Sight loss in later life: a vision for health service intervention

Visual impairment is one of the most prevalent and disabling conditions that arises in later life, yet it impacts on the lives of older people has received little attention compared with other problems such as impaired mobility and dementia. As a result, health care professionals have insufficient knowledge of the health and social care needs of this growing population, which makes it difficult to develop the appropriate services and define best practice (Hanson et al, 2002).

According to the Royal National Institute for the Blind (RNIB), two million people in the UK are affected by sight loss, two-thirds of whom have an additional disability or suffer from a serious health problem such as deafness, arthritis or diabetes. Significantly, 90 per cent of blind and partially sighted people are aged over 60 – a population group, which is set to rise steadily (RNIB, 2001).

A recently completed large-scale study (Evans et al, 2002) estimates that 12 per cent of people aged over 75 are blind or partially sighted – a figure the researchers admit is conservative and nearly a fifth have such poor vision that they would not be permitted to drive. These figures tell us nothing, of course, about people’s daily battle with visual impairment and what they need from health and social care services.

A recent study investigating priorities in health and social care for blind and partially sighted people (RNIB, 2001) found the system lacking. In general, visually impaired people are given inadequate help and information; are forced to deal with services that are under-resourced, inflexible and highly variable; and receive little attention to their emotional needs.

Deficiencies are likely to hit older people hard, given that they may well live alone, be coping with other health-related problems, and be less able to manage without help. Older people with visual impairment are especially vulnerable because they often lack the necessary support and skills to help them avoid injury (Coles et al, 1997).

Indeed, as many as 40 per cent of older people who present at A&E hospital departments after falls have visual impairment (RNIB, 1999).

Methods
Between March 2001 and July 2002, questionnaire-based interviews were conducted with 400 participants across three areas: Plymouth, Birmingham and London. Participants, aged 55 and over, were identified with the help of statutory and voluntary sector organisations, as well as housing agencies, and through local media publicity in each city.

We had to rely on the assistance of these organisations as there are no comprehensive lists of people who are visually impaired. However, this means that the sample included more individuals facing health, social care or housing need than might have been the case had we been able to draw more easily from a wider population of older people with a loss of sight.

Although we could not realistically hope to assemble a truly representative sample, we did achieve set targets for the inclusion of:

- Individuals who were not known to visual impairment specialist agencies (25 per cent);
- Individuals with additional disabilities or health problems (more than half);
- Individuals from ethnic minority groups (15 per cent).

The gender balance for the sample reflected the balance for the older age groups within the population at large (1.85 female:1 male). The sample included a high proportion of people aged 75–84 (42 per cent) and those aged 85 years and above (31 per cent), compared with those in the younger range, aged 55–74 (27 per cent).

This was justifiable, given that the study focused upon meeting the housing, support and care needs of people whose sight (and health) was already failing. However, we also deliberately lowered the minimum age for inclusion within the sample to 55, in order to reflect the attitudes and requirements of people who were at the threshold of later life.

Overall, our sample came from varied socioeconomic backgrounds and lived in a wide range of settings, from ordinary houses or flats, to sheltered accommodation and residential care. Some lived with a spouse or a relative, but most participants (60 per cent) lived alone.

The questionnaire sought details of each respondent’s sight condition, general health, support systems (if any), home circumstances, future housing preferences, financial resources, and social contacts. Specially trained ‘lay’ interviewers (mostly older people with relevant life experience and empathy to draw upon) carried out the interviews. Members of the research team carried out in-depth follow-up interviews and focus groups.

As a result, the study produced two main types of data: quantitative data deriving from questionnaire-based interviews with 400 people, and qualitative data arising...
from the detailed follow-up interviews with 75 respondents taken from the total sample, as well as information from focus group discussions held in each locality.

Results
Sight impairment and overall state of health
The vast majority of interviewees (92.5 per cent) reported a late onset of visual impairment. Nearly three-quarters of interviewees reported having a serious visual impairment, or no sight at all, while just over a fifth described their impairment as moderate.

The most common sight conditions were cataract, macular degeneration, glaucoma and diabetic retinopathy. A high proportion of respondents were experiencing health problems, ranging from one or more long-standing chronic complaints (85.5 per cent) to one or more seriously disabling problems (53.0 per cent). When invited to rank their overall state of health on a scale from excellent to poor, the distribution was skewed towards the ‘not very good’ and ‘poor’ end of the scale.

Of the 400 interviewees, a total of 168 were registered as blind and 97 as partially sighted. However, 104 (26 per cent) were not registered as either blind or partially sighted and a further 20 did not know whether they were registered.

Interestingly, just over half of the respondents said they were not in touch with any support services, and this included people who were registered. Indeed, only one in five of the sample had received any rehabilitation.

This service typically provides advice on the use of special equipment, help with orientation inside and outside the home and the development of compensatory skills with activities of daily living.

More than half of the interviewees had been seen by their GP within the last month or so and a further 46 had been seen within the last six months. Only 22 (5.5 per cent) had not visited their GP within the last five years.

Trends in GP visiting patterns were similar in all three areas, but this did not result in regular contact with eye specialists. Contact with ophthalmologists was much less common, with only a third of the sample having seen a specialist within the last five years.

Diagnosis and immediate patient care
Sharpe (2002) referred to her rehabilitation work with clients who have retinitis pigmentosa and indicated that older people who are visually impaired, such as the 77-year-old man who formed her case study, experience feelings such as low morale, denial and a sense of bereavement that often remain difficult to observe.

Our study, with its combination of survey and in-depth discussion, was able to probe often raw emotions and revealed that sudden or worsening sight loss in later life is commonly experienced as ‘devastating’, ‘shattering’ and a life-changing event.

The study suggests that some staff in eye clinics may not be aware of, or sensitive to, the emotional effects associated with late onset sight loss, as demonstrated in the following quote: ‘The very, very first thing ever said to me [by the eye infirmary] was “there’s nothing we can do, there’s no treatment, there’s no cure”, and that was it, goodbye. No counselling, no nothing... They didn’t prepare me for this at all... Three o’clock in the morning, I am thinking: Oh God, what am I going to do if I go blind, I’m on my own? It’s a terrible thing really is.’ (Mrs Martin, diagnosed with macular degeneration.)

While diagnosis of sight loss needs to include presentation of clinical facts and likely outcomes, interviewees such as Mrs Orr, another patient with macular degeneration, suggested that relevant eye clinic staff could ‘talk to you in a different way’.

Mrs Orr went on to say that easier acceptance of what was being revealed in the case of a poor prognosis would be possible if the patient knew about available help and sources of support ‘from the very beginning’. Mrs Orr, who had not been given such information, described herself as ‘quite depressed, I’m on antidepressants now’.

Of course, we understand that the comments of our more critical interviewees regarding eye clinics cannot be generalised to suggest that staff in eye clinics are dismissive of patients’ support needs.

However, the expression of sympathy and awareness of patients’ emotional needs, by doctors, nurses and allied specialist staff is clearly important. As Mr Russell, who had macular degeneration, said: ‘It’s knowing that someone understands that makes the difference.’

Such comments, when combined with the majority of favourable experiences recalled by interviewees, indicate that good patient care after diagnosis at eye clinics includes the provision of improved and accessible information. This should include local support services, the benefits of low-vision equipment and possible financial help – as well as the availability of counsellors.

It follows that eye clinics should have appropriately trained staff, who are available to talk directly with patients about their worries and provide advice about possible sources of further help. This is an issue that has also been identified by Barrick (2000), who found that only a third of ophthalmic nurses have received training in visual awareness.

Additionally, members of the health and social services’ sensory impairment team could further develop collaboration so that both clinical and social care personnel are available on site, in order to help individuals through a potentially traumatic diagnosis and its immediate aftermath.

Follow-up patient care
The study also indicated that, although many interviewees enjoyed positive relationships with general and specialist nursing and medical staff, some faced obstacles in regard to post-diagnosis follow-up.

Mrs Jackson cares for her 75-year-old husband, who has Parkinson’s disease as well as glaucoma, and she was not alone when she spoke about the difficulties of gaining access to clinics:

’We have great difficulty getting appointments for the eye infirmary... I have written four times and enclosed...’ (Mrs Jackson)

KeywORds ■ Visual impairment ■ Older people ■ Health and social care

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partially sighted people.


Regulation
Stanford and Shepherd (2001) point out that the vicious circle in which people with a visual impairment and learning disabilities find themselves includes a lack of recognition of their eligibility to be registered as blind or partially sighted.

The same neglect, on a larger scale, applies to older people with visual impairment, more than two-thirds of whom remain unregistered (RNIB, 2001). Registration is not merely a medical nicety. As indicated earlier, it is a process that sets in motion rehabilitative work in the home and the wider community, the provision of low-vision equipment and an assessment of social care needs by specialist social workers.

Our study exposed what could be described as significant gaps in the provision of such services – not least because of the failure to register people – and led to expressions of concern from our lay interviewees, who were critical of the low level of rehabilitation and support received by many of their interviewees.

One such interviewer said: ‘I think older visually impaired people are the forgotten people, with very little help available.’ Another referred to people she thought had been ‘neglected’.

The failure to register older people with serious visual impairment is a matter that requires more study and further explanation.

However, an obvious point can be made here that resonates with the difficulties described earlier in regard to diagnosis, immediate support and follow-up patient care: standards of ophthalmic care for older people are variable and do not always take account of the wider picture that is made up of health and social care needs running in close parallel throughout later life.

Ophthalmologists and their teams need to be aware of the consequences of lack of registration. Specialist doctors and nurses may benefit, in this regard, from the regular input of relevant case study material and outcomes, presented at clinical meetings by practice and district nurses, rehabilitation workers and sensory impairment social workers.

Conclusions
The findings of this wide-ranging study include an emphasis on needs that require attention and action by relevant health and social care professionals. These needs cannot be said to be common to all older people with sight loss, as our sample was not statistically representative, and conclusions are, therefore, tentative and indicative rather than categorical.

Nonetheless, this article has touched on three significant issues:

- The quality of patient care at the time of diagnosis;
- Difficulties in receiving and gaining access to outpatient follow-up;
- The consequences of low levels of registration.

These issues did not affect all interviewees. However, they did have an important impact on some people in respect of their ability to maintain self-esteem and well-being and adapt to sight loss.

Good health care practice helps to achieve these aims by forging close working relationships between eye clinics, primary health care staff and social services personnel. This, in turn, raises the profile of older people with visual impairment and increases the prospect of an integrated and holistic service approach to the health and social care of this section of the population, which is growing in number.

Further information
A short report in the form of an Occasional Paper, and the full report, both titled The Housing and Support Needs of Older People with Visual Impairment, by Julienne Hanson, Malcolm Johnson, John Percival and Reem Zako are available in a variety of formats from: Thomas Pocklington Trust, 5 Castle Row, Horticultural Place, London W4 4JQ. Tel: 020 8995 0880.