

Satisfaction of patients with macular disease: a service evaluation of eight eye clinics using the MacSSQ

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The MacSSQ macular disease service satisfaction questionnaire was used to evaluate services for macular disease (MD) patients in eye clinics at eight English hospitals from a total of 12 invited to participate. One Northern eye clinic, although eager to participate, was unable to obtain approval from their research and development office in the time available and three London hospital eye clinics, all with open plan consulting areas, did not accept the invitation to take part. It should be noted, therefore, that all clinics participating in this work provided private consulting rooms. Design work on the MacSSQ included interviews with patients who had attended open-plan clinics and they registered dissatisfaction with the lack of privacy. In this respect, the findings from the present service evaluation may overestimate satisfaction with services.

Questionnaires were distributed to MD patients attending the eight eye clinics. A total of 343 patients took part (221 women, 122 men, mean age 78.8 years).



Response rates for individual clinics varied between 60% and 23% (unreported for two clinics). Overall levels of satisfaction were high, with nine of 35 items eliciting more than 90% satisfaction. Shortcomings were primarily in the provision of information and support,

help or advice. At diagnosis, 14% reported being given no information about MD, 34% were given no information about monitoring their MD and 44% were not given information about the MD Society. Almost 50% of respondents were not given dietary advice, 40% reported not getting advice about protecting their eyes, 25% were not told what to do if their vision deteriorated suddenly and 22% were told nothing about the likely progress of their MD. Perceived levels of support from clinical staff, low vision services and low vision organisations were low, with 48% of respondents reporting that they received no support, help or advice from their eye doctor and 64% saying they received none from the nurse. These aspects of MD patient care are regarded by the MD Society as fundamental to good patient management.

Of 68 people who were registered as visually impaired and who said they needed low vision aids, only nine were not provided with any. Thirteen out of the 59 who had been provided with such aids received them from sources other than the National Health Service. For 22 of the 35 MacSSQ items,

people for whom no MD treatment was available were less satisfied than those for whom MD treatment was available. Proportions of those registered blind, partially sighted and not-registered were similar for both groups, so it cannot be assumed that the experiences of untreated patients were more difficult because of poorer vision. They may have been managed in a less satisfactory manner than treated patients. Those people with mild, untreatable MD may have been offered no further appointments, support or information and felt abandoned by the eye clinics. Effective and considerate management of MD patients for whom no treatment is available needs to be given priority as well as the management of treatable patients, so that they can adjust to the condition and maintain their quality of life.

Overall findings were encouraging and, where improvements are desirable, in provision of information and support, these would not be difficult or expensive to implement. Such changes would lead to increased satisfaction with services and help patients to adjust to their macular degeneration.