

Stability of home-based care arrangements for people living with dementia – *an innovative meta-study of mixed research*

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Projektteam: Kerstin Köhler, Jan Dreyer,
Milena von Kutzleben, Iris Hochgraeber, Bernhard Holle

- Most people with dementia live in the community.
(e.g. Alzheimer's Disease International 2015, WHO 2012)
- People living with dementia wish to **stay in their familiar environment as long as possible**. In most cases they are supported by informal (family) carers who strive to create and maintain a stable care situation over time.
(e.g. von Kutzleben et al. 2012, Thoma-Lürken et al. 2017, Vanleerberghe et al. 2017, Wackerbarth 1999)
- Worldwide the '**aging in place**' policy of social security systems today favors and supports community over institutional care.
(e.g. Ilinca 2015, Knapp et al. 2007, OECD 2005, Vanleerberghe et al. 2017)



Creating and maintaining stability is...

- a guiding principle of informal carers and
- a desirable outcome of contemporary health and social care policies.

How is „stability“ approached in current reserach?

- Empirical studies focus primarily on **instability**:
 - reasons, risk factors, predictors for **institutionalization**
(e.g. Afram et al. 2014, Dramé et al. 2012, Gallagher et al. 2011, Gaugler et al. 2009, Oliva y Hausmann et al. 2012, Luppá et al. 2008/2012, Sansoni 2013, Verbeek et al. 2015)
 - subjective experiences and decisions of informal carers with regard to the **transition to an institutional setting**.
(e.g. Caron et al. 2006, Ducharme et al. 2012, Kraijo et al. 2014/2015, McLennon et al. 2010, Stephan et al. 2015)
- Stability is often operationalized in a **binary** way:
“Person with dementia can stay at home: **Yes or No**”
(e.g. Dammert 2009, Kraijo 2014, Schäufele et al. 2008, Schacke & Zank 1998, von Kutzleben et al. 2015)

Does this represent the phenomenon of stability sufficiently?

- We assume that stability is a (more) complex phenomenon:
 - multi-dimensional
 - involvement of different actors (with different perceptions and goals)
 - time-course perspective
 - probably many influencing factors
 - context dependent



A theoretical understanding of the **complex phenomenon of stability** and its dimensions is lacking, but necessary!

- Aim: to **build theory** regarding the complex phenomenon of „stability of home-based care arrangements for people living with dementia”

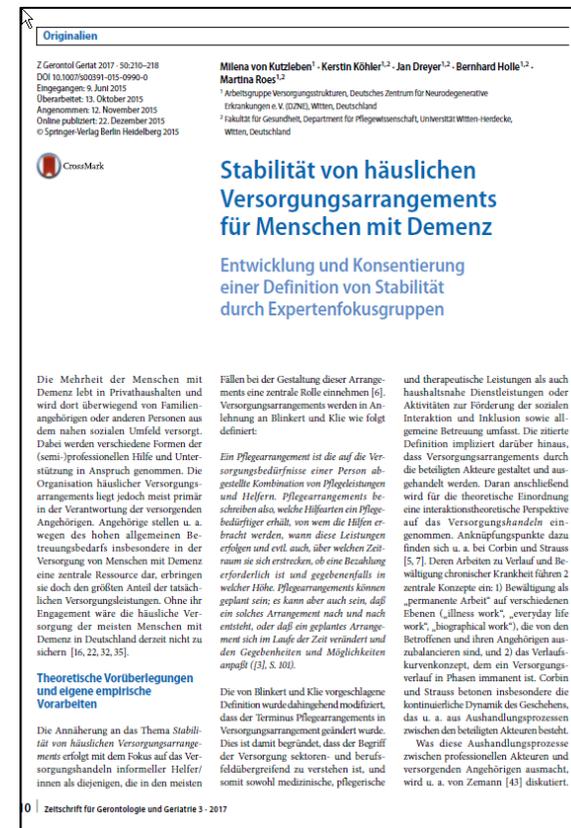
Development of a working definition of stability



Theory building knowledge synthesis



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



(von Kutzleben et al. 2017)

Challenge:

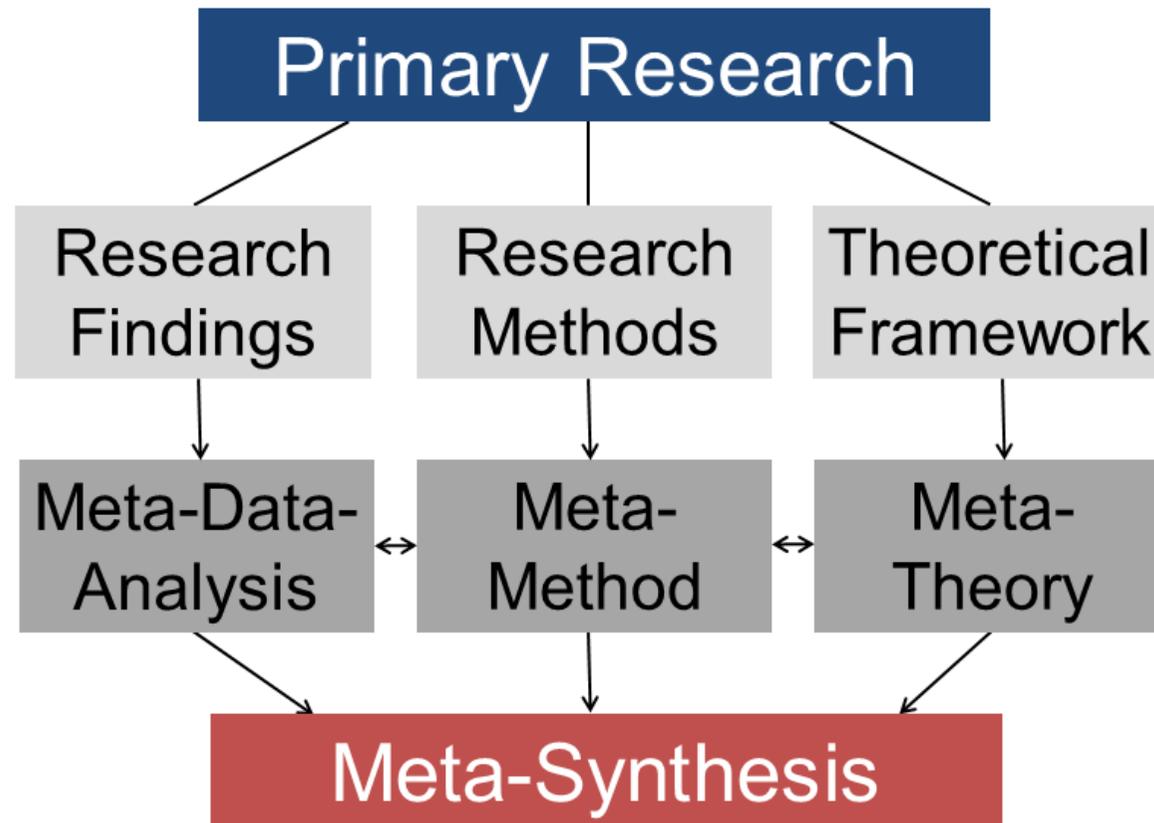
- Very few studies explicitly research stability.
- Relevant information regarding our target phenomenon may be...
 - hidden in studies that focus **related concepts and phenomena**.
 - provided by studies of **diverse study designs**.



The phenomenon of stability cannot to be sufficiently approached by a systematic review using a single search syntax.

Solution:

- Flexible methodology that allows an **iterative and hermeneutic** approaching to the target phenomenon.
- Integration of relevant studies **regardless of their study design**.



Searching related concepts and phenomena

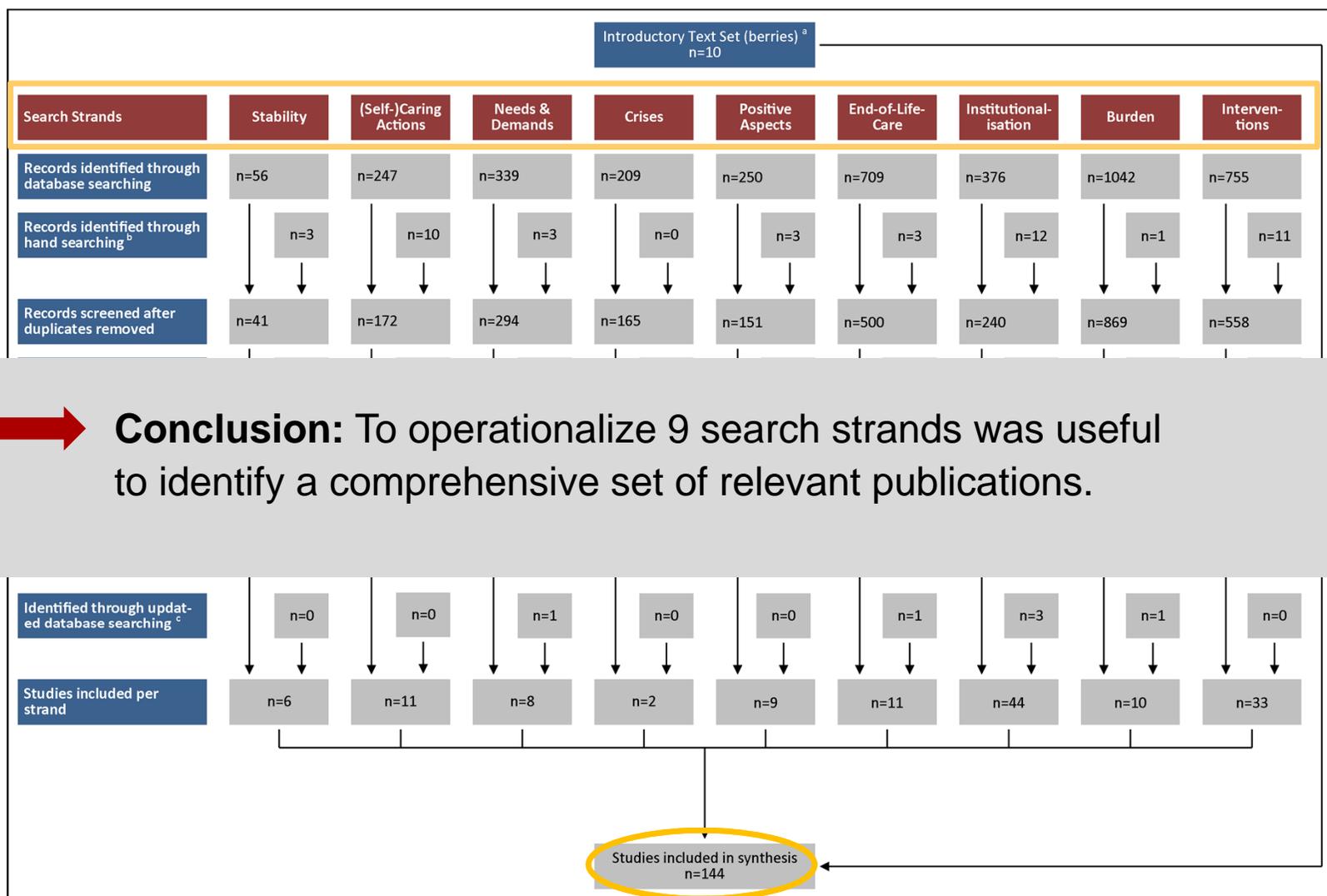
How can we approach the challenge that relevant information may be hidden in studies that focus related concepts and phenomena?

Basing on our working definition, we deduced concepts and phenomena related to stability.

For the literature search these concepts and phenomena were operationalized in 9 search strands.

MANDATORY	
<ul style="list-style-type: none"> • 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) 	
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.
	<ul style="list-style-type: none"> • (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 ...
Inclusion Criteria	Study makes a statement whether the person living with dementia can stay at home (longer/better) or not.

Searching related concepts and phenomena



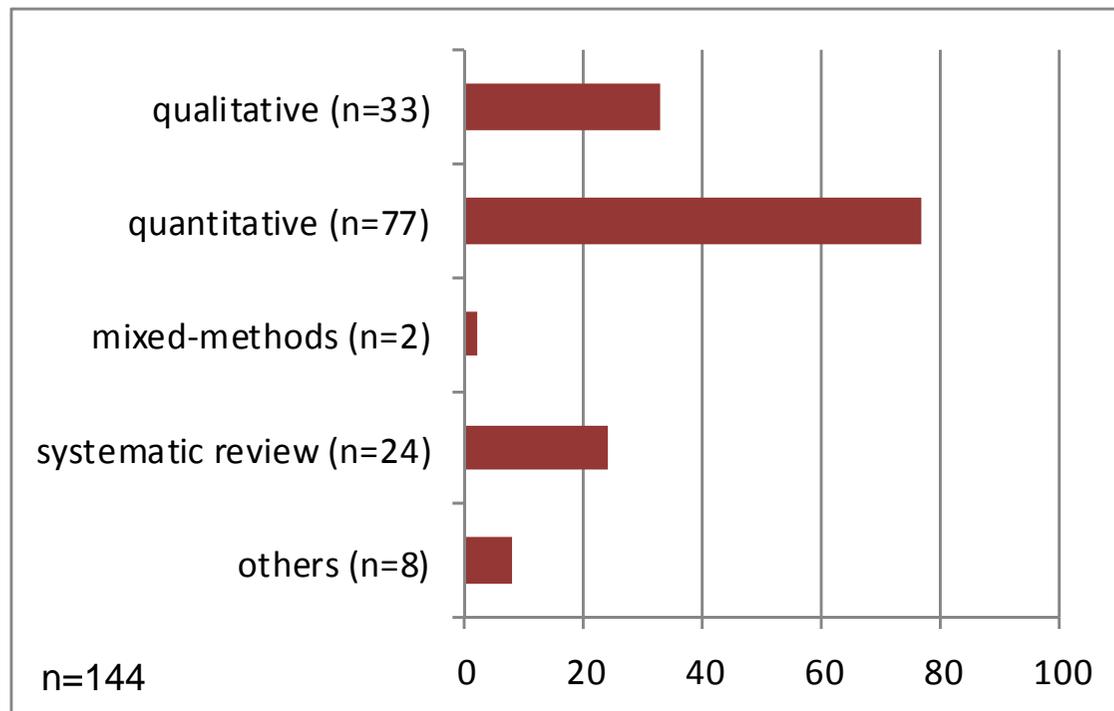
Conclusion: To operationalize 9 search strands was useful to identify a comprehensive set of relevant publications.

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

How do we approach the challenge that relevant information may be provided by studies of diverse study designs?

- Meta-study is originally designed for the interpretation of qualitative research.
- We knew that studies of diverse study designs would contribute to our theorization of stability.
- We extended the original methodology for the inclusion of qualitative, quantitative and mixed-methods studies, and (systematic) reviews.
- This is in line with the work of Dixon-Woods et al. (2005, 2006) who argue, that interpretive synthesis can be carried out on all types of evidence.

Inclusion of mixed studies



→ Conclusion:
Studies with various study designs contribute to the theorization of stability. For our purpose it is useful to extend the original methodology regarding the inclusion of mixed studies.

- Aim of this meta-study is to **build theory** regarding the complex phenomenon of „stability of home-based care arrangements for people living with dementia”.
- Meta-study is an appropriate and **flexible method** that could easily be adapted with regard to our research purpose.
- Stability may be an **innovative outcome** to be used in research and practice (e.g. for the evaluation and/or creation of interventions for families living in the community).

Thank you for your attention!



Kerstin
Köhler



Jan
Dreyer



Dr. Bernhard
Holle



Dr. Milena
von Kutzleben



Dr. Iris
Hochgraeber

Please contact:
Kerstin Köhler
kerstin.koehler@dzne.de
Tel. +49 2302 926-223