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**Category:** Care of the older person

**Study type:** Randomised controlled trial

**Citation:** "Laakkonen ML, Kautiainen H, Hölttä E et al. Effects of Self-Management Groups for People with Dementia and Their Spouses- Randomized Controlled Trial. J Am Geriatr Soc. 2016 Apr;64(4):752-60."

**Declarative title:** A self management program for people with dementia and their spouses demonstrates some benefits, but the model has limitations.

### **Implications for practice and research**

- Promotion of self-management is important following dementia diagnosis but questions remain regarding the level of disease severity which renders self management unachievable.
- Group based self management interventions are valued by those who participate but ability to tailor to individual needs is important.
- Researchers must work with people with dementia to co-produce and test the acceptability of these complex interventions.

Researchers also need to consider what the benefits of self management are for people with dementia and select the most appropriate outcomes to test the efficacy of such interventions.

### **Context**

Self-management for people with dementia has been a neglected area for practice and research. However the recently acknowledged importance of post diagnostic support is leading to questions regarding how to encourage self-management in people following diagnosis and limit excess disability. Studies such as the one reviewed here are important in developing an evidence base for practice to build upon.

### **Methods**

This study was a randomized controlled trial of a group self-management intervention for people with a recent diagnosis of dementia and their family caregivers, conducted in one site in Finland. A total of 136 spousal co-resident couples were randomised in blocks of 20 to either the 8-week intervention or usual care (which included additional advice on nutrition and exercise). All participants were assessed at baseline using a number of validated instruments and followed up 3 and 9 months post intervention delivery. Resource use was additionally assessed at 24 months using existing databases. People without mental capacity could be included if their spouse provided consent on their behalf.

Group facilitators visited couples randomised to the intervention before delivery commenced to identify ideas for sessions. The intervention was comprised of four hour long facilitated group sessions (with separate groups for carers) held weekly with transport and lunch provided. The facilitators were

health care practitioners, who received comprehensive training to deliver the intervention and were then supervised throughout. The paper does not report on fidelity assessment or any qualitative exploration of the impact of the intervention. The trial had to be highly pragmatic which means that certain scientific procedures are compromised by necessity.

## **Findings**

At three months post randomization, the physical component of quality of life (measured by the RAND 36) improved for spouses randomised to the intervention and worsened for the controls but this was not sustained at 9 months. There were no differences observed between the trial arms on the mental health dimension of the RAND or on spousal sense of competency (measured by the SCQ). People with dementia who received the intervention had significantly improved cognition compared to the controls as measured by the Verbal Fluency and Clock Drawing tests at 9 months post intervention. The intervention was cost neutral.

## **Commentary**

This is a study of an intervention reportedly designed to improve self management in couples where one has received a diagnosis of dementia. It was designed for couples living together in a spousal relationship, which omits a large number of people who could potentially benefit.

The literature review could have benefitted from being updated with more recent publications on self-management which are illustrative of the developing evidence base (1-5).

The majority of those who participated in the intervention sustained their attendance. However there are questions regarding the extent to which the intervention (as described) can truly promote self management; for example did any of the sessions take place in the community to promote skills enactment, and were participants encouraged to take an active role in running the group? Intervention design, which separated people with dementia from carers is good for promotion of self management (6) but the emphasis of this intervention was upon fostering shared information and support between the couple. How this was practically achieved and the benefits and limitations of this model warrant discussion, particularly within the context of a self management paradigm.

The selection of outcome measures demonstrates emphasis upon family caregiver burden and coping ability rather than upon the qualities required to assist the person with dementia to self manage as does the method of consent to participate in the study as described. Uncertainty regarding the goals of self management with people post diagnosis is also illustrated through the selected outcomes for people with dementia, which do not reflect abilities such as motivation and self-efficacy which are important for self management. How the cognition measures used with people with dementia translate into self-management abilities is questionable.

Finally it should be noted that the characteristics of those randomised to the control compared to those who received the intervention were different, which may have impacted on results. The range of cognitive ability of people with

dementia included 26 people with moderate to severe dementia despite the aim of post diagnostic recruitment.

## References

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**Competing interests: none**