

EXTENDED REPORT

The development of the Indian vision function questionnaire: questionnaire content

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Aim: To elicit problem statements describing the consequences of vision impairment as a first step towards the development of a vision related quality of life instrument for use in India**Methods:** 46 focus groups were conducted in three regions of India. Separate focus groups were held for men and women and according to disease categories: cataract (24), glaucoma (six), diabetic retinopathy or macular degeneration (10), and "mixed low vision" (six). Facilitators followed a topic guide and sessions were audio taped and transcribed. Problem statements were extracted and coded and summarised into major problem domain areas.**Results:** Nearly 5000 problem statements, an average of 15 statements per participant, were consolidated into 18 broad domain areas. The most important problem areas accounting for over 50% of all statements were ambulation, household or occupational activities, vision symptoms, and people recognition. A further quarter of statements related to difficulties with eating and drinking, psychological concerns, self care, reading, and watching television. Problem statements were similar across the disease groups, although rankings varied.**Conclusions:** The functional and psychological impacts described by visually impaired participants in India are similar to those reported in other population settings although the context and impact of problems vary.

The use of patient defined measures of vision function in ophthalmic assessment and treatment evaluation is now well accepted^{1,2} and a number of questionnaires have been developed, primarily in high income country settings.³ There are comparatively few vision function questionnaires developed for use with visually impaired or blind populations living in low income countries. Those that do exist have been primarily developed by expert opinion^{4,5} or modified from existing health related quality of life questionnaires such as the WHOQOL⁶ or other vision specific instruments.⁷ None has been developed de novo from patient opinions and experiences following recommended steps of instrument development.^{8,9}

The objective of this study was to develop a patient defined vision function questionnaire in a population of visually impaired and blind people living in a low income country. This questionnaire was developed in India—a low income country accounting for nearly a quarter of the global burden of blindness.¹⁰ For practical reasons—namely, literacy levels and reading difficulties due to disease impact, the instrument was developed as an interview administered questionnaire. This paper describes the first phase of instrument development.

METHODS

This was a three centre study in linguistically (Hindi, Telegu, and Tamil) and geographically distinct areas of India (Delhi, Andhra Pradesh, and Tamil Nadu). All three eye hospitals are urban based offering walk-in treatment services and rural outreach screening services. Focus groups were used to explore patient perceptions about their eye conditions and associated impacts upon daily life. Although our aim was to develop a general vision function questionnaire (rather than a disease specific questionnaire) we recruited participants to focus groups to be representative of people with serious eye conditions and included both urban and rural populations.

To facilitate focus group conversation and participation, participants were grouped by eye condition type and sex, and limited to 10 people per focus group. Since cataract is the most prevalent eye condition in the Indian population, we weighted the proportion of focus groups to have a higher representation of people with cataract, to be equally recruited from both the urban and rural settings. Patients with other serious eye conditions (diabetic retinopathy, glaucoma, and age related macular degeneration) were recruited only from specialist hospital clinics at the three centres since there are no rural clinics for these conditions.

It was planned to conduct 42 condition specific focus groups—24 cataract, six glaucoma, and 12 retinal (diabetic retinopathy and macular degeneration)—equally proportioned across the three centres, and a further six "mixed low vision" groups (two per centre). Focus groups were conducted both at rural screening sites and at hospital based settings except for mixed low vision groups which were conducted *only* in rural outreach settings. With the exception of cataract identification, facilities for comprehensive ophthalmic differential diagnoses were limited at these outreach screening camps, hence the lack of condition specificity for the mixed low vision group. To ensure the inclusion of participants with varying severity of vision, separate focus groups were conducted for cataract and retinal patients according to visual acuity criteria. All centres used predefined study case definitions for cataract, glaucoma, and retinal conditions and visual acuity (see below).

Each focus group was steered by a facilitator and a co-facilitator. The co-facilitator took responsibility for tape recording the session, and made written observations about levels of participant involvement. Focus group facilitators and co-facilitators were graduates from social science or community development backgrounds. All underwent special

Abbreviations: IND-VFQ, Indian vision function questionnaire

training for the study. A study coordinator in each centre was responsible for monitoring the conduct of the focus groups and, for quality control purposes, listened to at least 15 minutes of the tape recordings of each focus group to check the quality of facilitation and checked the co-facilitator's notes to ensure high levels of group participation.

Facilitators used a topic guide for exploration with participants (table 1). The content of the topic guide was informed by reviewing the literature,^{1-3 5 11} and piloted in five non-study focus groups similar in participant characteristic to the main study. Additionally, 36 individual semistructured interviews were conducted (12 per centre) with male and female patients across different disease groups to explore whether or not different topics were raised in one to one situations compared to focus group settings. No differences were identified. The pilot study also tested other aspects of the data capture: audiotaping, transcription, translation, and preliminary coding of the problem statements.

Patient population

Eligible participants were 40 years of age or older, with at least a 3 month history of eye disease that satisfied predefined clinical selection criteria: (1) participants with bilateral cataracts had presenting visual acuity (VA) less than 6/60 in both eyes; (2) unilateral cataract patients had presenting VA <6/60 in the worse eye with better eye presenting VA \geq 6/18 (an aphakic or pseudophakic eye was acceptable); (3) glaucoma patients had a primary diagnosis of open angle glaucoma and any two of the following—visual field defects (minimum nasal step or an abnormal glaucoma hemifield test), optic nerve head/fibre defects, or at least one intraocular pressure of greater than 21 mm Hg; (4) bilateral retinal conditions were required to have a primary diagnosis of diabetic retinopathy or age related macular degeneration in both eyes with presenting VA <6/60 in the better eye; (5) retinal patients with unilateral impairment had presenting VA \geq 6/36 in the better eye and <6/60 in the worse eye); (6) participants in the “mixed low vision” focus groups had visual acuity <6/18 in presenting better eye and not attributable to cataract, at least 50% of subjects had VA \leq 6/18 to 6/60 in their better eye).

Focus groups with cataract patients were conducted preoperatively, either in the hospital or at rural screening camps. Focus groups for glaucoma and retinal conditions

were conducted in study hospitals with participants recruited from outpatient clinic registers of attenders over the previous 4 months.

Patients who were deaf or communication impaired, significantly physically disabled, with multiple ocular pathology, or not conversant in the language of the given centre were excluded. Patient domicile within 50 km of the study hospital was a geographical guide to recruitment for both hospital based and outreach clinic patient recruitment. Distance was not an exclusion criterion if the participant was willing to travel. Individual informed verbal consent was obtained from all participants. Ethical approval was obtained from the respective state authorities responsible for each centre.

Data extraction and translation

A written bilingual transcript (mother tongue and English) was compiled for each focus group discussion because three different languages are specific to each regional centre. A common language (English) was required for collation of coded data across the three sites. English was chosen because all study investigators, and many of the team, are bilingual in English and their Indian mother tongue language. At each centre, the research team extracted problem statements from the transcripts in the local language. Independent bilingual translators then translated focus group transcripts and problem statements. For purposes of standardisation, translators at each centre compiled a bilingual dictionary of local words and terms that were commonly used by participants. Quality control checks were carried out on transcription, translation, and extraction of problem statements from focus group transcripts.

Problem statements (in English) were entered onto a Visual FoxPro (Version 6) database at each centre and statements were consolidated where it was judged the underlying difficulty was similar. For example, statements which described problems with eating because of difficulty locating unwanted objects in the food were grouped together, even though a variety of unwanted objects such as flies, stones, etc. were specified. Statements were further loosely grouped into domain areas by type of problem experienced—for example, problems concerned with eating, using the bus. These domain areas were data driven and were agreed upon across centres following a preliminary review of early focus group transcripts. In this way, it was possible to establish a common coding frame used across the three centres. The coded database for each centre (including the frequency of problem statements) and full details of focus groups and participant clinical and sociodemographic information were sent to the coordinating centre (Dr Rajendra Prasad Centre) for merging and analysis.

RESULTS

Forty six of 48 planned focus groups were conducted. In one centre it was not possible to find sufficient patients with retinal problems causing bilateral vision impairment. Participant response rates across centres ranged from 68–78%. The overall focus group response rate was 71%, with higher levels of acceptance by people with cataracts and “mixed low vision” focus group participants (87% and 89% respectively) than glaucoma and retinal participants (46% and 54% respectively). This was because participants of the latter two groups, unlike people with cataracts and mixed low vision, were required to return to the hospital on a separate occasion especially to attend the group. The characteristics of participants by disease group are shown in table 2.

There were nearly 5000 vision related problem statements from the participants in the 46 focus groups, an average of nearly 15 statements per participant. These statements were

Table 1 Topic guide

Topic	Examples of suggested subtopics or probe questions
● Description of vision	● Do you a vision problem—what is it/ describe it?
● Impact of vision problem on day to day life	● Independent mobility ● Self care (grooming, dressing, eating/ drinking, etc) ● Fulfilment of daily responsibilities
● Impact of vision problem on self	● Does your vision problem affect how you feel about yourself—how? ● Affect on mood/self confidence/feelings about future ● Concern about appearance (general and/or specifically eyes)?
● Impact of vision problem on other people and social relations	● Does your vision problem affect the lives of other people living with you, or other people important to you? How? ● Does your vision problem affect how others view or treat you? How?
● Vision problem and coping strategies	● How do you try and cope, or get around, the challenges that your vision presents

Table 2 Characteristics of focus group participants

	Cataract	Retinal	Mixed low vision	Glaucoma	Total (%)
Number of focus groups	24	10	6	6	46
Presenting better eye VA by focus group type:					
≥6/18	78	25	21	26	
<6/18 to ≥6/60	8	17	14	4	
<6/60 to ≥3/60	38	15	4	3	
<3/60	36	8	4	0	
Number of participants	160	71	43	34	308
Age (%):					
40–60 years	89 (50.8)	46 (26.2)	22 (12.6)	18 (10.2)	175 (56.8)
60+ years	71 (53.3)	25 (18.8)	21 (15.8)	16 (12.0)	133 (43.2)
Men (%):	79 (49.4)	35 (49.3%)	22 (51.2)	19 (55.9)	155 (50.3)
Occupation:					
Daily wages	48	2	12	2	64 (20.8)
Farmer	30	4	5	2	41 (13.3)
Household work	42	33	13	11	99 (33.1)
Business	8	3	3	1	15 (4.9)
Retired	5	9	4	9	27 (8.8)
Others	27	20	6	9	62 (20.1)
Illiterate (%)	98 (61.3)	18 (25.4)	17 (39.5)	6 (17.6)	139 (45.1)

grouped into 210 separate codes in 18 domain related areas (table 3). The most frequent statements described problems with ambulation and accounted for nearly 16% of all statements. The problems in the ambulation area related to difficulties in walking, stumbling, or falling because of inability to see bumps or uneven surfaces in the road, banging into objects or people, the need for an accompanying person, or not being able to go out of the home because of lack of vision. Problems in carrying out occupational or household activities comprised the second most important area (13% overall). Nearly half the participants (both men and women) reported that they could not undertake paid work, or that their work was severely restricted because of their vision. Most of the statements relating to difficulties with household activities were made by women, with well over half reporting that they were unable to carry out their household tasks. Specific difficulties mentioned were the inability to clean stones or dirt from rice or pulses, to see worms or insects in vegetables before cooking, or to stitch garments. Visual symptoms (such as blurred, dim, or cloudy vision) and problems recognising people were the next two

most frequent domains accounting for 12% each of all problem statements. These four topic areas accounted for over half of all statements. Many participants (339 statements) described difficulty with eating and drinking, primarily because of not being able to see unwanted objects in food. Five per cent of statements related to psychological problems such as feeling a burden on others, ashamed of not being able to see, and a sense of uselessness. Difficulties with self care related to going to the toilet, getting dressed, and oiling and grooming hair. There were a number of other domain areas which, though of relatively lower frequency, are shown separately (table 3). Not surprisingly in this population with low levels of car ownership, driving was only mentioned by a few participants. Because of the importance of household activities for women there was a greater frequency of reporting these problems by women. There were some differences between women and men in the relative frequency of statements for some other specific activities, such as problems going out without an accompanying person (21% in women and 9% in men) (part of problems with ambulation), reading (2.5% and 5.7% respectively), and

Table 3 Functional problem areas, visual symptoms, and psychological problems reported by participants

Domain	Men (%)	Women (%)	Total statements (%)	Average number per participant
Ambulation	338 (15.4)	390 (16.1)	728 (15.8)	2.36
Occupation/household activities	160 (7.3)	448 (18.6)	608 (13.2)	1.97
Visual symptoms	251 (11.5)	306 (12.7)	557 (12.1)	1.81
Recognising people/faces	306 (14.0)	229 (9.5)	535 (11.6)	1.74
Eating and drinking	163 (7.4)	176 (7.3)	339 (7.4)	1.10
Psychological	112 (5.1)	138 (5.7)	250 (5.4)	0.81
Self care	87 (4.0)	123 (5.1)	210 (4.6)	0.68
Reading	126 (5.7)	60 (2.5)	186 (4.0)	0.60
Watching television	88 (4.0)	90 (3.7)	178 (3.9)	0.58
Using the bus	111 (5.1)	54 (2.2)	165 (3.6)	0.54
Trouble seeing in bright light	92 (4.2)	63 (2.6)	155 (3.4)	0.50
Using stairs or steps	80 (3.6)	63 (2.6)	143 (3.1)	0.46
Night vision	56 (2.6)	87 (3.6)	143 (3.1)	0.46
Using money	72 (3.3)	59 (2.4)	131 (2.8)	0.43
Other small object recognition	63 (2.9)	50 (2.1)	113 (2.5)	0.37
Participation in social functions	42 (1.9)	34 (1.4)	76 (1.6)	0.25
Trouble seeing colours	16 (0.7)	33 (1.4)	49 (1.1)	0.16
Driving	29 (1.3)	14 (0.6)	43 (0.9)	0.14
Total statements	2192	2417	4190	
Average number of statements	14.14	15.80		14.96

Table 4 Ten most frequently reported problem areas by disease/vision group

Problem area	Cataract		Retinal		Low vision		Glaucoma	
	Number of statements	% of total statements	Problem area	% of total statements	Problem area	% of total statements	Problem area	% of total statements
Ambulation	481	17.9	Ambulation	161	Visual symptoms	104	Visual symptoms	66
Household/occupation	392	14.6	Recognising people/faces	150	Household / occupation	74	Ambulation	35
Recognising people/faces	304	11.3	Symptoms	128	Recognising people/faces	57	Trouble seeing in bright light	26
Symptoms	259	9.6	Household / occupation	120	Ambulation	51	Recognising people/faces	24
Eating and drinking	234	8.7	Eating and drinking	78	Reading	51	Using the bus	23
Psychological	174	6.5	Reading	66	Self care	27	Household/occupation	22
Self care	146	5.4	Using stairs or steps	54	Small object recognition	27	Psychological	18
Watching television	106	3.9	Trouble seeing in bright light	45	Bus/using public transport	24	Reading	18
Night vision	96	3.6	Using money	43	Trouble seeing in bright light	24	Watching television	11
Using the bus	81	3.0	Psychological	42	Eating, pouring drinking	22	Other small object recognition	9
Number of statements in top 10 areas	2273	84.6%		887		461		252
Total number of statements	2688			1080		556		285
Average number of statements per participant	16.8			15.2		12.9		8.4
Number of participants per group	160			71		43		34

using the bus (2.2% and 5.1% respectively), which to some extent reflect the relative literacy rates and mobility of women compared to men. Otherwise, problem reporting was similar in men compared to women.

People with cataract described the highest number of problem statements (average of 16.8) and those with glaucoma the lowest (8.4) (table 4). Visual symptoms were most frequently mentioned by glaucoma patients (23%) while in cataract patients the highest frequency of problems dealt with ambulation (18%). Care must be taken in interpreting any differential impact of different eye diseases on function and wellbeing (table 4) since other important social and economic differences existed between the disease groups (table 2).

DISCUSSION

Vision related impacts on quality of life described by our focus group participants showed both similarities to and differences from those in other settings. In the United States, focus groups conducted for the development of the NEI-VFQ identified problems with mobility, reading, social relations and activities, and mood or mental health as the main impacts of their eye problem, while vision symptoms, especially blurred vision, were the most frequently mentioned group of problem statements.² In-depth interviews with vision impaired patients in the United Kingdom elicited concerns over self esteem, self care, emotion, safety, domestic activities, financial aspects, as well as vision symptoms.¹² A large number of studies in visually impaired individuals have concentrated on vision function using questionnaires developed predominantly from clinical judgment.³⁻⁶ These studies have variously reported problems with mobility (walking, using public transport, car driving), face recognition (near and distance), reading, watching TV, and light related difficulties such as glare, and difficulties with night driving. In Malawi—a developing country setting with some similarities to our own study—a vision function questionnaire, developed from eye care workers and patient focus groups included questions on difficulties avoiding potholes, using the latrine, participating in social activities, sorting stones from rice or beans.⁶ The two studies described above^{2,12} were unusual in that they sought the views of visually impaired people at an early stage in questionnaire development and did not restrict the content area to function only. In both studies, as in ours, psychological problems emerged as a concern, even in people with reversible vision problems such as cataract. Thus, although population settings may vary the functional and psychological impacts are similar (for example, problems with mobility relate to car driving in the United States while in our population, problems with mobility are described by difficulties in walking especially on unpaved paths), the functional and psychological impacts are very similar.

However, a striking difference between the participants in this study compared to their counterparts in more affluent settings is the greater impact of vision problems. For example there were 242 statements that the participant either did not go out at all or only went out if there was someone to help; 218 statements that the participants could not carry out paid or household work; and 92 statements expressing concern of being a burden on others, including 33 statements that it would be better to die than to live with poor eyesight. The impacts described reflect both the severity of the visual impairment of our participants and the implications of vision impairment for people on low incomes. Our participants were typical of the visually impaired population in India, where more than one in 10 of the population over 50 years have presenting bilateral visual acuity worse than 6/60,^{11,13} with

cataracts being the principal cause of blindness in at least one eye in around 70% of people.

There were some limitations in our methods. Although focus groups were conducted in the local language, a common language was required in order to pool the statements across the three centres. English was chosen as the common language and considerable efforts made to ensure high quality of translations through using bilingual translators and quality control checks. None the less, some subtle differences in meaning may have been missed. The process of extraction, merging, and collation of such a large number of problem statements required judgments to be made, for example, in deciding which were semantically similar statements. We endeavoured to minimise variation between individuals and centres through quality control checks at all stages. Focus group methodology has limitations. Participants in focus groups may provide unrepresentative views of the target group or, if poorly conducted, may not enable full participation by all group members or may fail to elicit participant views, especially in sensitive areas. In order to minimise volunteer bias, we randomly selected participants and achieved a good overall response rate but with lower levels for the glaucoma and retinal condition specific groups. However, no marked differences were observed in the nature or severity of problem statements reported by these groups when compared to cataract and mixed low vision focus groups. Focus group audiotapes and transcripts were monitored to check for participation, coverage of the topic guide, spontaneity of responses, and lack of leading questions. We conducted some semistructured one to one interviews with very similar issues emerging. It is possible that certain areas are sensitive and unlikely to be identified in either situation.

Problem statements were very similar across the three centres, which were unsurprising given lifestyles, income levels and social values were very similar across these three regions. The questionnaire may be less relevant to high income groups in India where the impact of eye diseases on lifestyle may be less severe. It is likely that similar problems statements would be generated in other areas of India but there may be more context specific differences, for example, in mountainous areas. The identification of these problems is the first step in the development of the IND-VFQ, a vision related quality of life instrument for use with visually impaired people in India.

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