

Living with macular disease

Macular Society-funded project

Final Report

The experience of care by people with macular degeneration and their caregivers

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In the Macular Society's 2013 survey, 558 respondents (52%) reported that someone provided unpaid care, support or assistance to them because of their age-related macular degeneration (AMD). Of these, 53% reported receiving support for seven hours or more a week.

Other research has focused on the impact of providing support, or 'caregiver burden', for caregivers of people with wet macular degeneration. We designed a follow-up study to investigate the perspectives of caregivers and care recipients with wet or dry AMD.

People with AMD completed the Instrumental Activities of Daily Living questionnaire about how much difficulty they had carrying out important 'everyday tasks'

(e.g. preparing meals) and if they received help with them. They also completed the Daily Living Tasks Dependent on Vision scale, which asked about difficulty with selected 'vision-dependent tasks' such as watching TV.

Caregivers completed the Caregiver Reaction Assessment. This explores the impact of providing support on various aspects of life such as finances, daily schedule and health.

All respondents were asked to complete the Wellbeing Questionnaire, demographic information, details about their macular condition and questions on general health.

We received 72 completed questionnaires from people with AMD/caregiver pairs. Forty nine pairs were spouses. Of the rest, 21 pairs had caregivers who were adult offspring, and for two pairs, they were a neighbour or friend. Mean age of caregivers was 61 years for adult offspring and 79 years for spouse caregivers. The majority of caregivers (69%) were women.

We used structural equation modelling to examine predictors of wellbeing in the person with AMD and their caregiver, caregiver general health and caregiver reactions towards providing support. The preliminary results reported here, based on a modest sample size, need to be interpreted cautiously. Nevertheless, the main findings are:

- The amount of help received and provided for AMD was not related to the wellbeing of the person with AMD or to caregiver wellbeing, health or their reactions to providing support.
- The amount of support received and provided was mainly determined by the level of difficulty the person with AMD

had with carrying out everyday tasks, but not with the more specific vision-dependent tasks, nor their general health status.

- The ability of people with AMD to carry out vision-dependent tasks and their general health predicted their wellbeing. However, difficulties with everyday tasks were not related to their wellbeing.
- Poorer general health in people with AMD predicted more negative caregiver reactions to providing support. This indirectly predicted poorer caregiver wellbeing and general health.
- Caregiver reactions towards providing support impacted on their own wellbeing and health, but were unrelated to the wellbeing of the recipient of their care.

Analyses found that caregivers' ratings of their role as enjoyable/rewarding or causing resentment, and the overall positive effect caregiving had on their lives was unrelated to reports from the person with AMD about their level of difficulty with tasks, their general health or the amount of help they received.

▶▶ The experience of care by people with macular degeneration

The results might reassure people with AMD that the level of difficulty they experience carrying out vision-dependent tasks does not directly impact on their caregiver's wellbeing, health or their reactions to providing support. Targeting the general health of people with AMD in interventions may be more effective at reducing caregiver burden and consequently improve caregiver wellbeing and health. It may be more important for interventions to focus on caregiver appraisals of providing support than the amount of support provided. The results add to the evidence base showing that interventions designed to improve the visual functioning of people with AMD may improve their wellbeing.

We interviewed eight pairs to explore the topics in more detail. The results suggest that living with AMD is very much a shared experience. Pairs spoke about changes in lifestyle and roles following diagnosis, managing both people's independence, difficulties in getting professional help and problems seeking or accepting help from family and friends.

Two example quotes:

"I try to do as much as I can with the help of my wife. We still try to do things that we're able to do together..." (Husband with AMD.)

"... thinking of all the disabilities, you know like accidents and losing an arm or a leg, I think I could cope with any of that but I could not cope with being blind, really couldn't, cos I've seen what it does, you know. It is really difficult." (Daughter of mother with AMD.)

The findings from both of the above research studies will be useful for developing services, to inform Macular Society campaigns and to stimulate future research and interventions of value to people with AMD and their caregivers.

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