

Article

Facilitators and barriers to participation in mental well-being programs by older Australians with vision impairment: community and stakeholder perspectives

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1 **Title**

2 Facilitators and barriers to participation in mental wellbeing programs by older Australians
3 with vision impairment: community and stakeholder perspectives

4 **Running title**

5 Vision impairment and mental wellbeing programs

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33 **Abstract**

34 **Objective:** Older adults with vision impairment experience high rates of mental health
35 problems, but very few access psychological support. We investigated community and
36 stakeholder perspectives of the barriers and facilitators to participation in mental wellbeing
37 programs for older adults with vision impairment.

38 **Methods:** Adults aged ≥ 50 years with vision impairment (community) were recruited from
39 the client database, and low vision rehabilitation (LVR) professionals (stakeholders) from
40 staff of a LVR provider. Participants completed one-on-one semi-structured interviews which
41 were designed and analysed using behaviour change theory.

42 **Results:** Twenty-nine participants were interviewed; 16 community members and 13
43 stakeholders. Both groups cited mental health problems as a major concern, with many
44 stakeholders reporting the grief and distress associated with vision loss experienced by their
45 clients as having a negative impact on their mental and physical health. Major barriers to
46 participation in mental wellbeing programs included a lack of awareness and difficulties
47 accessing such programs, with stakeholders adding that their clients' lack of insight into their
48 own mental health problems may reduce motivation to participate. Facilitators to
49 participation in programs included the appeal of social interaction and inspirational speakers.
50 An appropriate intervention could overcome these barriers, or enhance participation through
51 education, persuasion, incentivisation, modeling, environmental restructuring, training, and
52 enablement.

53 **Conclusions:** While barriers were discussed more than facilitators to participation, there
54 was general support for mental wellbeing programs. This study provides guidance from
55 stakeholders for the development of mental wellbeing programs to address mental health
56 problems in the growing number of older adults with vision impairment.

57 **Introduction**

58 Globally, it is estimated that the number of people living with vision impairment
59 (encompassing low vision or blindness that cannot be corrected with glasses or surgery) will
60 rise from 38.5 million in 2020 to 115 million people by 2050; most of which (78%) are aged
61 50 years or older [1]. Older age and vision impairment are associated with an increased risk
62 of developing a mental health condition, particularly depression [2]. An estimated 69,519
63 non-Indigenous Australians aged 50 years or above and 4,282 Indigenous Australians aged
64 40 years or above were living with irreversible vision impairment in 2016 [3]; all at
65 consequent risk of mental health problems.

66 Older adults with vision impairment are approximately three times more likely to experience
67 significant depressive symptoms, compared with those without vision impairment [2, 4]. This
68 is attributed to the impacts of vision impairment on functional capacity and activities of daily
69 living [5-8]. Research suggests that low vision rehabilitation (LVR) services, and
70 psychological interventions involving self-management and problem-solving, may be
71 effective in reducing depressive symptoms and depressive disorders among adults with
72 vision impairment [9-12]. However, although 70% of adults with vision impairment report
73 wanting psychological support, only 9% report receiving it [13], and it remains unclear why
74 uptake of support is so low.

75 One study of LVR professionals' (hereafter stakeholders) perspectives of a mental wellbeing
76 program found a number of barriers to the problem-solving treatment for primary care (PST-
77 PC) being delivered in a LVR setting, that could be overcome through professional training,
78 support and improved screening [14]. The only other study reported on the reasons older
79 adults with vision impairment withdrew early from PST-PC, and found responses ranging
80 from the program being perceived as not relevant, to the program goals being achieved early
81 [10]. Given this scant literature, the aim of this qualitative study is to investigate the barriers
82 and facilitators to participation in a mental wellbeing programs, from the perspectives of

83 community-dwelling older adults with vision impairment (community members) and
84 stakeholders.

85 **Subjects and Methods**

86 This qualitative study involved semi-structured, one-on-one telephone or face-to-face
87 interviews with community members and stakeholders, including orientation and mobility
88 specialists and optometrists. This study was conducted within New South Wales (NSW) and
89 the Australian Capital Territory (ACT), Australia.

90 Community members and stakeholders were recruited using purposive sampling through
91 invitation letters and follow-up phone calls between August and October 2019. To address
92 the study aim, we expected to recruit up to 20 community members and up to 15
93 stakeholders for interview, or until data was saturated in each group, which was assessed by
94 researchers (LD, LK) at regular meetings. Community members were recruited from the
95 client database of an Australian vision rehabilitation organisation, Guide Dogs NSW/ACT.
96 Clients ~~that~~ who had consented to be contacted regarding research were sent an email and
97 invited to contact the research team directly to express interest in the study. Participants
98 were required to be aged 50 years and older and speak conversational English. Stakeholder
99 participants were employed in a client-facing capacity by Guide Dogs NSW/ACT, and were
100 similarly sent an email and invited to contact the research team directly to express interest in
101 the study.

102 The behaviour change wheel [15] was used as a framework to design the interview guides
103 (Supplementary File 1 and 2), and consequent analysis of the data. The behaviour of
104 interest was participation in a mental wellbeing program. Specifically, the wheel uses the
105 COM-B model to explain an individual's propensity to adopt a behaviour (see the inner wheel
106 of Figure 1). Behaviour can be in turn targeted by nine intervention functions: coercion,
107 education, enablement, environmental restructuring, incentivisation, modelling, persuasion,

108 restriction, training [15]. The wheel also includes policy categories which can impact the
109 intervention functions; however, these were considered outside the scope of this study.

110 Semi-structured interviews, lasting 15-45 minutes, were conducted by two Master of Clinical
111 Optometry students (AW, RM) and a Faculty of Medicine and Health PhD student (DT). The
112 students were given initial training and ongoing support by two experienced public health
113 qualitative researchers (LD, LK). Interviews were audio recorded using digital recorders,
114 transcribed verbatim, and analysed using NVivo software, using deductive analysis [16],
115 following the COM-B and intervention functions of the behaviour change wheel [15]. We
116 took an iterative approach to data analysis [17], whereby data were revisited, coded, and
117 themes discussed many times to ensure analytic reflexivity. Transcripts were coded
118 separately by two of the students (AW, RM). Initial coding was then presented and critiqued
119 in a meeting including all three students, chaired by LD. Two of the students (AW, RM) then
120 collaborated to establish themes under each subset of the COM-B model, which were
121 discussed and agreed upon at regular fortnightly meetings with LD and LK. Themes were
122 then coded using intervention functions, and categorised as barriers or facilitators to
123 participation in a mental wellbeing program by LD and DT.

124 **Patient and public involvement**

125 No patient under medical care or members of the general public were involved in the design,
126 recruitment or conduct of the study. However, there will be formal engagement with the LVR
127 provider's advisory panel to discuss the next stages of developing and implementing a
128 mental wellbeing program. Those participants who requested feedback will be informed via
129 email or telephone call about the results.

130 **Ethics approval**

131 Ethics approval was granted by the University of New South Wales Human Research Ethics
132 Committee (HC190356). A participation information statement was sent to interested
133 participants, and oral informed consent was gained before commencement of the interview.

134 The study is reported in line with the COREQ statement[18], supporting transparency in
135 reporting of qualitative research.

136 **Results**

137 Of the 35 community members and stakeholders invited, 29 (83%, 16 community members
138 and 13 stakeholders) completed an interview. The 13 stakeholders included 12 orientation
139 and mobility specialists and one optometrist. All stakeholder interviews were conducted over
140 the phone, while seven of the community participants requested face-to-face interviews in
141 their homes due to difficulties with hearing and/or accessing a phone.

142 We identified twelve themes (Figure 1); eight represented barriers, and four facilitators to
143 mental wellbeing program participation. Illustrative quotes associated with each theme are
144 presented below, with intervention functions in brackets next to the COM-B component.

145 Participants are identified as C for community members and S for stakeholders, followed by
146 an identification number.

147 Both participant groups showed a high level of interest through long and engaging
148 discussions around the mental wellbeing of people with vision impairment. Stakeholders
149 expressed that many of their clients have concerns regarding their mental wellbeing,
150 indicating the importance of this topic and need for such programs:

151 *"I'm finding most of the clients that I...work with, express that they have anxiety,*
152 *depression, or have had nervous breakdowns, or are currently having mental health*
153 *issues."* (S002)

154 **Barriers**

155 ***Physical capability (Enablement, Training)***

156 *Mobility impacts participation*

157 Participants reported difficulties in mobility as a result of their vision loss which prevented
158 them from engaging with their community and/or programs:

159 *"Because you can't go out. That's the biggest problem..." (C008)*

160 *"So, you don't tread on little kids or get tangled up in dog leads...that's always in the*
161 *back of your mind. I think I'll just stay at home."* (C004)

162 In particular, there were concerns regarding loss of the ability to drive:

163 *"You're not going to get them in a group scenario, but also they can't drive so they can't*
164 *get to anywhere."* (S008)

165 Some participants also found that their mobility limitations and location of residence
166 interfered with their ability to connect with other individuals with vision impairment and
167 contributed to feelings of isolation:

168 *"I would love to have a group of other people who were also vision impaired, but they*
169 *seem to be scattered all over the country."* (C020)

170 *Vision loss impacts everyday activities*

171 The inability to accomplish activities of daily living deterred participation in programs and
172 other activities:

173 *"Because of their vision impairment, I don't think they integrate as much with others in*
174 *their community."* (S009)

175 *"I can't watch TV and I do like TV actually. I can't read anything anymore and I used to*
176 *love a newspaper."* (C020)

177 ***Psychological capability (Education, Training, Enablement)***

178 *Ripple effects*

179 Stakeholders expressed concerns about mental health problems extending into other
180 aspects of their client's lives and preventing participation in mental wellbeing programs:

181 *“Stress and mental health, the physiological changes to the body... impacts on people’s*
182 *functional vision. There’s all these ripple effects if the mental health component is not*
183 *addressed.” (S006)*

184 *“I’d be the only person they’d see that week and maybe they’d have a cry...need to work*
185 *through the issues they have before they can start doing routes and getting out in their*
186 *community.” (S015)*

187 *Self-perception of mental health*

188 The acknowledgement of having a mental health problem varied among participants:

189 *“One very good friend who’s also legally blind...when I bring up the subject with him he*
190 *says, Oh, better not even to think about it. And he’s not really getting all the services*
191 *that he should be getting as a blind person.” (C004)*

192 *“Has it affected me? I lost my licence. I’m pretty much housebound. My doctor wants*
193 *me to see... a psychologist. And I said, No, I’m not that bad.” (C008)*

194 *“I try to prepare myself for the future, but I don’t think it’s affected my mental health, as*
195 *far as others are concerned anyway.” (C009)*

196 ***Physical opportunity (Environmental restructuring, Enablement)***

197 *Facilitation of services*

198 Participants expressed concerns about their ability to access mental wellbeing programs
199 following their vision loss:

200 *“When I lost my sight I had to really scabble and... call for information.” (C007)*

201 *“If there is support, they [support provider] could call our clients ...[so] the client doesn’t*
202 *have to initiate [seeking services] themselves...because I have a lot of clients who once*
203 *they lose their vision, they’re not able to navigate a phone.” (S003)*

204 Stakeholders also expressed their concerns about how they can best assist their clients to
205 receive support for their mental health problems:

206 *“If we had a script or a proper format that once a client has identified that they’ve got*
207 *mental health issues that we should say because you’ve mentioned that to us can we*
208 *write some information down and pass it on to someone to suggest help or at least to*
209 *refer.” (S013)*

210 *Lack of awareness of services*

211 Community and stakeholders were unaware of current mental wellbeing programs targeted
212 at Australians with vision impairment:

213 *“I’m not aware of any program for... people with vision impairment.” (S012)*

214 *“In a major Sydney hospital and they didn’t ever say to me that I needed to be referred*
215 *to Vision Australia or Guide Dogs or anywhere like that. And I just said, Okay, well, I can*
216 *do this. But the trouble is I couldn’t see.” (C005)*

217 ***Social opportunity (Environmental restructuring, Enablement, Modelling)***

218 *Stigma about mental health problems*

219 Participants described the negative stigma surrounding mental health issues as a barrier to
220 participation:

221 *“...it doesn’t seem to be talked about a lot.” (C015)*

222 *“People have a perception, there’s still a stigma around mental illness, so a lot of them*
223 *might not disclose.” (S005)*

224 *“I would say don’t call it a mental health program.” (C005)*

225 ***Reflective motivation (Education, Persuasion, Incentivisation)***

226 *Grief associated with vision loss*

227 Feelings of grief and beliefs regarding vision loss can make participation and engagement
228 unmotivating:

229 *“If a person is depressed and feels like they can’t do anything, then it’s likely they’re not*
230 *going to go into orientation or mobility training with high expectations, and a good*
231 *learning frame of mind.” (S012)*

232 **Facilitators**

233 **Social opportunity (Environmental restructuring, Enablement, Modelling)**

234 *Community connections*

235 The desire for a connection to the community particularly with those experiencing similar
236 vision loss was described by participants:

237 *“...having a group that comes together that has a focus on adapting to change and*
238 *understanding... I think is fairly powerful.” (C015)*

239 *“Although technology and online stuff is cool and innovative...it sort of takes away from*
240 *that human connection that you have when you sit in the same room as somebody.”*
241 *(S015)*

242 *“There’s others there to talk to and pass the time of day with. It’s not a discussion group,*
243 *it’s just to pass the time. You know, with the social aspect of it, but they’re getting to*
244 *know me.” (C003)*

245 *“For so long I just thought our family was a family of freaks because not knowing of*
246 *anyone else that had it...30 years ago I joined up with the Nepean Blind Sports Club...I*
247 *met a couple of people with the same condition and... went to social events out there.”*
248 *(C012)*

249 *Who can facilitate mental wellbeing programs*

250 Participants also expressed their opinions about who they think would be best suited to
251 deliver low vision mental wellbeing programs. Different levels of expertise were articulated
252 ranging from lay-facilitators to mental health professionals like psychologists:

253 *“Anybody who has got group-based skills and some level of working with groups.”*

254 (C005)

255 *“I always feel that if someone’s been through a situation they’re the ones I think are the*
256 *better ones.”* (C012)

257 *A consultant psychologist with a good knowledge of grief... it would be great to be able*
258 *to run scenarios by that person. And say, this is what I’m dealing with, or this is what I’ve*
259 *done. It would be lovely to be able to say to clients If you want to talk more about this,*
260 *we have a psychologist on staff that might be able to give you a ring.”* (S004)

261 *“It would be good if we had one person that they could make a call to that has more*
262 *specific information and then can put them in touch with people in their own area... or*
263 *what organisations are close to them.”* (S013)

264 **Automatic motivation (Modelling, Enablement)**

265 *Inspiration/role model*

266 Some participants stated how a role model is an inspiring motivation for participating in
267 mental wellbeing programs:

268 *“Those have been some of our better meetings when we’ve been inspired by others in*
269 *other words.”* (C009)

270 *“...hearing people’s stories about how they might have done it is really powerful for*
271 *people who might be going through that part of the process.”* (C005)

272 **Reflective motivation (Education, Persuasion, Incentivisation)**

273 *Self-efficacy*

274 Many participants believed they were self-sufficient and capable of handling their own
275 issues:

276 *"I can't change it, I've just got to learn to adjust to it and that's just going to be my life."*

277 (C011)

278 *"I don't feel sorry for myself, there's no point. I've got two legs, I can walk, so life's
279 good."* (C022)

280

281 **Discussion**

282 Consistent with evidence of the high burden of mental health problems in older adults with
283 vision impairment [2, 4], we found strong interest in developing mental wellbeing programs
284 among community members and stakeholders. The interviews revealed that both groups
285 acknowledged the substantial negative impacts of mental health problems. However, both
286 groups were unaware of any mental wellbeing programs specific to people with vision
287 impairment, thus, confirming the importance of developing a mental wellbeing program
288 tailored to this population group.

289 We identified two times more barriers than facilitators (i.e. eight vs four) to effective
290 participation in a mental wellbeing program. The intervention function *Enablement* was
291 relevant to all three facilitators, and the majority of barriers. Enablement refers to increasing
292 means, and reducing barriers [15], and is key to designing a program for this population. A
293 major concern related to Enablement, along with Environmental Restructuring (changing the
294 physical or social context [15]), was functional disability. Many community members felt that
295 vision loss limited their capability and opportunity to access programs due to difficulty
296 reading or finding information, and travelling to where programs were held. Travel concerns
297 are a common barrier in this population [19], and is influenced by the severity of vision
298 impairment, distance to program location, and availability of support people.

299 Recommendations to overcome these barriers, as they relate to intervention functions [15],

300 include: producing material in larger, easy-to-read print (*Enablement*); LVR professionals
301 telling community members what options are available (*Education*; increasing knowledge or
302 understanding); and program organisers making community transport available
303 (*Environmental Restructuring*) or provide orientation and mobility services (*Training*;
304 imparting skills), if travel is required.

305 In addition to physical limitations, the acknowledgement of having a mental health problem
306 influenced participation and varied among participants. Some mentioning conditions like
307 depression and anxiety, others downplaying any concerns and associating it with
308 complaining, and the remainder stating that their vision loss did not have any impact on their
309 mental health. The intervention functions of *Modelling* (an example for people to aspire to or
310 imitate) and *Education* are particularly relevant to alleviate these concerns and key to
311 tackling the barriers of social stigma and self-perception. Nyman et al. [20] identified that
312 vision impairment can impact psychosocial well-being through social isolation; while
313 acceptance of vision loss, and social support were facilitators of adjustment. We also
314 identified self-efficacy as a facilitator, which has been shown to lead to good mental health
315 outcomes in other contexts [21]. Given there was general consensus among both groups of
316 the benefits of social connection and positive role models, it is recommended interventions
317 include this in their design.

318 A pilot feasibility study in Australia recently investigated the delivery of PST-PC by LVR
319 professionals to older adults with vision impairment who met the criteria for mild symptoms
320 of depression [10]. PST-PC, based on Cognitive Behavioural Therapy (CBT) principles, is a
321 low-intensity approach designed to assist with functional adjustment, resilience building and
322 generalised well-being. PST-PC can be delivered by non-mental health professionals, face-
323 to-face, as well as over the phone, or over video conference, significantly increasing its
324 reach. Holloway et al. [10] found that those that who stayed in the study had significant
325 reductions in depressive symptoms, and improvements in health-related quality-of-life and
326 problem-focused coping. Those who withdrew from the study early were typically older, with

327 complex needs, as has been found in other studies [22-24]. Thus, it is critical that any future
328 interventions must consider methods to retain adherence of older participants with
329 competing health priorities.

330 Varying levels of mental health problems and requirements for support were reported by
331 community members as well as stakeholders about their clients. A stepped-care approach
332 may be the most efficient in this context, as not all clients require the same type or intensity
333 of intervention [25]. Stepped-care comprises different intervention components, with the
334 idea that if the first, less intensive step does not lead to a reduction in symptoms, then a
335 person moves to the next step, consisting of more intensive and potentially more expensive
336 interventions [9]. Several randomised controlled trials conducted outside the field of low
337 vision have found that a stepped-care approach can be effective in minimising depression
338 and/or anxiety [26, 27], and has been endorsed to address depression in older adults in
339 clinical guidelines, such as the UK NICE guidelines [28]. The ideas for interventions
340 identified in this study could be integrated within a stepped-care approach, including social
341 groups, psychologist referral and PST-PC.

342 **Strengths and limitations**

343 This is the first study to explore the perspectives of older adults with vision impairment and
344 client-facing professionals involved in LVR regarding mental health problems. The inclusion
345 of client-facing professionals provides essential insight needed to design a stakeholder-
346 driven intervention. A second strength is the semi-structured nature of the interviews which
347 allowed for tailored discussions to explore each participant's personal outlook and
348 interpretation of the impacts of mental health problems and vision impairment. However, this
349 also resulted in interviews of varying length, and occasional tangents in conversation.
350 Despite compelling findings, the authors acknowledge that the study is limited to one
351 community organisation and therefore the presented results are only a preliminary indicator
352 of the mental health perspectives in this population group. Moreover, community member
353 participants were recruited through purposive sampling from the client base of one

354 Australian LVR provider, and specifically only those clients who had agreed to be contacted
355 about participating in research, and had also agreed to participate in this particular study.
356 This potential selection bias may have influenced our results, and may limit the
357 generalisability of findings to those not associated with an Australian LVR provider, or those
358 not interested in participating in research or this particular study. Similarly, stakeholder
359 participants were orientation and mobility specialists and one optometrist from the one
360 Australian LVR organisation, which may limit the generalisability of findings to these LVR
361 providers in other organisations, or other professions involved in LVR, such as occupational
362 therapists, orthoptists, assistive technology specialists and social workers. Nonetheless, as
363 data saturation was achieved, we are confident the range of themes and corresponding
364 intervention functions suitably address the study aim. ~~Moreover, as participants were~~
365 ~~recruited through purposive sampling, there may be influences of selection bias influencing~~
366 ~~results and perhaps likely underestimating the mental health problems of individuals not~~
367 ~~associated with an LVR provider.~~ Furthermore, information on visual acuity, cause of vision
368 loss and presence of comorbidities was not available for collection. This information may
369 have been valuable in terms of interpreting the qualitative data.

370 This study has several key implications for clinical practice. First, improving the mental
371 wellbeing of visually impaired older adults is a priority. We postulate this may enhance their
372 participation in other programs, such as orientation and mobility, and this in turn could
373 improve their physical health, community connections, and overall well-being. Second, LVR
374 professionals, such as orientation and mobility specialists, and optometrists, are in a unique
375 position to identify those at risk of, or already experiencing mental health problems and can
376 refer as necessary, if provided with the necessary training. Third, older adults with vision
377 impairment may benefit from appropriate education and training to better support them as
378 they adjust to living with a vision impairment. We suggest this may be in the form of
379 evidence-based education regarding their vision diagnosis and prognosis, or psychological
380 support from an appropriately trained mental health practitioner. Fourth, providing older

381 adults with vision impairment the opportunity to connect with others in similar situations, as
382 well as those who are living well with vision impairment, is likely to improve their community
383 connections and social engagement. As a next step, the suggestions for future interventions
384 collected here will be presented through round tables with older adults with vision
385 impairment and service providers. This will ensure that any developed strategies are
386 practical and acceptable to the community and stakeholders, with the aim to improve the
387 ultimate adoption and scalability of a mental wellbeing program.

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393 **Conflict of Interest**

394 The authors declare that they have no conflict of interest.

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479 **Titles and legends to figures**

480 Figure 1 Barriers and facilitators to mental wellbeing program participation mapped on the
481 behaviour change wheel[15]. Barriers to participation appear in bold, while facilitators
482 appear underlined, with their relative intervention function presented in the outer wheel.