TELEPHONE-BASED SUPPORT GROUPS WITH DEMENTIA

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Funding: University Leipzig and GKV-Spitzenverband

Principal investigator: Margareta Halek

Project coordination: Martin Dichter

Scientific staff: Bernd Albers

Background

The support of and the care for persons with dementia (PwD) requires an enormous amount of time, organization, and commitment. Informal caregivers, most-times relatives, of PwD often feel a high burden. Relief and recognition of their own efforts are often denied. Support groups are desired, but either relatives have no time or opportunity to leave the PwD alone or such groups are not organized in the vicinity. Telephone-based support groups are one opportunity to fill this gap. As yet unknown in Germany, international studies show that a telephone network of informal caregivers can have positive effects. The project REDEZEIT aims to establish and to evaluate telephone-based support groups. The support group sessions will be conducted by the team at Leipzig University, the evaluation of the project will be done by the team at the DZNE site Witten within a randomized controlled trial.
Aims and Research Interest

The evaluation encompasses two levels:

1. The effectiveness of telephone-based support groups
2. The process evaluation concerning the practicability and acceptability of telephone-based support groups

Methods

The evaluation is planned as a cluster adjusted randomized controlled trial. To achieve this, the intervention group is controlled by a waiting group at t(0) baseline, t(1) post intervention and t(2) three-month post intervention follow-up. All standardized interviews will be done by telephone. Participants will be randomized into clusters of five persons.

Target group of the intervention are relatives caring for PwD. Relatives are eligible if they care for the PwD for more than 4 h/d, or have lived in the same household for the last 6 months, and do not suffer from an acute psychiatric disease. Precise inclusion and exclusion criteria are available on request.

The primary endpoint of the evaluation of effectiveness is the health-related quality of life of the participating relatives. This is covered by the General Health Survey Questionnaire Short Form 12 (SF-12). Secondary endpoints are (1) perceived social support of caregivers (measured with the Perceived Social Support caregiving scale), (2) reaction of the informal caregiver regarding the care situation (assessed with the Caregiver Reaction Scale) and (3) possible challenging behavior of people with dementia (measured with the Neuropsychiatric Inventory Questionnaire, NPI-Q). The data analysis will be based on the original treatment assignment (intention to treat).

Concerning the evaluation of the effectiveness, primary and secondary endpoints will be compared at each data point using descriptive and inferential statistics. Process evaluation will be done descriptively.
Results/ Applicability

Telephone-based support groups provide a new opportunity to relieve a support groups will be investigated in the REDEZEIT study.

Contact

Martin Dichter
+49 23 02 - 926 253
martin.dichter(at)dzne.de