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Bradley C and Mitchell J (2006) Satisfaction with diagnosis and care of people with MD: Opportunities for Improvement. *Macular Disease Society Digest* 2006 31-34.

Elizabeth Thomas Seminar Lecture October 2005

**Satisfaction with diagnosis
and care of people with MD:**

Opportunities for Improvement

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We know from the results of the Macular Disease Society Questionnaire survey that there is considerable dissatisfaction with experiences in eye clinics, particularly at the time of diagnosis (Mitchell et al 2002 *Br J Ophth*). We need a questionnaire to identify the problems and to evaluate attempts to solve them.

An existing measure of satisfaction with the service provided for people with diabetes has proved valuable in providing evidence about the need for resources to overcome dissatisfaction reported. In one centre, the major problems were long waiting times, patients seeing a different

doctor at each visit, and inadequate privacy for consultations. In response, an extra clinic was introduced to reduce waiting times, doctors' lists were rearranged to improve continuity of care, and walls were built to ensure privacy. Follow-up use of the questionnaire showed significant improvements in satisfaction with all three aspects of the service.

In 2004 we started working on a similar instrument for people with MD (the Macular Service Satisfaction Questionnaire or MacSSQ). We visited four local groups of the MD Society. The Leicester group generated items spontaneously in

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response to a question about sources of satisfaction and dissatisfaction with their eye clinic. They also advised on the questionnaire layout. The Croydon group generated items spontaneously and completed a first draft of the questionnaire produced using the Leicester group's feedback. Second and third drafts were completed by groups at Fareham and Basingstoke.

The results from the three centres where members had completed a draft MacSSQ were analysed to determine the average response in each centre to each of the 39 items in the draft questionnaire. It was encouraging to find that for 23 items (59%) all the three centres were, on average, satisfied. Not all members of each group were talking about their local hospital. Some had experience of London teaching hospitals and some had received treatment elsewhere. These data should not be interpreted as if they are comparing specific hospitals. What we are seeing here are the views of several different local groups of the MD Society. Generally participants were satisfied with how they were treated as people and with privacy. However, the average responses to the privacy item conceal a tiny minority who had attended a London hospital where consultations are conducted in an open plan consulting

area. Some individuals were distressed by having their eye problems discussed in the hearing of other patients. If we were to sample patients from an open plan clinic we might expect to see dissatisfaction with the lack of privacy.

Six of the 39 items (15%) produced a mixed response across the three groups: some satisfied on average and some dissatisfied. In one centre members were dissatisfied with waiting times in the clinic but they were more satisfied than in other centres with their discussions with the ophthalmologist and advice given about where to go if deterioration occurs. These findings suggest it may be unwise to focus too much on waiting times which may be improved by speeding up appointments but with unsatisfactory consequences for care provided.

There were ten items concerning aspects of care with which all three centres were dissatisfied (26%). Six of these 10 items were specifically concerned with experiences at diagnosis. The data support findings from our earlier work with the MDS Questionnaire survey. There have been some excellent patient initiatives to improve experiences of diagnosis including the introduction of macular clinic support desks at Leicester, Croydon, Peterborough

and Torbay manned by volunteers from the local MD Society who provide information and support as required. Enthusiasm from some other groups has been thwarted by opposition from within hospitals. Ophthalmologists at clinics with established support desks find that the volunteers' contributions are of great value. The MD Society is now actively supporting the setting up of help desks nationwide.

Members of the Leicester group went further in providing six weekly peer support discussion groups for people newly diagnosed with MD recruited at a macular clinic help desk. Course evaluation showed that the groups were very successful



in providing support and helping people to adjust to the diagnosis of MD. The results are reported in detail elsewhere (P Bradley et al *Proceedings of Vision 2005; International Congress Series 1282*, in press).

There are many ways in which ophthalmologists themselves can improve patient satisfaction simply and inexpensively.

These include:

- Give patients the name of their condition and an accurate explanation in lay terms including why they will not go completely blind from MD.
- Describe the likely course of MD
- Avoid euphemisms, simplistic analogies and emphasis on 'ageing' as a cause.
- Mention the possibility of hallucinations to save unnecessary distress if hallucinations occur.
- Provide opportunities for, and encourage questions while understanding that some people may, initially, be too distressed for questions. A follow-up appointment with an ophthalmologist or ophthalmic nurse within a month can be valuable.

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- Provide written information including:
 - booklet explaining MD (available from the MD Society on request)
 - MD Society introductory information
 - name and details of local MD Society contact
 - list of useful websites
 - date of next appointment in large print
- Relevant advice to protect eyes including:
 - visit optometrist regularly
 - avoid smoking
 - dietary advice
 - use of sunglasses, hats
 - use of Amsler grid to monitor MD and gain reassurance when no changes occur
 - how to fast track back to consultant if sudden deterioration is noticed
- Ophthalmologists may also take up a service now offered by the Macular Disease Society of providing volunteers on macular clinic days. They meet newly diagnosed patients and either on the day or later give advice and support on living with the condition and on the rehabilitation and low vision services available in the area.

The MacSSQ is now ready for use in clinics in a context of continuing development of the questionnaire which we plan to shorten in the light of data obtained. Please contact the copyright holder, Clare Bradley, if you would like to use the MacSSQ now or in the future.

In summary, although the MacSSQ has identified satisfaction with many aspects of care experienced, there was also considerable dissatisfaction, particularly around diagnosis. Peer support from people with MD can help, but only with the active support of health professionals and hospitals. Experience of care can be improved simply and inexpensively and clinic / service satisfaction can be measured and monitored with the MacSSQ. Patient satisfaction can be improved!

***Professor Clare Bradley and Dr Jan Mitchell's work was conducted in collaboration with Dr Alison Woodcock and Charles Gilbride and with the help of four local groups of the Macular Disease Society.**