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### Review

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## Interventions to support people with dementia and their caregivers during the transition from home care to nursing home care: A systematic review



Christian Müller<sup>a,b,\*</sup>, Sindy Lautenschläger<sup>c</sup>, Gabriele Meyer<sup>a</sup>, Astrid Stephan<sup>a</sup>

<sup>a</sup> Institute for Health and Nursing Science, Medical Faculty, Martin Luther University Halle-Wittenberg, Germany

<sup>b</sup> University of Cooperative Education in Health Care and Welfare Saarland, Saarbrücken, Germany

<sup>c</sup> University of Applied Sciences Saarbrücken, School of Social Sciences, Germany

#### ARTICLE INFO

#### ABSTRACT

*Background:* During the transition of people with dementia from home to nursing home family caregivers often feel burdened.

*Objectives:* We aimed to 1) identify interventions which support people with dementia and their caregivers in the transition from home care to nursing home care, 2) synthesize the evidence for efficacy of these interventions, and 3) examine whether the identified interventions have been systematically developed, evaluated and implemented according to the Medical Research Council guidance on complex interventions.

*Design:* A systematic review of randomised controlled trials was conducted according to the recommendations specified in the Cochrane Handbook for Intervention Reviews. The review protocol was registered in PROSPERO (2015: CRD42015019839). Reporting follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA statement.

Data sources: MEDLINE, CENTRAL, PsycINFO, CINAHL, OTseeker, and PEDro, were searched. Other sources included Google Scholar, and ALOIS.

*Review methods:* Two reviewers independently assessed the eligibility of the articles. Data extraction was performed by one reviewer and verified independently by another. The Cochrane Risk of Bias tool was used for critical appraisal. Development and evaluation of the identified interventions were assessed, taking the Medical Research Council guidance into account. Review findings were synthesized narratively.

*Results*: The search yielded 1278 records. Five studies were included, all conducted in the United States (4 RCTs and 1 cRCT with a total of 695 participants). The psychosocial interventions were individual and family counseling via telephone or ad hoc all of which addressed only informal caregivers. The intervention components, content and mode of delivery differed widely with inconsistent results. Significant intervention effects were found for the reduction of caregivers' depressive symptoms, burden, feeling of guilt, emotional distress, overload, and interactions with staff. Other outcomes, i.e. stress, placement adaptation, role overload, and role captivity, were not statistically significantly affected. The assessment for bias risk across studies varied from moderate to low. Only two studies tested the feasibility of the intervention before full scale evaluation, none evaluated the implementation process according to the Medical Research Council framework.

*Conclusions:* We identified only a few studies with heterogeneous outcomes; evidence regarding the effectiveness of psychosocial interventions is thus insufficient. Further research is needed focusing on the development and evaluation of complex psychosocial interventions and more well-designed RCTs with larger sample sizes based on a rigorous methodology. Reporting on feasibility and implementation processes of interventions should be guaranteed, since it is crucial to evaluate transferability across care settings.

#### What is already known about the topic?

caregivers.

 The transition from home care to nursing home care is a decisive moment in the life of persons with dementia and their informal  Informal caregivers suffer from stress, burden, anxiety and often feel unprepared for the transition period with little information and support.

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<sup>\*</sup> Corresponding author at: Konrad-Zuse-Straße 3a, 66115 Saarbrücken, Germany.

*E-mail addresses*: chri.mueller@bagss.de (C. Müller), s.lautenschlaeger@htwsaar.de (S. Lautenschläger), gabriele.meyer@medizin.uni-halle.de (G. Meyer), astrid.stephan@medizin.uni-halle.de (A. Stephan).

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- Most people with dementia show behavioral and neuropsychiatric symptoms during the transition period, associated with a lower quality of life, lower general well-being, anxiety and/or depression.
- Although numerous systematic reviews of non-pharmacological interventions, either for people with dementia or for informal caregivers, have been published, not one is dedicated to the transition from home care to nursing home care.

#### What this paper adds

- This systematic review provides evidence on the effects of psychosocial interventions supporting informal caregivers during the transition from home care to nursing home care. None of the included studies targeted people with dementia during this transition period.
- Psychosocial intervention comprising individual and family counseling, telephone counseling or ad hoc counseling was found to be the sole strategy used to support informal caregivers.
- Psychosocial interventions have the potential to improve specific caregivers' outcome, but the methodological quality of the included studies varied, as did the intervention characteristics (e.g. components, content, and mode of delivery).
- The review highlights the need for greater attention to the development and evaluation of complex psychosocial interventions in a stepwise approach according to the MRC framework and also for more well-designed studies with larger sample sizes and rigorous methods.

#### 1. Introduction

The majority of people with dementia live in their own homes and most are cared for by at least one caregiver, usually a spouse, a partner or a relative (Brodaty and Donkin, 2009; Boots et al., 2014). These caregivers take care of their loved ones in their homes for months or years and, during the course of the disease, they provide extensive care and support that may be physically, emotionally and socially demanding (Brodaty and Donkin, 2009). Recent studies indicate that caregivers' physical and emotional health often suffers and they are at increased risk of becoming burdened, stressed, having sleep disturbances, depression and other health complications (Rose and Lopez, 2012; Li et al., 2012). As dementia progresses over time and the burden of care exceeds the informal caregiver's resources, at a certain point the decision about nursing home placement becomes inevitable (Nikzad-Terhune et al., 2010). This transition is characterized by different stages, milestones, changes and turning points prior to, during and after nursing home placement, and this can be a difficult period for most informal caregivers and people with dementia (Meleis 2010; Afram et al., 2015). From the caregivers' point of view, problems become apparent prior to and during admission due to being unprepared for the transition period, having limited support, being uninformed about care alternatives or financial options, lacking knowledge about dementia, and having insufficient exchange of information with healthcare professions (Bramble et al., 2009; Givens et al., 2012). Dementia caregiving does not end with nursing home placement. After admission, informal caregivers suffer from emotional concerns, such as self-doubt, feeling guilty and regretting the placement decision as well as dissatisfaction with staff communication (Bramble et al., 2009; Afram et al., 2015). Not only informal caregivers, but also people with dementia are affected. The transition from their home into a nursing home is a decisive experience for them, representing loss of their home, neighborhood and time with family and friends compared with previous periods (Sury et al., 2013). Moreover, for most of those admitted to a nursing home, anxiety, depression and behavioral disturbances occur, which may have a negative impact on quality of life and general well-being, leading also to poorer physical health (Brodaty et al., 2001; Scocco et al., 2006). Accordingly, influencing these circumstances and improving health-related quality of life of people with dementia and their informal caregivers is imperative. There is a growing need for the provision of appropriate support for both sides.

Existing systematic reviews of interventions have analyzed trials dealing with a specific type of intervention either for people with dementia or for informal caregivers, for example 1) psychosocial interventions to improve behavioral and psychological symptoms in people with dementia (Testad et al., 2014), 2) social support group interventions for people with dementia (Leung et al., 2015), 3) psychosocial interventions for caregivers (Pusey and Richards 2001; Brodaty et al., 2003), 4) information and support interventions for caregivers (Thompson et al., 2007), 5) psychological interventions for caregivers (Selwood et al., 2007) and 6) internet-based interventions for caregivers dealing with assistive technologies (Boots et al., 2014). None of these systematic reviews focused on interventions to support people with dementia and their informal caregivers during the transition from home care to nursing home care.

#### 2. Objectives and rationale

We carried out this systematic review in order to identify interventions that could effectively support people with dementia and their informal caregivers during transition from home care to nursing home care. We described the intervention characteristics carefully (e.g. components, content, and mode of delivery), and investigated whether the interventions were systematically developed, evaluated and implemented through a gradual approach as recommended in the UK Medical Research Council Framework (Craig et al., 2008, 2013) and the Criteria for Reporting the Development and Evaluation of Complex Interventions (CReDECI) (Möhler et al., 2015).

The systematic review aimed at answering the following three research questions:

- 1) What are the characteristics of interventions to support people with dementia and their informal caregivers during the transition period from home care to nursing home care?
- 2) Which interventions might work or fail to be effective in supporting people with dementia and their informal caregivers during the transition period from home care to nursing home care?
- 3) In what way do studies follow a systematic approach for development, evaluation and implementation of interventions?

#### 3. Methods

#### 3.1. Design

This systematic review was carried out according to a review protocol (Müller et al., 2016)which has also been published in the Prospective Register of Systematic Reviews (PROSPERO 2015: Registration number: CRD42015019839). The recommendations specified in the Cochrane Handbook for Intervention Reviews V.5.1.0 (Higgins and Green, 2011) have been followed and reporting follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009).

#### 3.2. Inclusion and exclusion criteria

#### 3.2.1. Study types

Randomised controlled trials (RCTs), cluster-randomised controlled trials (cRCTs) and clinical controlled trials (CCTs) published in German or English were eligible for inclusion. Studies without a control group, prospective cohort studies, mixed methods studies, cross-sectional surveys, case reports or review articles were excluded. Download English Version:

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