"Vision related quality of life in visually impaired patients"

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ABSTRACT

Background: *The scale of the low vision problems is considerable. Most elderly people who experience visual impairment do so due to age-related macular degeneration, cataract, and glaucoma. A study in Devon concluded that an integrated approach to low vision rehabilitation can, as measured by patient's satisfaction and low vision aids usage rate, result in a more successful service than traditional dispensing services.*

Aim: *To assess vision –related quality of life (QOL) of patients with low vision.*

Objectives: *To assess degree of difficulty with and importance of activities of daily living and to establish vision-related quality of life (QOL) scores.*

Material & Method: *Each patients completed a 'restrictions in activities of daily living questionnaire'(MLVQ) and vision specific QOL assessment (VCM1) to establish baseline measurements of vision related QOL in a group of low vision patients prior to their first clinic visit.*

Results & Interpretation: *One hundred and ten patients who had low vision clinic appointments would be willing to participate in the study. Any patients who had been seen by other low vision services during the last six month were excluded &patients aged 16 years or less were excluded. A total of 80 patients (72.72% of those approached) agreed to take participate in the study.*

Conclusion: *Most of the patients in the study were already in possession of low vision aids but many did not find them helpful for the various tasks of daily living that they were attempting to perform. Vision-related QOL issues causing patients most concern were: inability to carry out preferred activities due to their eyesight, frustration and annoyance due to their eyesight, fear of their vision deteriorating, safety outside the home and eyesight interfering with their life in general. Vision-related QOL issues causing patients less concern were: coping with everyday life, depression, embarrassment and loneliness due to their vision, and safety within the home. Ninety – nine percent of those patients in the study before their appointment at the Low Vision clinic were happy to be re-interviewed again six months later.*

Key Word: *Quality of life, visually impaired patients*

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INTRODUCTION

The scale of the low vision problems is considerable. Most elderly people who experience visual impairment do so due to age-related macular degeneration, cataract, and glaucoma. Many visually impaired people retain some useful sight. However, utilization of even the limited sight that may be available to them can be restricted by under-provision of visual aids, inadequate training in how best to use them and lack of understanding of simple methods of improving visual function e.g.by improved lighting.

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, in conjunction with appropriate follow-up and training. 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 and social rehabilitation functioning independently.

A study in Devon concluded that an integrated approach to low vision rehabilitation can, as measured by patient's satisfaction and low vision aids usage rate, result in a more successful service than traditional dispensing services. The aims of the study included assessment of the impact of the Low Vision Service on patients' quality of life (QOL), assessment of patients satisfaction with low vision service, investigation of usage of low vision aids at 6 months after initial clinic visit, assessment of the information needs of low vision patients and their carers and identification of those elements of community follow-up that are perceived to contribute to successful outcome.

Many different instruments are in use and a standardized approach to QOL assessment in ophthalmology is lacking. For this study it was not possible to develop our own instrument due to time constrains, so we concentrated on vision-targeted instruments which had already been validated. The most appropriate vision-specific instrument (VCM1) that we discovered has been developed by researchers

at the Bristol Eye Hospital. This instrument is currently being used in several outcome studies in the U.K, including low vision rehabilitation, macular surgery, and corneal surgery.

The VCM1 is based on issues defined by extensive interviews with visually impaired patients, professionals and support workers. It consist 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. These include: coping with everyday life; embarrassment; life interference; inability to do preferred activities; anger; safety at home; loneliness; safety outside the home; depression; and fear of deterioration in vision.

We decided to use the VCM1 in this study in conjunction with a 'restrictions of daily living questionnaire' developed to establish baseline measurements of vision-related QOL in a group of low vision patients prior to their first clinic visit. We are now seeking further funding to assess the impact of the low vision clinic on the QOL of these patients 6 months after their clinic appointment.

AIM

To assess vision –related quality of life (QOL) of patients withlow vision.

OBJECTIVES

- To assess degree of difficulty with and importance of activities of daily living.
- To establish vision-related quality of life (QOL) scores for patient prior to their appointment with the low vision clinic.
- To use their measurement as a baseline when patient are re-assessed 6 months after their low vision clinic visit in order to examine the impact of the low vision services on patients QOL.

METHOD& METHODS

Patient who had recently attended the low vision clinic at Department of Ophthalmology M.L.B. Medical College Jhansi (U.P) between 2012 to 2013 were identified and invite to participate in the study. The questionnaire was re- evaluated and revised where necessary. A section which attempted to establish the importance of performing different tasks of daily living in relation to each other was removed for it was difficult for me to administer and confusing for patients. Patients who had been seen in either low vision clinic during the previous six months were excluded. Patients called for study are contact with either telephone or sent a letter with suggested date and time for study.

Each patients completed a 'restrictions in activities of daily living questionnaire' (MLVQ). Patients were asked which of 15 different activities they had attempted to perform over the past month, to assess 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. Patients were then given the opportunity to identify any other tasks that they had experienced particular difficulty in attempting over the past month. A crude measure of visual acuity established by measuring prints size and reading speed for the majority of patients (80%).

Each patient's visual functions assessed using a 'vocational near vision test type' booklet routinely employed by the Low Vision Clinic for measuring visual acuity. The booklet contains paragraphs of text with lettering of different size, each headed with an 'N' number, the N standing for 'near' and the number indicating the point size of the lettering. We recorded the smallest print size that the patients could comfortably read with any visual aids that they would normally use. Their reading speed (words per minute) at this 'N' size was also measured with the aid of a digital stop-watch. Patients then completed a vision-specific QOL assessment (VCM1) consisting of a core questionnaire with 10 broadly applicable items referring to physical, social and psychological QOL issues.

RESULTS & INTERPRETATION

One hundred and ten patients who had low vision clinic appointments between June 2012 to May 2013 were contacted to ask if they would be willing to participate in the study. Any patients who had been seen by low vision services during the last six month were excluded and patients aged 16 years or less were not contacted. A total of 80 patients (72.72% of those approached) agreed to take participate in the study.

Table 1: Patients who agreed to participate in the study

	N
Patients invite to participate	110
No of patients who agreed to participate in study	80

One hundred ten patients invite to participate for the study only 80 patients agreed to participate in study.

Age wise distribution of patients:

Majority of the patient were between the age group of 60years and over, that is, about 52.5% of the total patients in study.

Table 2: Age wise distribution of patients

Age group	**No. of patients**	**Percentage (%)**
30-39	16	20
40-59	22	27.5
60 and over	42	52.5
Total	80	100

Sex wise distribution of patients: Males were slightly more 60(54.54%) as compared to females 50 (45.46%).

Table 3: Sex wise distribution of patients

Sex	No. of patients	Percentage (%)
Male	44	55
Female	36	45
	80	**100**

Low vision patients using Low Vision aids before this study: When asked to the low vision patient they are using low vision aids before the study.

Table 4: Low vision patients using Low Vision aids before this study

	n	%
Yes	0	0
No answer	80	100
Total	**80**	**100**

Eighty patients (100%) in the study were not using any low visual aids before the study but most the patients using simple spectacles.

Types of low vision devices: Majority of low vision devices used as low vision aids were magnifying glasses 85 (77.27%) followed by Hand held magnifiers 15 (13.63%), Stand magnifiers 5 (4.55 %) and Telescope 5 (4.55%).

Table 5: Types of low vision devices

Low vision devices	No. of cases	Percentage (%)
Magnifying glasses	58	72.5%
Hand held magnifiers	14	17.5%
Stand Magnifiers	6	7.5%
Telescope	2	2.50%

Activities of daily Living: Patients were asked if they had attempted any of the fallowing activities during the past one year (2012-2013). If they answered yes they were asked how much difficulty they had with task.

a. **Reading of Large Print:** Fifty-four patients (68%) had read or tried to read large prints book, newspaper, newspaper heading over the past month, 12 of them (22%) with much difficulty. Thirty-eight patients (70%) who had attempted this activity identified being able to read large prints reading materials as extremely important. Eight patients (10% of patients in the study) who had not attempted to read large print books over the past month still identified this activity as extremely important to them.

b. **Reading ordinary print:** Forty-nine patients (61%) had read or tried to read ordinary print book, newspaper, magazines or the TV time over the past month, 20 respondents (41%) with much difficulty. Thirty-nine (80%) patients who had attempted this activity identified being able to read ordinary prints reading materials as extremely important. Twenty one patients (19% of all patients) who had not attempted to read 'ordinary' print reading materials over the past month still identified this activity as extremely important to them.

c. **Reading shop prices, labels & Tickets:** Fifty-three (66%) patients had read or tried to read shops prices, labels and tickets over past months, 23(43%) patients with much difficulty. Thirty-seven (70%) patients who had attempted this activity identified being able to read shop prices as extremely important. Eight patients (10% of all interviewed) who had not attempted to read shop prices over the past month still identified this activity as extremely important to them.

d. **Identifying money:** Seventy-seven patients (96%) patients had identified or tried to identify money over the past month, Twenty-nine (37.66%) patients with much difficulty. Seventy-three (95%) patients who had attempted this activity identified being able to identified money as extremely important. One of the patients who had not attempted to identify money over the past month still identified this activity quite a bit important to them.

e. **Reading Correspondence:** Sixty-six patients (83%) patients had read or tried to read letters cords banks statements and other correspondence over the past month, Twenty-three of them (35%) patients read with much difficulty. Fifty-five patients (83%) who had attempted this activity identified being able to read their correspondence as extremely important. Nine patients (11% of all patients in the study) not able to read there correspondence over the past month.

f. **Signing name and Filling forms:** Forty-six patients (58%) patients had filled and signing or tried to fill form, cheques and cords and signing over the past month, 19 (41%) patients do with much difficulty. Thirty-eight (83%) patients who had attempted this activity identified being able to fill in forms and cheques, as extremely important. Eighteen patients (22.5% all patients interviewed) patients they not do the signing name and filling forms over past month still identified this activity as extremely important to them.

g. **Sewing Knitting and Mending:** Sewing, knitting and mending is mostly done by females in Indian families so male patients are not taken in this type of works. Thirty (83.3%) female patients had sewed kitted and mended are attempted to do so over the past month, Fourteen (46.6%) female

patients attempted they do with much difficulty. Six (16.6% of all female patients interviewed) of the patients who had not attempted to sew, knit or mend over the past month still identified this activity as extremely important to them.

h. Watching Television: Seventy-six patients (95%) had watched or attempted to watched television over the past month, twenty-six(34 %) with much difficulty. Fifty-one (67.61%) patients who had attempted this activity identified being able to watch television as extremely important. Two of the patients (3% of all patients in the study) who had not attempted to watch television over the past month still identified this activity as extremely important to them.

i. Print size and reading speed: Print of different N sizes that patients attempted to read from a 'vocational near vision test type' booklet.

Table 6: Smallest print size comfortably read with usual low vision aid

Print size	n
N /6	4
N/8 - N/10	18
N/12 – N/18	26
N/24	7
N/36	7
N/48	4
Attempted unsuccessfully	13
Not Attempted	1
Total	**80**

The smallest print size that could be read comfortably read with usual low vision aid was successfully recorded for 66 (83%) patients. The ability of those interviewed to read print of different 'N' size varied greatly. Eighteen of the patients tested (23%) were able to read N/8 to N/10, whilst thirteen of the 14 patients for whom no print size was recorded were unable to read even the largest print on the cord (N48).

a. Reading speed: Reading speed (words per minute) was recorded for 88 of the 91 patients for whom a print size had already been established.

Table 7: Reading speed

Words /minute	n
16-40	19
42-78	28
81-100	10
104 - 130	7
Attempted unsuccessfully	2
Not attempted	14
Total	**80**

Measurement of prints size and reading speed which were recorded for patients provide a baseline measure of visual acuity in the patient's home environment

b. Vision – related Quality of Life (QOL): Patients were asked ten questions concerning how their vision had affected various physical, social and psychological QOL- related issues over the past month. Patient's responses to QOL questions are displayed.

Table 8: How patients vision had affected various physical, social and psychological QOL- related issue over the past month

	Not at all	Very rarely	A little of time	A fair amount of the time	A lot of the time	All of the time
	Number of patients =110					
Have you felt embarrassed because of your eyesight?	33	5	15	11	8	8
Have you felt frustrated or annoyed because of yours eyesight?	12	5	11	10	16	26
Have you felt lonely or isolated because of your eyesight?	43	6	12	3	11	5
Have you felt sad or low because of your eyesight	30	4	13	12	13	8
Have you worried about your eyesight getting worse?	12	5	15	15	15	18
How often has your eyesight made you concerned or worried about your general safety at home?	41	11	14	6	7	1
How often has your eyesight made you concerned or worried about your general safety when out of home?	21	5	13	10	10	17
How often has your eyesight made you concerned or worried about coping with everyday life?	23	13	17	12	6	4
How often has your eyesight stopped you doing the things you want to do?	9	4	14	15	18	18
How much has your eyesight interfered with your life in general?	8	8	15	21	14	13

According to validation studies carried out by the researchers who developed the VCM1 all items were weighted evenly, so that using a single index score is appropriate. It is currently recommended that a score of between 0 and 5 is assigned to each answer (table 9). Score of the individual items are then added up to produce an index score of between 0 and 5 for each patient.

Table 9: Scoring for vision – related QOL questions

Response	Score
Not at all	0
Very rarely	1
A little of the time	2
A fair amount of the Time	3
A lot of the time	4
All of the time	5

Table 10 shows the mean patients index score for each of the 10 QOL areas covered by the VCM1, so that the higher the score in each category, the greater the degree of concern with the particular issue.

Table 10: Mean patients Index score for vision related QOL questions

	Mean score n=110
In the past month	
Have you felt embarrassed because of your eyesight?	1.8
Have you felt frustrated or annoyed because of your eyesight?	3.1
Have you felt lonely or isolated because of your eyesight?	1.4
Have you felt sad or low because of your eyesight?	2.0
Have you worried about your eyesight getting worse?	2.9
How often has your eyesight made you concerned or worried about your general safety at home?	1.1
How often has your eyesight made you concerned or worried about your general safety out of your home?	2.4
How often has your eyesight made you concerned or worried about coping with everyday life?	1.7
How often has your eyesight stopped you doing the things you want to do?	3.1
How much has your eyesight interfered with your life in general?	2.8

The items generating mean scores of 2.0 or below, i.e. items of the questionnaire causing less concern to patients were: loneliness (1.4), embarrassment (1.8), depression (2.0) and safety at home (1.1) Those areas causing most concerns i.e. means scores of 2.9 and above were frustration and annoyance (3.1), fear of deterioration in vision (2.9) and inability to do preferred activities (3.1).

When VCM1 index scores for each patient were analyses against self-reported state of health using one way analysis of variance, patients who said that their health was 'very good' had a significantly higher index score ($p \leq 0.05$) compared with those who stated that their health was 'fair' or 'poor'.

c. **Health of the patient during Study:** Patients were asked to describe their health during study. In study about (9) 11.25% patients have poor health, whilst 62.5 % stated that it was either good, very good or excellent and about 26.25% patients have fair health.
d. **Recent illness, Injury or upset:** Patients were asked if they had a recent illness, injury or upset that may have affected. Eight patients (10%) said that they had answered some illness, injury or upset that may have affected how they had answered some of questions. These included death of spouse, need for hospital care for other illnesses and moving house.
e. **Patients follow-up after Low Vision Clinic appointments:** When asked if they would be prepared to be interviewed again after their appointment with the Low Vision Clinic, all the patients who answered said 'yes' (79, 99%).

CONCLUSIONS

A total of 80 (72.72% of low vision patients contacted) agreed for study, a good response rate particularly in view of the age and poor health of many of respondents. Approximately 52.5% of patients in study were age between 60 years and over, reflecting the generally elderly nature of the low vision population.

A total of 80 patients 44 (55%) are male patients and 36(45%) female patients. Eighty patients (100%) in the study were not using any low visual aids before the study but most the patients using simple spectacles. Most of the patients in the study were already in possession of low vision aids but many did not find them helpful for the various tasks of daily living that they were attempting to perform.

In this study majority of low vision devices used as low vision aids were magnifying glasses 85 (77.27%) followed by Hand held magnifiers 15 (13.63%), Stand magnifiers 5 (4.55 %) and Telescope 5 (4.55%).

Three- quarter of patients in study identified the following activities as extremely important for them to be able to perform: identifying money, signing their own name, reading instructions on packets, tins,

bottles or medicines, reading letters, bank statements, or other correspondence and reading dials on household appliances.

Between half and three-quarters of the low vision patients identified the following activities as being extremely important for them to be able to perform: filling in forms and cheques, reading 'ordinary' sized print books and newspapers, watching television, going on a trip or special day out, reading shop prices and labels, reading the time on a watch, reading their own writing and reading street signs and bus numbers.

Less than half of low vision patients identified activities as being extremely important for them to be able to perform: sewing, knitting or mending, writing their own letters, reading the telephone directory to check numbers, carrying out a hobby and doing DIY or repair.

Vision-related QOL issues causing patients most concern were: inability to carry out preferred activities due to their eyesight, frustration and annoyance due to their eyesight, fear of their vision deteriorating, safety outside the home and eyesight interfering with their life in general.

Vision-related QOL issues causing patients less concern were: coping with everyday life, depression, embarrassment and loneliness due to their vision, and safety within the home.

Ninety – nine percent of those patients in the study before their appointment at the Low Vision clinic were happy to be re-interviewed again six months later.

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