# Changing trends in barriers to cataract surgery in India

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Cataract is a major cause of blindness in Asia. Efforts in India to provide cataract surgical services have had limited success in reaching the cataract-blind population. Earlier studies identified the major barriers to cataract surgery as poverty, lack of transportation or felt need, or sex related; and the critical barriers in rural areas as lack of awareness, difficult access, and cost. Compared with these earlier data, the results of the present study in Karnataka State indicate a shift in the character of the barriers. They now appear to be more related to case selection and service provision. These shifts are analysed and alternative strategies to increase the uptake of cataract surgery are recommended.

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## Introduction

Cataract is the major cause of blindness in Asia (1). In India it is estimated that there are about 9 million people who are blind due to cataract (2). Incidence studies of cataract in India have reported that about 1.8-3.8 million new cases are added to the backlog every year (3, 4). There are nearly 9000 ophthalmologists in India and, as is the case in many developing countries, there is an imbalance in the distribution of eve specialists. While service providers are concentrated in major cities and towns, individuals who require cataract surgery predominantly live in villages. This has led to inadequate service provision to the rural poor. India has a long history of providing cataract surgical services through outreach eye camps organized by nongovernmental organizations (NGOs) and district mobile units (DMUs) from the government sector. However, such efforts appear to have limited success in reaching the cataract-blind population. Despite major efforts towards information, education and communication (IEC) by the providers to increase the uptake of surgery by the cataract blind, several barriers at the community level and among individuals continue to hamper the efforts to motivate them for cataract surgery.

In 1991, Brilliant et al. estimated that about 20% of all cataract-blind persons in India receive

## **Materials and methods**

A rapid assessment was conducted in 1995 to estimate the prevalence of cataract blindness in 19 out of 20 districts of Karnataka State in the southwest of India. Bangalore city district was not included in the survey due to its highly urbanized character, which would be expected to influence the survey results. Among other things, the survey collected data from the sample population on the reasons for not having an operation for cataract blindness. This study analyses these data. Details of sampling and survey methodology are described elswhere (8).

surgery (10). More recently, a population study in Karnataka State in India (5) indicated that 53% of persons and 35% of all eyes blind due to cataract (visual acuity, VA < 3/60) have been operated upon. Earlier studies (6, 7) identified the major barriers to cataract surgery as "poverty", "no transportation", "need not felt" and "sex related". The low literacy rate among females and poor accessibility of the surgical sites were identified as important barriers in rural areas. Hitherto, the awareness of possible treatment by an operation, access to the surgical site, and affordable cost were the critical deciding factors among rural populations. However, the results from the Karnataka study indicate a shift in the character of these barriers. They appear to be related more to case selection and the nature of service provision than to patients' awareness, attitudes or ability to afford services. The present study attempts to analyse these changes. Alternative strategies are recommended in order to increase uptake and thereby improve the coverage for cataract surgery, and to reduce the backlog.

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According to census data, the population of Karnataka State was 45 million in 1991. A systematic random cluster sampling method was used. The number and size of the cluster were calculated using the 1986 estimates of prevalence (4.4 % for bilateral cataract blind at the VA <3/60 level for the population aged ≥ 50 years), assuming a confidence level of 80% with a 20% error and a design effect of 1.5. A sample size of 1350 persons from 15 clusters with 90 persons per cluster was selected for each of the 19 districts. The sample population included only persons aged ≥50 years. Cataract blindness was defined as the presence of an obvious opacity in the lens and a VA < 3/60 with available correction. A person is defined as "blind due to cataract" if both eves meet these criteria.

A pre-tested data collection sheet was administered to the sample population. It contained five sections — individual identification, vision testing and lens status examination, reasons for not having surgery, service indicators for those operated, and anecdotal information from the relatives if the person concerned was not present during the visit. The data were collected by qualified ophthalmic assistants after training in the methodology to standardize the recording of vision, lens status and response about barriers.

The VA of the sample population was assessed with the available correction using a simplified chart with tumbling "E" equal to sizes 60 and 18 in the standard Snellen's chart. All patients were also examined with a distant direct ophthalmoscope without dilatation of the pupil under semidark conditions in their own house. The lens status on examination was classified as normal, obvious opacity present or pseudo aphakia present. Patients

identified with "blinding cataract" were asked to state their reasons for not receiving surgery. The first clear response was recorded. Responses such as waiting for maturity, operation denied, and need not felt were further probed and reported. The data were analysed using Epi Info version 6.04 software and STATA intercooled version 5.0.

The test of proportion (Z-test) was applied to assess the statistical association between two categorical variables (9). Further, the barriers to cataract surgery given in the present study in 1995 were then compared with a similar study (10) carried out in the adjoining state, Tamil Nadu, in 1986. Both studies adopted similar data collection methods to record the barriers. The response categories were also comparable.

# Results

A total of 26 084 eligible persons were identified for the sample, 21 950 (84.2%) of whom were examined in their homes. Three clusters were not included in the analysis, due to exogenous factors affecting the data collection during the study. A total of 3259 persons from the sample population, blind due to cataract in one (2114) or both (1145) eyes, indicated their reasons for not having an operation for cataract (Table 1).

Nearly 24% of people bilaterally blind and 33% of those unilaterally blind due to cataract reported to the service facility at least once, but were told to wait as the "cataract has yet to mature". Males mentioned this more often as a barrier than females in both the bilateral and unilateral category of cataract blind (P < 0.001). The second major

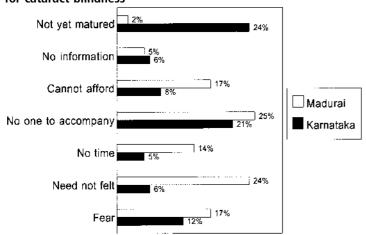
Table 1. Percentage distribution of reasons, by sex and category of blindness, for not having an operation for cataract, Karnataka, 1995

Barrier	В	Unilaterally blind				
	Males (n = 359)	Females ( <i>n</i> = 786)	Total ( n = 1 145)	Males ( <i>n</i> = 794)	Females ( <i>n</i> = 1 320)	Total (n = 2 114)
Curse of God	0.3	0.6	0.5	0.1	0.1	0.1
Waiting to mature	30.0	20.7	23.6	36.9	31.1	33.4
No service	2.8	2.7	2.7	2.5	2.3	2.4
No information	7.2	4.8	5.6	5.8	4.1	4.7
Operation denied	8.1	4.3	5.5	5.4	3.3	4.1
Cannot afford	7.0	7.4	7.2	6.7	5.9	6.2
No one to accompany	14.2	24.9	21.6	8.1	14.9	12.3
No time	2.5	2.3	2.4	4.4	3.2	3.6
Other priorities	3.3	2.8	3.0	2.4	2.7	2.6
Need not felt	4.5	6.7	6.0	9.1	7.7	8.2
One eye operated	0.0	0.0	0.0	6.3	7.9	7.3
Fear	7.5	14.5	12.3	5.9	11.7	9.5
Contraindications	12.0	7.9	9.2	5.5	3.9	4.5
No faith	0.6	0.1	0.3	0.3	0.6	0.5
Others	0.0	0.3	0.2	0.6	0.6	0.6
Total	100	100	100	100	100	100

#### Research

barrier mentioned (21.6% of the bilaterally blind) was "no one to accompany" the patients to the surgical centres. Females (24.9%) stated this nearly twice as frequently as males (14.2%) (P < 0.001). As expected, this response was less frequent in unilaterally blind people. "Fear of operation" was the third major barrier for 12.3% of the bilaterally blind population. In both categories of blindness, females (14.5% and 11.7%) expressed this response more often than males (7.5% and 5.9%). Surpris-

Fig. 1. Comparison of the results of the Madurai (1986) and Karnataka (1995) studies on reasons for not having an operation for cataract blindness



ingly, it was still an important barrier for nearly 10% of the unilaterally blind population. As expected, ill health and other contraindications to surgery due to old age were also given as barriers, more by males than by females. "Need not felt" and "one eye operated" were more common in the unilaterally than bilaterally blind population. "No services" and "no information" about services were less frequently indicated as barriers, against the expected trend (Table 2 and Fig. 1).

The analysis further showed that there were differences in the perception of barriers to cataract surgery not only by sex and by number of blind eyes, but also between the districts. While "waiting for maturity" for cataract operation is the leading overall barrier in the state (range, 0-41%), with Chitra durga, Belgaum, Dharwad, Tumkur and Bellary districts reporting incidences of ≥30%, Dakshin Kannada district did not report this barrier at all. Most districts reported "no one to accompany" and "other medical problems" as second and third major barriers. "Cannot afford surgery" due to economic conditions was reported as a barrier most often in Bangalore, Bijapur, Gulbarga, and Raichur rural districts. In Belgaum, Kodagu, Kolar and Tumkur districts, "no information" was one of the major barriers. While Shimoga and Kodagu districts gave "need not felt" as one of the main barriers in the community, Uttar Kannada was the only district to show a high incidence for the barrier "no time and other priorities".

Table 2. Percentage distribution of reasons for not being operated on for cataract (in the bilaterally blind), by district in Karnataka, 1995

District	Not yet mature	Fear	No need	Cannot afford it	No one to accompany	Other diseases	No time <sup>a</sup>	Not aware	Other reasons
Danaslava	10	12	0	17	22	20	4	0	0
Bangalore	16	12	9	17	22	20	4	0	0
Belgaum	36	6	8	6	18	2	2	8	14
Bellary	30	10	1	9	16	21	3	5	5
Bidar	14	14	0	2	29	14	6	16	6
Bijapur	28	16	5	18	22	7	2	1	0
Chikmagalur	26	3	0	10	39	13	6	0	3
Chitra durga	41	8	1	4	18	15	7	5	1
D. Kannada	0	30	7	2	21	21	14	5	2
Dharwad	36	8	8	6	9	21	6	0	6
Gulbarga	28	9	6	12	24	10	3	6	3
Hassan	18	21	8	5	26	11	3	5	3
Kodagu	19	13	13	0	19	6	6	19	6
Kolar	27	18	9	4	19	8	1	14	1
Mandya	15	18	10	0	29	19	3	2	5
Mysore	5	19	9	3	33	14	7	5	5
Raichur	17	10	5	12	27	12	2	7	7
Shimoga	16	10	20	4	16	22	8	2	2
Tumkur	34	7	1	2	21	16	7	11	1
U. Kannada	13	8	5	5	11	26	24	3	5
All Karnataka	24	12	6	7	22	15	5	6	4
Range	0–41	3–30	0–20	0–18	9–39	2–26	1–24	0–19	0–14

<sup>&</sup>lt;sup>a</sup> No time and other priorities.

Having analysed the inter-district and sex differentials in the perception of barriers, an attempt was made to analyse such differentials over a period of time. For this, a comparison was made with a 1986 study conducted in Madurai, Tamil Nadu, south India, an area with similar sociocultural and demographic conditions. In the Madurai study, the definition of cataract blindness and the response categories for barriers were similar to the ones used in the present study. Both studies recorded the reasons among the bilaterally blind population. There was an interval of nearly a decade between the two studies.

"Need not felt" (24%), "cannot afford" (17%) and "no one to accompany" to the treatment centre (25%) were the most important barriers for the study population in the Madurai study. Only a small proportion (2%) expressed "waiting for cataract to mature" as a barrier. "Cannot afford" was a barrier for 17% in the Madurai study.

Comparison of the two studies shows that there has been a major shift in the barriers to cataract treatment. While the "waiting for maturity" barrier was reported only occasionally in the Madurai study in 1986, by 1995 it had emerged as a major barrier among the communities. Similarly, "need not felt" and "cannot afford" as major barriers exhibited a considerable decline between the two study periods. However, "no one to accompany" as a barrier has remained more or less the same. Comparison of the two studies thus indicates that there has been a positive shift in awareness of surgery and of the need for better vision among the population. This can be further analysed (Table 3) when the individual responses are combined into four broad types; attitudinal, economic, service, and illnessrelated.

Seven reasons, namely "curse of God", "fear", "no faith", "need not felt", "no time", "other priorities", and "one eye operated", which are individual decisions and perception oriented, were classified as attitude-related. "Waiting for cataract to mature", "no services", "no one to accompany", and "no information" are directly related to service delivery. Of the remaining three reasons, one was related to cost and affordability and two were related to contraindications and systemic illness in patients. In the Madurai study, eight different responses were reported as the major barriers. Data on illnessrelated responses were not available and therefore could not be compared with the results in the Karnataka study. In 1995, over 53% of the responses from Karnataka were related to service delivery, whereas in Madurai in 1986 the proportion was only 32%. The personal and attitudinal type of barriers have declined by more than 50% between the two study time points. The inter-study comparison of barriers shows that in 1986 the incidence of attitudinal and personal barriers was high (54.3%) and the service-related barriers were comparatively less frequent, whereas in 1995 the opposite trend appeared to be the case.

# Discussion

The National Programme for Control of Blindness (NPCB) was started in India in 1976. The development of infrastructure and increased manpower in ophthalmology have resulted in an increase in cataract surgical output from 0.5 million in 1982 to over 2.7 million in 1996. Nevertheless, the backlog of cataract blindness in India has not yet been eliminated. Health education methods and strategies will only be effective if they are able to reduce the barriers that prevent the cataract blind from seeking treatment services. Present strategies have so far focused on the barriers related to cost, fear and awareness. But the results of the present study indicate a shift in those barriers in the community. Today, the main barriers in India appear to be more related to service providers. This assessment of blindness in Karnataka State covered a large sample of the population. The social, economic, demographic, and health indicators in Karnataka are comparable to those in the other major states of India. It is therefore possible to extrapolate the study findings to the country in general.

The wide variation in the barriers between the districts in Karnataka, and the shift in barrier perception between the two studies over nearly a decade, not only show a general increase in awareness of surgical care for cataract but also the need for a district-specific understanding of the barriers. Even among communities with similar sociocultural practices within a single state, the perception of barriers to the uptake of cataract surgery has been found to differ. This should be an area in which eye care managers and social scientists can investigate the inter-district dynamics in terms of these barriers.

The broad classification of the responses about barriers clearly indicates the shift. With improvements in overall development in districts and states, there is likely to be an increased awareness about eye care and willingness for surgery by individuals and the community as a whole. However, the nature of service delivery appears to prevent people from being operated on in time. If patients report for treatment and are told to wait, this would indicate that either the capacity of the providers to take care of the increased demand is limited or the VA indica-

Table 3. Percentage distribution of barriers to cataract surgery, in Madurai (1986) and Karnataka (1995)

Karnataka ( <i>n</i> = 11 459)		
24.5		
7.4		
53.5		
32.0		

a Not available.

tion for surgery is too low. Similar results were found in Mohadi (Maharashtra State) in 1992 (11), where nearly 34% of the reasons given as barriers were service related. As the attitudinal barriers diminish, the demand for services has increased as expected. Consequently, the service delivery-related barriers have also increased.

Although the attitudinal barriers have declined over time, they are still high enough to prompt a call for better understanding. Apparently, the present methods of IEC and health education used to motivate people to undergo cataract surgery have become either routine or less effective in changing community behaviour. It is perhaps time to reevaluate the types of message, their content and the methods used to reach cataract-blind persons by means of issue-specific participatory studies.

This study suggests that the uptake of surgery is governed by two factors. First, rural patients with a VA of <6/60 or with lens opacification, although by definition classified as blind, do not consider themselves to be so and do not perceive the need for surgery at this stage. Blindness as a disability for them is taken to mean complete dependency and lack of functional mobility. Until such time, they tend to wait. This is similar to the findings of a national survey in Lebanon (1995) (12), where the senior citizens believed that surgery should be delayed till the cataract is fully mature. In Karnataka, this barrier is more commonly seen among females than males, and females appear to avail themselves of surgery at a later stage than males. More in-depth and gender-specific analysis of this barrier needs to be undertaken.

Second, providing better post-operative care with individually adjusted spectacles to such patients presents logistic problems. Popularizing fixed day services and surgeries at fixed centres can improve follow-up care postoperatively. Implanting an intraocular lens (IOL) in patients with an "immature" cataract by trained surgeons with proper equipment, and exploring contractual arrangements with local opticians to provide individually adjusted glasses, could reduce the logistic problems for the providers.

Since not having anyone to accompany them is the second most commonly reported barrier, sending cataract-blind patients away is likely to demotivate them from returning for surgery in future. It is necessary to evaluate the case rejection criteria by service providers in order to improve the uptake and to meet the demand. The eye care providers at both the district and state level should therefore give greater consideration to providing surgery before people go totally blind in both eyes. The study has also shown that affordability and cost considerations are less significant barriers to surgery. They are likely to be more important in economically backward areas, urban slums, and in districts which are close to metropolitan cities. However, in most situations, the distance to be travelled by patients and by accompanying persons could still be a barrier, especially for females, which may influence service delivery. Elderly women from rural areas with cataract or poor vision prefer an attendant to be with them during their treatment. Augmenting outreach services can help to bring the cataract surgeries closer to the community. Providing accommodation for attendants closer to hospital facilities and reducing the length of the hospital stay can be other ways to reduce such barriers.

In conclusion, the study has demonstrated that in Karnataka, awareness, attitudes and the affordability of surgery are no longer the major barriers in most districts. The community feels that there is a need for surgery, but patients are often turned away because they are considered by the providers to be not yet blind enough for cataract surgery. Eye camps are still a major source of service delivery in the periphery and are still popular among the rural poor. Camps, however, have a limited capacity and many surgeons prefer to operate when the VA is 1/60. This has become a norm for case selection and to regulate the capacity in camps. With the change in the strategy in favour of institutional surgeries through the base hospital approach, it should be possible for service providers to take more cases, operate early if needed with IOLs, and provide better quality services to the cataract blind population. The interdistrict variations and the change in the perception of barriers over the last decade indicate that addressing the barriers through a general and routine health education approach will not be sufficient. Need-related, useroriented and community-specific strategies will be required by IEC and motivational campaigns at the national, state and district level, both for the patients and providers.

### Résumé

## Evolution dans les obstacles au traitement chirurgical de la cataracte en Inde

La cataracte est une cause majeure de cécité en Asie. Les efforts qui ont été faits en Inde pour offrir un traitement chirurgical de la cataracte n'ont guère permis d'atteindre les populations touchées. Selon des travaux antérieurs, les principaux obstacles sont liés à la pauvreté, à l'absence de moyens de transport, au fait que la nécessité n'en n'est pas toujours ressentie ou encore à des facteurs en rapport avec le sexe. En milieu rural, l'information, l'accessibilité et le coût jouent un

rôle déterminant. Les résultats de la présente étude, menée dans l'Etat de Karnataka, révèlent un changement par rapport aux données antérieures. Il apparaît en effet que les principaux obstacles au traitement chirurgical tiennent désormais à la sélection des patients et aux prestations de services. Les auteurs analysent cette évolution et recommandent un certain nombre d'autres stratégies pour que le traitement de la cataracte soit mieux accepté.

#### Resumen

## Cambio en las barreras que se oponen a la cirugía de la catarata en la India

La catarata es una importante causa de ceguera en Asia. Los esfuerzos desplegados en la India para prestar servicios de cirugía de la catarata han tenido poco éxito debido a la dificultad para llegar a los afectados. Según estudios anteriores, los principales obstáculos eran la pobreza, la falta de transporte, el hecho de que los enfermos no sintieran la necesidad de operarse o factores relacionados con el sexo y, en las zonas rurales, el desconocimiento de que la afección pudiera operarse,

la falta de acceso y el costo. En comparación con esos datos, los resultados del presente estudio realizado en el estado de Karnataka revelan un cambio en el tipo de obstáculos, que ahora parecen estar más relacionados con la selección de casos y la prestación de servicios. Se analizan esos cambios y se recomiendan nuevas estrategias para aumentar el recurso a la cirugía de la catarata.

#### References

- Foster A. World blindness, increasing but avoidable! Seminars in ophthalmology, 1993, 8: 166–170.
- 2. **Thylefors B et al.** Global data on blindness. *Bulletin of the World Health Organization,* 1995, **73**: 115–121.
- Minassian DC, Mehra V. 3.8. million blinded by cataract each year–projections from first epidemiological study of incidence of cataract blindness in India. *British journal of ophthalmology*, 1990, 74: 341–343.
- 4. **Limburg H, Vaidyanathan K et al.** *Incidence of cataract blindness in Maharashtra, India*, (unpublished data).
- Danish Assistance to National Programme for Control of Blindness. Rapid assessment of cataract blindness, Karnataka — report of survey design, methodology and results. 1997.
- Venkataswamy G, Brilliant GE. Social and economic barriers to cataract surgery in rural south India: a preliminary report. Visual impairment and blindness, 1981, 75: 405–408.

- Courtright P et al. Barriers to acceptance of cataract surgery among patients presenting to district hospitals in rural Malawi. *Tropical and geographical medicine*, 1995, 47: 1518.
- Limburg H et al. Rapid assessment of prevalence of cataract blindness at district level. *International journal of epidemiology*, 1997, 26(5): 1049–1054.
- Altman DG. Practical statistics for medical research. London, Chapman & Hall, 1991: 232–234.
- Brilliant GE et al. Social determinants of cataract surgery utilisation in south India. Archives of ophthalmology, 1991, 109: 584–589.
- Limburg H et al. Cataract blindness on the rise? Results of a door-to-door examination in Mohadi. *Indian journal of ophthal-mology*, 1996; 44: 241–244.
- Mansour AM et al. National survey of blindness and low vision in Lebanon. *British journal of ophthalmology*, 1997, 81: 905–906.