

## EXTENDED REPORT

## Impact of an interdisciplinary low vision service on the quality of life of low vision patients

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**Aim:** To investigate the impact of an interdisciplinary low vision service on the vision related quality of life of service users.**Methods:** 71 patients were interviewed 2 weeks before their appointment with the service and again 6 months later to assess any changes in their vision related quality of life. The majority of these patients had age related macular degeneration.**Results:** After contact with the service the majority of patients indicated a reduction in concern about most quality of life issues. They were significantly less anxious about deterioration of their vision, safety within the home, and coping with everyday life.**Conclusion:** Improvements in many areas of their vision related quality of life indicate that this interdisciplinary low vision service has a positive impact on the lives of service users. However many patients were still unable to carry out their preferred everyday activities, and feelings of loneliness and isolation were unchanged. The identification of issues unrelieved by input from the service will be important in planning future service delivery.

The scale of the low vision problem is considerable. There are estimated to be nearly one million visually impaired people in Britain, 90% of whom are over the age of 60 years.<sup>1</sup> Serious sight loss can lead to depression, loneliness, and anxiety<sup>2,3</sup> and is an important risk factor for restriction in an older person's ability to carry out everyday activities.<sup>4,5</sup> The most common causes of visual impairment in elderly people are age related macular degeneration (ARMD), cataract, and glaucoma.<sup>6</sup>

Approximately 85% of those known to be visually impaired have useful residual vision and could benefit from visual rehabilitation.<sup>1,7</sup> Several studies have shown that visually impaired people can be helped to achieve some improvement in visual skills through a combination of clinical assessment, advice, and the prescription of low vision aids (LVAs), in conjunction with appropriate follow up and training.<sup>7,8</sup> These different stages of care, however, are commonly fragmented, with those responsible for providing a clinical assessment of low vision and those involved in providing education, rehabilitation, and social work services functioning independently.<sup>9</sup>

A study undertaken to determine the type and location of low vision services within the United Kingdom concluded that in comparison with the probable number of people with a visual impairment in the United Kingdom, there are apparent inadequacies in terms of distribution, magnitude, and coordination of services.<sup>10</sup> Recent reports have suggested that multidisciplinary models of low vision care offer considerable benefits to patients.<sup>9,11</sup> A Royal College of Ophthalmologists publication in 1998 on the provision of low vision care also recommended multidisciplinary working.<sup>12</sup>

The interdisciplinary low vision service (ILVS) in this study was established in 1995 and is unique in the United Kingdom. Professionals from ophthalmology (associate specialist and staff grade), ophthalmic nursing, social work, and rehabilitation carry out joint assessments with patients and carers. An evaluation of the ILVS was undertaken in 1997 in order to investigate the benefits of interdisciplinary working practice and how such a service should be effectively

managed. This study concluded that there were clear advantages of interdisciplinary working for staff, including shared knowledge and expertise and improved communication between professions, but that further study was required to assess the benefits of such a model to the service users.<sup>13</sup>

Throughout this study, the ILVS operated from two district general hospital low vision clinics. Patients who were referred to the clinics received a range of services tailored to their individual requirements. These included clinical assessment; diagnosis; referral for treatment; blind or partially sighted registration; refraction and prescription of LVAs, together with information, counselling, and support (Table 1). A rehabilitation worker or social worker shared the consultation with the ophthalmology staff at the low vision clinics and they also provided domiciliary follow up visits. There are close links with the low vision scheme provided by local community optometrists who see patients in their own locality, funded by the local health board.<sup>14</sup> Approximately 500 patients are seen by the ILVS each year.

There has been a great deal of interest recently in quality of life (QOL) in relation to vision,<sup>15</sup> particularly with respect to cataract surgery<sup>16</sup> and glaucoma.<sup>17</sup> Some studies investigating vision related QOL issues have employed generic QOL instruments which have been validated with low vision patients.<sup>18,19</sup> However, it is unlikely that the full range of vision related problems can be adequately described within a general QOL framework as there are issues specifically related to vision.<sup>20</sup>

A variety of vision specific instruments have been developed to assess the impact of visual impairment on function and QOL. These include the Daily Living Tasks Dependent upon Vision (DLTV),<sup>21</sup> the National Eye Institute Visual function questionnaire (NEI-VFQ),<sup>22</sup> the Visual Function Index (VF-14),<sup>17</sup> and the Vision-Related Quality of Life Questionnaire (VQOL).<sup>23</sup> The VQOL, which has been employed in several outcome studies in the United Kingdom, including low vision rehabilitation<sup>24</sup> and macular surgery,<sup>25</sup> was selected as the most appropriate vision specific instrument for use in this study. It has been validated for use with ARMD patients, was relatively short and simple to

**Table 1** Components of ILVS

Patient history, visual assessment, LVA provision and initial training	Ophthalmic nurse and ophthalmologist
Examination and diagnosis	Ophthalmologist
Provision of information to patient and carer	Ophthalmic nurse and ophthalmologist, social work/rehabilitation
Registration if appropriate	Ophthalmologist
Follow up phone call	Social work/rehabilitation
Domiciliary visit(s) addressing: independent living skills, mobility, LVA training, social benefits	Social work/rehabilitation
Re-referral to LV clinic if necessary	Social work/rehabilitation

administer, and resulted in a total patient score which was useful for comparative purposes.

The VQOL consists of a core questionnaire with 10 broadly applicable items referring to physical, social, and psychological QOL issues identified by patients as being most important to them (VCM1). Each VCM1 item is a 6 point ordinal scale which ranges from 0 (no problem) to 5 (extreme problem). The single index score which can be derived by taking the mean of the scores for individual items provides a global measure of concern about vision.

The VQOL was used in this study in conjunction with a "restrictions of daily living questionnaire" developed by researchers at the Manchester Royal Eye Hospital (MLVQ).<sup>24-26</sup> The MLVQ can be used to assess which of 19 different activities patients have attempted to perform over the past month, the degree of difficulty that they experienced in carrying out the task, and how important it was to them to be able to perform it.

## METHODS

Ethical approval was granted by the local research ethics committee to carry out the study before its commencement.

All patients with appointments at either of the two low vision clinics between November 1998 and February 1999 were invited to participate in the study. Patients who had attended a low vision clinic during the previous 6 month period were excluded as were patients aged 16 years or less.

Patients were sent a letter in large print giving details of the study approximately 2 weeks before their appointment at the low vision clinic. An interviewer then contacted each patient by telephone to ask if they were willing to participate and if so, to arrange an interview in their home.

Patients who consented were interviewed in their own home 2 weeks before their ILVS clinic appointment. A total of 80 patients (67% of those approached) agreed to be interviewed.

Each patient completed a VCM1 and MLVQ questionnaire in order to assess the impact of their visual impairment on vision related QOL and performance of activities of daily living. Participants also answered some general questions about their health and living arrangements over the past 6 months.

Six months after their appointment with the ILVS, 71 of the 80 patients (89%) originally interviewed agreed to be reassessed. Of the remaining nine patients, two had died and seven were in poor health and were unable to be interviewed. Vision related QOL and restrictions in activities of daily living were measured using the VCM1 and MLVQ. In addition, patients were asked if they had attempted to use any of the LVAs that they may have been prescribed for each of the tasks in the MLVQ and if so, how useful they had found the LVA for the task.

The questionnaires were analysed using dBaseIV and SPSS. Statistical tests used for comparing results from the

**Table 2** Diagnosis

	No (%)
ARMD alone	38 (53)
ARMD + other diagnosis	11 (15)
Diabetic retinopathy	9 (13)
Glaucoma	2 (3)
Cataract	2 (3)
Retinitis pigmentosa	2 (3)
High myopia	2 (3)
Stroke	2 (3)
Other	3 (4)
<b>Total</b>	<b>71</b>

original study with the follow up study were the one way analysis of variance, Wilcoxon signed rank test, and the McNemar test.

## RESULTS

The majority of participants recruited to the study were diagnosed with ARMD alone (38, 53%) or ARMD with an additional diagnosis (11, 15%) (Table 2).

The majority of participants were 71 years of age or older (55, 78%) and approximately two thirds (49, 69%) were female (Table 3).

Fifty five (78%) of the original cohort had not been seen previously by the ILVS (Table 3). Sixteen patients (22%) had used the service on at least one occasion previously, although not within the 6 month period preceding their first interview for this study. Ten of the 16 patients (62%) had not been seen for at least 1 year (Table 4).

Over half of the patients who participated in this study were living alone at the time of interview (38, 54%).

## ACTIVITIES OF DAILY LIVING

The results of the MLVQ completed 2 weeks before contact with the ILVS and repeated 6 months later are summarised in Table 5.

There was a statistically significant increase in the number of patients who had read or tried to read ordinary print 6 months after their appointment with the low vision service compared with at their first interview. There was a significant decrease in the number of respondents who had read large print and shop prices/labels/tickets.

When interviewed 6 months after their appointment with the ILVS, 93% of patients had been prescribed an LVA. Approximately three quarters of interviewees stated that they had attempted using their prescribed LVAs for the following

**Table 3** Age and sex of participants

Age (years)	No (%)
34-55	2 (3)
56-70	14 (19)
71-85	38 (54)
86 and over	17 (24)
<b>Sex</b>	
Female	49 (69)
Male	22 (31)
<b>Seen by ILVS before?</b>	
Yes	16 (22)
No	55 (78)
<b>Live alone?</b>	
Yes	38 (54)*
No	33 (46)

\*37 patients (52%) were living alone before their ILVS appointment and one patient's living arrangements had altered to living alone when followed up 6 months later.

**Table 4** Patients seen by ILVS before

	No (%)
Between 6 and 12 months	6 (38)
1–2 years	4 (24)
2 years	6 (38)
<b>Total</b>	<b>16 (100)</b>

activities: reading ordinary sized print reading materials, reading their own correspondence, and reading instructions on packets, tins and medicines (Table 6).

At least half of those patients had found the LVAs quite helpful for performing these tasks (Table 7).

All of the low vision patients with one exception had used the LVA that they had been prescribed by the ILVS for at least one of the 19 activities listed in this section of the questionnaire.

Over half of those interviewed stated that they used their preferred LVA for reading several times each day but 10 patients (14%) never used their preferred LVA for reading (Table 8).

Approximately half of the patients used their preferred LVA to read for up to 30 minutes and a quarter of those interviewed were able to use their LVA for short periods of “spot reading” (Table 9).

## VISION RELATED QOL

The results of the VCM1 before and 6 months after contact with the ILVS are shown in Table 10. There was a statistically significant reduction in concern in three particular areas after contact with the ILVS: fear of deterioration of vision, safety at home, and coping with everyday life.

No statistically significant differences were found between baseline VCM1 index scores of patients who had been seen by the ILVS before and those who had not (Table 11), or

between those patients who lived alone and those who did not (Table 12).

## DISCUSSION

While it would have been preferable to have interviewed only those patients who had never had contact with the ILVS before, this would have reduced the size of the study population and excluded many patients with more advanced eye disease. Of the 22% of participants who had had contact with the ILVS before this study, more than half had not been seen for at least a year, at a much earlier stage in the disease process. There was no statistically significant difference in vision related QOL as measured by baseline VCM1 index scores between patients who had been seen by the ILVS before and those who had not at the start of the study.

It was felt that following up patients 6 months after contact with the ILVs would allow sufficient time for them to acquire the independent living skills which are an integral part of the rehabilitation process without a significant deterioration in their visual pathology. Patients were re-interviewed face to face rather than by telephone, which has been shown by the researchers who developed the VCM1 to cause a general bias towards under-reporting.<sup>27</sup>

A “restrictions in activities of daily living” questionnaire<sup>24</sup> was used to assess degree of difficulty patients experienced with task performance because of visual impairment. The majority of tasks with which patients reported most difficulty related to reading, which is consistent with the view that this is the principal handicap for most patients with visual impairment.<sup>8</sup> However, the wide range of tasks attempted by most interviewees suggests that low vision rehabilitation should concentrate on improvement of all activities of daily living rather than simply sustained reading. Leat *et al*<sup>7</sup> identify “survival or spot” reading tasks of limited duration as being vitally important to the visually impaired.

There was a significant increase in the number of patients who had read or tried to read ordinary print 6 months after their appointment with the ILVS compared with at their first

**Table 5** During the past month have you done or attempted to do the following tasks

	Yes		No		Missing		p Values for differences between distributions
	Initial	Follow up	Initial	Follow up	Initial	Follow up	
Read or tried to read ordinary print books/newsprint/magazines/TV times	45	54	26	16	0	1	<b>0.049*</b>
Read or tried to read large print books, large print newspapers, or newspaper headlines	48	37	20	34	3	0	<b>0.015*</b>
Read or tried to read letters/cards/bank statements/other correspondence	59	54	12	17	0	0	0.332
Read or tried to read your own writing	51	48	19	23	1	0	0.454
Read or tried to read instructions on packets, tins, bottles, medicines, etc	55	57	16	14	0	0	0.791
Read or tried to read shop prices/labels/tickets	49	34	22	37	0	0	<b>0.001*</b>
Read or tried to read the markings on dials—eg, on the cooker, radio, hi-fi, washing machine, etc	59	54	12	17	0	0	0.302
Read or tried to read the telephone directory to check numbers	21	25	49	45	1	1	0.344
Read or tried to read the time on your watch	52	52	19	18	0	1	1.00
Tried to fill in forms, cheques, cards, etc	42	33	29	38	0	0	0.108
Signed or tried to sign your own name	69	67	2	4	0	0	0.5
Written or tried to write your own letters	24	22	47	49	0	0	0.791
Identified or tried to identify money	70	67	1	4	0	0	0.375
Sewed/knitted/mended or attempted to sew, knit, or mend	16	20	55	51	0	0	0.344
Done or tried to do a special hobby	11	14	57	57	3	0	1.000
Carried out or attempted to carry out DIY/repairs/fix things	16	10	54	61	1	0	0.210
Watched or attempted to watch TV	68	70	3	1	0	0	0.500
Read or attempted to read street signs/bus numbers/directions, etc	39	34	32	37	0	0	0.302
Been on a trip or special day out	39	40	32	31	0	0	1.000

\*Significant difference between values  $p < 0.05$ .

**Table 6** Have you tried using your magnifier(s) for this?

	Yes		No		Missing	
	No	%	No	%	No	%
<b>During the past month, have you:</b>						
Read or tried to read ordinary print books/newsprint/magazines/TV times	53	75	14	20	4	6
Read or tried to read large print books, large print newspapers, or newspaper headlines	22	31	35	49	14	20
Read or tried to read letters/cards/bank statements/other correspondence	51	72	15	21	5	7
Read or tried to read your own writing	24	34	39	55	8	11
Read or tried to read instructions on packets, tins, bottles, medicines, etc	51	72	17	24	3	4
Read or tried to read shop prices/labels/tickets	22	31	32	45	17	24
Read or tried to read the markings on dials—eg, on the cooker, radio, hi-fi, washing machine, etc	18	25	50	70	3	4
Read or tried to read the telephone directory to check numbers	25	35	40	56	6	9
Read or tried to read the time on your watch	6	9	57	80	8	11
Tried to fill in forms, cheques, cards, etc	24	34	41	58	6	9
Signed or tried to sign your own name	11	16	57	80	3	4
Written or tried to write your own letters	7	10	55	78	9	13
Identified or tried to identify money	13	18	55	78	3	4
Sewed/knitted/mended or attempted to sew, knit, or mend	9	13	54	76	8	11
Done or tried to do a special hobby	3	4	46	65	22	31
Carried out or attempted to carry out DIY/repairs/fix things	2	3	45	63	24	34
Watched or attempted to watch TV	8	11	57	80	6	9
Read or attempted to read street signs/bus numbers/directions, etc	2	3	56	79	13	18
Been on a trip or special day out	7	10	51	72	13	18

**Table 7** If you have tried to use your magnifier(s) for this how helpful have you found them?

	Extremely/ moderately helpful (n)	Slightly/not at all helpful (n)	Total (n)
	<b>During the past month, have you:</b>		
Read or tried to read ordinary print books/newsprint/magazines/TV times	38	15	53
Read or tried to read large print books, large print newspapers or newspaper headlines	12	10	22
Read or tried to read letters/cards/bank statements/other correspondence	37	14	51
Read or tried to read your own writing	15	9	24
Read or tried to read instructions on packets, tins, bottles, medicines, etc	29	22	51
Read or tried to read shop prices/labels/tickets	13	9	22
Read or tried to read the markings on dials—eg, on the cooker, radio, hi-fi, washing machine, etc	6	12	18
Read or tried to read the telephone directory to check numbers	12	13	25
Read or tried to read the time on your watch	2	4	6
Tried to fill in forms, cheques, cards, etc	12	12	24
Signed or tried to sign your own name	5	6	11
Written or tried to write your own letters	4	3	7
Identified or tried to identify money	5	8	13
Sewed/knitted/mended or attempted to sew, knit or mend	6	3	9
Done or tried to do a special hobby	0	3	3
Carried out or attempted to carry out DIY/repairs/fix things	1	1	2
Watched or attempted to watch TV	4	4	8
Read or attempted to read street signs/bus numbers/directions, etc	0	2	2
Been on a trip or special day out	5	2	7

interview. This was paralleled by a significant decrease in the number of respondents who had read large print, which implies that patients were using their LVAs successfully.

The mean patient index scores for vision related QOL issues indicated that the area of least concern for patients was safety within their own home and items provoking greatest concern were frustration and annoyance because of their poor sight and inability to carry out preferred activities. The use of a single index score has been recommended in QOL assessment,<sup>28</sup> although such scores are inevitably associated with a loss of information about more specific issues. The VCM1 score estimates patients' degree of overall concern but does not determine the cause of concern. However, some causes may be highly specific to individual patients or may concern issues which escape inclusion in even longer questionnaires.

Comparison of the baseline VCM1 index score recorded for each patient in this study with a score generated 6 months after the patient's encounter with the ILVS provided a useful

measure of any changes in vision related QOL. The mean index scores for eight of the 10 categories were lower when patients were re-interviewed; the exceptions were feelings of loneliness and isolation and inability to carry out preferred activities because of poor eyesight. This resulted in a statistically significant decrease in total mean index score 5 months after contact with the ILVS, indicating a reduction in patients' overall degree of concern. There was a statistically significant reduction in concern in three particular areas after contact with the ILVS: fear of deterioration of vision, safety at home, and coping with everyday life.

Patients were given information about their eye condition and visual prognosis by ILVS staff. ARMD is the most common diagnosis of patients attending ILVS clinics; 69% of the study group had this condition. The knowledge that ARMD causes central visual loss and not total blindness is reassuring for ARMD sufferers. It is also likely that rehabilitation support including optical and non-optical LVAs could result in patients feeling safer at home and able

**Table 8** How often do you use your preferred LVA for reading?

	No	%
Several times each day	36	51
Once each day	7	10
A few times each week	3	4
Once each week	6	9
Rarely	4	6
Never	10	14
No answer	5	7
<b>Total</b>	<b>71</b>	<b>100</b>

**Table 9** How long can your preferred LVA be used at any one time for reading?

	No	%
Less than 1 minute	2	3
1-5 minutes	17	24
6-10 minutes	12	17
11-30 minutes	15	21
More than 30 minutes	9	13
Not applicable	3	4
No answer	13	18
<b>Total</b>	<b>71</b>	<b>100</b>

to cope better with everyday activities. The fact that patients may have had time to accept the deterioration in their vision during the 6 month period between the two interviews may be reflected in how they rated their visually related QOL. However, this could have been offset by the fact that many of the patients are likely to have experienced a worsening of their vision over the 6 month period.

Approximately half of those patients who participated in the study lived alone. Many interviewees commented that they felt lonely and isolated because of their poor vision but were afraid of leaving the familiar environment of their home to venture outside. However, no statistically significant differences were found between VCM1 index scores of patients living alone compared with those who lived with their spouse or other family members. This suggests that feelings of loneliness and isolation were not restricted to those participants who lived alone.

**Table 11** Mean baseline VCM1 index scores for patients seen by ILVS before compared with those of patients not seen before

	Patients who had been seen by ILVS before (n = 55)	Patients who had not been seen by ILVS before (n = 16)	p Values for differences between distributions
Mean baseline VCM1 score	2.0	2.1	0.2347

The concerns which were least affected by contact with the service were inability to carry out preferred activities because of failing vision and feelings of loneliness and isolation. In a study undertaken with partially sighted and blind people in 1998, loneliness was also identified as a particular problem.<sup>29</sup> In response to the findings of this study we have made social isolation a strategic priority for the ILVS and are arranging appropriate training for social services staff and volunteers to try to address the situation. Many rehabilitation services have reduced their emphasis on this area in favour of other aspects of rehabilitation. Our study would indicate that social isolation must now more than ever be tackled by services for people with low vision.

An example of a scheme already initiated by the ILVS is a new service whereby a group of volunteers offer "telecare" to clients who live alone. The volunteers make regular telephone calls to clients and are trained to pick up on key words that might suggest a change in circumstances. They can then refer relevant issues to professional staff.

This study highlighted the reading of packet instructions and medicine labels as a cause for frustration. The difficulty patients experience in reading medicine labels has been brought to the attention of the chief pharmacist in the area.

Since November 2000, the ILVS clinics have been held in a new sensory impairment centre where many agencies, including the local society for people with visual impairment, the deaf communication and audiology services, the Royal National Institute for the Blind, and several volunteer groups are based. The low vision clinic team now includes visually impaired volunteers who informally give information and support to patients attending the clinics. The greater

**Table 10** Mean patient index scores for vision related QOL questions (VCM1)

	Mean scores for VCM1 before contact with ILVS (n = 71)	Mean scores for VCM1 6 months after contact with ILVS (n = 71)	p Values for differences between distributions
Have you felt embarrassed because of your eyesight?	1.7	1.5	0.2749
Have you felt frustrated or annoyed because of your eyesight?	3.0	2.9	0.4588
Have you felt lonely or isolated because of your eyesight?	1.3	1.5	0.2733
Have you felt sad or low because of your eyesight?	1.9	1.5	0.0791
Have you worried about your eyesight getting worse?	<b>2.9</b>	<b>2.1</b>	<b>0.0004*</b>
How often has your eyesight made you concerned or worried about your general safety at home?	<b>1.2</b>	<b>0.5</b>	<b>0.0005*</b>
How often has your eyesight made you concerned or worried about your general safety when out of your home?	2.3	2.0	0.3714
How often has your eyesight made you concerned or worried about coping with everyday life?	<b>1.6</b>	<b>1.2</b>	<b>0.0095*</b>
How often has your eyesight stopped you doing the things you want to do?	3.0	3.0	0.8696
How much has your eyesight interfered with your life in general?	2.8	2.7	0.4544
Average index score	<b>2.2</b>	<b>1.8</b>	<b>0.0061*</b>

\* Significant difference between values p<0.05.

**Table 12** Mean baseline VCM1 index scores for patients living alone compared with those who did not live alone

	Patients who lived alone (n = 37)	Patients who did not live alone (n = 34)	p Values for differences between distributions
Mean baseline VCM1 score	2.1	2.1	0.7253

collaboration now possible between the ILVS and the other agencies should improve support to people with low vision.

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