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## Patients' Perspectives of Blindness in a North-Central Community of Nigeria



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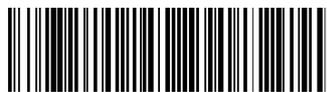
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### ABSTRACT

**Aim:** To determine patient's perspective of blindness in a North-Central Community of Nigeria. **Methods:** Non-randomized observational study. **Results:** There were 106 subjects, 32 males and 74 females, in the ratio of 0.4:1. Mean age was 53+/-5.37, and age range was 15-88 years. Blindness was the most feared by 80.2% of the subjects. Death, cancers made up the other percentage. With a p-value of 0.03 (95% CI= 0.026-0.032), only age showed statistically significant relationship with subjects perspective. **Conclusion:** Blindness was the most feared disability among the participants.



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## INTRODUCTION

Blindness, like any other disability, is undesirable but the quantification of undesirability especially when compared with other disabilities is scarce in scientific publications. It has been projected that about 90 million people will be blind worldwide by year 2020 if nothing pragmatic is done to curtail the trend (Ajite and Fadamiro, 2013). With increasing life expectancy and improved neonatal services ensuring more survivals, there is increasing trend of age-related blindness (Abegunde *et al.*, 2007; Christensen *et al.*, 2009). Some 90% of the blindness in the world occur in developing countries (WHO, 1997). Therefore, it is apt to find out how blindness as a disability is perceived in a sample population in which high prevalence has been reported. An earlier closely related Nigerian study conducted among medical students by Owoye *et al.*, 2007 was unlikely to reflect heartfelt burden of the actual sufferers being conducted among medical students. However, since some of the students would be ophthalmologists, it brought to the fore the perception of blindness among future providers of eye care services.

The main purpose of ophthalmic epidemiological studies such as Baltimore and Beaver Dam eye studies in the USA (Ronald *et al.*, 1991), the Visual Impairment Project and Blue Mountains Eye Study from Australia (Cugati *et al.*, 2007), the Rotterdam Study (Netherlands), the Andhra Pradesh Eye Study, (India) (Klaver *et al.*, 1998) and the studies in Melton Mowbray and North London (Gibson *et al.*, 1985; Reidy *et al.*, 1998) was to provide the important information needed for the planning of national eye health programmes and priorities. Similarly, this study's aim was to sample perceived impression about blindness as a handicap weighed against common debilitating handicaps, terminal ailments such as deafness, cancers, lameness and even death. It was thought that how eye health programs are accepted and utilized have a great bearing to the understanding of the sequelae of flouting preventive or interventional measures. The hope is that the information gathered here would serve as a catalyst to the providers, the recipients and the regulatory bodies of eye health programs for improved efficiency in curtailing blindness.

## MATERIALS AND METHODS

Nigeria has six-geopolitical zones of which North-Central is one. Unlike other zones with relatively homogenous inhabitants, North-Central Nigeria has the most variegated tribes making it appropriate for epidemiological studies on perception. The study was conducted in

Kabba, a semi-urban town in Kogi state, Nigeria. It is the political headquarters of Kabba-Bunu Local Government Area and the Okuns, one of the three major ethnic groups in the state. With a population of 145,446 (Nigerian census, 2006), it lies on 7°49'43"N, 6°04'23"E and has a land mass of 2,706 km<sup>2</sup>.

This was an observational study conducted in December 2016 during a free health screening exercise. A structured questionnaire was specifically designed to collect information on respondents' demographic characteristics and their perception towards blindness, deafness, lameness, death, poverty, cancer and dumbness. Questionnaires were administered by the researchers and where necessary interpretations were carried out by two nurses from the community who were part of the eye screening team. All participants granted written or thumb-printed on specially consent forms in line with Helsinki declaration on research in living subjects. In addition, they also granted verbal consents at the point of questionnaire administration after being told the purpose of the study and what the community could benefit from the outcome of the study.

Data were coded and entered into SPSS 21.0 (SPSS Inc., Chicago, IL, USA), and analyzed. Baseline characteristics of the study population were expressed either as mean (with standard deviation) and frequencies. Bivariate analyses of subjects' responses and sex, responses and age and responses and diagnoses were determined at 95% confidence interval using the *Chi-square* test which was considered significant at a level of  $P < 0.05$ .

## RESULTS

There were 106 subjects with female participants (74) more than male participants (32). Male to female ratio was 0.4:1. Mean age was 53+/-5.37, and age range was 15-88 years. More details on age and sex distributions are in table 1. Visual acuity in the cohorts is as presented in table 2.

Refractive errors, allergic conjunctivitis, cataract and glaucoma were the common diagnoses. Other diagnoses are shown in table 3.

In table 4, blindness was the most feared by 80.2% of the subjects. Death, cancers made up the other percentage with 4.7% abstaining from making a choice. It is shown in table 5 reasons respondents gave for considering blindness the worst of all other scenarios.

Bivariate analyses of subjects' responses and sex ( $p=0.23$ , 95% confidence interval [CI] 0.22-0.24), responses and diagnoses ( $p=0.94$ , 95% CI 0.94-0.95), were not statistically significant. Subjects' responses and occupation ( $p=0.09$ , 95% CI 0.08-0.17), subjects' responses and education ( $p=0.087$ , 95% CI 0.082-0.093) were also not statistically significant. Subjects' responses and age ( $p=0.03$ , 95% CI 0.026-0.032) was statistically significant.

**Table 1: Age and sex distribution**

Age range (years)	Male	Female	Total	Percent (%)
<18	2	4	6	5.6
18-39	7	11	18	17.0
40-59	8	26	34	32.1
>60	15	33	48	45.3
<b>TOTAL</b>	<b>32</b>	<b>74</b>	<b>106</b>	<b>100</b>

**Table 2: Visual acuity**

Visual Acuity	Right Eye	Left eye
6/18 or better	43	50
<6/18-6/36	2	3
<6/36-3/60	5	3
<3/60-NPL	12	6

**Table 3: response to questions**

Diagnoses	Frequency	Percent
Cataract	12	11.3
Optic atrophy	12	11.3
Chorioretinal scar	1	0.9
AMD+allergy+pterygium	1	0.9
Pterygium	3	2.8
Dry eye syndrome	6	5.7
Myopic degeneration	1	0.9
Refractive error	17	16.0
Blind eye	5	4.7
Anterior staphyloma	1	0.9
Allergic conjunctivitis	15	14.2
Cataract and glaucoma	3	2.8
Herpes Zoster Ophthalmicus	1	0.9
Pseudophakia	1	0.9
Normal	27	25.5
<b>Total</b>	<b>106</b>	<b>100.0</b>

**Table 4: Responses to disabilities, poverty or death**

Sr. No.	Which do you consider worse	Frequency	Percent
1	Blindness	85	80.2
2	Death	15	14.2
3	Cancer	1	0.9
4	Deafness	0	0
5	Lameness	0	0
6	Dumbness	0	0
7	Poverty	0	0
8	Abstain	5	4.7
	<b>TOTAL</b>	<b>106</b>	<b>100</b>

**Table 5: Reasons 85 respondents considered blindness as the worst of the undesirable scenarios**

Reasons	Frequency	Percent
Vision allows mobility, see beauty and oncoming danger	54	63.5
Blindness is worse because death is like going to rest	10	11.8
Blindness means every other thing is gone	8	9.4
Blindness is shameful	5	5.9
Blindness means not being able to care for oneself	5	5.9
Blindness means one can be given a poison to eat	3	3.5
<b>Total</b>	<b>85</b>	<b>100</b>

## DISCUSSION

Handicap due to loss of any of the sense organs is vastly devastating. It is therefore prudent to preserve them as much as possible. Fortunately, most diseases of the organs are preventable, treatable or viable ample rehabilitation available in the event of loss or malfunctioning of any of them. For sight, its loss means not being able to see friends and relations, watch television or nature’s beauty. Jogging or running becomes a huge challenge.

In our cohorts, blindness was the most feared disability. Blindness was also feared in comparison with poverty and death. Some studies have reported a significantly higher prevalence of fear of blindness compared to deafness (Lau *et al*, 2004; Gridhar *et al*, 2001). In one of such studies, while 35.7% considered going blind their worst fear, only 1% chose deafness (Lau *et al*, 2004). Deaf people can still communicate well enough. They will be able to lip read, read sign languages and in addition, computers have tools for deaf people. The available internet or computer tool for the blind largely relies on phonating whatever is on

desktop. This is unlikely to provide same satisfaction the deaf would experience. The unsighted cannot move away from encroaching danger and largely dependent on the assistance of a sighted friend, colleague and family members for day-to-day accomplishment of tasks or chores.

Blindness has a greater impact on education, social interaction, family relationships, and overall human development. In a study by Owoeye *et al*, 2007 in Ilorin, North-Central Nigeria, it was reported that about 60% considered blindness worse than deafness while only 6% considered deafness worse. Blindness (29.8%), deaf/blindness (26.1%), mental retardation (15.5%), and quadriplegia (14.3%) were additional handicaps regarded as worst with lower frequencies. Only 4(2.5%) thought deafness was the worst handicap. A much greater proportion (53-61%) considered blindness had a greater effect on education, social interaction, family relationships, and overall potential development than deafness (6-20%). The current study was carried out among ophthalmic patients and may explain why as much as 80% feared being blindness. This is likely to be a better reflection of perception among the general population than the previous study conducted among students who were not patients.

Only Age showed statistical significance with the responses of the cohorts unlike sex, education and diagnoses. It is thought that regardless of the sex, level of education or even the cause of blindness itself (diagnoses), the debilitation and incapacitation resulting from blindness impact significantly on daily living and quality of life. On the other hand, the young who is still dependent and needs meant by the parents is likely to perceive blindness differently from a much older adults who provide food, education and shelter to the children and other dependants.

Estimate of total economic burden of eye disorders and vision loss putatively was \$139 billion, based on the 2011 U.S. population in 2013 dollars (Wittenborn and Rein, 2013; Frick, 2010). In addition, uncorrectable vision loss resulted in a social burden of 283,000 disability adjusted life years (DALYs) lost. At an estimate of \$50,000 per DALY, the economic burden would increase by \$14 billion to a total of \$153 billion. Indirect costs constitute 52% of total costs (\$72.2 billion) and capture the burden of consequences of low vision, including productivity losses, long-term care, informal care, and the costs of transfer and entitlement programs (Wittenborn and Rein, 2013; Frick, 2010). Often when a member of the family is blind in the developing countries, a relation usually a young child, is designated to be a companion whenever the need to go outside arises (Shamanna *et al*, 1998; Adio and Onua,

2012). This prevents the child from going to school leading to avoidable absenteeism with the consequence of poor outcome in exams.

The study was among ophthalmic patients in a free healthcare outreach, patients with different medical conditions may have different perceptions of blindness. The outcome of this survey did not take into account relative morbidity of each disability nor quantify the impact on daily living. These are cofounders that could impact significantly on perception and tilt response either way. Well-designed prospective comparative studies specifically targeted at those living with disabilities would present different scenarios and true life pictures. However, this study achieved its aim, especially with regards to eye health, that blindness is undesirable and most feared by the respondents. This creates room for acceptance and utilization of new eye health interventional strategies with the right advocacy, community mobilization and participation, removal of bureaucratic bottlenecks, improved access and cost containment.

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