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BMJ Open Barriers to uptake of referral services from secondary care to tertiary care and its associated factors in L V Prasad Eye Institute network in Southern India: a cross-sectional study

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ABSTRACT

Objective To examine barriers to the uptake of referral services from secondary care centres to higher level tertiary care centres.

Design Cross-sectional study.

Setting Secondary care hospital in Khammam District in the Telangana state of India.

Participants Nine hundred and three patients who were referred from a secondary care centre to tertiary care centres between June 2011 and December 2012, were over the age of 18 and lived within 50 km of the secondary care centre were identified. Six hundred and sixteen (68.2%) of these patients were successfully contacted, and 611 (99%) of those contacted consented to participation in the study.

Interventions Those who attended at higher centres after referral (compliant) and those who failed to attend (non-compliant) were interviewed with a standard questionnaire designed for the study.

Primary and secondary outcome measures Outcome measures were barriers to the uptake of eye care services for the non-compliant participants and the associated risk factors for non-compliance.

Results Of the contacted patients, 418 (68.4%) were compliant and 193 (31.6%) were non-compliant. The mean age of interviewed patients was 48.4 years (SD: 17.9 years) and 365 (59.7%) were male. Of those who did not comply with their referral, the major identified barriers were 'cannot afford treatment cost' (30%) and 'able to see adequately' (20.7%). Multivariable analysis showed that participants in the non-compliant group were more likely to have had only one prior visit to the centre (OR: 2.5, 95% Cl 1.6 to 3.9), be referred for oculoplastic services (OR: 3.0, 95% Cl 1.0 to 8.8) and to be the main earning member of the family (OR: 1.9, 95% Cl 1.2 to 2.8).

Conclusions Non-compliance with referrals in this population is largely attributable to economic and attitudinal reasons. Focusing on these specific barriers and targeting groups at higher risk of non-compliance could potentially improve uptake of referral services.

Strengths and limitations of this study

- This is the first study in ophthalmology conducted in low-income and middle-income countries that examines non-compliance with referral services to tertiary care centres.
- It highlights the key factors that are responsible for non-compliance with referral service uptake.
- This study identifies the characteristics of patients who are less likely to comply with their referral, allowing a targeted intervention to increase compliance with high-risk patients.
- This study was conducted within a unique healthcare network in Southern India, thus may not be generalisable to all settings.
- Nearly one-third of eligible patients identified by the medical records could not be contacted.

INTRODUCTION

Poor access to healthcare is a global issue that disproportionally affects resource-poor countries and correlates with poor health outcomes. Specifically, visual impairment affects an estimated 253 million people worldwide, with the vast majority of these people residing in low-income and middle-income countries.^{1 2} Although there has been a recent trend towards the increased utilisation of eye care services, the issue of poor uptake of services still persists.³ Even when high-quality eye care services are readily available, there is often a disconnect between what is available and what is actually used.^{3–5} A number of studies have examined such barriers within the primary stages of eye care delivery, particularly related to the uptake of cataract services.⁶⁻¹³ Major barriers cited in these studies include economic barriers,^{11 13} no felt need or desire for surgery,⁶¹² no one to accompany or issue with transportation,¹⁰¹¹

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fear of surgery,¹² and lack of awareness.¹⁰ Few studies from developed nations have also looked at the non-compliance of referral services for low vision and rehabilitation services.^{14 15} However, there are no studies from low-income and middle-income countries that examine patients who have previously used eye care services at the primary or secondary level of care but fail to comply with referrals to more specialised care at tertiary care centres.

The L V Prasad Eye Institute (LVPEI) is an eye care institution in India (www.lvpei.org) that provides the ideal infrastructure to study such barriers. The LVPEI is a not-for-profit, comprehensive eye care network that opened in 1987 in Hyderabad, India. It has developed a pyramidal model of eye care to sustainably deliver highquality services.¹⁶ At the top of the pyramidal model, the Centre of Excellence (CoE) provides the highest level of care and serves a population of 50 million people. This is followed by multiple tertiary care centres (TCs) that serve populations of 5 million, secondary care centres (SCs) that serve 500 000, vision centres (VCs) for 50000 and vision health guardians for 5000. At present, there is 1 CoE, 3 TCs, 18 SCs and 171 VCs. There is clear delineation and demarcation of function as well as a referral system at each level of care. Approximately 80%-90% of eye care problems could be dealt at the level of SC, VC and VG. Those requiring specialised care are referred to TC or CoE. Over 50% of services in the network are provided free of cost, irrespective of the complexity and severity of the disease. Approximately 60%-70% of those who are referred to higher levels of care (SC to TC/CoE)

comply with their referrals. However, it is not known which factors are responsible for uptake of services or why some patients comply with referral services and others do not.

Hence, this study was carried out to look at the referrals from one SC to TCs. Our objectives are (1) to identify barriers to the uptake of referral services from this SC to TCs, (2) to understand the characteristic differences between those who were compliant with referral services and those who were non-compliant, and (3) to examine the associated factors for non-compliance with referral services.

MATERIALS AND METHODS

The Institutional Review Board of Hyderabad Eye Research Foundation L V Prasad Eye Institute approved the study, and the study adhered to the tenets of the Declaration of Helsinki.¹⁷

Location

This cross-sectional study was carried out at Nava Bharat Eye Centre (NBEC), an SC of the LVPEI network located in Khammam District of the Indian state of Telangana (figure 1). This centre was established in February 2011 and provides comprehensive eye care. Since the inception of the centre, all the medical records are electronically maintained. All patients requiring highly specialised care (including procedures requiring general anaesthesia) are referred to the nearby TCs located in Hyderabad in the

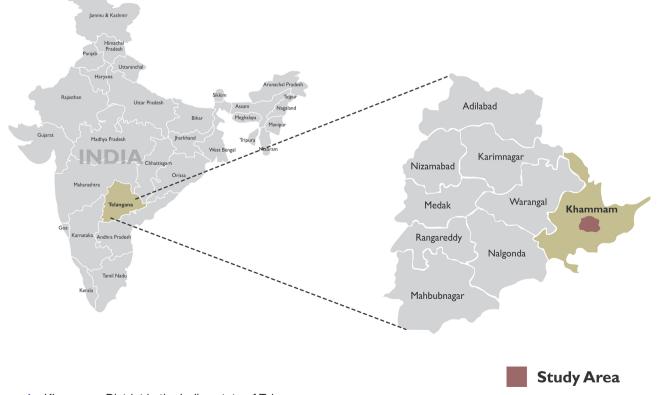


Figure 1 Khammam District in the Indian state of Telangana.

state of Telangana (approximately 300 km away) or Vijayawada in Krishna District in the Indian state of Andhra Pradesh (approximately 150 km away).

Inclusion and exclusion criteria

For this study, we reviewed the case records of all patients referred from the NBEC to Hyderabad or Vijayawada between June 2011 and December 2012. Inclusion criteria included being at least 18 years of age and residing within 50 km of the NBEC. Referral data were collected through electronic medical records to identify eligibility. Those who visited a TC after referral were categorised as 'Compliant' and those who failed to follow up at a TC were categorised as 'Non-compliant'.

Patient and public involvement

None of the patients were involved in the research design or development of the research question and outcome measures. They were also not involved in the recruitment and conduct of the study. The results of the study would be disseminated to all stakeholders.

Study questionnaire

A preliminary structured questionnaire was designed and used in a pilot study in July 2012 with 48 patients, 24 compliant and 24 non-compliant. Appropriate modifications were made to the questionnaire based on the experience with the pilot study. The main study was conducted from March 2014 to October 2014 with the revised questionnaire (enclosed as online supplementary files 1 and 2).

The questionnaire was divided into three parts: information collected from existing medical records, individual and family demographic details, and information about compliance/non-compliance of referral. Information collected from medical records included the demographic data of the individual, number of visits to the eye centre, their presenting and best corrected visual acuity, reason for referral, and the department to which the patient was referred (cornea, glaucoma, retina, oculoplastics, children's eye clinic, low vision and rehabilitation and other referral).

Following this initial data collection from online medical records, house visits were conducted to administer standardised questionnaires to elicit barriers and compliance status within the referral process. A trained field investigator conducted house visits and used a standardised structured questionnaire to interview these patients in their preferred language. Before administering the questionnaire, a written consent was obtained.

The questionnaire consisted of information on marital status, primary language spoken in the house, that is, local language (Telugu) or other language (non-Telugu), education, and earning status of the member of the family. Formal schooling was defined as at least primary school education. Subsequently, additional information from the standardised questionnaire was elicited based on the subject's compliance status. Compliant participants were asked about their reasons for obtaining further care at the TC, and non-compliant participants were asked to identify major barriers to their uptake of referral services. For the purpose of analysis, barriers were further divided into those related to economics, logistics, knowledge and attitude. For patients who were not available at the time of the house visit, three attempts were made, at least a week apart, before they were categorised as 'not available'.

Statistical analysis

Following data collection, each data form was checked for completion and accuracy and transported to the data centre located in Hyderabad. Data were input into a database using double data entry to minimise errors. Stata V.13 was used to clean and statistically analyse the database. The WHO categories of visual impairment were used for analysis, which categorised vision based on presenting visual acuity (VA) in better eye (ie, normal for VA of 6/18 or better, moderate visual impairment for less than 6/18 to 6/60, severe visual impairment for less than 6/60 to 3/60, and blind for anything lower than 3/60). Continuous variables were analysed with the Student's t-test. Categorical variables were analysed with the χ^2 test. Logistic regression was used for univariate and multivariate analyses to examine risk factors for defaulting.

RESULTS

From June 2011 to December 2012, 903 patients were referred to the TC in Hyderabad or Vijayawada. Of these patients, 616 (68.2%) could be contacted and 611 (99%) were interviewed. Of the contacted patients, 418 (68.4%) were compliant and 193 (31.6%) were non-compliant. The remaining 292 (32.4%) patients were unable to be contacted for interviews for the following reasons: 29 (3.2%) had died, 37 (4.1%) had changed their address, 205 (22.7%) had not provided complete and correct addresses, 5 (0.6%) refused to participate, and 16 (1.8%) were non-ophthalmology-related referrals (referral to physician for other health conditions).

The mean age was 48.4 years (SD: 17.9 years) in those interviewed and 51.7 years (SD: 18.9 years) in those not interviewed. The difference was statistically significant (p=0.01). Additionally, when compared with the group that was interviewed, the non-interviewed group had a higher percentage of women (51.7% vs 40.3%; p=0.01), a higher percentage of non-paying patients (34.3% vs 19.3%; p<0.001) and a higher number of mean visits to the NBEC (2.46 vs 1.98; p=0.003). However, there was no statistical difference (20.2 km vs 18.8 km; p=0.2) in the distance from the centre.

Table 1 shows the differences in demographic, socioeconomic and ocular factors of the compliant versus non-compliant groups. Those non-compliant were more often younger than 45 years of age (p=0.002), had only one visit to the centre (p<0.001) and deferred by the department they were referred to (p=0.02).

Table 1 Differences in demographic, socioeconomic and ocular factors of compliant versus non-compliant groups								
Non-								
	Compliant (418)		P values					
Status								
Paying	342 (81.8)	151 (78.2)	0.3					
Non-paying	76 (18.2)	42 (21.8)						
Age (years) (median)								
≤45	162 (38.8)	100 (51.8)	0.002					
>45	256 (61.2)	93 (48.2)						
Gender								
Male	249 (59.6)	116 (60.1)	0.9					
Female	169 (40.4)	77 (39.9)						
Mean distance from SC	18.8 (14)	18.9 (14.2)	0.9					
Visits to SC								
More than one visit	172 (41.2)	41 (21.2)						
One visit	246 (58.8)	152 (78.8)	<0.001					
Presenting vision in better eye								
Normal	247 (59.1)	114 (59.1)	0.09					
Moderate VI	113 (27)	40 (20.7)						
Severe VI	30 (7.2)	16 (8.3)						
Blind	28 (6.7)	23 (11.9)						
Referral clinic								
Neuro- ophthalmology	25 (6)	6 (3.1)	0.02					
Cornea	116 (27.8)	64 (33.2)						
Glaucoma	36 (8.6)	10 (5.2)						
Retina	173 (41.4)	67 (34.7)						
Children's eye clinic	9 (2.2)	7 (3.6)						
Low vision and rehabilitation	6 (1.4)	9 (4.7)						
Oculoplastic	31 (7.4)	23 (11.9)						
Others	22 (5.3)	7 (3.6)						
Marital status								
Married	287 (68.7)	125 (64.8)	0.34					
Single	131 (31.3)	68 (35.2)						
Primary language								
Telugu	372 (89)	170 (88.1)	0.74					
Others	46 (11)	23 (11.9)						
Education								
No schooling	97 (23.2)	42 (21.8)	0.7					
Formal schooling	321 (76.8)	151 (78.2)						
Earning member								
No	181 (43.3)	71 (36.8)						
Yes	237 (56.7)	122 (63.2)	0.13					

 Table 1
 Differences in demographic, socioeconomic and

SC, secondary care centres; VI, visual impairment.

Table 2 shows the univariable and multivariable analyses of factors for defaulting. In univariable analysis, patients who were younger than or were 45 years of age, had fewer number of visits to the centre, and were referred to low vision, rehabilitation and oculoplastic services were more likely to be non-compliant. In multivariable analysis, those who were more likely to be non-compliant had only one visit to the centre (OR: 2.5, 95% CI 1.6 to 3.9), were referred to oculoplastic services (OR: 3.0, 95% CI 1.0 to 8.8) and were the earning member of the family (OR: 1.9, 95% CI 1.2 to 2.8).

Table 3 shows the major barriers identified in the non-compliant group. The most common barrier was 'Cannot afford treatment costs' (30%), followed by 'able to see adequately' (20.7%).

DISCUSSION

As mentioned earlier, there are a number of studies looking at the barriers within the primary stages of eye care delivery.⁶⁻¹³ However, this is the first study in ophthal-mology from a low-income/middle-income country looking at barriers to the uptake of services in patients who have previously used eye services at the primary or secondary level of care but subsequently failed to comply with their referrals to TCs for further management.

The most common barrier to the uptake of services was 'cannot afford treatment cost', and it seems that the cost and effort needed to undergo treatment seem greater than the perceived value of visual rehabilitation. This is similar to prior studies examining poor uptake of services at the primary eye care delivery level.¹¹ ¹³ Nirmalan et al¹¹ found that nearly 78.2% participants could not use services due to economic reasons. Similarly, Snellingen et al^{13} found that in Nepal nearly 50% could not seek care due to financial reasons. Another study from South India from the same state found it to be nearly 30%.⁷ As SCs are located in remote rural areas and TCs are in urban areas, there is likely a component of perceived financial limitations in paying for services, as well as additional incurred expenses for travel and accommodation in urban settings. However, the LVPEI model provides low-cost or free services for many patients. These perceived economic barriers demonstrate a lack of understanding and effective communication regarding financial assistance services. This could be addressed with increased financial counselling and patient education about the referral services at the time of referral during the SC appointment.

The second most common barrier was 'able to see adequately'. This is somewhat consistent with studies examining poor utilisation of primary care services which identified 'no need or desire for surgery'.^{5 6 12} Patients who reported that they were 'able to see adequately' were likely able to manage with their present vision and did not feel the need for further care. However, there is a need for understanding this aspect in greater depth and looking at the social and cultural factors responsible for this.

	Compliant (418)		complaince Non-compliant (193)	
	Univariable		Multivariable OR (95% CI)	 P values
	OR (95% CI)	P values		
Status				
Paying	Reference		Reference	
Non-paying	1.3 (0.8 to 1.9)	0.3	1.4 (0.8 to 2.3)	0.2
Age (years)	· · · · · ·		· · · · · · · · · · · · · · · · · · ·	
>45	Reference		Reference	
≤45	1.7 (1.2 to 2.4)	0.002	1.4 (0.9 to 2.2)	0.1
Gender				-
Male	Reference		Reference	
Female	1.0 (0.7 to 1.4)	0.9	1.2 (0.8 to 1.9)	0.4
Mean distance from SC	1 (0.99 to 1.01)	0.9	1 (0.98 to 1.01)	0.6
Visits to SC	(· · · · · · · · · · · · · · · · · · ·		(
More than one visit	Reference		Reference	
One visit	2.6 (1.7 to 3.9)	<0.001	2.5 (1.6 to 3.9)	<0.001
Presenting vision				
Normal	Reference		Reference	
Moderate VI	0.8 (0.5 to 1.2)	0.2	0.9 (0.6 to 1.4)	0.6
Severe VI	1.2 (0.6 to 2.2)	0.7	1.1 (0.6 to 2.3)	0.7
Blind	1.8 (1.0 to 3.2)	0.06	1.8 (0.9 to 3.5)	0.1
Referral clinic				••••
Neuro-ophthalmology	Reference		Reference	
Cornea	2.3 (0.9 to 5.9)	0.08	2.3 (0.9 to 6.0)	0.1
Glaucoma	1.2 (0.4 to 3.6)	0.8	1.5 (0.5 to 4.9)	0.5
Retina	1.6 (0.6 to 4.1)	0.3	1.6 (0.6 to 4.1)	0.4
Children's eye clinic	3.2 (0.9 to 12.3)	0.08	2.7 (0.7 to 10.9)	0.2
Low vision and rehabilitation	6.2 (1.6 to 24.5)	0.008	3.8 (0.8 to 17.1)	0.08
Oculoplastic	3.1 (1.1 to 8.8)	0.03	3.0 (1.0 to 8.8)	0.05
Others	1.3 (0.4 to 4.5)	0.65	1.3 (0.4 to 4.6)	0.7
Marital status	10 (011 10 110)	0.00		0.1
Single	Reference		Reference	
Married	0.8 (0.6 to 1.2)	0.34	1.1 (0.7 to 1.7)	0.6
Primary language	5.5 (0.0 to 1.2)	0.07		0.0
Telugu	Reference		Reference	
Others	1.1 (0.6 to 1.9)	0.74	1 (0.6 to 1.8)	0.9
Education	1.1 (0.0 10 1.3)	0.74	1 (0.0 to 1.0)	0.9
No schooling	Reference		Reference	
Formal schooling	1.1 (0.7 to 1.6)	0.7	1.0 (0.6 to 1.7)	0.9
Earning member		0.7		0.9
No	Reference		Reference	
Yes	1.3 (0.9 to 1.9)	0.1	1.9 (1.2 to 2.8)	0.005
100	1.0 (0.9 to 1.9)	0.1	1.5 (1.2 to 2.0)	0.005

SC, secondary care centre; VI, visual impairment.

The majority of the other barriers mentioned in table 3 are modifiable, and initiatives should be taken to address each barrier. For example, economic barriers and

knowledge-related barriers could be relatively simple to address, with financial assistance/counselling and patient education, respectively. On the other hand, logistic and

Table 3Major barriers identified in the non-compliantgroup					
Categories	Major barriers	Numbers (%)			
Economics	Cannot afford to travel to tertiary centre.	13 (6.7)			
	Cannot afford treatment costs.	58 (30)			
Knowledge	Do not know where tertiary centre is located.	6 (3.1)			
	Do not understand why referral needed.	4 (2.1)			
	Was informed that vision will not improve.	4 (2.1)			
	Was not aware of the referral.	4 (2.1)			
Logistics	Nobody to accompany to tertiary centre.	6 (3.1)			
	Tertiary centre is located very far.	7 (3.6)			
	Other health problems prevent travel.	10 (5.2)			
	LVPEI did not help facilitate referral.	6 (3.1)			
Attitudes	Fear of travelling.	2 (1)			
	Too busy to go to tertiary centre.	8 (4.2)			
	Fear of procedure.	7 (3.6)			
	Dominant family member does not feel need.	1 (0.5)			
Able to see adequately.		40 (20.7)			
	Old age-do not see need for treatment at my age.	8 (4.2)			
	Not satisfied with treatment at LVPEI.	3 (1.6)			
	Decided to visit somewhere else.	1 (0.5)			
Others*	Other.	5 (2.6)			

*Others included transferred to other places (2), father had poor health (2) and waiting for health insurance approval (1). LVPEI, L V Prasad Eye Institute.

attitude changes require a much more multifaceted and complex approach to elicit change after understanding the social, cultural and economic factors. It is notable that while prior studies demonstrated 'fear of surgery' and 'nobody to accompany' as common barriers to primary eye care services,¹⁰ ¹¹ these barriers were uncommonly listed in our study, at 3.6% and 3.1%, respectively.

Overall, the major predictors for non-compliance with the uptake of referral services included having only one prior visit to the SC, being referred to oculoplastics services and being the main earning member in the family. Patients who had only had one visit to the SC also had poor follow-up with referral services, which could be due to less familiarity with the healthcare system, compared with their counterparts with multiple prior visits. Finger *et al*¹⁸ also found that one of the predictors for uptake of services was knowing and having faith in the

service provider. The lower uptake of referral services in the main earning member could be attributed to these patients having less leisure time to travel for follow-up care to TCs. The main earning members are less likely to have conditions causing blindness and severe visual impairment, as job duties commonly require adequate visual ability. It was also shown by Finger *et al*¹⁸ that the uptake of services is less if the participant has functional vision. These patients and those referred for oculoplastics likely have less disability from their eye conditions and may be less motivated to receive further care at a TC. These findings allow for identification of patients who are less likely to comply with their referral, allowing targeted counselling for these high-risk groups of participants.

Patients who were blind or referred for low vision and rehabilitation services had slightly higher odds of non-compliance, although this distinction was not statistically significant. On further analysis, we found that more than 50% of these participants were suffering from retinitis pigmentosa and were aware of the disease condition as well as its poor prognosis. It is likely that these patients may not have followed up due to their belief of lack of further benefit from the referral services. Such patients could benefit from extra counselling that explains the importance of referral services for their eye condition. Poor uptake of referral services for low vision and rehabilitation has also been identified in other studies.^{14 15}

The major strength of the study is its novelty. This is the first study in ophthalmology conducted in a low-income and middle-income country to examine non-compliance with referrals to higher levels of care. It highlights the key factors that may be responsible for the low uptake of referral services and identifies target groups who are more likely to be non-compliant. One of this study's limitations is that it is conducted in a unique healthcare network in Southern India; thus, its findings may not be generalisable to all settings. As with any novel study, there is a need for more research in various settings to validate our findings. Additionally, nearly one-third of eligible patients could not be successfully contacted despite multiple attempts. Lastly, this study was cross-sectional in nature, which identifies associations rather than direct causation.

CONCLUSION

In conclusion, our study identifies areas for potential intervention to improve compliance with higher level eye care services. This could be addressed through additional counselling of patients who are at high risk of non-compliance, particularly those who are younger, referred for non-blinding conditions, and those who are incurably blind and referred for low vision and rehabilitation services. In addition, those who have economic barriers and cannot afford services at the TC should receive financial counselling at the time of their SC visit in order to ensure free services, once referred. Moving forward, comprehensive and effective counselling at the SC and follow-up phone calls to referred patients, particularly for groups that are at high risk of non-compliance, and a dedicated staff at the TC to handle referral from SC could lead to increased uptake of referral services.

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Data sharing statement Data are available with the institute and can be accessed on request.

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