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Title: Peer support for people newly diagnosed with macular degeneration: a pilot study.

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Abstract: Aims: To conduct a pilot study of peer group support and information provision to help newly diagnosed patients to adjust to macular degeneration (MD). Method: Twelve patients were randomised to two groups. For each group, members of the Macular Disease Society ran a programme of six discussion groups. Participants received guideline leaflets relevant to the weekly topics. Participants completed overview quality of life (QoL) items (taken from the MacDQoL measure of the impact of MD on QoL) and the 12-item Well-being Questionnaire on four occasions during the study. At final follow-up, participants completed a course evaluation questionnaire. Results: Those reporting more negative well-being at recruitment showed greater improvement in negative well-being after the programme than those who began with better well-being ($p < 0.005$). Course evaluation indicated that participants found the leaflets informative and that the aims of the programme had been met. Ten participants said they would be willing to help with future discussion groups. Conclusion: Members of the local MD Society self-help group, using guideline leaflets and discussions, were able to give positive support and information from their own experiences of

living with MD. These findings suggest that other newly diagnosed patients would benefit from similar courses.

Peer support for people newly diagnosed with macular degeneration: a pilot study.

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Abstract. **Aims:** To conduct a pilot study of peer group support and information provision to help newly diagnosed patients to adjust to macular degeneration (MD). **Method:** Twelve patients were randomised to two groups. For each group, members of the Macular Disease Society ran a programme of six discussion groups. Participants received guideline leaflets relevant to the weekly topics. Participants completed overview quality of life (QoL) items (taken from the MacDQoL measure of the impact of MD on QoL) and the 12-item Well-being Questionnaire on four occasions during the study. At final follow-up, participants completed a course evaluation questionnaire. **Results:** Those reporting more negative well-being at recruitment showed greater improvement in negative well-being after the programme than those who began with better well-being ($p < 0.005$). Course evaluation indicated that participants found the leaflets informative and that the aims of the programme had been met. Ten participants said they would be willing to help with future discussion groups. **Conclusion:** Members of the local MD Society self-help group, using guideline leaflets and discussions, were able to give positive support and information from their own experiences of living with MD. These findings suggest that other newly diagnosed patients would benefit from similar courses.

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1. Introduction

For the majority of people who are diagnosed with macular degeneration (MD) no medical treatment is available and management is limited to support and rehabilitation [1]. Diagnosis of this incurable condition can be very distressing although, in the early stages, there may be little sight loss [2]. Support is needed immediately [3] but all too often patients are dismissed from the consulting room inadequately informed about their condition and with no offer of further help. A study of 1420 people with MD [4] reported that 40% were dissatisfied with their diagnostic consultations. Of these, 43% gave 'the attitude of the consultant' as a reason for dissatisfaction and the same number cited a 'lack of information' about the condition and the support services that might be available. Over 70% of respondents to the survey had been told that 'Nothing can be done' about their MD and this led to 60% of those people feeling depressed or anxious;

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54 people reported feeling suicidal. While there is often nothing that can be done medically, there are ways in which people can be helped to adjust to living with MD.

Courses in self-management for people with MD have been associated with decreased emotional distress, and increased self-efficacy and activity [5,6]. Improved mood was also demonstrated, with greater improvement reported by those who were initially more distressed [6]. In that study, health professionals led the 6 weekly 2-hour courses, which consisted of a didactic presentation and a group problem-solving component.

The UK Macular Disease Society promotes the establishment of local self-help groups in which the benefits of peer support are recognised. Members of the Leicester MD Society group considered that a programme of discussion groups for people newly-diagnosed with MD and led by people experienced in living with MD might help newly diagnosed people to adjust to the condition. The research reported here was a pilot study aimed at assessing the potential benefits of self-management programmes led by people experienced in living with MD for people newly diagnosed with MD.

2. Method

2.1 Participants

Patients at the Windsor Eye Clinic, Leicester Royal Infirmary who had been newly diagnosed with MD between October 2001 and late 2002 were invited to participate in the study.

2.2 Materials

A series of 6 leaflets about living with MD, printed in large black print (Arial 16 font) on a yellow background and entitled : 1) Awareness of the condition 2) Around the home 3) Outside the home 4) Enjoying life 5) General health 6) Looking ahead.

2.3 Procedure

The first author (PB) attended MD clinic sessions at the eye clinic. Some patients who were newly diagnosed with MD were referred to PB by the consultant ophthalmologist if they wished to have support and information about MD. They were given immediate information, as required, by PB. The patients were asked if they would like to take part in the pilot study, which involved attending 6 weekly sessions of 1.5 hours each. Those who consented to take part completed the 12-item Well-being Questionnaire (W-BQ12) [7] and two quality of life (QoL) overview items taken from the MacDQoL measure of the impact of MD on QoL [8] at the time of recruitment. The W-BQ12 is a measure of well-being consisting of three 4-item subscales measuring Negative Well-being (NWB), Energy and Positive Well-being. The three subscales, each scored from 0-12 (higher scores indicating greater levels of the mood concerned), can be combined to give an overall General Well-being score. The first MacDQoL overview item is a generic item (*In general, my present quality of life is: excellent – extremely bad*), scored from +3 (*excellent*) through 0 (*neither good nor bad*) to -3 (*extremely bad*). The second, MD-specific item (*If I did not have MD, my quality of life would be: very much better –*

worse) is scored from -3 (*very much better*, indicating high negative impact of MD on QoL), through 0 (*the same*, i.e. no impact of MD on QoL) to +1 (*worse*, i.e. positive impact of MD on QoL). Demographic and general health data were collected. When all 12 participants had been recruited they were randomised to attend either the first or second series of discussion groups. Carers and partners of the participants were also welcome to attend. The W-BQ12 and QoL items were again completed by participants at the start of the first course, at the end of the first course/start of the second course and at the end of the second course. In this study, the W-BQ12 and MacDQoL were included to assess their acceptability to participants at this early stage in their experience of MD. At the end of both series of discussion groups, participants completed a final course evaluation questionnaire.

Ethics approval was obtained from the Ethics committee of the University Hospitals of Leicester NHS Trust.

3. Results

Twelve participants were recruited (6 women, 6 men, mean age 75.7 years [s.d. 9.7]), of whom eleven were white and one was Asian. Five people lived alone. Eight people had other medical conditions. The average number of sessions attended was five (s.d. 1.2). There were no differences between the two groups on any of these variables ($p > 0.05$)

All participants fully completed the W-BQ12 and the two MacDQoL overview items on all occasions. With this small sample, no significant findings were anticipated from the questionnaire data. However, when participants were divided into those with high NWB (NWB \geq 3) and those with low NWB at baseline (NWB $<$ 3), Mann Whitney comparison indicated that NWB improved significantly more in the group with high NWB at baseline (mean change = -1.75, s.d. = 1.89, $n = 4$) than in the group with low NWB at baseline (mean change = 0.25, s.d. = 1.03, $n = 8$) (Mann Whitney = 6.000, $n = 12$, $p = 0.042$).

Eleven people completed the course evaluation questionnaire at the end of the study. Participants graded the leaflets on a scale of 1 (*not at all helpful*), 2 (*helpful*), 3 (*extremely helpful*). Individual scores for five of the leaflets ranged between *helpful* and *extremely helpful* (Table 1). The questionnaire investigated the extent to which the aims of the study had been met. Participants responded on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*) to the statements shown in Table 2. The high mean and median scores indicate that the participants thought the aims of the course had been met.

Table1. Usefulness of leaflets: mean (s.d.), median and range of scores: possible range = 1 (not at all helpful) to 3 (extremely helpful).

Leaflet	Mean (sd)	Median	Range
Awareness of the condition	2.55 (0.5)	3	2-3
Around the home	2.09 (0.5)	2	1-3
Outside the home	2.09 (0.3)	2	2-3
Enjoying life	2.36 (0.5)	2	2-3
General health	2.18 (0.4)	2	2-3
Looking ahead	2.45 (0.5)	2	2-3

Ten of the eleven respondents said they would be willing to take part in similar discussion groups if they were set up, to provide information and support to other people newly diagnosed with MD. Three open-ended questions were included concerning adjustment to MD, suggestions for improving the group discussions and the make-up of the groups. Questions asked and a representative selection of responses to the questions are reported in Table 3.

Table 2. Extent to which the aims of the course were met: mean (s.d.), median and range of scores: possible range = 1 (strongly disagree) to 5 (strongly agree)

Aims of the course	Mean (sd)	Median	Range
The discussion groups provided relevant information about MD	4.82 (0.4)	5	4-5
The discussion groups helped me to build confidence and adjust to the condition	4.55 (0.7)	5	3-5
The discussion groups provided group support and friendship	4.55 (0.5)	5	4-5

Table 3. Comments on aspects of the discussion groups

Questions and participants' comments about the course

From your experience of taking part in the 6-week discussion programme, how do you think the sessions have helped you to adjust to MD?

- “They helped me to come to grips with my circumstances and to plan ahead for a time when my sight might be severely impaired”.
- “The group sessions were enjoyable and informative and have helped in creating a more positive attitude...”
- “The leaflets provided a useful source of information. I found this helpful when coming to terms....and some confidence for the future”
- “...made one aware that people continue to live a full life”.

What improvements to the discussion groups could be made?

- “...if the leaflets were made available before the meeting, say a week or a fortnight, allowing for some preparation”.
- “more time is needed as people have lots to say”.

How did you feel about having mixed discussion groups including carers and members who have had MD for more than 5 years as well as people newly diagnosed with MD?

- “I think it was helpful to have people with MD at all stages there”
- “We can all learn from each other. As a new ‘MD’ I have been much encouraged and gained useful know-how”
- “It is probably a good idea for members and carers as well as newcomers to be in the same discussion groups. No doubt they should all be able to learn from one another”.

4. Discussion

This pilot study investigated the potential value of peer-led self-management programmes for people newly diagnosed with MD. The aim of the course was to provide support, friendship and information about MD and about living with MD. The high attendance rate on the two programmes suggests that participants continued to be motivated to attend their course throughout its duration.

The W-BQ12 and MacDQoL overview items were completed fully by all participants on four occasions, suggesting that the measures were highly acceptable. The significantly greater improvement in negative well-being reported by those who had

poor negative well being at diagnosis has been reported by others [6] and might have been expected with a larger sample, but the similar significant finding in this study, with such a small sample, is encouraging. The finding emphasises the importance of providing support for people when they are newly diagnosed with MD, particularly those who are more depressed or anxious at diagnosis.

The end-of-study evaluation indicated that participants found the leaflets helpful or very helpful. In the Macular Disease Society Questionnaire [4], one of the two most common reasons for dissatisfaction with the diagnostic consultation was lack of information. Even when information was provided, it was likely to be limited to a description of the condition and its symptoms. The opportunities for questions and discussion were inadequate. The series of leaflets designed for this study provided information on a variety of aspects of living with MD.

The participants reported that the objectives of the programmes had been met, with no participants disagreeing. The finding that the great majority of participants would be willing to take part in similar courses in order to provide other newly diagnosed patients with the support and help they had themselves received showed that participants valued the benefits gained from the experience.

The success of this small pilot study is encouraging. Further work is now needed to evaluate the programme using a larger sample, by setting up similar courses in different parts of the country. Peer group members have shown their willingness to make essential contributions to new discussion groups. Vital to such development is the interest, enthusiasm and active involvement of ophthalmologists.

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