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'

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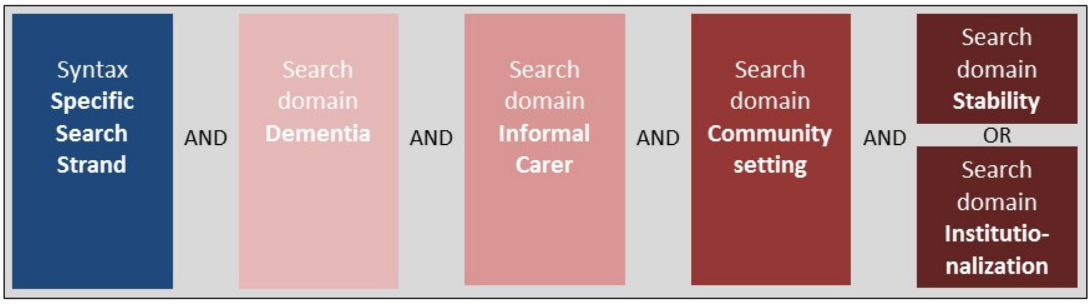
Content

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. <u>Search strand 'Stability'</u>

(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:

<table>
<tr><th colspan="2">MANDATORY</th></tr>
<tr><td colspan="2">• 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</td></tr>
<tr><th colspan="2">AND</th></tr>
<tr><th>EITHER…</th><th>OR…</th></tr>
<tr><td rowspan="3">Study defines or researches stability of home-based care arrangements for people living with dementia.</td><td>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</td></tr>
<tr><th>… AND …</th></tr>
<tr><td>Study makes a statement whether the person living with dementia can stay at home (longer/better) or not.</td></tr>
</table>

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 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	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

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