

Awareness and eye health-seeking practices for cataract among urban slum population of Delhi: The North India eye disease awareness study

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Purpose: The objective of the study was to assess the awareness and health-seeking practices related to cataract in urban slums of Delhi. **Methods:** This study design was a population-based cross-sectional study. Participants aged 18–60 years were recruited from randomly selected five slums of South Delhi. They were interviewed using a semi-structured interview schedule on awareness and eye health-seeking practices related to cataract. The practices were recorded if the respondents themselves or any other member of the family was diagnosed with cataract in previous 2 years. **Results:** A total of 1552 respondents participated in the study, of which, 89.9% had heard of cataract but only (42%) were aware of any symptom of cataract. The common symptoms of cataract reported by the participants were white opacity in eyes (25.9%) and loss of vision (20.6%). Surgery as a treatment of cataract was known to only 559 (40.1%) participants. Awareness about surgery as treatment of cataract was significantly higher among people aged 45–60 years (adjusted odds ratio = 2.89, 95% confidence interval = 2.11–3.97) and in educated people (adjusted OR = 3.69 95% CI = 2.37–5.73). Out of 84 respondents who had been diagnosed with cataract, the health-seeking practices were observed by 70 (83.3%) participants. Among them, 51 (72.9%) had undergone surgery and another 19 (27.1%) had been advised to wait for surgery. Most of the operated patients 48 (94.1%) attended the postoperative follow-up. **Conclusion:** The study findings suggest the majority of participants have heard of cataract, but there is low awareness of its symptoms and treatment, and good eye health-seeking practices observed for cataract in urban slum population. Gaps in awareness observed can be filled up by implementing proper eye health education programs.

Key words: Awareness, cataract, eye health-seeking practices, knowledge, urban slums

Globally, cataract is the leading cause of blindness.^[1] In India, cataract alone is responsible for nearly two-third of blindness burden despite nationwide initiatives implemented under the “National Program for Control of Blindness” (NPCB) in the past two decades.^[2] The NPCB was launched in 1976 with the goal to reduce the prevalence of blindness with a focus on cataract, it being the major cause of blindness.^[2] Other efforts include the World Bank assisted “Cataract Blindness Control Program” from 1994 to 2001.^[3] “Vision 2020: The Right to Sight initiatives launched in India in 2004 following the initiatives of WHO and International Agency for Prevention of Blindness for global elimination of avoidable blindness.” Under this, eliminating blindness due to cataract was a major priority.^[4] One of the major factors for high burden of blindness has been the poor awareness about prevention of eye diseases and available eye care services.

Delhi, being capital city of India, witnesses an inflow of migrants from other parts of the country. These migrants due to poor socioeconomic status have to settle down in urban slums where dwellings are unfit owing to lack of physical

infrastructure, poor housing, and sanitation. Nearly 1.8 million people reside in slum clusters of Delhi.^[5] The health care to slum dwellers in the country has been accorded priority with launch of National Urban Health Mission.^[6] The focus of this mission is largely centric to reproductive and child health care, with a lesser priority for eye care diseases, despite a high burden of blinding eye diseases. Correspondingly, demand for eye care services at community level also need to be increased. To know community perspectives, it is imperative to study their understanding of common eye care conditions. Against this background, a North India Eye Disease Awareness Study was planned in Delhi. This study aimed to determine the awareness and health-seeking practices related to common eye conditions. We report here the findings of a part of the study pertaining to most common eye condition, cataract in urban slums population of Delhi.

Methods

This population-based cross-sectional study was conducted from August 2013 to June 2014, in randomly selected five out of

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twenty slum areas where primary eye care services are available through the vision centers of our institute. Primary eye care services include refraction services, provision of free ocular medicines, and referral services. Cataract patients are screened and referred to the base hospital for free investigations, surgery, and postoperative follow-ups. The sample size for this study was estimated using the reported level of awareness for eye care conditions in India. Among all the eye conditions, the least awareness was reported for glaucoma as 13.5% and this was used for estimating the sample size.^[7] Assuming 95% confidence limits, 20% relative error, design effect of 2, and response rate of 85%, the estimated sample size was 1500. This sample was almost equally divided into each of the five slum clusters. People in the age group of 18–60 years were interviewed by house-to-house visit.

A list of household and individuals above 18 years of age in the five slum areas was collected from the electoral office (Municipal Corporation of Delhi office, Kashmiri Gate, New Delhi). The total population of five selected slums was approximately 120,000 residing in nearly 20,400 households, with slums having 15,000–40,000 residents. One cluster within each slum was selected using compact segment sampling technique.^[8] Each slum area was subdivided into segments of 300–350 households each with the help of electoral list [Fig. 1] making a total of 66 cluster segments. One cluster segment was randomly selected from each of the five slum areas through lottery method using concealed envelopes. All the households in the randomly selected cluster segments were included in the study.

A survey team comprising social workers and field attendants was trained for study procedures. Total population

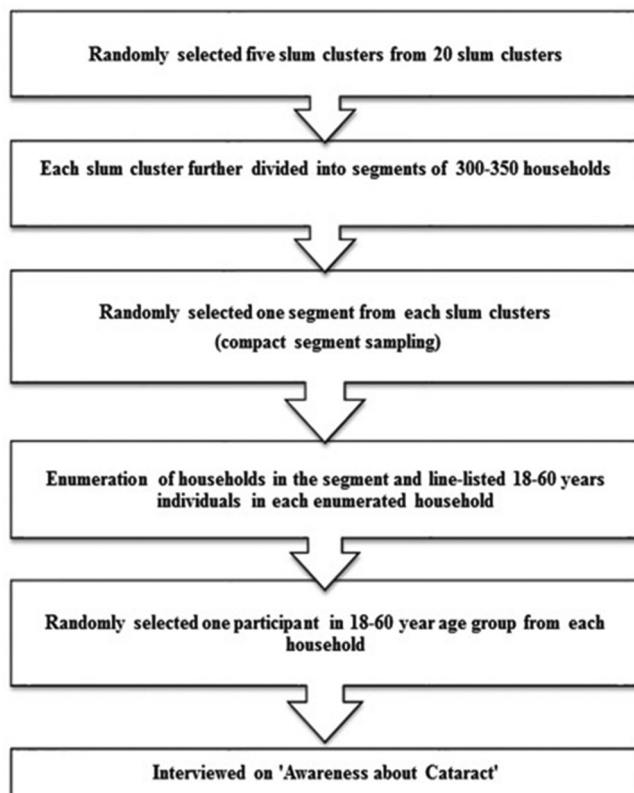


Figure 1: Sampling procedures in the study

in the age group of 18–60 years in the cluster segment was enumerated. One person in this age group was randomly selected from each household using computer-generated sequences. The interview team was given the list of households and selected participant from each household for conducting the interview. In case the participant was not available in the first visit, they were revisited for interview. They were considered absentee if not available in three visits. Minimum 300 participants were interviewed from each slum segment.

A piloted, semi-structured interview schedule was used for seeking study-related information. The schedules were initially prepared in English and further translated into the local language Hindi, back translated and examined for consistency. Expressions and terms known locally for cataract were identified and incorporated into the schedule. The standardized questionnaire was administered verbatim during the interview by the trained survey team members. The first section of the interview schedule contained questions about the participant's sociodemographic details (age, gender, education level, occupation type of family, etc.). Socioeconomic categories were based on Kuppuswamy's social scale (modified version 2012) meant for urban India.^[9] For simplification in the analysis, II and III categories (upper middle and middle/lower middle) are merged as "middle," similarly IV and V categories (lower/upper lower and lower) are merged as "lower" categories. The second section of the questionnaire sought information on participant's awareness and health-seeking practices toward cataract. The initial questions included basic assessment about awareness of cataract. All the participants

Table 1: The socio-demographic details of study participants and who had "Heard of cataract" among them

Characteristics	No of participants (n=1552), n (%)	Heard of Cataract (n=1395), n (%)
Gender		
Male	914 (58.9)	827 (59.3)
Female	638 (41.1)	568 (40.7)
Age group (years)		
18-29	620 (40.0)	519 (37.2)
30-44	554 (35.6)	514 (36.9)
45-60	378 (24.4)	362 (26.0)
Education		
Illiterate	444 (28.6)	379 (27.2)
Primary School	365 (23.5)	334 (23.9)
Middle/high School Certificate	553 (35.6)	500 (35.8)
Above high school	190 (12.3)	182 (13.1)
Occupation		
Unemployed/homemaker	768 (49.5)	678 (48.6)
Unskilled Worker	494 (31.8)	445 (31.9)
Semi-skilled Worker	18 (1.2)	15 (1.1)
Skilled Worker	172 (11.1)	161 (11.5)
Clerical, Shop owner	89 (5.7)	85 (6.1)
Semi-Profession/Profession	11 (0.7)	11 (0.8)
Socio-economic Status		
Lower	1278 (82.3)	1138 (81.6)
Middle	274 (17.6)	257 (18.4)

were asked whether they have heard of cataract (*Motia bind*) in their local language. Those who had heard of cataract were further asked in detail for their awareness about common age group in which cataract occurs, signs and symptoms of cataract and the treatment of cataract, etc. In case the participant had never heard of cataract, the interview was closed.

Subsequently, cataract-related health-seeking practices were inquired. The participants were asked if they themselves or any other member of the family had been diagnosed with cataract and advised cataract surgery in the past 2 years. In case of an affirmative reply, details of the surgery were recorded. Information was sought about the place of surgery, postsurgery followups, refraction, and the precautions taken after the surgery. In case no surgery was done, reason for the same was asked as an open-ended response which was subsequently coded.

All data were entered in MS Access™-based software. The analysis was performed using Stata version 12.0 (StataCorp, College Station, Texas, USA). Association of categorical variables with awareness of cataract was assessed by Chi-square test. Univariate and multiple variable logistic regression with removal probability ($P_r = 0.21$) and probability to enter ($P_e = 0.05$) were used to calculate unadjusted and adjusted odds ratios. The result was considered significant if $P < 0.05$.

The study was approved by the Institute Ethics Committee and adhered to the principles in the Declaration of Helsinki. Before initiating the interview, the participants were elucidated about the detailed procedure of the survey through patient information sheet, and a written informed consent was obtained.

Results

A total of 1703 participants were enumerated from the five cluster segments. Among them, 1552 participants (91.1%)

were enrolled in the study. Out of the remaining 151 (8.9%) enumerated participants, 117 could not be covered even after making three visits to their households and 34 refused to participate in the study. The coverage was similar for male (93.2%) and female (91.8%) eligible participants. The mean age of the participants was 34.5 ± 12.1 years. Of all participants, 620 (40%) were in the age group of 18–29 years, 554 (35.6%) and 378 (24.4%) in the age group of 30–44 years and 45–60 years, respectively [Table 1]. Out of the total participants, 914 (58.9%) were males, and about 50% (809) were illiterate or educated up to primary level. Almost half of the participants were unemployed or homemakers. Further 494 (31.8%) were unskilled workers. A majority of participants, i.e. 1278 (82.3%), belonged to the lower and upper-lower socioeconomic status.

Awareness about cataract

Majority of the participants, 1395 (89.9%), had heard of cataract. The sociodemographic distribution of the study participants and who had heard of cataract among them is shown in Table 1.

Among those who had heard of cataract, only 390 (28.0%) knew that cataract occurs mostly in “above 50 years” age group. More than half of the participants, 809 (58.0%), were not aware of any symptom of cataract. The most common reported symptoms of cataract were white opacity in eyes (25.9%) and loss of vision (20.6%). Surgery as a treatment of cataract was known to only 559 (40.1%) participants, whereas rest of the participants reported misconceptions about treating cataract (836; 59.9%). Among the participants who were aware of surgery as treatment for cataract, 82.7% knew that intraocular lens (IOL) is used for cataract surgery [Table 2].

Awareness of symptoms of cataract was not significantly associated with age ($P = 0.079$), but it was higher among males ($P = 0.017$) [Table 3]. On the other side, awareness about cataract treatment was significantly higher among females ($P < 0.001$). Awareness of cataract treatment was also higher among aged ($P < 0.001$) and educated people ($P < 0.001$) [Table 4].

Table 2: Awareness of cataract among the study participants

Awareness about cataract (n=1395)	Male (%)	Female (%)	Total (%)
Age group in which cataract commonly occur? (n=1395)			
Above 50 years	242 (29.3)	148 (26.1)	390 (28.0)
Don't know	585 (70.7)	420 (73.9)	1005 (72.0)
Common symptoms of cataract? (n=1395)			
White opacity in eyes	227 (27.5)	135 (23.8)	362 (26.0)
Loss of vision in eyes	178 (21.5)	109 (19.2)	287 (20.6)
Painless loss of vision	6 (0.7)	5 (0.95)	11 (0.8)
Gradual loss of vision	6 (0.7)	1 (0.2)	7 (0.5)
Polyopia	2 (0.2)	0	2 (0.1)
Glare	0	1 (0.2)	1 (0.1)
Don't know any symptom of cataract	458 (55.4)	351 (61.8)	809 (58.0)
Treatment for cataract? (n=1395)			
Surgery	314 (38.0)	245 (43.1)	559 (40.1)
Don't know/misconceptions	513 (62.0)	323 (56.9)	836 (59.9)
Awareness about the IOL in cataract surgery? (n=559)			
Awareness	262 (83.4)	200 (81.6)	462 (82.7)
No awareness	52 (16.6)	45 (18.4)	97 (17.3)

IOL: Intraocular lens

Table 3: Association of age and gender with “awareness of cataract symptoms” (n=1395)

Demographic variable (n=1395)	Aware of at least one symptom (n=586), n (%)	Don't know any symptom (n=809), n (%)	Statistical significance* (P)
Age group (years)			
18-29 (n=519)	198 (38.2)	321 (61.9)	0.079
30-44 (n=514)	229 (44.6)	285 (55.5)	
45-60 (n=362)	159 (43.9)	203 (56.1)	
Gender			
Male (n=827)	369 (44.6)	458 (55.4)	0.017
Female (n=568)	217 (38.2)	351 (61.8)	

*Chi-square test

Table 4: Association of demographic characteristics with “awareness of cataract treatment” (n=1395)

Demographic variables	Total (n=1395)	Awareness of cataract surgery (%)	Unadjusted OR (95% CI)	Statistical significance (P)	Adjusted OR (95% CI)	Statistical significance (P)
Gender						
Male	827	314 (38.0)	1		1	<0.001
Female	568	245 (43.1)	1.23 (0.99-1.54)	0.053	1.73 (1.34-2.24)	
Age group (years)						
18-29	519	160 (30.8)	1		1	
30-44	514	229 (44.6)	1.80 (1.39-2.32)	<0.001	2.32 (1.75-3.06)	<0.001
45-60	362	170 (47.0)	1.98 (1.50-2.62)	<0.001	2.89 (2.11-3.97)	<0.001
Education						
Illiterate	379	127 (33.5)	1		1	
Primary school	334	150 (44.9)	1.61 (1.19-2.19)	0.002	2.23 (1.61-3.10)	<0.001
High school	500	194 (38.8)	1.25 (0.95-1.66)	0.107	2.22 (1.58-3.11)	<0.001
Above high school	182	88 (48.4)	1.85 (1.29-2.66)	0.001	3.69 (2.37-5.73)	<0.001
Occupation						
Unemployed	678	269 (39.7)	1		1	
Unskilled worker	445	167 (37.5)	0.91 (0.71-1.16)	0.470	-	0.630
Skilled worker and above	272	123 (45.2)	1.25 (0.94-1.66)	0.117	1.23 (0.91-1.66)	0.160
Religion						
Hindu	1161	468 (40.3)	1		1	0.876
Muslim	234	91 (38.9)	0.94 (0.70-1.25)	0.686	-	
Socioeconomic status						
Lower	1138	437 (38.4)	1		1	0.137
Middle	257	122 (47.5)	1.44 (1.10-1.90)	0.008	1.25 (0.93-1.69)	

CI: Confidence interval, OR: Odds ratio

Health seeking practices for treatment of cataract

Health-seeking practices were assessed for 84 participants who were either diagnosed with cataract themselves or had a case of cataract in their family in the past 2 years. The health-seeking practices were observed by 70 (83.3%) participants. In 51 (72.9%) cases, the patient had undergone surgery and another 19 (27.1%) cases had visited doctor and were told to wait for surgery [Fig. 2]. Among 14 patients who did not seek care, six mentioned lack of time, three had fear of surgery, and two stated financial difficulties as reasons. Majority of the participants (78.4%) opted surgery at government hospitals, 19.7% (10) got operated at private hospitals whereas only one patient was operated at non-governmental organization (NGO) hospital. Out of the total operated patients, 96.1% (49) participants were aware that IOL was implanted in the cataract surgery. Multiple responses

were obtained when participants were asked to enumerate about the precautions to taken postoperatively. Majority of operated patients (94.1%) reported for follow-up examination and 72.5% (37) got refraction done, of whom 81.1% (30) did get their spectacles made.

Discussion

This study was conducted to assess the awareness and health-seeking practices about cataract among the people aged 18–60 years living in slum areas in Delhi. The proportion of females registered in the study was 41.1% compared to 58.9% males. The gender distribution of our sample was similar to the overall female population distribution in the five slum areas. The male preponderance may be due to higher male migration from the rural areas leaving behind spouses and children in the villages. While other studies have included 40 years and above

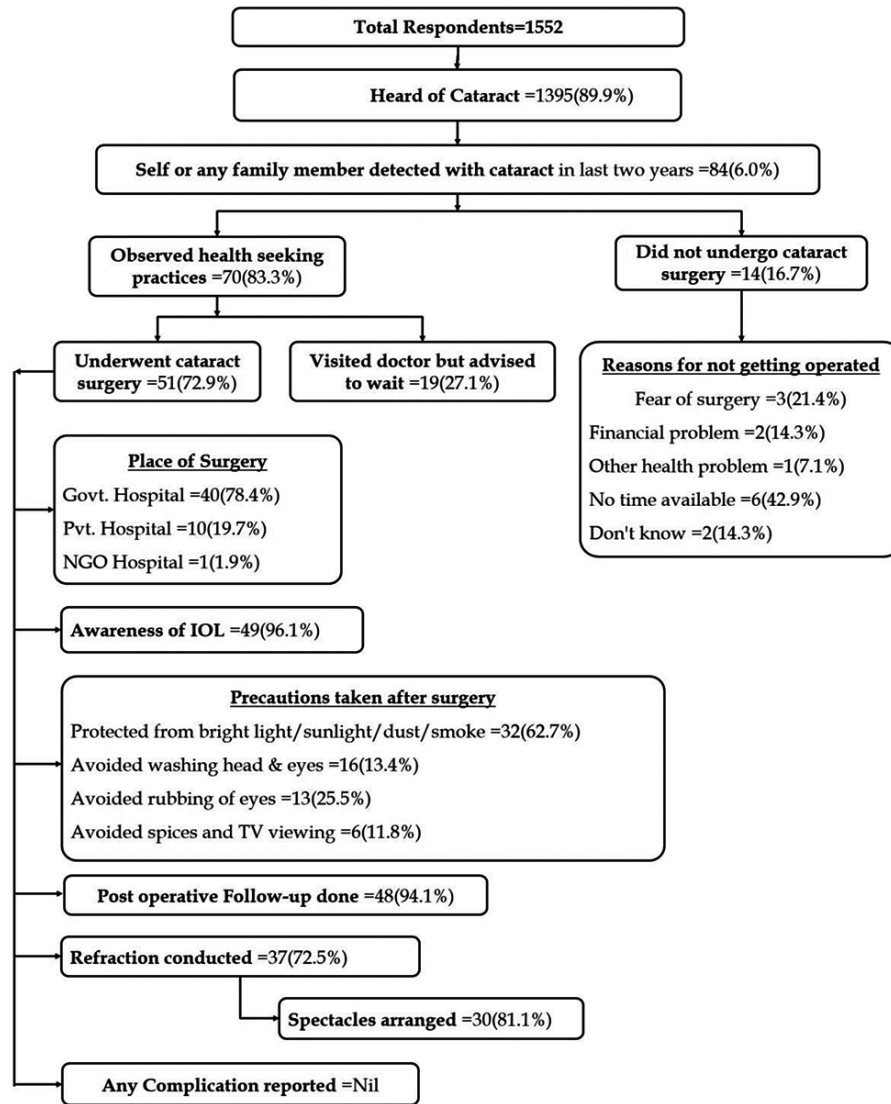


Figure 2: Health-seeking practices for the treatment of cataract

population for assessing awareness and eye health-seeking practices about cataract, we included also younger population due to their higher proportion in slums and their involvement in decision-making for their families.^[10-12]

In the study, majority of the participants had heard of cataract (89.9%). This is higher than the Andhra Pradesh Eye Disease Study which reported 68.9% of participants ever heard of cataract.^[13] Our results were found closer to international studies including the Australian Blue Mountain Eye Studies (98%), Australian Visual Impairment Study (92%), and Hong Kong Study (92.9%), The Bangladesh population-based diabetes and eye study (91%).^[10,11,14,15] In Nepal, two different studies reported cataract awareness as 6.7% and 49.6%, respectively.^[12,16] The majority of people had heard of cataract in this study may be attributed to several reasons. Cataract is the most common cause of blindness in India and government gives a lot of emphasis on treatment of cataract blindness under the NPCB. Under 12th 5-year plan, the government has envisioned performing about 33 million cataract surgeries with a target of IOL implantation in 95%

of these surgeries.^[17] As government provides funds to the NGOs for performing cataract surgeries, a large number of NGOs are involved in conducting cataract screening camps and publicity in the general population for attending these camps.

Even though majority of people had heard of cataract, awareness about various other aspects of cataract such as symptoms and treatment was found to be low. Similar findings were reported from Hong Kong where awareness about cataract symptoms (22.9%) and treatment (57.6%) was low,^[14] whereas, in other studies, good awareness about the treatment of cataract among those who had heard of cataract has also been reported.^[12,13]

It has been observed that among the diagnosed cataract cases reported in the past 2 years, the eye health-seeking practices were good (83.3%). Among them, 72.8% had undergone cataract surgery and another 27.1% had sought care but advised to wait for the surgery. Most of the patients had got their surgery from government hospitals. These hospitals offer free surgical extraction services and most of the slum dwellers being poor,

resort to free services. This is contrary to rural or remote areas where majority of surgeries are performed by the local NGOs. Most of the operated patients had taken some precautions after cataract surgery and pursued the surgeons' instructions to a greater extent. Majority of the operated patients (94.1%) had gone for their follow-up after surgery and obtained the refraction services postoperatively. There was good awareness about IOL (96.1%) among the people who have undergone surgery. Most of the cataract surgeries in India are undertaken with IOL. This is much higher than a previous study conducted more than one decade earlier, where reported only 31.4% participants were aware of IOL.^[13]

We found that good health-seeking behavior exists in spite of poor awareness about treatment of cataract. This may be due to higher awareness among the older age groups where cataract is most prevalent. The cataract surgical services are arranged through the eye camps. While the respondents may not be aware of surgery as only treatment, it may happen that the family member developing cataract sought advice from the care provider and received correct surgical advice.

Based on these findings, a need is realized for initiating eye health education programs specifically targeting awareness about the treatment of cataract and other common eye conditions and including younger age group and illiterate slum populations. Eye health promotion has been found to be associated with higher motivation to seek timely treatment and thus preventing blindness.^[18]

Our study had certain limitations. The study was conducted in the field practice area of the hospital, and higher awareness might be expected in these slums population, as primary eye care services are provided in these areas. However, the population catered here is largely migratory which may dilute this bias. Furthermore, in the study, information about health-seeking practices for the operated family members was asked from participants, this may not be a very reliable, especially when the participant's literacy level was low. Some degree of bias might creep here due to information sought from proxy participants.

Conclusion

This is probably the first study in this urban area in North India covering a large sample of population and detailed cataract awareness and practices have been obtained from the slum dwellers. Even though the awareness about the cataract treatment was low, still the health-seeking practices were high. Our study has programmatic implications. There is a need to augment awareness activities for eye care services to help in demand generation among the affected people and they may visit hospitals timely before cataract leads to blindness. The single important message that cataract can only be treated with surgery and there is no need to wait for maturing of cataract may aid in increasing uptake of cataract surgical services. We envisage such focused information and communication opportunities when offered to urban poor, will successfully enhance demand for cataract surgical services, and will lead to early restoration of vision.

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Conflicts of interest

There are no conflicts of interest.

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