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# Self-management programs for adults with low vision: Needs and challenges

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**Abstract**

*Objective:* To explore the needs of individuals with low vision in order to inform the contents of a low vision self-management (SM) program and determine potential barriers to participation.
*Methods:* Semi-structured interviews were conducted with 48 participants with low vision resulting different from eye conditions. Qualitative analysis was conducted in order to identify major themes.
*Results:* All participants described a range of consequences as a result of vision loss including difficulties with functional activities, social interaction and emotional distress. Less than half were interested in attending a SM program. Barriers included practical reasons as well as a perceived lack of need and unclear or negative perceptions of such a program.
*Conclusion:* SM programs for low vision are a promising way to help address the range of difficulties experienced by this population if barriers to participation can be overcome.
*Practice implications:* SM programs should include vision-specific strategies, training in generic problem-solving and goal setting skills and how to cope with emotional reactions to vision impairment. Programs should be delivered and promoted in such a way to enhance access and encourage uptake by those with a range of vision loss in the community.
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*Keywords:* Patient education; Self-management; Vision impairment

## 1. Introduction

Low vision refers to significant vision loss that is not correctable by refraction or treatment. Due common age-related eye conditions such as macular degeneration, glaucoma and diabetic retinopathy the number of individuals with low vision is projected to increase as a result of the increased life expectancy and aging population [1]. Individuals with low vision have some usable vision, but experience a range of behavioural restrictions, especially with regard to reading and accessing information, mobility, leisure and activities related to household and personal care [2–4]. These restrictions are likely to result in loss of independence which may account for the increased social isolation, decreased general life satisfaction and high levels of depression often experienced by these individuals [5]. The negative impact of vision loss on quality of life has been found to be comparable to that of other major medical conditions including stroke, coronary heart disease, diabetes and asthma [6].

Low vision rehabilitation services have been implemented to address the restriction posed by low vision and enhance independence. Different models of low vision services exist and vary widely in intensity although the majority involve provision of aids, devices, and training to enhance use of residual vision. Current low vision services in Victoria, Australia consist of an assessment with a member of the multidisciplinary team, and an optometric assessment and prescription of optical aids. This may be followed by further training provided by the multi-disciplinary team. A detailed description of this service has been previously provided [7]. A recent study of individuals attending this service indicated that whilst the majority of clients purchase a low vision device, only a third of clients participated in rehabilitation training programs beyond the low

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vision assessment, and the majority do not utilise other aspects of the comprehensive service, although the reasons for this are not known [7]. A few recent studies have attempted to compare the outcomes of optometric and multidisciplinary approaches to vision rehabilitation. These studies have suggested that enhanced, comprehensive vision rehabilitation services do not improve quality of life significantly more than standard optometric care [8–10]. Recent studies evaluating multidisciplinary low vision services also indicate that these services have a modest impact on quality of life [11,12].

Studies of alternative approaches to rehabilitation indicate substantial benefits on patient outcomes. In particular, self-management approaches shown to be effective in improving health status and quality of life in a range of chronic conditions [13,14], have recently been adopted in low vision rehabilitation. Self-management (SM) involves learning the skills necessary to continue an active and emotionally satisfying life in the face of a health condition [15]. SM represents a new paradigm in health care in which patients with chronic conditions are considered active partners in their health care with responsibility for managing their own conditions with support and advice from health care professionals [16,17]. A critical component of SM training is to provide participants with the skills to problem-solve difficulties that they encounter [17]. This is different from the professional teaching particular solutions or making changes to the client's home environment. SM aims to provide the client with skills and resources to manage the practical, social and emotional consequences of their condition and to seek specialist support when needed. The extent to which vision rehabilitation is provided in a SM manner will vary on the culture of the rehabilitation organisation and the individual approach of each rehabilitation worker.

Evaluations of SM interventions for people with age-related macular degeneration (AMD) have been reported in United States, Sweden, and Germany [18–23]. Results from a randomised controlled trial of a group-based SM course found that participants in the intervention group showed improvements in functioning and self-efficacy, as well as reductions in emotional distress which were sustained at a six month follow-up [19,20]. Whilst AMD is the main cause of low vision in older people, over a third of individuals attending for low vision rehabilitation for the first time in Victoria have vision loss caused by other conditions including diabetic retinopathy and glaucoma [7]. The development of a generic low vision SM program would therefore be applicable to a wider population and has been highlighted as a key action point in the Australian National Eye Health Framework [24].

Whilst the results of self-management programs for chronic disease and AMD in particular appear promising, the ease of implementing programs within community settings has been questioned [25]. In general, SM training involves several hours of structured group sessions which may be supplemented by individual sessions. Studies to date on self-management programs for AMD have reported little data regarding the uptake rate and barriers to attendance, although ill health and practical barriers to attending have been indicated [21,23]. This study was designed to (a) explore the needs of individuals with a range of eye conditions causing low vision in order to inform the contents of a generic low vision SM course, (b) determine the level of interest in a low vision SM program, and (c) identify barriers to participation.

## 2. Methods

### 2.1. Participants

Participants were recruited from public and private eye clinics in Melbourne, Australia. Participants were required to have presenting visual acuity <6/12 in the better eye, and be over the age of 18. Other criteria for inclusion were fluency in English and the absence of cognitive or hearing deficits that would impact on the ability to participate in the interview. Previous research has shown that demographic factors such as gender, utilisation of vision rehabilitation services and metropolitan or rural address can influence views of individuals with low vision [26–30]. Therefore a purposive sampling technique was adopted. Purposive sampling involves selecting participants for the study based on particular characteristics that may influence responses and is commonly used in qualitative research as a technique to ensure that a wide range of views are explored [31–33]. Participants were therefore selected to ensure that the sample included participants with a range of demographic characteristics.

### 2.2. Interview procedure

Ethical approval was received from the Human Research and Ethics Committee of the Royal Victorian Eye and Ear Hospital. Semi-structured face to face interviews were conducted using an interview schedule. This schedule included structured questions to collect demographic data as well as open-ended questions to elicit participants' views. Open ended questions designed to determine the impact of low vision and needs of people with low vision were 'What does poor vision mean to you?' and 'What are your greatest problems or difficulties in living with poor vision?' The interviewer followed participants' responses with prompts and encouragers. Participants were then provided with the following brief description of a self-management program and asked if they would be interested in attending 'We are designing a group-based course for people with poor vision that will teach them the skills and knowledge to manage poor vision. It would run for 1/2 a day, once a week for 6–8 weeks. Would this course be of interest to you?' The subsequent line of questioning was based on the participant's response. Those who stated that they would be interested in attending a SM program were asked further open-ended questions to determine what they would like to be covered in the course and what they hoped to gain from such a course. Participants who were not interested in attending a SM program were further asked to express their reasons. Recruitment continued until the target population had been recruited and until 'thematic saturation' had been reached, the point at which no new issues were emerging from the interviews [34].

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