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# BMJ Open

## The effects of stereotyping on social participation from the perspective of older adults with low vision: A focus group study

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3 The effects of stereotyping on social participation  
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5 from the perspective of older adults with low vision: A focus group study  
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The effects of stereotyping on social participation  
from the perspective of older adults with low vision: A focus group study

**ABSTRACT**

**Objective:** In order to better understand the barriers that limit the social participation of older people with low vision, the aim of this study was to describe and better understand the factors that shape the social experiences and functioning of people with vision loss.

**Design/Setting:** As part of a study on rehabilitation access barriers, focus groups were conducted in a private room in a hospital, with 21 individuals with low vision (aged 38-92 years) who had or had not accessed low vision services. During the focus groups, participants often spoke of the challenges they faced when interacting with people with normal vision, this discussion led to a modification of the interview guide in order to capture barriers to social participation. Focus group discussions were audiotaped, transcribed and content analysis was conducted.

**Results:** Content analysis revealed that personal as well as environmental factors influenced the social participation of people with low vision. Four themes emerged: 1) experiencing the onset of impairment and degenerating ability, 2) the physical environment, 3) attitudes and responses from others, and 4) individual internal attitude and responses during social interactions. Lived and perceived stigma from the perspective of the insider (person living with low vision) interacting with an outsider (person with normal vision) and difficult environmental contexts were described as barriers to social participation and optimal functioning.

**Conclusions:** At a personal level, transitioning from an outsider to an insider influenced self-identity and social participation. Further, insiders experiencing stereotypes associated with people who are blind had a negative impact on their social participation. Findings highlight the importance of stigma and stereotyping in the lived experience of people with low vision. Stigma is persistent, but strategies to reduce stigma will ultimately facilitate the social participation of people with low vision.

## ARTICLE SUMMARY

### Strengths and Limitations:

- A focus group study exploring the perspectives of older people with low vision
- Focus group guide modified to target an issue raised by the group: barriers to social participation
- Heterogeneous sample with varied exposure to low vision rehabilitation services
- Secondary analysis may have limited the content related to other aspects of low vision stigmatization

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3 The effects of stereotyping on social participation from the perspective of older adults with low  
4 vision: A focus group study  
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## 7 8 INTRODUCTION 9

10 In the domain of visual impairment rehabilitation, a person with low vision is defined as  
11 someone “who has difficulty accomplishing visual tasks, even with prescribed corrective lenses,  
12 but who can enhance his or her ability to accomplish these tasks with the use of compensatory  
13 visual strategies, low vision and other assistive devices, and environmental modifications” [p.4,  
14 1]. In order to study these factors that influence outcomes for an older individual with this  
15 condition, a suitable framework needs to encompass these varied aspects. One commonly used  
16 framework is the International Classification of Functioning, Disability and Health (ICF) from  
17 the World Health Organization (WHO) [2]. The ICF takes into account functional aspects (i.e.,  
18 low vision, participation) as well as contextual factors (i.e., the environment and personal  
19 factors) and has been applied to populations with low vision [3,4]. Psychological health and  
20 social participation are both functional elements that can potentially be negatively affected by  
21 vision loss. Numerous studies have highlighted the increased risk for depression among older  
22 persons with visual impairment [5–8], in addition to decreased perception of quality of life [9].  
23 Participation restrictions in particular have been shown to be linked to psychological wellbeing  
24 in older adults with visual impairment [10] who are often limited in their ability to get around  
25 independently, especially in new environments, making it more difficult to attend social  
26 functions.  
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49 In addition, for individuals with age-related vision loss, their impairment may affect  
50 communication strategies, such as face recognition and the ability to distinguish facial  
51 expressions, critical for social interaction [11–13]. Communication challenges and other aspects  
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3 of life with visual impairment can threaten social participation, thereby possibly isolating the  
4 person, negatively affecting their health and reducing their degree of engagement with society  
5 [14]. During low vision rehabilitation, various intervention approaches and tools have the  
6 potential to assist the person with low vision to overcome the many barriers they may face and/or  
7 perceive, including barriers to social participation [15]. For example, adapted day center services  
8 for older adults with sensory loss have shown promise in maintaining functional abilities and  
9 social integration over time [16] and a multi-disciplinary rehabilitation approach has been shown  
10 to improve quality of life as well as social participation [17,18].

21 Despite the availability of effective rehabilitation approaches, one environmental barrier  
22 that may restrict engagement in low vision rehabilitation is the stigma and stereotypes associated  
23 with their health status [19,20]. Stigma occurs when an individual or group has a characteristic  
24 (i.e., low vision) that is devalued in certain social contexts (Crocker, Major & Steele, 1998).  
25 Chronic age-related health conditions, such as vision loss, are commonly stigmatized [21–24].  
26 Stereotypes about disability are learned at a young age due to persistent socio-cultural  
27 conditioning [25,26]. In Western cultures, the media portray individuals with disabilities as sick,  
28 helpless and in pain [27]. These stereotypes often result in marginalization and social exclusion  
29 [28–30]. People who have visual impairments may come to expect discrimination, creating a  
30 self-fulfilling prophecy [31–33]. Anticipating situations of stigma may have negative impacts on  
31 quality of life as older adults with low vision may forego opportunities for social participation. In  
32 recent years, increasing attention has been paid to patient-centered outcome measures and an  
33 involvement of patients as research partners through participatory action research [34]. In visual  
34 impairment research, this trend has allowed researchers to pay closer attention to insider  
35 perspectives (e.g., the viewpoint of persons with the visual impairment) as part of the research  
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3 process in domains such as information access [35] or quality of life [36]. However, this  
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5 perspective remains under-represented in the peer-reviewed literature and would be specifically  
6  
7 pertinent in the context of stigmatization.  
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### 10 **The origins of low vision stigmatization**

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12 As with many other chronic impairments, the general public does not easily make the  
13  
14 distinction between absolute and partial loss of function [37]. As a result, the general public may  
15  
16 stigmatize people with partial vision loss in the same manner that they would stigmatize people  
17  
18 who are blind. Stigma is a social phenomenon that is greatly influenced by both historical and  
19  
20 cultural forces [38]. Present-day stereotypes attributed to people with any level of vision loss  
21  
22 date back to prejudicial attitudes held against people who were considered blind in Ancient  
23  
24 Greek societies [39,40]. We now live in a society that relies upon traditional communication,  
25  
26 such as vocalized speech and eye contact (which is often difficult or unknown to individuals with  
27  
28 partial or complete vision loss), whereby stereotypes are housed and maintained within language  
29  
30 [41]. Should one encounter a person who is unable to communicate in a “normal” manner, one  
31  
32 might revert to (or rely upon) historically and culturally constructed stereotypes in order to  
33  
34 understand what is perceived to be “deviant” behaviours. Like other cultural beliefs, prejudicial  
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36 beliefs are transmitted from one generation to the next. There is evidence that derivations of  
37  
38 ancient prejudices toward people who are blind continue to impact upon the present-day  
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40 community, and are extended to include persons with partial vision as well. Kent [40] reviewed  
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42 literary references to blindness, and found that a lack of sight was almost always framed in a  
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44 negative fashion. In some ways, the stereotypes about people who are blind have impacted the  
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46 perception of all people who have vision loss, in part rooted in preconceived ideas and a lack of  
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48 awareness about persons with low vision, resulting in the exclusion of both groups.  
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3 Critical to the experience of stigmatization is social context. Characteristics of the  
4 physical and social environment influence the meanings assigned to situations and events by  
5 those present (Crocker & Quinn, 2000). For example, the nature of marginalization and  
6 mistreatment is likely different when a person who has a stigmatizing trait is interacting with  
7 friends and family, as opposed to that same person interacting with a group of strangers. The  
8 extent to which a person is familiar with people who have the stigmatizing trait is an important  
9 consideration when assessing how threatened an individual will feel by the presence of stigma  
10 [42]. Some may decrease their stigmatization because they are familiar with people who have the  
11 stigmatizing trait while others will increase it based on their previous negative interactions with a  
12 person with low vision.  
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26 In a previous study, members of this team sought to explore older adults' perspectives on  
27 the barriers to low vision rehabilitation. Focus group participants described stressful or negative  
28 interactions with sighted others in which they felt they were being negatively judged due to their  
29 vision status [19]. These descriptions were unsolicited (as this was not the goal of the study), but  
30 we recognized a pattern emerging early on in our data analysis and modified our interview guide  
31 in order to include follow-up questions to further explore this issue as data collection progressed.  
32 Given the unprompted nature of the data and the lack of research on this topic, we deemed the  
33 descriptions of social interactions would provide more information on the stigma perceived  
34 and/or experienced by older adults with low vision. Given the relative paucity of research on the  
35 stigma associated with low vision and the important implications for the rehabilitation and social  
36 participation for this population, as well as the rich detail arising from these interviews, we  
37 decided to conduct a secondary analysis of the focus group interviews from Southall and Wittich  
38 [19]. The aim of the study was to describe and better understand the factors that shape the social  
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3 experiences and functioning of people with vision loss. This understanding would provide a  
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5 more holistic comprehension of functioning that considers the person, the impairment, and the  
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7 environment to promote the health and wellbeing of older adults with vision loss.  
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## 10 11 12 **METHOD**

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14 The *Centre de recherche interdisciplinaire en réadaptation (CRIR) du Montréal*  
15  
16 *métropolitain* provided ethical approval for the focus group study protocol. Secondary analysis  
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18 of qualitative data is a common qualitative methodology procedure [43], whereby the analysis of  
19  
20 an existing data set allows for examination of a topic *different* than that of the original project  
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22 [44]. The results are presented here using the COREQ guidelines [45]. During the focus group  
23  
24 sessions and upon revisiting the original transcripts, it was obvious that most participants  
25  
26 provided in-depth narratives about their interactions with other individuals in their community  
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28 who have normal vision. This interaction between people with low vision and those with normal  
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30 vision became the focus of this investigation.  
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### 35 **Participants**

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37 The focus group participants were recruited through their involvement in the Montreal  
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39 Barriers Study [46] and all provided written and informed consent. Each focus group was  
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41 composed of participants who had not heard of low vision rehabilitation services, had heard of  
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43 but not accessed these services, or who knew of and accessed these services. Six focus groups  
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45 were conducted with a total of 21 individuals (*F* 14, *M* 7), ranging in age from 38 to 92 (please  
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47 note: only one participant was under the age of 65 years). Heterogeneous groups were selected so  
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49 that differences in perspectives on the barriers to low vision rehabilitation services would be  
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51 most apparent to the investigators during the focus group discussions and subsequent analyses.  
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## Data Collection

As described in the original protocol [19], the team members with the most extensive experience as a qualitative researcher (KS), led focus groups. The principal topic of interest (positive and negative perceptions on low vision rehabilitation) was explained to participants, including the central three questions: *What enabled you to access low vision rehabilitation services? What served as obstacles to you accessing low vision rehabilitation services? and What could be done to make it easier to access low vision rehabilitation services?* The research team aimed to create an informal and comfortable atmosphere, allowing participants to freely discuss and share their perceptions, while encouraging discussion among the participants. During focus group discussions, barriers to social participation were described by the participants, as such the interview guide was modified to include questions about barriers to social participation and interactions with sighted individuals. Focus groups were conducted in a private room at the Jewish General Hospital in Montreal (Canada). Focus group discussions lasted 60-90 minutes. In addition, field notes were taken as a secondary data source to supplement the audio-recorded information [47]. During verbatim transcription, identifying information was removed to ensure confidentiality, while proper names were replaced with pseudonyms.

## Analyses

For the present study, we employed content analysis of the interview transcripts [48] to describe and better understand the factors that shape the social experiences and functioning of people with vision loss. Content analysis involves open coding when the researchers familiarize themselves with the data and identify narratives that answer the question [49]. In the margins of interview transcripts, labels are assigned to relevant data. The aim is to assign the necessary labels so as to describe fully the content of the text [50]. Next, categories of codes are created in

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3 order to generate manageable chunks of information [51]. The final phase involves extracting  
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5 general descriptors of the data. To this end, we uploaded the data into ATLAS-ti [52], a software  
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7 program that is designed to aid in the analysis of large bodies of text, and to identify meaningful  
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9 patterns within and across the transcripts of interviews. A number of representative interview  
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11 excerpts were selected for inclusion in the results section [49]. All data analyses were conducted  
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13 by two of the co-authors (KS and WW) in face-to-face meetings, whereby team coding was  
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15 performed and discrepancies were resolved immediately through discussion and presentation of  
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17 rationale for items being addressed, a technique the authors have successfully implemented  
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19 before [53–55].  
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24 **Patient and Public Involvement:** This research was done without patient involvement. Patients  
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26 were not invited to comment on the study design and were not consulted to develop patient  
27  
28 relevant outcomes or interpret the results. Patients were not invited to contribute to the writing or  
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30 editing of this document for readability or accuracy.  
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## 34 35 RESULTS

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37 In this study we sought to answer the research question ‘What are the factors that shape  
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39 the social experiences and functioning of people with vision loss?’ Our analyses uncovered four  
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41 interwoven factors shape social participation for this sample, including 1) experiencing the onset  
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43 of impairment and degenerating ability, 2) the physical environment, 3) attitudes and responses  
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45 from others, and 4) individual internal attitude and responses. These findings further suggest that,  
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47 depending on the nature and interactions of these factors, the social participation of people with  
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49 vision loss may be described anywhere on a spectrum from empowering to disabling.  
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3 **Experiencing the onset of impairment and degenerating ability:** The first theme represents  
4 changes in functional status, self-reflections, and the emotions associated with transitioning from  
5 a person with normal vision to one that has reduced visual abilities. In terms of changes in  
6 functional abilities participants described “losses” and their ability to perform social roles as well  
7 as activities of daily living. These changes initially resulted in negative emotions, such as  
8 frustration, feelings of helplessness and hopelessness shortly after the onset of the impairment. In  
9 the paragraphs that follow, we provide excerpts that demonstrate the intersections of stereotypes  
10 associated with vision loss, as well as the desire and need for social participation.  
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21 Focus group participants revealed the ways in which the experience of losing vision  
22 impacts their social engagement and participation. All participants experienced the onset of  
23 vision loss later in life, and therefore had to adjust to the (emotional and psychological) loss of a  
24 previously experienced ability. Later, the onset of vision loss resulted in participants being  
25 unable to engage in their daily activities in the same way they did prior to vision loss. For  
26 example, one participant indicated that the experience of impairment can be particularly  
27 devastating later in life, whereby her “whole world” appears to crumble, stating:  
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37 *I am going to be 77 years old. I had my eyesight for 76 years and now I lost it and losing*  
38 *it...When I found out I felt like my whole world was crumbling from under me and I said*  
39 *how am I going to survive?*  
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45 Another participant described an example of engagement in social activities and roles,  
46 whereby she was not seeing well enough to read, cook, or drive as she believe she should be able  
47 to. She said, “*I renewed my [driving] license in February and in March I cancelled it myself*  
48 *because I couldn't see too clear. That hurt me a lot.*”  
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3 For another individual, not being able to do things in the way he used to made him feel  
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5 ridiculous,

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7 *You cannot do things that you normally would think of, like, for example, I have to go to*  
8 *the cleaners to bring my cleaning. Am I going to hire a driver or take a taxi that is five*  
9 *blocks or six blocks because I have spinal stenosis so that I cannot walk a lot of blocks? I*  
10 *mean you feel ridiculous, you know.*

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17 At times, even when it was possible to accomplish habitual tasks in new ways, individuals may  
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19 struggle with a great sense of helplessness and the commonly held perception that nothing can be  
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21 done to improve their visual abilities. One participant recalled,

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23 *One woman, I will never forget that...I walked into the support group. All the woman was*  
24 *doing was crying because she couldn't peel a potato and an onion. Lady, get with it. She*  
25 *cried for a whole hour because she couldn't peel that potato. That potato was so*  
26 *important to her, it was her whole life. All she was worried about, I can't peel the*  
27 *potato...The lady that was running the program was telling her that there are so many*  
28 *alternatives out there that you can do with that potato. There is electric this, there is a*  
29 *special peeler, I can show you techniques and then she started screaming at that poor*  
30 *lady. What do you know about blindness? Are you blind? Do you know what I am going*  
31 *through?*

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44 In addition to its later onset, the degenerative nature of visual impairment among  
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46 participants meant that ability and functioning are not static, which required continual  
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48 adjustment. One individual described the challenge of coping with gradually shifting visual  
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50 ability,  
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3 *It's hard. It's really, really hard, you know. It changes your life. It's a struggle every*  
4 *single day for me. I get up in the morning and I struggle... you got to put in your*  
5 *mind that you can't go back. You can say, well last week I saw this, this and this and*  
6 *this week I can't. You cannot dwell on that.*  
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15 **Physical environment:** The second theme represents the intersection of the physical  
16 environment, commonly accepted beliefs people hold about visual impairment, and their effects  
17 on social engagement. This includes the social experiences and participation for people with  
18 vision loss in the physical environment, particularly in terms of the ways in which the public  
19 physical environment is constructed. For example, participants described encountering barriers to  
20 mobility in the way public transportation is designed and structured, such as streets, sidewalks,  
21 buses, and the subway. One person explained, *"You take the bus; you don't know what number*  
22 *you are getting onto. I ask the driver all the time. To cross the street is very difficult."* Another  
23 added, *"I have been once nearly run over...so this is a dangerous thing."*, highlighting the  
24 perceived vulnerability of this population when engaging in social encounters in public spaces.  
25 Participants also described the numerous disabling ways in which other public spaces are  
26 constructed, including elevators, grocery stores, banks, pharmacies, restaurants, and recreation  
27 centers, pointing at the inequalities that persons with visual impairment encounter on a daily  
28 basis. One individual recounted a commonly encountered experience among participants,  
29 stating, *"I went into a store two weeks ago and I didn't know where the cashes are, I could not*  
30 *find anything. I could not find the exit."*  
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3 One woman further articulated how the publicly shared physical environment is often  
4 structured in ways that result in the social exclusion of those who are not ‘normal’: those with  
5 vision loss. She described,  
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10 *When I was growing up, people would talk about integration: how to bring a*  
11 *handicapped person into the regular world. That is very nice, it's all nice and well and*  
12 *it's a great project. The only problem is that when you do grow up and you want to be in*  
13 *the normal world, example again for the gym, well I am told - I am sorry we can't help*  
14 *you so go to your visually impaired centers and let them help you. And you know I can't*  
15 *go shopping on my own anymore. I have to have somebody sighted with me because I*  
16 *literally get lost in the store. So, this is what I find, it's very hard. It's... all my life I have*  
17 *been told go, go, go and I went, went, went and now that I am actually losing my*  
18 *eyesight, I am at the point where I need help, I am told, sorry by the regular world. Sorry*  
19 *we can't help you so go back to your people, go back to your kind and stay there.*  
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35 Some participants made a distinction between the impacts of the impairment itself and  
36 the impacts of environmental conditions on their social experiences and social functioning. For  
37 many participants, challenges in the physical environment in public spaces resulted in them  
38 retreating to the private sphere, for example at home, where they could exert more control over  
39 the way in which the environment is constructed and therefore experience greater comfort and  
40 better functioning. One participant said, *“I was hiding at home because at home I felt secure and*  
41 *I could do my chores and listen to classical music.”* Similarly, another participant described that,  
42 rather than facing the various environmental barriers involved in going out as she used to, *“I do*  
43 *not see my good friends anymore. I talk to them over the phone but I don't see them.”*  
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6 **Attitudes and responses of others:** This third theme represents social attitudes and responses  
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8 that impact the social experiences and participation of other people as persons with vision loss  
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10 encounter them. Participants described misunderstandings and unwanted attention from others  
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12 based on their visual impairment. Additionally, some participants reported being treated with  
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14 disgust or disrespect by sighted people. One male participant described what he felt was a lack of  
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16 understanding, and that individuals like him are not worthy of the respect of others. He described  
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18 a situation on public transportation,  
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22 *[Sighted passengers] don't get up. They tell a legally blind person to go to the back of the*  
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24 *bus which they have to watch for their stop, you know, and you got to push your way*  
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26 *through their backpacks, they hit you on the head, they hit the dog in the head. You got to*  
27  
28 *fight every chap on that bus.*  
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33 Another individual suggested that ignorance and stigmatizing attitudes that exist regarding  
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35 people with vision loss potentially result in social exclusion and in interruption to the natural  
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37 flow of communication,  
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40 *When you're visually impaired it's like, you drink out of my cup, you are going to get it.*  
41  
42 *It's contagious, if I touch you, I sneeze on you, that's it, tomorrow you are going to be*  
43  
44 *blind. That's the conception out there.*  
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50 Such negative attitudes and responses from others created a hostile social experience for this  
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52 group of people with vision loss. One individual further illustrates this in the following passage,  
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3 *People don't respect [people with vision loss]. You go downstairs, they may push you and*  
4 *make you fall down. Or in the bus. Now I have my little low vision card. My low vision*  
5 *card, it helps me but not very much. People do not respect the elderly people first of all*  
6 *and the people that have problem eyesight. They don't respect all the handicapped*  
7 *people. And this just makes your daily life miserable [sic].*

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17 Having previously encountered negative attitudes, some participants indicated that at  
18 some point they began anticipate being devalued by others in social settings, and that the strategy  
19 most often employed to mitigate this risk was to hide their vision loss from others. One  
20 participant remarked, *"I have a friend...he has been blind his whole life...and he used to say he*  
21 *doesn't want to use cane or dog because he doesn't want people to know that he has a*  
22 *disability."* Another participant describes an attempt to hide his impairment, saying,  
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33 *I try to ask strangers to do something for me and I am going to find one excuse... Oh I'm*  
34 *sorry I don't have my reading glasses, or something like this, please you do it for me...I*  
35 *don't want to tell them I can't see [sic].*

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42 One participant explained how feeling misunderstood or rejected by sighted people  
43 caused her to disconnect from relationships that had previously been very important to her. She  
44 stated,  
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3 *People who are well don't know what this is like. They don't want to hear it. They have*  
4 *their own problems. You understand, that's the truth. My own dear friends, I don't*  
5 *discuss anything with them about my eyes. That's why I don't want to see them anymore.*  
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12 Some participants indicated that among sighted individuals, even those who have positive  
13 intentions, their response can have a negative impact on the social experience of people with  
14 vision loss. One participant recalled,  
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21 *I was coming home late...and this person comes up behind, the man, I know he wanted to*  
22 *help me, poor guy. He came up behind me but he put his hand on my shoulder but so*  
23 *aggressively and at that time, I was actually studying judo. I grabbed the guy's arm and I*  
24 *flipped him and passed him over me and the guy is lying on the floor and I'm like, 'Don't*  
25 *ever do that again.'* He said, *'I just wanted to help.'*  
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35 **Individual internal attitude and responses:** The fourth theme represents the intersection of  
36 personal beliefs and attitudes about visual impairment and its impact. Some participants  
37 described an understanding that not everyone responds to the onset of visual impairment the  
38 same way. Responses are influenced by personal characteristics, such as personality, age, gender,  
39 etc., as well as by an internal or external locus of control. Some may perceive themselves as  
40 potential victims, or may choose to overcome that perception by consciously engaging in  
41 proactive coping mechanisms. One participant asserted, *"A lot of it has to be up to the*  
42 *individual,"* as well as, *"You know I have a little bit of chutzpah, you know, a little bit of*  
43 *nerve...You know what, it's helped me."* Similarly, another participant described,  
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3 *I would say, to be honest, I think it depends on your state of mind. It depends if you*  
4 *are willing to say, 'ok this is my problem'. I was just going to say, as I said,*  
5 *eventually you have two choices; it's either you stand up and fight and say, 'if you*  
6 *can't help me, who can?' and find out what you can and cannot do, or you sit in your*  
7 *little corner and say, 'poor me'.*

14  
15 One participant explained that her outlook changed over time. When she first began  
16 experiencing vision loss, she felt discouraged and powerless, which, in turn, impacted her social  
17 engagement. With time, she described acquiring more of a fighting spirit, stating that her current  
18 outlook is,  
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24 *I just turned 56, my life is not over it's just starting. All my friends are retiring and I*  
25 *am going back to school and get my Masters and I want to work with kids who are at*  
26 *risk. I have a lot still to do and if I lose my vision completely, I feel that I am*  
27 *prepared, I have the dog, and I have the JAWS program. I don't need my husband by*  
28 *my side any more. Because that's what I used for a long time and I was dragging him*  
29 *around. He's got his own work.*

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38 A central idea iterated among participants in terms of personal attitude was the  
39 importance of fighting to maintain independence rather than relying completely on others. One  
40 person said, "*What I found is like they have said, you have to keep your independence.*" Another  
41 agreed, stating,  
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47 *My pride went on the backburner, when I realized that I was dependent on someone. I*  
48 *wanted my independence back. I gave up driving a car, too. So when I started thinking*  
49 *about the car and how I felt and all the things that I had to give up, so I said, 'No, I don't*  
50 *have to give up, I have to learn how to do things.'*  
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3 However, participants also expressed that while personal attitudes shaped experience, this  
4 was not the only influencing factor. A fighting spirit, positive outlook, and determination to be  
5 independent cannot overcome all of the obstacles to social participation experienced by people  
6 with vision loss. One person stated, *“The only thing that I find very hard is when you are losing*  
7 *your eyesight, there are a lot of things that, no matter how much you want to be independent, you*  
8 *can’t.”*  
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## 19 DISCUSSION

20  
21 The purpose of this study was to describe and better understand the factors that shape the  
22 social experiences and functioning of people with vision loss. Our findings suggest that  
23 respondents experience social participation through the personal lens of transition from an  
24 outsider (someone with normal vision) to an insider (someone with low vision). Our findings  
25 also document stereotyping, both from insiders (persons with low vision) and outsiders (sighted  
26 people). These (primarily) negative assumptions that others may make have important impacts  
27 on their social participation. Two social settings: family and friends (private setting) versus the  
28 public at large emerged as important to the individuals in our sample. The analyses revealed that  
29 the onset of vision loss initiates changes in the individual who has the impairment (as they  
30 become an insider), as well as how others (the outsiders) perceive this person. These analyses  
31 also highlight that there exist both internal as well as external factors that influence the nature of  
32 social participation for an individual with low vision, as characterized in the ICF with the  
33 personal and environmental factors.  
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### 51 **Personal Factor: Adapting to change with the onset of impairment**

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3 Individuals perceive themselves as insiders or outsiders based on characteristics they  
4 believe they have that aligns them with one or the other groups [56]. Their identity is in jeopardy  
5 when they are in limbo or transitioning, somewhere between perceiving themselves as a sighted  
6 person or a person with acquired vision loss. This threatens their identity as they are uncertain as  
7 to what this “new” version of themselves will be. When people who have vision loss find  
8 themselves in social settings with those who are sighted, tension can arise. For the insider, a  
9 number of factors may contribute to this tension, including that the insider has not yet accepted  
10 the loss, and may not yet be comfortable using assistive technologies or orientation strategies to  
11 facilitate and reduce this tension and facilitate social participation [57–59].  
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24 Within the context of family and friends, the onset of impairment gave rise to three  
25 stereotypes, as described by the participants: helpless, lazy and useless, specifically in the  
26 context of maintaining and performing social roles. This supports what we know from the  
27 research literature [40,60], whereby previous reports have highlighted the stereotype maintained  
28 in folklore writings that people with visual impairment are helpless [39]. In the example of our  
29 participant who described her experience of feeling (and being perceived as) helpless in the  
30 context of kitchen work, this stereotype may be threatening her social role in one specific setting  
31 but may not exist in a different setting, depending on what the context may be. In some  
32 instances, people with low vision will construct environments (with the help of rehabilitation  
33 services) whereby they have optimal control over their level of functioning, thereby limiting the  
34 possible threat of task failure, improving their adaptation to change and diminishing the resulting  
35 stereotyping in social situations [61].  
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51 Within the public at large, stereotypes about people with low vision have also previously  
52 been described in the literature, such as people with low vision are disabled, all the same,  
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3 contagious, old, and dependent [20,62,63]. There is a history of tension, discrimination,  
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5 marginalization, and institutionalization that informs and guides interactions between sighted  
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7 (insider) and non-sighted (outsider) groups [56]. For the insiders, in line with research on  
8  
9 disability [64], the individuals with low vision in our sample do not want to be thought of as  
10  
11 different, or as dependent. This desire may make it difficult for an individual who is having an  
12  
13 onset of vision loss to accept the situation [57]. There is great variability of social responsiveness  
14  
15 to being stereotyped. Insiders may respond differently to stereotyping depending on the length of  
16  
17 time since diagnosis. It is normal with people with vision loss to wait for years before seeking  
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19 help [62]. Presumably during this time the individuals' identity is changing. The extent to which  
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21 the new identity of the person with vision loss has been integrated into the individual's social  
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23 identity will shape their responses to stereotyping [65,66].

### 24 **Environmental factors: Public stigma & Physical Environment**

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31 The most apparent difference between private and public setting categories as they relate  
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33 to our findings is the degree of *familiarity* outsider groups have with insiders who have low  
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35 vision. Familiarity is a topic that has been previously explored as it relates to stereotype threat  
36  
37 [67]. Outsider groups are presumed to have knowledge of the stereotypes about the health  
38  
39 condition and its treatment, and may be familiar with the individual. This line of research  
40  
41 suggests that familiarity impacts on likelihood of stereotyping another individual [68,69]. Many  
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43 of the passages from the participants describe outsiders as being unfamiliar with visual  
44  
45 impairment and/or relying on preconceived notions of vision loss. Many sighted individuals  
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47 simply do not understand that only a small percentage of people with vision loss are totally blind  
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49 and that the remainder have various levels of remaining visual function [70,71]. For most  
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51 outsiders their understanding is that people are either blind or have normal vision. So any  
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3 manifestation or use of rehabilitation strategies employed by people with vision loss will lead  
4 outsiders to assign the label of blind, and contemplate all of the associated stereotypes. This  
5 public stigma can hinder the help-seeking process of people with low vision, as they may  
6 actively avoid these negative stereotypes by not identifying themselves as an insider. This is  
7 commonly apparent when deciding to adopt a white cane for mobility [72], which identifies a  
8 person as having an impairment in vision. Within our sample, one person experiencing changes  
9 in their vision actually identifies with a friend who does not use a cane or a guide dog to avoid  
10 being singled out as disabled. While the cane or guide dog can improve function and  
11 participation, its use may be circumvented to avoid the larger problem of stigma.  
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24 With respect to the present findings, two points about insiders are particularly  
25 noteworthy. First, individuals with *acquired* disability have been shown to differ in their  
26 perception of and approach towards their disability and their disability identity [73]; however,  
27 this topic has not been extensively in the context of visual impairment [74]. Our participants with  
28 acquired vision loss, however, are likely differentially impacted by stereotyping, compared to  
29 those living with congenital impairment, specifically as their experience of loss differs. These  
30 individuals initially had ‘normal’ vision, and have thus been part of the outsiders’ group. They  
31 themselves may have stereotyped others for vision impairment in the past. Second, according to  
32 the modified labeling theory [75], when stereotyping does occur (in both public and private  
33 settings), this confirms insider expectations and may lead insiders to expect future stereotyping.  
34 This can lead to a self-fulfilling prophecy whereby insiders subconsciously expect persistent  
35 stereotyping in both public and private settings, and make decisions that result in negative  
36 outcomes such as social isolation, reduced social engagement and self-stigmatization. The quotes  
37 exemplify that some do ask “strangers” for help but without revealing their impairment or not  
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3 talking to their friends anymore because “they do not want to hear it”.  
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5 For insiders, perhaps past experiences of stereotyping with people who have normal  
6 vision have left an emotional scar, which makes it difficult to interact normally. Outsiders may  
7 not be sure how to approach a person with vision loss, may not know how to help or even to  
8 offer help. This is clear in the example where an outsider grabs the shoulder of a participant with  
9 low vision (insider), resulting in a negative experience for both. The outsider may also  
10 experience shame for considering stereotypes. Participants’ accounts of stereotyping in private  
11 settings are consistent with familiarity and the modified labelling theory. There was a virtual  
12 consensus that sighted people, even those who have a close connection with an insider, do not  
13 understand the realities of visual impairments, their treatment, and do not know how to assist a  
14 person with vision loss. While it is reasonable to assume that most people have good intentions,  
15 this lack of knowledge about low vision contributes to stereotyping.  
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31 Characteristics of the environment in which the social interaction takes place may also  
32 come into play. Several quotes in our findings illustrate that physical environments are often  
33 structured in inaccessible ways for people with vision loss, and that this structure, contributed to  
34 reduced mobility, independence, and sense of security for these individuals. In addition,  
35 contextual factors such as: the number of people present, the purpose of the event, as well as the  
36 presence of other people who have vision loss or knowledge of vision loss all factor into  
37 potential stereotyping. Moreover, all of these factors may give rise to the level of stress for both  
38 the insiders and outsiders. For example one participant discussed transportation as stressful and  
39 described their reliance on the bus driver or others for help. According to the stigma induced  
40 identity threat model [76], the balance between demands of the situation and personal resources  
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3 will determine the level of identity threat and will in many ways govern responses by both  
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5 insiders and outsiders.  
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### 7 **Reducing the barriers to social participation of people with low vision**

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10 It remains unclear how people with vision loss should approach social gatherings  
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12 knowing and expecting that assumptions will be made about them, and that some of these  
13  
14 assumptions will be erroneous and potentially marginalizing. It is our contention that people with  
15  
16 vision loss may be best served by repeatedly disclosing to others relevant information about their  
17  
18 low vision and how communication partners can aid them in their social participation. In the  
19  
20 stigma reduction literature [60], there is a general consensus that stigma reduction campaigns  
21  
22 should incorporate four types of activities: educational and awareness campaigns, face-to-face  
23  
24 interactions or personal contact, persuasion (changing people's beliefs about low vision) and  
25  
26 disability simulations (have outsiders, in particular familiar outsiders, experience what it is like  
27  
28 to have low vision). Wainapel [72] proposed that peers may be best situated to counsel a newly  
29  
30 diagnosed person. However, the findings from the present study, and from previous work on  
31  
32 familiarity and stereotyping, suggest that relying only on one-to-one interactions to reduce the  
33  
34 stigma associated with low vision might not be advisable. . It is possible that stigma reduction  
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36 may only result from more intimate, or at least developed, connections with people who have  
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38 stigmatizing traits. If this is the case, stigma reduction programs might test building upon  
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40 existing relations with people who have stigmatizing traits. With respects to outsiders who are  
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42 unfamiliar with visual impairment, increased education, persuasion from the insider about their  
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44 capabilities and experiential trials that simulate low vision can help reduce these environmental  
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46 barriers to social participation for people with low vision.  
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### 53 **Clinical Implications: Importance to rehabilitation of clients with low vision**

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3 In some cases, stereotyping extends into clinical/healthcare settings [77]. Familiarity with  
4 visual impairments and the manifestations of low vision, combined with a charged daily  
5 appointment list may lead some clinicians to make assumptions about the challenges and abilities  
6 of their clients. Stereotyping by clinicians will reduce opportunities for client-centered care for  
7 people with low vision. It is therefore vital to increase the awareness of stereotyping and its  
8 pitfalls by clinicians who work with individuals who have low vision. All clinicians should  
9 assess their own attitudes toward this population. Recent work [78] with health care providers  
10 suggests that some professionals may not adopt stereotypical views of their clients. This work, in  
11 dual sensory impairment (DSI: hearing and vision losses), suggests that strong familiarity with a  
12 marginalized group (in this case people with DSI) can actually be an asset. Many of the  
13 professionals that were interviewed were strong advocates for their clients and generally did not  
14 seem to have a stereotypical approach to their clientele. However, several mentioned the daily  
15 public stigma their clients faced and that interactions with professionals not specifically trained  
16 in DSI often resulted in stereotypical responses [78].

17  
18 You can have the most perfectly rehabilitated client at a functional level, yet, they may  
19 remain fearful of being identified, faced with barriers created by the sighted community and  
20 socially excluded. Rehabilitation specialists should consider the different spheres in which the  
21 individual needs to function, and the professionals need to frame their interventions accordingly,  
22 with a client centered approach [79] that encourages attempting different devices and strategies  
23 to reduce and/or minimize the barriers faced, and help people with low vision to be active  
24 participants in their physical and social environment [80].

## 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 **Limitations**

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3 One potential limitation of secondary analyses of qualitative data sets concerns  
4 theoretical saturation [44]. Content analysis involves identification of incidents, events activities  
5 which are grouped to form categories. The category is 'saturated' when new information which  
6 adds to the understanding of the category is not forthcoming. If the data set is being used  
7 'inappropriately', there will be limited data, resulting in a premature saturation of the category.  
8 This was not a concern for this data set. The participants in this study were proud to discuss their  
9 experiences of low vision and social participation. There was thus ample information to analyze.  
10 However, the initial focus of data collection was not to probe into the topic of stigmatization;  
11 therefore, it is possible that some aspects of low vision and stigmatization, beyond the topics that  
12 were spontaneously self-identified by our participants, are not covered in our data, but might  
13 emerge in future studies designed to address this topic in more depth.  
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### 31 CONCLUSION

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33 People with low vision experience a number of changes when they begin to demonstrate  
34 functional impairments in their vision. From the perspective of the participants in our study (the  
35 insiders) their personal perceptions transitioning to an insider, as well as, their interactions with  
36 people with normal vision (outsiders) influence their social participation. The stereotypes and  
37 stigma that surround low vision was clearly a topic that negatively influenced our participants'  
38 social participation as this was a topic that they repeatedly discussed in our focus groups and as a  
39 result became a secondary analysis from this data set. Stigma in the environment perceived or  
40 experienced is a critical factor to address for older adults with low vision as it has the potential to  
41 reduce social participation, in some cases diminish help-seeking and ultimately impact health.  
42 Strategies to improve awareness and educate the general public and health care providers on low  
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3 vision could reduce the stigma associated with this condition and ultimately improve the health  
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5 of older individuals with low vision.  
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10 **Author Statement:** Drs. Kenneth Southall & Walter Wittich planned this project. Dr. Southall  
11 led the focus groups and Dr. Southall and Wittich analyzed the data and created the code list  
12 together. Irene Beeman was a graduate student learning qualitative research and she worked  
13 directly with Dr. Southall to create a rough draft of this paper. Dr. Fraser was involved in the  
14 write-up of this project and worked with Dr. Southall and Wittich to revise, edit and produce the  
15 final version of this manuscript.  
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25

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27

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For peer review only

**Title of study:** The effects of stereotyping on social participation from the perspective of older adults with low vision: A focus group study

### Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? <ul style="list-style-type: none"> <li>• Dr. Kenneth Southall</li> </ul>
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i> <ul style="list-style-type: none"> <li>• PhD</li> </ul>
3.	Occupation	What was their occupation at the time of the study? <ul style="list-style-type: none"> <li>• Qualitative Researcher at McGill University in the School of Social Work</li> </ul>
4.	Gender	Was the researcher male or female? <ul style="list-style-type: none"> <li>• Male</li> </ul>
5.	Experience and training	What experience or training did the researcher have? <ul style="list-style-type: none"> <li>• The researcher completed a qualitative research PhD and was at the time a New Investigator with a New Investigator Career award (from the Quebec provincial government, in Canada) for his proposed qualitative research studies</li> </ul>

No	Item	Guide questions/description
Relationship with participants		
6.	Relationship established	<p>Was a relationship established prior to study commencement?</p> <ul style="list-style-type: none"> <li>No</li> </ul>
7.	Participant knowledge of the interviewer	<p>What did the participants know about the researcher? e.g. <i>personal goals, reasons for doing the research</i></p> <ul style="list-style-type: none"> <li>Researchers background and aims of the study were discussed at the beginning of focus group session</li> </ul>
8.	Interviewer characteristics	<p>What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i></p> <ul style="list-style-type: none"> <li>Reasons and interests in the research topic were discussed. The researcher had a strong background in qualitative health research on people with hearing impairments and wanted to extend this to better understand people with vision impairments</li> </ul>
<b>Domain 2: study design</b>		
Theoretical framework		
9.	Methodological orientation and Theory	<p>What methodological orientation was stated to underpin the study? e.g. <i>grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i></p> <ul style="list-style-type: none"> <li>Content analysis was chosen</li> </ul>

No	Item	Guide questions/description
Participant selection	10.	Sampling How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i> <ul style="list-style-type: none"> <li>It was purposive sampling as people with low vision who participated in the Montreal Barriers Study were solicited to gain their perspectives on barriers to social participation</li> </ul>
	11.	Method of approach How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i> <ul style="list-style-type: none"> <li>Face-to-face</li> </ul>
	12.	Sample size How many participants were in the study? <ul style="list-style-type: none"> <li>21 participants</li> </ul>
	13.	Non-participation How many people refused to participate or dropped out? Reasons? <ul style="list-style-type: none"> <li>None of the participants approached refused or dropped out of the study</li> </ul>
Setting	14.	Setting of data collection Where was the data collected? <i>e.g. home, clinic, workplace</i> <ul style="list-style-type: none"> <li>In a clinical setting (at the Jewish General Hospital), in a private room</li> </ul>
	15.	Presence of non-participants Was anyone else present besides the participants and researchers? <ul style="list-style-type: none"> <li>No</li> </ul>
	16.	Description of sample What are the important characteristics of the sample? <i>e.g. demographic data, date</i> <ul style="list-style-type: none"> <li>We included age and sex</li> </ul>

No	Item	Guide questions/description
Data collection		
17.	Interview guide	<p>Were questions, prompts, guides provided by the authors? Was it pilot tested?</p> <ul style="list-style-type: none"> <li>The leader of the focus group had a guide for the focus group discussions and this guide was modified based on issues that the participants raised</li> </ul>
18.	Repeat interviews	<p>Were repeat interviews carried out? If yes, how many?</p> <ul style="list-style-type: none"> <li>No</li> </ul>
19.	Audio/visual recording	<p>Did the research use audio or visual recording to collect the data?</p> <ul style="list-style-type: none"> <li>Audio recording</li> </ul>
20.	Field notes	<p>Were field notes made during and/or after the interview or focus group?</p> <ul style="list-style-type: none"> <li>Yes. These were conducted by a second researcher who was also in the room but did not guide the focus group discussion.</li> </ul>
21.	Duration	<p>What was the duration of the interviews or focus group?</p> <ul style="list-style-type: none"> <li>60-90 minutes</li> </ul>
22.	Data saturation	<p>Was data saturation discussed?</p> <ul style="list-style-type: none"> <li>Yes</li> </ul>
23.	Transcripts returned	<p>Were transcripts returned to participants for comment and/or correction?</p> <ul style="list-style-type: none"> <li>No</li> </ul>
<b>Domain 3: analysis and findingsz</b>		

No	Item	Guide questions/description
Data analysis		
24.	Number of data coders	How many data coders coded the data? <ul style="list-style-type: none"> <li>• Two</li> </ul>
25.	Description of the coding tree	Did authors provide a description of the coding tree? <ul style="list-style-type: none"> <li>• Not in the manuscript.</li> </ul>
26.	Derivation of themes	Were themes identified in advance or derived from the data? <ul style="list-style-type: none"> <li>• Derived from the data</li> </ul>
27.	Software	What software, if applicable, was used to manage the data? <ul style="list-style-type: none"> <li>• Atlas.ti</li> </ul>
28.	Participant checking	Did participants provide feedback on the findings? <ul style="list-style-type: none"> <li>• No</li> </ul>
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i> <ul style="list-style-type: none"> <li>• Yes participant quotations were presented but they were not identified</li> </ul>
30.	Data and findings consistent	Was there consistency between the data presented and the findings? <ul style="list-style-type: none"> <li>• Yes</li> </ul>
31.	Clarity of major themes	Were major themes clearly presented in the findings? <ul style="list-style-type: none"> <li>• Yes</li> </ul>

No	Item	Guide questions/description
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? <ul style="list-style-type: none"><li data-bbox="883 386 1354 415">• No, only major themes presented</li></ul>

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# BMJ Open

## Stereotyping as a barrier to the social participation of older adults with low vision: A qualitative focus group study

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Stereotyping as a barrier to the social participation of older adults with low vision:

A qualitative focus group study

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Stereotyping as a barrier to the social participation of older adults with low vision:

A qualitative focus group study

### ABSTRACT

**Objective:** In order to better understand the barriers that limit the social participation of older people with low vision, the aim of this study was to describe and clarify the factors that shape the social participation of people with vision loss.

**Methods:** As part of a study on rehabilitation access barriers, six qualitative focus groups were conducted in a private room in a hospital, with 21 individuals with low vision (aged 38-92 years) who had or had not accessed low vision services. During the focus groups, participants often spoke of the challenges they faced when interacting with people with normal vision, this discussion led to a modification of the interview guide in order to capture barriers to social participation. Focus group discussions were audiotaped, transcribed and content analysis was conducted.

**Results:** Content analysis revealed that personal as well as environmental factors influenced the social participation of people with low vision. Four themes emerged: 1) experiencing the onset of impairment and degenerating ability, 2) the physical environment, 3) attitudes and responses from others, and 4) individual internal attitude and responses during social interactions. Lived and perceived stigma from the perspective of the insider (person living with low vision) interacting with an outsider (person with normal vision) and difficult environmental contexts were described as barriers to social participation and optimal functioning.

**Conclusions:** At a personal level, transitioning from an outsider to an insider influenced self-identity and social participation. Further, insiders experiencing stereotypes associated with people who are blind had a negative impact on their social participation. Findings highlight the importance of stigma and stereotyping in the lived experience of people with low vision. Stigma is persistent, but strategies to reduce stigma will ultimately facilitate the social participation of people with low vision.

## ARTICLE SUMMARY

### Strengths and Limitations:

- The relevance of this secondary analysis emerged through the unsolicited nature and priority of focus group participants to provided rich data on the important of factors influencing social participation among individuals with low vision.
- Qualitative focus group data provide a raw and personal perspective and insight on the experience of social participation and social isolation of older adults with low vision
- Given the focus on older participants with acquired/age-related visual impairment, the presented perspective on social participation may not generalize to persons with congenital visual impairment of all ages
- Though stereotyping emerged as an important theme, this dimension was not specifically solicited during the interview process and may be under-represented in this dataset

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3 Stereotyping as a barrier to the social participation of older adults with low vision:  
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5 A qualitative focus group study  
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## 8 INTRODUCTION 9

10 In the domain of visual impairment rehabilitation, a person with low vision is defined as  
11 someone “who has difficulty accomplishing visual tasks, even with prescribed corrective lenses,  
12 but who can enhance his or her ability to accomplish these tasks with the use of compensatory  
13 visual strategies, low vision and other assistive devices, and environmental modifications” [p.4,  
14 1]. In order to study these factors that influence outcomes for an older individual with this  
15 condition, a suitable framework needs to encompass these varied aspects. One commonly used  
16 framework is the International Classification of Functioning, Disability and Health (ICF) from  
17 the World Health Organization (WHO) [2]. The ICF takes into account functional factors (i.e.,  
18 low vision, participation) as well as contextual factors (i.e., the environment and personal  
19 factors) and has been applied to populations with low vision [3,4]. Participation has been defined  
20 as “involvement in a life situation” (pg. 8, 10) and encompasses social participation elements  
21 such as: interpersonal interactions and relationships as well as involvement in community, social  
22 and civic life [2]. Psychological health and social participation are both functional factors that  
23 can potentially be negatively affected by vision loss. Numerous studies have highlighted the  
24 increased risk for depression among older persons with visual impairment [5–8], in addition to  
25 decreased perception of quality of life [9]. Participation restrictions in particular have been  
26 shown to be linked to psychological wellbeing in older adults with visual impairment [10] who  
27 are often limited in their ability to get around independently, especially in new environments,  
28 making it more difficult to attend social functions.  
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3 In addition, for individuals with age-related or acquired vision loss (i.e., age-related  
4 macular degeneration, glaucoma, diabetic retinopathy, stroke-related vision loss) their  
5 impairment may affect communication strategies, such as face recognition and the ability to  
6 distinguish facial expressions, critical for social interaction [11–13]. Communication challenges  
7 and other aspects of life with visual impairment can threaten social participation, thereby  
8 possibly isolating the person, negatively affecting their health and reducing their degree of  
9 engagement with society [14]. During low vision rehabilitation, various intervention approaches  
10 and tools have the potential to assist the person with low vision to overcome the many barriers  
11 they may face and/or perceive, including barriers to social participation [15]. For example,  
12 adapted day center services for older adults with sensory loss have shown promise in maintaining  
13 functional abilities and social integration over time [16] and a multi-disciplinary rehabilitation  
14 approach (including ophthalmology, optometry, occupational therapy, low vision therapy,  
15 orientation and mobility, orthoptics, and welfare and mental health specialists) has been shown  
16 to improve quality of life as well as social participation [17,18].

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19 Despite the availability of effective rehabilitation approaches, one environmental barrier  
20 that may restrict engagement in low vision rehabilitation is the stigma and stereotypes associated  
21 with their health status [19,20]. Stigma occurs when an individual or group has a characteristic  
22 (i.e., low vision) that is devalued in certain social contexts [21]. Chronic age-related health  
23 conditions, such as vision loss, are commonly stigmatized [22–25]. Stereotypes about disability  
24 are learned at a young age due to persistent socio-cultural conditioning [26,27]. In Western  
25 cultures, the media portray individuals with disabilities as sick, helpless and in pain [28]. These  
26 stereotypes often result in marginalization and social exclusion [29–31]. People who have a  
27 visual impairment may come to expect discrimination, creating a self-fulfilling prophecy [32–

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3 34]. Anticipating situations of stigma may have negative impacts on quality of life as older adults  
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5 with low vision may forego opportunities for social participation. In recent years, increasing  
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7 attention has been paid to patient-centered outcome measures and an involvement of patients as  
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9 research partners through participatory action research [35]. In visual impairment research, this  
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11 trend has allowed researchers to pay closer attention to insider perspectives (e.g., the viewpoint  
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13 of persons with the visual impairment) as part of the research process in domains such as  
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15 information access [36] or quality of life [37]. However, this perspective remains under-  
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17 represented in the peer-reviewed literature and would be specifically pertinent in the context of  
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19 stigmatization.  
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### 23 24 **The origins of low vision stigmatization**

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26 As with many other chronic impairments, the general public does not easily make the  
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28 distinction between absolute and partial loss of function [38–40]. As a result, the general public  
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30 may stigmatize people with partial vision loss in the same manner that they would stigmatize  
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32 people who are blind. Stigma is a social phenomenon that is greatly influenced by both historical  
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34 and cultural forces [41]. Present-day stereotypes attributed to people with any level of vision loss  
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36 date back to prejudicial attitudes held against people who were considered blind in Ancient  
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38 Greek societies [42,43]. We now live in a society that relies upon traditional communication,  
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40 such as vocalized speech and eye contact (which is often difficult or unknown to individuals with  
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42 partial or complete vision loss), whereby stereotypes are housed and maintained within language  
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44 [44]. Should one encounter a person who is unable to communicate in a “normal” manner, one  
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46 might revert to (or rely upon) historically and culturally constructed stereotypes in order to  
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48 understand what is perceived to be “deviant” behaviours. Like other cultural beliefs, prejudicial  
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50 beliefs are transmitted from one generation to the next. There is evidence that derivations of  
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3 ancient prejudices toward people who are blind continue to impact upon the present-day  
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5 community, and are extended to include persons with partial vision as well. Kent [43] reviewed  
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7 literary references to blindness, and found that a lack of sight was almost always framed in a  
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9 negative fashion. In some ways, the stereotypes about people who are blind have impacted the  
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11 perception of all people who have vision loss, in part rooted in preconceived ideas and a lack of  
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13 awareness about persons with low vision, resulting in the exclusion of both groups (for several  
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15 relevant research articles on stigma and low vision, please see the following resource from the  
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17 Royal National Institute for the blind: [https://www.rnib.org.uk/professionals/knowledge-and-](https://www.rnib.org.uk/professionals/knowledge-and-research-hub)  
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19 [research-hub](https://www.rnib.org.uk/professionals/knowledge-and-research-hub)).  
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24 Critical to the experience of stigmatization is social context. Characteristics of the  
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26 physical and social environment influence the meanings assigned to situations and events by  
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28 those present [45]. For example, the nature of marginalization and mistreatment is likely  
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30 different when a person who has a stigmatizing trait is interacting with friends and family, as  
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32 opposed to that same person interacting with a group of strangers. The extent to which a person  
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34 is familiar with people who have the stigmatizing trait is an important consideration when  
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36 assessing how threatened an individual will feel by the presence of stigma [46]. Some may  
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38 decrease their stigmatization because they are familiar with people who have the stigmatizing  
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40 trait while others will increase it based on their previous negative interactions with a person with  
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42 low vision.  
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47 In a previous study, members of this team sought to explore older adults' perspectives on  
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49 the barriers to low vision rehabilitation. Focus group participants described stressful or negative  
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51 interactions with people with normal vision in which they felt they were being negatively judged  
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53 due to their vision status [19]. These descriptions were unsolicited (as this was not the goal of the  
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3 study), but we recognized a pattern emerging early on in our data analysis and modified our  
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5 interview guide in order to include follow-up questions to further explore this issue as data  
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7 collection progressed. Given the unprompted nature of the data and the lack of research on this  
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9 topic, we deemed the descriptions of social interactions would provide more information on the  
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11 stigma perceived and/or experienced by older adults with low vision. Given the relative paucity  
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13 of research on the stigma associated with low vision and the important implications for the  
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15 rehabilitation and social participation for this population, as well as the rich detail arising from  
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17 these interviews, we decided to conduct a secondary analysis of the focus group interviews from  
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19 Southall and Wittich [19]. The aim of the study was to describe and better understand the factors  
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21 that shape the social participation of people with vision loss. This understanding would provide a  
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23 more holistic comprehension of functioning that considers the person, the impairment, and the  
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25 environment to promote the health and wellbeing of older adults with vision loss.  
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### 33 **METHOD**

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35 The *Centre de recherche interdisciplinaire en réadaptation (CRIR) du Montréal*  
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37 *métropolitain* provided ethical approval for the focus group study protocol. Secondary analysis  
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39 of qualitative data is a common qualitative methodology procedure [47], whereby the analysis of  
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41 an existing data set allows for examination of a topic *different* than that of the original project  
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43 [48]. The results are presented here using the COREQ guidelines [49]. During the focus group  
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45 sessions and upon revisiting the original transcripts, it was obvious that most participants  
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47 provided in-depth narratives about their interactions with other individuals in their community  
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49 who have normal vision. This interaction between people with low vision and those with normal  
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51 vision became the focus of this investigation.  
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## Participants

The focus group participants were recruited through their involvement in the Montreal Barriers Study [50] and all provided written and informed consent. Each focus group was composed of participants who had not heard of low vision rehabilitation services, had heard of but not accessed these services, or who knew of and accessed these services. Six focus groups of 2-5 participants were conducted with a total of 21 participants (14 Female, 7 Male), ranging in age from 38 to 92 (please note: only one participant (age: 38 years; was under the age of 65 years; given the similarity of her response content to that of all other participants, her data were maintained in the analyses). Participant characteristics are presented in Table 1. Heterogeneous groups were selected so that differences in perspectives on the barriers to low vision rehabilitation services would be most apparent to the investigators during the focus group discussions and subsequent analyses.

## Data Collection

As described in the original protocol [19], the team members with the most extensive experience as a qualitative researcher (KS), led focus groups. The principal topic of interest (positive and negative perceptions on low vision rehabilitation) was explained to participants, including the central three questions: *What enabled you to access low vision rehabilitation services? What served as obstacles to you accessing low vision rehabilitation services? and What could be done to make it easier to access low vision rehabilitation services?* The research team aimed to create an informal and comfortable atmosphere, allowing participants to freely discuss and share their perceptions, while encouraging discussion among the participants. At the beginning of the focus group session, to facilitate communication for people with visual impairments, it was stated that all cues would be auditory and that there would be turn taking so

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3 that only one person spoke at a time. All participants introduced themselves to facilitate auditory  
4 localization of each individual and to let participants become more familiar with everyone's tone  
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6 of voice. The participant or the leader of the group would state the name of the person speaking  
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8 and anyone who wished to comment could raise their hand and the leader would facilitate their  
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10 turn in speaking. During focus group discussions, barriers to social participation were described  
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12 by the participants, as such the interview guide was modified to include questions about barriers  
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14 to social participation and interactions with people with normal vision. Focus groups were  
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16 conducted in a private room at the Jewish General Hospital in Montreal (Canada). Each focus  
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18 group had one group discussion session that lasted 60-90 minutes. In addition, field notes were  
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20 taken by the last author (WW) as a secondary data source to supplement the audio-recorded  
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22 information [51]. During verbatim transcription, identifying information was removed to ensure  
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24 confidentiality, while proper names were replaced with pseudonyms.  
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### 30 **Analyses**

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33 For the present study, we employed qualitative content analysis of the interview  
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35 transcripts [52] to describe and better understand the factors that shape the social participation of  
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37 people with vision loss. Content analysis involves open coding when the researchers familiarize  
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39 themselves with the data and identify narratives that answer the question [53]. In the margins of  
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41 interview transcripts, labels are assigned to relevant data. The aim is to assign the necessary  
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43 labels so as to describe fully the content of the text [54]. Next, categories of codes are created in  
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45 order to generate manageable chunks of information [55]. The final phase involves extracting  
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47 general descriptors of the data. To this end, we uploaded the data into ATLAS-ti [56], a software  
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49 program that is designed to aid in the analysis of large bodies of text, and to identify meaningful  
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51 patterns within and across the transcripts of interviews. A number of representative interview  
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3 excerpts were selected for inclusion in the results section [53]. All data analyses were conducted  
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5 by two of the co-authors (KS and WW) in face-to-face meetings, whereby team coding was  
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7 performed, discussions about different ways of “seeing” the data were explored and  
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9 discrepancies were resolved through discussion and presentation of rationale for items being  
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11 addressed, a technique the authors have successfully implemented before [57–59].  
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14 **Patient and Public Involvement:** This research was done without patient involvement. Patients  
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16 were not invited to comment on the study design and were not consulted to develop patient  
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18 relevant outcomes or interpret the results. Patients were not invited to contribute to the writing or  
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20 editing of this document for readability or accuracy. . However, indirectly, the study was driven  
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22 by patient priorities, given that the content on stigma and social participation was unsolicited but  
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24 substantial enough to warrant secondary analyses.  
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## 31 RESULTS

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33 In this study we sought to answer the research question ‘What are the factors that shape  
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35 the social participation of people with vision loss?’ Our analyses uncovered four interwoven  
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37 factors that shape social participation for this sample, including 1) experiencing the onset of  
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39 impairment and degenerating ability, 2) the physical environment, 3) attitudes and responses  
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41 from others, and 4) individual internal attitude and responses. These findings further suggest that,  
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43 depending on the nature and interactions of these factors, the social participation of people with  
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45 vision loss may be described anywhere on a spectrum from empowering to disabling.  
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49 **Experiencing the onset of impairment and degenerating ability:** The first theme represents  
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51 changes in functional status, self-reflections, and the emotions associated with transitioning from  
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53 a person with normal vision to one that has reduced visual abilities. In terms of changes in  
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3 functional abilities participants described “losses” and their ability to perform social roles as well  
4 as activities of daily living. These changes initially resulted in negative emotions, such as  
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6 frustration, feelings of helplessness and hopelessness shortly after the onset of the impairment. In  
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8 the paragraphs that follow, we provide excerpts that demonstrate the intersections of stereotypes  
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10 associated with vision loss, as well as the desire and need for social participation.  
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15 Focus group participants revealed the ways in which the experience of losing vision  
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17 impacted their social participation. All participants experienced the onset of vision loss later in  
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19 life, and therefore had to adjust to the (emotional and psychological) loss of a previously  
20  
21 experienced ability. Later, the onset of vision loss resulted in participants being unable to engage  
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23 in their daily activities in the same way they did prior to vision loss. For example, one  
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25 participant indicated that the experience of impairment can be particularly devastating later in  
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27 life, whereby her “whole world” appears to crumble, stating:  
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31 *I am going to be 77 years old. I had my eyesight for 76 years and now I lost it and losing*  
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33 *it...When I found out I felt like my whole world was crumbling from under me and I said*  
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35 *how am I going to survive?*  
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39 Another participant described an example of engagement in social activities and roles,  
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41 whereby she was not seeing well enough to read, cook, or drive as she believe she should be able  
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43 to. She said, “*I renewed my [driving] license in February and in March I cancelled it myself*  
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45 *because I couldn't see too clear. That hurt me a lot.*”  
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48 For another participant, not being able to do things in the way he used to made him feel  
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50 ridiculous,

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52 *You cannot do things that you normally would think of, like, for example, I have to go to*  
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54 *the cleaners to bring my cleaning. Am I going to hire a driver or take a taxi that is five*  
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3 *blocks or six blocks because I have spinal stenosis so that I cannot walk a lot of blocks? I*  
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5 *mean you feel ridiculous, you know.*  
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8 At times, even when it was possible to accomplish habitual tasks in new ways, individuals may  
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10 struggle with a great sense of helplessness and the commonly held perception that nothing can be  
11  
12 done to improve their visual abilities. One participant recalled,  
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15 *One woman, I will never forget that...I walked into the support group. All the woman was*  
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17 *doing was crying because she couldn't peel a potato and an onion. Lady, get with it. She*  
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19 *cried for a whole hour because she couldn't peel that potato. That potato was so*  
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21 *important to her, it was her whole life. All she was worried about, I can't peel the*  
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23 *potato...The lady that was running the program was telling her that there are so many*  
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25 *alternatives out there that you can do with that potato. There is electric this, there is a*  
26  
27 *special peeler, I can show you techniques and then she started screaming at that poor*  
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29 *lady. What do you know about blindness? Are you blind? Do you know what I am going*  
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31 *through?*  
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35 In addition to its later onset, the degenerative nature of visual impairment among  
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37 participants meant that ability and functioning are not static, which required continual  
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39 adjustment. One individual described the challenge of coping with gradually shifting visual  
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41 ability,  
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45 *It's hard. It's really, really hard, you know. It changes your life. It's a struggle every*  
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47 *single day for me. I get up in the morning and I struggle... you got to put in your*  
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49 *mind that you can't go back. You can say, well last week I saw this, this and this and*  
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51 *this week I can't. You cannot dwell on that.*  
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3 **Physical environment:** The second theme represents the intersection of the physical  
4 environment, commonly accepted beliefs people hold about visual impairment, and their  
5 perceived influence on social participation. This includes the social participation for people with  
6 vision loss in the physical environment, particularly in terms of the ways in which the public  
7 physical environment is constructed. For example, participants described encountering barriers to  
8 mobility in the way public transportation is designed and structured, such as streets, sidewalks,  
9 buses, and the subway. One person explained, *“You take the bus; you don’t know what number  
10 you are getting onto. I ask the driver all the time. To cross the street is very difficult.”* Another  
11 added, *“I have been once nearly run over...so this is a dangerous thing.”* highlighting the  
12 perceived vulnerability of this population when engaging in social encounters in public spaces.  
13 Participants also described the numerous disabling ways in which other public spaces are  
14 constructed, including elevators, grocery stores, banks, pharmacies, restaurants, and recreation  
15 centers, pointing at the inequalities that persons with visual impairment encounter on a daily  
16 basis. One individual recounted a commonly encountered experience among participants,  
17 stating, *“I went into a store two weeks ago and I didn’t know where the cashes are, I could not  
18 find anything. I could not find the exit.”*

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One woman further articulated how the publicly shared physical environment is often  
structured in ways that result in the social exclusion of those who are not ‘normal’: those with  
vision loss. She described,

*When I was growing up, people would talk about integration: how to bring a  
handicapped person into the regular world. That is very nice, it’s all nice and well and  
it’s a great project. The only problem is that when you do grow up and you want to be in  
the normal world, example again for the gym, well I am told - I am sorry we can’t help*

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3 *you so go to your visually impaired centers and let them help you. And you know I can't*  
4 *go shopping on my own anymore. I have to have somebody sighted with me because I*  
5 *literally get lost in the store. So, this is what I find, it's very hard. It's... all my life I have*  
6 *been told go, go, go and I went, went, went and now that I am actually losing my*  
7 *eyesight, I am at the point where I need help, I am told, sorry by the regular world. Sorry*  
8 *we can't help you so go back to your people, go back to your kind and stay there.*  
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19 Some participants made a distinction between the impacts of the impairment itself and  
20 the impacts of environmental conditions on their social participation. For many participants,  
21 challenges in the physical environment in public spaces resulted in them retreating to the private  
22 sphere, for example at home, where they could exert more control over the way in which the  
23 environment is constructed and therefore experience greater comfort and better functioning. One  
24 participant said, *"I was hiding at home because at home I felt secure and I could do my chores*  
25 *and listen to classical music."* Similarly, another participant described that, rather than facing the  
26 various environmental barriers involved in going out as she used to, *"I do not see my good*  
27 *friends anymore. I talk to them over the phone but I don't see them."*  
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43 **Attitudes and responses of others:** This third theme represents social attitudes and responses  
44 that impact the social participation of other people as persons with vision loss encounter them.  
45 Participants described misunderstandings and unwanted attention from others based on their  
46 visual impairment. Additionally, some participants reported being treated with disgust or  
47 disrespect by people with normal vision. One male participant described what he felt was a lack  
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3 of understanding, and that individuals like him are not worthy of the respect of others. He  
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5 described a situation on public transportation,  
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8 *[passengers with normal vision] don't get up. They tell a legally blind person to go to the*  
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10 *back of the bus which they have to watch for their stop, you know, and you got to push*  
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12 *your way through their backpacks, they hit you on the head, they hit the dog in the head.*  
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14 *You got to fight every chap on that bus.*  
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19 Another individual suggested that ignorance and stigmatizing attitudes that exist regarding  
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21 people with vision loss potentially result in social exclusion and in interruption to the natural  
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23 flow of communication,  
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26 *When you're visually impaired it's like, you drink out of my cup, and you are going to get*  
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28 *it. It's contagious, if I touch you, I sneeze on you, that's it, tomorrow you are going to be*  
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30 *blind. That's the conception out there.*  
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35 Such negative attitudes and responses from others created a hostile social participation  
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37 experience for this group of people with vision loss. One individual further illustrates this in the  
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39 following passage,  
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44 *People don't respect [people with vision loss]. You go downstairs, they may push you and*  
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46 *make you fall down. Or in the bus. Now I have my little low vision card. My low vision*  
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48 *card, it helps me but not very much. People do not respect the elderly people first of all*  
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50 *and the people that have problem eyesight. They don't respect all the handicapped*  
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52 *people. And this just makes your daily life miserable [sic].*  
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6 Having previously encountered negative attitudes, some participants indicated that at  
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8 some point they began to anticipate being devalued by others in social settings, and that the  
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10 strategy most often employed to mitigate this risk was to hide their vision loss from others. One  
11  
12 participant remarked, *“I have a friend...he has been blind his whole life...and he used to say he*  
13  
14 *doesn't want to use a cane or dog because he doesn't want people to know that he has a*  
15  
16 *disability.”* Another participant describes an attempt to hide his impairment, saying,  
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21 *I try to ask strangers to do something for me and I am going to find one excuse... Oh I'm*  
22  
23 *sorry I don't have my reading glasses, or something like this, please you do it for me...I*  
24  
25 *don't want to tell them I can't see [sic].*  
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30  
31 One participant explained how feeling misunderstood or rejected by people with normal  
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33 vision caused her to disconnect from relationships that had previously been very important to  
34  
35 her. She stated,  
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40 *People who are well don't know what this is like. They don't want to hear it. They have*  
41  
42 *their own problems. You understand, that's the truth. My own dear friends, I don't*  
43  
44 *discuss anything with them about my eyes. That's why I don't want to see them anymore.*  
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50 Some participants indicated that among individuals with normal vision, even those who  
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52 have positive intentions, their response can have a negative impact on the social participation of  
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54 people with vision loss. One participant recalled,  
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6 *I was coming home late...and this person comes up behind, the man, I know he wanted to*  
7 *help me, poor guy. He came up behind me but he put his hand on my shoulder but so*  
8 *aggressively and at that time, I was actually studying judo. I grabbed the guy's arm and I*  
9 *flipped him and passed him over me and the guy is lying on the floor and I'm like, 'Don't*  
10 *ever do that again.'* He said, *'I just wanted to help.'*  
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19 **Individual internal attitude and responses:** The fourth theme represents the intersection of  
20 personal beliefs and attitudes about visual impairment and its impact. Some participants  
21 described an understanding that not everyone responds to the onset of visual impairment the  
22 same way. Responses are influenced by personal characteristics, such as personality, age, gender,  
23 etc., as well as by an internal or external locus of control. Some may perceive themselves as  
24 potential victims, or may choose to overcome that perception by consciously engaging in  
25 proactive coping mechanisms. One participant asserted, *"A lot of it has to be up to the*  
26 *individual,"* as well as, *"You know I have a little bit of chutzpah, you know, a little bit of*  
27 *nerve...You know what? It's helped me."* Similarly, another participant described,  
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40 *I would say, to be honest, I think it depends on your state of mind. It depends if you*  
41 *are willing to say, 'ok this is my problem'. I was just going to say, as I said,*  
42 *eventually you have two choices; it's either you stand up and fight and say, 'if you*  
43 *can't help me, who can?'* and find out what you can and cannot do, or you sit in your  
44 *little corner and say, 'poor me'.*  
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51 One participant explained that her outlook changed over time. When she first began  
52 experiencing vision loss, she felt discouraged and powerless, which, in turn, impacted her social  
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3 participation. With time, she described acquiring more of a fighting spirit, stating that her current  
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5 outlook is,

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7 *I just turned 65, my life is not over it's just starting. All my friends are retiring and I*  
8 *am going back to school and get my Masters and I want to work with kids who are at*  
9 *risk. I have a lot still to do and if I lose my vision completely, I feel that I am*  
10 *prepared, I have the dog, and I have the JAWS program. I don't need my husband by*  
11 *my side any more. Because that's what I used for a long time and I was dragging him*  
12 *around. He's got his own work.*  
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21 A central idea iterated among participants in terms of personal attitude was the  
22 importance of fighting to maintain independence rather than relying completely on others. One  
23 person said, *"What I found is like they have said, you have to keep your independence."* Another  
24 agreed, stating,  
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30 *My pride went on the backburner, when I realized that I was dependent on someone. I*  
31 *wanted my independence back. I gave up driving a car, too. So when I started thinking*  
32 *about the car and how I felt and all the things that I had to give up, so I said, 'No, I don't*  
33 *have to give up, I have to learn how to do things.'*  
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40 However, participants also expressed that while personal attitudes shaped experience, this  
41 was not the only influencing factor. A fighting spirit, positive outlook, and determination to be  
42 independent cannot overcome all of the obstacles to social participation experienced by people  
43 with vision loss. One person stated, *"The only thing that I find very hard is when you are losing*  
44 *your eyesight, there are a lot of things that, no matter how much you want to be independent, you*  
45 *can't."*  
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## DISCUSSION

The purpose of this study was to describe and better understand the factors that shape the social participation of people with vision loss. Our findings suggest that respondents experience social participation through the personal lens of transition from an outsider (someone with normal vision) to an insider (someone with low vision). Our findings also document stereotyping, both from insiders (persons with low vision) and outsiders (people with normal vision). These (primarily) negative assumptions that others may make seemed to have an important influence on their social participation. Two social settings: family and friends (private setting) versus the public at large emerged as important to the individuals in our sample. The analyses revealed that the onset of vision loss initiates changes in the individual who has the impairment (as they become an insider), as well as how others (the outsiders) perceive this person. These analyses also highlight that there exist both internal as well as external factors that influence the nature of social participation for an individual with low vision, as characterized in the ICF with the personal and environmental factors.

### **Personal Factor: Adapting to change with the onset of impairment**

Individuals perceive themselves as insiders or outsiders based on characteristics they believe they have that aligns them with one or the other groups [21]. Their identity is in jeopardy when they are in limbo or transitioning, somewhere between perceiving themselves as a person with normal vision or a person with acquired vision loss. This threatens their identity as they are uncertain as to what this “new” version of themselves will be. When people who have vision loss find themselves in social settings with those who have normal vision, tension can arise. For the insider, a number of factors may contribute to this tension, including that the insider has not yet

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2  
3 accepted the loss, and may not yet be comfortable using assistive technologies or orientation  
4 strategies to facilitate and reduce this tension and facilitate social participation [60–62].  
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8         Within the context of family and friends, the onset of impairment gave rise to the  
9  
10 perceived stereotype of being helpless, as described by the participants, specifically in the  
11 context of maintaining and performing social roles. This supports what we know from the  
12 research literature [43,63], whereby previous reports have highlighted the stereotype maintained  
13 in folklore writings that people with visual impairment are helpless [42]. In the example of our  
14 participant who described her experience of feeling (and being perceived as) helpless in the  
15 context of kitchen work, this stereotype may be threatening her social role in one specific setting  
16 but may not exist in a different setting, depending on what the context may be. In some  
17 instances, people with low vision will construct environments (with the help of rehabilitation  
18 services) whereby they have optimal control over their level of functioning, thereby limiting the  
19 possible threat of task failure, improving their adaptation to change and diminishing the resulting  
20 stereotyping in social situations [64].  
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35         Within the public at large, stereotypes about people with low vision have also previously  
36 been described in the literature, such as people with low vision are disabled, all the same,  
37 contagious, old, and dependent [20,65,66]. There is a history of tension, discrimination,  
38 marginalization, and institutionalization that informs and guides interactions between people  
39 with visual impairment (insider) and those with normal vision (outsider) groups [21]. For the  
40 insiders, in line with research on disability [67], the individuals with low vision in our sample do  
41 not want to be thought of as different, or as dependent. This desire may make it difficult for an  
42 individual who is experiencing the onset/progression of vision loss to accept the situation [60].  
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There is great variability of social responsiveness to being stereotyped. Insiders may respond

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3 differently to stereotyping depending on the length of time since diagnosis. It is normal with  
4 people with vision loss to wait for years before seeking help from low vision rehabilitation  
5 services [65]. Presumably during this time the individuals' identity is changing. The extent to  
6 which the new identity of the person with vision loss has been integrated into the individual's  
7 social identity will shape their responses to stereotyping [68,69].  
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### 14 **Environmental factors: Public Stigma & Physical Environment**

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17 The most apparent difference between private and public setting categories as they relate  
18 to our findings is the degree of *familiarity* outsider groups have with insiders who have low  
19 vision. Familiarity is a topic that has been previously explored as it relates to stereotype threat  
20 [70]. Stereotype threat is a real or perceived threat of being judged and treated badly in “settings  
21 where negative stereotypes about one's group applies” [pg. 385, 70]. Outsider groups are  
22 presumed to have knowledge of the stereotypes about the health condition and its treatment, and  
23 may be familiar with the individual. This line of research suggests that familiarity impacts on  
24 likelihood of stereotyping another individual [71,72]. Many of the passages from the  
25 participants describe outsiders as being unfamiliar with visual impairment and/or relying on  
26 preconceived notions of vision loss. The perception was that many individuals with normal  
27 vision simply do not understand that only a small percentage of people with vision loss are  
28 totally blind and that the remainder have various levels of remaining visual function or functional  
29 vision [73–75]. For most outsiders their understanding is that people are either blind or have  
30 normal vision [75]. So any manifestation or use of rehabilitation strategies employed by people  
31 with vision loss may lead outsiders to assign the label of blind, and contemplate all of the  
32 associated stereotypes. This public stigma can hinder the help-seeking process of people with  
33 low vision, as they may actively avoid these negative stereotypes by not identifying themselves  
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3 as an insider. This is commonly apparent when deciding to adopt a white cane for mobility [76],  
4 which identifies a person has having an impairment in vision. Within our sample, one person  
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6 experiencing changes in their vision actually identified with a friend who did not use a cane or a  
7  
8 guide dog to avoid being singled out as disabled. While the cane or guide dog can improve  
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10 function and participation, its use may be circumvented to avoid the larger problem of stigma.  
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14  
15 With respect to the present findings, two points about insiders are particularly  
16  
17 noteworthy. First, individuals with *acquired* disability have been shown to differ in their  
18  
19 perception of and approach towards their disability and their disability identity [77]; however,  
20  
21 this topic has not been extensively in the context of visual impairment [78]. Research by Bogart  
22  
23 [77], suggests that people with a congenital mobility disabilities report having a higher  
24  
25 satisfaction with life, a better disability identity and disability self-efficacy than people with  
26  
27 acquired mobility disabilities. The authors suggest that those with congenital disabilities have  
28  
29 adapted to and take pride in their disability identity. In contrast, those with acquired disabilities  
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31 may be influenced by rehabilitation professionals attempt to “normalize” people and have more  
32  
33 difficulty adapting to their new identity [77]. Our participants with acquired vision loss,  
34  
35 however, are likely differentially impacted by stereotyping, compared to those living with  
36  
37 congenital impairment, specifically as their experience of loss differs. These individuals initially  
38  
39 had ‘normal’ vision, and have thus been part of the outsiders’ group. They themselves may have  
40  
41 stereotyped others for vision impairment in the past. Second, according to the modified labeling  
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43 theory [79], when stereotyping does occur (in both public and private settings), this confirms  
44  
45 insider expectations and may lead insiders to expect future stereotyping. This can lead to a self-  
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47 fulfilling prophecy whereby insiders subconsciously expect persistent stereotyping in both public  
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49 and private settings, and make decisions that result in negative outcomes such as social isolation,  
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3 reduced social engagement and self-stigmatization. The quotes exemplify that some do ask  
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5 “strangers” for help but without revealing their impairment or not talking to their friends  
6  
7 anymore because “People who are well don’t know what this is like. They don’t want to hear it.”.  
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10 For insiders, perhaps past experiences of stereotyping with people who have normal  
11  
12 vision have left an emotional scar, which makes it difficult to interact normally. Outsiders may  
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14 not be sure how to approach a person with vision loss, may not know how to help or even to  
15  
16 offer help. This is clear in the example where an outsider grabs the shoulder of a participant with  
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18 low vision (insider), resulting in a negative experience for both. The outsider may also  
19  
20 experience shame for considering stereotypes. Participants’ accounts of stereotyping in private  
21  
22 settings are consistent with familiarity and the modified labelling theory. There was a virtual  
23  
24 consensus that people with normal vision, even those who have a close connection with an  
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26 insider, do not understand the realities of visual impairments, their treatment, and do not know  
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28 how to assist a person with vision loss. While it is reasonable to assume that most people have  
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30 good intentions, this lack of knowledge about low vision can contribute to stereotyping.  
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35 Characteristics of the environment in which the social interaction takes place may also  
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37 come into play. This is not surprising, since those who design the built environment (typically  
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39 outsiders with power) assume ‘normalcy’ and ignore the potential of universal design that would  
40  
41 make the physical environment accessible to all people [80]. Several quotes in our findings  
42  
43 illustrate that physical environments are often structured in inaccessible ways for people with  
44  
45 vision loss, and that this structure, contributed to reduced mobility, independence, and sense of  
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47 security for these individuals. In addition, contextual factors such as: the number of people  
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49 present, the purpose of the event, as well as the presence of other people who have vision loss or  
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51 knowledge of vision loss all factor into potential stereotyping. Moreover, all of these factors may  
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3 give rise to the level of stress for both the insiders and outsiders. For example one participant  
4 discussed transportation as stressful and described their reliance on the bus driver or others for  
5 help. According to the stigma induced identity threat model [81], the balance between demands  
6 of the situation and personal resources will determine the level of identity threat and will in many  
7 ways govern responses by both insiders and outsiders.  
8  
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### 14 **Reducing the barriers to social participation of people with low vision**

16  
17 It remains unclear how people with vision loss should approach social interactions  
18 knowing and expecting that assumptions will be made about them, and that some of these  
19 assumptions will be erroneous and potentially marginalizing. It is our contention that people with  
20 vision loss may be best served by repeatedly disclosing to others relevant information about their  
21 low vision and how communication partners can aid them in their social participation thereby  
22 advocating for themselves. In the stigma reduction literature [63], there is a general consensus  
23 that stigma reduction campaigns should incorporate four types of activities: educational and  
24 awareness campaigns, face-to-face interactions or personal contact, persuasion (changing  
25 people's beliefs about low vision) and disability simulations (have outsiders, in particular  
26 familiar outsiders, experience what it is like to have low vision). Wainapel [76] proposed that  
27 peers may be best situated to counsel a newly diagnosed person. However, the findings from the  
28 present study, and from previous work on familiarity and stereotyping, suggest that relying only  
29 on one-to-one interactions to reduce the stigma associated with low vision might not be  
30 advisable. It is possible that stigma reduction may only result from more intimate, or at least  
31 developed, connections with people who have stigmatizing traits. If this is the case, stigma  
32 reduction programs might test building upon existing relations with people who have  
33 stigmatizing traits. With respect to outsiders who are unfamiliar with visual impairment,  
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3 increased education, persuasion from the insider about their capabilities and experiential trials  
4 that simulate low vision can help reduce these environmental barriers to social participation for  
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6 people with low vision.  
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### 9 10 **Clinical Implications: Importance to rehabilitation of clients with low vision**

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12 In some cases, stereotyping extends into clinical/healthcare settings [82]. Familiarity with  
13  
14 visual impairments and the manifestations of low vision, combined with a charged daily  
15  
16 appointment list may lead some clinicians to make assumptions about the challenges and abilities  
17  
18 of their clients. Stereotyping by clinicians will reduce opportunities for client-centered care for  
19  
20 people with low vision. It is therefore vital to increase the awareness of stereotyping and its  
21  
22 pitfalls by clinicians who work with individuals who have low vision. All clinicians should  
23  
24 assess their own attitudes toward this population. Recent work [83] with health care providers  
25  
26 suggests that some professionals may not adopt stereotypical views of their clients. This work, in  
27  
28 dual sensory impairment (DSI: combined hearing and vision losses), suggests that strong  
29  
30 familiarity with a marginalized group (in this case people with DSI) can actually be an asset.  
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32 Many of the professionals that were interviewed were strong advocates for their clients and  
33  
34 generally did not seem to have a stereotypical approach to their clientele. However, several  
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36 mentioned the daily public stigma their clients faced and that interactions with professionals not  
37  
38 specifically trained in DSI often resulted in stereotypical responses [83].  
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45 Even the most perfectly rehabilitated client at a functional level may remain fearful of  
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47 being identified, faced with barriers created by the sighted community and socially excluded.  
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49 Rehabilitation specialists should consider the different spheres in which the individual needs to  
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51 function, and the professionals need to frame their interventions accordingly, with a client-  
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53 centered approach that supports a respectful partnership between client and health care  
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professionals [84]. Professionals that work with clients with low vision should, based on the clients' needs, encourage attempting different devices and strategies to reduce and/or minimize the barriers faced, and help people with low vision to be active participants in their physical and social environment [85].

### **Limitations**

One potential limitation of secondary analyses of qualitative data sets concerns theoretical saturation [48]. Content analysis involves identification of incidents, events activities which are grouped to form categories. The category is 'saturated' when new information which adds to the understanding of the category is not forthcoming. If the data set is being used 'inappropriately', there will be limited data, resulting in a premature saturation of the category. This was not a concern for this data set. The participants in this study were proud to discuss their experiences of low vision and social participation. There was thus ample information to analyze. However, the initial focus of data collection was not to probe into the topic of stigmatization; therefore, it is possible that some aspects of low vision and stigmatization, beyond the topics that were spontaneously self-identified by our participants, are not covered in our data, but might emerge in future studies designed to address this topic in more depth. Future studies should target this area of inquiry directly and ideally have several focus group sessions to increase the amount of data acquired.

### **CONCLUSION**

People with low vision experience a number of changes when they begin to demonstrate functional impairments in their vision. From the perspective of the participants in our study (the insiders) their personal perceptions transitioning to an insider, as well as, their interactions with

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2  
3 people with normal vision (outsiders) influence their social participation. The stereotypes and  
4  
5 stigma that surround low vision was clearly a topic that negatively influenced our participants'  
6  
7 social participation as this was a topic that they repeatedly discussed in our focus groups and as a  
8  
9 result became a secondary analysis from this data set. Stigma in the environment perceived or  
10  
11 experienced is a critical factor to address for older adults with low vision as it has the potential to  
12  
13 reduce social participation, in some cases diminish help-seeking and ultimately impact health.  
14  
15 Strategies to improve awareness and educate the general public and health care providers on low  
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17 vision could reduce the stigma associated with this condition and ultimately improve the health  
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19 of older individuals with low vision.  
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26 **Author Statement:** Drs. Kenneth Southall & Walter Wittich planned this project. Dr. Southall  
27  
28 led the focus groups and Dr. Southall and Wittich analyzed the data and created the code list  
29  
30 together. Irene Beeman was a graduate student learning qualitative research and she worked  
31  
32 directly with Dr. Southall to create a rough draft of this paper. Dr. Fraser was involved in the  
33  
34 write-up of this project and worked with Dr. Southall and Wittich to revise, edit and produce the  
35  
36 final version of this manuscript.  
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40 **Data Statement:** Data available on request only, with appropriate ethics approval  
41

42 **Conflicts of Interest:** There are no conflicts of interest to report in this study.  
43

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45  
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Table 1  
*Participant Characteristics*

<u>Participants</u>	<u>Diagnosis</u>	<u>Gender</u>	<u>Awareness</u>	<u>Accessed</u>
1	RP	Female	Yes	Yes
2	DR/GL	Male	Yes	Yes
3	Stroke	Female	Yes	Yes
4	RD/DR/GL	Female	Yes	Yes
5	DR/GL	Female	Yes	Yes
6	AMD	Male	Yes	No
7	AMD	Female	Yes	Yes
8	GL	Female	No	No
9	AMD	Male	No	No
10	Ocular Trauma	Male	Yes	Yes
11	Corneal Transplant/Keratitis	Female	Yes	Yes
12	AMD	Female	Yes	Yes
13	AMD/GL	Female	Yes	Yes
14	AMD/RD	Female	Yes	Yes
15	AMD/GL	Female	Yes	Yes
16	GL	Male	Yes	Yes
17	AMD	Female	Yes	Yes
18	AMD	Female	Yes	Yes
19	DR	Male	Yes	Yes
20	AMD	Male	Yes	Yes
21	AMD	Female	Yes	Yes

*Note:* Awareness = aware of rehabilitation services for vision loss (Yes or No); Accessed = Accessed low vision services (Yes or No). RD = Retinal Detachment; RP = Retinitis Pigmentosa; DR = Diabetic Retinopathy; GL = Glaucoma; AMD = Age-related macular degeneration;

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**Title of study:** Stereotyping as a barrier to the social participation of older adults with low vision:  
A qualitative focus group study

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? <ul style="list-style-type: none"> <li>• Dr. Kenneth Southall</li> </ul>
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i> <ul style="list-style-type: none"> <li>• PhD</li> </ul>
3.	Occupation	What was their occupation at the time of the study? <ul style="list-style-type: none"> <li>• Qualitative Researcher at McGill University in the School of Social Work</li> </ul>
4.	Gender	Was the researcher male or female? <ul style="list-style-type: none"> <li>• Male</li> </ul>
5.	Experience and training	What experience or training did the researcher have? <ul style="list-style-type: none"> <li>• The researcher completed a qualitative research PhD and was at the time a New Investigator with a New Investigator Career award (from the Quebec provincial government,</li> </ul>

No	Item	Guide questions/description
		in Canada) for his proposed qualitative research studies
	Relationship with participants	
6.	Relationship established	<p>Was a relationship established prior to study commencement?</p> <ul style="list-style-type: none"> <li>No</li> </ul>
7.	Participant knowledge of the interviewer	<p>What did the participants know about the researcher? e.g. <i>personal goals, reasons for doing the research</i></p> <ul style="list-style-type: none"> <li>Researchers background and aims of the study were discussed at the beginning of focus group session</li> </ul>
8.	Interviewer characteristics	<p>What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i></p> <ul style="list-style-type: none"> <li>Reasons and interests in the research topic were discussed. The researcher had a strong background in qualitative health research on people with hearing impairments and wanted to extend this to better understand people with vision impairments</li> </ul>
<b>Domain 2: study design</b>		
	Theoretical framework	
9.	Methodological orientation and Theory	<p>What methodological orientation was stated to underpin the study? e.g. <i>grounded theory,</i></p>

No	Item	Guide questions/description
Participant selection	10. Sampling	<p><i>discourse analysis, ethnography, phenomenology, content analysis</i></p> <ul style="list-style-type: none"> <li>Content analysis was chosen</li> </ul> <p>How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i></p> <ul style="list-style-type: none"> <li>It was purposive sampling as people with low vision who participated in the Montreal Barriers Study were solicited to gain their perspectives on barriers to social participation</li> </ul>
11.	Method of approach	<p>How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i></p> <ul style="list-style-type: none"> <li>Face-to-face</li> </ul>
12.	Sample size	<p>How many participants were in the study?</p> <ul style="list-style-type: none"> <li>21 participants</li> </ul>
13.	Non-participation	<p>How many people refused to participate or dropped out? Reasons?</p> <ul style="list-style-type: none"> <li>None of the participants approached refused or dropped out of the study</li> </ul>
Setting	14.	<p>Where was the data collected? <i>e.g. home, clinic, workplace</i></p> <ul style="list-style-type: none"> <li>In a clinical setting (at the Jewish General Hospital), in a private room</li> </ul>
15.	Presence of non-participants	<p>Was anyone else present besides the participants and researchers?</p> <ul style="list-style-type: none"> <li>No</li> </ul>

No	Item	Guide questions/description
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i> <ul style="list-style-type: none"> <li data-bbox="883 386 1253 415">• We included age and sex</li> </ul>
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? <ul style="list-style-type: none"> <li data-bbox="883 638 1403 785">• The leader of the focus group had a guide for the focus group discussions and this guide was modified based on issues that the participants raised</li> </ul>
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many? <ul style="list-style-type: none"> <li data-bbox="883 924 971 953">• No</li> </ul>
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data? <ul style="list-style-type: none"> <li data-bbox="883 1092 1143 1121">• Audio recording</li> </ul>
20.	Field notes	Were field notes made during and/or after the interview or focus group? <ul style="list-style-type: none"> <li data-bbox="883 1251 1403 1407">• Yes. These were conducted by a second researcher who was also in the room but did not guide the focus group discussion.</li> </ul>
21.	Duration	What was the duration of the interviews or focus group? <ul style="list-style-type: none"> <li data-bbox="883 1545 1117 1575">• 60-90 minutes</li> </ul>
22.	Data saturation	Was data saturation discussed? <ul style="list-style-type: none"> <li data-bbox="883 1671 980 1701">• Yes</li> </ul>
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction? <ul style="list-style-type: none"> <li data-bbox="883 1839 971 1869">• No</li> </ul>

No	Item	Guide questions/description
<b>Domain 3: analysis and findingsz</b>		
Data analysis		
24.	Number of data coders	How many data coders coded the data? <ul style="list-style-type: none"> <li>• Two</li> </ul>
25.	Description of the coding tree	Did authors provide a description of the coding tree? <ul style="list-style-type: none"> <li>• Not in the manuscript.</li> </ul>
26.	Derivation of themes	Were themes identified in advance or derived from the data? <ul style="list-style-type: none"> <li>• Derived from the data</li> </ul>
27.	Software	What software, if applicable, was used to manage the data? <ul style="list-style-type: none"> <li>• Atlas.ti</li> </ul>
28.	Participant checking	Did participants provide feedback on the findings? <ul style="list-style-type: none"> <li>• No</li> </ul>
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i> <ul style="list-style-type: none"> <li>• Yes participant quotations were presented but they were not identified</li> </ul>
30.	Data and findings consistent	Was there consistency between the data presented and the findings? <ul style="list-style-type: none"> <li>• Yes</li> </ul>

No	Item	Guide questions/description
31.	Clarity of major themes	Were major themes clearly presented in the findings? <ul style="list-style-type: none"><li>• Yes</li></ul>
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? <ul style="list-style-type: none"><li>• No, only major themes presented</li></ul>

# BMJ Open

## Stereotyping as a barrier to the social participation of older adults with low vision: A qualitative focus group study

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Stereotyping as a barrier to the social participation of older adults with low vision:

A qualitative focus group study

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8 Stereotyping as a barrier to the social participation of older adults with low vision:

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10 A qualitative focus group study

11  
12 **ABSTRACT**

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15 **Objective:** In order to better understand the barriers that limit the social participation of older  
16 people with low vision, the aim of this study was to describe and clarify the factors that shape the  
17 social participation of older adults with vision loss.

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20 **Methods:** As part of a study on rehabilitation access barriers, six qualitative focus groups were  
21 conducted in a private room in a hospital, with 21 individuals with low vision (aged 38-92 years)  
22 who had or had not accessed low vision services. During the focus groups, participants often  
23 spoke of the challenges they faced when interacting with people with “normal” vision, this  
24 discussion led to a modification of the interview guide in order to capture barriers to social  
25 participation. Focus group discussions were audiotaped, transcribed and content analysis was  
26 conducted.

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32 **Results:** Content analysis revealed that personal as well as environmental factors influenced the  
33 social participation of older adults with low vision. Four themes emerged: 1) experiencing the  
34 onset of impairment and degenerating ability, 2) the physical environment, 3) attitudes and  
35 responses from others, and 4) individual internal attitude and responses during social  
36 interactions. Lived and perceived stigma from the perspective of the insider (person living with  
37 low vision) interacting with an outsider (person with “normal” vision) and difficult  
38 environmental contexts were described as barriers to social participation and optimal  
39 functioning.

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46 **Conclusions:** At a personal level, transitioning from an outsider to an insider influenced self-  
47 identity and social participation. Further, insiders experiencing stereotypes associated with older  
48 adults who are blind had a negative impact on their social participation. Findings highlight the  
49 importance of stigma and stereotyping in the lived experience of older adults with low vision.  
50 Stigma is persistent, but strategies to reduce stigma will ultimately facilitate the social  
51 participation of older adults with low vision.  
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## ARTICLE SUMMARY

### Strengths and Limitations:

- The relevance of this secondary analysis emerged through the unsolicited nature and priority of focus group participants to provided rich data on the important factors influencing social participation among individuals with low vision.
- Qualitative focus group data provide a raw and personal perspective and insight on the experience of social participation and social isolation of older adults with low vision
- Given the focus on older participants with acquired visual impairment, the presented perspective on social participation may not generalize to persons with congenital visual impairment of all ages
- Though stereotyping emerged as an important theme, this dimension was not specifically solicited during the interview process and may be under-represented in this dataset

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## 8 INTRODUCTION 9

10 Functionally, a person with low vision can be defined as someone “who has difficulty  
11 accomplishing visual tasks, even with prescribed corrective lenses, but who can enhance his or  
12 her ability to accomplish these tasks with the use of compensatory visual strategies, low vision  
13 and other assistive devices, and environmental modifications” [p.4, 1]. In order to study these  
14 factors that influence outcomes for an older individual with low vision, a suitable framework  
15 needs to encompass these varied aspects. One commonly used framework is the International  
16 Classification of Functioning, Disability and Health (ICF) from the World Health Organization  
17 (WHO) [2]. The ICF takes into account functional factors (i.e., low vision, participation) as well  
18 as contextual factors (i.e., the environment and personal factors) and has been applied to  
19 populations with low vision [3,4]. In the ICF, participation has been defined as “involvement in a  
20 life situation” (pg. 8, 10) and encompasses social participation elements such as: interpersonal  
21 interactions and relationships as well as involvement in community, social and civic life [2].  
22 Psychological health and social participation are both functional factors that can potentially be  
23 negatively affected by vision loss. Numerous studies have highlighted the increased risk for  
24 depression among older persons with visual impairment [5–8], in addition to decreased  
25 perception of quality of life [9]. Participation restrictions in particular have been shown to be  
26 linked to psychological wellbeing in older adults with visual impairment [10] who are often  
27 limited in their ability to get around independently, especially in new environments, making it  
28 more difficult to attend social functions.  
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3 In addition, for individuals with acquired vision loss (i.e., age-related macular  
4 degeneration, glaucoma, diabetic retinopathy, stroke-related vision loss) their impairment may  
5 affect communication strategies, such as face recognition and the ability to distinguish facial  
6 expressions, critical for social interaction [11–13]. Communication challenges and other aspects  
7 of life with visual impairment can threaten social participation, thereby possibly isolating the  
8 person, negatively affecting their health and reducing their degree of engagement with society  
9 [14]. During low vision rehabilitation, various intervention approaches and tools have the  
10 potential to assist the person with low vision to overcome the many barriers they may face and/or  
11 perceive, including barriers to social participation [15]. For example, day center services that are  
12 adapted for older adults with sensory loss have shown promise in maintaining functional abilities  
13 and social integration over time [16] and a multi-disciplinary rehabilitation approach (including  
14 ophthalmology, optometry, occupational therapy, low vision therapy, orientation and mobility,  
15 orthoptics, and welfare and mental health specialists) has been shown to improve quality of life  
16 as well as social participation [17,18].

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19 Despite the availability of effective rehabilitation approaches, one environmental barrier  
20 that may restrict engagement in low vision rehabilitation is the stigma and stereotypes associated  
21 with their health status [19,20]. Stigma occurs when an individual or group has a characteristic  
22 (i.e., low vision) that is devalued in certain social contexts [21]. Chronic age-related health  
23 conditions, such as vision loss, are commonly stigmatized [22–25]. Stereotypes about disability  
24 are learned at a young age due to persistent socio-cultural conditioning [26,27]. In Western  
25 cultures, the media portray individuals with disabilities as sick, helpless and in pain [28]. These  
26 stereotypes often result in marginalization and social exclusion [29–31]. People who have a  
27 visual impairment may come to expect discrimination, creating a self-fulfilling prophecy [32–

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3 34]. Anticipating situations of stigma may have negative impacts on quality of life as older adults  
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5 with low vision may forego opportunities for social participation. In recent years, increasing  
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7 attention has been paid to patient-centered outcome measures and an involvement of patients as  
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9 research partners through participatory action research [35]. In visual impairment research, this  
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11 trend has allowed researchers to pay closer attention to insider perspectives (e.g., the viewpoint  
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13 of persons with the visual impairment) as part of the research process in domains such as  
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15 information access [36] or quality of life [37]. However, this perspective remains under-  
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17 represented in the peer-reviewed literature and would be specifically pertinent in the context of  
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19 stigmatization.  
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### 23 24 **The origins of low vision stigmatization**

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26 As with many other chronic impairments, the general public does not easily make the  
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28 distinction between absolute and partial loss of function [38–40]. As a result, the general public  
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30 may stigmatize people with partial vision loss in the same manner that they would stigmatize  
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32 people who are blind. Stigma is a social phenomenon that is greatly influenced by both historical  
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34 and cultural forces [41]. Present-day stereotypes attributed to people with any level of vision loss  
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36 date back to prejudicial attitudes held against people who were considered blind in Ancient  
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38 Greek societies [42,43]. We now live in a society that relies upon traditional communication,  
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40 such as vocalized speech and eye contact (which is often difficult or unknown to individuals with  
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42 partial or complete vision loss), whereby stereotypes are housed and maintained within language  
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44 [44]. Should one encounter a person who is unable to communicate in a “normal” manner, one  
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46 might revert to (or rely upon) historically and culturally constructed stereotypes in order to  
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48 understand what is perceived to be “deviant” behaviours. Like other cultural beliefs, prejudicial  
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50 beliefs are transmitted from one generation to the next. There is evidence that derivations of  
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3 ancient prejudices toward people who are blind continue to impact upon the present-day  
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5 community, and are extended to include persons with partial vision as well. Kent [43] reviewed  
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7 literary references to blindness, and found that a lack of sight was almost always framed in a  
8  
9 negative fashion. In some ways, the stereotypes about people who are blind have impacted the  
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11 perception of all people who have vision loss, in part rooted in preconceived ideas and a lack of  
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13 awareness about persons with low vision, resulting in the exclusion of both groups (for several  
14  
15 relevant research articles on stigma and low vision, please see the following resource from the  
16  
17 Royal National Institute for the blind: [https://www.rnib.org.uk/professionals/knowledge-and-](https://www.rnib.org.uk/professionals/knowledge-and-research-hub)  
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19 [research-hub](https://www.rnib.org.uk/professionals/knowledge-and-research-hub)).  
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24       Critical to the experience of stigmatization is social context. Characteristics of the  
25  
26 physical and social environment influence the meanings assigned to situations and events by  
27  
28 those present [45]. For example, the nature of marginalization and mistreatment is likely  
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30 different when a person who has a stigmatizing trait is interacting with friends and family, as  
31  
32 opposed to that same person interacting with a group of strangers. The extent to which a person  
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34 is familiar with people who have the stigmatizing trait is an important consideration when  
35  
36 assessing how threatened an individual will feel by the presence of stigma [46]. Some may  
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38 decrease their stigmatization because they are familiar with people who have the stigmatizing  
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40 trait while others will increase it based on their previous negative interactions with a person with  
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42 low vision.  
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47       In a previous study, members of this team sought to explore older adults' perspectives on  
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49 the barriers to low vision rehabilitation. Focus group participants described stressful or negative  
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51 interactions with people with "normal" vision in which they felt they were being negatively  
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53 judged due to their vision status [19]. These descriptions were unsolicited (as this was not the  
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3 goal of the study), but we recognized a pattern emerging early on in our data analysis and  
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5 modified our interview guide in order to include follow-up questions to further explore this issue  
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7 as data collection progressed. Given the unprompted nature of the data and the lack of research  
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9 on this topic, we deemed the descriptions of social interactions would provide more information  
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11 on the stigma perceived and/or experienced by older adults with low vision. Given the relative  
12  
13 paucity of research on the stigma associated with low vision and the important implications for  
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15 the rehabilitation and social participation for this population, as well as the rich detail arising  
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17 from these interviews, we decided to conduct a secondary analysis of the focus group interviews  
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19 from Southall and Wittich [19]. The aim of the study was to describe and better understand the  
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21 factors that shape the social participation of older people with vision loss. This understanding  
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23 would provide a more holistic comprehension of functioning that considers the person, the  
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25 impairment, and the environment to promote the health and wellbeing of older adults with vision  
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27 loss.  
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## 35 METHOD

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37 The *Centre de recherche interdisciplinaire en réadaptation (CRIR) du Montréal*  
38 *métropolitain* provided ethical approval for the focus group study protocol. Secondary analysis  
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40 of qualitative data is a common qualitative methodology procedure [47], whereby the analysis of  
41  
42 an existing data set allows for examination of a topic *different* than that of the original project  
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44 [48]. The methods and results follow the consolidated criteria for reporting qualitative research  
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46 (COREQ) guidelines: a 32-item comprehensive checklist used in the reporting of data from  
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48 interviews and focus groups [49]. During the focus group sessions and upon revisiting the  
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50 original transcripts, it was obvious that most participants provided in-depth narratives about their  
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3 interactions with other individuals in their community who have “normal” vision. This  
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5 interaction between people with low vision and those with “normal” vision became the focus of  
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7 this investigation.  
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## 10 **Participants**

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12 The focus group participants were recruited through their involvement in the Montreal  
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14 Barriers Study [50] and all provided written and informed consent. Each focus group was  
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16 composed of participants who had not heard of low vision rehabilitation services, had heard of  
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18 but not accessed these services, or who knew of and accessed these services. Six focus groups of  
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20 2-5 participants were conducted with a total of 21 participants (14 Female, 7 Male), ranging in  
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22 age from 38 to 92 (please note: only one participant (age: 38 years; was under the age of 65  
23  
24 years; given the similarity of her response content to that of all other participants, her data were  
25  
26 maintained in the analyses). Participant characteristics are presented in Table 1. Heterogeneous  
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28 groups were selected so that differences in perspectives on the barriers to low vision  
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30 rehabilitation services would be most apparent to the investigators during the focus group  
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32 discussions and subsequent analyses.  
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## 38 **Data Collection**

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40 As described in the original protocol [19], the team members with the most extensive  
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42 experience as a qualitative researcher (KS), led focus groups. The principal topic of interest  
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44 (positive and negative perceptions on low vision rehabilitation) was explained to participants,  
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46 including the central three questions: *What enabled you to access low vision rehabilitation*  
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48 *services? What served as obstacles to you accessing low vision rehabilitation services?* and  
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50 *What could be done to make it easier to access low vision rehabilitation services?* The research  
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52 team aimed to create an informal and comfortable atmosphere, allowing participants to freely  
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3 discuss and share their perceptions, while encouraging discussion among the participants. At the  
4 beginning of the focus group session, to facilitate communication for people with visual  
5 impairments, it was stated that all cues would be auditory and that there would be turn taking so  
6 that only one person spoke at a time. All participants introduced themselves to facilitate auditory  
7 localization of each individual and to let participants become more familiar with everyone's tone  
8 of voice. The participant or the leader of the group would state the name of the person speaking  
9 and anyone who wished to comment could raise their hand and the leader would facilitate their  
10 turn in speaking. During focus group discussions, barriers to social participation were described  
11 by the participants, as such the interview guide was modified to include questions about barriers  
12 to social participation and interactions with people with "normal" vision. Focus groups were  
13 conducted in a private room at the Jewish General Hospital in Montreal (Canada). Each focus  
14 group had one group discussion session that lasted 60-90 minutes. In addition, field notes were  
15 taken by the last author (WW) as a secondary data source to supplement the audio-recorded  
16 information [51]. During verbatim transcription, identifying information was removed to ensure  
17 confidentiality, while proper names were replaced with pseudonyms.

### 37 **Analyses**

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39 For the present study, we employed qualitative content analysis of the interview  
40 transcripts [52] to describe and better understand the factors that shape the social participation of  
41 people with vision loss. Content analysis involves open coding when the researchers familiarize  
42 themselves with the data and identify narratives that answer the question [53]. In the margins of  
43 interview transcripts, labels were assigned to relevant data. The aim was to assign the necessary  
44 labels so as to describe fully the content of the text [54]. Next, categories of codes were created  
45 in order to generate manageable chunks of information [55]. The final phase involved extracting  
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3 general descriptors of the data. To this end, we uploaded the data into ATLAS-ti [56], a software  
4 program that is designed to aid in the analysis of large bodies of text, and to identify meaningful  
5 patterns within and across the transcripts of interviews. A number of representative interview  
6 excerpts were selected for inclusion in the results section [53]. All data analyses were conducted  
7 by two of the co-authors (KS and WW) in face-to-face meetings, whereby team coding was  
8 performed, discussions about different ways of “seeing” the data were explored and  
9 discrepancies were resolved through discussion and presentation of rationale for items being  
10 addressed, a technique the authors have successfully implemented before [57–59].

11  
12 **Patient and Public Involvement:** This research was done without patient involvement. Patients  
13 were not invited to comment on the study design and were not consulted to develop patient  
14 relevant outcomes or interpret the results. Patients were not invited to contribute to the writing or  
15 editing of this document for readability or accuracy. However, indirectly, the study was driven  
16 by patient priorities, given that the content on stigma and social participation was unsolicited but  
17 substantial enough to warrant secondary analyses.

## 38 RESULTS

39  
40 In this study we sought to answer the research question ‘What are the factors that shape  
41 the social participation of people with vision loss?’ Our analyses uncovered four interwoven  
42 factors that shape social participation for this sample, including 1) experiencing the onset of  
43 impairment and degenerating ability, 2) the physical environment, 3) attitudes and responses  
44 from others, and 4) individual internal attitude and responses during social interactions. These  
45 findings further suggest that, depending on the nature and interactions of these factors, the social  
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3 participation of people with vision loss may be described anywhere on a spectrum from  
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5 empowering to disabling.  
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7 **Experiencing the onset of impairment and degenerating ability:** The first theme represents  
8 changes in functional status, self-reflections, and the emotions associated with transitioning from  
9 a person with “normal” vision to one that has reduced visual abilities. In terms of changes in  
10 functional abilities participants described “losses” and their ability to perform social roles as well  
11 as activities of daily living. These changes initially resulted in negative emotions, such as  
12 frustration, feelings of helplessness and hopelessness shortly after the onset of the impairment. In  
13 the paragraphs that follow, we provide excerpts that demonstrate the intersections of stereotypes  
14 associated with vision loss, as well as the desire and need for social participation.  
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26 Focus group participants revealed the ways in which the experience of losing vision  
27 impacted their social participation. All participants experienced the onset of vision loss later in  
28 life, and therefore had to adjust to the (emotional and psychological) loss of a previously  
29 experienced ability. Later, the onset of vision loss resulted in participants being unable to engage  
30 in their daily activities in the same way they did prior to vision loss. For example, one  
31 participant indicated that the experience of impairment can be particularly devastating later in  
32 life, whereby her “whole world” appears to crumble, stating:  
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42 *I am going to be 77 years old. I had my eyesight for 76 years and now I lost it and losing*  
43 *it...When I found out I felt like my whole world was crumbling from under me and I said*  
44 *how am I going to survive?*  
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49 Another participant described an example of engagement in social activities and roles,  
50 whereby she was not seeing well enough to read, cook, or drive as she believe she should be able  
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3 to. She said, *“I renewed my [driving] license in February and in March I cancelled it myself*  
4 *because I couldn’t see too clear. That hurt me a lot.”*

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8 For another participant, not being able to do things in the way he used to made him feel  
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10 ridiculous,

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12 *You cannot do things that you normally would think of, like, for example, I have to go to*  
13 *the cleaners to bring my cleaning. Am I going to hire a driver or take a taxi that is five*  
14 *blocks or six blocks because I have spinal stenosis so that I cannot walk a lot of blocks? I*  
15 *mean you feel ridiculous, you know.*

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21 At times, even when it was possible to accomplish habitual tasks in new ways, individuals may  
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23 struggle with a great sense of helplessness and the commonly held perception that nothing can be  
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25 done to improve their visual abilities. One participant recalled,

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28 *One woman, I will never forget that...I walked into the support group. All the woman was*  
29 *doing was crying because she couldn’t peel a potato and an onion. Lady, get with it. She*  
30 *cried for a whole hour because she couldn’t peel that potato. That potato was so*  
31 *important to her, it was her whole life. All she was worried about, I can’t peel the*  
32 *potato...The lady that was running the program was telling her that there are so many*  
33 *alternatives out there that you can do with that potato. There is electric this, there is a*  
34 *special peeler, I can show you techniques and then she started screaming at that poor*  
35 *lady. What do you know about blindness? Are you blind? Do you know what I am going*  
36 *through?*

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49 In addition to its later onset, the degenerative nature of visual impairment among  
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51 participants meant that ability and functioning are not static, which required continual  
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3 adjustment. One individual described the challenge of coping with gradually shifting visual  
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5 ability,

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7 *It's hard. It's really, really hard, you know. It changes your life. It's a struggle every*  
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9 *single day for me. I get up in the morning and I struggle... you got to put in your*  
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11 *mind that you can't go back. You can say, well last week I saw this, this and this and*  
12  
13 *this week I can't. You cannot dwell on that.*  
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19 **Physical environment:** The second theme represents the intersection of the physical  
20  
21 environment, commonly accepted beliefs people hold about visual impairment, and their  
22  
23 perceived influence on social participation. This includes the social participation for people with  
24  
25 vision loss in the physical environment, particularly in terms of the ways in which the public  
26  
27 physical environment is constructed. For example, participants described encountering barriers to  
28  
29 mobility in the way public transportation is designed and structured, such as streets, sidewalks,  
30  
31 buses, and the subway. One person explained, *"You take the bus; you don't know what number*  
32  
33 *you are getting onto. I ask the driver all the time. To cross the street is very difficult."* Another  
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35 added, *"I have been once nearly run over...so this is a dangerous thing."*, highlighting the  
36  
37 perceived vulnerability of this population when engaging in social encounters in public spaces.  
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39 Participants also described the numerous disabling ways in which other public spaces are  
40  
41 constructed, including elevators, grocery stores, banks, pharmacies, restaurants, and recreation  
42  
43 centers, pointing at the inequalities that persons with visual impairment encounter on a daily  
44  
45 basis. One individual recounted a commonly encountered experience among participants,  
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47 stating, *"I went into a store two weeks ago and I didn't know where the cashes are, I could not*  
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49 *find anything. I could not find the exit."*  
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3 One woman further articulated how the publicly shared physical environment is often  
4 structured in ways that result in the social exclusion of those who are not ‘normal’: those with  
5 vision loss. She described,  
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10 *When I was growing up, people would talk about integration: how to bring a*  
11 *handicapped person into the regular world. That is very nice, it's all nice and well and*  
12 *it's a great project. The only problem is that when you do grow up and you want to be in*  
13 *the normal world, example again for the gym, well I am told - I am sorry we can't help*  
14 *you so go to your visually impaired centers and let them help you. And you know I can't*  
15 *go shopping on my own anymore. I have to have somebody sighted with me because I*  
16 *literally get lost in the store. So, this is what I find, it's very hard. It's... all my life I have*  
17 *been told go, go, go and I went, went, went and now that I am actually losing my*  
18 *eyesight, I am at the point where I need help, I am told, sorry by the regular world. Sorry*  
19 *we can't help you so go back to your people, go back to your kind and stay there.*  
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35 Some participants made a distinction between the impacts of the impairment itself and  
36 the impacts of environmental conditions on their social participation. For many participants,  
37 challenges in the physical environment in public spaces resulted in them retreating to the private  
38 sphere, for example at home, where they could exert more control over the way in which the  
39 environment is constructed and therefore experience greater comfort and better functioning. One  
40 participant said, *“I was hiding at home because at home I felt secure and I could do my chores*  
41 *and listen to classical music.”* Similarly, another participant described that, rather than facing the  
42 various environmental barriers involved in going out as she used to, *“I do not see my good*  
43 *friends anymore. I talk to them over the phone but I don't see them.”*  
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6 **Attitudes and responses of others:** This third theme represents social attitudes and responses  
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8 that impact the social participation of other people as persons with vision loss encounter them.  
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10 Participants described misunderstandings and unwanted attention from others based on their  
11  
12 visual impairment. Additionally, some participants reported being treated with disgust or  
13  
14 disrespect by people with “normal” vision. One male participant described what he felt was a  
15  
16 lack of understanding, and that individuals like him are not worthy of the respect of others. He  
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18 described a situation on public transportation,  
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21  
22 *[passengers with “normal” vision] don’t get up. They tell a legally blind person to go to*  
23  
24 *the back of the bus which they have to watch for their stop, you know, and you got to*  
25  
26 *push your way through their backpacks, they hit you on the head, they hit the dog in the*  
27  
28 *head. You got to fight every chap on that bus.*  
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33 Another individual suggested that ignorance and stigmatizing attitudes that exist regarding  
34  
35 people with vision loss potentially result in social exclusion and in interruption to the natural  
36  
37 flow of communication,  
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41 *When you’re visually impaired it’s like, you drink out of my cup, you are going to get it.*  
42  
43 *It’s contagious, if I touch you, I sneeze on you, that’s it, tomorrow you are going to be*  
44  
45 *blind. That’s the conception out there.*  
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49  
50 Such negative attitudes and responses from others created a hostile social participation  
51  
52 experience for this group of people with vision loss. One individual further illustrates this in the  
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54 following passage,  
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5 *People don't respect [people with vision loss]. You go downstairs, they may push you and*  
6 *make you fall down. Or in the bus. Now I have my little low vision card. My low vision*  
7 *card, it helps me but not very much. People do not respect the elderly people first of all*  
8 *and the people that have problem eyesight. They don't respect all the handicapped*  
9 *people. And this just makes your daily life miserable [sic].*

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19 Having previously encountered negative attitudes, some participants indicated that at  
20 some point they began to anticipate being devalued by others in social settings, and that the  
21 strategy most often employed to mitigate this risk was to hide their vision loss from others. One  
22 participant remarked, *"I have a friend...he has been blind his whole life...and he used to say he*  
23 *doesn't want to use a cane or dog because he doesn't want people to know that he has a*  
24 *disability."* Another participant describes an attempt to hide his impairment, saying,  
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35 *I try to ask strangers to do something for me and I am going to find one excuse... Oh I'm*  
36 *sorry I don't have my reading glasses, or something like this, please you do it for me...I*  
37 *don't want to tell them I can't see [sic].*

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44 One participant explained how feeling misunderstood or rejected by people with  
45 "normal" vision caused her to disconnect from relationships that had previously been very  
46 important to her. She stated,  
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3 *People who are well don't know what this is like. They don't want to hear it. They have*  
4 *their own problems. You understand, that's the truth. My own dear friends, I don't*  
5 *discuss anything with them about my eyes. That's why I don't want to see them anymore.*  
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12 Some participants indicated that among individuals with “normal” vision, even those who  
13 have positive intentions, their response can have a negative impact on the social participation of  
14 older adults with vision loss. One participant recalled,  
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21 *I was coming home late...and this person comes up behind, the man, I know he wanted to*  
22 *help me, poor guy. He came up behind me but he put his hand on my shoulder but so*  
23 *aggressively and at that time, I was actually studying judo. I grabbed the guy's arm and I*  
24 *flipped him and passed him over me and the guy is lying on the floor and I'm like, 'Don't*  
25 *ever do that again.'* He said, *'I just wanted to help.'*  
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35 **Individual internal attitude and responses:** The fourth theme represents the intersection of  
36 personal beliefs and attitudes about visual impairment and its impact. Some participants  
37 described an understanding that not everyone responds to the onset of visual impairment the  
38 same way. Responses are influenced by personal characteristics, such as personality, age, gender,  
39 etc., as well as by an internal or external locus of control. Some may perceive themselves as  
40 potential victims, or may choose to overcome that perception by consciously engaging in  
41 proactive coping mechanisms. One participant asserted, *“A lot of it has to be up to the*  
42 *individual,”* as well as, *“You know I have a little bit of chutzpah, you know, a little bit of*  
43 *nerve...You know what? It's helped me.”* Similarly, another participant described,  
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3 *I would say, to be honest, I think it depends on your state of mind. It depends if you*  
4 *are willing to say, 'ok this is my problem'. I was just going to say, as I said,*  
5 *eventually you have two choices; it's either you stand up and fight and say, 'if you*  
6 *can't help me, who can?' and find out what you can and cannot do, or you sit in your*  
7 *little corner and say, 'poor me'.*

14  
15 One participant explained that her outlook changed over time. When she first began  
16 experiencing vision loss, she felt discouraged and powerless, which, in turn, impacted her social  
17 participation. With time, she described acquiring more of a fighting spirit, stating that her current  
18 outlook is,  
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24 *I just turned 65, my life is not over it's just starting. All my friends are retiring and I*  
25 *am going back to school and get my Masters and I want to work with kids who are at*  
26 *risk. I have a lot still to do and if I lose my vision completely, I feel that I am*  
27 *prepared, I have the dog, and I have the JAWS program. I don't need my husband by*  
28 *my side any more. Because that's what I used for a long time and I was dragging him*  
29 *around. He's got his own work.*

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38 A central idea iterated among participants in terms of personal attitude was the  
39 importance of fighting to maintain independence rather than relying completely on others. One  
40 person said, "*What I found is like they have said, you have to keep your independence.*" Another  
41 agreed, stating,  
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47 *My pride went on the backburner, when I realized that I was dependent on someone. I*  
48 *wanted my independence back. I gave up driving a car, too. So when I started thinking*  
49 *about the car and how I felt and all the things that I had to give up, so I said, 'No, I don't*  
50 *have to give up, I have to learn how to do things.'*  
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3 However, participants also expressed that while personal attitudes shaped experience, this  
4 was not the only influencing factor. A fighting spirit, positive outlook, and determination to be  
5 independent cannot overcome all of the obstacles to social participation experienced by older  
6 adults with vision loss. One person stated, *“The only thing that I find very hard is when you are*  
7 *losing your eyesight, there are a lot of things that, no matter how much you want to be*  
8 *independent, you can’t.”*  
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## 19 DISCUSSION

20  
21 The purpose of this study was to describe and better understand the factors that shape the  
22 social participation of older adults with vision loss. Our findings suggest that respondents  
23 experience social participation through the personal lens of transition from an outsider (someone  
24 with “normal” vision) to an insider (someone with low vision). Our findings also document  
25 stereotyping, both from insiders (persons with low vision) and outsiders (people with “normal”  
26 vision). These (primarily) negative assumptions that others may make seemed to have an  
27 important influence on their social participation. Two social settings: family and friends (private  
28 setting) versus the public at large emerged as important to the individuals in our sample. The  
29 analyses revealed that the onset of vision loss initiates changes in the individual who has the  
30 impairment (as they become an insider), as well as how others (the outsiders) perceive this  
31 person. These analyses also highlight that there exist both internal as well as external factors that  
32 influence the nature of social participation for an individual with low vision, as characterized in  
33 the ICF with the personal and environmental factors.  
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### 51 **Personal Factor: Adapting to change with the onset of impairment**

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3 Individuals perceive themselves as insiders or outsiders based on characteristics they  
4 believe they have that aligns them with one or the other groups [21]. Their identity is in jeopardy  
5 when they are in limbo or transitioning, somewhere between perceiving themselves as a person  
6 with “normal” vision or a person with acquired vision loss. This threatens their identity as they  
7 are uncertain as to what this “new” version of themselves will be. When people who have vision  
8 loss find themselves in social settings with those who have “normal vision”, tension can arise.  
9 For the insider, a number of factors may contribute to this tension, including that the insider has  
10 not yet accepted the loss, and may not yet be comfortable using assistive technologies or  
11 orientation strategies to facilitate and reduce this tension and facilitate social participation [60–  
12 62].  
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26 Within the context of family and friends, the onset of impairment gave rise to the  
27 perceived stereotype of being helpless, as described by the participants, specifically in the  
28 context of maintaining and performing social roles. This supports what we know from the  
29 research literature [43,63], whereby previous reports have highlighted the stereotype maintained  
30 in folklore writings that people with visual impairment are helpless [42]. In the example of our  
31 participant who described her experience of feeling (and being perceived as) helpless in the  
32 context of kitchen work, this stereotype may be threatening her social role in one specific setting  
33 but may not exist in a different setting, depending on what the context may be. In some  
34 instances, people with low vision will construct environments (with the help of rehabilitation  
35 services) whereby they have optimal control over their level of functioning, thereby limiting the  
36 possible threat of task failure, improving their adaptation to change and diminishing the resulting  
37 stereotyping in social situations [64].  
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3 Within the public at large, stereotypes about people with low vision have also previously  
4 been described in the literature, such as people with low vision are disabled, all the same,  
5 contagious, old, and dependent [20,65,66]. There is a history of tension, discrimination,  
6 marginalization, and institutionalization that informs and guides interactions between people  
7 with visual impairment (insider) and those with “normal” vision (outsider) groups [21]. For the  
8 insiders, in line with research on disability [67], the individuals with low vision in our sample do  
9 not want to be thought of as different, or as dependent. This desire may make it difficult for an  
10 individual who is experiencing the onset/progression of vision loss to accept the situation [60].  
11 There is great variability of social responsiveness to being stereotyped. Insiders may respond  
12 differently to stereotyping depending on the length of time since diagnosis. It is “normal” with  
13 people with vision loss to wait for years before seeking help from low vision rehabilitation  
14 services [65]. Presumably during this time the individuals’ identity is changing. The extent to  
15 which the new identity of the person with vision loss has been integrated into the individual’s  
16 social identity will shape their responses to stereotyping [68,69].

### 35 **Environmental factors: Public Stigma & Physical Environment**

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37 The most apparent difference between private and public setting categories as they relate  
38 to our findings is the degree of *familiarity* outsider groups have with insiders who have low  
39 vision. Familiarity is a topic that has been previously explored as it relates to stereotype threat  
40 [70]. Stereotype threat is a real or perceived threat of being judged and treated badly in “settings  
41 where negative stereotypes about one’s group applies” [pg. 385, 70]. Outsider groups are  
42 presumed to have knowledge of the stereotypes about the health condition and its treatment, and  
43 may be familiar with the individual. This line of research suggests that familiarity impacts on  
44 likelihood of stereotyping another individual [71,72]. Many of the passages from the  
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3 participants describe outsiders as being unfamiliar with visual impairment and/or relying on  
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5 preconceived notions of vision loss. The perception was that many individuals with “normal”  
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7 vision simply do not understand that only a small percentage of people with vision loss are  
8  
9 totally blind and that the remainder have various levels of remaining visual function or functional  
10  
11 vision [73–75]. For most outsiders their understanding is that people are either blind or have  
12  
13 “normal” vision [75]. So any manifestation or use of rehabilitation strategies employed by people  
14  
15 with vision loss may lead outsiders to assign the label of blind, and contemplate all of the  
16  
17 associated stereotypes. This public stigma can hinder the help-seeking process of people with  
18  
19 low vision, as they may actively avoid these negative stereotypes by not identifying themselves  
20  
21 as an insider. This is commonly apparent when deciding to adopt a white cane for mobility [76],  
22  
23 which identifies a person has having an impairment in vision. Within our sample, one person  
24  
25 experiencing changes in their vision actually identified with a friend who did not use a cane or a  
26  
27 guide dog to avoid being singled out as disabled. While the cane or guide dog can improve  
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29 function and participation, its use may be circumvented to avoid the larger problem of stigma.  
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35 With respect to the present findings, two points about insiders are particularly  
36  
37 noteworthy. First, individuals with *acquired* disability have been shown to differ in their  
38  
39 perception of and approach towards their disability and their disability identity [77]; however,  
40  
41 this topic has not been extensively in the context of visual impairment [78]. Research by Bogart  
42  
43 [77], suggests that people with a congenital mobility disabilities report having a higher  
44  
45 satisfaction with life, a better disability identity and disability self-efficacy than people with  
46  
47 acquired mobility disabilities. The authors suggest that those with congenital disabilities have  
48  
49 adapted to and take pride in their disability identity. In contrast, those with acquired disabilities  
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51 may be influenced by rehabilitation professionals attempt to “normalize” people and have more  
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3 difficulty adapting to their new identity [77]. Our participants with acquired vision loss,  
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5 however, are likely differentially impacted by stereotyping, compared to those living with  
6  
7 congenital impairment, specifically as their experience of loss differs. These individuals initially  
8  
9 had ‘normal’ vision, and have thus been part of the outsiders’ group. They themselves may have  
10  
11 stereotyped others for vision impairment in the past. Second, according to the modified labeling  
12  
13 theory [79], when stereotyping does occur (in both public and private settings), this confirms  
14  
15 insider expectations and may lead insiders to expect future stereotyping. This can lead to a self-  
16  
17 fulfilling prophecy whereby insiders subconsciously expect persistent stereotyping in both public  
18  
19 and private settings, and make decisions that result in negative outcomes such as social isolation,  
20  
21 reduced social engagement and self-stigmatization. The quotes exemplify that some do ask  
22  
23 “strangers” for help but without revealing their impairment or not talking to their friends  
24  
25 anymore because “People who are well don’t know what this is like. They don’t want to hear it.”  
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30  
31 For insiders, perhaps past experiences of stereotyping with people who have “normal”  
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33 vision have left an emotional scar, which makes it difficult to interact normally. Outsiders may  
34  
35 not be sure how to approach a person with vision loss, may not know how to help or even to  
36  
37 offer help. This is clear in the example where an outsider grabs the shoulder of a participant with  
38  
39 low vision (insider), resulting in a negative experience for both. The outsider may also  
40  
41 experience shame for considering stereotypes. Participants’ accounts of stereotyping in private  
42  
43 settings are consistent with familiarity and the modified labelling theory. There was a virtual  
44  
45 consensus that people with “normal” vision, even those who have a close connection with an  
46  
47 insider, do not understand the realities of visual impairments, their treatment, and do not know  
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49 how to assist a person with vision loss. While it is reasonable to assume that most people have  
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51 good intentions, this lack of knowledge about low vision can contribute to stereotyping.  
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Characteristics of the environment in which the social interaction takes place may also come into play. This is not surprising, since those who design the built environment (typically outsiders with power) assume ‘normalcy’ and ignore the potential of universal design that would make the physical environment accessible to all people [80]. Several quotes in our findings illustrate that physical environments are often structured in inaccessible ways for people with vision loss, and that this structure, contributed to reduced mobility, independence, and sense of security for these individuals. In addition, contextual factors such as: the number of people present, the purpose of the event, as well as the presence of other people who have vision loss or knowledge of vision loss all factor into potential stereotyping. Moreover, all of these factors may give rise to the level of stress for both the insiders and outsiders. For example one participant discussed transportation as stressful and described their reliance on the bus driver or others for help. According to the stigma induced identity threat model [81], the balance between demands of the situation and personal resources will determine the level of identity threat and will in many ways govern responses by both insiders and outsiders.

### 35 **Reducing the barriers to social participation of older adults with low vision**

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It remains unclear how older adults with vision loss should approach social interactions knowing and expecting that assumptions will be made about them, and that some of these assumptions will be erroneous and potentially marginalizing. It is our contention that older adults with vision loss may be best served by repeatedly disclosing to others relevant information about their low vision and how communication partners can aid them in their social participation thereby advocating for themselves. In the stigma reduction literature [63], there is a general consensus that stigma reduction campaigns should incorporate four types of activities: educational and awareness campaigns, face-to-face interactions or personal contact, persuasion

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3 (changing people's beliefs about low vision) and disability simulations (have outsiders, in  
4 particular familiar outsiders, experience what it is like to have low vision). Wainapel [76]  
5  
6 proposed that peers may be best situated to counsel a newly diagnosed person. However, the  
7  
8 findings from the present study, and from previous work on familiarity and stereotyping, suggest  
9  
10 that relying only on one-to-one interactions to reduce the stigma associated with low vision  
11  
12 might not be advisable. It is possible that stigma reduction may only result from more intimate,  
13  
14 or at least developed, connections with people who have stigmatizing traits. If this is the case,  
15  
16 stigma reduction programs might test building upon existing relations with people who have  
17  
18 stigmatizing traits. With respect to outsiders who are unfamiliar with visual impairment,  
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20 increased education, persuasion from the insider about their capabilities and experiential trials  
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22 that simulate low vision can help reduce these environmental barriers to social participation for  
23  
24 older adults with low vision.  
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### 30 **Clinical Implications: Importance to rehabilitation of clients with low vision**

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33 In some cases, stereotyping extends into clinical/healthcare settings [82]. Familiarity with  
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35 visual impairments and the manifestations of low vision, combined with a charged daily  
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37 appointment list may lead some clinicians to make assumptions about the challenges and abilities  
38  
39 of their clients. Stereotyping by clinicians will reduce opportunities for client-centered care for  
40  
41 people with low vision. It is therefore vital to increase the awareness of stereotyping and its  
42  
43 pitfalls by clinicians who work with individuals who have low vision. All clinicians should  
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45 assess their own attitudes toward this population. Recent work [83] with health care providers  
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47 suggests that some professionals may not adopt stereotypical views of their clients. This work, in  
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49 dual sensory impairment (DSI: combined hearing and vision losses), suggests that strong  
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51 familiarity with a marginalized group (in this case older adults with DSI) can actually be an  
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3 asset. Many of the professionals that were interviewed were strong advocates for their clients and  
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5 generally did not seem to have a stereotypical approach to their clientele. However, several  
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7 mentioned the daily public stigma their clients faced and that interactions with professionals not  
8  
9 specifically trained in DSI often resulted in stereotypical responses [83].  
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12 Even the most perfectly rehabilitated client at a functional level may remain fearful of  
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14 being identified, faced with barriers created by the sighted community and socially excluded.  
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16 Rehabilitation specialists should consider the different spheres in which the individual needs to  
17  
18 function, and the professionals need to frame their interventions accordingly, with a client-  
19  
20 centered approach that supports a respectful partnership between client and health care  
21  
22 professionals [84]. Professionals that work with clients with low vision should, based on the  
23  
24 clients' needs, encourage attempting different devices and strategies to reduce and/or minimize  
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26 the barriers faced, and help older adults with low vision to be active participants in their physical  
27  
28 and social environment [85].  
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### 32 33 **Limitations**

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35 One potential limitation of secondary analyses of qualitative data sets concerns  
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37 theoretical saturation [48]. Content analysis involves identification of incidents, events activities  
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39 which are grouped to form categories. The category is 'saturated' when new information which  
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41 adds to the understanding of the category is not forthcoming. If the data set is being used  
42  
43 'inappropriately', there will be limited data, resulting in a premature saturation of the category.  
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45 This was not a concern for this data set. The participants in this study were proud to discuss their  
46  
47 experiences of low vision and social participation. There was thus ample information to analyze.  
48  
49 However, the initial focus of data collection was not to probe into the topic of stigmatization;  
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51 therefore, it is possible that some aspects of low vision and stigmatization, beyond the topics that  
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3 were spontaneously self-identified by our participants, are not covered in our data, but might  
4 emerge in future studies designed to address this topic in more depth. Future studies should  
5 target this area of inquiry directly and ideally have several focus group sessions to increase the  
6 amount of data acquired.  
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## 15 CONCLUSION

16  
17 Older adults with low vision experience a number of changes when they begin to  
18 demonstrate functional impairments in their vision. From the perspective of the participants in  
19 our study (the insiders) their personal perceptions transitioning to an insider, as well as, their  
20 interactions with people with “normal” vision (outsiders) influence their social participation. The  
21 stereotypes and stigma that surround low vision was clearly a topic that negatively influenced  
22 our participants’ social participation as this was a topic that they repeatedly discussed in our  
23 focus groups and as a result became a secondary analysis from this data set. Stigma in the  
24 environment perceived or experienced is a critical factor to address for older adults with low  
25 vision as it has the potential to reduce social participation, in some cases diminish help-seeking  
26 and ultimately impact health. Strategies to improve awareness and educate the general public and  
27 health care providers on low vision could reduce the stigma associated with this condition and  
28 ultimately improve the health of older individuals with low vision.  
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47 **Author Statement:** Drs. Kenneth Southall & Walter Wittich planned this project. Dr. Southall  
48 led the focus groups and Dr. Southall and Wittich analyzed the data and created the code list  
49 together. Irene Beeman was a graduate student learning qualitative research and she worked  
50 directly with Dr. Southall to create a rough draft of this paper. Dr. Fraser was involved in the  
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3 write-up of this project and worked with Dr. Southall and Wittich to revise, edit and produce the  
4  
5 final version of this manuscript.  
6

7  
8 **Data Statement:** Data available on request only, with appropriate ethics approval  
9

10 **Conflicts of Interest:** There are no conflicts of interest to report in this study.  
11

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13  
14 *du Québec*. Funders were not involved in data collection, interpretation or reporting.  
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Table 1

*Participant Characteristics*

<u>Participants</u>	<u>Diagnosis</u>	<u>Gender</u>	<u>Awareness</u>	<u>Accessed</u>
1	RP	Female	Yes	Yes
2	DR/GL	Male	Yes	Yes
3	Stroke	Female	Yes	Yes
4	RD/DR/GL	Female	Yes	Yes
5	DR/GL	Female	Yes	Yes
6	AMD	Male	Yes	No
7	AMD	Female	Yes	Yes
8	GL	Female	No	No
9	AMD	Male	No	No
10	Ocular Trauma	Male	Yes	Yes
11	Corneal Transplant/Keratitis	Female	Yes	Yes
12	AMD	Female	Yes	Yes
13	AMD/GL	Female	Yes	Yes
14	AMD/RD	Female	Yes	Yes
15	AMD/GL	Female	Yes	Yes
16	GL	Male	Yes	Yes
17	AMD	Female	Yes	Yes
18	AMD	Female	Yes	Yes
19	DR	Male	Yes	Yes
20	AMD	Male	Yes	Yes
21	AMD	Female	Yes	Yes

*Note:* Awareness = aware of rehabilitation services for vision loss (Yes or No); Accessed = Accessed low vision services (Yes or No). RD = Retinal Detachment; RP = Retinitis Pigmentosa; DR = Diabetic Retinopathy; GL = Glaucoma; AMD = Age-related macular degeneration;

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**Title of study:** Stereotyping as a barrier to the social participation of older adults with low vision:  
A qualitative focus group study

### Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? <ul style="list-style-type: none"> <li>• Dr. Kenneth Southall</li> </ul>
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i> <ul style="list-style-type: none"> <li>• PhD</li> </ul>
3.	Occupation	What was their occupation at the time of the study? <ul style="list-style-type: none"> <li>• Qualitative Researcher at McGill University in the School of Social Work</li> </ul>
4.	Gender	Was the researcher male or female? <ul style="list-style-type: none"> <li>• Male</li> </ul>
5.	Experience and training	What experience or training did the researcher have? <ul style="list-style-type: none"> <li>• The researcher completed a qualitative research PhD and was at the time a New Investigator with a New Investigator Career award (from the Quebec provincial government,</li> </ul>

No	Item	Guide questions/description
		in Canada) for his proposed qualitative research studies
	Relationship with participants	
6.	Relationship established	<p>Was a relationship established prior to study commencement?</p> <ul style="list-style-type: none"> <li>No</li> </ul>
7.	Participant knowledge of the interviewer	<p>What did the participants know about the researcher? e.g. <i>personal goals, reasons for doing the research</i></p> <ul style="list-style-type: none"> <li>Researchers background and aims of the study were discussed at the beginning of focus group session</li> </ul>
8.	Interviewer characteristics	<p>What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i></p> <ul style="list-style-type: none"> <li>Reasons and interests in the research topic were discussed. The researcher had a strong background in qualitative health research on people with hearing impairments and wanted to extend this to better understand people with vision impairments</li> </ul>
	<b>Domain 2: study design</b>	
	Theoretical framework	
9.	Methodological orientation and Theory	<p>What methodological orientation was stated to underpin the study? e.g. <i>grounded theory,</i></p>

No	Item	Guide questions/description
		<p><i>discourse analysis, ethnography, phenomenology, content analysis</i></p> <ul style="list-style-type: none"> <li>• Content analysis was chosen</li> </ul>
Participant selection		
10.	Sampling	<p>How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i></p> <ul style="list-style-type: none"> <li>• It was purposive sampling as people with low vision who participated in the Montreal Barriers Study were solicited to gain their perspectives on barriers to social participation</li> </ul>
11.	Method of approach	<p>How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i></p> <ul style="list-style-type: none"> <li>• Face-to-face</li> </ul>
12.	Sample size	<p>How many participants were in the study?</p> <ul style="list-style-type: none"> <li>• 21 participants</li> </ul>
13.	Non-participation	<p>How many people refused to participate or dropped out? Reasons?</p> <ul style="list-style-type: none"> <li>• None of the participants approached refused or dropped out of the study</li> </ul>
Setting		
14.	Setting of data collection	<p>Where was the data collected? <i>e.g. home, clinic, workplace</i></p> <ul style="list-style-type: none"> <li>• In a clinical setting (at the Jewish General Hospital), in a private room</li> </ul>
15.	Presence of non-participants	<p>Was anyone else present besides the participants and researchers?</p> <ul style="list-style-type: none"> <li>• No</li> </ul>

No	Item	Guide questions/description
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i> <ul style="list-style-type: none"> <li data-bbox="883 386 1253 415">• We included age and sex</li> </ul>
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? <ul style="list-style-type: none"> <li data-bbox="883 638 1403 785">• The leader of the focus group had a guide for the focus group discussions and this guide was modified based on issues that the participants raised</li> </ul>
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many? <ul style="list-style-type: none"> <li data-bbox="883 924 971 953">• No</li> </ul>
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data? <ul style="list-style-type: none"> <li data-bbox="883 1092 1143 1121">• Audio recording</li> </ul>
20.	Field notes	Were field notes made during and/or after the interview or focus group? <ul style="list-style-type: none"> <li data-bbox="883 1251 1403 1407">• Yes. These were conducted by a second researcher who was also in the room but did not guide the focus group discussion.</li> </ul>
21.	Duration	What was the duration of the interviews or focus group? <ul style="list-style-type: none"> <li data-bbox="883 1545 1110 1575">• 60-90 minutes</li> </ul>
22.	Data saturation	Was data saturation discussed? <ul style="list-style-type: none"> <li data-bbox="883 1671 980 1701">• Yes</li> </ul>
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction? <ul style="list-style-type: none"> <li data-bbox="883 1839 971 1869">• No</li> </ul>

No	Item	Guide questions/description
<b>Domain 3: analysis and findingsz</b>		
Data analysis		
24.	Number of data coders	How many data coders coded the data? <ul style="list-style-type: none"> <li>• Two</li> </ul>
25.	Description of the coding tree	Did authors provide a description of the coding tree? <ul style="list-style-type: none"> <li>• Not in the manuscript.</li> </ul>
26.	Derivation of themes	Were themes identified in advance or derived from the data? <ul style="list-style-type: none"> <li>• Derived from the data</li> </ul>
27.	Software	What software, if applicable, was used to manage the data? <ul style="list-style-type: none"> <li>• Atlas.ti</li> </ul>
28.	Participant checking	Did participants provide feedback on the findings? <ul style="list-style-type: none"> <li>• No</li> </ul>
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i> <ul style="list-style-type: none"> <li>• Yes participant quotations were presented but they were not identified</li> </ul>
30.	Data and findings consistent	Was there consistency between the data presented and the findings? <ul style="list-style-type: none"> <li>• Yes</li> </ul>

No	Item	Guide questions/description
31.	Clarity of major themes	Were major themes clearly presented in the findings? <ul style="list-style-type: none"><li data-bbox="883 386 971 415">• Yes</li></ul>
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? <ul style="list-style-type: none"><li data-bbox="883 554 1354 583">• No, only major themes presented</li></ul>