

# How do older people with sight loss manage their general health? A Qualitative Study

## Abstract

*Purpose:* Older people with sight loss experience a number of barriers to managing their health. The purpose of this qualitative study was to explore how older people with sight loss manage their general health and explore the techniques used and strategies employed for health management.

*Methods:* Semi-structured face-to-face interviews were conducted with 30 participants. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis. *Results:* Health management challenges experienced included: managing multiple health conditions; accessing information; engaging in health behaviours; and maintaining wellbeing. Positive strategies included: joining support groups, clubs and societies; using low vision aids; seeking support from family and friends; and accessing support through health and social care services. *Conclusions:* Healthcare professionals need to be more aware of the challenges faced by older people with sight loss. Improved promotion of group support and charity services which are best placed to share information, provide fora to learn about coping techniques and strategies, and give older people social support to prevent isolation is needed. Rehabilitation and support services and equipment can only be beneficial if patients know what is available and how to access them. Over reliance on self-advocacy in current healthcare systems is not conducive to patient-centred care.

Key words: Vision Impairment, Healthcare, Health Management, Older People

## Implications for rehabilitation

- Sight loss in older people can impact on many factors including health management. This study identifies challenges to health management and highlights strategies used by older people with sight loss to manage their health.
- Access to support often relies on patients seeking information for themselves. However self-advocacy is challenging due to information accessibility barriers.
- Informal groups and charities play an important role in educating patients about their condition and advising on available support to facilitate health management.

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## Introduction

Sight loss is one of the most common disabling conditions in the ageing population and evidence suggests impairment can impact on the day-to-day life of older people regardless of its level of severity<sup>1</sup>. Older people with sight loss have reported problems with many different aspects of life: mobility and transport, reading and writing, leisure activities, household tasks, personal care, pain and discomfort<sup>2</sup>, negative emotions<sup>3</sup> and maintaining social interactions<sup>4</sup>. In addition, higher levels of vision impairment are associated with poorer general health<sup>5</sup> and psychosocial wellbeing<sup>6</sup>.

Literature concerning the management of health in people with sight loss has mainly focused on poor compliance with eyedrop medication in patients with Glaucoma. A variety of reasons have been proposed for this: low health literacy, problems administering medication, underestimating seriousness of the condition, lack of faith in efficacy of treatment, memory problems, and lack of information about the condition<sup>7-10</sup>. People with other forms of sight loss may also experience challenges when managing their eye condition. For example, The Age Related Eye Disease Study (AREDS) demonstrated that in patients with Age Related Macular Degeneration (AMD) categories 3 (intermediate) and 4 (advanced AMD in one eye), suitable dietary supplements are protective against progression of visual loss<sup>11,12</sup>. Despite this, evidence suggests that many suitable patients do not use these supplements or fail to take the correct dose, while patients with advanced disease, in which there is no proven benefit, are keen to take them<sup>13,14</sup>

In addition to sight loss many older people are living with co-morbid chronic health problems<sup>15,16</sup>. The management of these conditions can be challenging, for example the onset of sight loss caused by diabetic retinopathy can make controlling diabetes more difficult<sup>17,18</sup>. Older people with sight loss often report needing support from others in order to take prescribed medication<sup>19</sup> and many experience difficulties when visiting their pharmacist for “over the counter” medications to prevent or treat minor illness<sup>20</sup>.

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As well as barriers regarding the management of medication, older people with sight loss may struggle to access general health services<sup>21</sup>. Sharts-Hopko, Smeltzer, Ott, Zimmerman, & Duffin<sup>22</sup> found that older women with vision impairment had to overcome a variety of barriers to healthcare services including: a lack of health professional awareness of their condition and its impact, difficulty accessing information in written format, problems accessing healthcare environments (e.g. inaccessible settings, transport issues and cost), feelings of isolation (living alone and not wanting to burden others), a need for self-advocacy and knowing what services to ask for, and concerns about the perception of others (i.e. assumptions about being deaf/mentally deficient and healthcare professionals not recognising their needs). Patients with AMD have also been shown to feel frustration and mistrust towards healthcare services with some not seeking help due to attributing their condition to 'normal ageing'<sup>23</sup>. These challenges are exacerbated when patients with sight loss are provided with information in written formats which are inaccessible without assistance<sup>24-26</sup>.

## **The current study**

The purpose of this qualitative study was to understand how older people with sight loss manage their general health and to identify barriers and facilitators encountered by this patient group. The study also explored how older people with sight loss overcome barriers in order to aid the development of recommendations for rehabilitation and improving health. The research questions guiding this work included: (i) What barriers and facilitators to health management do older people with sight loss experience? (ii) What strategies do older people with sight loss use to manage their general health?

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## **Method**

Ethical and research and development permissions were obtained from the North Staffordshire NHS Research Ethics Committee, Aston University Ethics Committee and West Birmingham and Sandwell NHS Trust

## **Procedure**

Eligible patients were identified by a Consultant Ophthalmologist or an Eye Clinic Liaison Officer (clinic team member responsible for helping patients make sense of their diagnosis, registering patients as partially sighted and signposting additional support services) and provided with a large print information sheet. Consent to pass on contact details to the research team was obtained and patients were then contacted by phone to offer the opportunity to ask questions about the research and schedule an interview. In addition participants were recruited through local support groups for older adults with sight loss. The researcher introduced the study at group meetings and large print information sheets were distributed. Interested individuals were able to ask questions and provide their contact details. These individuals were then contacted by phone to arrange interviews. All participants gave written consent.

## **Participants**

Thirty older adults with sight loss were recruited (20 from clinics and 10 from support groups). Participants were aged 69-95; 14 were male, 16 female; 15 lived alone, 13 with a partner, and 2 with a family member; 29 were white, 1 was South Asian. A wide variety of eye conditions were represented including AMD, glaucoma and diabetic retinopathy (see tables 1 and 2).

**INSERT TABLES 1 AND 2 ABOUT HERE**

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## **Data collection**

### **Semi-structured interviews**

An interview guide was created, informed by the literature and discussions of the project advisory group (made up of the research team, older people with sight loss, and representatives from the Macular Society, Vision 2020 UK Ltd and Thomas Pocklington Trust). The guide included open questions about: participants' life contexts; eye conditions; engagement with health, social care and charity services; and engagement in health behaviours including diet and physical activity. Interviews lasted between 45 minutes and 2.5 hours, were audio-recorded and transcribed verbatim.

### **Measures**

Participants recruited through clinics gave consent to access medical records which were used to determine visual function, eye condition diagnosis, and co-morbidities. For participants recruited through support groups, co-morbidities and eye condition diagnosis were self-reported and the National Eye Institute Visual Function Questionnaire (NEI VFQ-25) was administered to assess visual function.

### **Data analysis**

Thematic analysis<sup>27</sup> was conducted assisted by computer software (NVivo). Data were coded in an iterative manner by the first and third authors and developing codes were discussed during meetings with the Project Advisory Group. The initial coding frame was modified as new themes were identified in subsequent participant cases as part of a cyclical process. The final set of themes were presented to the Project Advisory Group for discussion and it was agreed that these represented participants' concerns and conveyed the meaning of their experiences.

## **Results**

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Four main themes are presented: managing complex health needs, access to information, health behaviours, and maintaining wellbeing. Barriers and facilitators to health management and strategies and techniques for managing health in relation to each of these issues is discussed.

### **Managing complex health needs**

As well as sight loss, all participants lived with long-term conditions including angina, arthritis, cancer, diabetes, hypertension, and osteoporosis; others had experienced stroke, heart attack, and kidney failure. Managing multiple conditions usually required multiple clinic appointments, and medications. This posed problems when medications interacted and caused side effects.

*"The doctor at [the hospital] said, 'I want you to take these tablets because it will help with the bleeding at the back of the eyes.' So I said, 'OK'. She said, 'See your doctor and ask them to prescribe', and she gave me a note, like, to give to my doctor. I took that down and the doctor seemed a bit dubious about giving them to me because I was taking cholesterol tablets. And she said that one of the side effects is muscle ache. So I thought, 'Well, that's alright, like you know, I'll just cope with it.' But oh God, it's terrible! The pain in my arms and my back and my legs. I can't walk now. I mean before I started taking them I was right as anything like, you know. But I've told them but they said it's the lesser of two evils really. But I would sooner that than my eyes get worse, you know." (Marion)*

The extract above demonstrates the dilemmas experienced but also the pain participants were willing to suffer to prevent their vision from deteriorating further. Despite these challenges participants reported a variety of strategies and techniques to overcome problems faced (see supplementary file for a full list by theme) for example, the majority took multiple medications without difficulty and most were able to manage by devising a routine.

*I am pretty good because I do have a routine of taking [medications] at certain times of the day or having them after*

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*specific meals or just before you go to bed, you know? So you do tend to remember them. (Bill)*

Others used the blister packets prepared by pharmacists (which organise tablets by days of the week) but one participant complained about them saying, *"I declined those because once you open the pack the tablets inside spring everywhere and it's difficult then for me to collect them up and take them"* (George). Another participant was worried about her daughter's dog finding and eating tablets that had fallen on the floor and becoming ill.

*[My daughter] has to go round the bedroom looking for tablets before she gets the dog off the lead. Because I've dropped them sometimes and I can't see to pick them up, so I just leave them. (Margaret)*

Another challenge was attending appointments and many participants reported not going to the doctors' surgery for fear of falling, inadequate public transport and no other means by which to get there, except for those who felt they could afford it, by taxi. This was particularly prohibitive in the winter months. Some participants, especially those living with their partner, were happy to walk to the surgery if they lived close by in the summer months but would be practically housebound in the winter.

*"If it's an early appointment, we always go in a taxi. If it's a later appointment, and it's a very nice day -if I went out today and had to walk to the doctors, I couldn't because I wouldn't be able to breathe with the cold air. But in the summer months, we try, we go on the bus which is only one stop, then it's a walk, a four or five minute walk. Not so far. But we are tending to use the taxi more than we are the bus."*  
(Henry)

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Other participants reported depending on their family for lifts to hospital and surgery appointments. Some participants did not have family or friends to rely on and without knowledge of services available to help them get to appointments could go for months without appropriate care. Access to information was a significant barrier to health management for these participants.

### **Access to information**

Examples of challenges when accessing information included being dependent on friends and family to read letters informing them of appointments and lack of knowledge about transport services. A few participants knew about the hospital taxi service for getting patients to their appointments, but none was aware of the local government provision (available at the time of interview) of Dial-a-Ride services for people on Disability Living Allowance to access healthcare services.

Problems with multiple health conditions were made worse by poor relationships with General Practice doctors (GP) which acted as another barrier to information and appointment attendance.

*"I don't have the confidence in the doctors so much. So unless it was something really, really desperate that I couldn't work out for myself, I won't be going." (Joyce)*

One perceived risk was being prescribed new medications that would interact with current medication regimens and have a negative impact on health. One patient's experience suggested that some GPs may not be adequately informed about individuals' co-morbidities to ensure conflicting medications are not prescribed:

*Interviewer: how do you access or find out health information?*

*Mary: I don't.[...]Well...they've never mentioned my eyesight the doctors haven't to me never. I remember years ago when I was going to the hospital they said, 'Watch what your doctor gives you because they'll give you tablets that'll send your*

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*pressure up' and the doctors just give you things. And I say, 'is that all right with glaucoma?', 'oh, no, no', they say.*

As a regular point of contact, participants felt it would be useful if GPs were aware of the limitations sight loss could pose when combined with other health complaints. Routine primary care for older people with sight loss in which all aspects of health are discussed is needed to better co-ordinate care and reduce negative health outcomes.

One important source of information for some participants was support groups. For example, Henry did not attend a support group for his own condition (wet AMD and diabetes) but had previously joined his wife in attending groups for her glaucoma.

*[My wife] used to go to a meeting every month with the glaucoma. Which they held by the hospital in [town]. They were very, very good. Excellent, marvellous speakers giving you advice and giving you things to help you. They were excellent. But, no, I'm not affiliated to.. I'm not a member of any [...] whenever [my wife] went to the meetings, I went with her. And this lady was talking about aids for reading and that. She made me an appointment. And that was through... when she came to give a talk with the glaucoma. But I've never been in any society. (Henry)*

Through access to this group Henry was able to get information and advice and was even referred for an assessment for magnifying glasses. This suggests that condition specific support groups may not always be required; a general source of information about sight loss for older people may be sufficient to make a difference to the lives of patients and help them manage their general health.

## **Health behaviours**

Health behaviours are those activities of everyday life which are protective and help prevent lifestyle-related conditions, such as diabetes, from getting worse, e.g., eating a healthy diet and

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being physically active. A fear of falling prevented many participants from physical activity outside of the home.

*"I try not to go out unless there's somebody holding me up like, because in point of fact I have fallen now on five occasions and it's only about five, maybe six weeks ago that I was cut underneath my nose, there, all the way down inside my lip and I had ten stitches." (George)*

Others felt confident to go out, and made a point of doing so especially in summer. For some living in retirement homes there were gyms available on site which made keeping active much easier and others living in the community talked of groups they attended to keep active.

*I go to a swimming club because I like swimming...it's a big club. It's called 'Nifty Fifties'. But most of them are over 70 there. (Margaret)*

One participant described exercises done while sitting in a chair using a walking stick when the weather prevented him from going outside.

*Jim: I'll sit on the chair and I'll start doing exercises.*

*Interviewer: OK. What kinds of exercises will you do?*

*Jim: Well I've got a book and it's with the walking stick. And you sit on that chair and you hold the stick like that, my walking stick. And just do that like, doing that [holds stick out to the side].*

One participant was aware of the need for self-motivation in keeping active, something which has been identified many times in research regardless of age.

*"You have to look after yourself, you know, nobody can do it for you. I go out everyday from 2 to 3 and I walk about a mile every day to keep [fit]- you have to." (Arthur)*

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Cooking also posed problems for participants. Several participants described difficulties shopping, chopping vegetables, for some the pans were too heavy and others had difficulty detecting when meat had browned or where butter had been spread.

*I have difficulty with if I do any cooking at all, I can't see when anything's gone...you know? When the meat's gone brown or..it's simple things really. If I do a sandwich, I can't see where I have spread the butter to! (Marion)*

Many developed techniques or changed their habits in order to manage. For example, one participant now bought red skinned potatoes so she could see where she has peeled, and another had talking lids for canned food to avoid mistaking her beans for peaches.

*I've got talking lids for all my tins in the pantry...now I couldn't be without them or I would be opening peaches for beans or whatever, you know. So, the talking lids are marvellous! (Barbara)*

## **Maintaining wellbeing**

Those participants who lived alone described times when they felt completely isolated from others and some felt that giving up favourite pastimes was just a part of growing old. Again, this was particularly highlighted when there was bad weather but for some it was routine.

*"Friday, I'm totally on my own. Saturday, I'm totally on my own and Sunday, I'm totally on my own, which I just laze about, do nothing basically." (Trevor)*

The loss of previous pastimes was felt particularly strongly by some. The majority of participants described not being able to read anymore; they were unaware of talking books and newspapers or

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of the benefits of e-readers. When asked about technology there was an expected fear that they were too late to learn but one participant loved her e-reader.

*“Most evenings I watch television or I read, I’ve got a Kindle which is very useful because if I can’t see I can increase the size of the font.” (Ethel)*

The majority of participants relied on existing friendship groups and family to get out and about; most did not feel comfortable seeking support elsewhere. One participant imagined that support groups “overdo it a bit” which was a threat to him as “an independent-minded individual” (Brian). But those who did attend groups were hugely grateful for what they had given them; for most that was a revived sense of social interaction and enjoyment.

## **Discussion**

This research explored experiences of how older people with sight loss manage their health. The findings lend support to and reiterate past literature highlighting the wide variety of barriers experienced. In addition new insight has been gained into the methods used by older people with sight loss to keep well and active. Many older people have chronic health conditions such as diabetes or are managing the after-effects of acute conditions such as stroke and our findings illustrate that sight loss makes managing these conditions more challenging. However, they also had long lists of techniques for managing their health conditions and continuing to remain independent (see supplementary file). These ranged from major life changes such as moving house to be closer to services, to smaller day-to-day changes such as using pharmacist-provided blister packs and using talking lids to label food.

Education in self-management strategies may be beneficial both for vision problems and to help individuals take care of themselves and improve their physical health<sup>28</sup>. However, the current

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approach to rehabilitation can be criticised for focusing too heavily on functional issues rather than adaptive cognitive processes. Evidence suggests that it is the individual's perception and cognitive appraisal of their condition which predicts distress and disability rather than objective and functional measures such as visual acuity <sup>29</sup>. This study has illustrated that, despite all the difficulties faced, older people often talk positively about their health, feeling they are doing okay "for their age". Personal characteristics such as self-reliance, stoicism, and self-determination may help older adults to cope with sight loss but overriding determination to remain independent may also impact on patients' willingness to accept help which can have a negative impact on health <sup>16</sup>.

Several participants lacked confidence in healthcare professionals and experienced challenges in making appointments in addition to receiving confusing or conflicting advice. It is important that all healthcare professionals are aware when their patients have sight loss and adapt care appropriately. In support of previous research <sup>22,24,25</sup> this study has highlighted that patients may not be provided with information in a format accessible to them and increasing awareness about the needs of patients with sight loss will help to overcome this problem. In addition, healthcare professionals need to be educated about the impacts low vision can have on the lives of their patients. A recent report by the Royal National Institute for Blind People (RNIB) assessing service provision for patients with vision loss within East Sussex NHS clinics has also highlighted this need to improve vision impairment awareness among healthcare staff <sup>30</sup> and the RNIB have created a 'top tips for healthcare professionals' to enhance this awareness <sup>31</sup>. Furthermore, eye health has been named as a clinical priority by the Royal College of General Practitioners <sup>32</sup>. The need for GPs to understand vision impairment and its impact on patients is particularly important, especially when patients are accessing primary and secondary care for multiple health conditions which may require a co-ordinated medication regime.

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Our participants often relied on family support for help with reading letters and attending appointments but when that was absent, they faced these challenges alone and threatened their privacy by relying on neighbours or friends. Information needs to be in a format accessible to the patients themselves. Furthermore, patients need to feel empowered to ask questions of healthcare professionals. We found examples of those who stayed quiet and those who pro-actively sought clarification in clinic. Management of complex conditions and seeking treatment if conditions deteriorate is dependent on accessible information and open dialogue at consultations. It is clear that older adults with sight loss need on-going support to manage their eye condition alongside co-morbidities signifying the limitations of services that are time-limited or only available at diagnosis

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Additional factors associated with managing sight loss and long-term conditions include medication regimes and engaging in health behaviours to maintain a healthy lifestyle. Some participants experienced challenges in taking their medication, cooking, and physical activity. Access to healthcare services, including hospital clinics and GP surgeries were also difficult for some. Accessible packaging and the delivery of medication are issues which require a co-ordinated response from GP surgeries and community pharmacies. However, our findings indicate that even when such services are available older adults are not always aware of them. Awareness of aids for cooking and different types of exercises was also poor among some participants. A key facilitator of awareness and access of aids and services was attending a support group.

Support groups, whether related to vision impairment specifically or not, offered advice and support to participants and opened doors to services of which patients were otherwise unaware. Support groups also acted as a way to maintain wellbeing in terms of an opportunity to be socially engaged and provided an opportunity to interact with other older people coming to terms with sight loss. For some participants, this led to sharing novel coping strategies for managing with vision loss. Brennan

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& Cardinali<sup>34</sup> have reported that the use of novel coping strategies are associated with better adjustment and a reduction of depression symptoms in older people with age related sight loss.

Hayeems, Geller, Finkelstein, & Faden<sup>35</sup> highlighted that patients who identify as visually impaired will reveal their condition, use low vision aids, and become more independent while those who identify as sighted hide their condition, reject low vision aids, and gradually become more dependent. Participants in our sample also showed this pattern. As well as providing practical support using vision aids can help avoid the internalised feelings of stigma and shame exhibited by those keen to hide their vision loss. It is worth considering whether older adults with vision impairment require emotional support to come to terms with how it will affect their daily living.

To close, changing attitudes to old age represents a serious societal challenge. There is a need to highlight the capabilities of older people rather than to focus only on the deficits associated with old age. Widely held western attitudes about ageing have important implications for older patients' health management behaviours. The internalised stigma associated with both vision impairment and advancing age can have a negative impact on patients' abilities to both manage health and seek help and support. Featherstone & Hepworth<sup>36</sup> described the ageing body as a 'mask' which is judged by appearance, function, cultural values, and used to classify a person as old. Behind the mask is the lived body a person knows and experiences according to their own individual context and biography. It is this experience of the body which should be acknowledged and explored within healthcare. Ageing has been reduced to the mechanics of the body creating a deficit model which was familiar to participants. Nevertheless, there is a need to encourage older adults to seek advice and support instead of suffering with something which could help them to adjust with the help of aids, technology or support networks. The notion of support seeking is complex though, and we found some participants felt that seeking support would detract from their independence. A shift in

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mindset or perhaps more simply increased awareness of the aids and support that are available would enable older adults with sight loss to retain their independence for longer.

## **Limitations**

A limitation of the present study is that each participant was only interviewed once and therefore our research was not able to capture the fluid and ever changing nature of the challenges and solutions experienced by the participants over time. However, contextualised data were collected and participants were encouraged to reflect on experiences during interviews which have enabled some understanding of this issue particularly in relation to access to services. In addition it is acknowledged that participants recruited from support groups were more likely to highlight the value of this resource, however evidence of the value of support groups in those recruited through hospital clinics adds to the evidence regarding the importance of these services for all patients. Finally, despite aiming to recruit a diverse range of participants there was a lack of ethnic diversity within the sample. It is likely that our data do not fully represent the experiences of individuals from different cultures and therefore further research in this area is needed.

## **Conclusions**

This qualitative study about older adults' experience of managing general health when living with vision impairment supports the existing literature and adds depth and specificity in terms of how older adults with vision impairment can overcome barriers faced and maintain their general health and wellbeing. The accounts provided from older adults have identified a number of barriers which need to be addressed, examples of stoicism which prevent older adults from seeking support, but also a range of techniques for adapting in everyday situations. The resourcefulness and foresight of some participants is admirable; we hope that in passing on these findings they will help others adapt and effectively manage their health and wellbeing while living with sight loss.

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## **Declaration of interest**

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