BMJ Open

Towards a middle-range theory of 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem): Findings from a meta-study on mixed research

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-042515
Article Type:	Original research
Date Submitted by the Author:	08-Jul-2020
Complete List of Authors:	Köhler, Kerstin; German Center for Neurodegenerative Diseases (DZNE); Witten/Herdecke University, Faculty of Health, School of Nursing Science Dreyer, Jan; German Center for Neurodegenerative Diseases (DZNE); Witten/Herdecke University, Faculty of Health, School of Nursing Science, Hochgraeber, Iris ; German Center for Neurodegenerative Diseases (DZNE); Witten/Herdecke University, Faculty of Health, School of Nursing Science von Kutzleben, Milena; Carl von Ossietzky Universität Oldenburg, Faculty of Medicine and Health Sciences, Department of Health Services Research; German Center for Neurodegenerative Diseases (DZNE) Pinkert, Christiane; German Center for Neurodegenerative Diseases (DZNE); Witten/Herdecke University, Faculty of Health, School of Nursing Science Roes, Martina; German Center for Neurodegenerative Diseases (DZNE); Witten/Herdecke University, Faculty of Health, School of Nursing Science Holle, Bernhard; German Center for Neurodegenerative Diseases (DZNE); Witten/Herdecke University, Faculty of Health, School of Nursing Science
Keywords:	Dementia < NEUROLOGY, QUALITATIVE RESEARCH, PUBLIC HEALTH, MENTAL HEALTH

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

For peer review only

Title Page

Towards a middle-range theory of 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem): Findings from a meta-study on mixed research

Corresponding author:
Kerstin Köhler
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany
E-mail: kerstin.koehler@dzne.de
Telephone number: +49 2302 - 926 223
Postal address: Stockumer Straße 12, 58453 Witten, Germany

Co-authors:
Jan Dreyer
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany
E-mail: jan.dreyer@dzne.de

Iris Hochgraeber
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Milena von Kutzleben
Carl von Ossietzky Universität Oldenburg, Faculty of Medicine and Health Sciences, Department of Health Services Research, Oldenburg, Germany
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany

Christiane Pinkert
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Martina Roes
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Bernhard Holle
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Word Count: 8868

ABSTRACT

Background: Most people with dementia and their informal carers live at home and strive to create a stable care situation for as long as possible. This preference of dyads is consistent with the global policy of ageing in place.

Objective: We aimed to develop a middle-range theory of stability guided by the following research questions: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors influencing stability?

Study-design and methodology: Within the DZNE SoCA project, we conducted a meta-study on mixed research. The analytical steps of meta-data analysis, meta-method and meta-theory are merged in an integrative synthesis. Eligible publications were identified through systematic database searches, backward/forward citation tracking, and snowballing. All publications were screened against predefined inclusion criteria and evaluated through a quality appraisal. The analytical approach was thematic synthesis.

Results: In total, 99 publications were included. The newly developed middle-range theory conceptualises stability as a complex phenomenon comprising three components including eight concepts that are dynamically interrelated. The conceptual model comprises (1) the trajectory of the dementia care arrangement, which involves a cyclic process of *change* and *balancing* over time; (2) the characteristics of the care arrangement, including *needs*, the *carer role*, the *dyadic relationship* and *resources*; and (3) the context, which is determined by *society and culture* and the respective *health care system*. The relevance of each concept in relation to stability changes over time. The forming of each concept is actively shaped by the informal carer.

Conclusion: This middle-range theory provides a thorough understanding of the stability of home-based care arrangements for people living with dementia and can be used to guide future research and practice. We encourage the scientific community to use, reflect and further develop this middle-range theory.

PROSPERO registration number CRD42016041727.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The first meta-study of the phenomenon of the ‘stability of home-based care arrangements for people living with dementia’ introduces a new middle-range theory and conceptual model.
- The meta-study methodology includes a critical analysis of the theoretical assumptions and the methodology of the included studies and provides findings extending beyond conventional synthesis, thereby allowing the development of innovative theory.
- Despite our critical reflection of the sample, the theoretical perspectives, choice of methods and essence of the findings of the included studies necessarily confined our modelling of ‘stability’ as follows: as a consequence (currently), the perspective of only one actor in the care arrangement (the informal carer) is the focus.
- The so-called SoCA-Dem theory has translational potential since the integration of the perspectives of all actors (including the person with dementia) involved in care arrangements is possible and intended. Furthermore, this middle-range theory has translational potential for use in other chronic diseases.
- The middle-range theory is applicable to guide subsequent research and policy and improve health and social care practice.

INTRODUCTION

Worldwide, most people with dementia live at home.[1] It is the explicit wish of most people with dementia to stay in their familiar environments,[2] and most informal carers wish to support the person with dementia at home for as long as possible.[3 4] Driven by this motivation, informal carers are a vital resource for people living with dementia at home and play a crucial role in supporting dementia care in the community.[5] In current research, policy, and practice, these preferences are mirrored in programmatic agendas, such as ‘ageing in place’[6], and reflected by an increasing focus on ‘social health’.[7] These agendas emphasise the capability of people with dementia, their families and their social networks and aim to create prerequisites to enable dyads to live well with dementia in the places of their choice.[8]

This dyadic perspective can be complemented by the perspective of the social security and health care system. In light of demographic changes and the constantly growing prevalence of dementia worldwide,[9] societies are challenged to provide adequate health and social care for an increasing number of ageing individuals and, thus, need to appropriately address limited financial resources. As dementia is among the strongest predictors of cost-intensive institutional care,[10] the support of home-based care has been discussed as an option to reduce expenses.[11]

The stability of home-based care arrangements is an important goal for people living with dementia and their informal carers and reflected by current social security and health care policy. Accordingly, the term ‘stability’ is used as a buzz word in research[12] and policy[13] contexts, but a thorough definition of stability is usually not provided. Often, stability and instability are recognised as opposing phenomena and are operationalised in a binary way. Thus, the transition of a person with dementia from home to an institution is often understood as a demarcation line between stability and instability. The time until institutionalisation greatly varies, and numerous studies have uncovered the predictors and risk factors of institutionalisation,[14] but these studies did not focus on the process that finally leads to the termination of home-based care. Other studies have illuminated the interactions between individuals involved in home-based care,[15] but these interactions were not clearly linked to the phenomenon of stability or instability. In our understanding, continuing to live at home does not necessarily indicate a stable situation, and in the worst case, the needs of the involved persons can be neglected, leading to an exhausting situation for the person with dementia or the informal carer.[16 17] In contrast, living in a nursing home can be perceived as a satisfying and stable living situation. At first glance, the prevalent binary conceptualisation of stability versus instability based on the criterion of institutionalisation is appealing, but at a second glance, this conceptualisation does not capture the complexity of the phenomenon.

The significance of the interactions between all persons involved in a home-based dementia care arrangement and the central importance of the needs of these persons are highlighted in a published working definition of stability (see Figure 1).[18] Here, stability is defined as a dynamic process that unfolds over the trajectory of dementia care that is intentionally shaped by the actors and can be achieved only if the needs of the person with dementia and the informal carer are addressed. This definition is an essential part of the foundation of this meta-study. It reflects the work conducted by Corbin and Strauss[19] regarding managing chronic illness, Nolan, Grant and Keady[20] regarding family care, and von Kutzleben[21] regarding informal dementia care trajectories, all of which conceptualise care as a process of vibrant interactions between individuals over time.

[insert Figure 1: Definition of 'stability of home-based care arrangements for people living with dementia']

The working definition and the meta-study are integral parts of the SoCA project (**S**tability **o**f home-based **C**are **A**rrangements for people living with dementia project) at the German Center for Neurodegenerative Diseases (DZNE), site Witten, Germany. The SoCA project strives to develop a sound theory-based understanding of the complex phenomenon of stability and further explore the newly-developed middle-range theory and conceptual model by conducting subsequent empirical studies using qualitative and quantitative research methodologies to finally identify and develop stability promoting interventions and care structures.

AIM

The aim of this study was to develop a middle-range theory of the 'stability of home-based care arrangements for people living with dementia'. The theory generation process was driven by the following research questions: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors influencing stability?

METHODOLOGY

Study design

We performed a meta-study according to the approach described by Paterson and colleagues.[22] During the theory development process, we considered the recommendations by Liehr and Smith,[23] Im[24] and Risjord[25] regarding the creation of middle-range theories. In the subsequent sections, we provide a very brief description of our methodology. The details of the methodology were published in the respective study protocol.[26] This meta-study is registered at the International Prospective Register of Systematic Reviews (PROSPERO registration number CRD42016041727). The reporting of this publication follows the recommendations in the ENTREQ statement.[27]

Literature search

Following the framework described by Boell and Cecez-Kecmanovic,[28 29] we searched for literature in open-ended 'hermeneutic loops', including the repeated steps of searching, sorting, selecting, acquiring, reading, identifying and refining, until we sufficiently encircled our phenomenon of interest by reaching conceptual saturation.[30] The following search techniques were combined: berry picking,[31] database searches (MEDLINE, CINAHL, and PsycINFO), backward and forward citation tracking, and snowballing. The complete syntaxes are available in the appendix of the study protocol.[26] Since the phenomenon of stability is seldom directly studied in the context of home-based care, we created individual syntaxes for nine separate search strands, which we deduced from the published definition of stability,[18] as shown in the flow diagram (see Figure 2).

Screening process

The titles and abstracts of all identified studies were screened by four authors (KK, JD, IH, and MvK) in alternating teams of two authors. Full-text screening was performed by one author, who discussed his/her decision with at least one colleague. If disagreement occurred, consensus was reached by discussion. EndNote X7® was used to manage the screening process.

Eligibility criteria

The original meta-study methodology was designed for the synthesis of qualitative research only. In contrast, we decided to include all types of empirical research and (systematic) reviews. The rationale for this decision and the inclusion criteria are shown in the study protocol.[26] We included publications written in English, German, or French; no time limits were set.

Quality appraisal

We applied the quality appraisal recommended by Dixon-Woods and colleagues[32], which includes five criteria to identify studies with major methodological deficits. The decision to include or exclude a publication was made based on this quality appraisal and the publication's contribution to the proposed middle-range theory. Each paper was assessed by one researcher. If he/she was in doubt of the methodological quality, he/she discussed the paper with at least one other researcher until consensus was reached.

Analysis and data collection process

A meta-study combines the following three analytical steps, leading to a final meta-synthesis: meta-theory, meta-method and meta-data analyses. During our iterative analytical process, these steps were considered in an integrated process rather than individually. The insights gained from one analytical step immediately shaped the subsequent analyses. All analyses were performed using the Professional Research Software for Qualitative, Quantitative and Mixed Methods Research (MAXQDA 2018). The coding of the data was performed in teams of at least two researchers. A thematic synthesis performed according to the approach described by Thomas and Harden[33] was the primary analytic method.

Meta-theory

Meta-theory involves a critical exploration of the theoretical frameworks that guided the included research.[22] For each publication, we analysed the stated research gaps, aim(s), research question(s), explicitly stated theoretical frameworks and/or underlying concepts.

Meta-method

Meta-method analyses consider how the application of research methodologies influences the findings and shapes the current understanding of the phenomenon under research.[22] For this purpose, we analysed the study design, methodology, sample, sampling, setting, data collection, data analysis, and standardised measures used in each publication.

Meta-data analysis

A meta-data analysis is a comparative analysis of the findings of all included studies; this analysis contributes to the creation of an integrated body of knowledge.[22] Following Thomas and Harden,[33] we analysed the findings in three stages. Through an iterative coding process of inductive 'line-by-line coding' and the organisation of these codes into 'descriptive themes', we created major 'analytical themes' that form the components and concepts of the proposed middle-range theory. The key criterion indicating the completion of the iterative coding process was conceptual saturation.[30]

Meta-synthesis

In the meta-synthesis, we elaborated upon the relationship between the analytical themes. While we engaged more deeply with the material, at a certain point, the emerging middle-range theory no longer substantially changed. To ensure that the meta-synthesis was complete, we sampled a selection of publications from our sample and reviewed these publications again to determine whether the statements were all consistent with the status quo of the middle-range theory or any statements that might change the theory were overlooked. The heart of our middle-range theory is a conceptual model that visualises the interplay among the components and concepts in an organised form.

Comments on writing the results section

The progress of the iterative analysis and synthesis process shaped the creation of the middle-range theory, and vice versa. We refrained from an artificial distinction among the individual analytical steps and wrote the results in an integrated form. This publication presents the middle-range theory and conceptual model developed in this meta-study. To guide the reader, we start with an introduction to the components and concepts of the conceptual model and provide basic descriptions of their interplay within the middle-range theory. This overview is followed by detailed conceptualisations of the single concepts in the context of the middle-range theory. Each paragraph starts with a general conceptualisation of each concept, followed by explanatory results from the analyses.

Usually, systematic literature reviews reference all sources that support a specific argument. To ensure the readability of the explanatory results of the concepts, we decided to cite only one key reference for each argument. The reason for this decision is twofold as follows: our sample was very extensive, and most arguments were embodied in many publications. Consistent with the principle of conceptual saturation, we did not code each argument in each publication. In the appendix of this publication, we provide a complete bibliography of the publications included (Appendix B). Appendix A presents for each of the included publications if it contributed to our understanding of a specific concept of the developed middle-range theory.

Patient and public involvement

Patients or the public were not involved in this meta-study.

RESULTS

Sample description

We included n=99 publications in our meta-study. The detailed process of searching and selecting eligible publications is documented in the flow diagram in Figure 2. During the screening process, n=5 publications were excluded during the quality appraisal. During the analysis phase, the whole 'interventions' search strand was excluded from the sample because the content of the retrieved intervention reviews and studies did not contribute to the intended theory generation. A statement explaining the reasons for this decision is provided in Appendix C. Detailed information of each publication is provided in Appendix A.

The included publications were authored by researchers in North America (the USA n=31 and Canada n=12) and Europe (Germany n=12, the UK n=11, the Netherlands n=8, and other European countries n=12); members of international consortia (n=8); and researchers in Asia or Australia (n=5); however, no publications authored by researchers in Africa or South America were included. The publications cover a wide range of scientific fields, including geriatrics, geriatric psychiatry, gerontology, dementia, nursing, palliative care, social sciences, etc. More than half of the included publications (n=56) were published from 2010 onwards, n=26 were published between 2000 and 2010, n=13 were published in the 1990s, and n=4 were published in the 1980s.

N=50 included studies used quantitative methodologies, and n=31 studies used qualitative methodologies. Furthermore, we included n=7 mixed-methods studies and n=11 systematic reviews (3 synthesised qualitative studies and 9 synthesised quantitative studies). N=54 publications reported studies involving cross-sectional designs, and n=34 publications reported studies involving longitudinal designs.

Only n=21 publications explicitly stated the theoretical framework guiding their research process. Thereby, stress theories and stress models were chosen the most frequently (n=10). In n=78 publications, no explicit theoretical framework was indicated, but the dominance of a stress/burden perspective was also apparent in these publications. For instance, n=71 publications in our sample refer to the work conducted by Zarit[34], Pearlin[35] and/or Aneshensel,[36] who are researchers that advanced the understanding of stress and burden in caregiving. In the discussion section of our article, this conceptual bias and its impact on the development of our middle-range theory are reflected.

[insert Figure 2: Flow diagram]

Components and concepts of the middle-range theory and their interplay

In this meta-study, we developed a middle-range theory of the stability of home-based care arrangements for people living with dementia (called the SoCA-Dem theory) that emphasises the perspective of the informal carer.

The current focus on the informal carer perspective in this middle-range theory is driven by our own previous work concerning informal dementia care trajectories, which identified stability as a guiding principle of informal carers.[21] Therefore, we created a search strategy in which the presence of an informal carer in the home-based care arrangement was mandatory.[26] As a consequence, most identified studies placed the informal carer at the centre of the research. Nevertheless, we are keenly aware that the perspectives of all actors (including the person living with dementia) in care arrangements are meaningful and shape the respective care arrangement, and we reflect upon this conceptual bias in the discussion section of this publication.

We illustrate the middle-range theory in a conceptual model. The model visualises three components comprising eight concepts that altogether constitute stability of home-based care arrangements for people living with dementia from the perspective of the informal carer (see Figure 3).

→ Component 1 – **trajectory**: According to our understanding and consistent with Corbin[37], a chronic illness trajectory refers to the course of an illness/condition over time and the actions that shape that course. The arrow at the bottom visualises the time course of the trajectory of a home-based care arrangement that covers the time span from the onset of the care arrangement to its termination. Above the arrow, a cyclic process displays the events and actions that shape the trajectory. This cyclic process comprises the two concepts of *change* and *balancing* and reruns in many loops over the trajectory.

→ Component 2 – **characteristics**: Four concepts, namely, *needs*, *carer role, dyadic relationship*, and *resources,* and the forming of these concepts characterise the stability of a home-based care arrangement.

→ Component 3 – **context**: The trajectory of a home-based care arrangement and its characteristics are influenced by the context, which includes the two concepts *society and culture* and the *health care system*.

[insert Figure 3: Conceptual model of the stability of home-based care arrangements for people with dementia (SoCA-Dem)]

The components and concepts of this middle-range theory are related in a dynamic interplay and cannot be interpreted in isolation from each other. Each component and concept is entwined with the other components and concepts, and all components and concepts influence and are influenced by the other components and concepts.

At any time in the trajectory, change may occur and trigger an action (balancing) of the informal carer. This balancing influences whether the needs of the person with dementia and the informal carer are successfully met or remain unmet. Balancing influences the informal carer's experience of the carer role, the development of the dyadic relationship and the management of resources. In contrast, met or unmet needs, the specific experiences of the informal carer, the development of the dyadic relationship and the management of resources may enable or hinder the informal carer from balancing in such a way that supports the stability of the care arrangement. In addition, this interplay between change and balancing over time and the characteristics of the care arrangement is influenced by the societal and cultural background and the respective health care system.

Thus, the forming of each concept is variable rather than static; each concept can assume a forming that promotes the stability of the home-based care arrangement or a forming that may challenge the stability. When one concept transitions to a challenging forming, another concept may assume a promoting forming and buffer the negative impact of the concept in the challenging forming. In addition, all these processes change over time, which increases the complexity of the conceptual model. A specific concept in a specific form may have a minor impact on stability at the beginning of the trajectory but a major influence during the late phases, and vice versa. At any time, there can be stable and instable phases.

These mechanisms of the dynamic interplay between the components and concepts of the SoCA-Dem theory are further clarified in the subsequent paragraphs, which introduce the concepts one-by-one.

Change

Conceptualisation

To a great extent, the trajectories of home-based dementia care arrangements are driven by change. One major change is the progression of dementia. Dementia is a neurodegenerative syndrome associated with a progressive deterioration of cognitive and physical functioning that increasingly challenges the person with dementia in managing his/her daily life independently. Consequently, the person with dementia often relies on the support of family members, friends, neighbours and professional service providers. The change caused by dementia introduces various additional challenges to the home-based care arrangement. In general, gradual changes can mostly be well balanced, whereas unexpected changes challenge the stability of the home-based care arrangement.

Analyses and synthesis

Table 1 provides an overview of the fields in which change occurs.

[Please format Table 1]

Change related to…	**Fields of change**
the person with dementia	cognition, behaviour, ADL/IADL functioning, physical health, mental health, age
the informal carer	physical health, mental health, ADL/IADL functioning, age
needs	needs of the person with dementia, needs of the informal carer
the carer role	self-conception and external conception of the carer role, having/assuming other roles
the dyadic relationship	roles in the dyad, reciprocity, relationship quality
resources	practical skills, mental resources, financial resources, arrangement of informal/formal networks
society and culture	policy strategy, societal discourse of dementia, demographics, spatial environment
the health care system	policy strategy, availability and financing of health and social care services

Table 1: Overview of the fields of change addressed in the meta-study sample

If change occurs, the informal carer appraises the change and decides whether and how he/she needs to balance the changed situation. The appraisal of change is highly individual as follows: some informal carers interpret the first cognitive symptoms of the person with dementia as a part of normal ageing, while others identify these changes as pathologic and seek a diagnosis.[38] During this phase, some dyads experience a period of uncertainty while coping with 'diagnostic shock',[39] whereas others feel relieved by the final diagnosis.[40] This appraisal of the impact and meaning of a specific change by the informal carer is as important as the change per se.[41]

In the context of this middle-range theory, change is the most crucial if it challenges the stability of the home-based care arrangement and provokes crises that cannot be balanced. MacNeil Vroomen and colleagues[42] built a theory of crises in dementia care. Their conceptualisation of the dementia crisis process and the repeating alternation between imbalance and homeostasis is consistent with our understanding of stability.

Change can trigger positive or negative consequences. If the informal carer can accept the (unavoidable) changes in the person with dementia and the related changes in his/her own life[43] and decide to acknowledge the positive aspects of his/her situation, this may result in supportive changes in his/her attitude and ultimately facilitate the finding of meaning.[44]

Change can be slow, developmental and predictable or rapid, situational and unexpected.[45] In general, changes that can be foreseen (such as a progressive cognitive decline) are easier to balance than changes that are unexpected (such as a fall).[15] Gradual changes can be monitored without time pressure, whereas in the face of a rapid change, informal carers are must act spontaneously.[46] Some authors have concluded that serious and unexpected changes rather than constant changes are the initial triggers leading the informal carer to start thinking about the termination of home-based care.[47] Liken[48] reported that 80% of the informal carers in her sample moved their relatives with dementia to institutions due to unexpected events.

Balancing

Conceptualisation

Change in a current care situation triggers an action by the informal carer. The most prominent action strategy in the proposed middle-range theory is balancing. Informal carers strive to balance the situation to maintain the stability of their care arrangements. Balancing can either target internal processes (e.g., changing mindset) or practical actions. Imbalance occurs if there is a mismatch between the acute challenge caused by a change and the informal carer's repertoire to adapt to this challenge. If the informal carer loses control and fails to balance the situation, the home-based care arrangement often moves into a crisis, followed by a period of instability.

Analyses and synthesis

We identified balancing as a process that is often divided into four steps. First, the informal carer appraises a change and reflects upon whether he/she should adapt to the change. Thus, the informal carer weighs the risk of taking no action against the perceived benefit of adaptation. Second, the informal carer decides how to adapt to maintain the stability of the situation. Third, the informal carer acts with the intention to balance the care situation. Fourth, the informal carer evaluates whether his/her balancing was adequate to maintain the stability of the care arrangement.[49]

The notion of different types of informal carers who perform balancing in different ways was very prominent in our sample. In some studies, a distinction was made between informal carers who proactively plan ahead for the future and informal carers who delay decisions and actions until they obviously need to react in a crisis.[50] Regarding the maintenance of stability of the home-based care arrangement, a proactive balancing strategy seems to promote stability, whereas a reactive attitude challenges stability.[49]

The following examples illustrate that the fields of actions targeted by the balancing of an informal carer are diverse; informal carers balance the needs of the person with dementia with their own needs to care for their physical and emotional well-being.[51] Regarding the carer role, informal carers balance their mindsets; they accept the fact that their family members have dementia and choose to have a positive attitude,[44] modify their beliefs and expectations,[52] and attempt to find peace of mind.[43] Furthermore, informal carers balance the duties they face in their carer roles with their duties in other roles, such as being a parent or having a professional occupation.[53] Informal carers balance the reciprocity in their dyadic relationships[54] and the interactions within their informal[55] and formal[56] support networks and strive to establish collaborative partnerships.[50] In this context, informal carers value their support networks as an essential source of the support needed to continue in their carer roles.[57] In addition, they balance the challenge of caring for a person with dementia by developing expertise in their knowledge regarding dementia and their practical skills.[40]

Related to our understanding of a trajectory as a cyclic process of change and balancing over time, some publications in our sample contextualised their research with theories concerning chronic illness trajectories[39] and conceptualised dementia care as occurring in phases over time.[58] Some studies shed light on informal carers' balancing throughout the whole care trajectory.[59] However, overall, our sample strongly focused on the decision making of informal carers regarding the institutionalisation of the person with dementia.[60] Therefore, in extent research there is an emphasis on balancing during the phase of the trajectory in which instability is impending or already definite.

Needs

Conceptualisation

The needs of the person living with dementia and the informal carer occupy a central position in our conceptual model because a stable care arrangement can be created and maintained only if these needs are met. Over the trajectory of a home-based care arrangement, needs change, and continuous balancing is necessary. Conflicts due to the competing needs of one person or the divergent needs of both persons in the dyad can emerge and must be resolved to the greatest extent possible.

Analyses and synthesis

A prevailing assumption among the studies in the sample was that the stability of a care arrangement is at risk if the needs of the person with dementia or his/her informal carer are unmet.[61]

Regarding the person with dementia, the commonly stated needs were health-related needs or needs related to limitations in the activities of daily living.[62] These needs were discussed as a consequence of the progression of dementia or ageing and multimorbidity in general. Regarding the informal carer, the identified needs were often related to the consequences of giving care, the informal carers' well-being[63] or lack of resources.[64] Needs related to the lack of resources often included needs for professional support services or educational programmes.[46]

Furthermore, during the analysis process, we identified numerous needs of the person with dementia and the informal carer that were related to one of the concepts of the characteristics of the care arrangement, such as the need to find meaning in the demanding carer role,[44] the need to preserve reciprocity in the dyadic relationship,[43] and the need for resources in the form of a supporting network of family, friends, neighbours and professionals[58] or specific services (such as care).[65] According to these findings, needs represent a concept with a very large conceptual overlap with the other concepts and major influence; whether needs are met or unmet shapes the forming of the other concepts, which, in turn, either promotes or challenges stability. Therefore, our conceptual model positions needs as the central concept.

As dementia progresses, the informal carer becomes increasingly responsible for anticipating the needs of the person with dementia. Considering the needs of the person with dementia and his/her own needs is not an easy task for the informal carer as these needs can be conflicting.[48] Furthermore, the anticipated needs of the person with dementia could also conflict with each other, such as the need for autonomy versus the need for safety.[66] Additionally, the informal carer could have conflicting needs, such as the need to be a dedicated carer and the need to care for him/herself. Therefore, these conflicts in needs could be distinguished as inter-need conflicts (i.e., the persons in the dyad have conflicting needs) and intra-need conflicts (i.e., the needs of one person conflict with each other).

Carer role

Conceptualisation

The way an informal carer forms his/her carer role has a crucial impact on the stability of home-based care arrangements. Becoming and being an informal carer can be perceived as a positive mission, an undesired obligation or a mélange of both positive and negative experiences. Regarding the stability of home-based care arrangements, how the informal carer assumes the carer role and manages to balance this role with other social roles seem to be important.

Analyses and synthesis

At the very beginning of the trajectory, assuming the carer role is a gradual and unconscious process.[39] Subsequently, informal carers realise their actions and identify as carers.[38] Adapting to the new role is often challenging;[40] for instance, because informal carers assume new responsibilities[67] and feel unprepared,[56] adapting to the new role can be particularly challenging if the beginning of the care trajectory is unexpected.[68]

Assuming the carer role is usually motivated by the dyadic relationship between the informal carer and the person with dementia.[66] In general, there are societal expectations to care for family members. These expectations vary across countries and cultures and are reflected in the respective health care systems.[69]

Informal carers have different feelings regarding their roles. For some informal carers, caring is a reciprocal act as follows:[38] adult children often understand caring as an opportunity to give back to their parents,[44] and spouses often view caring as fulfilling their marriage vows.[54] Being intrinsically motivated to provide care supports stability.[51] A positive appraisal of giving care increases the motivation of the informal carer[66] and the likelihood that he/she will continue caring at home.[70] Intrinsically motivated informal carers take pride in their roles and often experience personal growth.[44] For other informal carers, assuming the carer role is considered a moral obligation.[40] Such carers feel as if they have no choice[48] either because no one else is available[71] or others expect them to provide care.[55] This situation can lead to feelings of entrapment and overload in the carer role.[66] Informal carers who experience few if any positive aspects and feel burdened by their duties have a lower commitment to continue caring at home, tend to develop a desire to institutionalise the person being cared for in the future,[72] and actually end the home-based care arrangement sooner.[73] Attitudes towards the carer role can change over the trajectory of the care arrangement, which was described in the studies in the sample as a modification of beliefs or personal expectations,[52] a cognitive shift,[38] or a result of adapting and learning.[39]

A consequence of assuming the carer role may be role conflicts with other obligations in the life of the informal carer.[53] These obligations can be a professional occupation,[74] the informal carer’s family life (especially among carers who have children),[46] or other social interactions with friends or neighbours.[75] In particular, adult children are concerned with conflicting obligations.[49] If the informal carer does not successfully balance his/her social roles, the stability of the care arrangement could be endangered.[76]

Dyadic relationship

Conceptualisation

Caring occurs within relationships, and most informal carers perceive caring as a natural continuation of the dyadic relationship with the person living with dementia. Therefore, the structure of the dyadic relationship (i.e., kinship relation, family status and living situation) and the quality of the dyadic relationship (i.e., primarily the renegotiation of roles and the maintenance of reciprocity) impact the stability of the home-based care arrangement. The direction of the effect of the relationship quality on stability may reverse over the trajectory.

Analyses and synthesis

Most studies in our sample stated that close kinship relationships promote the stability of a home-based care arrangement,[64] whereas distanced kinship relationships increase the likelihood of a prompt cessation of home-based care.[75] In general, spouses tend to continue to care at home the longest,[77] children tend to end home-based care sooner than spouses[78] and other informal carers tend to institutionalise sooner than children.[79] Regarding the family status of the person with dementia, there is consensus that being married or living in a partnership supports whereas being single challenges the continuation of home-based care.[80] The availability of at least one informal carer seems to be indispensable.[81] Living in the same household as the informal carer is supportive of the maintenance of a stable situation at home, whereas living alone is often a challenge.[82] These structural aspects of the dyadic relationship do not directly influence stability but rather function as indicators of the other concepts included in our middle-range theory. The kinship relationship, family status and living situation influence the quality of the dyadic relationship (e.g., spousal affection versus filial piety), the self-construction of the carer role (e.g., motives to provide care), and the availability of informal and formal resources (e.g., having adult children).

A prevailing assumption among the studies in the sample was that a good past or present relationship quality supports the continuation of home-based care, whereas a low past or present relationship quality challenges stability.[43] Over the trajectory, the forming of the dyadic relationship is influenced by changes in the person with dementia. In many chronic illness trajectories, dyadic relationships tend to develop an asymmetric structure, with the carer being dominant. These changes are especially meaningful in a dementia care trajectory as they usually lead to a shift in former roles and are often accompanied by a strong decline in the reciprocity of the dyadic relationship.

In the dementia care trajectory, premorbid roles within the dyadic relationship are questioned and adapted to the current situation.[66] Sometimes, a swap of premorbid (often traditional and gender-related) roles occurs, e.g., carer husbands perform household tasks, carer wives manage financial issues[40] and children assume parent-like roles.[83] Many informal carers perceive this process of adapting long-standing roles in their dyadic relationships as a challenging transition that may be accompanied by a decline in the quality of the dyadic relationship, which is often conceptualised as shrinking reciprocity.

In reciprocal relationships, informal carers have a high willingness to continue care at home.[51] If informal carers appreciate the opportunity to reward the love and care they received in the past,[44] succeed in maintaining affectionate bonds,[57] and continue engaging in activities and rituals that they previously enjoyed,[54] they tend to value their dyadic relationships as reciprocal and find meaning in their carer roles.[84] In contrast, if informal carers start to complain about a decline in the reciprocity of their dyadic relationships, they lost a major source for continuing care.[54] These informal carers report changes in their feelings towards their relatives with dementia,[66] a decreased level of affection,[85] emotional distance and estrangement,[38] and a perception of having fallen out of love[71] and ultimately describe the relationship with the relative with dementia as lost.[66]

Over the trajectory of a care arrangement, the direction of the effect of the dyadic relationship on the stability of the home-based care arrangement may change. At the onset and during the early phases of the trajectory, it is assumed that the closer the kinship relationship is and the higher the quality of the dyadic relationship is, the higher the chance that the home-based care arrangement will remain stable. However, at some point, the direction of this effect may reverse. In the long term, the intent to keep the person with dementia at home for as long as possible is often associated with the expense of the informal carer's physical and mental well-being or the health and safety of the person with dementia.[86] If the informal carer does not anticipate the critical phase when he/she will no longer be able to balance the care situation adequately, he/she might miss the opportunity to ensure a smooth and well-planned termination of home-based care.

Resources

Conceptualisation

Resources are pivotal for informal carers to balance the consequences of constant change and create and maintain a stable care arrangement. The more resources available in general, the more available resources fit the dyad's needs, and the smarter these resources are mobilised, the better the stability of the care arrangement. The availability and use of resources change over the trajectory and can be differentiated as intra-personal resources and inter-personal resources.

Analyses and synthesis

In many publications, various resources were studied to examine their impacts on stability. If informal carers judge their resources as inadequate to balance the situation, the stability of the care arrangement could be endangered.[87]

In the category of intra-personal resources, mental resources (e.g., resilience and related concepts, such as mastery, a sense of competence, and self-efficacy) were the most common resources researched.[88] Skills, such as hands-on care skills or communication skills, were the second most studied group of resources researched in the intra-personal category.[50] Furthermore, many studies focused on the education, income levels[80] and the physical health[89] of the informal carer.

In the category of inter-personal resources, the studies in our sample investigated social support (e.g., family members, friends or neighbours)[80] and formal support (e.g., respite care, community nurses or meal services).[15] Regarding inter-personal resources, notably, the overall amount of potential social or formal support is often less important than the quality of the relationships and interactions between the persons involved.[85] Meaningful interactions and communication between the informal carer and his/her supporters is highly important for the creation of stable care arrangements.[40]

All resources are dynamic and may change during the trajectory of a home-based care arrangement. For instance, the informal carer may experience a decline in support from his/her social network and an increase in social isolation if family members and friends withdraw.[39] In contrast, meaningful new relationships, e.g., with the members of a support group, could grow over the trajectory.[3] The possible positive development of resources, such as increased resilience or the learning of new skills, were discussed as gains of caring,[66] while a decline in resources, such as deteriorating health or decreasing financial resources, were discussed as burdens that may endanger the stability of home-based care.[90]

One study in our sample adopted an explicit strength-based perspective as its theoretical foundation and highlighted the meaning of resources in the context of positive outcomes of caregiving.[3] Other studies explicitly referred to a stress model, e.g., the stress process model[35] or the stress-coping model.[91] In these stress models, resources play an important role in coping with challenging life events. Studies adopting a theoretical perspective focusing on social inequality in the allocation of resources were missing in our sample, which could be interpreted as the lack of a societal perspective and emphasis on the individual/dyadic perspective.

Society and culture

Conceptualisation

Home-based dementia care arrangements are influenced by the society and culture in which the persons with dementia and their informal carers live. Therefore, the prevailing values of a specific culture shape the stability-related context.

Analyses and synthesis

Regarding cultural values, we included studies addressing the societal expectations of different cultures in different geographical regions, e.g., China[92] and Europe,[93] and research addressing the societal expectations of different ethnic groups in one country, e.g., Chinese people in Australia[74] or Latinos in the USA.[94] In some cultures and ethnic groups, prevailing traditional values lead people to prefer family care and refuse to involve professional support services. In such contexts, the included studies described 'caregiving as a fulfilment of cultural values'[94] or a 'powerful cultural tradition of family care'.[93] In a German study, von Kutzleben and colleagues[95] identified the country of origin of the person living with dementia as a significant influencing factor as follows: informal carers who cared for a person with dementia with a migrant background perceived the care situation as more stable than informal carers caring for a care recipient who was native born. Mausbach and colleagues[94] and Sun and colleagues[96] reported that in the USA, Latinos and African Americans tend to institutionalise their relatives later than their Caucasian counterparts.

In cultures bound to traditional values, (mostly female) family members are expected to assume the informal carer role. On the one hand, these informal carers often feel valued by their social networks and tend to have positive attitudes towards their carer roles.[94] On the other hand, informal carers are frequently placed under pressure (by the care recipient him/herself or other family members) to fulfil the expected traditional roles regardless of the personal cost or consequences. Particularly if there are divergent notions of familial obligation between different family members and/or the informal carer refuses to accept the assigned traditional role, role conflicts and family disagreement emerge with possible consequences on the stability of the care arrangement.[74]

Regarding the cultural/societal context, distinctive changes in the near future are expected. The profound demographic changes, increasing number of elderly people, reduction in family size, geographic spread of family members, and workplace participation (of women) could result in the older generation relying on fewer potential family caregivers and a smaller amount of informal resources than before.[97] In relation to cultures still bound to traditional values, 'modern' families may no longer be able to maintain the traditional roles[90] or may consciously shift from the traditional values held by older generations.[74]

Health care system

Conceptualisation

The national policy agenda, the associated promotion of specific formal support services, and the availability and financing of such services affect the informal carer's options to use or reject the use of formal services. In addition, the national policy context and the respective health care system are shaped by the perceived cultural and societal values. This context influences the stability of home-based care arrangements.

Analyses and synthesis

Dramé and colleagues[97] identified the following universally accepted principles in all member countries of the Organisation for Economic Cooperation and Development (OECD): remaining at home for as long as possible, delaying institutionalisation, supporting informal carers, and coordinating services at a local level whenever possible. However, how these principles are incorporated into national policy agendas and implemented in health care insurance systems and care practice widely differ across different cultures and countries worldwide.[69] Some national policy agendas rely on extensive family participation (e.g., Asia, eastern and southern Europe, Germany, and the USA), while in other agendas, the additional integration of formal support services (including institutional care) is highly accepted (e.g., Australia, Western Europe, and Scandinavia). According to these diverse policy aims, how financial resources are governed and allocated varies, which often influences the decision of informal carers to continue or end home care.[81]

In our sample, there was a consensus that most home-based care arrangements require some type of formal support services at some point during the trajectory.[56] Therefore, the use of formal support services may either function as a protective factor for stability because the unmet needs of the care arrangements are addressed or accelerate the termination of home-based care because positive experiences with the increasing integration of formal support services pave the way for the final decision to institutionalise the person with dementia.[78] Informal carers particularly value education and training,[46] case management,[42] home care services,[82] respite services,[95] support groups,[39] hospice services,[98] and financial aid[77] to support the maintenance of a stable situation at home.

The setup of different health care systems and how formal services are promoted and funded seriously affect the availability and use of such services. Informal carers state a need for adequate financial aid.[67] In the US context, Cepoiu-Martin and colleagues[80] reported that a higher percentage of spending on in-home care services and a higher number of home health agencies decreased the risk of nursing home placement. In the Italian context, Sansoni and colleagues[99] argued that the coverage of nursing home costs by the state could increase the rate of nursing home placement. Families who cannot afford to pay for a nursing home avoid placement and tend to continue care at home,[47] but if the costs for institutional care are covered by the state, families with a lower income tend to institutionalise their relatives earlier, while families with a higher income more often continue home-based care as they can pay for community-based services out of pocket.[100]

In summary, the existence and availability of formal support services and adequate financial resources (either covered by a health care system or private means) allow informal carers to decide which formal support services support the maintenance of stability in their current situations.

DISCUSSION

In this meta-study, we developed a middle-range theory of the stability of home-based care arrangements for people living with dementia (SoCA-Dem theory) that emphasises the perspective of the informal carer. We conceptualised stability as a complex phenomenon comprising the following three components: 1. the trajectory of the home-based care arrangement comprising a cyclic process of change and balancing over time; 2. the characteristics of the care arrangement, including the concepts needs, carer role, dyadic relationship and resources; and 3. the context, including the concepts of society and culture and the health care system. Most concepts of the proposed middle-range theory have been well studied individually but have not been examined from an integrative perspective. The strength of this study and additional value of our new middle-range theory are that this study links the concepts to the phenomenon of stability and sheds light on the dynamics linking the components and concepts.

The following three ongoing debates in the scientific community became obvious in our meta-theory and meta-method analyses, influenced our conceptualisation of stability and allowed us to recognise some limitations: 1. the debate concerning predominant research focusing on dyads (mostly from the perspective of the informal carer) versus a more heterogeneous understanding of care arrangements; 2. the debate concerning the predominant stress/burden perspective in research focusing on informal care versus a framing of informal care that also considers positive aspects; and 3. the debate concerning the predominance of retrospective and cross-sectional studies versus the need for prospective and longitudinal studies.

1. As a consequence of the predominant focus of most studies in our sample on informal carers, our middle-range theory primarily reflects the perspective of one actor in the dyadic care arrangement and highlights the pivotal role of the informal carer in the creation and maintenance of stability. This emphasis on the informal caregiver can be interpreted as a limitation that, to some extent, may have been triggered by our search strategy in which the involvement of an informal carer in the care arrangement was chosen as an inclusion criterion. Although we were actually interested in the perspectives of all actors in dyadic care arrangements, the included publications nearly exclusively adopted the perspective of the informal carer and failed to provide insight into the perspectives of the person with dementia and other actors in the care arrangement. There is a vivid debate regarding this prevalent shortcoming in research concerning informal dementia care. For example, Ceci, Brown and Purkis[101] criticised that the heterogeneity of care arrangements is often overlooked. We do not question that the person with dementia has a voice and plays an active role in the creation and maintenance of his/her care arrangement;[2 102] we are aware that there is a growing population of people with dementia who live alone and need to cope without the help of an informal carer;[103] and we know that most home-based care arrangements rely on the support of formal service providers and have a triadic structure.[104] Home-based care arrangements are often diverse 'convoys of care'[105] and will likely become even more diverse in the future due to demographic shifts and changes in gender roles and family structures. In subsequent research, this middle-range theory should be extended to include diverse actors' perspectives regarding stability, ideally through participative research approaches.[106 107] However, even in its present form, the SoCA-Dem theory is open to a heterogeneous conceptualisation of care arrangements as it already positions diverse informal and formal support networks as pivotal resources for the dyadic care arrangement. In addition, we assume that this middle-range theory may also be valid in the context of diverse chronic diseases. Currently, we hypothesise that our middle-range theory can be applied in future research

focusing on more diverse care arrangements and other chronic diseases, but the components and concepts of the theory might change in their meaning and forming.

2. Many publications included in our sample highlighted the progression of dementia as the main driver of change leading to a growing care dependency of the person with dementia and increasing stress and burden for the informal carer. This assumption is mirrored by a high number of publications in our sample that (explicitly or implicitly) used a stress/burden framework as their theoretical perspective and therefore relied on a dominant but increasingly questioned research paradigm.[108] Informal carer burden has often been identified as a main outcome to be studied and targeted in intervention studies, but it has been criticised that this approach usually leads to a mismatch between the simple research logic of 'identified problem – targeted outcome' and the individual and much more complex real-life experiences of dyads living at home.[109] In depth-qualitative research focusing on the structure and underlying meanings of informal caring has been found to be very valuable in this respect. For example, von Kutzleben[21] revealed that informal carers follow their own logics and strategies in response to change. Informal caring proved to be the expression of an individual informal care concept, which can be defined as the intra-personal manifestation of motives, aims and personal boundaries. Considering these individual informal care concepts helps enhance our understanding of how informal carers perceive burden and that the reduction in burden is not necessarily the most important priority of all carers. The authors of the publications included in our meta-study had very diverse understandings of the phenomena of stress and burden. This conceptual ambiguity has also been critically discussed in the literature,[110] and in our case, it complicated a coherent interpretation of the study results regarding burden and its influence on stability. Although the stress/burden perspective was dominant in our sample, in some included studies, the nascent paradigm shift to a more multifaceted understanding of informal dementia care, including positive experiences, was apparent.[5] The SoCA-Dem theory emphasises the coexistence of both positive and negative experiences; for meaningful interpretation, burden and positive experiences always need to be contextualised within the complex interplay of all theory components and concepts.

3. Several up-to-date phase models[21 111 112] emphasise constant change in the everyday lives of dyads living at home, followed by ongoing adaptation in a dynamic non-linear process. Our views are consistent with those described by von Kutzleben,[21] who highlighted the importance of distinguishing between different phases of the dementia care trajectory as in each phase, a different type of change may affect stability in a specific way. According to this study, the middle stages of the trajectory during which the person with dementia is still quite actively involved in everyday life but already has difficulties mastering the activities of daily living independently might be perceived as particularly challenging with regard to the maintenance of stability. In some studies in our sample, the research was contextualised using theories concerning chronic illness trajectories[19] and transitions,[113] and n=34 longitudinal studies showed that researchers valued following dyads over a certain time span. However, there are methodological challenges to assessing the development of trajectories, even in longitudinal research. The definite beginning of a trajectory is difficult to determine. Consequently, the studies in our sample largely included care arrangements in various and undefined phases within their individual trajectories and did not acknowledge this issue as a limitation. Furthermore, most studies focused on rather late phases of the trajectory, often on the phase during which a transition to an institution occurred. To generate deeper knowledge of stability in all phases of the trajectory, as recommended by Kralik, Visentin and van Loon[114], there is a need for future longitudinal studies that provide valid assessments of the current stage of the trajectory of the individual care

arrangement, ideally include care arrangements at the very beginning of their trajectories and follow such trajectories over a long period. In this type of longitudinal study, the focus should be on the specific forming of each concept of our middle-range theory during each phase of the trajectory and the influence of each concept on the creation of stability.

In summary, this middle-range theory of stability is well aligned with the existing knowledge, current research and ongoing debates. Thus, the conceptual model provides an innovative framework that is open to the integration of upcoming research perspectives and considers the heterogeneity of home-based dementia care arrangements and their individual development over time.

CONCLUSION

This middle-range theory conceptualises the phenomenon of the stability of home-based care arrangements for people living with dementia. By adopting the perspective of the informal carer, the SoCA-Dem theory contributes to an enhanced understanding of the dynamic processes that contribute to stable or instable phases within the often long-lasting dementia care trajectory.

Elaborating upon the perspective of the person with dementia is a necessary important goal for future research focusing on 'stability' and will enhance our understanding of the identified components and concepts. This goal is consistent with the research conducted at the DZNE site in Witten on person-centred care and the development of participatory research methods involving persons living with dementia as co-researchers. In addition to the aspired inclusion of the perspective of the person with dementia and other actors involved in home-based care arrangements, we highlight the need to further clarify the conceptual overlap and interplay of the theoretical components and concepts and the need to better understand the development of stability in all phases of the dementia care trajectory. In the DZNE SoCA project, we address these knowledge gaps in subsequent empirical research applying qualitative and quantitative methods. We aim to be able to distinguish between stable and unstable care arrangements and identify or develop interventions suitable for the needs of the person with dementia and his/her informal carer at a particular point of time within the trajectory to support the stability of individual care arrangements.

Our middle-range theory of stability already provides an opportunity to further develop innovative care structures and advance routine care practice. Therefore, we encourage the scientific community, policy makers and health care providers to use, reflect upon and refine the SoCA-Dem theory and contribute to the ongoing discourse regarding stability to better enable dyads to live in the place of their choice currently and in the future.

Author Contributions

KK, JD, IH, MvK and BH substantially contributed to the conception and design of this meta-study, including the development of the research questions, search strategies, eligibility criteria, data extraction schemes and analytic procedures. KK, JD, IH and MvK performed the coding process. KK, JD, and IH performed the data analysis and synthesis process. The proposed middle-range theory was discussed and finalised as a team by all authors. KK, JD and IH contributed to the draft of this manuscript. All authors read, provided feedback and approved the final manuscript.

Acknowledgements

René Müller-Widmer, Saskia Kelinski, Christina Manietta and Jana Isabelle Braunwarth supported the author team in specific analyses and the layout of the tables and graphic material.

Competing interests

None declared.

Funding

This meta-study was financed by the German Center for Neurodegenerative Diseases (DZNE).

Ethical approval

Ethical approval is not required for this meta-study.

Patient consent

Not required.

REFERENCES

1. World Health Organization. Dementia: a public health priority. Geneva: World Health Organization 2012.
2. von Kutzleben M, Schmid W, Halek M, et al. Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging Ment Health* 2012;16(3):378-90. doi: 10.1080/13607863.2011.614594 [published Online First: 2012/01/18]
3. Peacock S, Forbes D, Markle-Reid M, et al. The Positive Aspects of the Caregiving Journey With Dementia: Using a Strengths-Based Perspective to Reveal Opportunities. *J Appl Gerontol* 2010;29(5):640-59. doi: 10.1177/0733464809341471
4. Wadham O, Simpson J, Rust J, et al. Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. *Aging Ment Health* 2016;20(5):463-73. doi: 10.1080/13607863.2015.1023769 [published Online First: 2015/03/27]
5. Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud* 2018;79(1–26):1-26. doi: 10.1016/j.ijnurstu.2017.10.008
6. Vasunilashorn S, Steinman BA, Liebig PS, et al. Aging in Place: Evolution of a Research Topic Whose Time Has Come. *J Aging Res* 2012;2012:120952. doi: 10.1155/2012/120952
7. Dröes RM, Chattat R, Diaz A, et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging Ment Health* 2017;21(1):4-17. doi: 10.1080/13607863.2016.1254596 [published Online First: 2016/11/21]
8. Bartlett R, Brannelly T. Life at home for people with a dementia. Abingdon & New York: Routledge 2019.
9. Prince M, Wimo A, Guerchet M, et al. World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International 2015.

10. Hajek A, Brettschneider C, Lange C, et al. Longitudinal Predictors of Institutionalization in Old Age. *PloS one* 2015;10(12):e0144203. doi: 10.1371/journal.pone.0144203 [published Online First: 2015/12/15]

11. Schaller S, Mauskopf J, Kriza C, et al. The main cost drivers in dementia: a systematic review. *Int J Geriatr Psychiatry* 2015;30(2):111-29. doi: 10.1002/gps.4198 [published Online First: 2014/10/17]

12. Vukoman M, Rüßler H. (Ehe-)Partnerschaft im Kontext der Pflegebedürftigkeit. *Z Gerontol Geriatr* 2019 doi: 10.1007/s00391-019-01639-8

13. Bundesministerium für Gesundheit. Zukunftswerkstatt Demenz. Berlin2017.

14. Toot S, Swinson T, Devine M, et al. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatr* 2017;29(2):195-208. doi: 10.1017/s1041610216001654

15. Caron CD, Ducharme F, Griffith J. Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Can J Aging* 2006;25(2):193-205. doi: 10.1353/cja.2006.0033 [published Online First: 2006/07/06]

16. Wiglesworth A, Mosqueda L, Mulnard R, et al. Screening for Abuse and Neglect of People with Dementia. *J AM GERIATR SOC* 2010;58(3):493-500. doi: 10.1111/j.1532-5415.2010.02737.x

17. Wharton TC, Ford BK. What Is Known About Dementia Care Recipient Violence and Aggression Against Caregivers? *J Gerontol Soc Work* 2014;57(5):460-77. doi: 10.1080/01634372.2014.882466

18. von Kutzleben M, Köhler K, Dreyer J, et al. Stabilität von häuslichen Versorgungsarrangements für Menschen mit Demenz. Entwicklung und Konsentierung einer Definition von Stabilität durch Expertenfokusgruppen. *Z Gerontol Geriatr* 2017;50(3):210-18. doi: 10.1007/s00391-015-0990-0 [published Online First: 22.12.2015]

19. Corbin JM, Strauss A. Unending work and care: Managing chronic illness at home. San Francisco: Jossey-Bass 1988.

20. Nolan M, Grant G, Keady J. Understanding family care: a multidimensional model of caring and coping. Milton Keynes: Open University Press 1996.

21. von Kutzleben M. Häusliche Versorgung von Menschen mit Demenz - Rekonstruktion des Versorgungshandelns informeller Versorgungspersonen im Zeitverlauf: Beltz Juventa 2018.

22. Paterson BL, Thorne SE, Canam C, et al. Meta-Study of Qualitative Health Research. Thousand Oaks, London, New Delhi: Sage Publications 2001.

23. Liehr P, Smith MJ. Middle Range Theory: A Perspective on Development and Use. *ANS Adv Nurs Sci* 2017;40(1):51–63. doi: 10.1097/ANS.0000000000000162

24. Im E-O. Theory Development Strategies for Middle-Range Theories. *ANS Adv Nurs Sci* 2018;41(3):275-92. doi: 10.1097/ans.0000000000000215

25. Risjord M. Middle-range theories as models: New criteria for analysis and evaluation. *Nurs Philos* 2019;20(1):e12225. doi: 10.1111/nup.12225

26. Dreyer J, Köhler K, Hochgraeber I, et al. Stability of home-based care arrangements for people living with dementia: protocol of a meta-study on mixed research. *BMJ Open* 2018;8:e021156. doi: 10.1136/bmjopen-2017-021156

27. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12:181. doi: 10.1186/1471-2288-12-181 [published Online First: 2012/11/29]

28. Boell SK, Cecez-Kecmanovic D. Literature reviews and the hermeneutic circle. *AARL* 2010;41(2):129-44. doi: 10.1080/00048623.2010.10721450 [published Online First: 2013/07/08]

29. Boell SK, Cecez-Kecmanovic D. A hermeneutic approach for conducting literature reviews and literature searches. *Commun Assoc Inf Syst* 2014;34(12):257-86. doi: 10.17705/1CAIS.03412 [published Online First: 2012/05/17]

30. Finfgeld-Connett D, Johnson ED. Literature search strategies for conducting knowledge-building and theory-generating qualitative systematic reviews. *J Adv Nurs* 2013;69(1):194-204. doi: 10.1111/j.1365-2648.2012.06037.x [published Online First: 2014/01/01]
31. Bates MJ. The design of browsing and berrypicking techniques for the online search interface. *Onl Rev* 1989;13(5):407-24. doi: 10.1108/eb024320
32. Dixon-Woods M, Kirk MD, Agarwal MS, et al. Vulnerable groups and access to health care: a critical interpretive review. National Coordinating Centre NHS Service Delivery Organ RD (NCCSDO)2005.
33. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8(45) doi: 10.1186/1471-2288-8-45 [published Online First: 2008/07/10]
34. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649-55. doi: 10.1093/geront/20.6.649 [published Online First: 1980/12/01]
35. Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30(5):583-94. [published Online First: 1990/10/01]
36. Aneshensel CS, Pearlin LI, Mullan JT, et al. Profiles in caregiving: The unexpected career: Elsevier 1995.
37. Corbin JM. The Corbin and Strauss Chronic Illness Trajectory model: an update. *Sch Inq Nurs Pract* 1998;12(1):33-41.
38. Willoughby J, Keating N. Being in control: the process of caring for a relative with Alzheimer's disease. *Qual Health Res* 1991;1(1):27–50. doi: 10.1177/104973239100100103
39. Lindgren CL. The caregiver career. *J Nurs Scholarsh* 1993;25(3):214-19. doi: 10.1111/j.1547-5069.1993.tb00784.x
40. Frewer-Graumann S. Zwischen Fremdfürsorge und Selbstfürsorge: Familiale Unterstützungsarrangements von Menschen mit Demenz und ihren Angehörigen. Wiesbaden: Springer VS 2014.
41. de Vugt ME, Stevens F, Aalten P, et al. A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *Int Psychogeriatr* 2005;17(4):577-89. doi: 10.1017/S1041610205002292 [published Online First: 2005/09/27]
42. MacNeil Vroomen J, Bosmans JE, van Hout HP, et al. Reviewing the definition of crisis in dementia care. *BMC Geriatr* 2013;13(10) doi: 10.1186/1471-2318-13-10
43. Shim B. Finding Meaning in the Dementia Caregiving Relationship. (Doctoral dissertation) Duke University, 2011.
44. Lloyd J, Patterson T, Muers J. The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London)* 2016;15(6):1534-61. doi: 10.1177/1471301214564792 [published Online First: 2014/12/31]
45. Liken MA. Caregivers in crisis: moving a relative with Alzheimer's to assisted living. *Clin Nurs Res* 2001;10(1):52-68. doi: 10.1177/c10n1r6 [published Online First: 2002/03/08]
46. Toot S, Hoe J, Ledgerd R, et al. Causes of crises and appropriate interventions: the views of people with dementia, carers and healthcare professionals. *Aging Ment Health* 2013;17(3):328-35. doi: 10.1080/13607863.2012.732037 [published Online First: 2012/11/16]
47. Oliva y Hausmann A, Schacke C, Zank S. Pflegende Angehörige von demenziell Erkrankten : welche Faktoren beeinflussen den Transfer von der häuslichen in die stationäre Pflege? *Psychother Psychosom Med Psychol* 2012;62(9-10):367-74. doi: 10.1055/s-0032-1323708
48. Liken MA. Critical incidents precipitating institutionalization of a relative with Alzheimer's. *West J Nurs Res* 2001;23(2):163-78. doi: 10.1177/019394590102300205 [published Online First: 2001/03/29]
49. Wackerbarth S. Modeling a Dynamic Decision Process: Supporting the Decisions of Caregivers of Family Members with Dementia. *Qual Health Res* 1999;9(3):294-314. doi: 10.1177/104973299129121875

50. Davis LL, Chestnutt D, Molloy M, et al. Adapters, strugglers, and case managers: a typology of spouse caregivers. *Qual Health Res* 2014;24(11):1492-500. doi: 10.1177/1049732314548879 [published Online First: 2014/09/04]

51. Donovan ML. Edification of dementia caregiver uplifts characteristics. (Doctoral dissertation) Capella University, 2006.

52. Coe M, Neufeld A. Male caregivers' use of formal support. *West J Nurs Res* 1999;21(4):568-88. doi: 10.1177/01939459922044045

53. Schirra-Weirich L, Wiegelmann H. Typenbildung als Beitrag zur Weiterentwicklung von Versorgungsstrukturen für Menschen mit Demenz und ihren versorgenden Angehörigen. Ergebnisse einer Tandem-Studie im Rahmen des Modellprojekts "DemenzNetz Städte Region Aachen". In: Schäfer-Walkmann S, Traub F, eds. Evolution durch Vernetzung - Beiträge zur interdisziplinären Versorgungsforschung. Wiesbaden: Springer VS 2017:59-76.

54. Wuest J, Ericson PK, Stern PN. Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. *J Adv Nurs* 1994;20(3):437–43. doi: 10.1016/j.pec.2014.01.009

55. Chang YP, Schneider JK, Sessanna L. Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *J Aging Stud* 2011;25(4):436-44. doi: 10.1016/j.jaging.2011.05.001

56. Lethin C, Hallberg IR, Karlsson S, et al. Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scand J Caring Sci* 2016;30(3):526-34. doi: 10.1111/scs.12275 [published Online First: 2015/09/09]

57. Donovan ML, Corcoran MA. Description of Dementia Caregiver Uplifts and Implications for Occupational Therapy. *Am J Occup Ther* 2010;64(4):590-95 doi: 10.5014/ajot.2010.09064

58. Daly L, McCarron M, Higgins A, et al. 'Sustaining Place' - a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *J Clin Nurs* 2012;22(3-4):501-12. doi: 10.1111/jocn.12003 [published Online First: 2012/11/21]

59. Groen-van de Ven L, Smits C, Oldewarris K, et al. Decision Trajectories in Dementia Care Networks Decisions and Related Key Events. *J Aging Res* 2017;39(9):1039-71. doi: 10.1177/0164027516656741 [published Online First: 2016/07/08]

60. Ducharme F, Couture M, Lamontagne J. Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Serv Q* 2012;31(3):197-218. doi: 10.1080/01621424.2012.681572

61. Scholzel-Dorenbos CJ, Meeuwsen EJ, Olde Rikkert MG. Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. *Aging Ment Health* 2010;14(1):113-9. doi: 10.1080/13607860903046495 [published Online First: 2010/02/16]

62. Gaugler JE, Kane RL, Kane RA, et al. Unmet care needs and key outcomes in dementia. *J AM GERIATR SOC* 2005;53(12):2098-105. doi: 10.1111/j.1532-5415.2005.00495.x [published Online First: 2005/10/07]

63. McLennon SM, Habermann B, Davis LL. Deciding to institutionalize: Why do family members cease caregiving at home? *J Neurosci Nurs* 2010;42(2):95-103. doi: 10.1097/JNN.0b013e3181ce5c45

64. Gallagher D, Mhaolain AN, Crosby L, et al. Determinants of the desire to institutionalize in Alzheimer's caregivers. *AM J ALZHEIMERS DIS* 2011;26(3):205-11. doi: 10.1177/1533317511400307 [published Online First: 2011/03/04]

65. Glass AP. Family Caregiving and the Site of Care: Four Narratives About End-of-Life Care for Individuals with Dementia. *J Soc Work End Life Palliat Care* 2016;12(1-2):23-46. doi: 10.1080/15524256.2016.1156605 [published Online First: 2016/05/04]

66. Quinn C, Clare L, Woods RT. Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London)* 2015;14(2):220-37. doi: 10.1177/1471301213495863 [published Online First: 2013/12/18]

67. Afram B, Verbeek H, Bleijlevens MHC, et al. Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *Int Psychogeriatr* 2015;27(6):891-902. doi: 10.1017/S1041610214002154 [published Online First: 2014/10/07]

68. Gaugler JE, Kane RL, Kane RA, et al. The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychol Aging* 2005;20(1):100-16. doi: 10.1037/0882-7974.20.1.100

69. Afram B, Stephan A, Verbeek H, et al. Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *J AM MED DIR ASSOC* 2014;15(2):108-16. doi: 10.1016/j.jamda.2013.09.012 [published Online First: 2013/11/12]

70. Kajiwara K, Nakatani H, Ono M, et al. Positive appraisal of in-home family caregivers of dementia patients as an influence on the continuation of caregiving. *PSYCHOGERIATRICS* 2015;15(1):26-31. doi: 10.1111/psyg.12074 [published Online First: 2014/12/18]

71. Lewis LF. Caregiving for a Loved One With Dementia at the End of Life. *AM J ALZHEIMERS DIS* 2015;30(5):488-96. doi: 10.1177/1533317514559829 [published Online First: 2014/11/25]

72. Cohen CA, Gold DP, Shulman KI, et al. Positive aspects in caregiving: An overlooked variable in research. *Can J Aging* 1994;13(3):378-91. doi: 10.1017/S071498080000619X

73. Gaugler JE, Yu F, Krichbaum K, et al. Predictors of nursing home admission for persons with dementia. *Med Care* 2009;47(2):191-8. doi: 10.1097/MLR.0b013e31818457ce [published Online First: 2009/01/27]

74. Caldwell L, Low LF, Brodaty H. Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *Int Psychogeriatr* 2014;26(3):413-24. doi: 10.1017/s1041610213002020 [published Online First: 2013/11/22]

75. Gilhooly MLM. Senile dementia: Factors associated with caregivers' preference for institutional care. *Br J Med Psychol* 1986;59(2):165-71. doi: 10.1111/j.2044-8341.1986.tb02681.x

76. Kwon SH, Tae YS. Nursing Home Placement: The Process of Decision Making and Adaptation among Adult Children Caregivers of Demented Parents in Korea. *Asian Nurs Res* 2012;6(4):143-51. doi: 10.1016/j.anr.2012.10.005 [published Online First: 2012/12/01]

77. Luppa M, Luck T, Brähler E, et al. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord* 2008;26(1):65-78. doi: 10.1159/000144027 [published Online First: 2008/07/12]

78. Runte R. Predictors of institutionalization in people with dementia: a survey linked with administrative data. *Aging Clin Exp Res* 2018;30(1):35-43. doi: 10.1007/s40520-017-0737-4 [published Online First: 2017/03/01]

79. Ebly EM, Hogan DB, Rockwood K. Living alone with dementia. *Dement Geriatr Cogn Disord* 1999;10(6):541-8. doi: 10.1159/000017202

80. Cepoiu-Martin M, Tam-Tham H, Patten S, et al. Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis. *Int J Geriatr Psychiatry* 2016;31(11):1151-71. doi: 10.1002/gps.4449 [published Online First: 2016/04/04]

81. Saks K, Tiit EM, Verbeek H, et al. Most appropriate placement for people with dementia: individual experts' vs. expert groups' decisions in eight European countries. *J Adv Nurs* 2015;71(6):1363-77 doi: 10.1111/jan.12544 [published Online First: 2014/10/10]

82. Ledgerd R, Hoe J, Hoare Z, et al. Identifying the causes, prevention and management of crises in dementia. An online survey of stakeholders. *Int J Geriatr Psychiatry* 2016;31(6):638-47. doi: 10.1002/gps.4371 [published Online First: 2015/10/23]

83. Redfern S, Norman I, Briggs K, et al. Care at home for people with dementia: routines, control and care goals. *QAOA* 2002;3(4):12-23. doi: 10.1108/14717794200200023

84. Hirschfeld M. Home care versus institutionalization: family caregiving and senile brain disease. *Int J Nurs Stud* 2003;40(5):463-9. doi: 10.1016/S0020-7489(03)00063-4

85. Spitznagel MB, Tremont G, Davis JD, et al. Psychosocial predictors of dementia caregiver desire to institutionalize: caregiver, care recipient, and family relationship factors. *J Geriatr Psychiatry Neurol* 2006;19(1):16-20. doi: 10.1177/0891988705284713

86. Kraijo H, de Leeuw R, Schrijvers G. How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scand J Caring Sci* 2015;29(1):101-9. doi: 10.1111/scs.12137 [published Online First: 2014/04/05]

87. Schacke C, Zank S. Zur familiaren Pflege demenzkranker Menschen: Die differentielle Bedeutung spezifischer Belastungsdimensionen fur das Wohlbefinden der Pflegenden und die Stabilitat der hauslichen Pflegesituation. *Z Gerontol Geriatr* 1998;31(5):355-61. [published Online First: 1998/12/16]

88. Gaugler JE, Kane RL, Newcomer R. Resilience and transitions from dementia caregiving. *J GERONTOL B-PSYCHOL* 2007;62(1):P38-44. doi: 10.1093/geronb/62.1.P38

89. Bakker C, de Vugt ME, van Vliet D, et al. Predictors of the time to institutionalization in young- versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *J AM MED DIR ASSOC* 2013;14(4):248-53. doi: 10.1016/j.jamda.2012.09.011 [published Online First: 2012/11/02]

90. Chang YP, Schneider JK. Decision-making process of nursing home placement among Chinese family caregivers. *PERSPECT PSYCHIATR C* 2010;46(2):108-18. doi: 10.1111/j.1744-6163.2010.00246.x [published Online First: 2010/05/25]

91. Lazarus RS, Folkman S. Stress, Appraisal, and Coping. New York: Springer Publishing Company 1984.

92. Cheng ST, Mak EP, Lau RW, et al. Voices of Alzheimer Caregivers on Positive Aspects of Caregiving. *Gerontologist* 2015 doi: 10.1093/geront/gnu118 [published Online First: 2015/01/24]

93. Verbeek H, Meyer G, Challis D, et al. Inter-country exploration of factors associated with admission to long-term institutional dementia care: Evidence from the RightTimePlaceCare study. *J Adv Nurs* 2015;71(6):1338-50. doi: 10.1111/jan.12663 [published Online First: 2015/04/14]

94. Mausbach BT, Coon DW, Depp C, et al. Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. *J AM GERIATR SOC* 2004;52(7):1077-84. doi: 10.1111/j.1532-5415.2004.52306.x [published Online First: 2004/06/24]

95. von Kutzleben M, Reuther S, Dortmann O, et al. Care arrangements for community-dwelling people with dementia in Germany as perceived by informal carers - a cross-sectional pilot survey in a provincial-rural setting. *Health Soc Care Community* 2015;24(3):283-96. doi: 10.1111/hsc.12202 [published Online First: 2015/03/03]

96. Sun F, Durkin DW, Hilgeman MM, et al. Predicting desire for institutional placement among racially diverse dementia family caregivers: the role of quality of care. *Gerontologist* 2013;53(3):418-29. doi: 10.1093/geront/gns110 [published Online First: 2012/09/11]

97. Dramé M, Lang PO, Jolly D, et al. Nursing home admission in elderly subjects with dementia: predictive factors and future challenges. *J AM MED DIR ASSOC* 2012;13(1):83.e17-20. doi: 10.1016/j.jamda.2011.03.002 [published Online First: 2011/04/13]

98. Badrakalimuthu V, Barclay S. Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age Ageing* 2014;43(1):13-9. doi: 10.1093/ageing/aft151 [published Online First: 2013/10/14]

99. Sansoni J, Anderson KH, Varona LM, et al. Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Ann Ig* 2013;25(3):235-46. doi: 10.7416/ai.2013.1926 [published Online First: 2013/04/20]

100. Mittelman MS, Ferris SH, Shulman E, et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA* 1996;276(21):1725-31. doi: 10.1001/jama.1996.03540210033030 [published Online First: 1996/12/04]

101. Ceci C, Symonds Brown H, Purkis ME. Seeing the collective: family arrangements for care at home for older people with dementia. *Ageing Soc* 2018;39(6):1200-18. doi: 10.1017/S0144686X17001477 [published Online First: 01/11]

102. Read ST, Toye C, Wynaden D. The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia (London)* 2018:1471301218784806. doi: 10.1177/1471301218784806

103. Eichler T, Hoffmann W, Hertel J, et al. Living Alone with Dementia: Prevalence, Correlates and the Utilization of Health and Nursing Care Services. *J Alzheimers Dis* 2016;52(2):619-29. doi: 10.3233/jad-151058 [published Online First: 2016/04/01]

104. Quinn C, Clare L, McGuinness T, et al. Negotiating the balance: the triadic relationship between spousal caregivers, people with dementia and Admiral Nurses. *Dementia (London)* 2013;12(5):588-605. doi: 10.1177/1471301212437780 [published Online First: 2013/12/18]

105. Kemp CL, Ball MM, Perkins MM. Convoys of care: theorizing intersections of formal and informal care. *J Aging Stud* 2013;27(1):15-29. doi: 10.1016/j.jaging.2012.10.002 [published Online First: 2013/01/01]

106. Gove D, Diaz-Ponce A, Georges J, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health* 2018;22(6):723-29. doi: 10.1080/13607863.2017.1317334

107. Bethell J, Commisso E, Rostad HM, et al. Patient engagement in research related to dementia: A scoping review. *Dementia (London)* 2018;17(8):944-75. doi: 10.1177/1471301218789292 [published Online First: 2018/10/31]

108. Purkis ME, Ceci C. Problematising care burden research. *Aging Soc* 2015;35(7):1410 - 28.

109. Ceci C, Symonds Brown H, Judge H. Rethinking the assumptions of intervention research concerned with care at home for people with dementia. *Dementia (London)* 2018 doi: 10.1177/1471301218790037

110. Bastawrous M. Caregiver burden - A critical discussion. *Int J Nurs Stud* 2013;50(3):431-41. doi: 10.1016/j.ijnurstu.2012.10.005 [published Online First: 2012/11/08]

111. Esandi N, Nolan M, Alfaro C, et al. Keeping Things in Balance: Family Experiences of Living With Alzheimer's Disease. *Gerontologist* 2018;58(2):e56-e67. doi: 10.1093/geront/gnx084 [published Online First: 2017/06/22]

112. Clemmensen TH, Busted LM, Soborg J, et al. The family's experience and perception of phases and roles in the progression of dementia: An explorative, interview-based study. *Dementia (London)* 2019;18(2):490-513. doi: 10.1177/1471301216682602 [published Online First: 2016/12/09]

113. Meleis AI, Sawyer LM, Im EO, et al. Experiencing transitions: an emerging middle-range theory. *Ans Adv Nurs Sci* 2000;23(1):12-28. [published Online First: 2000/09/02]

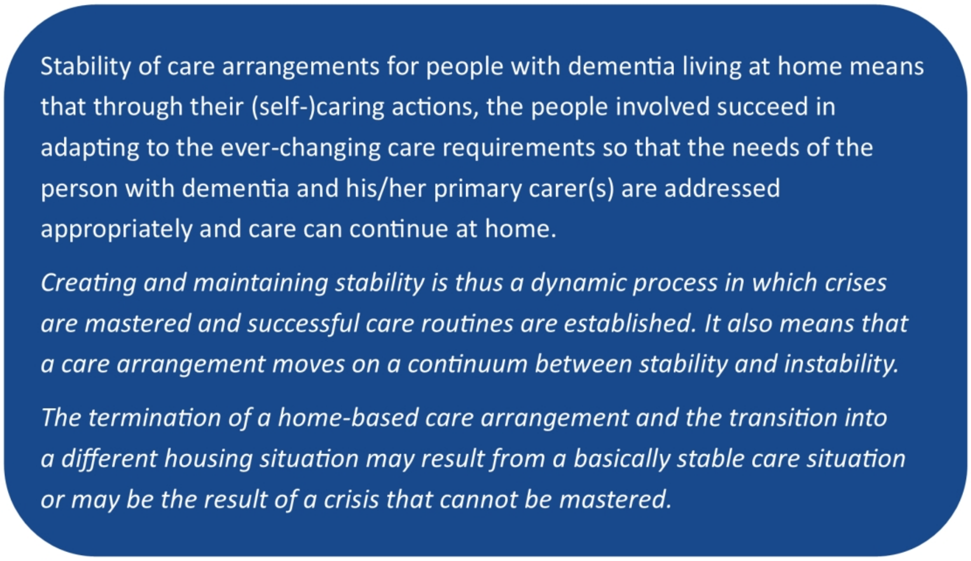
114. Kralik D, Visentin K, Van Loon A. Transition: a literature review. *J Adv Nurs* 2006;55 doi: 10.1111/j.1365-2648.2006.03899.x

Figure legends

Figure 1: Definition of stability of home-based care arrangements for people living with dementia

Figure 2: Flow diagram

Figure 3: Conceptual model of stability of home-based care arrangements for people living with dementia (SoCA-Dem)



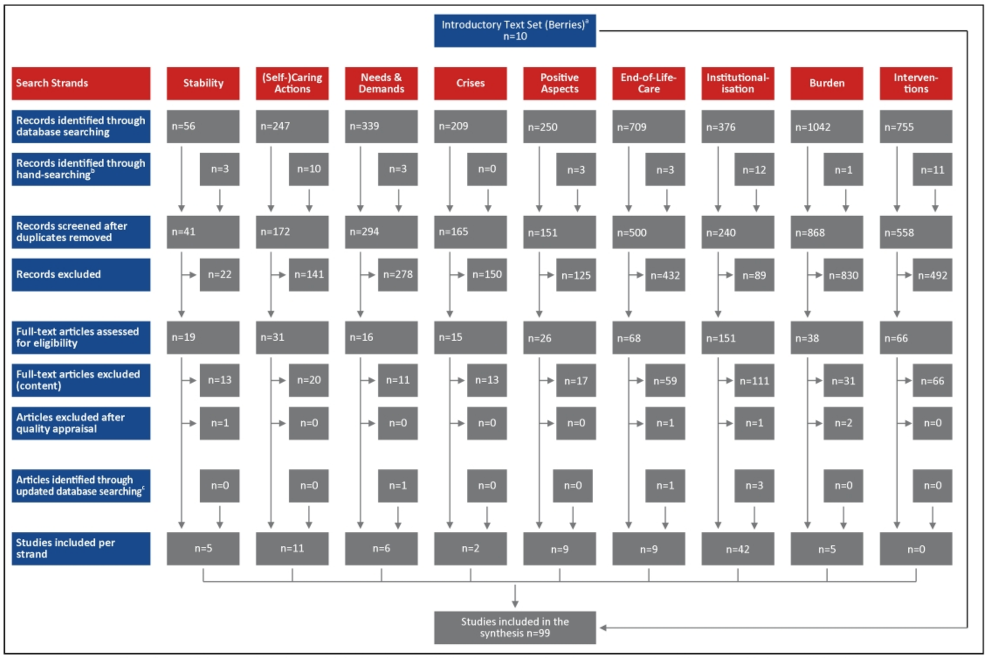
Stability of care arrangements for people with dementia living at home means that through their (self-)caring actions, the people involved succeed in adapting to the ever-changing care requirements so that the needs of the person with dementia and his/her primary carer(s) are addressed appropriately and care can continue at home.

Creating and maintaining stability is thus a dynamic process in which crises are mastered and successful care routines are established. It also means that a care arrangement moves on a continuum between stability and instability.

The termination of a home-based care arrangement and the transition into a different housing situation may result from a basically stable care situation or may be the result of a crisis that cannot be mastered.

Figure 1: Definition of 'stability of home-based care arrangements for people living with dementia'

163x96mm (300 x 300 DPI)



a: the introductory text set ("berries") was established prior to the database search; **b**: hand-searching included backward citation tracking, forward citation tracking, and snowballing; c: updated database search followed the same process as the initial search, with the removal of duplicates, screening and assessment for eligibility

Figure 2: Flow diagram

303x209mm (300 x 300 DPI)

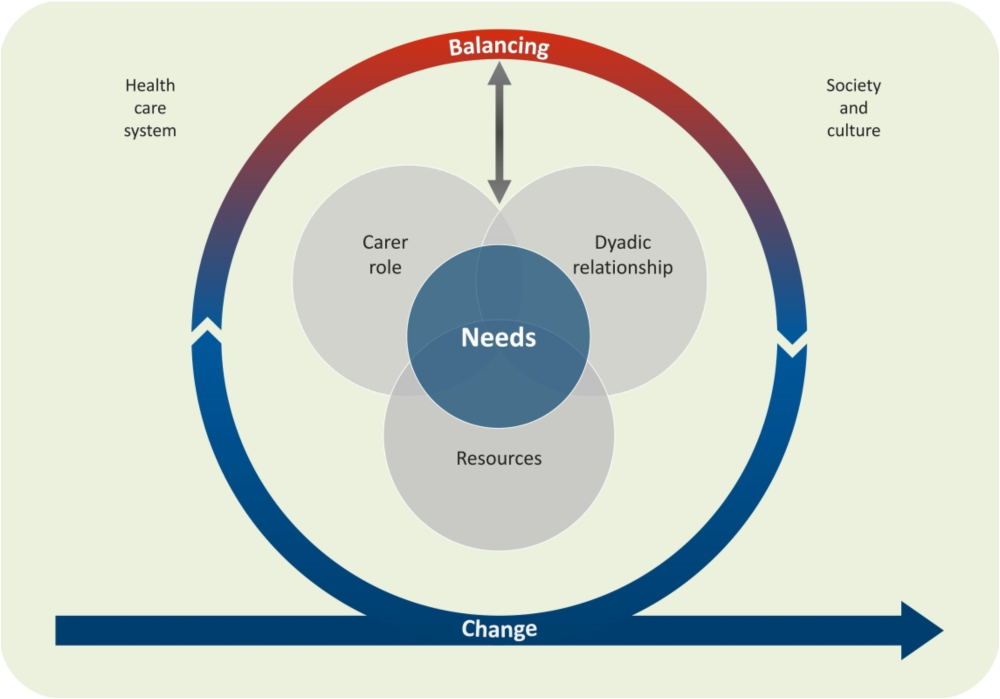


Figure 3: Conceptual model of the stability of home-based care arrangements for people with dementia (SoCA-Dem)

337x235mm (300 x 300 DPI)

Appendix 'Towards a middle-range theory of 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem): Findings from a meta-study on mixed research'

Kerstin Köhler[1,2], Jan Dreyer[1,2], Iris Hochgraeber[1,2], Milena von Kutzleben[3,1], Christiane Pinkert[1], Martina Roes[1,2], Bernhard Holle[1,2]

[1] German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
[2] Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany
[3] Carl von Ossietzky Universität Oldenburg, Faculty of Medicine and Health Sciences, Department of Health Services Research, Oldenburg, Germany

Content

Appendix A: Overview of the meta-study sample

The following table gives an overview of the n=99 publications that we included in this meta-study. For each included publication we list the author(s), year of publication, country, search strand, aim, study design, sample/setting, main findings, and contribution to theory concepts. In in addition to the study design, we indicate for quantitative studies if they have a longitudinal or a cross-sectional approach. For all other studies we only indicate if they have a longitudinal approach. In the column 'contribution to theory concept(s)' we indicate to which concept(s) of our middle-range theory the respective publication contributed. The concepts of the theory are: change, balancing, needs, carer role, dyadic relationship, resources, society and culture, health care system. Thereby, concepts that are addressed very prominent in a publication are displayed in bold type; further addressed concepts are displayed in regular type. Following the principles of conceptual saturation within the coding process, we did not code all information on each concept in each publication. For this reason it is probable, that a publication includes information with regard to a theory concept, but the concept is not listed in the respective column.

Abbreviations

AChEI	Acetylcholinesterase inhibitor	GP	General Practitioner	NPI	Neuropsychiatric Inventory
AD	Alzheimer's disease	HRQoL	Health Related Quality of Life	PwD	Person with dementia
ADL	Activity of daily living	LOD	Late onset dementia	PwAD	Person with Alzheimer's disease
DLB	Dementia with Lewy bodies	MMSE	Mini Mental State Examination	YOD	Young onset dementia
FC	Formal carer	NH	Nursing home		
IC	Informal carer	NHP	Nursing home placement		

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to theory concept(s)
Afram et al. (2014) (International Consortium: Estonia, Germany, Finland, France, Netherlands, UK, Spain, Sweden)	Berries	to explore reasons for institutionalisation of PwDs according to ICs as well as variation in reasons between countries	mixed methods	786 ICs (PwD institutionalised)	Mainly PwD-related reasons were stated (neuropsychiatric symptoms, care dependency, cognition). Neuropsychiatric symptoms were among the most often mentioned reasons in most countries. Besides PwD-related reasons, IC burden and the inability to care were stated. Countries differ significantly in reasons according to ICs. Spouses more often stated reasons related to themselves compared with child ICs.	**change**, carer role, resources, society and culture, health care system
Afram et al. (2015) (Netherlands)	Needs & Demands	to provide insights into problems and needs of ICs of PwDs during care transition from home-based care to institutional long-term-care	systematic review: qualitative synthesis	13 publications	Regarding the needs and problems of ICs during the care-transition period, the most stated topics were emotional concerns, knowledge/information, and support. The care-transition period should be considered as a continuum, as similar needs and problems were identified prior and after admission to long-term-care.	**needs**, carer role, resources, health care system
Andrén and Elmståhl (2008) (Sweden)	Institutionalisation	to determine the effectiveness of a psychosocial intervention for ICs in delaying institutionalisation of PwDs	quantitative: experimental (longitudinal)	intervention group: 153 ICs, control group: 155 ICs	There were significant delays (6 months) in institutionalisation for PwDs with adult children as ICs. Factors associated with institutionalisation are the ICs' influence on intervention, IC gender and the PwD severity of dementia.	**change,** dyadic relationship
Badrakalimuthu et al. (2014) (UK)	End-of-life-care	to undertake a systematic review and narrative synthesis of the literature concerning place of death of PwDs, and the PwDs, ICs and health-care-providers preferences for place of death of PwDs	systematic review: narrative review	6 publications	Studies of death certificate data show that PwDs die more commonly in NHs than in other locations. In contrast, prospective studies show that death is more common in own residence or hospital. Older age, male gender, availability of hospital were associated with hospital death, availability of NH beds was associated with death in NH and enrolment in hospice was associated with death in own residence. Little is known about patient, IC and health professional preferences or the extent to which PwDs discuss their preferences with their families and healthcare providers. Preferences of proxy decision-makers are met more often than those of the PwDs.	needs, resources, health care system
Bakker et al. (2013) (Netherlands)	Institutionalisation	to investigate time from symptom onset to institutionalisation and predicting factors for PwDs with YOD compared to PwDs with LOD	quantitative: observational (longitudinal)	308 dyads, 226 dyads YOD, 102 dyads LOD (PwD living at home at baseline)	Time from symptom onset to institutionalisation was nearly 9 years for PwDs with YOD and 4 years for PwDs with LOD. Time to institutionalisation was significantly predicted by apathy in the YOD group and by IC's competence in caring for the PwDs in both groups.	**change,** carer role, dyadic relationship, resources

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Caldwell et al. (2014) (Australia)	Institutionalisation	to investigate the decision-making process for placing a PwD on a waiting list for a NH; why offers of a place in a NH are accepted or declined; the influence of cultural factors in people living in Australia from a Chinese background compared with those from an English-speaking background	qualitative: unspecific design	27 ICs (PwD institutionalised or on a NH waiting list)	ICs were at different stages of decision-making when they applied for a waiting list (ready for placement, just in case, urgent need for placement). IC's decisions were influenced by their emotions and expectations of NHs. The decision-making process was similar for both cultural groups, but Chinese ICs spoke more about their sense of duty, the need for a Chinese specific facility, and declining a place because of family disagreement.	change, balancing, carer role, dyadic relationship, **society and culture**, health care system
Caron et al. (2006) (Canada)	Institutionalisation	to explore the decision-making process with regards to institutionalisation of a PwD, from the perspective of the IC; to develop a theoretical model	qualitative: Grounded Theory	14 ICs for 8 PwDs (PwD institutionalised)	A theoretical model of the decision-making process was developed and three factors that were central to the process were identified: IC's perceptions of their ability to provide care, IC's evaluations of the PwD to make care decisions, and the evolving influence of contextual factors and interactions with healthcare professionals.	change, **balancing**, needs, carer role, resources
Cepoiu-Martin et al. (2016) (Canada)	Institutionalisation	to summarise the effects of various individual, IC and system-related factors on the risk of institutionalisation of PwDs residing in the community	systematic review: narrative review and meta-analysis	review part: 59 publications, meta-analysis: 37 publications	White race, dementia severity and older age increased the risk of institutionalisation. Married PwDs living with their carer had a lower risk. Behavioural and psychological symptoms of dementia, the degree of functional impairment, and carer burden had a consistent effect on the risk of institutionalisation.	change, dyadic relationship, resources, society and culture, health care system
Chang et al. (2010) (USA, data collection in Taiwan)	Institutionalisation	to understand the process and difficulties that Chinese ICs experience when making a NH placement decision for a PwD	qualitative: Grounded Theory	30 Chinese ICs in Taiwan (PwD institutionalised)	A stage-based model describes how ICs go through the decision-making process (initiating the placement decision, assessing and weighing the decision, finalising the decision, evaluating the decision), how they overcome difficulties to reach decisions, and how the decision-making process is related to the concept of Chinese filial piety, which is changing in modern Taiwanese society.	change, **balancing**, carer role, resources, **society and culture**, health care system

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Chang et al. (2011) (USA, data collection in Taiwan)	Institutionalisation	to describe factors influencing decisional conflict among Chinese ICs regarding NH placement of PwDs	qualitative: unspecific design	30 Chinese ICs in Taiwan (PwD institutionalised)	Factors influencing IC's decisional conflict included the Chinese value of filial piety, limited financial resources and information, placement willingness of the PwD, family disagreement, distrust of NH care quality, and limited NH availability. Factors influencing IC's·decisional conflict post placement included disappointment with NH care quality and self-blame for the placement decision.	change, **balancing**, carer role, resources, **society and culture**, health care system
Coe et al. (1999) (Canada)	Needs & Demands	to explore male ICs perceptions of formal support	qualitative: Grounded Theory (longitudinal)	24 male ICs (PwD living at home or institutionalised)	The male ICs experienced a process of making concessions for care in four stages: resisting, giving in, opening the door, making the match. Personal barriers deterred the ICs from seeking help, and once the ICs engaged formal help, the influence of characteristics of the health care system and FCs had both enabling and disabling effects. For ICs who institutionalised, the phase of making the match was followed by redesigning their IC role.	**balancing**, needs, carer role
Cohen et al. (1994) (Canada)	Positive aspects	to review different concepts and measures of positive aspects of caring, and to describes the use of a simple measure of 'enjoyable aspects of caregiving'	quantitative: observational (longitudinal)	196 dyads (PwD living at home at baseline)	The measure of 'enjoyable aspects of caregiving' attained significant test-retest reliability and significantly correlated with IC burden and health. It also predicted IC desire to institutionalise but not actual institutionalisation. The paper calls for greater use of measures related to positive aspects and a better understanding of how these measures relate to one another and to outcomes.	**carer role**, dyadic relationship, resources
Cox (1996) (USA)	Institutionalisation	to identify what factors influence the IC hospital discharge decision and the IC satisfaction with the discharge plan, and to analyse if influences/ satisfaction differ between discharges to home or to NH	quantitative: observational (cross-sectional)	172 ICs (PwD in hospital)	Social workers are important influencers in the decision to discharge from hospital to home or to NH. IC satisfaction depends on the amount of involvement in the discharge process.	change, balancing, needs, **resources**, health care system
Daly et al. (2012) (Ireland)	Berries	to develop a theory to explain the social processes employed by ICs to manage alterations to interactions within their social worlds	qualitative: Grounded Theory	20 ICs, 1 PwD (PwD living at home), 10 FCs from the health, social care and disability sectors	IC's main concern was identified as 'Living on the fringes', which was stimulated by dementia-related stigma and living a different life. The theory of 'Sustaining Place' explains the social pattern of actions employed by ICs to manage this problem on behalf of themselves and the PwD.	change, **balancing**, **needs**, society and culture

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Davis et al. (2014) (USA)	(Self-)caring actions	to examine the conceptualisation of care problems by AD and by Parkinson's disease spouse ICs and the efficacy of their problem management strategies, to propose a typology of IC management styles that can provide a contextual frame for understanding their experiences of burden	qualitative: unspecific design	12 ICs of a partner with: 6 AD and 6 Parkinson's disease (living at home)	Three types of IC spouses are identified: adapters, strugglers, and case managers. The findings suggest that IC burden might be influenced more by the IC management style than by the demands of the care situation.	**balancing**, carer role, **resources**
De Vugt et al. (2005) (Netherlands)	Burden	to examine the impact of specific behavioural disorders and IC's emotional reaction on institutionalisation	quantitative: observational (longitudinal)	119 dyads (PwD living at home)	IC distress related to PwD behaviour was a significant predictor of institutionalisation, while behaviour did not predict NHP. The study did not find a differential impact of specific aspects of PwD behaviour. Child ICs, especially daughters, were associated with shorter time to institutionalisation compared to spouse ICs.	**change**, dyadic relationship
Donovan (2006) (USA)	Positive aspects	to identify and understand the positive aspects of the lived experiences of ICs	qualitative: phenomeno-logical approach	15 spousal ICs (PwD living at home)	The study revealed more positive than negative aspects of caring. ICs indicated positive aspects of caring through their behaviour and communication. A mélange of different actions facilitated the ICs to gain a feeling of competence and satisfaction in their carer role.	balancing, **carer role**, dyadic relationship, resources
Donovan et al. (2010) (USA)	Positive aspects	to give an in-depth description of how uplifted ICs think about care and conduct care	qualitative: phenomeno-logical approach	15 spousal ICs (PwD living at home)	The study identified two primary themes of IC thinking and acting: (1) engaging in positive behaviours and (2) making adjustments in attitudes.	balancing, **carer role**, dyadic relationship, resources
Dramé et al. (2012) (France)	Institutionalisation	to identify factors predictive of institutionalisation over a period of 1 year among PwDs	quantitative: observational (longitudinal)	425 PwDs (PwD living at home at baseline)	There were 4 factors increasing the risk of institutionalisation: age 85 or older, inability to use the toilet, balance disorders and living alone. 3 factors decreased the risk: inability to transfer, increased number of children and increased initial MMSE score.	change, society and culture, health care system
Ducharme et al. (2012) (Canada)	Institutionalisation	to develop an explanatory model of the IC decision-making process regarding NHP of a PwD	qualitative: Grounded Theory (longitudinal)	18 ICs (7 PwD living at home, 11 PwD living in a retirement residence)	A theoretical model illustrates that the institutionalisation decision-making process is activated when the IC or a health care professional introduces the possibility of institutionalisation. The IC's assessment of the pros and cons of institutionalisation is modulated primarily by interactions with the formal and informal social network.	change, **balancing**, resources, health care system

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Ebly et al. (1999) (Canada)	Institutionalisation	to describe differences in short-term institutionalisation rates for PwDs who live alone as compared to PwDs residing with an IC	quantitative: observational (longitudinal)	317 dyads (PwD living at home at baseline)	One third of PwDs lived alone. Thinking about institutionalisation (intent) was predictive for actual short-term (2-year) institutionalisation and appeared to be influenced by living arrangements. ICs of PwDs living alone provided less hands-on assistance, experienced less burden, and were less likely to be depressed than those living with the PwD, but were more likely to have considered institutionalisation, driven by concerns about safety and support.	change, carer role, **dyadic relationship**
Feldman et al. (2009) (International Consortium: Belgium, Canada, Finland, France, Germany, UK)	Institutionalisation	to evaluate patient and treatment (galantamine and other AChEIs) factors associated with the time until institutionalisation	quantitative: experimental (longitudinal)	548 PwDs (PwD living at home at baseline)	Long-term treatment with galantamine or other AChEIs appears to be associated with a significant delay in the time to institutionalisation in PwDs. For each year of treatment the risk within a given period was reduced by 31% (galantamine) and 29% (other AChEI).	**change**, resources, health care system
Forbes et al. (2012) (Canada)	Needs & Demands	to enable FCs, ICs, and PwDs (living in rural areas) to use dementia care information more effectively by examining their information needs, how these change over time, and how they access, assess, and apply the knowledge	qualitative: unspecific design (longitudinal)	5 PwDs (living at home), 14 ICs, 14 FCs	6 stages of the dementia care journey were described. ICs identified the need for different types of knowledge during each stage. Barriers to knowledge exchange included: lack of rural community-based services; ICs reluctant to seek help and had limited energy; and lack of integration of dementia-related services and supports. Facilitators included: ICs with healthcare experience who were actively seeking information; development of trusting relationships between FCs, ICs, and PwDs; and formal mechanisms for exchanging information within and across rural community-based organisations.	balancing, **needs**
Frewer-Graumann (2014) (Germany)	(Self-)caring actions	to explore the construction of informal home-based care arrangements from the perspective of ICs	qualitative: Grounded Theory	14 dyads (PwD living at home)	Home-based care arrangements for PwDs are constructed by ICs in very different ways. Care arrangements are influenced by the progression of dementia, family dynamics, coping strategies, inner familiar relationships, professional occupation of ICs and secondary and tertiary social networks.	change, **balancing**, **carer role**, dyadic relationship, resources
Gallagher et al. (2011) (Ireland)	Institutionalisation	to determine whether modifiable IC attributes are significantly associated with desire to institutionalise; and whether these variables may be independent predictors in the context of other established PwD and IC-related variables	quantitative: observational (cross-sectional)	102 dyads (PwD living at home)	IC desire to institutionalise was significantly associated with a number of modifiable variables including IC coping style, self-efficacy, depression, burden, and the presence of an unmet service need. In a multivariate analysis, IC burden, IC depression, and non-spousal status were the only significant independent predictors for desire to institutionalise.	needs, dyadic relationship, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Gaugler et al. (2005a) (USA)	Institutionalisation	to determine how behaviour problems that occur early in the caring influence time to NHP and change into burden and depression over time	quantitative: observational (longitudinal)	4761 dyads (PwD living at home at baseline)	ICs who have to manage frequent behaviour problems early, were more likely to institutionalise. ICs who were faced with severe, early behaviour problems reported greater increases in burden and depression over the 3 years study.	**change**, carer role
Gaugler et al. (2005b) (USA)	Needs & Demands	to determine how unmet needs for activity of daily living tasks influenced NHP, death, or loss to follow-up in dementia	quantitative: observational (longitudinal)	5831 dyads (PwD living at home)	Greater unmet needs were predictive for institutionalisation, death, and loss to follow-up. Unmet needs may be useful in identifying PwDs at risk of institutionalisation and death.	**needs**
Gaugler et al. (2007) (USA)	Positive aspects	to examine the concept of resilience in dementia caring, and determine how resilience is potentially predictive of key exit transitions from at-home dementia care	quantitative: observational (longitudinal)	1979 ICs (PwD living at home at baseline)	The present study utilized data from ICs to ascertain whether resilience influences transitions from PwD caring, such as institutionalisation, care recipient death, or loss to follow-up. It was revealed that high baseline resilience (low burden, high care demands) was associated with less frequent institutionalisation and loss to follow-up as well as more frequent care recipient mortality.	**resources**
Gaugler et al. (2001) (USA)	Institutionalisation	to determine factors that predict the problems and help ICs perceive while institutionalising the PwD	quantitative: observational (longitudinal)	185 ICs (PwD living at home at baseline)	The personal and social resources of ICs prior to NHP (e.g., mastery, family conflict, socioemotional support, duration of care, education, and physical health) were predictors of difficulties during searching for a NH, perceived family help, and perceived professional help.	**resources**
Gaugler et al. (2011) (USA)	Burden	to determine whether IC burden is a mediator between the effects of behavioural disturbance and institutionalisation	quantitative: experimental (longitudinal)	5831 ICs (PwD living at home at baseline)	IC burden fully mediated the relationship between four behavioural disturbances and institutionalisation.	**change**
Gaugler et al. (2009) (USA)	Institutionalisation	to identify factors that predict NHP of PwDs	systematic review: meta-analysis	80 publications	Identification of numerous factors (with regard to PwDs and their ICs) that predict institutionalisation. PwD and IC factors should be considered when assessing the risk of institutionalisation.	**change**, carer role, dyadic relationship, resources
Gilhooly (1986) (UK)	Institutionalisation	to shed light on features of caring which are associated with IC's preference for institutional care	quantitative: observational (cross-sectional)	48 ICs (PwD living at home), 2 groups: co-resident and non-resident	The dyadic relationship is an important determinant of motivation to continue care at home. In addition, variables associated with institutionalisation included age of ICs, IC's contacts with friends, satisfaction with help from relatives, another dependent relative, and the employment of ICs. Help from services and IC's well-being were not correlated with preference for institutionalisation.	carer role, **dyadic relationship**, resources

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Glass (2016) (USA)	End-of-life-care	to document and examine the experiences of end-of-life care of PwDs and ICs and the role that environment and hospice play in these experiences	qualitative: phenomeno-logical approach	4 ICs (PwD living at home or institutionalised)	The cases reveal a range of end-of-life experiences, suggesting that there is not just one 'good' path. The extent of care needed, the responsiveness of the individual, the health of the ICs, and the residence and support situations can all intersect in a variety of ways that make no single scenario the answer for all.	balancing, needs, resources
Gort et al. (2007) (UK)	Burden	to analyse the Zarit Burden Scale's ability to identify signs of IC collapse	quantitative: observational (cross-sectional)	66 ICs (PwD living at home)	The Zarit Burden Scale was useful to identify IC burden and to predict collapse of IC.	change
Groen-van de Ven et al. (2017) (Netherlands)	(Self-)caring actions	to examine the decisions made and the related key events in the trajectories of care networks including PwDs, their FCs and ICs	qualitative: unspecific design (longitudinal)	113 respondents altogether (23 PwDs, 44 ICs, and 46 FCs) (PwD living at home or institutionalised)	Four decision themes were constructed: managing daily life, arranging support, community living, and preparing for the future; eight key events delineate decision trajectories of PwD; decisions and key events differ between PwD living alone and living with IC.	**balancing**
Hagen (2001) (Canada)	Institutionalisation	to explore factors influencing ICs decision-making process related to placing a PwD in a NH	qualitative: unspecific design (longitudinal)	5 ICs (PwD living at home)	The study develops a theoretical model of factors influencing institutionalisation-related decision-making, including independence, perceived presence of others, fear of loneliness, negative NH attitudes, sense of existential self, and guilt.	**carer role**, dyadic relationship, resources
Hill et al. (2017) (UK)	End-of-life-care	to identify and describe the aspects of end-of-life care for PwDs that are most important to them and their carers	mixed methods	14 PwDs, 21 ICs (PwD living at home), 22 bereaved ICs	Different views on what is important about end-of-life care were identified and grouped into four viewpoints: family involvement, managing the present, pragmatic expectations and autonomy and independence.	balancing, needs, dyadic relationship
Hirschfeld (2003) (Israel, data collection in the USA)	Positive aspects	to present the concept of mutuality, which emerged as the crucial factor in continuing home care vs. institutionalisation	mixed methods	30 dyads (PwD living at home)	Mutuality emerged as the major parameter for families managing life with senile brain disease and influenced the decision to institutionalise an impaired family member.	balancing, **dyadic relationship**
Janssen et al. (2017) (International Consortium: Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, UK)	Stability	to identify different profiles of ICs and to investigate differences between the identified carer profiles in quality of life, in depression and in perseverance time	quantitative: observational (cross-sectional)	453 dyads (PwD living at home)	Five profiles of ICs were identified. These profiles differ statistically significant with regard to quality of life, depressive symptoms and perseverance time.	balancing, carer role, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Kajiwara et al. (2015) (Japan)	Positive aspects	to identify factors that influence the continuation of in home care of PwDs	quantitative: observational (cross-sectional)	354 ICs, 343 PwDs (PwD living at home)	IC's current feelings about caring and the continuation of caring of PwDs with worsening symptoms were affected by a positive appraisal of caring and by the burden experienced by the ICs. The continuation of caring was indirectly affected by the PwDs cognitive impairment and by the behavioural and psychological symptoms of dementia score.	change, **carer role**
Kellett (1999) (Australia)	Institutionalisation	to explore the experience of family breakdown and NHP	qualitative: phenomeno-logical approach	14 ICs (PwD institutionalised)	The analysed IC stories of institutionalisation uncovered 5 shared meanings: experiencing a loss of control; being disempowered; feeling guilt, sadness and relief simultaneously; possessing a sense of failure; and having to make a forced and negative choice.	**balancing**, carer role
Kraijo et al. (2014) (Netherlands)	Stability	to introduce the concept 'perseverance time' and to validate it in a sample of ICs	quantitative: observational (cross-sectional)	223 ICs (PwD living at home)	The concept of 'perseverance time' (Pt) is a valid measure for the IC ability and willingness to continue home care. Health of PwD, IC living apart from the patient, and male gender of IC were positively associated with Pt; need for supervision, intensity of informal care provision, and reductions in working hours and hobbies in order to be able to provide care were negatively associated.	**change**
Kraijo et al. (2015) (Netherlands)	Institutionalisation	to focus the final decision by ICs to have their PwDs placed in a NH and to question whether the admission took place at the right time in the IC's point of view	mixed methods	14 spousal ICs (PwD institutionalised)	The placement decision had to be made in phases over time: placement of the PwD on a waiting list, and actual placement in a NH (stage-based model). The second and final decision often had to be taken under time pressure. The following classification emerged: Placement was at the right time, too early, too late or out of control.	**balancing**, dyadic relationship, resources
Kwon et al. (2012) (South Korea)	Institutionalisation	to explore and describe the process of NHP decision-making and adaptation among adult child carers of PwDs in Korea	qualitative: Grounded Theory	16 ICs (adult children, PwD institutionalised)	The core category in the process of decision making and adaptation to institutionalisation among ICs was accepting the inevitable and reorienting to changes. The developed stage-based model consisted of four phases: realizing a dead end, seeking a way out, accepting the inevitable decision, and reorienting to changes. Though ICs were confronted with various challenges, they managed to accept the decision and learned to reorient themselves to the changed care situation.	**balancing**, carer role, society and culture

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Ledgerd et al. (2016) (UK)	Crises	to identify the main causes of crisis and interventions to treat or prevent crisis in PwDs based on different stakeholder perspectives	quantitative: observational (cross-sectional)	719 participants: 20 academics, 562 health care sector staff, 54 ICs, 23 social care sector staff, 16 emergency service staff, 12 voluntary sector staff, 4 PwDs, 28 others	Wandering, falls and infection were highly rated as risk factors for crises across all stakeholder groups. Consumers rated aggression as less important, but severity of memory impairment as much more important than the other groups did. Education and support for ICs, and home care staff were highly valued for preventing crises. Well-trained home care staff, communication equipment, emergency contacts and access to respite were highly valued for managing crises.	**change**, **resources,** health care system
Lethin et al. (2016) (Sweden)	(Self-)caring actions	to investigate IC's experiences of formal care when caring for a PwD through the stages of the dementia	qualitative: unspecific design	23 ICs (PwD living at home or PwD institutionalised)	ICs require collaboration with FCs to get support adjusted to individual's needs, specific to stages of dementia. Three main turning points are experienced: the dementia diagnosis; when ICs realise increased need for FCs to continue caring at home; when PwD is institutionalised, ICs experience FCs reactive to needs, proactive reaction is required.	balancing, needs, **carer role**, health care system
Lewis (2015) (USA)	End-of-life-care	to discover a substantive theory that identifies the main problems that ICs of PwDs face at the end of life and the basic social processes by which they resolve that problem	qualitative: Grounded Theory	83 ICs (PwD passed away or living at home or institutionalised)	Carers attempt to resolve the challenge of caring at the end of life through a 5-stage basic social psychological process of rediscovering including missing the past, sacrificing self, yearning for escape, reclaiming identity, and finding joy. Health care professionals can support ICs through this journey by validating, preparing them for future stages, and encouraging natural coping strategies identified in this process.	balancing, **carer role,** dyadic relationship
Liken (2001a) (USA)	Crises	to examine crises experienced by ICs	qualitative: unspecific design	20 ICs (PwD institutionalised within the past 6 months)	All elements of a crisis were evident among ICs in the process of institutionalisation of the PwD. Dangerous behaviours resulting from cognitive decline led to IC fear and anxiety, which served as crisis precipitants. Perceived lack of family support in conjunction with physical and psychological exhaustion were crisis mediators. These factors, along with the IC's failed attempts to keep the PwD at home, caused the crisis process moving toward the outcome of institutionalisation.	**change**, balancing

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Liken (2001b) (USA)	Institutionalisation	to examine underlying values that precipitated the NHP	qualitative: unspecific design	23 ICs (PwD institutionalised)	Three major themes describe values underpinning the critical incident surrounding the move of the PwD to an assisted living facility. Critical incidents centred on two major factors: the PwDs safety and the ICs emotional well-being. Conflicting values underpinning the critical incident were the PwDs autonomy versus the IC's responsibility, obligation to PwD versus obligation to self, and logic versus emotion.	**change**, balancing, needs, carer role
Lindgren (1993) (USA)	(Self-)caring actions	to conceptualise the experiences of ICs over time and to portray IC careers in the context of dementia	qualitative: unspecific design	10 ICs (PwD living at home)	In the IC career a process of learning, adaptation to role demands and restructuring of the IC's life evolves, and unique stages of the IC career are formed. The Encounter Stage is characterized by the need for rapid adjustment to major changes, for information about illness characteristics, and instruction in providing quality care. The Enduring Phase is the long-term, heavy-duty caring phase where supportive interventions are needed. During the Exit Stage, institutionalisation is best done when time can be taken to choose a place. Finding the right home and financial issues are two problems that need to be solved.	change, balancing, **carer role**, dyadic relationship, resources, health care system
Lloyd et al. (2016) (UK)	Positive aspects	to critically evaluate the empirical findings of qualitative studies that have explored positive aspects of caring in dementia	systematic review: qualitative synthesis	14 publications	Multiple positive dimensions of caring and several factors that were important in supporting their positive caring experience are identified. Conceptualisations of positive aspects of caring (PAC): role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, sense of duty and reciprocity. IC's perceptions of the process of PAC: acceptance, choosing positive caregiving attitude, commitment to relationship, creating opportunities, drawing strength from faith/past challenges/others.	change, balancing, needs, carer role, dyadic relationship
Lord et al. (2016) (UK)	Institutionalisation	to understand the NHP decision-making process, the needs and difficulties that PwDs and ICs encounter and how these may be overcome	qualitative: unspecific design	7 PwDs, 13 ICs (PwD living at home, 1 PwD institutionalised)	Decision-makers balanced the competing priorities of remaining somewhere familiar, family's wish they remain at home, reduction of risk and effects on ICs and PwDs physical health. The PwDs frequently presented their lack of autonomy as decisions about institutionalisation were made. Family consultation usually helped ICs but sometimes exacerbated tensions. Direct professional support was appreciated where it was available.	**balancing**, needs
Luppa et al. (2008) (Germany)	Berries	to review publications that analyse predictors of institutionalisation of PwDs	systematic review: narrative review	42 publications	Predictors of institutionalisation were classified according to a provided conceptual framework in the categories sociodemographic and relationship characteristics of PwDs and caregivers, primary stressors, secondary stressors and resources.	**change**, needs, dyadic relationship, resources, health care system

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Luppa et al. (2012) (Germany)	Berries	to investigate risk factors for institutionalisation for PwDs, considering characteristics at the time of the diagnosis.	quantitative: observational (longitudinal)	254 PwDs (living at home at baseline)	30% of PwDs were institutionalised over the study course (6 years). Mean time until NHP was 4.1 years. Significant characteristics of NHP were marital status (being single or widowed), higher severity of cognitive impairment and mobility impairment.	change, dyadic relationship
MacNeil Vroomen et al. (2013) (Netherlands)	Berries	to review definitions of crises, and to create a standardised definition that can be utilised for research, policy and clinical practice	systematic review: qualitative synthesis	27 publications	Crisis in dementia is defined as a process where a stressor causes an imbalance requiring an immediate decision to be made which leads to a desired outcome and therefore a resolution of the crisis. If the crisis is not resolved, the cycle continues.	**change, balancing,** resources, health care system
Markiewicz et al. (1997) (Canada)	(Self-)caring actions	to examine the influence of IC's attachment styles and personality traits on their experiences of caring for a PwD	quantitative: observational (longitudinal)	113 dyads (PwD living at home)	The attachment style can contribute to explain aspects of ICs' experiences. Those who chose to institutionalise the PwD were higher on the avoidance factor than those choosing to maintain the PwD in the community.	**carer role**, dyadic relationship
Mausbach et al. (2004) (USA)	Institutionalisation	to compare institutionalisation rates of PwDs cared for by Latina and Caucasian female ICs, and to explore IC and PwD related predictors	quantitative: observational (longitudinal)	264 female ICs (154 female Caucasians, 110 female Latinas) (PwD living at home at baseline)	Hispanic Americans delayed institutionalisation longer than their Caucasian counterparts. PwD characteristics or IC demographics did not explain these results, although Hispanic Americans who identified greater benefits or more-positive aspects in caring at baseline were less likely to institutionalise the PwD than those who reported fewer benefits.	carer role, **society and culture**
McLennon et al. (2010) (USA)	Institutionalisation	to identify common themes from the statements of ICs who decided to institutionalise their relative with AD or Parkinson's disease	qualitative: unspecific design (longitudinal)	9 ICs of PwD, 2 ICs of persons with Parkinson's disease (PwD living at home at baseline)	2 categories identified from the ICs stories were 'anticipating the inevitable' and 'reaching the limit' (stage-based model). 3 to 4 months before institutionalisation, ICs discussed knowing that they would not be able to continue caring at home. The most frequent reasons for institutionalisation were serious health events. There were more institutionalisations in the AD participant group than in the Parkinson's disease group.	**change**, needs
Mitchell et al. (2004) (USA)	End-of-life-care	to examine and contrast the end-of-life experience of PwDs who died within one year of admission to either a NH or a community-based home care service	quantitative: observational (cross-sectional)	2730 PwDs institutionalised, 290 PwDs living at home	NH residents dying with advanced dementia were older, had greater functional impairment, and more behaviour problems compared to home care clients. Few subjects in the NH and home care cohorts were perceived to have less than 6 months to live. Only few individuals were referred to hospice. Hospitalizations were frequent. Pain and shortness of breath were common in both settings.	**change**

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Morycz (1985) (USA)	Institutionalisation	to explore whether the strain experienced by ICs of PwDs will be strongly related to the desire to institutionalise	quantitative: observational (longitudinal)	80 dyads (PwD living at home)	Results rely to the self-developed theoretical model: The desire to institutionalise a PwD was found to be greater when the IC's experiences increased strain or burden, when PwD is widowed, when there is more physical labour involved in caring tasks, and when PwD lives alone. Intensity of family strain (or felt stress) can best be predicted by the availability of social support to the IC: Less support implies more strain. For male IC groups and for all black ICs, strain does not predict desire to institutionalise.	dyadic relationship, resources
Okura et al. (2011) (International Consortium: Japan, USA, UK)	Institutionalisation	to examine the association between neuropsychiatric symptoms and risk of institutionalisation and death	quantitative: observational (longitudinal)	537 PwDs living at home at baseline, 109 PwDs institutionalised	The presence of one or more neuropsychiatric symptoms was not associated with higher risk of institutionalisation or death during the 5-year study period. Although when assessing each symptom individually, depression, delusions, and agitation were each associated with a higher risk of institutionalisation. IC distress mediated the association between delusions, agitation and institutionalisation. Depression and hallucinations were associated with significantly higher mortality.	**change**
Oliva y Hausmann et al. (2012) (Germany)	Institutionalisation	to explore the influence of IC needs, IC burden and role conflicts on the risk of institutionalisation of PwD	quantitative: observational (longitudinal)	373 ICs (PwD living at home at baseline)	A greater distance between households, increased need in housekeeping, higher income, increased IC burden and low self-evaluation of caring-quality are related to an increase in chance for institutionalisation. A constant need for supervision and lack of social appreciation are associated with a smaller chance.	change, dyadic relationship, health care system
Peacock et al. (2010) (Canada)	Positive aspects	to better understand family care by applying a strength-based perspective	qualitative: unspecific design	39 ICs (PwD living at home alone, PwD living with IC, PwD institutionalised)	ICs can view their role as an opportunity to give back, to discover personal strengths, and to become closer to the PwD. The results suggest that identifying and mobilising the IC's strengths can be an effective strategy for supporting ICs in their role.	carer role, **resources**
Pimouguet et al. (2016) (France)	Institutionalisation	to investigate the influence of early specialist referral for PwDs on the risk of institutionalisation and functional decline	quantitative: observational (longitudinal)	179 PwDs (for institutionalisation analysis), 243 PwDs (for ADL analysis), (PwD living at home at baseline)	One third of the incident PwDs had consulted a specialist for cognitive problems early in the disease course. PwDs who had consulted a specialist early presented a higher rate of being institutionalised than those who did not. Early specialist referral was not associated with functional decline.	resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Pinquart and Sörensen (2006) (Germany and USA)	Berries	to identify average effects of interventions found on IC burden, depression, indicators of positive subjective well-being, ability/knowledge of ICs, symptoms of ICs, and the risk of institutionalisation	systematic review: meta-analysis	127 publications	Interventions for ICs of PwDs had small but significant effects on burden, depression, ability/knowledge, subjective well-being and symptoms of PwDs. Only structured multicomponent interventions reduced the risk of institutionalisation.	**resources**
Pinzon et al. (2013) (Germany)	End-of-life-care	to describe the preferred and actual places of death, symptom prevalence, and quality of care of PwDs	quantitative: observational (cross-sectional)	310 ICs of PwDs and 931 ICs of people without dementia, who died at home or in an institution	Almost half of the PwDs died at home. Compared to other countries this number is high. Most PwDs and their ICs preferred death at home to death anywhere else. PwDs living with at least one relative were more likely to die at home. The ICs were critical of the quality of care on standard hospital wards, citing the limited temporal availability of staff and limited emotional support.	dyadic relationship, society and culture, health care system
Porter et al. (2016) (USA)	Institutionalisation	to investigate the association between total NPI score, the NPI-4 (an agitation/aggression sub-scale) and individual domains of the NPI and NHP	quantitative: observational (longitudinal)	641 ICs: 352 cases (PwD institutionalised in the first 6 months of study), 289 controls (PwD living at home)	An increase in the NPI score implied an increase in odds of institutionalisation, also being married or being a male IC predicted institutionalisation. PwDs who entered a NH were significantly more likely to have behavioural and psychological symptoms of dementia related to agitation/aggression one month prior to institutionalisation than PwDs who stayed at home.	**change**
Quinn et al. (2015) (UK)	Needs & Demands	to investigate how meaning, motivation and relationship dynamics influence the IC's subjective experience of caring	qualitative: phenomeno-logical approach	12 ICs (10 PwD living at home, 2 PwD institutionalised)	6 key themes emerged, which were encompassed under an overarching theme of 'balancing needs'. This theme describes the IC's struggle to balance their own needs against those of the PwD. Dilemmas emerged from the desire to try to preserve the ICs relationship with the PwD, while recognising that this relationship was changing. The IC's relationship with the PwD influenced the IC's motivations to provide care and gave caring meaning. Although ICs were motivated to provide care the battle to balance needs meant that ICs recognized there might come a time when they may need to cease caring.	**balancing**, needs, **carer role**, **dyadic relationship,** resources
Redfern et al. (2002) (UK)	(Self-)caring actions	to advance the understanding of care for a PwD at home with an emphasis on routines, control and care goals	qualitative: unspecific design	20 dyads (PwD living at home)	Accomplishing care is a major challenge for PwDs and their ICs. In most cases development of effective coping strategies, handling competing goals, controlling the situation and maintaining a preferred sense of self are challenges in dementia care that have to be mastered.	**balancing**, dyadic relationship

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Romero-Moreno et al. (2014) (Spain)	Institutionalisation	to analyse the potential of both frequency of and satisfaction with leisure to explain IC's distress, risk of institutionalisation, IC's stressors and resources variables	quantitative: observational (cross-sectional)	275 ICs (PwD living at home)	ICs with a high satisfaction with and high frequency of leisure showed a more positive profile on resource variables, health outcomes and lower levels of risk of institutionalisation compared with the other groups. ICs with low satisfaction with and low frequency of leisure used significantly less adaptive emotional regulation strategies and showed worse consequences on health outcomes.	**carer role**
Rongve et al. (2014) (Norway)	Institutionalisation	to study time until and predictors for NHP for persons with mild dementia and to compare differences in time to NHP between PwDs with DLB and PwADs	quantitative: observational (longitudinal)	189 PwDs (PwD living at home at baseline)	Patients diagnosed with DLB had nearly 2 years shorter time to institutionalisation than those diagnosed with AD. Predictors of shorter time to institutionalisation were a DLB diagnosis, the use of antipsychotic medication, more advanced age, longer duration of dementia symptoms prior to diagnosis, living alone, higher reported carer distress, and more neuropsychiatric symptoms. The use of AChEIs was associated with halved risk of institutionalisation. In the DLB group, the use of antipsychotics was associated with increased risk of institutionalisation.	**change**, resources
Runte (2018) (Germany)	Institutionalisation	to analyse a cohort of PwDs in respect of institutionalisation over a follow-up period of 4.5 years and to investigate factors associated with the institutionalisation of PwDs, in general and stratified by sex	quantitative: observational (longitudinal)	652 PwDs (PwD living at home at baseline)	Risk of institutionalisation is higher in women than in men and when cared for by a care service in comparison to an IC. Inhibiting factors are care level and positive evaluation of caring by ICs. Stratified analysis by sex revealed that the risk of institutionalisation in men is influenced by their relationship to their IC, in women by duration of care at baseline.	**change**, dyadic relationship, resources, health care system
Saks et al. (2015) (International Consortium: Estonia, Germany, Spain, Finland, Sweden, France, UK)	(Self-)caring actions	to investigate the extent of variability in decisions of individuals and multidisciplinary groups from different European countries about the most appropriate setting for PwDs	quantitative: observational (cross-sectional)	161 experts in dementia care	There is considerable variation in individual's recommendations for the most appropriate setting for PwDs. Group-based decisions were more consistent, but country-specific patterns remained.	dyadic relationship, resources, society and culture, health care system
Sansoni et al. (2013) (Italy)	Institutionalisation	to review literature about factors that influence the institutionalisation of PwDs	unsystematic review	17 publications	Factors like IC burden, hours involved in care, stress, social isolation, gender, relationship to the PwD, availability of support resources, and IC characteristics influence the decision for institutionalisation.	change, society and culture, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Schacke et al. (1998) (Germany)	Stability	to analyse the meaning of various dimensions of IC burden for the IC's well-being and the stability of the care situation	quantitative: observational (cross-sectional)	78 ICs (PwD living at home)	Stability of home care is associated with perceived inadequacy of IC resources. Lower resources determine a higher probability of institutionalisation within the next 12 months. Other dimensions of IC stress/burden were not significant. An explicit distinction is made between IC burden which directly refers to the situation and the more general concept of well-being which is potentially, but not necessarily, affected by the caring situation. IC's life satisfaction, self-esteem, and their subjective perception of the stability of the care situation were regarded as indicators for potential outcomes of caring.	resources
Schäufele et al. (2005) (Germany)	Stability	to identify care gaps and possible undesirable development and to determine factors that stabilise or endanger the care situation	quantitative: observational (cross-sectional)	151 PwDs, 155 persons without dementia and their IC	Most care arrangements are judged as stable by the IC. Subjective burden, inadequate support and male gender of IC are associated with instable care arrangements.	change, resources
Schirra-Weirich and Wiegelmann (2017) (Germany)	Stability	to develop a typology of PwD and IC dyads to better address their specific needs in a case management approach	quantitative: observational (longitudinal)	40 dyads (PwD living at home)	Dyads are divided into three types based on generational distinctions of care concepts. Case management is a mental support for intra-generational care settings and a functional support for inter-generational care settings. Case management based on a typology seems to be an appropriate support for ICs and PwDs.	balancing, **carer role**
Schoenmakers et al. (2009) (Belgium)	Institutionalisation	to investigate the differences between characteristics of community dwelling PwDs and non-demented elderly and their ICs at the moment of definitive institutionalisation	quantitative: observational (cross-sectional)	143 GPs (reporting data of 300 PwDs and 507 non demented controls, already institutionalised)	PwDs with concomitant diseases were mainly placed because of unmanageable behavioural disturbances. Strikingly, these PwDs were more often confronted with a delay in definitive institutionalisation due to their high care dependence. Although IC burden was an important motivation, it did not seem to be a motive in the final institutionalisation. Behavioural disturbances are independently of IC burden, FC support, or a spousal relationship the main direct reason for institutionalisation.	**change**, resources
Schölzel-Dorenbos et al. (2010) (Netherlands)	Needs & Demands	to make an inventory of needs assessment instruments, to explore the interaction between unmet needs and HRQoL and to relate these to the conceptual model of Maslow's hierarchy of needs in order to design a dementia-specific model	systematic review: qualitative synthesis	2 needs assessment instruments: CANE and CNA-D	PwDs identified significantly fewer needs than ICs. The most important needs, that also determine a large part of HRQoL, are: need for information, support with regard to symptoms of dementia, social contact and company, and health monitoring and safety. Focusing unmet needs can improve HRQoL.	**needs**

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Shega et al. (2008) (USA)	End-of-life-care	to evaluate the impact that hospice enrolment has on the terminal care of PwDs, and to describe the symptom burden these patients face at the end of life	quantitative: observational (cross-sectional)	135 ICs (PwD living at home or in a hospice)	The results suggest that dying PwDs who are enrolled in hospice programs are more likely to die in their locations of choice and their ICs are more likely to perceive that care is excellent or good than those who do not obtain hospice services. No effects on pain or other symptoms could be demonstrated in this analysis.	resources
Shim (2011) (USA)	Positive aspects	to explore how ICs of PwDs are able to have positive care experiences, how the relationship between the ICs and the PwADs changes over time, and how this relationship differs between dementia ICs who report positive care experiences and those who do not	mixed methods	PwD and people with Parkinson's disease (living at home). Study 1: n= 91 IC/PwAD dyads, Study 2: n= 21 spousal ICs of PwAD, Study 3: n= 12 ICs of PwAD	The relational dynamics between ICs and PwDs are important and can be the source of a positive care experience. For the ICs their current attitude toward the relationship dynamic with the PwD is what seemed to bring the most meaning. By finding caregiving meaningful, ICs can obtain peace and pleasure in the currently lived experience. IC attitudes toward the relationship with PwDs and the PwD's degenerative decline influence the quality of the care experience.	change, balancing, **dyadic relationship**
Spitznagel et al. (2006) (USA)	Berries	to understand predictors of desire to institutionalise in ICs of PwDs	quantitative: observational (cross-sectional)	72 ICs (PwD living at home)	ICs with a desire to institutionalise had significantly higher burden, greater dementia knowledge, more family dysfunction, and decreased social support compared with no-desire ICs. Findings emphasise the importance of IC and family relationship variables in desire to institutionalise, suggesting potentially modifiable targets for IC interventions. Dementia knowledge was associated with higher desire to institutionalise, suggesting that educational programs alone may not be helpful to delay institutionalisation.	change, dyadic relationship, resources
Stephan et al. (2015) (International Consortium: Estonia, Germany, Finland, France, Netherlands, UK, Spain, Sweden)	Institutionalisation	to explore the perceptions of ICs and FCs regarding reasons for the institutionalisation of PwDs in eight European countries	mixed methods	1160 ICs (PwD living at home) and their health care practitioners (number not reported)	Agreement about reasons for institutionalisation between ICs and FCs was low-to-moderate. Discrepancy was high for reasons related to IC burden. Furthermore differences between countries emerged.	**change**, resources, society and culture, health care system

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Stiens et al. (2006) (Germany)	Institutionalisation	to investigate associations of filial maturity with PwD institutionalisation and IC burden by using the Louvain Filial Maturity Scale	quantitative: observational (longitudinal)	61 filial ICs (PwD living at home at baseline)	Filial maturity had no influence on the IC's feelings of burden, but higher 'parental consideration' resulted in lower IC burden. Adult children with more 'filial obligation' continued to care for their parents more often, even when experiencing great burden and stress. Institutionalisation was caused mainly by PwDs growing needs and increasing behavioural problems.	carer role
Sun et al. (2013) (USA)	Institutionalisation	to understand the role of quality of care in mediating between caring stressors and IC desire to institutionalise a PwD	quantitative: observational (cross-sectional)	612 racially diverse ICs (PwD living at home)	Potentially harmful behaviours of the ICs were positively related to IC's desire to institutionalise their care recipients. The mediation effect of exemplary care was significant in the African American group only.	needs, society and culture
Toot et al. (2013) (UK)	Berries	to identify which factors may lead to crisis for PwDs and ICs and identify interventions these individuals believe could help in crisis	qualitative: unspecific design	18 PwDs (living at home), 15 ICs, 19 FCs	Causes of crises for PwDs were risks and hazards in their home, whereas for ICs carer stress and their own mental health problems were predominant. FCs focused on problems with service organisation and coordination leading to crisis. PwDs valued support from family and friends, access to mobile phones and home adaptations to reduce risks. ICs valued assistive technology and home adaptation. Both ICs and FCs valued carer training and education, care plans and well-coordinated care.	**change**, needs, carer role, **resources,** health care system
Toot et al. (2017) (UK)	Institutionalisation	to understand the factors that influence the decision for PwDs to move into NHs, with particular emphasis on factors that might be responsive to intervention	systematic review: narrative review and meta-analysis	systematic review: 26 publications, meta-analysis: 15 publications	Poorer cognition and behavioural and psychological symptoms were associated with an increased risk of institutionalisation. Impairments in ADLs were identified as a significant risk. There was an association between IC burden and risk of institutionalisation, but findings with regard to IC depression varied, as did physical health associations, with some studies showing an increased risk of institutionalisation following hip fracture, reduced mobility, and multiple comorbidities.	**change**, needs, carer role, resources
Treloar et al. (2009) (UK)	End-of-life-care	to undertake detailed interviews of ICs who had supported PwDs at home, with the aim of identifying the major factors which make such care feasible	mixed methods	14 bereaved ICs (PwD living at home or institutionalised)	The study revealed blockages to accessing support as a result of poor understanding of the needs of advanced dementia care as well as organisational prejudice. Home based palliative care of PwDs can be achieved with very positive outcomes.	change, **needs**, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Tucker et al. (2016) (International Consortium: UK, Estonia, Netherlands, Spain, Sweden, Finland, Germany, France)	Institutionalisation	to explore the extent to which client characteristics, decision-maker attributes, and country influence judgments of institutional long-term care appropriateness for PwDs	quantitative: observational (cross-sectional)	161 experts in dementia care	Client characteristics, decision-maker attributes, and country seemed to play a role in influencing FC's perceptions of the appropriateness of NHs for PwDs. Decision-makers were more likely to recommend NHs for PwDs who required help with mobility or had multiple care needs, and appeared to give more weight to IC's than PwD's wishes. Community-based social workers were less likely than other FC groups to favour NHP. Experts in Finland, Germany, and the UK were less likely to recommend NHP than experts in France, the Netherlands, and Estonia. Experts in Sweden and Spain took an intermediate position.	change, resources, **society and culture**
Verbeek et al. (2015) (International Consortium: Estonia, Germany, Finland, France, Netherland, UK, Spain, Sweden)	Institutionalisation	to explore inter-country variations associated with institutionalisation of PwDs	quantitative: observational (longitudinal)	2014 dyads (PwD living at home or recently institutionalised)	Inter-country differences were found in recently institutionalised PwD's characteristics. Most consistent factors associated with institutionalisation were ADL and IC burden, although country differences may be more prominent for this factor.	change, dyadic relationship, **society and culture**
Volicer et al. (2003) (USA)	End-of-life-care	to evaluate the quality of care in home settings and compare it with care provided in institutions	quantitative: observational (cross-sectional)	154 ICs (PwD living at home or institutionalised (various institutions))	Psychiatric symptoms and increased IC burden were the most common reason for institutionalisation, and psychiatric care was associated with longer stay at home. Presence of advance directives decreased hospital stay and increased the likelihood of dying in a NH. Care recipients dying at home had fewer symptoms and less discomfort than care recipients dying in other settings. These results indicate that quality end-of-life care can be provided at home and is facilitated by hospice programs, effective pain control, and psychiatric care.	change, **resources**
von Kutzleben et al. (2015) (Germany)	Berries	to assess home-based care arrangements, to illustrate utilisation of formal services, and to identify factors associated with perceived stability of the care situation from the IC's perspective	quantitative: observational (cross-sectional)	84 dyads (PwD living at home)	Most frequently used formal services were home care nursing services, day care, and respite care. Companion home visit, home care nursing services and day care were used over the longest periods of time. IC's perceived stability of care situation was high, and was associated with the country of origin and sex of PwD.	dyadic relationship, **society and culture**, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Wackerbarth (1999a) (USA)	Berries	to understand the decision processes of ICs and to develop a model of their decision processes	qualitative: unspecific design	28 ICs (PwD living at home or institutionalised)	The proposed model charts the caring experience over time and documents decisions made to maintain a stable care situation. It has three main components: tolerance line, status points, and decision events. ICs are divided into 5 types: ICs who plan ahead, take it one day at a time, have difficulty implementing decision, receive decision support from FCs and ICs who feel that decisions are made by others or by the disease itself.	**change**, **balancing**, needs
Wackerbarth (1999b) (USA)	(Self-)caring actions	to describe the complexities of the overall decision making situation, to characterise a specific care decision, and to identify decision support needs	mixed methods	80 ICs (PwD living at home or institutionalised)	Most prevalent decisions involved institutionalisation, communicating the diagnosis and the driving privilege. Most challenging decisions involved providing care and relocation. The most prevalent question involved the timing of actions.	**balancing**
Wattmo et al. (2011) (Sweden)	Institutionalisation	to identify risk factors for early institutionalisation in AD, focusing on the impact of longitudinal change in cognition, ADL, service utilisation, and AChEIs	quantitative: observational (longitudinal)	880 PwDs (PwD living at home at baseline)	Factors that precipitated institutionalisation were: lower cognitive and functional abilities at baseline, faster rate of decline in Instrumental Activities of Daily Living Scale, female gender, living alone, substantial increase in adult day care, and a lower mean dose of AChEI. The rate of functional but not cognitive decline was a strong risk factor for institutionalisation.	**change**
Willoughby et al. (1991) (Canada)	(Self-)caring actions	to understand the process of caring from the perspective of ICs of PwDs	qualitative: Grounded Theory	10 ICs (PwD institutionalised)	The finding yield a five-stage model of gaining and relinquishing control of caring (emerging recognition, taking control, losing control, adjusting to the psychiatric institution, moving on). Shifts in the understanding of the process delineated each stage.	change, **balancing**, **carer role**, dyadic relationship
Winslow et al. (1999) (USA)	Burden	to describe the longitudinal pattern of IC burden and to compare IC burden of wives who continue in home-based care and those who institutionalised the PwD	quantitative: observational (longitudinal)	376 ICs (PwD living at home) and 523 ICs (PwD institutionalised)	Spouse ICs who provided home-based care to their husbands experienced an increase in burden over time. There appeared to be a threshold of burden when institutionalisation occurred. Immediately after placement the IC appeared to experience a reduction in burden.	change, needs
Wuest et al. (1994) (Canada)	(Self-)caring actions	to explore the reciprocal process of becoming strangers in Canadian ICs and PwDs and their interaction on a continuum from intimacy to alienation	qualitative: Grounded Theory	15 dyads (PwD living at home)	The continuum from intimacy to alienation comprises three dimensions: dawning, holding on and letting go. ICs struggle on a daily basis with their commitment to the person they knew and their increasing detachment from the stranger the PwD has become.	change, **balancing**, carer role, **dyadic relationship**

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Zarit et al. (1986) (USA)	Burden	to investigate changes over time for ICs of PwDs, with a focus on factors associated with institutionalisation, to determine if differences between husbands and wives found at the initial testing remained stable over time	quantitative: observational (longitudinal)	64 ICs (PwD living at home)	Institutionalisation was more strongly associated with subjective factors, particularly IC burden, than with objective indicators of the severity of dementia. Although wives initially reported more burden than husbands, no differences were found at the follow-up.	**change**

Appendix B: Bibliography of the meta-study sample

All 99 publications included in our meta-study are listed below.

Afram, B., Stephan, A., Verbeek, H., Bleijlevens, M. H., Suhonen, R., Sutcliffe, C., . . . Hamers, J. P. (2014). Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *Journal of the American Medical Directors Association, 15*(2), 108-116. doi:10.1016/j.jamda.2013.09.012

Afram, B., Verbeek, H., Bleijlevens, M. H. C., & Hamers, J. P. H. (2015). Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *International psychogeriatrics / IPA, 27*(6), 891-902. doi:10.1017/S1041610214002154

Andren, S., & Elmstahl, S. (2008). Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: a five-year follow-up study. *International psychogeriatrics / IPA, 20*(6), 1177-1192. doi:10.1017/s1041610208007503

Badrakalimuthu, V., & Barclay, S. (2014). Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and ageing, 43*(1), 13-19. doi:10.1093/ageing/aft151

Bakker, C., de Vugt, M. E., van Vliet, D., Verhey, F. R. J., Pijnenburg, Y. A., Vernooij-Dassen, M. J. F. J., & Koopmans, R. T. C. M. (2013). Predictors of the time to institutionalization in young- versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *Journal of the American Medical Directors Association, 14*(4), 248-253. doi:10.1016/j.jamda.2012.09.011

Caldwell, L., Low, L. F., & Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *International psychogeriatrics / IPA, 26*(3), 413-424. doi:10.1017/s1041610213002020

Caron, C. D., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Canadian journal on aging / La revue canadienne du vieillissement, 25*(2), 193-205. doi:10.1353/cja.2006.0033

Cepoiu-Martin, M., Tam-Tham, H., Patten, S., Maxwell, C. J., & Hogan, D. B. (2016). Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis. *International Journal of Geriatric Psychiatry, 31*(11), 1151-1171. doi:10.1002/gps.4449

Chang, Y. P., & Schneider, J. K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in psychiatric care, 46*(2), 108-118. doi:10.1111/j.1744-6163.2010.00246.x

Chang, Y. P., Schneider, J. K., & Sessanna, L. (2011). Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *Journal of Aging Studies, 25*(4), 436-444. doi:10.1016/j.jaging.2011.05.001

Coe, M., & Neufeld, A. (1999). Male caregivers' use of formal support. *Western journal of nursing research, 21*(4), 568-588. doi:10.1177/01939459922044045

Cohen, C. A., Gold, D. P., Shulman, K. I., & Zucchero, C. A. (1994). Positive aspects in caregiving: An overlooked variable in research. *Canadian journal on aging / La revue canadienne du vieillissement, 13*(3), 378-391. doi:10.1017/S071498080000619X

Cox, C. B. (1996). Discharge planning for dementia patients: factors influencing caregiver decisions and satisfaction. *Health & social work, 21*(2), 97-104. doi:10.1093/hsw/21.2.97

Daly, L., McCarron, M., Higgins, A., & McCallion, P. (2012). 'Sustaining Place' - a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *Journal of clinical nursing, 22*(3-4), 501-512. doi:10.1111/jocn.12003

Davis, L. L., Chestnutt, D., Molloy, M., Deshefy-Longhi, T., Shim, B., & Gilliss, C. L. (2014). Adapters, strugglers, and case managers: a typology of spouse caregivers. *Qualitative Health Research, 24*(11), 1492-1500. doi:10.1177/1049732314548879

de Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., & Verhey, F. R. J. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International psychogeriatrics / IPA, 17*(4), 577-589. doi:10.1017/S1041610205002292

Donovan, M. L. (2006). *Edification of dementia caregiver uplifts characteristics*. (Doctoral dissertation, Capella University).

Donovan, M. L., & Corcoran, M. A. (2010). Description of Dementia Caregiver Uplifts and Implications for Occupational Therapy. *The American journal of occupational therapy, 64*(4), 590-595 doi:10.5014/ajot.2010.09064

Dramé, M., Lang, P. O., Jolly, D., Narbey, D., Mahmoudi, R., Laniece, I., . . . Novella, J. L. (2012). Nursing home admission in elderly subjects with dementia: predictive factors and future challenges. *Journal of the American Medical Directors Association, 13*(1), 83.e17-20. doi:10.1016/j.jamda.2011.03.002

Ducharme, F., Couture, M., & Lamontagne, J. (2012). Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home health care services quarterly, 31*(3), 197-218. doi:10.1080/01621424.2012.681572

Ebly, E. M., Hogan, D. B., & Rockwood, K. (1999). Living alone with dementia. *Dementia and Geriatric Cognitive Disorders, 10*(6), 541-548. doi:10.1159/000017202

Feldman, H. H., Pirttila, T., Dartigues, J. F., Everitt, B., Van Baelen, B., Schwalen, S., & Kavanagh, S. (2009). Treatment with galantamine and time to nursing home placement in Alzheimer's disease patients with and without cerebrovascular disease. *International Journal of Geriatric Psychiatry, 24*(5), 479-488. doi:10.1002/gps.2141

Forbes, D. A., Finkelstein, S., Blake, C. M., Gibson, M., Morgan, D. G., Markle-Reid, M., . . . Thiessen, E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. *Rural and remote health, 12*(4), 1-15

Frewer-Graumann, S. (2014). *Zwischen Fremdfürsorge und Selbstfürsorge: Familiale Unterstützungsarrangements von Menschen mit Demenz und ihren Angehörigen*. Wiesbaden: Springer VS.

Gallagher, D., Mhaolain, A. N., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., . . . Lawlor, B. A. (2011). Determinants of the desire to institutionalize in Alzheimer's caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 26*(3), 205-211. doi:10.1177/1533317511400307

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005a). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and aging, 20*(1), 100-116. doi:10.1037/0882-7974.20.1.100

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005b). Unmet care needs and key outcomes in dementia. *Journal of the American Geriatrics Society, 53*(12), 2098-2105. doi:10.1111/j.1532-5415.2005.00495.x

Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *The journals of gerontology. Series B, Psychological sciences and social sciences, 62*(1), P38-44. doi:10.1093/geronb/62.1.P38

Gaugler, J. E., Pearlin, L. I., Leitsch, S. A., & Davey, A. (2001). Relinquishing in-home dementia care: Difficulties and perceived helpfulness during the nursing home transition. *American Journal of Alzheimer's Disease and Other Dementias, 16*(1), 32-42. doi:10.1177/153331750101600102

Gaugler, J. E., Wall, M. M., Kane, R. L., Menk, J. S., Sarsour, K., Johnston, J. A., . . . Newcomer, R. (2011). Does caregiver burden mediate the effects of behavioral disturbances on nursing home admission? *The American Journal of Geriatric Psychiatry, 19*(6), 497-506. doi:10.1097/JGP.0b013e31820d92cc

Gaugler, J. E., Yu, F., Krichbaum, K., & Wyman, J. F. (2009). Predictors of nursing home admission for persons with dementia. *Medical care, 47*(2), 191-198. doi:10.1097/MLR.0b013e31818457ce

Gilhooly, M. L. M. (1986). Senile dementia: Factors associated with caregivers' preference for institutional care. *The British journal of medical psychology, 59*(2), 165-171. doi:10.1111/j.2044-8341.1986.tb02681.x

Glass, A. P. (2016). Family Caregiving and the Site of Care: Four Narratives About End-of-Life Care for Individuals with Dementia. *Journal of Social Work in End-of-Life & Palliative Care, 12*(1-2), 23-46. doi:10.1080/15524256.2016.1156605

Gort, A. M., Mingot, M., Gomez, X., Soler, T., Torres, G., Sacristan, O., . . . Cabau, J. (2007). Use of the Zarit scale for assessing caregiver burden and collapse in caregiving at home in dementias. *International Journal of Geriatric Psychiatry, 22*(10), 957-962. doi:10.1002/gps.1770

Groen-van de Ven, L., Smits, C., Oldewarris, K., Span, M., Jukema, J., Eefsting, J., & Vernooij-Dassen, M. (2017). Decision Trajectories in Dementia Care Networks Decisions and Related Key Events. *Research on Aging, 39*(9), 1039-1071. doi:10.1177/0164027516656741

Hagen, B. (2001). Nursing home placement. Factors affecting caregivers' decisions to place family members with dementia. *Journal of gerontological nursing, 27*(2), 44-53. doi:10.3928/0098-9134-20010201-14

Hill, S. R., Mason, H., Poole, M., Vale, L., & Robinson, L. (2017). What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International Journal of Geriatric Psychiatry, 32*(9), 1037-1045. doi:10.1002/gps.4564

Hirschfeld, M. (2003). Home care versus institutionalization: family caregiving and senile brain disease. *International journal of nursing studies, 40*(5), 463-469. doi:10.1016/S0020-7489(03)00063-4

Janssen, E. P., de Vugt, M., Köhler, S., Wolfs, C., Kerpershoek, L., Handels, R. L., . . . Verhey, F. R. (2017). Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health. *Aging & Mental Health, 21*(1), 49-57. doi:10.1080/13607863.2016.1255716

Kajiwara, K., Nakatani, H., Ono, M., & Miyakoshi, Y. (2015). Positive appraisal of in-home family caregivers of dementia patients as an influence on the continuation of caregiving. *Psychogeriatrics : the official journal of the Japanese Psychogeriatric Society, 15*(1), 26-31. doi:10.1111/psyg.12074

Kellett, U. M. (1999). Transition in care: family carers' experience of nursing home placement. *Journal of advanced nursing, 29*(6), 1474-1481. doi:10.1046/j.1365-2648.1999.01035.x

Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., & van Exel, J. (2014). The perseverance time of informal carers of dementia patients: validation of a new measure to initiate transition of care at home to nursing home care. *Journal of Alzheimer's disease, 40*(3), 631-642. doi:10.3233/jad-132420

Kraijo, H., de Leeuw, R., & Schrijvers, G. (2015). How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scandinavian Journal of Caring Sciences, 29*(1), 101-109. doi:10.1111/scs.12137

Kwon, S. H., & Tae, Y. S. (2012). Nursing Home Placement: The Process of Decision Making and Adaptation among Adult Children Caregivers of Demented Parents in Korea. *Asian nursing research, 6*(4), 143-151. doi:10.1016/j.anr.2012.10.005

Ledgerd, R., Hoe, J., Hoare, Z., Devine, M., Toot, S., Challis, D., & Orrell, M. (2016). Identifying the causes, prevention and management of crises in dementia. An online survey of stakeholders. *International Journal of Geriatric Psychiatry, 31*(6), 638-647. doi:10.1002/gps.4371

Lethin, C., Hallberg, I. R., Karlsson, S., & Janlov, A. C. (2016). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences, 30*(3), 526-534. doi:10.1111/scs.12275

Lewis, L. F. (2015). Caregiving for a Loved One With Dementia at the End of Life. *American Journal of Alzheimer's Disease and Other Dementias, 30*(5), 488-496. doi:10.1177/1533317514559829

Liken, M. A. (2001a). Caregivers in crisis: moving a relative with Alzheimer's to assisted living. *Clinical nursing research, 10*(1), 52-68. doi:10.1177/c10n1r6

Liken, M. A. (2001b). Critical incidents precipitating institutionalization of a relative with Alzheimer's. *Western journal of nursing research, 23*(2), 163-178. doi:10.1177/019394590102300205

Lindgren, C. L. (1993). The caregiver career. *Image: the journal of nursing scholarship, 25*(3), 214-219. doi:10.1111/j.1547-5069.1993.tb00784.x

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London), 15*(6), 1534-1561. doi:10.1177/1471301214564792

Lord, K., Livingston, G., Robertson, S., & Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. *BMC Geriatrics, 16*(68). doi:10.1186/s12877-016-0242-1

Luppa, M., Luck, T., Brähler, E., König, H. H., & Riedel-Heller, S. G. (2008). Prediction of institutionalisation in dementia. A systematic review. *Dementia and Geriatric Cognitive Disorders, 26*(1), 65-78. doi:10.1159/000144027

Luppa, M., Riedel-Heller, S. G., Stein, J., Leicht, H., Konig, H. H., van den Bussche, H., . . . Weyerer, S. (2012). Predictors of institutionalisation in incident dementia--results of the German Study on Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe study). *Dementia and Geriatric Cognitive Disorders, 33*(4), 282-288. doi:10.1159/000339729

MacNeil Vroomen, J., Bosmans, J. E., van Hout, H. P., & de Rooij, S. E. (2013). Reviewing the definition of crisis in dementia care. *BMC Geriatrics, 13*(10). doi:10.1186/1471-2318-13-10

Markiewicz, D., Reis, M., & Gold, D. P. (1997). An exploration of attachment styles and personality traits in caregiving for dementia patients. *International journal of aging & human development, 45*(2), 111-132. doi:10.2190/T4Q4-E8F0-JWT5-DBAG

Mausbach, B. T., Coon, D. W., Depp, C., Rabinowitz, Y. G., Wilson-Arias, E., Kraemer, H. C., . . . Gallagher-Thompson, D. (2004). Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. *Journal of the American Geriatrics Society, 52*(7), 1077-1084. doi:10.1111/j.1532-5415.2004.52306.x

McLennon, S. M., Habermann, B., & Davis, L. L. (2010). Deciding to institutionalize: Why do family members cease caregiving at home? *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses, 42*(2), 95-103. doi:10.1097/JNN.0b013e3181ce5c45

Mitchell, S. L., Morris, J. N., Park, P. S., & Fries, B. E. (2004). Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of palliative medicine, 7*(6), 808-816. doi:10.1089/jpm.2004.7.808

Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*(3), 329-361. doi:10.1177/0164027585007003002

Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. J., Potter, G. G., & Langa, K. M. (2011). Neuropsychiatric symptoms and the risk of institutionalization and death: the aging, demographics, and memory study. *Journal of the American Geriatrics Society, 59*(3), 473-481. doi:10.1111/j.1532-5415.2011.03314.x

Oliva y Hausmann, A., Schacke, C., & Zank, S. (2012). Pflegende Angehörige von demenziell Erkrankten : welche Faktoren beeinflussen den Transfer von der häuslichen in die stationäre Pflege? *Psychotherapie, Psychosomatik, Medizinische Psychologie, 62*(9-10), 367-374. doi:10.1055/s-0032-1323708

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., . . . Henderson, S. R. (2010). The positive aspects of the caregiving journey with dementia: using a strengths-based perspective to reveal opportunities. *Journal of applied gerontology: the official journal of the Southern Gerontological Society, 29*(5), 640-659 doi:10.1177/0733464809341471

Pimouguet, C., Le-Goff, M., Rizzuto, D., Berr, C., Leffondre, K., Peres, K., . . . Helmer, C. (2016). Effect of Early Referral to Specialist in Dementia on Institutionalization and Functional Decline: Findings from a Population-Based Study. *American Journal of Alzheimer's Disease and Other Dementias, 49*(3), 819-828. doi:10.3233/JAD-150574

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International psychogeriatrics / IPA, 18*(4), 577-595. doi:10.1017/S1041610206003462

Pinzon, L. C., Claus, M., Perrar, K. M., Zepf, K. I., Letzel, S., & Weber, M. (2013). Dying with dementia: symptom burden, quality of care, and place of death. *Deutsches Ärzteblatt international, 110*(12), 195-202. doi:10.3238/arztebl.2013.0195

Porter, C. N., Miller, M. C., Lane, M., Cornman, C., Sarsour, K., & Kahle-Wrobleski, K. (2016). The influence of caregivers and behavioral and psychological symptoms on nursing home placement of persons with Alzheimer's disease: A matched case-control study. *SAGE open medicine, 4*, 1-9. doi:10.1177/2050312116661877

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London), 14*(2), 220-237. doi:10.1177/1471301213495863

Redfern, S., Norman, I., Briggs, K., & Askham, J. (2002). Care at home for people with dementia: routines, control and care goals. *Quality in ageing and older adults, 3*(4), 12-23. doi:10.1108/14717794200200023

Romero-Moreno, R., Losada, A., Márquez-González, M., & Mausbach, B. T. (2014). Effects of the frequency and satisfaction with leisure profile on dementia caregivers distress. *Anales de psicología (Murcia, Spain), 30*(3), 878-886. doi:10.6018/analesps.30.3.148381

Rongve, A., Vossius, C., Nore, S., Testad, I., & Aarsland, D. (2014). Time until nursing home admission in people with mild dementia: comparison of dementia with Lewy bodies and Alzheimer's dementia. *International Journal of Geriatric Psychiatry, 29*(4), 392-398. doi:10.1002/gps.4015

Runte, R. (2018). Predictors of institutionalization in people with dementia: a survey linked with administrative data. *Aging clinical and experimental research, 30*(1), 35-43. doi:10.1007/s40520-017-0737-4

Saks, K., Tiit, E. M., Verbeek, H., Raamat, K., Armolik, A., Leibur, J., . . . Consortium, R. (2015). Most appropriate placement for people with dementia: individual experts' vs. expert groups' decisions in eight European countries. *Journal of advanced nursing, 71*(6), 1363-1377 doi:10.1111/jan.12544

Sansoni, J., Anderson, K. H., Varona, L. M., & Varela, G. (2013). Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Annali di igiene : medicina preventiva e di comunità, 25*(3), 235-246. doi:10.7416/ai.2013.1926

Schacke, C., & Zank, S. (1998). Zur familiaren Pflege demenzkranker Menschen: Die differentielle Bedeutung spezifischer Belastungsdimensionen fur das Wohlbefinden der Pflegenden und die Stabilitat der hauslichen Pflegesituation. [Family caregiving: The meaning of specific dimensions of burden for the caregiver's well-being and the stability of the caregiving situation]. *Zeitschrift für Gerontologie und Geriatrie, 31*(5), 355-361.

Schäufele, M., Köhler, L., Teufel, S., & Weyerer, S. (2005). *Betreuung von demenziell erkrankten Menschen in Privathaushalten: Potenziale und Grenzen* Retrieved from München:

Schirra-Weirich, L., & Wiegelmann, H. (2017). Typenbildung als Beitrag zur Weiterentwicklung von Versorgungsstrukturen für Menschen mit Demenz und ihren versorgenden Angehörigen. Ergebnisse einer Tandem-Studie im Rahmen des Modellprojekts "DemenzNetz Städte Region Aachen". In S. Schäfer-Walkmann & F. Traub (Eds.), *Evolution durch Vernetzung - Beiträge zur interdisziplinären Versorgungsforschung* (pp. 59-76). Wiesbaden: Springer VS.

Schoenmakers, B., Buntinx, F., Devroey, D., Van Casteren, V., & DeLepeleire, J. (2009). The process of definitive institutionalization of community dwelling demented vs non demented elderly: data obtained from a network of sentinel general practitioners. *International Journal of Geriatric Psychiatry, 24*(5), 523-531. doi:10.1002/gps.2147

Scholzel-Dorenbos, C. J., Meeuwsen, E. J., & Olde Rikkert, M. G. (2010). Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. *Aging & Mental Health, 14*(1), 113-119. doi:10.1080/13607860903046495

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2008). Patients dying with dementia: experience at the end of life and impact of hospice care. *Journal of pain and symptom management, 35*(5), 499-507. doi:10.1016/j.jpainsymman.2007.06.011

Shim, B. (2011). *Finding Meaning in the Dementia Caregiving Relationship*. (Doctoral dissertation, Duke University).

Spitznagel, M. B., Tremont, G., Davis, J. D., & Foster, S. M. (2006). Psychosocial predictors of dementia caregiver desire to institutionalize: caregiver, care recipient, and family relationship factors. *Journal of geriatric psychiatry and neurology, 19*(1), 16-20. doi:10.1177/0891988705284713

Stephan, A., Afram, B., Koskenniemi, J., Verbeek, H., Soto, M. E., Bleijlevens, M. H., . . . Consortium, R. (2015). Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals. *Journal of advanced nursing, 71*(6), 1392-1404. doi:10.1111/jan.12493

Stiens, G., Maeck, L., & Stoppe, G. (2006). Filial maturity as a predictor for the burden of demented parents' caregivers. [Filiale Reife als Prädiktor der Belastung von erwachsenen pflegenden Kindern Demenzkranker.] *Zeitschrift für Gerontologie und Geriatrie, 39*(2), 120-125. doi:10.1007/s00391-006-0336-z

Sun, F., Durkin, D. W., Hilgeman, M. M., Harris, G., Gaugler, J. E., Wardian, J., . . . Burgio, L. D. (2013). Predicting desire for institutional placement among racially diverse dementia family caregivers: the role of quality of care. *Gerontologist, 53*(3), 418-429. doi:10.1093/geront/gns110

Toot, S., Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell, M. (2013). Causes of crises and appropriate interventions: the views of people with dementia, carers and healthcare professionals. *Aging & Mental Health, 17*(3), 328-335. doi:10.1080/13607863.2012.732037

Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *International psychogeriatrics / IPA, 29*(2), 195-208. doi:10.1017/s1041610216001654

Treloar, A., Crugel, M., & Adamis, D. (2009). Palliative and end of life care of dementia at home is feasible and rewarding: results from the 'Hope for Home' study. *Dementia (London), 8*(3), 335-347. doi:10.1177/1471301209104975

Tucker, S., Brand, C., Sutcliffe, C., Challis, D., Saks, K., Verbeek, H., . . . Soto, M. E. (2016). What Makes Institutional Long-Term Care the Most Appropriate Setting for People With Dementia? Exploring the Influence of Client Characteristics, Decision-Maker Attributes, and Country in 8 European Nations. *Journal of the American Medical Directors Association, 17*(5), 465.e469-465.e415. doi:10.1016/j.jamda.2016.02.025

Verbeek, H., Meyer, G., Challis, D., Zabalegui, A., Soto, M. E., Saks, K., . . . Hamers, J. P. (2015). Inter-country exploration of factors associated with admission to long-term institutional dementia care: Evidence from the RightTimePlaceCare study. *Journal of advanced nursing, 71*(6), 1338-1350. doi:10.1111/jan.12663

Volicer, L., Hurley, A. C., & Blasi, Z. V. (2003). Characteristics of dementia end-of-life care across care settings The American journal of hospice & palliative care*, 20*(3), 191-200. doi:10.1177/104990910302000307 von Kutzleben, M., Reuther, S., Dortmann, O., & Holle, B. (2015). Care arrangements for community-dwelling people with dementia in Germany as perceived by informal carers - a cross-sectional pilot survey in a provincial-rural setting. *Health & social care in the community, 24*(3), 283-296. doi:10.1111/hsc.12202

Wackerbarth, S. (1999a). Modeling a Dynamic Decision Process: Supporting the Decisions of Caregivers of Family Members with Dementia. *Qualitative Health Research, 9*(3), 294-314. doi:10.1177/104973299129121875

Wackerbarth, S. (1999b). What decisions are made by family caregivers? *American Journal of Alzheimer's Disease, 14*(2), 111–119. doi:10.1177/153331759901400210

Wattmo, C., Wallin, A. K., Londos, E., & Minthon, L. (2011). Risk factors for nursing home placement in Alzheimer's disease: a longitudinal study of cognition, ADL, service utilization, and cholinesterase inhibitor treatment. *Gerontologist, 51*(1), 17-27. doi:10.1093/geront/gnq050

Willoughby, J., & Keating, N. (1991). Being in control: the process of caring for a relative with Alzheimer's disease. *Qualitative Health Research, 1*(1), 27–50. doi:10.1177/104973239100100103

Winslow, B. W., & Carter, P. (1999). Patterns of burden in wives who care for husbands with dementia. *The Nursing clinics of North America, 34*(2), 275-287.

Wuest, J., Ericson, P. K., & Stern, P. N. (1994). Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. *Journal of advanced nursing, 20*(3), 437–443. doi:10.1016/j.pec.2014.01.009

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist, 26*(3), 260-266. doi:10.1093/geront/26.3.260

Appendix C: Statement of the reasons for the exclusion of the publications from the ‚interventions' search strand

In the literature search one of our nine search strands was the 'interventions' strand. Our motive to operate this search strand was to include intervention studies or reviews that used the 'odds of institutionalisation' and/or 'time to institutionalisation' (in this case interpreted as a manifestation of stability/instability) as outcomes. We expected that these intervention studies and reviews might explicate in detail why and how the respective intervention was supposed to and has succeeded or failed to prolong a stable situation at home. Actually, the retrieved intervention reviews (Brodaty, Green, & Koschera, 2003; Olazaran et al., 2010; Pimouguet, Lavaud, Dartigues, & Helmer, 2010; Pinquart & Sörensen, 2006; Reilly et al., 2015; Smits et al., 2007; Spijker et al., 2008; Zabalegui et al., 2014) suggest, that (in particular multicomponent) interventions may decrease the odds of institutionalisation and increase the time that dyads spent at home. But both, intervention studies and reviews, remained vague in their statements with relation to our target phenomenon 'stability' in general and specifically to its constitutive concepts. Therefore they did not contribute meaningful to the creation of the midrange theory, and in deviation to the study protocol we decided during the analysis process to remove the whole search strand from the meta-study sample. This experience with the 'interventions' search strand points to an ongoing debate on an emerging reorientation of intervention research in the field of home-based and informal dementia care that should to be considered in future research (e.g. Ceci, Symonds Brown, & Judge, 2018; Dawson, Bowes, Kelly, Velzke, & Ward, 2015).

Literature:

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society, 51*(5), 657-664. doi:10.1034/j.1600-0579.2003.00210.x

Ceci, C., Symonds Brown, H., & Judge, H. (2018). Rethinking the assumptions of intervention research concerned with care at home for people with dementia. *Dementia (London)*. doi:10.1177/1471301218790037

Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics, 15*(59), 1-17. doi:10.1186/s12877-015-0053-9

Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., Del Ser, T., . . . Muniz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders, 30*(2), 161-178. doi:10.1159/000316119

Pimouguet, C., Lavaud, T., Dartigues, J. F., & Helmer, C. (2010). Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. *J Nutr Health Aging, 14*(8), 669-676. doi:10.1007/s12603-010-0314-4

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International psychogeriatrics / IPA, 18*(4), 577-595. doi:10.1017/S1041610206003462

Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D., & Orrell, M. (2015). Case management approaches to home support for people with dementia. *The Cochrane database of systematic reviews, 5*(1). doi:10.1002/14651858.CD008345.pub2

Smits, C. H. M., de Lange, J., Droes, R. M., Meiland, F., Vernooij-Dassen, M., & Pot, A. M. (2007). Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry, 22*(12), 1181-1193. doi:10.1002/gps.1805

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis. *Journal of the American Geriatrics Society, 56*(6), 1116-1128. doi:10.1111/j.1532-5415.2008.01705.x

Zabalegui, A., Hamers, J. P. H., Karlsson, S., Leino-Kilpi, H., Renom-Guiteras, A., Saks, K., . . . Cabrera, E. (2014). Best practices interventions to improve quality of care of people with dementia living at home. *Patient education and counseling, 95*(2), 175-184 doi:10.1016/j.pec.2014.01.009

ENTREQ Statement according to Tong, Flemming, McInnes, Oliver & Craig (2012)

Item	Description	On Page
1. Aim	To generate a middle-range theory of ‘Stability of home-based care arrangements for people living with dementia’. Research questions: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors influencing stability?	5
2. Synthesis methodology	Meta-Study	5
3. Approach to searching	Systematic searches in electronic databases combined with hand searches until saturation of concepts was reached	5
4. Inclusion criteria	Described in the study protocol (Dreyer, Köhler, Hochgraeber, Holle, & von Kutzleben, 2018)	Study Protocol 5
5. Data sources	MEDLINE, CINAHL, PsycINFO for systematic database searches	5
6. Electronic search strategy	Described in the study protocol (Dreyer et al., 2018)	Study Protocol 5
7. Study screening methods	Titles and abstracts were screened by two researchers, full texts were screened by one researcher and final inclusion or exclusion was discussed with at least one other researcher.	5-6
8. Study characteristics	Study characteristics are presented in Appendix A in Table 1.	Appendix A 1-21
9. Study selection results	The number of screened studies and the process of screening is presented in Figure 2 (flow diagram). Details on the iterative process of literature searching, screening and selecting is described in detail in the study protocol (Dreyer et al., 2018).	8 Study Protocol 4-5
10. Rationale for appraisal	The appraisal aimed to exclude studies that either had major methodological deficits, or did not contribute meaningful to the theory building process and proposed middle-range theory.	6 Study Protocol 6
11. Appraisal items	We applied the quality appraisal recommended by Dixon-Woods and colleagues (2005).	6
12. Appraisal process	Each study was appraised by one researcher, who discussed her/his appraisal with one other researcher.	6
13. Appraisal results	5 studies were excluded.	Figure 2
14. Data extraction	All text in the results, discussion and conclusion sections of the included studies were extracted. To do this, all studies were entered into the computer software MAXQDA 2018.	6
15. Software	We used EndNote X7 to manage the literature screening process and MAXQDA 2018 for data extraction and analysis.	6

		Study Protocol 5
16. Number of reviewers	KK, JD, IH and MvK performed the coding process. KK, JD and IH performed the analysis and synthesis process. The middle-range theory in creation was discussed and finalized as a team by all the authors.	20
17. Coding	According to the methodology of thematic synthesis (Thomas & Harden, 2008) an initial 'line-by-line' coding was performed. In subsequent coding rounds the 'line-by-line' codings were organised into descriptive themes. Basing on the descriptive themes the final analytical themes were created.	6
18. Study comparison	Study comparisons within and across the studies were made throughout the iterative analytic process (see also item 17).	6-7
19. Derivation of themes	The derivation of analytical themes (middle-range theory concepts) was inductive.	6-7
20. Quotations	This meta-study is a synthesis of qualitative, quantitative and mixed-methods studies and of (systematic) reviews. Due to this heterogeneous sample and due to the intent of this publication to introduce a new middle-range theory it was not appropriate to provide quotations from selected primary studies.	
21. Synthesis output	This meta-study generates a new middle-range theory including a conceptual model of 'stability of home-based care arrangements for people living with dementia' (SoCA-Dem). This publication portrays all the theory concepts and their dynamic interplay.	8-17

Literature:

Dreyer, J., Köhler, K., Hochgraeber, I., Holle, B., & von Kutzleben, M. (2018). Stability of home-based care arrangements for people living with dementia: protocol of a meta-study on mixed research. *BMJ Open, 8*, e021156. doi:10.1136/bmjopen-2017-021156

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(45). doi:10.1186/1471-2288-8-45

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol, 12*, 181. doi:10.1186/1471-2288-12-181

Woods, M. D., Kirk, M. D., Agarwal, M. S., Annandale, E., Arthur, T., Harvey, J., . . . Smith, L. (2005). Vulnerable groups and access to health care: a critical interpretive review. *National Coordinating Centre NHS Service Delivery Organ RD (NCCSDO) Retrieved May, 27*, 2012.

BMJ Open

Towards a middle-range theory of 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem): Findings from a meta-study on mixed research

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-042515.R1
Article Type:	Original research
Date Submitted by the Author:	16-Dec-2020
Complete List of Authors:	Köhler, Kerstin; German Centre for Neurodegenerative Diseases, Site Witten; University of Witten/Herdecke, Faculty of Health, School of Nursing Science Dreyer, Jan; German Centre for Neurodegenerative Diseases, Site Witten; University of Witten/Herdecke, Faculty of Health, School of Nursing Science Hochgraeber, Iris ; German Centre for Neurodegenerative Diseases, Site Witten; University of Witten/Herdecke, Faculty of Health, School of Nursing Science von Kutzleben, Milena; University of Oldenburg School of Medicine and Health Sciences, Department of Health Services Research; German Centre for Neurodegenerative Diseases, Site Witten Pinkert, Christiane; German Centre for Neurodegenerative Diseases, Site Witten; University of Witten/Herdecke, Faculty of Health, School of Nursing Science Roes, Martina; German Centre for Neurodegenerative Diseases, Site Witten; University of Witten/Herdecke, Faculty of Health, School of Nursing Science Holle, Bernhard; German Centre for Neurodegenerative Diseases, Site Witten; University of Witten/Herdecke, Faculty of Health, School of Nursing Science
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Nursing, Mental health, Qualitative research, Public health
Keywords:	Dementia < NEUROLOGY, QUALITATIVE RESEARCH, PUBLIC HEALTH, MENTAL HEALTH

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

For peer review only

Title Page

Towards a middle-range theory of ‘Stability of home-based care arrangements for people living with dementia’ (SoCA-Dem): Findings from a meta-study on mixed research

Corresponding author:
Kerstin Köhler
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany
E-mail: kerstin.koehler@dzne.de
Telephone number: +49 2302 - 926 223
Postal address: Stockumer Straße 12, 58453 Witten, Germany

Co-authors:
Jan Dreyer
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany
E-mail: jan.dreyer@dzne.de

Iris Hochgraeber
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Milena von Kutzleben
Carl von Ossietzky Universität Oldenburg, Faculty of Medicine and Health Sciences, Department of Health Services Research, Oldenburg, Germany
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany

Christiane Pinkert
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Martina Roes
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Bernhard Holle
German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany

Word Count: 9005

ABSTRACT

Background: Most people with dementia and their informal carers live at home and strive to create a stable care situation for as long as possible. This preference of dyads is consistent with the global policy of ageing in place. Therefore, we aimed to develop a middle-range theory of stability guided by two research questions: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors influencing stability?

Methods: Within the DZNE SoCA project, we conducted a meta-study on mixed research. The analytical steps of meta-data analysis, meta-method and meta-theory are merged in an integrative synthesis. Eligible publications were identified through systematic database searches (MEDLINE, CINAHL, PsycINFO; last searched on 03 January 2017), backward/forward citation tracking, and snowballing. All publications were screened against predefined inclusion criteria and evaluated through a quality appraisal. The analytical approach was thematic synthesis.

Results: 99 publications were included. The middle-range theory conceptualises stability as a complex phenomenon comprising three components including eight concepts that are dynamically interrelated. The conceptual model visualises (1) the trajectory of the dementia care arrangement, which involves a cyclic process of *change* and *balancing* over time; (2) the characteristics of the care arrangement, including *needs*, the *carer role*, the *dyadic relationship* and *resources*; and (3) the context, which is determined by *society and culture* and the respective *health care system*. The relevance of each concept in relation to stability changes over time. The forming of each concept is actively shaped by the informal carer.

Discussion: This middle-range theory provides a thorough understanding of the stability of home-based care arrangements for people living with dementia and can be used to guide future research and practice.

Other: This meta-study was funded by the German Center for Neurodegenerative Diseases (DZNE) and registered in PROSPERO (registration number CRD42016041727).

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We developed a middle-range theory (SoCA-Dem theory) that provides an innovative conceptualisation of the phenomenon ‘stability of home-based care arrangements for people living with dementia’.
- The SoCA-Dem theory can guide future research and policy development, and can also be used to improve health and social care practice.
- Currently, we elaborate the interplay of the concepts that constitute ‘stability’ on a descriptive level: causal relationships need to be explored in subsequent empirical research.
- To better understand the complexity of home-based care arrangements, the predominant perspective of the informal carer within the SoCA-Dem theory should be complemented by the perspective of the person living with dementia and the diverse informal and professional supporters.
- This meta-study is based primarily on research from Europe and North America, which might limit the applicability of the SoCA-Dem theory in societies with different cultural contexts.

INTRODUCTION

Worldwide, most people with dementia live at home.[1] It is the explicit wish of most people with dementia to stay in their familiar environments,[2] and most informal carers wish to support the person with dementia at home for as long as possible.[3 4] Driven by this motivation, informal carers are a vital resource for people living with dementia at home and play a crucial role in supporting dementia care in the community.[5] In current research, policy, and practice, these preferences are mirrored in programmatic agendas, such as ‘ageing in place’[6], and reflected by an increasing focus on ‘social health’.[7] These agendas emphasise the capability of people with dementia, their families and their social networks and aim to create prerequisites to enable dyads to live well with dementia in the places of their choice.[8]

This dyadic perspective can be complemented by the perspective of the social security and health care system. In light of demographic changes and the constantly growing prevalence of dementia worldwide,[9] societies are challenged to provide adequate health and social care for an increasing number of ageing individuals and, thus, need to appropriately address limited financial resources. As dementia is among the strongest predictors of cost-intensive institutional care,[10] the support of home-based care has been discussed as an option to reduce expenses.[11]

The stability of home-based care arrangements is an important goal for people living with dementia and their informal carers and reflected by current social security and health care policy. Accordingly, the term ‘stability’ is used as a buzz word in research[12] and policy[13] contexts, but a thorough definition of stability is usually not provided. Often, stability and instability are recognised as opposing phenomena and are operationalised in a binary way. Thus, the transition of a person with dementia from home to an institution is often understood as a demarcation line between stability and instability. The time until institutionalisation greatly varies, and numerous studies have uncovered the predictors and risk factors of institutionalisation,[14] but these studies did not focus on the process that finally leads to the termination of home-based care. Other studies have illuminated the interactions between individuals involved in home-based care,[15] but these interactions were not clearly linked to the phenomenon of stability or instability. In our understanding, continuing to live at home does not necessarily indicate a stable situation, and in the worst case, the needs of the involved persons can be neglected, leading to an exhausting situation for the person with dementia or the informal carer.[16 17] In contrast, living in a nursing home can be perceived as a satisfying and stable living situation. At first glance, the prevalent binary conceptualisation of stability versus instability based on the criterion of institutionalisation is appealing, but at a second glance, this conceptualisation does not capture the complexity of the phenomenon.

The significance of the interactions between all persons involved in a home-based dementia care arrangement and the central importance of the needs of these persons are highlighted in a published working definition of stability (see Figure 1).[18] Here, stability is defined as a dynamic process that unfolds over the trajectory of dementia care that is intentionally shaped by the actors and can be achieved only if the needs of the person with dementia and the informal carer are addressed. This definition is an essential part of the foundation of this meta-study. It reflects the work conducted by Corbin and Strauss[19] regarding managing chronic illness, Nolan, Grant and Keady[20] regarding family care, and von Kutzleben[21] regarding informal dementia care trajectories, all of which conceptualise care as a process of vibrant interactions between individuals over time.

[insert Figure 1: Definition of 'stability of home-based care arrangements for people living with dementia']

The working definition and this meta-study are integral parts of the SoCA project (**S**tability **o**f home-based **C**are **A**rrangements for people living with dementia project) at the German Center for Neurodegenerative Diseases (DZNE), site Witten, Germany. The SoCA project strives to develop a sound theory-based understanding of the complex phenomenon of stability and further explore the newly-developed middle-range theory by conducting subsequent empirical studies using qualitative and quantitative research methodologies to finally identify and develop stability promoting interventions and care structures.

AIM

The aim of this study was to develop a middle-range theory of the 'stability of home-based care arrangements for people living with dementia'. The theory generation process was driven by the following research questions: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors influencing stability?

METHODOLOGY

Study design

We aimed to generate theory from published research findings.[22 23] For this purpose, we performed a meta-study according to the approach described by Paterson and colleagues,[24] and adapted the original meta-study methodology for the integration of mixed research by not only including qualitative but also quantitative, mixed-method studies, as well as systematic reviews. During the theory development process, we considered the recommendations by Liehr and Smith,[25] Im[23] and Risjord[26] regarding the creation of middle-range theories. In the subsequent sections, we provide a very brief description of our methodology. The details of the methodology were published in the respective study protocol.[27] This meta-study is registered at the International Prospective Register of Systematic Reviews (PROSPERO registration number CRD42016041727). The reporting of this publication follows the recommendations in the ENTREQ statement.[28]

Literature search

Following the framework described by Boell and Cecez-Kecmanovic,[29 30] we searched for literature in open-ended 'hermeneutic loops', including the repeated steps of searching, sorting, selecting, acquiring, reading, identifying and refining. In parts, the cyclic literature search process was performed simultaneously with the ongoing data analysis: the final goal of the whole theory building process was to sufficiently encircle our phenomenon of interest by reaching conceptual saturation.[31] The following search techniques were combined: berry picking,[32] database searches, backward and forward citation tracking, and snowballing. The database searches were performed between 24 September 2015 and 16 November 2015 in MEDLINE, CINAHL, and PsycINFO and updated again on 03 January 2017 (referred to as 'updated database searching' in Figure 2). Since the phenomenon of stability is rarely investigated directly, we used our previously published definition of stability[18] to draw from it nine separate search strands and nine syntaxes. The complete syntaxes of the database searches are shown in Appendix A. During the iterative cyclic process of searching and analysing, we included further publications identified through citation tracking and snowballing.

Screening process

The titles and abstracts of all identified studies were screened by four authors (KK, JD, IH, and MvK) in alternating teams of two authors. Full-text screening was performed by one author, who discussed his/her decision with at least one colleague. If disagreement occurred, consensus was reached by discussion. EndNote X7® was used to manage the screening process.

Eligibility criteria

The original meta-study methodology was designed for the synthesis of qualitative research only. In contrast, we decided to include all types of empirical research and (systematic) reviews. The rationale for this decision has been described elsewhere.[27] The inclusion criteria are shown in Appendix B. We included publications written in English, German, or French; no time limits were set.

Quality appraisal

We applied the quality appraisal recommended by Dixon-Woods and colleagues[33], which includes five criteria to identify studies with major methodological deficits (Appendix B). The decision to include or exclude a publication was made based on this quality appraisal and the publication's contribution to the proposed middle-range theory. Each paper was assessed by one researcher. If he/she was in doubt of the methodological quality, he/she discussed the paper with at least one other researcher until consensus was reached.

Analysis and data collection process

A meta-study combines the following three analytical steps, leading to a final meta-synthesis: meta-theory, meta-method and meta-data analyses. During our iterative analytical process, these steps were considered in an integrated process rather than individually. The insights gained from one analytical step immediately shaped the subsequent analyses. All analyses were performed using the Professional Research Software for Qualitative, Quantitative and Mixed Methods Research (MAXQDA 2018). The coding of the data was performed in teams of at least two researchers. As Thomas and Harden[34] translated the widespread method of thematic analysis for the use in systematic reviews, we chose this analysis approach.

Meta-theory

Meta-theory involves a critical exploration of the theoretical frameworks that guided the included research.[24] For each publication, we analysed the stated research gaps, aim(s), research question(s), explicitly stated theoretical frameworks and/or underlying concepts.

Meta-method

Meta-method analyses consider how the application of research methodologies influences the findings and shapes the current understanding of the phenomenon under research.[24] For this purpose, we analysed the study design, methodology, sample, sampling, setting, data collection, data analysis, and standardised measures used in each publication.

Meta-data analysis

A meta-data analysis is a comparative analysis of the findings of all included studies; this analysis contributes to the creation of an integrated body of knowledge.[24] In our extended meta-study approach that included mixed research, we 'qualitised' the quantitative data. Our aim was to understand which concepts applied in quantitative studies are associated with 'stability' and how. Following Pope and colleagues[35] and Sandelowski and colleagues[36] our main approach for 'qualitising' quantitative data was to extract relevant concepts from the texts, tables, and figures of included quantitative studies, mixed-methods studies, and systematic reviews and to compare these concepts across all studies. Concepts applied in quantitative studies often gave indications of an association with (in-)stability, which was examined in depth in qualitative studies. For details on 'qualitising' see also Dreyer and colleagues.[27] We deduced a preliminary coding scheme based on our working definition.[18] Following Thomas and Harden,[34] we extended this coding scheme and analysed the findings of the included studies in three stages. We started the 'line-by-line coding' with a small introductory text set (Figure 2). Gradually, the code system grew by induction, and the new codes were applied for each publication that was added over time while going back and forth in iterative loops of searching and analysing literature. In several coding rounds, the codes were translated to and compared across all publications of the meta-study sample. We organised these codes into 'descriptive themes' and we created major 'analytical themes' that formed the components and concepts of the proposed middle-range theory. Finally, no additional codes emerged from the added studies and conceptual saturation was reached. [31]

Meta-synthesis

In the meta-synthesis, we elaborated upon the relationship between the analytical themes. While we engaged more deeply with the material, at a certain point, the emerging middle-range theory no longer substantially changed. To ensure that the meta-synthesis was complete, we sampled a selection of publications from our sample and reviewed these publications again to determine whether the statements were all consistent with the status quo of the middle-range theory or any statements that might change the theory were overlooked. Our middle-range theory is visualised in a conceptual model that displays the interplay among the components and concepts in an organised form.

Patient and public involvement

Patients or the public were not involved in this meta-study.

RESULTS

Sample description

We included n=99 publications in our meta-study. The detailed process of searching and selecting eligible publications is documented in the flow diagram in Figure 2. During the screening process, n=5 publications were excluded during the quality appraisal. During the analysis phase, the whole 'interventions' search strand was excluded from the sample because the content of the retrieved intervention reviews and studies did not contribute to the intended theory generation. A statement explaining the reasons for this decision is provided in Appendix C. Detailed information of each publication is provided in Appendix D, and a complete bibliography of the included papers is displayed in Appendix E.

The included publications were authored by researchers in North America (the USA n=31 and Canada n=12) and Europe (Germany n=12, the UK n=11, the Netherlands n=8, and other European countries n=12); members of international consortia (n=8); and researchers in Asia or Australia (n=5); however, no publications authored by researchers in Africa or South America were included. The publications cover a wide range of scientific fields, including geriatrics, geriatric psychiatry, gerontology, dementia, nursing, palliative care, social sciences, etc. More than half of the included publications (n=56) were published from 2010 onwards, n=26 were published between 2000 and 2010, n=13 were published in the 1990s, and n=4 were published in the 1980s.

N=50 included studies used quantitative methodologies, and n=31 studies used qualitative methodologies. Furthermore, we included n=7 mixed-methods studies and n=11 systematic reviews (3 synthesised qualitative studies and 9 synthesised quantitative studies). N=54 publications reported studies involving cross-sectional designs, and n=34 publications reported studies involving longitudinal designs.

Only n=21 publications explicitly stated the theoretical framework guiding their research process. Thereby, stress theories and stress models were chosen the most frequently (n=10). In n=78 publications, no explicit theoretical framework was indicated, but the dominance of a stress/burden perspective was also apparent in these publications. For instance, n=71 publications in our sample refer to the work conducted by Zarit[37], Pearlin[38] and/or Aneshensel,[39] who are researchers that advanced the understanding of stress and burden in caregiving. In the discussion section of our article, this conceptual bias and its impact on the development of our middle-range theory are reflected.

[insert Figure 2: Flow diagram]

Components and concepts of the middle-range theory and their interplay

In this meta-study, we developed a middle-range theory of the stability of home-based care arrangements for people living with dementia (called the SoCA-Dem theory) that emphasises the perspective of the informal carer.

The current focus on the informal carer perspective in this middle-range theory is driven by our own previous work concerning informal dementia care trajectories, which identified stability as a guiding principle of informal carers.[21] Therefore, we created a search strategy in which the presence of an informal carer in the home-based care arrangement was mandatory.[27] As a consequence, most identified studies placed the informal carer at the centre of the research. Nevertheless, we are keenly aware that the perspectives of all actors (including the person living with dementia) in care arrangements are meaningful and shape the respective care arrangement, and we reflect upon this conceptual bias in the discussion section of this publication.

We illustrate the middle-range theory in a conceptual model. The model visualises three components comprising eight concepts that altogether constitute stability of home-based care arrangements for people living with dementia from the perspective of the informal carer (see Figure 3).

→ Component 1 – **trajectory**: According to our understanding and consistent with Corbin[40], a chronic illness trajectory refers to the course of an illness/condition over time and the actions that shape that course. The arrow at the bottom visualises the time course of the trajectory of a home-based care arrangement that covers the time span from the onset of the care arrangement to its termination. Above the arrow, a cyclic process displays the events and actions that shape the trajectory. This cyclic process comprises the two concepts of *change* and *balancing* and reruns in many loops over the trajectory.

→ Component 2 – **characteristics**: Four concepts, namely, *needs*, *carer role, dyadic relationship*, and *resources,* and the forming of these concepts characterise the stability of a home-based care arrangement.

→ Component 3 – **context**: The trajectory of a home-based care arrangement and its characteristics are influenced by the context, which includes the two concepts *society and culture* and the *health care system*.

[insert Figure 3: Conceptual model of the stability of home-based care arrangements for people with dementia (SoCA-Dem)]

The components and concepts of this middle-range theory are related in a dynamic interplay and cannot be interpreted in isolation from each other. Each component and concept is entwined with the other components and concepts, and all components and concepts influence and are influenced by the other components and concepts.

At any time in the trajectory, change may occur and trigger an action (balancing) of the informal carer. This balancing influences whether the needs of the person with dementia and the informal carer are successfully met or remain unmet. Balancing influences the informal carer's experience of the carer role, the development of the dyadic relationship and the management of resources. In contrast, met or unmet needs, the specific experiences of the informal carer, the development of the dyadic relationship and the management of resources may enable or hinder the informal carer from balancing in such a way that supports the stability of the care arrangement. In addition, this interplay between change and balancing over time and the characteristics of the care arrangement is influenced by the societal and cultural background and the respective health care system.

Thus, the forming of each concept is variable and change happens over the course of time, here over the care trajectory; each concept can assume a forming that promotes the stability of the home-based care arrangement or a forming that may challenge the stability. In addition, a specific concept in a specific form may have a minor impact on stability at the beginning of the trajectory but a major influence during the late phases, and vice versa. At any time, there can be stable and instable phases.

These mechanisms of the dynamic interplay between the components and concepts of the SoCA-Dem theory are further clarified in the subsequent paragraphs, which introduce the concepts one-by-one. To ensure the readability of the results section, we decided to cite only one key reference for each argument. Appendix D presents information (for each of the included publications) on the question if a publication contributed to our understanding of a specific concept of the developed middle-range theory.

Change

Conceptualisation

To a great extent, the trajectories of home-based dementia care arrangements are driven by change. One major change is the progression of dementia. Dementia is a neurodegenerative syndrome associated with a progressive deterioration of cognitive and physical functioning that increasingly challenges the person with dementia in managing his/her daily life independently. Consequently, the person with dementia often relies on the support of family members, friends, neighbours and professional service providers. The change caused by dementia introduces various additional challenges to the home-based care arrangement. In general, gradual changes can mostly be well balanced, whereas unexpected changes challenge the stability of the home-based care arrangement.

Analyses and synthesis

Table 1 provides an overview of the fields in which change occurs.

[Please format Table 1]

Change related to…	**Fields of change**
the person with dementia	cognition, behaviour, ADL/IADL functioning, physical health, mental health, age
the informal carer	physical health, mental health, ADL/IADL functioning, age
needs	needs of the person with dementia, needs of the informal carer
the carer role	self-conception and external conception of the carer role, having/assuming other roles
the dyadic relationship	roles in the dyad, reciprocity, relationship quality
resources	practical skills, mental resources, financial resources, arrangement of informal/formal networks
society and culture	policy strategy, societal discourse of dementia, demographics, spatial environment
the health care system	policy strategy, availability and financing of health and social care services

Table 1: Overview of the fields of change addressed in the meta-study sample

If change occurs, the informal carer appraises the change and decides whether and how he/she needs to balance the changed situation. The appraisal of change is highly individual as follows: some informal carers interpret the first cognitive symptoms of the person with dementia as a part of normal ageing, while others identify these changes as pathologic and seek a diagnosis.[41] During this phase, some dyads experience a period of uncertainty while coping with 'diagnostic shock',[42] whereas others feel relieved by the final diagnosis.[43] This appraisal of the impact and meaning of a specific change by the informal carer is as important as the change per se.[44]

In the context of this middle-range theory, change is the most crucial if it challenges the stability of the home-based care arrangement and provokes crises that cannot be balanced. MacNeil Vroomen and colleagues[45] built a theory of crises in dementia care. Their conceptualisation of the dementia crisis process and the repeating alternation between imbalance and homeostasis is consistent with our understanding of stability.

Change can trigger positive or negative consequences. If the informal carer can accept the (unavoidable) changes in the person with dementia and the related changes in his/her own life[46] and decide to acknowledge the positive aspects of his/her situation, this may result in supportive changes in his/her attitude and ultimately facilitate the finding of meaning.[47]

Change can be slow, developmental and predictable or rapid, situational and unexpected.[48] Different forms of dementia or rather late or early onset of dementia, can result in different changes.[49] In general, changes that can be foreseen (such as a progressive cognitive decline) are easier to balance than changes that are unexpected (such as a fall).[15] Gradual changes can be monitored without time pressure, whereas in the face of a rapid change, informal carers are must act spontaneously.[50] Some authors have concluded that serious and unexpected changes rather than constant changes are the initial triggers leading the informal carer to start thinking about the termination of home-based care.[51] Liken[52] reported that 80% of the informal carers in her sample moved their relatives with dementia to institutions due to unexpected events.

Balancing

Conceptualisation

Change in a current care situation triggers an action by the informal carer. The most prominent action strategy in the proposed middle-range theory is balancing. Informal carers strive to balance the situation to maintain the stability of their care arrangements. Balancing can either target internal processes (e.g., changing mindset) or practical actions. Imbalance occurs if there is a mismatch between the acute challenge caused by a change and the informal carer's repertoire to adapt to this challenge. If the informal carer loses control and fails to balance the situation, the home-based care arrangement often moves into a crisis, followed by a period of instability.

Analyses and synthesis

We identified balancing as a process that is often divided into four steps. First, the informal carer appraises a change and reflects upon whether he/she should adapt to the change. Thus, the informal carer weighs the risk of taking no action against the perceived benefit of adaptation. Second, the informal carer decides how to adapt to maintain the stability of the situation. Third, the informal carer acts with the intention to balance the care situation. Fourth, the informal carer evaluates whether his/her balancing was adequate to maintain the stability of the care arrangement.[53]

The notion of different types of informal carers who perform balancing in different ways was very prominent in our sample. In some studies, a distinction was made between informal carers who proactively plan ahead for the future and informal carers who delay decisions and actions until they obviously need to react in a crisis.[54] Regarding the maintenance of stability of the home-based care arrangement, a proactive balancing strategy seems to promote stability, whereas a reactive attitude challenges stability.[53]

The following examples illustrate that the fields of actions targeted by the balancing of an informal carer are diverse; informal carers balance the needs of the person with dementia with their own needs to care for their physical and emotional well-being.[55] Regarding the carer role, informal carers balance their mindsets; they accept the fact that their family members have dementia and choose to have a positive attitude,[47] modify their beliefs and expectations,[56] and attempt to find peace of mind.[46] Furthermore, informal carers balance the duties they face in their carer roles with their duties in other roles, such as being a parent or having a professional occupation.[57] Informal carers balance the reciprocity in their dyadic relationships[58] and the interactions within their informal[59] and formal[60] support networks and strive to establish collaborative partnerships.[54] In this context, informal carers value their support networks as an essential source of the support needed to continue in their carer roles.[61] In addition, they balance the challenge of caring for a person with dementia by developing expertise in their knowledge regarding dementia and their practical skills.[43]

Related to our understanding of a trajectory as a cyclic process of change and balancing over time, some publications in our sample contextualised their research with theories concerning chronic illness trajectories[42] and conceptualised dementia care as occurring in phases over time.[62] Some studies shed light on informal carers' balancing throughout the whole care trajectory.[63] However, overall, our sample strongly focused on the decision making of informal carers regarding the institutionalisation of the person with dementia.[64] Therefore, in extent research there is an emphasis on balancing during the phase of the trajectory in which instability is impending or already definite.

Needs

Conceptualisation

The needs of the person living with dementia and the informal carer occupy a central position in our conceptual model because a stable care arrangement can be created and maintained only if these needs are met. Over the trajectory of a home-based care arrangement, needs change, and continuous balancing is necessary. Conflicts due to the competing needs of one person or the divergent needs of both persons in the dyad can emerge and must be resolved to the greatest extent possible.

Analyses and synthesis

A prevailing assumption among the studies in the sample was that the stability of a care arrangement is at risk if the needs of the person with dementia or his/her informal carer are unmet.[65]

Regarding the person with dementia, the commonly stated needs were health-related needs or needs related to limitations in the activities of daily living.[66] These needs were discussed as a consequence of the progression of dementia or ageing and multimorbidity in general. Regarding the informal carer, the identified needs were often related to the consequences of giving care, the informal carers' well-being[67] or lack of resources.[68] Needs related to the lack of resources often included needs for professional support services or educational programmes.[50]

Furthermore, during the analysis process, we identified numerous needs of the person with dementia and the informal carer that were related to one of the concepts of the characteristics of the care arrangement, such as the need to find meaning in the demanding carer role,[47] the need to preserve reciprocity in the dyadic relationship,[46] and the need for resources in the form of a supporting network of family, friends, neighbours and professionals[62] or specific services (such as care).[69] According to these findings, needs represent a concept with a very large conceptual overlap with the other concepts and major influence; whether needs are met or unmet shapes the forming of the other concepts, which, in turn, either promotes or challenges stability. Therefore, our conceptual model positions needs as the central concept.

As dementia progresses, the informal carer becomes increasingly responsible for anticipating the needs of the person with dementia. Considering the needs of the person with dementia and his/her own needs is not an easy task for the informal carer as these needs can be conflicting.[52] Furthermore, the anticipated needs of the person with dementia could also conflict with each other, such as the need for autonomy versus the need for safety.[70] Additionally, the informal carer could have conflicting needs, such as the need to be a dedicated carer and the need to care for him/herself.

Therefore, these conflicts in needs could be distinguished as inter-need conflicts (i.e., the persons in the dyad have conflicting needs) and intra-need conflicts (i.e., the needs of one person conflict with each other).

Carer role

Conceptualisation

The way an informal carer forms his/her carer role has a crucial impact on the stability of home-based care arrangements. Becoming and being an informal carer can be perceived as a positive mission, an undesired obligation or a mélange of both positive and negative experiences. Regarding the stability of home-based care arrangements, how the informal carer assumes the carer role and manages to balance this role with other social roles seem to be important.

Analyses and synthesis

At the very beginning of the trajectory, assuming the carer role is a gradual and unconscious process.[42] Subsequently, informal carers realise their actions and identify as carers.[41] Adapting to the new role is often challenging;[43] for instance, because informal carers assume new responsibilities[71] and feel unprepared,[60] adapting to the new role can be particularly challenging if the beginning of the care trajectory is unexpected.[72]

Assuming the carer role is usually motivated by the dyadic relationship between the informal carer and the person with dementia.[70] In general, there are societal expectations to care for family members. These expectations vary across countries and cultures and are reflected in the respective health care systems.[73]

Informal carers have different feelings regarding their roles. For some informal carers, caring is a reciprocal act as follows:[41] adult children often understand caring as an opportunity to give back to their parents,[47] and spouses often view caring as fulfilling their marriage vows.[58] Being intrinsically motivated to provide care supports stability.[55] A positive appraisal of giving care increases the motivation of the informal carer[70] and the likelihood that he/she will continue caring at home.[74] Intrinsically motivated informal carers take pride in their roles and often experience personal growth.[47] For other informal carers, assuming the carer role is considered a moral obligation.[43] Such carers feel as if they have no choice[52] either because no one else is available[75] or others expect them to provide care.[59] This situation can lead to feelings of entrapment and overload in the carer role.[70] Informal carers who experience few if any positive aspects and feel burdened by their duties have a lower commitment to continue caring at home, tend to develop a desire to institutionalise the person being cared for in the future,[76] and actually end the home-based care arrangement sooner.[77] Attitudes towards the carer role can change over the trajectory of the care arrangement, which was described in the studies in the sample as a modification of beliefs or personal expectations,[56] a cognitive shift,[41] or a result of adapting and learning.[42]

A consequence of assuming the carer role may be role conflicts with other obligations in the life of the informal carer.[57] These obligations can be a professional occupation,[78] the informal carer's family life (especially among carers who have children),[50] or other social interactions with friends or neighbours.[79] In particular, adult children are concerned with conflicting obligations.[53] If the informal carer does not successfully balance his/her social roles, the stability of the care arrangement could be endangered.[80]

Dyadic relationship

Conceptualisation

Caring occurs within relationships, and most informal carers perceive caring as a natural continuation of the dyadic relationship with the person living with dementia. Therefore, the structure of the dyadic relationship (i.e., kinship relation, family status and living situation) and the quality of the dyadic relationship (i.e., primarily the renegotiation of roles and the maintenance of reciprocity) impact the stability of the home-based care arrangement. The direction of the effect of the relationship quality on stability may reverse over the trajectory.

Analyses and synthesis

Most studies in our sample stated that close kinship relationships promote the stability of a home-based care arrangement,[68] whereas distanced kinship relationships increase the likelihood of a prompt cessation of home-based care.[79] In general, spouses tend to continue to care at home the longest,[81] children tend to end home-based care sooner than spouses[82] and other informal carers tend to institutionalise sooner than children.[83] Regarding the family status of the person with dementia, there is consensus that being married or living in a partnership supports whereas being single challenges the continuation of home-based care.[84] The availability of at least one informal carer seems to be indispensable.[85] Living in the same household as the informal carer is supportive of the maintenance of a stable situation at home, whereas living alone is often a challenge.[86] These structural aspects of the dyadic relationship do not directly influence stability but rather function as indicators of the other concepts included in our middle-range theory. The kinship relationship, family status and living situation influence the quality of the dyadic relationship (e.g., spousal affection versus filial piety), the self-construction of the carer role (e.g., motives to provide care), and the availability of informal and formal resources (e.g., having adult children).

A prevailing assumption among the studies in the sample was that a good past or present relationship quality supports the continuation of home-based care, whereas a low past or present relationship quality challenges stability.[46] Over the trajectory, the forming of the dyadic relationship is influenced by changes in the person with dementia. In many chronic illness trajectories, dyadic relationships tend to develop an asymmetric structure, with the carer being dominant. These changes are especially meaningful in a dementia care trajectory as they usually lead to a shift in former roles and are often accompanied by a strong decline in the reciprocity of the dyadic relationship.

In the dementia care trajectory, premorbid roles within the dyadic relationship are questioned and adapted to the current situation.[70] Sometimes, a swap of premorbid (often traditional and gender-related) roles occurs, e.g., carer husbands perform household tasks, carer wives manage financial issues[43] and children assume parent-like roles.[87] Many informal carers perceive this process of adapting long-standing roles in their dyadic relationships as a challenging transition that may be accompanied by a decline in the quality of the dyadic relationship, which is often conceptualised as shrinking reciprocity.

In reciprocal relationships, informal carers have a high willingness to continue care at home.[55] If informal carers appreciate the opportunity to reward the love and care they received in the past,[47] succeed in maintaining affectionate bonds,[61] and continue engaging in activities and rituals that they previously enjoyed,[58] they tend to value their dyadic relationships as reciprocal and find meaning in their carer roles.[88] In contrast, if informal carers start to complain about a decline in the reciprocity of their dyadic relationships, they lost a major source for continuing care.[58] These informal carers report changes in their feelings towards their relatives with dementia,[70] a decreased level of affection,[89] emotional distance and estrangement,[41] and a perception of having fallen out of love[75] and ultimately describe the relationship with the relative with dementia as lost.[70]

Over the trajectory of a care arrangement, the direction of the effect of the dyadic relationship on the stability of the home-based care arrangement may change. At the onset and during the early phases of the trajectory, it is assumed that the closer the kinship relationship is and the higher the quality of the dyadic relationship is, the higher the chance that the home-based care arrangement will remain stable. However, at some point, the direction of this effect may reverse. In the long term, the intent to keep the person with dementia at home for as long as possible is often associated with the expense of the informal carer's physical and mental well-being or the health and safety of the person with dementia.[90] If the informal carer does not anticipate the critical phase when he/she will no longer be able to balance the care situation adequately, he/she might miss the opportunity to ensure a smooth and well-planned termination of home-based care.

Resources

Conceptualisation

Resources are pivotal for informal carers to balance the consequences of constant change and create and maintain a stable care arrangement. The more resources available in general, the more available resources fit the dyad's needs, and the smarter these resources are mobilised, the better the stability of the care arrangement. The availability and use of resources change over the trajectory and can be differentiated as intra-personal resources and inter-personal resources.

Analyses and synthesis

In many publications, various resources were studied to examine their impacts on stability. If informal carers judge their resources as inadequate to balance the situation, the stability of the care arrangement could be endangered.[91]

In the category of intra-personal resources, mental resources (e.g., resilience and related concepts, such as mastery, a sense of competence, and self-efficacy) were the most common resources researched.[92] Skills, such as hands-on care skills or communication skills, were the second most studied group of resources researched in the intra-personal category.[54] Furthermore, many studies focused on the education, income levels[84] and the physical health[45] of the informal carer.

In the category of inter-personal resources, the studies in our sample investigated social support (e.g., family members, friends or neighbours)[84] and formal support (e.g., respite care, community nurses or meal services).[15] Regarding inter-personal resources, notably, the overall amount of potential social or formal support is often less important than the quality of the relationships and interactions between the persons involved.[89] Meaningful interactions and communication between the informal carer and his/her supporters is highly important for the creation of stable care arrangements.[43]

All resources are dynamic and may change during the trajectory of a home-based care arrangement. For instance, the informal carer may experience a decline in support from his/her social network and an increase in social isolation if family members and friends withdraw.[42] In contrast, meaningful new relationships, e.g., with the members of a support group, could grow over the trajectory.[3] The possible positive development of resources, such as increased resilience or the learning of new skills, were discussed as gains of caring,[70] while a decline in resources, such as deteriorating health or decreasing financial resources, were discussed as burdens that may endanger the stability of home-based care.[93]

One study in our sample adopted an explicit strength-based perspective as its theoretical foundation and highlighted the meaning of resources in the context of positive outcomes of caregiving.[3] Other studies explicitly referred to a stress model, e.g., the stress process model[38] or the stress-coping model.[94] In these stress models, resources play an important role in coping with challenging life events. Studies adopting a theoretical perspective focusing on social inequality in the allocation of resources were missing in our sample, which could be interpreted as the lack of a societal perspective and emphasis on the individual/dyadic perspective.

Society and culture

Conceptualisation

Home-based dementia care arrangements are influenced by the society and culture in which the persons with dementia and their informal carers live. Therefore, the prevailing values of a specific culture shape the stability-related context.

Analyses and synthesis

Regarding cultural values, we included studies addressing the societal expectations of different cultures in different geographical regions, e.g., China[95] and Europe,[96] and research addressing the societal expectations of different ethnic groups in one country, e.g., Chinese people in Australia[78] or Latinos in the USA.[97] In some cultures and ethnic groups, prevailing traditional values lead people to prefer family care and refuse to involve professional support services. In such contexts, the included studies described 'caregiving as a fulfilment of cultural values'[97] or a 'powerful cultural tradition of family care'.[96] In a German study, von Kutzleben and colleagues[98] identified the country of origin of the person living with dementia as a significant influencing factor as follows: informal carers who cared for a person with dementia with a migrant background perceived the care situation as more stable than informal carers caring for a care recipient who was native born. Mausbach and colleagues[97] and Sun and colleagues[99] reported that in the USA, Latinos and African Americans tend to institutionalise their relatives later than their Caucasian counterparts.

In cultures bound to traditional values, (mostly female) family members are expected to assume the informal carer role. On the one hand, these informal carers often feel valued by their social networks and tend to have positive attitudes towards their carer roles.[97] On the other hand, informal carers are frequently placed under pressure (by the care recipient him/herself or other family members) to fulfil the expected traditional roles regardless of the personal cost or consequences. Particularly if there are divergent notions of familial obligation between different family members and/or the informal carer refuses to accept the assigned traditional role, role conflicts and family disagreement emerge with possible consequences on the stability of the care arrangement.[78]

Regarding the cultural/societal context, distinctive changes in the near future are expected. The profound demographic changes, increasing number of elderly people, reduction in family size, geographic spread of family members, and workplace participation (of women) could result in the older generation relying on fewer potential family caregivers and a smaller amount of informal resources than before.[100] In relation to cultures still bound to traditional values, 'modern' families may no longer be able to maintain the traditional roles[93] or may consciously shift from the traditional values held by older generations.[78]

Health care system

Conceptualisation

The national policy agenda, the associated promotion of specific formal support services, and the availability and financing of such services affect the informal carer's options to use or reject the use of formal services. In addition, the national policy context and the respective health care system are shaped by the perceived cultural and societal values. This context influences the stability of home-based care arrangements.

Analyses and synthesis

Dramé and colleagues[100] identified the following universally accepted principles in all member countries of the Organisation for Economic Cooperation and Development (OECD): remaining at home for as long as possible, delaying institutionalisation, supporting informal carers, and coordinating services at a local level whenever possible. However, how these principles are incorporated into national policy agendas and implemented in health care insurance systems and care practice widely differ across different cultures and countries worldwide.[73] Some national policy agendas rely on extensive family participation (e.g., Asia, eastern and southern Europe, Germany, and the USA), while in other agendas, the additional integration of formal support services (including institutional care) is highly accepted (e.g., Australia, Western Europe, and Scandinavia). According to these diverse policy aims, how financial resources are governed and allocated varies, which often influences the decision of informal carers to continue or end home care.[85]

In our sample, there was a consensus that most home-based care arrangements require some type of formal support services at some point during the trajectory.[60] Therefore, the use of formal support services may either function as a protective factor for stability because the unmet needs of the care arrangements are addressed or accelerate the termination of home-based care because positive experiences with the increasing integration of formal support services pave the way for the final decision to institutionalise the person with dementia.[82] Informal carers particularly value education and training,[50] case management,[45] home care services,[86] respite services,[98] support groups,[42] hospice services,[101] and financial aid[81] to support the maintenance of a stable situation at home.

The setup of different health care systems and how formal services are promoted and funded seriously affect the availability and use of such services. Informal carers state a need for adequate financial aid.[71] In the US context, Cepoiu-Martin and colleagues[84] reported that a higher percentage of spending on in-home care services and a higher number of home health agencies decreased the risk of nursing home placement. In the Italian context, Sansoni and colleagues[102] argued that the coverage of nursing home costs by the state could increase the rate of nursing home placement. Families who cannot afford to pay for a nursing home avoid placement and tend to continue care at home,[51] but if the costs for institutional care are covered by the state, families with a lower income tend to institutionalise their relatives earlier, while families with a higher income more often continue home-based care as they can pay for community-based services out of pocket.[103]

In summary, the existence and availability of formal support services and adequate financial resources (either covered by a health care system or private means) allow informal carers to decide which formal support services support the maintenance of stability in their current situations.

DISCUSSION

In this meta-study, we developed a middle-range theory of the stability of home-based care arrangements for people living with dementia (SoCA-Dem theory) that emphasises the perspective of the informal carer. We conceptualised stability as a complex phenomenon comprising the following three components: 1. the trajectory of the home-based care arrangement comprising a cyclic process of change and balancing over time; 2. the characteristics of the care arrangement, including the concepts needs, carer role, dyadic relationship and resources; and 3. the context, including the concepts of society and culture and the health care system. Most concepts of the proposed middle-range theory have been well studied individually but have not been examined from an integrative perspective. The strength of this study and additional value of our new middle-range theory are that this study links the concepts to the phenomenon of stability and sheds light on the dynamics linking the components and concepts.

The following three ongoing debates in the scientific community became obvious in our meta-theory and meta-method analyses, influenced our conceptualisation of stability and allowed us to recognise some limitations: 1. the debate concerning predominant research focusing on dyads (mostly from the perspective of the informal carer) versus a more heterogeneous understanding of care arrangements; 2. the debate concerning the predominant stress/burden perspective in research focusing on informal care versus a framing of informal care that also considers positive aspects; and 3. the debate concerning the predominance of retrospective and cross-sectional studies versus the need for prospective and longitudinal studies.

1. As a consequence of the predominant focus of most studies in our sample on informal carers, our middle-range theory primarily reflects the perspective of one actor in the dyadic care arrangement and highlights the pivotal role of the informal carer in the creation and maintenance of stability. This emphasis on the informal caregiver can be interpreted as a limitation that, to some extent, may have been triggered by our search strategy in which the involvement of an informal carer in the care arrangement was chosen as an inclusion criterion. Although we were actually interested in the perspectives of all actors in dyadic care arrangements, the included publications nearly exclusively adopted the perspective of the informal carer and failed to provide insight into the perspectives of the person with dementia and other actors in the care arrangement. There is a vivid debate regarding this prevalent shortcoming in research concerning informal dementia care. For example, Ceci, Brown and Purkis[104] criticised that the heterogeneity of care arrangements is often overlooked. We do not question that the person with dementia has a voice and plays an active role in the creation and maintenance of his/her care arrangement;[2 105] we are aware that there is a growing population of people with dementia who live alone and need to cope without the help of an informal carer;[106] and we know that most home-based care arrangements rely on the support of formal service providers and have a triadic structure.[107] Home-based care arrangements are often diverse 'convoys of care'[108] and will likely become even more diverse in the future due to demographic shifts and changes in gender roles and family structures. In subsequent research, this middle-range theory

should be extended to include diverse actors' perspectives regarding stability, ideally through participative research approaches.[109 110] However, even in its present form, the SoCA-Dem theory is open to a heterogeneous conceptualisation of care arrangements as it already positions diverse informal and formal support networks as pivotal resources for the dyadic care arrangement. In addition, we assume that this middle-range theory may also be valid in the context of diverse chronic diseases. Currently, we hypothesise that our middle-range theory can be applied in future research focusing on more diverse care arrangements and other chronic diseases, but the components and concepts of the theory might change in their meaning and forming.

2. Many publications included in our sample highlighted the progression of dementia as the main driver of change leading to a growing care dependency of the person with dementia and increasing stress and burden for the informal carer. This assumption is mirrored by a high number of publications in our sample that (explicitly or implicitly) used a stress/burden framework as their theoretical perspective and therefore relied on a dominant but increasingly questioned research paradigm.[111] Informal carer burden has often been identified as a main outcome to be studied and targeted in intervention studies, but it has been criticised that this approach usually leads to a mismatch between the simple research logic of 'identified problem – targeted outcome' and the individual and much more complex real-life experiences of dyads living at home.[112] In depth-qualitative research focusing on the structure and underlying meanings of informal caring has been found to be very valuable in this respect. For example, von Kutzleben[21] revealed that informal carers follow their own logics and strategies in response to change. Informal caring proved to be the expression of an individual informal care concept, which can be defined as the intra-personal manifestation of motives, aims and personal boundaries. Considering these individual informal care concepts helps enhance our understanding of how informal carers perceive burden and that the reduction in burden is not necessarily the most important priority of all carers. The authors of the publications included in our meta-study had very diverse understandings of the phenomena of stress and burden. This conceptual ambiguity has also been critically discussed in the literature,[113] and in our case, it complicated a coherent interpretation of the study results regarding burden and its influence on stability. Although the stress/burden perspective was dominant in our sample, in some included studies, the nascent paradigm shift to a more multifaceted understanding of informal dementia care, including positive experiences, was apparent.[5] The SoCA-Dem theory emphasises the coexistence of both positive and negative experiences; for meaningful interpretation, burden and positive experiences always need to be contextualised within the complex interplay of all theory components and concepts.

3. Several up-to-date phase models[21 114 115] emphasise constant change in the everyday lives of dyads living at home, followed by ongoing adaptation in a dynamic non-linear process. Our views are consistent with those described by von Kutzleben,[21] who highlighted the importance of distinguishing between different phases of the dementia care trajectory as in each phase, a different type of change may affect stability in a specific way. According to this study, the middle stages of the trajectory during which the person with dementia is still quite actively involved in everyday life but already has difficulties mastering the activities of daily living independently might be perceived as particularly challenging with regard to the maintenance of stability. In some studies in our sample, the research was contextualised using theories concerning chronic illness trajectories[19] and transitions,[116] and n=34 longitudinal studies showed that researchers valued following dyads over a certain time span. However, there are methodological challenges to assessing the development of trajectories, even in longitudinal research. The definite beginning of a trajectory is difficult to determine. Consequently,

the studies in our sample largely included care arrangements in various and undefined phases within their individual trajectories and did not acknowledge this issue as a limitation. Furthermore, most studies focused on rather late phases of the trajectory, often on the phase during which a transition to an institution occurred. To generate deeper knowledge of stability in all phases of the trajectory, as recommended by Kralik, Visentin and van Loon[117], there is a need for future longitudinal studies that provide valid assessments of the current stage of the trajectory of the individual care arrangement, ideally include care arrangements at the very beginning of their trajectories and follow such trajectories over a long period. In this type of longitudinal study, the focus should be on the specific forming of each concept of our middle-range theory during each phase of the trajectory and the influence of each concept on the creation of stability.

Limitations

This meta-study has limitations. Although we critically reflected and discussed its results with peer researchers, our theoretical perspective as well as our previous empirical research influenced the development of the SoCA-Dem theory. Theoretically, we conceptualised dementia care as a trajectory that is shaped by the interaction of individuals over time.[19 20] Empirically, the study by von Kutzleben[21] identified the maintenance of stability as a leading principle of informal carers and shed light on this specific perspective. Furthermore, our working definition[18] guided the deduction of the search strands and the preliminary coding scheme for this meta-study. Though the concepts of the new theory were created in an inductive and reflexive approach in the analysis phase, further research is needed to reduce existing bias within the SoCA-Dem theory. According to Roy,[118] the circular relationship of theory to research to practice is particularly evident in middle-range theories. Their use in research and practice provides feedback for further theory development.[25] Currently, we elaborate the interplay of the theory concepts on a descriptive level. We provide a middle-range theory that helps to organise and interpret the relationships of relevant concepts, and that is rather constitutive than causal.[26] To enhance the explanatory power of the SoCA-Dem theory, the causal relationships between the concepts need clarification beyond the current level. Another limitation concerns the dominance of research from Europe and North America in our sample. The possibility to reflect social and cultural differences was incorporated in the concept *society and culture* as well as in the concept *health care system*. Nevertheless, our SoCA-Dem theory might be influenced by a western perspective and therefore its applicability in other contexts needs to be explored. Finally, an additional limitation is grounded in the large number of included studies. To analyse and synthesise all these studies was time-consuming. For this reason, we did not perform the theoretical sampling as extensively as we planned according to the study protocol,[27] and the time between the last database search and the publication of this meta-study is rather long.

CONCLUSION

This middle-range theory conceptualises the phenomenon of the stability of home-based care arrangements for people living with dementia. By adopting the perspective of the informal carer, the SoCA-Dem theory contributes to an enhanced understanding of the dynamic processes that contribute to stable or instable phases within the often long-lasting dementia care trajectory.

Elaborating upon the perspective of the person with dementia is a necessary important goal for future research focusing on 'stability' and will enhance our understanding of the identified components and concepts. In addition to the aspired inclusion of the perspective of the person with dementia and other actors involved in home-based care arrangements, we highlight the need to further clarify the conceptual overlap and interplay of the theoretical components and concepts and the need to better understand the development of stability in all phases of the dementia care trajectory. All this will contribute to an ongoing improvement of the explanatory power of the SoCA-Dem theory and to its usefulness for scientists and health care practitioners. In the SoCA project, we address the current knowledge gaps in subsequent empirical research applying qualitative and quantitative methods. We aim to be able to distinguish between stable and unstable care arrangements and identify or develop interventions. Already, our middle-range theory can provide guidance for health care providers and policy makers: The concepts of the SoCA-Dem theory define topics that need to be considered to support the stability of home-based care arrangements. Support should be adapted to the individual forming of the concepts in the respective care arrangement. Effective interventions have to take into account the specific needs of the person living with dementia and the informal carer at a particular point of time.

Finally, we encourage the scientific community, policy makers and health care providers to use, reflect upon and refine the SoCA-Dem theory and contribute to the ongoing discourse regarding stability to better enable dyads to live in the place of their choice currently and in the future.

Author Contributions

KK, JD, IH, MvK and BH substantially contributed to the conception and design of this meta-study, including the development of the research questions, search strategies, eligibility criteria, data extraction schemes and analytic procedures. KK, JD, IH and MvK performed the coding process. KK, JD, and IH performed the data analysis and synthesis process. The proposed middle-range theory was repeatedly discussed, refined and finalised as a team by all authors (KK, JD, IH, MvK, CP, MR, BH). KK, JD and IH contributed to the draft of this manuscript. All authors read, provided feedback and approved the final manuscript.

Acknowledgements

René Müller-Widmer, Saskia Kelinski, Christina Manietta and Jana Isabelle Braunwarth supported the author team in specific analyses and the layout of the tables and graphic material.

Competing interests

None declared.

Funding

This meta-study was financed by the budget of the German Center for Neurodegenerative Diseases (DZNE). Award/Grant number is not applicable.

Ethical approval

Ethical approval is not required for this meta-study.

Patient consent

Not required.

Data availability statement

No additional data available.

REFERENCES

1. World Health Organization. Dementia: a public health priority. Geneva: World Health Organization 2012.
2. von Kutzleben M, Schmid W, Halek M, et al. Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging Ment Health* 2012;16(3):378-90. doi: 10.1080/13607863.2011.614594 [published Online First: 2012/01/18]
3. Peacock S, Forbes D, Markle-Reid M, et al. The Positive Aspects of the Caregiving Journey With Dementia: Using a Strengths-Based Perspective to Reveal Opportunities. *J Appl Gerontol* 2010;29(5):640-59. doi: 10.1177/0733464809341471
4. Wadham O, Simpson J, Rust J, et al. Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. *Aging Ment Health* 2016;20(5):463-73. doi: 10.1080/13607863.2015.1023769 [published Online First: 2015/03/27]
5. Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud* 2018;79(1–26):1-26. doi: 10.1016/j.ijnurstu.2017.10.008
6. Vasunilashorn S, Steinman BA, Liebig PS, et al. Aging in Place: Evolution of a Research Topic Whose Time Has Come. *J Aging Res* 2012;2012:120952. doi: 10.1155/2012/120952
7. Dröes RM, Chattat R, Diaz A, et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging Ment Health* 2017;21(1):4-17. doi: 10.1080/13607863.2016.1254596 [published Online First: 2016/11/21]
8. Bartlett R, Brannelly T. Life at home for people with a dementia. Abingdon & New York: Routledge 2019.
9. Prince M, Wimo A, Guerchet M, et al. World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International 2015.
10. Hajek A, Brettschneider C, Lange C, et al. Longitudinal Predictors of Institutionalization in Old Age. *PloS one* 2015;10(12):e0144203. doi: 10.1371/journal.pone.0144203 [published Online First: 2015/12/15]
11. Schaller S, Mauskopf J, Kriza C, et al. The main cost drivers in dementia: a systematic review. *Int J Geriatr Psychiatry* 2015;30(2):111-29. doi: 10.1002/gps.4198 [published Online First: 2014/10/17]
12. Vukoman M, Rüßler H. (Ehe-)Partnerschaft im Kontext der Pflegebedürftigkeit. *Z Gerontol Geriatr* 2019 doi: 10.1007/s00391-019-01639-8
13. Bundesministerium für Gesundheit. Zukunftswerkstatt Demenz. Berlin2017.
14. Toot S, Swinson T, Devine M, et al. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatr* 2017;29(2):195-208. doi: 10.1017/s1041610216001654
15. Caron CD, Ducharme F, Griffith J. Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Can J Aging* 2006;25(2):193-205. doi: 10.1353/cja.2006.0033 [published Online First: 2006/07/06]

16. Wiglesworth A, Mosqueda L, Mulnard R, et al. Screening for Abuse and Neglect of People with Dementia. *J AM GERIATR SOC* 2010;58(3):493-500. doi: 10.1111/j.1532-5415.2010.02737.x

17. Wharton TC, Ford BK. What Is Known About Dementia Care Recipient Violence and Aggression Against Caregivers? *J Gerontol Soc Work* 2014;57(5):460-77. doi: 10.1080/01634372.2014.882466

18. von Kutzleben M, Köhler K, Dreyer J, et al. Stabilität von häuslichen Versorgungsarrangements für Menschen mit Demenz. Entwicklung und Konsentierung einer Definition von Stabilität durch Expertenfokusgruppen. *Z Gerontol Geriatr* 2017;50(3):210-18. doi: 10.1007/s00391-015-0990-0 [published Online First: 22.12.2015]

19. Corbin JM, Strauss A. Unending work and care: Managing chronic illness at home. San Francisco: Jossey-Bass 1988.

20. Nolan M, Grant G, Keady J. Understanding family care: a multidimensional model of caring and coping. Milton Keynes: Open University Press 1996.

21. von Kutzleben M. Häusliche Versorgung von Menschen mit Demenz - Rekonstruktion des Versorgungshandelns informeller Versorgungspersonen im Zeitverlauf: Beltz Juventa 2018.

22. Smith MJ, Liehr PR. Middle Range Theory for Nursing, Fourth Edition. 4th ed. ed. New York: Springer Publishing Company 2018.

23. Im E-O. Theory Development Strategies for Middle-Range Theories. *ANS Adv Nurs Sci* 2018;41(3):275-92. doi: 10.1097/ans.0000000000000215

24. Paterson BL, Thorne SE, Canam C, et al. Meta-Study of Qualitative Health Research. Thousand Oaks, London, New Delhi: Sage Publications 2001.

25. Liehr P, Smith MJ. Middle Range Theory: A Perspective on Development and Use. *ANS Adv Nurs Sci* 2017;40(1):51–63. doi: 10.1097/ANS.0000000000000162

26. Risjord M. Middle-range theories as models: New criteria for analysis and evaluation. *Nurs Philos* 2019;20(1):e12225. doi: 10.1111/nup.12225

27. Dreyer J, Köhler K, Hochgraeber I, et al. Stability of home-based care arrangements for people living with dementia: protocol of a meta-study on mixed research. *BMJ Open* 2018;8:e021156. doi: 10.1136/bmjopen-2017-021156

28. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12:181. doi: 10.1186/1471-2288-12-181 [published Online First: 2012/11/29]

29. Boell SK, Cecez-Kecmanovic D. Literature reviews and the hermeneutic circle. *AARL* 2010;41(2):129-44. doi: 10.1080/00048623.2010.10721450 [published Online First: 2013/07/08]

30. Boell SK, Cecez-Kecmanovic D. A hermeneutic approach for conducting literature reviews and literature searches. *Commun Assoc Inf Syst* 2014;34(12):257-86. doi: 10.17705/1CAIS.03412 [published Online First: 2012/05/17]

31. Finfgeld-Connett D, Johnson ED. Literature search strategies for conducting knowledge-building and theory-generating qualitative systematic reviews. *J Adv Nurs* 2013;69(1):194-204. doi: 10.1111/j.1365-2648.2012.06037.x [published Online First: 2014/01/01]

32. Bates MJ. The design of browsing and berrypicking techniques for the online search interface. *Onl Rev* 1989;13(5):407-24. doi: 10.1108/eb024320

33. Dixon-Woods M, Kirk MD, Agarwal MS, et al. Vulnerable groups and access to health care: a critical interpretive review. National Coordinating Centre NHS Service Delivery Organ RD (NCCSDO)2005.

34. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8(45) doi: 10.1186/1471-2288-8-45 [published Online First: 2008/07/10]

35. Pope C, Mays N, Popay J. Synthesising qualitative and quantitative health evidence. A guide to methods: McGraw-Hill Education (UK) 2007.

36. Sandelowski M, Voils CI, Barroso J. Defining and Designing Mixed Research Synthesis Studies. *Res Sch* 2006;13(1):29. [published Online First: 2006/04/01]

37. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649-55. doi: 10.1093/geront/20.6.649 [published Online First: 1980/12/01]

38. Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30(5):583-94. [published Online First: 1990/10/01]

39. Aneshensel CS, Pearlin LI, Mullan JT, et al. Profiles in caregiving: The unexpected career: Elsevier 1995.

40. Corbin JM. The Corbin and Strauss Chronic Illness Trajectory model: an update. *Sch Inq Nurs Pract* 1998;12(1):33-41.

41. Willoughby J, Keating N. Being in control: the process of caring for a relative with Alzheimer's disease. *Qual Health Res* 1991;1(1):27–50. doi: 10.1177/104973239100100103

42. Lindgren CL. The caregiver career. *J Nurs Scholarsh* 1993;25(3):214-19. doi: 10.1111/j.1547-5069.1993.tb00784.x

43. Frewer-Graumann S. Zwischen Fremdfürsorge und Selbstfürsorge: Familiale Unterstützungsarrangements von Menschen mit Demenz und ihren Angehörigen. Wiesbaden: Springer VS 2014.

44. de Vugt ME, Stevens F, Aalten P, et al. A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *Int Psychogeriatr* 2005;17(4):577-89. doi: 10.1017/S1041610205002292 [published Online First: 2005/09/27]

45. MacNeil Vroomen J, Bosmans JE, van Hout HP, et al. Reviewing the definition of crisis in dementia care. *BMC Geriatr* 2013;13(10) doi: 10.1186/1471-2318-13-10

46. Shim B. Finding Meaning in the Dementia Caregiving Relationship. (Doctoral dissertation) Duke University, 2011.

47. Lloyd J, Patterson T, Muers J. The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London)* 2016;15(6):1534-61. doi: 10.1177/1471301214564792 [published Online First: 2014/12/31]

48. Liken MA. Caregivers in crisis: moving a relative with Alzheimer's to assisted living. *Clin Nurs Res* 2001;10(1):52-68. doi: 10.1177/c10n1r6 [published Online First: 2002/03/08]

49. Bakker C, de Vugt ME, van Vliet D, et al. Predictors of the time to institutionalization in young-versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *J AM MED DIR ASSOC* 2013;14(4):248-53. doi: 10.1016/j.jamda.2012.09.011 [published Online First: 2012/11/02]

50. Toot S, Hoe J, Ledgerd R, et al. Causes of crises and appropriate interventions: the views of people with dementia, carers and healthcare professionals. *Aging Ment Health* 2013;17(3):328-35. doi: 10.1080/13607863.2012.732037 [published Online First: 2012/11/16]

51. Oliva y Hausmann A, Schacke C, Zank S. Pflegende Angehörige von demenziell Erkrankten : welche Faktoren beeinflussen den Transfer von der häuslichen in die stationäre Pflege? *Psychother Psychosom Med Psychol* 2012;62(9-10):367-74. doi: 10.1055/s-0032-1323708

52. Liken MA. Critical incidents precipitating institutionalization of a relative with Alzheimer's. *West J Nurs Res* 2001;23(2):163-78. doi: 10.1177/019394590102300205 [published Online First: 2001/03/29]

53. Wackerbarth S. Modeling a Dynamic Decision Process: Supporting the Decisions of Caregivers of Family Members with Dementia. *Qual Health Res* 1999;9(3):294-314. doi: 10.1177/104973299129121875

54. Davis LL, Chestnutt D, Molloy M, et al. Adapters, strugglers, and case managers: a typology of spouse caregivers. *Qual Health Res* 2014;24(11):1492-500. doi: 10.1177/1049732314548879 [published Online First: 2014/09/04]

55. Donovan ML. Edification of dementia caregiver uplifts characteristics. (Doctoral dissertation) Capella University, 2006.

56. Coe M, Neufeld A. Male caregivers' use of formal support. *West J Nurs Res* 1999;21(4):568-88. doi: 10.1177/01939459922044045

57. Schirra-Weirich L, Wiegelmann H. Typenbildung als Beitrag zur Weiterentwicklung von Versorgungsstrukturen für Menschen mit Demenz und ihren versorgenden Angehörigen. Ergebnisse einer Tandem-Studie im Rahmen des Modellprojekts "DemenzNetz Städte Region Aachen". In: Schäfer-Walkmann S, Traub F, eds. Evolution durch Vernetzung - Beiträge zur interdisziplinären Versorgungsforschung. Wiesbaden: Springer VS 2017:59-76.

58. Wuest J, Ericson PK, Stern PN. Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. *J Adv Nurs* 1994;20(3):437–43. doi: 10.1016/j.pec.2014.01.009

59. Chang YP, Schneider JK, Sessanna L. Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *J Aging Stud* 2011;25(4):436-44. doi: 10.1016/j.jaging.2011.05.001

60. Lethin C, Hallberg IR, Karlsson S, et al. Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scand J Caring Sci* 2016;30(3):526-34. doi: 10.1111/scs.12275 [published Online First: 2015/09/09]

61. Donovan ML, Corcoran MA. Description of Dementia Caregiver Uplifts and Implications for Occupational Therapy. *Am J Occup Ther* 2010;64(4):590-95 doi: 10.5014/ajot.2010.09064

62. Daly L, McCarron M, Higgins A, et al. 'Sustaining Place' - a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *J Clin Nurs* 2012;22(3-4):501-12. doi: 10.1111/jocn.12003 [published Online First: 2012/11/21]

63. Groen-van de Ven L, Smits C, Oldewarris K, et al. Decision Trajectories in Dementia Care Networks Decisions and Related Key Events. *J Aging Res* 2017;39(9):1039-71. doi: 10.1177/0164027516656741 [published Online First: 2016/07/08]

64. Ducharme F, Couture M, Lamontagne J. Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Serv Q* 2012;31(3):197-218. doi: 10.1080/01621424.2012.681572

65. Scholzel-Dorenbos CJ, Meeuwsen EJ, Olde Rikkert MG. Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. *Aging Ment Health* 2010;14(1):113-9. doi: 10.1080/13607860903046495 [published Online First: 2010/02/16]

66. Gaugler JE, Kane RL, Kane RA, et al. Unmet care needs and key outcomes in dementia. *J AM GERIATR SOC* 2005;53(12):2098-105. doi: 10.1111/j.1532-5415.2005.00495.x [published Online First: 2005/10/07]

67. McLennon SM, Habermann B, Davis LL. Deciding to institutionalize: Why do family members cease caregiving at home? *J Neurosci Nurs* 2010;42(2):95-103. doi: 10.1097/JNN.0b013e3181ce5c45

68. Gallagher D, Mhaolain AN, Crosby L, et al. Determinants of the desire to institutionalize in Alzheimer’s caregivers. *AM J ALZHEIMERS DIS* 2011;26(3):205-11. doi: 10.1177/1533317511400307 [published Online First: 2011/03/04]

69. Glass AP. Family Caregiving and the Site of Care: Four Narratives About End-of-Life Care for Individuals with Dementia. *J Soc Work End Life Palliat Care* 2016;12(1-2):23-46. doi: 10.1080/15524256.2016.1156605 [published Online First: 2016/05/04]

70. Quinn C, Clare L, Woods RT. Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London)* 2015;14(2):220-37. doi: 10.1177/1471301213495863 [published Online First: 2013/12/18]

71. Afram B, Verbeek H, Bleijlevens MHC, et al. Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *Int Psychogeriatr* 2015;27(6):891-902. doi: 10.1017/S1041610214002154 [published Online First: 2014/10/07]

72. Gaugler JE, Kane RL, Kane RA, et al. The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychol Aging* 2005;20(1):100-16. doi: 10.1037/0882-7974.20.1.100

73. Afram B, Stephan A, Verbeek H, et al. Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *J AM MED DIR ASSOC* 2014;15(2):108-16. doi: 10.1016/j.jamda.2013.09.012 [published Online First: 2013/11/12]

74. Kajiwara K, Nakatani H, Ono M, et al. Positive appraisal of in-home family caregivers of dementia patients as an influence on the continuation of caregiving. *PSYCHOGERIATRICS* 2015;15(1):26-31. doi: 10.1111/psyg.12074 [published Online First: 2014/12/18]

75. Lewis LF. Caregiving for a Loved One With Dementia at the End of Life. *AM J ALZHEIMERS DIS* 2015;30(5):488-96. doi: 10.1177/1533317514559829 [published Online First: 2014/11/25]

76. Cohen CA, Gold DP, Shulman KI, et al. Positive aspects in caregiving: An overlooked variable in research. *Can J Aging* 1994;13(3):378-91. doi: 10.1017/S071498080000619X

77. Gaugler JE, Yu F, Krichbaum K, et al. Predictors of nursing home admission for persons with dementia. *Med Care* 2009;47(2):191-8. doi: 10.1097/MLR.0b013e31818457ce [published Online First: 2009/01/27]

78. Caldwell L, Low LF, Brodaty H. Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *Int Psychogeriatr* 2014;26(3):413-24. doi: 10.1017/s1041610213002020 [published Online First: 2013/11/22]

79. Gilhooly MLM. Senile dementia: Factors associated with caregivers' preference for institutional care. *Br J Med Psychol* 1986;59(2):165-71. doi: 10.1111/j.2044-8341.1986.tb02681.x

80. Kwon SH, Tae YS. Nursing Home Placement: The Process of Decision Making and Adaptation among Adult Children Caregivers of Demented Parents in Korea. *Asian Nurs Res* 2012;6(4):143-51. doi: 10.1016/j.anr.2012.10.005 [published Online First: 2012/12/01]

81. Luppa M, Luck T, Brähler E, et al. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord* 2008;26(1):65-78. doi: 10.1159/000144027 [published Online First: 2008/07/12]

82. Runte R. Predictors of institutionalization in people with dementia: a survey linked with administrative data. *Aging Clin Exp Res* 2018;30(1):35-43. doi: 10.1007/s40520-017-0737-4 [published Online First: 2017/03/01]

83. Ebly EM, Hogan DB, Rockwood K. Living alone with dementia. *Dement Geriatr Cogn Disord* 1999;10(6):541-8. doi: 10.1159/000017202

84. Cepoiu-Martin M, Tam-Tham H, Patten S, et al. Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis. *Int J Geriatr Psychiatry* 2016;31(11):1151-71. doi: 10.1002/gps.4449 [published Online First: 2016/04/04]

85. Saks K, Tiit EM, Verbeek H, et al. Most appropriate placement for people with dementia: individual experts' vs. expert groups' decisions in eight European countries. *J Adv Nurs* 2015;71(6):1363-77 doi: 10.1111/jan.12544 [published Online First: 2014/10/10]

86. Ledgerd R, Hoe J, Hoare Z, et al. Identifying the causes, prevention and management of crises in dementia. An online survey of stakeholders. *Int J Geriatr Psychiatry* 2016;31(6):638-47. doi: 10.1002/gps.4371 [published Online First: 2015/10/23]

87. Redfern S, Norman I, Briggs K, et al. Care at home for people with dementia: routines, control and care goals. *QAOA* 2002;3(4):12-23. doi: 10.1108/14717794200200023

88. Hirschfeld M. Home care versus institutionalization: family caregiving and senile brain disease. *Int J Nurs Stud* 2003;40(5):463-9. doi: 10.1016/S0020-7489(03)00063-4

89. Spitznagel MB, Tremont G, Davis JD, et al. Psychosocial predictors of dementia caregiver desire to institutionalize: caregiver, care recipient, and family relationship factors. *J Geriatr Psychiatry Neurol* 2006;19(1):16-20. doi: 10.1177/0891988705284713

90. Kraijo H, de Leeuw R, Schrijvers G. How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scand J Caring Sci* 2015;29(1):101-9. doi: 10.1111/scs.12137 [published Online First: 2014/04/05]

91. Schacke C, Zank S. Zur familiaren Pflege demenzkranker Menschen: Die differentielle Bedeutung spezifischer Belastungsdimensionen fur das Wohlbefinden der Pflegenden und die Stabilitat

der hauslichen Pflegesituation. *Z Gerontol Geriatr* 1998;31(5):355-61. [published Online First: 1998/12/16]

92. Gaugler JE, Kane RL, Newcomer R. Resilience and transitions from dementia caregiving. *J GERONTOL B-PSYCHOL* 2007;62(1):P38-44. doi: 10.1093/geronb/62.1.P38
93. Chang YP, Schneider JK. Decision-making process of nursing home placement among Chinese family caregivers. *PERSPECT PSYCHIATR C* 2010;46(2):108-18. doi: 10.1111/j.1744-6163.2010.00246.x [published Online First: 2010/05/25]
94. Lazarus RS, Folkman S. Stress, Appraisal, and Coping. New York: Springer Publishing Company 1984.
95. Cheng ST, Mak EP, Lau RW, et al. Voices of Alzheimer Caregivers on Positive Aspects of Caregiving. *Gerontologist* 2015 doi: 10.1093/geront/gnu118 [published Online First: 2015/01/24]
96. Verbeek H, Meyer G, Challis D, et al. Inter-country exploration of factors associated with admission to long-term institutional dementia care: Evidence from the RightTimePlaceCare study. *J Adv Nurs* 2015;71(6):1338-50. doi: 10.1111/jan.12663 [published Online First: 2015/04/14]
97. Mausbach BT, Coon DW, Depp C, et al. Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. *J AM GERIATR SOC* 2004;52(7):1077-84. doi: 10.1111/j.1532-5415.2004.52306.x [published Online First: 2004/06/24]
98. von Kutzleben M, Reuther S, Dortmann O, et al. Care arrangements for community-dwelling people with dementia in Germany as perceived by informal carers - a cross-sectional pilot survey in a provincial-rural setting. *Health Soc Care Community* 2015;24(3):283-96. doi: 10.1111/hsc.12202 [published Online First: 2015/03/03]
99. Sun F, Durkin DW, Hilgeman MM, et al. Predicting desire for institutional placement among racially diverse dementia family caregivers: the role of quality of care. *Gerontologist* 2013;53(3):418-29. doi: 10.1093/geront/gns110 [published Online First: 2012/09/11]
100. Dramé M, Lang PO, Jolly D, et al. Nursing home admission in elderly subjects with dementia: predictive factors and future challenges. *J AM MED DIR ASSOC* 2012;13(1):83.e17-20. doi: 10.1016/j.jamda.2011.03.002 [published Online First: 2011/04/13]
101. Badrakalimuthu V, Barclay S. Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age Ageing* 2014;43(1):13-9. doi: 10.1093/ageing/aft151 [published Online First: 2013/10/14]
102. Sansoni J, Anderson KH, Varona LM, et al. Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Ann Ig* 2013;25(3):235-46. doi: 10.7416/ai.2013.1926 [published Online First: 2013/04/20]
103. Mittelman MS, Ferris SH, Shulman E, et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA* 1996;276(21):1725-31. doi: 10.1001/jama.1996.03540210033030 [published Online First: 1996/12/04]
104. Ceci C, Symonds Brown H, Purkis ME. Seeing the collective: family arrangements for care at home for older people with dementia. *Ageing Soc* 2018;39(6):1200-18. doi: 10.1017/S0144686X17001477 [published Online First: 01/11]
105. Read ST, Toye C, Wynaden D. The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia (London)* 2018:1471301218784806. doi: 10.1177/1471301218784806
106. Eichler T, Hoffmann W, Hertel J, et al. Living Alone with Dementia: Prevalence, Correlates and the Utilization of Health and Nursing Care Services. *J Alzheimers Dis* 2016;52(2):619-29. doi: 10.3233/jad-151058 [published Online First: 2016/04/01]
107. Quinn C, Clare L, McGuinness T, et al. Negotiating the balance: the triadic relationship between spousal caregivers, people with dementia and Admiral Nurses. *Dementia (London)* 2013;12(5):588-605. doi: 10.1177/1471301212437780 [published Online First: 2013/12/18]

108. Kemp CL, Ball MM, Perkins MM. Convoys of care: theorizing intersections of formal and informal care. *J Aging Stud* 2013;27(1):15-29. doi: 10.1016/j.jaging.2012.10.002 [published Online First: 2013/01/01]

109. Gove D, Diaz-Ponce A, Georges J, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health* 2018;22(6):723-29. doi: 10.1080/13607863.2017.1317334

110. Bethell J, Commisso E, Rostad HM, et al. Patient engagement in research related to dementia: A scoping review. *Dementia (London)* 2018;17(8):944-75. doi: 10.1177/1471301218789292 [published Online First: 2018/10/31]

111. Purkis ME, Ceci C. Problematising care burden research. *Aging Soc* 2015;35(7):1410 - 28.

112. Ceci C, Symonds Brown H, Judge H. Rethinking the assumptions of intervention research concerned with care at home for people with dementia. *Dementia (London)* 2018 doi: 10.1177/1471301218790037

113. Bastawrous M. Caregiver burden - A critical discussion. *Int J Nurs Stud* 2013;50(3):431-41. doi: 10.1016/j.ijnurstu.2012.10.005 [published Online First: 2012/11/08]

114. Esandi N, Nolan M, Alfaro C, et al. Keeping Things in Balance: Family Experiences of Living With Alzheimer's Disease. *Gerontologist* 2018;58(2):e56-e67. doi: 10.1093/geront/gnx084 [published Online First: 2017/06/22]

115. Clemmensen TH, Busted LM, Soborg J, et al. The family's experience and perception of phases and roles in the progression of dementia: An explorative, interview-based study. *Dementia (London)* 2019;18(2):490-513. doi: 10.1177/1471301216682602 [published Online First: 2016/12/09]

116. Meleis AI, Sawyer LM, Im EO, et al. Experiencing transitions: an emerging middle-range theory. *Ans Adv Nurs Sci* 2000;23(1):12-28. [published Online First: 2000/09/02]

117. Kralik D, Visentin K, Van Loon A. Transition: a literature review. *J Adv Nurs* 2006;55 doi: 10.1111/j.1365-2648.2006.03899.x

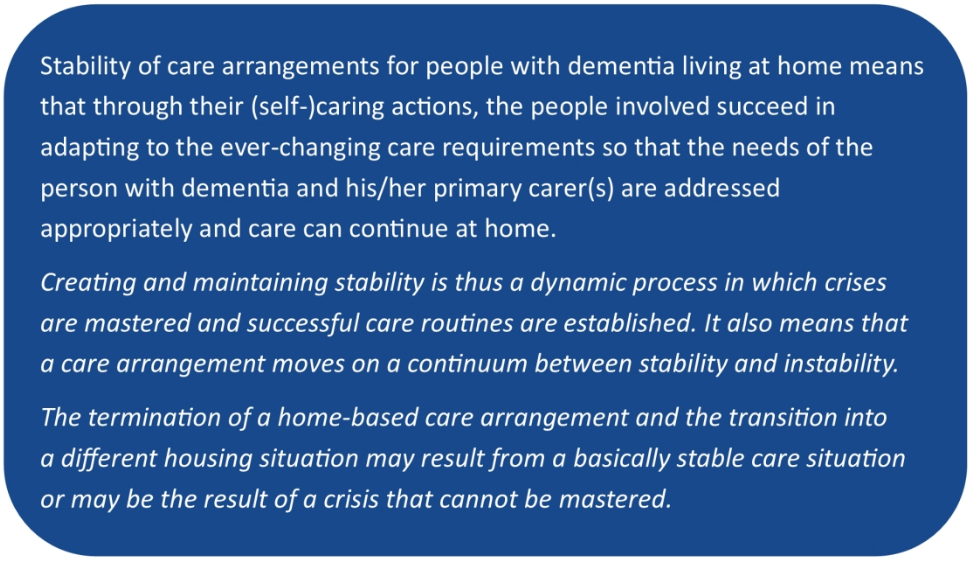
118. Roy C. Generating middle range theory. From evidence to practice. New York: Springer Pub 2014.

Figure legends

Figure 1: Definition of stability of home-based care arrangements for people living with dementia

Figure 2: Flow diagram

Figure 3: Conceptual model of stability of home-based care arrangements for people living with dementia (SoCA-Dem)



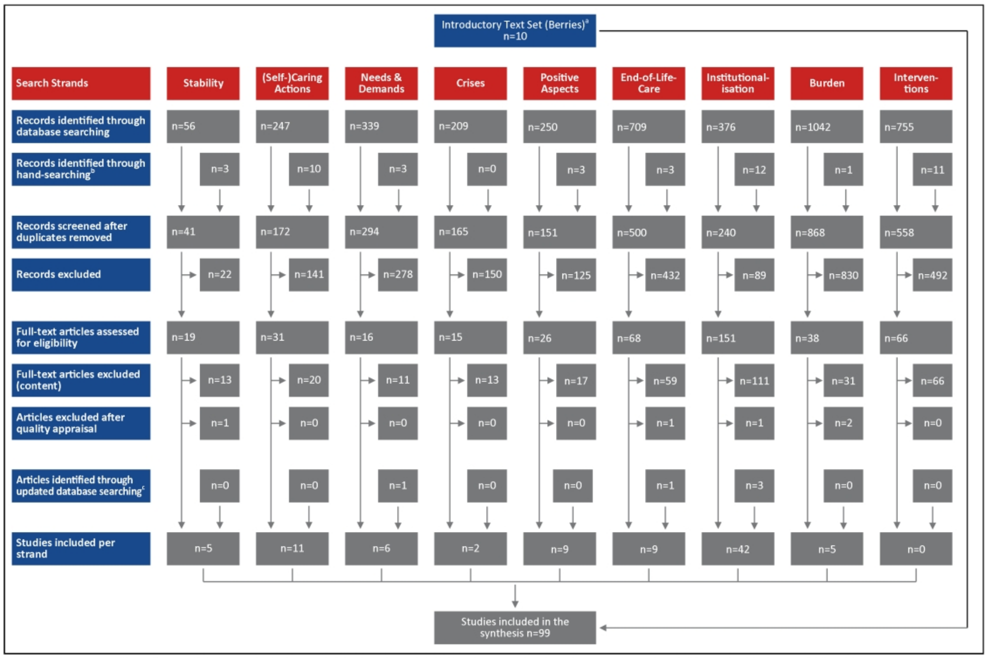
Stability of care arrangements for people with dementia living at home means that through their (self-)caring actions, the people involved succeed in adapting to the ever-changing care requirements so that the needs of the person with dementia and his/her primary carer(s) are addressed appropriately and care can continue at home.

Creating and maintaining stability is thus a dynamic process in which crises are mastered and successful care routines are established. It also means that a care arrangement moves on a continuum between stability and instability.

The termination of a home-based care arrangement and the transition into a different housing situation may result from a basically stable care situation or may be the result of a crisis that cannot be mastered.

Figure 1: Definition of ‘stability of home-based care arrangements for people living with dementia’

163x96mm (300 x 300 DPI)



a: the introductory text set ("berries") was established prior to the database search; **b**: hand-searching included backward citation tracking, forward citation tracking, and snowballing; c: updated database search followed the same process as the initial search, with the removal of duplicates, screening and assessment for eligibility

Figure 2: Flow diagram

303x209mm (300 x 300 DPI)

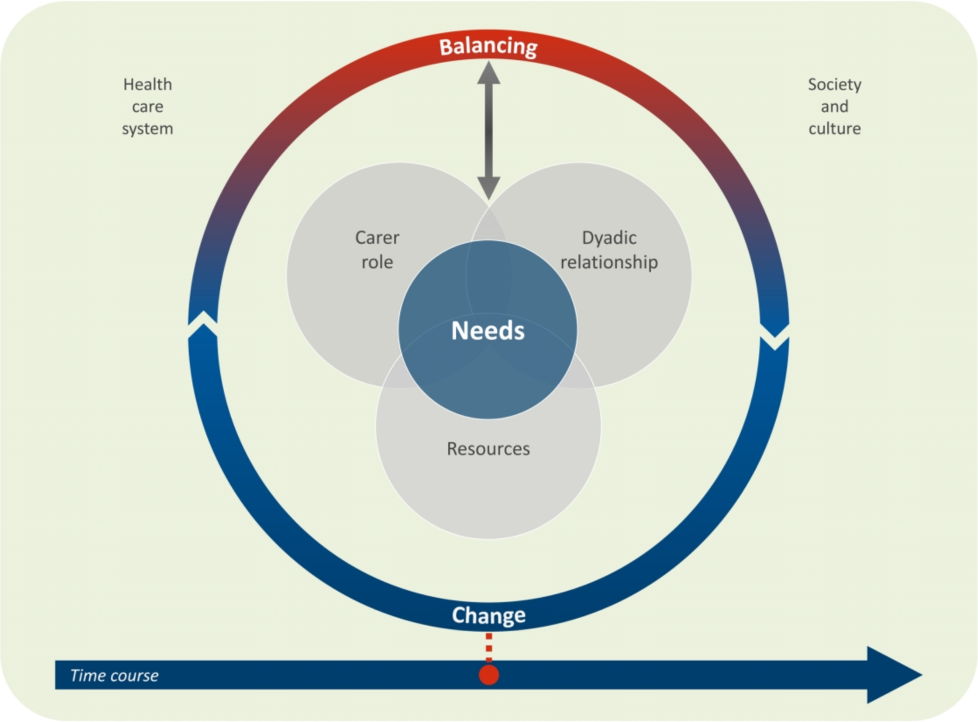


Figure 3: Conceptual model of stability of home-based care arrangements for people living with dementia (SoCA-Dem)

Appendix ‘Towards a middle-range theory of ‘Stability of home-based care arrangements for people living with dementia’ (SoCA-Dem): Findings from a meta-study on mixed research’

Kerstin Köhler[1,2], Jan Dreyer[1,2], Iris Hochgraeber[1,2], Milena von Kutzleben[3,1], Christiane Pinkert[1], Martina Roes[1,2], Bernhard Holle[1,2]

[1] German Center for Neurodegenerative Diseases (DZNE), Witten, Germany
[2] Witten/Herdecke University, Faculty of Health, School of Nursing Science, Witten, Germany
[3] Carl von Ossietzky Universität Oldenburg, Faculty of Medicine and Health Sciences, Department of Health Services Research, Oldenburg, Germany

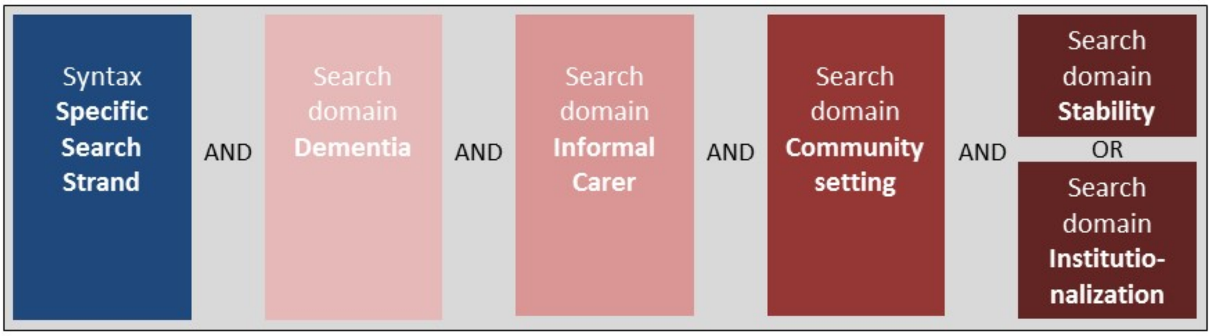
Content

Appendix A: Systematic database searches

We searched the databases MEDLINE, CINAHL and PsycINFO with nine separate search strands:

1. search strand stability
2. search strand (self-)caring actions
3. search strand needs & demands
4. search strand crises
5. search strand positive aspects
6. search strand end-of-life-care
7. search strand institutionalization
8. search strand burden
9. search strand interventions

All search syntaxes consist of similar domains. The first domain addresses the specific topic of the search strand. The next three domains define the population (the person with dementia, the informal carer) and the setting (community setting). The last domain defines the outcomes (stability OR institutionalization). Depending on the respective search strand, these domains were used in different ways to either increase or decrease the sensitivity of the search. Thereby, at least the syntax for the specific search strand and the search domain for dementia were used for every search strand.



Exemplary, the search syntaxes for all search strands for the database search in MEDLINE via PubMed are displayed. No filters were applied.

1. Search strand ‘Stability’

(stability [tiab] OR stable [tiab] OR maintain* [ti] OR sustain* [ti]) **AND** (dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti]) **AND** (caregivers [Mesh] OR caregiv* [tiab] OR carer* [tiab] OR informal care* [tiab]) **AND** (“Home Nursing” [Mesh] OR home nursing [tiab] OR community living [tiab]OR home care [tiab] OR domestic [tiab] OR community dwelling [tiab] OR home dwelling [tiab])

2. Search strand ‘(Self-)caring action’

(care manag* [tiab]OR care coordination [tiab] OR care strateg* [tiab] OR supportive strategy* [tiab] OR caregiv* style [tiab] OR caregiv* career [tiab] OR trajectory [tiab] OR adjustment [tiab] OR social support [tiab] OR decision making [tiab] OR service utilization [tiab] OR service utilisation [tiab] OR service use [tiab]) **AND** (Dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti]) **AND** (Caregivers [Mesh] OR caregiv* [tiab] OR carer* [tiab] OR informal care* [tiab]) **AND** ((institutionalization [ti] OR institutionalization [ti] OR nursing home placement [ti] OR nursing home admission [ti] OR institutional placement [ti]) **OR** (stability [tiab] OR stable [tiab] OR maintain* [ti] OR sustain* [ti]))

3. Search strand ‘Needs and demands’

(need [ti] OR needs [ti] OR demand [ti] OR demands [ti] OR “Needs Assessment” [Mesh] OR "Health Services Needs And Demand" [Mesh] OR “Personal Satisfaction” [Mesh] OR "Patient Satisfaction" [Mesh]) **AND** (Dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti]) **AND** (“Home Nursing” [Mesh] OR home nursing [tiab] OR community living [tiab] OR home care [tiab] OR domestic [tiab] OR community dwelling [tiab] OR home dwelling [tiab])

4. Search strand ‘Crises’

(crisis [ti] OR crises [ti] OR critical incident* [ti]) **AND** (Dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti])

5. Search strand ‘Positive aspects’

(positive aspect* [ti] OR gain [ti] OR uplift* [ti] OR satisfaction [ti] OR meaning [ti]) **AND** (dementia [ti] OR alzheimer* [ti] OR demented [ti] OR Dementia[MeSH]) **AND** (caregiv* [tiab] OR caregivers [tiab] OR carer* [tiab] OR infORmal care* [tiab])

6. Search strand ‘End-of-life care’

(“end of life” [ti] OR “Palliative Care” [Mesh] OR palliative [ti] OR „Terminal Care” [Mesh] OR terminal care [ti] OR death [ti] OR dying [ti] OR hospice [ti]) **AND** (Dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti]) **AND** (Caregivers [Mesh] OR caregiv* [tiab] OR carer* [tiab] OR infORmal care* [tiab])

7. Search strand ‘Institutionalisation’

(institutionalization [ti] OR institutionalization [ti] OR nursing home placement [ti] OR nursing home admission [ti] OR institutional placement [ti]) **AND** (Dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti]) **AND** (Caregivers [Mesh] OR caregiv* [tiab] OR carer* [tiab] OR informal care* [tiab])

8. Search strand ‘Burden’

(burden [ti] OR stress [ti] OR strain [ti]) **AND** (Dementia [Mesh] OR dementia [ti] OR alzheimer* [ti] OR demented [ti]) **AND** (Caregivers [Mesh] OR caregiv* [tiab] OR carer* [tiab] OR informal care* [tiab]) **AND** (institutionalization [Mesh] OR institutionaliz* [ti] OR institutionalis* [ti] OR nursing home placement [ti] OR nursing home admission [ti] OR institutional placement [ti] OR stability [ti] OR stable [ti] OR maintain* [ti] OR sustain* [ti] OR prolong* [ti] OR "Independent Living" [Mesh] OR continu* [ti] OR lengthen* [ti] OR at home [ti] OR remain* [ti] OR stay* [ti] OR keep* [ti] OR extend* [ti] OR preserv* [ti] OR perseverance time [tiab])

9. Search strand ‘Interventions’

(Intervention* [tiab] OR "Case Reports"[Publication Type] OR "Controlled Before-After Studies" [Mesh] OR "Crisis Intervention" [Mesh] OR "Clinical Trial"[Publication Type] OR "Cohort Studies" [Mesh] OR "Longitudinal Studies" [Mesh] OR mixed methods [tiab] OR "Clinical Trials As Topic" [Mesh] OR experimental study [tiab] OR "Treatment Outcome" [Mesh] OR outcome* [tiab] OR program [tiab] OR therapy [tiab] OR treatment [tiab] OR psychoeducation [tiab] OR information [tiab] OR education [tiab] OR counseling [tiab] OR counselling [tiab] OR support [tiab] OR training [tiab]) **AND** (Dementia [Mesh] OR dementia [ti] OR demented [ti] OR alzheimer* [ti]) **AND** ("Caregivers" [Mesh] OR caregiv* [tiab] OR carer* [tiab] OR informal care* [tiab]) **AND** ("Home Nursing" [Mesh] OR home nursing [tiab] OR home care [tiab] OR domestic [tiab] OR community dwelling [tiab] OR home dwelling [tiab] OR community living [tiab]) **AND** (Institutionalization [Mesh] OR institutionalis* [tiab] OR institutionaliz* [tiab] OR nursing home placement [tiab] OR nursing home admission [tiab] OR institutional placement [tiab] OR prolong*[TIAB] OR stability [tiab] OR stable [tiab] OR maintain* [tiab] OR continue* [tiab] OR sustain* [tiab] OR "Independent Living" [Mesh] OR lengthen* [tiab] OR at home [tiab] OR remain* [tiab] OR stay* [tiab] OR keep* [tiab] OR extend* [tiab] OR preserve* [tiab] OR perseverance time [tiab])

Appendix B: Inclusion criteria and quality appraisal

To be included in the meta-study, the studies had to fulfil the following inclusion criteria:

MANDATORY	
• study focuses on care arrangements for people living with dementia • involvement of informal carer(s) in care arrangement • community setting (or institutional setting if study is retrospective or reflects the transition process) • written in English, German, or French	
AND	
EITHER…	OR…
Study defines or researches stability of home-based care arrangements for people living with dementia.	Study defines or analyses one of the following concepts or phenomena included in the working definition of stability: • (self-)caring actions • needs/demands of people living with dementia and their carer(s) • dynamics in care arrangements • crises • successful caring routines • transition to an institutional setting
	… AND …
	Study makes a statement whether the person living with dementia can stay at home (longer/better) or not.

The decision to include or exclude a publication was made in light of the contribution of the publication to the synthesis. Nevertheless, to avoid the inclusion of 'fatally flawed' publications, the following questions suggested by Dixon-Woods and colleagues (2005) were applied to judge the methodological quality of the publications:

- Are the aims and objectives of the research clearly stated?
- Is the research design clearly specified and appropriate for the aims and objectives of the research?
- Do the researchers provide a clear account of the process by which their findings were produced?
- Do the researchers display enough data to support their interpretations and conclusions?
- Is the method of analysis appropriate and adequately explicated?

Reference:

Dixon-Woods M, Kirk MD, Agarwal MS, et al. Vulnerable groups and access to health care: a critical interpretive review. National Coordinating Centre NHS Service Delivery Organ RD (NCCSDO)2005.

Appendix C: Statement of the reasons for the exclusion of the publications from the ‚interventions‘ search strand

In the literature search one of our nine search strands was the ‘interventions’ strand. Our motive to operate this search strand was to include intervention studies or reviews that used the ‘odds of institutionalisation’ and/or ‘time to institutionalisation’ (in this case interpreted as a manifestation of stability/instability) as outcomes. We expected that these intervention studies and reviews might explicate in detail why and how the respective intervention was supposed to and has succeeded or failed to prolong a stable situation at home. Actually, the retrieved intervention reviews (Brodaty, Green, & Koschera, 2003; Olazaran et al., 2010; Pimouguet, Lavaud, Dartigues, & Helmer, 2010; Pinquart & Sörensen, 2006; Reilly et al., 2015; Smits et al., 2007; Spijker et al., 2008; Zabalegui et al., 2014) suggest, that (in particular multicomponent) interventions may decrease the odds of institutionalisation and increase the time that dyads spent at home. But both, intervention studies and reviews, remained vague in their statements with relation to our target phenomenon ‘stability’ in general and specifically to its constitutive concepts. Therefore, they did not contribute meaningful to the creation of the midrange theory, and in deviation to the study protocol we decided during the analysis process to remove the whole search strand from the meta-study sample. This experience with the ‘interventions’ search strand points to an ongoing debate on an emerging reorientation of intervention research in the field of home-based and informal dementia care that should to be considered in future research (e.g. Ceci, Symonds Brown, & Judge, 2018; Dawson, Bowes, Kelly, Velzke, & Ward, 2015).

Literature:

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society, 51*(5), 657-664. doi:10.1034/j.1600-0579.2003.00210.x

Ceci, C., Symonds Brown, H., & Judge, H. (2018). Rethinking the assumptions of intervention research concerned with care at home for people with dementia. *Dementia (London)*. doi:10.1177/1471301218790037

Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics, 15*(59), 1-17. doi:10.1186/s12877-015-0053-9

Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., Del Ser, T., . . . Muniz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders, 30*(2), 161-178. doi:10.1159/000316119

Pimouguet, C., Lavaud, T., Dartigues, J. F., & Helmer, C. (2010). Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. *J Nutr Health Aging, 14*(8), 669-676. doi:10.1007/s12603-010-0314-4

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International psychogeriatrics / IPA, 18*(4), 577-595. doi:10.1017/S1041610206003462

Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D., & Orrell, M. (2015). Case management approaches to home support for people with dementia. *The Cochrane database of systematic reviews, 5*(1). doi:10.1002/14651858.CD008345.pub2

Smits, C. H. M., de Lange, J., Droes, R. M., Meiland, F., Vernooij-Dassen, M., & Pot, A. M. (2007). Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry, 22*(12), 1181-1193. doi:10.1002/gps.1805

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis. *Journal of the American Geriatrics Society, 56*(6), 1116-1128. doi:10.1111/j.1532-5415.2008.01705.x

Zabalegui, A., Hamers, J. P. H., Karlsson, S., Leino-Kilpi, H., Renom-Guiteras, A., Saks, K., . . . Cabrera, E. (2014). Best practices interventions to improve quality of care of people with dementia living at home. *Patient education and counseling, 95*(2), 175-184 doi:10.1016/j.pec.2014.01.009

Appendix D: Overview of the meta-study sample

The following table gives an overview of the n=99 publications that we included in this meta-study. For each included publication we list the author(s), year of publication, country, search strand, aim, study design, sample/setting, main findings, and contribution to theory concepts. In in addition to the study design, we indicate for quantitative studies if they have a longitudinal or a cross-sectional approach. For all other studies we only indicate if they have a longitudinal approach. In the column 'contribution to theory concept(s)' we indicate to which concept(s) of our middle-range theory the respective publication contributed. The concepts of the theory are: change, balancing, needs, carer role, dyadic relationship, resources, society and culture, health care system. Thereby, concepts that are addressed very prominent in a publication are displayed in bold type; further addressed concepts are displayed in regular type. Following the principles of conceptual saturation within the coding process, we did not code all information on each concept in each publication. For this reason, it is probable, that a publication includes information with regard to a theory concept, but the concept is not listed in the respective column.

Abbreviations

AChEI	Acetylcholinesterase inhibitor	GP	General Practitioner	NPI	Neuropsychiatric Inventory
AD	Alzheimer's disease	HRQoL	Health Related Quality of Life	PwD	Person with dementia
ADL	Activity of daily living	LOD	Late onset dementia	PwAD	Person with Alzheimer's disease
DLB	Dementia with Lewy bodies	MMSE	Mini Mental State Examination	YOD	Young onset dementia
FC	Formal carer	NH	Nursing home		
IC	Informal carer	NHP	Nursing home placement		

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to theory concept(s)
Afram et al. (2014) (International Consortium: Estonia, Germany, Finland, France, Netherlands, UK, Spain, Sweden)	Berries	to explore reasons for institutionalisation of PwDs according to ICs as well as variation in reasons between countries	mixed methods	786 ICs (PwD institutionalised)	Mainly PwD-related reasons were stated (neuropsychiatric symptoms, care dependency, cognition). Neuropsychiatric symptoms were among the most often mentioned reasons in most countries. Besides PwD-related reasons, IC burden and the inability to care were stated. Countries differ significantly in reasons according to ICs. Spouses more often stated reasons related to themselves compared with child ICs.	**change**, carer role, resources, society and culture, health care system
Afram et al. (2015) (Netherlands)	Needs & Demands	to provide insights into problems and needs of ICs of PwDs during care transition from home-based care to institutional long-term-care	systematic review: qualitative synthesis	13 publications	Regarding the needs and problems of ICs during the care-transition period, the most stated topics were emotional concerns, knowledge/information, and support. The care-transition period should be considered as a continuum, as similar needs and problems were identified prior and after admission to long-term-care.	**needs**, carer role, resources, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to theory concept(s)**
Andrén and Elmståhl (2008) (Sweden)	Institutionalisation	to determine the effectiveness of a psychosocial intervention for ICs in delaying institutionalisation of PwDs	quantitative: experimental (longitudinal)	intervention group: 153 ICs, control group: 155 ICs	There were significant delays (6 months) in institutionalisation for PwDs with adult children as ICs. Factors associated with institutionalisation are the ICs' influence on intervention, IC gender and the PwD severity of dementia.	**change,** dyadic relationship
Badrakalimuthu et al. (2014) (UK)	End-of-life-care	to undertake a systematic review and narrative synthesis of the literature concerning place of death of PwDs, and the PwDs, ICs and health-care-providers preferences for place of death of PwDs	systematic review: narrative review	6 publications	Studies of death certificate data show that PwDs die more commonly in NHs than in other locations. In contrast, prospective studies show that death is more common in own residence or hospital. Older age, male gender, availability of hospital were associated with hospital death, availability of NH beds was associated with death in NH and enrolment in hospice was associated with death in own residence. Little is known about patient, IC and health professional preferences or the extent to which PwDs discuss their preferences with their families and healthcare providers. Preferences of proxy decision-makers are met more often than those of the PwDs.	needs, resources, health care system
Bakker et al. (2013) (Netherlands)	Institutionalisation	to investigate time from symptom onset to institutionalisation and predicting factors for PwDs with YOD compared to PwDs with LOD	quantitative: observational (longitudinal)	308 dyads, 226 dyads YOD, 102 dyads LOD (PwD living at home at baseline)	Time from symptom onset to institutionalisation was nearly 9 years for PwDs with YOD and 4 years for PwDs with LOD. Time to institutionalisation was significantly predicted by apathy in the YOD group and by IC's competence in caring for the PwDs in both groups.	**change,** carer role, dyadic relationship, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Caldwell et al. (2014) (Australia)	Institutionalisation	to investigate the decision-making process for placing a PwD on a waiting list for a NH; why offers of a place in a NH are accepted or declined; the influence of cultural factors in people living in Australia from a Chinese background compared with those from an English-speaking background	qualitative: unspecific design	27 ICs (PwD institutionalised or on a NH waiting list)	ICs were at different stages of decision-making when they applied for a waiting list (ready for placement, just in case, urgent need for placement). IC's decisions were influenced by their emotions and expectations of NHs. The decision-making process was similar for both cultural groups, but Chinese ICs spoke more about their sense of duty, the need for a Chinese specific facility, and declining a place because of family disagreement.	change, balancing, carer role, dyadic relationship, **society and culture**, health care system
Caron et al. (2006) (Canada)	Institutionalisation	to explore the decision-making process with regards to institutionalisation of a PwD, from the perspective of the IC; to develop a theoretical model	qualitative: Grounded Theory	14 ICs for 8 PwDs (PwD institutionalised)	A theoretical model of the decision-making process was developed and three factors that were central to the process were identified: IC's perceptions of their ability to provide care, IC's evaluations of the PwD to make care decisions, and the evolving influence of contextual factors and interactions with healthcare professionals.	change, **balancing**, needs, carer role, resources
Cepoiu-Martin et al. (2016) (Canada)	Institutionalisation	to summarise the effects of various individual, IC and system-related factors on the risk of institutionalisation of PwDs residing in the community	systematic review: narrative review and meta-analysis	review part: 59 publications, meta-analysis: 37 publications	White race, dementia severity and older age increased the risk of institutionalisation. Married PwDs living with their carer had a lower risk. Behavioural and psychological symptoms of dementia, the degree of functional impairment, and carer burden had a consistent effect on the risk of institutionalisation.	change, dyadic relationship, resources, society and culture, health care system
Chang et al. (2010) (USA, data collection in Taiwan)	Institutionalisation	to understand the process and difficulties that Chinese ICs experience when making a NH placement decision for a PwD	qualitative: Grounded Theory	30 Chinese ICs in Taiwan (PwD institutionalised)	A stage-based model describes how ICs go through the decision-making process (initiating the placement decision, assessing and weighing the decision, finalising the decision, evaluating the decision), how they overcome difficulties to reach decisions, and how the decision-making process is related to the concept of Chinese filial piety, which is changing in modern Taiwanese society.	change, **balancing**, carer role, resources, **society and culture**, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Chang et al. (2011) (USA, data collection in Taiwan)	Institutionalisation	to describe factors influencing decisional conflict among Chinese ICs regarding NH placement of PwDs	qualitative: unspecific design	30 Chinese ICs in Taiwan (PwD institutionalised)	Factors influencing IC's decisional conflict included the Chinese value of filial piety, limited financial resources and information, placement willingness of the PwD, family disagreement, distrust of NH care quality, and limited NH availability. Factors influencing IC's·decisional conflict post placement included disappointment with NH care quality and self-blame for the placement decision.	change, **balancing**, carer role, resources, **society and culture**, health care system
Coe et al. (1999) (Canada)	Needs & Demands	to explore male ICs perceptions of formal support	qualitative: Grounded Theory (longitudinal)	24 male ICs (PwD living at home or institutionalised)	The male ICs experienced a process of making concessions for care in four stages: resisting, giving in, opening the door, making the match. Personal barriers deterred the ICs from seeking help, and once the ICs engaged formal help, the influence of characteristics of the health care system and FCs had both enabling and disabling effects. For ICs who institutionalised, the phase of making the match was followed by redesigning their IC role.	**balancing**, needs, carer role
Cohen et al. (1994) (Canada)	Positive aspects	to review different concepts and measures of positive aspects of caring, and to describes the use of a simple measure of 'enjoyable aspects of caregiving'	quantitative: observational (longitudinal)	196 dyads (PwD living at home at baseline)	The measure of 'enjoyable aspects of caregiving' attained significant test-retest reliability and significantly correlated with IC burden and health. It also predicted IC desire to institutionalise but not actual institutionalisation. The paper calls for greater use of measures related to positive aspects and a better understanding of how these measures relate to one another and to outcomes.	**carer role**, dyadic relationship, resources
Cox (1996) (USA)	Institutionalisation	to identify what factors influence the IC hospital discharge decision and the IC satisfaction with the discharge plan, and to analyse if influences/ satisfaction differ between discharges to home or to NH	quantitative: observational (cross-sectional)	172 ICs (PwD in hospital)	Social workers are important influencers in the decision to discharge from hospital to home or to NH. IC satisfaction depends on the amount of involvement in the discharge process.	change, balancing, needs, **resources**, health care system
Daly et al. (2012) (Ireland)	Berries	to develop a theory to explain the social processes employed by ICs to manage alterations to interactions within their social worlds	qualitative: Grounded Theory	20 ICs, 1 PwD (PwD living at home), 10 FCs from the health, social care and disability sectors	IC's main concern was identified as 'Living on the fringes', which was stimulated by dementia-related stigma and living a different life. The theory of 'Sustaining Place' explains the social pattern of actions employed by ICs to manage this problem on behalf of themselves and the PwD.	change, **balancing**, **needs**, society and culture

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Davis et al. (2014) (USA)	(Self-)caring actions	to examine the conceptualisation of care problems by AD and by Parkinson's disease spouse ICs and the efficacy of their problem management strategies, to propose a typology of IC management styles that can provide a contextual frame for understanding their experiences of burden	qualitative: unspecific design	12 ICs of a partner with: 6 AD and 6 Parkinson's disease (living at home)	Three types of IC spouses are identified: adapters, strugglers, and case managers. The findings suggest that IC burden might be influenced more by the IC management style than by the demands of the care situation.	**balancing**, carer role, **resources**
De Vugt et al. (2005) (Netherlands)	Burden	to examine the impact of specific behavioural disorders and IC's emotional reaction on institutionalisation	quantitative: observational (longitudinal)	119 dyads (PwD living at home)	IC distress related to PwD behaviour was a significant predictor of institutionalisation, while behaviour did not predict NHP. The study did not find a differential impact of specific aspects of PwD behaviour. Child ICs, especially daughters, were associated with shorter time to institutionalisation compared to spouse ICs.	**change**, dyadic relationship
Donovan (2006) (USA)	Positive aspects	to identify and understand the positive aspects of the lived experiences of ICs	qualitative: phenomeno-logical approach	15 spousal ICs (PwD living at home)	The study revealed more positive than negative aspects of caring. ICs indicated positive aspects of caring through their behaviour and communication. A mélange of different actions facilitated the ICs to gain a feeling of competence and satisfaction in their carer role.	balancing, **carer role**, dyadic relationship, resources
Donovan et al. (2010) (USA)	Positive aspects	to give an in-depth description of how uplifted ICs think about care and conduct care	qualitative: phenomeno-logical approach	15 spousal ICs (PwD living at home)	The study identified two primary themes of IC thinking and acting: (1) engaging in positive behaviours and (2) making adjustments in attitudes.	balancing, **carer role**, dyadic relationship, resources
Dramé et al. (2012) (France)	Institutionalisation	to identify factors predictive of institutionalisation over a period of 1 year among PwDs	quantitative: observational (longitudinal)	425 PwDs (PwD living at home at baseline)	There were 4 factors increasing the risk of institutionalisation: age 85 or older, inability to use the toilet, balance disorders and living alone. 3 factors decreased the risk: inability to transfer, increased number of children and increased initial MMSE score.	change, society and culture, health care system
Ducharme et al. (2012) (Canada)	Institutionalisation	to develop an explanatory model of the IC decision-making process regarding NHP of a PwD	qualitative: Grounded Theory (longitudinal)	18 ICs (7 PwD living at home, 11 PwD living in a retirement residence)	A theoretical model illustrates that the institutionalisation decision-making process is activated when the IC or a health care professional introduces the possibility of institutionalisation. The IC's assessment of the pros and cons of institutionalisation is modulated primarily by interactions with the formal and informal social network.	change, **balancing**, resources, health care system

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Ebly et al. (1999) (Canada)	Institutionalisation	to describe differences in short-term institutionalisation rates for PwDs who live alone as compared to PwDs residing with an IC	quantitative: observational (longitudinal)	317 dyads (PwD living at home at baseline)	One third of PwDs lived alone. Thinking about institutionalisation (intent) was predictive for actual short-term (2-year) institutionalisation and appeared to be influenced by living arrangements. ICs of PwDs living alone provided less hands-on assistance, experienced less burden, and were less likely to be depressed than those living with the PwD, but were more likely to have considered institutionalisation, driven by concerns about safety and support.	change, carer role, **dyadic relationship**
Feldman et al. (2009) (International Consortium: Belgium, Canada, Finland, France, Germany, UK)	Institutionalisation	to evaluate patient and treatment (galantamine and other AChEIs) factors associated with the time until institutionalisation	quantitative: experimental (longitudinal)	548 PwDs (PwD living at home at baseline)	Long-term treatment with galantamine or other AChEIs appears to be associated with a significant delay in the time to institutionalisation in PwDs. For each year of treatment the risk within a given period was reduced by 31% (galantamine) and 29% (other AChEI).	**change**, resources, health care system
Forbes et al. (2012) (Canada)	Needs & Demands	to enable FCs, ICs, and PwDs (living in rural areas) to use dementia care information more effectively by examining their information needs, how these change over time, and how they access, assess, and apply the knowledge	qualitative: unspecific design (longitudinal)	5 PwDs (living at home), 14 ICs, 14 FCs	6 stages of the dementia care journey were described. ICs identified the need for different types of knowledge during each stage. Barriers to knowledge exchange included: lack of rural community-based services; ICs reluctant to seek help and had limited energy; and lack of integration of dementia-related services and supports. Facilitators included: ICs with healthcare experience who were actively seeking information; development of trusting relationships between FCs, ICs, and PwDs; and formal mechanisms for exchanging information within and across rural community-based organisations.	balancing, **needs**
Frewer-Graumann (2014) (Germany)	(Self-)caring actions	to explore the construction of informal home-based care arrangements from the perspective of ICs	qualitative: Grounded Theory	14 dyads (PwD living at home)	Home-based care arrangements for PwDs are constructed by ICs in very different ways. Care arrangements are influenced by the progression of dementia, family dynamics, coping strategies, inner familiar relationships, professional occupation of ICs and secondary and tertiary social networks.	change, **balancing**, **carer role**, dyadic relationship, resources
Gallagher et al. (2011) (Ireland)	Institutionalisation	to determine whether modifiable IC attributes are significantly associated with desire to institutionalise; and whether these variables may be independent predictors in the context of other established PwD and IC-related variables	quantitative: observational (cross-sectional)	102 dyads (PwD living at home)	IC desire to institutionalise was significantly associated with a number of modifiable variables including IC coping style, self-efficacy, depression, burden, and the presence of an unmet service need. In a multivariate analysis, IC burden, IC depression, and non-spousal status were the only significant independent predictors for desire to institutionalise.	needs, dyadic relationship, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Gaugler et al. (2005a) (USA)	Institutionalisation	to determine how behaviour problems that occur early in the caring influence time to NHP and change into burden and depression over time	quantitative: observational (longitudinal)	4761 dyads (PwD living at home at baseline)	ICs who have to manage frequent behaviour problems early, were more likely to institutionalise. ICs who were faced with severe, early behaviour problems reported greater increases in burden and depression over the 3 years study.	**change**, carer role
Gaugler et al. (2005b) (USA)	Needs & Demands	to determine how unmet needs for activity of daily living tasks influenced NHP, death, or loss to follow-up in dementia	quantitative: observational (longitudinal)	5831 dyads (PwD living at home)	Greater unmet needs were predictive for institutionalisation, death and loss to follow-up. Unmet needs may be useful in identifying PwDs at risk of institutionalisation and death.	**needs**
Gaugler et al. (2007) (USA)	Positive aspects	to examine the concept of resilience in dementia caring, and determine how resilience is potentially predictive of key exit transitions from at-home dementia care	quantitative: observational (longitudinal)	1979 ICs (PwD living at home at baseline)	The present study utilized data from ICs to ascertain whether resilience influences transitions from PwD caring, such as institutionalisation, care recipient death, or loss to follow-up. It was revealed that high baseline resilience (low burden, high care demands) was associated with less frequent institutionalisation and loss to follow-up as well as more frequent care recipient mortality.	**resources**
Gaugler et al. (2001) (USA)	Institutionalisation	to determine factors that predict the problems and help ICs perceive while institutionalising the PwD	quantitative: observational (longitudinal)	185 ICs (PwD living at home at baseline)	The personal and social resources of ICs prior to NHP (e.g., mastery, family conflict, socioemotional support, duration of care, education, and physical health) were predictors of difficulties during searching for a NH, perceived family help, and perceived professional help.	**resources**
Gaugler et al. (2011) (USA)	Burden	to determine whether IC burden is a mediator between the effects of behavioural disturbance and institutionalisation	quantitative: experimental (longitudinal)	5831 ICs (PwD living at home at baseline)	IC burden fully mediated the relationship between four behavioural disturbances and institutionalisation.	**change**
Gaugler et al. (2009) (USA)	Institutionalisation	to identify factors that predict NHP of PwDs	systematic review: meta-analysis	80 publications	Identification of numerous factors (with regard to PwDs and their ICs) that predict institutionalisation. PwD and IC factors should be considered when assessing the risk of institutionalisation.	**change**, carer role, dyadic relationship, resources
Gilhooly (1986) (UK)	Institutionalisation	to shed light on features of caring which are associated with IC's preference for institutional care	quantitative: observational (cross-sectional)	48 ICs (PwD living at home), 2 groups: co-resident and non-resident	The dyadic relationship is an important determinant of motivation to continue care at home. In addition, variables associated with institutionalisation included age of ICs, IC's contacts with friends, satisfaction with help from relatives, another dependent relative, and the employment of ICs. Help from services and IC's well-being were not correlated with preference for institutionalisation.	carer role, **dyadic relationship**, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Glass (2016) (USA)	End-of-life-care	to document and examine the experiences of end-of-life care of PwDs and ICs and the role that environment and hospice play in these experiences	qualitative: phenomeno-logical approach	4 ICs (PwD living at home or institutionalised)	The cases reveal a range of end-of-life experiences, suggesting that there is not just one 'good' path. The extent of care needed, the responsiveness of the individual, the health of the ICs, and the residence and support situations can all intersect in a variety of ways that make no single scenario the answer for all.	balancing, needs, resources
Gort et al. (2007) (UK)	Burden	to analyse the Zarit Burden Scale's ability to identify signs of IC collapse	quantitative: observational (cross-sectional)	66 ICs (PwD living at home)	The Zarit Burden Scale was useful to identify IC burden and to predict collapse of IC.	change
Groen-van de Ven et al. (2017) (Netherlands)	(Self-)caring actions	to examine the decisions made and the related key events in the trajectories of care networks including PwDs, their FCs and ICs	qualitative: unspecific design (longitudinal)	113 respondents altogether (23 PwDs, 44 ICs, and 46 FCs) (PwD living at home or institutionalised)	Four decision themes were constructed: managing daily life, arranging support, community living, and preparing for the future; eight key events delineate decision trajectories of PwD; decisions and key events differ between PwD living alone and living with IC.	**balancing**
Hagen (2001) (Canada)	Institutionalisation	to explore factors influencing ICs decision-making process related to placing a PwD in a NH	qualitative: unspecific design (longitudinal)	5 ICs (PwD living at home)	The study develops a theoretical model of factors influencing institutionalisation-related decision-making, including independence, perceived presence of others, fear of loneliness, negative NH attitudes, sense of existential self, and guilt.	**carer role**, dyadic relationship, resources
Hill et al. (2017) (UK)	End-of-life-care	to identify and describe the aspects of end-of-life care for PwDs that are most important to them and their carers	mixed methods	14 PwDs, 21 ICs (PwD living at home), 22 bereaved ICs	Different views on what is important about end-of-life care were identified and grouped into four viewpoints: family involvement, managing the present, pragmatic expectations and autonomy and independence.	balancing, needs, dyadic relationship
Hirschfeld (2003) (Israel, data collection in the USA)	Positive aspects	to present the concept of mutuality, which emerged as the crucial factor in continuing home care vs. institutionalisation	mixed methods	30 dyads (PwD living at home)	Mutuality emerged as the major parameter for families managing life with senile brain disease and influenced the decision to institutionalise an impaired family member.	balancing, **dyadic relationship**
Janssen et al. (2017) (International Consortium: Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, UK)	Stability	to identify different profiles of ICs and to investigate differences between the identified carer profiles in quality of life, in depression and in perseverance time	quantitative: observational (cross-sectional)	453 dyads (PwD living at home)	Five profiles of ICs were identified. These profiles differ statistically significant with regard to quality of life, depressive symptoms and perseverance time.	balancing, carer role, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Kajiwara et al. (2015) (Japan)	Positive aspects	to identify factors that influence the continuation of in home care of PwDs	quantitative: observational (cross-sectional)	354 ICs, 343 PwDs (PwD living at home)	IC's current feelings about caring and the continuation of caring of PwDs with worsening symptoms were affected by a positive appraisal of caring and by the burden experienced by the ICs. The continuation of caring was indirectly affected by the PwDs cognitive impairment and by the behavioural and psychological symptoms of dementia score.	change, **carer role**
Kellett (1999) (Australia)	Institutionalisation	to explore the experience of family breakdown and NHP	qualitative: phenomeno-logical approach	14 ICs (PwD institutionalised)	The analysed IC stories of institutionalisation uncovered 5 shared meanings: experiencing a loss of control; being disempowered; feeling guilt, sadness and relief simultaneously; possessing a sense of failure; and having to make a forced and negative choice.	**balancing**, carer role
Kraijo et al. (2014) (Netherlands)	Stability	to introduce the concept 'perseverance time' and to validate it in a sample of ICs	quantitative: observational (cross-sectional)	223 ICs (PwD living at home)	The concept of 'perseverance time' (Pt) is a valid measure for the IC ability and willingness to continue home care. Health of PwD, IC living apart from the patient, and male gender of IC were positively associated with Pt; need for supervision, intensity of informal care provision, and reductions in working hours and hobbies in order to be able to provide care were negatively associated.	**change**
Kraijo et al. (2015) (Netherlands)	Institutionalisation	to focus the final decision by ICs to have their PwDs placed in a NH and to question whether the admission took place at the right time in the IC's point of view	mixed methods	14 spousal ICs (PwD institutionalised)	The placement decision had to be made in phases over time: placement of the PwD on a waiting list, and actual placement in a NH (stage-based model). The second and final decision often had to be taken under time pressure. The following classification emerged: Placement was at the right time, too early, too late or out of control.	**balancing**, dyadic relationship, resources
Kwon et al. (2012) (South Korea)	Institutionalisation	to explore and describe the process of NHP decision-making and adaptation among adult child carers of PwDs in Korea	qualitative: Grounded Theory	16 ICs (adult children, PwD institutionalised)	The core category in the process of decision making and adaptation to institutionalisation among ICs was accepting the inevitable and reorienting to changes. The developed stage-based model consisted of four phases: realizing a dead end, seeking a way out, accepting the inevitable decision, and reorienting to changes. Though ICs were confronted with various challenges, they managed to accept the decision and learned to reorient themselves to the changed care situation.	**balancing**, carer role, society and culture

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Ledgerd et al. (2016) (UK)	Crises	to identify the main causes of crisis and interventions to treat or prevent crisis in PwDs based on different stakeholder perspectives	quantitative: observational (cross-sectional)	719 participants: 20 academics, 562 health care sector staff, 54 ICs, 23 social care sector staff, 16 emergency service staff, 12 voluntary sector staff, 4 PwDs, 28 others	Wandering, falls and infection were highly rated as risk factors for crises across all stakeholder groups. Consumers rated aggression as less important, but severity of memory impairment as much more important than the other groups did. Education and support for ICs, and home care staff were highly valued for preventing crises. Well-trained home care staff, communication equipment, emergency contacts and access to respite were highly valued for managing crises.	**change**, **resources,** health care system
Lethin et al. (2016) (Sweden)	(Self-)caring actions	to investigate IC's experiences of formal care when caring for a PwD through the stages of the dementia	qualitative: unspecific design	23 ICs (PwD living at home or PwD institutionalised)	ICs require collaboration with FCs to get support adjusted to individual's needs, specific to stages of dementia. Three main turning points are experienced: the dementia diagnosis; when ICs realise increased need for FCs to continue caring at home; when PwD is institutionalised, ICs experience FCs reactive to needs, proactive reaction is required.	balancing, needs, **carer role**, health care system
Lewis (2015) (USA)	End-of-life-care	to discover a substantive theory that identifies the main problems that ICs of PwDs face at the end of life and the basic social processes by which they resolve that problem	qualitative: Grounded Theory	83 ICs (PwD passed away or living at home or institutionalised)	Carers attempt to resolve the challenge of caring at the end of life through a 5-stage basic social psychological process of rediscovering including missing the past, sacrificing self, yearning for escape, reclaiming identity, and finding joy. Health care professionals can support ICs through this journey by validating, preparing them for future stages, and encouraging natural coping strategies identified in this process.	balancing, **carer role,** dyadic relationship
Liken (2001a) (USA)	Crises	to examine crises experienced by ICs	qualitative: unspecific design	20 ICs (PwD institutionalised within the past 6 months)	All elements of a crisis were evident among ICs in the process of institutionalisation of the PwD. Dangerous behaviours resulting from cognitive decline led to IC fear and anxiety, which served as crisis precipitants. Perceived lack of family support in conjunction with physical and psychological exhaustion were crisis mediators. These factors, along with the IC's failed attempts to keep the PwD at home, caused the crisis process moving toward the outcome of institutionalisation.	**change**, balancing

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Liken (2001b) (USA)	Institutionalisation	to examine underlying values that precipitated the NHP	qualitative: unspecific design	23 ICs (PwD institutionalised)	Three major themes describe values underpinning the critical incident surrounding the move of the PwD to an assisted living facility. Critical incidents centred on two major factors: the PwDs safety and the ICs emotional well-being. Conflicting values underpinning the critical incident were the PwDs autonomy versus the IC's responsibility, obligation to PwD versus obligation to self, and logic versus emotion.	**change**, balancing, needs, carer role
Lindgren (1993) (USA)	(Self-)caring actions	to conceptualise the experiences of ICs over time and to portray IC careers in the context of dementia	qualitative: unspecific design	10 ICs (PwD living at home)	In the IC career a process of learning, adaptation to role demands and restructuring of the IC's life evolves, and unique stages of the IC career are formed. The Encounter Stage is characterized by the need for rapid adjustment to major changes, for information about illness characteristics, and instruction in providing quality care. The Enduring Phase is the long-term, heavy-duty caring phase where supportive interventions are needed. During the Exit Stage, institutionalisation is best done when time can be taken to choose a place. Finding the right home and financial issues are two problems that need to be solved.	change, balancing, **carer role**, dyadic relationship, resources, health care system
Lloyd et al. (2016) (UK)	Positive aspects	to critically evaluate the empirical findings of qualitative studies that have explored positive aspects of caring in dementia	systematic review: qualitative synthesis	14 publications	Multiple positive dimensions of caring and several factors that were important in supporting their positive caring experience are identified. Conceptualisations of positive aspects of caring (PAC): role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, sense of duty and reciprocity. IC's perceptions of the process of PAC: acceptance, choosing positive caregiving attitude, commitment to relationship, creating opportunities, drawing strength from faith/past challenges/others.	change, balancing, needs, carer role, dyadic relationship
Lord et al. (2016) (UK)	Institutionalisation	to understand the NHP decision-making process, the needs and difficulties that PwDs and ICs encounter and how these may be overcome	qualitative: unspecific design	7 PwDs, 13 ICs (PwD living at home, 1 PwD institutionalised)	Decision-makers balanced the competing priorities of remaining somewhere familiar, family's wish they remain at home, reduction of risk and effects on ICs and PwDs physical health. The PwDs frequently presented their lack of autonomy as decisions about institutionalisation were made. Family consultation usually helped ICs but sometimes exacerbated tensions. Direct professional support was appreciated where it was available.	**balancing**, needs
Luppa et al. (2008) (Germany)	Berries	to review publications that analyse predictors of institutionalisation of PwDs	systematic review: narrative review	42 publications	Predictors of institutionalisation were classified according to a provided conceptual framework in the categories sociodemographic and relationship characteristics of	**change**, needs, dyadic relationship,

					PwDs and caregivers, primary stressors, secondary stressors and resources.	resources, health care system
Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Luppa et al. (2012) (Germany)	Berries	to investigate risk factors for institutionalisation for PwDs, considering characteristics at the time of the diagnosis.	quantitative: observational (longitudinal)	254 PwDs (living at home at baseline)	30% of PwDs were institutionalised over the study course (6 years). Mean time until NHP was 4.1 years. Significant characteristics of NHP were marital status (being single or widowed), higher severity of cognitive impairment and mobility impairment.	change, dyadic relationship
MacNeil Vroomen et al. (2013) (Netherlands)	Berries	to review definitions of crises, and to create a standardised definition that can be utilised for research, policy and clinical practice	systematic review: qualitative synthesis	27 publications	Crisis in dementia is defined as a process where a stressor causes an imbalance requiring an immediate decision to be made which leads to a desired outcome and therefore a resolution of the crisis. If the crisis is not resolved, the cycle continues.	**change**, **balancing**, resources, health care system
Markiewicz et al. (1997) (Canada)	(Self-)caring actions	to examine the influence of IC's attachment styles and personality traits on their experiences of caring for a PwD	quantitative: observational (longitudinal)	113 dyads (PwD living at home)	The attachment style can contribute to explain aspects of ICs' experiences. Those who chose to institutionalise the PwD were higher on the avoidance factor than those choosing to maintain the PwD in the community.	**carer role**, dyadic relationship
Mausbach et al. (2004) (USA)	Institutionalisation	to compare institutionalisation rates of PwDs cared for by Latina and Caucasian female ICs, and to explore IC and PwD related predictors	quantitative: observational (longitudinal)	264 female ICs (154 female Caucasians, 110 female Latinas) (PwD living at home at baseline)	Hispanic Americans delayed institutionalisation longer than their Caucasian counterparts. PwD characteristics or IC demographics did not explain these results, although Hispanic Americans who identified greater benefits or more-positive aspects in caring at baseline were less likely to institutionalise the PwD than those who reported fewer benefits.	carer role, **society and culture**
McLennon et al. (2010) (USA)	Institutionalisation	to identify common themes from the statements of ICs who decided to institutionalise their relative with AD or Parkinson's disease	qualitative: unspecific design (longitudinal)	9 ICs of PwD, 2 ICs of persons with Parkinson's disease (PwD living at home at baseline)	2 categories identified from the ICs stories were 'anticipating the inevitable' and 'reaching the limit' (stage-based model). 3 to 4 months before institutionalisation, ICs discussed knowing that they would not be able to continue caring at home. The most frequent reasons for institutionalisation were serious health events. There were more institutionalisations in the AD participant group than in the Parkinson's disease group.	**change**, needs
Mitchell et al. (2004) (USA)	End-of-life-care	to examine and contrast the end-of-life experience of PwDs who died within one year of admission to either a NH or a community-based home care service	quantitative: observational (cross-sectional)	2730 PwDs institutionalised, 290 PwDs living at home	NH residents dying with advanced dementia were older, had greater functional impairment, and more behaviour problems compared to home care clients. Few subjects in the NH and home care cohorts were perceived to have less than 6 months to live. Only few individuals were referred to hospice. Hospitalizations were frequent. Pain and shortness of breath were common in both settings.	**change**

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Morycz (1985) (USA)	Institutionalisation	to explore whether the strain experienced by ICs of PwDs will be strongly related to the desire to institutionalise	quantitative: observational (longitudinal)	80 dyads (PwD living at home)	Results rely to the self-developed theoretical model: The desire to institutionalise a PwD was found to be greater when the IC's experiences increased strain or burden, when PwD is widowed, when there is more physical labour involved in caring tasks, and when PwD lives alone. Intensity of family strain (or felt stress) can best be predicted by the availability of social support to the IC: Less support implies more strain. For male IC groups and for all black ICs, strain does not predict desire to institutionalise.	dyadic relationship, resources
Okura et al. (2011) (International Consortium: Japan, USA, UK)	Institutionalisation	to examine the association between neuropsychiatric symptoms and risk of institutionalisation and death	quantitative: observational (longitudinal)	537 PwDs living at home at baseline, 109 PwDs institutionalised	The presence of one or more neuropsychiatric symptoms was not associated with higher risk of institutionalisation or death during the 5-year study period. Although when assessing each symptom individually, depression, delusions, and agitation were each associated with a higher risk of institutionalisation. IC distress mediated the association between delusions, agitation and institutionalisation. Depression and hallucinations were associated with significantly higher mortality.	**change**
Oliva y Hausmann et al. (2012) (Germany)	Institutionalisation	to explore the influence of IC needs, IC burden and role conflicts on the risk of institutionalisation of PwD	quantitative: observational (longitudinal)	373 ICs (PwD living at home at baseline)	A greater distance between households, increased need in housekeeping, higher income, increased IC burden and low self-evaluation of caring-quality are related to an increase in chance for institutionalisation. A constant need for supervision and lack of social appreciation are associated with a smaller chance.	change, dyadic relationship, health care system
Peacock et al. (2010) (Canada)	Positive aspects	to better understand family care by applying a strength-based perspective	qualitative: unspecific design	39 ICs (PwD living at home alone, PwD living with IC, PwD institutionalised)	ICs can view their role as an opportunity to give back, to discover personal strengths, and to become closer to the PwD. The results suggest that identifying and mobilising the IC's strengths can be an effective strategy for supporting ICs in their role.	carer role, **resources**
Pimouguet et al. (2016) (France)	Institutionalisation	to investigate the influence of early specialist referral for PwDs on the risk of institutionalisation and functional decline	quantitative: observational (longitudinal)	179 PwDs (for institutionalisation analysis), 243 PwDs (for ADL analysis), (PwD living at home at baseline)	One third of the incident PwDs had consulted a specialist for cognitive problems early in the disease course. PwDs who had consulted a specialist early presented a higher rate of being institutionalised than those who did not. Early specialist referral was not associated with functional decline.	resources

Author (Year) (Country)	Search Strand	Aim	Study Design	Sample/Setting	Main Findings	Contribution to Concepts
Pinquart and Sörensen (2006) (Germany and USA)	Berries	to identify average effects of interventions found on IC burden, depression, indicators of positive subjective well-being, ability/knowledge of ICs, symptoms of ICs, and the risk of institutionalisation	systematic review: meta-analysis	127 publications	Interventions for ICs of PwDs had small but significant effects on burden, depression, ability/knowledge, subjective well-being and symptoms of PwDs. Only structured multicomponent interventions reduced the risk of institutionalisation.	**resources**
Pinzon et al. (2013) (Germany)	End-of-life-care	to describe the preferred and actual places of death, symptom prevalence, and quality of care of PwDs	quantitative: observational (cross-sectional)	310 ICs of PwDs and 931 ICs of people without dementia, who died at home or in an institution	Almost half of the PwDs died at home. Compared to other countries this number is high. Most PwDs and their ICs preferred death at home to death anywhere else. PwDs living with at least one relative were more likely to die at home. The ICs were critical of the quality of care on standard hospital wards, citing the limited temporal availability of staff and limited emotional support.	dyadic relationship, society and culture, health care system
Porter et al. (2016) (USA)	Institutionalisation	to investigate the association between total NPI score, the NPI-4 (an agitation/aggression sub- scale) and individual domains of the NPI and NHP	quantitative: observational (longitudinal)	641 ICs: 352 cases (PwD institutionalised in the first 6 months of study), 289 controls (PwD living at home)	An increase in the NPI score implied an increase in odds of institutionalisation, also being married or being a male IC predicted institutionalisation. PwDs who entered a NH were significantly more likely to have behavioural and psychological symptoms of dementia related to agitation/aggression one month prior to institutionalisation than PwDs who stayed at home.	**change**
Quinn et al. (2015) (UK)	Needs & Demands	to investigate how meaning, motivation and relationship dynamics influence the IC's subjective experience of caring	qualitative: phenomeno-logical approach	12 ICs (10 PwD living at home, 2 PwD institutionalised)	6 key themes emerged, which were encompassed under an overarching theme of 'balancing needs'. This theme describes the IC's struggle to balance their own needs against those of the PwD. Dilemmas emerged from the desire to try to preserve the ICs relationship with the PwD, while recognising that this relationship was changing. The IC's relationship with the PwD influenced the IC's motivations to provide care and gave caring meaning. Although ICs were motivated to provide care the battle to balance needs meant that ICs recognized there might come a time when they may need to cease caring.	**balancing**, needs, **carer role**, **dyadic relationship,** resources
Redfern et al. (2002) (UK)	(Self-)caring actions	to advance the understanding of care for a PwD at home with an emphasis on routines, control and care goals	qualitative: unspecific design	20 dyads (PwD living at home)	Accomplishing care is a major challenge for PwDs and their ICs. In most cases development of effective coping strategies, handling competing goals, controlling the situation and maintaining a preferred sense of self are challenges in dementia care that have to be mastered.	**balancing**, dyadic relationship

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Romero-Moreno et al. (2014) (Spain)	Institutionalisation	to analyse the potential of both frequency of and satisfaction with leisure to explain IC's distress, risk of institutionalisation, IC's stressors and resources variables	quantitative: observational (cross-sectional)	275 ICs (PwD living at home)	ICs with a high satisfaction with and high frequency of leisure showed a more positive profile on resource variables, health outcomes and lower levels of risk of institutionalisation compared with the other groups. ICs with low satisfaction with and low frequency of leisure used significantly less adaptive emotional regulation strategies and showed worse consequences on health outcomes.	**carer role**
Rongve et al. (2014) (Norway)	Institutionalisation	to study time until and predictors for NHP for persons with mild dementia and to compare differences in time to NHP between PwDs with DLB and PwADs	quantitative: observational (longitudinal)	189 PwDs (PwD living at home at baseline)	Patients diagnosed with DLB had nearly 2 years shorter time to institutionalisation than those diagnosed with AD. Predictors of shorter time to institutionalisation were a DLB diagnosis, the use of antipsychotic medication, more advanced age, longer duration of dementia symptoms prior to diagnosis, living alone, higher reported carer distress, and more neuropsychiatric symptoms. The use of AChEIs was associated with halved risk of institutionalisation. In the DLB group, the use of antipsychotics was associated with increased risk of institutionalisation.	**change**, resources
Runte (2018) (Germany)	Institutionalisation	to analyse a cohort of PwDs in respect of institutionalisation over a follow-up period of 4.5 years and to investigate factors associated with the institutionalisation of PwDs, in general and stratified by sex	quantitative: observational (longitudinal)	652 PwDs (PwD living at home at baseline)	Risk of institutionalisation is higher in women than in men and when cared for by a care service in comparison to an IC. Inhibiting factors are care level and positive evaluation of caring by ICs. Stratified analysis by sex revealed that the risk of institutionalisation in men is influenced by their relationship to their IC, in women by duration of care at baseline.	**change**, dyadic relationship, resources, health care system
Saks et al. (2015) (International Consortium: Estonia, Germany, Spain, Finland, Sweden, France, UK)	(Self-)caring actions	to investigate the extent of variability in decisions of individuals and multidisciplinary groups from different European countries about the most appropriate setting for PwDs	quantitative: observational (cross-sectional)	161 experts in dementia care	There is considerable variation in individual's recommendations for the most appropriate setting for PwDs. Group-based decisions were more consistent, but country-specific patterns remained.	dyadic relationship, resources, society and culture, health care system
Sansoni et al. (2013) (Italy)	Institutionalisation	to review literature about factors that influence the institutionalisation of PwDs	unsystematic review	17 publications	Factors like IC burden, hours involved in care, stress, social isolation, gender, relationship to the PwD, availability of support resources, and IC characteristics influence the decision for institutionalisation.	change, society and culture, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Schacke et al. (1998) (Germany)	Stability	to analyse the meaning of various dimensions of IC burden for the IC's well-being and the stability of the care situation	quantitative: observational (cross-sectional)	78 ICs (PwD living at home)	Stability of home care is associated with perceived inadequacy of IC resources. Lower resources determine a higher probability of institutionalisation within the next 12 months. Other dimensions of IC stress/burden were not significant. An explicit distinction is made between IC burden which directly refers to the situation and the more general concept of well-being which is potentially, but not necessarily, affected by the caring situation. IC's life satisfaction, self-esteem, and their subjective perception of the stability of the care situation were regarded as indicators for potential outcomes of caring.	resources
Schäufele et al. (2005) (Germany)	Stability	to identify care gaps and possible undesirable development and to determine factors that stabilise or endanger the care situation	quantitative: observational (cross-sectional)	151 PwDs, 155 persons without dementia and their IC	Most care arrangements are judged as stable by the IC. Subjective burden, inadequate support and male gender of IC are associated with unstable care arrangements.	change, resources
Schirra-Weirich and Wiegelmann (2017) (Germany)	Stability	to develop a typology of PwD and IC dyads to better address their specific needs in a case management approach	quantitative: observational (longitudinal)	40 dyads (PwD living at home)	Dyads are divided into three types based on generational distinctions of care concepts. Case management is a mental support for intra-generational care settings and a functional support for inter-generational care settings. Case management based on a typology seems to be an appropriate support for ICs and PwDs.	balancing, **carer role**
Schoenmakers et al. (2009) (Belgium)	Institutionalisation	to investigate the differences between characteristics of community dwelling PwDs and non-demented elderly and their ICs at the moment of definitive institutionalisation	quantitative: observational (cross-sectional)	143 GPs (reporting data of 300 PwDs and 507 non demented controls, already institutionalised)	PwDs with concomitant diseases were mainly placed because of unmanageable behavioural disturbances. Strikingly, these PwDs were more often confronted with a delay in definitive institutionalisation due to their high care dependence. Although IC burden was an important motivation, it did not seem to be a motive in the final institutionalisation. Behavioural disturbances are independently of IC burden, FC support, or a spousal relationship the main direct reason for institutionalisation.	**change**, resources
Schölzel-Dorenbos et al. (2010) (Netherlands)	Needs & Demands	to make an inventory of needs assessment instruments, to explore the interaction between unmet needs and HRQoL and to relate these to the conceptual model of Maslow's hierarchy of needs in order to design	systematic review: qualitative synthesis	2 needs assessment instruments: CANE and CNA-D	PwDs identified significantly fewer needs than ICs. The most important needs, that also determine a large part of HRQoL, are: need for information, support with regard to symptoms of dementia, social contact and company, and health monitoring and safety. Focusing unmet needs can improve HRQoL.	**needs**

		a dementia-specific model				
Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Shega et al. (2008) (USA)	End-of-life-care	to evaluate the impact that hospice enrolment has on the terminal care of PwDs, and to describe the symptom burden these patients face at the end of life	quantitative: observational (cross-sectional)	135 ICs (PwD living at home or in a hospice)	The results suggest that dying PwDs who are enrolled in hospice programs are more likely to die in their locations of choice and their ICs are more likely to perceive that care is excellent or good than those who do not obtain hospice services. No effects on pain or other symptoms could be demonstrated in this analysis.	resources
Shim (2011) (USA)	Positive aspects	to explore how ICs of PwDs are able to have positive care experiences, how the relationship between the ICs and the PwADs changes over time, and how this relationship differs between dementia ICs who report positive care experiences and those who do not	mixed methods	PwD and people with Parkinson's disease (living at home). Study 1: n= 91 IC/PwAD dyads, Study 2: n= 21 spousal ICs of PwAD, Study 3: n= 12 ICs of PwAD	The relational dynamics between ICs and PwDs are important and can be the source of a positive care experience. For the ICs their current attitude toward the relationship dynamic with the PwD is what seemed to bring the most meaning. By finding caregiving meaningful, ICs can obtain peace and pleasure in the currently lived experience. IC attitudes toward the relationship with PwDs and the PwD's degenerative decline influence the quality of the care experience.	change, balancing, **dyadic relationship**
Spitznagel et al. (2006) (USA)	Berries	to understand predictors of desire to institutionalise in ICs of PwDs	quantitative: observational (cross-sectional)	72 ICs (PwD living at home)	ICs with a desire to institutionalise had significantly higher burden, greater dementia knowledge, more family dysfunction, and decreased social support compared with no-desire ICs. Findings emphasise the importance of IC and family relationship variables in desire to institutionalise, suggesting potentially modifiable targets for IC interventions. Dementia knowledge was associated with higher desire to institutionalise, suggesting that educational programs alone may not be helpful to delay institutionalisation.	change, dyadic relationship, resources
Stephan et al. (2015) (International Consortium: Estonia, Germany, Finland, France, Netherlands, UK, Spain, Sweden)	Institutionalisation	to explore the perceptions of ICs and FCs regarding reasons for the institutionalisation of PwDs in eight European countries	mixed methods	1160 ICs (PwD living at home) and their health care practitioners (number not reported)	Agreement about reasons for institutionalisation between ICs and FCs was low-to-moderate. Discrepancy was high for reasons related to IC burden. Furthermore differences between countries emerged.	**change**, resources, society and culture, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Stiens et al. (2006) (Germany)	Institutionalisation	to investigate associations of filial maturity with PwD institutionalisation and IC burden by using the Louvain Filial Maturity Scale	quantitative: observational (longitudinal)	61 filial ICs (PwD living at home at baseline)	Filial maturity had no influence on the IC's feelings of burden, but higher 'parental consideration' resulted in lower IC burden. Adult children with more 'filial obligation' continued to care for their parents more often, even when experiencing great burden and stress. Institutionalisation was caused mainly by PwDs growing needs and increasing behavioural problems.	carer role
Sun et al. (2013) (USA)	Institutionalisation	to understand the role of quality of care in mediating between caring stressors and IC desire to institutionalise a PwD	quantitative: observational (cross-sectional)	612 racially diverse ICs (PwD living at home)	Potentially harmful behaviours of the ICs were positively related to IC's desire to institutionalise their care recipients. The mediation effect of exemplary care was significant in the African American group only.	needs, society and culture
Toot et al. (2013) (UK)	Berries	to identify which factors may lead to crisis for PwDs and ICs and identify interventions these individuals believe could help in crisis	qualitative: unspecific design	18 PwDs (living at home), 15 ICs, 19 FCs	Causes of crises for PwDs were risks and hazards in their home, whereas for ICs carer stress and their own mental health problems were predominant. FCs focused on problems with service organisation and coordination leading to crisis. PwDs valued support from family and friends, access to mobile phones and home adaptations to reduce risks. ICs valued assistive technology and home adaptation. Both ICs and FCs valued carer training and education, care plans and well-coordinated care.	**change**, needs, carer role, **resources,** health care system
Toot et al. (2017) (UK)	Institutionalisation	to understand the factors that influence the decision for PwDs to move into NHs, with particular emphasis on factors that might be responsive to intervention	systematic review: narrative review and meta-analysis	systematic review: 26 publications, meta-analysis: 15 publications	Poorer cognition and behavioural and psychological symptoms were associated with an increased risk of institutionalisation. Impairments in ADLs were identified as a significant risk. There was an association between IC burden and risk of institutionalisation, but findings with regard to IC depression varied, as did physical health associations, with some studies showing an increased risk of institutionalisation following hip fracture, reduced mobility, and multiple comorbidities.	**change**, needs, carer role, resources
Treloar et al. (2009) (UK)	End-of-life-care	to undertake detailed interviews of ICs who had supported PwDs at home, with the aim of identifying the major factors which make such care feasible	mixed methods	14 bereaved ICs (PwD living at home or institutionalised)	The study revealed blockages to accessing support as a result of poor understanding of the needs of advanced dementia care as well as organisational prejudice. Home based palliative care of PwDs can be achieved with very positive outcomes.	change, **needs**, resources

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Tucker et al. (2016) (International Consortium: UK, Estonia, Netherlands, Spain, Sweden, Finland, Germany, France)	Institutionalisation	to explore the extent to which client characteristics, decision-maker attributes, and country influence judgments of institutional long-term care appropriateness for PwDs	quantitative: observational (cross-sectional)	161 experts in dementia care	Client characteristics, decision-maker attributes, and country seemed to play a role in influencing FC's perceptions of the appropriateness of NHs for PwDs. Decision-makers were more likely to recommend NHs for PwDs who required help with mobility or had multiple care needs, and appeared to give more weight to IC's than PwD's wishes. Community-based social workers were less likely than other FC groups to favour NHP. Experts in Finland, Germany, and the UK were less likely to recommend NHP than experts in France, the Netherlands, and Estonia. Experts in Sweden and Spain took an intermediate position.	change, resources, **society and culture**
Verbeek et al. (2015) (International Consortium: Estonia, Germany, Finland, France, Netherland, UK, Spain, Sweden)	Institutionalisation	to explore inter-country variations associated with institutionalisation of PwDs	quantitative: observational (longitudinal)	2014 dyads (PwD living at home or recently institutionalised)	Inter-country differences were found in recently institutionalised PwD's characteristics. Most consistent factors associated with institutionalisation were ADL and IC burden, although country differences may be more prominent for this factor.	change, dyadic relationship, **society and culture**
Volicer et al. (2003) (USA)	End-of-life-care	to evaluate the quality of care in home settings and compare it with care provided in institutions	quantitative: observational (cross-sectional)	154 ICs (PwD living at home or institutionalised (various institutions))	Psychiatric symptoms and increased IC burden were the most common reason for institutionalisation, and psychiatric care was associated with longer stay at home. Presence of advance directives decreased hospital stay and increased the likelihood of dying in a NH. Care recipients dying at home had fewer symptoms and less discomfort than care recipients dying in other settings. These results indicate that quality end-of-life care can be provided at home and is facilitated by hospice programs, effective pain control, and psychiatric care.	change, **resources**
von Kutzleben et al. (2015) (Germany)	Berries	to assess home-based care arrangements, to illustrate utilisation of formal services, and to identify factors associated with perceived stability of the care situation from the IC's perspective	quantitative: observational (cross-sectional)	84 dyads (PwD living at home)	Most frequently used formal services were home care nursing services, day care, and respite care. Companion home visit, home care nursing services and day care were used over the longest periods of time. IC's perceived stability of care situation was high, and was associated with the country of origin and sex of PwD.	dyadic relationship, **society and culture**, health care system

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Wackerbarth (1999a) (USA)	Berries	to understand the decision processes of ICs and to develop a model of their decision processes	qualitative: unspecific design	28 ICs (PwD living at home or institutionalised)	The proposed model charts the caring experience over time and documents decisions made to maintain a stable care situation. It has three main components: tolerance line, status points, and decision events. ICs are divided into 5 types: ICs who plan ahead, take it one day at a time, have difficulty implementing decision, receive decision support from FCs and ICs who feel that decisions are made by others or by the disease itself.	**change**, **balancing**, needs
Wackerbarth (1999b) (USA)	(Self-)caring actions	to describe the complexities of the overall decision making situation, to characterise a specific care decision, and to identify decision support needs	mixed methods	80 ICs (PwD living at home or institutionalised)	Most prevalent decisions involved institutionalisation, communicating the diagnosis and the driving privilege. Most challenging decisions involved providing care and relocation. The most prevalent question involved the timing of actions.	**balancing**
Wattmo et al. (2011) (Sweden)	Institutionalisation	to identify risk factors for early institutionalisation in AD, focusing on the impact of longitudinal change in cognition, ADL, service utilisation, and AChEIs	quantitative: observational (longitudinal)	880 PwDs (PwD living at home at baseline)	Factors that precipitated institutionalisation were: lower cognitive and functional abilities at baseline, faster rate of decline in Instrumental Activities of Daily Living Scale, female gender, living alone, substantial increase in adult day care, and a lower mean dose of AChEI. The rate of functional but not cognitive decline was a strong risk factor for institutionalisation.	**change**
Willoughby et al. (1991) (Canada)	(Self-)caring actions	to understand the process of caring from the perspective of ICs of PwDs	qualitative: Grounded Theory	10 ICs (PwD institutionalised)	The finding yield a five-stage model of gaining and relinquishing control of caring (emerging recognition, taking control, losing control, adjusting to the psychiatric institution, moving on). Shifts in the understanding of the process delineated each stage.	change, **balancing**, **carer role**, dyadic relationship
Winslow et al. (1999) (USA)	Burden	to describe the longitudinal pattern of IC burden and to compare IC burden of wives who continue in home-based care and those who institutionalised the PwD	quantitative: observational (longitudinal)	376 ICs (PwD living at home) and 523 ICs (PwD institutionalised)	Spouse ICs who provided home-based care to their husbands experienced an increase in burden over time. There appeared to be a threshold of burden when institutionalisation occurred. Immediately after placement the IC appeared to experience a reduction in burden.	change, needs
Wuest et al. (1994) (Canada)	(Self-)caring actions	to explore the reciprocal process of becoming strangers in Canadian ICs and PwDs and their interaction on a continuum from intimacy to alienation	qualitative: Grounded Theory	15 dyads (PwD living at home)	The continuum from intimacy to alienation comprises three dimensions: dawning, holding on and letting go. ICs struggle on a daily basis with their commitment to the person they knew and their increasing detachment from the stranger the PwD has become.	change, **balancing**, carer role, **dyadic relationship**

Author (Year) (Country)	**Search Strand**	**Aim**	**Study Design**	**Sample/Setting**	**Main Findings**	**Contribution to Concepts**
Zarit et al. (1986) (USA)	Burden	to investigate changes over time for ICs of PwDs, with a focus on factors associated with institutionalisation, to determine if differences between husbands and wives found at the initial testing remained stable over time	quantitative: observational (longitudinal)	64 ICs (PwD living at home)	Institutionalisation was more strongly associated with subjective factors, particularly IC burden, than with objective indicators of the severity of dementia. Although wives initially reported more burden than husbands, no differences were found at the follow-up.	**change**

Appendix E: Bibliography of the meta-study sample

All 99 publications included in our meta-study (including those, that are not cited in the publication itself) are listed below.

Afram, B., Stephan, A., Verbeek, H., Bleijlevens, M. H., Suhonen, R., Sutcliffe, C., . . . Hamers, J. P. (2014). Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *Journal of the American Medical Directors Association, 15*(2), 108-116. doi:10.1016/j.jamda.2013.09.012

Afram, B., Verbeek, H., Bleijlevens, M. H. C., & Hamers, J. P. H. (2015). Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *International psychogeriatrics / IPA, 27*(6), 891-902. doi:10.1017/S1041610214002154

Andren, S., & Elmstahl, S. (2008). Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: a five-year follow-up study. *International psychogeriatrics / IPA, 20*(6), 1177-1192. doi:10.1017/s1041610208007503

Badrakalimuthu, V., & Barclay, S. (2014). Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and ageing, 43*(1), 13-19. doi:10.1093/ageing/aft151

Bakker, C., de Vugt, M. E., van Vliet, D., Verhey, F. R. J., Pijnenburg, Y. A., Vernooij-Dassen, M. J. F. J., & Koopmans, R. T. C. M. (2013). Predictors of the time to institutionalization in young- versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *Journal of the American Medical Directors Association, 14*(4), 248-253. doi:10.1016/j.jamda.2012.09.011

Caldwell, L., Low, L. F., & Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *International psychogeriatrics / IPA, 26*(3), 413-424. doi:10.1017/s1041610213002020

Caron, C. D., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Canadian journal on aging / La revue canadienne du vieillissement, 25*(2), 193-205. doi:10.1353/cja.2006.0033

Cepoiu-Martin, M., Tam-Tham, H., Patten, S., Maxwell, C. J., & Hogan, D. B. (2016). Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis. *International Journal of Geriatric Psychiatry, 31*(11), 1151-1171. doi:10.1002/gps.4449

Chang, Y. P., & Schneider, J. K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in psychiatric care, 46*(2), 108-118. doi:10.1111/j.1744-6163.2010.00246.x

Chang, Y. P., Schneider, J. K., & Sessanna, L. (2011). Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *Journal of Aging Studies, 25*(4), 436-444. doi:10.1016/j.jaging.2011.05.001

Coe, M., & Neufeld, A. (1999). Male caregivers' use of formal support. *Western journal of nursing research, 21*(4), 568-588. doi:10.1177/01939459922044045

Cohen, C. A., Gold, D. P., Shulman, K. I., & Zucchero, C. A. (1994). Positive aspects in caregiving: An overlooked variable in research. *Canadian journal on aging / La revue canadienne du vieillissement, 13*(3), 378-391. doi:10.1017/S071498080000619X

Cox, C. B. (1996). Discharge planning for dementia patients: factors influencing caregiver decisions and satisfaction. *Health & social work, 21*(2), 97-104. doi:10.1093/hsw/21.2.97

Daly, L., McCarron, M., Higgins, A., & McCallion, P. (2012). 'Sustaining Place' - a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *Journal of clinical nursing, 22*(3-4), 501-512. doi:10.1111/jocn.12003

Davis, L. L., Chestnutt, D., Molloy, M., Deshefy-Longhi, T., Shim, B., & Gilliss, C. L. (2014). Adapters, strugglers, and case managers: a typology of spouse caregivers. *Qualitative Health Research, 24*(11), 1492-1500. doi:10.1177/1049732314548879

de Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., & Verhey, F. R. J. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International psychogeriatrics / IPA, 17*(4), 577-589. doi:10.1017/S1041610205002292

Donovan, M. L. (2006). *Edification of dementia caregiver uplifts characteristics*. (Doctoral dissertation, Capella University).

Donovan, M. L., & Corcoran, M. A. (2010). Description of Dementia Caregiver Uplifts and Implications for Occupational Therapy. *The American journal of occupational therapy, 64*(4), 590-595 doi:10.5014/ajot.2010.09064

Dramé, M., Lang, P. O., Jolly, D., Narbey, D., Mahmoudi, R., Laniece, I., . . . Novella, J. L. (2012). Nursing home admission in elderly subjects with dementia: predictive factors and future challenges. *Journal of the American Medical Directors Association, 13*(1), 83.e17-20. doi:10.1016/j.jamda.2011.03.002

Ducharme, F., Couture, M., & Lamontagne, J. (2012). Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home health care services quarterly, 31*(3), 197-218. doi:10.1080/01621424.2012.681572

Ebly, E. M., Hogan, D. B., & Rockwood, K. (1999). Living alone with dementia. *Dementia and Geriatric Cognitive Disorders, 10*(6), 541-548. doi:10.1159/000017202

Feldman, H. H., Pirttila, T., Dartigues, J. F., Everitt, B., Van Baelen, B., Schwalen, S., & Kavanagh, S. (2009). Treatment with galantamine and time to nursing home placement in Alzheimer's disease patients with and without cerebrovascular disease. *International Journal of Geriatric Psychiatry, 24*(5), 479-488. doi:10.1002/gps.2141

Forbes, D. A., Finkelstein, S., Blake, C. M., Gibson, M., Morgan, D. G., Markle-Reid, M., . . . Thiessen, E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. *Rural and remote health, 12*(4), 1-15

Frewer-Graumann, S. (2014). *Zwischen Fremdfürsorge und Selbstfürsorge: Familiale Unterstützungsarrangements von Menschen mit Demenz und ihren Angehörigen*. Wiesbaden: Springer VS.

Gallagher, D., Mhaolain, A. N., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., . . . Lawlor, B. A. (2011). Determinants of the desire to institutionalize in Alzheimer’s caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 26*(3), 205-211. doi:10.1177/1533317511400307

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005a). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and aging, 20*(1), 100-116. doi:10.1037/0882-7974.20.1.100

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005b). Unmet care needs and key outcomes in dementia. *Journal of the American Geriatrics Society, 53*(12), 2098-2105. doi:10.1111/j.1532-5415.2005.00495.x

Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *The journals of gerontology. Series B, Psychological sciences and social sciences, 62*(1), P38-44. doi:10.1093/geronb/62.1.P38

Gaugler, J. E., Pearlin, L. I., Leitsch, S. A., & Davey, A. (2001). Relinquishing in-home dementia care: Difficulties and perceived helpfulness during the nursing home transition. *American Journal of Alzheimer's Disease and Other Dementias, 16*(1), 32-42. doi:10.1177/153331750101600102

Gaugler, J. E., Wall, M. M., Kane, R. L., Menk, J. S., Sarsour, K., Johnston, J. A., . . . Newcomer, R. (2011). Does caregiver burden mediate the effects of behavioral disturbances on nursing home admission? *The American Journal of Geriatric Psychiatry, 19*(6), 497-506. doi:10.1097/JGP.0b013e31820d92cc

Gaugler, J. E., Yu, F., Krichbaum, K., & Wyman, J. F. (2009). Predictors of nursing home admission for persons with dementia. *Medical care, 47*(2), 191-198. doi:10.1097/MLR.0b013e31818457ce

Gilhooly, M. L. M. (1986). Senile dementia: Factors associated with caregivers' preference for institutional care. *The British journal of medical psychology, 59*(2), 165-171. doi:10.1111/j.2044-8341.1986.tb02681.x

Glass, A. P. (2016). Family Caregiving and the Site of Care: Four Narratives About End-of-Life Care for Individuals with Dementia. *Journal of Social Work in End-of-Life & Palliative Care, 12*(1-2), 23-46. doi:10.1080/15524256.2016.1156605

Gort, A. M., Mingot, M., Gomez, X., Soler, T., Torres, G., Sacristan, O., . . . Cabau, J. (2007). Use of the Zarit scale for assessing caregiver burden and collapse in caregiving at home in dementias. *International Journal of Geriatric Psychiatry, 22*(10), 957-962. doi:10.1002/gps.1770

Groen-van de Ven, L., Smits, C., Oldewarris, K., Span, M., Jukema, J., Eefsting, J., & Vernooij-Dassen, M. (2017). Decision Trajectories in Dementia Care Networks Decisions and Related Key Events. *Research on Aging, 39*(9), 1039-1071. doi:10.1177/0164027516656741

Hagen, B. (2001). Nursing home placement. Factors affecting caregivers' decisions to place family members with dementia. *Journal of gerontological nursing, 27*(2), 44-53. doi:10.3928/0098-9134-20010201-14

Hill, S. R., Mason, H., Poole, M., Vale, L., & Robinson, L. (2017). What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International Journal of Geriatric Psychiatry, 32*(9), 1037-1045. doi:10.1002/gps.4564

Hirschfeld, M. (2003). Home care versus institutionalization: family caregiving and senile brain disease. *International journal of nursing studies, 40*(5), 463-469. doi:10.1016/S0020-7489(03)00063-4

Janssen, E. P., de Vugt, M., Köhler, S., Wolfs, C., Kerpershoek, L., Handels, R. L., . . . Verhey, F. R. (2017). Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health. *Aging & Mental Health, 21*(1), 49-57. doi:10.1080/13607863.2016.1255716

Kajiwara, K., Nakatani, H., Ono, M., & Miyakoshi, Y. (2015). Positive appraisal of in-home family caregivers of dementia patients as an influence on the continuation of caregiving. *Psychogeriatrics : the official journal of the Japanese Psychogeriatric Society, 15*(1), 26-31. doi:10.1111/psyg.12074

Kellett, U. M. (1999). Transition in care: family carers' experience of nursing home placement. *Journal of advanced nursing, 29*(6), 1474-1481. doi:10.1046/j.1365-2648.1999.01035.x

Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., & van Exel, J. (2014). The perseverance time of informal carers of dementia patients: validation of a new measure to initiate transition of care at home to nursing home care. *Journal of Alzheimer's disease, 40*(3), 631-642. doi:10.3233/jad-132420

Kraijo, H., de Leeuw, R., & Schrijvers, G. (2015). How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scandinavian Journal of Caring Sciences, 29*(1), 101-109. doi:10.1111/scs.12137

Kwon, S. H., & Tae, Y. S. (2012). Nursing Home Placement: The Process of Decision Making and Adaptation among Adult Children Caregivers of Demented Parents in Korea. *Asian nursing research, 6*(4), 143-151. doi:10.1016/j.anr.2012.10.005

Ledgerd, R., Hoe, J., Hoare, Z., Devine, M., Toot, S., Challis, D., & Orrell, M. (2016). Identifying the causes, prevention and management of crises in dementia. An online survey of stakeholders. *International Journal of Geriatric Psychiatry, 31*(6), 638-647. doi:10.1002/gps.4371

Lethin, C., Hallberg, I. R., Karlsson, S., & Janlov, A. C. (2016). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences, 30*(3), 526-534. doi:10.1111/scs.12275

Lewis, L. F. (2015). Caregiving for a Loved One With Dementia at the End of Life. *American Journal of Alzheimer's Disease and Other Dementias, 30*(5), 488-496. doi:10.1177/1533317514559829

Liken, M. A. (2001a). Caregivers in crisis: moving a relative with Alzheimer's to assisted living. *Clinical nursing research, 10*(1), 52-68. doi:10.1177/c10n1r6

Liken, M. A. (2001b). Critical incidents precipitating institutionalization of a relative with Alzheimer's. *Western journal of nursing research, 23*(2), 163-178. doi:10.1177/019394590102300205

Lindgren, C. L. (1993). The caregiver career. *Image: the journal of nursing scholarship, 25*(3), 214-219. doi:10.1111/j.1547-5069.1993.tb00784.x

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London), 15*(6), 1534-1561. doi:10.1177/1471301214564792

Lord, K., Livingston, G., Robertson, S., & Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. *BMC Geriatrics, 16*(68). doi:10.1186/s12877-016-0242-1

Luppa, M., Luck, T., Brähler, E., König, H. H., & Riedel-Heller, S. G. (2008). Prediction of institutionalisation in dementia. A systematic review. *Dementia and Geriatric Cognitive Disorders, 26*(1), 65-78. doi:10.1159/000144027

Luppa, M., Riedel-Heller, S. G., Stein, J., Leicht, H., Konig, H. H., van den Bussche, H., . . . Weyerer, S. (2012). Predictors of institutionalisation in incident dementia--results of the German Study on Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe study). *Dementia and Geriatric Cognitive Disorders, 33*(4), 282-288. doi:10.1159/000339729

MacNeil Vroomen, J., Bosmans, J. E., van Hout, H. P., & de Rooij, S. E. (2013). Reviewing the definition of crisis in dementia care. *BMC Geriatrics, 13*(10). doi:10.1186/1471-2318-13-10

Markiewicz, D., Reis, M., & Gold, D. P. (1997). An exploration of attachment styles and personality traits in caregiving for dementia patients. *International journal of aging & human development, 45*(2), 111-132. doi:10.2190/T4Q4-E8F0-JWT5-DBAG

Mausbach, B. T., Coon, D. W., Depp, C., Rabinowitz, Y. G., Wilson-Arias, E., Kraemer, H. C., . . . Gallagher-Thompson, D. (2004). Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. *Journal of the American Geriatrics Society, 52*(7), 1077-1084. doi:10.1111/j.1532-5415.2004.52306.x

McLennon, S. M., Habermann, B., & Davis, L. L. (2010). Deciding to institutionalize: Why do family members cease caregiving at home? *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses, 42*(2), 95-103. doi:10.1097/JNN.0b013e3181ce5c45

Mitchell, S. L., Morris, J. N., Park, P. S., & Fries, B. E. (2004). Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of palliative medicine, 7*(6), 808-816. doi:10.1089/jpm.2004.7.808

Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*(3), 329-361. doi:10.1177/0164027585007003002

Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. J., Potter, G. G., & Langa, K. M. (2011). Neuropsychiatric symptoms and the risk of institutionalization and death: the aging, demographics, and memory study. *Journal of the American Geriatrics Society, 59*(3), 473-481. doi:10.1111/j.1532-5415.2011.03314.x

Oliva y Hausmann, A., Schacke, C., & Zank, S. (2012). Pflegende Angehörige von demenziell Erkrankten : welche Faktoren beeinflussen den Transfer von der häuslichen in die stationäre Pflege? *Psychotherapie, Psychosomatik, Medizinische Psychologie, 62*(9-10), 367-374. doi:10.1055/s-0032-1323708

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., . . . Henderson, S. R. (2010). The positive aspects of the caregiving journey with dementia: using a strengths-based perspective to reveal opportunities. *Journal of applied gerontology: the official journal of the Southern Gerontological Society, 29*(5), 640-659 doi:10.1177/0733464809341471

Pimouguet, C., Le-Goff, M., Rizzuto, D., Berr, C., Leffondre, K., Peres, K., . . . Helmer, C. (2016). Effect of Early Referral to Specialist in Dementia on Institutionalization and Functional Decline:

Findings from a Population-Based Study. *American Journal of Alzheimer's Disease and Other Dementias, 49*(3), 819-828. doi:10.3233/JAD-150574

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International psychogeriatrics / IPA, 18*(4), 577-595. doi:10.1017/S1041610206003462

Pinzon, L. C., Claus, M., Perrar, K. M., Zepf, K. I., Letzel, S., & Weber, M. (2013). Dying with dementia: symptom burden, quality of care, and place of death. *Deutsches Ärzteblatt international, 110*(12), 195-202. doi:10.3238/arztebl.2013.0195

Porter, C. N., Miller, M. C., Lane, M., Cornman, C., Sarsour, K., & Kahle-Wrobleski, K. (2016). The influence of caregivers and behavioral and psychological symptoms on nursing home placement of persons with Alzheimer's disease: A matched case-control study. *SAGE open medicine, 4*, 1-9. doi:10.1177/2050312116661877

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London), 14*(2), 220-237. doi:10.1177/1471301213495863

Redfern, S., Norman, I., Briggs, K., & Askham, J. (2002). Care at home for people with dementia: routines, control and care goals. *Quality in ageing and older adults, 3*(4), 12-23. doi:10.1108/14717794200200023

Romero-Moreno, R., Losada, A., Márquez-González, M., & Mausbach, B. T. (2014). Effects of the frequency and satisfaction with leisure profile on dementia caregivers distress. *Anales de psicología (Murcia, Spain), 30*(3), 878-886. doi:10.6018/analesps.30.3.148381

Rongve, A., Vossius, C., Nore, S., Testad, I., & Aarsland, D. (2014). Time until nursing home admission in people with mild dementia: comparison of dementia with Lewy bodies and Alzheimer's dementia. *International Journal of Geriatric Psychiatry, 29*(4), 392-398. doi:10.1002/gps.4015

Runte, R. (2018). Predictors of institutionalization in people with dementia: a survey linked with administrative data. *Aging clinical and experimental research, 30*(1), 35-43. doi:10.1007/s40520-017-0737-4

Saks, K., Tiit, E. M., Verbeek, H., Raamat, K., Armolik, A., Leibur, J., . . . Consortium, R. (2015). Most appropriate placement for people with dementia: individual experts' vs. expert groups' decisions in eight European countries. *Journal of advanced nursing, 71*(6), 1363-1377 doi:10.1111/jan.12544

Sansoni, J., Anderson, K. H., Varona, L. M., & Varela, G. (2013). Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Annali di igiene : medicina preventiva e di comunità, 25*(3), 235-246. doi:10.7416/ai.2013.1926

Schacke, C., & Zank, S. (1998). Zur familiaren Pflege demenzkranker Menschen: Die differentielle Bedeutung spezifischer Belastungsdimensionen fur das Wohlbefinden der Pflegenden und die Stabilitat der hauslichen Pflegesituation. [Family caregiving: The meaning of specific dimensions of burden for the caregiver's well-being and the stability of the caregiving situation]. *Zeitschrift für Gerontologie und Geriatrie, 31*(5), 355-361.

Schäufele, M., Köhler, L., Teufel, S., & Weyerer, S. (2005). *Betreuung von demenziell erkrankten Menschen in Privathaushalten: Potenziale und Grenzen* Retrieved from München:

Schirra-Weirich, L., & Wiegelmann, H. (2017). Typenbildung als Beitrag zur Weiterentwicklung von Versorgungsstrukturen für Menschen mit Demenz und ihren versorgenden Angehörigen. Ergebnisse einer Tandem-Studie im Rahmen des Modellprojekts "DemenzNetz Städte Region Aachen". In S. Schäfer-Walkmann & F. Traub (Eds.), *Evolution durch Vernetzung - Beiträge zur interdisziplinären Versorgungsforschung* (pp. 59-76). Wiesbaden: Springer VS.

Schoenmakers, B., Buntinx, F., Devroey, D., Van Casteren, V., & DeLepeleire, J. (2009). The process of definitive institutionalization of community dwelling demented vs non demented elderly: data obtained from a network of sentinel general practitioners. *International Journal of Geriatric Psychiatry, 24*(5), 523-531. doi:10.1002/gps.2147

Scholzel-Dorenbos, C. J., Meeuwsen, E. J., & Olde Rikkert, M. G. (2010). Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. *Aging & Mental Health, 14*(1), 113-119. doi:10.1080/13607860903046495

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2008). Patients dying with dementia: experience at the end of life and impact of hospice care. *Journal of pain and symptom management, 35*(5), 499-507. doi:10.1016/j.jpainsymman.2007.06.011

Shim, B. (2011). *Finding Meaning in the Dementia Caregiving Relationship*. (Doctoral dissertation, Duke University).

Spitznagel, M. B., Tremont, G., Davis, J. D., & Foster, S. M. (2006). Psychosocial predictors of dementia caregiver desire to institutionalize: caregiver, care recipient, and family relationship factors. *Journal of geriatric psychiatry and neurology, 19*(1), 16-20. doi:10.1177/0891988705284713

Stephan, A., Afram, B., Koskenniemi, J., Verbeek, H., Soto, M. E., Bleijlevens, M. H., . . . Consortium, R. (2015). Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals. *Journal of advanced nursing, 71*(6), 1392-1404. doi:10.1111/jan.12493

Stiens, G., Maeck, L., & Stoppe, G. (2006). Filial maturity as a predictor for the burden of demented parents' caregivers. [Filiale Reife als Prädiktor der Belastung von erwachsenen pflegenden Kindern Demenzkranker.] *Zeitschrift für Gerontologie und Geriatrie, 39*(2), 120-125. doi:10.1007/s00391-006-0336-z

Sun, F., Durkin, D. W., Hilgeman, M. M., Harris, G., Gaugler, J. E., Wardian, J., . . . Burgio, L. D. (2013). Predicting desire for institutional placement among racially diverse dementia family caregivers: the role of quality of care. *Gerontologist, 53*(3), 418-429. doi:10.1093/geront/gns110

Toot, S., Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell, M. (2013). Causes of crises and appropriate interventions: the views of people with dementia, carers and healthcare professionals. *Aging & Mental Health, 17*(3), 328-335. doi:10.1080/13607863.2012.732037

Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *International psychogeriatrics / IPA, 29*(2), 195-208. doi:10.1017/s1041610216001654

Treloar, A., Crugel, M., & Adamis, D. (2009). Palliative and end of life care of dementia at home is feasible and rewarding: results from the 'Hope for Home' study. *Dementia (London), 8*(3), 335-347. doi:10.1177/1471301209104975

Tucker, S., Brand, C., Sutcliffe, C., Challis, D., Saks, K., Verbeek, H., . . . Soto, M. E. (2016). What Makes Institutional Long-Term Care the Most Appropriate Setting for People With Dementia?

Exploring the Influence of Client Characteristics, Decision-Maker Attributes, and Country in 8 European Nations. *Journal of the American Medical Directors Association, 17*(5), 465.e469-465.e415. doi:10.1016/j.jamda.2016.02.025

Verbeek, H., Meyer, G., Challis, D., Zabalegui, A., Soto, M. E., Saks, K., . . . Hamers, J. P. (2015). Inter-country exploration of factors associated with admission to long-term institutional dementia care: Evidence from the RightTimePlaceCare study. *Journal of advanced nursing, 71*(6), 1338-1350. doi:10.1111/jan.12663

Volicer, L., Hurley, A. C., & Blasi, Z. V. (2003). Characteristics of dementia end-of-life care across care settings The American journal of hospice & palliative care*, 20*(3), 191-200. doi:10.1177/104990910302000307

von Kutzleben, M., Reuther, S., Dortmann, O., & Holle, B. (2015). Care arrangements for community-dwelling people with dementia in Germany as perceived by informal carers - a cross-sectional pilot survey in a provincial-rural setting. *Health & social care in the community, 24*(3), 283-296. doi:10.1111/hsc.12202

Wackerbarth, S. (1999a). Modeling a Dynamic Decision Process: Supporting the Decisions of Caregivers of Family Members with Dementia. *Qualitative Health Research, 9*(3), 294-314. doi:10.1177/104973299129121875

Wackerbarth, S. (1999b). What decisions are made by family caregivers? *American Journal of Alzheimer's Disease, 14*(2), 111–119. doi:10.1177/153331759901400210

Wattmo, C., Wallin, A. K., Londos, E., & Minthon, L. (2011). Risk factors for nursing home placement in Alzheimer's disease: a longitudinal study of cognition, ADL, service utilization, and cholinesterase inhibitor treatment. *Gerontologist, 51*(1), 17-27. doi:10.1093/geront/gnq050

Willoughby, J., & Keating, N. (1991). Being in control: the process of caring for a relative with Alzheimer's disease. *Qualitative Health Research, 1*(1), 27–50. doi:10.1177/104973239100100103

Winslow, B. W., & Carter, P. (1999). Patterns of burden in wives who care for husbands with dementia. *The Nursing clinics of North America, 34*(2), 275-287.

Wuest, J., Ericson, P. K., & Stern, P. N. (1994). Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. *Journal of advanced nursing, 20*(3), 437–443. doi:10.1016/j.pec.2014.01.009

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist, 26*(3), 260-266. doi:10.1093/geront/26.3.260

ENTREQ Statement according to Tong, Flemming, McInnes, Oliver & Craig (2012)

Item	Description	On Page
1. Aim	To generate a middle-range theory of 'Stability of home-based care arrangements for people living with dementia'. Research questions: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors influencing stability?	5
2. Synthesis methodology	Meta-Study	5
3. Approach to searching	Systematic searches in electronic databases combined with hand searches until saturation of concepts was reached	5
4. Inclusion criteria	Described in the study protocol (Dreyer, Köhler, Hochgraeber, Holle, & von Kutzleben, 2018)	Study Protocol 5
5. Data sources	MEDLINE, CINAHL, PsycINFO for systematic database searches	5
6. Electronic search strategy	Described in the study protocol (Dreyer et al., 2018)	Study Protocol 5
7. Study screening methods	Titles and abstracts were screened by two researchers, full texts were screened by one researcher and final inclusion or exclusion was discussed with at least one other researcher.	5-6
8. Study characteristics	Study characteristics are presented in Appendix A in Table 1.	Appendix A 1-21
9. Study selection results	The number of screened studies and the process of screening is presented in Figure 2 (flow diagram). Details on the iterative process of literature searching, screening and selecting is described in detail in the study protocol (Dreyer et al., 2018).	8 Study Protocol 4-5
10. Rationale for appraisal	The appraisal aimed to exclude studies that either had major methodological deficits, or did not contribute meaningful to the theory building process and proposed middle-range theory.	6 Study Protocol 6
11. Appraisal items	We applied the quality appraisal recommended by Dixon-Woods and colleagues (2005).	6
12. Appraisal process	Each study was appraised by one researcher, who discussed her/his appraisal with one other researcher.	6
13. Appraisal results	5 studies were excluded.	Figure 2
14. Data extraction	All text in the results, discussion and conclusion sections of the included studies were extracted. To do this, all studies were entered into the computer software MAXQDA 2018.	6
15. Software	We used EndNote X7 to manage the literature screening process and MAXQDA 2018 for data extraction and analysis.	6

		Study Protocol 5
16. Number of reviewers	KK, JD, IH and MvK performed the coding process. KK, JD and IH performed the analysis and synthesis process. The middle-range theory in creation was discussed and finalized as a team by all the authors.	20
17. Coding	According to the methodology of thematic synthesis (Thomas & Harden, 2008) an initial 'line-by-line' coding was performed. In subsequent coding rounds the 'line-by-line' codings were organised into descriptive themes. Basing on the descriptive themes the final analytical themes were created.	6
18. Study comparison	Study comparisons within and across the studies were made throughout the iterative analytic process (see also item 17).	6-7
19. Derivation of themes	The derivation of analytical themes (middle-range theory concepts) was inductive.	6-7
20. Quotations	This meta-study is a synthesis of qualitative, quantitative and mixed-methods studies and of (systematic) reviews. Due to this heterogeneous sample and due to the intent of this publication to introduce a new middle-range theory it was not appropriate to provide quotations from selected primary studies.	
21. Synthesis output	This meta-study generates a new middle-range theory including a conceptual model of 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem). This publication portrays all the theory concepts and their dynamic interplay.	8-17

Literature:

Dreyer, J., Köhler, K., Hochgraeber, I., Holle, B., & von Kutzleben, M. (2018). Stability of home-based care arrangements for people living with dementia: protocol of a meta-study on mixed research. *BMJ Open, 8*, e021156. doi:10.1136/bmjopen-2017-021156

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(45). doi:10.1186/1471-2288-8-45

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol, 12*, 181. doi:10.1186/1471-2288-12-181

Woods, M. D., Kirk, M. D., Agarwal, M. S., Annandale, E., Arthur, T., Harvey, J., . . . Smith, L. (2005). Vulnerable groups and access to health care: a critical interpretive review. *National Coordinating Centre NHS Service Delivery Organ RD (NCCSDO) Retrieved May, 27*, 2012.