Social Science & Medicine 75 (2012) 976–985

Contents lists available at SciVerse ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Review

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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ARTICLE INFO

Article history:
Available online 21 May 2012

Keywords:
Ageing
Vision loss
Meta-synthesis
Age related macular degeneration

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 to 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.

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, & Desai, 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, 2008); increased depression (Brody et al., 2001); and increased difficulties with activities of daily living (Cahill, Stinnett, Banks, Freedman, & Toth, 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, Brown, Brown, Hollands, & Sharma, 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 decision to undertake a systematic review of qualitative evidence. The value of qualitative research in advising on best practice has been recognised both by health psychology and NICE (Kelly et al., 2009; Mulrow, Langhorne, & Grimshaw, 1997; Smith, 2011) yet it is often excluded from reviews. Here we report a systematic

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doi:10.1016/j.socscimed.2012.04.023

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 (Dixon-Woods et al., 2007; Rycroft-Malone et al., 2004), 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.

Methods

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

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 to 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 (Fig. 1). Articles were read, re-read and details of the studies recorded (Table 2). Data 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). 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

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 enquiry?	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				
Dahlin-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 and 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, McGwin, Scilley, Dreer, et al. (2006)	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