

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Stereotyping as a barrier to the social participation of older adults with low vision: A qualitative focus group study
AUTHORS	Fraser, Sarah; Beeman, Irene; Southall, Kenneth; Wittich, Walter

VERSION 1 – REVIEW

REVIEWER	Jennifer Kaldenberg Boston University, Boston, MA USA
REVIEW RETURNED	11-Mar-2019

GENERAL COMMENTS	<p>Concern: manuscript needs more focus on social participation. It goes back and forth or clearly define what you are referring to as social participation. This should not be the same as function. Also, please make sure to use person first language throughout manuscript</p> <p>How do you differentiate between those who have experienced LVRS and those who have not in your qualitative analysis? Does that affect your results? Are there differences between race/ethnicity/age/gender?</p> <p>Page 4: Lines 22-30: Needs transition Page 5: Line 17: Might be important to identify who are the key members of the multidisciplinary team Page 5: Line 35: Is this true in the VI literature? May need to be specific in terms of which cultures, not sure this is universal as presented. Page 6: Line 12: Is there evidence to support your statement? Page 8: Line 47-: Not clear Page 9: Line 44/45: functioning- please be clear in your terminology throughout function and social participation do not mean the same thing Page 11: Line 21-29: What about experiences with loss/ past losses Page 20: Line 26: Who defined these terms? Page 21: Line 17-26: impact on LVRS? Page 21: Line 52: visual function or functional vision? Last sentence needs a reference Page 22: Line 3: vision loss may lead... Page 22: Line 26/27: How is this identified in the data presented?</p>
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REVIEWER	Heather Waterman Cardiff University Newport Road Cardiff UK
REVIEW RETURNED	27-Mar-2019

GENERAL COMMENTS	<p>Thank-you for inviting me to review this article on stigma and social participation from the perspective of older adults with visual impairment. The article, which is written very well, brings to the audience's attention the difficulties which this group of people experience with social participation but as the article acknowledges this was an unexpected finding from their research. The data to support their case is teased out as a secondary analysis from their research on barriers to low vision rehabilitation. And unsurprisingly, as a consequence, the article has a tendency to scratch the surface of the issues and the theoretical discussion is speculative. It's a shame that the work is not based on more thorough qualitative research as it could be extremely enlightening but, as it is, the reader is left wanting more.</p> <p>Amendments required;</p> <ol style="list-style-type: none"> 1. The discussion on stigma and visual impairment could be expanded by including material from Royal National Institute for the Blind, London, UK which had quite a collection of past research on stigma and blindness. https://www.rnib.org.uk/professionals/knowledge-and-research-hub 2. It appears the data is collected from a maximum of 9 hours data collection (1.5 hrs x 6 focus groups), this raises questions about the adequacy of the sample size and needs to be discussed in the context of the limitations of secondary analysis in the Limitations Section. 3. Hence the writing should be made more tentative throughout, ie 'it appears' rather than 'it is'. 4. More information is needed on who were the sample (how many men and women, what were their age ranges, level of education, retired, lived alone etc) so the reader can understand from whom the claims about the research are being made. 5. There needs to be a section added which discusses how the authors mediated the focus groups given the participants' visual impairment. IE How did they support people to communicate given that they would not have been able to see visual cues? Did you have anybody decline participation in the focus group given the issues with social participation?
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REVIEWER	Colleen McGrath Western University, London, Ontario, Canada
REVIEW RETURNED	24-May-2019

GENERAL COMMENTS	<p>Title</p> <ul style="list-style-type: none"> - I would change the title to: "The effects of stereotyping on the social participation of older adults with low vision: A focus group study" <p>Abstract</p> <ul style="list-style-type: none"> - Reword objective so that it does not state "to better understand" twice - How many focus groups were conducted? <p>Strengths & Limitations</p> <ul style="list-style-type: none"> - Unclear why your first point is a strength? Why is a focus group study so necessary? Also, you make reference to exploring the perspectives of older people with low vision
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	<p>broadly but not the specific focus of your study. Suggest re-wording</p> <p>Introduction</p> <ul style="list-style-type: none"> - You introduce the ICF in the introduction but don't explain its link to your study and it does not come back up really in the rest of the paper - Define what you mean by participation early in the introduction - Be sure to define ARVL the first time you use it as well as what conditions you are referring to when using that term - It is unclear how participatory action research is being defined here? Is the suggestion that any qualitative work in which older adults are consulted is considered PAR? - Great section of the origins of low vision stigmatization <p>Method</p> <ul style="list-style-type: none"> - What was the underlying methodology that guided this work? (narrative, phenomenology, ethnography, grounded theory, etc.) or was it more generic qualitative work? - Did you exclude data from the one participant that was under 65? If so, clearly state this. - You mentioned that 6 focus groups were conducted but was that 6 separate focus groups or did any group meet on more than one occasion? - In discussing your analysis process, I wonder if the discussions between the two coders was about discussing discrepancies and trying to come to a shared decision or perhaps more about having conversations about different ways of "seeing" the data? <p>Results</p> <ul style="list-style-type: none"> - I would introduce your research question much earlier in the paper - Though the findings in the first theme make sense, I am not clear how they are linked to the topic of your paper which is about stereotyping? - In talking about the physical barriers, why is it that the environment has been structured in such a way as to "disable" those with vision loss? Could it be that social attitudes discriminate against those perceived as 'abnormal'? - For the final theme, again I would make sure the link to stereotypes is very clear. <p>Discussion</p> <ul style="list-style-type: none"> - Define stereotype threat for the reader. Is it that the more familiar someone is the more likely they are to stereotype or vice versa? - You discuss how those with an acquired disability have been shown to have a different approach towards their disabled identity. Can you expand on their perceptions
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	<p>and how those differ from those that have had a lifelong disability?</p> <ul style="list-style-type: none"> - In the discussion, you refer to the participants as no longer talking to their friends because “they do not want to hear it.” Who are you referring to here and what don't they want to hear? - When you are talking about the influence of the environment, I think it's also important to acknowledge that the way in which the physical environment is built is premised on the assumption of 'normalcy.' Those who have the power and influence to shape how the physical environment is built do so with a stereotypical assumption that all persons function within a state of 'normalcy' - Your point about the physicians working with individuals who have dual sensory loss is interesting. I wonder, however, if that also extends to family physicians, for example, who are not working with a specialized clientele. Are experiences of being stereotyped more common among general healthcare practitioners, for example? - You would benefit from defining client centred practice as not all persons may be familiar with the term - Please include future research possibilities within the discussion. Based on your findings, what is the next research step you or other researchers should take? <p>Conclusion</p> <ul style="list-style-type: none"> - No comments. <p>Overall</p> <ul style="list-style-type: none"> - Watch your sentence structure. I would recommend a thorough read through of the paper to address any run-on or incomplete sentences - Make sure to be consistent in referring to the participants in your study as older people. At many times throughout the paper you refer to “people” and so it is unclear if the focus is on older adults exclusively
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VERSION 1 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 1

Reviewer Name: Jennifer Kaldenberg

Institution and Country: Boston University, Boston, MA USA

Please state any competing interests or state 'None declared': None declared

1) Concern: manuscript needs more focus on social participation. It goes back and forth or clearly define what you are referring to as social participation. This should not be the same as function.

Response: We thank the reviewer for this comment and have provided more context on the WHO ICF model in the first paragraph of the Introduction pg. 5: “Participation has been defined as “involvement in a life situation” (pg. 8, 10) and encompasses social participation elements such as: interpersonal interactions and relationships as well as involvement in community, social and civic life

[2].” Importantly, the WHO model considers participation as the “functioning as a member of society” and considers “**Functioning** is an umbrella term for body function, body structures, activities and participation” as such with this model participation is a part of functioning.

2) Also, please make sure to use person first language throughout manuscript

Response: Throughout the manuscript we have used people with low vision or older people with low vision to respect first person language. We did however in some cases use “sighted people” which does not respect first person language. We have changed this throughout the manuscript to people with normal vision which is the accepted terminology in the low vision literature.

3) How do you differentiate between those who have experienced LVRS and those who have not in your qualitative analysis? Does that affect your results? Are there differences between race/ethnicity/age/gender?

Response: We thank the reviewer for this comment. We have added Table 1 (pg. 31) to provide some additional details on our sample including diagnosis, gender, awareness of services, and accessed services or not. You will see in the Table that only two people were unaware of the available low vision services and only 3 had not accessed the services. Therefore, the majority of our sample (18 people) had experienced low vision services. We are unable to distinguish from this sample if accessing or not accessing the services influenced the responses given by participants. Similarly, we cannot distinguish how the responses were influenced by the different characteristics of the participants but there was a mix of men and women in each of the focus groups except our smallest group, which contained only two older women.

4) Page 4: Lines 22-30: Needs transition

Response: We hope that the additional text that was added to the Introduction (now pg. 5): “Participation has been defined as “involvement in a life situation” (pg. 8, 10) and encompasses social participation elements such as: interpersonal interactions and relationships as well as involvement in community, social and civic life [2].” improves the transition in this paragraph.

5) Page 5: Line 17: Might be important to identify who are the key members of the multidisciplinary team

Response: This will depend immensely on the rehabilitation center. For the articles cited with this statement, multidisciplinary teams included: optometrists, occupational therapy, orientation and mobility, orthoptics, and welfare specialists. We have added this to the manuscript (pg. 6, end of first paragraph): “...and a multi-disciplinary rehabilitation approach (*including ophthalmology, optometry, occupational therapy, low vision therapy, orientation and mobility, orthoptics, and welfare and mental health specialists*) has been shown to improve quality of life as well as social participation [17,18].

6) Page 5: Line 35: Is this true in the VI literature? May need to be specific in terms of which cultures, not sure this is universal as presented.

Response: This statement concerns “disability” in general but it is also found in terms of the visual impairment literature. Please see the recent work by Livneh, Chan & Kaya (2014): Stigma related to physical and sensory disabilities, reference 63 in this manuscript. It is quite common across cultures that value productivity and success, the beautiful body, and fear the potential economic burden associated with disease or disability, etc. (Livneh 1982: *On the Origins of Negative Attitudes toward People with Disabilities. Rehabilitation Literature, 43, 338-347.*). In addition, qualitative work in Africa has found extreme responses to blindness in rural tribes – one tribe deciding with the elders that it is best to drown the baby born with blindness as they will be a burden on the tribe (not a productive member) and will bring bad luck [see Munsaka & Charnley (2013). We do not have chiefs who are disabled: disability, development and culture in a continuing complex emergency. *Disability and Society, 28:6, 756-769* (doi: 10.1080/09687599.2013.802221)].

6) Page 6: Line 12: Is there evidence to support your statement?

Response: The line the reviewer is referring to (now on pg. 7) is: “As with many other chronic impairments, the general public does not easily make the distinction between absolute and partial loss of function [38-40].” We have added two references to support this statement. An example of the evidence from the first reference (Sharts-Hopko et al. (2010): Several participants commented on the tendency for people to equate blindness with “being deaf or mentally incompetent.” One woman reported that a psychiatrist said, “No wonder you are bipolar—you’re also blind.” It is a common frustration that people fail to recognize the participants’ needs because they look “normal.” One

woman noted that now, with life skills training, blind people carry themselves well—they “don’t look blind.” Participants noted that it is not other people’s fault that they do not recognize their needs; rather, “you have to tell people... make them aware.” Further, the second reference Orzolek-Kronner et al. (2011) discusses how we use the terms blind and low vision interchangeably when we should not.

Sharts-Hopko, N. C., Smeltzer, S., Ott, B. B., Zimmerman, V., & Duffin, J. (2010). *Healthcare experiences of women with visual impairment. Clinical Nurse Specialist CNS, 24(3), 149–153.* <https://doi.org/10.1097/NUR.0b013e3181d82b89>

Orzolek-Kronner, C., & Desimone, J. (2011). *Seeing through the eyes of the blind: Psychodynamically informed work with persons with low vision. In J. Berzof (Ed.), Falling Through the Cracks: Psychodynamic Practice with Vulnerable and Oppressed Populations. New York, NY: Columbia University Press.*

7) Page 8: Line 47-: Not clear

Response: We have tried to clarify this line with additional information and referring the reader to the new Table that we have added (text is on pg. 10, Participant section): “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.

8) Page 9: Line 44/45: functioning- please be clear in your terminology throughout function and social participation do not mean the same thing

Response: We thank the reviewer for this comment and have more clearly defined social participation in the Introduction (see Response to comment 1 above). We have also gone through the entire manuscript and referred only to social participation (as described in the Introduction) and cut reference to experiences and functioning as these are encompassed in the WHO model definition of Participation. We hope this facilitates the flow of ideas for the reader.

9) Page 11: Line 21-29: What about experiences with loss/ past losses

Response: The focus was on the changes in vision and we did not solicit participants directly about other losses. This is an excellent point and could have provided other details on how participants managed other losses and how this may have helped or hindered them in the management of their current changes in vision. We will keep this in mind for future work.

10) Page 20: Line 26: Who defined these terms?

Response: We thank the reviewer for pointing this discrepancy out. In fact we had intended to edit this section and only discuss helplessness which was a stereotype which our participants spoke about. As such we have edited this sentence so that it now reads (pg. 22, paragraph 3): “Within the context of family and friends, the onset of impairment gave rise to the perceived stereotype of being helpless, as described by the participants, specifically in the context of maintaining and performing social roles.”

11) Page 21: Line 17-26: impact on LVRS?

Response: If the reviewer is questioning if this section is about helpseeking in the context of low vision rehabilitation services, it is. And we have added text to clarify this Pg. 23, end of second paragraph: “It is normal with people with vision loss to wait for years before seeking help from low vision rehabilitation services”

12) Page 21: Line 52: visual function or functional vision? Last sentence needs a reference Pg. 24, first paragraph: “The perception was that many individuals with normal vision simply do not understand that only a small percentage of people with vision loss are totally blind and that the remainder have various levels of remaining visual function or functional vision [73–75]. For most outsiders their understanding is that people are either blind or have normal vision [75].”

Added reference [75]: Colenbrander, A. (2003). Aspects of vision loss - Visual functions and functional vision. *Visual Impairment Research, 5(3), 115–136.*

13) Page 22: Line 3: vision loss may lead...

Response: We thank the reviewer for the suggestion and have changed the text accordingly (on page 24)

14) Page 22: Line 26/27: How is this identified in the data presented?

Response: We believe the reviewer is referring to pg. 24: "With respect to the present findings, two points about insiders are particularly noteworthy. First, individuals with acquired disability have been shown to differ in their perception of and approach towards their disability and their disability identity [77].." We are excited to be presenting data and contributing to the literature on insiders perspectives specifically for those with acquired vision loss – as we state in the remainder of the sentence (from above): "however, this topic has not been extensively in the context of visual impairment [78]." We do not claim to contrast people with acquired versus congenital vision loss – but rather just contribute to the literature on older adults with acquired vision loss by providing their insider perspectives. We have however added some discussion of the research we have cited to clarify this point: "Research by Bogart [77], suggests that people with a congenital mobility disabilities report having a higher satisfaction with life, a better disability identity and disability self-efficacy than people with acquired mobility disabilities. The authors suggest that those with congenital disabilities have adapted to and take pride in their disability identity. In contrast, those with acquired disabilities may be influenced by rehabilitation professionals attempt to "normalize" people and have more difficulty adapting to their new identity [77]."

Reviewer: 2

Reviewer Name: Heather Waterman

Institution and Country: Cardiff University - UK

Please state any competing interests or state 'None declared': None declared

1) Thank-you for inviting me to review this article on stigma and social participation from the perspective of older adults with visual impairment. The article, which is written very well, brings to the audience's attention the difficulties which this group of people experience with social participation but as the article acknowledges this was an unexpected finding from their research. The data to support their case is teased out as a secondary analysis from their research on barriers to low vision rehabilitation. And unsurprisingly, as a consequence, the article has a tendency to scratch the surface of the issues and the theoretical discussion is speculative. It's a shame that the work is not based on more thorough qualitative research as it could be extremely enlightening but, as it is, the reader is left wanting more.

Response: We thank the reviewer for their positive comments on our work and hope that we can provide "more" in the future with some of the suggestions of the reviewers in mind.

2) The discussion on stigma and visual impairment could be expanded by including material from Royal National Institute for the Blind, London, UK which had quite a collection of past research on stigma and blindness. <https://www.rnib.org.uk/professionals/knowledge-and-research-hub>

Response: We thank the reviewer for pointing-out this excellent resource and have added the link to the knowledge and research hub to the manuscript on page 8 (end of 1st paragraph): "In some ways, the stereotypes about people who are blind have impacted the perception of all people who have vision loss, in part rooted in preconceived ideas and a lack of awareness about persons with low vision, resulting in the exclusion of both groups (*for several relevant research articles on stigma and low vision, please see the following resource from the Royal National Institute for the blind: <https://www.rnib.org.uk/professionals/knowledge-and-research-hub>*). "

3) It appears the data is collected from a maximum of 9 hours data collection (1.5 hrs x 6 focus groups), this raises questions about the adequacy of the sample size and needs to be discussed in the context of the limitations of secondary analysis in the Limitations Section.

Response: We thought we had addressed this concern in the last sentence of the limitations (pg.29): "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." Perhaps this statement is too vague in relation to the amount of time spent with our focus groups so we have added an additional sentence

to address this reviewers' concern: "Future studies should target this area of inquiry directly and ideally have several focus group sessions to increase the amount of data acquired."

4) Hence the writing should be made more tentative throughout, i.e. 'it appears' rather than 'it is'.

Response: We had attempted to use tentative language throughout the discussion, however we did notice some instances that could be adjusted and have done so based on this reviewers' comment. Please see page. 21 "seemed to"; page 24. "the perception was that..." and "may lead to" and page. 26 "can contribute to".

5) More information is needed on who were the sample (how many men and women, what were their age ranges, level of education, retired, lived alone etc.) so the reader can understand from whom the claims about the research are being made.

Response: We thank the reviewer for this comment. Although we do not have all the details requested by this reviewer, we do have several sample characteristics to report that we have included in this revised version. Please see Table 1 (pg.31) which provides some additional details on our sample including diagnosis, gender, awareness of services, and accessed services or not.

6) There needs to be a section added which discusses how the authors mediated the focus groups given the participants' visual impairment. IE How did they support people to communicate given that they would not have been able to see visual cues? Did you have anybody decline participation in the focus group given the issues with social participation?

Response: This is a great question and we have provided additional information to address this in the text on end of pg. 10 top of page 11 in the Data Collection section: "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 that only one person spoke at a time. All participants introduced themselves to facilitate auditory localization of each individual and to let participants become more familiar with everyone's tone of voice. The participant or the leader of the group would state the name of the person speaking and anyone who wished to comment could raise their hand and the leader would facilitate their turn in speaking." We did not have anybody decline due to difficulties with social participation.

Reviewer: 3

Reviewer Name: Colleen McGrath

Institution and Country: Western University, London, Ontario, Canada

Please state any competing interests or state 'None declared': None

Please see attached. It was a pleasure reading your paper! **Response:** Thank-you!

Title

1) I would change the title to: "The effects of stereotyping on the social participation of older adults with low vision: A focus group study"

Response: We have altered the title, it now reads: Stereotyping as a barrier to the social participation of older adults with low vision: A qualitative focus group study

Abstract

2) Reword objective so that it does not state "to better understand" twice

- How many focus groups were conducted?

Response: Thank you for this comment, we have removed one of the "to better understand" statements and replaced with "clarify" and we have added that six qualitative focus groups were conducted.

3) Strengths & Limitations

- Unclear why your first point is a strength? Why is a focus group study so necessary? Also, you make reference to exploring the perspectives of older people with low vision broadly but not the specific focus of your study. Suggest re-wording

Response: This section has been rewritten.

4) Introduction

- You introduce the ICF in the introduction but don't explain its link to your study and it does not come back up really in the rest of the paper
- Define what you mean by participation early in the introduction

Response: We thank the reviewer and reviewer 1 for this comment and have provided more context on the WHO ICF model in the first paragraph of the Introduction pg. 5: "Participation has been defined as "involvement in a life situation" (pg. 8, 10) and encompasses social participation elements such as: interpersonal interactions and relationships as well as involvement in community, social and civic life [2]."

- 5) Be sure to define ARVL the first time you use it as well as what conditions you are referring to when using that term

Response: This is a good point and we have added details regarding ARVL on the top of pg. 6 when the term is first introduced: "In addition, for individuals with age-related vision loss (*i.e.*, *age-related macular degeneration, glaucoma, diabetic retinopathy, stroke-related vision loss*) their impairment may affect communication strategies, such as face recognition and the ability to distinguish facial expressions, critical for social interaction."

- 6) It is unclear how participatory action research is being defined here? Is the suggestion that any qualitative work in which older adults are consulted is considered PAR?

Response: Participatory action research is discussed at the top of pg. 7 in the manuscript. One of the most succinct definitions of this type of research is: "Participatory action research (PAR) is considered a subset of action research, which is the "systematic collection and analysis of data for the purpose of taking action and making change" by generating practical knowledge (Gillis & Jackson, 2002, p.264).... Ideally, the purpose of all action research is to impart social change, with a specific action (or actions) as the ultimate goal (Greenwood & Levin, 1998; Kach & Kralik, 2006; McNiff & Whitehead, 2006)." *Quoted from: MacDonald (2012, pg. 35). Understanding participatory action research: A qualitative research methodology option. Canadian Journal of Action Research Volume 13, Issue 2, 2012, pages 34-50.*

We are not trying to suggest that any qualitative work in which older adults are consulted is PAR, and certainly the research work presented in this manuscript is not PAR. Rather PAR and patient-centered outcomes mentioned at the top of pg. 7 refer to a shift towards working towards the concerns of the person with the condition first (as they have the experience and they have or should have a voice when it concerns their health/rehabilitation).

- 7) Great section of the origins of low vision stigmatization

Response: Thank you!

Method

- 8) What was the underlying methodology that guided this work? (narrative, phenomenology, ethnography, grounded theory, etc.) or was it more generic qualitative work?

Response: We mention in the methods that we are using qualitative content analysis (pg. 11, 2nd paragraph). While this is very similar to Grounded Theory, it does not have the goal of generating a theory that will explain a specific phenomenon rather the goal is to describe the meanings that emerge from the data and extract categories (For a discussion and contrast of these two methodologies (Grounded Theory & Qualitative Content Analysis see: *Cho, J. Y., & Lee, E. (2014). Reducing Confusion about Grounded Theory and Qualitative Content Analysis: Similarities and Differences. The Qualitative Report, 19(32), 1-20.*)

- 9) Did you exclude data from the one participant that was under 65? If so, clearly state this.

Response: We did not exclude the data from the participant that was under 65 years of age. Given the similarity of her response content to that of all other participants, her data were maintained in the analyses. We have added this clarification in the methods section.

- 10) You mentioned that 6 focus groups were conducted but was that 6 separate focus groups or did any group meet on more than one occasion?

Response: We thank the reviewer for this comment and have added information at the top of page 11 to clarify that each focus group met once: "Each focus group had one group discussion session that lasted 60-90 minutes." We have also included this as a limitation in the limitation section of the

paper stating on pg. 29: “Future studies should target this area of inquiry directly and ideally have several focus group sessions to increase the amount of data acquired.”

11) In discussing your analysis process, I wonder if the discussions between the two coders was about discussing discrepancies and trying to come to a shared decision or perhaps more about having conversations about different ways of “seeing” the data?

Response: The reviewer raises a good point, it was not as simplistic as described in the methods, we added some text based on the reviewers comment to pg. 12 to clarify that much discussion went into understanding the data: “All data analyses were conducted by two of the co-authors (KS and WW) in face-to-face meetings, whereby team coding was performed, *discussions about different ways of “seeing” the data were explored*, and discrepancies were resolved through discussion and presentation of rationale for items being addressed, a technique the authors have successfully implemented before [53–55].”

Results

12) I would introduce your research question much earlier in the paper

Response: We did state our research question at the end of the Introduction in a similar way to how it is stated at the beginning of the results: pg. 9, 1st paragraph: “The aim of the study was to describe and better understand the factors that shape the social participation of people with vision loss.”

13) Though the findings in the first theme make sense, I am not clear how they are linked to the topic of your paper which is about stereotyping?

Response: This theme, although very much a theme that emerged from the focus group discussions, does seem a bit tangential to the topic of stereotyping. However, as described in our introduction and discussion, it is difficult if not impossible to disentangle stereotypical attitudes from personal factors and environmental factors that might influence (in part) how people with low vision are treated and their social participation. As such, how the individual perceives their change in vision might be a factor that influences how others respond to them (i.e., with stereotypical attitudes or not) and may have an impact on their social participation.

14) In talking about the physical barriers, why is it that the environment has been structured in such a way as to “disable” those with vision loss? Could it be that social attitudes discriminate against those perceived as ‘abnormal’?

Response: These are both very good points raised by the reviewer. We have tried in the results to showcase quotes from the focus groups that identify how an inaccessible environment makes it more difficult for people with low vision (to get around, to participate, etc.). And there is research that supports the reviewers second point that social attitudes can lead to discrimination against those perceived as abnormal- our manuscript supports this see quote in Results section on pg. 16 “...*now that I am actually losing my eyesight, I am at the point where I need help, I am told, sorry by the regular world. Sorry we can’t help you so go back to your people, go back to your kind and stay there*”. The physical environment may facilitate social participation or impede it. Many described the physical environment as a barrier to social participation. In the Discussion, on pg. 26, 2nd paragraph (based on this reviewers comments) we further discuss how characteristics of the environment can contribute to diminished social participation: “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].”

15) For the final theme, again I would make sure the link to stereotypes is very clear.

Response: The final theme is about individual internal attitudes, while we present quotes from individuals who have in general or overtime taken a “chutzpah” approach to their vision loss even those interviewed state that “A lot of it has to be up to the individual”. We do not want to over-interpret the participants perspectives but what we think they were trying to get across is that how they are received by society/whether stereotypes and social participation are facilitated or hindered, may in part be associated with how they perceive themselves. We have discussed this on bottom of pg. 24/top of pg. 25 of the discussion.

Discussion

16) Define stereotype threat for the reader. Is it that the more familiar someone is the more likely they are to stereotype or vice versa?

Response: We thank the reviewer for this comment and have added a definition for stereotype threat in the discussion (pg. 23, last paragraph): “Familiarity is a topic that has been previously explored as it relates to stereotype threat [70]. *Stereotype threat is a real or perceived threat of being judged and treated badly in “settings where negative stereotypes about one’s group applies” (pg. 385) [70].*” Since the people in our sample mostly discussed outsider’s perspectives from people that were not familiar with them and that many relied on pre-existing stereotypes of the blind in their interactions with people we chose to discuss familiarity from this perspective (where in this case people that are less familiar with people with vision loss seem to rely on stereotypes more).

17) You discuss how those with an acquired disability have been shown to have a different approach towards their disabled identity. Can you expand on their perceptions and how those differ from those that have had a lifelong disability?

Response: This is an excellent point and although there is a lack of literature on this topic in low vision, the paper that was cited in the manuscript makes an excellent case for differences in disability identity based on whether the impairment is congenital or acquired. In order to elaborate on this point in the discussion on the bottom of pg. 24 and top of pg. 25 we have added some information from the findings of Bogart et al. (2014) – reference 77:

Research by [77], suggests that people with a congenital mobility disabilities report having a higher satisfaction with life, a better disability identity and disability self-efficacy than people with acquired mobility disabilities. The authors suggest that those with congenital disabilities have adapted to and take pride in their disability identity. In contrast, those with acquired disabilities may be influenced by rehabilitation professionals attempt to “normalize” people and have more difficulty adapting to their new identity [77].

18) In the discussion, you refer to the participants as no longer talking to their friends because “they do not want to hear it.” Who are you referring to here and what don’t they want to hear?

Response: We apologize, this refers to part of a participants quote in the results on the top of pg. 19. Perhaps we chose to small a portion of this quote in the discussion, as such we have selected a little bit more of the quote to bring back in the discussion to provide a bit more context: “*People who are well don’t know what this is like. They don’t want to hear it.*” We hope this clarifies the reference for the reviewer.

19) When you are talking about the influence of the environment, I think it’s also important to acknowledge that the way in which the physical environment is built is premised on the assumption of ‘normalcy.’ Those who have the power and influence to shape how the physical environment is built do so with a stereotypical assumption that all persons function within a state of ‘normalcy’

Response: We completely agree with the reviewer and have added a statement to this effect in the discussion on pg. 26, 2nd paragraph: “*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].*” and have added the following reference [80]: Story, M. F. (1998). Maximizing usability: the principles of universal design. *Assistive Technology: The Official Journal of RESNA*, 10(1), 4–12. <https://doi.org/10.1080/10400435.1998.10131955>

20) Your point about the physicians working with individuals who have dual sensory loss is interesting. I wonder, however, if that also extends to family physicians, for example, who are not working with a specialized clientele. Are experiences of being stereotyped more common among general healthcare practitioners, for example?

Response: We don’t have the answer to this question at this time. In our previous work (Fraser et al., 2019), we did put it as a limitation that the health care professionals that we interviewed had all worked with older people with dual sensory loss and seemed for the most part to be advocates for this population. Anecdotally, as the interviewer for that work, I can tell you that I only interviewed one general practitioner. It was my impression, as I was the interviewer for all the interviews, that this professional had the most narrow view of people with low vision and what could be done to meet their needs and he did tell me that he did not refer to rehabilitation services because of a belief that it would not be helpful (despite them being 5 minutes away from the office he practiced in).

21) You would benefit from defining client centred practice as not all persons may be familiar with the term

Response: We have added a definition of client centered approach and added some text to exemplify this in paragraph 2 on pg. 28: “ Rehabilitation specialists should consider the different spheres in which the individual needs to function, and the professionals need to frame their interventions accordingly, with a client centered approach *that supports a respectful partnership between client and health care 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].

22) Please include future research possibilities within the discussion. Based on your findings, what is the next research step you or other researchers should take?

Response: Again we thank the reviewer for her comments, and we have added the following statement about future directions on the top of pg. 29: “Future studies should target this area of inquiry directly and ideally have several focus group sessions to increase the amount of data acquired.”

Conclusion

- No comments.

Overall

22) Watch your sentence structure. I would recommend a thorough read through of the paper to address any run-on or incomplete sentences

Response: We have reviewed the manuscript with this comment in mind, you will see minor edits throughout the manuscript to address this concern.

23) Make sure to be consistent in referring to the participants in your study as older people. At many times throughout the paper you refer to “people” and so it is unclear if the focus is on older adults exclusively

Response: We have corrected this throughout the manuscript.

VERSION 2 – REVIEW

REVIEWER	Jennifer Kaldenberg Boston University USA
REVIEW RETURNED	28-Jun-2019

GENERAL COMMENTS	<p>Thank you for the revision of this paper. There are a few minor edits/considerations:</p> <p>I wonder if "normal" vision should be in ""</p> <p>Page 4: second line- omit of; second bullet, age-related is redundant (age related is acquired)</p> <p>Page 5: Your definition of low vision is confusing. As written is a blend of low vision and vision rehab</p> <p>Page 5 Line 5: instead of this condition use low vision</p> <p>Page 6: Line 1- again age related is acquired vision loss; Line 10: unclear what you mean by adapted day center</p> <p>Page 11: Tense used?</p>
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	Page 12: Line 13- remove extra (.); Line 14- should be a (,) after priorities instead of a (.)
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REVIEWER	Colleen McGrath Western University, Canada
REVIEW RETURNED	19-Jul-2019

GENERAL COMMENTS	<p>This recommended edits are very minor and I do not feel I need to see the paper again. With these small changes made, I would be happy to recommend accept.</p> <p>Strengths & Limitations - Fist bullet- It should be “the importance of factors...”</p> <p>Introduction - You need a bridge between talking about the ICF and introducing participation. It feels out of place how it is currently organized. Even if it just to say “As defined by the ICF, participation is...”</p> <p>Method - I suggest defining what the COREQ guidelines are</p> <p>Results - The wording of your fourth theme here does not match the wording in the abstract - I am still not seeing the intersection of stereotypes and the need for social participation in the first theme.</p> <p>Discussion - Explain what the modified labelling theory is</p> <p>Conclusion - No comments.</p> <p>Overall - Make sure to be consistent in referring to the participants in your study as older people. At many times throughout the paper you refer to “people” and so it is unclear if the focus is on older adults exclusively. I continued to notice this issue on this re-submission.</p>
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VERSION 2 – AUTHOR RESPONSE

Responses to reviews: July 25, 2019

Manuscript ID bmjopen-2019-029940.R1 entitled "Stereotyping as a barrier to the social participation of older adults with low vision: A qualitative focus group study"

Again we would like to thank the reviewers and the editor for the time invested in providing critical feedback that has greatly improved this manuscript. You will see below and in the attached documents we have addressed all the final comments of the reviewers/editor.

Reviewer: 1

Reviewer Name: Jennifer Kaldenberg

Institution and Country:

Boston University

USA

Please state any competing interests or state 'None declared': None declared

Response: We have added a statement on the cover page. There were no competing interests.

Please leave your comments for the authors below Thank you for the revision of this paper. There are a few minor edits/considerations:

I wonder if "normal" vision should be in ""

Response: We have changed normal throughout the paper to “normal” with the exception of direct quotes from the participants.

Page 4: second line- omit of; second bullet, age-related is redundant (age related is acquired)

Response: We have made the requested changes in the Highlights.

Page 5: Your definition of low vision is confusing. As written is a blend of low vision and vision rehab

Response: As we are describing the definition of functional vision (at the level of the person and what they do/are able to do) – we have changed the first sentence and removed reference to the domain of visual impairment rehabilitation and stated instead: “*Functionally*, a person with low vision *can be* defined as someone “who has difficulty accomplishing visual tasks, even with prescribed corrective lenses, but who can enhance his or her ability to accomplish these tasks with the use of compensatory visual strategies, low vision and other assistive devices, and environmental modifications” [p.4, 1].”

Page 5 Line 5: instead of this condition use low vision

Response: Corrected in text.

Page 6: Line 1- again age related is acquired vision loss; Line 10: unclear what you mean by adapted day center

Response: We have remove age-related in Line 1. And changed the sentence regarding the adapted day center to: “For example, day center services *that are adapted for* older adults with sensory loss have shown promise in maintaining functional abilities and social integration over time...”.

This reflects the type of center being described and cited. From the original paper: The Day Centre of the MAB-Mackay Rehabilitation Centre (MMRC) falls into the category of *Special Purpose ADS* (Weissert, 1976, 1977), given that it is designed specifically considering the needs of older adults that have low vision or are blind. Its objectives are to (1) maintain or improve the seniors’ biological, psychological, and social health; (2) maintain or improve the seniors’ abilities through post-rehab follow-up; and (3) offer support to the caregivers.

Page 11: Tense used?

Response: We have corrected the tense in several places in the Analyses section on pg. 11.

Page 12: Line 13- remove extra (.); Line 14- should be a (,) after priorities instead of a (.)

Response: Corrected in text.

Reviewer: 3

Reviewer Name: Colleen McGrath

Institution and Country: Western University, Canada Please state any competing interests or state ‘None declared’: None declared

Please leave your comments for the authors below This recommended edits are very minor and I do not feel I need to see the paper again. With these small changes made, I would be happy to recommend accept.

Strengths & Limitations

- Fist bullet- It should be “the importance of factors...”

Response: Based on the comments of Reviewer 1 we have altered this sentence to state: “provided rich data on the important factors influencing social participation among individuals with low vision.”

Introduction

- You need a bridge between talking about the ICF and introducing participation. It feels out of place how it is currently organized. Even if it just to say “As defined by the ICF, participation is...”

Response: We have changed this sentence to: “In the ICF, participation has been defined as “involvement in a life situation”...”

Method

- I suggest defining what the COREQ guidelines are

Response: We have added some additional details to clarify the COREQ: “The methods and results follow the consolidated criteria for reporting qualitative research (COREQ) guidelines: a 32-item comprehensive checklist used in the reporting of data from interviews and focus groups [49]”

Results

- The wording of your fourth theme here does not match the wording in the abstract

Response: We have corrected this in the list of the themes at the beginning of the results (pg.11) but have maintained the shortened version for the subtitle within the results on page 18

- I am still not seeing the intersection of stereotypes and the need for social participation in the first theme.

Response: The first theme was a strong theme that emerged from the data and highlights that most people tend to have these stereotypes in mind and that these stereotypes can influence an older adults social participation when experiencing a change in their health status (in this case visual impairment).

Discussion

- Explain what the modified labelling theory is

Response: We have defined the modified labelling theory on pg. 24: “according to the modified labeling theory [79], when stereotyping does occur (in both public and private settings), this confirms insider expectations and may lead insiders to expect future stereotyping. This can lead to a self-fulfilling prophecy whereby insiders subconsciously expect persistent stereotyping in both public and private settings, and make decisions that result in negative outcomes such as social isolation, reduced social engagement and self-stigmatization.”

Conclusion

- No comments.

Overall

- Make sure to be consistent in referring to the participants in your study as older people. At many times throughout the paper you refer to “people” and so it is unclear if the focus is on older adults exclusively. I continued to notice this issue on this re-submission.

Response: Thank you for re-iterating this point. In all sections of the manuscript that we discuss the results of this study (abstract, results, discussion) we have changed the wording of people to older adults to reflect our sample. However, in certain instances (i.e., the Introduction (pg. 6-7) or Discussion (pg. 24); we are reviewing literature that is about people with low vision or blindness and these findings are not specific to older adults. In those instances we have left the word people to reflect the literature being cited.