

# Self-reported eye disease in elderly South Asian subjects from an inner city cluster in Bradford: a small-scale study to investigate knowledge and awareness of ocular disease

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## Abstract

**Purpose** To investigate various issues relating to eye diseases in a sample of 200 South Asian residents living in an inner city regional cluster in Bradford.

**Methods** Door to door interviews were carried out by one investigator who spoke English, Punjabi and Urdu. Visual acuity and pinhole acuity were measured using a portable LogMAR acuity chart. A structured questionnaire investigated various issues including self-reported eye disease, knowledge of eye disease, the effectiveness of various sources for eye-related information, the importance of early detection of eye diseases and the need for adequate control of systemic diseases linked to eye diseases such as diabetes.

**Results** Data revealed poor knowledge of self-reported eye diseases and of the importance of early detection and inadequate knowledge of the link between the control of systemic disease such as diabetes and ocular complications. Language barrier problems and poor utilisation of available ocular health care services were also evident.

**Conclusions** These data, although not exhaustive, give an insight into various factors that affect the ocular health of the South Asian community in Bradford.

**Key words** Eye disease, South Asian

In the UK, South Asians constitute a large percentage of the ethnic minority population. Although many previous studies have investigated various systemic diseases, such as diabetes and cerebrovascular disease, amongst the different ethnic groups, very few have

explored the prevalence of eye diseases in the South Asian communities in the UK. Of these few, one study conducted recently in Leicester reported that South Asians had a significantly higher prevalence of age-related cataract<sup>1</sup> compared with Caucasians. Another study, based in Birmingham, investigated the prevalence of diseases and health problems (not just eye diseases)<sup>2</sup> and reported that South Asians experienced more visual problems than other ethnic groups.

Literature concerning racial-ethnic differences in health care utilisation shows that ethnic groups are less likely to receive health care.<sup>3</sup> Evidence of this has been shown for coronary artery diseases<sup>4</sup> and referral rates and attendance in emergency departments.<sup>5</sup> A recent report examining the accessibility and use of health care services in the British Asian community shows that Asians have difficulty obtaining good health care.<sup>6</sup> Contact with community health and social services has been shown to be low among Asians, as is awareness of the availability of services such as Meals On Wheels, home helps, social workers and chiropody.<sup>2,7</sup> Various reasons have been put forward including language barriers and dependency on the extended family. Ritch *et al.*<sup>2</sup> reported that in their study of older Asians only 15% spoke English and therefore communication with English-speaking health personnel was a major barrier to effective health care. Other factors, including physician bias<sup>8</sup> and unwillingness to accept referral for surgery, have also been suggested as possible reasons.<sup>4</sup>

Bradford presents an ideal location for examining the South Asian population. This group represents just under one-sixth of the total population in Bradford. The actual breakdown based on the 1991 Census was as

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follows: white, 81.2%; Indian, 2.7%; Pakistani, 12.5%; Bangladeshi, 1%; black, 1.2%; and other, 1.3%. The literature demonstrates a higher prevalence of certain diseases, for example, heart diseases and diabetes, amongst the Asian population in the UK.<sup>9</sup> This may be due to their genetic make-up, environmental influence or both. Despite continuing improvements in health, sometimes at a faster rate than those taking place in England as a whole, Bradford residents are still less healthy than the average for England and Wales.<sup>9</sup> South Asian residents in Bradford have 4 times the rate of diabetes of the overall population. Although the incidence of some diseases, such as cancer, is lower, clear examples of high rates of certain diseases such as diabetes affecting the South Asian population exist. This occurs even though the Asian group is subject to similar environmental influences and external risk factors as the local Caucasian community.

The aim of this study was to investigate self-reported eye diseases, the level of knowledge of eye disease and the awareness of the importance of early screening and monitoring of the disease in a small sample of South Asians living in one inner city area. The study explored factors that may prohibit the full use of ocular health services such as language barriers, and lack of awareness of the appropriate health services and of early screening for eye disease such as glaucoma. It investigated cultural and/or religious factors including lack of support and apprehension in accessing the available sources of eye-related information. To our knowledge, no previous study has looked at such issues in the South Asian population in the UK.

## Materials and methods

A structured questionnaire was designed following recommendations from a recent report on strategies and methodological issues for researchers who want to conduct community-based research within a racial/ethnic minority community.<sup>10</sup> The questionnaire was compiled following discussions with clinicians and focus interviews with South Asian subjects. Validation of the questionnaire was carried out by detailed interviews where different ways of questioning and phrasing questions were employed and which were subsequently modified following patients' responses and feedback. Difficult questions and potentially ambiguous ones were clarified. The questions were also checked for their 'political correctness'.

Table 1 summarises the issues in the questionnaire. The issues investigated can be grouped broadly under the following sections:

1. Demographics.
2. Medical history.
3. Ocular history.
4. Knowledge of eye diseases.
5. Sources of available information on eye diseases.
6. Support in dealing with eye disease.

In addition, visual acuity and pinhole acuity were also measured.

**Table 1. Questionnaire**

<i>Demographic details</i>
Age
Gender
Marital status
Employment status
Personal income
Education and qualifications
Household structure
<i>Medical history</i>
Last medical check-up?
Prescription drugs?
Self-prescribed drugs?
Aware of hypertension?
Suffer from hypertension?
Aware of cholesterol?
Cholesterol check?
Advised to reduce cholesterol?
Aware of diabetes?
Suffer from diabetes?
Ever had a diabetes check?
If diabetic: how strict in monitoring sugar levels?
<i>Ocular health</i>
Presence of eye disease?
If yes to above: what eye disease/s?
Referral to hospital for eyes?
Operation on your eyes?
<i>Knowledge of ocular disease</i>
What eye diseases are you aware of?
Knowledge of own eye disease
Medication for eye disease?
Possibility of inheritance of eye disease?
Can diabetes affect your eyes?
Can poor control of diabetes affect your eyes?
Awareness of possible diabetic complications?
Is it possible to control progression of eye disease?
Can you screen for early detection of eye disease?
Can cataract increase to reduce vision?
How strict are you in following treatment?
Restriction of everyday activities due to eye disease?
Worried about eye problems?
<i>Sources of information regarding eye disease</i>
Is more information about eye disease required?
Is it easy to acquire information?
Barriers to obtaining more information?
Best source of information about eye disease?
Can your optometrist detect and give information about eye diseases?
What is the main work of your optometrist?
<i>Support regarding eye disease</i>
Family support in keeping appointments?
Support from family in dealing with eye disease?
Support from friends in dealing with eye disease?
Apprehension of disclosing eye disease to others?

Door to door interviews were conducted on 200 Asian subjects over the age of 50 years living in an inner city regional cluster and with one postal code. This study was intended as a pilot investigative study and it meant to target older South Asian people in Bradford who reside mostly in Bradford 7 and 8. Interviews were conducted during the day. Twenty per cent of the people were not at home and a second or third visit was made in the evening. Four per cent were not contactable even after the third visit. Four per cent of the people approached refused to take part. The religious divisions seen in the

sample population are representative of Bradford. This is not representative of the South Asian profile of UK as a whole since the ethnic mix will vary according to the geographical location in the UK. South Asians in Leicester are mostly Indians from East Africa whereas the majority of the South Asian population in Bradford is from Pakistan.

Informed consent was obtained from all the subjects after the nature of the procedures had been fully explained. All procedures followed were in accordance with the ethics standards approved by the University of Bradford's Ethics Committee. All interviews were conducted by one of the authors (N.M.) in English, Urdu or Punjabi, as necessary. All the subjects spoke at least one of these languages and therefore nobody was excluded on the basis of language.

The visual status of the subjects was assessed by measuring normal and pinhole LogMAR visual acuity.

## Results

### *Demographics*

Subjects were between 50 and 90 years old. The majority of the population sampled were female (62%). Fifty-four per cent were older than 60 years. A majority (86%) were recipients of income support. Although the subjects participating were from different cultures (Muslim 87%, Indians 12%, other 1%), they were considered as one South Asian ethnic socio-economic group. A majority (90%) lived in extended households.

Approximately 50% claimed to be unskilled with neither knowledge nor practical experience of any kind in any profession. Sixty-one per cent had no formal education. Forty-three had children educated to at least A-level standard.

### *Medical history*

Visits to the doctor were relatively frequent, with at least 94% having had an appointment with their doctor in the previous year. Over half the sample (62%) were on prescribed drugs. Overall, all subjects were aware of what hypertension meant (23% suffered from it). A majority (85%) were not aware of the term cholesterol (in any of the languages) and were unaware of ever having had a cholesterol check. Of the subjects interviewed, 16% were diabetics. A majority of all subjects (98%) were aware of diabetes as being a disease 'related to increase in blood sugar' and 85% were aware of having had a test for diabetes at some time in their life. Of the diabetics, 31% exercised strict control, 38% exercised moderate control and 31% did not feel it necessary to be strict in monitoring their sugar levels.

### *Visual acuity and pinhole acuity*

It was possible to measure the visual acuity in LogMAR value in 98% of the subjects. Thirty-two per cent had a best eye acuity of less than LogMAR = 0 (VA greater than 6/6), 44% had best eye acuity between 0 and 0.25

LogMAR units (VA between 6/6 and 6/10.6), 20% had best eye acuity between 0.26 and 0.50 LogMAR units (VA between 6/10.9 and 6/19) and 2% had best eye acuity of greater than 0.51 LogMAR units (VA less than 6/19). Pinhole improved the right eye acuity in 30% and left eye acuity in 31% of the subjects.

### *Knowledge of various eye diseases*

General awareness of eye diseases amongst the whole sample was investigated. All the subjects were familiar with cataract when translated into its Punjabi/Urdu equivalent. Only two ocular conditions were known by the sample, namely cataract and diabetic-related eye changes.

### *Self-reported eye problems*

Fifty-three per cent of the total reported having an eye disease. Sixty-five per cent of all subjects over the age of 60 years had a cataract. Seven per cent had diabetes-related eye changes (this constituted 44% of all diabetics). All the subjects who had diabetic changes also had cataract. Twelve per cent were unaware of what eye disease they had. None of the subjects knew what glaucoma was even though at least 6% suffered from it. The presence of glaucoma was identified by the interviewer after seeing the prescribed anti-glaucoma eyedrops. None of the subjects were aware of macular degeneration. Of the total, 32% had had an operation in at least one eye at some time in their life, with 13% not knowing what the operation was for. The investigator, who was a qualified optometrist, confirmed the self-reported eye disease.

### *Knowledge of own eye disease and importance of adequate control*

On questioning the whole group, a majority (90%) believed that there was no possibility of inheritance of eye disease or of any linkage between poor control of diabetes and ocular complications. Most believed that eye disease occurred anyway due to ageing or just chance. Sixty-nine per cent of those with eye disease felt that they had no control over their eye disease at all. Most felt that progression was in the hands of God. Forty per cent of the total sample were unaware that it was possible to screen for early detection of eye disease and 65% were unaware that cataract could progress with a resulting decrease in vision. All diabetics were aware of possible eye complications. Despite this knowledge, only 10 of 32 diabetics knew of the possibility of eye complications related to inadequate control of diabetes. These 10 individuals also claimed to be strict in monitoring of their sugar levels. None of the glaucoma sufferers followed a strict regime with their treatment.

In determining the extent of concern over their eye disease, 31% claimed to be very worried about it, 53% to be moderately worried and 16% claimed not to be

worried at all. Twenty-five per cent claimed that their everyday activities were severely restricted due to their eye disease and 40% reported no restriction.

### *The effectiveness of the various sources of information*

The knowledge of various sources of eye-related information and utilisation of health services were investigated. Of those subjects with eye disease, 57% thought that more information was required to support and inform patients with eye disease. When questioned on how easy it was to access the information already available, 71% claimed language barriers and 67% reported that they were not sure of what information to seek and from where.

When questioned on effective sources of information, 83% of the total sample claimed that their general practitioner (GP) was the best source for advice. Immediate family was the next best source (17%). Various other community services were also used by some, which included: health visitor (10%), chiropodist (5%) and dietician (15%). Only a small minority (5%) would consider going to the optometrist for advice. Only 18% of the total were aware that optometrists were able to detect ocular pathology such as cataracts. Overall, the vast majority of the subjects believed that the role of an optometrist was only to prescribe spectacles.

Of the sample with eye diseases, 73% reported that support and assistance in arranging and keeping hospital and doctor appointments were provided by the extended family and not by support groups, religious community or friends (61% claimed not to belong to a community).

Generally, subjects were not apprehensive in disclosing information about their eye problem and 84% strongly denied attachment of a stigma regarding their eye disease.

### **Discussion**

Data for this study were collected from a small inner city area in order that the sample could be treated as a culturally homogeneous group, because the subjects share much in common in terms of their age, lifestyles, values and principles.

Although the sample was relatively small, data agree with other large-scale studies. Self-reported hypertension in 23% of the total sample compares with the 20% reported by Ritch *et al.*<sup>2</sup> Diabetes reported by 16% of patients in our study is also comparable to Ritch *et al.*<sup>2</sup> study which showed a prevalence of 12%. As regards ocular diseases, Das *et al.*<sup>1</sup> compared the prevalence of eye disease in South Asians and Caucasians in Leicester and reported that 68% of their sample over the age of 60 years had cataract – which agrees well with the 65% in the same age group in our study. None of our subjects was aware of macular degeneration and therefore could not report it. The incidence of glaucoma, the presence of which was identified by inspection of eye-drops, was, however, much higher (at 6%) than shown by Das *et al.*,<sup>1</sup> who reported that only 7 subjects from a sample of 165

suffered from it. Our data also agree with those of Ritch *et al.*<sup>2</sup> who reported that, with the exception of the GP service, for which the consultation rates were high, Asians made little use of community health services even though they did not enjoy better health.

Although the data from this study are not exhaustive, our results demonstrate that just over half the sample over the age of 50 years suffer from eye disease. Nearly an eighth of the whole sample (12%) were unaware of what eye disease they had. Only 31% of the diabetics were aware of the importance of good control of diabetes and its relationship with eye disease. This study was not designed to compare data from age-matched Caucasians but was meant to highlight some issues that arise within the South Asian group. However, interviewing a similar number of age-matched Caucasian subjects would have been useful for comparative purposes. This is to be undertaken in the near future.

None of the glaucoma sufferers had much knowledge of the eye disease or the fact that it was important to keep to a strict regime of treatment. The glaucoma sufferers were also unaware of the importance of having their immediate family members screened for glaucoma. None of the glaucoma sufferers followed a strict regime with their treatment. It is well known that compliance with glaucoma medication can be quite poor in some cases. Various studies have investigated non-compliance<sup>12-16</sup> and the factors that influence it. The number of visits to an ophthalmologist has been shown to be significant, with fewer visits being related to non-compliance.<sup>17</sup> Other factors include the inability to apply eye-drops,<sup>18</sup> single versus multiple applications,<sup>19</sup> presence of other medications in the patient's drug regimen,<sup>17</sup> the packaging of ophthalmic drugs,<sup>20</sup> effects of age (with older patients being more compliant),<sup>21</sup> the duration of treatment<sup>22</sup> and the use of aids.<sup>23</sup> A survey showed that the principal causes of poor compliance are forgetfulness, time constraints with other duties, poor doctor-patient relationship and lack of sufficient knowledge about the disease and its treatment.<sup>22</sup> Monane *et al.*'s study<sup>21</sup> also showed that his Caucasian subjects were more compliant than non-Caucasians.

The data from this study are not exhaustive and we are aware that the study has its own limitations, which include the sample being small and concentrated in a relatively small area of Bradford. It may have benefited from comparative data from age-matched Caucasians. However, it highlights various important issues which could be used to improve the ocular health of this ethnic group. A large percentage of our subjects claimed language barriers and were not aware of what information to seek. Difficulties in communication during consultation with the doctor, ophthalmologist, health visitor, etc., could lead to lack of knowledge or, worse still, to inaccurate information. Although health care leaflets are available in ethnic languages they may not be useful for people who are unable to read. Ritch *et al.*<sup>2</sup> showed that only 15% of the subjects in his study spoke English. Donaldson<sup>7</sup> reported that 37% of men and only 2% of women could speak English. Other ways of

disseminating information, perhaps by an appropriate culturally sensitive person, are needed. These could include information in Asian radio programmes and home videos.<sup>7</sup> Language barrier problems could be overcome, to a certain extent, by their children. A large number of subjects live in extended families which provide support in arranging and keeping hospital appointments. The family, usually the eldest son, is normally the most influential and the main source of information. Involving family members in specific programmes and providing them with written information about support groups etc., may be beneficial. There is a tendency to rely on the local doctor for every aspect of health care. This may be due to the fact that the local GP is likely to be of Asian origin, hence enabling the older person to have direct interaction with him or her.

Awareness of other health-related services was generally low amongst the subjects. Interestingly, only 5% would consider going to their optometrist for advice about health of their eyes or screening. Most would consult an optometrist only for spectacles. If optometrists are to be considered as health care professionals then more effort needs to be directed towards changing this opinion that they only prescribe spectacles. A previous study has shown that older Asians were willing to use the community nursing service when this role was explained. Awareness of the available community services, delivered in a more culturally sensitive manner, may also help towards a more ocularly healthy community.

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