Special Article - Change in Vision or Sudden Loss of Vision

Why do Individuals Refuse or Stop Using Low Vision Devices? A Cross-Sectional Study

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Abstract

Objectives: We designed the present study to understand the reasons for refusing the use of Low Vision Aids (LVAs) after initial trial or stopping their use after a while. We also studied the association between demographic factors and reasons for refusal of these devices.

Methods: We included 44 individuals for this present study. Of these, 36 refused LVA after initial trial and eight had discontinued the use of LVAs after using it for some time. All these participants stated reasons for refusal or stopping the use of LVAs. The responses were collected on a five-point Likert Scale (Strongly Agree to Strongly Disagree). We also had a sixth category of 'no response'.

Results: The most common reasons for not accepting LVA devices were have to hold it closer to read (92%); cannot use it while walking (81%); and not satisfied with vision (75%). Individuals less than 40 years of age were significantly more likely to agree that the device was costly (19% vs. 0%, p=0.006) and not cosmetically appealing (56% vs. 16%, p=0.02). However, older individuals were not satisfied with visual performance (95% vs. 50%, p=0.002). The most common reasons for refusal of LVA devices were vision related issues and restricted activity. The common reasons for stopping the use of device were restriction of activities, vision related issues, and difficult to use.

Conclusion: In both groups, we found that visual satisfaction and activity restriction were the most important reasons for abandoning the device. Thus, there is a need to focus on maintenance of activities after the use of LVA. Strategies and modules to ameliorate 'restriction of activities of daily living' are important to ensure success of low vision aids in these individuals.

Introduction

Corn and Luck have defined low vision as "a person who has measurable vision but has difficulty accomplishing or cannot accomplish 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 devices and environmental modifications" [1]. Of the estimated 253 million visually impaired people, about 14% are blind and the remaining 86% have mild to severe visual impairment [2]. The common reported causes of visual impairment are refractive errors, which remain uncorrected (52%), cataract related visual impairment (25%), macular degeneration due to age (4%), and glaucoma (2%), retinopathy associated with diabetes (1%) and other causes (13%) (such as congenital reasons) [3]. However, in those above the age of 50, the common reasons for visual impairment are cataract followed by uncorrected refractive errors [3]. Blindness and low vision contribute to about 1.9% of disability-adjusted life years and 4% of years lived with disability globally [4]. Furthermore, about 89% of the visually impaired individuals are in developing nations, and 55% are women [2]. Thus, this is an important health issue globally - particularly in developing countries.

Visual impairment can have an effect of learning ability, daily activities, quality of life, mental stress, and potentially be associated

with depression [5-8]. Some of these individuals may face economic hardship due to restriction of movement, inability to participate in all activities, and cost of care [9]. The Low Vision Aid (LVA) devices that attempt to improve visual function may be optical, non-optical, or electronic [10,11]. These may include devices such as magnifiers, telescopes, electronic head mounted devices, or tablet based Low Vision Aids (LVAs) [10-15]. Even though it has been shown that these devices improve visual function and psychosocial function, the uptake of these services is low [11,16,17]. This may be due to multiple factors: low availability of these services (particularly in developing countries), lack of awareness among the population at-risk, poor referrals by the health care professionals (including ophthalmologists and optometrists), or due to stigma associated with the use of these devices [18-20].

Though, an important barrier is access to these services, it is equally important to understand the continuation of these services in people who access them. In fact, a study found that about 29% of individuals who had received a low vision device had abandoned it after three months of the intervention [21]. As discussed earlier, though many studies have highlighted the barriers for access to low vision services, few [22] have discussed the reasons for abandoning these devices. The reasons for refusing these devices or stopping these devices will help us develop relevant interventions - particularly in low vision rehabilitation settings where access to services is limited

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and challenging.

Thus, with the above-mentioned background, we conducted the present study to understand the reasons for refusing the use of LVAs after initial trial or stopping their use after a while. We also studied the association between demographic factors and reasons for refusal of these devices.

Methods

The present study is a cross sectional analyses of 44 patients who were recommended LVA use.

Study site and population

The study was conducted at Laxmi Eye Institute, a tertiary care eye center situated at about 50kms from Mumbai, in the Western part of India. The center has all the ophthalmologic and optometry specialties, including a special clinic for low vision. The participants for the present study were individuals who had accessed services of this low vision clinic.

We included 44 individuals for this present study. Of these, 36 refused LVA after initial trial and eight had discontinued the use of LVAs after using it for some time. All these participants responded to the reasons for refusal or stopping the use of LVAs. The responses were collected on a five-point Likert Scale (Strongly Agree to Strongly Disagree). We also had a sixth category of 'no response'.

We included eight statements to examine refusal to use the device after initial trial. The statements were based on the following: ease of use, visual performance, stigma, cost, and daily activity. We included 17 statements to assess the reasons for stopping the use of device after using it for a while. The questions were based on the following: knowledge/perception about the device, ease of use, visual performance, stigma, and daily activities. These two response sheets have been developed to follow-up patients who have been advised LVAs or use LVAs in our clinic. The statements have been presented in Table 1 and 2 and Figure 1.

Statistical methods

Data were entered in MsExcel 2007 (® Ms Office, Microsoft, USA) and analysed using Stata version 15.1 (® StataCorp, College Station, Texas, USA). We estimated the means and standard deviations for linear variables (such as age). We estimated proportions for categorical variables (such as categorical responses to the statement). We compared the means between groups using the t-test. We compared the proportions across groups using the chi square test or the Fisher's exact test for low expected cell counts.

We analysed the responses to each individual item in the questionnaire. We compared the responses according to age and gender. Furthermore, we also analysed the responses thematically. The themes in the group which refused the device were visual performance, stigma, use of device (difficult to use etc.), and cost of the device. The themes in the group that stopped the device after use were visual performance, activities, stigma, use of device (difficult), and knowledge/perception about the device. The statements in the individual questionnaire were grouped in above-mentioned themes. For example, statements like 'I cannot use it while walking' or 'I am not able to play sports or watch a movie' were grouped under

'restriction of activities'.

We estimated the means for agree, disagree, and neutral for each theme. For example, ease of use had two statements in the questionnaire administered to those who refused the device. If the individual responded as strongly agree or agree, then the individual response was considered under agree. Similarly, if they responded as strongly disagree or disagree, they were considered under disagree. If the response was neutral, then they were categorized as neutral. However, if the there was 'no response' to a statement, then the individual was not considered for either the denominator or numerator for the theme; thus, the denominator included only those statements for which the response was 'strongly disagree to strongly agree'. We calculated the total response score (for agree/ disagree/ neutral) for each theme individually. An example of the calculation of the mean: if the individual responded to both statements in the 'use theme', then the denominator was 2 (since both statements were answered). If the individual was classified as agree for statement - 1, then the score for agree was ½=0.5. If the individual was classified as disagree for statement - 2, then the score for disagree was ½ = 0.5. We then estimated the mean across all individuals thematically (Appendix I).

The study was approved by the Institutional Ethics Committee.

Results

The mean age of participants who refused to use LVA after initial trial was 43.3 years. Of these, 28 (78%) were males and eight (22%) were females (p=0.55). There was no significant difference in the mean age of male and female participants. Most of these individuals were students (33%), working adults (28%), retired (25%), and homemakers (14%). Majority of them had retinal diseases (58%) followed by neuro-ophthalmic diseases (39%) and corneal diseases (3%). The mean age of the eight individuals who have stopped using the device was 29.9 years. In this group, six individuals were male and two were female. Majority of these individuals were students (five) and the remaining were homemakers, working adults, and retired (one each). Four individuals had retinal disorders and three had neuro-ophthalmic diseases.

The most common reasons for not accepting the LVA devices were: they have to hold it closer to read (92%); cannot use it while walking (81%); and not satisfied with vision (75%). We found that individuals less than 40 years of age were significantly more likely to agree that the device was not cosmetically appealing compared with older individuals (56% vs. 16%, p=0.02). The younger group was also significantly more likely to agree with the statement that the device was expensive (19% vs. 0%, p=0.006). However, older individuals were not satisfied with vision (95% vs. 50%, p=0.002) (Table 1). There were no significant differences in the reasons for not accepting the device across genders (Table 2).

The most common reasons for stopping the use of LVA after having used it for some time were: not confident of using it (88%); have to hold objects closer to read (88%); did not help in daily activities (88%); unable play sports /watch a movie (75%); and did not like the device (75%). We have provided details of reasons for stopping the device in Graph 1.

Table 1: Table showing the reasons for not accepting low vision device according to age in 36 individuals, India.

Reasons	Total N (%)	≤40 years n (%)	>40 years n (%)	p value
	36 (100)	16 (44)	20 (56)	
It is hard to use				
Agree	16 (44)	8 (50)	8 (40)	0.052
Disagree	14 (39)	8 (50)	6 (30)	
Neutral	6 (17)	0 (0)	6 (30)	
No opinion	0 (0)	0 (0)	0 (0)	
It seems bulky				
Agree	24 (67)	12(75)	12 (60)	0.638
Disagree	9 (25)	3(19)	6 (30)	
Neutral	3 (8)	1(6)	2 (10)	
No opinion	0 (0)	0 (0)	0 (0)	
I have to hold closer to read				
Agree	33 (92)	15 (94)	18 (90)	0.413
Disagree	1 (3)	0 (0)	1 (5)	
Neutral	1 (3)	1 (6)	0 (0)	
No opinion	1 (3)	0 (0)	1 (5)	
I can't use it while walking				
Agree	29 (81)	12 (75)	17 (85)	0.449
Disagree	5 (14)	3 (19)	2 (10)	
Neutral	1 (3)	0 (0)	1 (5)	
No opinion	1 (3)	1 (6)	0 (0)	
It is cosmetically not appealing				
Agree	12 (33)	9 (56)	3 (16)	0.021
Disagree	17 (47)	6 (38)	11 (55)	
Neutral	7 (20)	1 (6)	6 (30)	
No opinion	0 (0)	0 (0)	0 (0)	
It is expensive				
Agree	3 (8)	3 (19)	0 (0)	0.006
Disagree	26 (72)	7 (44)	19 (95)	
Neutral	4 (11)	4 (25)	0 (0)	
No opinion	3 (9)	2 (13)	1(5)	
I am not satisfied with the vision				
Agree	27 (75)	8 (50)	19 (95)	0.002
Disagree	9 (25)	8 (50)	1 (5)	
Neutral	0 (0)	0 (0)	0 (0)	
No opinion	0 (0)	0 (0)	0 (0)	

We also assessed the mean scores for agreement and disagreement for thematic reasons for refusal of the LVA device or stopping them after use. The mean agreement scores were highest for vision related issues (0.85) and restricted activity (0.81) in the group, which had refused LVA devices. In the same group, the mean disagreement scores were highest for cost (0.72) and stigma (0.47).

The mean agreement scores were highest for restriction of activity

Table 2: Table showing the reasons for not accepting low vision device according to gender in 36 individuals, India.

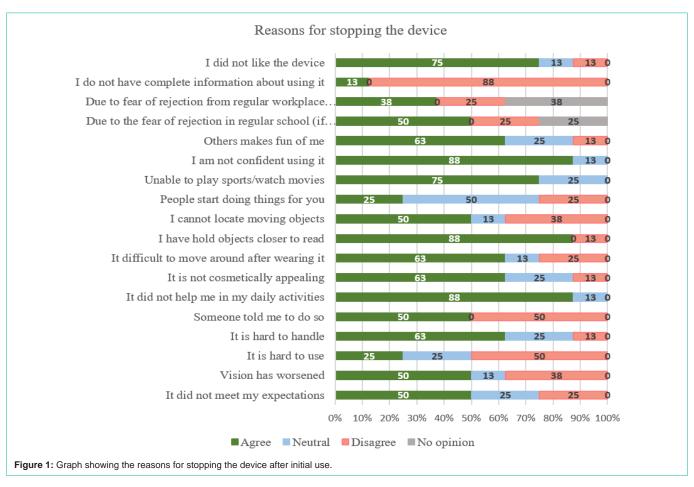
Reasons	Total N (%)	Males n (%)	Females n (%)	p value
	36 (100)	28 (100)	8 (100)	
It is hard to use				
Agree	16 (44)	12 (43)	4 (50)	0.656
Disagree	14 (39)	12 (43)	2 (25)	
Neutral	6 (17)	4 (14)	2 (25)	
No opinion	0 (0)	0 (0)	0 (0)	
It seems bulky				
Agree	24 (67)	17 (61)	7 (88)	0.450
Disagree	9 (25)	8 (29)	1 (13)	
Neutral	3 (8)	3 (11)	0 (0)	
No opinion	0 (0)	0 (0)	0 (0)	
I have to hold closer to read				
Agree	33 (92)	26 (93)	7 (88)	0.541
Disagree	1 (3)	1 (4)	0 (0)	
Neutral	1 (3)	0 (0)	1 (13)	
No opinion	1 93)	1 (4)	0 (0)	
I can't use it while walking				
Agree	29 (81)	23 (82)	6 (75)	0.742
Disagree	5 (14)	3 (11)	2 (25)	
Neutral	1 (3)	1 (4)	0 (0)	
No opinion	1 (3)	1 (4)	0 (0)	
It is cosmetically not appealing				
Agree	12 (33)	9 (32)	3 (38)	0.77
Disagree	17 (47)	14 (50)	3 (38)	
Neutral	7 (19)	5 (18)	2 (25)	
No opinion	0 (0)	0 (0)	0 (0)	
It is costly				
Agree	3 (8)	2 (7)	1 (13)	0.114
Disagree	26 (72)	22 (79)	4 (50)	
Neutral	4 (11)	3 (11)	1 (13)	
No opinion	3 (8)	1 (4)	2 (25)	
I am not satisfied with the vision				
Agree	27 (75)	21 (75)	6 (75)	
Disagree	9 (25)	7 (25)	2 (25)	
Neutral				
No opinion				

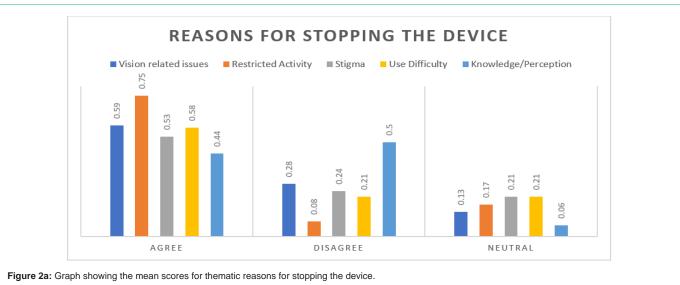
(0.75), vision related issues (0.59), and difficult to use (0.58) in the group which had stopped using the device. In this group, the mean disagreement scores were highest for knowledge/perception of the device (0.50).

Discussion

Thus, we found that some of the important reasons for not accepting low vision aids after initial trial were visual dissatisfaction,

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size of the instrument, and restriction of activities. The most important reason for stopping the use of device after using it initially was restriction of activities due to these devices. The next common reasons were 'not satisfied with vision' and 'difficult to use'. A significantly higher proportion of individuals greater than 40 years of age were not satisfied with vision after LVAs. Furthermore, a

significantly higher proportion of individuals less than 40 years found the device to be costly and cosmetically unappealing.

Previous studies have highlighted the important barriers and facilitators of access to LVAs. Kaldenberg has identified some important barriers; they are public policy, community related issues (awareness and stigma), organizational, interpersonal, and individual

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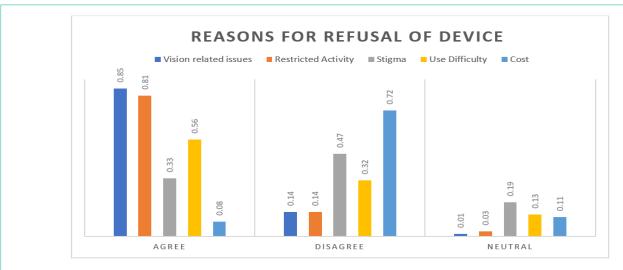


Figure 2b: Graph showing the mean scores for thematic reasons for refusing to use the device.

[23]. Thus, the author had suggested low vision services should consider socio-demographic factors while designing the programme. As seen in our study, older individuals were more concerned about the visual outcomes whereas the younger individuals were bothered about the cosmetic look and cost. A study by Sivakumar and colleagues [24] found that low affordability was a barrier in 25% of individuals; the proportion was highest in those under the age of 15 years (12%). Another study by Sarika and colleagues [25] (qualitative component of mixed methods study) also found that stigma, hope of getting cured by other medical or surgical interventions, using residual vision, and psychological factors (denial, depression) were important barriers. In general, lack of awareness in individuals with low vision, low perception for the need of LVAs, inadequate referrals by the ophthalmologists and optometrists, and perceived stigma about these devices are important barriers for access to these services [19,20,25-29]. A study by Overburry and Wittich [19] found that about 13% of individuals with low vision did not access the services despite being aware of it. Other authors [20] reported that about 40% of individuals did not feel the need of using this device. In our study, stigma was not an important factor in either refusal of the device or stopping the device after starting it. However, a mixed methods study by Sarika and colleagues found that social stigma was reported as a barrier for uptake of low vision devices. Another study by Sivakumar and colleagues [24] found that 76% reported social stigma as a barrier for low vision device use; the proportion was highest in those aged 16-40 years. In our study as well, younger patients (<40 years) of age were concerned about the cosmetic appearance of the device. Thus, it is quite likely after the device has been made cosmetically appealing; it is more likely to be accepted by individuals with low vision. Another study conducted by Monteiro de Carvalho and colleagues [30] in elderly patients found that 21.1% of them ignored the prescription because they did not practice reading or writing activities and 31.5% thought their eyesight was satisfactory for daily activities.

The role of health care providers, referral systems, and health care system in improving the access of LVA in population with low vision has also been discussed in literature [27,31]. Lu and colleagues have presented a holistic model which includes a multidisciplinary

team of social workers, occupation therapists, and counsellors in addition to the ophthalmologists and optometrists [32]. As seen in our study, the two most important reasons for refusal after initial trial and stopping to use the device were visual dissatisfaction and restriction of activities. A previous study by Lamoureux and coworkers [33] also found that there was no significant improvement in mobility and independence after initiating the therapy. However, Leat and colleagues [17] have reported improvement in vision and activities of daily living. Furthermore, visual field loss has been shown an important reason for stopping these devices [22].

As it is, individuals with low vision have restriction of activities. This may have an adverse effect on their mental and psycho-social health, and may also adversely affect the economic situation of affected individuals and their care-givers [8,9,34]. Even after using the device for some time, restriction of activities was an important reason for stopping their use. At the same time, in our study, knowledge about the device and stigma did not score very high for refusal of the device. Thus, it is quite likely that even though individuals with low vision are counselled adequately about the type of device and its use, there is a need to involve occupational therapists in a big way as well. They should focus on the use of these devices in day-to-day function with minimal restriction of activities. Furthermore, there is a need to provide a realistic expectation of gain in vision after the use of these devices.

We did not study the quality of life [35,36] in these individuals. It is quite likely that visual quality of life may have also had effect on refusal of the device after initial trial or stopping the device. The study was questionnaire-based study to identify the common reasons for refusing or stopping LVAs. Nonetheless, the study is a useful addition to the literature on the use of LVAs. We compared the reasons for refusal as well for stopping the devices. In both the groups, we found that visual satisfaction and activity restriction were the most important reasons for abandoning the device. Thus, there is a need to focus on maintenance of activities after the use of LVA. Strategies and modules to ameliorate 'restriction of activities of daily living' are important to ensure success of low vision aids in these individuals.

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