Psychosocial needs of elderly visually impaired patients: pilot study of patients’ perspective

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ABSTRACT

Background The diagnosis of severe eye disease is a traumatic event that may result in depression that, if untreated, has a poor prognosis, and can exacerbate effects of co-existing medical conditions. The perceived psychosocial needs of patients have not been well studied.

Method In this pilot study we interviewed 66 elderly (65+ years) sight-impaired patients recruited from general practitioner (GP) practices and members of a local Society for the Blind, in one-off appointments using four interviewer-administered measures. We recorded their recollections of reaction to diagnosis; support received from clinicians; and current levels of functioning and health with a view to identifying unmet needs. Thirty-six of the 66 respondents were registered blind (21) or partially–sighted (15), and 30 were not registered.

Results Over 70% of the blind or partially sighted respondents had felt depressed following diagnosis, and 81% of the blind and 60% of the partially sighted were currently depressed. Mean Geriatric Depression Scale (GDS) scores for blind individuals were significantly higher than for not-registered individuals. Visual Functioning Questionnaire (VFQ-25) scores indicated lower levels of social functioning for blind than partially sighted individuals. Many respondents reported difficulty in talking about their worries to their doctors, and expressed a need for more information about their diagnosis.

Conclusion Severe sight loss appears to be associated with long-term emotional distress and poor social functioning, but many respondents did not perceive their doctors as sympathetic. Regular health checks in primary care of severely visually impaired older patients could both identify depression, and monitor changing needs of patients with degenerative sight problems.

Keywords: blind, elderly, psychosocial needs

Introduction

Severe vision loss is a major disability, particularly in the elderly, that can lead to social isolation, loneliness and depression. Acquired blindness is one of the most feared disabilities, ranking second to fear of death from cancer. Older adults worry about disabilities that may threaten their independence, and the negative impact of such fears when sight deteriorates may more than double the risk of depression.
Recognition and treatment of elderly depression is important since the prognosis for untreated depression is poor; the effects on functioning and well-being are additive with those of co-existing medical conditions, and treatment can improve the physical functioning of older adults.

It has been suggested that physicians can help visually impaired patients cope with the sequelae of vision loss by:

- recognising that vision care must be a major part of the patient’s medical care and not adopting the attitude that ‘there is nothing I can do’;
- specifically asking about the emotional and practical problems associated with vision loss, since ‘older persons tend to just accept the problems as part of the ageing process and tell no one’;
- allowing patients to ventilate their feelings so that the extent and degree of any significant psychosocial problems can be assessed and appropriate interventions initiated;
- recognising that close co-operation between physicians and mental health professionals is key to helping blind patients to re-integrate in society.

This study identifies patients’ perceptions of communication with their clinicians and the recognition of their needs. Ways in which both can be improved are suggested.

Aim

Our aim was to interview a sample of elderly (≥65 years) visually impaired individuals, in order to record their recollections of their emotional reactions to the diagnosis, whether their distress was recognised, and how it was treated, and to compare current levels of visual functioning and health in registered blind/partially sighted and unregistered individuals.

Methods

Severely visually impaired elderly patients were identified from three large practices and invited by their general practitioner (GP) to be interviewed. Large-print letters explained the purpose of the study, and patients were told that they could ask another person to be present during the interview. Willing participants supplied a telephone number, and an appointment was arranged.

To maximise participation, Southampton Society for the Blind (SSB) members were recruited by displaying large-print explanatory notices seeking volunteers at the venue, and by one researcher (SG) explaining the study at the start of group activities and inviting interested participants to give contact information to SSB staff.

Participating individuals were interviewed at home on a single occasion. A semi-structured interview guide (see Appendix) was designed to record quantitative and qualitative information that included social and demographic data, cause and length of visual impairment, and also to elicit respondents’ recollections of their reaction to their diagnosis, their worst fears and how they coped with these, whether they had been able to talk to a doctor about their concerns, and if not, why not, and who or what was most helpful at the time of diagnosis. Three quantitative measures were used: Hospital Anxiety Scale (HAD-A) to assess anxiety, the Geriatric Depression Scale (GDS-15) to assess depression, and the Visual Functioning Questionnaire (VFQ-25) to assess aspects of vision, social functioning, and general health.

The registered blind (B), registered partially sighted (PS) and not-registered (NR) groups were compared using t-tests for continuous variables and Chi-square tests for categorical variables.

Results

Fifty-one (37%) of 137 identified GP patients agreed to participate, but only 15 SSB clients volunteered. Twenty-one participants were registered blind, 15 were registered partially sighted, and 30 were not registered. The three registration groups were very similar with respect to age, years of impaired vision, household composition, and cause of vision loss (see Table 1). Age-related macular degeneration (ARMD) and diabetic retinopathy were the most common causes.

Interview visits lasted 1–4 h (average = 2 h); some respondents were reluctant to let the interviewer leave.

Patients’ recollections: responses to questions in Appendix

Fears

Q13: What were your worst fears when you realised you were losing your sight?

Q14: How did you cope with your fears?

One in four patients 17/66 reported no fears at diagnosis. Almost half (45%) reported fearing total
blindness. Other common fears included loss of independence (24%) or inability to cope without support (22%). Only seven respondents mentioned fears of loss of enjoyment of life. Feared losses included: inability to see grandchildren (1B), not being able to read or write (1B; 1PS), having to give up needlework (1PS), inability to go on holiday (1PS), and two (NR) respondents were afraid they would have to stop driving. Although most respondents coped with these fears by talking to family and/or friends, over one-third (37%) had talked to nobody.

**Depression**

Q15: Did you feel depressed because of your sight problems?

Q16: Did you ever feel so depressed that you felt life was not worth living?

Significantly more blind (71%) and partially sighted (73%) patients than not-registered patients (37%) patients reported feeling depressed at diagnosis ($\chi^2 = 8.38$; 1 degree of freedom (df); $P < 0.01$).

Fourteen patients (21%), including 9/21 blind patients, admitted feeling so depressed that they felt that life was not worth living, and two had felt suicidal. Other reactions included frustration (9/66), annoyance (5/66), worry (9/66), shock (11/66), disbelief (4/66) and anger (2/66), but 29/66 ‘just accepted it’.

Q17: Did anyone recognise you were depressed? If ‘yes’ who was it?

Only 13/27 (35%) ‘depressed’ respondents felt their sight-loss-related depression had been recognised: nine by the GP, two by the consultant, and two only by the family.

Q23: Did your doctor prescribe any treatment for the depression?

All 13 patients recognised as depressed had been treated with selective serotonin reuptake inhibitors (SSRIs) (10) or tricyclic antidepressants (TCAs) (3); 71% of these patients were still taking them.
Support

Q27: Is there anything that could have made life easier when your sight loss became a problem?
More information about their diagnosis, or someone to talk to about the disease, at the time of diagnosis was most commonly cited in answer to this question. Only three patients felt that their GP or eye doctor had been helpful. In terms of day-to-day practical help, most respondents felt that they had received enough support from family and friends.

Q30: Who was most helpful?

Q31: What was most helpful?
The patient liaison officer, and the 6-week Insight Course, offered by Hampshire County Council Social Services Department to patients with newly diagnosed sight problems were mentioned as being particularly helpful by those who used them.

Social worker input after diagnosis and registration was appreciated, but partially sighted respondents, in particular, complained that no follow-up contact or assessments were made to re-assess the effect of deteriorating vision, from progressive, degenerating diseases such as age-related macular degeneration and diabetic retinopathy, on their ability to cope. Voluntary sector services for the visually impaired were mentioned as particularly helpful by 17 respondents (12B, 4PS and 1NR).

Current functioning and health

Effect of sight loss on daily functioning
VFQ-25 subscale scores, where lower scores indicate lower levels of functioning, confirmed that mean scores for blind and partially sighted patients were significantly lower than for not-registered patients, not only on all vision-related subscales, but also on dependency, social functioning and role difficulty subscales (see Figure 2).

VFQ-25 responses revealed that more blind patients were housebound, not only because they were unable to go out alone, but also because they were also more afraid that they would embarrass themselves or others. One in three blind patients had given up entertaining friends and family at home because of their blindness.

General health

Mean VFQ-25 scores for general health of <50 for each registration group (see Figure 2) suggest a population with only fair or poor health.

Mental health

From Table 2 it can be seen that, although the prevalence of anxiety symptoms (~50%) was similar in each registration group, the proportion showing evidence of any depressive symptoms was significantly higher among the registered blind (52.4%) and partially sighted patients (53.3%) on the HAD scale, than among non-registered patients (10%). The proportion of blind patients (80.9%), but not partially sighted patients (60%), with GDS scores indicating possible or probable depression, was significantly higher ($P<0.01$) than for non-registered (31.4%) patients. Blind patients also scored signifi-
Box 1 Reasons for not discussing worries with the consultant ophthalmologist

1  ‘He was always too busy’
2  ‘They are too busy for normal conversation’
3  Felt the eye consultant was too pressured but was a ‘nice man’
4  Busy man, doesn’t explain things very well
5  They are too busy for trivial worries
6  They are too busy to discuss ‘feelings’.
7  Too busy, he didn’t have time to answer any questions
8  Too busy, he didn’t really have time
9  He was too busy to explain the condition properly
10 Didn’t feel able to, he was busy and had lots of patients waiting
11 Just got on with it and the consultant was a bit abrupt
12 Usually so busy ‘in and out’, don’t have time to talk about other things
13 Too much to do, time with the patient was too brief so didn’t feel she could talk
14 Didn’t think he would care
15 ‘He thought the body ended at the neck’. Not very good at communicating
16 Consultant never asked, quite stand-offish and sharp
17 Didn’t feel ‘at ease’ enough to be able to talk to him
18 Didn’t know him very well
19 Didn’t seem the right thing to do
20 He was never interested, consultant’s attitude was ‘You’ve lost your sight, get on with your life’
21 Consultants don’t listen so she doesn’t bother to tell them
22 He wasn’t very approachable
23 He wasn’t very approachable
24 Didn’t feel he could talk to him
25 Not very approachable so wouldn’t have told him anything important
26 Original consultant very offhand, since then much better but he is still put off talking
27 Didn’t think to trouble him with ‘that kind of thing’
28 Sometimes the doctors were offhand and he has been given almost no information on his eye problem
29 Would have been a ‘waste of time,’ consultants don’t want to know you
30 Doesn’t know him, only met him once
31 Felt that he didn’t really know his consultant, just ‘in and out’
32 Hardly saw him, didn’t know him well enough
33 Very brisk, quite nice but just did his job
34 Not sure, doesn’t really like worrying people
35 Private person, didn’t like to discuss worries
36 ‘Isn’t one to talk much’
37 Used to keeping things to herself
38 Didn’t want to talk to anybody
39 Never saw her eye problems as a problem big enough to warrant talking to the eye doctor
40 Relied on his wife to talk any worries over with
41 Talked to the family instead
42 Only needs to talk to his brothers and sisters about this kind of thing
43 Didn’t have any real worries to discuss
44 Didn’t have any worries
45 Didn’t have anything to ask him
46 Nothing really worried her
47 No real worries, but gets on well with eye consultant
48 No real worries
49 No real worries
cantly lower on the VFQ-25 mental health subscale, calculated from responses to questions about ‘worrying about eyesight’, and a measure of anxiety, than not-registered patients.

GDS scores for individual questions revealed that, compared with partially sighted patients, blind patients had significantly increased prevalence of feelings of hopelessness (B: 28.5%; PS: 0%; difference = 28.6%; 95% confidence interval (CI) = 9.2 to 47.9) and worthlessness (B: 52.4%; P: 6.7%; difference = 45.7%; 95% CI = 20.9 to 70.5) than partially sighted patients.

VFQ-25 mental health subscale scores, calculated from responses to questions about ‘worrying about eyesight’, and a measure of anxiety, not only showed similar low scores for the blind (mean = 44.6) and partially-sighted (mean = 45.8) groups, but also showed that the mental health scores for both registered groups were significantly lower \((P<0.01)\) than for the not registered group (mean = 76.7), confirming a lower level of mental health functioning among registered patients.

**Discussion**

The fact that significantly fewer of the blind (5%) and partially sighted (20%) patients than not-registered (43%) patients had felt able to talk about their worries with either their consultant or GP is disturbing. This suggests that, despite being aware of the impact of the diagnosis, the doctors did not convey this in a sympathetic manner to the patient, and patients do not always know with whom the responsibility for discussing their worries, or for assessing and addressing their needs, lies.

There was no difference in the proportion of patients who felt that their eye consultant was ‘too busy’ to talk about the effect of their loss of sight among those patients who were diagnosed before the opening of the specialist eye unit in Southampton about 10 years ago, and those diagnosed since. The eye unit now has 11 consultants. This is an area that needs to be addressed in both secondary and primary care settings.

The significance of the degenerative nature of the diseases suffered by patients registered as partially

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**Box 2 Reasons for not discussing worries with the GP**

1. Too proud to ask for help
2. Didn’t feel ready to talk to anyone, even the GP who was a family friend
3. Didn’t feel ready to talk to him
4. Didn’t know him very well, her family GP had recently left
5. Didn’t know him well enough
6. Didn’t see much of him, didn’t feel like he knew him well enough
7. Doesn’t know him very well, doesn’t feel that he can talk to him
8. Don’t see him very often
9. Didn’t want to bother him
10. Didn’t want to bother him
11. Just didn’t want to worry him, he was very busy
12. GP didn’t really know anything about eyes
13. GP doesn’t really know much about eyes
14. He has no faith in doctors
15. Not a big fan of doctors. Very private person, keeps himself to himself
16. No real worries, but did feel her GP was unapproachable, talked to the computer
17. Seen as ‘just a number’
18. ‘Have to be at deaths door before he sees you’, private man
19. Hated his GP
20. Private person, likes to deal with her problems herself
21. Just tends to keep things within the family, i.e. his two sons
22. Never liked discussing things with people other than her husband
23. Doesn’t like talking to anyone about her problems
24. Nothing really worried her
25. Never had any serious problems
26. Never had any worries
27. Didn’t really have any worries
28. Didn’t have any worries
sighted is still under-recognised by social services, in that no routine follow-up assessments were made to assess the effect of decreasing visual functioning after the initial pre-registration assessment.

The strength of this pilot study is the combined use of a semi-structured interview and standardised rating scales to provide both quantitative and qualitative data on mental state and level of functioning.

The weaknesses in this pilot study are: that the semi-structured tool used to elicit qualitative data was being piloted and has not been tested for reliability or validity; that the length of time between diagnosis and interview may have affected recollections in this elderly population; and the low recruitment rate that may have resulted in a biased study population.

However, most interviewees seemed to remember their reaction to the diagnosis well. Possible reasons for the low recruitment rate included: not realising that so many elderly severely visually impaired patients lived completely alone and could not read, or even have read to them, the large-print letter sent by the GP, and not requesting contact details for SSB client volunteers immediately after the presentation and explanation of the study. Many of the very elderly clients probably forgot to contact staff after the activity. These methodological problems would need to be addressed in any subsequent study.

Comparison with existing literature

Our results describe a population of predominantly isolated vision-impaired individuals in poor general health that is very similar in their characteristics to the population surveyed by the Royal National Institute for the Blind in 1998. Many were living isolated and lonely lives; 50% lived alone. Their worries, about their decreasing ability to cope with daily living, or to live independently, mirrored those reported by Bruce.

The reported association between decreased vision and depression has also been confirmed in this population. Significantly more mental health problems were found among the elderly blind or partially sighted patients than their not-registered contemporaries, even though the groups were similar in respect of living conditions, diagnostic groups and low scores for general health, all of which could be associated with depression.

Implications for clinical practice and further research

The relationship between patients’ perceptions of the attitudes of clinicians towards emotional problems, and clinicians’ perception of their role, needs further investigation.

The patients’ expressed need for more information could be met by making information about eye diseases and support sources available in accessible forms, such as large-print leaflets or audiotapes produced by the RNIB, in surgery waiting rooms. If the sight loss becomes severe, the practical and financial benefits of registration should be emphasised, since registration is a pre-requisite for access to some support facilities, and a referral to social services should be made.
### Table 2: Comparison between mental health measures for registered blind (B) or partially-sighted (PS) patients and not-registered (NR) patients

<table>
<thead>
<tr>
<th>Rating scale</th>
<th>Registration group</th>
<th>n</th>
<th>Number with symptoms, n (%)</th>
<th>Score</th>
<th>Significant differences between registration groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Range</td>
<td>Median</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Possible (≥8) Probable (≥11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HAD-Anxiety</td>
<td>Blind</td>
<td>21</td>
<td>5 (23.8) 4 (19.0)</td>
<td>3–14</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Partially sighted</td>
<td>15</td>
<td>5 (33.3) 4 (26.7)</td>
<td>2–13</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Not registered</td>
<td>30</td>
<td>9 (30.0) 3 (10.0)</td>
<td>1–13</td>
<td>7</td>
</tr>
<tr>
<td>HAD-Depression</td>
<td>Blind</td>
<td>21</td>
<td>2 (9.5) 9 (42.9)*</td>
<td>2–15</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Partially sighted</td>
<td>15</td>
<td>6 (40.0) 2 (13.3)</td>
<td>2–13</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Not registered</td>
<td>30</td>
<td>2 (6.7%) 1 (3.3)</td>
<td>0–12</td>
<td>4.5</td>
</tr>
<tr>
<td>GDS</td>
<td>Blind</td>
<td>21</td>
<td>13 (61.9) 4 (19.0)</td>
<td>2–11</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Partially sighted</td>
<td>15</td>
<td>8 (53.3) 1 (6.7)</td>
<td>1–11</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Not Registered</td>
<td>30</td>
<td>8 (26.7) 2 (6.7)</td>
<td>1–11</td>
<td>3.5</td>
</tr>
<tr>
<td>VFQ-25 Mental Health</td>
<td>Blind</td>
<td>21</td>
<td>18.8–68.8</td>
<td>44.39</td>
<td>15.38</td>
</tr>
<tr>
<td></td>
<td>Partially sighted</td>
<td>15</td>
<td>0–87.5</td>
<td>45.13</td>
<td>24.08</td>
</tr>
<tr>
<td></td>
<td>Not registered</td>
<td>30</td>
<td>6.2–100</td>
<td>76.67</td>
<td>23.67</td>
</tr>
</tbody>
</table>
The significantly increased prevalence of depression among elderly patients registered as blind or partially sighted suggests that mental health screening should be routinely undertaken. Although the government proposal that all patients aged ≥75 years should receive annual health checks has never been implemented, studies have shown that such checks, even if only made by a telephone call, can identify some unmet needs.20,21 Since many elderly patients in this study were reluctant to visit their GP, and many were living alone and housebound, some specific follow-up, in the form of regular practice reviews of those with severe visual impairment might provide the opportunity to improve the quality of life of a very vulnerable group. It could also reduce the risk of suicide, since loneliness, both major and minor depression, and suffering from sight problems have all been specifically linked to increased suicide risk.22

There could be a role for primary care ‘nurse specialists’ to offer help to people with newly diagnosed sight impairment. This role could include counselling, screening for mental health problems, reviewing needs on a regular basis for those with deteriorating sight conditions, possibly by telephone, and facilitating social service involvement. The latter could be particularly important, as reports by the RNIB concluded that the effect of visual impairment is still poorly understood by social services: ‘blind’ people who can walk are not considered ‘mobility impaired’, even though 60% never go out on their own; and their disability is not considered life-threatening, despite the high prevalence of depression and suicidal ideation associated with vision loss.23

Recommendations for further research include: assessing the attitudes of primary and secondary clinicians with respect to their role at diagnosis and assessment of mental health of newly diagnosed patients with severe sight problems; how and by whom needs can be best assessed; and ways in which identified needs can be addressed. Controlled trials should then be undertaken to test the effectiveness of implemented suggestions.

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**ETHICS APPROVAL**

Ethics approval was granted by the Southampton and SW Hants Local Research Ethics Committee, Ref: 189/03/w.

**CONFLICTS OF INTEREST**

None.

**ADDRESS FOR CORRESPONDENCE**

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*Received ?????*  
*Accepted ?????*
Appendix: blindness study interview guide

You need not answer any questions that you do not wish to, and can stop the interview at any time

1 Patient ID

2 Date of interview

3 Age

4 Gender:
   Male
   Female

5 Location of the interview:
   Home
   Surgery
   Elsewhere

6 When did you first realise that you were losing your sight?
   Which year?
   How many years ago?

7 Who first told you that you had a serious problem with your sight?
   GP
   Consultant
   Other person

8 Who was the ‘other person’?

9 What were you told was the cause of your sight loss?
   Macular degeneration
   Diabetic retinopathy
   Cataract
   Other cause

10 What was the ‘other cause’?

11 Did the problem affect both eyes or only one eye?

Now I would like to ask you some questions about how you felt when you realised that you were losing your sight

12 How did you feel when you realised you were losing your sight?

13 What were your worst fears when you realised you were losing your sight?

14 How did you cope with your fears?

If depression has not been previously mentioned go to question 15

Otherwise go to question 16
15 Did you feel depressed because of your sight problems?

If the answer is yes, or depression was previously mentioned go to question 16

16 Did you ever feel so depressed that you felt that life was not worth living?

17 Did anyone recognise that you were depressed?

If yes:

18 Who was it?

19 Did you talk to your eye consultant about your feelings?

If no:

20 Why not?

21 Did you talk to your family doctor?

If no:

22 Why not?

23 Did your doctor prescribe any treatment for depression?

If yes:

24 Which drug?

25 How long did you take tablets for?

26 Are you still taking tablets for your depression?

27 Is there anything that could have made life easier when your sight loss became a problem?

28 Is there anything that could make life easier now?

I would now like to ask you to help me fill in a questionnaire about how your sight problems have affected your activities.

Complete the Visual Functioning Questionnaire (VFQ-25)

29 Did you feel supported in any other way when you realised that your sight was deteriorating?

30 What was most helpful?

31 Who was most helpful?

32 Was there anything that was unhelpful?

If yes:

33 What was unhelpful?
34  Do you attend any special centres for people with sight problems?

If yes:

35  Which centre(s)?

36  Do you use any special aids to help with your sight problem?

If yes:

37  What aids do you use?

38  Which aids do you find most helpful?

39  Have you ever been assessed by a social worker for the blind?

If yes:

39  Who suggested that you should be assessed?

40  Are you registered as blind or partially sighted?

If yes:

41  Who suggested that you should be registered?

If not:

42  Why not?

43  Is there anything else you would like to tell me about the support you have had?

44  If yes: describe

45  Is there any support that you would like but that is not available?

I would like to finish by completing two short questionnaires about how you have felt recently and about how you are feeling now

Complete Geriatric Depression Scale for feelings in past week

Complete HAD Scale for feelings now

Thank you so much for helping me with my study

Name and address of GP if not invited by GP to participate

GP: ........................................................................................................

Surgery address: ....................................................................................

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