

FACTORS AFFECTING REHABILITATION SEEKING BEHAVIOUR OF INDIVIDUALS WITH LEGAL BLINDNESS IN LAGOS, NIGERIA

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Abstract

Blindness and low vision have profound negative impact on the quality of life of persons affected and it reduces ability to live independently. There are apparent inadequacies in vision rehabilitation services (VRS) in terms of access to and uptake of VRS. This study investigated factors affecting VRS seeking behaviour of 120 legally blind participants in Lagos, Nigeria. Participants had Visual Acuity (VA) worse than 6/60 (+1.0LogMAR) and were aged between 20 and 80 years. Eighteen (18, 15%) of the participants reported having undertaken VRS while 102 participants (85%) reported that they never had any form of VRS. Data concerning reasons for non-uptake of VRS were obtained from the 102 participants (85%) who reported that they had never taken any VRS after diagnosis of visual impairment. Findings show that a majority of the participants who had never had VRS had no knowledge of VRS (86, 84.31%) and many of them reported that they were never referred for VRS (82, 80.39%). Logistic regression analysis of reasons for non-uptake of VRS showed that males were significantly less likely to report that they had no knowledge of VRS (OR:0.53; 95% Confidence Interval [CI], 0.31-0.91; $p<0.05$). Participants aged 61 years and over (OR: 1.48; 95% CI, 0.72-3.09; $p<0.05$) as well as those blind for more than eleven years (OR: 1.16; 95% CI, 0.56-2.34; $p<0.05$) were more likely to report that VRS was not needed. Participants aged 61 and over were also more likely to state that they were never referred for VRS (OR: 2.88; 95% CI, 1.62-5.20; $p<0.05$). The study concludes that there is a need to increase awareness and knowledge of VRS among low vision patients as well as provide accessible infrastructure and manpower for VRS. A case is also made for prompt referral of legally blind patients for VRS.

Introduction

Visual impairment refers to vision with Visual Acuity (VA) of 6/18 (0.5LogMAR) or worse and cannot be fully recovered with medical treatment, surgery, or conventional glasses, or corresponding visual field loss to $<10^\circ$ in the better eye with best correction.¹⁻³ Visual impairment broadly encompasses low vision or partial sightedness and blindness.¹ The term Legal blindness refers to a medically diagnosed central visual acuity of 6/60 or less in the better eye with the best possible correction, and/or a visual field of 20 degrees or less.¹⁻³ The current burden of visual impairment in Nigeria is estimated at 1 million legally blind adults and 3 million people with low vision.⁴ In 2010, the US Census IDB data showed that the prevalence

1. Colenbrander A. Measuring vision and vision loss. Duane's clinical ophthalmology. 2001;5:1-39.

2. World Health Organization (WHO). Available data on Blindness (Update 1987) Geneva: WHO/PBL; 1987; 14: 1-23.

3. World Health Organization (WHO) Fact Sheet No 282, Nov. 2004

4. Ademola-Popoola DS, Tunde-Ayinmode MF, Akande TM. Psychosocial characteristics of totally blind people in a Nigerian city. Middle East African journal of Ophthalmology. 2010;17(4):335-345.

of legal blindness in Nigeria was 0.2% (95% CI, 0.1–0.3%), giving an estimated total of over 55,000 people across Nigeria, or 340 per million population.⁵ Globally, the prevalence of vision impairment is increasing as more than 37 million people are living with vision impairment³, and as such, vision rehabilitation (VR) is becoming an issue of public health concern.⁶ Among people with blindness, ability to accomplish daily tasks as (such as reading, moving out and about, driving, recognizing people's faces, and discerning colour) independently becomes extremely difficult if not impossible. Vision rehabilitation services (VRS) enable people who are blind, or have low vision to continue to live independently and maintain their accustomed quality of life.^{7,8} It includes a wide range of professional services provided by a team of specially trained professionals, which may include low vision therapists, Vision Rehabilitation Therapists (VRTs), and orientation and mobility specialists to restore functioning after vision loss. In principle, adults who are blind, or have low vision are usually referred to VRTs to learn adaptive independent living skills (AILS). AILS include Communication skills, reading and writing skills, braille and assistive computer technology, personal self-care, financial management, vocational rehabilitation, orientation and mobility skills, and travelling safely outdoors. These skill-set enable visually impaired individuals attain maximum function, personally satisfying level of independence, a sense of well-being, and optimum quality of life.^{8,9}

There is, however, ample evidence regarding the unmet needs of legally blind persons in Nigeria.^{4,10,11} Research suggests that although legally blind persons have an increased need for self-reliance¹² and that their quality of life is more restrained by lost sources of independence and confidence due to their reliance on others for support in accomplishing daily living tasks,¹³ not many legally blind individuals in Nigeria have access to support for psychological and social adjustments.^{10,11} There are evidences suggesting that legally blind patients rarely receive counselling about rehabilitation options and little or no information about where to access training for independent living.^{10,14,15} There are gaps in knowledge concerning what factors currently affect vision rehabilitation seeking behaviour among visually impaired persons in Nigeria. The current study investigated factors affecting vision rehabilitation seeking behaviour of individuals with legal blindness in an urban setting in Nigeria (Lagos metropolis) in order to inform intervention programmes for uptake of vision rehabilitation services (VRS).

Materials and Methods

A multi-stage sampling technique was used to recruit respondents for this study. First, a simple random sampling method was used to select five LGAs from the 20 LGAs within the five Administrative Divisions of the state. Thus, Ikeja, Lagos-mainland, Ikorodu, Amuwo-Odofin, and Epe LGAs were selected. Second, in each of the selected LGAs, the local government

3. World Health Organization (WHO) Fact Sheet No 282, Nov. 2004
4. Ademola-Popoola DS, Tunde-Ayinmode MF, Akande TM. Psychosocial characteristics of totally blind people in a Nigerian city. *Middle East African journal of Ophthalmology*. 2010;17(4):335-345.
5. US Census Bureau (2010) International Data Base. Retrieved from: <https://www.census.gov/programs-surveys/international-programs.html>. Accessed March 30, 2017. <http://iovs.arvojournals.org/article.aspx?articleid=2186207>
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15. Percival J. Whole system care and social inclusion of people with sight loss: implications of key research for policy and service development. *Journal of Integrated Care*. 2011;19(5):47-57

headquarters was purposively included in the study (because of their sub-urban nature) and thereafter, two communities each were selected from the LGAs using simple random sampling methods. Thus, three communities each from the selected LGAs were included in the study. The communities added to their respective LGA headquarters included: Opebi, Ogba, Yaba, Akoka, Imota, Igbobo, Festac Town, Odofin, Abomiti, and Aboriji. Only respondents residing in these communities were recruited for the study. The respondents were recruited using purposive and snowball sampling procedure. Criteria for inclusion in the study were: aged 20 years and over, visual acuity of 6/60 or less in the better eye, not having cognitive impairment, and able to communicate in English language. We focused only on legally blind participants (VA less than 6/60 [+1.0LogMAR]) rather than individuals with low vision (visual acuity less than 6/18 [+0.50LogMAR] to 6/36 [+0.80LogMAR]) because often, people with low-vision usually have the misconception that VRS are mainly for legally blind persons and that their vision is not poor enough to need VRS.^{16,17,18} Presumably, there are also tendencies of misconception that seeking VRS is conceding total blindness or giving-up on hopes of regaining their sight. Adequate and essential precautions were engaged to shun sample bias with the data collected. Snowball sampling was used to recruit participants considering that the sample for the study was limited to a very small subgroup of the population (i.e those with legal blindness – VA 6/60 [+1.0LogMAR] or less in the better eye). In principle, snowball sampling method is often suggested when the participants are aware of persons with similar and required attributes that qualify them to be included in the sample.¹⁹ In this study, snowball sampling was adopted since identifying legally blind persons on random basis or casually was challenging due to

limitation of the population. The sample for survey was therefore identified through a chain of referral from eye care practitioners located in the selected study areas, other participants as well as through references of social and support group meetings of vision-related charities in the selected areas. The 2010 US Census IDB estimates of Prevalence of Functional Low Vision and Total Blindness in Nigeria was used in the determination of sample for the study.⁵ An estimated blindness prevalence of 5%, with an absolute precision of 5% at 95% confidence, assuming a design effect of 1.75 and a response rate of 85% was used to compute sample size. The calculated sample size, using these parameters, was 73 persons. Effort was made to encourage blind older people to participate, including offering practical support such as funding their transport to the clinics where data were collected. However, for some potential participants, other difficulties made them reluctant to attend as a total of 138 eligible participants were invited for the study but 120 participated in the study via invitations sent. This sample size was large enough to give a precise estimate of the prevalence of total blindness in Lagos state (i.e., 4.2% with an absolute precision of 5% at 95% confidence).²⁰ Audio-recorded consent was sought and obtained from all participants. The study was conducted in accordance with institutional and national guidelines for conduct of research with human subjects. Ethical approval was sought from the Institutional Review Board of the College of Medicine, University of Lagos. The investigation was carried out in accordance with the Declaration of Helsinki of 1975 (As revised in Tokyo in 2004).²¹ Informed consent was obtained from all participants as they were briefed about the study and their verbal consent obtained before participation. Personal and demographic data were collected at the time of administration of the survey questionnaires. Data collection took place between June and November 2017. We categorized

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21. Carlson RV, Boyd KM, Webb DJ. The revision of the Declaration of Helsinki: past, present and future. *British journal of clinical pharmacology*. 2004;57(6):695-713.

individuals with Primary and Lower Secondary education as Low levels of education, and participants with Upper Secondary and Post-Secondary non-tertiary Degree as Medium level education. Respondents with Ordinary or Higher National Diploma, Bachelor's or Master's degree, or a Doctorate degree were classified as High education levels. These classifications were based on the International Standard Classification of Education (ISCED-2011) which provided guidance to countries within Organisation for Economic Cooperation and Development (OECD) on how to implement ISCED-2011 framework in international data collection.²² The survey questions investigated knowledge of VRS and whether participants had taken any VRS or training for coping with blindness. The reasons for non-uptake of VRS were also investigated by asking participants to state why they had not sought any VRS from a list of four possible options, namely: "No knowledge of VRS", "Not needed", "Perceived cost of rehabilitation", and "Never referred for VRS". Perceived cost of rehabilitation was regarded as the belief that seeking VRS was expensive. As the participants were blind, survey questions were read aloud to them and their responses documented. Surveys questionnaires were offered either at home, or at clinics of the eye care professional who recommended the participant as many of the participants were either previous or current patients of the clinics approached to assist with recruitment of participants. All data were collected by trained field staff who accompanied the Principal Investigator as well as the Co-Principal Investigator to the interview site. The core investigators comprised two Optometrists, and a Biostatistician. Data was analysed using SPSS (version 21.0). Chi-square tests were applied to identify the association between variables. Univariate and logistic regression modelling were used to explore associations with demographic factors.

Results

A total of 102 participants (85%) reported that they

had not received any form of vision rehabilitation service to enable them cope with sight loss. Only 18 (15%) of participants mentioned that they have had a vision rehabilitation training following diagnosis of vision impairment (Table 2). Over 78 per cent (94 participants) reported that they had no knowledge of vision rehabilitation services. Although 26 participants (21.66%) had knowledge of VRS, only 10 (8.33%) out of the 120 participants reported that they have taken VRS. Not having knowledge of VRS (84.31%) as well as not being referred for VRS (80.39%) were the major reasons for non-uptake of VRS (Table 3). Explanations for non-uptake of VRS were further investigated using logistic regression. Results (Table 4) showed that males were significantly less likely to report that they had no knowledge of VRS. Although participants aged 61 and over were more likely to report that they had no knowledge of VRS, this result was not statistically significant. In addition, participants with high level of education were significantly less likely to state that they had no knowledge of VRS. Male participants were significantly more likely to report that VRS was not needed (OR: 1.12; CI, 0.56-2.34; $p < 0.05$). Across age demographics, participants aged 61+ (OR: 1.48; CI, 0.72-3.09; $p < 0.05$) and those with longer duration of blindness (11+ years) (OR: 1.16; CI, 0.56-2.34; $p < 0.05$) were significantly more likely to report that VRS was not needed while those with higher level of education were less likely to report so (OR: 0.18; CI, 0.07-0.45; $p < 0.05$). Analysis of perception of cost of VRS showed that participants between the ages of 41-60 and those with 11+ years of blindness were more likely to mention cost of VRS as prohibitive – these results were, however, not statistically significant. Participants with high level of education were significantly less likely to perceive cost of VRS as hindering uptake (OR: 0.45; CI, 0.23-0.76; $p < 0.01$). While the results showed that males were more likely to report that they were never referred for VRS, this result was not statistically significant at any level. Participants aged 61+ (OR: 2.88; CI, 1.62-5.20, $p < 0.05$) and those with 11+ years duration of blindness (OR: 2.25; CI, 1.30-3.99; $p < 0.05$) were significantly more likely to report that they were never referred for VRS.

22. ISCE International Standard Classification of Education (2011). Retrieved from: [http://ec.europa.eu/eurostat/statistics-explained/index.php/International_Standard_Classification_of_Education_\(ISCED\)](http://ec.europa.eu/eurostat/statistics-explained/index.php/International_Standard_Classification_of_Education_(ISCED)) (Accessed: 07/05/2018).

Table 1
Demographic profile of participants

Variables	Frequency (n)	%
Gender		
Male	57	47.50
Female	63	52.50
Age		
20-40	24	20.00
41-60	37	30.83
61+	59	49.17
Education		
Low	51	42.50
Medium	44	36.67
High	25	20.83
Duration of Blindness		
0-5	20	16.67
6-10	45	37.50
11+	55	45.83

Table 2
Knowledge of vision rehabilitation services and pattern of uptake of rehabilitation services

Knowledge of vision rehabilitation services	Rehabilitation taken		Total
	Yes (n, %)	No (n, %)	
Yes	10(8.33)	16(13.33)	26(21.66)
No	8(6.67)	86(71.67)	94(78.34)
Total	18(15.00)	102(85.00)	120(100%)

Table 3
Reasons for non-uptake of vision rehabilitation services

Reasons for non-uptake of vision rehabilitation services	n (%)
No Knowledge of vision rehabilitation services	86 (84.31)
Not needed	45 (44.11)
Perceived cost of rehabilitation	70 (68.62)
Never referred for vision rehabilitation services	82 (80.39)

Table 4
Reasons for non-uptake of vision rehabilitation services analysed using Logistic regression

Explanatory variable	No knowledge	Not needed	Perceived cost of rehabilitation	Never referred
Constant	0.20*	0.10	0.15	0.19
Gender (Reference: Female)				
Male	0.53*	1.12*	1.35	1.15
Age (Reference: 20–40)				
41 - 60	0.67	0.81	1.41	1.47
61+	1.51	1.48*	0.48	2.88*
Educational Level (Reference: Low)				
Medium	1.16	0.59	1.09	1.13
High	0.26*	0.18*	0.45**	1.18
Duration of blindness (Reference: 0-5)				
6-10	0.99	0.58*	0.43	1.41
11+	0.89	1.16*	1.03	2.25*
Chi-Square test	12.40	17.07	10.27	19.65***
Nagelkerke R ²	0.14	0.23	0.19	0.15

*Significant at $p < 0.05$, **Significant at $p < 0.01$, ***Significant at $p < 0.001$

DISCUSSION

Findings from this study suggest that the two major barriers precluding uptake of vision rehabilitation services (VRS) are the lack of knowledge about VRS and the non-referral of blind persons for VRS. Many participants who never had VRS believed that seeking VRS was expensive while some others did not feel that they needed VRS. As these participants had never taken up VRS, the belief that seeking VRS was expensive was presumably borne out of misconception. This finding echoes a previous report that patients may not wish to take up low-vision rehabilitation due to misconceptions about VRS, inadequate understanding of their visual impairment and lack of knowledge on the available services.¹⁶

The findings suggest that many blind persons are unaware of VRS and how accessing VRS could enable them cope with the challenges of living with vision impairment. Furthermore, the study showed that inadequate referral of blind persons for VRS by eye care professionals significantly contribute to the problem of access to VRS. Arguably, it is likely that such inadequacy in referral is due to the scarcity of VRS providers. A major challenge with the subspecialty of vision rehabilitation is the lack of Vision Rehabilitation Therapists (VRTs). Whereas there are about 3000 Optometrists in Nigeria²³, opportunities for postgraduate Diploma, Masters or PhD trainings in the field of VRT are limited. The problem of scarce human resources in rehabilitation is, however, not limited to vision rehabilitation and efforts should be made to improve opportunities for training rehabilitation professionals.²⁴ In addition, at the referral level in Nigeria, awareness of available VRS services from Ophthalmologists and Optometrists

is unknown and there might be a need for increased co-operation and referral between VRS providers.

A useful way of increasing patients' knowledge of VRS is to incorporate vision rehabilitation into the continuum of eye care thus encouraging every Ophthalmologist and Optometrist to advise patients with VA less than 6/18, scotoma, visual field loss or contrast sensitivity loss, that vision rehabilitation options exist. In the United States and Canada, Optometrists and Ophthalmologists provide components of vision rehabilitation in private practices, academic departments, and independent rehabilitation agencies.²⁵ There is a continuum of vision rehabilitation care in both countries, beginning with diagnosis and moving to visual function assessment, assessment for optical devices, rehabilitation planning, and on to training and services such as orientation and mobility, and finally to numerous support services that make a difference for patients with low vision or legal blindness.²⁵

Our study revealed that males were more likely to mention that they did not need VRS. This finding is consistent with previous studies showing that men are less likely to admit weakness and seek medical attention.²⁶ It is therefore not surprising that in the investigated explanations for non-uptake of VRS conducted within this study, men were more likely than women to not see the need for VRS. Findings further revealed that participants aged 61 years and over as well as those that were blind for more than eleven years were more likely to report that VRS was not needed. It is also possible that with increasing years of living with blindness, adaptation skills are uniquely and personally developed based on the individuals' personal experiences²⁷ thus increasing the patients' reluctance to seek VRS.

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27. Orr KS, Leven T. Community care and mental health services for adults with sensory impairment in Scotland. *Scottish Executive Social Research*; 2006. Retrieved from: <http://www.scotland.gov.uk/Resource/Doc/129826/0030944.pdf> (Accessed: 7/05/2018)

As soon as patients are diagnosed of low vision, raising their awareness of the VRS as well as the rationale behind VR might help increase service uptake. The Queensland Referral Pathway Pilot Project identified late referral with advanced visual loss as an issue.²⁸ Adam and Pickering²⁹ noted that 62 per cent of Canadian ophthalmologists consider vision of less than 6/60 should be immediately referred. Adopting this recommended practice on referring patients could prevent them reaching a crisis point of unwillingness to take-up VRS.

study design lies in the use of snowball sampling techniques to access potential participants. As snowball sampling technique was employed, the degree to which the sample is a true representative of the population is uncertain. Another limitation of the present study which makes it difficult to generalize finding to the overall population of blind persons is that the data were collected from a single city. In addition, the study did not investigate the barriers to referrals from clinicians.

Limitations of study

The study did not investigate the presence of co-morbidities and how such factors could contribute to the low uptake of VRS. A major limitation of the

CONCLUSION AND RECOMMENDATION

Uptake of vision rehabilitation services among many blind persons in urban Nigeria remains poor. Knowledge of VRS and inadequate referrals for vision rehabilitation by eye care professionals are major barriers precluding access to VRS. The perception that cost of VRS is exorbitant appears to be another key reason why some people with blindness do not seek rehabilitation.

The scope and focus of the study was on blind participants only. Future studies could explore the challenges of low uptake of VRS from the perspectives of VRTs, optometrists and ophthalmologists. Lastly, although the explored explanatory variables for non-uptake of VRS among participants are moderate and consistent with previous studies of factors influencing uptake of vision care services, it is not necessarily exhaustive. Future research should investigate additional explanatory factors that can provide more robust explanations for blind people's non-uptake of VRS.

28. Queensland Vision Initiative Inc. Referral Pathway Pilot Project Summary. Brisbane, 2010.

29. Adam R, Pickering D. Where are all the clients? Barriers to referral for low vision rehabilitation. *Visual Impairment Research*. 2007; 9(2-3):45-50.