

Review of: "Effectiveness of a novel multi-modal intervention for family caregivers of persons with age-related macular degeneration: a randomised controlled trial"

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Potential competing interests: No potential competing interests to declare.

Ivan Jin et al. Effectiveness of a novel multi-modal intervention for family caregivers of persons with age-related macular degeneration: a randomised controlled trial.

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Increasingly, the families and close friends of older people who are ill or who have a chronic health condition are assuming caring/caregiving roles, tasks and responsibilities, often due to service inadequacies or gaps in health systems. This paper is important because it presents the results of a study about the needs of family carers of people with AMD; and how an intervention (that the authors have designed) meets those needs. Moreover, there does not appear to be any intervention currently for this group of carers and the paper merits being read and discussed by AMD health care professionals and service managers. I have noted below some points for consideration by the authors.

Some family carers do not tend to see themselves as carers/caregivers in the way in which professionals or researchers conceptualise the role - is there a need to provide a definition of a family carer? Also, the term, burden, is used commonly in studies (mea culpa!) and in policies about carers. Yet, I have learned that many carers do not view their relationship and their caregiving as a burden. Is there a need to consider a less pejorative term? Indeed, some carers report positive aspects about caregiving as well as the challenges and 'burden'. Did the study gather any study about positive aspects or discuss how these positive aspects might affect the results?

The authors might want to consider the merits (or otherwise) of using some of the guides for intervention development and reporting such as:

GUIDED (https://bmjopen.bmj.com/content/10/4/e033516) and

TIDIER (https://www.bmj.com/content/348/bmj.g1687).

Insights might be derived from these guides that would point to ways in which the intervention could be improved. Do you need to clarify the nature and content of usual care or the comparator condition?

Presumably, AMD patients and their family carers who used private ophthalmology had higher incomes and more resources. Do you need to comment about the significance of this factor for patients and carers with lower incomes or who



use public health care?

There is no information about the primary outcome or about whether or not the number of carers in each group is sufficient to detect a meaningful difference or effect size in the primary end point or validated measures. Has M-CBT been validated for use with older people and with older people who are carers? The CONSORT flow shows significant loss to follow-up with only 31 carers in the intervention group compared to 46 in the control group. Do the attrition reasons and the levels of dissatisfaction indicate that the intervention may not be acceptable or deemed worthwhile to carers? What is the profile of these caregivers compared to caregivers who stayed the course and adhered to the intervention course?

I noticed that the Discussion section contains information about sample size and the power of the study (as well as attrition). The authors may wish to move this information to the Methods section of their paper.

Is there a significant degree of caregiving that is reciprocal between patient and carer? According to Table 1, it appears that significant proportions of carers in the study had poor health status - approximately one-third of carers in the intervention group and almost one-quarter of carers in the control group were described as having scores indicative of 'substantial co-morbidity'. Was any subgroup analysis undertaken regarding carers with and without poor general health status? Indeed, was any subgroup analysis (mindful of small sample size) undertaken for other variables?

There is very helpful discussion about the (non-significant) results in relation to change scores and how to interpret a meaningful change or difference in the context of the sample size. The paper indicates that despite the non-statistically significant results, the intervention has much potential via further development and testing to make a positive difference to the health and wellbeing of informal carers of AMD patients.

Minor points

Last sentence in first paragraph of the abstract – do you mean...reduce rather than improve the burden and improve the wellbeing of family carers...?

Effectiveness in title and efficacy in text – probably more appropriate to call your study a test of effectiveness?

Hope that these comments are helpful and good luck with the further development and testing of the intervention.