

CONFERENCE ABSTRACT

Opportunities and challenges to enhance the social network of home-dwelling people with dementia and their family carers

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Introduction: In many countries, initiatives are introduced to enable people with dementia to live at home for longer. In the practice-based research project VitaDem 2014-2017, we developed and evaluated an integral, multi-component, need-driven and tailor-made approach. The goal of VitaDem is to empower home-dwelling persons with dementia PWD and their family carers to live at home as long as possible through the enhancement of self-sufficiency, vitality and social inclusion. The approach consists of six steps: 1 needs assessment by a case manager; 2 goal setting; 3 case conference; 4 advice; 5 intervention; and 6 evaluation. The aim of the current study is to explore the opportunities and challenges to enhance the social network of PWDs and their informal carers.

Theory/Methods: We used a mixed-method multiple case study approach with one-year follow-up. We included 21 dyads of a PWD and a family carer. Qualitative data were derived from the transcribed needs assessments, post-intervention interviews with the dyads and focus groups with the professionals involved. Quantitative data comprised, amongst other things, questions about the use of informal help baseline, and 6 and 12 months after the start of the intervention.

Results: Some dyads have an active social network. Other dyads, however, have not. In such instances, there may be a need for social network enhancement. Family carers, in particular, have an explicit need for emotional support and social contacts. Objective barriers for social network activation include geographical distance and loss of network members. In addition, decreased mobility and physical problems e.g., hearing problems are barriers for social participation. Subjective barriers are the idea that children are too busy or fear of losing independence. Facilitators for an active social network include decisive network members or a crisis, resulting in successful examples of social network activation. In contrast to their spouse, the mostly married PWDs in our study often have no or only implicit needs for an active social network.

Discussions: From the professionals' view, an active social network may contribute to the dyad's wellbeing, especially in instances where PWDs or family carers have an implicit and unmet need for social inclusion. It is a challenge for professionals to recognize such implicit need and make PWDs and their family carers aware of the importance of a social network for

support and participation. Timely activation of such network can be realized through, for example, family meetings. An integral approach may address the barriers.

Conclusions: Some home-dwelling PWDs and their family carers have a strong social network, but relatively often there are barriers for social network activation that should be taken away first.

Lessons learned: Some barriers for social network activation can be overcome, whereas others cannot. PWDs more often have implicit needs for enhancing their social network than their spouses.

Limitations: Transferability may be limited to home-dwelling PWDs and their spouse caregivers.

Suggestions for future research: Further explore the value of proactive family meetings in which the potential of the social support system to fulfil PWDs' and informal carers' needs are discussed.

Keywords: dementia; informal carers; social network; social inclusion; need-driven
