



Interventions to support people with dementia and their informal caregivers during the transition from home care to nursing home care - a protocol for a systematic review

Interventionen zur Unterstützung von Menschen mit Demenz und ihren Angehörigen während des Übergangs von der häuslichen Pflege ins Pflegeheim – ein Studienprotokoll für eine systematische Übersichtsarbeit

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Abstract

Background. The transition from home care to nursing home care is a significant event in the life of a person with dementia and also for informal caregiver, who deal with many crises and changes.

Aim. To describe a protocol for a systematic review based on the 'PRISMA-P 2015 statement'. We will carry out this review firstly to identify interventions that support people with dementia and their informal caregivers in the transition from home care to nursing home care, secondly to synthesise the available evidence for the efficacy of identified interventions, and thirdly to examine whether the identified interventions have been systematically developed, evaluated and implemented according to the MRC framework.

Design. This systematic review will be conducted according to the recommendations specified in the *Cochrane Handbook for Intervention Reviews*; reporting will follow the PRISMA statement.

Methods. The search strategy covers six electronic bibliographic databases, Google Scholar and ALOIS. In addition, backward citation tracking will be applied. The protocol includes decisions made on the research questions, inclusion/exclusion criteria, search methods, study selection, data extraction, assessment of risk of bias, data synthesis and plans for dissemination and funding.

Discussion. This systematic review will summarise the body of evidence of interventions supporting people with dementia and their informal caregivers during the transition from home care to nursing home care.

Protocol Registration. This review protocol has been registered on the Prospective Register of Systematic Reviews (PROSPERO 2015: CRD42015019839).

Abstract

Hintergrund. Der Übergang von der eigenen Häuslichkeit in ein Pflegeheim ist ein einschneidendes Ereignis im Leben eines dementiell erkrankten Menschen genauso wie für die pflegenden Angehörigen, die lernen müssen, mit vielen krisenhaften Situationen und Veränderungsprozessen umzugehen.

Ziel. Studienprotokoll für ein sich anschließendes systematisches Review basierend auf PRISMA-P 2015 Statement. Wir werden ein systematisches Review durchführen, um: (1) Interventionen zu identifizieren, die Menschen mit Demenz und deren pflegende Angehörige während des Überganges von der eigenen Häuslichkeit in ein Pflegeheim unterstützen, (2) die verfügbare Evidenz der Interventionen zusammenzufassen und (3) zu untersuchen, inwiefern die Interventionen in Übereinstimmung mit dem MRC-Framework systematisch und schrittweise entwickelt, evaluiert und implementiert wurden.

Design. Die systematische Übersichtsarbeit erfolgt entlang den Empfehlungen des Cochrane Handbuchs sowie dem PRISMA Statement 2010.

Methoden. Die Literatursuche wird in sechs elektronischen Datenbanken, der wissenschaftlichen Suchmaschine Google Scholar sowie dem Register ALOIS durchgeführt und durch das „Backward Citation Tracking“ ergänzt. Das Protokoll dokumentiert die Forschungsfrage, Ein- und Ausschlusskriterien, Suchstrategie, Studienselektion, Datenextraktion, Einschätzung des Risikos für Bias, die Datensynthese sowie das Vorgehen zur Verbreitung der Ergebnisse.



Diskussion. Die Übersichtsarbeit wird die Evidenz der Interventionen zusammenfassen, die Menschen mit Demenz und ihre pflegenden Angehörigen während des Überganges von der eigenen Häuslichkeit in ein Pflegeheim unterstützt.

Registrierung des Studienprotokolls. Das Studienprotokoll wurde in einem Register für Übersichtsarbeiten (PROSPERO 2015: CRD42015019839) registriert.

Schlüsselbegriffe. Demenz; Alzheimer-Krankheit; Gesundheitsfachberufe; pflegende Angehörige; Übergänge; Pflegeheim; Institutionalisierung; Ambulante Versorgung; Unterstützung; Interventionen

Keywords

Dementia – Alzheimer's disease – healthcare professionals – informal caregivers – transition – nursing home – institutionalisation – home care services – support – interventions

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BACKGROUND

Alzheimer's disease and vascular dementia are chronic and degenerative diseases caused by neurodegeneration (Prince et al., 2013). They mainly affect older people and often cause disability and dependency (Sousa et al., 2009). It is estimated that approximately 35.6 million people worldwide suffer from dementia; in Germany, more than 1.5 million people are currently affected by this disorder (Prince et al., 2013). Furthermore, projections for Germany assume that by 2050, as a result of the population growing older, there will be 2.6 million people suffering from dementia (Leicht & König, 2012). The majority of people with dementia live in their own homes and most have at least one informal caregiver, usually a spouse, a partner or a relative (Brodaty & Donkin, 2009). These informal caregivers provide a substantial amount of the care and support that may be physically, emotionally and socially demanding. They face many obstacles as they combine caregiving at home with other demands, including employment, career and relationships, and they are at an increased risk of becoming burdened or stressed, of having sleep disturbances or depression and a variety of other health complications (Rose & Lopez, 2012). The nature of progression of dementia means that the level of care and burden on informal caregivers tends to increase over time. When informal caregivers are unable to care for a person with dementia at home at a certain time point, the decision about nursing home placement is inevitable. This period is described as a transition from home to nursing home. Transitions are characterised by different dynamic stages, milestones and turning points, and can be defined through processes and outcomes (Meleis, 2010). In Germany, up to 80% of people with dementia are admitted to a nursing home because of disease progression (Leicht & König, 2012). Between 75% and 90% of people with dementia are placed in a nursing home as a result of changes in dementia severity, behavioural disturbances, night-time misbehaviour, progressive mental deterioration, wandering, caregivers'

burden as well as the inability of informal caregivers to maintain care (Luppa, Luck, Brähler, König & Riedel-Heller, 2008; Sury, Burns & Brodaty, 2013). While nursing home placement helps to reduce the direct care of informal caregivers, it does not necessarily reduce informal caregiver distress and burden (Brodaty & Donkin, 2009). Following nursing home placement, there are other tasks and demands for informal caregivers to manage, such as administrative tasks, communication and coordination with healthcare professions or dealing with financial matters (Strang, Koop, Dupuis-Blanchard, Nordstrom & Thompson, 2006; Bramble, Moyle & McAllister, 2009). Finally, dementia caregiving does not end with nursing home placement.

As a consequence, this period can be a difficult transition for both sides - for people with dementia and for their informal caregivers. This period refers to the time prior to admission when admission is contemplated through to an adjustment period after admission into a nursing home (Afram, Verbeek, Bleijlevens & Hamers, 2014). It is associated with many changes prior to, during and after admission. Problems reported by informal caregivers during and after the transition period are related to emotional concerns, such as self-doubt, feeling guilty and regretting the placement decision as well as feelings of loneliness and isolation (Davies & Nolan, 2004; Afram, Verbeek, Bleijlevens & Hamers, 2014). Other reported issues prior to and during admission include lack of knowledge about dementia and its prognosis, not being informed about available care alternatives, not being informed about financial options or simply being unprepared for the transition period with little support offered to informal caregivers (Bramble, Moyle & McAllister, 2009; Givens, Lopez, Mazor & Mitchell, 2012; Sury, Burns & Brodaty, 2013). Additional problems were addressed prior to and during admission in terms of insufficient contact with and little information from healthcare professions (Bramble, Moyle & McAllister, 2009) and after admission, the issues mentioned referred to dissatisfaction with staff communication



(Bramble, Moyle & McAllister, 2009). Not only informal caregivers but also people with dementia are concerned. The transition from their home into a nursing home is a decisive experience, representing loss of their home, neighbourhood and time with family and friends compared with previous periods (Sury, Burns & Brodaty, 2013). Furthermore, being admitted to a nursing home is often associated with anxiety, which may have a negative impact on the quality of life or general well-being (Scocco, Rapattoni & Fantoni, 2006). It is known that unmet needs, as well as a lack of stimulating activities or training for memory and/or sensory problems are associated with poorer mental health and increased behavioural problems during and after this period (Hancock, Woods, Challis & Orrell, 2006). Achterberg, Pot, Kerkstra & Ribbe (2006) reported that after admission, nearly 90% of nursing home residents showed behavioural and neuropsychiatric symptoms associated with a lower quality of life or depression.

If people with dementia, however, have been informed about or involved in the decision-making process and their informal caregivers have received support, they were more likely to be satisfied with the decision (Sury, Burns & Brodaty, 2013). Prior to and during the care-transition period, informal caregivers pointed out specific needs for formal support, such as being receiving education or counseling with regard to dementia. Furthermore, they expressed needs for practicing communication and learning how to communicate better with persons with dementia and a need for getting support to handle the situation (Bramble, Moyle & McAllister, 2009). Regarding the time after nursing home placement, informal caregivers have a need for skills in self-care, such as caring for their own mental and physical health (Afram, Verbeek, Bleijlevens & Hamers, 2014). It was also reported that interprofessional collaboration between healthcare professionals and informal caregivers can help to ease the transition for informal caregivers, as well as to improve the quality of life for people with dementia (Sury, Burns & Brodaty, 2013). Finally, it is important that healthcare services are arranged well and that people with dementia and their informal caregivers receive the support they need. Meleis and Trangenstein (1994) and Meleis, Sawyer, Im, Hilfinger and Schumacher (2000) established a theory of transition that recognises modifying factors that could facilitate or inhibit a successful transition to a nursing home (e.g., preparation, cultural attitudes, interaction, socioeconomic status). This also included the experiences made by people with dementia and caregivers during such transitions (coping strategies, social engagement, communication with healthcare professionals) and also the outcomes (health,

skills in managing a transition and integrative identity) (Gaugler, Roth, Haley & Mittelman, 2011). This theory may also serve as a useful guide to help nurses and other healthcare professionals in identifying appropriate strategies for supporting people with dementia and their informal caregivers during the period of nursing home admission (Davies, 2005; Rose & Lopez, 2012).

Regarding the care of people with dementia, many healthcare professionals are involved, such as nurses, occupational therapists, social workers, physiotherapists, speech therapists, psychologists, doctors and other professions as well as volunteers (NICE & SCIE, 2007). They provide complex interventions to support people with dementia and their informal caregivers through building up relationships, teaching skills, providing training programmes, education and counselling, helping with conflict resolution and care planning. For example, interventions for people with dementia include (a) training for people, who are dependent, in activities of daily living (ADL), (b) cognitive training, (c) sensory stimulation, (d) activity exercises to improve physical functions, (e) therapeutic communication strategies, (f) measures to promote patient safety and to reduce the risk of falls, (g) measures to prevent and manage agitated behaviour and to provide support for informal caregivers, (h) promoting psychoeducational-skill building, (i) reducing emotional distress, (j) involving informal caregivers in the plan of care, (k) organising and coordinating services and (l) giving psychotherapy-counselling as well as (m) advice for physical environmental modification (Steultjens et al., 2004; Joosse, Palmer & Lang, 2011; Kaur, Sharma & Mittal, 2012; Kim, Yoo, Jung, Park & Park, 2012; Elvisha, Levera, Johnstonea, Cawleya & Keadya, 2013). However, this support should be available and coordinated among the various service providers and healthcare professionals, in particular to support people with dementia and their informal caregivers as well as to avoid delays and waiting times for services (Caron, Ducharme & Griffith, 2006). Questions arise as to how healthcare professionals can support people with dementia and their informal caregivers during the care-transition period. We will carry out this systematic review in order to (1) identify interventions that could support people with dementia and their informal caregivers during the transition from home care to nursing home care, (2) synthesise the available evidence of the identified healthcare interventions (e.g. nursing, occupational therapy, physiotherapy) and (3) examine whether the identified interventions have been systematically developed, evaluated and implemented according to the approach for development and evaluation suggested by the UK Medical Research Council (MRC) Framework.



Table 1: Summary Statement

What is already known about this topic

- The transition from home care to nursing home care is a decisive moment in the life of persons with dementia and their informal caregivers.
- Informal caregivers suffer from stress, burden, anxiety and often feel not prepared for the transition period with little information and support.
- 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.

Why this systematic review is needed?

- Although a number of systematic reviews on non-pharmacological interventions either for people with dementia or informal caregivers have been published, none have specifically focused supportive techniques and interventions for people with dementia and their informal caregivers during the transition period from home care to nursing home care.
- It remains unknown so far whether interventions delivered by nurses, occupational therapists, social workers, physiotherapists or other healthcare professionals are effective.

Implications for practice and/or policy

- An overview of the existing knowledge on treatment programs will be generated aimed to inform healthcare professionals, policy makers and decision makers how to improve healthcare provision for people with dementia or their informal caregivers.

RESEARCH QUESTIONS

The systematic review aims to answer the following three research questions:

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

OBJECTIVES AND RATIONALE

A preliminary systematic literature search was performed in order to check whether current systematic reviews (SRs), integrative reviews (IRs) or literature reviews (LRs) dealing with this topic already exist. The search was performed in the following electronic databases: Cochrane Database of Systematic Reviews, Medline (via Pubmed) and CINAHL. In addition, we searched the International Register for Reviews PROSPERO to identify on-going reviews to avoid accidental duplication. However, no SRs, IRs or LR about supporting people with dementia and their informal caregivers during the transition from home care to nursing home care have been

conducted. Therefore, there is a call for a SR to synthesise the available evidence of healthcare interventions (e.g. nursing interventions, occupational therapy interventions, physiotherapy interventions) to support people with dementia and their informal caregivers during this period.

DESIGN

This systematic review will be conducted according to the recommendations specified in the Cochrane Handbook for Intervention Reviews V.5.1.0 (Higgins & Green, 2011) and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement upon completion of the systematic review (Moher, Liberati, Tetzlaff & Altman, 2009; Moher, Liberati, Tetzlaff & Altman, 2010). This protocol has been registered on the National Institute of Health Research (NIHR) Prospective Register of Systematic Reviews (PROSPERO, 2015: CRD42015019839). It is based on the 'PRISMA-P 2015 statement' (Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols), a reporting guideline that defines standards of a robust protocol for a systematic review and gives adequate consideration to relevant aspects in the preparation of systematic reviews (Moher et al., 2015). With regard to the 'PRISMA-P 2015 statement', 14 of 17 Items have been taken into account for this protocol, the exceptions being items 15a, 15b, 15c, 16 and 17, which will not be applied in this systematic review.

METHODS

Inclusion/exclusion criteria

The following inclusion and exclusion criteria have been defined:

Types of studies

Studies suitable for inclusion are randomised controlled trials (RCTs), cluster randomised controlled trials (cRCTs) and clinical controlled trials (CCTs), which have been published. Studies without a control group (including controlled before-and-after studies), prospective cohort studies, mixed methods studies, cross-sectional surveys, case reports and publications where original data is not reported, such as review articles, editorials, discussion papers or commentaries, will be excluded.

Types of participants

People with dementia

People with mild to severe dementia who live at home and are at risk of nursing home admission are registered on a waiting list or have currently been institutionalised



(nursing home admission ≤ 3 months) will be eligible for inclusion. These people require or receive professional nursing care, a therapeutic treatment programme or any other support, regardless of the type of intervention, from healthcare professionals in their own home or in a nursing home. Any type of dementia will be included: Alzheimer's disease, vascular dementia, fronto-temporal dementia.

Informal caregivers of people with dementia

Informal caregivers are individuals such as spouses, partners, relatives or friends on a voluntary basis who provide care for people with dementia and who are involved in the decision-making processes concerning the person they care for. In this context volunteers will also be included.

Types of settings

This review will include only studies that aim to support people with dementia and their informal caregivers during the transition from home care to nursing home care. Studies conducted in acute or rehabilitation hospitals, rehabilitation facilities, day centers or during respite care will be excluded. All involved healthcare professionals are individuals such as nurses, advanced practice nurses, occupational therapists, social workers, psychologists, physiotherapists who provide care, therapeutic treatment, education and counselling or other support for people with dementia and their informal caregivers during the transition period. These healthcare professionals possess formal professional education in health care and are paid for their job.

Types of interventions

Interventions included will be those targeted at people with dementia or their informal caregivers, the objective of which is offering support during the transition from home care to nursing home care. This period refers to the time prior to admission when admission is contemplated and includes an adjustment period after admission into a nursing home. Following intervention components of support, either alone or in combination, are characteristic for healthcare professionals and they will therefore be included: activities of daily living (ADL), instrumental activities of daily living (iADL), education and counselling, physical or mental treatment, skills training, aid and support for technical equipment, assistive technology, telecare, environmental modification, psychosocial support, stress management, psychotherapeutic or psychoeducative components. Multi-disciplinary interventions, including cooperation of nurses, occupational therapists, social workers, physiotherapists or any other group of healthcare

professional, will also be included. Pharmacological interventions will be excluded.

Types of comparator(s) / control

The intervention should be compared with standard care or treatment as usual.

Types of outcome measures

A variety of possible interventions can be assumed with a range of different outcome measures. These potential outcomes are characterized for both the people with dementia and their informal caregivers. We expect studies addressing the following outcome categories:

People with dementia	Informal caregiver(s)
<ul style="list-style-type: none"> • Quality of life • Mental well-being • Physical well-being • Participation in daily activities • Mood • Performance in activities and instrumental activities of daily living (ADL/IADL) • Depression • Mortality • Changing behaviour (e.g. agitation, aggression) 	<ul style="list-style-type: none"> • Quality of life • Mental well-being • Physical well-being • Social participation of informal caregiver(s) • Burden/stress of care • Informal caregiver(s) knowledge • Informal caregiver(s) satisfaction with support or care • Coping • Sense of competence • Depression

SEARCH METHODS

We will develop the search strategy according to the Cochrane Handbook of Systematic Reviews of Interventions, part 2, chapter 6, version 5.1.0 (Higgins & Green, 2011) and the standards for literature searches (Booth, 2006; Sinclair et al., 2013).

Electronic searches

The following six electronic databases will be searched: MEDLINE (via PubMed), CENTRAL, PsycINFO, CINAHL, OTseeker and PEDro. The search will be limited by the English and German languages. We will also search the Specialized Register of the Cochrane Dementia and Cognitive Improvement Group (ALOIS). In addition to our electronic database search, we will conduct a search in the electronic search engine Google Scholar to identify potentially relevant studies not indexed in electronic databases. The detailed search strategy for databases and register is outlined in Appendix 1.

Hand Searching

Backward citation tracking will be done, searching the references for all the included articles in order to prevent



omission of relevant key articles which were not captured by our electronic search.

Managing the references

To ensure a systematic management of the information, references located through the searches will be downloaded into the bibliographical software package Citavi 4 and duplicates will be automatically identified and removed.

Study Selection

Studies will be screened and reviewed by two independent reviewers (CM and SL). First, titles and abstracts will be screened for relevance to the review, whereas final eligibility will be determined through full-text screening. If a final decision cannot be made based on title and/or abstract alone, we will assess the full article. Any possible discrepancies and/or disagreement will be resolved by discussion and consensus and by consultation with a third reviewer (AS or GM) if needed. The reason for exclusion of full-text articles will also be stated.

Data Extraction

The Cochrane data extraction sheet for reviews on interventions (Cochrane, 2014) has been slightly modified. This sheet will be pilot-tested using two studies before starting the full data extraction. Data from each study that met the inclusion criteria will be extracted by one reviewer (CM) and checked by a second reviewer (SL). Data will be extracted from included reviews according to pre-determined categories relating to: first author, country of publication, year of publication, study design (sample size, randomisation, blinding, study follow-up) and study setting. For each intervention/control group, the number of participants, target group (informal caregivers or people with dementia), intervention components, frequency of intervention, duration and length of intervention, healthcare professionals involved in the transition process, outcomes measured and characteristics of participants (total number of participants, diagnostic criteria, age, sex, co-morbidity) will be extracted from each study. The categories for missing data will be filled in with 'not reported'. After both reviewers have completed their review, the results will be compared for consistency. Inconsistencies will be identified and resolved through discussion with a third reviewer (AS or GM), if necessary.

Assessment of risk of bias

The methodological quality of the studies included in the review will be assessed by two independent reviewers (CM and SL).

The first step will be to assess the methodological quality of the RCTs by using the 'risk of bias assessment tool' (RoB) by Cochrane, which describes the potential risk of bias in randomised controlled trials (Higgins et al., 2011). If cluster-randomised trials or other trials are included, we will also use the methods and recommendations described by Cochrane (Higgins et al., 2011). The data analysis will be supported by the Review Manager Software 'RevMan 5' version 5.3.5, described in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins & Green, 2011). First, we will describe the relevant trial characteristics of each study, using a table of the summary of findings on which the judgement about the risk of bias is grounded. Second, the risk of bias will be judged, the findings of which will show either a 'low risk' of bias, a 'high risk' of bias or an 'unclear risk' of bias. The following seven features are of interest: sequence generation (selection bias), allocation sequence concealment (selection bias), blinding of participants and personnel (performance bias), blinding of outcome assessment (detection bias), incomplete outcome data (attrition bias), selective outcome reporting (reporting bias) and other potential sources of bias (Higgins et al., 2011). The two reviewers (CM and SL) will rate each of these seven categories with an 'adequate description' (e.g. 'low risk' of bias) or 'inadequate description' rating (e.g. 'high risk' of bias) or in case of no information with 'unclear risk' of bias. If disagreements occur, these will be resolved through discussion with a third reviewer (AS or GM). The results will be presented as 'risk of bias' tables for each RCT included in the review and, in addition, a figure will illustrate the risk of bias across all the studies. A narrative description of the risk of bias assessment will be used for interpreting the results of the review.

Assessment of individual studies according to the MRC framework

In a second step, we will apply the UK MRC framework (Craig et al., 2008) to assess whether the identified interventions have been systematically developed, evaluated and implemented through a gradual approach. According to the MRC framework, complex interventions should be developed systematically and in an iterative process, starting with a series of pilot studies and moving on to an exploratory study, followed by a definitive evaluation and finally by long-term implementation and monitoring (Craig et al., 2013). In this regard, we will assess for example, example, whether

- a clear description of the intervention is provided to enable replication of the study,
- a study registration was performed or a study protocol was published before the study was conducted,
- the rationale for choosing the intervention components were mentioned,



- information is available about discrepancies between expected and observed outcomes,
- any information is presented about the feasibility, acceptability and practicability of the intervention as part of a pilot study,
- information about cost-effectiveness is available or
- whether any information about process evaluation is reported in the included studies (MRC, 2006; Möhler, Köpke & Meyer, 2015).

We will search for supplemental information of eligible studies about trial registration, feasibility studies, implementation studies, economic evaluation studies or ongoing studies. This will include searching in Medline, trial registries, and Google using the name of the corresponding author and text words for identifying further information.

Strategy for data synthesis

A narrative approach to synthesise the findings will be used because the studies are expected to be heterogeneous with respect to study type and outcome measures. This narrative synthesis provides an analysis and enables a description of patterns across the included studies as well as the exploration of relationships within and between included studies, in line with the guidance from the Centre for Reviews and Dissemination (CRD, 2009). At an early stage the included studies will be grouped into three target groups: (1) people with dementia, (2) their informal caregivers and (3) people with dementia and their informal caregivers. The synthesis of the findings will contain text and tables to provide a descriptive summary and explanation of the characteristics according to intervention components, the role and type of healthcare professions, frequency of intervention, duration of intervention, outcomes measured, statistically significant change (e.g. effect size) and comparator interventions (type, duration and healthcare profession). Furthermore, the methodological quality of the findings identified in Stage 1 will be tabulated and graphically displayed. The findings in stage 2 will be presented with textual descriptions and tabulation.

Dissemination plans

This systematic review will be published in a peer-reviewed journal and presented at conferences. We will also circulate a one-page plain language summary of the findings according to Cochrane's standards for plain language summaries and outline our research findings as a brief report in an open-access journal for practitioners and policy-makers, thus ensuring that our project findings are used by people from a wide range of disciplines and sectors.

DISCUSSION

Support for informal caregivers and/or treatment of people with dementia during the transition from home care to nursing home care is of importance, as it is known to have negative consequences on their physical and psychosocial health, general well-being or quality of life (Scocco, Rapattoni & Fantoni, 2006; Bramble, Moyle & McAllister, 2009; Givens, Lopez, Mazor & Mitchell, 2012; Afram, Verbeek, Bleijlevens & Hamers, 2014). This paper describes the research protocol of the forthcoming systematic review. The protocol has been designed to meet PRISMA standards (Liberati et al., 2009; Moher, Liberati, Tetzlaff & Altman, 2009; Moher, Liberati, Tetzlaff & Altman, 2010; Moher et al., 2015) and is being disclosed so that our methods can be reproducible and evaluated against the final analysis and interpretation of findings. This review will summarise the body of evidence of interventions of people with dementia and their informal caregivers across the continuum of therapeutic treatment, educational support or nursing care. It is also of interest to determine whether the identified interventions for supporting people with dementia and their informal caregivers have been systematically developed, evaluated and implemented for a better understanding as to why interventions might work or fail to be effective. Thus we will get an overview of the existing knowledge on treatment programs and initiatives that can be used to improve the quality of treatment or healthcare provision for people with dementia or their informal caregivers. Whereas most strategies emphasise delaying transitions from home to nursing home placement (Mittelman, Haley, Clay & Roth, 2006) and devote less attention to supporting people with dementia and their informal caregivers during this transition period, this systematic review is timely and warranted. Findings will be of potential interest to healthcare providers or policy-makers and will offer valuable information for further national dementia strategies.

AUTHORS' CONTRIBUTIONS

All of the authors meet the criteria recommended by the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals by the International Committee of Medical Journal Editors (ICMJE) and have agreed on the final version 2014 (International Committee of Medical Journal Editors, 2014). All of the authors contributed to the ideas of the study protocol, read and approved the final draft of the manuscript. In detail, CM and JP were responsible for the design of the study protocol and responsible for the conceptual development of the research questions. GM participated in the design of the study, particularly



in the development of the analytic strategy; AS, GM and SL contributed to development of the research questions, study selection and helped to draft the manuscript.

FUNDING

This research received no specific grant from any funding agency in the public or commercial sectors.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

Table 2: Appendix

Search Strategy Medline (via Pubmed)

Search	Queries	Results
#1	Caregivers [Mesh ^a]	22.920
#2	Family Nursing [Mesh]	1.118
#3	Caregiver* [tw]	46.698
#4	Social Support [Mesh]	53.546
#5	Decision Support Systems, Clinical [Mesh]	5.175
#6	Counseling [Mesh]	34.148
#7	Patient education [tw]	82.524
#8	Treatment program* [tw]	15.186
#9	Exercise program* [tw])	8.570
#10	Exercise training [tw]	69.001
#11	Social Adjustment [Mesh]	21.379
#12	Adaptation, Psychological [Mesh]	104.155
#13	Coping [tw]	127.099
#14	Dementia [Mesh]	123.448
#15	Nursing Homes [Mesh]	32.704
#16	Long-Term Care [Mesh]	22.143
#17	Home Nursing [Mesh]	8.746
#18	Home Care Services [Mesh]	40.564
#19	Randomized controlled trial [pt ^b]	496.068
#20	Randomly [tiab ^c]	235.769
#21	non-randomized controlled trials	1.002
#22	controlled clinical trial	102.573
#23	cluster-randomized trial	1.936
#24	Search (((“Caregivers”[Mesh ^a]) OR “Family Nursing”[Mesh])) OR caregiver*	47.714
#25	Search (((“Social Support”[Mesh]) OR “Decision Support Systems, Clinical”[Mesh]) OR “Counseling”[Mesh]) OR patient education [tw]	167.418
#26	Search ((treatment program* [tw ^d]) OR exercise program* [tw]) OR exercise training [tw]	88.542
#27	Search (((“Social Adjustment”[Mesh]) OR “Adaptation, Psychological”[Mesh])) OR coping [tw]	143.824
#28	#24 OR #25 OR #26 OR #27	411.518
#29	Search (((“Nursing Homes”[Mesh]) OR “Long-Term Care”[Mesh]) OR “Home Nursing”[Mesh]) OR “Home Care Services”[Mesh]	88.751
#30	#14 AND #29	5.271
#31	#28 AND #30	1.758
#32	Search (randomized controlled trial [pt ^b] OR randomly [tiab ^c] OR non-randomized controlled trials [tiab ^c] OR controlled clinical trial [tiab ^c] OR cluster-randomized trial [tiab ^c])	723.273
#33	#31 AND #32	195
Search Date	between 1 January 2000 and 15 July 2015	
Explanation of terms		
^a Mesh = medical subject headings		
^b Pt = publication type		
^c Tiab = title and abstract		
^d tw = textword		



Continued **Table 2: Appendix**

Search Strategy Cinahl (via Ovid)

Search	Queries	Results
#1	Family nursing interventions	2.751
#2	Caregiver of dementia	3.801
#3	Decision Support Systems, Clinical [MH]	1.653
#4	Support, Psychosocial [MH]	37.760
#5	Patient education	92.014
#6	Relatives or family support	31.416
#7	Education	375.375
#8	Counseling interventions	2.768
#9	Treatment program*	32.063
#10	Exercise program for people with dementia	9
#11	Exercise training	15.395
#12	Social Adjustment [MH]	1.987
#13	Coping	28.907
#14	Dementia	29.193
#15	Home care services or home health care	38.913
#16	Nursing home placement	728
#17	Transition	14.128
#18	Randomised controlled trial or randomized controlled trial	13.365
#19	Randomly [AB ^b]	31.154
#20	Randomly [TI ^c]	61
#21	Family Nursing interventions OR caregiver of dementia	6.464
#22	Decision Support Systems, Clinical [MH] OR Support, Psychosocial [MH] OR patient education OR relatives or family support OR education OR counseling interventions	424.874
#23	Treatment program* OR exercise program for people with dementia OR exercise training	46.156
#24	Social Adjustment [MH] OR coping	30.690
#25	#21 OR #22 OR #23 OR #24	482.569
#26	Home care services or home health care OR nursing home placement OR Transition	52.629
#27	#14 AND #26	1.797
#28	#25 AND #27	862
#29	Randomised controlled trial or randomized controlled trial OR TI randomly OR AB randomly	47.387
#30	#28 AND #29	135
Explanation of terms		
^a MH = medical subject headings		
^b AB = abstract		
^c TI = title		

Search Strategy CENTRAL

Search	Queries	Results
#1	Caregivers [Mesh] explode all trees	1.063
#2	Family nursing [ti,ab,kw]	1.358
#3	Social Support [Mesh] explode all trees	1.930
#4	Patient education [ti,ab,kw]	14.429
#5	Family [ti,ab,kw]	14.588
#6	Relative [ti,ab,kw]	31.996
#7	Education [ti,ab,kw]	27.082
#8	Counseling [ti,ab,kw]	8.439
#9	Social adjustment [ti,ab,kw]	1.572
#10	Adaptation, Psychological [Mesh] explode all trees	3.969
#11	Exercise program* [ti,ab,kw]	10.595



Continued **Table 2: Appendix**

Search	Queries	Results
#12	Treatment program* [ti,ab,kw]	20.073
#13	Exercise training [ti,ab,kw]	3.130
#14	Dementia [Mesh] explode all trees	3.206
#15	Long-Term Care [Mesh] explode all trees	1115
#16	Home care [ti,ab,kw]	2.831
#17	Nursing home* [ti,ab,kw]	3.785
#18	Trials, Randomized Clinical [Mesh] explode all trees	20.970
#19	MeSH descriptor: [Caregivers] explode all trees OR family nursing:ti,ab,kw (Word variations have been searched)	2.508
#20	MeSH descriptor: [Social Support] explode all trees OR patient education:ti,ab,kw (Word variations have been searched) OR "family":ti,ab,kw OR "relative" OR "education" (Word variations have been searched) OR "counseling":ti,ab,kw (Word variations have been searched)	80.511
#21	Social adjustment:ti,ab,kw (Word variations have been searched) OR MeSH descriptor: [Adaptation, Psychological] explode all trees	5.413
#22	Exercise program*:ti,ab,kw (Word variations have been searched) OR treatment program*:ti,ab,kw (Word variations have been searched) OR "exercise training":ti,ab,kw (Word variations have been searched)	29.068
#23	#19 OR #20 OR #21 OR #22	103.770
#24	MeSH descriptor: [Long-Term Care] explode all trees OR "home care":ti,ab,kw (Word variations have been searched) OR nursing home*:ti,ab,kw (Word variations have been searched)	6.351
#25	#14 AND #24	425
#26	#23 AND #25	193
#27	#26 AND #18	169

Search Strategy PsycInfo (via Ovid)

Search	Queries (only textwords used)	Results
#1	Caregiver*	39.226
#2	Family nursing interventions	4.501
#3	Decision support systems	1.041
#4	transitional care interventions	225
#5	Support, psychosocial	25.797
#6	Relatives	161,630
#7	Family support	64.257
#8	Education	515,407
#9	supportive care	6.321
#10	Counseling interventions	31.265
#11	Treatment program*	109.176
#12	Exercise program*	13,206
#13	Exercise training	9.741
#14	Social adjustment	51.257
#15	Coping	68,574
#16	Dementia*	52.555
#17	Home care	47.232
#18	Nursing home*	22.687
#19	Long term care	19.930
#20	Randomised controlled trial	3.822
#21	Randomized controlled trial	21,443
#22	Randomly TI	195
#23	Randomly AB	55.160
#24	Caregiver* OR family nursing interventions	42.859
#25	Decision support systems, clinical* OR support, psychosocial OR relatives OR family support AND education OR care interventions OR counseling intervention OR supportive care	745.170
#26	Treatment program* OR exercise program* OR exercise training	125.059



Continued *Table 2: Appendix*

Search	Queries (only textwords used)	Results
#27	Social adjustment OR coping	115.951
#28	#24 OR #25 OR #26 OR #27	934.414
#29	Home care OR nursing home* OR long term care	66.847
#30	#16 AND #29	6.607
#31	#28 AND #30	3.782
#32	Randomised controlled trial or randomized controlled trial OR TI randomly OR AB randomly	76.307
#33	#31 AND #32	209

Search Strategy OTSeeker

Search	Queries (only textwords used)	Results
#1	Dementia	410
#2	Caregivers	412
#3	Transition	76
#4	Adjustment	287
#5	Nursing Home	285
#6	Home care	780
#7	Counseling	419
#8	Education	1477
#9	Support	1949
#10	Social Support	470
#11	Treatment program	1070
#12	Exercise program	890
#13	Randomised controlled trial	1026
#14	Randomized controlled trial	3340
#15	[Any Field] like 'Caregivers' OR [Any Field] like 'transition'	484
#16	[Any Field] like 'Adjustment' OR [Any Field] like 'Nursing Home' OR [Any Field] like 'home care'	1148
#17	#15 AND #16 AND #1	699
#18	[Any Field] like 'Counseling' OR [Any Field] like 'Education' OR [Any Field] like 'Support'	3303
#19	[Any Field] like 'treatment program' OR [Any Field] like 'exercise program'	1710
#20	#18 AND #19	2566
#21	#17 AND #20	2159
#22	#21 AND randomised controlled trial [ti,ab] OR randomized controlled trial [ti,ab]	397

Search Strategy PeDro

Search	Queries	Results
#1	Dementia AND home nursing	35
#2	Dementia AND long term care	18
#3	Dementia AND nursing homes	16
#4	Dementia AND therapy	47
#5	Dementia AND support	29
#6	Dementia AND transition	1
sum		146
Remarks Combined search with more than two textwords was not applicable.		



Continued **Table 2: Appendix**

Search Strategy ALOIS

Search	Queries	Results
#1	Caregivers	371
#2	Support	290
#3	Training	476
#4	Exercise	353
#5	Treatment	3,759
#5	Home care	259
#5	Nursing home	320
#6	Transition	9
#7	Caregivers OR support OR training OR exercise OR treatment	4,192
#8	Home care OR nursing home OR transition	176
#9	#7 AND #8	353
#10	#9 AND Non-pharmacological OR RCT OR CCT	115

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