

BMJ Open Stability of home-based care arrangements for people living with dementia: protocol of a meta-study on mixed research

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ABSTRACT

Introduction Worldwide, most people with dementia live at home and are cared for by informal carers. During the dementia care trajectory, creating and maintaining a stable care situation is a guiding principle of informal carers and a desirable outcome of contemporary healthcare policies. However, though there is an extensive body of research focusing on the course of dementia care trajectories, it remains unclear how stability of home-based care arrangements is constituted and what are the essential factors that influence this stability. This paper outlines a protocol of a systematic review that aims to address these gaps in knowledge.

Methods and analysis To theorise the complex phenomenon of stability of home-based care arrangements for people with dementia, we will conduct a meta-study. Meta-studies include three analytical components (meta-data analysis, meta-method and meta-theory) that are combined and finally culminate in an integrative knowledge synthesis. Originally, meta-study was designed to include qualitative studies only. To capture relevant contributions to our target phenomenon from all types of evidence, we will extend the original methodology and apply it to studies with qualitative, quantitative and mixed-methods designs and to (systematic) reviews. Eligible studies will be identified by systematic database searches (PubMed, CINAHL and PsycINFO), backward/forward citation tracking, snowballing and theoretical sampling. All identified studies will be screened against predefined inclusion criteria. The main analytical approach for all analyses is thematic synthesis. The meta-study will generate a more comprehensive understanding of dementia care trajectories and will be used to identify research gaps, develop future research questions and define relevant outcomes.

Dissemination The findings of the meta-study will be published in a series of articles in peer-reviewed scientific journals and will be presented at national and international scientific conferences.

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INTRODUCTION

The prevalence of dementia is growing worldwide. Today, over 46 million people live with dementia, and this number is estimated

Strengths and limitations of this study

- This meta-study will provide a contemporary synthesis of research related to the complex phenomenon of stability of home-based care arrangements for people living with dementia, a phenomenon that has been overlooked by research until now.
- The meta-study methodology allows reflection on and discussion of the findings in light of the applied theories and methodologies of the included studies.
- The original design of the meta-study will be extended to include studies with qualitative, quantitative and mixed-methods designs and (systematic) reviews and will contribute to an advancement of meta-study methodology.
- For this meta-study, care arrangements for people living with dementia who are not supported by informal carers were not considered. This should be done in future research.

to increase to 131.5 million by 2050.¹ Most people with dementia live at home.² It is their express wish to stay in their familiar environment,³ and the majority of informal carers also wish to keep the person with dementia at home for as long as possible.⁴ Furthermore, the ‘ageing in place’ policy of present-day social security systems favours and supports community over institutional care.^{5–8} This preference reflects a general trend towards social inclusion and participation of people living with dementia in healthcare policy and research.⁹ Stable home-based care arrangements for people living with dementia are therefore a desirable outcome of contemporary health and social care policies.

Care arrangements are characterised by the combination of different forms of care and support and by who coordinates and provides this care and support.¹⁰ In most home-based care arrangements, an informal carer assumes the role of the key care provider.¹¹ In our understanding, an informal carer is a relative,

partner, friend or neighbour who provides ongoing assistance to a person with a chronic or disabling condition.² Informal carers do not work on a formal basis and are usually unpaid, although there may be forms of reimbursement, for example, monetary transfers or tax relief.¹² There is a debate regarding terminology: some informal carers reject the term 'informal carer' and prefer the term 'family carer'.¹³ Nevertheless, we use the broader term 'informal carer' because 'family carer' could be understood to include only relatives. Informal carers not only shoulder a vast amount of hands-on care but also are in charge of managing care arrangements and different forms of support and serving as gatekeepers at the interface between informal and formal care. In most cases, it is the responsibility of the informal carer to initiate contact with the formal care system and to adapt the care mix to the upcoming and changing needs over the dementia care trajectory to keep the system—the care arrangement—running.^{2 14} Creating and maintaining stability is a leading principle of this process.^{15 16} However, informal carers face multiple challenges. They often start their caregiving career with no significant knowledge of dementia, and care trajectories are rarely anticipated or planned.^{17 18} Informal carers must constantly adjust to the unpredictable dynamics and ever-changing conditions of the care situation.^{19 20} These challenges over the course of the dementia care trajectory lead to higher rates of carer burden for informal carers of individuals with dementia than for carers of people without dementia.^{21 22} Dementia itself is one of the strongest predictors of institutionalisation,²³ and the transition to a long-term care institution eventually becomes a reality for many people with dementia.

Complementing this picture, the positive aspects and gains of caregiving are receiving increasing attention in dementia research, and scholars have noted that the dementia care trajectory is not necessarily a journey of loss and strain.²⁴ Furthermore, researchers argue that the understanding of and reaction to dementia are affected by the social context.²⁵ Therefore, recent research suggests a more heterogeneous and resource-oriented picture that considers positive and successful informal dementia care trajectories. This approach is confirmed by the statements of many informal carers who judge their care arrangement to be stable^{26 27} and are willing to continue caregiving.²⁸

Even though a multitude of studies illuminates the risk factors and predictors of institutionalisation, the dynamics of the care situation are not well understood.^{23 29 30} Consequently, the studies add little to our understanding of the diverse dementia care trajectories and the complexity of care arrangements for people living with dementia. Other studies in this field portray the experiences of informal carers but pay little attention to their direct impact on whether a home-based care arrangement can be maintained.^{18 31 32} In light of this limited knowledge, research is needed to better understand the phenomenon of stability of home-based care arrangements for people living with dementia.

In this protocol, we introduce a meta-study that aims to explore and theorise the complex phenomenon of stability. The meta-study is currently in progress and is estimated to be completed by the end of 2018. The expected result(s) can be used to identify research gaps, guide the development of future research questions and adequate study designs, define outcomes and develop innovative interventions for the community setting.

This protocol is designed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) guidelines.^{33 34}

AIM AND GUIDING RESEARCH QUESTIONS

The guiding research questions of this meta-study are as follows: How is stability of home-based care arrangements for people living with dementia constituted? What are the essential factors that influence stability? Referring to Finfgeld-Connett and Johnson,³⁵ we use these research questions as the starting point for our research project; they may be refined and/or extended at any time during the research process.

METHOD AND ANALYSIS

Study design

Regarding the different approaches to synthesise knowledge,^{36–38} we sought a framework that would meet the following requirements:

1. We are interested in a better understanding and theorisation of the phenomenon of stability. Therefore, the synthesis method should lead to an interpretation and configuration of the included findings that generates new theory and not to an aggregation of results.
2. As a result of our previous groundwork¹⁶ on the phenomenon of stability, we had learnt that we would exclude relevant evidence if we would restrict the studies to be included to only one type of research design. Therefore, the synthesis method should be able to combine the strengths of qualitative, quantitative and mixed-method study designs and (systematic) reviews.
3. We presume that the phenomenon of stability is highly dependent on the context in which it is considered and that theoretical assumptions and applied research methods have a strong influence on the understanding and conceptualisation of stability. For example, informal caring for people with dementia is predominantly understood and researched from a stress/burden perspective.¹³ Such a predominant research perspective could lead to an incomplete or even biased understanding of the phenomenon under investigation. Therefore, the synthesis method should enable critical reflection on the influence of theoretical assumptions and applied methods on the findings of the included studies.

Carefully considering the different approaches, meta-study methodology developed by Paterson and colleagues³⁹ best met our requirements and was chosen as

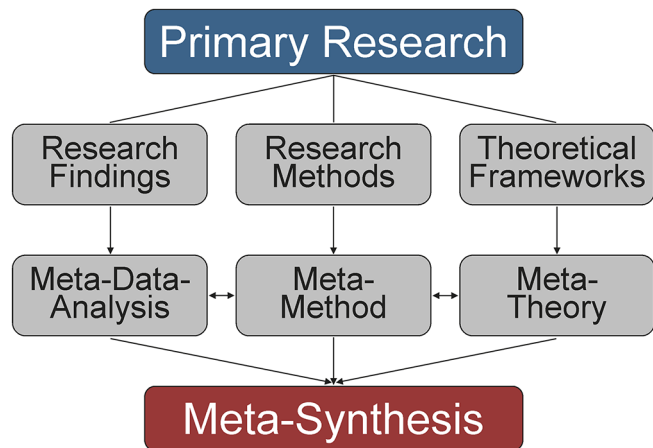


Figure 1 Components of a meta-study.³⁹

our research design. The aim of a meta-study is to develop mid-range theory. Paterson and colleagues argue that to achieve this aim, it is necessary to analyse the theories and methods of the included studies because ‘method and theory are often inextricably linked with both data and conclusions about data’ (p5). Only then will it be possible to draw conclusions that go beyond the findings of the individual studies and develop new theory. Compared with other theory-generating synthesis methods, the meta-study methodology gives high priority to the consideration of theoretical frameworks and research methods which is our main rationale to choose meta-study for the conceptualisation and theorisation of stability. Meta-studies combine three analytical components: meta-data analysis, meta-method and meta-theory. The final meta-synthesis follows these three analytical components to generate new theorisations and create a comprehensive understanding of the phenomenon. The components of a meta-study are illustrated in figure 1.

However, meta-study was originally designed for interpreting qualitative research only, and Paterson and colleagues explicitly state that the inclusion of quantitative research is problematic because of the differing epistemological perspectives of qualitative and quantitative research. Nevertheless, we decided to use the meta-study methodology and extend it by including evidence from quantitative and mixed-method studies, as well as systematic reviews. The comparability of qualitative and quantitative research is controversial in the scientific community. Thereby the differences between qualitative and quantitative research are judged as either ‘irreconcilable’ or ‘reconcilable by converting the one into the other’.⁴⁰ The decision to extend the meta-study methodology to include mixed research is in line with the latter position and also with the work of Dixon-Woods and colleagues who argue that interpretive syntheses can be conducted with all types of evidence⁴¹ and who explicitly suggest that meta-studies have the potential to handle diverse types of evidence.³⁶ Our decision also reflects the findings of Voils and colleagues⁴² who conclude that findings from qualitative and quantitative studies in their

review were comparable in their interpretative depth and that the line between qualitative and quantitative findings is less distinct than assumed beforehand. Of the different possibilities for combining diverse research methodologies, we choose an integrated design that will ‘qualitise’ quantitative data to combine it with other, qualitative findings.^{43–45} The procedures to extract and analyse data from diverse types of studies are described in more detail in the Analysis and data collection process section. We will not perform any quantitative analysis in this meta-study.

Tailored research questions

Because we chose the meta-study methodology, we tailored our basic research questions to meet the needs of the three analytical components and the synthesis phase of the meta-study design. Our initial research questions serve as overarching questions for the entire meta-study and will guide our meta-data analysis:

- How is stability of home-based care arrangements for people living with dementia constituted?
- What are the essential factors that influence stability of home-based care arrangements?

For meta-theory, we ask the following questions:

- Regarding stability of home-based care arrangements, what are the underlying theoretical assumptions of the included studies?
- How are the theories applied over time in the relevant research, and what trends can we observe?

For meta-method, we ask the following questions:

- What research methodologies are applied in the included studies?
- How is stability or how are specific aspects of stability operationalised in the included studies?

For the final meta-synthesis, we will combine the results of these three analytical components to evaluate...

- how the underlying theoretical assumptions (meta-theory) and applied methods (meta-methods) shape the understanding of stability (meta-data analysis) in current research.

With this synthesis, we aim to explain how stability of home-based care arrangements is constituted and what factors influence this stability over the dementia care trajectory. This emerging theory of the complex phenomenon of stability creates a sound basis for evaluating the related concepts and influencing factors and for determining which knowledge gaps should be addressed in future research.

Relevant groundwork and theoretical alignment

As a first important step in the preparation of the meta-study, we developed a working definition of ‘stability of home-based care arrangements for people living with dementia’ (see figure 2) in a consensus process with scientific experts.^{16 46} With this definition, we framed stability as a dynamic process over the dementia care trajectory

Stability of care arrangements for people with dementia living at home means that through their (self-)caring actions the people involved succeed in adapting 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 2 Definition of 'stability of home-based care arrangements for people living with dementia'.

that is shaped by all the actors involved and which can be achieved only if their needs and demands are successfully addressed. Furthermore, this definition reflects our theoretical alignment with the scientific tradition of symbolic interactionism,⁴⁷ specifically that of Strauss⁴⁸ and Corbin and Strauss,^{49 50} who focus on the trajectory of chronic illness and describe its management as work.⁵¹ In pursuing this understanding and emphasising the role of informal carers, the work of Nolan and colleagues^{13 52} on family care influences our perspective. Additionally, our meta-study builds on theories about transitions that focus on transitions between stable states and conceptualise them as a complex person–environment interaction.^{53 54} These theoretical contributions build our theoretical frame and will guide us throughout the research process.

Literature search

During the consensus process in which we developed our working definition,¹⁶ we started to search for, collect and read publications which inspired our initial ideas regarding the phenomenon of stability. In the process we learnt that very few studies explicitly investigate the stability of home-based care arrangements for people living with dementia, although a huge body of knowledge contributes to the conceptualisation of stability. In conjunction with this experience and while designing the literature search procedure for this meta-study, we expected that a conventional literature search based on a narrow list of relevant keywords would identify only a few studies. To locate all the relevant primary research, we needed an innovative and flexible literature search approach. Conventional aggregative literature reviews are typically based on a fixed research question and run reproducible

database searches. In contrast, knowledge-building and theory-generating syntheses—like meta-studies—require that the literature search be a dynamic and iterative process and that various techniques be combined to encompass the relevant body of literature throughout the entire synthesis process.^{35 39} Therefore, we oriented our literature search procedures towards the framework of Boell and colleagues^{55 56} who introduce an open-ended 'hermeneutic loop' that includes the repeated steps of searching, sorting, selecting, acquiring, reading, identifying and refining. The overall aim of our literature search is the saturation of concepts and the explication of their inter-relationships.^{35 41 57}

For our meta-study, we will combine the following search techniques:

Berry picking

As mentioned above, during the process of establishing consensus for our working definition, we assembled a set of publications (berries) that provided us with initial ideas regarding the phenomenon of stability. This purposive sampling strategy was driven by the aim of continuously broadening our understanding of stability, and it was very much in line with the browsing technique of 'berry picking' as described by Marcia Bates.⁵⁸ 'Berry picking' is a purposive sampling strategy that uses various approaches such as footnote, citation, journal, author or area searching and is recommended in methodological publications on literature search techniques for knowledge-building syntheses, for example, by Barroso *et al*,⁵⁹ Boell and Cezek-Kecmanovic,⁵⁵ and Fingfeld-Connert and Johnson.³⁵ For the present meta-study, we decided to include a selection of 10 very informative publications

(the berry pool) in the meta-study text set. The berry pool guided us in the development of the working definition of stability which in turn guided the development of our systematic database searches. To avoid bias, the berry publications will undergo the same procedures of coding, analysing and recoding in iterative loops (see section 'Analysis and data collection process') as every other publication, and they will be considered in light of the whole body of publications throughout the meta-study process.

Database searches

Referring to our previous research in the field and preceding unsystematic searches, we know that a narrow search strategy restricted to the terms 'stability' or 'stable' might yield insufficient hits to perform a qualitative knowledge synthesis. Therefore, we will encircle our phenomenon of interest by creating nine separate search strands. Of these strands, seven will paraphrase central concepts included in our working definition of stability (namely, stability, (self-)caring actions, needs and demands, crises, positive aspects, end-of-life care and institutionalisation) and two will be based on theoretical assumptions (namely, burden and interventions). An individual syntax will be created to describe each specific strand. Furthermore, we will create syntaxes to capture the condition of interest (dementia), the population (informal carers), the setting of interest (home/community) and the two outcomes, stability and instability. Using Boolean operators, we will combine the individual strand syntaxes with the syntaxes for the condition, population, setting and outcomes (see online supplementary appendix A). Three relevant databases (PubMed, CINAHL, and PsycINFO) will be used for this systematic search. Referring to Boell and colleagues, we will be open to adjusting the search strategies during the process of this meta-study.^{55 56}

The following search techniques are also in line with the goals of berry picking; however, while the berry pool was collected in advance of the meta-study, the search procedures described below will be performed throughout the meta-study process.

Backward citation tracking

For all included publications, we will perform backward citation tracking.

Forward citation tracking

For selected, supremely informative publications, we will conduct forward citation tracking using Google Scholar to identify the latest research.

Snowballing

Throughout the entire meta-study process, we will include relevant publications identified by snowballing techniques.

Theoretical sampling

According to Finfgeld-Connett,⁶⁰ theoretical sampling is better suited to theory development than exhaustive

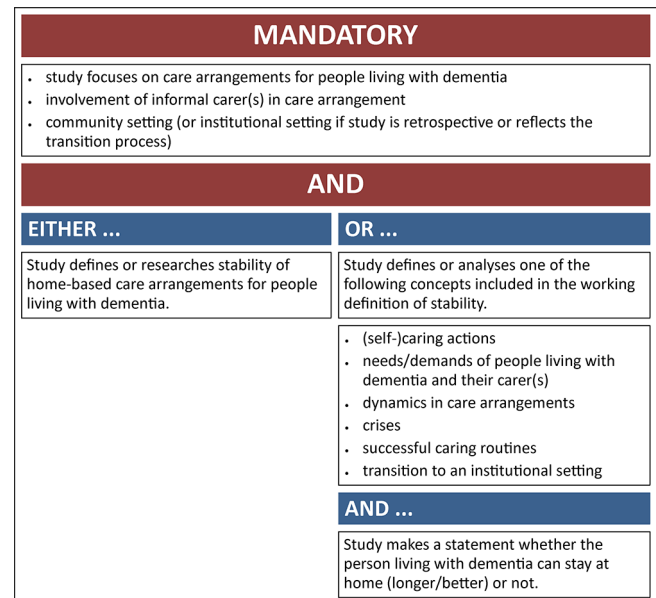


Figure 3 Inclusion criteria.

sampling is. We will search and add publications to our text sample during the analysis to overcome knowledge gaps in the emerging theorisation.

Furthermore, we will screen relevant journals.

Screening process and flow diagram

The titles and abstracts of all identified studies will be screened by two authors in alternating teams (KK, JD, IH and MvK). Full-text screening will be performed by one author, who will discuss his/her appraisal with at least one colleague. If disagreement occurs, consensus will be achieved by discussion. The flow of studies throughout the synthesis process will be recorded using the standard PRISMA guidelines.⁶¹ EndNote X7 will be used to manage the screening process. A draft of the flow diagram is available in online supplementary appendix B.

Eligibility criteria

Figure 3 displays the inclusion criteria for this meta-study. A mandatory criterion is that studies must focus on a care arrangement for a person living with dementia. Furthermore, an informal carer must be involved in caring for this person, and the person with dementia must live in a community setting or have been recently institutionalised. To be included in our sample, a study must *either* define or research stability of home-based care arrangements *or* define or research one of the concepts included in our working definition of stability *and* make a statement regarding whether the person with dementia could stay home (longer/better). The last criterion is important for the inclusion of only studies that make explicit statements about how a specific concept (eg, burden) influences stability. All types of empirical research and (systematic) reviews will be accepted for inclusion, and no time limit will be set. Only publications written in English, German or French will be included in the meta-study; we will not

use a language filter for the databases but will manually exclude publications written in other languages.

Quality appraisal

We are aware that there is a brisk scientific debate regarding whether studies included in qualitative syntheses or mixed-research syntheses should be assessed by a standardised quality-appraisal tool.^{36 37 62–65} As it is our priority that the findings of the studies considered for inclusion make a valuable contribution to a further theorisation of the complex phenomenon of stability, methodological quality is a secondary consideration. This decision is in line with the conclusions of other scholars in the field of healthcare science, who argue that the exclusion of papers for reasons of methodological quality may result in the neglect of studies that are rich in content but are excluded for the sake of surface mistakes or fragmentary reporting. At the same time, uninspired studies may be privileged due to their technical correctness even if they do not make a valuable contribution to the synthesis.^{36 64 66 67} Therefore, a rigid quality appraisal may not be useful for our meta-study. Nevertheless, to avoid the inclusion of ‘fatally flawed’ publications, we will apply the following criteria suggested by Dixon-Woods and colleagues⁴⁵ to every paper, regardless of its study design:

- ▶ 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?

The decision to include or exclude a publication will be made in light of these criteria and the contribution of the publication to the theorisation of stability. This means that there will be no compulsory exclusion if a publication does not meet a certain number of criteria. Every paper will be assessed by one researcher. If he/she is in doubt of the methodological quality of the paper, he/she will discuss the paper with at least one other researcher, and they will decide together whether to exclude the paper. All decisions will be recorded in tabular form.

Analysis and data collection process

The procedures planned for each analytical component (meta-data, meta-method, meta-theory) and for the final meta-synthesis are described separately below. Based on our hermeneutic and iterative approach, the analytical procedures might be adapted and extended as the meta-study progresses. All analyses will be performed using the Professional Research Software for Qualitative, Quantitative and Mixed Methods Research (MAXQDA 12).

Basing on our previous work and theoretical alignment, we deductively created a preliminary coding system for data extraction (see online supplementary

appendix C). The codes are related to the study sample, meta-data analysis, meta-theory and meta-method. The content of selected codes will be summarised in tabular form, namely, author, year of publication, country, study aim, study design, theoretical framework, key concepts, sample/setting, main findings and core statement related to stability. This table will provide a general overview of the study sample and preserve the context of each study at a glance.

Meta-data analysis

Meta-data analysis is the comparative analysis of the findings of all the included studies; it contributes to the creation of an integrated body of knowledge of the phenomenon of interest.³⁹ Thematic synthesis is our leading analytical approach not only for the meta-data analysis but also for the analytical components that follow.⁵⁷ Thematic synthesis is based on the widespread method of thematic analysis which has been developed for the analysis of primary research.^{68 69} Thomas and Harden translated this method for use in systematic reviews.⁵⁷ Like us, they face the challenge of collecting a set of primary studies that did not directly address their review question. This circumstance made their concept of thematic synthesis particularly useful for our purpose. Thematic synthesis includes three stages: free ‘line-by-line coding’ of the findings, the organisation of these codes into related areas to construct ‘descriptive themes’ and the development of more abstract ‘analytical themes’. Likewise, thematic synthesis is applied for the analysis of all types of primary research and is therefore used as well to ‘qualitise’ the quantitative data in the meta-study text set. Following Pope and colleagues,⁴⁴ our main approach for ‘qualitising’ quantitative data is to extract relevant concepts from the quantitative studies and to compare them across all studies. The goal is to identify, organise and interpret recurring themes that contribute to the conceptualisation of our target phenomenon stability. Therefore, we will code relevant information in the running text, the tables and the figures of the quantitative studies. In this meta-study, we will not perform statistical analysis. Instead, we intend to develop a clear understanding of which concepts and/or influencing factors that were researched in the quantitative studies are associated with stability and how.

At the beginning of the analysis phase, teams of three researchers will code the studies of our berry pool. For each code, we will write a code memo to define the information that should be assigned to the code. In the process, we will develop an increasingly clearer common understanding of the coding system and codes and will continue the initial round of coding of all the included studies in teams of two researchers. During this process, new codes will be inductively developed (‘line-by-line coding’) and discussed among the whole team. After the initial coding round, we will review and extend our codings and codes to construct ‘descriptive themes’ by grouping the codes into a more hierarchical structure.

A draft summary of the core findings will be written for each descriptive theme by one author, who will discuss his/her summary with the entire author team. Within these draft summaries, we will formulate hypotheses regarding our target phenomenon of stability that will be questioned, confirmed or rejected during the analytical process.³⁹ In the next step, we will return to our concrete research questions and review the findings and hypotheses of the descriptive theme summaries regarding their contribution to answering our research questions and to supporting an emerging theory of stability of home-based care arrangements for people living with dementia. Thus, we will encompass and finally identify the major analytical themes that will inform the final meta-synthesis.

Meta-theory

Meta-theory involves the critical exploration of theoretical frameworks that have provided direction for the included primary research.³⁹ Our aim is to identify and describe the explicitly stated and/or underlying theoretical assumptions of relevant research, to analyse the application of theories over time and to observe potential trends. Specifically, the identification of hidden and underlying theories and concepts in the primary research is an interpretive procedure that will be performed by at least two authors and discussed among the whole team. We will generate further codes related to meta-theory in our coding system. For each study, we will extract the scientific disciplines and affiliated institutions of the (first) authors and the publishing journal. We will code the stated research gaps and the aim and research questions of all the studies and determine their theoretical foundation. Finally, we will analyse whether the studies have implications for further research that are related to the theory. Furthermore, we will use the backward citation tracking (see the Literature search section) for analytical purposes, namely, to identify core authors and central publications that might have influenced subsequent research related to our target phenomenon. We presume that additional analytical steps may be performed during the iterative meta-theory analysis process.

Meta-method

According to Paterson and colleagues, the purpose of meta-method is to consider how the application of research methodologies influences research findings, shapes the understanding of the phenomenon of interest and affects emerging theory.³⁹ Our aim is to describe and evaluate the study design and methodologies used in the included studies and to analyse how the complex phenomenon of stability is operationalised in the relevant research. To inform meta-method, we will use selected codes in our coding system, namely, study design and methodology, sample, sampling, setting, data collection and data analysis. In addition, we will code all standardised assessment instruments that have been applied in the included studies. Following our own theoretical alignment in terms of the trajectory perspectives

of home-based dementia care, we will perform a separate evaluation of longitudinal studies, the time span that they cover and the number and frequency of data collections. We presume that additional analytical steps may be performed during the iterative meta-method analysis process.

Meta-synthesis

Due to the hermeneutic nature of configurative and theory-generating synthesis, this step of the synthesis is the most difficult to foresee and describe in advance. The purpose of the meta-synthesis of data, theory and method is to dig below the surface of the current understanding of the phenomenon of interest, to question the validity of ideas that are currently in favour and to emerge with a new understanding.³⁹ Paterson and colleagues resist the prescription of definitive procedural steps and instead encourage a dynamic circle of thinking, interpreting, creating, theorising and reflecting. Our aim for the meta-synthesis is to understand and deconstruct the inter-relation of our meta-data, meta-theory and meta-method findings. The analytical themes derived from the meta-data analysis will provide the most substantial content related to a new theorisation of stability of home-based care arrangements for people with dementia. The meta-theory analysis will illuminate the theoretical routes of stability-related research agendas, and the meta-method analysis will reveal a specific shape of the study findings. Theories and methodologies will be questioned based on their informative value and explanatory power regarding the complex phenomenon of stability.

Teamwork

The whole meta-study process will be performed with the collaboration of all the authors. To ensure that each author is aware of the current status of all steps of the literature search and appraisal, analyses and findings at any time, we will maintain a research diary for daily notes, extensively use the memo functions of MAXQDA and hold team meetings at least weekly to discuss our meta-study project and to produce intersubjectivity and comprehensibility.⁷⁰ Furthermore, we will regularly introduce and discuss our methodology and findings in specific working groups (eg, a working group for qualitative methodology), and we plan to communicate with scientists in related fields via expert consultations (eg, meetings or telephone conferences) regarding specific themes/questions.

Patient and public involvement

Patients and public were not involved in the present study.

CONCLUSION AND LIMITATIONS

This meta-study will provide a contemporary synthesis of evidence related to the complex phenomenon of stability of home-based care arrangements for people living with dementia. It is designed to explore and finally theorise how stability is constituted and what are the

essential factors that influence stability. A theory-based understanding can be used to identify the research gaps, guide the development of future research questions and adequate study designs, define outcomes and develop innovative interventions for the community setting.

There are limitations regarding the design and realisation of this meta-study. We consciously restrict our analysis to the care arrangements of people with dementia and their informal carer(s). We are aware that a growing population of people with dementia live alone in the community, and we assume that stability might need to be conceptualised differently in relation to the specific situations, needs and demands of that population. Furthermore, we expect to find little research that directly addresses our target phenomenon. Therefore, we will need to resort to studies that indirectly address our research questions. Regarding the nine search strands, we might identify a plethora of potentially relevant studies, leading to an extensive and unmanageable sample of publications. We will attempt to overcome this potential challenge by searching in iterative loops until we reach theoretical/conceptual saturation.^{35 55}

DISSEMINATION

The results of this meta-study will be published in a series of articles in peer-reviewed scientific journals and will be presented at relevant national and international scientific conferences. The planned first article will provide a comprehensive overview of the phenomenon of stability. Additional articles will add deep analyses of specific sub-themes. Furthermore, we intend to report our extension of the meta-study design in a separate publication focused on methodology. If we refine the procedures described in this protocol, we will document the amendments in the PROSPERO database and disclose them in future publications related to this meta-study.

Contributors JD, KK, IH, BH and MvK contributed substantially to the conception and design of this meta-study project, including the development of research questions, search strategies, eligibility criteria, data extraction schemes and analytic procedures. JD and KK contributed equally to the draft of this protocol. All the authors read, provided feedback for and approved the final manuscript.

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REFERENCES

1. Alzheimer's Disease International. *World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International, 2015.
2. WHO. *Dementia: a public health priority*. Geneva: World Health Organization, 2012.
3. 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;16:378–90.
4. Wackerbarth S. What decisions are made by family caregivers? *Am J Alzheimer's Dis* 1999;14:111–9.
5. Knapp M, Comas-Herrera A, Somani A, et al; *Dementia: international comparisons*. London, 2007.
6. Low LF, Fletcher J. Models of home care services for persons with dementia: a narrative review. *Int Psychogeriatr* 2015;27:1593–600.
7. OECD. *Long-term Care for Older People*: OECD Publishing, 2005.
8. Wiles JL, Leibing A, Guberman N, et al. The meaning of "aging in place" to older people. *Gerontologist* 2012;52:357–66.
9. 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;21:4–17.
10. Blinkert B, Klie T. *Pflege im sozialen Wandel: eine Untersuchung über die Situation von häuslich versorgten Pflegebedürftigen nach Einführung der Pflegeversicherung im Auftrag des Sozialministeriums Baden-Württemberg*: Vincentz, 1999.
11. Orpin P, Stirling C, Hetherington S, et al. Rural dementia carers: formal and informal sources of support. *Ageing Soc* 2014;34:185–208.
12. Simonazzi A. Care regimes and national employment models. *Cambridge J Econ* 2009;33:211–32.
13. Nolan M, Grant G, Keady J. *Understanding family care: a multidimensional model of caring and coping*. Milton Keynes: Open University Press, 1996.
14. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009;11:217.
15. von Kutzleben M, Holle B. Assessing the stability of home-based care arrangements for people with dementia – A concept far too complex for a single binary item Alzheimer Europe Conference "Excellence in dementia research and care". Copenhagen, 2016.
16. 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;50:210–8.
17. Di Gregorio D, Ferguson S, Wiersma E. From beginning to end: perspectives of the dementia journey in northern Ontario. *Can J Aging* 2015;34:100–12.
18. 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;30:526–34.
19. McCabe M, You E, Tatangelo G. Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. *Gerontologist* 2016;56:e70–88.
20. Robinson L, Gemski A, Abley C, et al. The transition to dementia--individual and family experiences of receiving a diagnosis: a review. *Int Psychogeriatr* 2011;23:1026–43.
21. Bertrand RM, Fredman L, Saczynski J. Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *J Aging Health* 2006;18:534–51.
22. Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2003;58:P112–28.
23. Luppá M, Luck T, Brähler E, et al. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord* 2008;26:65–78.
24. Lloyd J, Patterson T, Muers J. The positive aspects of caregiving in dementia: a critical review of the qualitative literature. *Dementia* 2016;15:1534–61.
25. Downs M. Dementia in a socio-cultural context: an idea whose time has come. *Ageing Soc* 2000;20:369–75.
26. 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* 2016;24:283–96.
27. Schäufele M, Köhler L, Teufel S, et al. Betreuung von demenziell erkrankten Menschen in Privathaushalten: Potenziale und Grenzen selbständiger Lebensführung in privaten Haushalten (MuG III) Repräsentativbefunde und Vertiefungsstudien zu häuslichen pflegearrangements, Demenz und professionellen Versorgungsangeboten München, 2005:99–144.
28. Kraijo H, Brouwer W, de Leeuw R, et al. 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. *J Alzheimers Dis* 2014;40:631–42.
29. Gaugler JE, Yu F, Krichbaum K, *et al*. Predictors of nursing home admission for persons with dementia. *Med Care* 2009;47:191–8.
 30. 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;29:195–208.
 31. Davis LL, Chestnutt D, Molloy M, *et al*. Adapters, strugglers, and case managers: a typology of spouse caregivers. *Qual Health Res* 2014;24:1492–500.
 32. Groen-van de Ven L, Smits C, Oldewarris K, *et al*. Decision Trajectories in Dementia Care Networks: Decisions and Related Key Events. *Res Aging* 2017;39:1–33.
 33. Moher D, Shamseer L, Clarke M, *et al*. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* 2015;4:1.
 34. Shamseer L, Moher D, Clarke M, *et al*. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ* 2015;349:g7647.
 35. Fingeld-Connett D, Johnson ED. Literature search strategies for conducting knowledge-building and theory-generating qualitative systematic reviews. *J Adv Nurs* 2013;69:194–204.
 36. Dixon-Woods M, Agarwal S, Jones D, *et al*. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy* 2005;10:45–53.
 37. Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol* 2009;9:59.
 38. Kastner M, Antony J, Soobiah C, *et al*. Conceptual recommendations for selecting the most appropriate knowledge synthesis method to answer research questions related to complex evidence. *J Clin Epidemiol* 2016;73:43–9.
 39. Paterson BL, Thorne SE, Canam C, *et al*. *Meta-Study of Qualitative Health Research*. Thousand Oaks, London, New Delhi: Sage Publications, 2001.
 40. Sandelowski M, Voils CI, Barroso J. Comparability work and the management of difference in research synthesis studies. *Soc Sci Med* 2007;64:236–47.
 41. Dixon-Woods M, Cavers D, Agarwal S, *et al*. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;6:35.
 42. Voils CI, Sandelowski M, Barroso J, *et al*. Making Sense of Qualitative and Quantitative Findings in Mixed Research Synthesis Studies. *Field methods* 2008;20:3–25.
 43. Sandelowski M, Voils CI, Barroso J. Defining and Designing Mixed Research Synthesis Studies. *Res Sch* 2006;13:29.
 44. Pope C, Mays N, Popay J. *Synthesising qualitative and quantitative health evidence*. McGraw-Hill Education (UK: A guide to methods, 2007).
 45. 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 Organisation R & D (NCCSDO), 2005:496.
 46. Köhler K, von Kutzleben M, Dreyer J, *et al*; *Stability of home-based care arrangements for people with dementia – Development of a working definition in a consensus approach with expert-focus groups*. 26th Alzheimer Europe Conference. Copenhagen, Denmark, 2016.
 47. Blumer H. *Symbolic interactionism; perspective and method*. Englewood Cliffs, N.J.: Prentice-Hall, 1969.
 48. Strauss AL. *Chronic illness and the quality of life*. Mosby: Saint Louis, 1975.
 49. Corbin J, Strauss A. Managing chronic illness at home: three lines of work. *Qual Sociol* 1985;8:224–47.
 50. Corbin JM, Strauss A. *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass, 1988.
 51. Corbin JM. The Corbin and Strauss Chronic Illness Trajectory model: an update. *Sch Inq Nurs Pract* 1998;12:33–41.
 52. Nolan M, Lundh U, Grant G, *et al*; *Partnerships in family care*. Maidenhead: Open University Press, 2003.
 53. Chick N, Meleis AI. Transitions: A nursing concern. Chinn PL, ed. *Nursing research methodology*. Boulder: Aspen Publication, 1986:237–57.
 54. Schumacher KL, Meleis AI, Al M. Transitions: a central concept in nursing. *Image J Nurs Sch* 1994;26:119–27.
 55. Boell SK, Cecez-Kecmanovic D. Literature Reviews and the Hermeneutic Circle. *Australian Academic & Research Libraries* 2010;41:129–44.
 56. Boell SK, Cecez-Kecmanovic D. A hermeneutic approach for conducting literature reviews and literature searches. *CAIS* 2014;34.
 57. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8:45.
 58. Bates MJ. The design of browsing and berrypicking techniques for the online search interface. *Online Review* 1989;13:407–24.
 59. Barroso J, Gollop CJ, Sandelowski M, *et al*. The challenges of searching for and retrieving qualitative studies. *West J Nurs Res* 2003;25:153–78.
 60. Fingeld-Connett D. The Future of Theory-Generating Meta-Synthesis Research. *Qual Health Res* 2016;26:291–3.
 61. Moher D, Liberati A, Tetzlaff J, *et al*. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ* 2009;339:b2535.
 62. Mays N, Pope C, Popay J. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *J Health Serv Res Policy* 2005;10(Suppl 1):6–20.
 63. Pluye P, Gagnon MP, Griffiths F, *et al*. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *Int J Nurs Stud* 2009;46:529–46.
 64. Thorne S. Metasynthetic Madness: What Kind of Monster Have We Created? *Qual Health Res* 2017;27:3–12.
 65. Whittemore R, Chao A, Jang M, *et al*. Methods for knowledge synthesis: an overview. *Heart Lung* 2014;43:453–61.
 66. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001;322:1115–7.
 67. Pawson R. Digging for Nuggets: How ‘Bad’ Research Can Yield ‘Good’ Evidence. *Int J Soc Res Methodol* 2006;9:127–42.
 68. Boyatzis RE. *Transforming Qualitative Information - Thematic Analysis and Code Development*. Thousand Oaks: SAGE Publications 1998.
 69. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
 70. Steinke I. Quality criteria in qualitative research. In: Flick U, von Kardorff E, Steinke I, eds. *A companion to qualitative research*. London: SAGE Publications, 2004:184–90.