### Facilitating factors in overcoming barriers to cataract surgical services among the bilaterally cataract blind in Southern India: A cross-sectional study

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Purpose: To effectively address cataract blindness, increasing sight-restoring surgeries among the bilaterally blind are essential. To improve uptake of surgical services among this group, evidence regarding the problems of access is vital. Barriers in accessing eye care services have previously been reported but not specific to bilaterally cataract blind patients. Further, there is a gap in knowledge regarding factors facilitating access to eye care. Our aims were to (1) report proportion of bilaterally cataract blind patients undergoing surgery and sight restoration rate (SRR) and (2) analyze barriers and factors enabling access to eye care services among bilaterally cataract blind patients. Methods: Retrospective analysis of interview and clinical data of bilaterally cataract blind patients undergoing surgery through outreach services at the base hospital, from June 2015 to May 2016, was performed. Demographic data, vision, postoperative visual outcomes, barriers, and facilitating factors in accessing cataract surgical services were obtained. Results: Bilateral cataract blindness was present in 196/3178 (6.2%, 95% confidence interval 5.4-7.06) patients. SRR was 6.5%. Fear of surgery (24.2%) and lack of family support/escort (22.9%) were the most common barriers. Neighbors and acquaintances (28.6%), general health workers (20.2%), and persons who had undergone cataract surgery (19.6%) were the most common facilitating factors. Conclusion: Proportion of bilaterally cataract blind people undergoing surgery and consequently SRR were low. The most common barriers were at the individual level while facilitating factors at the community level were instrumental in promoting uptake of services. Interventions involving community-based support for the blind may be useful in overcoming barriers to eye care.



Key words: Access, barriers, bilaterally cataract blind, cataract surgical services, facilitating factors

Despite the availability of economical and effective treatment,<sup>[1]</sup> cataract continues to be the leading cause of blindness worldwide.<sup>[2]</sup> The burden of cataract blindness is higher in developing nations,<sup>[2]</sup> including India. Cataract contributes to over 75% of blindness in India,<sup>[3]</sup> despite high-volume, good-quality, free cataract surgeries through the National Programme for Control of Blindness (NPCB). Although an increase in the aging population is partly contributory,<sup>[3]</sup> barriers to accessing appropriate eye care remain crucial for this backlog.<sup>[4]</sup>

Cataract surgical rates (CSRs) and cataract surgical coverage (CSC)<sup>[5]</sup> are regularly quoted in monitoring cataract surgical programs, and CSR has increased commendably.<sup>[6-8]</sup> To truly address the problem of cataract blindness, it is important to study the accessibility issues among the bilaterally cataract blind people and monitor sight restoration rate (SRR)<sup>[6]</sup> which would represent sight-restoring surgery in this group.

In earlier reports, 33%–43%<sup>[9]</sup> of surgeries were performed among bilaterally blind people; this proportion was reported as 17.2% in the 2011 Sentinel Surveillance Unit (SSU) data, indicating that increasing numbers without bilateral blindness are being operated upon.<sup>[10]</sup> This could either be due to reduction in the numbers of bilaterally blind or due to reflection of poor access to eye care services this group.<sup>[11]</sup>

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While barriers to accessing eye care services have been well documented in the literature,<sup>[12-14]</sup> to the best of our knowledge, there is a paucity of information regarding factors that facilitate access to eye care. Knowledge of facilitating factors would be invaluable in improving access to this group. Therefore, the objective of this study was to report barriers causing delay in access and facilitating factors which finally brought bilaterally blind persons to our surgical services. We also estimated the SRR of our cataract surgical services.

#### **Methods**

#### Study design

This cross-sectional study was carried out on data from the patients who presented for cataract surgery through the outreach services to our base hospital. Data were retrospectively analyzed.

#### Setting

Outreach services of the department of ophthalmology of a teaching hospital in Tamil Nadu, Southern India, which

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undertakes comprehensive screening camps and clinics for ocular diseases held within the district in collaboration with NPCB, as well as in two neighboring districts liaising with local nongovernmental organizations. Weekly clinics are also held at secondary/primary care hospitals of the institution serving rural and urban-slum populations. Patients needing further management like cataract surgery are provided transport or referred to the base hospital. Cataract surgery is performed subsidized or free (for within district patients under the NPCB or those from other districts through donor or institutional support). Patients are provided free food during their hospital stay.

#### **Participants**

All bilaterally cataract blind patients who underwent cataract surgery in our outreach services from June 2015 to May 2016 were included in the study. Institutional review board (IRB) approval was obtained (IRB No. 10015, dated March 23, 2016).

Patients underwent a comprehensive preoperative ocular examination. Presenting and best-corrected visual acuity (BCVA) was tested using an illuminated Snellen's chart at 6 m as regular standard of care by an experienced optometrist who was not aware of the study to avoid measurement bias. Slit-lamp examination, applanation tonometry, dilated fundus examination (media permitting), and B-scan ultrasonography were done when required. Axial length measurements using applanation ultrasound and keratometry were done for intraocular lens power calculation. On the 1<sup>st</sup> postoperative day, patients underwent BCVA, slit-lamp examination, tonometry, and fundus examination. Those presenting for a 4–6-week follow-up underwent BCVA and a comprehensive ocular examination.

#### Variables

Numbers of patients screened, referred, and presenting to the base hospital from outreach services were obtained from the outreach services database. Demographic data, occupation, and duration of decrease in vision were obtained from clinical charts. Distance from the nearest fixed eye screening facility of the institution (including base hospital) was calculated using the address/pin code available or the patient identification document copy. Presenting and BCVA at admission, 4–6 weeks postoperative BCVA, details of patients who had surgery in the second eye, and duration after the first surgery were obtained from the clinical charts. Bilateral cataract blindness was defined as BCVA of 6/60 or less in the better eye;<sup>[15]</sup> manifest blindness was defined as vision of 1/60 to perception of light<sup>[16]</sup> (equivalent to WHO Visual Impairment Category 4) where cataract was the only contributing pathology to blindness.

Those identified as bilateral cataract blind were interviewed by the evaluating postgraduate registrar in charge of this data collection during their rotation lasting 2–4 months. They were trained in the beginning of the rotation to gather information using two open-ended questions in the local language for the cataract blind alone. – "What are the reasons for not coming to an eye care center/camp before this for your vision problem?" and "Who or what was instrumental in your accessing eye care services this visit?" Telephonic contact was attempted for those who did not undergo surgery in the second eye and the reason for failure to undergo surgery was obtained from those available. SRR was calculated using the formula:[9]

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Number of blind preoperative

-Number of blind postoperative

Total surgeries in the year
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Data were analyzed using STATA I/C 13.1 (Copyright 1985-2017 StataCorp LLC College Station, Texas 77845 USA). Proportions and percentages were obtained for all categorical variables, while means and standard deviations were calculated for continuous variables. Chi-square test was used for bivariate analysis; P < 0.5 was considered statistically significant.

#### Results

Of 4682 patients referred for cataract surgery from screening clinics between June 2015 and May 2016, 3577 (76.4%) presented to the base hospital, of whom 3178 (88.8%) underwent surgery. Of these, 230/3178 (7.2%) patients were bilaterally blind. Cataract was the only cause of bilateral blindness in 196 (6.2%, 95% confidence interval [CI] 5.4–7.06), of whom 56.4% had manifest blindness. In the remaining 34, causes other than cataract also contributed to blindness, retinal pathology being the most common (17/34) [Fig. 1].

Mean age was 64.61 years (±10.8; range: 25–100), 62% were females, 39.3% were unemployed, 50.5% were from urban areas, and 53.4% lived within 10 km of fixed eye screening facilities. Of the 196 bilaterally cataract blind patients, 128 (65.3%) presented to eye camps rather than to fixed eye care facilities, 74 (57.8%) of whom lived within 10 km of fixed eye screening facilities. Mean duration of perceived diminution in vision was 10.3 months (±7.7, range: 1–36) months.

Comparative analysis of demographic data is shown in Table 1.



Figure 1: Flowchart of the study

Table 1: Sociodemographic data of bilateral cataract bilind patients											
	Total	Manifest (<1/60)	Blind (<6/60)	Р	Rural	Urban	Р	<10 km	>10 km	Р	
Mean age (years)	64.61±10.78	65.8±11.5	63.2±9.6	0.045	63.6±11.9	65.6±9.5	0.89	63.9±9.9	65.1±11.6	0.76	
Females (%)	62.2	65.5	57.7	0.27	61.9	62.6	0.91	64.1	60	0.56	
Unemployed (%)	39.3	40.9	36.5	0.73	38.1	40.5	0.78	36.9	42.2	0.51	
Duration (decrease in vision) months	10.3±7.7	10.1±7.08	10.8±8.3	0.81	10.1±7.6	10.5±7.7	0.69	8.9±6.6	10.9±8.1	0.22	
<10 km (%)	53.4	55.5	51.2	0.56	39.6	67	0.00				
Urban (%)	50.5	53.64	45.88	0.28				67	33	0.0	
Presented to peripheral screening camp (%)	65.3	60.9	71.7	0.11	54.6	75.8	0.002	71.8	58.9	0.058	

4.6.0

Details on barriers were available for 181/196 (92.3%) and on facilitating factors for 160/196 (81.6%) persons. There was no statistically significant difference between those with data and those where data were missing with respect to age, gender, place of residence, or distance from eye care facilities. Some patients gave more than one response. All responses were combined to ascertain the most common barriers and facilitating factors. The following results represent 223 responses for barriers and 168 for facilitating factors in accessing cataract surgical services.

Fear (24.2%, 54/223) and lack of family support/escort (22.9%, 51/223) were the most common barriers to access eye care services for surgery [Table 2]. Neighbors and acquaintances (28.6%), general health workers (20.2%), and persons who had previously undergone cataract surgery (19.6%) were the most common facilitating factors [Fig. 2].

On bivariate analysis, significantly, more persons from urban areas (P = 0.04) reported lack of accompanying person as a barrier to accessing eye care services. Uncontrolled systemic morbidities were more commonly reported from the rural population (P = 0.01). Neighbors and acquaintances played a significant facilitator role in bringing those living within 10 km of fixed eye care facilities to eye care (P = 0.02). Approach to eye care services for females was more likely to be through a person who had already had cataract surgery (P = 0.03).

BCVA at 4–6 weeks follow-up was available for 185 patients. Details are provided in Table 3. Second eye surgery was performed at our institution itself in 63/196 patients (32.1%). Mean duration to second eye surgery was 9.5 weeks (range 0.5-48 weeks). Forty-three (68.3%) of those underwent second eye surgery during the first 2 months after the first eye. Of those who did not undergo surgery here, 59 could be contacted telephonically, three of whom had undergone surgery elsewhere. The most common reason for not getting second eye operated (38.6%, 22 of 57 responses) was "busy with household responsibilities." Other common reasons were medical comorbidities preventing them from seeking eye care and managing with vision in one eye.

The total number of surgeries during the study period was 3178, of whom 230 were bilaterally blind preoperatively [Fig. 1]. At 4–6 weeks after surgery, 24 persons were blind giving an SRR of 6.5% using blindness criteria as for this study.



Figure 2: Facilitating factors in accessing eye care services this visit (% of all responses). Facilitators 1 = Neighbors/acquaintances, 2 = Family members, 3 = General clinic/health worker, 4 = Announcements, 5 = Postcataract surgery acquaintances, 6 = Camp nearby home

#### Discussion

This retrospective, institution-based study provides an insight into facilitating factors that helped overcome barriers to access in bilaterally cataract blind patients presenting to base hospital surgical services after screening and referral from peripheral outreach clinics. While barriers causing delay in accessing services in our study may not be representative of the general population, information about facilitating factors could only be obtained from those who had finally presented to eye care services. Majority of the barriers were related to lack of family support and fear. Neighbors, acquaintances, health workers, and persons with previous cataract surgery were the most common facilitators.

The study had limitations as the data collected were analyzed retrospectively. There were missing data for both barriers and facilitating factors. Bias could have been introduced in information regarding barriers and facilitators due to multiple interviewers. To avoid this, they were trained in asking open-ended questions to avoid suggestions. Answers were noted in the patient's words and later categorized by the principal investigator.

In this study, bilateral cataract blindness was present in 6.2% (95% CI 5.4–7.06) of those presenting for cataract surgery. Bilateral cataract blindness in population-based studies from India has been reported to be below 3%.[3,17] Our data are a reflection of patients presenting to any of our outreach camps/

## Table 2: Barriers to accessing eye care among cataract blind patients (*n*=223)

Barriers	Respones, <i>n</i> (%)
No one to accompany	51 (22.9)
Financial constraints	18 (8.1)
Systemic comorbidities	23 (10.3)
Able to manage	35 (15.7)
Fear of surgery	54 (24.2)
Unaware of eye care facilities	14 (6.3)
Unaware how to approach eye care facilities	5 (2.2)
Gave More priority to household matters	15 (6.7)
Ocular comorbidities	2 (0.9)
Thought visual loss transient	5 (2.2)
No access to health care	1 (0.5)

# Table 3: Visual outcomes in the first eye among bilaterally cataract blind patients (best-corrected visual acuity at 4-6 weeks postsurgery)

Vision	WHO postoperative visual outcome classification	n (%)
6/18 or better	Good	175 (94.6)
<6/18-6/60	Borderline	8 (4.3)
<6/60	Poor	2 (1.08)

clinics, rather than being strictly population based. Moreover, comparisons are difficult due to differing denominators and definitions of blindness.

According to the 2011 National SSU data,<sup>[10]</sup> 17.2% of surgeries were done on bilaterally blind (all-cause) patients with presenting vision <6/60 in the better eye. Our lower numbers can be attributed to the inclusion of patients where cataract alone was contributory to blindness and stricter criteria of BCVA rather than presenting vision. While SSU data were collated from centers across India, our lower rate may be an indication of lower cataract blindness prevalence in Tamil Nadu which has one of the highest CSRs<sup>[8]</sup> in the country or a reflection of poor access of the bilaterally cataract blind to eye care services. A population-based study would provide the prevalence of bilateral cataract blindness and CSC in our service area.

Similar to other reports from India,<sup>[12]</sup> majority of the barriers in this study were on an individual level, indicating a shift from system to person-related barriers. Fear has been reported as one of the most frequent barriers (21%–41%) from various reports from India<sup>[18-20]</sup> as well as other developing countries (20%–24%).<sup>[21,22]</sup> This barrier has previously been reported more commonly from Tamil Nadu (33.4%)<sup>[18]</sup> as compared to a recent study from Andhra Pradesh (4.7%).<sup>[12]</sup> This could represent a regional difference or a changing trend in attitudes toward cataract surgery. Different forms of fear have been reported,<sup>[18,19]</sup> that of surgery, hospitals, or losing remaining vision. The most common form of fear among our patients was that of surgery. However, further exploratory studies are needed to identify the exact form and sources of fear to be able to better address this barrier.

Lack of family support and no one to accompany the patient to eye care services were the next most common barriers. This ranking is similar to other reports from Southern India (first<sup>[23]</sup> and third most common<sup>[12,24]</sup>). However, in contrast to Marmamula *et al.*,<sup>[12]</sup> our patients from urban areas quoted this barrier significantly more often than rural patients (P = 0.04). This could be related to a systemic factor wherein rural patients are transported to the base hospital while urban patients living within the town in proximity are expected to find their own way to the hospital.

"Able to manage with the current vision" was the next most common barrier even in these bilaterally cataract blind patients, similar to other reports.<sup>[13,14,18,25]</sup> However, these were not in exclusively cataract blind population as ours. In their study among tribal patients from Andhra Pradesh, Kovai *et al.*<sup>[20]</sup> reported that 76% of bilaterally blind patients felt they could see well. This barrier among bilaterally blind patients needs to be studied in greater depth using qualitative methods to ascertain vision levels at which patients perceive visual disability.

Uncontrolled systemic comorbidities as a barrier were more common in rural patients (P = 0.01) similar to the report by Marmamula et al.,<sup>[12]</sup> probably related to poor access to general health care in rural areas.<sup>[26]</sup> Place of residence itself was, however, not a barrier to access with an almost equal distribution from rural and urban areas as well as those living closer or further than 10 km from fixed eye care facilities. This could indicate improved access even in remote and rural areas through our outreach services. Moreover, outreach camps and regular weekly ophthalmology clinics in fixed facilities of secondary hospitals have been held in the same locations for several years in both rural and urban areas, thus improving acceptance rates from both areas.<sup>[27]</sup> Above 60% of cataract blind persons presented to eye camps rather than fixed eye facilities, indicating continuing preference of patients in approaching eye camps. Even though a significantly higher number of urban patients lived closer than 10 km from fixed eye care facilities, they still preferred to attend a peripheral eye camp (P = 0.002). This could be attributed to association of eye camps with free surgery or to perceived ease of access.<sup>[28]</sup>

Neighbors and acquaintances (48/168, 28.6%), general medical personnel (34/168, 20.2%), and persons who had earlier undergone cataract surgery (33/168, 19.6%) were the most common facilitating factors followed by family members (27/168, 16.1%). Provider-related facilitating factors such as announcements and proximity of outreach camps were less common [Fig. 2]. This is understandable since majority of the barriers were also individual rather than system related. To the best of our knowledge, there have been no earlier reports on facilitating factors for bilaterally blind patients accessing cataract surgical services to make comparisons.

The importance of social dynamics in the decision regarding cataract surgery and role of neighbors and family members as information providers has been stressed by Finger *et al.*<sup>[19]</sup> In our study, if considered together, neighbors, acquaintances, and family members were instrumental in 75/168 (44.6%) responses. However, neighbors and acquaintances rather than family members were more commonly quoted as facilitators in accessing cataract surgical services. Considering that the most common barrier was lack of family support or escort, this finding is not surprising. This also emphasizes the role

played by community members in improving access to eye care services and needs strengthening by improving community awareness and involvement.

General health personnel were the next most common facilitating agents. Of the 34 patients who quoted this facilitating factor, 22 (64.7%) were screened and referred from the institution's fixed primary/secondary health-care facilities. This highlights the role of general health-care workers of all levels in blindness prevention, especially those caring for systemic comorbidities, which can improve with adequate training and awareness of availability of eye care services. This will also be a step toward integration of eye care services with general primary and secondary health services.

It was interesting to note that persons who had undergone previous cataract surgery were the next most common facilitators. This is contrary to the previous reports<sup>[18]</sup> where no patient quoted a previously operated person as a reason for attending an eye camp. In fact, in 5% of people, postsurgical patients were deterrents to cataract surgery. Such reports are, however, more than a decade old when visual outcomes of cataract surgery were poor, and majority had aphakia. However, more recent population-based studies as well as SSU data<sup>[10]</sup> report the prevalence of good visual outcomes (>6/18 BCVA in operated eye to be above 75%),<sup>[23,29]</sup> indicating an overall improvement in quality and outcomes of cataract surgery over time. Since patients with good outcomes can be powerful motivators;<sup>[19]</sup> this positive trend needs to be continued and further improved by quality control measures by cataract surgery providers. Moreover, since significantly more females (P = 0.03) were likely to be motivated by a person with previous cataract surgery, they can be utilized as agents of change in improving surgical rates among women.

Our proportion of good visual outcomes was acceptable according to the WHO criteria.[30] Causes of fair vision were preexisting disc pallor, retinal pathology, and complications related to surgery. Two patients had poor vision: one had a subluxated lens preoperatively and the other wound-related complications. Good visual outcomes should have promoted the second eye surgery, and though all patients were encouraged to have early cataract surgery in the second eye, only 32.1% of patients underwent surgery at our institution within the next 1 year. Studies from various settings have also reported the prevalence of second<sup>[31]</sup> eye surgery ranging from 28% to 34%.[23] The most common reason for failure to follow-up for the second eye surgery in our study was "busy with household responsibilities," indicating that these patients had been rehabilitated well enough to be able to adequately manage daily life with useful vision in one eye. Other reports<sup>[12,19,20]</sup> corroborate this where patients were happy with vision in one eye. Since all patients had visually significant cataract in the second eye, more intense counseling and strategies to identify and encourage the second eye surgery during their postoperative follow-up are needed.

#### Conclusion

Proportions of cataract blind and hence SRR were low in our setting. Concerted efforts are necessary to improve access to more bilaterally cataract blind patients. Since neighbors and acquaintances played a pivotal role as facilitators, this support can be further built on by improving community awareness and using community members as key informants and support groups. General health workers similarly can be utilized for identification and referral of the visually disabled through appropriate training. Finally, since previously operated individuals are valuable advocates of cataract surgery especially among women, high surgical quality and good patient experiences should be priorities of cataract surgical programs.

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#### **Conflicts of interest**

There are no conflicts of interest.

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