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Experiences of macular disease and the UK health care system

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Objectives

To examine the relationship between experiences of the health care system and long term well-being in people with macular disease.

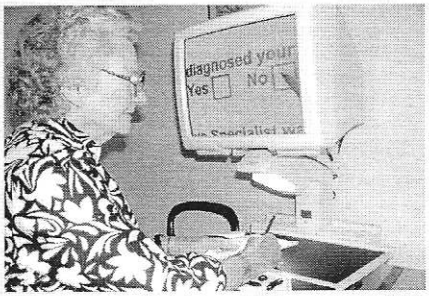
Background

- Macular Disease (MD)
  - Chronic, progressive eye condition leading to loss of central vision with peripheral vision retained
  - Mainly affects people over 50 years, more common in women
  - Leading cause of new blind/partially-sighted registrations in UK
  - For majority, no treatment currently available
- Macular Disease Society Questionnaire (MDSQ)
  - Designed for self-administration by people with MD
  - Questions about :
    - experiences of health professionals at diagnosis and subsequently
    - visual changes, including hallucinations, resulting from MD
  - 12-Item Well-being Questionnaire (W-BQ12).[1]
    - excellent psychometric properties for use with MD
    - 3 subscales measuring Negative Well-being (NegW-B), Energy and Positive Well-being (PosW-B) (range 0 - 12). summed to give total General Well-being (GenW-B) (range 0 - 36).Higher scores indicqte more NegW-B, Energy, PosW-B or GenW-B.

    The W-BQ12 is available from Professor Clare Bradley at the above address.

Method

- 2000 members of MD Society received MDSQ by post
- 1421 returned completed MDSQ (response rate 71%)
- 69% women
- Mean age 76 years
- Mean duration of MD 7.34 years



Using a low-vision aid (closed-circuit TV) to complete the MDSQ

Results

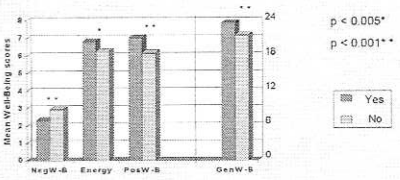
- Experiences with eye specialists

  Question 1 *'Did you feel that the eye specialist who diagnosed your MD was interested in you as a person?'*

  Yes = 634 (44.6%) No = 736 (51.8%)

  See Figure 1 for associations with well-being

Figure1. Mean Well-being scores associated with responses to Question 1 concerning eye specialist's interest in person



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Question 2.*'Did you feel that the interview with the eye specialist was satisfactory?'*

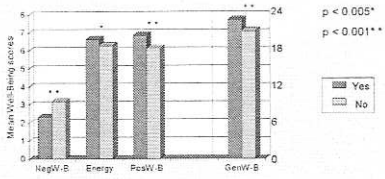
Yes = 801 (56.4%) No = 558 (39%)

Most commonly cited reasons for dissatisfaction:

- attitude of specialist
- lack of information

See Figure 2 for associations with well-being.

Figure 2. Mean Well-being scores associated with responses to Question 2 concerning satisfaction with consultation

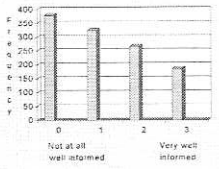


- Experiences with General Practitioners (GPs)

  Question 3: *Around the time of diagnosis, to what extent was your GP well-informed about MD?*

  Participants responded on 0-3 Likert scale. See Figure 3 for frequencies and correlations with Well-being.

Figure 3. Frequencies of responses to question 3 on GP knowledge and correlations with Well-being

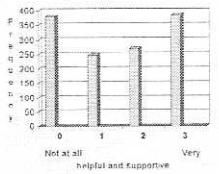


Ratings of GP supportiveness showed small but significant correlations with Well-being subscales and GenW-B (p's < 0.01)

Question 4: *To what extent has your General Practitioner been helpful and supportive?*

See Figure 4 for frequencies and correlations with Well-being.

Figure 4. Frequencies of responses to question 4 on GP supportiveness and correlations with Well-being



Ratings of GP supportiveness showed small but significant correlations with Energy ($p < 0.05$), PosW-B ($p < 0.01$) and GenW-B ($p < 0.05$) but correlation with NegW-B was non-significant ($p > 0.05$)

- Provision of information

  Question 5: *Were you ever told that "nothing can be done for your MD"?*

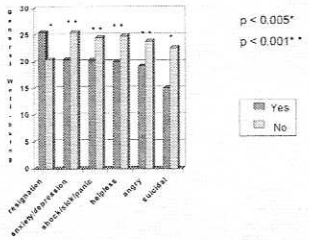
  Yes = 1,247 (87.7%) No = 135 (9.55%)

  Often nothing can be done medically, but resources are available to help people to live with MD:

  - low vision aids
  - rehabilitation training

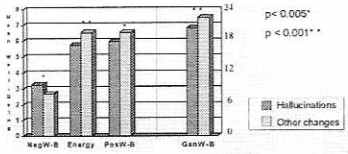
  Figure 5 shows GenW-B scores of those who did or did not experience a range of reactions to being told 'nothing can be done', and inferential statistics.

Figure 5. Reactions to being told "Nothing can be done to help with your MD"



- **Visual changes**
  - Number experiencing visual changes such as flashing lights, coloured patterns = 1,111
  - Among those, number with hallucinations = 282
  - Poorer well-being was experienced by those reporting hallucinations than by those experiencing other visual changes. Figure 6 shows mean scores and inferential statistics.

Figure 6 Mean Well-Being scores in those experiencing hallucinations and those reporting other visual changes



Explanations for visual changes

Only 122 participants talked to health professionals about their hallucinations. Of those only 59 received an explanation. The latter showed greater well-being than those who were offered no explanation, but the differences were not significant. Possible explanations for non-significance are:

- Some explanations were inaccurate and alarming and these may have depressed the mean Well-being scores.
- Hallucinations often disappear after a time. Some participants may no longer have been experiencing them when they completed the MDSQ.
- MD society members may be generally well-informed about hallucinations.

Discussion

The W-BQ12 elicits how people have felt *over the last few weeks*. All participants had had MD for at least 6 months, most for several years. In chronic disease, psychological outcomes are positively associated with:

- good doctor-patient communication[2]
- adequate and accurate provision of information[3]

Our evidence suggests that experiences with health professionals at diagnosis and subsequently may be associated with long term well-being in people with MD. Other factors which may bear upon the data are:

- Baseline levels of well-being, not measured in this cross-sectional study, may influence perceptions of the quality of the consultation.
- Doctors may behave differently towards people with poorer levels of well-being e.g. give less information.
- Doctors may be less at ease with patients for whom they can offer no medical help.

Conclusion

The evidence suggests that the quality of health care may affect subsequent well-being. However, in this cross-sectional study causal inferences are uncertain. A longitudinal, prospective study is now underway.

References

1. Bradley, C. (2000). The 12-Item Well-Being Questionnaire. *Diabetes Care*, 23 (6): 1.
2. Stewart, MA. (1995). Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal*, 152(9): 1423-1433.
3. Fallowfield, L. (1997). Truth sometimes hurts, but deceit hurts more. *Annals New York Academy of Sciences*, 809:525-536.