

Perceived quality of health care in macular disease: A survey of members of the Macular Disease Society

Jan Mitchell⁽¹⁾, Peggy Bradley⁽²⁾, Stephen Anderson⁽³⁾, Timothy ffytche⁽²⁾, Clare Bradley⁽¹⁾

¹Health Psychology Research, Royal Holloway, University of London. ²Macular Disease Society. ³Neurosciences Research Institute, Aston University.

1) Introduction

Macular disease (MD):

- is a chronic, progressive eye condition. The macula is a small area of the retina responsible for detailed, central vision needed for tasks such as reading, driving, face recognition.
- damages the macula, resulting in loss of central vision. Peripheral vision is retained.
- mainly affects people over the age of 55 years.
- is the cause of 90% of new registrations as blind among people over the age of 65.
- can sometimes be treated to stabilise, but not cure. Currently treatment is possible for only a small percentage of cases (< 5%).

Macular Disease Society (MDS)

- A patient organisation set up and run by people with MD, for people with MD.
- MDS members' dissatisfaction with diagnosis and living with MD led to Leicester MDS local group initiating and pilot testing a questionnaire. This was subsequently developed further to form the Macular Disease Society Questionnaire (MDSQ)¹ and used to survey the experiences of members of the MDS.

2) Method

- MDSQ sent to 2000 members of MDS (membership at the time, February 1999: 7,500).
- 1420 (71%) returned completed questionnaires.
 - ◊ Mean age 76 yrs; 69% women.
 - ◊ Mean duration MD 7.3 yrs.



Member of MD Society using a low-vision aid (closed-circuit television) to complete MDSQ

3) Results

Experiences with ophthalmologists

Did you feel that your interview with the Eye Specialist was satisfactory?

Yes = 59% No = 41%

Reasons for dissatisfaction included:

- attitude of specialist (brusque, unfeeling, dismissive, uninterested, patronising).
- lack of information.
- management problems, often leading to delays.
- lack of time with consultant.
- no opportunity for questions.

Were you told that 'nothing can be done' to help with your MD?

Yes = 1247 No = 135

Percentages of people experiencing specified emotional reactions to being told that nothing could be done are shown in the figure below and include 54 (4.3%) reporting feeling suicidal.



Experiences with General Practitioners

- 379 people said their GP was not at all well informed, while only 185 said he/she was very well informed. 266 people did not answer the question and some mentioned that they had had no contact with their GP about their MD.
- 383 said their GP was very helpful and supportive and 379 said he/she was not at all helpful/supportive.

Visual changes

Visual changes such as blurred vision, seeing flashes of light or hallucinations are common in MD.

- 1,111 participants reported visual changes, of whom 282 (25%) experienced hallucinations.
- Only 59 (21%) of those reporting hallucinations were given explanations for them by a health professional. Explanations were not always accurate or reassuring.

4) Conclusions

- Many people with MD have unsatisfactory experiences with health professionals, particularly around the time of diagnosis.
- The data indicate shortcomings in the quality of consultations and the provision of information. Many problems could be resolved with more sensitive awareness of patients' anxieties and of their need for information at diagnosis.
- When no medical treatment is available, it is all the more important to give help and information about low vision aid and rehabilitation services. Such support helps people to adjust successfully to living with MD, retain their independence and protect their quality of life.

References

Mitchell J, Bradley P, Anderson SJ, ffytche T, Bradley C. (2002) Perceived quality of health care in macular disease: A survey of members of the Macular Disease Society. *British Journal of Ophthalmology*. In press.

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Enquiries:

Corresponding author:

Jan Mitchell BSc, Dept of Psychology
Royal Holloway, University of London, Egham, Surrey, TW20 0EX,
UK. E-mail: j.mitchell@rhul.ac.uk

Access to questionnaires:

Clare Bradley PhD, Professor of Health Psychology
Royal Holloway, University of London, Egham, Surrey, TW20 0EX,
UK. E-mail: c.bradley@rhul.ac.uk