

Title: What do we know about the experience of age-related macular degeneration? A systematic review and meta-synthesis of qualitative research

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Abstract

Age Related Macular Degeneration (AMD) is the leading cause of registerable blindness with a high medical and societal cost burden. Much of the research examining experiences of living with AMD has been conducted independently with small sample sizes and has failed to impact on practice. Meta-synthesis of qualitative research can improve the understanding of the experience of living with AMD by drawing together findings of qualitative studies. This article presents a systematic review and meta-synthesis of qualitative studies investigating the experience of AMD (literature searched up to April 2012; published studies identified range from 1996-2009). The review highlights themes relating to: functional limitations, adaptation and independence; feelings about the future with vision impairment; interaction with the health service; social engagement; disclosure; and the emotional impacts of living with AMD. Attention to the experience of living with AMD can help us to better understand the needs of patients. This meta-synthesis aimed to bring together the findings of qualitative research studies and highlights important areas for consideration when caring for patients with AMD. Our findings suggest that a holistic approach to service provision and support for AMD is needed which takes into account individuals' needs and experiences when coping with and adjusting to living with AMD. This support should aim to reduce stigma, increase social engagement, and develop the psychological resources of patients with AMD.

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Introduction

Age Related Macular Degeneration (AMD) is the leading cause of registerable blindness in old age in many developed countries including the United Kingdom (UK) (Bunce & Wormald, 2006). In 2010 608,213 people were estimated to be living with AMD with this number expected to increase to 755,867 by the end of the decade (Minassian, Reidy, Lightstone & Desari, 2011). In addition, prevalence studies have shown that cases of AMD increase dramatically exponentially with age (Bonastre et al., 2002; Gibson, Rosenthal, & Lavery, 1985). One recent study found late stage AMD (the most disabling form of the condition) to be present in 4.8% of the over 65's, and 12.2% of the over 80's (Owen et al, 2011). AMD is a progressive disease of the retina in which the photoreceptor cells in the macula degenerate, leading to a gradual deterioration in central vision, and potentially severe disability for the affected individual. Persons with AMD have been found to experience: reduced quality-of-life (Mitchell et al., 2005; Mitchell et al., 2008); increased depression (Brody et al. 2001); and increased difficulties with activities of daily living (Cahill et al., 2005). AMD also has a high medical and societal cost burden; patients report substantial health related problems and health resource utilisation including: increased risk of falling, provision of vision enhancing equipment, higher needs for depression/anxiety treatment, and assistance with activities of daily living (Cruess et al., 2008).

Research with health care professionals, the public, and AMD patients has shown that there may be gross under-estimates of AMD's impact on quality of life (QoL) (Stein et al., 2003).

The National Institute for Health and Clinical Excellence (NICE) recommend the use of time trade off (TTO) methods to determine QoL but Mitchell and Bradley (2006) argue they are insufficiently sensitive to the context of older adult care. This discrepancy in health care

advice and the lack of detailed evidence about the experience of living with AMD led to the
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decision to undertake a systematic review of qualitative evidence. The value of qualitative research in advising on best practice has been recognized both by health psychology and NICE (Smith, 2011, Mulrow et al., 1997, Kelly et al., 2009) yet it is often excluded from reviews. Here we report a systematic literature search and meta-synthesis of qualitative evidence in order to examine in-depth the existing knowledge base. We explore people's experiences of living with AMD in order to ensure recommendations for practice fit with patients' demands.

The meta-synthesis of qualitative evidence is a relatively new technique developed in the health and social sciences (e.g., Campbell et al., 2003, Malpass et al., 2009). It is modelled on primary qualitative techniques involving interpretative activity rather than the aggregative techniques in meta-analysis. The goal is to synthesise findings from primary studies to generate a new theoretical understanding of a phenomenon that is 'greater than the sum of parts' (Campbell et al., 2003. p. 672). This involves critical reflection during synthesis and requires a rigorous process to assess the quality of qualitative evidence included (Rycroft-Malone et al., 2004, Dixon-Woods, Sutton, Shaw et al., 2007), a persistent area of debate (Spencer & Ritchie, in press). Some reject the creation of quality appraisal tools for qualitative research, which by design are not prescriptive, while others demand different criteria for different methods (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). In practice the criteria employed by meta-synthesists tend to aim for a 'paradigm neutral' approach. In this paper we present a meta-synthesis guided by this ethos both in terms of appraising included original studies and in ensuring quality in the conduct of the review.

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Methods

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

Systematic Search and screening

Searches of four major databases (Web of knowledge, Pubmed, Science Direct and Psycarticles) were conducted by AB in October 2010 and updated in October 2011 and April 2012. All studies included were identified in the original search and dates range from 1996-2009. No further studies meeting the inclusion criteria were identified in the 2011 or 2012 literature searches. Grey literature was not included in this review. Keywords included: older people, old age, macular degeneration, AMD, qualitative, focus group(s), and interview(s). Terms were selected to include “who” (older people), “what” (macular degeneration) and “how” (qualitative methods). Inclusion criteria were (a) qualitative research; (b) investigating experiences of AMD.

Critical appraisal

Quality was assessed initially using prompts developed by Dixon-Woods et al., (2004) which are designed to encourage critical assessment whilst remaining methodologically neutral (Table 1). Papers were then rated independently and agreed by each author using the coding: KP (key paper which is conceptually rich); SAT (satisfactory paper); IRR (irrelevant paper); or FF (fatally flawed methodology) (Dixon-Woods, et al., 2007; Malpass et al., 2009).

Synthesis of the studies

The synthesis involved interpretative analysis following the principles of meta-synthesis (Figure 1). Articles were read, re-read and details of the studies recorded (Table 2). Data

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extraction forms were used to record details of findings coded as first and second order constructs (see Malpass et al. 2009). First order constructs are study participants' interpretations of their experience (direct quotes from participants); second order constructs are study authors' interpretations of the participants' accounts.

Thematic coding began with data extraction forms of key papers and continued through all eight studies. Synthesis was a cyclical process; when a new theme was identified we returned to the other papers to check for occurrence of the theme. A matrix of shared themes was produced by AB including illustrative quotes from each theme (available as an online appendix [INSERT LINK TO ONLINE FILE]). This matrix was used collaboratively to complete the analytic process and develop third order constructs, i.e. higher order themes (Malpass et al., 2009). This was achieved by taking the first and second order constructs as data and analysing them thematically following Braun and Clarke's (2006) principles. AB led the synthesis with independent input from RS and JG to confirm the third order constructs. The findings presented are organised by themes.

Results

The review yielded 589 reports excluding duplicates. Titles and abstracts were screened against the inclusion criteria. Reasons for exclusion included: quantitative research (581), qualitative papers that did not include participants with AMD (1), and evaluations of rehabilitation programmes (2). During the search two papers were identified which utilised qualitative data collection methods with quantitative data analysis techniques (Mangione, et al., 1998; Owsley et al., 2006a) preventing them from being included in the meta-synthesis. Reference chaining and an additional search of Google Scholar was completed using the same search terms, this yielded a further eight articles (Figure 2).

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Twelve articles were identified and full copies obtained. Following assessment of the full text, two (Brouwer et al., 2005, Rudman et al., 2010) were rejected because AMD status of the participants was unclear. One (Moore & Miller, 2005) was found to be a second analysis of data from another included article and was excluded. One was rejected as it investigated ideas about cause of AMD rather than experiences of living with AMD (Crossland et al., 2007). The final review is based on the findings of the eight remaining articles (Table 2).

Quality appraisal

The papers reviewed were judged to be of generally good quality. However, only four of the eight papers were found to provide adequate information to satisfy each of the quality prompt questions (Table 1). Common weaknesses included the lack of a clear description of analytic method, insufficient raw data to support interpretations, and limited contextual information about participants. However, it is acknowledged that restrictions in journal word limits may cause problems for authors (Walsh & Downe, 2004). Contextual information regarding the sample is needed to ensure transferability, i.e. whether the findings are applicable to other populations. Transparency is essential to achieve trustworthiness, i.e. whether methods are sufficiently vigorous for findings to be used to inform practice or policy. No papers were excluded on the basis of critical appraisal; appraisal was completed not as a basis for exclusion but to highlight potential limitations with individual papers and the sample overall. It was felt that synthesising findings from a variety of studies may allow for the limitations in some studies to be offset by the strengths in others (Dixon-Woods et al., 2006).

Theoretical standpoints

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

Synthesis findings

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

Emotional Impacts

Shock was commonly reported as participants’ first reaction to diagnosis, however, there were contradictions regarding how patients went on to cope with AMD. Some made a conscious decision to remain positive and accept that their vision would not be restored (Moore, 2000; Moore & Miller, 2003). In contrast, Wong et al. (2004) reported findings from

both ends of the spectrum indicating that some participants reacted with feelings of
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powerlessness and despair while others reported acceptance; one 75 year old woman explained, “I am not depressed about it [AMD], I just accept it. I mean, I am 75 years old. Goodness gracious me, I have done very well, I think, to be where I am. But then again, it really does upset your life” (p.645)

Moore’s studies suggest an overall theme of hope and optimism (Moore, 2000; Moore & Miller, 2003). In direct contrast, Owsley et al., (2006b) found that AMD patients were more likely to make negative emotional comments about their experiences than positive ones. While positive comments in the study revealed themes of gratitude and hope, the negative themes of frustration, fear, and sadness, were reported twice as often as positive statements (Owsley et al., 2006b).

One of the most relevant outcomes of the synthesis for clinical practice was the reports of depressive symptoms. Wong et al. (2004) described some participants as having “fallen victim” (p.645) to AMD; these participants had become isolated and seemed unable to cope. Stanford et al.’s (2009) participants described living in a sad and lonely world; “I find myself sleeping during the day as I have ‘no leisure for pleasure’” (p. 136). Owsley et al. (2006b) reported that negative experiences were not confined to those with the most severe AMD suggesting that “negative emotional burden of the disease is not synonymous with disease severity as defined” (p. 27). Most important of all were the thoughts of suicide expressed; “some days I think, well, suicide is far better than going through this” (participant, Wong et al. 2004: p. 646). Given that negative feelings can occur at any stage and severity of AMD the danger of suicide evident in some patients’ accounts indicates a dire need for support services for these patients as these needs are not currently being met.

Functional limitations, adaptation and independence

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

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

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

As is evidenced by the man’s experiences in church, daily activities with AMD require additional concentration and planning (Wong et al. 2004). Dahlin-Ivanoff et al. (1996) suggested that patients used four main strategies to adapt to difficulties with activities of daily living: changing how the activity was performed; using assistive devices; avoidance; and asking for help. Other strategies reported included: using other senses; memory; and vision training (Moore, 2000).

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

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

One of the main threats to independence was the loss of the ability to drive (Moore & Miller, 2005). This was one of the key factors leading to dependence on others and the risk of isolation (Moore, 2000; Wong et al. 2004). In the study by Moore and Miller (2003) driving was mentioned by almost all of the men interviewed, in addition, women in Moore's earlier

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study reported the loss of driving as the loss of activity which gave them pleasure (Moore, 2000). Moore and Miller (2005) conducted a second analysis of their data with a specific focus on driving, an important finding was that participants were willing to go to great lengths and risks to continue driving and maintain their independence.

The future with vision impairment

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

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

Participants often acknowledged that AMD was unlikely to improve in terms of their acceptance of their condition and whatever future that may bring; "When you lose your centre vision, it's just like your virginity; once it's gone, it's gone." (Participant, Moore, This paper should be cited as: Bennion, A.E., Shaw, R.L. & Gibson, J.M. (in press). What do we know about the experience of age-related macular degeneration? A systematic review and meta-synthesis of qualitative research. *Social Science & Medicine*).

2000: p 578). Moore's studies suggested that this acceptance was part of the positivity shown by participants as they "grew to recognize that nothing could be carried out to improve their vision or stop the progression of visual loss" (Moore & Miller, 2003: p 14).

Social Engagement

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

Reduced participation in social activities and increased isolation can result from a lack of independence and transport difficulties (Wong et al., 2004). This can lead to frustration (Owsley et al., 2006b) and a detrimental effect on AMD patients' well-being. There are potential benefits of social engagement, for example the men interviewed by Moore and Miller (2003) emphasised the importance of maintaining connections with others as a coping strategy allowing them to maintain their independence, "You have to keep up with what's going on in the world. That's why I take classes...there is a lot of companionship in taking classes" (Participant, Moore & Miller., 2003: p. 14).

Unfortunately public knowledge of AMD appears to be limited. Participants reported feeling patronised by their family members (Feely et al., 2007), and finding family members to be

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unsympathetic and lacking understanding (Wong et al., 2004). Without social support patients expressed fear of being labelled as a fraud (Mogk, 2008; Wong et al., 2004); however, the diagnosis of legal blindness gave some the affirmation they needed and alleviated this concern (Wong et al., 2004).

Disclosure

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

Participants expressed concerns about being viewed as a fraud due to their invisible disability (Mogk, 2008). Despite being registered as legally blind one participant explained "Well, I told them [friends] that I am legally blind; I can't see them. They said jokingly, 'Well, I wouldn't like to drop a \$10 bill out in front of you to see if you pick it up' ... I feel that people that I have seen many times and told them that I am blind, legally blind, they don't

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believe it” (Participant, Wong et al., 2004: p. 643). Wong et al., (2004) concluded that “whilst participants did not “blame” others for not understanding their condition, they did resent others’ unintentional insensitivity toward it” (p. 645). As a result some participants made active decisions to conceal their AMD, in some circumstances declining equipment given to assist them.

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

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

Interaction with Health services

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

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

Other lay theories expressed by participants related to potential causes of AMD were unrelated to their hospital encounters. Many viewed AMD as a normal part of the ageing process. Dahlin-Ivanoff et al. (1996) suggested that patients feel that “[AMD] merely means that you are getting older and that it is a part of the normal ageing process. Some people believe that nothing can be done about it, except accepting that one is getting older” (p. 518). However, within the same article participants referred to a wide variety of potential external causes for AMD unrelated to age including: heredity, occupations in which vision is exposed, other diseases, chemical substances, violent sports, reading and watching TV a lot. Scientific knowledge about the risk factors for AMD (i.e. age, sun exposure, smoking, diet, etc) suggests that these participants’ assumptions are unfounded. Dahlin-Ivanoff et al. (1996) highlight that problematic behaviour may arise if patients are uncertain about issues regarding

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

Discussion

This meta-synthesis has important implications for understanding the experience of AMD, the provision of services and support for patients, and the future direction of health psychology research. The development of new anti-vascular endothelial growth factor therapies, such as Ranubizumab, have transformed the visual outlook in some wet AMD (Brown, et al., 2009) meaning the impact of AMD may be less severe in coming years. However, for patients who do not respond to treatment and those with advanced wet AMD, negative impacts of the condition remain prominent.

The emotional impacts and associated dangers of depression is a major concern. GPs and nurses may struggle to identify depression in older patients and the associated stigma experienced by older people and their families may be the main source of distress (Murray et al., 2006). The potential isolating impact of AMD and decisions not to disclose the condition to others suggests a need for support aimed at: alleviating the stigma associated with AMD; enhancing social engagement; and fostering family support in order to avoid potential

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depression. It is also important to consider the impact of vision impairment on family members of the individual living with AMD. The role of family members in providing low vision and psychological support for individuals with vision loss has received attention in the literature, however research which focuses on the experiences of and coping strategies used by the family members themselves is lacking (Bambara et al., 2009). There is evidence to suggest that family members providing care for visually impaired adults may be at risk of psycho-social issues and depression (Bambara et al., 2009b). This area needs further research to improve support services for patients, family members, and carers.

Given the day-to-day difficulties experienced by AMD patients and in order to prevent the emotional impacts of the condition, there is a need to develop services to help individuals adapt. Owsley et al. (2006b) argued for incorporating mental health services into AMD management. While this is necessary for extreme cases, services aimed at the prevention of stress and mental health issues may be more beneficial long-term. For example, the provision of intervention services aimed at influencing cognitive appraisals of coping through enhanced social support and personal social resources may improve perceptions of mastery, self-efficacy and self-esteem and in turn reduce the discrepancies between idealised self-expectations and the limitations imposed by disabling conditions (Penninx et al., 1997). Older people with fewer psychological resources are at increased risk of developing disability (Kempen et al., 1999) therefore interventions aimed at improving the psychological resources for AMD patients may help to limit its impact.

An important aspect of older people's perceptions of their lives, regardless of social and cultural background, is the ability to get on with life and maintain physical and social functioning (Cartwright, 2007). The disabling effects of AMD may be a barrier to achieving

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this goal. Wong et al. (2004) highlighted that rehabilitation may help to reduce emotional distress, overcome barriers to daily routines, and encourage participants to maintain a positive outlook in order to increase their QoL. Dahlin-Ivanoff et al. (1996) recommended that it would be beneficial for these services to include health education designed to improve patients' function in activities of daily living, which could include the provision of information, teaching of strategies to continue with daily activities, support, and problem solving techniques. Stanford et al. (2009) reported that adjustment remains similar or may even decline over 12 months. They suggested that current service provision does not meet needs in terms of cognitive, emotional and practical support again highlighting the need for improved support services for AMD patients.

Methodological considerations

While the qualitative evidence synthesised has highlighted some important areas of interest there are some limitations to the studies undertaken. Firstly many of the papers did not adequately describe the analytic methods used nor provide sufficient raw data to back up their claims. It is vital for qualitative evidence to detail this information to allow findings to be assessed for suitability to be applied to wider populations.

Most of the studies employed one-off data collection methods (with the exception of Stanford et al., 2009 which employed longitudinal data collection methods) which are only able to provide information from a single time point, comparing different age cohorts, or largely retrospective data. One possibility for expanding the insights gained within qualitative research is to collect longitudinal data. Longitudinal qualitative methods have been used in health research to investigate a variety of long term diseases and disorders (e.g. HIV; Baumgartner, 2007, diabetes; Peel et al., 2007, Chronic Fatigue Syndrome; Whitehead,

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2006). A benefit of longitudinal designs is that analysis may be able to highlight changes in experience over time (Lawton et al., 2009).

Another limitation is the variability within samples. The length of time participants had been living with AMD varied both within and between studies. By under-reporting the details and context of the participants' experiences studies are failing to meet the level of transparency (Yardley, 2000) necessary for the production of good quality research. The length of time an individual has been living with AMD may have important implications for their perceptions or experience of the disease. Reports about reactions to diagnosis were frequently based on retrospective data with the earliest data collection being between 1-30 months post diagnosis (Wong et al., 2004), therefore we only learn about perceptions of diagnosis once participants have had time to reflect on their condition. Given the potential speed of disease progression, thirty months is a large amount of time in which the experience of AMD for the participant may have changed substantially. Research which focuses on groups of participants with smaller variation in time since diagnosis may provide more detailed information about individual experience at specific time points over the course of the disease.

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

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the differences between bilateral and unilateral impairment. Longitudinal research on individual experiences which focuses on specific types of AMD would help to improve understanding of the experience and management of AMD.

Conclusions

Many of the issues identified in this meta-synthesis may be applicable to patients with a wide variety of visual impairments (Nyman, Dibb, Victor, & Gosney, 2011). However this study has focused on the specific needs and unique experiences of patients with AMD, and illustrates the need to tailor support which is specific to patient's individual diagnosis and life contexts.

Understanding experiences is vital in order to “give voice” (Larkin et al., 2006) to the concerns and every day experiences of individuals. This meta-synthesis has highlighted that AMD can impact on multiple areas of individuals' lives and can cause major changes within reports of everyday experiences. It is only through a greater understanding of experiences that we can develop methods to ensure that AMD is only a minimal intrusion on patients' lives. It is also important to be aware of the contradictory findings in some studies. Context and cultural factors are vital to the understanding of individuals' experiences with AMD, therefore it is important to take a holistic approach to the provision of services and support for patients (Mogk, 2008). Quantitative evidence and survey research is unable to help us understand the nuances of patient experiences. There is a need for diverse evidence to ensure we can understand and prepare for the psychosocial, economic vectors alongside the biomedical and treat the person as well as the disease to improve QoL and in order to ensure patients receive the care they are due. Qualitative evidence is therefore vital to improve understanding in order to ensure that policy and practice are informed by the best available

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evidence and should be included in future systematic reviews of the literature for the development of NICE guidelines.

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Table 1: Assessment of Quality Based on Prompts Approach Dixon-Woods et al., (2004)

Study	Are the research questions clear?	Are the research questions suited to qualitative inquiry?	Are the following clearly described?			Are the following appropriate to the research question?			Are the claims made supported by sufficient evidence?	Are the data, interpretations and conclusions clearly integrated?	Does the paper make a useful contribution?	Rating (KP, SAT, IRR, FF)
			Sampling	Data collection	Analysis	Sampling	Data collection	Analysis				
Ivanoff et al (1996)	Yes	Yes	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	SAT
Moore et al (2000)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	SAT
Moore & Miller (2003)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	KP
Wong et al (2004)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	KP
Owsley et al (2006b)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	SAT
Feely et al (2007)	Yes	Yes	Yes	Yes	No	Yes	Yes	No	No	No	Yes	SAT
Mogk (2008)	No	Yes	No	Yes	No	Yes	Yes	Yes	No	Yes	Yes	SAT
Stanford et al (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	KP

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Table 2: Details collected from reviewed articles (n=9)

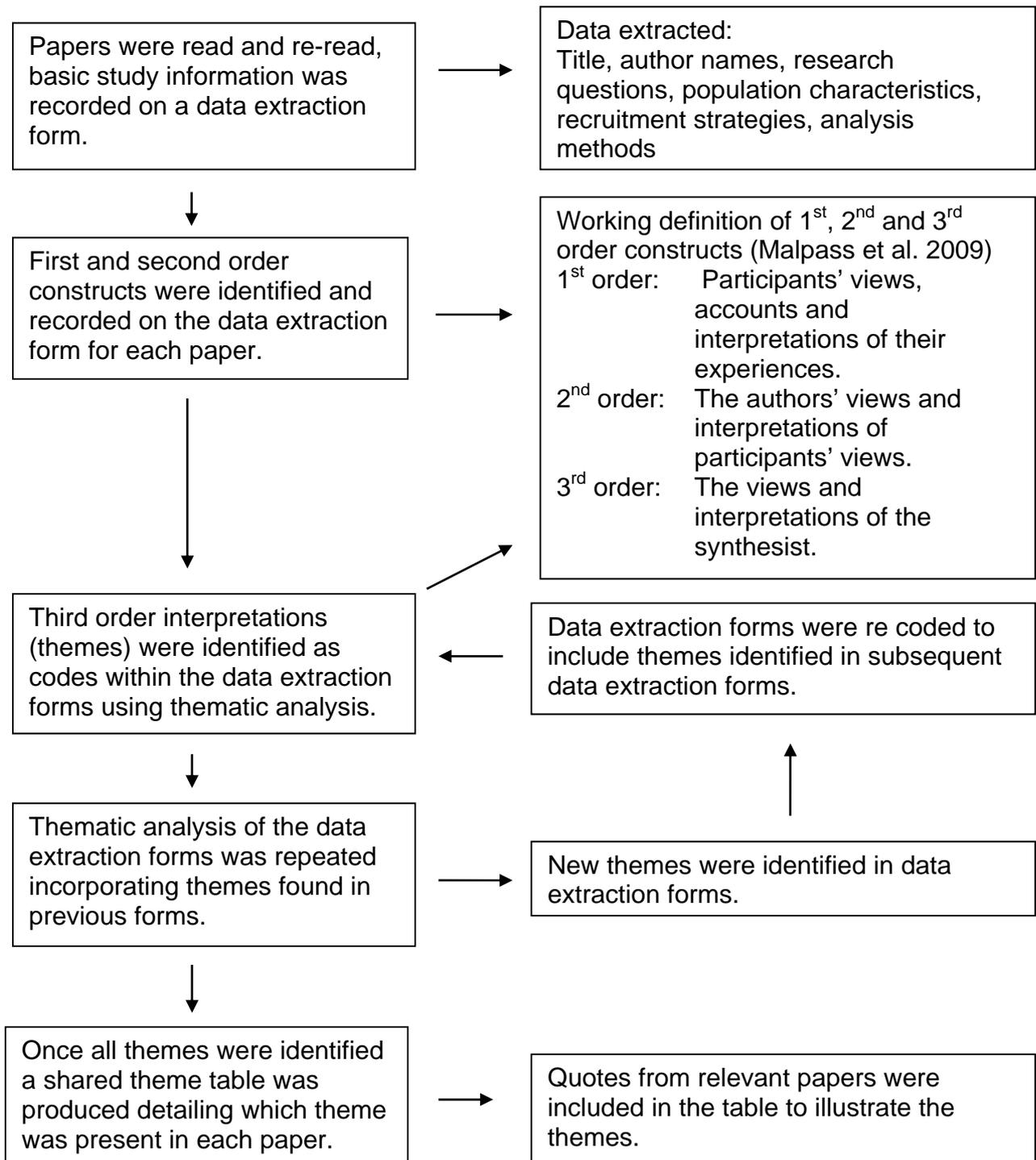
Study	Aim	Participants					Data Collection		Analysis	Results and Themes
		Sampling Method	Age	No. and Gender	AMD Type	Length of time with AMD	Type	duration		
Ivanoff et al 1996	Perceptions of AMD and impact on activities of daily living	Purposive	68-91	25 (M=10 F=15)	-	-	5 focus groups	> 2 hours	Kreuger's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

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Stanford et al (2009)	Longitudinal assessment of psychosocial adjustment to AMD	Subsample from randomised controlled trial.	73-92	37 (F=20 M=17)	-	-	Weekly semi-structured self completed diaries	1 year	Grounded theory	family. Desire to be normal; vision loss as an abnormality. Safety, loss of independence, isolation, support mechanisms, mood, effects of the media and psychosocial adjustment. There was little evidence in the diaries of psychosocial adjustment to visual loss.
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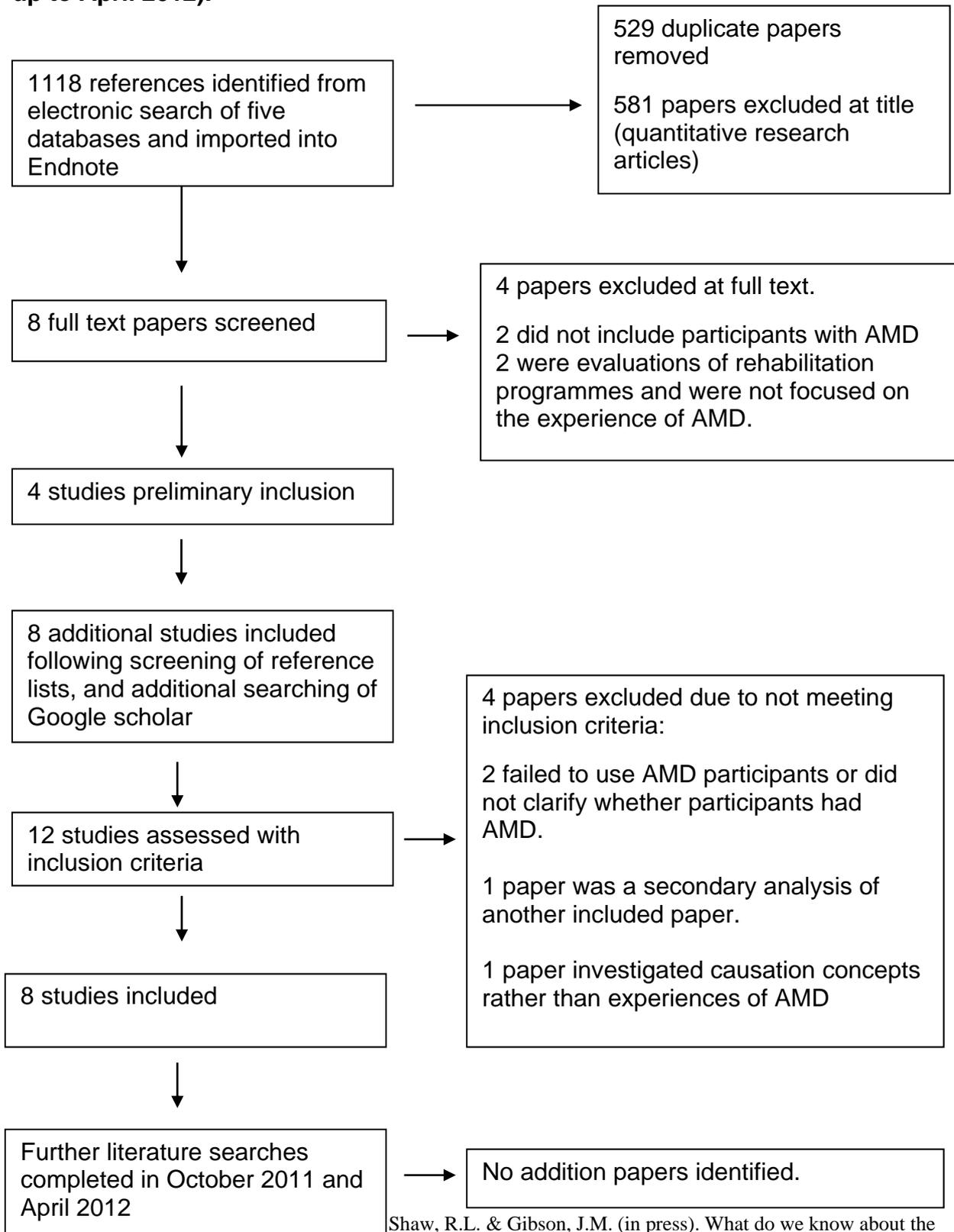
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Figure 1: Flow chart outlining the synthesis process



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Figure 2: Flow chart outlining the number of articles retrieved, and included or excluded at each stage of the review process (including all articles published up to April 2012).



Shaw, R.L. & Gibson, J.M. (in press). What do we know about the experience of age-related macular degeneration? A systematic review and meta-synthesis of qualitative research. *Social Science & Medicine*.

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