Barriers to Accessing Comprehensive Cataract Surgical Services in the North-East Indian Region

Amit Mondal[1], Shobhana Chavan[2], Pankaj Vishwakarma[3*], SG Prem Kumar[4], Elizabeth Kurian[5]
[1-5]*Mission for Vision, Nariman Point, Mumbai, India*

Abstract- Background: Access to comprehensive cataract surgical services (CSS) is the cornerstone of the blindness control efforts in India, but systematic data on the patient-specific barriers emanating from the northeast Indian region are not readily available.
Method: A cross-sectional study was designed to understand bottlenecks for the uptake of CSS. Face-to-face interviews were conducted with patients with confirmed cataract diagnoses but remained untreated. Descriptive statistics and Chi-square tests were conducted to assess the association between the barriers quoted and socio-demographic and clinical variables.
Results: A total of 161 (73.9%) patients participated in the study, of whom 51.6% were women. The median age for men and women was 68 and 70 years respectively. Significant barriers reported were related to attitudes, beliefs, and fatalism (p=0.002), followed by structural issues like bad roads, lack of transportation, and distance to health facilities (p=0.001).
Conclusion: Investing in human resource capacities and intensifying awareness generation activities would negate most of the barriers reported.

Key words—Barriers, comprehensive cataract surgical services, north-east India, patient, demand, blindness, community health worker.

I. INTRODUCTION

Cataract is one of the commonest surgeries and a major contributor to surgical needs in India.[1] Despite high rates of cataract surgical coverage, India continues to have one of the highest burden of untreated cataracts in the world.[2] India has implemented a series of effective measures in its ongoing National Program for Control of Blindness and Visual Impairment (NPCB&VI) to combat the situation, which resulted in a significant decline in the prevalence of blindness over the past few decades.[3] Yet, for a vast majority of populations, specifically those in remote, rural areas, access to cataract surgical services is limited.[4,5] The north-eastern region of India is one such underserved region, consisting of eight states, has a difficult terrain, vast hilly regions, large forest cover, and diverse ethnic groups which make it challenging to provide normal eye healthcare services to the people of the region. Moreover, due to inadequate infrastructure and communication facilities throughout the region, healthcare services have become unavailable to the majority. [4,6]

Understanding what hinders populations from accessing eye healthcare is vital as India moves closer to achieving universal health coverage. By addressing these barriers, policymakers can improve access to healthcare, reduce health inequalities, and achieve better health outcomes for all. Against this backdrop, a cross-sectional study was designed to understand and document patient-specific barriers to access towards comprehensive CSS in four north-eastern states.

II. METHOD

A multi-site, cross-sectional survey was carried out at four tertiary not-for-profit eye hospitals in four northeast Indian states. Ethics approval for this study was obtained from a participating eye hospital.

Study design and sampling

All adults who visited either the community eye screening camps (CESC) or vision centres (VC) within the operational zones of these four base partner eye hospitals (BPEH) were screened for cataracts by trained optometrists. All suspected and/or diagnosed cataract patients or those with a visual acuity reading of <6/24 were referred to the BPEH for further evaluation and treatment. A non-probabilistic purposive sampling approach was adopted with the aim to recruit all the patients diagnosed with cataracts at these CESC or at VC but have failed to visit the BPEH for cataract surgery even after three months from the date of initial diagnosis. A list of such patients was prepared and subsequent preparations for a face-to-face interview were made. These interviews aimed to understand the reasons for not availing of free-of-cost CSS. All adults who could

understand at least one of the six languages – Assamese, Mizo, Khasi, Jaintia, Hindi, or English were considered eligible for participation.

Data collection

The data collection happened from October 2019 to March 2020. This study adhered to the tenets of the *Helsinki Declaration*. Each potential participant was contacted by an interviewer trained in the study procedures. Interviews were conducted at the residence of the participants. Before starting the interview, each participant was explained the nature and purpose of the interview and their written consent for participation sought. Subsequently, interviews were conducted in an isolated area within the home premises. The average interview time was 45 minutes and responses were recorded on paper copies.

Measures

A questionnaire was designed specifically to meet the objectives of this study based on a thorough literature review and on a previous assessment of patient-specific barriers undertaken from the same region.[4] This interview documented socio-demographic and clinical characteristics of patients, and barriers to accessing CSS. Two rounds of pilot-testing of the study questionnaire were undertaken prior to the start of the study. The measures of visual acuity (VA) were classified into three broad categories as defined by the WHO as good, borderline, or poor.[7] VA was measured using a tumbling E Snellen chart. All measurements were taken in full daylight with available correction.

Statistical analysis

Microsoft Office Excel 2013, SPSS software (version 20.0, IBM SPSS Science Inc., Chicago, IL) were used for data analysis. Barriers quoted were grouped into five themes – (i) attitudes, beliefs and fatalism, (ii) ageism, (iii) affordability, (iv) awareness and knowledge, and (v) structural issues. Quantitative analysis included χ^2 tests to assess the association between the barriers quoted by the individuals and sociodemographic and clinical variables. A p-value of 0.05 was considered statistically significant for all the estimates.

III. RESULT

Patient-specific barriers to uptake of CSS

Participation

A total of 4,491 adults were screened at various CESC and VCs. Of these, 636 (14.2%, 95% CI 13.2% - 15.2%) were identified with cataracts and were referred to the BPEH for further treatment. A total of 337 (53%) patients reported at BPEHs and were operated whereas the remaining 299 (47%) did not turn up at the hospital even after three months after the initial diagnosis. This study included all of these 299 adults. From this subset, about 81.3% (n=243) were successfully contacted, of which, 218 (89.7%) agreed to participate in this study. A total of 57 (26.1%) did not complete the interview.

Socio-demographic and clinical characteristics

A total of 161 (73.9%) adults provided complete interviews. The median age for men and women was 68 and 70 years respectively. About 52% of the participants were female patients. The majority (52%) were literate and over half (55.9%, n=90) were involved in either domestic or outdoor work. Over two-thirds reported living beyond 50 kilometres from the BPEH. About 61% had either a borderline or poor visual acuity reading with men registering significant moderate to severe VI as compared to women ($p<0.001$). Over three-quarters reported that they were finding it difficult to perform their daily tasks, again men reported significant difficulty as compared to women (Table 1).

Patient-specific barriers to uptake of CSS

Majority of barriers reported in table 2were pertaining to ‘attitudes, beliefs and fatalism’ (36.1%, n=58), which significantly appear to decrease with age (p=0.002). Specific barriers like ‘fear of surgery’ (23%, n=37) and ‘can see well with the fellow eye’ (6.2%, n=10) were predominant barriers reported under this thematic head. A little over a quarter of all patient-specific barriers reported were associated with the theme ‘ageism’ (26.7%, n=43), specifically ‘lack of an escort to accompany’ (18%), although these associations were not significant. ‘Affordability’ was yet another significant thematic barrier reported, particularly ‘worried about the medical costs involved’ (11.8%, n=19), which was predominantly reported by male subjects (14.1%, p=0.04). Barriers pertaining to ‘awareness and knowledge’ and ‘structural issues’ were other significant barriers reported with 12.4% and 13% respectively, and these barriers too seem to increase with increasing age (p=0.026 and p=0.035, respectively) and are predominantly reported by women (p=0.001).

IV. DISCUSSION

Predominant patient-specific barriers seen amongst the elderly population seem to be more related to 'attitudes, beliefs and fatalism', which greatly hamper the provision and uptake of CSS in this region. Patient-specific barriers like 'fear of surgery', 'curse of God', 'no perceived need for surgery', neighbour's/relative advice against surgery' could be addressed by health care providers through investments in patient counselling initiatives and in further strengthening awareness and information, education and communication (IEC) activities in the region. Out of the four participating BPEH in this study, only one reported employing a full-time counsellor functioning out of the main hospital campus. It's a common practice for an ophthalmic nurse or an optometrist to provide patient counselling at the campsite or VC, including at the time of discharge, and such allied ophthalmic personnel are not trained to provide counselling services. The role of counselling in the uptake of CSS is well documented.[8] Counselling improves the quality of service and builds up the confidence of patients, which in turn increases motivation in the community to receive eye care services. Investing in human resources to enable patient counselling services is crucial and is recommended as a model for the provision of primary eye care services.[9]

Lack of adequate 'awareness and knowledge' is yet another thematic barrier reported in this population. 'Lack of information about surgery' and 'unaware of a place of treatment' were significant barriers reported. Though treating BPEH organise regular awareness activities in the operational geographic zones, such activities are often limited to certain fixed locations. Apart from such routine publicity events, BPEHs should also focus on recruiting and training existing community health workers (CHW) such as Accredited Social Health Activists (ASHA) and Anganwadi workers (AWW), and utilising their services to promote awareness in the rural remote communities is a practical option available.[10] Active and sustained involvement of local CHWs in delivering primary eye care services including generating awareness can resolve this barrier of misinformation, and miscommunication and nullify any myths and misconceptions surrounding CSS.

V. CONCLUSION

In summary, the northeast Indian region is unique and is unlike the rest of India. Several barriers are reported that greatly hamper access to CSS in this region. Investing in human resource capacities and intensifying awareness generation activities would negate most of the barriers reported. Sustained engagement of isolated and rural communities by actively engaging existing CHWs locally would generate demand for CSS. To ensure eye health equity for all in this region, addressing these barriers is warranted and this study provides robust local data needed to inform policy and planning.

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Table 1. Distribution of select socio-demographic and clinical characteristics among patients.

Variable	Categories	Patients who failed to get cataract surgical services		
		Total; N = 161 (%)	Male; N = 78 (%)	Female; N = 83 (%)
Age	*≤ 50 years*	10 (6.2)	6 (7.7)	4 (4.8)
	51 to 75 years	118 (73.3)	53 (67.9)	65 78.3)
	> 75 years	33 (20.5)	19 (24.4)	14(16.9
Education	*Illiterate*	77 (47.8)	29 (37.2)	48 (57.8)
	Literate (read and write)	84 (52.2)	49 (62.8)	35 (42.2)
Occupation	*Indulge in outdoor work*	47 (29.2)	27 (26.9)	20 (24.1)
	Indulge in domestic work	43 (26.7)	21 (26.9)	22 (26.5)
	Do not work	71 (44.1)	30 (38.5)	41 (49.4)
Distance from base hospital	*< 50 kilometers*	47 (29.2)	22 (28.2)	25 (30.1)
	51 to 100 kilometers	48 (29.8)	22 (28.2)	26 (31.3)
	> 100 kilometers	66 (41)	34 (43.6)	32 (38.6)
Currently wear spectacles	*Yes*	46 (28.9)	24 (31.6)	22 (26.5)
	No	113 (71.1)	52 (68.4)	61 (73.5)
Duration of poor vision	*≤ 1 years*	38 (23.6)	18 (23.1)	20 (24.1)
	2 to 5 years	99 (61.5)	49 (62.8)	50 (60.2)
	> 5 years	24 (14.9)	11 (14.1)	13 (15.7)
Source of information about the eye camp/vision center	*Family/relatives/friends*	47 (29.2)	21 (26.9)	26 (31.3)
	Other villagers	43 (26.7)	24 (30.8)	19 (22.9)
	ASHA/health worker	14 (8.7)	6 (7.7)	8 (9.6)
	Publicity by organisers	55 (34.2)	27 (34.6)	28 (33.7)
	Others	2 (1.2)	0 (0)	2 (2.4)
Diagnosis at camp or vision center	*Cataract*	143 (88.8)	65 (83.3)	78 (94)
	Refractive error	13 (8.1)	9 (11.5)	4 (4.8)
	Others (Squint, Pterygium, general eye infection)	5 (3.1)	4 (5.1)	1 (1.2)
Uncorrected visual acuity in the better eye	*Good*	62 (38.5)	28 (35.9)	34 (41)
	Borderline	63 (39.1)	30 (38.5)	33 (39.8)
	Poor	36 (22.4)	20 (25.6)	16 (19.3)
Eye advised for cataract surgery	*Right eye*	72 (44.7)	40 (51.3)	32 (38.6)
	Left eye	33 (20.5)	13 (16.7)	20 (24.1)
	Both eyes	56 (34.8)	25 (32)	31 (37.3)
Difficulty in performing daily tasks	*Yes*	125 (77.6)	65 (83.3)	60 (73.2)
	No/Can't say	36 (22.4)	13 (16.7)	22 (26.8)
Willingness to undergo surgery at the base hospital in the next one month	*Yes*	86 (53.4)	45 (58.4)	41 (49.4)
	No/Can't say	74 (46.6)	32 (41.6)	42 (50.6)

Table 2. Patient-specific barriers for the uptake of cataract surgical services by gender, age and uncorrected refractive error in the better eye among elderly patients

Type of barrier	Thematic category	Individual barriers	Thematic barriers	Gender (%)		Age-years (%)		
		Total (%)	Total (%)	Male	Female	≤ 50 years	51 to 75 years	> 75 years
Can see well with the fellow eye	Attitudes, beliefs and fatalism†	10 (6.2)	58 (36)	29 (37.2)	29 (34.9)	6 (60)	44 (37.3)	8 (24.2)
Fear of surgery		37 (23)						
Curse of God		3 (1.9)						
Friends/neighbours advised against visit to hospital		2 (1.2)						
Heard/seen vision getting worse in others post-surgery		1 (0.6)						
No perceived need for surgery		2 (1.2)						
Aware of the problem, but can manage		3 (1.9)						
No escort to accompany	Ageism¶	29 (18)	43 (26.7)	20 (25.6)	23 (27.7)	2 (20)	30 (25.4)	11 (33.4)
Suffer from other health problems		13 (8.1)						
Awaiting cataract maturation		1 (0.6)						
Worried about medical costs involved	Affordability§	18 (11.2)	19 (11.8)	11 (14.1)	8 (9.6)	0 (0)	13 (11)	6 (18.2)
Could not afford local travel expenses		1 (0.6)						
Lack of information about surgery	Awareness and knowledge‡	7 (4.3)	20 (12.4)	8 (10.3)	12 (14.5)	1 (10)	15 (12.7)	4 (12.1)

† Chi-square test for significance p=0.448 and 0.002 for gender and age respectively.

¶ Chi-square test for significance p=0.453 and 0.586 for gender and age respectively.

§ Chi-square test for significance p=0.040 and 0.259 for gender and age respectively.

‡ Chi-square test for significance p=0.286 and 0.026 for gender and age respectively.

†† Chi-square test for significance p=0.001 and 0.035 for gender and age respectively.