA is the Caregiver Reaction Assessment. The total scale ranges from 1 to 5, where higher scores indicate more negative impact of providing support. [i] Quality of life (QoL) is measured on a 7-point scale scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad). [j]MD- specific quality of life is measured on a 5-point scale scored from -3 which indicates their quality of life would be ‘very much better’ (if they did not have their macular condition), through to 0 (the same), to +1 (where it would be ‘worse’). More negative scores for both QoL and MD-specific QoL indicate greater perceived negative impact on QoL. [k] Subscales of the W-BQ16 are scored so that higher scores indicate more of the type of well-being for that subscale, e.g. higher score on the negative well-being subscale indicate greater negative well-being. [l] General well-being is on a scale of 0 to 48 where higher scores indicate better well-being.

Some of the findings from the bivariate analysis of the 2013 survey findings presented in Chapter 4 are replicated here in this sub-sample. The pwAMD who reported receiving more support for AMD were more likely to be registered as SI or SSI, have poorer general health status, and report living with their caregiver. In bivariate analyses of the 2013 survey responses, respondents who reported receiving more care for AMD were more likely to report poorer QoL (both general and MD-specific) and well-being. However in multivariate analyses, the relationship between general QoL and the amount-of-care-received was no longer significant. In the present study, pwAMD reported hours- of-care-received was not significantly associated with their general QoL, but it was with their MD-specific QoL and well-being. In the 2013 survey, pwAMD who were male and reported their caregiver was their wife were more likely to report receiving 'more than 35 hours of care a week'. In the present study, there were no gender differences or differences in type of pwAMD/caregiver relationship across the hours-of-care groups.

Further examination of the mean and median scores indicate the trends weren't always linear. For instance, the 7-14 hours-of-care group reported higher DLTV scores (indicative of poorer visual function) than the 15-35 hours-of-care a week group. The fewer-than-7-hours-a-week group had the lowest scores, and the more-than-35-hours-a-week group had the highest (as would be predicted).

The quantitative second study added to the 2013 survey study findings by including the caregivers' perspective. The amount of care provided to pwAMD was significantly associated with caregivers' negative appraisals of the impact of caregiving. Caregivers who provided more care were more likely to rate the pwAMD as more dependent on them, perceive a more negative overall impact of providing support on their lives, have poorer general QoL and well-being, and perceive greater 'burden' as a result of providing support (i.e. a higher total CRA score). (See Table 7.9.)

In contrast, providing more care for AMD was not significantly associated with caregivers perceiving a lower positive impact from providing support, and higher resentment and lower enjoyment from caregiving (i.e. their score on the esteem subscale of the CRA). The amount of care provided to the pwAMD was not associated with caregivers’ scores on the energy and positive well-being subscales of the W-BQ16. (See Table 7.9.)

The last column in Table 7.9 shows whether the bivariate analyses using caregivers’ appraisal of the amount of help they provide produced similar findings compared to when the pwAMDs’ appraisal of the amount of care received is used. There were some differences in the results. For instance, caregivers who provided more care reported poorer well-being. Whereas pwAMD reported hours-of-care-received was not significantly associated with caregiver well-being. Similarly caregivers’ general health was related to their own appraisal of the amount of care they provide, but not to the appraisal by pwAMD. This indicates (depending on the outcome under consideration), that it may be important to collect data from the ‘actor’ in order to determine how factors affect outcomes.

Secondary appraisals (Caregiver reactions towards providing support)

Table 7.10 presents the mean scores for the subscales and total score on the CRA. The mean scores of below 3 might indicate that caregivers (on average) reported little impact of caregiving in these areas of their lives. However there is huge variability in scores (as seen in the range of scores). Some caregivers report the maximum negative reaction whilst others report minimal negative reactions. The esteem subscale seems to be the least impacted (mean score= 2.0), whilst the schedule subscale is the most impacted (mean score= 3.0). The maximum negative reactions were recorded on both the schedule subscale and family support subscale.

Table 7.10. Reactions to providing care, CRA subscale and total scores[a].

CRA		Mean (SD)	Range	n missing
	Self-esteem	2.0 (0.67)	1.00-4.71	0
	Impact on finances	2.1 (0.89)	1.00-4.67	2
	Impact on health	2.4 (0.84)	1.00-4.50	3
	Disrupted schedule	3.0 (0.98)	1.00-5.00	0
	Lack of family support	2.3 (0.91)	1.00-5.00	6
	CRA total	2.4 (0.65)	1.14-3.80	8

[a] Internal consistency was assessed using Cronbach's alpha. This was 0.92 for the CRA. The CRA is the Caregiver Reaction Assessment. The total and subscale scores range from 1 to 5, where higher scores indicate more negative impact of providing support. The subscale scores are the average score of the items on the subscale which are scored from 1 to 5, and where lower scores indicate respondents feel this area of life has not been affected by caregiving and higher scores indicate it has been greatly affected. A score of 3 is 'neither agree nor disagree.' The total score is the average of all the subscales.

Table 7.8 presents Spearman's correlations between the 'stressors' and caregivers' appraisals of the impact of providing support. In particular, pwAMD who reported greater difficulties with tasks of everyday living (IADL), vision-dependent tasks (DLTV) and poorer general health status were more likely to have caregivers who perceived greater negative impact of providing care (as measured by the total CRA score).

There were no significant associations between IADL, DLTV scores, and pwAMD general health with caregivers' appraisal of the positive impact of providing support on their lives. Neither was there an association between these 'stressors' with scores on the CRA subscale for caregiver esteem. (See Table 7.8.)

None of the individual CRA subscales (all $p>0.05$) nor the total CRA scale score ($H(2)= 4.53$, $p=0.10$) were significantly associated with registration status.

Caregivers' appraisal of the positive impact of caregiving had a moderate correlation with caregivers' appraisal of the negative impact of providing support ($r_s= -0.35$, $p=0.004$, $n=67$), suggesting that the two are not measuring two ends of the same spectrum.

Well-being

Table 7.11. PwAMD and caregiver general well-being, W-BQ12[a] and W-BQ16[b].

General well-being	Mean (SD)	Range	n missing
pwAMD General well-being (*W-BQ12*)	21.21 (7.69)	4.00-34.00	1
pwAMD General well-being (*W-BQ16*)	28.94 (9.83)	6.00-45.00	1
Caregiver General well-being (*W-BQ12*)	23.23 (6.42)	10.00-36.00	2
Caregiver General well-being (*W-BQ16*)	31.07 (9.10)	10.00-48.00	2

[a] The W-BQ12 is on a scale of 0 to 36 where higher scores indicate better well-being. [b] The W-BQ16 is on a scale of 0 to 48 where higher scores indicate better well-being.

Caregiver mean and median general well-being scores were only slightly higher than pwAMD scores (caregiver general well-being mean score= 31.07, median=32.00, Standard deviation= 9.10; pwAMD general well-being mean score= 30.32, median= 31.00, Standard deviation= 8.99). The descriptive statistics for the W-BQ12 and W-BQ16 are presented in Table 7.11. The results of the W-BQ12 are presented here for comparison with other populations however the General well-being score from the W-BQ16, which includes a subscale measuring stress, is used in the present study.

There were significant correlations between the ‘stressors’ and general well-being. Fewer difficulties with tasks of everyday living (IADL), vision-dependent tasks and better general health were associated with better pwAMD general well-being scores. (See Table 7.8.) Caregivers’ well-being was significantly associated with pwAMDs’ IADL scores, DLTV scores and general health, in the same direction.

Registration status was significantly associated with pwAMDs' well-being (H (2)= 16.49, $p<0.001$), but not caregivers' well-being (H (2)= 1.91, $p=0.38$). There were significant trends in the data for the more severe the registration status, the poorer pwAMD well-being (for all well-being subscales $p<0.01$, and the general well-being score $p<0.001$).

Both pwAMD and caregivers' appraisal of the hours of care they receive/provide was associated with the pwAMD general well-being score. PwAMD who received more support were more likely to report poorer well-being. Caregivers' appraisal of the amount of support they provide was related to their general well-being scores (in the same direction as for pwAMD). However pwAMDs' appraisal of the amount of care they receive was not significantly associated with caregiver well-being.

There was a strong correlation between caregivers' appraisals of the impact of providing care (CRA total score) and their well-being (r_s= -0.82, $p<0.001$, n=63). Caregivers who reported more negative reactions to providing support were more likely to report poorer well-being. There was also a strong correlation between caregivers' health and their well-being (r_s= 0.62, $p<0.001$). Poorer health was associated with poorer well-being. There was a significant association between caregiver health and pwAMD well-being (r_s=0.51, $p<0.001$). There was a large significant correlation between pwAMD and caregiver well-being scores (r_s= 0.54, $p<0.001$).

Quality of life and MD-specific QoL

PwAMD reported lower mean QoL scores than caregivers, however the median scores were the same (pwAMD QoL mean score= 0.71, median= 1.00, standard deviation= 1.16; caregiver QoL mean score= 1.13, median=1.00, standard deviation= 1.05).

PwAMD who reported fewer difficulties with tasks of everyday living (IADL) or vision-dependent tasks were more likely to have better generic QoL and MD-specific QoL (see Table 7.8). In line with the findings from multivariable analyses of the 2013 survey responses, better pwAMD general health was associated with better pwAMD general QoL, but not pwAMD MD-specific QoL.

There were significant correlations between caregivers' QoL and pwAMD DLTV scores, IADL scores and general health ratings. Poorer caregiver QoL was related to poorer pwAMD visual functioning, greater difficulties with IADL and poorer pwAMD health. (See Table 7.8.)

Caregivers' total CRA score (i.e. their reactions to providing support to the pwAMD), were significantly correlated with both pwAMDs' QoL and caregivers' QoL. A greater reported negative impact of providing support was related to poorer pwAMD and caregiver QoL. (See Table 7.8.)

Caregiver health

PwAMDs' difficulties with IADL and visual functioning (DLTV) scores both had moderate correlations with caregivers' general health (r_s= -0.44, p<0.001, n=72; r_s= -0.42, p<0.001, n=72, respectively). It is interesting to note that there was a similar effect size for the correlation between pwAMDs' own health and their difficulty with IADLs (r_s= -0.44, p<0.001, n=71). Interestingly, the effect size for the correlation between pwAMDs' DLTV score and caregivers' health was larger than that with pwAMDs' own health (r_s= -0.42 vs r_s= -0.38, respectively), perhaps suggestive of the effect of providing support related to pwAMDs' level of visual functioning, on caregivers' health. As mentioned above, pwAMDs' general health and caregivers' health were moderately correlated.

Caregiver general health and pwAMD registration status were not significantly associated (H (2)= 4.88, p=0.09).

Caregivers' health was strongly correlated with their reactions towards providing support for the pwAMD (r_s= -0.57, p<0.001, n=64). Caregivers who reported more negative reactions towards providing support were more likely to report poorer health.

As stated above, caregivers' appraisal of the amount of help they provided was significantly related to their health however pwAMDs' appraisal of the amount of help received was not significantly related to caregiver health.

MULTIVARIATE ANALYSIS

DEVELOPMENT OF THE STRUCTURAL MODEL

Following bivariate analyses, structural equation modelling (SEM) was used to help assess direct and indirect pathways to pwAMD and caregiver outcomes.

Figure 6.1 provides a conceptual overview of the initial structural model that was tested using MPlus (version 7). Observed or ‘manifest’ variables are presented as rectangles. Direct effects from one variable to another are indicated by a single-headed arrow indicating the hypothesised direction of influence. A correlation is indicated by a double-headed curved arrow between variables. Each dependent variable has an associated error term, which represents measurement error.

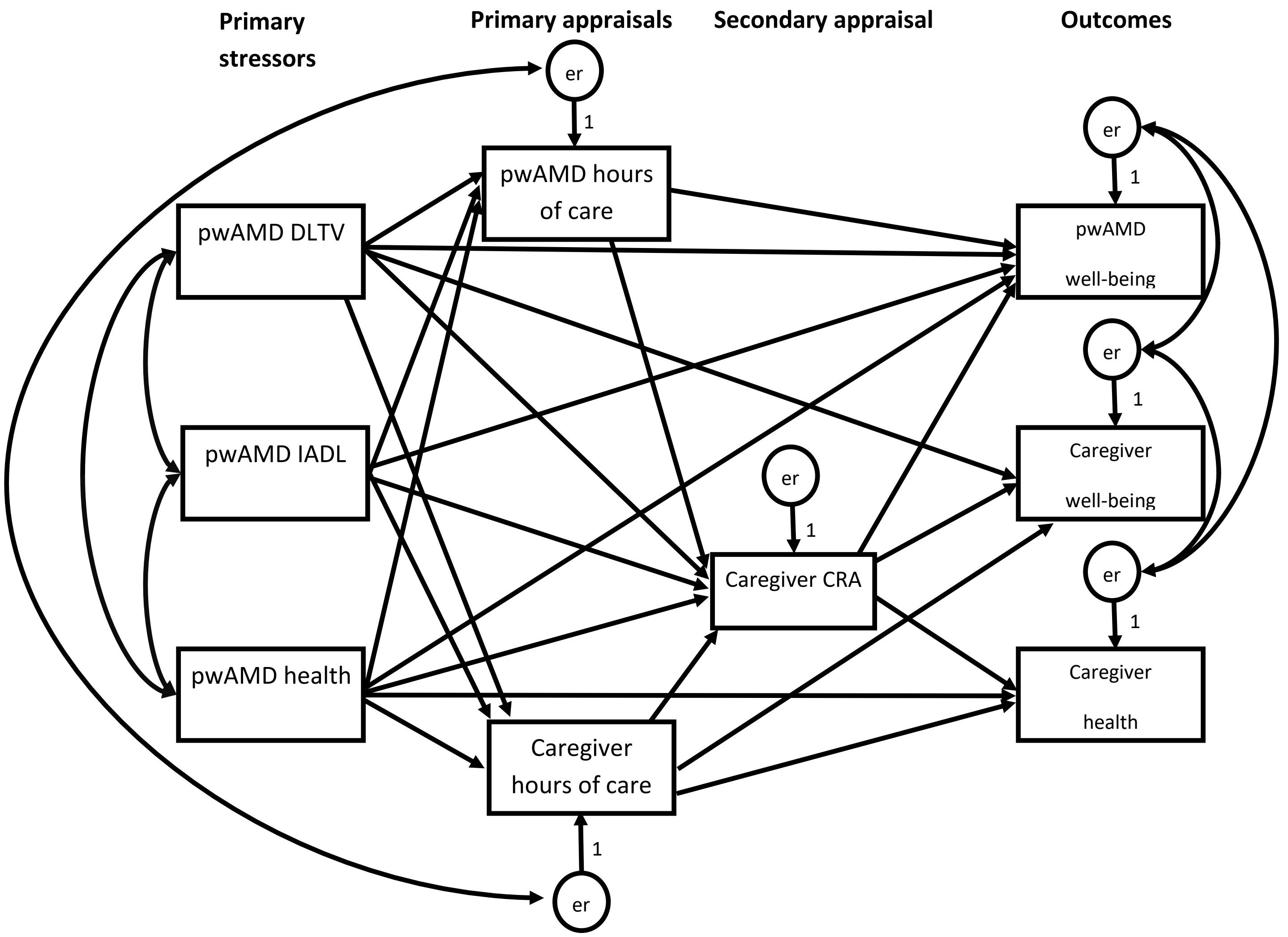

Figure 6.1. Initial path model for the impact of receiving and providing support for age-related macular degeneration.

DLTV denotes the Daily Living Tasks dependent on Vision scale. IADL is Instrumental Activities of Daily Living. CRA is the Caregiver Reaction Assessment.

Given that there are currently no theoretical models on the experience of living with AMD using a dyadic perspective, the initial model was designed based on the research literature considered to be relevant. The Yates et al. (1999) stress process model in the caregiver literature was used as a starting point. According to this model, the 'primary stressors' (in this study- pwAMDs' visual functioning, their difficulties with IADLs, and their general health) would directly influence the primary appraisal variable of 'hours of care per week'. It was hypothesised that these would predict both pwAMD and their caregiver's primary appraisals (patients' primary appraisal is not included in the Yates et al. (1999) model). The 'stressors' would also predict caregivers' secondary appraisal of providing care (in this study- their total CRA score). In the stress process model, 'stressors' directly affect the caregiver outcome of well-being. For this dyadic model, pwAMDs' well-being was included in addition to caregivers' well-being. Caregivers' health is included as an outcome in the Stress Process Model designed by Pearlin et al. (1990), and this was included as an outcome here. Direct relationships were predicted between pwAMDs' 'stressors' and their well-being, however for reasons of relevance and parsimony only two direct relationships between pwAMDs' stressors and caregiver outcomes were predicted. First pwAMDs' and caregivers' health were predicted to be related, given their close proximity. In order to investigate indirect relationships between these variables, it was necessary to have a unidirectional arrow between them. Therefore it was predicted that pwAMDs' health would impact on caregivers' health. This is in line with the stress process models that suggest pwAMD health is a 'stressor' that impacts on caregiver primary and secondary appraisals and outcomes. Based on the researcher's interest, a pathway between pwAMDs' DLTV score and caregivers' well-being was included to investigate if there was a direct relationship between the impact of AMD on pwAMDs' functioning (this 'vision-specific' measure) and caregivers' well-being. Indirect relationships between caregivers' well-being and health with pwAMDs' 'stressors' were examined, via primary and secondary appraisals of providing care.

Caregivers' appraisal of the hours of support they provided was hypothesised to have a direct effect on their secondary appraisal (i.e. their CRA score) and both direct and indirect effects on their outcomes (caregiver well-being and caregiver health). PwAMDs' appraisal of the amount of care received is not typically included in caregiver ‘stress process’ models, however, in line with the 2013 survey findings, it was predicted to influence their outcome directly (i.e. their well-being). It was also predicted to influence caregivers’ secondary appraisals of providing care (i.e. caregivers’ CRA score).

It was hypothesised that caregivers who experience greater negative impacts from providing support (i.e. higher CRA scores) may have a negative impact on their pwAMDs’ well-being. A direct pathway tested whether caregivers’ CRA score might predict pwAMDs’ well-being.

To account for the non-independence of the data, error terms were correlated for dependent variables where both the caregiver and pwAMD were asked to complete the same or potentially related measures (i.e. their appraisals of the amount of care received/ provided, and their well-being). The correlation between residuals controls for sources of non-independence not accounted for by the other variables in the model (Cook & Kenny, 2005). All independent variables were correlated since this is a requirement of SEM.

The goal of SEM analysis is to determine the extent to which the proposed theoretical model is supported by the data. Three indices were used to evaluate the fit of the model: chi-square χ^2 with an insignificant p value ($p>0.05$); a comparative fit index (CFI) value of above 0.95; and a root mean square error of approximation (RMSEA) value of less than 0.05, were considered to be indicative of good model fit (Hooper, Coughlan, & Mullen, 2008). SRMR (standardised root mean square residual) values below 0.08 suggest an adequate model fit (Hu & Bentler, 1999). The chi-square test is sensitive to sample size, so multiple indices were used. Ullman (2013) stated a rough rule of thumb for a good-fitting model may be indicated when the ratio of the χ^2 to the degrees of freedom is less than 2.

Modification indices are provided by path analysis software packages after the model has been fitted. They are a list of paths that, if added, may improve model fit. However changes to the model should be theoretically justified and not purely data driven. Bias-corrected bootstrapped confidence intervals were requested for indirect pathways.

FIT OF INITIAL MODEL

The initial model showed a good fit to the data in three of the four indicators of model fit (χ^2 (7)= 8.77, *p* = 0.27, CFI= 0.99, RMSEA= 0.06, SRMR= 0.02). The RMSEA value was slightly above the 0.05 level considered to be indicative of good model fit. Standardised parameters, their standard errors and *p* values are presented in Table 7.12 for each specified pathway. Figure 7.1 shows the significant and non-significant pathways.

Table 7.12. Standardised parameter estimates for initial model (shown in Figure 6.1 and 7.1).

Parameters		Standardised path coefficients	Standard error	p value
DLTV[a]	pwAMD hours of care	0.13	0.12	0.30
	Caregiver hours of care	0.18	0.12	0.14
	Caregiver CRA	0.17	0.14	0.21
	pwAMD well-being[f]	-0.29	0.10	0.01*
	Caregiver well-being	0.02	0.09	0.80
IADL[b]	pwAMD hours of care	0.60	0.12	<0.001***
	Caregiver hours of care	0.55	0.12	<0.001***
	Caregiver CRA	0.05	0.17	0.77
	pwAMD well-being	-0.16	0.12	0.19
pwAMD health[c]	pwAMD hours of care	-0.04	0.10	0.66
	Caregiver hours of care	-0.08	0.10	0.43
	Caregiver CRA	-0.35	0.10	0.001**
	pwAMD well-being	0.36	0.08	<0.001***
	Caregiver health	0.17	0.11	0.12
pwAMD hours of care[d]	Caregiver CRA	0.01	0.17	0.96
	pwAMD well-being	-0.02	0.11	0.88

Caregiver hours of care[d]	Caregiver CRA	0.17	0.18	0.35
	Caregiver well-being	-0.06	0.09	0.51
	Caregiver health	-0.16	0.11	0.14
Caregiver CRA[e]	pwAMD well-being	-0.17	0.10	0.07
	Caregiver well-being	-0.79	0.06	<0.001***
	Caregiver health	-0.35	0.12	0.002**
Covariances				
pwAMD hours of care received and Caregiver hours of care provided		0.59	0.08	<0.001***
pwAMD well-being and Caregiver well-being		0.37	0.11	0.001**
Caregiver well-being and caregiver general health		0.39	0.11	<0.001***
Caregiver general health and pwAMD well-being		0.18	0.12	0.14
IADL and DLTV		0.70	0.06	<0.001***
IADL and pwAMD general health		-0.45	0.10	<0.001***
DLTV and pwAMD general health		-0.39	0.10	<0.001***

Residual variances			
CRA	0.65	0.09	<0.001***
Caregiver well-being	0.35	0.07	<0.001***
pwAMD hours of care received	0.52	0.09	<0.001***
Caregiver hours of care provided	0.48	0.08	<0.001***
pwAMD well-being	0.38	0.07	<0.001***
Caregiver general health	0.69	0.09	<0.001***
R-square			
CRA	0.36	0.09	<0.001***
Caregiver well-being	0.65	0.07	<0.001***
pwAMD hours of care received	0.48	0.09	<0.001***
Caregiver hours of care provided	0.52	0.08	<0.001***
pwAMD well-being	0.62	0.07	<0.001***
Caregiver general health	0.31	0.09	<0.001***

*p<0.05, ** p<0.001, ***p<0.001. [a] DLTV is the Daily Living Tasks Dependent on Vision scale. Scale ranges from 22 to 88 where higher scores indicate poorer visual function. [b] IADL is the Instrumental Activities of Daily Living scale. Scale ranges from 0 (no disability) to 8 (high disability). [c] Self-rated health is measured using a single item. Higher scores indicate better health. [d] Hours-of-care is measured using a 4-point ordinal scale where higher scores indicate more care is received by the pwAMD/caregiver provides more care per week. [e]CRA is the Caregiver Reaction Assessment. The total scale ranges from 1 to 5, where higher scores indicate more negative impact of providing support. [f] General well-being is on a scale of 0 to 48 where higher scores indicate better well-being.

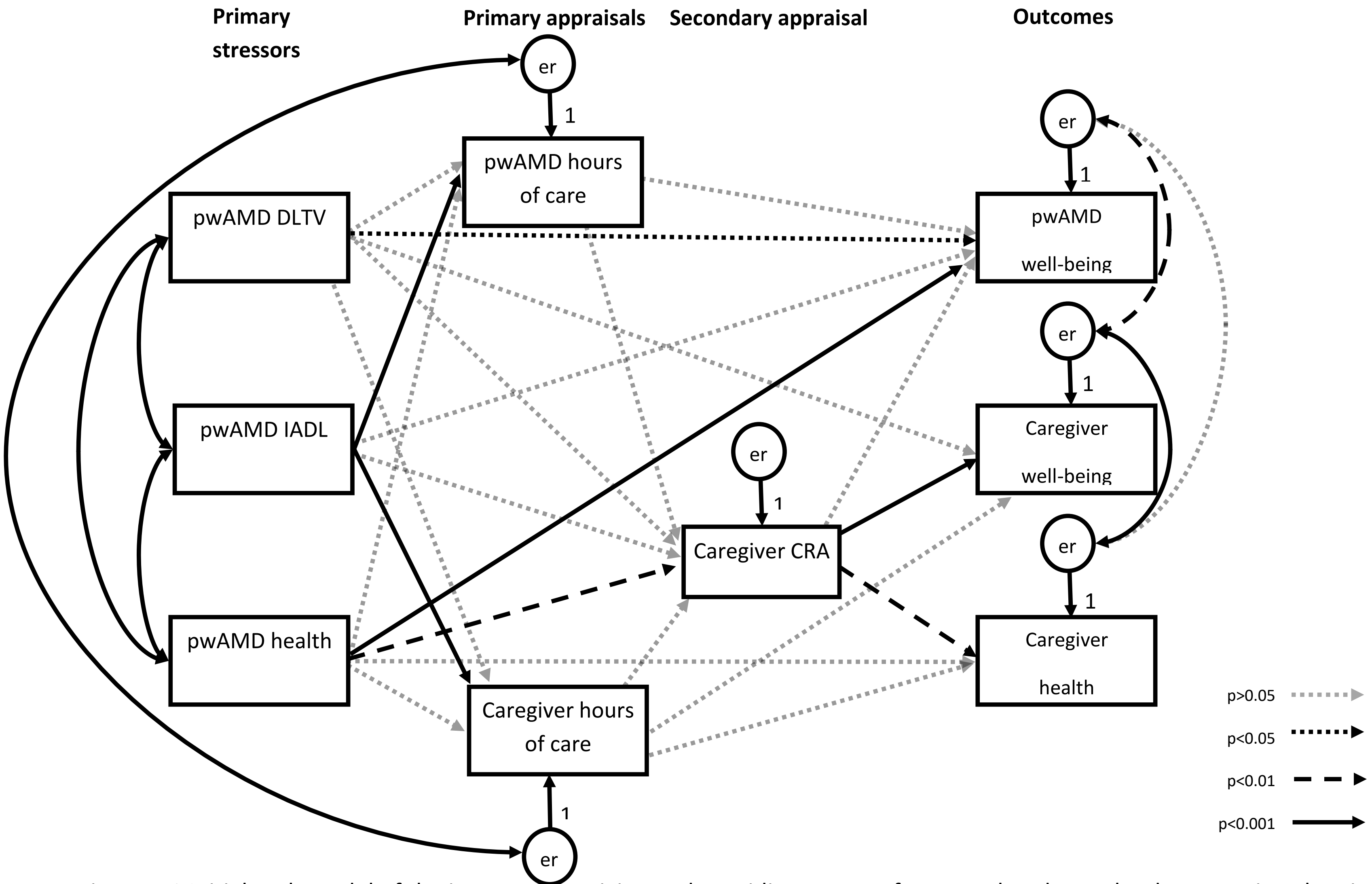

Figure 7.1 Initial path model of the impact of receiving and providing support for age-related macular degeneration showing significant pathways. DLTV denotes the Daily Living Tasks dependent on Vision scale. IADL is Instrumental Activities of Daily Living. CRA is the Caregiver Reaction Assessment.

The impact of the 'stressors'

The three 'stressors' included in the model (pwAMD visual functioning, difficulties with IADLs and pwAMD health) all significantly correlated with each other. Although all three were predicted to affect caregiver and pwAMD primary appraisals of giving/receiving support, only difficulties with IADL were significantly associated with pwAMD and caregivers' appraisal of the amount of help they received or provided.

Similarly, although all three 'stressors' were hypothesised to explain caregivers' secondary appraisal of the impact of providing support (i.e. their CRA scores), only pwAMDs' general health was significantly associated with this appraisal.

Of the outcomes, pwAMD 'stressors' were all hypothesised to predict pwAMDs' well-being. Poorer pwAMDs' level of visual functioning and poorer pwAMD general health predicted poorer pwAMD well-being. In this sample of pwAMD receiving support for AMD, difficulties with IADL were not significantly associated with pwAMDs' well-being.

Of the impacts of the 'stressors' on caregiver outcomes, pwAMDs' level of visual functioning did not directly predict caregivers' well-being. Additionally pwAMDs' health did not directly predict caregivers' general health.

Impact of primary appraisals 'hours of care provided/ received'

Both pwAMDs' and caregivers' appraisals of the amount of support received/ provided were hypothesised to predict caregivers' secondary appraisal of the impact of providing support (their CRA scores), however neither pathway was significant.

PwAMDs' appraisal of the amount of care they received was predicted to affect their well-being. This relationship was significant in the multivariable analysis of the 2013 survey findings presented in Chapter 4. It was also significant in the bivariate analysis presented in this chapter (Table 7.9). However in bivariate analysis, only the pairwise comparison between those pwAMD who reported receiving the least amount of care for AMD (the 'fewer than 7 hours of care a week' group) and those who received the most amount of help (the 'more than 35 hours of care a week' group) was significant. In multivariate analyses presented in Table 7.12 and Figure 7.1, the relationship was not significant.

Caregivers' appraisal of the amount of care they provided was hypothesised to impact on their well-being and general health, however neither relationship was found to be significant in the multivariate model.

There was a significant correlation between pwAMDs' and caregivers' appraisals of the amount of help they receive/ provide.

Impact of secondary appraisal using the 'Caregiver Reaction Assessment'

The SEM found that caregivers' CRA scores predicted their own outcomes (i.e. their well-being and general health), but not the pwAMDs' outcome (well-being).

The present model explained around 35.5% of the variance in CRA scores ($R^2 = 0.355$), indicating that there were factors not included in the present model that could be used to predict caregiver reactions towards providing support. The only significant predictor of CRA scores included in the model was pwAMDs' general health.

Outcomes

The predictors of pwAMD and caregiver outcomes are described above. Briefly, pwAMDs' well-being was predicted by their level of visual functioning (i.e. their DLTV score) and their general health, but not by their difficulties with IADL. Neither their primary appraisal of the amount of care they receive, nor their caregiver's CRA score were significantly related to their well-being.

There were no significant indirect pathways between pwAMDs' DLTV scores and their well-being (see Table 7.13). Neither pwAMDs' nor caregivers' primary appraisals of the amount of care received/provided nor caregivers' CRA score acted as mediators. There was a similar pattern for the relationship between pwAMDs' health and their well-being. Only the direct pathway was significant, and not the indirect pathway via primary appraisals or CRA scores.

There were no significant direct or indirect pathways from pwAMDs' IADL scores to their well-being scores (via the mediators of pwAMDs' and caregivers' primary appraisals of the amount of care received/ provided or caregivers' CRA score).

Caregiver well-being and general health were directly predicted by CRA scores, but not caregivers' primary appraisal of the amount of support they provide to the pwAMD nor the pwAMD ‘stressors’. Additionally there were no significant indirect pathways from pwAMDs’ IADL or DLTV scores to caregivers’ well-being or health. However there was a significant indirect pathway from pwAMDs’ health to caregiver well-being via caregivers CRA score. Additionally, pwAMDs’ health indirectly affected caregivers’ health via caregivers’ CRA score.

Caregiver and pwAMD well-being were significantly correlated, as predicted. Caregivers’ well-being and their health were also correlated. There was no significant association between pwAMDs’ well-being and caregivers’ health.

The present model explained approximately 64.9% of the variance in caregivers’ wellbeing ($R^2 = 0.649$), 61.6% of the variance in pwAMDs’ well-being ($R^2 = 0.616$), and 31.2% of the variability in caregivers’ health ($R^2 = 0.312$) (all significant at ps<0.01). Together with the model fit statistics, this indicates that the model fitted the data reasonably well, however there was a substantial amount of the variance in caregivers’ health that could not be explained by the model.

Table 7.13. Indirect pathways for initial model.

Model pathways			Standardised path coefficients	Standard error	p value
Effects from DLTV to pwAMD well-being		Total effect	-0.33	0.10	0.002**
		Total indirect effect	-0.04	0.03	0.26
		Direct effect	-0.29	0.10	0.005**
	Indirect effects				
	pwAMD well-being → CRA → DLTV		-0.03	0.03	0.30
	pwAMD well-being → pwAMD help received → DLTV		-0.002	0.01	0.88
	pwAMD well-being → CRA → pwAMD help received → DLTV		0.000	0.004	0.96
	pwAMD well-being → CRA → Caregiver help provided → DLTV		-0.01	0.01	0.47
Effects from IADL to pwAMD well-being		Total effect	-0.19	0.11	0.07
		Total indirect effect	-0.04	0.07	0.60
		Direct effect	-0.16	0.12	0.19
	Indirect effects				
	pwAMD well-being → CRA → IADL		-0.01	0.03	0.77

	pwAMD well-being → pwAMD help received → IADL		-0.01	0.06	0.88
	pwAMD well-being → CRA → pwAMD help received → IADL		-0.001	0.02	0.96
	pwAMD well-being → CRA → Caregiver help provided → IADL		-0.02	0.02	0.42
Effects from pwAMD health to pwAMD well-being		Total effect	0.43	0.08	0.00***
		Total indirect effect	0.06	0.04	0.11
		Direct effect	0.36	0.08	0.00***
	Indirect effects				
	pwAMD well-being → CRA → pwAMD health		0.06	0.04	0.12
	pwAMD well-being → pwAMD help received → pwAMD health		0.001	0.005	0.88
	pwAMD well-being → CRA → pwAMD help received → pwAMD health		0.000	0.001	0.96
	pwAMD well-being → CRA → Caregiver help provided → pwAMD health		0.002	0.004	0.56
Effects from DLTV to Caregiver well-being		Total effect	-0.15	0.13	0.26

		Total indirect effect	-0.17	0.11	0.13
		Direct effect	0.02	0.09	0.80
	Indirect effects				
	Caregiver well-being → CRA → DLTV		-0.14	0.11	0.22
	Caregiver well-being → Caregiver help provided → DLTV		-0.01	0.02	0.55
	Caregiver well-being → CRA → pwAMD help received → DLTV		-0.001	0.02	0.96
	Caregiver well-being → CRA → Caregiver help provided → DLTV		-0.02	0.03	0.42
Effects from IADL to Caregiver well-being		Total effect	-0.15	0.12	0.22
		Total indirect effect	-0.15	0.12	0.22
	Indirect effects				
	Caregiver well-being → CRA → IADL		-0.04	0.13	0.77
	Caregiver well-being → Caregiver help provided → IADL		-0.03	0.05	0.52
	Caregiver well-being → CRA → pwAMD help received → IADL		-0.004	0.08	0.96
	Caregiver well-being → CRA → Caregiver help provided → IADL		-0.07	0.08	0.36
Effects from pwAMD		Total effect	0.29	0.09	0.001**

health to Caregiver well-being					
		Total indirect effect	0.29	0.09	0.001**
	Indirect effects				
	Caregiver well-being → CRA → pwAMD health		0.27	0.09	0.001**
	Caregiver well-being → Caregiver help provided → pwAMD health		0.004	0.01	0.61
	Caregiver well-being → CRA → pwAMD help received → pwAMD health		0.000	0.01	0.96
	Caregiver well-being → CRA → Caregiver help provided → pwAMD health		0.01	0.02	0.54
Effects from DLTV to Caregiver health		Total effect	-0.10	0.06	0.09
		Total indirect effect	-0.10	0.06	0.09
	Indirect effects				
	Caregiver health → CRA → DLTV		-0.06	0.05	0.25
	Caregiver health → Caregiver help provided → DLTV		-0.03	0.03	0.30
	Caregiver health → CRA → pwAMD help received → DLTV		0.000	0.01	0.96

	Caregiver health → CRA → Caregiver help provided → DLTV		-0.01	0.01	0.44
Effects from IADL to Caregiver health		Total effect	-0.14	0.08	0.07
		Total indirect effect	-0.14	0.08	0.07
	Indirect effects				
	Caregiver health → CRA → IADL		-0.02	0.06	0.77
	Caregiver health → Caregiver help provided → IADL		-0.09	0.06	0.16
	Caregiver health → CRA → pwAMD help received → IADL		-0.002	0.04	0.96
	Caregiver health → CRA → Caregiver help provided → IADL		-0.03	0.04	0.38
Effects from pwAMD health to Caregiver health		Total effect	0.31	0.10	0.003**
		Total indirect effect	0.14	0.06	0.02*
		Direct effect	0.17	0.11	0.12

Indirect effects			
Caregiver health → CRA → pwAMD health	0.12	0.06	0.03*
Caregiver health → Caregiver help provided → pwAMD health	0.01	0.02	0.48
Caregiver health → CRA → pwAMD help received → pwAMD health	0.000	0.003	0.96
Caregiver health → CRA → Caregiver help provided → pwAMD health	0.01	0.01	0.55

*p<0.05, ** p<0.001, ***p<0.001.

Model development

The initial model was a good fit with the data and no modification indices were produced to suggest that adding or removing pathways might improve the fit of the model. Nevertheless, in the initial model there were 16 non-significant pathways (see Table 7.12 or Figure 7.1). A more parsimonious model might be explained by removing non-significant pathways. It is normally considered good practice for one to take into account the previous literature before removing pathways, however since there was no relevant dyadic model that could be used to inform decisions, all 16 non-significant pathways were removed. A pathway was added between pwAMD health and caregiver well-being in order to compare the direct and indirect effects between these two variables given that the initial model found a significant indirect effect for pwAMD health on caregiver well-being via caregivers' CRA score.

The revised model is shown in Figure 7.2 with the standardised path coefficients. Examination of the fit indices indicated the revised model fitted the data fairly well (χ^2 (22)= 35.22, *p* = 0.04, CFI= 0.96, RMSEA= 0.09, SRMR= 0.14), although not as well as the initial model. Most standardised path coefficients were significant at $p<0.001$. The exceptions were for the correlations between caregiver well-being and pwAMD well-being ($p=0.01$), and between caregiver well-being and caregiver health ($p=0.001$). The only insignificant pathway was the test of a direct effect between pwAMD health and caregiver well-being added into this second model ($p=0.64$), but the indirect effect via caregivers' CRA scores remained significant ($p<0.001$). Matching the initial model, the indirect effect of pwAMD health on caregivers' health via CRA scores was significant ($p<0.001$). No modification indices were produced.

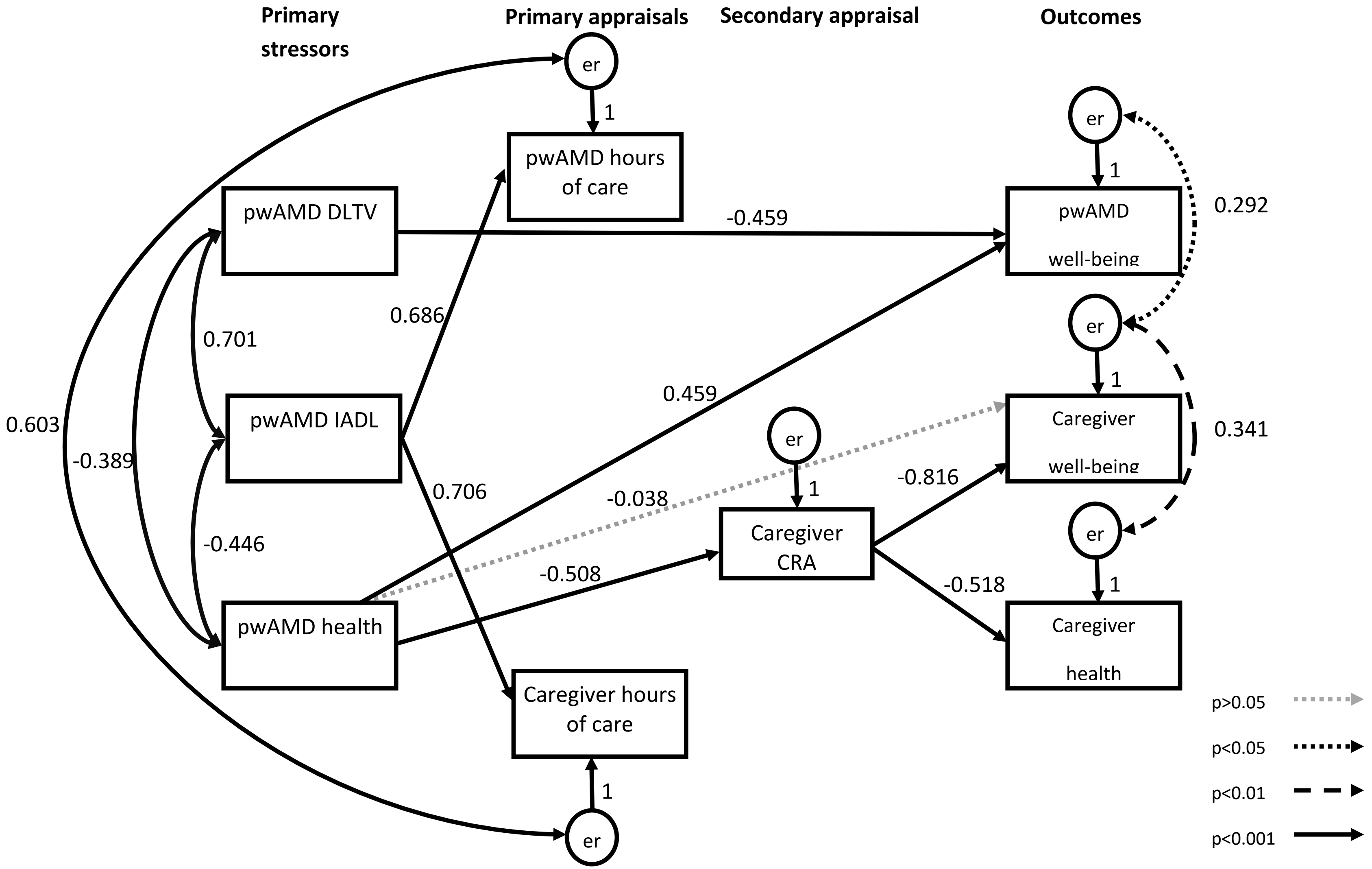

Figure 7.2 Standardised path coefficients for the re-specification of the initial path model for the impact of receiving and providing support for age-related macular degeneration. DLTV denotes the Daily Living Tasks dependent on Vision scale. IADL is Instrumental Activities of Daily Living. CRA is the Caregiver Reaction Assessment.

The R^2 statistics suggest the initial model predicted the variability in the dependent variables slightly better than the second model. For instance, the second model predicted 25.8% of the variance in CRA scores compared to 35.5% of the variance in the initial model. The second model predicted 63.5% of the variability in caregiver well-being (vs 64.9% in the initial model), 58.5% of the variability in pwAMD well-being (vs 61.6% in the initial model) and 26.8% of the variability in caregiver health (vs 31.2% in the initial model). The second model also had poorer model fit statistics than the initial model. Thus although the second model included only the significant pathways from the initial model, the initial model still fitted the data better.

DISCUSSION

The results from the 2013 survey (presented in Chapter 4) suggested that the relationship between the amount-of-care-received and the well-being of the pwAMD, after adjusting for severity of vision loss (using registration status and patient-reported change in vision status since diagnosis), was counterintuitive: well-being deteriorated as the amount of care received for AMD increased. This second study included a more detailed measure of ability to carry out vision-dependant tasks (the DLTV) as an indicator of present level of VI. The SEM found that pwAMD well-being was significantly associated with difficulties carrying out vision-dependent tasks, but not with the amount of care received. There was also no significant indirect effect of level of visual functioning on pwAMD well-being via the amount of care they received. Thus when visual functioning was used instead of registration status and change in vision status since diagnosis, receiving more care for AMD was no longer associated with poorer well-being. Therefore this thesis took an important step forward by including visual functioning to investigate if the relationship between receiving more care for AMD and poorer well-being persisted after controlling for the impact of present level of VI.

Model summary

Supporting the theoretical underpinnings of the Yates et al. (1999) Stress Process model, the ‘stressor’ of difficulties with IADL predicted both pwAMDs’ and caregivers’ primary appraisals of the number of hours of care they reported receiving or providing. In this multivariable analyses with all three ‘stressors’ included, the other variables classified as ‘stressors’ (pwAMDs’ DLTV score and general health) were not associated with these primary appraisals. This is particularly surprising for the DLTV score as participants were asked to indicate the amount of help they received or provided *for AMD* and thus one might expect a significant association with this condition-specific ‘stressor’. However it may be that pwAMD receive help with the tasks of daily living included in the IADL measure (e.g. preparing meals, getting to places beyond walking distance), but are less likely to receive help with some of the more specific vision-dependent tasks included in the DLTV (e.g. enjoying the scenery if out for a drive or distinguishing a person’s features across the street).

PwAMDs’ health was measured using a single-item asking participants to rate their general health on a scale from 1 to 7 where 1 is ‘extremely bad’ and 7 is ‘excellent’. In contrast to the DLTV and the IADL, this measure did not assess pwAMDs’ level of functioning, thus we might expect a poorer association with the appraisals of the amount of help received/ provided.

Both the models tested in the present study (Figures 6.1 and 7.2) add to the Yates et al. (1999) model by including both pwAMD and caregiver primary appraisals of the number of hours of support received/provided. It is interesting to note that they were both predicted by the same ‘stressor’ (IADL) and not by others (DLTV score and general health). The R^2 statistics showed a reasonable amount of the variability in pwAMDs’ appraisals (48.1%) and caregivers’ appraisals (52.0%) could be explained by the model, but there is still a moderate amount left unexplained. Perhaps a measure that specifically assesses the amount of help provided for AMD might predict these primary appraisals better, however none currently appear in the literature.

The amount of help received and provided for MD was not related to the well-being of the pwAMD or to caregiver well-being, caregiver health or caregiver reactions towards providing support. These findings contradict the theoretical underpinnings of the Yates et al. (1999) stress model. One might question the usefulness of these primary appraisal measures given their inability to predict secondary appraisals or the outcomes in the present model. However it may that these primary appraisals are useful in predicting pwAMD secondary appraisals of the impact of receiving support (not measured in this study), and thus should not be immediately discounted.

Poorer general health in pwAMD (but not difficulties with vision-dependent or everyday tasks) predicted more negative caregiver reactions to providing support. This indirectly predicted poorer caregiver well-being and general health. Although caregivers were asked to complete the CRA to investigate ‘how providing care for your friend or family member *with a macular condition* has affected you, your family and your daily routine’ (emphasis added), caregivers may not have considered only the aspects of providing support related to the AMD, but rather the impact of providing support for the person in general, thus taking into account other reasons for providing support such as other medical conditions or general frailty. Indeed in the preliminary analyses, there was a moderate correlation between the total CRA score with the number of other conditions the pwAMD had ($r_s = 0.29$, $p<0.05$). It is interesting to note that poorer pwAMD general health predicted more negative caregiver reactions to providing support whereas pwAMDs’ level of visual functioning or their difficulties with tasks of everyday living did not. This finding suggests that targeting the general health of pwAMD in interventions may be effective at reducing caregiver ‘burden’ and consequently improve caregiver well-being and health alongside pwAMD well-being.

Caregiver reactions towards providing support (their CRA score) predicted their general health. In line with stress process models, pwAMD health was predicted to act as a ‘stressor’ and predict the caregiver outcome of general health. However a significant direct effect for this was not found. Instead there was an indirect relationship between pwAMD and caregiver health via caregivers’ CRA scores. The findings suggest that poorer pwAMD health predict more negative caregiver reactions to providing support which in turn predict poorer caregiver health. It is worth noting that the CRA contains an ‘impact on health’ subscale. There is a strong correlation between this subscale of the CRA and caregivers’ general health ($r_s = -0.69$, $p<0.001$). Thus although the CRA asks about the impact that caregiving specifically has on one’s health, there is an indication that there may be some overlap between this and caregivers’ ratings of their general health that might account for the significant relationship between CRA total scores and caregiver health.

As predicted, caregivers’ reactions towards providing support to the pwAMD were predictive of their well-being. Similar to the findings above, CRA scores mediated the relationship between pwAMDs’ health and caregivers’ well-being. Thus poorer pwAMDs' health predicted poorer caregivers' reactions to providing support (i.e. higher caregiver 'burden') which predicted poorer caregiver general health and lower caregiver well-being.

In this sample of 72 dyads of pwAMD and their caregivers, caregiver outcomes (well-being and general health) were predicted by the impact of providing support for the pwAMD, however this was influenced by pwAMD general health rather than pwAMD level of visual functioning or difficulties with tasks associated with everyday living. PwAMDs' well-being was predicted by their general health and the impact of vision loss on tasks dependent on vision but not with how much difficulty they had with tasks of everyday living. Caregiver 'burden' did not predict pwAMD well-being. Neither pwAMD nor caregiver outcomes were affected by the amount of care for AMD they reported receiving/providing.

Contrary to expectations, pwAMDs' difficulties with vision-dependent tasks were not significantly associated with caregivers' reported hours-of-care-provided, caregiver 'burden' or caregiver well-being. There may be other aspects of living with AMD that impact on the caregiver. Indeed part of the shared residual covariance between pwAMDs' and caregivers' well-being might be explained by factors associated with AMD that affect both pwAMD and their caregivers (or by shared factors unrelated to AMD). Some of the caregivers in this study reported having to give up work or reduce their working hours in order to provide care to the pwAMD. Some pwAMD reported a change in registration status since the 2013 survey; most were registered as SI at the time of the 2013 survey and were registered as SSI at the time of the second study. This might suggest a recent deterioration in vision which could affect both pwAMD and caregiver outcomes. The qualitative part of the study may shed some light on factors associated with pwAMD and caregiver outcomes that weren't included in the quantitative study.

It is interesting to note that the measure of vision impairment used in the 2013 survey study (registration status) was not associated with caregiver secondary appraisals of providing care (their CRA scores) or their outcomes (caregiver well-being and health) in the second study. However the DLTV, which measures pwAMDs' difficulties with vision-dependent tasks, was associated with these variables (in bivariate analysis, but not multivariate analysis). This may provide further evidence of the suitability of the use of the DLTV in the quantitative second study.

The study findings provide evidence to suggest that caregivers' ratings of their role as enjoyable/rewarding or whether it causes resentment (as measured by the CRA esteem subscale), and the overall positive effect caregiving had on their lives were unrelated to reports from the pwAMD about their level of difficulty with tasks, their general health or the amount of help they received. This suggests that these 'stressors' and 'primary appraisal' aren't taken into account when appraising the positive aspects of providing care. Caregivers' appraisal of the overall positive impact of providing support was significantly associated with higher well-being and a lower total CRA score (indicating less negative impact of caregiving or 'burden'). There were no other variables that significantly correlated with positive appraisals and could be used to help predict caregivers' overall positive appraisal of providing care (e.g. age, gender, pwAMD/caregiver relationship type). These findings add to the small amount of data on positive appraisals of providing care for someone with AMD in the literature. The qualitative study will explore both positive and negative appraisals in more detail.

Whilst caregivers' positive appraisals of the impact of providing care were unrelated to the 'stressors' and 'primary appraisal' used in the present study, negative appraisals of caregiving were associated with these factors. This suggests that caregivers may not take into account pwAMD level of functioning when appraising the positive impact of providing support on their lives, but they do take this into account when thinking of the negative impact of providing support. Thus highlighting perhaps, an important distinction that needs to be made when assessing caregiver reactions to providing support. The correlation between the single-items measuring positive and negative appraisals of caregiving was moderate but not large. This suggests these two subjective appraisals may be constructs that are similar but assess different aspects of the caregiver's situation.

The analyses of the 2013 survey data controlled for pwAMD gender. Indeed the multivariate analyses presented in Chapter 4 found that men with MD were more likely to report better well-being, but there was no sex difference in generic or MD-specific QoL. Unfortunately the small sample in the present study meant that the gender of the pwAMD or caregiver could not be included in the SEM. The present study included more men with MD than the 2013 survey sample used in the multivariate analyses presented in Chapter 4. There was almost an even balance of gender in the second study (51% male, 49% female) whereas in the 2013 study, men made up 35% of the sample. It is likely that the views of men with MD are overrepresented in the present study when compared to the 2013 survey study. However the well-being of the sample included in the quantitative second study was not significantly different to the well-being of those included in the 2013 survey findings.

There was a strong, but not a perfect correlation between pwAMDs' and caregivers' appraisals of the amount of help they received/provided. Caregivers' appraisal of the amount of care they provided was related to some of their outcomes, whereas pwAMDs' appraisal was not related to caregiver outcomes (e.g. for caregiver well-being and caregiver general health- see Table 7.9). Therefore it was considered important to include both in the SEM on these data-driven grounds, in addition to including these on theoretical grounds in order to test a dyadic model. The SEMs presented in Figures 6.1 and 7.2 were repeated with either the pwAMD hours-of-care-received variable or caregiver hours-of-care-provided variable (not both). The direct and indirect pathways showed similar results to the model presented in Figure 6.1 in this chapter (which included both pwAMD and caregiver primary appraisals). However the model fit statistics showed a slightly poorer fit to the data. For example, when the model shown in Figure 6.1 was run with only pwAMD hours-of-care-received included, the model fit statistics were (χ^2 (4)= 8.20, p = 0.09, CFI= 0.98, RMSEA= 0.12, SRMR= 0.03). Model fit statistics for the model including only caregiver reported hours-of-care-provided were: (χ^2 (4)= 5.50, p = 0.24, CFI= 0.99, RMSEA= 0.07, SRMR= 0.02). Thus the original SEM results (including both pwAMD and caregiver primary appraisals) are presented in this chapter[2].

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[2] Three indices were used to evaluate the fit of the model: chi-square χ^2 with an insignificant p value (p>0.05); a comparative fit index (CFI) value of above 0.95; and a root mean square error of approximation (RMSEA) value of less than 0.05, were considered to be indicative of good model fit (Hooper et al., 2008). SRMR (standardised root mean square residual) values below 0.08 suggest an adequate model fit (Hu & Bentler, 1999). The initial model showed a satisfactory fit to the data (χ^2 (7)= 8.77, p = 0.27, CFI= 0.99, RMSEA= 0.06, SRMR= 0.02).

The average CRA total score was much lower than that seen in the study of caregivers who take patients with wet AMD to treatment (mean of 2.4 vs 3.2, respectively; Gohil et al. (2015)). Mean scores on all subscales of the CRA but caregiver esteem, were lower in the present study: self-esteem (mean for Gohil et al. study= 2.0, mean for present study= 2.0), impact on finances (mean for Gohil et al. study= 3.9, mean for present study= 2.1), impact on health (mean for Gohil et al. study= 2.9, mean for present study= 2.4), impact on schedule (mean for Gohil et al. study= 3.3, mean for present study= 3.0), and lack of family support (mean for Gohil et al. study= 3.8, mean for present study= 2.3). Indeed, Gohil et al. (2015) concluded that caregivers of people who assisted pwAMD with travelling to treatment for AMD reported high levels of burden, and this was said to be comparable to studies of caregivers who take patients to treatment for atrial fibrillation (Coleman et al., 2012). In the present study, 17% of pwAMD reported they were currently receiving eye injections as treatment for AMD. Whilst the lower *average* CRA scores in the present study for caregivers of people receiving treatment and those not receiving treatment may suggest that caregivers of people not receiving treatment may experience lower burden, future research would need to confirm this. Caregivers of those receiving treatment may indeed experience higher burden as a result of providing care, however they may also be more hopeful of a positive outcome.

Gohil et al. (2015) reported that child or sibling caregivers of people with wet AMD receiving treatment had higher CRA scores than friends or spouse caregivers. They suggested this may be because child or sibling caregivers were younger and more likely to be employed with a greater potential of disruption to their daily routine. In the present study, although the mean CRA total scores for adult-offspring caregivers were higher than spouse caregivers, this difference was not statistically significant (see Table 7.6). Adult-offspring caregivers tended to score higher on all subscales apart from the ‘impact on health’ subscale (although these differences weren’t significant). There were also no significant differences between the caregiver relationship types on any other caregiver secondary appraisal measures. This is despite the adult-offspring caregivers being younger than spouse caregivers in the present study. Gohil et al. (2015) suggestion that adult-offspring caregivers might perceive greater burden as a result of conflicting commitments whilst providing care, is supported by role theories in the caregiver ‘burden’ literature. This suggests that stress occurs due to ‘role overload’ (where individuals lack the time and resources to fulfil obligations associated with each of their roles, (Goode, 1960, as cited in Bastawrous, 2013), or ‘role conflict’ (when the expectations of the various roles an individual holds become incompatible, Biddle, 1986). The qualitative study will investigate differences in pwAMD/caregiver relationships further.

Perhaps there were no significant differences between caregiver relationship types in this study because adult-offspring caregivers had adapted to the caregiving role. Any difficulties caregivers had with managing the support they provide around other commitments may be managed better given time to adjust to the role. In the present study there were no significant differences in how long caregivers had been providing support to the pwAMD between spouse and adult-offspring caregivers. The majority of adult-offspring caregivers (76%) reported providing support for ‘more than 5 years’ and thus may have had time to adapt to the role and had perhaps taken the decision to reduce other role commitments. Caregivers in the Gohil et al. (2015) study were on average five years younger than those in the present study (average age of caregivers in the Gohil et al. (2015) study was 56 years for adult-child caregivers, and 74 years for spouse caregivers, compared with 61 years and 79 years in the present study, respectively). Younger caregivers may be juggling more roles and responsibilities and thus experience greater caregiver burden. An alternative interpretation may be that the CRA measure did not effectively assess the impact that providing support had on the sample of caregivers of pwAMD in the present study. There may be aspects of providing care for AMD that are specific to the caregiver relationship type. This will be investigated in the qualitative study that follows.

CRA subscale scores indicate that the sample of caregivers of pwAMD in the present study had lower negative impacts on their health, finances, schedule, esteem and family support than caregivers of people with multiple sclerosis (Forbes et al., 2007). Partners of people with rheumatoid arthritis (RA) reported more negative impacts on their schedule, family and finances than the caregivers in the present study, but lower impacts on their health and esteem (Jacobi et al., 2003). Partners of patients with colorectal cancer reported lower negative impacts of providing care across all subscales than the sample in the present study (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Similar to partners of patients with RA, the caregivers in the present study reported the most negative impact on the schedule subscale (Jacobi et al., 2003). The subscale least impacted by caregiving was impact on caregiver self-esteem. Of course it is important to note that in addition to the different medical conditions, there are other factors associated with well-being and appraisals of providing care that varied between these studies (e.g. gender, age, type of patient-caregiver relationship), so one should be wary of making direct comparisons across studies.

Bivariate analyses in the present study found no significant differences in pwAMD QoL (general or MD-specific) or well-being between those whose spouse was their caregiver and those whose adult-offspring was their caregiver. This is supported by the results from multivariate analysis of the 2013 survey responses presented in Chapter 4 which found that the type of pwAMD/caregiver relationship was not associated with pwAMD QoL or well-being. The qualitative study findings may add to this finding of lack of differences in pwAMD outcomes between spouse pairs and adult-offspring/parent pairs.

Gopinath et al. (2015) found caregivers who perceived the pwAMD was ‘highly dependent’ on them were more likely to report caregiver distress. Caregiver distress was measured by caregiver self-reports of feeling down, sad, frustrated, isolated and/ or pessimistic as a result of providing care. The present study included validated measures of caregiver ‘burden’ and well-being. There was evidence to support the findings of Gopinath et al. (2015): there was a large significant correlation between care-recipient dependency (using the same measure used in the Gopinath et al., 2015 study) and the total CRA score (see Table 7.8). There was also a significant correlation between care-recipient dependency and caregiver well-being (see Table 7.8). Higher pwAMD dependency on the caregiver was associated with caregivers reporting a greater negative impact of providing support and poorer well-being.

To the author’s knowledge, this is the first study to use the W-BQ16 in pwAMD and the first to use the W-BQ12 or W-BQ16 to measure well-being in caregivers. The low number of missing data suggest that respondents felt the items on the measure were acceptable. Whilst the W-BQ12 has been evaluated for use in pwAMD (Mitchell &

Bradley, 2001), further work is needed to carry out full psychometric evaluation of the W-BQ16 in this sample. The shorter version of the W-BQ16 (the W-BQ12) has been used more widely. W-BQ12 scores are provided in Table 7.11 for comparison with other groups. The sample of pwAMD receiving support for AMD in the present study reported lower mean general well-being scores (mean=21.21) than: pwAMD who completed the W-BQ12 in the 1999 survey (mean= 22.40) (Mitchell & Bradley, 2001), adults with growth hormone deficiency (mean= 22.53) (McMillan, Bradley, Gibney, Russell-Jones, & Sönksen, 2006), and women who have experienced pregnancy loss (mean=21.68) (Koch, Santos, & Santos, 2012). The poorer well-being of pwAMD in the present study than these other groups may demonstrate the impact that AMD or receiving care for AMD has on well-being. However, as noted above, there are other factors that differ between these studies and may affect well-being (such as differences in age or gender) so one should be wary of making direct comparisons across studies. Since there are no previous studies with caregivers that have included the Well-Being measure, there were no data available for comparison. Caregivers had slightly better well-being than pwAMD in this study (mean=23.23).

STRENGTHS AND LIMITATIONS

Importantly, this is the first study to investigate the impact of providing support for AMD using a dyadic perspective, including both pwAMD and caregiver factors as outcomes and controlling for the non-independence between dyads. To the knowledge of the researcher, this is the first study in the AMD literature to do this.

The use of SEM over ordinary regression analysis in this study, had several advantages. First it allowed all pathways in the model to be assessed simultaneously. Secondly, for dyadic analysis specifically, it controlled for non-independence of the pwAMD and caregiver by the correlation of errors between their dependent variables. It also allowed for the testing of indirect and direct effects.

The present study includes both psychological and physical health outcomes for caregivers, which is important as focusing on only one outcome may lead to the mistaken conclusion that some people are not affected by the caregiving role (Pearlin, 1989). It investigates the predictors of these, as well as of caregiver ‘burden’, thus adding to the literature which has only examined caregiver ‘burden’ as an outcome

(Gohil et al., 2015), or caregiver distress and changes to retirement or lifestyle plans (Gopinath et al., 2015). It also used validated measures to assess caregiver reactions to providing support (the Caregiver Reaction Assessment) and well-being (the W-BQ 16).

However one must approach the findings with caution. A number of caveats must be noted. First, one must be aware of the increased risk of type I error occurring in the results of the bivariate analyses since corrections were not applied following multiple testing. (See Chapter 2 for the reasoning behind not applying corrections.) Thus these results should only be taken as indicative of associations between variables where they exist rather than definitive.

Second, structural equation modelling is generally a large-sample technique (see discussion of sample size in Chapter 6). Only the variables that were pertinent to analyses were included, and other variables such as gender that were not included, could be tested with larger samples.

All variables included in the model were treated as continuous variables. However both the variables for general health and 'hours of care received/ provided' could be considered to be ordinal. General health was measured using a 7-point Likert scale, whilst 'hours of care received/ provided' used was measured using an ordered 4-point scale. It has been suggested that treating ordinal variables as if they were normally distributed interval-scaled variables is more realistic if they contain at least 5 possible values, and are at least 'nearly normal' (Blunch, 2008). This would be appropriate for the general health variables, but not for the hours of care variables used in the present study. Given that preliminary analyses found non-linear trends for the pwAMD and caregiver 'hours of care received/ provided' variable with several other variables (e.g. DLTV total scores), it might be particularly important for this variable to be considered as ordinal (or categorical) in future replications of this study.

Other limitations to this study should be noted. The initial model fitted the data well, however there was still a moderate amount of variability in the dependent variables that remained unexplained by the model (i.e. caregiver reactions to providing support, amount of support provided/ received, pwAMD and caregiver well-being and caregivers' health). There may be other factors not measured in this study that help predict these variables. Nevertheless, this study provides the beginnings of a picture for how these variables interact to predict pwAMD and caregiver outcomes. The findings of the qualitative study may help to provide a more comprehensive picture.

The direction of relationships between variables in the SEM were based on the directions between variables in a model described in the caregiver literature (Yates et al., 1999 stress process model). There are currently no models in the literature that describe the dyadic impact of providing support for AMD. Therefore the assumptions made about the direction of relationships may not be accurate. For instance, stress process models suggest that patient's health is a 'stressor' and is predictive of caregiver outcomes such as their health. This direct relationship was not significant in the present study, although an indirect relationship via caregiver 'burden' (CRA scores) was significant. Future models might treat both pwAMD and caregiver health as outcomes. Longitudinal work might help to explain the relationship between variables such as patient and caregiver health, e.g. to see if they are directly or indirectly related or if the relationship between them is reciprocal.

Previous research on the impact of providing support for someone with AMD has focused on the experiences of people who support someone living with wet AMD (e.g. Gohil et al., 2015; Gopinath et al., 2015; Varano et al., 2015, 2016; Vukicevic et al., 2016). The present study has added to this research literature by including the experiences of caregivers of people with dry AMD. Around 40% of the pwAMD included in this second study reported having dry AMD at the time of the 2013 survey (however this may have turned to wet AMD since then and we did not include a question on what type of AMD the pwAMD had in this second study). This percentage is lower than the number of people with dry AMD in the UK population. It is estimated that only 10-15% have wet AMD, with the rest having dry AMD (Bonastre et al., 2002). Therefore although this study includes a broader range of caregivers of pwAMD, it is likely that the experiences of caregivers of people with wet AMD may be over-represented.

Non-responders to the second study had poorer general health at the time of MSQ 2013 completion than responders. Health status may have changed in the two years following the 2013 survey (when participants were asked to complete the second study), however the most common reason for non-response stated by non-responders to the second study who returned paperwork was ‘poor health’. Therefore it is possible that those in better health are over-represented in this study. However there were no significant differences in general health status between those who took part in the second study and the 2013 MSQ respondents who were included in the analyses examining the impact of care on QoL and well-being presented in Chapter 4. Furthermore pwAMD health was included in the multivariate analyses reported in this chapter.

The SEM included a measure of caregivers’ ‘secondary appraisal’ of the impact of providing support but not a pwAMD ‘secondary appraisal’ of the impact of receiving support. At the time of designing the study, the author could not find a standardised measure assessing patients’ perceptions of receiving support. The research literature in the vision loss field has focused on the concept of overprotection as a negative impact of receiving support however other negative impacts and indeed, positive impacts of receiving support have yet to be investigated in detail. Including a measure of the ‘secondary appraisal’ of receiving support might be a mediator for the relationship between pwAMD’s primary appraisal of the amount of help received and their well-being. This may help to explain the non-significant pathway between the amount-of-care-received variable and well-being in the present study. It would also be interesting to examine how pwAMD and caregiver secondary appraisals of receiving/providing support impact on each other’s outcomes and if the effects are equal. This would involve testing for actor and partner effects, which can be investigated using the Actor-Partner Interdependence Model (APIM) as a framework (Cook & Kenny, 2005). Perceptions of the support received will be investigated in the qualitative study that follows.

One must note that the secondary appraisal measure for caregivers included in this study was not AMD-specific although it has been used previously in studies assessing caregiver ‘burden’ in caregivers of people with wet AMD (Gohil et al., 2015). The internal consistency of the measure, which indicates how well the items on the measure fit together conceptually, was measured using Cronbach’s alpha coefficient. The present study reported an alpha of 0.92 which is above the minimal 0.90 level recommended for instruments already in use (Bland & Altman, 1997; DeVon et al., 2007). In the present study, the CRA total scores were strongly correlated with other similar measures, as would be expected. For instance, there was a strong, significant correlation between CRA scores and caregiver well-being, indicating that a greater negative impact of providing care was associated with poorer well-being. This provides evidence of concurrent validity of the CRA in this sample of caregivers of pwAMD. There were some missing data on the subscales, for instance, the ‘family support’ scale had six missing data. This may indicate that this group of caregivers were unable or unwilling to answer the items on this subscale. In the present study, caregivers were asked on the questionnaire if providing care impacted on any other areas of their lives not asked about in the CRA. Additionally they were asked if they found any of the questions on the CRA particularly difficult to answer or if they felt the question did not apply to them. Unfortunately, a lack of time meant that these responses have yet to be analysed but analysis of this data would provide insight into the whether this group of caregivers of pwAMD found the items on the CRA applicable to their experiences and acceptable (they were willing to answer the questions).

Summary

The SEM tested in this chapter provides support for the proposed dyadic model of the impact of providing and receiving support for AMD (see Figure 6.1). The model suggests there are different predictors of what might be considered the more objective measures of support (i.e. the ‘primary appraisals’ of the amount of help pwAMD reported receiving and caregivers reported providing), from those predicting more subjective appraisals of help provided (caregiver reactions to providing support), and pwAMD and caregiver outcomes (well-being and health). The results from the 2013 survey suggested that receiving care for AMD was associated with poorer well-being, whilst controlling for registration status and change in vision status since diagnosis as indicators of level of VI. The present study measured the impact of VI by examining the impact that AMD had on vision-dependent tasks. When this measure was used, receiving more care for AMD was not associated with poorer pwAMD well-being. The qualitative study that follows will examine pwAMD/ caregiver dyad experiences in more detail to add to the quantitative study findings.

Chapter 8:

The impact of providing and receiving support for AMD: Results and Discussion of the qualitative study.

Results

Eight pwAMD/ caregiver pairs were interviewed. Four were spouse pairs (including two husband with AMD/ wife caregivers pairs, and two wife with AMD/ husband caregiver pairs). The four remaining pairs were adult-offspring/ parent pairs. Three caregivers were the daughter of the pwAMD, one was the son. All adult-offspring caregivers were supporting their mother with AMD.

Three key themes were identified: (a) Managing independence, (b) Accepting the ‘new normal’, and (c) External support. Whilst these three themes were identified in the transcripts of spouse pairs and adult-offspring/parent pairs, there were important differences in their descriptions of their experiences, and therefore they will be presented separately. Tied to this was the view that spouse pairs were experiencing the impact of providing and receiving support for AMD in ‘partnership’ with one another, whilst adult-offspring/parent pairs described ‘looking after mother.’ This cut across all aspects of their experiences and is reported as the overarching theme: “Managing the changes: living with AMD in partnership vs looking after mother”, which will be discussed after presenting the themes.

ANALYSIS OF THE THEMES IDENTIFIED AMONGST SPOUSE CAREGIVER/ PERSON WITH AMD PAIRS[3]

Theme 1: Managing independence

Vision loss caused by AMD led to changes in, or loss of, previously-enjoyed activities. The emotional consequences of this was noted in the pairs. Caregivers were aware of the distress, frustration and sadness this caused, and empathised with their partner.

> *He does get frustrated and it has been times when he's at the beginning he was very depressed, obviously. Because you know a major part of his activities in his life have been robbed from him and that lasted quite a while*. (Participant 121a, wife of husband with AMD) QUOTE 1

Some pairs felt this resulted in the pwAMD losing confidence in their ability to carry out activities. Pair 121 and 121a illustrate how low confidence/ self-efficacy resulted in the pwAMD feeling dependent on their caregiver, and this caregiver reported feeling more restricted.

> *I still get by because I've got my dear wife doing anything that I wish I could be able to do.* (Participant 121, husband with AMD) QUOTE 2
>
> *…he doesn't like me to go out on my own because he thinks that if anything happens to me, he'll be absolutely lost and I'm restricted in as much as I can't do as much as I would like to do independently anymore.* (Participant 121a, wife of husband with AMD) QUOTE 3

The majority of pairs described pwAMDs' determination to continue with activities as normal. PwAMD described their spouses encouraging them to continue with activities independently and caregivers noted being aware of not overly restricting the pwAMD (i.e. giving them the choice of whether they would like help instead of stepping in to help straight away).

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[3] '…' indicates quotation beginning mid-sentence or speech omitted.

Material within square brackets has been added by the author for clarification.

Underlined text indicate an emphasis in speech.

Material within rounded brackets indicates where the audio recording wasn't clear and so a best guess was made as to what was said.

> *I mean he's not an invalid by any means and he doesn't um, doesn't like me barging in and saying 'oh let me do that' (laughs). Um (pause) yeah, he gets very cross about things like that…He likes to plod on and um, do it himself if he can.* (Participant 28a, wife of husband with AMD) QUOTE 4

This required a balancing act for pair 121 and 121a, as the caregiver reported wanting to encourage her husband to continue to try things independently but also being aware that pushing too much might affect his confidence.

> *Yeah I have asked him to do things and once he says I can't do it, I don't ask him anymore…Then I think well there's no point in making him er frustrated and feel inadequate so I won't ask him to do that anymore*. (Participant 121a, wife of husband with AMD) QUOTE 5

Pairs recognised the importance of maintaining confidence in the pwAMDs' abilities to prevent over-reliance on the caregiver and to maintain individual independence. Only caregivers reported concern over their potential to provide too much help to the pwAMD; no pwAMD reported receiving too much help.

Pairs engaged in a variety of strategies to help the pwAMD continue with activities. This included acquiring low-vision aids (LVAs) and doing activities together. Environmental barriers (e.g. unreadable bus numbers, poor lighting), problems with reading material (e.g. very small writing), problems with LVAs (e.g. lack of interest in talking book topics), day-to-day differences in vision, as well as negative past experiences (e.g. getting lost when out and about) were barriers to doing activities independently. Furthermore, having left a long time between a previous perceived unsuccessful attempt and further attempts at carrying out an activity, was also cited as a barrier. Caregivers provided support and encouragement to push past these barriers, for example:

> *… he [husband] would encourage me to go in to town by myself if I wanted to because many time[s] he said there's no reason why you can't try anyway and he'd help me to get on the bus... But he thinks that it would be a good thing for me and I think it would be a good thing for him as well that I go a bit further away than the area where we live.* (Participant 128, wife with AMD) QUOTE 6

Safety concerns were raised. All pwAMD who drove reported giving up driving due to concerns over their own and other peoples' safety. This restricted their ability to get out and about which had a knock-on effect on their freedom and independence. They noted a reliance on others for lifts. Getting out and about independently was limited to local areas where pairs were familiar with the roads and knew where to cross safely.

> *I like to be independent if I can be... You know, for instance crossing roads and things like that, as I say, I go out alone but only in my local area. I wouldn't go anywhere strange. If I'm in my local area I know where the traffic is coming from and where best to cross the road and so on*. (Participant 81, wife with AMD) QUOTE 7

Doing activities together had a dual purpose. First caregivers could take over the more risky activities whilst still completing the activity together. Secondly it meant that any non-serious mistakes or mishaps could be averted (e.g. putting in wrong ingredients whilst cooking). When pwAMD were aware of mistakes they had made by accident, pairs who described using humour found this was a helpful coping strategy.

> *…when she gets things wrong, either she sees something wrong or something like that we have a really good laugh about it. You've got to be able to laugh and that really does help*. (Participant 81a, husband of wife with AMD) QUOTE 8

Otherwise, caregivers reported not drawing attention to mistakes with the presumed purpose that the pwAMDs' confidence would be protected.

> *I don't really want to interfere with her pulling things up and doing the wrong thing. Cos it doesn't matter a great deal in the garden does it…whether she makes a mess of things or not.* (Participant 128a, husband of wife with AMD) QUOTE 9

Theme 2: Accepting the 'new normal'

It was notable that spouse pairs spoke about the help received and provided being an accepted part of their marriage together. Pairs spoke of the reciprocal nature of providing support throughout their marriage and in particular, how the pwAMD had provided support to the caregiver when needed. Thus providing support for AMD was also seen as a way of providing support within their partnership. For instance, participant 121a talked about how her husband had provided her with support whilst she was going through treatment for cancer:

> *He used to take me to the hospital and cos I, when I after I'd had the radiotherapy I couldn't, I couldn't move my arms very much and very tired when I came back. Yes he supported me then and um I've gotta support him now. That's what a partnership's all about isn't it?* (Participant 121a, wife of husband with AMD) QUOTE 10

Pairs reported providing support to the pwAMD for other illnesses and medical conditions in addition to AMD. These were sometimes reported to have a greater impact on the pwAMD's quality of life than the AMD, and caregivers reported greater difficulty providing support for these conditions.

> *So I think deafness is her biggest problem, more than sight because any sight problems she has I can deal with, I can do whatever it is for her, you know. But I can't hear for her*. (Participant 81a, husband of wife with AMD) QUOTE 11

Co-morbidities were therefore sometimes used as a frame of reference that affected pairs' perceptions of the help received or provided for AMD.

Many pairs reported viewing the diagnosis of AMD as part of the process of ageing and them '*both growing old'* together and thus may be a somewhat expected change in their lives.

> *I feel fine. As I say, it's just one of the things that happens…neither of us are as fit as we would like to be, as we used to be, by any means but we are both, I'm nearly 80 and [husband] is [a similar age] um, and you do slow down. And er, if you have a good marriage, a happy marriage, you just, you just carry on and er make the best of it.* (Participant 28a, wife of husband with AMD). QUOTE 12

> *But I suppose we looked at it both in the same way really, we thought it's part of getting old you know (laughs).* (Participant 81a, husband of wife with AMD) QUOTE 13

Living together in partnership meant that AMD affected both the pwAMD's and their caregiver's activities. This affected activities for leisure as well as household tasks.

> *…life has been reduced by half in our, you know our activities*. (Participant 121a, wife of husband with AMD) QUOTE 14

Whilst limitations were noted, they were mainly viewed as part of living with AMD in partnership and were generally accepted. There was some evidence that pairs used positive reinterpretation of the limitations on activities caused by sight loss.

> *I think even if she hadn't had AMD we'd probably be doing pretty much the same things as we do now anyway. We like walking… we can still manage a bit of that. So we go to the places we like. Yeah I, not a huge impact on our way of life probably…* (Participant 81a, husband of wife with AMD) QUOTE 15

Changes in activities that required the greatest adjustment tended to be those resulting from changes in established roles within the partnership. These were sometimes specific to traditional gender roles within a household. For instance, wives became the main driver in the household since male pwAMD had stopped driving. Whilst male pwAMD reported having enjoyed driving and thus experienced a great loss since having to stop, their wives who were less familiar with driving reported more anxiety and perhaps a lack of confidence in this task.

> *I wouldn't say I'm a confident driver because I've always had my husband to do the driving er but I've had to steel myself for long journeys um on the motorway and it's not something I enjoy* (Participant 121a, wife of husband with AMD) QUOTE 16

Men reported doing household tasks they '*don't normally do'* including cooking and sewing. They reported some trepidation about doing these activities, however wives reported they completed the tasks adequately. Doing these tasks in partnership, with the caregiver following the pwAMDs' instructions, was commonplace, as illustrated by pair 128a and 128:

> *…day to day I find myself doing things that I don't normally do…cooking for example, and er um er household repairs and er sewing (laughs) would you believe? (both laugh). Which I'm no good at but I have to assist – not a question of doing it, I just have to follow instructions*. (Participant 128a, husband of wife with AMD) QUOTE 17
>
> *…the sewing is very good, he's very good at threading needles (laughs) and he's got, he learned how to sew buttons and things like that.* (Participant 128, wife with AMD) QUOTE 18

These changes in roles and responsibilities generally led to only minor changes in roles for female caregivers (apart from becoming the main driver);

> *I provide all the domestic support but that's not particularly because of the macular, I would be doing it anyway, most of it anyway. Um (pause). No, just, just help him when he can't see very well and um, and I say driving because he's not allowed to do that.* (Participant 28a, wife of husband with AMD) QUOTE 19

However male caregivers now took on more of the household responsibilities. Both the wives with AMD and their husbands reported these tasks were considered part of providing support for AMD. For instance participant 81a described how he considered cooking and cleaning as part of the support he provides to his wife:

> *Well it [the amount of time I spend helping my wife with AMD per week] varies a lot but it's pretty simple really. I mean, every day we have a routine like everybody I guess. I get up and make breakfast and all that sort of thing. Um and then we, we always go out every day, regardless. We never stay in all day and er but then of course there's things like sometimes we eat out at lunchtime but we always have a dinner in the evening – well I do that. Then at the weekends I do the traditional Sunday roast, you know and all that kind of thing. And so, on the cooking side that's pretty straightforward, um and on the household side I have a routine again of doing all of the housework on Sunday morning while [my wife's] at church. So she hasn't got to sit there and watch me.* (Participant 81a, husband of wife with AMD) QUOTE 20

Male caregivers generally reported accepting these changes in roles and responsibilities. Whilst these changes were '*not expected'*, they also reported reasons why these new responsibilities were benefitting them, including keeping them '*healthy*' by '*having something to do'*, giving them exercise, easing them into retirement and preventing them from focusing on their own '*worries*' by forcing them to think of others. There was evidence they used benefit finding and positive reframing as coping strategies.

> *… I never thought that at the end of the, when I got older that I would suddenly end up doing this…I have no complaints and absolutely she'd do twice as much for me so it's never been an issue at all. You do what you have to do. And I don't mind it, and I - actually the way to not mind it is to enjoy it, which I do.* (Participant 81a, husband of wife with AMD) QUOTE 21

Theme 3: External support

The majority of the time, pairs reported managing the impact of AMD together in partnership. However there were occasions when outside help was required. This happened when pairs didn't have the skills, knowledge, tools or physical ability to do particular tasks themselves. It included, for instance, help with home maintenance and repairs as well as everyday tasks around the home. However there were barriers to receiving help. Getting help from outside the pair involved putting their trust in strangers. Pairs reported that this was a barrier to seeking help, for instance, with getting a cleaner to help with household tasks.

> *…people are urging her [my wife] to get in a cleaner but I'm not keen on getting in a cleaner to do things…I don't like people coming into my house and knowing, looking everywhere and examining everything and (pause) which a cleaner should do. I'm not keen on that.* (Participant 128a, husband of wife with MD) QUOTE 22

Others had sought practical help but had unsatisfactory experiences which resulted in a distrust of services. Pair 121 reported feeling that the practical help they sought had *'taken advantage of'* the pwAMD's sight loss and consequently did a '*very sloppy*' job, which led to the pwAMD feeling helpless and frustrated.

> *…out of everything I think that if we had more practical help we'd be a lot happier. He* [husband] *would certainly too because he feels that he can't do it, somebody else comes and does it, doesn't do the job properly and that's when it gets to him and he says if only I had my sight, you know, I'd be able to do this.* (Participant 121a, wife of husband with AMD) QUOTE 23

Pairs also reported unsatisfactory experiences with eye care professionals. Reasons for unsatisfactory experiences included being given the diagnosis of AMD in an uncaring manner and not being given enough information and support.

> *… that was how I found out and this guy was, this medic that I saw was pathetic. His diagnosis was right but the thought that he had of how I might feel, looking after me and the caring… was zero.* (Participant 28, husband with AMD) QUOTE 24

Similarly, participant 121a reported being disappointed with the lack of attention paid to the patient perspective when they were given the news that treatment for AMD was no longer effective. The consultant who had been seeing them through the treatment did not deliver the news themselves. The pair perceived this as them being ‘*brushed aside’* by the consultant ‘*because she couldn’t do any more for us’*. This lack of continuity with seeing the same consultant was seen as being ‘*heartless*’ and led to the pair feeling ‘*disappointed*’ and ‘*unhappy*’ with the healthcare system.

> *…we were the last to be seen and on that last appointment the consultant who had been seeing us all the way through gave the job to somebody else who we had never seen to tell us there was nothing else that could be done….I thought that was very heartless. Very heartless. You know at least, to be told by someone that was familiar with you, that had seen you through your treatment, and then that you knew, would have been much better…. I felt we’d just been brushed aside because she couldn’t do any more for us…* (Participant 121a, wife of husband with AMD). QUOTE 25

Caregivers sometimes reported acting as advocates for the pwAMD when they had negative experiences. For instance, following the above experience, participant 121a wrote to the consultant to say ‘*how disappointed and upset we were that she hadn’t spared us the time’.* Similarly, participant 121a reported taking on an advocacy role when dealing with people who had completed poor practical work in their home:

> *I do get a bit feisty when I have to support him and that’s the only way round it I have to make sure that you know he’s not taken advantage of.* (Participant 121a, wife of husband with AMD). QUOTE 26

Difficulties arose when pwAMD made attempts to seek outside help which were hindered by other peoples’ perception that help was not needed. For instance, participant 28 reported trying to access LVAs from a charity, only to be told that his sight loss was ‘*not quite bad enough’* to access help. However others reported receiving more satisfactory help from charities in the form of LVAs, counselling by telephone, and up-to-date information on research into treatments for AMD.

Pairs mentioned receiving only occasional help from their adult-offspring. There were several reasons for this. Pairs perceived themselves to still be in the role of caregiver to their adult-offspring (they saw themselves in the traditional roles of parents and children, or felt they could not break the traditional roles since their adult-offspring was perceived to be in poorer health). Furthermore some pairs perceived their adult-offspring had too many other responsibilities to be able to provide support. Lastly, pairs felt that their adult-offspring were unaware of the consequences of sight loss and thus perhaps did not perceive they needed help, as illustrated below by participant 121a:

> *…I think they [my children] don't realise that er how difficult life is sometimes for us and we don't tell them but they certainly don't realise it. How can they? I mean they've never been in that same position it's difficult for them to, to know.* (Participant 121a, wife of husband with AMD) QUOTE 27

No pwAMD reported receiving too much help from adult-offspring. However, caregiver 81a noted how offers of help from outside the pair were received gratefully, but could sometimes be considered over-helping. It could be inferred that this happened because people outside the pair do not see the day-to-day limitations posed by AMD which provides a guide to knowing how much help to provide.

> *P: Well my daughter's very sympathetic…They don't fully understand the impact I don't think but then they're not living with it every day. Not because they don't, they're not unsympathetic, it's because they don't realise in certain instances just what the limitations are.*
>
> *R: Mm. So can you give me maybe an example of what kind of things that they think wouldn't be affected?*
>
> *P: Well it's a bit I think over the top sometimes you know, I somet', we visit one daughter and she makes her husband sort of take hold of [wife's name] arm, march her down the steps, and across the paths and holds the car door open, as if she can't find her own way back to the car, you know. She finds that a little bit irritating which I would as well. But you can't say anything because it's meant well of course.*
>
> (Participant 81a, husband of wife with AMD) QUOTE 28

On the whole, pairs reported being satisfied with the amount of help provided by their adult-offspring. However there were occasions when pairs reported struggling on their own (e.g. if the caregiver was taken ill and someone was needed to provide additional support to the pair). Others reported researching professional services for emergency cover in case they fell ill in the future. None reported having talked to their children about this, reinforcing the idea that pairs either preferred or felt the need to keep the provision of care within the boundaries of their partnership as much as possible.

> *… I can't think that I would want any help from anybody. An emergency is always a bit of a worry, you know if I broke a leg and had to go to hospital, then that emergency situation like that is a worry. But there are, there are institutions which do help in that case. Which I have contacted, yeah*. (Participant 128a, husband of wife with AMD) QUOTE 29

Meeting other people who had experienced sight loss acted as a source of inspiration for pwAMD. This challenged their own preconceptions about the skills and abilities of people living with sight loss.

> *… it's amazed me what some blind people do.* (Participant 28, husband with AMD) QUOTE 30

PwAMD reported benefitting from attending local groups by sharing their experiences and this led to them feeling they were '*not alone, you know, suffering from this horrible thing'*.

> *I like to chat and um, so I go to that group... you meet other people and you know that everybody there is suffer from macular so it's something that I've been going for oh a number of years as well. I like to go to these meetings because you feel that you're not alone, you know, suffering from this horrible thing.* (Participant 128, wife with AMD) QUOTE 31

Thus whilst pairs reported mostly coping together with AMD in partnership, some pwAMD noted the benefits of meeting people outside the pair, who had experienced sight loss.

Meeting other people with sight loss who were widowed led pairs to report being '*very lucky'* to have each other as a source of support and solace in living with AMD.

> *I mean I'm just fortunate that I've still got my husband because lots of women of my age are widows and it must be a great deal more difficult for them. And I think because I've got him, my life hasn't changed so much, it has changed of course but you know, it could have been, it could be much worse*. (Participant 81, wife with AMD) QUOTE 32

ANALYSIS OF THE THEMES IDENTIFIED AMONGST ADULT- OFFSPRING CAREGIVER/PARENT WITH AMD PAIRS

Theme 1: Managing independence

Similar to the experiences of spouse pairs, individuals with AMD in adult-offspring/ parent pairs reported the negative impact that AMD had on hobbies, their ability to carry out everyday activities, and the resulting frustration and sadness they felt as they dealt with this loss. Their adult-offspring caregivers were empathetic to these losses.

> *… thinking of all the disabilities, you know like accidents and losing an arm or a leg, I think I could cope with any of that but I could not cope with being blind, really couldn't, cos I've seen what it does, you know. It is really difficult... Oh yeah, when you see the effect it has on their quality of life and how they have to make their lifestyle so different*. (Participant 37a, daughter of mother with AMD) QUOTE 33

Some caregivers reported building up a frame of reference of how much they believed their mother could and could not see.

> *I mean, when she tells me what she can and can't see I'm quite amazed really. Sometimes, because she'll say 'oh what's that' beside her and I think how on earth have you seen that (laughs). But it's just the light catching something or suddenly she'll see it whereas actually her field of vision is very, very limited…* (Participant 19a, daughter of mother with AMD) QUOTE 34

Caregivers were trying to make sense of the extent of their mother's sight loss. They used this to build their understanding of how much help their mother required. Sometimes there were conflicts in this frame of reference, as illustrated in the quote above, and this resulted in some confusion over the extent of their mother's limitations. This led to difficulties when caregivers felt their mother asked for more help than needed. One daughter described how her mother asked for help but was still able to do things independently, which led to confusion and feeling that her mother might sometimes exaggerate her limitations in order to receive her help.

> *Yeah, well this is the strange thing, you know. When she needs to go to the doctors she walks down to the village on her own, on a Monday to the club she walks on her own, on a Friday afternoon she walks on her own and I often think, well if she can do that on her own (laughs) why is she always saying to me 'oh can you just do this?' you know. I mean I know she knows the area and she knows the path but it just seems sometimes I wonder if she exaggerates a bit, you know?* (Participant 37a, daughter of mother with AMD) QUOTE 35

Generally, pwAMD reported wanting to remain as independent as possible, and tried things alone before seeking assistance. Some caregivers reported that this meant they felt their mothers were reluctant to ask for help and thus reported having to pick up on what their mother may need help with rather than being asked directly. A barrier to this was if pairs did not live together and thus caregivers could not see the day-to-day impact of sight loss.

Caregivers sometimes reported helping in secret. For example, one daughter reported she believed that sight loss caused by AMD was the reason for her mother's kitchen becoming dirtier over time. She described cleaning her mother's kitchen when her mother had gone upstairs. This was possibly to avoid seeming critical, reducing the impact on her mother's self-efficacy and to enable her mother to continue living independently.

> *… Just pick up odd things so that I think oh I think she probably needs more help with that now. I mean I must admit you see um you know I notice like the kitchen isn't as clean as it used to be, things like that so she wouldn't see all that... And I would have thought oh I'm sure if she realises they were grubby she'd be very upset about it… I don't mention it to her but if she's upstairs doing something then I'll get a cloth out …But again you see it's hard because she, she is so independent.* (Participant 1a, daughter of mother with AMD) QUOTE 36

Caregivers reported finding ways to enable their mother to continue with hobbies or activities. This often involved doing the activity together, with the caregiver doing the part of the activity that was more risky to the person with sight loss or carrying out the initial part of the task that required sight.

> *… I've got her some really thick, chunky knitting needles. And then I cast on some stitches, like 20 or 30 stitches, and then she'll sit there and knit until the big ball, the big ball of wool's gone and I make them into blankets for cats. So she thinks she's making things that are needed and then, cos you know what I mean, you know, she doesn't know when she drops a stitch or anything so there's the odd hole here and there, so I mean they couldn't be given away to anybody but I say to her 'right, there's another pussy blanket' you know. (laughs) So she's quite pleased that she's still doing that.* (Participant 37a, daughter of mother with AMD) QUOTE 37

Caregivers also provided aids to help their mother live independently as much as possible. Some pwAMD only reported using these when perceived as necessary. There was some indication that caregivers provided aids before they were required by their mother. This was not perceived negatively by the pwAMD.

> *She uses a stick outside but she doesn't use a stick in the house and we bought her a sort of pushing pusher trolley thing, she won't have anything to do with that.* (Participant 19a, daughter of mother with AMD) QUOTE 38

Pairs reported coping with non-serious mistakes and mishaps related to the AMD with humour. Some pwAMD reported '*not letting on*' about mistakes they had made. Reasons for hiding mistakes were to avoid embarrassment and not wanting to burden the caregiver. Trips and falls were a constant worry. One pair struggled to come to an agreement on the best way to manage this. There were indications that the pwAMD had difficulty accepting changes in their life that might help to prevent falls, whilst the caregiver reported feeling frustrated that changes could not be made.

> *But see the trouble is, where she can't see, she's walking, always walking into things and hurting herself so we're always running to and fro the minors unit to get dressings done or stitches done or bruises and bangs on her head done…*(Participant 37a, daughter of mother with AMD)
>
> *Well, I keep saying to her, you know-also to cut down on weeding and gardening- what I said to her is why don't I put all the pots in to the flowerbed so then all the area of the garden is clear… I try and make alterations, you know for safety and then the answer always is 'oh no, daddy did that' or 'daddy put that there' or 'daddy built that' so she won't let me make any alterations. It's so frustrating you know.* (Participant 37a, daughter of mother with AMD) QUOTE 39

Theme 2: Accepting the 'new normal'

Within the theme 'accepting the 'new normal'', spouse pairs described providing care to one another as part of their marriage and living in partnership together. For adult-offspring/ parent pairs, caregiving for AMD typically began when the pwAMD's husband had died. A central theme present in caregivers' accounts was adjusting to the perceived responsibility they had for the pwAMD or 'looking after their mother'. For some, this was unexpected and overwhelming.

> *…my Dad died [over ten] years ago and so everything basically came to- down on me after that (laughs). And I mean everything.* (Participant 37a, daughter of mother with AMD) QUOTE 40

Feeling that they were responsible for their mother was woven into various aspects of their lives. For instance, one daughter felt a responsibility for keeping her mother company, and reported feeling pressured to take her mother out and about with her whenever she went out. This restricted her freedom.

> *But I have thought that ever since my father died because I mean that was over 10 years ago, because he would take her everywhere…but I have noticed that she's more my responsibility now for her happiness of going out etc.* (Participant 1a, daughter of mother with AMD) QUOTE 41
>
> *…cos I know when she's away, it's an absolute relief. All that is gone from my mind, I think oh if I want to go to [town] I can because she's not around, so I don't have to lie to her* (Participant 1a, daughter of mother with AMD) QUOTE 42

PwAMD reported requiring assistance for travelling to unfamiliar places and places further afield. The reasons for this included them not being able to drive to places beyond walking distance, needing guidance in unfamiliar environments, and requiring help for activities that involved reading including entering PIN numbers and reading labels. The majority of pwAMD reported a reduced social circle due to family and friends of similar age or older having died. Participant 37a reported how her mother was no longer able to go out on group trips because her sight loss meant that an increased risk of falls made her '*too much of a liability*' for insurance purposes. These factors meant that pwAMD mainly relied on their adult-offspring to get out and about.

There appeared to be some gender differences in caregivers' perceptions of providing care. The one son who took part in this study, had a stoic approach to the reasons why he provided care as well as the provision of care which could indicate acceptance of his role.

> *…it's what sons are for really* (Participant 120a, son of mother with AMD). QUOTE 43

Female caregivers were more likely to report more numerous impacts of providing support and difficulties fitting caregiving into their lives.

There were differences between pwAMDs' and caregivers' perception of the adult-offspring's reaction to taking on the caregiver role. PwAMD were matter of fact about the situation. For instance participant 1 reported her daughter had '*taken it in her stride'*. There were some indications that pwAMD had not thought about the implications providing care had on their adult-offspring, or perhaps, that they preferred not to think about this.

> *I suppose you could say in one way I'm a bit of a tie in that respect aren't I? … I try not to be, but um you know she, she does um - I don't go to the doc very often I'm glad to say or the hospital but I would be dependent entirely on her if I did*. (Participant 19, mother with AMD) QUOTE 44

Some pwAMD discussed ways in which they provided help to their adult-offspring (either now or in the past), perhaps as a way to emphasise the reciprocal nature of providing support in their relationship.

> *… my daughter's husband had a stroke [number] years ago…I feel that I am able to be a bit of company for her you know at times. I always know when there's trouble, she opens my door and comes down. So I'm hoping and I don't honestly think I've made her life worse*. (Participant 19, mother with AMD) QUOTE 45

> *I try to help them. Sometimes they forget things – mind you I do as well, my god I do, but I try to diplomatically (laughing) suggest something or other you know. I, the main thing is not to interfere but if you remember something and they've forgotten it, you know you think well it's stupid, why the hell don't you say something but on the other hand you think you're interfering you know!* (Participant 19, mother with AMD) QUOTE 46

Caregivers and pwAMD referred to this as 'looking after' each other, however it was accepted that this was now weighted more heavily in terms of the adult-offspring providing help to their mother.

Two of the four pairs interviewed lived together. For participant 19 who lived with her daughter and son-in-law, it was important to her to emphasise that she '*was invited, I didn't ask to come*'. This suggests a concern about being a burden on her daughter and son-in-law. She emphasised how well the situation had worked and her aim to remain independent:

> *They've been extremely good and it's worked very well. I made sure I wouldn't be 'and my mother came too' you know I'm up here, I've got my talking books which are my saviour. Absolutely. I listen to those and I'm quite happy*. (Participant 19, mother with AMD). QUOTE 47

Indeed her daughter (participant 19a) echoed the positive relationship she had with her mother: '*I wouldn't want anyone else to look after her*'. She acknowledged that having separate spaces in the house for each of them was '*the secret of it working'* and contributed to this positive evaluation of them living together. Of the pairs who didn't live together, the caregivers reported having thought about this potentiality and had discussed it with their partner or siblings. Whilst this was considered the next step if sight deteriorated further, there were barriers to this, for example, if they reported relationship strains with their mother.

It appeared that many pairs did not discuss the impact providing care had on the caregiver, thus mothers were unaware of them. Occasionally, when such matters were discussed, solutions (if possible) were found.

> *… she goes to [place] every Sunday and most Sundays I've picked her up. But then some Sundays I've been working so it's quite a rush for me… I have really resented that but I have found out now, that these people that come and collect her will bring her home if I'm working, so that's such, that's a huge relief …so that's been a great help but she didn't say that until recently…* (Participant 1a, daughter of mother with AMD) QUOTE 48

However in some cases, even when matters were discussed caregivers still reported feeling concerned, showing that the issue was unresolved despite communication. One caregiver suggested she used positive reinterpretation to cope:

> *Sometimes I just wish I could do things a bit more quietly in the morning rather than race around trying to do everything to get there at whatever time it is. And*

> *she [mother] just says to me 'tell what time you're coming, it doesn't matter' but sometimes in the morning you can't always, you know, things happen in the morning... and that starts my day off, sometimes, a bit fraught. I try and, I know she needs to know that and it gives me a deadline to work to I suppose.* (Participant 19a, daughter of mother with AMD) QUOTE 49

Caregivers reported several ways in which providing care impacted on their lives, including their health, their finances, social life, relationships with other family members, plans for the future and employment. These were discussed in terms of managing their wants and needs with the responsibility they had for their mother. Some caregivers reported difficulty accepting these changes in their lives.

Two caregivers who were still working described difficulty getting time off work to take their mother to medical appointments for AMD. There were differences in caregivers' appraisals of the difficulties in getting 'time off'. The son who took part in this study reported being '*a little bit miffed'* towards his employer as he perceived that caregiving should come first.

> *My mother's welfare, whether it's to do with eyes, or to do with her medical condition at the moment, is more important, than any erm objectives or ticking boxes* (Participant 120a, son of mother with AMD). QUOTE 50

A female caregiver described guilt and difficulty managing these competing priorities. She reported not wanting to '*take advantage'* of her employer by taking time 'off' for appointments.

> *But I mean because I work part time it, it is easier – I found when I was working full time the pressure was great because I'd have to um request the days off that she went down to [hospital], you know monthly, um and sometimes I'd think well I might not be able to get this day off and she'd say 'well you'll just have to tell them, you'll just have to tell them'. I said look it's not a quite like that mum, so, so that did worry me and also because I had to use up some of my annual leave because I didn't work so many weekends meant I didn't have the days off in the week. So then I was using up my annual leave and I was feeling resentful of that.* (Participant 1a, daughter of mother with AMD) QUOTE 51

> *…I don’t like to take advantage, I’m all you know even when I was working full time in the [company] I felt I sort of gave them my first um priority as it were.* (Participant 1a, daughter of mother with AMD) QUOTE 52

These differences in reactions to taking time ‘off’ work to accompany their mother to medical appointments between the son and the daughter caregivers, may indicate gender differences in caregivers’ perception of this situation. Participant 37a felt that providing care prevented her from entering employment and that this had affected her finances and social life.

As discussed above, pwAMD viewed their caregiver’s reaction to providing care as something the caregiver got on with. Whilst they recognised that the help received from their adult-offspring was needed and therefore accepted, they also wished to remain as independent as possible.

Theme 3: External support

As discussed above, adult-offspring caregivers’ feelings of responsibility for their mother brought significant changes to their lives, occasionally resulting in stress and resentment of the situation. They sometimes found it difficult to discuss the impact with their mother, and thus their mother was unaware of the impact. It was generally the caregivers who sought outside help when needed (as opposed to pwAMD). When outside help was required, pairs reported difficulty putting their trust in others. External support was required for cover when the caregiver needed to be away from home (e.g. to go on holiday or to visit an ill relative), and for ‘at home’ medical help for other medical conditions. This distrust of others was also reflected in caregivers’ concerns about the future living circumstances of the pwAMD- many reported a distrust of care homes. These concerns highlighted the feeling of responsibility caregivers had over their mother’s welfare.

> *…I think when you get very old to be uprooted and put in to some kind of institutionalised situation is very, very difficult. And I don’t know, I would hate it, it may happen to me one day, I suppose. But I think you’re relying on people that you don’t know, I would be quite worried about it. You can’t, you do trust when you’re older, you’re quite vulnerable to people*. (Participant 19a, daughter of mother with AMD) QUOTE 53

When non-relatives (who were perceived as not having an obligation to provide help) offered help, some caregivers reported difficulty accepting help and handing over responsibility for their mother to others. Participant 1a reported she didn't want to '*abuse*' the help provided as she didn't want them to get '*fed up'* of providing help to her mother.

Some caregivers reported difficulty getting help from others. Male relatives (spouses, brothers) of the daughter caregivers were reported to provide occasional support. For participant 37a, she attributed this to a '*typical sort of son attitude*' where '*as long as he knew I was around he did basically nothing'*. In contrast, others reported being more satisfied with the small amount of help provided by spouses or brothers, as they perceived this was the most care they could provide (e.g. some had their own health problems, others lived further away).

> *R: Does he [brother] come up and help with the day-to-day things at all or?*
>
> *P: No cos he's such a, such a distance away.*
>
> *R: Right yeah. I mean how do you feel, would you prefer that he did a bit more or?*
>
> *P: No, no I'm quite happy with the way things are because I do know that if we hit like a crisis or something then he would do his utmost to come up and help*. (Participant 1a, daughter of mother with AMD) QUOTE 54

There were difficulties receiving help from health and social services. Some pairs described anger and resentment at having to pay for services needed for the treatment and care of the pwAMD, with the underlying message that this help must not be perceived by the 'outside' to be needed if it had to be paid for. Participant 120 reported of charities, '*I don't bother them anymore than I can possibly help*…'- highlighting the different expectations pairs had of services from the charity and the health and social care sector.

Pairs described a lack of continuity from services for AMD and this led to them feeling abandoned. Participant 19a described help from the NHS as '*very reactive, not at all proactive so they don't offer any help'*. A couple of pairs reported receiving unexpected and unexplained one-off visits from health and social care services only to find they were never contacted again.

A lack of information about AMD within health and social care services as well as within the general public led participant 120 to report '*you get very, very little information about eye problems. They will publicise everything, every medical condition under the sun, but you very rarely hear anything about eyes'* QUOTE 55. She also reported having received '*no help, outside help, whatsoever'.* These factors contributed to her perception that pwAMD had been forgotten about.

Caregivers reported that the fact they were providing care for their mother meant that formal services perceived their mother was not in need of any additional help.

> *… a few years ago, out of the blue, er mother had a phone call from social services that (hesitation) took both of us completely by surprise. And this person for some reason best (hesitation) I'll explain, decided to pick a fight for no apparent reason…And she turned round and said 'oh you've got a son'… And I just don't know where that came from… And as I (stutter) and I was saying, I thought charming I thought these people were supposed to help! … But anyway that's my job at the moment.* (Participant 120a, son of mother with AMD) QUOTE 56

> *P: The doctor is aware of the situation but I think he feels, probably quite rightly, that I am at home all day and I do a good job of looking after my Mum and more people, more needy who perhaps live on their own are less well off or whatever, who are more deserving of the care of the overstretched professionals.*
>
> *R: How do you feel about that though?….*
>
> *P: Well, I probably agree with him. I try not to bother him unless it's something important.*(Participant 19a, daughter of mother with AMD) QUOTE 57

The lack of help from social and healthcare services because caregivers were around to help their mothers provoked different reactions from these caregivers. Participant 19a was more likely to agree with the conclusion that others who were coping alone were '*more deserving of the care of the overstretched professionals'*. However the male caregiver (participant 120a) felt abandoned by these services that were '*supposed to help'*.

Overarching theme bringing together the spouse pairs and adult-offspring/parent pairs: "Managing the changes: living in partnership vs looking after mother"

Transcending the aforementioned themes and bringing together the findings from spouse and adult-offspring/parent pairs was the concept of managing the changes brought about by the onset of receiving and providing support for AMD through 'living in partnership' with one another (spouse pairs) or 'looking after mother' (adult-offspring/parent pairs).

Spouse pairs lived together with AMD in partnership. They were together at diagnosis, sought information together on AMD, developed strategies for coping together, and caregivers were aware of the pwAMDs' changes in sight having been together since diagnosis. In comparison, adult-offspring caregivers generally had little recall of the diagnosis and only started providing care when their father had died. It is mentioned in both the spouse pair and adult-offspring/parent pair narratives that adult-offspring struggled to determine the appropriate amount of support to provide, perhaps because they were less aware of the pwAMD's limitations because they hadn't always been in close proximity to each other (e.g. see QUOTES 27, 28, 34, 35, 36).

Living in partnership meant that the limitations posed by AMD affected the spouse caregiver as well as the pwAMD, particularly in terms of the established roles within the pair such as being the main driver and being the person who undertook most of the domestic tasks. These changes in roles and responsibilities were handled together within their partnership whilst also trying to maintain the independence of the pwAMD. Adult-offspring/parent pairs spoke less about promoting the confidence of the pwAMD and providing encouragement, perhaps because they viewed providing help as part of looking after their mother. For instance, whilst a husband caregiver (participant 128a) reported not wanting to tell his wife that she was pulling up flowers instead of weeds because he considered this was '*not important'* (QUOTE 9), a pwAMD (participant 37) whose daughter was her primary caregiver reported that her daughter informed her when such mistakes were made:

> *… there's so many things I can't do in the garden now. I go out there, I thought I'll try and do some weeding, but if [daughter] standing there next to me of course I'm pulling out rather flower plants as well as weeds you see* (Participant 37, mother with AMD)

The close relationship between spouses may mean they have a greater understanding of their partner's feelings and do not want to upset their partner and affect their confidence. They may also perceive a greater risk to their relationship if pointing out mistakes was perceived as criticising their spouse.

The spouses who took part in this study saw each other as equals and 'partners' and thus tried to manage household tasks together. Whilst the majority of pwAMD seemed to be proactive in providing help in the home, one pwAMD required more encouragement. Their caregiver reported a strategy of only asking the pwAMD to help with household tasks once, with the purpose of preventing them from getting frustrated and protecting their confidence by not asking them several times (QUOTE 5). In contrast, for adult-offspring/parent pairs who lived together, the caregiver tended to take over the household tasks completely.

Whilst the care provided between spouses was seen as part of their partnership/ marriage together, the responsibility adult-offspring caregivers felt they had for their mother was not already built into their lives. The newfound responsibility adult-offspring caregivers felt they had for their mother was reflected in various aspects of their lives, and some caregivers reported more difficulty adjusting and 'accepting the 'new norm'' than others. Adult-offsprings' other responsibilities (e.g. looking after their spouse or their own children, employment) were highlighted by spouse pairs as reasons for receiving occasional help from their children. Adult-offspring who were the primary caregivers in this study also reported difficulties fitting in these competing responsibilities around caregiving.

The concept of spouse pairs coping with AMD together in partnership whilst adult-offspring caregivers had the responsibility of looking after their mother also transcended the theme of 'external support'. Adult-offspring caregivers reported needing help from others as they were managing competing responsibilities, whilst spouse pairs only reported requiring help in an emergency situation. Despite both pairs describing receiving little help from health and social care services, adult-offspring/ parent pairs were more likely to report feeling abandoned by these services. Both spouse and adult-offspring/parent pairs reported difficulties putting their trust in other people to provide services needed (e.g. QUOTES 22, 26, 53).

Adult-offspring/parent pairs reported a lack of communication between them regarding: the impact of providing support on the adult-offspring caregiver, and pwAMD limitations and need for help (e.g. QUOTE 36). PwAMD were hesitant to tell their adult-offspring about mistakes and falls, perhaps as they didn't want to be a burden to their adult-offspring.

> *…cos I hate having to take up her time the way I do but when she says 'why do you sound like that?' she knows when I've hurt myself, even if, when I haven't told her you know… She'll say 'Why do you sound like that, what have you done?' I said 'oh well' you know then I have to own up then when I've had a fall or injured my leg.* (Participant 37, mother with AMD).

The narratives from spouse pairs suggested they had difficulty with the changing of the traditional parent child roles within their relationship. This was seen as a reason why they received only occasional help from their adult-offspring. The adult-offspring /parent narratives echoed some of this; some pairs reported that the pwAMD was 'independent', and didn't ask for help. This meant that the adult-offspring caregiver often had to keep a look out for what help might be needed. In some cases, caregivers described their mother as 'stubborn' because they refused to make changes that might benefit them (e.g. moving plant pots to somewhere where they were less likely to be tripped over) (QUOTE 39). This suggests that parents may have difficulty accepting changes and accepting help from their adult-offspring (indeed they may not perceive this as help).

The adult-offspring caregivers spoke about 'looking after my mother' and equally, their mother spoke about 'being looked after'. Instead of pwAMD becoming dependent when their adult-offspring takes over their care, they report being determined to remain as independent as possible. Thus instead of adult-offspring/parent pairs using the term ‘caring for’ the pwAMD, the term ‘looking after’ was an alternative phrase to show that the support received and provided was more supervisory, less clinical and was considered part of their family relationship.

DISCUSSION

The overall aim of the mixed-methods study (presented in Chapter 7 and the present chapter) was to explore the impact of receiving and providing support for AMD. A dyadic approach was used for both the quantitative and qualitative studies to take into account the interactive relationship between the support recipient and provider.

HOW THE QUALITATIVE FINDINGS HELP EXPLAIN AND ADD TO THE QUANTITATIVE FINDINGS

Key research question: Why did the amount of care received by pwAMD predict pwAMD well-being in the first study (the Macular Society 2013 survey) but not the quantitative part of the second study (the pwAMD/caregiver study)? How can the qualitative study help to explain this finding?

In the quantitative second study, pwAMD difficulties with vision-dependent tasks was used as a measure of the impact of VI instead of registration status and patient-reported change in vision status since diagnosis (which were used in the first study). This may more precisely reflect the pwAMD’s experience of VI. When pwAMD difficulties with vision-dependent tasks were included in the model, the amount of care received for AMD was no longer associated with pwAMD well-being. The qualitative data reflect the quantitative study findings. PwAMD discussed the impact of vision loss on changes to everyday tasks and their previously-enjoyed hobbies. This resulted in frustration and sadness which impacted on their well-being.

Whilst the majority of pairs felt the pwAMD was determined to remain independent and tried to continue with their activities, it was noted that sometimes low self-efficacy and other barriers (e.g. problems with LVAs, small writing in books and on food labels) prevented pwAMD from completing tasks independently, and this was when help was provided for vision-related tasks. Thus the qualitative findings suggest that it is a combination of the degree of sight loss as well as other factors such as self-efficacy, the determination to remain independent, and the availability of aids that determines pwAMD need for help with vision-related tasks. This may help to explain why difficulties with vision-dependent tasks were unrelated to the amount of help received/ provided in the multivariate analysis as these other factors weren't taken into account. In addition, DLTV scores were not associated with the amount of help caregivers reported providing. The qualitative data suggest that some caregivers may be unaware of the amount of help needed. Adult-offspring in particular, reported uncertainty of their mother's limitations, difficulty understanding the extent of their parent's sight loss and how much help was needed. Thus the qualitative data provide more detail on how vision-dependent tasks affect pwAMD well-being and the amount of care received/ provided.

The qualitative investigation reflected the quantitative study finding that participants thought about the help they received/ provided for activities of daily living when deciding on the amount of help received/ provided. Many of these tasks (e.g. cooking for or with the pwAMD) were built into the everyday lives of spouses or adult-offspring/parent pairs who lived together. Since these tasks required little or no change to their routine, it might be expected that they would not impact on their well-being or appraisals of caregiving. However, tasks that fell outside of their 'norm' might be more likely to impact on these outcomes. Indeed the qualitative results under the theme 'Accepting the 'new normal'', show that caregivers reported some anxiety doing tasks outside of their established roles and responsibilities (e.g. for women this was becoming the main driver, and for men this was having more responsibility for domestic tasks such as cooking and sewing). The qualitative investigation highlighted that pairs worked together to manage the impact for instance by doing tasks together with the pwAMD giving instructions. Since spouse pairs had been living in partnership in their marriage together, these changes seemed to be managed easily. In contrast, for adult-offspring/parent pairs who lived together, caregivers were more likely to report doing all the household tasks. Perhaps this is because pwAMD had moved into their adult-offspring's home and caregivers continued their routine of household responsibilities without pwAMD involvement. It should be noted that the discussion of how household tasks were negotiated between co-residing pwAMD and adult-offspring caregivers wasn't discussed in the interviews, so requires confirmation. For adult-offspring/ parent pairs who didn't live together, caregivers reported having twice as much to do; they were responsible for carrying out activities of daily living (e.g. household tasks) for their parent and in their own home, although some activities, such as food shopping, were carried out once but involved twice as much work in terms of getting food for the pwAMD as well as themselves. Thus whether or not pwAMD/ caregiver pairs lived together impacted on whether support tasks were carried out in addition to their normal tasks. This might be included in future models to see if this affects caregivers' secondary appraisals or burden of providing care.

The results presented in this thesis suggest there may be a number of factors that affect pwAMD and caregiver appraisals of the amount of help received/ provided. In the first study (the 2013 survey), participants in the 'more than 35 hours of care a week' group were more likely to be male, be married and their primary caregiver was more likely to be their wife. In comparison, in the second study there were no significant differences in gender or the type of relationship the pwAMD had with their caregiver (i.e. spouse or parent) between the 'hours of care' groups. There was a significant difference in the proportion of pairs who reported living together. All pwAMD who reported receiving more than 35 hours of care a week were living with their caregiver. This association may be due to these pwAMD requiring more help which resulted in them living with their primary caregiver. Alternatively it might be that pairs who live together find it difficult to distinguish between the help provided for AMD and help provided as part of everyday living. The latter was reflected in the qualitative study findings, in particular for spouse pairs who viewed the receipt and provision of support as part of their everyday lives.

The qualitative data provide further explanations for how participants came to decide on how much support they receive/ provide and what tasks count as providing care. Under the theme 'accepting the 'new normal'', both female pwAMD and their husbands reported that the household tasks the husband had taken on since their wife's sight deterioration were considered additional tasks that they wouldn't 'normally' do. These were more likely to be considered as support for AMD and thus be counted as part of the amount of help received/ provided per week than for female caregivers who provided domestic responsibilities for their husbands with AMD. All spouse pairs in this study reported taking on the traditional roles of husband and wife in their marriage (where men were responsible for earning and women for domestic tasks). The age range of spouse pairs was between 77-83 years and this age group may be of a generation where this is considered the ‘norm’. Thus there may be gender differences in the types of activities considered as support for AMD and this may affect the reports of the amount of support provided.

Both spouse and adult-offspring caregivers reported that the impact of AMD on the pwAMD was always in the back of their mind even if they were not providing direct support at the time. Concerns over trips and falls were a constant worry. Pairs reported the caregiver needing to be on hand to help with situations as they arose (e.g. falls or if the pwAMD had put something down and couldn’t remember where they left it). The unpredictable nature of the support required made it difficult for pairs to decide on how much help they received/provided in quantitative terms (i.e. the amount of hours per week they spent receiving/providing support).

The qualitative data suggest the experience of providing/ receiving support is different between spouse and adult-offspring/parent pairs. Whilst similar issues arose in the management of providing support for AMD the experiences for spouses and adult-offspring/parent pairs were notably different in terms of how they adjusted to changes in roles and responsibilities, how they managed the independence of the pwAMD and that of the caregiver, and their experiences of seeking external support. The multivariate findings from the 2013 survey analysis, and bivariate analysis in the second quantitative study suggest there were no significant differences between these types of pairs in pwAMD or caregiver well-being, health or caregivers’ appraisal of the impact of providing support. However the small sample size in the second study prevented the inclusion of the type of pwAMD/caregiver relationship in multivariate analysis. The qualitative findings suggest it is important to consider these types of pairs separately in their experiences of the impact of receiving and providing support for AMD.

The main aim of the present study was to investigate the impact of receiving and providing support for AMD. For the spouse pairs interviewed in the qualitative study, the focus was instead on how they managed the impact of AMD together, since providing support was part of being married. There was a shared impact of AMD on the pairs' tasks and activities and these were managed together. Providing support was seen as part of the reciprocal nature of marriage. Thus the perception that the receipt and provision of support was reciprocal was a key appraisal for spouse pairs that determined how they coped and accepted this support.

Difficulties breaking away from the established roles of parent and children were mentioned as one of the reasons why the spouse pairs received only occasional help from their adult-offspring. There were some indications that pwAMD in this study whose primary caregiver was their adult-offspring, still felt the need to provide support to their offspring and did this where they could. Being able to provide help to their offspring led them to feel that help was reciprocal and reduced their concerns that they were a burden. This may contribute to better well-being. However it is possible that for other people, the perception that one is a burden in the first place, or resentment at feeling the need to provide help in return, may actually contribute to poorer well-being. It might be interesting for future research to investigate reciprocal support within adult-offspring/ parent with AMD pairs and the impact this has on well-being.

PwAMDs' ratings of their general health predicted their well-being and caregivers' reactions towards providing care (their CRA scores). The quantitative study findings suggest pwAMDs' health is a better indicator of CRA scores than pwAMDs' level of visual functioning, their difficulties with instrumental activities of daily living and the amount of help provided/ received. There are few qualitative data to help explain this finding, perhaps because providing support for other medical conditions was not the focus of the interviews. Nevertheless, spouse pairs reported helping each other in partnership with their health conditions. There were indications that pairs compared their other health conditions to AMD. For instance participant 81a reported how he felt there was little he could do to help his wife with her hearing loss, whereas he felt he could do more to help his wife with her sight loss. Thus, for caregivers, feeling able to provide help to the pwAMD to help them cope with sight loss may have a positive or protective effect on caregivers' feelings of usefulness and hence well-being.

The belief that pwAMD were willing to try activities before asking for help was important for both pwAMD and caregivers in how they appraised the receipt and provision of support. A determination to manage independently reduced pwAMDs' feelings of guilt that they would burden their caregiver- knowing that they had exhausted the options before asking for help. Similarly, caregivers reported feeling they were less taken advantage of if they knew the pwAMD was only asking for help when needed. The qualitative findings highlight that pwAMD self-efficacy was considered an important factor in their determination to carry out activities. Pairs used strategies (e.g. doing tasks together, not over-helping the pwAMD, asking the pwAMD to try to do an activity only once) to attempt to encourage or maintain confidence and prevent the pwAMD feeling frustrated and helpless. In addition, help from outside the pair was sometimes considered to be helpful in promoting pwAMD confidence. Meeting others who had also experienced sight loss was noted by spouse pairs to be a source of inspiration.

The quantitative study found that caregivers' reactions towards providing support (their CRA scores) did not predict pwAMDs' well-being. The qualitative findings provide some evidence to support this. PwAMD whose spouse was their primary caregiver generally reported that the provision of support was an accepted part of their marriage and did not mention that caring had produced any major problems for their spouse. PwAMD whose primary caregiver was their adult-offspring reported not knowing or having thought much about the ways in which caregiving had impacted on their caregiver. This lack of awareness may be due to these pairs not having discussed the impact. Thus pwAMDs' well-being might not be related to caregivers' reactions towards providing support if pwAMD were unaware of any impact.

HOW MIGHT THE MODEL TESTED IN THE QUANTITATIVE STUDY BE MODIFIED FOLLOWING THE QUALITATIVE STUDY RESULTS?

The model may help to explain the impact of the receipt and provision of support for AMD better by including factors mentioned above, e.g. type of pwAMD/ caregiver relationship and whether the pwAMD lived alone or with their caregiver. In particular there are two factors worth highlighting. First, as mentioned above, the impact of AMD on ability to carry out previously-enjoyed activities appeared to be related to both pwAMD and their caregiver's well-being. Some of these activities may be captured in the DLTV (e.g. reading newspaper print). However others, such as driving or shared activities such as walking and holidays, may be affected and do not appear in the DLTV.

Second, it is worth considering including a measure of pwAMD self-efficacy in ability to carry out vision-related tasks. This factor could be targeted in interventions. In addition, pwAMD confidence to carry out vision-dependent tasks may be related to caregiver appraisals of providing support and well-being.

The model tested in the quantitative study did not include a measure of the perception of help received from health and social services or professional services, however the qualitative findings suggest this might be useful in understanding the broader context of receiving and providing support for AMD. Both the spouse and adult-offspring/parent pairs reported difficulties getting help when needed. Pairs reported a distrust of professional services, for example, for getting practical help around the home, and receiving respite help. In addition, a lack of help from others either when pairs had sought help and not received it, or by not being offered help, led pairs to feel that others did not perceive they required help. This contributed to pairs feeling abandoned which may have affected their well-being. This was a particularly poignant issue when it came to receiving help from professionals who pairs perceived should be providing help (e.g. social care services). Help from charities or from other family members was not so expected. The CRA measure used in this study included a subscale measuring caregivers' perception of lack of family support. However there was no measure of support from formal services, and this study suggests that this may be important in understanding caregiver's appraisals of providing support.

There were some similarities and some differences in pwAMD and caregivers' coping strategies. Both reported that using humour when dealing with mistakes caused by sight loss was a useful coping strategy. There was some evidence that adult-offspring caregivers in particular had difficulties fitting in looking after their mother around their other roles and responsibilities. There were indications that caregivers sometimes did not discuss the impact of providing care with their mothers. This may have been because they wished to protect their mother and this required adult-offspring caregivers to suppress their emotions around their mother. Both spouse and adult-offspring caregivers described ways in which they reinterpreted the changes to find positives, for instance male spouse caregivers reported that providing care had helped ease them into retirement. Other positive appraisals of providing support included: feeling that they are able to pay back help received in the past from the pwAMD, and being able to do something that can help reduce the negative impact that AMD had on their loved one.

The present qualitative study found some indications that adult-offspring caregivers had difficulty understanding the pwAMD's vision loss. Caregivers' perceptions of the pwAMD's vision loss guided the support they provided. Previous research found that spouses of people with Huntingdon's disease (HD) reported that the person with HD experienced more symptoms and less control over the condition, than were self-reported by the person with HD (Kaptein et al., 2007). This illustrates that people with a chronic condition may perceive their condition differently from their caregiver. Illness perceptions were found to affect outcomes. Kaptein et al. (2007) reported that both the person with HD and their spouse's illness perceptions correlated with the person with HD's health status (measured using the SF-36). Kaptein et al. (2007) used the Illness Perception Questionnaire (IPQ) to assess illness perceptions of the person with HD and their spouse. The revised form of the IPQ, the IPQ-R, contains the five subscales included in the IPQ (identity, timeline, cause, consequences and cure/control), plus two additional subscales (Moss-Morris et al., 2002). These two subscales assess participant's understanding of the condition (the illness coherence subscale) and their emotional reactions to the condition (the emotional representation subscale). Future research might include the IPQ-R to investigate pwAMD and their caregivers' illness perceptions and how these affect their outcomes. This would involve using a re-worded version to assess caregivers' own representations about the pwAMDs' condition. It would be interesting to see if pwAMD and their caregivers' illness perceptions correlated, for instance, on their understanding of the pwAMD's condition. Based on the qualitative study findings, it might be expected that scores on the 'illness coherence' subscale might correlate more highly between spouse pairs than adult-offspring/ parent pairs. Thus including this measure might help to identify differences between these types of pairs.

HOW DO THE RESULTS PRESENTED HERE COMPARE WITH OTHER PATIENT AND CAREGIVER GROUPS?

The quantitative study presented in Chapter 7 compared mean well-being (W-BQ12) scores of the pwAMD included in this study who received support for AMD with other patient populations. PwAMD reported lower well-being than people with adult growth hormone deficiency (McMillan et al., 2006) and women who have experienced pregnancy loss (Koch et al., 2012). Mean CRA subscale scores were also compared across different caregiver populations. The caregivers in this study reported a lower negative impact of providing care than caregivers of people receiving treatment for wet AMD (Gohil et al., 2015), and caregivers of people with multiple sclerosis (Forbes et al., 2007). They also reported less negative impact on their schedule, family and finances as a result of caregiving but more impact on health and self-esteem than caregivers of people with Rheumatoid arthritis (Jacobi et al., 2003). Of course it is important to note that in addition to the different medical conditions, there are other factors associated with well-being and appraisals of providing care that varied between these studies (e.g. gender, age, type of patient-caregiver relationship), so one should be wary of making direct comparisons across studies.

It is more difficult to compare qualitative findings across different populations since in each study there may be different philosophical assumptions that underlie the choice of research methods used and how the research is reported, and that comparing studies contradicts one of qualitative research's main strengths which emphasises the uniqueness and depth of data. However, meta-ethnography has been used as a form of interpretive synthesis to summarise qualitative research studies. It aims to develop a theory or a line of argument which integrates and helps to explain the findings from separate studies. They are becoming more widespread (e.g. Bennion et al., 2012; Greenwood & Mackenzie, 2010), however they tend to be condition-specific. A meta-ethnographic review of seven qualitative studies on the experiences of caring for someone who had experienced a stroke reported ten themes which had been identified in the majority of the studies (Greenwood & Mackenzie, 2010). Greenwood and Mackenzie (2010) suggested that reports of the experience of caring for a stroke survivor focused on change and loss. Changes included changes in roles, relationships and responsibilities, whilst losses included losses to former relationships, loss of autonomy and loss of taken-for-granted futures. These changes and losses challenged the caregiver's identity which moved from being that of the partner of the stroke survivor, to that of a caregiver. The authors suggested that this reflected a 'biographical disruption', a concept that has previously been used to describe the experiences of patients with chronic illness (Bury, 1982). This theory suggests that chronic illness disrupts the structures of everyday life, disrupts normal rules of reciprocity between the person with the illness and their families, involves growing dependency, and leads to re-examination of the expectations and plans held for the future (Bury, 1982). That some pairs in the present study reported similar issues such as difficulty adjusting to their new roles and loss of independence, suggest that they also experienced a biographical disruption and that there are similarities between the experiences of both pwAMD and caregivers and those of people with other chronic illnesses. Greenwood and Mackenzie (2010) also reported that caregivers used coping strategies to attempt to manage these changes. Strategies included those used by the pairs in the present study including keeping a sense of humour. The 'biographical disruption' led to re-evaluation of the lives of caregivers of stroke survivors. There were attempts to search for meaning and growth where caregivers identified positive outcomes of providing support (Greenwood & Mackenzie, 2010). Similarly, in the present study, caregivers used positive reappraisal to re-evaluate how providing support had been a positive influence on their life.

People with other medical conditions and their caregivers have also reported difficulties accessing formal services (e.g. Greenwood, Holley, Ellmers, Mein, & Cloud, 2016; Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2013). Caregivers' perception that providing care was part of their marriage and feeling that they would be better at providing support than others, were reasons for not persisting with efforts to access these services (Greenwood et al., 2016). These reasons were also reported by the caregivers of pwAMD in the present study. There are differences in the types of help needed for different medical conditions. Whilst caregivers of people who had experienced a stroke, for example, required help with personal care, this was generally not reported as being needed in the sample of pwAMD. Different types of care appear to carry with them different requirements. For people who required help with personal care, it was important that there was time to build a relationship with the person providing the care (Greenwood et al., 2016). Caregivers in the present study reported requiring external help with everyday tasks (particularly in an emergency situation if they could not be there to provide care) or with practical tasks around the home. Thus it is important to note that different conditions require different types of help, and that caregivers and people with the condition may have specific needs relevant to these types of support.

On average, the pwAMD in the present study were diagnosed 14 years ago. Many reported feeling abandoned by health and social care services. Apart from seeing ECPs at the time of diagnosis or for treatment, many did not report further contact with these services. Similarly, a nationwide survey of patients with motor neurone disease, Parkinson's disease and multiple sclerosis found that those diagnosed longer ago reported having more difficulty receiving help from health and social care services (Peters et al., 2013). This suggests a nationwide problem of lack of continuity of care and difficulty accessing services for all medical conditions.

The author is not aware of any publications synthesising qualitative research on the experiences of patient/ caregiver dyads. Research involving dyads provides a more detailed view of the shared experience of receiving and providing support. For instance, in the present study both pwAMD and their caregivers reported the effect of vision loss on pwAMDs' activities and hobbies, and also shared activities (e.g. walking, holidays). Caregivers empathised with the pwAMD and provided help where possible, however AMD had meant changes to both of their lives as reflected in the following quote from a wife caregiver:

> *…life has been reduced by half in our, you know our activities*. (Participant 121a, wife of husband with AMD) QUOTE 14

AMD has previously been referred to as an 'invisible disability' (Mogk, 2008). The lack of obvious signs that the pwAMD has a condition causing functional limitations led some pwAMD to report feeling that they might be viewed as a fraud (Mogk, 2008). Some pwAMD reported concealing their AMD diagnosis to avoid unwanted sympathy (Weaver Moore, Constantino, & Allen, 2000). A lack of communication about the extent of sight loss, plus a lack of obvious signs that indicate how much support might be needed may make it difficult for caregivers to know when support is needed. In particular, for the adult-offspring caregivers in the present study who were not present at diagnosis and were required to provide support suddenly, they also reported difficulty knowing the extent of sight loss and how much support was required. They were often concerned about over-helping as there was the potential that this might increase reliance on them and reduce both the pwAMDs' and caregivers' independence. The present qualitative study found caregivers were concerned about the impact of sight loss on the pwAMDs' safety. It may be that not understanding the extent of sight loss may increase caregivers' worry over pwAMDs' safety if they believe their sight loss puts them in danger, and this may contribute to over-helping. Indeed Cimarolli et al. (2013) suggested that overprotection may be a particularly salient issue for people with VI because of the increased risk of falls and injuries associated with this condition.

The impact of sight loss on shared vision-dependent activities for the pwAMD and caregiver, plus caregiver's knowledge of the pwAMD's sight loss and concern over pwAMD safety, are two ways in which the experiences of pwAMD/caregiver pairs may differ from pairs where the caregiver provides support for another reason or condition. Future research might directly compare whether the experiences of receiving and providing support for AMD is different to that received for other conditions or for old age generally. This might provide further evidence for interventions being AMD-specific.

IMPLICATIONS FOR THE STUDY FINDINGS IN LIGHT OF THE RESEARCH LITERATURE

This study adds a dyadic perspective to the experience of living with AMD where previous research has focused solely on the impact on the person diagnosed with AMD, or on caregivers who support someone diagnosed with wet AMD. The quantitative study provided a model for dyads that extends the models used in caregiver burden research. This indicated that for the pairs included in this study, the amount of care provided and received is not related to either caregiver appraisals of the impact of providing care nor pwAMD or caregiver well-being or caregiver health. Additionally there were different predictors for primary and secondary appraisals of providing care. However quantitative measures may fail to capture important contextual elements of the dyadic experience and some of the measures used were limited in not being specific to AMD. The qualitative study provided evidence that reflects and adds to the quantitative study findings. The combined findings provide information on how interventions may be targeted to help pairs living with AMD.

Previous research has found a strong relationship between loss of vision-related functional ability and symptoms of depression (e.g. Casten, Rovner, Leiby, and Tasman (2010); Cimarolli et al. (2016)). The present study findings support this relationship, and add to this by highlighting the emotional impact this has on those close to the pwAMD. This supports the findings from Strawbridge et al. (2007) who found that VI negatively impacted spouses' depression, physical functioning, well-being and marital quality. Cimarolli et al. (2016) suggested that for people with VI the distress resulting from loss of activities can lead to a vicious cycle whereby the decreased motivation resulting from depressive symptoms leads to less engagement in previously-enjoyed activities and this further exacerbates depressive symptoms. The qualitative study suggested that the pwAMD and their caregivers who took part in the study had created ways of managing the impact of AMD together. Pairs engaged in a variety of strategies to continue with activities with the aim of maintaining the pwAMDs' self-efficacy and independence.

Self-efficacy is the core component of social cognitive theory and is defined as a person's belief in his or her ability to succeed in a particular situation (Bandura, 1977). According to social cognitive theory, self-efficacy can be affected by four sources of information. These include: successful accomplishments of the task, vicarious experiences of observing other people succeeding, verbal persuasion that the person has the capability to perform successfully, and the person's perception of their level of physiological arousal from which they use to judge their level of anxiety and vulnerability to stress. Aspects of these were apparent in the qualitative results. Caregivers provided encouragement to the pwAMD, previous successful or unsuccessful attempts contributed to whether the pwAMD felt they could successfully accomplish a task, and meeting others who had sight loss was seen as a source of inspiration. Pairs reported using their own strategies to manage the pwAMDs' self-efficacy. Caregivers used humour to laugh off mistakes and make light of the situation with the aim of preventing this from impacting on the pwAMDs' confidence. Spouse caregivers reported avoiding pointing out mistakes that were perceived to be unimportant.

The theme of ‘maintaining independence’ described the strategy that pwAMD and their caregivers commonly adopted by asking for or providing support only when needed. The concept of overprotection or over-helping has been described in the literature and has been linked to negative outcomes in people who have experienced vision loss (e.g. Cimarolli (2006)). Thompson et al. (2002) found overprotection resulted from caregiver resentment and patient dependency. Cimarolli and Boerner (2005) reported negative aspects of receiving support for people of working age with VI, including people underestimating or overestimating their capabilities and thus providing too much or too little help. However in the present qualitative study, it was mainly caregivers who reported concerns about over-helping the pwAMD rather than the other way round. The present study provides the caregivers’ perspective to Cimarolli and Boerner (2005) findings. As suggested by Cimarolli et al. (2013), and corroborated by this study, is the concern of an increased risk of falls for pwAMD. One caregiver in the present qualitative study reported being concerned about low pwAMD self-efficacy, and perceived that providing support would prevent this from getting worse by protecting the pwAMD from experiencing failure. Thus instead of overprotection being due to caregiver resentment or hostility, this study suggests that it might stem from either empathy for the pwAMD, low pwAMD self-efficacy or concern over pwAMD safety, however it must be noted that no pwAMD reported a perception of receiving too much help from their caregiver.

Reports of over-helping related to family members outside of the pair. It was suggested that this was due to them not knowing the limitations posed by AMD. Since such instances only happened occasionally and were perceived as being ‘*meant well’*, the perception that this was ‘*irritating*’ was not mentioned to these family members. Similarly, adult-offspring caregivers reported being unsure of their mother’s limitations. This affected their perception of the amount of help to provide.

There have been some promising results for self-management interventions designed to increase the functional abilities of people with low vision and decrease depression, however the majority have only found short-term positive effects (for a review see

Cimarolli et al., 2016). Such interventions include teaching problem-solving techniques to remove barriers to activity engagement, training in the use of optical and assistive devices (LVAs), and the teaching of orientation and mobility skills. The majority of interventions, however, are designed solely for the person with low vision. The results presented here suggest that it may be beneficial to include the caregiver in such programmes in order to support the person with low vision. Having the support of the caregiver may act as a boost to encourage longer term effects by reinforcing what was learnt and reminding pwAMD to apply it in the future.

There are few reported evaluations of support groups for caregivers of adults with VI (e.g. Cimarolli, Sussman-Skalka, & Goodman, 2004; Larizza et al., 2011). One programme has been found to increase the caregivers' understanding of their visually impaired partners' vision (improved understanding of what their partner can see or do), improve their certainty about when, how and how much help to provide, improve their ability to talk openly about stressful situations that arise because of vision problems, and reduce the caregivers' negative appraisal of their role (Cimarolli et al., 2004). The intervention covered areas highlighted as important in the qualitative findings from the present study including: understanding your partner's vision loss, exploring emotional issues, getting around safely and garnering support from family and friends. Unfortunately, the support program was not found to increase caregivers' life satisfaction or depression. The authors attributed this to a ceiling effect- participants reported high levels of life satisfaction and low depression at the beginning of the program. The authors did not assess changes in the visually impaired person's outcomes and suggested that this would help to highlight the wider benefits of the programme including how the support programme for caregivers affects the person with vision loss.

The acceptability of interventions for caregivers of people with VI would need to be evaluated. The present qualitative study suggested that some pairs appeared to prefer to manage AMD within their pair and this may act as a barrier to engagement. Indeed previous research has found that spouse caregivers are less likely than other types of caregivers to have any informal helpers or to use service programmes designed to relieve caregiver burden (Pinquart & Sörensen, 2011). It may be that the limited use of helpers from outside the marital dyad reflect the desire of couples to manage as an independent unit.

The present study adds to the small amount of literature that observes differences between spouse and adult-offspring caregivers, particularly those using qualitative approaches. Pinquart and Sörensen (2011) conducted a meta-analysis of quantitative studies of caregivers of people with dementia or who were physically frail, and found that spouses reported more depressive symptoms than adult-offspring caregivers, and this was partially explained by spouses providing more care. In contrast, Chappell, Dujela, and Smith (2014) found adult-offspring caregivers of older adults with dementia reported more subjective burden than spouse caregivers. The bivariate analysis in the present quantitative study suggested no significant differences between spouse and adult-offspring caregivers for outcomes including well-being and reactions to providing support. However the qualitative study findings suggest similarities and differences in providing care for AMD between spouse and adult-offspring/parent pairs. Whilst similar issues were raised in managing the impact of AMD, maintaining the independence of the pwAMD and obtaining external support, there were differences in how pairs adjusted to providing support. It has been reported elsewhere that spouses view caregiving as normative and part of their marriage vows whilst adult-offspring caregivers view caregiving as an addition to their lives and experience a reversal of the traditional parent and child roles (Bastawrous, 2013; Lee & Smith, 2012). The qualitative study adds to this the ways in which adult-offspring/parent pairs were similar to and different from spouse pairs (as highlighted under the overarching theme). One of the key differences was that some adult-offspring caregivers reported difficulty adjusting to the new responsibility they felt they had for their parent, which could be seen to represent a change to traditional parent and child roles.

It is possible that caring for a pwAMD brings with it a condition-specific sense of responsibility. Sight loss can present barriers to social interaction (for example, pwAMD report difficulty recognising faces, Bennion et al., 2012). Communication theory suggests that sight loss may lead to difficulties picking up on non-verbal communication (NVC) (Heine & Browning, 2002). In addition, the parents with AMD in the qualitative study reported a small social circle due to friends and family of a similar age having died. All pwAMD in the current study were unable to drive and relied on their caregiver to take them to places. These factors might suggest that pwAMD have a reduced social circle and this may put pressure on their relationship with their caregiver. Indeed one adult-offspring caregiver in the present study reported that this led to an unwanted responsibility of having to take her mother out with her whenever she went out. Sight-specific reasons for difficulty communicating with others might undermine pwAMDs' confidence interacting with others. Not being able to see NVC and not being able to see what is going on around them, may potentially lead to pwAMD having difficulty putting trust in others. Indeed one pair in this study reported having felt that people who had been in their home to do practical work had 'taken advantage of' the pwAMD's sight loss and consequently done a 'sloppy' job. These factors may play a part in leading caregivers of pwAMD to feel more responsible for the pwAMD than for someone without AMD. These hypothesised relationships would need to be tested in future research.

The present study also added the perspective of parents with AMD and the expectations they had of their adult-offspring. Spouse pairs reported difficulty moving away from parent and child roles and reported this was a barrier to receiving help from their adult-offspring. For pwAMD whose primary caregiver was their adult-offspring, they reported providing help to their children- either financially or through practical or emotional means (e.g. being a 'listening ear', QUOTE 45). This reduced their concerns that they would become a burden. According to exchange theory, individuals are motivated to maintain a balance in how much support is received and provided (Walster, Berscheid, & Walster, 1973, 1978). Interventions may benefit from guiding pwAMD to identify ways in which they can provide help to their caregiver.

The present study findings suggest some agreement with gender role norms and expectations reported in the caregiver literature. In the qualitative study, daughters reported taking on the primary caregiver role over their male relatives such as their brothers. In agreement with past research (e.g. Leopold, Raab, & Engelhardt, 2014), this was primarily due to being in closer proximity to their mother, however one participant suggested this might be due to the expectation that the female relative should take on the role. This assumption that the daughter would be the primary caregiver is echoed in findings reported elsewhere (e.g. for a discussion of different perspectives behind gender norms and taking on the caregiver role, see Bastawrous et al., 2014). Prior gender experiences of providing care to children may mean that providing care to a parent is seen as an extension of these skills and thus women may be expected to be more competent caregivers. Since current society suggests women are expected to provide care, and that this may form part of their identity as a woman, to ask for help may be perceived by women as a disruption to this identity (Feld, Dunkle, Schroepfer, & Shen, 2010). Thus they may be more likely to provide care alone. There were mixed findings in the present study. Whilst one daughter in this study reported asking for help from her brother for any type of caregiver activity, two others reported only asking for help with practical tasks from their husbands or brothers. When it came to getting help from formal services, one daughter reported having accepted the lack of provision of help due to her availability as a caregiver (as opposed to having no caregiver), whereas the one male caregiver in the present study did not accept this as an adequate reason for not receiving help. According to gender-roles, male caregivers (sons) may perceive themselves not to have the skills or abilities to care and thus would prefer receiving more help. This may be the reason why the male caregiver required help, however he was also the only caregiver who was employed full-time and this may be the reason why help was required. Thus the gender differences noted in this study are speculative and may be due to differences in gender roles or other socio-demographic factors.

Included in the Stress Process Model proposed by Pearlin et al. (1990) are the use of coping resources as mediators between stressors and outcomes. The present study provides evidence to suggest that pairs engaged in the use of several coping strategies to manage the impact of AMD. Of particular note is the use of positive reappraisal and benefit finding. These emotion-focused coping strategies may be useful when dealing with unmodifiable stressors and uncontrollable events for which problem-focused coping is unlikely to be helpful (Lazarus & Folkman, 1984). Caregivers reported using this strategy to manage the uptake of new domestic tasks, to adjust to changes in roles and responsibilities and to manage competing responsibilities. Guided positive reappraisal has been found to lower depression, but not reduce overload or burden in a group of caregivers of people with Alzheimer’s disease, compared to a psychoeducation control group (Cheng et al., 2014). This intervention used a similar strategy to those used in cognitive-behavioural interventions by teaching caregivers the interconnectedness of their thoughts, emotions and behaviours and how modifying one's thoughts might improve well-being directly or indirectly through behaviour change.

The quantitative and qualitative study findings highlight that AMD is often managed alongside other medical conditions. The quantitative study findings suggest that targeting the general health of pwAMD in interventions may be effective at reducing caregiver 'burden' and consequently improve caregiver well-being and health alongside pwAMD well-being. The findings also suggest that it may be more important for interventions to focus on caregiver appraisals of providing support than the amount of support provided.

Participants in the present qualitative study reported unsatisfactory experiences with health and social care services. In particular, a lack of information and support provision at diagnosis echoes the findings from the first study (the 2013 survey) presented in this thesis. One pair also reported a lack of support and understanding of the patient perspective when being told that treatment would no longer be effective for AMD. Bennion et al. (2012) reported that AMD patients felt let down by the NHS because of a lack of treatment for (some types of) AMD, and they also had a distrust of the NHS, for example, because of a belief that past medical procedures had caused their AMD. They suggested that the negative views of the NHS that were reported to be held by pwAMD could impact on their future engagement with the service. This may be important for people diagnosed with early AMD which could turn to wet AMD. Seeking help quickly for changes in vision may be important for saving sight and a potential barrier to early help-seeking may be a feeling of disengagement from the health services.

The present qualitative study found a disparity in the amount of external help received from different services. Some pairs reported receiving sufficient information and help from charities (such as the Macular Society) and local blind associations through the provision of LVAs and telephone counselling. However there was a reluctance to use these services too much because of their charitable status. Pairs were more likely to report dissatisfaction with social services who were expected to help. The availability of the caregiver to provide help to the pwAMD was seen as a hindrance to receiving help from social services. Some pairs reported dissatisfaction with the lack of help offered.

Unfortunately, it appears that the lack of support from social services is likely to get worse. England remains one of the few major advanced countries that has not reformed the way it funds long-term care in response to the needs of an ageing population (Humphries, Thorlby, Holder, Hall, & Charles, 2016). A recent report from the King’s Fund (Humphries et al., 2016) suggests that access to social care has reduced considerably over the past decade, so that by 2010, 90% of local authorities were limited to providing help to those with ‘substantial’ or ‘critical’ needs only (Fernandez, Snell, Forder, & Wittenburg, 2013). The pressure on families to provide care to older people will undoubtedly increase in the future with an ageing population stretching public funding on the adult social care system. Some of the caregivers who took part in interviews suggested that taking on the caregiver role and the tasks associated with providing support to the pwAMD (e.g. cooking, sewing) were unexpected. The lack of public awareness of AMD, as mentioned by a participant in the qualitative study, and in previous research (Cimarolli et al., 2012), suggests that people may be unprepared for managing care for someone with AMD in the future. Thus it may be important for the general public to be informed about AMD and made aware of this increasing pressure on them to provide care in the future.

Alternatively, more innovative approaches are being put forward to enable older people to live independently for longer. In 2011 a number of cities around the world, including Manchester and Newcastle, signed the ‘Dublin Declaration for Age Friendly Cities’. This declaration sets priorities for cities to work towards meeting the topics set out in the World Health Organisation’s (WHO) Guide for Age Friendly Cities (WHO, 2007). This includes adapting or maintaining elements of the physical and social environment to recognise the importance this has on people’s quality of life. Of particular importance is including the voices of older people in initiatives to improve their neighbourhoods and thereby increasing their participation and empowerment in developing their neighbourhood. Age UK (a UK-based national charity) argue that local government investing in better neighbourhoods, for instance by repairing uneven pavement to prevent falls, may be a key factor that enables older people to feel confident to go out into their neighbourhoods (AgeUK, 2013). This may prevent the need to use NHS and social care services and enable older people to live alone instead of going into residential care, which ultimately would save on the cost of social care. They argue that the benefits of investing in age-friendly neighbourhoods are not yet recognised by local or national government. The findings of the present study suggest that pwAMD and their caregivers are concerned about the safety of the pwAMD. PwAMD reported being limited to walking alone in their local areas due to finding comfort in the familiarity of the area (e.g. knowing where to cross the road safely). Others cited environmental barriers such as unreadable bus numbers as reasons for not using public transport and going further afield. Therefore this study provides evidence to suggest that pwAMD might benefit from the development of age-friendly neighbourhoods, and should be involved in consultations for neighbourhood improvements.

In a similar vein is the development of ‘Cohousing communities’ which are created and run by their residents (see ‘http://cohousing.org.uk/’). Residents own a private household but have shared areas, such as for cooking and washing. They share activities and support one another. Another initiative called ‘Homeshare’ matches elderly and vulnerable people with younger people who are willing to offer help in exchange for cheap accommodation in the older person’s home (see ‘http://homeshare.org/programmes-worldwide/united-kingdom/’). These strategies could enable individuals with AMD to live independently and reduce a reliance on a primary caregiver. There have been some evaluative studies of such programmes in the UK (O'Shea, 2012; Thornton, 1995). Coffey (2010) evaluated a Homeshare pilot programme in three areas of the UK (Oxfordshire, West Sussex and Wiltshire). The homeowners reported that sharing their home with a ‘housesharer’ allowed them to gain independence, provided companionship, increased confidence (e.g. for walking independently) and reduced worries about being alone if they fell over or had an accident. ‘Housesharers’ reported benefits included: cheap accommodation, companionship, language and cultural education and an increased awareness of the challenges experienced by the homeowner. The evaluation included QoL and health status measures (the WHOQOLBREF and EQ-5D). Unfortunately there were too little data at follow-up to examine improvements in QoL over time.

COMMENTS ON THE MEASURES USED IN THE QUANTITATIVE STUDY

The qualitative findings provide some suggestions for how the measures used in the quantitative study could be adapted to be relevant to the study of dyads of pwAMD and their caregivers.

A potential way to make the CRA more relevant for caregivers of pwAMD could be to adjust the measure to allow caregivers to rate the importance of each item to their lives, following the design features of the MacDQoL (Mitchell et al., 2005). This would indicate which questions and subscales have a bigger impact on their lives. On analysing the interview data, it seems that for many of the interviewees (particularly adult-offspring caregivers), caregiving for AMD impacted heavily on their schedule as they tried to manage competing responsibilities. Although there were generally high scores for the 'impact on schedule' subscale in the quantitative study findings, the overall CRA score is quite low, perhaps due to averaging this score out with the other subscales which tended to have lower scores (such as 'impact on health'). This masks the impact that caregiving has on their schedule. If one could state the importance of the items on this subscale, then the overall CRA score might more accurately reflect the burden felt by caregivers. Indeed rating the importance of items on the CRA might help to highlight which items are more relevant for spouse or adult-offspring caregivers.

Large-scale studies would need to test and validate this adapted version of the CRA with importance ratings. If most caregivers of pwAMD agreed on the relative importance of items, then they could be weighted for general use. If there are differences (for example between spouse and adult-offspring caregivers as described above), then each respondent would need to rate each item and individual weightings would need to be used.

The qualitative study highlighted the emotional impact of difficulties with performing activities because of sight loss. Providing emotional support to the pwAMD was not measured in the quantitative study. Both the qualitative and quantitative study suggest that participants consider everyday tasks when deciding on how much support they receive or provide. It may be important to ask specifically about provision of emotional support as this type of support doesn't appear to be considered when deciding on the amount of support received/ provided. Providing emotional support may also impact on caregiver secondary appraisals of providing care, and pwAMD and caregiver well-being.

STRENGTHS AND LIMITATIONS OF THE STUDY AND IDEAS FOR FUTURE RESEARCH

As mentioned in Chapter 7, the results from the SEM are limited based on the small sample size used. Thus the results are only suggestive of possible relationships between the quantitative measures used and would benefit from the study being repeated using a larger sample.

There are several limitations to the study in common with the 2013 survey. First, both quantitative studies used questionnaires to collect data. In the second study, pwAMD were offered the opportunity for telephone completion, and three participants took this up. It is likely that some of the respondents who completed a paper version received help with questionnaire completion from someone else, however we did not ask if they received help in the second study and so we do not know the percentage who received this. It is possible that the answers from respondents who had assistance with questionnaire completion may not be a true reflection of their experiences. For instance, pwAMD well-being scores may be higher if they preferred their caregiver to be unaware of the true extent of their level of stress and negative well-being. Similarly, for dyads who completed their respective questionnaires at the same time, caregivers may not have wanted the pwAMD to be aware of low well-being and high perceived ‘burden’ resulting from caregiving. The author received anecdotal evidence for this when she was arranging interviews with participants for the qualitative study. A caregiver stated that she felt her answers weren’t very accurate because she completed the questionnaire with her mother present and didn’t want her to know her ‘true’ answers. Thus this may limit the validity of the questionnaire findings. In addition, in the present dyadic study, despite assurances of participant confidentiality, it is possible that the interview respondents were worried about their answers getting back to the other member of their pair and this may have affected their responses.

Secondly, this sample of pwAMD who were members of the Macular Society at the time of the first survey, may be more informed by the Macular Society about their AMD than the general AMD population, and would have had access to support from the Macular Society. Data was not available to see how long pwAMD had been members of the Macular Society. However since they had all been members at the time of the 2013 survey (end of 2013), and data collection for the second study took place at the end of 2015, it can be deducted that they had all at least known about the Macular Society for at least two years (whether they had discontinued membership since 2013 is unknown). Thus they had had the opportunity to access help from the Macular Society if needed.

One possibility is that caregivers who were the most overloaded or over-burdened didn't feel they had the time to complete the survey or take part in the interviews, and thus the caregiver experiences reported in the present study may not be representative of the population of caregivers of pwAMD. The CRA scores reported in the quantitative study may be an underestimation of the 'burden' faced by the population as a whole. Equally, it may be that caregivers who felt the most impact of providing support were more likely to volunteer as they felt able to contribute meaningfully to the research, would want to progress the research field to benefit caregivers or may want the opportunity to 'offload' and thus taking part may be considered therapeutic.

The 'ideal' sample size for use in interview research continues to be debated (see Chapter 6 for a discussion). It is difficult to know when 'saturation' has been reached, and the author could not be sure that enough data were collected to allow the topic to be explored fully. Also, the qualitative study did not include pairs consisting of daughters and fathers, whose experiences may differ from those included in the interview study here. Indeed, it would be interesting to investigate the issue of 'gendered roles' in these pairs. Only 6% (n=4) of respondents were father- daughter pairs, and in the one pair that volunteered for interview the pwAMD had another serious medical condition (cancer). It was felt that to include this pair might bias the results. This perhaps mirrors the percentage of father-daughter pairs in the population of pwAMD, since AMD is more common in women than men and women tend to outlive men (so male pwAMD may be more likely to receive support from their wives). Thus the findings reported here may reflect the AMD populations' demographics and thus be generalisable to the majority of this population.

The qualitative study indicated that there may be gender-specific responses to providing care (e.g. accepting the lack of help from formal services). However, as mentioned above, the study included only one male son caregiver and so larger studies would need to be carried out to see if these findings are generalisable.

The pairs included in the qualitative study reported having received or provided support for AMD for more than five years and thus they may have had time to develop the strategies to cope with the impact of providing and receiving support. Future research might see how pwAMD/caregiver dyads who have been providing support for AMD for a shorter duration are managing this change.

It is important to note that AMD is a degenerative condition and the qualitative findings illustrate the dynamic nature of living with AMD and sight loss. This is illustrated in the qualitative study through within- and between-pair comparisons (i.e. participants reflected on their own experiences since diagnosis and pairs differed in their time since diagnosis, pwAMDs' visual function scores etc.). This is a strength of the study as it allows us to generalise the results to the experiences of pairs at different stages. Though the results may be considered to be limited because they do not look at any particular stage in detail, and pairs may differ in their ability to cope at different stages. Thus a longitudinal study which follows up pairs over time may provide more reliable data on how pairs manage with providing support for AMD at different stages of this degenerative condition.

The qualitative study used separate interviews with caregivers and pwAMD. The researcher noted in her reflective notes how one person in a pair tended to be more verbose than the other, and that by having separate instead of joint interviews, this may have enabled the quieter of the pair to have their say. However there may have been benefits to using joint interviews including insights into how pairs discussed and managed AMD together. Additionally, since both members of the pair are present in joint interviews, this would overcome the issue of internal confidentiality. However joint interviews may have prevented participants from talking about the negative aspects of receiving or providing care that participants would prefer to be hidden from their counterpart.

The researcher took the approach of using thematic analysis to describe patterns in the data for all pairs interviewed. An alternative approach may be to focus on individual pairs. This was the approach taken by Burton et al. (2015) who focused on a married couple both living with AMD. They used interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) to conduct an in-depth analysis of participants' responses in order to understand their lived experience of living with AMD together. In addition, the guidelines for qualitative dyadic analysis suggested by Eisikovits and Koren (2010) could be used to help investigate features of 'togetherness and separateness' within pairs- a feature lost by using thematic analysis across more than one pair. A broader approach was taken in the current study so that results would reflect a wider variety of dyads' experiences and thus would have more generalisability. Also internal confidentiality issues prevented the presentation of detailed analysis and quotes from each member of the pair.

A key strength of this study was the use of a variety of research methods and analysis (i.e. mixed methods, dyadic methods and analysis, and structural equation modelling) that had relevance to the study of dyads and provided a more thorough exploration of the impact of receiving/providing support for AMD than has been used in previous studies focusing on either the pwAMD or the caregiver. In addition, the separation of the qualitative findings for spouse and adult-offspring/parent pairs, provided information on the differences between these pairs and gave some insight into changes in caring responsibilities as people get older.

Another strength of this study is the use of validated questionnaires to assess well-being and QoL. Previous studies including caregivers of people with wet AMD have relied on creating their own (untested) instruments to measure caregiver outcomes (e.g. Gopinath et al., 2015).

Lastly, the researcher noted only a small amount of research on dyadic analysis and in particular, the considerations that should be taken into account when using mixed methods. Further research could address this issue, particularly as the study of patient/caregiver dyads becomes more relevant in the future as the population ages and research is needed to determine ways to support dyads.

The present study focused on pwAMD who receive support however research is also needed to support those who are coping without a caregiver and the factors that lead to pwAMD requiring informal care.

Chapter 9: General discussion

The main research questions for this thesis were:

1. To investigate whether healthcare experiences of patients with age-related macular degeneration have improved since a similar survey was carried out in 1999. To determine whether significant improvements have been made since publication of the 1999 survey results in 2002, and/ or the Royal College of Ophthalmologists (RCOphth, 2009) management guidelines in 2009.
2. To examine other sources of information and support used by people with AMD (pwAMD) after the diagnostic consultation, in particular support from friends and family.
3. To explore the impact of receiving and providing care for AMD from the perspectives of pwAMD and their caregivers.

The studies that investigated these research questions used a pragmatic mixed-methods approach. This chapter will summarise the research findings and consider the implications of the research. A discussion of the limitations of the findings and possible avenues for future research are also included.

Overview of findings

Healthcare experiences – changes since 1999

The Macular Society 2013 survey (MSQ 2013) formed the first study of the thesis. This nationwide survey was sent to 4000 members of the Macular Society and received a 39% response rate (n=1571). The results of this 2013 survey, presented in Chapter 3, showed that people diagnosed with AMD since the 1999 survey, reported better experiences at diagnostic consultation. They were significantly more likely to be given the name of their macular condition, report that the HCP who diagnosed them was interested in them as a person, and report overall satisfaction with the diagnostic consultation. Within the 2013 sample, there were gradual trends of improvement over time in: provision of written information, Macular Society information and receiving appropriate help, support and advice at the time of diagnosis. In regard to the RCOphth guidelines, whilst overall satisfaction with the diagnostic consultation significantly improved following their publication in 2009, nine other areas of information and support provision remained low and did not significantly improve. There were no significant improvements associated with publication of the 1999 survey results in 2002. The top two reasons for dissatisfaction with the diagnostic consultation reported by the 1999 sample remained the same for the 2013 sample: a lack of information and advice given (e.g. on the condition, prognosis, further support) and poor attitude of the HCP who diagnosed them (they were seen as dismissive, patronising or unfeeling).

Sources of information and support used by people with AMD

The 2013 survey respondents reported lower levels of help and support from GPs than did the 1999 respondents. In addition, 39% reported their GP was ‘not at all well-informed’ about their macular condition. The 2013 survey respondents reported a need for information and support in several areas following diagnosis, but felt that they were not offered the information and support they required. Needs included access to psychological support and to a low-vision clinic.

Receiving informal care, support or assistance for AMD

Chapter 4 described the investigation of the receipt of support for AMD from family and friends. Of the 2013 survey respondents, 53% reported receiving care because of their AMD. Respondents who received care for AMD reported poorer QoL (both general and MD-specific) and well-being. Receiving more care for AMD (measured in number of hours per week) was associated with poorer well-being and MD-specific QoL, but not general QoL. These relationships were found despite controlling for the respondent’s degree of visual impairment (VI) using registration status and self-reported change in vision status since diagnosis (whether vision was better, the same or worse).

The impact of receiving and providing care for AMD

Subsequent studies (Chapters 6 to 8) used a mixed-methods approach to examine possible reasons for the relationship between receiving care for AMD and poor well-being. Previous research has neglected to take into account the close relationship between pwAMD and their caregivers (see literature review in Chapter 5). Unique to this area of research, the aim of the subsequent studies was to explore the impact of receiving and providing support for AMD using a dyadic perspective. The second quantitative study (Chapter 7) built on the 2013 survey findings by asking participants about the difficulty they had with carrying out vision-related tasks instead of using registration status and change in vision status since diagnosis as measures of VI. PwAMD's level of visual functioning, measured using the DLTV, may more accurately reflect the pwAMD's experience of VI. Structural equation modelling examined predictors of well-being of the pwAMD and their caregiver, caregiver general health and caregiver reactions towards providing support. When the DLTV measure was used as a measure of VI, the amount of help received for AMD was no longer associated with pwAMD well-being, nor was it associated with caregiver well-being or health. PwAMD who reported their vision caused them more difficulty carrying out vision-dependent tasks and who reported poorer general health, were more likely to report poorer well-being. Caregivers who reported greater negative impact of providing support, reported poorer well-being and health, however, caregiver reactions towards providing care did not impact on pwAMD well-being. Poorer pwAMD general health (but not difficulties with vision-dependent tasks or tasks associated with daily living) predicted more negative caregiver reactions to providing support. PwAMD general health indirectly predicted caregiver well-being and health via caregiver reactions to providing support. The amount of support received and provided was mainly determined by the level of difficulty pwAMD had with carrying out everyday tasks (IADLs), but not with more specific vision-dependent tasks nor their general health status.

The qualitative third study was designed to explore the experiences of pwAMD/caregiver dyads in more depth, and to help explain and elaborate on the second quantitative study findings. Chapter 8 reports the findings from qualitative interview data with eight dyads. Four pairs were spouses (for two pairs the husband had AMD, and for the other two pairs the wife had AMD). Of the remaining pairs, three caregivers were daughters and one was a son. All adult-offspring caregivers were providing support for their mother with AMD. The findings highlight the similarities and differences between pwAMD/caregiver pairs where the caregiver is the spouse of the pwAMD, and those where the caregiver is the adult-offspring of the pwAMD. Three themes were identified: (a) Managing independence, (b) Accepting the 'new normal’, and (c) External support. Whilst these three themes were identified in the transcripts of spouse pairs and adult-offspring/parent pairs, there were important differences in the descriptions of their experiences, and their results were therefore presented separately. Tied to this was the view that spouse pairs were experiencing the impact of providing and receiving support for AMD in ‘partnership’ with one another, whilst adult-offspring/parent pairs described ‘looking after mother’. This cut across all aspects of their experiences and was reported as the overarching theme; “Managing the changes: living with AMD in partnership vs looking after mother”.

The theme ‘managing independence’ described the impact that vision loss had on pwAMD activities and hobbies. Vision loss impacted on activities the pairs shared together. Pairs discussed strategies they used to maintain the pwAMD’s confidence in continuing with activities, thus enabling continued independence for the pwAMD and reducing reliance on the caregiver which impacted on the caregiver’s own independence. There were indications that adult-offspring caregivers had more difficulty determining the appropriate amount of support to provide. “Accepting the ‘new normal’” described how pairs had adapted to receiving and providing support for AMD. For spouse pairs, the majority spoke about providing and receiving support as an accepted part of their marriage together. Changes to established roles within the pair required the greatest adjustment (e.g. becoming the main driver). Adult-offspring caregivers tended to report more difficulty fitting the provision of care into their lives around their other responsibilities. Both spouse and adult-offspring/ parents pairs reported difficulty accessing external support from formal services (health and social care) and from family and friends (discussed under the theme ‘External support’).

Due to the small sample size of 72 dyads, the second quantitative study was unable to take into account the type of pwAMD/ caregiver relationship in multivariate analysis. However the qualitative third study highlights that the type of pwAMD/caregiver relationship is important for understanding how pwAMD and their caregivers adapt to living with AMD.

The third theme highlighted in the qualitative study, ‘External support’, reflected findings from study 1 which describe the lack of information and support provided to pwAMD at diagnosis and beyond.

Practical and theoretical implications

Before discussing the findings any further it is important to be mindful of the current squeeze on NHS and social care services in England. Furthermore, this pressure is only likely to increase with the rising older population at risk of developing AMD. Thus, where possible, suggestions for interventions that use existing resources (e.g. medical training, use of voluntary sector services) have been focused on here.

Information and support provision in healthcare

Patient experiences are an important indicator of the quality of healthcare. The results from the 2013 survey and the qualitative study suggest there is considerable room for improvement in information and support provision in the diagnostic consultation and thereafter. It is a concern that the RCOphth 2009 guidelines, which contain recommendations for what information and support should be provided in diagnostic consultations, were not associated with significant improvements in many areas of information and support. The 2002 publication of the 1999 survey results was also not associated with improvements suggesting that such publications alone are not enough to promote changes in practice.

Many respondents reported seeing their GP about their AMD, however several felt their GP was uninformed about their AMD or was not helpful or supportive. Whilst referral via a GP is no longer needed for diagnosis, the GP has a key role in the management of AMD. For instance, they act as a ‘gatekeeper’ for access to further support (e.g. referral to an eye specialist for registration as SI or SSI which may lead to benefits for the pwAMD). PwAMD may find it easier to access an appointment with their GP than with an eye specialist. There is the potential for GPs to provide important information and support for pwAMD after diagnosis. Study 1 found that, compared with the 1999 survey, fewer of the 2013 survey respondents who had experienced visual hallucinations reported that they had been to see a HCP about hallucinations. Without the knowledge that sight loss can cause visual hallucinations (also known as Charles Bonnet Syndrome or CBS), pwAMD may attribute the hallucinations to a serious mental illness such as dementia. It may thus be worthwhile to educate GPs about CBS and ask them to discuss this with their patients who have AMD. Such explanations could prevent unnecessary worry arising from attributing the symptoms to an alternative cause.

The multivariable analysis in Study 1 included several socio-demographic, eye- and health-related factors linked to patient experiences. Women were found to be less likely than men to report receiving information and support for five aspects of healthcare. Older respondents were more likely to report not receiving information at diagnosis on what to do if they experience a sudden deterioration in vision. This study did not examine whether differences in reported information and support provision were due to differences in patient characteristics (e.g. expectations) or differential treatment from HCPs (perhaps resulting from sex-role stereotypes (women are more likely to get upset) or ageist beliefs (older people won't recall the information provided)). Nevertheless, an awareness of the differences should prompt HCPs to check these particular 'at risk' groups have received and understood important information and take home written information for later reference. HCPs should be trained to self-reflect on their interactions with patients; to check that they have provided information and support to everyone regardless of age or gender.

Respondents who were registered as SI or SSI at the time of survey completion were more likely to report not having received, at time of diagnosis, information on what to do if they experience a sudden deterioration in vision. This suggests that lack of such information at diagnosis may cause subsequent sight loss sufficient to warrant registration.

The Macular Society produce a 'Guide to AMD' leaflet which contains information pertinent to the RCOphth guidelines. If these leaflets were handed to pwAMD and their caregivers, this could be a relatively simple way of providing this information to pwAMD. Leaflets could be given in consultations by HCPs or by eye clinic staff, or by volunteers post-consultation. Some pwAMD report having difficulty reading written information so the leaflet is likely to be more effective if the HCP or volunteer explains the information in the leaflet and highlights important points (e.g. to seek help immediately if the pwAMD experiences a sudden deterioration in vision).

It may be the case that ophthalmologists, optometrists and GPs do not see providing information and support as part of their role in the management of AMD. The results suggest that information given early on, may lead to better outcomes, e.g. as above, the 2013 survey respondents who reported not receiving information at diagnosis on what to do if they experience a sudden deterioration in vision were more likely to be registered as SI or SSI, thus demonstrating the importance of providing this information. Medical training should emphasise the benefits of providing information and support to patients, not only in terms of improving eye-related outcomes, but also in terms of improving patient experience. It has been suggested that examining how illness is represented in various art forms (e.g. novels, poems, movies or paintings) might help sensitise medical students and HCPs into humanising medical care (Kaptein, Meulenberg, & Smyth, 2013). There are some depictions of AMD in art, e.g. the painting '*Eyes'* by Cecil Riley illustrates the painter's visual hallucinations caused by his AMD (Riley, 2008). The painting of a series of eyes depict the visual hallucinations of eyes that floated across his vision. The use of vision simulators during medical training could facilitate a better understanding of AMD and its effect on functioning. Additionally, qualitative research provides rich, detailed accounts of patient's and caregiver's experiences that could be used to convey the impact of AMD to medical students and HCPs. For example, the HealthTalk online website (http://www.healthtalk.org/) includes short films of interviews with people with a range of conditions and their caregivers. The films are organised into themes based on the issues relevant to the patients and caregivers. The interviewees explain their experiences, in their own words. It is difficult not to be moved on hearing their experiences. Some of the short films have been developed into teaching resources for HCPs (see http://www.healthtalk.org/peoples-experiences/improving-health-care). These films were designed to trigger discussion and debate about patients and practice. Similar films including pwAMD and their caregivers could be used to illustrate the issues found in this thesis and be geared towards service improvement, for instance, highlighting the impact of lack of information and support provision at diagnosis and beyond. These films could be incorporated into medical training to help 'humanise' patient care.

The 2013 survey findings and interviews with pwAMD/caregiver dyads suggest that many are not receiving further information and support after being seen by a ECP at diagnosis. Previous studies have also found that people with VI aren't given access to support services after diagnosis (Hodge et al., 2015; Thetford et al., 2009, 2011). There is evidence to show that registration doesn't necessarily mean that people with VI are directed to the services and benefits they are entitled to (Hodge et al., 2015). Previous research has highlighted that pwAMD have different information and support needs at different stages, e.g. during treatment, or based on their type of AMD (wet or dry) (Burton et al., 2013). The qualitative study presented in Chapter 8 provides the perspective of pwAMD/caregiver pairs and showed that AMD impacts on those around the pwAMD as well as the pwAMD. This shared impact led to support needs including: household tasks both routine and for maintenance and repairs, plus respite for the caregiver as well as emergency cover. There appeared to be different support needs for pwAMD/caregiver pairs who were spouses and pairs where the caregiver was the adult-offspring of the pwAMD. For example, adult-offspring caregivers were more likely to report requiring respite help as they were managing competing responsibilities, whilst spouse pairs were more likely to only require help in an emergency situation. There were barriers to receiving and asking for help including: difficulty putting trust in others (e.g. for respite help or cleaning), and friends and family not being aware of the impact of vision loss or of providing care and therefore not offering help.

As noted in the paragraph above, the qualitative study showed that AMD impacts on the caregiver as well as the pwAMD. Under the theme 'External support' presented in the qualitative study, some caregivers noted negative interactions with HCPs. In particular, one caregiver described how she and her husband with AMD felt they had been '*brushed aside'* by a consultant when treatment for AMD was no longer effective. Such experiences fuel negative perceptions of the NHS and may lead to disengagement with it. Caregiver's and pwAMD's lives are interwoven and as such, caregivers are in a strong position to inform health and social care professionals about the consequences of negative interactions and experiences with health and social services. This may be particularly important for pairs where sight loss has led to depression in pwAMD, and they may not feel able to advocate for themselves. Therefore their caregivers might be able to represent the views of these pairs where the pwAMD may be less likely to put their views across.

On a practical level, health and social care services need to be aware that unexpected and unexplained one-off visits from professionals who never call again, cause not only confusion in pwAMD and their caregivers but also contribute to a sense of abandonment from these services. Informing pwAMD and their caregivers about home visits in advance will give them time to prepare questions beforehand to make sure that such 'one-off' visits are beneficial.

Another key finding of the present research was the importance of emotional support at initial diagnosis and the potential lack of this type of support. For example whilst 30% of respondents to the 2013 survey reported that they would have like to have been offered psychological support at the time of diagnosis, only 2% reported ever being offered such support. Almost one in ten of the 2013 sample reported they would have liked to have been offered psychological support at the time of survey completion. This shows the initial emotional impact of diagnosis of AMD and the on-going support needed. Eye clinics and GPs could easily be made aware of this need for emotional support and signpost appropriately.

Since 74% of the 2013 survey respondents, who were all members of the Macular Society at the time of survey completion, reported *not* being told about the Macular Society at diagnosis, this suggests that they found out about the Macular Society through other means. Indeed, 82% of respondents reported not being given other contacts for help and support at the time of diagnosis. This evidence adds to previous research showing people with VI are required to be proactive in seeking further information (Burton et al., 2013).

Further information may be obtained through attending local support groups. The qualitative study presented in this thesis indicated the benefits of attending these groups for the pwAMD in this study, including that meeting others with sight loss was used as a source of inspiration and motivation in managing the impact of VI. If ECPs in diagnostic consultations were to signpost pwAMD routinely to these groups and explain the benefits of attending, then pwAMD would not feel abandoned after diagnosis, they would be able to receive further important information on their AMD and they'd be able to build rapport with other people in a similar situation.

Awareness of the similarities and differences between pwAMD/caregiver pairs who are spouses and those who are adult-offspring/parent pairs

Whilst the quantitative studies (presented in Chapters 4 and 7) found no significant differences between pairs who were spouses or adult-offspring/ parent pairs in QoL or well-being, the qualitative study highlighted the similarities and differences between these types of pairs in managing the impact of sight loss. It may be important to take into account such differences when designing interventions. For instance, whilst for spouse pairs the provision and receipt of support for AMD was an accepted part of their marriage together, for adult-offspring/ parent pairs, caregivers reported more difficulty fitting caregiving into their lives and help from others was more likely to be needed. Additionally, adult-offspring caregivers were more likely to report difficulty understanding the extent of their parent's vision loss. They may benefit from interventions designed to improve understanding of the pwAMD's vision loss (e.g. Cimarolli et al., 2004). The use of vision simulators could facilitate a better understanding of AMD and its effect on functioning.

The importance of taking into account the dyad

As far as the author is aware, the current research is the first in this area to explore the interactive relationship between the care recipient and provider within pwAMD/caregiver pairs. The quantitative study found that pwAMD general health predicted caregiver reactions to providing support. There was an indirect relationship between pwAMD health and both caregiver well-being and caregiver health, via caregiver reactions to providing care. However pwAMD difficulties with vision-dependent tasks, everyday tasks or the amount of help the caregiver provided to the pwAMD did not predict these caregiver outcomes. By taking into account pwAMD and caregiver factors and by treating the dyad as the unit of analysis, this study has been able to indicate which factors may be useful for targeting in interventions. For instance, the results suggest that it may be useful to target pwAMD general health in order to reduce caregivers' negative reactions to providing care.

The addition of a qualitative methods approach provided a deeper understanding of how pairs managed the impact of AMD together. Previous self-management interventions for people with VI have targeted the patient only and have had limited long-term effects (for a review see Cimarolli et al., 2016). Such interventions include teaching problem-solving techniques to remove barriers to activity engagement, training in the use of optical and assistive devices (LVAs), and the teaching of orientation and mobility skills. The qualitative findings suggest that having the caregiver present to support the pwAMD may act as a boost to encourage longer term effects by reinforcing what was learnt and reminding them to apply it in the future. Using a qualitative approach allowed specific issues related to the shared experience of living with AMD to be recognised, which could be targeted in interventions. One important concern was that of safety. For example, several respondents expressed concerns about pwAMD not being able to see obstacles that might cause them to trip or fall, or that they might have an accident using kitchen appliances. This issue could be addressed by having facilitated discussion about changes needed to prevent accidents, particularly as the findings indicated that tension might arise if one member of the pair is reluctant to make changes. Facilitated discussion could perhaps happen in local support groups. Other interventions might include: advice on LVAs that can reduce the risk of accidents, and referral to vision rehabilitation support who can come to the home and provide help and advice on changes to improve safety.

Additionally, the pairs reported that vision loss from AMD had impacted on more than practical day-to-day living but also on their shared activities. These activities could be targeted in interventions, such as local support groups. Discussions might include how AMD has affected the activity and developing a plan for how the pwAMD and caregiver might jointly overcome the obstacles that prevent them from carrying out the activity or find substitute activities that better suit.

Lastly, the recent IVAN trial comparing the efficacy of two anti-VEGF treatments (ranibizumab and bevacizumab) for wet AMD primarily investigated changes in corrected distance visual acuity (using VAlogMAR) (Chakravarthy et al., 2013). Changes in visual function (using reading index, contrast sensitivity and near visual acuity) and the pwAMD’s QoL (using the MacDQoL) were also investigated. The findings of the pwAMD/ caregiver study presented in this thesis indicate that AMD is not experienced in isolation and caregivers are likely to be affected by treatment. For instance, stabilisation or an improvement in visual acuity may impact on the activities the pwAMD is able to do, thus maintaining their independence and reducing reliance on their caregiver. This may lead to a reduction in the amount of help provided, which could have subsequent impacts on various aspects of the caregivers' and pwAMDs' QoL (e.g. employment, social life) and health. Shared activities may be able to be continued for longer. The risk of trips and falls may reduce, as well as the subsequent need for hospitalisation, thus reducing the impact on health and social services. Long-term evaluations might investigate whether treatment leads to the pwAMD being able to stay in their home for longer (as opposed to entering residential care), and the resulting impact on both pwAMD and their caregiver's QoL.

Designing a model to understand the impact of receiving and providing support

A review of the literature could not find a model that proposed a way of examining the experience of living with AMD using a dyadic perspective. The Yates et al. (1999) stress-process model was used as a starting point in the second quantitative study, however the original model focuses on caregiver outcomes. PwAMD well-being was added as an outcome in the study presented in this thesis. As a result of the qualitative findings, I have suggested a variety of possible modifications to the model (see discussion section in Chapter 8). This thesis provides an important first step in assessing the experience of receiving and providing support for pwAMD/caregiver pairs.

By using a sequential mixed-methods approach to study the impact of receiving and providing support for AMD, this thesis has used the qualitative findings to suggest how the quantitative measures used in the second quantitative study may be adapted to be relevant to pwAMD and their caregivers. For instance, the CRA measure used to investigate caregiver reactions to providing support could be adapted to allow the participants to rate the importance of each item to their lives, following the design features of the MacDQoL measure of the impact of macular disease on QoL (Mitchell et al., 2005). This would indicate which items and subscales have a bigger impact on their life. The qualitative study highlighted differences between spouse and adult-offspring caregivers in their experiences of providing support; however the mean total

CRA scores were not significantly different between these types of caregivers. The adapted CRA measure with importance ratings may reveal where priorities differ for spouse or adult-offspring caregivers. In particular, the qualitative findings suggested that providing care may impact more heavily on adult-offspring caregivers' schedule and the adaptation proposed may help to show this.

A model of Health-related Quality of Life

The results of the studies reported in this thesis may provide evidence that could be used to inform the development of a disease-specific Health-related Quality of Life (HRQoL) model for AMD. This can be used to understand where intervention may be appropriate and the impact this is likely to have on outcomes that are important to the patient. For example, the most widely reported model of HRQoL, proposed by Wilson and Cleary (1995), suggested that functional status and general health perceptions are associated with overall QoL. The second quantitative study reported in this thesis found that pwAMDs' difficulties with visual functioning and their perception of general health were associated with their well-being, and therefore provides evidence to support these relationships in pwAMD. This suggests that an intervention to improve pwAMD's general health or level of visual functioning may lead to improvements in their well-being. In addition, Wilson and Cleary's (1995) model also suggested that characteristics of the individual's environment, such as interactions with healthcare providers and support received from family and friends, may affect the individual's perceptions of their symptoms, functional status, general health perceptions and overall quality of life. However the authors did not provide detail on how these characteristics may affect these outcomes. Whilst the first study in this thesis examined the information and support received in the diagnostic consultation, it did not go beyond this to understand how this might affect QoL. Evidence from qualitative interviews with pwAMD and their caregivers found that they were disappointed with the lack of support received from health and social services. As suggested in Chapter 8, it may be useful for the dyadic model to include a measure of the perception of help received from health and social services in order to understand how these factors might impact on outcomes. The impact of healthcare experiences on outcomes such as visual functioning, general health and QoL remain to be tested formally.

Impact

A potential way in which to train ECPs to provide much-needed information and support in consultations may be through professional meetings or training courses. The author and Professor Clare Bradley attended 'The Elizabeth Thomas seminar for Macular Disease' organised by the RCOphth in October 2016. This annual seminar is attended by ophthalmologists with varying amounts of experience in providing eye care. Some are more experienced and are involved in the supervision and training of less experienced ophthalmologists. The author and Professor Bradley presented the findings on healthcare experiences from this thesis (presented in Chapter 3), and emphasised that information pertinent to the RCOphth guidelines (RCOphth, 2009) are included in the leaflet produced by the Macular Society called 'Guide to AMD'. An impact questionnaire completed by ophthalmologists before the presentation found that over half of the ophthalmologists in attendance reported that they 'always' gave the leaflet to pwAMD. Of those who reported not already 'always' giving this leaflet to pwAMD, all but one ophthalmologist changed their response in the post-talk questionnaire to say that they would now give the leaflet to pwAMD 'all the time'. Thus professional seminars for ECPs may be another route in which to improve awareness of patient experiences. The use of post-talk questionnaires may facilitate ECPs to question their current practice, thus potentially leading them to make informed decisions about how they might change their future consultations with pwAMD and how they might train less experienced ECPs to do the same.

Limitations of the thesis

First, the participants with AMD who participated in all three studies presented in this thesis were members of the Macular Society at the time of the 2013 survey completion. One might question the representativeness of the sample. Individuals may have joined the Macular Society because they had unsatisfactory experiences in their diagnostic consultations and sought information and support elsewhere. Conversely, this sample may have received information about the Macular Society in the diagnostic consultation more often than the general AMD population and thus be more satisfied. Macular Society members may be more informed about AMD than the wider population of pwAMD, and may have accessed support from the Macular Society. This may have reduced the need for support from elsewhere (e.g. from family and friends, formal services). Thus caution should be applied when generalising the thesis findings to all pwAMD including those who are not members of the Macular Society.

Caregivers who didn’t volunteer to take part in the second quantitative study and qualitative third study may be the most overloaded or over-burdened and didn’t feel they had the time to complete the survey or take part in the interviews. Therefore the caregiver experiences reported in these studies may not be representative of the population of caregivers of pwAMD. Equally, it may be that caregivers who felt the most impact of providing support were more likely to volunteer as they felt able to contribute meaningfully to the research, would want to progress the research field to benefit caregivers or may want the opportunity to ‘offload’ and thus taking part may be considered therapeutic. There are other factors that might affect the generalisability of the caregivers included in the qualitative study, and are described in Chapter 8. For example, of the eight caregivers who took part in the qualitative interviews, four of them were spouses of the pwAMD and were retired. The other four were adult-offspring caregivers; two of which were still working (one part-time, one full-time). This small number of caregivers who were still working may be an underrepresentation of caregivers of pwAMD who are employed, however since there have been no previous studies on caregivers of pwAMD (including people with wet and dry AMD), the proportion of caregivers in work is not known.

The results of the model presented in the second quantitative study (in Chapter 7) are limited by the small sample size used. The results are only suggestive of possible relationships between the quantitative measures used. The small sample also meant that other factors that may have been relevant to studying the impact of receiving and providing support for AMD, including gender of the pwAMD and their caregiver and the type of pwAMD/ caregiver relationship, could not be included in the model for reasons discussed in Chapter 6.

In the two quantitative studies included in this thesis, the measure of general health used was a 7-point single-item self-assessment of general health, designed for the present study based on the generic QoL item from the MacDQoL. This single-item was used because the focus of the 2013 survey was to investigate experiences of living with a macular condition rather than general health, and to avoid licensing costs associated with using a validated questionnaire. The single-item was quick to administer, however there were limitations to what could be inferred from the research findings. For instance, in the second quantitative study, pwAMD general health was associated with caregiver reactions to providing support and pwAMD well-being. Using a more detailed measure of health status, such as the SF-36 (Jenkinson, Stewart-Brown, Petersen, & Paice, 1999), may provide more information on which aspects of health (e.g. physical functioning, pain) impact on these outcomes.

This is the first study to use the 16-item version of the Well-being questionnaire (W-BQ16) with pwAMD and their caregivers. A lack of time meant that the W-BQ16 could not be psychometrically evaluated in these samples. However the 12-item W-BQ has previously been used and validated for pwAMD (Mitchell & Bradley, 2001). The second quantitative study is the first study to use the CRA in a sample of caregivers of people with wet and/or dry AMD. Internal consistency of the CRA was good however full psychometric evaluation of these measures is needed to assess the acceptability, validity and reliability of these measures in this population.

The survey methodology used in the quantitative studies presented in this thesis assessed the participants' self-report of several of the key variables included the analyses including their well-being, quality of life, general health, vision status and experiences of healthcare. Common method variance states that variance in these factors may be due to the measurement method (i.e. self-report) rather than the construct of interest. Thus the relationships found (or not found) between variables may be due to an alternative explanation than the one hypothesised. Podsakoff, MacKenzie, Lee & Podsakoff (2003) summarised potential sources of common method biases. These included, for instance, common rater effects which refers to any artificial covariance between variables measured in the study being due to the same person providing the responses for two or more variables of interest being correlated in the study. Some of the issues of using self-report measures have been mentioned earlier in this thesis. For example in Chapter 8, some pwAMD and their caregivers reported completing questionnaires together and this may have led to them completing their responses in what they perceived to be a socially acceptable manner if they did not want the other person in the pair to know their true feelings. Thus caregivers' and pwAMDs' well-being and caregivers' reactions to providing care may have been artificially high/positive. The use of an alternative methodology in the form of qualitative interviews conducted separately with patients and their caregivers may have helped to ameliorate the effect of social desirability affecting participant's responses, thus increasing the validity of their interview responses. It was important to measure the participant's own appraisal of some of the variables included in the studies presented in this thesis, including their well-being and reactions to providing care. However one might control for the effects of common method variance, where feasible, by collecting the measures of variables from different sources, for instance, by using clinician reports of the participants' visual acuity or general health. Time limitations in the studies presented in this thesis meant that these variables were unable to be collected using this method.

Recommendations for future research

The findings from the first quantitative survey highlight that pwAMD are not receiving information and support needed to manage their condition. The reasons why they are not receiving this are unknown. Future research might investigate the reasons why ophthalmologists, optometrists and GPs might not be providing this information. An observational study might investigate the interaction between the pwAMD and HCP in the consultation. This would provide objective evidence about what information and support was provided in the consultation, and also look at *how* the information was conveyed; in particular, whether HCPs showed empathy with the pwAMD and whether they were sensitive to the information and support needs of the pwAMD. This research method could also be used to see if the gender differences found in provision of information and support in the first quantitative study were replicated and whether the HCP provided less or different information to women and to older people compared with that provided to men and younger people. If pwAMD and HCPs were to consent to the consultation being videotaped and used, there is the potential for these videos to be used in training HCPs. Follow-up interviews after the consultation could help to highlight whether pwAMD and HCPs were satisfied with the consultation and identify potential areas for improvement. Involving both HCPs and pwAMDs in working together towards service improvement might lead to better engagement with the research, and ultimately more patient-centred care.

The first quantitative study found that receiving care for AMD was associated with poorer QoL and well-being, despite controlling for degree of visual impairment. This study used registration status and pwAMD-reported change in vision status since diagnosis as measures of degree of VI. The second quantitative study used pwAMDs' self-reported level of visual functioning as the measure of VI (the DLTV). When this more detailed measure of visual impairment was used, the amount of care received for AMD was not associated with pwAMD well-being. It would be informative to repeat the first study using a more detailed measure of visual impairment (such as the DLTV) to see if receiving care for AMD (vs not receiving care) is still associated with poorer well-being. The qualitative data suggest that pwAMD appreciate, and perhaps rely on the help provided by their caregiver and believe that pwAMD who don't have this support may be struggling;

> *I mean I'm just fortunate that I've still got my husband because lots of women of my age are widows and it must be a great deal more difficult for them. And I think because I've got him, my life hasn't changed so much, it has changed of course but you know, it could have been, it could be much worse*. (Participant 81, woman with AMD)

It would be useful to investigate how people who do not have access to this support manage living with AMD, what can be done to support pwAMD living independently, as well as the factors that lead to pwAMD needing support.

Overall summary

The main survey in Chapter 3 reported a disappointing degree of improvement in information and support provision in the diagnostic consultation for pwAMD. Overall satisfaction with the diagnostic consultation improved in the time following publication of the RCOphth 2009 guidelines, however nine other areas of information and support provision didn't, nor was there any improvement associated with the publication of the 1999 survey results in 2002. Satisfaction with GPs was also low. Subsequent studies established that pwAMD, when they are not seen in the eye clinic for diagnosis or treatment, have little contact with health and social services for AMD-related support. Support came mainly from family and friends. Previous research has neglected to take into account the close relationship between pwAMD and their caregivers, and the considerable impact that vision loss has on the lives of both pwAMD and their caregiver. The rising population of older people at risk of AMD will put further pressure on overstretched health and social care services, and there is likely to be increased reliance on the caregiving of family and friends. Studies in this thesis have used dyadic methods to provide evidence-based suggestions for how pwAMD and their caregivers can be supported to manage the impact of AMD. There is a profound need for training ECPs on the importance of giving information and support in diagnostic consultations, and signposting to further support. Now is the time to create a co-ordinated network of information and support, designed by health and social care services working in partnership with pwAMD and caregivers.

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Appendices 1 to 12

Appendix 1: Search strategy for narrative literature review presented in Chapter 1.

The electronic databases searched were Web of Science and Google Scholar. Reference lists from the resources found were checked for relevant references and experts in the field were contacted for additional sources of information.
Although the review did not endeavour to be systematic in nature, several key words were used to retrieve relevant articles for discussion. The important key words included:

- ‘AMD’, ‘age-related macular degeneration’, ‘age related macular degeneration’
- ‘vision impairment’, ‘vision loss’, ‘low vision’

Electronic database searches were not limited by year of publication in order to maximise the literature that would be included in the review to understand how knowledge and theory on this topic has changed over time. Only articles published in the English language were included. Literature using either or both qualitative and quantitative methods were included. Review articles were included.

The author critically appraised the literature but did not use specific criteria to evaluate the quality of included studies which are recommended for use when conducting a systematic review (e.g. CASP checklist (Critical Appraisal Skills Programme, 2013); The Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, 1998)).

Thus it is acknowledged that by using a narrative review method instead of systematic review methodology, relevant articles may have been missed in the search (systematic reviews typically run searches in several electronic databases) and that studies of poor quality may have been included. All included literature has been assigned the same level of quality.

The Macular Disease (MD) Society Questionnaire

This questionnaire is designed to find out about the experiences and views of people with MD.

Please place a cross in the 'Yes', 'No' or 'Don't Know' boxes or write in the reply boxes. If any reply boxes are too small for your complete answer, please continue on the blank sheet of paper at the back of the questionnaire, indicating the question number you are responding to. Please also write any further information you would like to give on the extra sheet(s).

1. **Had you heard about MD before your own condition was diagnosed? Yes ☐ No ☐**

2. **Do you know of any other members of your family who have or had MD? Yes ☐ No ☐ Don't know ☐**

If 'Yes', please state in box their relationship to you (e.g. mother, brother etc.) and approximate age of onset if known.

☐

3. **Before your MD was diagnosed had you experienced any of the following conditions or circumstances?**

a. Other eye disease e.g.
Glaucoma, cataracts…………… Yes ☐ No ☐

If 'Yes', please describe

☐

b. Injury to head or eyes………….Yes ☐ No ☐

If 'Yes', please describe

☐

c. Diabetes………………………….. Yes ☐ No ☐

d. High blood pressure ……………Yes ☐ No ☐

e. Stroke…………………………….. Yes ☐ No ☐

If 'Yes' to and of the above (a, b, c, d, e) please note any medication taken in 'f' below.

f. Frequent use of any medication
(e.g. aspirin, sleeping pills)…….Yes ☐ No ☐

If 'Yes', please list

☐

g. Smoking…………………………. Yes ☐ No ☐

h. Living and/or working in smoky atmospheres due to others smoking…………………..Yes ☐ No ☐

i. Drinking alcohol………………… Yes ☐ No ☐

If ‘Yes’, please state the drink you then preferred e.g. red wine, beer, lager, whisky.

☐

j. Stress or bereavement……….. Yes ☐ No ☐

k. Working and/or living in hot temperatures/climate……… Yes ☐ No ☐

l. Frequent or lengthy exposure to sun………………… Yes ☐ No ☐

m. Other notable conditions/circumstances prior to developing MD (please state in box).

☐

4. When your MD was first diagnosed:

a. how was your MD described to you? (please state)

b. were you given the name of this condition? Yes ☐ No ☐

c. were you told of any possible cause of this condition?
Yes ☐ No ☐

If 'Yes', please state

d. did you feel that the Eye Specialist who diagnosed your MD was interested in you as a person? Yes ☐ No ☐

e. did you feel that the interview with the Eye Specialist was satisfactory? Yes ☐ No ☐

If 'No', please state why you felt dissatisfied

For questions 5 and 6 please circle one number where ‘3’ indicates ‘very’ and ‘0’ indicates ‘not at all’.

	very			not at all
5. Around the time you were first diagnosed with MD, to what extent was your General Practitioner well informed about MD? …………………	3	2	1	0
6. To what extent has your General Practitioner been helpful and supportive? …………………………………	3	2	1	0

7. Were you ever told by an Eye Specialist, G.P. or Optometrist (Optician) that **‘Nothing can be done’** to help with your MD?
Yes ☐ No ☐

If ‘Yes’, how did you react to being told

‘Nothing can be done’? Please answer ‘Yes’ or ‘No’ to each of a, b, c, d, e, f. Did you feel:

a) resigned ………………… Yes ☐ No ☐

b) shocked/sick/panic…… Yes ☐ No ☐

c) helpless…………………. Yes ☐ No ☐

d) angry…………………….. Yes ☐ No ☐

e) anxious or depressed… Yes ☐ No ☐

f) suicidal………………….. Yes ☐ No ☐

g) other, please state ☐

8. **Were you ever told by an Eye Specialist, G.P. or Optometrist (Optician) that you will not go completely blind because of your MD? Yes ☐ No ☐**

If 'Yes', how did you react to being told

'you will not go completely blind'? Did you feel:

a) relieved…………Yes ☐ No ☐

b) other, please state ☐

9. **Have you had any eye treatments or operations e.g. laser operation, operation to remove cataracts, treatment for glaucoma? Yes ☐ No ☐**

If 'Yes', please state which treatments or operations you have had:

☐

10. **Has your Eye Specialist, G.P. or Optometrist suggested that some eye treatments/operations may do more harm than good? Yes ☐ No ☐**

If 'Yes', which treatment was felt possibly to be harmful?

☐

11. Have you experienced any worsening of vision following a treatment or operation? Yes ☐ No ☐

If 'Yes', please state the treatment or operation

12. Have you found any improvement in vision since diagnosis of MD? Yes ☐ No ☐ Don't know ☐

If 'Yes', to what do you attribute the improvement?

13. Have you been told that MD is part of the ageing process? Yes ☐ No ☐

If 'Yes', by whom? (Eye Specialist, G.P., Optometrist, etc)

14. Did you see your Eye Specialist privately or on the N.H.S.?

N.H.S. only ☐

Private only ☐

Both private and N.H.S. ☐

15. After diagnosis of MD, did your Eye Specialist, G.P. or Optometrist recommend regular eye tests in case other conditions developed? Yes ☐ No ☐

16. Were you given any information about the MD society or local self-help groups? Yes ☐ No ☐

If 'Yes', please state who gave you the information.

17. Are you a member of a local MD self-help group? Yes ☐ No ☐

18. Were you able to get more information about your MD after diagnosis? Yes ☐ No ☐

If 'Yes', where did you find this information?

19. Have you experienced any vision changes that have caused you concern? E.g. pulsating lights, flashes, shimmering light, hallucinations such as animal, human or plant forms, changing coloured patterns, blurred vision, difficulty seeing depth or seeing at night. Yes ☐ No ☐

If 'Yes', please state

19 continued:

- **Have you talked about these experiences with your Eye Specialist, G.P. or Optometrist? Yes ☐ No ☐**

- **Were you told of any possible causes of these experiences?**
  Yes ☐ No ☐

  If 'Yes', please state ☐

20. Would you be prepared to keep a diary/record of your MD condition? Yes ☐ No ☐

The MD Society has funded this survey and funds other research. There are many other possible areas of research which you might wish to see funded.

21. How important to you are each of the following broad research areas? Please circle one number for each scale where 3 = very important and 0 = not important.

- **Causes and prevention of MD……….. 3 2 1 0**

- **New treatments ………………………… 3 2 1 0**

- **Low vision aids for people with MD… 3 2 1 0**

- **Improving care and support of people with MD………………………….. 3 2 1 0**

21 continued:
Please add any specific suggestions for research you would like to see carried out.

For items 22 and 23 please cross one of the 7 boxes offered

22. In general, my quality of life is:

- **excellent………………….. ☐**
- **very good………………… ☐**
- **good……………………… ☐**
- **neither good nor bad…... ☐**
- **bad……………………….... ☐**
- **very bad………………….. ☐**
- **extremely bad………….... ☐**

23. If I did not have MD, my quality of life would be:

- **very much better………. ☐**
- **much better ……………. ☐**
- **a little better ……………. ☐**
- **the same…………………. ☐**
- **a little worse……………. ☐**
- **much worse……………… ☐**
- **very much worse………. ☐**

24. Please circle a number on each scale to indicate how often each phrase has applied to you in the past few weeks: 3 = ‘all the time’, 0 =’not at all’.

	all the time			not at all
a) I have crying spells or feel like it	**3**	**2**	**1**	**0**
b) I feel downhearted and blue	**3**	**2**	**1**	**0**
c) I feel afraid for no reason at all	**3**	**2**	**1**	**0**
d) I get upset easily or feel panicky	**3**	**2**	**1**	**0**
e) I feel energetic, active or vigorous	**3**	**2**	**1**	**0**
f) I feel dull or sluggish	**3**	**2**	**1**	**0**
g) I feel tired, worn out, used up or exhausted	**3**	**2**	**1**	**0**
h) I have been waking up feeling fresh and rested	**3**	**2**	**1**	**0**
i) I have been happy, satisfied, or pleased with my personal life	**3**	**2**	**1**	**0**
j) I have lived the kind of life I wanted to	**3**	**2**	**1**	**0**
k) I have felt eager to tackle my daily tasks or make new decisions	**3**	**2**	**1**	**0**
l) I have felt I could easily handle or cope with any serious problem or major change in my life	**3**	**2**	**1**	**0**

Please make sure that you have considered each of the 12 statements and have circled a number for each.

25.Have you been to a Low Vision Clinic? Yes ☐ No ☐

26. Have you been visited at home by a rehabilitation officer?
Yes ☐ No ☐

27. Have you been shown how to use low vision aids?
Yes ☐ No ☐

28. Have you found low vision aids useful? Yes ☐ No ☐

If 'Yes', please note below which aids you have found useful.

If there are any low vision aids you have tried but did not find to be useful, please note which aids they were and why they were not useful.

29. **Please give the following details about yourself**

Please fill in the dates as accurately as you can.
These dates are important.

a) Date of birth _ _ / _ _ / _ _

b) Sex: Male ☐ Female ☐

c) Which form of MD do you have? Please indicate below for each eye.

- **Left eye: Wet ☐ Dry ☐ Don't know ☐ None ☐**

  Any other conditions ☐

- **Right eye: Wet ☐ Dry ☐ Don't know ☐ None ☐**

  Any other conditions ☐

d) Dates of diagnosis of MD

- **Left eye _ _ / _ _ / _ _ Right eye _ _ / _ _ / _ _**

e) Dates of onset of MD (your estimate)

- **Left eye _ _ / _ _ / _ _ Right eye _ _ / _ _ / _ _**

f) Are you registered as blind or partially sighted? Yes ☐ No ☐
If 'Yes', please give date or dates below

- **date registered as partially sighted _ _ / _ _ / _ _**
- **date registered as blind _ _ / _ _ / _ _**

g) Before MD was diagnosed, did you need to wear glasses?

- **for reading? Yes ☐ No ☐**
- **for distance? Yes ☐ No ☐**

h) Which hand do you prefer to use for writing?
Right ☐ Left ☐

i) Some children are made to use their right hand despite a left-hand preference. Did this apply to you? Yes ☐ No ☐

j) Please state in the boxes your occupation:

- **before diagnosis** ☐
- **after diagnosis** ☐
- **now** ☐

If you have had any changes of occupation were they:

- **due to MD? Yes ☐ No ☐**
- **due to other factors? Yes ☐ No ☐**

k) Please state in the boxes your main interests and activities:

- **before diagnosis** ☐
- **after diagnosis** ☐
- **now** ☐

If you have had any changes in activities or interests were they:
due to MD? Yes ☐ No ☐

due to other factors? Yes ☐ No ☐

l) Do you live alone? Yes ☐ No ☐

m) Do you have defective hearing? Yes ☐ No ☐

n) General health

Please cross one of the 5 boxes offered

In general, would you say your health is:

Excellent	**Very good**	**Good**	**Fair**	**Poor**
☐	☐	☐	☐	☐

o) Skin colour

Please circle a number to indicate depth of your skin colour where 1 is lightest (eg white European) and 5 is darkest (eg black African).

Light				Dark
1	2	3	4	5

p) Eye Colour

Please cross a box to describe the colour of your eyes or describe in your own words.

Blue ☐ **Green** ☐ **Hazel** ☐ **Brown** ☐ **Grey** ☐

Other (please state) ☐

Please circle a number to indicate the depth of your eye colour.

Light				Dark
1	2	3	4	5

q) Did someone else help you to complete this questionnaire?

Yes ☐ **No** ☐

If 'Yes', please state relationship to helper e.g. husband, daughter, friend etc ☐

r) Today's date _ _ / _ _ / _ _

Thank you very much for your help

Dept of Psychology, Royal Holloway, University of London, Egham, Surrey, TW20 0EX

Appendix 3: MSQ 2013

Questionnaire package sent to people with AMD in the first quantitative study.

Macular Society

ROYAL
HOLLOWAY
UNIVERSITY
OF LONDON

The Macular Society Survey 2013:

Understanding the experiences of people with macular conditions

Information for participants

Dear Society Member,

We would like to invite you to participate in a survey that is being carried out by The Macular Society and Royal Holloway, University of London. Please read the following information and discuss it with others if you wish.

Please contact the researchers using the contact details on page 4 if there is anything that is not clear or if you would like more information.

This research has been approved by the ethics committee of Royal Holloway, University of London.

What is the purpose of the survey?

This survey covers many aspects of living with macular conditions including experience of diagnostic consultations, rehabilitation services and satisfaction with treatment.

A similar survey was completed by Macular Society members in 1999 and this survey will tell us how the experiences of people with macular conditions have changed since then.

The results will help us provide support for people with macular conditions and help plan future research. You will be able to read summaries of the results in **Sideview** and **Digest**.

Who have we asked to participate?

We have invited randomly selected members of the Macular Society, who joined between 2000 and 2013, to participate in the survey. We wish to include members who have any type of macular condition, are aged over 18 and who currently live in the UK.

What will I need to do?

You will need to tick or write down the answers that apply to you. If the reply boxes are too small, you can use the continuation sheets at the end of the booklet but please include the question number with your response.

If you can complete the survey yourself or have someone who can help you then **please return it to us in the freepost envelope provided as soon as possible**.

If you would prefer to have the questions read to you, please ring the number on page 4. An interviewer will contact you to arrange a convenient time to complete the survey with you over the phone.

Some people may find recalling their past experiences uncomfortable. The Macular Society helpline is available to you if needed. The helpline number is **0300 3030 111**.

Do I have to take part?

No, you do not have to fill in the survey. Choosing not to will not disadvantage you in any way. If anything is not clear, or if you have any questions, please contact us on the phone number on page 4.

If you do not wish to take part, we would appreciate it if you could fill in the form headed '**Reasons for not taking part**' and return it to us in the freepost envelope provided and we will not trouble you again.

If you decide to take part, please be aware that you do not have to answer every question. You can leave it blank or give your reasons for not answering if you wish.

How will we maintain your privacy and confidentiality?

The answers you give will be treated in complete confidence. All data will be collected and stored in accordance with the Data Protection Act 1998. Reports from the project will summarise information, but will not identify individuals.

If you would prefer to answer the survey over the telephone with the researcher, the phone call will be audio-recorded and your responses will then be written onto a survey. The audio-recording will be stored confidentially and destroyed once the results are published.

All surveys will be given an ID number and will be anonymous. If you provide your name and contact details, these will be separated from your responses and put in a secure computer database to which only the researchers will have access.

What do I do next?

If you want to take part, please sign and date the consent form attached to the survey. This will be separated from your responses when they are received. Please continue on to the next pages of the survey and ensure you take rest breaks when needed.

Thank you

Contact details

Research Group:

Ms Emily Boxell	PhD Researcher
Professor Clare Bradley	Professor of Health Psychology

Contact details:

Health Psychology Research Unit,
Orchard Building,
Royal Holloway, University of London.
Egham, Surrey
TW20 0EX.

email:

emily.boxell.2013@rhul.ac.uk

c.bradley@rhul.ac.uk

(please include ‘Macular Society Survey’ in the subject line)

N.B. You may wish to keep this information sheet for reference.

For enquiries please telephone:

01784 443718 or 01784 443714

The Macular Society Survey 2013:

Understanding the experiences of people with macular conditions

Participant Consent Form

This study has been approved by the Royal Holloway, University of London Ethics Committee.

Thank you for considering taking part in this research. If you have any questions, please contact the researchers before you decide whether to take part (contact details are on page 4 of the Information for Participants).

Please tick below to show you agree with the following statements:

- I have read the information sheet about this study.
- If I had any questions, I have had the opportunity to ask these questions (using the contact details) and I have received satisfactory answers to these questions.
- I understand that I am free to withdraw from the study at any time, without giving a reason.

I agree to participate in this study .... Yes ☐ No ☐

Name of participant ____________________

Signature ____________________

Date ____________________

Please check that you have ticked the 'Yes' or 'No' box and have signed and dated this form. Thank you.

NB: This Consent form will be detached and stored separately from the responses you provide.

for office use

Please do not write on this page – thank you.

The Macular Society
Survey 2013

Macular Society

This survey is designed to find out about the experiences and views of people with any type of macular condition. If you do not have a macular condition, please return this uncompleted survey in the envelope provided.

Please tick the relevant boxes or write in the reply boxes. There are two blank pages at the end if you run out of space.

Your macular condition

1. Do you have age-related macular degeneration (AMD)?

Yes ☐ → (if 'yes' please go to Q2) No ☐ ↓

If 'no' write the name of your macular condition in the box below and go to Q3. ☐

2a). If you have AMD, which form do you have?

- **Left eye** Wet ☐ Dry ☐ Don't know ☐ None ☐
- **Right eye** Wet ☐ Dry ☐ Don't know ☐ None ☐

2b). If you have AMD, do you know what stage it is at now?

- **Left eye** Early/Intermediate ☐ Advanced ☐ Don't know ☐ None ☐
- **Right eye** Early/Intermediate ☐ Advanced ☐ Don't know ☐ None ☐

3. Dates (approximate) of diagnosis of your macular condition:

a) Left eye _ _ / _ _ / _ _ **b) Right eye** _ _ / _ _ / _ _

4. Had you heard of macular conditions before your own condition was diagnosed? .... Yes ☐ No ☐

5. Around the time of diagnosis, had you experienced stress or bereavement?.................... Yes ☐ No ☐

6. Apart from your macular condition, do you/did you have any other eye disease e.g. glaucoma, cataracts? .... Yes ☐ No ☐

If 'yes' describe the condition and dates of any major treatment:

☐

7a). How was your macular condition first noticed?

- By my optician at a routine eye test appointment:

  Yes ☐ ➡ (if 'yes' please go to Q8a on page 6) No ☐ ⬇

- I noticed the symptoms myself and sought medical help:

  Yes ☐ ➡ (if 'yes' please go to Q7b on page 5) No ☐ ⬇

- Someone else first noticed the signs of my macular condition:

  Yes ☐ ⬇ No ☐ ➡ (if 'no' please go to next option below)

  If 'yes' please describe what happened below and then go to Q7b on page 5.

☐

- Other, please state below:

☐

7b). I first sought help from a:

GP ☐ Optician ☐ Hospital Eye Clinic ☐

Other, please state:

☐

Please describe the symptom that led you to seek help:

☐

7c). Once symptoms were noticed, how quickly did you seek advice from a healthcare professional (GP, optician, hospital doctor)?

- Same or next day........................ ☐ (please go to Q8a on page 6)
- 2 to 6 days.................................... ☐
- 1 week to 1 month .... ☐
- More than 1 month .... ☐
- Can't remember .... ☐
- N/A .... ☐

7d). If your appointment with a healthcare professional about early symptoms was delayed for more than 2 days, please state reasons why below:

☐

8a). Who first diagnosed your macular condition? Please tick one box from the list below:

- hospital eye specialist.................................. ☐
- optician.. ☐
- GP.. ☐
- don't know .... ☐
- other, please state:

8b). Did you feel that this healthcare professional (who first diagnosed your macular condition), was interested in you as a person?

Yes ☐ No ☐

8c). Overall, did you feel that the diagnostic consultation with this healthcare professional was satisfactory?

Yes ☐ No ☐

Please explain why below:

8d). Were you given the name of your condition at the time of diagnosis?

Yes ☐ No ☐ → (if 'no' please go to Q8e)

If 'yes', what name was given for your eye condition at the time of diagnosis? Please tick one or more of the following:

- macular degeneration (MD)................................ ☐
- age-related macular degeneration (AMD)........ ☐
- juvenile macular degeneration .... ☐
- wet AMD .... ☐
- dry AMD .... ☐
- don't recall .... ☐
- other (please state in box) e.g. retinitis pigmentosa, cone dystrophy, rod dystrophy, Stargardt's disease:

8e). Were you given any written information about your macular condition at the time of diagnosis?

Yes ☐ No ☐

8f). Were you given any information around the time of diagnosis about what to do if you were to have a sudden deterioration in your vision?

Yes ☐ No ☐

8g). Do you feel you were given appropriate support, help or advice at the time of diagnosis?

Yes ☐ No ☐

8h). Were you given information about the Macular Society (or the Macular Disease Society, as it was previously called) at the time of diagnosis?

Yes ☐ No ☐

8i). Were you given any other contacts for help and support at the time of diagnosis?

Yes ☐ No ☐

If yes, please state:

☐

8j). Around the time of diagnosis, were you given information about the likely progress of your macular condition?

Yes ☐ No ☐

8k). If at initial diagnosis only one eye was affected, were you given information about how your second eye might be affected in the future?

Yes ☐ No ☐

If your macular condition was initially diagnosed by a hospital eye specialist please go to Q9a.

9. If your condition was not initially diagnosed by a hospital eye specialist, have you been to see a hospital eye specialist about your macular condition since diagnosis?

Yes ☐ ↓ No ☐ ➡ (if 'no' please go to Q10 on page 10)

If 'yes', please tick one or more reasons why you have been to see a hospital eye specialist from the list below:

- for confirmation of diagnosis .... ☐
- for low-vision service referral .... ☐
- for a certificate of visual impairment .... ☐
- for monitoring vision .... ☐
- for treatment .... ☐
- other, please state below:

☐

9a). Did you see your eye specialist privately or on the NHS?

- NHS only .... ☐
- private only .... ☐
- both private and NHS .... ☐

For questions 10 and 11 please circle one number where '3' indicates 'very' and '0' indicates 'not at all'. If you did not discuss your macular condition with your GP, please circle N/A for not applicable.

	very			not at all	
10. Around the time you were first diagnosed with your macular condition, to what extent was your GP well-informed about your condition?	3	2	1	0	N/A
11. To what extent has your GP been helpful and supportive about your macular condition?	3	2	1	0	N/A

12. Were you ever told by a healthcare professional that **'Nothing can be done'** to help with your macular condition?

Yes ☐ No ☐ ➡ (if 'no' please go to Q13 on page 11)

12a). If 'yes', which healthcare professional told you this? Please tick from the list below:

- hospital eye specialist ☐
- nurse ☐
- optician ☐
- GP ☐
- eye clinic liaison officer ☐
- other, please state:

12b). How did you react to being told, '**Nothing can be done**'? Please answer 'yes' or 'no' to each of a,b,c,d,e, and f.
Did you feel:

	Yes	No
a) resigned	☐	☐
b) shocked/sick/panic	☐	☐
c) helpless	☐	☐
d) angry	☐	☐
e) anxious or depressed	☐	☐
f) suicidal	☐	☐

g) other, please state below:

13. Were you ever told by a healthcare professional that **'You will not go completely blind'** because of your macular condition?

Yes ☐ No ☐ ➡ (if 'no' please go to Q14 on page 12)

13a). If 'yes', who told you this? Please tick from the list below:

- hospital eye specialist ☐
- nurse ☐
- optician ☐
- GP ☐
- eye clinic liaison officer ☐
- other, please state:

13b). How did you react to being told, '**You will not go completely blind**'? Did you feel:

	Yes	No
a) relieved	☐	☐
b) alarmed	☐	☐

c) other, please state below:

14. Have you been told that your macular condition is part of the ageing process?

Yes ☐ ↓ No ☐ → (if 'no' please go to Q15)

14a). If 'yes', who told you this? Please tick from the list below:

- hospital eye specialist ☐
- nurse ☐
- optician ☐
- GP ☐
- eye clinic liaison officer ☐
- other, please state:

15. Were you told by a healthcare professional, around the time of diagnosis, of the possibility of experiencing visual hallucinations as a side effect of sight loss?

Yes ☐ No ☐

16. In the past 12 months, have you seen an eye specialist or optician about your macular condition?

- Yes ☐
- No, and I haven't needed to ☐
- No, but I needed to ☐

If you ticked 'No, but I needed to' please give reasons for your response below:

For questions 17 and 18, please tick one of the boxes offered.

17. In general, my present quality of life is:

- excellent ☐
- very good ☐
- good ☐
- neither good nor bad ☐
- bad ☐
- very bad ☐
- extremely bad ☐

18. If I did not have a macular condition, my quality of life would be:

- very much better ☐
- much better ☐
- a little better ☐
- the same ☐
- worse ☐

19. Please circle one number on each scale, **from 3 (all the time) to 0 (not at all)**, to indicate how often you feel each statement has applied to you in the past few weeks:

	all the time			**not at all**
a) I have crying spells or feel like it	3	2	1	0
b) I feel downhearted and blue	3	2	1	0
c) I feel afraid for no reason at all	3	2	1	0
d) I get upset easily or feel panicky	3	2	1	0
e) I feel energetic, active or vigorous	3	2	1	0
f) I feel dull or sluggish	3	2	1	0
g) I feel tired, worn out, used up or exhausted	3	2	1	0
h) I have been waking up feeling fresh and rested	3	2	1	0
i) I have been happy, satisfied or pleased with my personal life	3	2	1	0
j) I have lived the kind of life I wanted to	3	2	1	0
k) I have felt eager to tackle my daily tasks or make new decisions	3	2	1	0
l) I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1	0

Continued on next page . . .

	all the time			**not at all**
m) I feel that too many demands are made on me	3	2	1	0
n) I feel frustrated by obstacles which occur in my life	3	2	1	0
o) I have too many problems to cope with	3	2	1	0
p) I feel stressed	3	2	1	0

20. Do you feel that your well-being has been affected by anything in particular in the past few weeks, e.g. any other health conditions, bereavement, retirement?

Yes ☐ No ☐

If 'yes' please state:

Questions 21 to 24 ask about any treatment you may have had for your macular condition.

21. Have you had any treatment for your macular condition, now or in the past?

Yes ☐ ↓ No ☐ → (if 'no' please go to Q25 on page 17)

If 'yes', please tick all the treatments you have had from the list below:

- injections into the eye (also called anti-VEGF injections, e.g. Avastin, Lucentis or Eylea) .... ☐
- laser treatment .... ☐
- photodynamic therapy .... ☐
- radiation therapy .... ☐
- intraocular lens implant .... ☐
- other, please state below:

22. What was your most recent treatment? Please state below:

a) Name of treatment:

b) Date of last treatment: _ _ / _ _ / _ _

c) Date of last follow-up appointment: _ _ / _ _ / _ _

23. How satisfied/dissatisfied were you with this treatment overall?

- satisfied .... ☐
- slightly satisfied .... ☐
- neither satisfied nor dissatisfied .... ☐
- slightly dissatisfied .... ☐
- dissatisfied .... ☐

Please give reasons for your response in the space below:

24. Did you feel involved in the decision-making about this treatment?

- Yes, and I wanted to be .... ☐
- Yes, but I didn't want to be .... ☐
- No, but I wanted to be .... ☐
- No, and I didn't want to be .... ☐

25. Since diagnosis, can you see:

- better .... ☐
- the same .... ☐
- worse .... ☐

The next questions are on the support you have received after diagnosis.

26. Are you a member of a local support group for people with macular conditions?

Yes ☐ No ☐

27. Were you able to get more information about your macular condition after diagnosis?

Yes ☐ No ☐ (if 'no' please go to Q28)

If 'yes', where did you find this information? Please state below:

☐

28. Have you attended a low-vision clinic?

a) Yes ☐ (if 'yes' please go to Q28c) No ☐

b) If 'no' would you like to attend a low-vision clinic?

Yes ☐ No ☐ Please now go to Q29 on page 19.

28c). Please rate your overall satisfaction/dissatisfaction with the low-vision clinic:

- satisfied .... ☐
- slightly satisfied .... ☐
- neither satisfied nor dissatisfied .... ☐
- slightly dissatisfied .... ☐
- dissatisfied .... ☐

28d). Please give reasons for your overall satisfaction/ dissatisfaction with the low-vision clinic.

☐

29. Have you ever been shown how to use low-vision aids?

a) Yes ☐ No ☐

b) If 'no' would you like to be shown how to use them?

Yes ☐ No ☐

30. Have you ever found low-vision aids (including electronic aids) useful?

a) Yes ☐ No ☐

Please use the space below for comments on the pros and cons of specific low-vision aids:

☐

30b). Have any particular low-vision aids or techniques helped you continue with work or leisure activities? If so, please describe:

☐

31. Have you heard of eccentric viewing? (techniques which help make the most of your remaining peripheral vision)

Yes ☐ No ☐

32. Have you ever been trained in eccentric viewing?

Yes ☐ No ☐ → (if 'no' please go to Q33)

If 'yes', how useful did you find the eccentric viewing training?

- very useful .... ☐
- moderately useful .... ☐
- slightly useful .... ☐
- not at all useful .... ☐

33. Have you ever had a home assessment done by a rehabilitation officer? (i.e. someone who assessed your home environment and provided advice to improve your daily living e.g. on lighting issues, mobility within the home.)

a) Yes ☐ No ☐

b) If 'no' would you like to have a home assessment done?

Yes ☐ No ☐

34. Have you ever been offered psychological support from the hospital or eye clinic?

a) Yes ☐ No ☐

b) If 'no' would you like/have liked to receive psychological support

- now? ....Yes ☐ No ☐
- at the time of diagnosis?..........Yes ☐ No ☐

35. Do you feel you have a need for services that have not been offered to you?

Yes ☐ No ☐

If 'yes' please comment below:

36. Do you have one or more friends or family members who provide unpaid care, support or assistance to you **because of your macular condition**?

Yes ☐ No ☐ → (if 'no' please go to Q37 on page 22)

If 'yes', please state:

- their relationship to you, e.g. husband, daughter, friend:

- the average hours per week in total they spend helping you:

Fewer than 7 hours per week .... ☐
7 to 14 hours .... ☐
15 to 35 hours .... ☐
More than 35 hours per week .... ☐

Question 37 is on experiences of visual hallucinations. These might appear as patterns, faces, people, plants, trees, animals or other objects. This condition is called Charles Bonnet Syndrome and is a common side effect of sight loss. If needed, contact the Macular Society for more information on 0300 3030 111 after completing this questionnaire.

37a). Since the diagnosis of your macular condition, have you experienced any visual hallucinations (i.e. seeing things that other people cannot see)?

Yes ☐ ↓ No ☐ ➡ (if 'no' please go to Q38 on page 23)

If 'yes', please describe:

☐

37b). Have you talked about the visual hallucination(s) with a healthcare professional, e.g. an eye specialist, GP or optician?

Yes ☐ ↓ No ☐ ➡ (if 'no' please go to Q38 on page 23)

37c). Were you told of any possible cause of these visual hallucination(s)?

Yes ☐ ↓ No ☐ ➡ (if 'no' please go to Q38 on page 23)

If 'yes', please state cause below:

☐

38. Around the time of diagnosis of your macular condition, were any of the following recommended to you?

38a). Having regular eye tests (at least every two years):

- Was this recommended around the time of diagnosis?

  Yes ☐ No ☐

- If 'yes' by whom?

  eye specialist ☐ optician ☐ other ☐

- To what extent do you have eye tests at least every two years?

  not at all ☐ sometimes ☐ mostly ☐ all the time ☐

38b). Eating a diet rich in fruit and vegetables, oily fish and eggs:

- Was this recommended around the time of diagnosis?

  Yes ☐ No ☐

- If 'yes' by whom?

  eye specialist ☐ optician ☐ other ☐

- To what extent do you have a diet rich in fruit, vegetables, oily fish and eggs now?

  not at all ☐ sometimes ☐ mostly ☐ all the time ☐

38c). Protecting your eyes from bright sunlight:

- Was this recommended around the time of diagnosis?

  Yes ☐ No ☐

- If 'yes' by whom?

  eye specialist ☐ optician ☐ other ☐

- To what extent do you protect your eyes from bright sunlight?

  not at all ☐ sometimes ☐ mostly ☐ all the time ☐

38d). Taking nutritional supplements (such as vitamins, minerals and antioxidants):

- Was this recommended around the time of diagnosis?

  Yes ☐ No ☐

- If 'yes' by whom?

  eye specialist ☐ optician ☐ other ☐

- To what extent do you take nutritional supplements regularly now?

  not at all ☐ sometimes ☐ mostly ☐ all the time ☐

- Which nutritional supplements do you take (if any)?

☐

38e). Monitoring your own vision (especially the better eye) using an Amsler grid and/or any straight line in your environment e.g. a window:

- Was this recommended around the time of diagnosis?

  Yes ☐ No ☐

- If 'yes' by whom?

  eye specialist ☐ optician ☐ other ☐

- To what extent do you monitor your vision now?

  not at all ☐ daily ☐ weekly ☐ monthly ☐ yearly ☐

38f). At the time of diagnosis of your macular condition, did you smoke?

- Yes ☐ ↓ No ☐ → (if 'no' please go to Q39)

- If 'yes', were you recommended to stop smoking by your eye specialist, GP or optician (in relation to your macular condition)?

  Yes ☐ No ☐

- Do you smoke now?

  Yes ☐ No ☐

39). Please state below any other recommendations and the extent to which you follow them:

☐

40. Have you ever felt that you have been treated differently from a person who doesn't have a macular condition? This could be at work, at home, with family or friends etc., and could be in a positive or negative way.

Yes ☐ No ☐

If 'yes', please give example/s and indicate if positive or negative:

41. Are you registered as severely sight impaired (blind) or sight impaired (visually impaired)?

41a). Yes ☐ No ☐ (if 'no' please go to Q41c on page 27)

If 'yes', please give date or dates below:

41b).
- date registered as sight impaired _ _/_ _/_ _
- date registered as severely sight impaired _ _/_ _/_ _

Please now go to Q42 on page 27.

41c). If you have not registered as severely sight impaired (blind) or sight impaired, please tick the reason(s) why below:

- I haven't been offered registration .... ☐
- I was offered registration but declined .... ☐
- I was offered registration and it is being processed .... ☐
- Other, please state below:

42. **Please give the following details about yourself:**

42a). Date of birth _ _/_ _/_ _

42b). Sex: Male ☐ Female ☐

42c). Please indicate your ethnic group below:

- White .... ☐
- Asian/Asian British .... ☐
- Black/Black British .... ☐
- Chinese .... ☐
- Other, please state below:

42d). Is English your first language?

Yes ☐ No ☐

If 'no' please rate your fluency in English on the scale below by putting a cross on the number that applies to you:

very basic	1	2	3	4	5	6	7	very fluent

42e). Age at leaving full time education: ☐ years

42f). Please state in the boxes your occupation.

before onset of symptoms of macular condition:

after diagnosis:

now:

42g). If you have had any changes of occupation, were they due to the macular condition?

Yes ☐ No ☐

If 'no', please state reason(s):

42h). Please state in the box below your main interests and activities:

42i). Have you needed to change your activities or interests because of your macular condition?

Yes ☐ No ☐

Please give any comments below:

43. How comfortable do you feel using a computer?

- very comfortable .... ☐
- comfortable .... ☐
- not at all comfortable ...... ☐

44. Do you live alone? ....Yes ☐ No ☐

45. Do you have any loss of hearing? ....Yes ☐ No ☐

46. In general, my health is:

- excellent .... ☐
- very good .... ☐
- good .... ☐
- neither good nor bad .... ☐
- bad .... ☐
- very bad .... ☐
- extremely bad .... ☐

47. Did someone else help you to complete this questionnaire?

Yes ☐ No ☐

48. Today's date: _ _ / _ _ / _ _

for office use

This section will be detached from the survey so that it remains anonymous.

49. Please write your postcode in the box below:

☐

Thank you – your contribution is greatly appreciated.

Please do not write on this page – thank you.

Your contact details

Thank you for taking part in this survey. Please write down your contact details below if you are willing to be contacted if we need more information about your replies.

Name ________________________________

Telephone ________________________________

Postal address ________________________________

____

____

____

Email address ________________________________

Would you be happy to be put on a database of people willing to be invited to participate in future research? (You would be under no obligation to take part).

- Yes, I am willing to be invited .... ☐
- No, I don’t wish to be invited................ ☐

Carer’s contact details

The research team at Royal Holloway, University of London may be conducting some research on the experiences of carers of people with macular conditions in the future. If you have a carer who may be interested in receiving an invitation to participate in this research, please provide their contact details below (they would be under no obligation to take part).

Name ____

Telephone ____

Postal address ____

____

____

____

Email address ____

Research team:
Ms Emily Boxell, PhD Researcher
Prof Clare Bradley, Professor of Health Psychology
Health Psychology Research Unit, Royal Holloway,
University of London. TW20 0EX
Telephone: 01784 443718 or 01784 443714

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Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
General modification made in the MSQ 2013:					"MD" (macular disease) in the MDSQ 1999 changed to "macular conditions" for all 2013 survey questions. The term 'macular conditions' is more commonly used now.
1*Used to select participants with AMD for analyses reported in Chapters 3 and 4, and to assist participant selection in the follow-on study.	29c (see below)	1	(See below.)	Do you have age-related macular degeneration (AMD)? Y/N If 'no' write the name of your macular condition in the box below and go to Q3: [free-text box response]	The author felt that q29c used in the MDSQ 1999 could be made clearer to ascertain whether the respondent had AMD (the most common macular condition) or another type of macular condition. In the modified version, only respondents who reported having AMD would be directed to answer further questions about the type and stage of AMD they had (which is only relevant for people with AMD) (q2a and b).
2*results reported in chapter 3	29c	2a)	Which form of MD do you have? Please indicate below for each eye. • Left eye Wet Dry	If you have AMD, which form do you have? • Left eye Wet Dry	(See 1 above.)

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
			Don’t know None Any other conditions [free-text response box] • Right eye Wet Dry Don’t know None Any other conditions [free-text response box]	Don’t know None • Right eye Wet Dry Don’t know None	
3	-	2b)	-	If you have AMD, do you know what stage it is at now? • Left eye Early/ intermediate Advanced Don’t know None • Right eye Early/ intermediate Advanced Don’t know	(See 1 above.)

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				None	
4*results reported in chapter 3	29d	3	Dates of diagnosis of MD - Left eye _ _ / _ _ / _ _ - Right eye _ _ / _ _ / _ _	Dates (approximate) of diagnosis of your *macular condition*: a) Left eye _ _ / _ _ / _ _ b) Right eye _ _ / _ _ / _ _	To explore the impact of the RCOphth guidelines for AMD published in February 2009, and the publication of the MDSQ 1999 results in July 2002, a new variable was created based on the 2013 survey respondents' date of diagnosis (before or after each of these dates). Also used to create new variable for age at diagnosis which was used for participant selection (see Figure 2.1 in Chapter 2).
5	1	4	Had you heard about MD before your own condition was diagnosed? Y/N	Had you heard of *macular conditions* before your own condition was diagnosed? Y/N	"MD" (macular disease) changed to "macular conditions" for all 2013 survey questions. The term 'macular conditions' is more commonly used now and the term 'disease' avoided by the Macular Society.
6	3j	5	Before your MD was diagnosed had you experienced any of the following conditions or circumstances? …	Around the time of diagnosis, had you experienced stress or bereavement? Y/N	The 1999 survey had a question covering the length of two pages that asked about possible risk factors for MD (question 3a-m). In the 2013 survey, these were reduced to two questions (question numbers 5 and 6). Since the 1999 survey there have been many well-designed studies that have investigated risk factors for macular conditions

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
			j) stress or bereavement (Y/N)		in great detail (e.g. see Chakravarthy et al., 2010; Guymer & Chong, 2006; Tomany et al., 2004). This was not a primary aim of the present study. Thus these 1999 survey questions (q3b-i, k-m) were removed from the 2013 survey.
7	3a & 9	6	3. Before your MD was diagnosed had you experienced any of the following conditions or circumstances? a) Other eye disease e.g. glaucoma, cataracts (Y/N) If 'yes', please describe [free-text box response] 9. Have you had any eye treatments or operations e.g. laser operation, operation to remove cataracts, treatment for glaucoma? Y/N If 'yes', please state which treatments or operations you have had: [free-text box response]	Apart from your macular condition, do you/ did you have any other eye disease e.g. glaucoma, cataracts? Y/N -If 'yes' describe the condition and dates of any major treatment: [free-text box response]	The MSQ 2013 included one question that asked about other eye conditions and treatments for these conditions. As above, the primary aim of the MDSQ 1999 question was to investigate the presence/ treatment for other eye conditions as a risk factor for the respondent's macular condition. This was not a primary aim of the MSQ 2013 study. The MSQ 2013 question was included to have this background information from the respondent. For instance, q7 below asked about seeking help for symptoms of the macular condition. It was hypothesised that having another eye condition may have affected help-seeking.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
8	-	7a)	-	How was your macular condition first noticed? • By my optician at a routine eye test appointment: Y/N • I noticed the symptoms myself and sought medical help: Y/N • Someone else first noticed the signs of my macular condition: Y/N If 'yes' please describe what happened below and then go to Q7b on page 5. • Other, please state below [free-text response box]	Based on the literature review discussed in chapter 1, gaps in the literature were identified and as a result, these newly-designed questions were included in the survey. (At the time of designing the 2013 survey, there were no relevant questionnaires available that had been designed and evaluated to measure this topic in people with macular conditions.)
9	-	7b)	-	I first sought help from a: • GP • Optician • Hospital Eye Clinic • Other, please state: [free-text response box]	As above.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
				Please describe the symptom that led you to seek help: [free-text response box]	
10	-	7c)	-	Once symptoms were noticed, how quickly did you seek advice from a healthcare professional (GP, optician, hospital doctor)? • Same or next day • 2 to 6 days • 1 week to 1 month • More than 1 month • Can't remember • N/A	As above.
11	-	7d)	-	If your appointment with a healthcare professional about early symptoms was delayed for more than 2 days, please state reasons why below: [free-text response box]	As above.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
12*results reported in chapter 3	-	8a)	-	Who first diagnosed your macular condition? Please tick one box from the list below: • Hospital eye specialist • Optician • GP • Don't know • Other, please state: [free-text response box]	This question was added to the 2013 survey to clarify who diagnosed the respondent's macular condition. Since the 1999 survey, optometrists have been able to give a diagnosis to the patient. The other response options were included to check whether respondents had seen an ECP or someone else about their macular condition.
13*results reported in chapter 3	4d	8b)	When your MD was first diagnosed: Did you feel that the Eye Specialist who diagnosed your MD was interested in you as a person? Y/N	Did you feel that *this healthcare professional (who first diagnosed your macular condition),* was interested in you as a person? Y/N	The wording was changed from 'eye specialist' (in the 1999 survey) to 'healthcare professional' (in the 2013 survey) to reflect the fact that optometrists can now diagnose macular conditions (whereas in 1999 this was not the case) and some respondents may only have seen their optometrist (or GP which is less likely but still possible), and may not have received a formal diagnosis from an ophthalmologist.
14*results reported in chapter 3	4e	8c)	When your MD was first diagnosed: Did you feel that the interview with the Eye Specialist was satisfactory?	Overall, did you feel that the diagnostic consultation with *this healthcare professional* was satisfactory? Y/N	As above. In the MDSQ 1999, respondents were asked to provide reasons for *dissatisfaction* with the consultation only. The MSQ 2013 used a modified version of this question which asked respondents to provide reasons for dissatisfaction or satisfaction with the diagnostic consultation.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			Y/N If 'no', please state why you felt dissatisfied: [free-text response box]	*Please explain why below*: [free-text response box]	
15*results reported in chapter 3	4b	8d)	When your MD was first diagnosed: b) Were you given the name of this condition? Y/N	Were you given the name of your condition at the time of diagnosis? Y/N *If 'yes', what name was given for your eye condition at the time of diagnosis? Please tick one or more of the following*: • Macular degeneration (MD) • Age-related macular degeneration (AMD) • Juvenile macular degeneration • Wet AMD • Dry AMD • Don't recall	Sub-question asking respondents to report what name they were given for their macular condition at the time of diagnosis was added to see if this had changed since diagnosis (i.e. using the response to q2a of the 2013 survey, we could see if dry AMD at diagnosis had changed to wet AMD since diagnosis, for example). Also used to investigate if HCPs were giving the name of the exact type of macular condition at the time of diagnosis.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
				- Other (please state in box) e.g. retinitis pigmentosa, cone dystrophy, rod dystrophy, Stargardt's disease: [free-text response box]	
16*results reported in chapter 3	-	8e)	-	Were you given any written information about your macular condition at the time of diagnosis? Y/N	New question designed to assess the incorporation of the RCOphth 2009 guidelines on AMD into practice, and focus on information and support provision around the time of diagnosis.
17*results reported in chapter 3	-	8f)	-	Were you given any information around the time of diagnosis about what to do if you were to have a sudden deterioration in your vision? Y/N	As above.
18*results reported in chapter 3	-	8g)	-	Do you feel you were given appropriate support, help or advice at the time of diagnosis? Y/N	As above.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
19*results reported in chapter 3	16	8h)	Were you given any information about the MD society or local self-help groups? Y/N If 'yes', please state who gave you the information. [free-text response box]	Were you given information about the Macular Society (or the Macular Disease Society, as it was previously called) *at the time of diagnosis*? Y/N	This question was modified slightly in order to investigate if this information was given in the diagnostic consultation specifically. Designed to assess the incorporation of the RCOphth 2009 guidelines on AMD into practice. Sub-question was removed as this question followed the other 2013 survey questions on experiences within the diagnostic consultation. Respondents had indicated in an earlier question which HCP had first diagnosed their macular condition (q8a).
20*results reported in chapter 3	-	8i)	-	Were you given any other contacts for help and support at the time of diagnosis? Y/N If yes, please state: [free-text response box]	New question designed to assess the incorporation of the RCOphth 2009 guidelines on AMD into practice, and focus on information and support provision around the time of diagnosis.
21*results reported in chapter 3	-	8j)	-	Around the time of diagnosis, were you given information about the likely progress of your macular condition? Y/N	As above.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
22	-	8k)	-	If at initial diagnosis only one eye was affected, were you given information about how your second eye might be affected in the future? Y/N	As above.
23	-	9	-	If your condition was not initially diagnosed by a hospital eye specialist, have you been to see a hospital eye specialist about your macular condition since diagnosis? Y/N If 'yes', please tick one or more reasons why you have been to see a hospital eye specialist from the list below: • For confirmation of diagnosis • For low-vision service referral • For a certificate of visual impairment	This question was added based on a suggestion from the Macular Society. Staff from the society were concerned that there may be people with macular conditions who are diagnosed in primary care or in the community and have not been seen in a hospital setting, and thus may be missing out on information and support or perhaps treatment. This question was added to investigate this and to determine the reasons why patients had been seen in the hospital.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				• For monitoring vision • For treatment • Other, please state below: [free-text response box]	
24	14	9a)	Did you see your eye specialist privately or on the N.H.S.? • N.H.S. only • Private only • Both private and N.H.S.	Did you see your eye specialist privately or on the NHS? • NHS only • Private only • Both private and NHS	No change.
25*results reported in chapter 3	5 and 6	10 and 11	**For questions 5 and 6 please circle one number where ‘3’ indicates ‘very’ and ‘0’ indicates ‘not at all’.** 5. Around the time you were first diagnosed with MD, to what extent was your General Practitioner well informed about MD?........................... Very not at all 3 2 1 0	**For questions 10 and 11 please circle one number where ‘3’ indicates ‘very’ and ‘0’ indicates ‘not at all’. *If you did not discuss your macular condition with your GP, please circle N/A for not applicable.*** 10. Around the time you were first diagnosed with *your macular condition*, to what extent was your *GP*	In the 1999 survey, missing data on responses to the two GP questions were considerable. Many wrote on the survey that they had not seen their GP about their macular condition (Mitchell, Bradley, Anderson, Ffytche, & Bradley, 2002). A “not applicable” option was therefore added in the 2013 survey to investigate how many had not visited their GP about their AMD. “MD” (macular disease) changed to “macular conditions” for all 2013 survey questions. The term ‘macular conditions’ is now preferred by the Macular Society.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			6. To what extent has your General Practitioner been helpful and supportive? ………………………………………. Very not at all 3 2 1 0	well-informed about *your condition*?........................... Very not at all 3 2 1 0 *N/A* 11. To what extent has your *GP* been helpful and supportive *about your macular condition*? ………… Very not at all 3 2 1 0 *N/A*	
26	7	12	Were you ever told by an eye specialist, G.P. or optometrist (optician) that ‘**Nothing can be done’** to help with your MD? Y/N If ‘yes’, how did you react to being told, ‘Nothing can be done’? Please answer ‘yes’ or ‘no’ to each of a,b,c,d,e, f. Did you feel: a) Resigned Y/N	Were you ever told by *a healthcare professional* that ‘**Nothing can be done’** to help with your *macular condition*? Y/N *12a) If ‘yes’, which healthcare professional told you this? Please tick from the list below:* • *Hospital eye specialist*	The MDSQ 1999 question was modified to account for the fact that healthcare professionals other than the eye specialist, GP or optometrist may have told respondents that ‘nothing can be done’ for their macular condition. The sub-question was added to investigate which healthcare professionals this was.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
			b) Shocked/ sick/ panic Y/N c) Helpless Y/N d) Angry Y/N e) Anxious or depressed Y/N f) Suicidal Y/N Other, please state; [free-text response box]	• *Nurse* • *Optician* • *GP* • *Eye clinic liaison officer* • *Other, please state: [free-text response box]* 12b) How did you react to being told, 'Nothing can be done'? Please answer 'yes' or 'no' to each of a,b,c,d,e, and f. Did you feel: a) Resigned Y/N b) Shocked/ sick/ panic Y/N c) Helpless Y/N d) Angry Y/N e) Anxious or depressed Y/N f) Suicidal Y/N g) Other, please state below; [free-text response box]	

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
27	8	13	Were you ever told by an eye specialist, G.P. or optometrist (optician) that you will not go completely blind because of your MD? Y/N If 'yes', how did you react to being told, 'You will not go completely blind'? Did you feel: a) Relieved Y/N b) Other, please state: [free-text response box]	Were you ever told by *a healthcare professional* that 'You will not go completely blind' because of your *macular condition?* Y/N *13a) If 'yes', who told you this? Please tick from the list below:* • *Hospital eye specialist* • *Nurse* • *Optician* • *GP* • *Eye clinic liaison officer* • *Other, please state: [free-text response box]* 13b) How did you react to being told, 'You will not go completely blind'? Did you feel: a) Relieved Y/N b) *Alarmed Y/N*	As above. 'Alarmed' was added to the MSQ 2013 question to investigate alternative reactions to being told that one will not go completely blind. It was hypothesised that whilst some people might be relieved that they will **not** go **completely** blind, others may not have considered that their macular condition would lead to severe vision loss and therefore this statement might be considered alarming.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				c) Other, please state below: [free-text response box]	
28	13	14	Have you been told that MD is part of the ageing process? Y/N If 'yes', by whom? (Eye specialist, G.P., Optometrist, etc) [free-text response box]	Have you been told that *your macular condition* is part of the ageing process? Y/N 14a) If 'yes', *who told you this? Please tick from the list below:* • *Hospital eye specialist* • *Nurse* • *Optician* • *GP* • *Eye clinic liaison officer* • *Other, please state: [free-text response box]*	Tick list provided for more straightforward data entry (only responses to the 'other' response category in the 2013 survey question required coding). The same tick list was provided as that used in the previous two questions (q12 and 13), as it was hoped that respondents might be familiar with the content and order of the list of healthcare professionals, and that this might make the question easier to complete.
29*results reported in chapter 3	-	15	-	Were you told by a healthcare professional, around the time of	New question designed to assess the incorporation of the RCOphth 2009 guidelines on AMD into practice, and focus

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				diagnosis, of the possibility of experiencing visual hallucinations as a side effect of sight loss? Y/N	on information and support provision around the time of diagnosis.
30*results reported in chapter 3	-	16	-	In the past 12 months, have you seen an eye specialist or optician about your macular condition? - Yes - No, and I haven't needed to - No, but I needed to If you ticked 'No, but I needed to' please give reasons for your response below: [free-text response box]	Question included to investigate gaps in support provision/ need for help and support.
31*results reported in chapter 3 and chapter 4	22 & 23	17 & 18	In general, my quality of life is: Excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad. If I did not have MD, my quality of life would be:	In general, my *present* quality of life is: Excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad.	These questions on quality of life appear in the MacDQoL (Mitchell et al., 2005). The changes to the MD-specific item reflect changes made to this item in the MacDQoL since 1999 (see Mitchell & Bradley, 2004). In particular, the number of positive response options for the MD-specific item was reduced from three to one (from '*a little worse, much worse* and *very much worse'* to '*worse*'). This change was made because few people use this end of the scale, as

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			Very much better/ much better/ a little better/ the same/ a little worse/ much worse/ very much worse.	If I did <u>*not*</u> have a macular condition, my quality of life would be: Very much better/ much better/ a little better/ the same/ *worse.*	it would indicate benefits of having a macular condition, which are usually perceived as being few if any. The wording of the question stem for the general QoL item has not changed since the design of the Audit of Diabetes Dependent quality of life (ADDQoL) questionnaire (Bradley et al., 1999), on which the MacDQoL is based. It is not known why the 1999 survey question omitted the word 'present' from this item.
32*results reported in chapter 3 and chapter 4	24 (a-l)	19 (a-p)	W-BQ 12	W-BQ 16	The longer version of this Well-Being Questionnaire (which includes a stress subscale) was used so that psychometric evaluation of this measure for people with AMD could be carried out. (Psychometric evaluation of the W-BQ 12 for people with macular conditions was carried out using data from the 1999 survey (Mitchell & Bradley, 2001)). The W-BQ16 has already been validated (along with other condition-specific subscales making up the W-BQ28) for use with patients with diabetes (Speight, Khagram, & Davies, 2012).
33	-	20	-	Do you feel that your well-being has been affected by anything in particular in the past few weeks, e.g. any other health conditions,	We anticipated that they may be other factors not measured in the survey questions that may affect respondent's well-being. This question asked if they felt anything in particular had affected their well-being in the past few weeks (which is the time period over which respondents are asked to consider their well-being).

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				bereavement, retirement? Y/N If ‘yes’, please state: [free-text response box]	
34	9	21	Have you had any eye treatments or operations e.g. laser operation, operation to remove cataracts, treatment for glaucoma? Y/N If ‘yes’, please state which treatments or operations you have had: [free-text box response]	Have you had any treatment for your macular condition, now or in the past? Y/N If ‘yes’, please tick all the treatments you have had from the list below: • Injections into the eye (also called anti-VEGF injections, e.g. Avastin, Lucentis or Eylea) • Laser treatment • Photodynamic therapy • Radiation therapy	The 2013 survey was changed to include separate questions on treatment for macular conditions and other eye conditions. The updated question here was modified to focus specifically on treatment for macular conditions. A tick list was provided as a prompt and for more straightforward data entry.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				• Intraocular lens implant • Other, please state below: [free-text response box]	
35	-	22	-	What was your most recent treatment? Please state below: a) Name of treatment: [free-text response box] b) Date of last treatment: _ _/ _ _/ _ _ c) Date of last follow-up appointment: _ _/ _ _/ _ _	This question was added to the MSQ 2013 to investigate whether respondents have received treatment for their macular condition and what this treatment is. They were asked dates of last treatment/ follow-up to investigate how long ago they had been seen and if their sight had been monitored recently. This question was included to investigate impact of treatment on patient-reported outcomes such as well-being and quality of life as well as visual outcomes (e.g. registration status).
36	-	23	-	How satisfied/ dissatisfied were you with this treatment overall? • Satisfied • Slightly satisfied • Neither satisfied nor dissatisfied • Slightly dissatisfied	Question was added to investigate respondents' satisfaction with recent treatment.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				• Dissatisfied Please give reasons for your response in the space below: [free-text response box]	
37	-	24	-	Did you feel involved in the decision-making about this treatment? • Yes, and I wanted to be • Yes, but I didn't want to be • No, but I wanted to be • No, and I didn't want to be	Question was added to investigate whether respondents' felt they had a say/ role in deciding whether they wanted treatment, and if they preferred to be involved in the decision-making process for treatment or not. Based on the literature review discussed in chapter 1, gaps in the literature were identified and as a result, this newly-designed question was included in the survey. (At the time of designing the 2013 survey, there were no relevant questionnaires available that had been designed and evaluated to measure this topic in people with macular conditions.)
38*results reported in chapter 4	12	25	Have you found any improvement in vision since diagnosis of MD? Yes/ No/ don't know If 'yes', to what do you attribute the improvement? [free-text response box]	Since diagnosis, can you see: • Better • The same • Worse	The MDSQ 1999 question was modified in order to find out if respondents' felt that their vision had remained the same or had become worse since diagnosis (a response of 'no' to the 1999 question does not tell us whether vision had remained the same or deteriorated, however a 'yes' answer tells us that sight has improved). The sub-question was removed from the 2013 survey as part of prioritising questions of relevance to the aims of the 2013 survey.

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39*results reported in chapter 3	17	26	Are you a member of a local MD self-help group? Y/N	Are you a member of a local *support group for people with macular conditions*? Y/N	"MD" (macular disease) changed to "macular conditions" for all 2013 survey questions. The term 'macular conditions' is preferred by the Macular Society now. 'Support group' used instead of 'self-help' group as this terminology is more commonly used now (e.g. by the Macular Society).
40*results reported in chapter 3	18	27	Were you able to get more information about your MD after diagnosis? Y/N -If 'yes', where did you find this information? [free-text box response]	Were you able to get more information about your *macular condition* after diagnosis? Y/N -If yes, where did you find this information? *Please state below.* [free-text box response]	"MD" (macular disease) changed to "macular conditions" for all 2013 survey questions. The term 'macular conditions' is more commonly used now.
41*results reported in chapter 3	25	28 a) & b)	Have you been to a low vision clinic? Y/N	Have you *attended* a low-vision clinic? Y/N *-if 'no' would you like to attend a low-vision clinic? Y/N*	Sub-question included to investigate gaps in support provision/ need for help and support.
42*results reported in chapter 3	-	28c)	-	Please rate your overall satisfaction/ dissatisfaction with the low-vision clinic: Satisfied/ slightly satisfied/ neither satisfied nor	Question added to investigate respondents' satisfaction with the low-vision clinic. Question adapted from the MacSSQ (Mitchell & Bradley, 2009, 2011).

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				dissatisfied/ slightly dissatisfied/ dissatisfied.	
43	-	28d)	-	Please give reasons for your overall satisfaction/ dissatisfaction with the low-vision clinic. [free-text response box]	Question added to investigate respondents' reasons for dis/satisfaction with the low-vision clinic.
44	27	29	Have you been shown how to use low vision aids? Y/N	Have you *ever* been shown how to use *low*-vision aids? Y/N *-If 'no' would you like to be shown how to use them? Y/N*	Sub-question included to investigate gaps in support provision/ need for help and support.
45	28	30	Have you found low vision aids useful? Y/N -If 'yes', please note below which aids you have found useful. [free-text box response] -If there are any low vision aids you have tried but did not find to be useful, please note which aids they were and why they were not useful. [free-text box response]	Have you *ever* found *low-vision* aids *(including electronic aids)* useful? Y/N *-Please use the space below for comments on the pros and cons of specific low-vision aids:* [free-text box response]	Two sub-questions were combined to save space. Included the term 'electronic aids' in the 2013 survey as a prompt for respondents to report these (if they were used).

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
46	-	30b)	-	Have any particular low-vision aids or techniques helped you continue with work or leisure activities? If so, please describe: [free-text response box]	This question was added to focus on whether respondents were able to continue with leisure and/or work activities at the time of survey completion, and which low-vision aids or techniques had helped them to continue with these.
47	-	31	-	Have you heard of eccentric viewing? (techniques which help make the most of your remaining peripheral vision) Y/N	In addition to the questions on low-vision aids, this question was added to investigate other strategies respondents' might use for managing the effects of vision loss.
48	-	32	-	Have you ever been trained in eccentric viewing? Y/N -If 'yes', how useful did you find the eccentric viewing training? Very useful/ moderately useful/ slightly useful/ not at all useful.	See above. Question added to investigate whether respondents had been trained in eccentric viewing and whether or not they had found it useful.
49	26	33 a) & b)	Have you been visited at home by a rehabilitation officer? Y/N	Have you ever had a home assessment done by a rehabilitation officer? *(i.e. someone who assessed*	Brief explanation provided in the 2013 survey in case respondents weren't aware of the role of a rehabilitation officer.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				your home environment and provided advice to improve your daily living e.g. on lighting issues, mobility within the home.) Y/N *If 'no' would you like to have a home assessment done? Y/N*	Sub-question included to investigate gaps in support provision/ need for help and support.
50*results reported in chapter 3	-	34 a) & b)	-	Have you ever been offered psychological support from the hospital or eye clinic? Y/N -If 'no' would you like/ have liked to receive psychological support: Now? Y/N At the time of diagnosis? Y/N	As reported in the literature review in chapter 1, many people experiencing vision loss have poor mental health. This question was added to investigate whether respondents had ever been offered/ received psychological support for their macular condition. Sub-question included to investigate gaps in support provision/ need for help and support.
51	-	35	-	Do you feel you have a need for services that have not been offered to you? Y/N -If 'yes' please comment below (free-text response box)	Question included to investigate whether respondents had any need for help and support that was not already covered in the previous questions.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
52*results reported in chapter 4	-	36	-	Do you have one or more friends or family members who provide unpaid care, support or assistance to you because of your macular condition? Y/N -If 'yes', please state: • Their relationship to you, e.g. husband, daughter, friend: (free-text response box) • The average hours per week in total they spend helping you: Fewer than 7 hours per week/ 7 to 14 hours/ 15 to 35 hours/ more than 35 hours per week.	Based on the literature review discussed in chapter 1, gaps in the literature were identified and as a result, these newly-designed questions were included in the survey. (At the time of designing the 2013 survey, there were no relevant questionnaires available that had been designed and evaluated to measure this topic in people with macular conditions.)
53*results reported in chapter 3	19	37a-c)	Have you experienced any vision changes that have caused you concern? E.g. pulsating lights, flashes, shimmering light, hallucinations such as animal, human or plant forms, changing coloured patterns,	***Question 37 is on experiences of visual hallucinations. These might appear as patterns, faces, people, plants, trees, animals or other objects. This condition is called Charles Bonnet Syndrome***	1999 survey question was modified for the 2013 survey to focus on the specific vision change of interest to the present study (experiencing visual hallucinations). It is possible that respondents may not have had knowledge of Charles Bonnet Syndrome before reading this survey. The Macular Society contact phone number was provided for information and support.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			blurred vision, difficulty seeing depth or seeing at night. Y/N If ‘yes’, please state. [free-text response box] • Have you talked about these experiences with your eye specialist, GP or optometrist? Y/N	***and is a common side effect of sight loss. If needed, contact the Macular Society for more information on 0300 3030 111 after completing this questionnaire.*** 37a) Since the diagnosis of your macular condition, have you experienced any *visual hallucinations (*i.e. seeing things that other people cannot see)? Y/N If ‘yes’, please describe: [free-text response box] 37b) [If ‘yes’ to q37a] Have you talked about the *visual hallucination(s*) with a *healthcare professional*, e.g. an eye specialist, GP or optician? Y/N	

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			- Were you told of any possible causes of these experiences? Y/N If 'yes', please state. [free-text box response]	37c) [If 'yes' to q37b] Were you told of any possible cause of these *visual hallucination*(s)? Y/N If 'yes', please state cause below: [free-text response box]	
54	15	38a)	After diagnosis of MD, did your eye specialist, G.P. or optometrist recommend regular eye tests in case other conditions developed? Y/N	Around the time of diagnosis of your *macular condition*, were any of the following recommended to you? a) Having regular eye tests (*at least every two years)*: - *Was this recommended around the time of diagnosis? Y/N* - *If 'yes' by whom? Eye specialist/ optician/ other (free-text response box)*	Based on the literature review discussed in chapter 1, gaps in the literature were identified and as a result, these new questions were included in the survey. Questions 38a-f were designed based on recommendations stated in the RCOphth 2009 guidelines for information that should be communicated to patients with AMD around the time of diagnosis. These recommendations include ways in which people with macular conditions can self-manage their condition (e.g. monitoring eyesight for sudden changes in vision).

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
				• *To what extent do you have eye tests at least every two years?* *Not at all/ sometimes/ mostly/ all the time*	
55	-	38b)	-	Around the time of diagnosis of your macular condition, were any of the following recommended to you? b) Eating a diet rich in fruit and vegetables, oily fish and eggs: • Was this recommended around the time of diagnosis? Y/N • If ‘yes’ by whom? Eye specialist/ optician/ other (free-text response box) • To what extent do you have a diet rich in fruit, vegetables, oily fish and eggs now? Not at all/ sometimes/ mostly/ all the time	As above.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
56	-	38c)	-	Around the time of diagnosis of your macular condition, were any of the following recommended to you? c) Protecting your eyes from bright sunlight: • Was this recommended around the time of diagnosis? Y/N • If 'yes' by whom? Eye specialist/ optician/ other (free-text box) • To what extent do you protect your eyes from bright sunlight? Not at all/ sometimes/ mostly/ all the time	As above.
57	-	38d)	-	Around the time of diagnosis of your macular condition, were any of the following recommended to you? d) Taking nutritional supplements (such as	As above.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				vitamins, minerals and antioxidants): • Was this recommended around the time of diagnosis? Y/N • If 'yes' by whom? Eye specialist/ optician/ other (free-text box) • To what extent do you take nutritional supplements regularly now? Not at all/ sometimes/ mostly/ all the time • Which nutritional supplements do you take (if any)?	
58	-	38e)	-	Around the time of diagnosis of your macular condition, were any of the following recommended to you? e) Monitoring your own vision (especially the better eye) using an	As above.

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				Amsler grid and/ or any straight line in your environment e.g. a window: • Was this recommended around the time of diagnosis? Y/N • If 'yes' by whom? Eye specialist/ optician/ other (free-text box) • To what extent do you monitor your vision now? Not at all/ daily/ weekly/ monthly/ yearly	
59	3g	38f)	Before your MD was diagnosed had you experienced any of the following conditions or circumstances? g. smoking Y/N	f) *At the time of diagnosis* of your macular condition, did you smoke? Y/N *If 'yes', were you recommended to stop smoking by your eye specialist, GP or optician (in*	As above. (Note that in the 1999 survey, the question was included mainly to investigate possible causes of AMD. In the 2013 survey the primary purpose was to find out if respondents had been recommended to stop smoking after diagnosis to help protect against further deterioration in vision.)

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				relation to your macular condition)? *Y/N* *Do you smoke now?* *Y/N*	
60	-	39)	-	Please state below any other recommendations and the extent to which you follow them: [free-text response box]	As above.
61	-	40)	-	Have you ever felt that you have been treated differently from a person who doesn't have a macular condition? This could be at work, at home, with family or friends etc., and could be in a positive or negative way. Y/N If 'yes', please give example/s and indicate if positive or negative: [free-text response box]	Based on the literature review discussed in chapter 1, gaps in the literature were identified and as a result, this newly-designed question was included in the survey. (At the time of designing the 2013 survey, there were no relevant questionnaires available that had been designed and evaluated to measure this topic in people with macular conditions.)

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
62*results reported in chapter 3 and 4	29f	41 a-c)	Are you registered as blind or partially sighted? Y/N If 'yes', please give date or dates below • Date registered as partially sighted __/__/__ • Date registered as blind __/__/__	41 a) Are you registered as *severely sight impaired* (blind) or *sight impaired* (visually impaired)? Y/N 41b) If 'yes', please give date or dates below: • Date registered as *sight impaired* __/__/__ • Date registered as *severely sight impaired* __/__/__ *41c) If you have not registered as severely sight impaired (blind) or sight impaired, please tick the reason(s) why below:* • *I haven't been offered registration* • *I was offered registration but declined*	Differences in the wording of the 1999 and 2013 survey questions reflect changes in terminology used since 1999. Sub-question included to investigate gaps in support provision/ need for help and support.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
				• *I was offered registration and it is being processed* • *Other, please state below: [free-text response box]*	
63*results reported in chapter 3 and 4	29a	42a	Date of birth _ _ / _ _ / _ _	Date of birth _ _ / _ _ / _ _	No change. (Used to create new variables for age at the time of survey completion and age at first diagnosis.)
64*results reported in chapter 3 and 4	29b	42b	Sex: Male/ Female	Sex: Male/ Female	No change.
65*results reported in chapter 3	29o	42c	Skin colour Please circle a number to indicate depth of your skin colour where 1 is lightest (eg white European) and 5 is darkest (eg black African). Light Dark 1 2 3 4 5	Please indicate your ethnic group below: • White • Asian/ Asian British • Black/ Black British • Chinese • Other, please state below: [free-text response box]	The 1999 survey question asked about depth of skin colour (which has been investigated as a risk factor for AMD). The 2013 survey question asked about ethnicity instead. The response options are typical of those included in other surveys, so it was perceived that respondents would be familiar with this type of question and that this would be easier to complete for the respondents, and provide data that could be compared with other research findings/ studies using these response options.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
66	-	42d	-	Is English your first language? Y/N If 'no' please rate your fluency in English on the scale below by putting a cross on the number that applies to you: Very basic Very fluent 1 2 3 4 5 6 7	Used as part of selection criteria- for respondents whose first language was not English and who rated their fluency in English as below 7, the hard copy survey responses were read and checked to see if they were able to understand and respond to the survey questions without difficulty.
67	-	42e	-	Age at leaving full time education: _ years	Included as a way of estimating socio-economic status (SES).
68	29j	42f	Please state in the boxes your occupation: • Before diagnosis [free-text response box] • After diagnosis [free-text response box] • Now [free-text response box]	Please state in the boxes your occupation. *Before onset of symptoms of macular condition*: [free-text response box] After diagnosis: [free-text response box] Now: [free-text response box]	This question was used to investigate if participants had changed their occupation due to the symptoms of the macular condition. The 2013 survey question was modified to account for possible delays to diagnosis meaning that the respondent may have changed occupation after onset of symptoms, but before diagnosis.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
69	-	42g	-	If you have had any changes of occupation, were they due to the macular condition? Y/N If 'no', please state reason(s): [free-text response box]	See above. This question was added to confirm whether or not the participant had changed occupation because of their macular condition. Sub-question added to investigate other reasons for change in occupation. It was hypothesised that some respondents may have changed occupation due to their macular condition AND other factors. These factors might be related to the macular condition. They would be able to state this in the free-text response box if applicable.
70	29k	42h	Please state in the boxes your main interests and activities: - Before diagnosis [free-text response box] - After diagnosis [free-text response box] - Now [free-text response box]	Please state in the box below your main interests and activities: [*free-text response box]*	Changes were made to make the questions more focused. Information on hobbies before and after diagnosis were not felt to be a priority for the 2013 survey.
71	29k continued	42i	If you have had any changes in activities or interests were they: Due to MD? Y/N Due to other factors? Y/N	Have you needed to change your activities or interests because of your macular condition? Y/N	See above. The MSQ 2013 question was reworded to ask whether changes were due to the macular condition. This was the main focus of interest (i.e. not whether they had needed to change activities due to other factors). Respondents

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
				Please give any comments below: [free-text response box]	could give more information in the free-text response box (e.g. if they felt that changes in activities were due to their macular condition AND other factors).
72	-	43	-	How comfortable do you feel using a computer? • Very comfortable • Comfortable • Not at all comfortable	This question was included to find out how many people with macular conditions are able to use a computer. This was included because a potential line of future research may be to use online survey methodology or for delivering online interventions for people with macular conditions.
73*results reported in chapter 4	29l	44	Do you live alone? Y/N	Do you live alone? Y/N	No change.
74	29m	45	Do you have defective hearing? Y/N	Do you have any *loss of hearing*? Y/N	Modified to reflect current terminology used for hearing loss.
75*results reported in chapter 3 and 4	29n	46	General health. Please cross one of the 5 boxes offered. In general, would you say your health is: • Excellent • Very good • Good • Fair • Poor	In general, my health is: • Excellent • Very good • Good • Neither good nor bad • Bad • Very bad • Extremely bad	1999 survey question used response options from the 36-item Short Form Health Survey (SF-36) (Ware & Sherbourne, 1992). To avoid license costs, it was decided to re-design the 2013 survey question response options. They were changed to the response options used in the general QoL item from the MacDQoL.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
76	29q	47	Did someone else help you to complete this questionnaire? Y/N If 'yes', please state relationship to helper e.g. husband, daughter, friend etc [free-text response box]	Did someone else help you to complete this questionnaire? Y/N	The 2013 survey omitted the sub-question used in the 1999 survey in order to keep the number of questions to a minimum.
77*results reported in chapter 3 and 4	29r	48	Today's date: _ _ / _ _ / _ _	Today's date: _ _ / _ _ / _ _	No change. (Used to create new variable for age at the time of survey completion.)
78	-	49	-	Please write your postcode in the box below: [free-text response box]	Included as a way of estimating socio-economic status (SES).
MDSQ 1999 questions removed from the 2013 survey					
79	2	-	Do you know of any other members of your family who have or had MD? Yes/ No/ Don't know If 'yes', please state in box their relationship to you (e.g. mother, brother etc.) and	-	Removed from 2013 survey because this question was included in the 1999 survey to investigate genetic/ family causes for MD. There has since been well-designed studies designed to examine genetic causes. This question was removed because investigating the information and support available/ provided to people with AMD were the main reasons for the present study, not investigating the causes of macular conditions.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
			approximate age of onset if known. [free-text response box]		
80	3	-	Before your MD was diagnosed had you experienced any of the following conditions or circumstances? a. Other eye disease e.g. Glaucoma, cataracts Y/N If 'yes', please describe [free-text response box] b. Injury to head or eyes Y/N If 'yes', please describe [free-text response box] c. Diabetes Y/N d. High blood pressure	-	Similar to above. Removed from 2013 survey because this question was included in the 1999 survey to investigate causes for MD. There has since been studies designed to examine causes. This question was removed because investigating the information and support provided to people with AMD were the main reasons for this study, not investigating the causes of macular conditions.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
			Y/N e. Stroke Y/N If 'yes' to any of the above (a,b,c,d,e) please note any medication taken in 'f' below. f. Frequent use of any medication (e.g. aspirin, sleeping pills) Y/N If 'yes', please list [free-text response box] g. smoking Y/N h. living and/or working in smoky atmospheres due to others smoking Y/N i. drinking alcohol Y/N If 'yes', please state the drink you then		

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Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
			preferred e.g. red wine, beer, lager, whisky. [free-text response box] j. stress or bereavement Y/N k. working and/or living in hot temperature/climate Y/N l. frequent or lengthy exposure to the sun Y/N m. Other notable conditions/ circumstance prior to developing MD (please state in box) [free-text response box]		
81	4a	-	When your MD was first diagnosed:	-	The responses to this question were not reported in the published paper of the 1999 survey results (Mitchell et al., 2002) nor the author's thesis (Mitchell, 2003). Thus it was

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			How was your MD described to you? (please state) [free-text response box]		removed from the 2013 survey as there were no data available for comparison. It was also perceived that the free-text responses would take a long time to analyse with the risk that the information may not be useful (particularly if responses could not be compared with the MDSQ 1999 responses).
82	4c	-	Were you told of any possible cause of this condition? Y/N If 'yes', please state [free-text response box]	-	Same as above.
83	10	-	Has your eye specialist, G.P. or optometrist suggested that some eye treatments/ operations may do more harm than good? Y/N If 'yes', which treatment was felt possibly to be harmful? [free-text response box]	-	Since 1999, there have been major advancements in treatment. For wet AMD, anti-VEGF injections have been shown to be effective in preventing vision loss and have a low risk of adverse events (see chapter 1 for summary). There is currently no effective treatment for dry AMD. This question was removed as part of prioritising questions of importance and relevance to the study aims.

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
84	11	-	Have you experienced any worsening of vision following a treatment or operation? Y/N If 'yes', please state the treatment or operation. [free-text response box]	-	See above.
85	12	-	Have you found any improvement in vision since diagnosis of MD? Y/N/ Don't know If 'yes', to what do you attribute the improvement? [free-text response box]	-	See above.
86	20	-	Would you be prepared to keep a diary/ record of your MD condition? Y/N	-	This question was removed as part of prioritising questions of importance and relevance to the study aims.
87	21	-	The MD Society funded this survey and funds other research. There are many other possible areas of research which you might wish to see funded.	-	In order to keep the length of the survey down, this question on preferences for future research topics was removed.

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Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			How important to you are each of the following broad research areas? Please circle one number for each scale where 3= very important and 0= not important. • Causes and prevention of MD……… 3 2 1 0 • New treatments…3 2 1 0 • Low vision aids for people with MD……..3 2 1 0 • Improving care and support of people with MD ……… 3 2 1 0 Please add any specific suggestions for research you would like to see carried out. [free-text response box]		

Appendix 4: Table 1. Comparison of questions included in the 1999 Macular Disease Society Questionnaire (MDSQ 1999) and 2013 Macular Society survey (MSQ 2013). Questions are in numerical order as they appear in the MSQ 2013. *indicates which questions were used/ selected in the analyses reported in this thesis.

Row number	MDSQ 1999 question number	MSQ 2013 question number	MDSQ 1999 question wording	MSQ 2013 question wording (changes are marked in *italics*)	Reason for any changes or for addition/ removal of this question
88	29e	-	Dates of onset of MD (your estimate) • Left eye _ _/_ _/ _ _ • Right eye _ _ /_ _/ _ _	-	The MSQ 2013 included a question on the date of diagnosis of the respondents' macular condition (see row 4, q3). Date of onset was not needed. This question was removed as part of prioritising questions of importance and relevance to the study aims.
89	29g	-	Before MD was diagnosed, did you need to wear glasses? • For reading? Y/N • For distance? Y/N	-	Removed from 2013 survey because this question was included in the 1999 survey to investigate causes for MD. There have since been studies designed to examine causes. This question was removed as part of prioritising questions of importance and relevance to the study aims.
90	29h	-	Which hand do you prefer to use for writing? Right/ left	-	As above.
91	29i	-	Some children are made to use their right hand despite a left-hand preference. Did this apply to you? Y/N	-	As above.
92	29p	-	Eye colour Please cross a box to describe the colour of your eyes or describe in your own words. Blue/ Green/ Hazel/ Brown/ Grey Other (please state)	-	As above.

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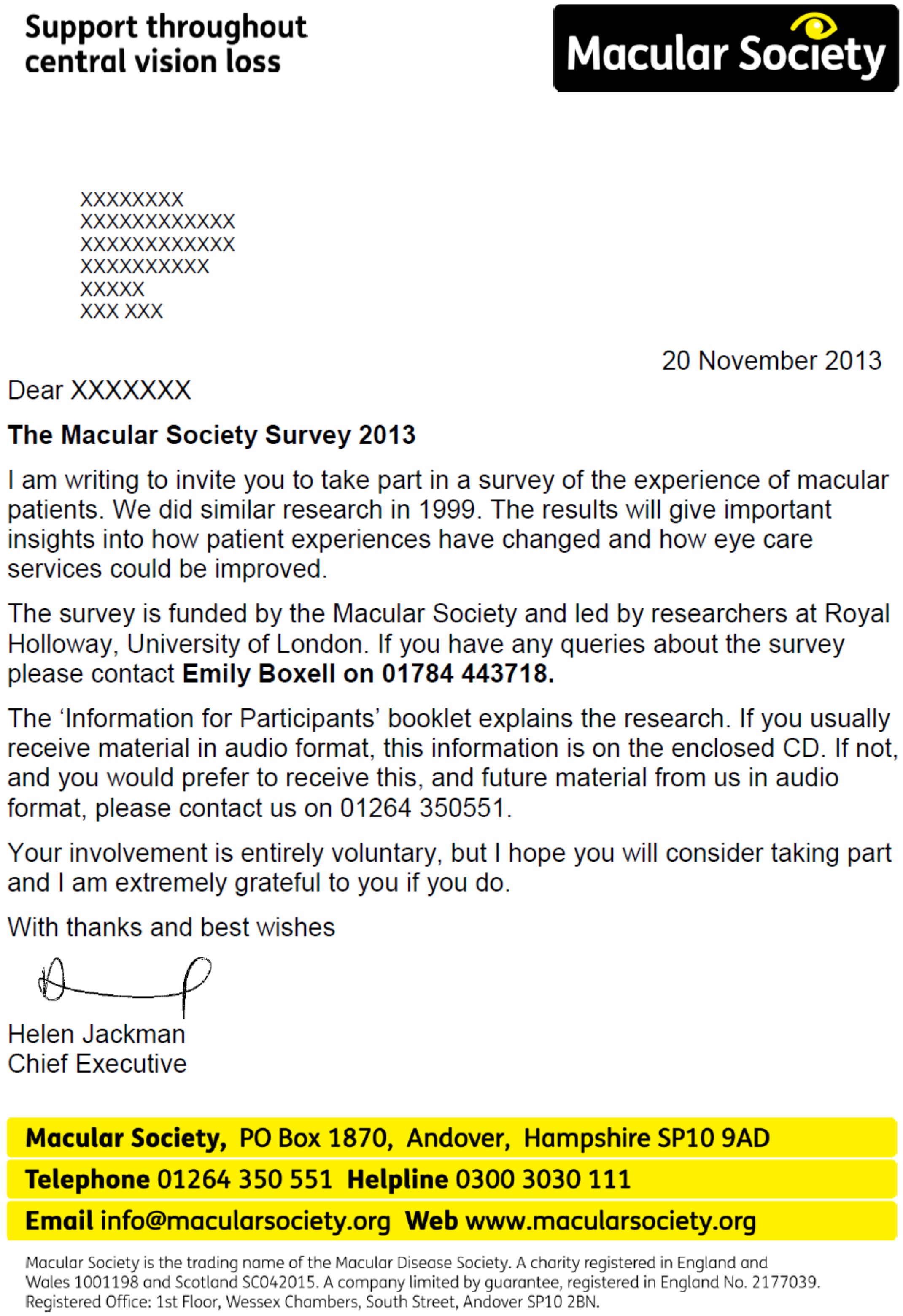
Row number	**MDSQ 1999 question number**	**MSQ 2013 question number**	**MDSQ 1999 question wording**	**MSQ 2013 question wording (changes are marked in *italics*)**	**Reason for any changes or for addition/ removal of this question**
			[free-text response box] Please circle a number to indicate the depth of your eye colour. Light Dark 1 2 3 4 5		

MD= macular disease, AMD= age-related macular degeneration, MDSQ 1999= Macular Disease Society 1999 Questionnaire, MSQ 2013= Macular Society 2013 survey, GP= general practitioner, HCP= healthcare professional, ECP= eye care professional, SES= socio-economic status.

Appendix 5: Covering letter for MSQ 2013.



Support throughout
central vision loss

Macular Society

XXXXXXXX
XXXXXXXXXXXX
XXXXXXXXXXXX
XXXXXXXXXX
XXXXX
XXX XXX

20 November 2013

Dear XXXXXXX

The Macular Society Survey 2013

I am writing to invite you to take part in a survey of the experience of macular patients. We did similar research in 1999. The results will give important insights into how patient experiences have changed and how eye care services could be improved.

The survey is funded by the Macular Society and led by researchers at Royal Holloway, University of London. If you have any queries about the survey please contact **Emily Boxell on 01784 443718.**

The ‘Information for Participants’ booklet explains the research. If you usually receive material in audio format, this information is on the enclosed CD. If not, and you would prefer to receive this, and future material from us in audio format, please contact us on 01264 350551.

Your involvement is entirely voluntary, but I hope you will consider taking part and I am extremely grateful to you if you do.

With thanks and best wishes

Helen Jackman
Chief Executive

Macular Society, PO Box 1870, Andover, Hampshire SP10 9AD
Telephone 01264 350 551 **Helpline** 0300 3030 111
Email info@macularsociety.org **Web** www.macularsociety.org

Appendix 6: Reply slip- reasons for not taking part in the MSQ 2013.

The Macular Society Survey 2013:

Understanding the experiences of people with macular conditions

Reasons for not taking part in the survey

We understand that some people may not want to take part in this survey. It would help us if you could let us know why. Please put your answer in the box below and return with the uncompleted survey in the freepost envelope provided. Please provide your address if you wish not to be contacted again about this research. Thank you.

Appendix 7: Detailed description of codes for reasons for satisfaction and dissatisfaction with the diagnostic consultation (responses from the MSQ 2013).

<u>Reasons for dissatisfaction with the diagnostic consultation</u>:

Lack of information or advice, including written information:

About condition, about prognosis, adjustment, low-vision aids, self-help groups, counselling, no referral to Low Vision Clinic/after care, information is not satisfactory (e.g. "written information *only*"). Include no help provided for the future and no explanation of what the future might bring. Include that information was not given in an appropriate format (e.g. written information given when participant couldn't see). Include comments relating to participant having to ask the healthcare professional (HCP) to write down the information, or comments on not being able to remember all that they were told (which suggests they needed information in a format that they could take away with them).

Include not being told diagnosis or name of condition under separate category of "macular condition not named."

Example from 2013 survey:

"I was not warned that my second eye could be affected at a later date"

"…just said I had AMD and that's it."

Specialist's/ healthcare professional's attitude:

Healthcare professional was described as being: dismissive, patronising, brusque, unfeeling, uninterested in patient/condition, used jargon, talked to colleagues whilst ignoring the patient, made patient feel of no consequence because of their age, matter of fact, brief, given no option/encouragement. Include information given in a blunt/ uninterested manner.

Example from 2013 survey:

"Made no attempt to reassure me…very curt and abrupt"

Told nothing could be done:

Code as this if the respondent had written exactly this or very similar.

Example from 2013 survey:

"I was told that I would go completely blind in that eye and nothing could be done"

Discharged after consultation:

No follow-up given, include had to ask for a referral or follow-up.

Example from 2013 survey:

“No follow-up given”

No opportunity for questions:

Example from 2013 survey:

“Very abrupt manner when questioned”

Macular condition not named:

Include not being told diagnosis or name of condition.

Example from 2013 survey:

“Did not give a name to my condition”

Problems with management:

Delay in getting appointments, paperwork/correspondence lost, seeing different doctors, doctor was not a macular specialist, delay in referral to social services, problems with test/ equipment and comments related to length of time taken to run the tests. Include aspects of the clinic experience such as staff not introducing themselves. Include not seeing eye specialist and sent letter with results in post instead. Include costs related to receiving a diagnosis, comments relating to location of eye clinic and/or difficulty getting to the clinic, diagnosis given by a non-specialist e.g. a nurse rather than a ECP (if respondent indicated they were dissatisfied with this).

Example from 2013 survey:

“Lost notes on two sessions”

Wanted second opinion:

Example from 2013 survey:

“Had a second opinion at XXX”

Lack of time with consultant:

Example from 2013 survey:

“Given short shift by the consultant”

Negative comment on treatment received:

Include cost of treatment, having to pay for private treatment, healthcare professional recommended treatment that was unsuccessful, had to make a quick decision about treatment. Include unhappy about having treatment. Include that respondent said they didn’t receive treatment when it was possible to have it. Include comments on not being informed about side effects of treatment.

Example from 2013 survey:

“It was in the early days of treatment and it wasn’t available on the NHS”

“Performed thermal laser treatment and failed to warn me about the difficulty of walking afterwards”.

Shocked by what they were told:

Example from 2013 survey:

“In all a very frightening experience”

Delay to diagnosis:

Include misdiagnosis before eventual correct diagnosis and problems with diagnosis. Include if respondents have written something that eludes to a late diagnosis, for example if they wrote that treatment would not be helpful as they were diagnosed too late.

Example from 2013 survey:

“Not given diagnosis for a long while”

Caused a delay to receiving treatment:

Include comments that mention that the diagnosis was made too late so that treatment was not viable, or that delays for other reasons caused a delay to treatment.

Example from 2013 survey:

“I saw XXX at XXX who said it was far too late to treat my AMD. Optician should have bypassed GP.”

Competence of healthcare professional (poor):

Include comments based on the professional’s incompetence including: lack of knowledge, making mistakes, not understanding urgency, misdiagnosis. Comments should mention the HCP specifically.

Example from 2013 survey:

“Did not know a lot at first”

“I rather feel GP did not understand about urgency”

Reasons for satisfaction with the diagnostic consultation:

Diagnosis made or confirmed:

Comments indicating participant was pleased that something was being done about their symptoms/ their diagnosis. Include comments that they were “finally” diagnosed, or were pleased to have the diagnosis confirmed.

Examples from 2013 survey:

“Pleased something being done, I had not imagined it”

“Consultant confirmed diagnosis.”

Information or advice was provided:

Information about: diagnosis, prognosis, adjustment, low-vision aids, self-help groups, counselling, nutrition, how to check eyes for deterioration, about the Macular Society, referral to LVC/aftercare was provided. Also include provided with information about treatment, and future outlook. Include comments on being told what activities respondent would still be able to do (if this was interpreted positively by the respondent). Include given information about how to check eye/s and what to do if they notice changes in vision.

Examples from 2013 survey:

“The consultant explained everything”

“…told I would still be able to cook, go for walks”

Specialist’s or healthcare professional’s attitude:

Polite, kind, interested in patient’s condition, encouraging, pleasant, sympathetic. Made patient feel comfortable. Took an interest in patient. Include descriptions where HCP took account of patient’s feelings.

Example from 2013 survey:

“He took an interest in me”

Prevention of delay:

Include comments relating to help was provided quickly e.g. appointments were received *quickly* in the post, paperwork/correspondence *prompt*, *fast* referrals.

Put any comments that relate to something that prevented a *delay to diagnosis or treatment* in here.

Example from 2013 survey:

“Received prompt help”

“Referred to hospital *immediately*” / “Optician sent me *straight to* an eye centre”

Referred to or within a hospital: (if respondent indicated that they were satisfied with this)

Comments related to being referred to hospital by an optician or GP, or from one hospital specialist to another specialist within the same hospital or to a different hospital.

Example from 2013 survey:

“Referred me to eye specialist”

“Local hospital consultant referred me to Bristol eye clinic”

Referred to GP: (if respondent indicated that they were satisfied with this)

Example from 2013 survey:

“She referred me to GP”

Treatment received or information on treatment:

Positive comment about treatment, e.g. treatment was effective. Or participant indicated in the first part of the question that they were satisfied with the consultation, and then wrote that they received treatment (so assume they were satisfied because they had **received** the treatment). Include comments related to respondents saying they were happy with the team that delivered the treatment.

Example from 2013 survey:

“Receiving Lucentis Injections”

Competence of healthcare professional (good):

Positive comments on professional’s competence including being an expert, knowledgeable or being professional.

Example from 2013 survey:

“She was an expert in the area”

Follow-up offered/ received:

Include if respondent was offered regular appointments to monitor condition. Include if respondent was told to come back if their condition worsens (comment must show that participant was satisfied with this action/advice).

Example from 2013 survey:

“Come back if there was further deterioration”

“I had a six month repeat consultation”

Thorough examination:

Healthcare professional took their time, was careful, carried out many tests to confirm diagnosis. Include that respondent was satisfied with the eye test.

Example from 2013 survey:

“Thorough examination included laser scans”

Appendix 8: Search strategy for narrative literature review presented in Chapter 5.

The electronic databases searched were Web of Science and Google Scholar.
Reference lists from the resources found were checked for relevant references and experts in the field were contacted for additional sources of information.
Although the review did not endeavour to be systematic in nature, several key words were used to retrieve relevant articles for discussion. The important key words included:

- ‘caregiver’, ‘carer’, ‘caregiving’, ‘caring’ ,‘care recipient’
- ‘AMD’, ‘age-related macular degeneration’, ‘age related macular degeneration’
- ‘burden’, ‘stress’ , ‘well-being’
- ‘vision impairment’, ‘vision loss’, ‘low vision’
- ‘social support’
- ‘dyad’, ‘couple’

The author searched other electronic resources, including the Carers UK website, for information on the impact of caring on the general UK population.

Electronic database searches were not limited by year of publication in order to maximise the literature that would be included in the review to understand how knowledge and theory on this topic has changed over time. Only articles published in the English language were included. Literature using either or both qualitative and quantitative methods were included. Review articles were included.

The author critically appraised the literature but did not use specific criteria to evaluate the quality of included studies which are recommended for use when conducting a systematic review (e.g. CASP checklist (Critical Appraisal Skills Programme, 2013); The Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, 1998)).

Thus it is acknowledged that by using a narrative review method instead of systematic review methodology, relevant articles may have been missed in the search (systematic reviews typically run searches in several electronic databases) and that studies of poor quality may have been included. All included literature has been assigned the same level of quality.

Appendix 9: Questionnaire package sent to people with AMD in the quantitative second study: INFORMATION SHEET, QUESTIONNAIRE BOOKLET, REPLY SLIP, CHANGE OF CONTACT DETAILS SLIP.

Information for participants

Dear (Enter name),

We would like to invite you to participate in a research study that is being carried out by Royal Holloway, University of London with the support of the Macular Society. Please read the following information and discuss it with others if you wish.

Please contact the researchers using the details at the end of this letter if there is anything that is not clear or if you would like more information. This research has been approved by the ethics committee of Royal Holloway, University of London.

What is the purpose of this research?

There has been very little previous research looking at the experiences of people who support someone living with macular degeneration. The results of the Macular Society 2013 Survey (also carried out by us) found that 54% of respondents reported that someone provided unpaid care, support or assistance to them because of their macular condition. Of these, 47% reported receiving support for 7 hours or more a week. However, little is known about the impact of providing this support on the carers themselves or those with macular conditions who they care for.

We recognise that this is an important topic that needs to be researched in order to provide support and develop services that may be needed, to help inform Macular Society campaigns, and to inform future research.

Who have we asked to participate?

We asked members of the Macular Society, who completed the Macular Society 2013 survey to write their name and contact details, and that of their carer's, at the end of the survey if they were interested in taking part in this research.

If you are not interested in research participation, we apologise for troubling you. We would be grateful if you could contact us (using the contact details below or by returning the enclosed reply slip), so that we know not to contact you again.

If you would like to take part, are aged over 18 and currently live in the UK, please carry on reading below.

What will I need to do?

Enclosed in the envelope with this information sheet, you will find a consent form and some questionnaires. These questionnaires ask about your current well-being, your quality of life and the impact your macular degeneration has on carrying out everyday tasks. There is also another short questionnaire which contains some questions about you (e.g. age, gender), your macular condition, general health, and on the support you receive.

Once you have read this information sheet, and if you would still like to take part, please sign the consent form, complete the questionnaires, and return them to us in the stamped addressed envelope. This should all take around 30 minutes to complete. If you would like help completing the questionnaires, you can phone the lead researcher who will go through them with you over the phone at a time convenient to you (01784 443718).

The second part of the research study, which you can choose to take part in if you wish, will include a one-to-one telephone interview with the lead researcher. The interviews will be at a time and date convenient to you.

The interview will include questions on your experiences since diagnosis, your well-being and the things that may affect your well-being, including your experiences of receiving support because of the macular degeneration. We anticipate that the interviews will last between 30-60 minutes.

Some people may find recalling these experiences uncomfortable. The Macular Society helpline is available to you if needed. The helpline number is 0300 30 30 111.

<u>Please note, that you can take part in the first part of the research study (the postal questionnaires) without completing the telephone interview, if you wish</u>.

Do I have to take part?

No, you do not have to take part. Choosing not to will not disadvantage you in any way. If anything is not clear, or if you have any questions, please contact us at the email address or phone number below.

If you do not wish to take part, please fill in the reply slip and return it to us in the stamped addressed envelope provided so we know not to trouble you again.

If you decide to take part, please be aware that you are not agreeing to answer every question. You can opt not to answer specific questions or in the case of the paper questionnaires, leave it blank.

If you agree to being contacted about taking part in the telephone interview, please tick the relevant box and write your contact number on the consent form in the space provided.

How will we maintain your privacy and confidentiality?

The answers you give will be treated in complete confidence. All data will be collected and stored in accordance with the Data Protection Act 1998. Reports from the project will summarise information, but will not identify individuals. You will be able to read summaries of the results in Sideview which all members of the Macular Society receive and/or Digest which is sent to members who indicate that they wish to receive it.

All questionnaires will be given an ID number and will be anonymous. If you provide any identifiable information, this will be separated from your responses and put in a secure computer database to which only the researchers will have access.

Telephone interviews will be audio-recorded and then transcribed. An ID number will be used on the transcript in place of your actual name. The audio-recording and transcribed interview will be stored confidentially and destroyed once the results are published.

What do I do next?

If you want to take part, please complete the consent form and questionnaires and return them in the stamped addressed envelope provided. Alternatively, phone 01784 443718 for telephone completion.

If we have incorrect contact details stored for you, please complete the change of contact details slip stating your correct details.

We appreciate the time you have taken to read this information sheet, and look forward to receiving your reply.

Thank you.

Research Group:

Ms Emily Boxell	PhD Researcher
Professor Clare Bradley	Professor of Health Psychology
Mrs Janet Bayfield	Administrator

Contact details:
Health Psychology Research Unit,
Orchard Building,
Royal Holloway, University of London.
Egham, Surrey.
TW20 0EX.

email: emily.boxell.2013@rhul.ac.uk;
c.bradley@rhul.ac.uk;
janet.bayfield@rhul.ac.uk.
(please include “Supporter research” in the subject line)

Telephone: 01784 443718 or 01784 443714 or 01784 443915

N.B. You may wish to keep this information sheet for reference. Please use this phone number to contact us with any queries.

Participant ID number:

Macular Society

ROYAL
HOLLOWAY
UNIVERSITY
OF LONDON

Participant consent form.

This study has been approved by the Royal Holloway, University of London Ethics Committee.

Thank you for considering taking part in this research. If you have any questions, please contact the researchers before you decide whether to take part (contact details overleaf).

Please tick below to show you agree with the following statements:

- I have read the information sheet about this study… ☐
- If I had any questions, I have had the opportunity to ask these questions (using the contact details overleaf) and I have received satisfactory answers to these questions…………………………………….. ☐
- I understand that I am free to withdraw from the study at any time, without giving a reason………….. ☐

I agree to participate in this study**…………**Yes ☐ No ☐

Would you be interested in being contacted about taking part in the one-to-one telephone interviews as described in the information sheet?

Yes ☐ No ☐

If yes, please state your preferred contact number below:

(Landline preferable)……………………………………………….

P.T.O. to sign and date this form.

Name of participant…

Signature ……………

Date…………………

Please check that you have ticked the ‘Yes’ or ‘No’ box and have signed and dated this form. **Thank you.**

Research Group:

Ms Emily Boxell	PhD Researcher
Professor Clare Bradley	Professor of Health Psychology
Mrs Janet Bayfield	Administrator

Contact details:

Health Psychology Research Unit,
Orchard Building,
Royal Holloway, University of London.
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email: emily.boxell.2013@rhul.ac.uk;
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janet.bayfield@rhul.ac.uk.

(please include “Supporter research” in the subject line)

Telephone: 01784 443718 or 01784 443714 or 01784 443915

NB: This Consent form will be stored separately from the responses you provide.

Participant ID number:

Activities of Daily Living

This questionnaire asks about your current experience carrying out tasks associated with everyday living. Please indicate how much difficulty you have carrying out each of the tasks below by circling a number on the scale. The 4-point scale ranges from being able to perform the task with; "no difficulty", "with difficulty, but without help", "with help" or "unable to perform task."

How much difficulty do you have…?	**No difficulty**	**With difficulty but without help**	**With help**	**Unable to perform task**
1. Preparing meals........................	1	2	3	4
2. Grocery shopping......................	1	2	3	4
3. Managing one's own money	1	2	3	4
4. Using a telephone.....................	1	2	3	4
5. Heavy housework	1	2	3	4
6. Light housework........................	1	2	3	4
7. Getting to places beyond walking distance	1	2	3	4
8. Taking medications...................	1	2	3	4

Thank you.

Participant ID number:

Macular Society

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Daily living tasks dependent on vision (DLTV)

Please circle one number on each scale, from 4 (no difficulty) to 1 (cannot see to do), to indicate how much difficulty your vision causes you when doing the following tasks:

How much difficulty do you have…?	**No difficulty**	**A little difficulty**	**A lot of difficulty**	**Cannot see to do**
1. distinguishing a person's features across the room	4	3	2	1
2. noticing objects off to either side	4	3	2	1
3. watching TV programmes	4	3	2	1
4. seeing steps and using them	4	3	2	1
5. enjoying the scenery if out for a drive	4	3	2	1
6. reading road signs or street names	4	3	2	1
7. distinguishing a person's features across the street	4	3	2	1
8. recognising seasonal changes in the garden	4	3	2	1
9. distinguishing a person's features at arm's length	4	3	2	1

Continued on the next page…

Participant ID number:

How much difficulty do you have…?	No difficulty	A little difficulty	A lot of difficulty	Cannot see to do
10. pouring yourself a drink..........	4	3	2	1
11. cutting up food on your plate...	4	3	2	1
12. cutting your finger nails..........	4	3	2	1
13. using kitchen appliances........	4	3	2	1
14. adjusting to darkness after being in the light.....................	4	3	2	1
15. adjusting to the light after being in the dark	4	3	2	1

How confident do you feel in your ability to walk around…?	Extremely	Somewhat	Barely	Not at all
16. in your immediate neighbourhood.....................	4	3	2	1
17. outside your immediate neighbourhood.....................	4	3	2	1

With your near glasses on how much difficulty do you have…?	No difficulty	A little difficulty	A lot of difficulty	Cannot see to do
18. reading normal sized newspaper print	4	3	2	1
19. reading newspaper headlines...	4	3	2	1
20. reading correspondence, e.g. bills, letters, cards	4	3	2	1
21. signing documents, e.g. cheques	4	3	2	1
22. identifying money from purse or wallet....................................	4	3	2	1

How would you rate…?	**Excellent**	**Good**	**Fair**	**Poor**
23. your overall distance vision...	4	3	2	1
24. your overall near vision, i.e. for close work.......................	4	3	2	1

Questions on driving

25. **Have you ever driven a car?**

Yes ☐ ⬇ No ☐➡ please go to question 28, next page.

26. **Do you currently drive?**

Yes ☐➡ please go to question 27. No ☐ ⬇

26a). **If no, have you stopped driving because of your macular condition or for another reason?**

- Mainly because of your macular condition………….. ☐➡ please go to question 28.
- Partly because of your macular condition and partly other reason(s)…………….. ☐➡ please state reason(s) in the box below and then go to question 28.
- Mainly other reason(s)……... ☐➡ please state reason(s) in the box below and then go to question 28.

Please state reason(s) below:

Continued on next page…

27. (For those who currently drive.)

Thinking about the impact of your macular condition on your vision, would you feel able to:

a) drive to familiar places in daylight?

Yes ☐ No ☐

b) drive to familiar places in the dark?

Yes ☐ No ☐

c) drive to unfamiliar places in daylight?

Yes ☐ No ☐

d) drive to unfamiliar places in the dark?

Yes ☐ No ☐

28. **Does your caregiver currently drive?**

Yes ☐ ⬇ No ☐ ➡ please continue onto the next page.

28a). **If yes, does your caregiver drive you to places?**

Yes ☐ No ☐

Thank you. Please continue onto the next page.

Participant ID number:

This questionnaire asks about your quality of life – in other words how good or bad you feel your life to be. Please put an "X" in the box that best indicates your response for each item. What we would like to know is how you feel about your life now.

I) In general, my present quality of life is:

- **excellent ....** ☐
- **very good...........................** ☐
- **good ....** ☐
- **neither good nor bad.........** ☐
- **bad.....................................** ☐
- **very bad ....** ☐
- **extremely bad....................** ☐

Participant ID number:

Now we would like to know how your quality of life is affected by your macular disease (MD), which includes macular degeneration, and can cause loss of central vision.

II) If I did not have MD, my quality of life would be:

- **very much better** .... ☐
- **much better**......................... ☐
- **a little better**........................ ☐
- **the same**.............................. ☐
- **worse**................................... ☐

Thank you. Please continue onto the next page.

Participant ID number:

Well-being Questionnaire (W-BQ16)

Please circle one number on each scale, from 3 (all the time) to 0 (not at all), to indicate how often you feel each statement has applied to you in the past few weeks.

		all the time			not at all
1.	I have crying spells or feel like it	3	2	1	0
2.	I feel downhearted and blue	3	2	1	0
3.	I feel afraid for no reason at all	3	2	1	0
4.	I get upset easily or feel panicky	3	2	1	0
5.	I feel energetic, active or vigorous	3	2	1	0
6.	I feel dull or sluggish	3	2	1	0
7.	I feel tired, worn out, used up or exhausted	3	2	1	0
8.	I have been waking up feeling fresh and rested	3	2	1	0
9.	I have been happy, satisfied or pleased with my personal life	3	2	1	0
10.	I have lived the kind of life I wanted to	3	2	1	0
11.	I have felt eager to tackle my daily tasks or make new decisions	3	2	1	0
12.	I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1	0

Continued on the next page…

Participant ID number:

	all the time			not at all
13. I feel that too many demands are made on me	3	2	1	0
14. I feel frustrated by obstacles which occur in my life	3	2	1	0
15. I have too many problems to cope with..	3	2	1	0
16. I feel stressed	3	2	1	0

Please make sure that you have considered each of the 16 statements and have circled one number in response to each statement.

Participant ID number:

Additional questions

1. Please give the following details about yourself:

a) Marital status:

- Married/ living with partner… ☐
- Widowed…………………….. ☐
- Divorced…………………….. ☐
- Separated…………………… ☐
- Single……………………….. ☐
- Civil partnership…………….. ☐

b) Employment status:

- Employed, full time……………………… ☐
- Employed, part time…………………….. ☐
- Self-employed………………………….. ☐
- Looking after family and/ or home ……. ☐
- Retired ………………………………….. ☐
- Seeking work/ unemployed…………….. ☐
- Disabled or too ill to work………………. ☐
- Student………………………………….. ☐
- Other…………………………………….. ☐

c) Highest level of education qualification obtained:

- Degree or higher degree………………………………………. ☐
- Higher education qualification below degree level ………. ☐
- A levels or equivalent……………………………………….. ☐
- O level or GCSE or equivalent ……………………………. ☐
- Still studying………………………………………………… ☐
- No formal qualifications…………………………………….. ☐
- Other, please state below:………………………………… ☐

…………………………………………………………………..

2. **Do you have one or more friends or family members who provide unpaid care, support or assistance to you because of your macular condition?**

Yes ☐ No ☐

a) Who is the person who most often provides help, support or assistance to you?

Please state their name, and their relationship to you (e.g. daughter, husband, neighbour).

Name:…………………………………………………………..

Relationship to you: ……………………………………………

b) Please tick how many hours per week this person spends helping you (on average):

- Fewer than 7 hours per week……...☐
- 7 to 14 hours…………………………...☐
- 15 to 35 hours………………………….☐
- More than 35 hours per week…….. ☐

c) Does anyone else provide you with assistance (because of your macular condition)?

Yes ☐ No ☐

If yes, please state their name(s) and relationship(s) to you:

3. **Have you ever had treatment for your macular condition?**

Yes ☐ ⬇ No ☐ ➡ please go to question 4, next page.

If 'yes', are you currently receiving treatment?

Yes ☐ ⬇ No ☐ ➡ please go to question 4, next page.

If 'yes', please state the name of this treatment. If you are receiving eye injections, please state the name of the injection if known:

4. **Are you registered as severely sight impaired (blind) or sight impaired (visually impaired)?**

- no……………………………………………………………... ☐
- yes, I am registered as sight impaired…………………..... ☐
- yes, I am registered as severely sight impaired (blind)… ☐

5. **In general, my health is:**

- excellent……………………… ☐
- very good…………………….. ☐
- good………………………….. ☐
- neither good nor bad………. ☐
- bad…………………………… ☐
- very bad…………………….... ☐
- extremely bad………………. ☐

6. **Do you have (or have you had) any of the following medical conditions? Please tick all that apply.**

- Diabetes……………………………………………………. ☐
- Stroke………………………………………………………. ☐
- Heart attack/ heart disease………………………………. ☐
- Kidney disease……………………………………………. ☐
- Asthma/ lung disease…………………………………….. ☐
- Other serious/ long-term condition (s) (please state) … ☐

……………………………………………………………………

Continued on next page…

7. **Today's date:** _ _ / _ _ / _ _

End of questionnaire. Thank you for your participation.

If you are interested in being contacted about taking part in a one-to-one telephone interview as part of this research, please make sure you tick the relevant box on the consent form.

Participant ID number:

Change of contact details.

If we have incorrect contact details for you, please write the correct details below:

Address: ……………………………………………………………….

………………………………………………………………………..

Postcode: ……………………………………………………………….

Contact phone number: ………………………………………………….

Email address: ……………………………………………………………

Please return this form in the stamped addressed envelope provided.

Participant ID number:

Reply slip for people not able or willing to complete the questionnaire.

Please tick the boxes below where applicable:

No thank you, I don’t want to take part in this research ➡ ☐

It would be helpful to us if you could let us know why you are not able or willing to take part in this research. Please tick the appropriate box(es) below.

- I’m too busy at the moment……………………………………………….. ☐
- The questionnaires are too long/ it would take too long to complete… ☐
- Poor general health………………………………………………………. ☐
- I don’t feel that the questions/ research applies to me………………… ☐
- Other, please state reason(s) below:

……………………………………………………………………………..

If you would prefer not to be contacted in the future, about other research from the Health Psychology Research Unit at Royal Holloway, University of London, please tick the following box ➡ ☐

Please return this form in the stamped addressed envelope provided.

Appendix 10: Questionnaire package sent to caregivers in the quantitative second study: INFORMATION SHEET, QUESTIONNAIRE BOOKLET, REPLY SLIP, CHANGE OF CONTACT DETAILS SLIP.

Information for participants

Dear (Enter name),

We would like to invite you to participate in a research study that is being carried out by Royal Holloway, University of London with the support of the Macular Society. Please read the following information and discuss it with others if you wish.

Please contact the researchers using the details at the end of this letter if there is anything that is not clear or if you would like more information. This research has been approved by the ethics committee of Royal Holloway, University of London.

What is the purpose of this research?

There has been very little previous research looking at the experiences of people who support someone living with macular degeneration. The results of the Macular Society 2013 Survey (also carried out by us) found that 54% of respondents reported that someone provided unpaid care, support or assistance to them because of their macular condition. Of these, 47% reported receiving support for 7 hours or more a week. However, little is known about the impact of providing this support on the carers themselves or on those with macular conditions who they care for.

We recognise that this is an important topic that needs to be researched in order to provide support and develop services that may be needed, to help inform Macular Society campaigns, and to inform future research.

Who have we asked to participate?

We asked members of the Macular Society, who completed the Macular Society 2013 survey to write their name and contact details, and that of their carer's, at the end of the survey if they considered that they might be interested in taking part in this research.

If you are not interested in research participation, we apologise for troubling you. We would be grateful if you could contact us (using the contact details below or by returning the enclosed reply slip), so that we know not to contact you again.

We are specifically interested in looking at the experiences of those who are the primary caregiver of someone with macular degeneration, and who are not fomally paid a salary for this role (although they may be receiving Carer's allowance or other benefits). If this is you, and you are aged over 18 and currently live in the UK, please carry on reading below.

What will I need to do?

Enclosed in the envelope with this information sheet, you will find a consent form and some questionnaires. These questionnaires ask about your current well-being and the impact of providing care to someone with macular degeneration. There is also another short questionnaire which contains some questions about you (e.g. age, gender), your general health, and on the support you provide.

Once you have read this information sheet, and if you would still like to take part, please sign the consent form, complete the questionnaires, and return them to us in the stamped addressed envelope. This should take around 30 minutes to complete. If you would like help completing the questionnaires, you can phone the lead researcher who will go through them with you over the phone at a time convenient to you (01784 443718).

The second part of the research study, which you can choose to take part in if you wish, will include a one-to-one telephone interview with the lead researcher. The interviews will be at a time and date convenient to you.

The interview will mainly look at your experiences of providing support to someone with macular degeneration.There will be questions on the impact of providing this support, and on the factors that might help or hinder the ability to provide this support. We anticipate that the interviews will last between 30-60 minutes.

Some people may find recalling these experiences uncomfortable. The Macular Society helpline is available to you if needed. The helpline number is 0300 30 30 111.

<u>Please note, that you can take part in the first part of the research study (the postal questionnaires) without completing the telephone interview, if you wish</u>.

Do I have to take part?

No, you do not have to take part. Choosing not to will not disadvantage you in any way. If anything is not clear, or if you have any questions, please contact us at the email address or phone number below.

If you do not wish to take part, please fill in the reply slip and return it to us in the stamped addressed envelope provided so we know not to trouble you again.

If you decide to take part, please be aware that you are not agreeing to answer every question. You can opt not to answer specific questions or in the case of the paper questionnaires, leave it blank.

If you agree to being contacted about taking part in the telephone interview, please tick the relevant box and write your contact number on the consent form in the space provided.

How will we maintain your privacy and confidentiality?

The answers you give will be treated in complete confidence. All data will be collected and stored in accordance with the Data Protection Act 1998. Reports from the project will summarise information, but will not identify individuals. You will be able to read summaries of the results in Sideview which all members of the Macular Society receive and/or Digest which is sent to members who indicate that they wish to receive it.

All questionnaires will be given an ID number and will be anonymous. If you provide any identifiable information, this will be separated from your responses and put in a secure computer database to which only the researchers will have access.

Telephone interviews will be audio-recorded and then transcribed. An ID number will be used on the transcript in place of your actual name. The audio-recording and transcribed interview will be stored confidentially and destroyed once the results are published.

What do I do next?

If you want to take part, please complete the consent form and questionnaires and return them in the stamped addressed envelope provided. Alternatively, phone 01784 443718 for telephone completion.

If we have incorrect contact details stored for you, please complete the change of contact details slip stating your correct details.

We appreciate the time you have taken to read this information sheet, and look forward to receiving your reply.

Thank you.

Research Group:

Ms Emily Boxell	PhD Researcher
Professor Clare Bradley	Professor of Health Psychology
Mrs Janet Bayfield	Administrator

Contact details:
Health Psychology Research Unit,
Orchard Building,
Royal Holloway, University of London.
Egham, Surrey.
TW20 0EX.

email: emily.boxell.2013@rhul.ac.uk;
c.bradley@rhul.ac.uk

janet.bayfield@rhul.ac.uk
(please include “Supporter research” in the subject line)

Telephone: 01784 443718 or 01784 443714 or 01784 443915

N.B. You may wish to keep this information sheet for reference. Please use this phone number to contact us with any queries.

Participant ID number:

Macular Society

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Participant consent form.

This study has been approved by the Royal Holloway, University of London Ethics Committee.

Thank you for considering taking part in this research. If you have any questions, please contact the researchers before you decide whether to take part (contact details overleaf).

Please tick below to show you agree with the following statements:

- I have read the information sheet about this study… ☐
- If I had any questions, I have had the opportunity to ask these questions (using the contact details overleaf) and I have received satisfactory answers to these questions……………………………………... ☐
- I understand that I am free to withdraw from the study at any time, without giving a reason………….. ☐

I agree to participate in this study**…………**Yes ☐ No ☐

Would you be interested in being contacted about taking part in the one-to-one telephone interviews as described in the information sheet?

Yes ☐ No ☐

If yes, please state your preferred contact number below:

(Landline preferable)…………………………………………………….

P.T.O. to sign and date this form.

Participant ID number:

Name of participant....

Signature ....

Date.......................

Please check that you have ticked the ‘Yes’ or ‘No’ box and have signed and dated this form. **Thank you.**

Research Group:

Ms Emily Boxell	PhD Researcher
Professor Clare Bradley	Professor of Health Psychology
Mrs Janet Bayfield	Administrator

Contact details:

Health Psychology Research Unit,

Orchard Building,

Royal Holloway, University of London.

Egham, Surrey. TW20 0EX.

email: emily.boxell.2013@rhul.ac.uk;

c.bradley@rhul.ac.uk;

janet.bayfield@rhul.ac.uk.

(please include “Supporter research” in the subject line)

Telephone: 01784 443718 or 01784 443714 or 01784 443915

NB: This Consent form will be stored separately from the responses you provide.

Participant ID number:

The Caregiver Reaction Assessment Instrument

This is a questionnaire which looks at how providing care for your friend or family member with a macular condition has affected you, your family and your daily routine. Each item is a statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (5). For each item we would like you to circle a number to show how much you disagree or agree with the statement.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this anonymous.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I feel privileged to care for ___.	1	2	3	4	5
2. Others have dumped caring for ___ onto me.	1	2	3	4	5
3. My financial resources are adequate to pay for things that are required for caregiving.	1	2	3	4	5
4. My activities are centred around care for ___.	1	2	3	4	5
5. Since caring for ___ it seems like I'm tired all of the time.	1	2	3	4	5
6. It is very difficult to get help from my family in taking care of ___.	1	2	3	4	5
7. I resent having to take care of ___.	1	2	3	4	5
8. I have to stop in the middle of work.	1	2	3	4	5
9. I really want to care for ___.	1	2	3	4	5
10. My health has gotten worse since I've been caring for ___.	1	2	3	4	5
11. I visit family and friends less since I have been caring for ___.	1	2	3	4	5

Participant ID number:

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
12.	I will never be able to do enough caregiving to repay ___.	1	2	3	4	5
13.	My family works together at caring for ___.	1	2	3	4	5
14.	I have eliminated things from my schedule since caring for ___.	1	2	3	4	5
15.	I have enough physical strength to care for ___.	1	2	3	4	5
16.	Since caring for ___, I feel my family has abandoned me.	1	2	3	4	5
17.	Caring for ___ makes me feel good.	1	2	3	4	5
18.	The constant interruptions make it difficult to find time for relaxation.	1	2	3	4	5
19.	I am healthy enough to care for ___.	1	2	3	4	5
20.	Caring for ___ is important to me.	1	2	3	4	5
21.	Caring for ___ has put a financial strain on the family.	1	2	3	4	5
22.	My family (brothers, sisters, children) left me alone to care for ___.	1	2	3	4	5
23.	I enjoy caring for ___.	1	2	3	4	5
24.	It’s difficult to pay for ___’s health needs and services.	1	2	3	4	5

Thank you.

Participant ID number:

Additional questions on the impact of providing care

1. Are there any other areas of your life that you feel have been impacted on by providing care for the person with a macular condition that were not asked about in these questionnaires?

2. Were there any questions that you found particularly difficult to answer, or that you felt did not apply to you? If so, which question(s)?

Please circle a number to show how much you disagree or agree with the following statements.

3. In general, I feel that providing care to my relative or friend with a macular condition, has a negative impact on me and my life:

Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
1	2	3	4	5	6

4. In general, I feel that providing care to my relative or friend with a macular condition, has a positive impact on me and my life:

Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
1	2	3	4	5	6

Please answer the following questions:

5. In general, my present quality of life is:

- excellent…….………………………☐
- very good..…………………………..☐
- good…………………………………☐
- neither good nor bad..……………... ☐
- bad……….…………………………..☐
- very bad…..………………………… ☐
- extremely bad….………………........☐

6. If I did not provide care to my friend or relative with a macular condition, my quality of life would be:

- very much better…………………☐
- much better………………………..☐
- a little better………………………☐
- the same……………………………☐
- a little worse………………………☐
- much worse……………………….. ☐
- very much worse…………………☐

Please continue onto the next page.

Participant ID number:

Well-being Questionnaire (W-BQ16)

Please circle one number on each scale, from 3 (all the time) to 0 (not at all), to indicate how often you feel each statement has applied to you in the past few weeks.

	all the time			not at all
1. I have crying spells or feel like it	3	2	1	0
2. I feel downhearted and blue	3	2	1	0
3. I feel afraid for no reason at all	3	2	1	0
4. I get upset easily or feel panicky	3	2	1	0
5. I feel energetic, active or vigorous	3	2	1	0
6. I feel dull or sluggish	3	2	1	0
7. I feel tired, worn out, used up or exhausted	3	2	1	0
8. I have been waking up feeling fresh and rested	3	2	1	0
9. I have been happy, satisfied or pleased with my personal life	3	2	1	0
10. I have lived the kind of life I wanted to	3	2	1	0
11. I have felt eager to tackle my daily tasks or make new decisions	3	2	1	0
12. I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1	0

Continued on the next page…

Participant ID number:

	all the time			not at all
13. I feel that too many demands are made on me	3	2	1	0
14. I feel frustrated by obstacles which occur in my life	3	2	1	0
15. I have too many problems to cope with..	3	2	1	0
16. I feel stressed	3	2	1	0

Please make sure that you have considered each of the 16 statements and have circled one number in response to each statement.

Participant ID number:

Macular Society

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Additional questions

<u>Demographic questions</u>

1. Please give the following details about yourself:

a) Date of Birth _ _ / _ _ / _ _ _ _

b) Highest level of education qualification obtained:

- Degree or higher degree………………………………….. ☐
- Higher education qualification below degree level ………. ☐
- A levels or equivalent……………………………………….. ☐
- O level or GCSE or equivalent …………………………….. ☐
- Still studying………………………………………………….. ☐
- No formal qualifications…………………………………….. ☐
- Other, please state below:………………………………… ☐

…………………………………………………………………..

c) Sex: Male ☐ Female ☐

d) Marital status:

- Married/ living with partner………. ☐
- Widowed…………………………… ☐
- Divorced…………………………….. ☐
- Separated………………………….. ☐
- Single………………………………. ☐
- Civil partnership…………………… ☐

e) Ethnic group:

- White British…………….. ☐
- Asian/ Asian British…….. ☐
- Black/ Black British…….. ☐
- Chinese………………… ☐
- Other, please state below:

………………………………………………………………………

f) Employment status:

- Employed, full time……………………… ☐
- Employed, part time…………………….. ☐
- Self-employed…………………………… ☐
- Looking after family and/ or home ……. ☐
- Retired …………………………………… ☐
- Seeking work/ unemployed…………… ☐
- Disabled or too ill to work………………. ☐
- Student…………………………………… ☐
- Other……………………………………… ☐

g) Employment status change, related to caring for person with a macular condition:

- Gave up work…………………… ☐
- Reduced work hours……………. ☐
- Took paid leave……………….. ☐
- Took unpaid leave………………. ☐
- Other (please state):

……………………………………………..

- None of the above………………. ☐

h) Is English your first language?

Yes ☐ No ☐

If no, please rate your fluency in English on the scale below by putting a cross on the number that applies to you:

Very basic	1	2	3	4	5	6	7	Very fluent

2. Do you have children?

Yes ☐ No ☐

If yes, please state how many and their age(s):

Questions about your caregiving role

3. What relationship are you to the person with a macular condition, that you provide support for? (e.g. husband, daughter.)

Participant ID number:

4. Please tick how many hours per week you spend helping them (on average):
    - Fewer than 7 hours per week……... ☐
    - 7 to 14 hours……………………….... ☐
    - 15 to 35 hours………………………. ☐
    - More than 35 hours per week…….. ☐

5. How long have you been providing care/ support/ assistance to the person with a macular condition, because of this condition?
    - Less than a year……………..……....☐
    - Between 1 and 5 years…………..... ☐
    - More than 5 years……..…………… ☐

6. Did you provide care/ support/ assistance to this person before they were diagnosed with a macular condition?

Yes ☐ No ☐

If yes, was this for a different medical condition? Please provide brief details.

7. Does anyone else provide them with assistance (because of their macular condition)?

   Yes ☐ No ☐

If yes, please state their name(s) and relationship to the person with the macular condition:

8. Do you live with the person who has a macular condition, that you provide care/ support/ assistance for?

   Yes ☐ No ☐

9. How dependent do you feel the person with the macular condition has been on you since diagnosis?

   - Not at all dependent…………… ☐
   - Somewhat dependent………….. ☐
   - Moderately dependent……….. ☐
   - Very dependent……………….... ☐
   - Extremely dependent………….. ☐

General health

10. In general, my health is:

- excellent…………………….. ☐
- very good…………………….☐
- good…………………………☐
- neither good nor bad……….☐
- bad…………………………..☐
- very bad…………………….. ☐
- extremely bad………………. ☐

11. Today's date _ _ / _ _ / _ _

Thank you for your participation

If you are interested in being contacted about taking part in a one-to-one telephone interview as part of this research, please make sure you tick the relevant box on the consent form.

Participant ID number:

Change of contact details.

If we have incorrect contact details for you, please write the correct details below:

Address: …………………………………………………………………….

……………………………………………………………………………..

Postcode: ……………………………………………………………………

Contact phone number: ……………………………………………………

Email address: ………………………………………………………………

Please return this form in the stamped addressed envelope provided.

Participant ID number:

Reply slip for people not able or willing to complete the questionnaire.

Please tick the boxes below where applicable:

No thank you, I don’t want to take part in this research ➡ ☐

It would be helpful to us if you could let us know why you are not able or willing to take part in this research. Please tick the appropriate box(es) below.

- I’m too busy at the moment……………………………………………….. ☐
- The questionnaires are too long/ it would take too long to complete… ☐
- Poor general health……………………………………………………….. ☐
- I don’t feel that the questions/ research applies to me………………… ☐
- Other, please state reason(s) below:

……………………………………………………………………………..

If you would prefer not to be contacted in the future, about other research from the Health Psychology Research Unit at Royal Holloway, University of London, please tick the following box ➡ ☐

Please return this form in the stamped addressed envelope provided.

Appendix 11: Interview guide for person with AMD (qualitative third study).

Interview questions (with prompts)

Experiences at diagnosis

- Tell me about your experience of diagnosis of AMD.
  - When were you diagnosed?
  - How did you feel when you received the diagnosis?

The impact of having AMD

- What effect has having AMD had on your life?
  (Prompt: Have there been any particularly difficult times, for you because of the macular condition? (further prompts: during diagnosis/ treatment, sudden deterioration of eyesight, stopping driving etc.)
  - Was there anything that helped or hindered this?

- What effect has AMD had on your (INSERT RELATIONSHIP TYPE OF CAREGIVER) life?
  (Prompt: Have there been any particularly difficult times, for them because of the macular condition? (further prompts: during diagnosis/ treatment, sudden deterioration of eyesight, stopping driving etc.)
  - Did anything help with this?
  - How do you feel they cope/d?

- Can you think of anything that could have helped you or your (INSERT RELATIONSHIP TYPE) manage the experience at diagnosis and any subsequent difficult times better? (prompts: outside help, information and support.)

Specific questions on support received (how much, how long…)

- How long has your (INSERT RELATIONSHIP TYPE) been providing unpaid care for you because of your macular condition?

- Is this since you were first diagnosed or was this later?
  - ➢ If later, what led to them providing care at this later time?
- Do they, or have they ever provided you with support related to another medical condition?
- You said you receive (INSERT RESPONSE FROM QUANTITATIVE SECOND STUDY) hours of support a week. Did you find this difficult to estimate? Why or why not?

Now I’m going to ask you about the types of activities your (INSERT RELATIONSHIP TYPE) helps you with. Some of them might be related to the macular condition, to other health conditions or something else, but we can discuss that as we go through them. I will read out a list, and please can you answer yes or no as to whether they do this.

(Read out each in turn and tick yes or no according to whether they report doing this) • Do they assist you with:	**Yes**	**No**
cooking or preparing food		
cleaning		
gardening		
making the bed		
washing / hanging laundry		
reading		
hobbies		
caring for your children or grandchildren (check if applicable)		
getting dressed		
personal grooming		
travelling/holidays		

using card machines (ATM’s) and/or entering PIN number.		
managing your finances		
playing/walking/feeding/ looking after your pet		
getting out and about		
driving you to places		
booking GP or hospital appointments for you		
attending GP or hospital appointments with you		
climbing stairs		
exercise and/or sport		
shopping		
providing emotional support		
Is there anything else that they do that wasn’t included in the list I just read out?		

The impact of receiving support

- Do you feel you receive the amount and kind of support or assistance you need from them, when you need it?
  - If no, can you explain why? (prompt: do you receive too much or too little support?)
  - how do you feel this could be improved?
- Is there anyone else who provides care/ support/ assistance to you? (anyone who helps with any of the activities we went through before?)
  - ➢ If yes, how do you feel having another person who also provides support impacts on you? (prompts: does it make things easier or more difficult for you?)
    - ▪ How do you think it impacts on your (INSERT RELATIONSHIP TYPE)? (prompts: does it make things easier or more difficult for them?)
  - ➢ If no, how do you feel that affects your relationship with (INSERT RELATIONSHIP TYPE), if it does at all?

- Have there been any negative consequences of receiving this support? (Prompts: impact on independence, impact on relationships etc.)
- Have there been any positive consequences of receiving this support? (Prompts: impact on relationships, practical and emotional support received etc.)
- Do you feel that your relationship with your (INSERT RELATIONSHIP TYPE) has changed since they started caring for you? (Prompts: how?)
- Do you think there is anything that could be done to help your (INSERT RELATIONSHIP TYPE), provide the support you need? (prompts: more outside support, financial support.)

Quality of life

The following question asks about your quality of life…

- In general, would you say that your present quality of life is: excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad.
- Can you tell me about anything else that you feel affects your quality of life and well-being? This could be to do with the macular condition, or could be completely unrelated. It could be positive, or negative.

Ending (neutral) question

- Please could you tell me which type of AMD you have? (i.e. wet or dry or both)?

THE CLOSING

(Summarise the interviewee’s experiences inviting them to correct as needed.)

Is there anything else you would like to add?

Appendix 12: Interview guide for caregivers of people with macular degeneration (qualitative third study).

Interview questions (with prompts)

- How long have you been providing unpaid care for your (INSERT RELATIONSHIP TYPE OF PWAMD) because of the macular degeneration?
- Is this since they were first diagnosed or was this later?
  - If later, what led to you providing care at this later time?
- Do you currently, or have you ever provided them with support related to another medical condition?

We've found that some people found it difficult to estimate the amount of time they spend helping the person with MD. You said you spend (INSERT RESPONSE FROM QUANTITATIVE SECOND STUDY) helping (INSERT RELATIONSHIP TYPE). Did you find this difficult to estimate? Why?

Experience of diagnosis

- Tell me about the experience of diagnosis of AMD.
  - When was your (INSERT RELATIONSHIP TYPE) diagnosed?
  - How did they cope with diagnosis?
  - How did you feel when they were diagnosed?

Impact of diagnosis

- What effect has the AMD had on their life? (Prompt: have there been any particularly difficult times, for them because of the macular condition? (further prompts: during diagnosis/ treatment, sudden deterioration of eyesight, stopping driving etc.))

- What effect has the AMD had on your life? (Prompt: have there been any particularly difficult times, for you because of the macular condition? (further prompts: during diagnosis/ treatment, sudden deterioration of eyesight, stopping driving etc.))
  - Was there anything that helped or hindered this?

- Can you think of anything that could have helped you or your (INSERT RELATIONSHIP TYPE), manage the experience of diagnosis and any subsequent difficult times better? (Prompts: outside help, information and support.)

Specific questions on support provided (how much, how long…)

Now I'm going to ask you about the types of support you provide to your (INSERT RELATIONSHIP TYPE) because of the macular condition. I will read out a list, and please can you answer yes or no as to whether you provide this support to them. It might be difficult to separate out the help you provide for the macular degeneration with help for another health condition or just what you help with generally, but we can discuss this.

(Read out each in turn and tick yes or no according to whether they report doing this.) • Do you provide them with help to do:	**Yes**	**No**
cook or prepare food		
cleaning		
gardening		
making the bed		
washing / hanging laundry		
reading		
hobbies		
caring for their children or grandchildren		
getting dressed		
personal grooming		
travelling/holidays		
using card machines (ATM's) and/or entering PIN number.		
managing their finances		
playing/walking/feeding/ looking after their pet		

getting out and about		
driving them to places		
booking GP or hospital appointments for them		
attending GP or hospital appointments with them		
climbing stairs		
shopping		
exercise and/or sport		
providing emotional support		
Is there anything else that you provide help with that wasn't included in the list I just read out?		

The impact of providing support

- Are their some aspects of care that are more difficult to provide than others?

- To what extent do you feel that the care you provide is sufficient/ more than sufficient?

- Is there anyone else who provides help/ support/ assistance to them? Yes No
- ➢ If yes, how do you feel having another person who also provides support impacts on you? (prompts: does it make things easier or more difficult for you?)
  - ▪ How do you think it impacts on your (INSERT RELATIONSHIP TYPE)? (prompts: does it make things easier or more difficult for them?)
- ➢ If no, how do you feel that affects your relationship with (INSERT RELATIONSHIP TYPE), if it does at all?

- How do you find that providing this support impacts on you? (Prompts: financially, socially, with paid work, with other family members, physical/ emotional well-being, health, managing your time…)

- Have there been specific times when the burden/ pressure on you has been greater? Why?
- Is there anything that helps reduce any negative impact of providing this support? (e.g. receiving help from other people, spirituality, relaxation time.)
- Do you feel that you get enough support from others in your role as a caregiver? (e.g. friends and family, healthcare professionals.)
- Do you feel that providing the support to your (INSERT RELATIONSHIP TYPE) has benefitted you in any way?
- Do you feel that your relationship with your (INSERT RELATIONSHIP TYPE) has changed since you have started caring for them?
- Is there anything that could be done to help you provide the support? (Prompt: more outside support, financial support.)
- In summary, how do you feel about your role as a carer? Is there anything else you would like to add to what you have already told me?

Quality of life

The following question asks about your quality of life…

- In general, would you say that your present quality of life is: excellent/ very good/ good/ neither good nor bad/ bad/ very bad/ extremely bad.
- Can you tell me about anything else that you feel affects your quality of life or well-being? This could be to do with caring for the person with the macular condition, or could be completely unrelated.

THE CLOSING

(Summarise the interviewee’s experiences inviting them to correct as needed.)

Is there anything else that you would like to add?