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Emotional safety of people living with dementia: a systematic review

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ABSTRACT

Background: Emotional safety is particularly important for people living with dementia. Although there have been efforts to define this concept, no systematic review has been performed.

Aim: We aimed to identify and analyze the knowledge available over a 10-year period regarding the emotional safety of people living with dementia to concretize this phenomenon.

Methods: Seven databases were searched. Qualitative, quantitative and mixed-methods studies published between November 2007 and October 2017 were included. Study selection and critical appraisal were performed by two reviewers. A content analysis of the qualitative data and a descriptive analysis of the quantitative data were performed.

Results: In total, 27 publications ($n = 26$ studies) were included. The following five main categories were identified: (1) “emotional safety as a primary psychological need”; (2) “emotional safety in the context of disease-related, biographical, demographic and socioeconomic factors”; (3) “inner conditions and strategies”; (4) “outer conditions and strategies”; and (5) “emotional safety as a condition”.

Conclusion: People living with dementia appear to be particularly vulnerable to decreased emotional safety. Research should focus on achieving a comprehensive understanding of their emotional safety needs.

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Introduction

Safety is described as a basic human need that can be compromised by various factors, e.g. disease-related factors (Maslow, 1943). Living with dementia can also be related to safety issues (Zingmark et al., 2002). Dementia is mostly a progressive, chronic syndrome characterized by cognitive dysfunction (e.g. memory problems) that affects certain abilities that are required in everyday life (World Health Organization, 2012). The consequences of this disease can contribute to decreased feelings of safety (Sørensen et al., 2008). However, feeling safe enables people living with dementia to act independently and to maintain relationships even at an early stage of the disease (Panke-Kochinke, 2013). In contrast, a decreased feeling of safety is associated with fear in the context of perceived dependencies (Panke-Kochinke, 2013). Hence, emotional safety appears to be an important topic for people living with dementia.

The concept of “emotional safety” has been described in relation to various settings. In nursing settings, emotional safety has been a topic in the field of patient safety in home care (Lang et al., 2008). In addition to physical, social and functional safety, emotional safety is considered a key dimension of patient safety; it “refers to the psychological impact of receiving/providing [health care] services” (Lang et al., 2008, p. 132). Research on emotional safety in nursing

and health services settings considers it in various contexts such as support groups (Panke-Kochinke, 2013) and special care units (Zingmark et al., 2002). In therapeutic and educational settings, the definition of emotional safety is based on the context of adventure therapy (Vincent, 1995). Vincent (1995, p. 76) reported that emotional safety “can be measured on a continuum from feeling threatened to feeling safe”. According to this definition, emotional safety depends on trust in oneself and in others (Vincent, 1995). However, a specific definition of emotional safety in the context of dementia is currently lacking. Therefore, based on existing research (Lang et al., 2008; Panke-Kochinke, 2013; Vincent, 1995; Zingmark et al., 2002), we defined emotional safety in the field of dementia as the experience of people living with dementia on a continuum between feeling safe and feeling threatened in the context of subjectively perceived inner and outer conditions.

Panke-Kochinke (2013, 2014, 2016) provided a further basis for the concept of emotional safety by proposing the “model of inner security”. This disease-specific model of actions related to coping focuses on the search for “inner security” in relationships. During the early stages of dementia, people are faced with dependencies and perceived incapacitation that appear in their relationships with others. The aim is to achieve a balance between the need for “security”, the degree of support that provides feelings of safety, and

feelings of fear related to external control. Fear in this context has been described more often as a fear of control and restriction rather than as a fear of an increase in symptoms such as forgetfulness (Panke-Kochinke, 2014). Achieving a perceived beneficial balance, e.g. by following familiar everyday routines, can improve the quality of life of people living with dementia (Panke-Kochinke, 2014, 2016). However, this perceived balance can be disturbed by confrontation with stigmatization (Panke-Kochinke, 2014). Therefore, the needs of people living with dementia appear to be central to understanding the process of searching for safety.

In addition, in terms of person-centered care, Kitwood (1993a, 1993b, 1997) emphasizes the necessity of addressing people living with dementia by considering the “complex interaction” among the unique factors associated with each person. These factors include personality (e.g. coping styles), biography, physical health status, neurological impairment and social psychology (Kitwood, 1993a, 1997). In the context of emotional safety, social psychology refers to both positive (e.g. acceptance) and negative (e.g. stigmatization) experiences in everyday life that influence the maintenance of personhood, and such experience “enhances or diminishes an individual’s sense of safety” (Kitwood, 1993a, p. 542).

However, only a few empirical studies have focused on the conditions of emotional safety needs. Although there have been some efforts to describe emotional safety, no systematic review that describes this concept in the context of people living with dementia has been performed. Therefore, the aim of this systematic review is to identify and analyze the knowledge available over a 10-year period regarding the emotional safety of people living with dementia to concretize the phenomenon of emotional safety.

Materials and methods

This systematic review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009) and is registered at the International Prospective Register of Systematic Reviews (PROSPERO, CRD42018082697).

Data sources and search strategy

We performed a systematic literature search using the following general and specialist electronic bibliographic databases: MEDLINE via PubMed, EMBASE via Scopus, CINAHL Plus via EBSCOhost, PsycINFO via EBSCOhost, PSYINDEX via EBSCOhost, the Cochrane Library and Journals@Ovid via Ovid. To enhance the sensitivity of the search strategy, we employed search terms related to five core components (“dementia”, “safety”, “emotion”, “needs” and “well-being”); these terms which were combined in three ways (for the full electronic search strategy, see [Appendices A and B](#)). The search component “dementia” is linked to all three combinations of terms and includes all types of dementia. First, we combined the search terms of the components “dementia”, “safety” and “emotion”. To

increase the sensitivity of the search strategy, we added the component “needs” as an alternative to “safety”. The search terms of the component “safety” were not always included in the title or abstract of the searched publications, but “needs” was mentioned as a main theme. We added the terms of the component “well-being” as an alternative to “emotion” because some studies have reported that emotional safety is related to living well with dementia (Panke-Kochinke, 2013; Zingmark et al., 2002). Second, “dementia” was combined with the terms “safety” and “needs”, and third, “dementia” was combined with the terms “emotion” and “well-being” to obtain further variations and to strengthen the sensitivity of the search strategy.

We used database specific Medical Subject Headings. We also used keywords that have been published in other reviews (Farina et al., 2017; Steeman et al., 2006) or that appear in the definitions described above in other settings (Lang et al., 2008; Panke-Kochinke, 2013; Vincent, 1995; Zingmark et al., 2002). We pretested our search strategy, and three authors performed a title-abstract screening of the first 200 hits. On this basis, we discussed and adjusted the search strategy by adding the term “security” to our search strategy ([Appendix A](#)). We also conducted a backward citation tracking of eligible studies and performed forward citation tracking using Google Scholar (Bakkalbasi et al., 2006).

Eligibility criteria

Studies that report or discuss the emotional safety of people living with dementia from several perspectives, e.g. the perspectives of people living with dementia and those of their informal and formal caregivers, were included. We have also included the perspectives of stakeholders (e.g. physicians, social workers and volunteers) to ensure a comprehensive view of emotional safety as a complex phenomenon.

We included studies published between November 2007 and October 2017 as a means of identifying current publications related to the emotional safety of people living with dementia. Only studies published in English or German were included. There were no restrictions regarding the type of study design eligible for inclusion. Gray literature was included only in the form of dissertations. We did not exclude studies of poor quality.

Study selection

We removed duplicates and verified the inclusion dates. We used database-specific filters for the publication dates when available. The titles and abstracts of all identified hits were screened independently by two reviewers. In total, three reviewers were involved. The hits were categorized as “included”, “excluded” or “unclear”. In cases of uncertainty, a third reviewer was consulted. The full text of the hits that were categorized as “included” or “unclear” was reviewed by two reviewers. Eligible studies were subsequently included. We also analyzed the reference lists of systematic reviews that addressed emotional safety as a means of identifying

additional publications. Backward citation tracking was performed by screening the references of the eligible included studies.

Data extraction and synthesis

We extracted the following data from the primary sources as a means of organizing and comparing the specific methodological characteristics of the identified studies (Table 1): author, year of publication, approaches and data collection methods, sample size, included participants, participant characteristics (age and sex), setting, recruitment, country, study focus and main findings regarding emotional safety. The data extraction was based on the study results pertaining to the emotional safety of people living with dementia. We developed a matrix in which the results are presented at different levels of abstraction, including perspectives and content, and used it to compare the data. All of the extracted data described above were critically discussed by the review team.

Consistent with an integrative review approach (Whittemore & Knafl, 2005), we performed data reduction and illustrated, compared and consolidated the data. Finally, we drew conclusions. We initiated the data reduction by classifying the identified studies and developed subgroups based on the study designs.

The data abstraction was performed via a predominantly qualitative data synthesis (Tables 2 and 3). The qualitative data were analyzed using a qualitative content analysis synthesis design (Elo & Kyngäs, 2008; Hong et al., 2017). The following two strategies were used for the synthesis of qualitative data: (i) a primary inductive content analysis was used to identify categories related to emotional safety and (ii) a deductive content analysis was used to orientate the analysis to a working definition at a high level of abstraction, thus identifying the inner and outer conditions. In both strategies, one reviewer read the material and selected relevant sections. In both procedures, the aim was to categorize the content of the study. Data synthesis of the inductive and deductive results was performed by data clustering, making comparisons, finding patterns and highlighting relations and differences. The inductive content analysis was started by open coding. A categorization matrix was developed for the deductive procedure considering the pre-defined categories “inner condition” and “outer condition”.

A quantitative data synthesis could be not performed due to the small number of studies; therefore, quantitative data were described separately. The results were interpreted in terms of the content of the studies. Finally, all findings were critically discussed, and conclusions were drawn.

Critical appraisal

The identified studies were critically appraised by two reviewers and discussed with a third reviewer. We used the following two design-specific tools: the quality appraisal checklist provided by the National Institute for Health and Care Excellence (NICE) for qualitative studies (National

Institute for Health and Care Excellence, 2012) and the Mixed Methods Appraisal Tool for quantitative and mixed-methods studies (Pace et al., 2012). After comparing the assessments and discussing the material, the studies were assessed using the NICE (National Institute for Health and Care Excellence, 2012, p. 73) checklist as “++ (All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter)”, “+ (Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter)” and “- (Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter)”.

The Cochrane Qualitative Research Methods Group reported the following three approaches to dealing with the results of the critical appraisal: (i) “include or exclude a study”; (ii) “give more weight to studies that scored high on quality”; and (iii) “describe what has been observed without excluding any studies” (Hannes, 2011, p. 11 – 12). Although the group recommends approaches (i) and (ii), they state that the decision must be made individually and that each approach has its value. Consistent with the recommended procedure for conducting a sensitivity analysis by Hannes (2011), we did not find any differences between the lower-quality studies and the higher-quality studies in the content of their results. However, the lower-quality studies provide more detailed information on emotional safety. Furthermore, there was a paucity of evidence addressing our research question. Additionally, emotional safety was not mentioned as a primary outcome in any of our identified studies. To ensure transparency and provide readers with a comprehensive overview of the current state of the studies, we have decided to report studies of all quality levels to highlight the research needs and not to exclude any of the studies.

Results

In total, 13,572 records were identified through the database search, and 43 records were identified through other sources (including identified references in systematic reviews; Figure 1). After removing the duplicates and publications that did not fall within the search period, we reviewed 6123 publications published between November 2007 and October 2017. In total, 27 publications ($n=26$ studies) were finally included. Two of these studies (Brorsson et al., 2011; Lawrence et al., 2011) were identified through a “snowball” search strategy using the publications of Brorsson et al. (2013) and Perrar et al. (2015). One study (Hung et al., 2017) was found in other sources.

Details of the identified studies are presented in Table 1. In total, 22 studies used qualitative methods, two used quantitative methods and two used a mixed-methods design. One of the two quantitative studies reported quantitative results in the context of emotional safety. The authors of the second study presented no results related to emotional safety but discussed their results in this context. None of the included studies reported the emotional safety of people living with dementia as the primary study focus.

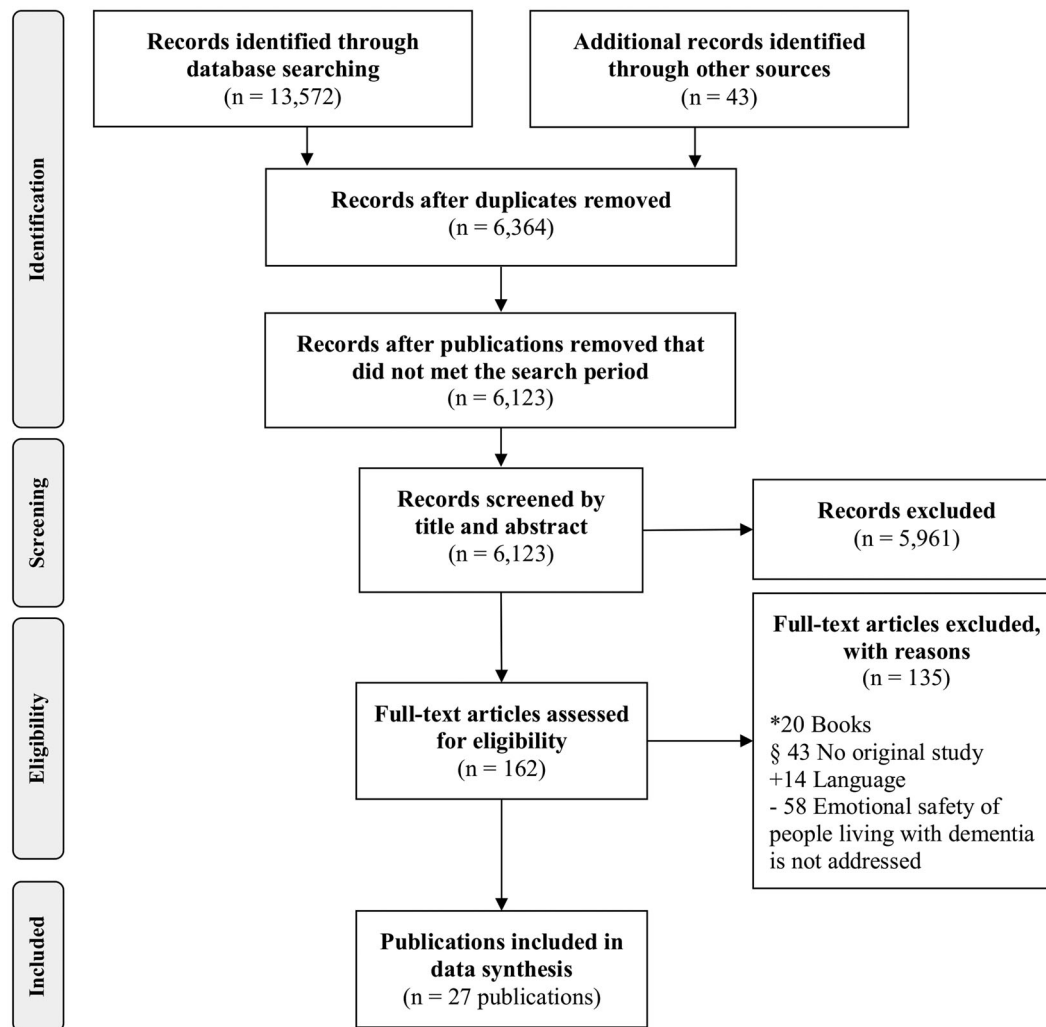


Figure 1. Study selection process (PRISMA-Statement) (Moher et al., 2009).

Most studies involved an in-depth interpretative or reconstructive approach, e.g. a phenomenological or ethnographic approach. For example, the data collection was performed through in-depth interviews, observation and group interviews. The sample size varied from four to 169 participants.

Participants with a variety of characteristics were included in the identified studies. Twelve studies included people living with dementia, seven studies included both people living with dementia and other proxies and six studies included proxies, e.g. family members and friends, health care providers, and other staff. One study included both people living with dementia and people living with mild cognitive impairment. The most frequently reported types of dementia in these studies were Alzheimer's disease (AD) ($n = 10$) and vascular dementia ($n = 6$). Most studies ($n = 12$) involved people with early or mild dementia. Nine studies included people with moderate dementia, and six studies included people with severe or advanced dementia. In total, five studies did not specify the stage of dementia.

The most frequently reported settings in these studies ($n = 15$) involved people with dementia who were living at home or in community dwellings. In this context, the main focus is on participation in public life and receipt of health services. In addition, a residential care/nursing home setting

and a hospital setting were reported. The participants in the studies were recruited in Europe ($n = 20$), the USA ($n = 2$), Asia ($n = 2$) and Canada ($n = 2$).

The critical appraisal showed that five studies fulfilled all or most of the criteria, 14 fulfilled some of the checklist criteria and seven fulfilled few or none of the criteria.

Emotional safety in the context of people living with dementia

The following five main categories of emotional safety were identified: (1) "emotional safety as a primary psychological need"; (2) "emotional safety in the context of disease-related, biographical, demographic and socioeconomic factors"; (3) "inner conditions and strategies"; (4) "outer conditions and strategies"; and (5) "emotional safety as a condition".

Emotional safety as a primary psychological need

Four identified studies addressed the phenomenon of emotional safety as a primary psychological need and included the perspectives of people living with dementia and those of

Table 1. Overview of the included studies.

Author (years)	Approaches (methods)	Sample size	Included participants	Participant characteristics			Country	Recruitment	Setting	Study focus	Main findings regarding emotional safety	Critical appraisal
				Age (years)	Sex	Severity						
<i>Qualitative studies</i>												
Braataas et al. (2010)	Descriptive design (narrative interviews)	n = 9 PLWD	Mild dementia	77 – 88	f (n = 7), m (n = 2)		Norway	Existing day care program	PLWD living at home and participating in a day care program	Experiences of a person-centered and collaborative day care program	Feelings of safety may be decrease by low self-efficacy. A day care program can strengthen feelings of safety, such as through organization of a safe transfer. Feeling safe can increase well-being.	+
Brittain et al. (2010)	Participatory design (focus groups, secondary data)	(a) n = 16 PLWD (b) n = 3 caregivers n = 4 focus groups	(a) Mild to moderate dementia (b) Not described	–	f, m		England	Local branches of the Alzheimer's Society	Aging with dementia in public environments	Experience of everyday technologies in public spaces	Contact with familiar people and the possibility of using a technical device to communicate with others can strengthen the feeling of safety in public spaces.	–
Bronsson et al. (2011)	Grounded theory (repeated in-depth interviews)	n = 7 PLWD n = 13 interviews	Early AD (MMSE: 18 – 30)	63 – 80	f (n = 5), m (n = 2)		Sweden	Dementia investigation unit and dementia association	PLWD living at home and visiting public spaces	Experiences of accessibility in public spaces	PLWD feel safe in familiar places, which improves orientation. PLWD feel insecure in payment situations or in the evening after dark.	+
Bronsson et al. (2013)	Grounded theory (repeated in-depth interviews and observations)	n = 6 PLWD n = 12 interviews n = 8 observations	Early AD (MMSE: 18 – 30)	63 – 80	f (n = 4), m (n = 2)		Sweden	Dementia investigation unit and dementia association	PLWD living at home and grocery shopping	Identification of problematic situations and critical incidents while grocery shopping	The presence of many background sounds while crossing roads and difficulties in retrieving learned behaviors reduces feelings of safety.	+
Clare et al. (2008)	Phenomenological design (unstructured conversations, secondary data)	n = 81 PLWD n = 307 conversations	Moderate to severe dementia (MMSE: 0 – 20)	59 – 96	f (n = 69), m (n = 12)		England, Wales	–	PLWD living in residential care homes	Experience and psychological impact of living with dementia in residential care homes	Dementia care should consider emotional experiences, help reduce anxiety and create feelings of safety.	+
Cronfalk et al. (2017)	Descriptive design (semistructured interviews)	n = 10 family members n = 10 interviews	Spouse, children and children-in-law of PLWD	–	f (n = 7), m (n = 3)		Sweden	Subsample of an intervention study	PLWD living in nursing homes who are regularly visited by their relatives	Experiences and coping strategies of people with advanced stage dementia who move into a nursing home	Increasing the feeling of safety is described during the change from home care to a nursing home by the assurance of access to help in the near surroundings.	–

(continued)

Table 1. Continued.

Author (years)	Approaches (methods)	Participant characteristics					Country	Study focus	Main findings regarding emotional safety	Critical appraisal
		Sample size	Included participants	Age (years)	Sex	Setting				
Duggan et al. (2008)	Grounded theory (semistructured interviews)	(a) $n = 22$ PLWD (b) $n = 14$ caregivers	(a) Mild to moderate dementia (MMSE: 15–29) (b) Spouse and children of PLWD and housekeeper	(a) 71–84 (b) –	(a) f ($n = 11$), m ($n = 11$) (b) Unclear	PLWD living at home and participating in public space	United Kingdom	View of PLWD and their caregivers of using outdoor environments and impact of the disease	PLWD feel safe when they visit familiar areas in public spaces.	+
Ericsson et al. (2013)	Grounded theory (Relational Time videotapes and interviews)	(a) $n = 9$ PLWD (b) caregivers $n = 24$ interviews (PLWD) $n = 8$ interviews (caregivers) $n = 24$ video sequences	(a) Moderate to severe dementia (FAST range 5–7) (b) Professional caregivers	(a) 75–97 (b) –	(a) f ($n = 8$), m ($n = 1$) (b) all were female	PLWD living at residential units for PLWD	Sweden	Description of the formation of relationships with PLWD	The feeling of safety can be strengthened within the context of relationship establishment in care situations, such as by enabling self-determination. Friendships can provide feelings of safety.	++
Faith (2014)	Phenomenological design (online blogs, secondary data)	$n = 9$ individual blogs of PLWD	Frontotemporal and vascular dementia, early onset AD and AD	50–65 $n = 2$ unknown	f ($n = 6$), m ($n = 3$)	Online blogs of PLWD	USA	Subjective experiences of PLWD presented in online blogs		+
Genoe and Dupuis (2011), Genoe (2009)	Phenomenological design (long interviews, observations and photovoice)	$n = 4$ PLWD $n = 16$ interviews $n = 66$ photos	Early stage AD and vascular dementia	Unclear	f ($n = 2$), m ($n = 2$)	PLWD living in the community	Canada	Meaning and experience of leisure in the dementia context	In familiar areas, especially in private spaces, PLWD feel safe.	++
Hadjri et al. (2015)	Descriptive design (semistructured interviews)	$n = 22$ manager of care homes	–	–	–	Care and nursing homes for PLWD in urban and rural settings	England	Identification of housing options for PLWD and their specific designs	The building design should allow PLWD to feel safe.	–
Hansen et al. (2017)	Descriptive design (semistructured focus group interviews)	$n = 24$ health care providers (focus groups with 5–8 participants)	Registered nurses and assistant nurses	–	f ($n = 24$)	Home care services for PLWD in a Norwegian setting	Norway	Perception and fulfillment of the psychological needs of PLWD by home care services	Feeling socially and physically safe is a primary psychosocial need. The hurried behavior of others can reduce feelings of safety. Feeling safe can increase psychological health.	+
Hung et al. (2017)	Participatory design (observations, go-along interviews and video recording)	$n = 5$ PLWD (all participants were interviewed twice alone or together with another participant)	AD and vascular and unspecified subtype of dementia	65–84	f ($n = 2$), m ($n = 3$)	PLWD were admitted to a medical unit of an urban hospital (different reasons and lengths of stay)	Canada	Experiences of PLWD with the physical and social environment in a hospital	Feeling psychologically safe is a primary psychosocial key aspect of a supportive hospital environment is the availability of a place of safety that includes access to help and an adapted building design.	++

(continued)

Table 1. Continued.

Participant characteristics											
Author (years)	Approaches (methods)	Sample size	Included participants	Age (years)	Sex	Setting	Recruitment	Country	Study focus	Main findings regarding emotional safety	Critical appraisal
Hynninen et al. (2015)	Descriptive design (individual and joint unstructured interviews)	(a) n = 7 PLWD (b) n = 5 relatives n = 4 interviews (PLWD) n = 2 interviews (relatives) n = 3 joint interviews	(a) Mild or moderate AD (b) Spouse, and children of PLWD	(a) 74 – 85 (b) 52 – 78	(a) f (n = 5), m (n = 2) (b) f (n = 4), m (n = 1)	Surgical wards of a university hospital	Head nurses instructed the nursing staff	Finland	View of PLWD and their relatives concerning the treatment of older PLWD in surgical wards	PLWD feel safe when their relatives are nearby.	+
Lawrence et al. (2011)	Unclear (in-depth interviews)	(a) n = 27 bereaved caregivers (b) n = 23 care professionals n = 50 interviews	(a) Family members and friends of PLWD (b) Physicians, nurses, health care assistants and manager	–	(a) f (n = 21), m (n = 6) (b) –	Different organizations providing end-of-life care for PLWD in four different boroughs in south London	Community mental health teams, care homes, hospitals, palliative care, and Alzheimer's Society, carer organizations	England	Definition and application of good end-of-life care for PLWD in different care settings	In a "warm atmosphere" in nursing homes, PLWD can feel safe.	++
Mazaheri et al. (2014)	Descriptive design (semistructured interviews)	n = 15 PLWD	AD and vascular dementia	66 – 88	f (n = 8), m (n = 7)	PLWD who were born in Iran living at home or in group dwellings for PLWD in Sweden	Staff of care centers for PLWD	Sweden	Experience of living with dementia among Iranian immigrants in Sweden	PWLD describe feeling safe in public spaces when they become lost but still find their way home. PLWD also feel safe when other people have a positive attitude towards PLWD.	+
Mjørud et al. (2017)	Phenomenological hermeneutic design (unstructured face-to-face interviews and observations)	n = 12 PLWD n = 20 interviews	Mild to severe dementia (clinical dementia rating scale (1 – 3))	71 – 95	f (n = 10), m (n = 2)	PLWD living in a nursing home for three to six months	Head nurse in the unit	Norway	Experience of living in a nursing home and identification of factors that improve or reduce well-being	The feeling of safety can be created in nursing homes through access to help with daily activities and the knowledge that PLWD are not alone. Coping with dementia was described as a constant equilibrium between the experience of a "successful life" and the experience of disenfranchisement processes, which can be represented in the model of "inner security".	++
Panke-Kochinke (2013)	Descriptive biographical design (group interviews and narrative biographical-oriented interviews)	n = 3 self-help groups n = 5 group interviews (5 – 9 PLWD) n = 8 interviews (4 PLWD)	Early stage dementia	Not clear	f, m	PLWD who engage in self-help groups	Bundesverband der Alzheimer Gesellschaft e. V.	Germany	Self-awareness of PLWD and the meaning of the self-help group related to the development of self-concept	Coping with dementia was described as a constant equilibrium between the experience of a "successful life" and the experience of disenfranchisement processes, which can be represented in the model of "inner security".	+
Sørensen et al. (2008)	Grounded theory (semistructured in-depth interviews)	n = 11 PLWD	Mild AD (MMSE: 22 – 27)	65 – 82	f (n = 5) m (n = 6)	PLWD living at home with a spouse	Subsample of the Danish Alzheimer Intervention Study	Denmark	Coping strategies of PLWD in everyday life and social relationships	Behavioral and psychological symptoms of dementia, such as difficulty communicating, are associated with reduced feeling of safety.	–

(continued)

Table 1. Continued.

Author (years)	Approaches (methods)	Participant characteristics					Recruitment	Country	Study focus	Main findings regarding emotional safety	Critical appraisal
		Included participants	Age (years)	Sex	Setting	Sample size					
Wang et al. (2012)	Exploratory research design (one-on-one in-depth interviews)	Spouse, children and children-in-law of PLWD	47 – 78	f (n = 12)	Family members caring for their relatives with AD with hoarding behavior for six or more months	Outpatient dementia clinic and local dementia association	Taiwan	Characteristics and underlying meaning of hoarding behavior in PLWD	Hoarding behavior as an expression of safety needs in situations in which there is a feeling of being financially exploited by others.	+	
Wang et al. (2015)	Exploratory research design (semistructured interviews)	Spouse, children, children-in-law and other relatives of PLWD	34 – 81	f (n = 47), m (n = 18)	Family caregiver of people living with AD and disruptive behaviors within the last two weeks	Outpatient dementia clinic at a university hospital and a home care center	Taiwan	Investigated and compared the needs of PLWD with five different disruptive behaviors	Disruptive behavior as an expression of unmet needs for feeling mentally and economically safe, especially among women.	+	
Yatczak (2014)	Ethnographic design (observations, informal semistructured interviews and videotaping)	(a) Moderate to advanced stage dementia (GDS: 5–7) (b) Family members of PLWD (c) Nursing staff, administrators, intake coordinators, dietary staff, housekeeping staff	–	f, m	PLWD living in a senior care community	Health care staff	USA	Relationship between PLWD and the “material world” (interaction with objects)	Routines in everyday life can strengthen the feeling of safety.	+	
Manera et al. (2016)	Feasibility study (self-reported questionnaires)	(a) AD, mixed and vascular dementia, primary progressive aphasia, organic brain syndrome (MMSE: 20.2 ± 3.1) (b) (MMSE: 25.4 ± 2.6)	(a) 65 – 90 (b) 62 – 89	(a) f (n = 12), m (n = 17) (b) f (n = 13), m (n = 15)	Participants visit an institute for regular medical consultation or neuropsychological assessments	Memory center and research unit	France	Assessed acceptability, interest and usability problems of Virtual Reality for PLWD compared to a paper condition for attention training	Participants reported high feelings of security in the Virtual Reality training (mean = 9.4/10, standard deviation = 1.3).	–	
Osborne et al. (2010)	Descriptive design (interviews and questionnaires)	(a) AD, vascular, frontotemporal, Lewy body and Korsakoff's dementia (b) Partner, children and siblings of PLWD	(a) 60 – 94 (b) –	(a) f (n = 32), m (n = 19) (b) f, m	PLWD living in the community or in residential/nursing homes	Health services, day centers, nursing homes and support groups	England	Analyzed the associations between demographic, cognitive and psychological factors and parent fixation in PLWD	PLWD can experience dependence on others and a loss of control. Those who previously gained a feeling of safety through independence and control may be less able to cope with dementia.	–	

(continued)

Table 1. Continued.

Author (years)	Approaches (methods)	Sample size	Included participants	Participant characteristics				Recruitment	Country	Study focus	Main findings regarding emotional safety	Critical appraisal
				Age (years)	Sex	Setting	Country					
<i>Mixed-methods studies</i>												
Groenewoud et al. (2017)	Unclear (observations and interviews)	n = 54 PLWD n = 177 observations n = 177 interviews	Mild to severe dementia	59 – 95	f (n = 30), m (n = 24)	PLWD participating in day care centers or living in facilities from health care organizations	The Netherlands	Health care staff	The Netherlands	Feelings about playing one-player causal games and access for PLWD	PLWD reported negative experiences and a reduced feeling of safety while playing games.	–
Nijhof et al. (2013)	Evaluation study (semistructured interviews, project group meetings, nurse diaries, cost analysis and observations)	(a) n = 14 PLWD (b) n = 14 informal caregivers (c) n = 14 formal caregiver n = 38 semi-structured interviews (informal caregivers) n = 8 project meetings	(a) Mild to severe dementia (MMSE: 13 – 29) (b) – (c) Health care providers, project manager, technician and research assistant	(a) 58 – 87 (b) – (c) 35 – 79	(a) f (n = 6), m (n = 8) (b) – (c) f (n = 8), m (n = 6)	PLWD living at home and receiving homecare services	The Netherlands	Formal caregivers selected clients diagnosed with dementia	The Netherlands	Evaluating preventive sensor technologies that detect behavior-related problems at home	The preventive sensor technology promoted a feeling of safety.	+

PLWD: people living with dementia; AD: Alzheimer's disease; f: female; m: male; MMSE: Mini Mental State Examination; FAST: Functional Assessment Staging Test; GDS: Global Deterioration Scale. Critical appraisal: “++ (all or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter), + (some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter), – (few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter)” (National Institute for Health & Care Excellence, 2012).

Table 2. Inner conditions of emotional safety in people living with dementia.

Dimensions	Inner condition	Specification	Context or setting	Self-reported strategies		
				Self-performed strategies of PLWD	Strategies performed by others	
Inner conditions related to psychological aspects	Perceived self-efficacy and self-determination [1 ^a , 3 ^a , 9 ^b , 12 ^a]	Perceived demands described as impossible to overcome and decreased feelings of safety [3 ^a]	Leaving home to visit public spaces [3 ^a]	Not leaving the house alone [3 ^a]	–	
		Feeling safe in problematic situations, ended positively from the point of view of PLWD [12 ^a]	Finding way back home [12 ^a]	Using visual aids (note with name/address or recognition of the physical landscape) [4 ^b , 10 ^a , 11 ^a]	–	
	Impairment of internal safety when self-efficacy is disturbed by processes of incapacitation [1 ^a]	Perceived self-determination leads to feelings of safety [9 ^b]	Relationships with close relatives [1 ^a]	Relationships with close relatives [1 ^a]	–	Support by self-help groups for the development of solution strategies [1 ^a]
			Professional caregiver considers the wishes of PLWD and reacts accordingly and quickly [9 ^b]	Professional caregiver considers the wishes of PLWD and reacts accordingly and quickly [9 ^b]	Leaving decisions that PLWD cannot make or can only make with difficulty to other people [9 ^b]	Other people make decision at PLWD's request [9 ^b]
	Willingness to receive support [1 ^a]	Perceived dependency on others [1 ^a]	PLWD search for what they describe as good [1 ^a]	PLWD search for what they describe as good [1 ^a]	–	–
			Coping with perceived dependency, negative perceived control and experience of safety [1 ^a]	Perceived dependency in relationship with others [1 ^a]	–	–
	Perceived mental stability [15 ^c]	Perceived mental stability [15 ^c]	Perceived mental stability increase feelings of safety [15 ^c]	Needs of PLWD and disruptive behaviors [15 ^c]	A desire to feel mentally safe expressed in repeated and altered eating behavior and delusions [15 ^c]	–
			Feelings of safety are present in familiar places [6 ^a , 8 ^b , 10 ^a , 11 ^a]	Finding way back home [6 ^a] PLWD living in the community [10 ^a , 11 ^a]	Claiming private spaces [10 ^a , 11 ^a]	Places no longer familiar are not visited by the PLWD and their relatives [6 ^a]
	Inner conditions related to economic aspects	Perceived information need [1 ^a]	Feeling safe when familiar faces are around PLWD [4 ^b]	Use of outdoor environments [8 ^b] Leaving home to visit public spaces [4 ^b]	–	Support from self-help groups [1 ^a]
			Providing information can strengthen feelings of safety [1 ^a]	The role of self-help groups [1 ^a]	–	Transition between home care and nursing home [7 ^c]
Assurance that others care for PLWD [2 ^a , 5 ^a , 7 ^c , 13 ^a , 14 ^b]		Feelings of safety were described as knowing that support is always available [2 ^a , 7 ^c , 13 ^a]	Living in a nursing home [7 ^c , 13 ^a]	Living in a nursing home [7 ^c , 13 ^a]	–	Use of monitoring systems [14 ^b]
		Perceived safety when knowing PLWD are monitored by formal caregiver [14 ^b]	Hospital environment [2 ^a] Living at home [14 ^b]	Hospital environment [2 ^a] Living at home [14 ^b]	–	Use physical assistive devices (e.g. traffic lights) [5 ^c]
Decreased feeling of safety when worrying that others are not cared for [5 ^c]		Perceived feeling of safety when worrying that others are not cared for [5 ^c]	Crossing roads [5 ^a]	Crossing roads [5 ^a]	Increased attention, waiting until an unsafe situation has changed, and changing behavior [5 ^c]	–
			“Ensuring a stable feeling for personal belongings” promotes feeling of safety [15 ^c , 16 ^c]	Hoarding behavior [15 ^c , 16 ^c]	A need for material safety expressed by hoarding and aggressive behavior [15 ^c , 16 ^c]	Identify patients' security needs [16 ^c]
Perceived preparedness for possible situations [16 ^c]		Perceived preparedness for possible situations [16 ^c]	“Gaining a steady feeling of preparedness” promotes feeling of safety [16 ^c]	Hoarding behavior [16 ^c]	PLWD feel safer when they express their concerns about maintaining self-control (though often in aggressive behavior) [15 ^c]	–
			PLWD do not feel safe when they are afraid of being exploited by others [6 ^a , 15 ^c , 16 ^c]	Payment situation [6 ^a] Hoarding behavior [15 ^c , 16 ^c]	–	–

[1] Panke-Kochinke (2013); [2] Hung et al. (2017); [3] Brataas et al. (2010); [4] Brittain et al. (2010); [5] Brorsson et al. (2011); [6] Brorsson et al. (2013); [7] Cronfalk et al. (2017); [8] Duggan et al. (2008); [9] Ericsson et al. (2013); [10] Genoe and Dupuis (2011); [11] Genoe (2009); [12] Mazaheri et al. (2014); [13] Mjørud et al. (2017); [14] Nijhof et al. (2013); [15] Wang et al. (2015); [16] Wang et al. (2012).
^aPerspectives of PLWD; [1, 2, 3, 5, 6, 10, 11, 12, 13].
^bPerspectives of PLWD and others; [4, 8, 9, 14].
^cPerspectives of family members; [7, 15, 16].

Table 3. Outer conditions of emotional safety in people living with dementia.

Dimensions	Self-reported strategies			
	Outer conditions	Specification	Context or setting	
Outer conditions related to social aspects	<p>Opportunity to interact socially [1^a, 2^a, 3^a, 12^a, 13^a, 17^c, 18^a, 19^a, 20^b]</p> <p>Attitude towards PLWD [1^a, 3^a, 12^a, 13^a]</p> <p>Behavior of others [2^a, 17^c, 18^a]</p> <p>Living in relationships [19^a, 20^b]</p> <p>Receiving support [1^a, 2^a, 3^a, 7^c, 9^b, 13^a, 15^c]</p> <p>Establish relationships in care [9^b]</p> <p>Performing stressful tasks [3^a]</p> <p>Access to help [1^a, 2^a, 7^c, 13^a, 15^c]</p>	<p>PLWD feel safe when they interact socially and are not alone [12^a]</p> <p>A subtheme of feelings of safety are positive attitudes (goodness, respect, understanding, considering each other equals, and open-mindedness) [3^a, 13^a]</p> <p>If others do not discriminate and express dissatisfaction with PLWD, PLWD feel safe [12^a]</p> <p>Unpleasant and offensive attitude (deficits PLWD are named (e.g. forgetfulness)) decrease feelings of safety [1^a]</p> <p>A place of sympathy and recognition increases feelings of safety [1^a]</p> <p>Unconcentrated or hurried behavior can decrease feelings of safety in PLWD [17^c]</p> <p>PLWD feel threatened when others move too fast [2^a]</p> <p>PLWD feel threatened when others are too close to them [2^a]</p> <p>Changes in relatives' behavior can decrease feelings of safety [18^a]</p> <p>PLWD feel safe in their relatives' presence [20^b]</p> <p>Friendships can provide feelings of safety [19^a]</p> <p>Continuum between external control creating fear and support providing a feeling of safety [1^a]</p> <p>Adaptability and empathy of strangers (e.g. changing behavior) can lead to a feeling of safety [9^b]</p> <p>Approach in a nonthreatening way provides a feeling of safety [9^b]</p> <p>An inviting environment and considering self-determination in approaching were important for feelings of safety [9^b]</p> <p>Other people organized stressful tasks for PLWD and thereby strengthened the feeling of safety [3^a]</p> <p>Access to care in the near surroundings gives a feeling of safety (e.g. in activities of daily living) [1^a, 2^a, 7^c, 13^a]</p> <p>Receiving care in activities of daily living can reduce feelings of safety (e.g. bathing by health care providers) [15^c]</p>	<p>Visiting public spaces [12^a]</p> <p>Participating in a day care program [3^a]</p> <p>Nursing home [13^a]</p> <p>Visiting public spaces [12^a]</p> <p>Living in a relationship [1^a]</p> <p>Meaning of self-help groups [1^a]</p> <p>Living at home and using home care services [17^c]</p> <p>Hospital environment [2^a]</p> <p>Hospital environment [2^a]</p> <p>Coping with changes in everyday life [18^a]</p> <p>Surgical wards [20^b]</p> <p>Online blogs [19^a]</p> <p>Coping with dementia [1^a]</p> <p>Establish relationships in residential units [9^b]</p> <p>Establish relationships in residential units [9^b]</p> <p>Establish relationships in residential units [9^b]</p> <p>Participate in a day care program [3^a]</p> <p>Coping with dementia [1^a]</p> <p>Changes in the living environment due to worsening of the disease [7^c]</p> <p>Nursing home [13^a]</p> <p>Hospital environment [2^a]</p> <p>PLWD and disruptive behavior [15^c]</p>	<p>Self-performed strategies of PLWD</p> <p>People who threaten feelings of safety are avoided [1^a, 7^c]</p> <p>Highlighted safety in care [17^c]</p> <p>Adjustment of the nursing service (consider emotional experience, repeat information, adapt behavior, provide time and identify patients' safety needs) [9^b, 16^c, 21^a]</p> <p>Ordering transfer for the right time and space from home to public spaces [3^a]</p> <p>Organization of transition between home care and nursing home [7^c]</p>

(continued)

Table 3. Continued.

Dimensions	Outer conditions	Specification	Context or setting	Self-reported strategies	
				Self-performed strategies of PLWD	Strategies performed by others
Outer conditions related to physical aspects	Time of day [6 ^a]	In later times of day and darkness, PLWD did not feel safe [6 ^a]	Visiting in public spaces [6 ^a]	-	Going outside with others in situations where they feel unsafe [6 ^a]
	Background sounds/stress of noises [2 ^a , 5 ^a]	PLWD did not feel safe when they could not differentiate sounds and do not know which sounds to pay attention to [5 ^a]	Crossing roads [5 ^a]	-	-
	Changing living home [7 ^c]	Noises from others (e.g. screaming or crying) have an impact on feelings of safety [2 ^a]	Hospital environment [2 ^a]	-	Have places to escape from the stress of noise [2 ^a]
	Private spaces [10 ^a , 11 ^a]	Changing the home situation can result in feeling safe [7 ^c]	Transition between home care and nursing home [7 ^c]	-	-
		Private spaces in which PLWD know where things are and can design themselves lead to a feeling of safety [10 ^a , 11 ^a]	PLWD living in the community [10 ^a , 11 ^a]	Leisure by claiming private space [10 ^a , 11 ^a]	-
	Building design [2 ^a , 22 ^c , 23 ^c]	Private spaces in which PLWD can practice their own skills "where risk of failure was relatively minimal" was also a space of feeling safe [10 ^a , 11 ^a]	PLWD living in the community [10 ^a , 11 ^a]	-	-
		Building design should enable PLWD to feel safe and maintain their mobility [22 ^c]	Design in nursing homes for PLWD [22 ^c]	-	A place of safety should afford opportunities to engage in familiar everyday activities such as going for walks [2 ^a]
	Technologies [4 ^b , 6 ^a , 14 ^b , 24 ^a , 25 ^b]	Aesthetics and practicality of the environment are related to feelings of safety (e.g. overcrowded corridors) [2 ^a]	Design for PLWD in hospital environments [2 ^a]	-	Creating a tidy and organized environment [2 ^a]
		In "a warm atmosphere", PLWD can feel safe [23 ^c]	Dying well with dementia [23 ^c]	-	-
		Using technology can decrease feelings of safety if they are not adapted to the abilities and interests of PLWD [6 ^a , 24 ^a]	Playing games [24 ^a] Using cash machines in public spaces [6 ^a]	Using technological aids (mobile phone, not accepted by everyone) [4 ^b]	-
Using technology can decrease feelings of safety when the purpose is unclear [24 ^a]		Playing games [24 ^a]	-	-	
	Monitoring systems can enhance feelings of safety [14 ^b]	Sensor technology at home [14 ^b]	-	-	
	PLWD who use Virtual Reality reported high feelings of safety [25 ^b]	Virtual Reality in cognitive training [25 ^b]	-	-	
	Technology that connects the physical and social environment can provide feelings of safety [4 ^b]	Mobile phones in public spaces [4 ^b]	-	-	

[1] Panke-Kochinke (2013); [2] Hung et al. (2017); [3] Brataas et al. (2010); [4] Brittain et al. (2010); [5] Brorsson et al. (2013); [6] Brorsson et al. (2011); [7] Cronfalk et al. (2017); [9] Ericsson et al. (2013); [10] Genoe and Dupuis (2011); [11] Genoe (2009); [12] Mazaheri et al. (2014); [13] Mjørud et al. (2017); [14] Nijhof et al. (2013); [15] Wang et al. (2015); [16] Wang et al. (2012); [17] Hansen et al. (2017); [18] Sørensen et al. (2008); [19] Faith (2014); [20] Hyminen et al. (2015); [21] Clare et al. (2008); [22] Hadjri et al. (2015); [23] Lawrence et al. (2011); [24] Groenewoud et al. (2017); [25] Manera et al. (2016).
^aPerspective of PLWD: [1, 2, 3, 5, 6, 10, 11, 12, 13, 18, 19, 21, 24].
^bPerspective of PLWD and others: [4, 9, 14, 20, 25].
^cPerspective of proxies: [7, 15, 16, 17, 22, 23].

health care providers and family caregivers. Similar to physical safety (Hung et al., 2017), emotional safety is described as a primary need among people living with dementia (Hansen et al., 2017). We identified the following four dimensions of emotional safety: feeling psychologically safe (Hung et al., 2017; Wang et al., 2015), feeling economically safe (Wang et al., 2015), feeling socially safe (Hansen et al., 2017) and feeling physically safe (Hansen et al., 2017). People living with dementia can express their “unmet needs” to feel safe in different ways, such as engaging in disruptive behavior (Wang et al., 2012; 2015). According to Wang et al. (2012, 2015), the need to feel economically safe can be expressed through hoarding behavior. Additionally, repetitive behavior, altered eating behavior and delusions have been described as indicators of the need to feel psychologically safe.

Emotional safety in the context of disease-related, biographical, demographic and socioeconomic factors

A total of nine studies reported that changes and difficulties due to dementia can threaten the feeling of safety. Most studies solely interviewed people living with dementia ($n = 7$). Two studies also included other perspectives (family members and staff members).

Living with forgetfulness (Brataas et al., 2010; Brorsson et al., 2011; 2013; Hung et al., 2017; Mazaheri et al., 2014; Panke-Kochinke, 2013; Sørensen et al., 2008) was related to changes such as not remembering passwords (Brorsson et al., 2011; 2013) and encountering “new” places that had previously been perceived as familiar but were gradually forgotten (Sørensen et al., 2008). Another mentioned change was difficulty in focusing attention due to the presence of too many stimuli (Brorsson et al., 2013; Hung et al., 2017), e.g. street noises (Brorsson et al., 2013) or the presence of many people in the immediate surroundings (Hung et al., 2017). Difficulties were reported in retrieving learned behaviors (Brorsson et al., 2013; Sørensen et al., 2008) that were easily followed in the past but were currently difficult or no longer possible due to dementia (Sørensen et al., 2008), e.g. correct behavior while crossing a road (Brorsson et al., 2013). Two studies showed communication difficulties (Hung et al., 2017; Sørensen et al., 2008), e.g. problems understanding several words (Sørensen et al., 2008). In addition, people living with dementia were reported to feel unsafe because things that previously created a feeling of safety, such as control and independence, are restricted in the course of dementia (Osborne et al., 2010). According to Osborne et al. (2010), people who experience these restrictions are less able to cope with the disease. Living in the present and following routines appear to be strategies for coping with dementia-related changes in the context of emotional safety (Panke-Kochinke, 2013; Yatzak, 2014).

Five studies of people living with dementia or family members reported that biographical, demographic and socioeconomic factors related to the emotional safety of people living with dementia should be considered in the context of emotional safety. Four studies concluded that past experiences without dementia may have an effect on the experience

of emotional safety in the current situation (Mazaheri et al., 2014; Osborne et al., 2010; Wang et al., 2012; 2015).

Women seem to have a greater need for safety (Wang et al., 2015) and to be at higher risk for a decreased feeling of safety (Panke-Kochinke, 2013) than men. Wang et al. (2015) explained this observation from a biographical perspective as follows: women are often assigned a certain social role and often experience dependency on their families or husbands. Another biographical factor is related to individuals’ experiences with living in their own country or in a foreign country. Mazaheri et al. (2014) interviewed Iranian people who lived in Sweden about their experiences with dementia. The participants reported high feelings of safety in public spaces, a finding that differs from the results of other studies involving people who lived in their own countries. The differences among these countries in terms of cultural factors and health care systems appear to have an impact on perceived safety (Mazaheri et al., 2014).

From a demographic perspective, women generally consider their male partners protectors against the disease (Panke-Kochinke, 2013). A male partner who does not behave according to this role (e.g. by having a negative response to forgetfulness) could increase feelings of insecurity in people living with dementia (Panke-Kochinke, 2013).

A socioeconomic factor related to experiences with prior financial crises has been reported to strengthen the desire to feel safe in the present and is expressed by behaviors such as hoarding (Wang et al., 2012, 2015).

Inner and outer conditions and strategies for achieving emotional safety

Inner conditions and strategies were reported in 15 studies (Table 2). Eight of these studies included people living with dementia, four also considered other perspectives and three solely considered the perspectives of family members. The dimensions of the conditions include “inner conditions related to psychological aspects” and “inner conditions related to economic aspects”. Both dimensions are based on self-reported, subjectively perceived conditions that can strengthen or decrease emotional safety.

Seven main “inner conditions related to psychological aspects” were identified: “perceived self-efficacy and self-determination” (Brataas et al., 2010; Ericsson et al., 2013; Mazaheri et al., 2014; Panke-Kochinke, 2013), “willingness to receive support” (Panke-Kochinke, 2013), “perceived dependency on others” (Panke-Kochinke, 2013), “perceived mental stability” (Wang et al., 2015), “perceived familiarity” (Brittain et al., 2010; Brorsson et al., 2011; Duggan et al., 2008; Genoe, 2009; Genoe & Dupuis, 2011), “perceived information need” (Panke-Kochinke, 2013) and “assurance that others care for PLWD” (Brorsson et al., 2013; Cronfalk et al., 2017; Hung et al., 2017; Mjørud et al., 2017; Nijhof et al., 2013). These conditions were often reported in a context or setting related to the use of outdoor environments and to interacting with others, e.g. relatives, professionals and other people living with dementia. The self-reported strategies are related to several different aspects, including

strategies involving visual/technical aids and other people for support and strategies that are employed only by people living with dementia.

Three main “inner conditions related to economic aspects” were identified: “perceived material stability and control” (Wang et al., 2012, 2015), “perceived preparedness for possible situations” (Wang et al., 2012) and “fear of being exploited by others” (Brorsson et al., 2011; Wang et al., 2012, 2015). The expression of feelings of decreased economic safety through disruptive behavior is described as an internal strategy among people living with dementia (Wang et al., 2012, 2015). The only strategy performed by other people refers to identify safety needs (Wang et al., 2012).

Outer conditions and strategies were reported in 23 studies (Table 3). Twelve of these studies solely included people living with dementia, five also considered other perspectives and six only considered other proxies. The conditions were divided into two dimensions, “outer conditions related to social aspects” and “outer conditions related to physical aspects”. These dimensions are characterized by situations that cannot be directly controlled by people living with dementia.

Two “outer conditions related to social aspects” were identified: “opportunity to interact socially” (Brataas et al., 2010; Faith, 2014; Hansen et al., 2017; Hung et al., 2017; Hynninen et al., 2015; Mazaheri et al., 2014; Mjørud et al., 2017; Panke-Kochinke, 2013; Sørensen et al., 2008) and “receiving support” (Brataas et al., 2010; Cronfalk et al., 2017; Ericsson et al., 2013; Hung et al., 2017; Mjørud et al., 2017; Panke-Kochinke, 2013; Wang et al., 2015). The first category comprises the following three conditions related to the basics of social interaction among people: “attitude towards people living with dementia” (Brataas et al., 2010; Mazaheri et al., 2014; Mjørud et al., 2017; Panke-Kochinke, 2013), “behavior of others” (Hansen et al., 2017; Hung et al., 2017; Sørensen et al., 2008) and “living in relationships” (Faith, 2014; Hynninen et al., 2015). The second category is related to the special care situation and focuses on the implementation and receipt of support. This category includes “establishing relationships in care” (Ericsson et al., 2013), “performing stressful tasks” (Brataas et al., 2010) and “access to help” (Cronfalk et al., 2017; Hung et al., 2017; Mjørud et al., 2017; Panke-Kochinke, 2013; Wang et al., 2015) as the three main conditions. Only the avoidance of interactions is described as a strategy performed by people living with dementia (Cronfalk et al., 2017; Panke-Kochinke, 2013). The strategies performed by other people highlight the adjustment of health care services at the organizational level or at higher levels (no longer at the individual level) (Wang et al. 2012; Clare et al., 2008; Ericsson et al., 2013).

Six “outer conditions related to physical aspects” were identified: “time of day” (Brorsson et al., 2011), “background sounds/stress of noises” (Brorsson et al., 2013; Hung et al., 2017), “changing living home” (Cronfalk et al., 2017), “private spaces” (Genoe, 2009; Genoe & Dupuis, 2011), “building design” (Hadjri et al., 2015; Hung et al., 2017; Lawrence et al., 2011) and “technologies” (Brittain et al., 2010; Brorsson et al., 2011; Groenewoud et al., 2017; Manera et al., 2016; Nijhof et al., 2013). Various contexts

and settings are considered, ranging from living at home to transitioning between home care and a nursing home. Several external strategies refer to activities of others that are intended to create a good environment for people living with dementia. In a quantitative study conducted by Manera et al. (2016), a self-reported questionnaire was used to measure feelings of safety. People with mild cognitive impairment and dementia were asked how they experienced a cognitive training session using paper and virtual reality conditions (10-cm analog scale ranging from “not at all” to “extremely”). Under both conditions, the participants reported high feelings of safety (mean = 9.4/9.7, standard deviation = 1.3/1.1).

In five studies, the inner and outer conditions of emotional safety were described as interrelated. For example, access to help (social-related outer condition) is relevant to the emotional safety of people living with dementia, but it is also important that the individual be willing to receive support (psychological-related inner condition) (Panke-Kochinke, 2013). Brorsson et al. (2013) reported that in the context of crossing roads, emotional safety in people living with dementia depends not only on the assurance that others care for them (psychological-related inner conditions) but also on existing background noise (physical-related outer condition). Despite the fact that emotional safety in such situations depends on the perception of the person living with dementia, these situations can objectively represent an increased risk of a decreased feeling of safety.

Emotional safety as a condition for people living with dementia

Emotional safety as a condition that improves the situations of people living with dementia was reported in eight studies; five of these studies involved people living with dementia, two involved people living with dementia and other proxies and one involved healthcare providers. The studies showed that emotional safety can improve psychosocial health and sociocultural well-being (Brataas et al., 2010; Hansen et al., 2017), improve everyday situations, e.g. orientation in public spaces (Brorsson et al., 2011, 2013), and enable people living with dementia to establish relationships with other people (e.g. caregivers) (Ericsson et al., 2013; Panke-Kochinke, 2013). Feeling safe allows people living with dementia to form relationships, perceive the support provided as good and develop themselves (Panke-Kochinke, 2013). From the caregiver’s perspective, a feeling of safety can also facilitate care in daily activities (e.g. bathing) (Hansen et al., 2017). In contrast, feeling unsafe can promote difficulties in orientation (Brorsson et al., 2011, 2013), increase anxiety (Hung et al., 2017; Panke-Kochinke, 2013) and negatively affect (disease) coping situations (e.g. activating one’s own resources) (Hung et al., 2017; Osborne et al., 2010; Panke-Kochinke, 2013).

Discussion

The present systematic review, which includes 27 eligible publications ($n = 26$ studies), is the first review to address the emotional safety of people living with dementia. The

perspective of people living with dementia is well represented overall in the analyzed studies. Emotional safety as a phenomenon, including the core dimensions of psychological, economic, social and physical safety, appears to be a primary psychological need; namely, it seems to be related to relationship building and well-being. We saw that disease-related, biographical, demographic and socioeconomic factors, as well as inner and outer conditions, have an impact on feelings of safety. Inner conditions related to psychological aspects and outer conditions related to social aspects were more strongly represented than inner conditions related to economic aspects and outer conditions related to physical aspects. Inner and outer conditions seem to be closely related and situational. The use of appropriate strategies can strengthen emotional safety.

Findings in the context of theoretical frameworks and other studies

In the light of the existing theories in the context of “inner security” (Panke-Kochinke, 2013, 2014, 2016) and “person-centeredness” (Kitwood, 1993a, 1993b, 1997), the perspective of people living with dementia was included in several of our identified studies. This perspective is mentioned as being highly important to improve the current understanding of the perspective of people living with dementia (Fazio et al., 2018; Kitwood, 1997) and should be included in research (von Kutzleben et al., 2012).

None of the identified studies address emotional safety as a primary focus of the study. This finding is surprising because several studies have reported that emotional safety is a primary psychological need and that people living with dementia represent a vulnerable group that is susceptible to a reduced feeling of safety (Bossen et al., 2006; Zingmark et al., 2002).

In the context of disease-related factors, our review showed that the emotional safety of people living with dementia can be decreased due to a loss of orientation. Steeman et al. (2006, p. 732) showed that people with early-stage dementia often feel insecure because of the “incomprehensibility and unpredictability of their disease” and the changes associated with it. Based on a dementia-specific “model of inner security”, Panke-Kochinke (2014) reports that living in relationships, existing skills and knowing one’s self are central. In contrast, among people with multiple sclerosis, “inner security” is related to energy balance and survival. Based on Panke-Kochinke’s results, the course of the disease can affect emotional safety. This finding is confirmed by another study showing changes in the need for safety among people living with dementia (Karlsson et al., 2011). Despite the increased risk, people living with dementia can also feel safe with their illness and its consequences (Mazaheri et al., 2014). This finding can be analyzed in more detail by referring to theoretical works, including the chronic illnesses trajectory model (Corbin & Strauss, 1991). The “model of inner security” postulates that individuals determine what is best for them by achieving a balance between the need for “security”, the degree of

support that provides feelings of safety, and feelings of fear related to external control (Panke-Kochinke, 2014).

Biographical, demographic and socioeconomic factors appear to be relevant to perceived emotional safety. Other authors recommend a holistic view of one’s life story (Grøndahl et al., 2017; Scholl et al., 2014). However, supporting evidence is lacking (Grøndahl et al., 2017). Kitwood (1993b, p. 56) described past experiences in the context of interpersonal communication and personality as “a unique cluster of personal resources and psychic defences, formed in situations where the individual has had a sense of power and competence, or of impotence and threat”.

The dimensions of the inner and outer conditions are closely interrelated and must be described in their specific context. However, these associations are not described in detail in the identified studies. In addition, the results show that many conditions are present in an interactive context according to the dimensions of the individual’s psychologically related and economically related inner conditions and his or her socially related outer conditions. In the present study, emotional safety was reported in terms of the attachment style theory (Osborne et al., 2010). Another study proposed that promoting a good life for people living with dementia is a relationship-centered task (Zingmark et al., 2002). In the context of the models of “inner security” and “person-centered” dementia care, maintaining relationships is a central component (Kitwood, 1993b; Panke-Kochinke, 2013). Our identified conditions might facilitate or inhibit maintaining a balance of “inner security”. However, notably, the terminology used differs across these studies (e.g. “feeling safe”, “inner security” and “sense of safety”).

The studies identified in our review reported only a few strategies for feeling safe that are performed by people living with dementia. Some strategies are related to avoidance behavior. Situations, places or people that could restrict the feeling of safety are avoided by people living with dementia. This withdrawal behavior is considered particularly problematic (Harris, 2006; Zingmark et al., 2002). Kitwood and Bredin (1992, p. 284) described this withdrawal as “terminal apathy and despair” caused by the loss of self-esteem and social confidence. Furthermore, maintaining routines helps people living with dementia feel safe (Yatczak, 2014). Panke-Kochinke (2016) argues that in the context of coping with disease, maintaining self-performed routines with the support of an accepting partner can have positive effects on “inner security”.

Implications for dementia research and health care

To improve participation and develop a comprehensive concept of emotional safety, it is important in dementia research and health care to consider the perspective of people living with dementia. Nevertheless, other perspectives also offer added value in understanding the complex factors that underlie emotional safety, especially in regard to outer conditions and strategies.

As emotional safety is reported to be a primary need of people living with dementia, it is important to consider this concept in person-centered health care. According to

Hansen et al. (2017), the clarification of the concept of psychosocial needs (e.g. feeling safe) and a discussion of who should be responsible for meeting these needs and how these needs can be met, should be areas of focus. In addition, further research and health care should take into account the fact that dementia-related factors have an impact on emotional safety. Based on the described changes in safety needs during the course of the disease, personal factors and inner and outer conditions influencing emotional safety, we agree that a dementia-specific view of emotional safety is needed.

In developing patient-centered practices that focus on the needs of people living with dementia, critical attention should be paid to self-reported strategies as well as the strategies used by others. Strengthening the feeling of safety seems to help people living with dementia build relationships and perceive support positively. In this way, it may be possible to improve the care situation for both people living with dementia and their caregivers.

Limitations

A comprehensive search was conducted using multiple databases to provide an interdisciplinary approach and to present a broad spectrum of the specialist literature. By limiting the search period, current available knowledge was predominantly identified and analyzed. However, there is a risk that some relevant publications were not included due to the publication date restrictions.

An inductive approach was a high priority in the data syntheses. However, a working definition of “emotional safety” was used as a deductive starting point and as an orientation to the phenomenon of emotional safety. The identified data seem insufficient for the development of a comprehensive definition. More evidence is needed. A quantitative data synthesis could not be conducted due to the small number of identified quantitative studies. In addition, we observed that emotional safety was not the primary focus of the studies. Therefore, it is conceivable that studies that do not explicitly mention emotional safety in the title or abstract but do include these components in the results were not identified. However, due to our additional approaches to expanding sensitivity, the risk of missed studies seems to be low.

Conclusion

People living with dementia appear to be particularly vulnerable to decreased emotional safety, indicating the need to strengthen their emotional safety in everyday life. Emotional safety is a primary psychological need of people living with dementia and is influenced by disease-related, biographical, demographic and socioeconomic factors. In addition, inner and outer conditions, strategies as well as specific health outcomes seem to be associated with emotional safety. It can be assumed that inner and outer conditions are involved in the creation of a suitable environment for different strategies to enhance emotional safety. Due to the small number of studies, recommendations for practice have been carefully deduced.

In practice, critical attention should be paid to the need for, the conditions surrounding and the (self-reported) strategies used to achieve emotional safety in the context of dementia. Theories and models that frame emotional safety can provide a helpful orientation in health care and research. Further research should focus on obtaining a comprehensive picture of the emotional safety needs of people living with dementia to enable person-centered strategies.

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Disclosure statement

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Appendix A

1. Search strategy for MEDLINE (via PubMed)

Research period: 01 November 2007 to 31 October 2017

Date of research: 02 November 2017

Step of search	Hits	Search terms
1	214,405	"dementia" [Mesh Terms] OR dementia[Title/Abstract] OR demen*[Title/Abstract] OR dementias[Title/Abstract] OR demented[Title/Abstract] OR alzheimer[Title/Abstract] OR alzheimer's[Title/Abstract] OR alzheimers[Title/Abstract] OR alzheimer*[Title/Abstract] OR pwd[Title/Abstract] OR lewy-body-dementia[Title/Abstract] OR "lewy-body disease"[Title/Abstract] OR "lewy body disease"[Title/Abstract] OR "binswanger disease"[Title/Abstract]

(continued)

Continued.

Step of search	Hits	Search terms
2	1,257,625	"safety" [Mesh Terms] OR "patient harm" [Mesh Terms] OR "patient safety" [Mesh Terms] OR "safety management"[Mesh Terms] OR "risk management" [Mesh Terms] OR safe[Title/Abstract] OR safe*[Title/Abstract] OR safeties[Title/Abstract] OR safety[Title/Abstract] OR secure[Title/Abstract] OR secure*[Title/Abstract] OR secureness[Title/Abstract] OR safeness[Title/Abstract] OR harm[Title/Abstract] OR harms[Title/Abstract] OR threatened[Title/Abstract] OR threats[Title/Abstract] OR threat[Title/Abstract] OR threat*[Title/Abstract] OR threateningly[Title/Abstract] OR threatens[Title/Abstract] OR threatenful[Title/Abstract] OR uncertain*[Title/Abstract] OR uncertain[Title/Abstract] OR uncertainty[Title/Abstract] OR unsure[Title/Abstract] OR insecure[Title/Abstract] OR unsafe[Title/Abstract]
3	1,357,497	"emotions" [Mesh Terms] OR emotions[Title/Abstract] OR emotion[Title/Abstract] OR emotion*[Title/Abstract] OR feeling[Title/Abstract] OR feelings[Title/Abstract] OR feel[Title/Abstract] OR feel*[Title/Abstract] OR emotional[Title/Abstract] OR socio-emotional[Title/Abstract] OR psychological[Title/Abstract] OR psychosocial[Title/Abstract] OR psychical[Title/Abstract] OR experience[Title/Abstract] OR experienced[Title/Abstract] OR experiences[Title/Abstract]
4	968,267	needs[Title/Abstract] OR need[Title/Abstract] OR desire[Title/Abstract] OR desires[Title/Abstract] OR wish[Title/Abstract] OR wishes[Title/Abstract]
5	341,648	"living well"[Title/Abstract] OR "live well"[Title/Abstract] OR "meaningful lives"[Title/Abstract] OR "meaningful life"[Title/Abstract] OR "good life"[Title/Abstract] OR ("give meaning"[Title/Abstract] AND life[Title/Abstract]) OR "quality of life"[Title/Abstract] OR "life quality"[Title/Abstract] OR "health-related quality of life"[Title/Abstract] OR "health related quality of life"[Title/Abstract] OR "quality of life" [Mesh Terms] OR "HRQoL"[Title/Abstract] OR "QoL"[Title/Abstract] OR well-being[Title/Abstract] OR wellbeing[Title/Abstract] OR (human[Title/Abstract] AND living[Title/Abstract])
6	1547	#1 AND #2 AND #3
7	2841	#1 AND #4 AND #3
8	732	#1 AND #2 AND #5
9	1381	#1 AND #4 AND #5
10	5221	#6 OR #7 OR #8 OR #9
11	1254	#1 AND #2 AND #4
12	2440	#1 AND #3 AND #5
13	3611	#11 OR #12
14	6435	(#10 OR #13) AND medline[<i>sb</i>]
15	3870	(#10 OR #13) AND medline[<i>sb</i>] AND ("2007/11/01"[<i>PDAT</i>]: "2017/10/31"[<i>PDAT</i>]))

2. Search strategy "security" for MEDLINE (via PubMed)

Research period: 01 November 2007–31 October 2017

Date of research: 26 January 2018

Step of search	Hits	Search terms
1	218,062	"dementia" [Mesh Terms] OR dementia[Title/Abstract] OR demen*[Title/Abstract] OR dementias[Title/Abstract] OR demented[Title/Abstract] OR alzheimer[Title/Abstract] OR alzheimer's[Title/Abstract] OR alzheimers[Title/Abstract] OR alzheimer*[Title/Abstract] OR pwd[Title/Abstract] OR lewy-body-dementia[Title/Abstract] OR "lewy-body disease"[Title/Abstract] OR "lewy body disease"[Title/Abstract] OR "binswanger disease"[Title/Abstract]
2	48,903	insecurity[Title/Abstract] OR security[Title/Abstract] OR securi*[Title/Abstract] OR insecure*[Title/Abstract]
3	1,378,008	"emotions" [Mesh Terms] OR emotions[Title/Abstract] OR emotion[Title/Abstract] OR emotion*[Title/Abstract] OR feeling[Title/Abstract] OR feelings[Title/Abstract] OR feel[Title/Abstract] OR feel*[Title/Abstract] OR emotional[Title/Abstract] OR socio-emotional[Title/Abstract]

(continued)

Continued.

Step of search	Hits	Search terms
		Abstract] OR psychological[Title/Abstract] OR psychosocial[Title/Abstract] OR psychical[Title/Abstract] OR experience[Title/Abstract] OR experienced[Title/Abstract] OR experiences[Title/Abstract]
4	985,297	needs[Title/Abstract] OR need[Title/Abstract] OR desire[Title/Abstract] OR desires[Title/Abstract] OR wish[Title/Abstract] OR wishes[Title/Abstract]
5	348,791	"living well"[Title/Abstract] OR "live well"[Title/Abstract] OR "meaningful lives"[Title/Abstract] OR "meaningful life"[Title/Abstract] OR "good life"[Title/Abstract] OR ("give meaning"[Title/Abstract] AND life[Title/Abstract]) OR "quality of life"[Title/Abstract] OR "life quality"[Title/Abstract] OR "health-related quality of life"[Title/Abstract] OR "health related quality of life"[Title/Abstract] OR "quality of life" [Mesh Terms] OR "HRQoL"[Title/Abstract] OR "QoL"[Title/Abstract] OR well-being[Title/Abstract] OR wellbeing[Title/Abstract] OR (human[Title/Abstract] AND living[Title/Abstract])
6	83	#1 AND #2 AND #3
7	38	#1 AND #2 AND #5
8	98	#6 OR #7
9	73	#1 AND #2 AND #4
10	114	(#8 OR #9) AND medline[sb]
11	75	(#8 OR #9) AND medline[sb] AND ("2007/11/01"[PDAT]: "2017/10/31"[PDAT])

3. Search strategy for EMBASE (via Scopus)

Research period: 2007–2017

Date of research: 02 November 2017

Step of search	Hits	Search terms
1	71,755	TITLE-ABS (dementia OR demen* OR dementias OR demented OR alzheimer OR alzheimers OR alzheimer* OR pwd OR "lewy-body-dementia" OR "lewy body disease" OR "lewy-body disease" OR "binswanger disease") AND NOT INDEX(medline)
2	1,733,027	TITLE-ABS (safe OR safe* OR safeties OR safety OR secure OR secure* OR secureness OR safeness OR harm OR harms OR threatened OR threats OR threat OR threateningly OR threatens OR threatful OR threat* OR uncertain OR uncertain* OR uncertainty OR unsure OR insecure OR unsafe) AND NOT INDEX(medline)
3	1,587,762	TITLE-ABS (emotion* OR emotion OR emotions OR feeling OR feelings OR feel OR feel* OR emotional OR socio-emotional OR psychological OR psychosocial OR psychical OR experience OR experienced OR experiences) AND NOT INDEX(medline)
4	1,842,543	TITLE-ABS (needs OR need OR desire OR desires OR wish OR wishes) AND NOT INDEX(medline)
5	212,159	TITLE-ABS ("living well" OR "live well" OR "meaningful lives" OR "meaningful life" OR "good life" OR ("give meaning" AND life) OR "quality of life" OR "life quality" OR "health-related quality of life" OR "health related quality of life" OR HRQoL OR QoL OR well-being OR wellbeing OR (human AND living)) AND NOT INDEX(medline)
6	562	#1 AND #2 AND #3
7	1479	#1 AND #4 AND #3
8	312	#1 AND #2 AND #5
9	682	#1 AND #4 AND #5
10	2433	6 OR 7 OR 8 OR 9
11	546	#1 AND #2 AND #4
12	1106	#1 AND #3 AND #5
13	1606	#11 OR #12
14	2571	#10 OR #13 (LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007)

4. Search strategy "security" for EMBASE (via Scopus)

Research period: 2007–2017

Date of research: 26 January 2018

Step of search	Hits	Search terms
1	73,203	TITLE-ABS (dementia OR demen* OR dementias OR demented OR alzheimer OR alzheimers OR alzheimer* OR pwd OR "lewy-body-dementia" OR "lewy body disease" OR "lewy-body disease" OR "binswanger disease") AND NOT INDEX(medline)
2	482,930	TITLE-ABS (security OR insecurity OR secure* OR securi*) AND NOT INDEX(medline)
3	1,617,616	TITLE-ABS (emotion* OR emotion OR emotions OR feeling OR feelings OR feel OR feel* OR emotional OR socio-emotional OR psychological OR psychosocial OR psychical OR experience OR experienced OR experiences) AND NOT INDEX(medline)
4	1,878,690	TITLE-ABS (needs OR need OR desire OR desires OR wish OR wishes) AND NOT INDEX(medline)
5	217,186	TITLE-ABS ("living well" OR "live well" OR "meaningful lives" OR "meaningful life" OR "good life" OR ("give meaning" AND life) OR "quality of life" OR "life quality" OR "health-related quality of life" OR "health related quality of life" OR HRQoL OR QoL OR well-being OR wellbeing OR (human AND living)) AND NOT INDEX(medline)
6	82	#1 AND #2 AND #3
7	44	#1 AND #2 AND #5
8	71	#1 AND #2 AND #4
9	143	#6 OR #7 OR #8
10	104	#9 (LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007)

5. Search strategy for CINAHL Plus (via EBSCOhost)

Research period: 01 November 2007–31 October 2017

Date of research: 02 November 2017

Step of search	Hits	Search terms
1	67,339	(MH "Dementia+") OR TI dementia OR AB dementia OR TI demen* OR AB demen* OR TI dementias OR AB dementias OR TI demented OR AB demented OR TI alzheimer OR AB alzheimer OR TI alzheimer's OR AB alzheimer's OR TI alzheimers OR AB alzheimers OR TI alzheimer* OR AB alzheimer* OR TI pwd OR AB pwd OR TI "lewy-body-dementia" OR AB "lewy-body-dementia" OR TI "lewy body disease" OR AB "lewy body disease" OR TI "lewy-body disease" OR AB "lewy-body disease" OR TI "binswanger disease" OR AB "binswanger disease"
2	355,762	(MH "Safety+") OR (MH "Patient Safety+") OR (MH "Risk Management+") OR TI safe OR AB safe OR TI safe* OR AB safe* OR TI safeties OR AB safeties OR TI safety OR AB safety OR TI secure OR AB secure OR TI secure* OR AB secure* OR TI secureness OR AB secureness OR TI safeness OR AB safeness OR TI harm OR AB harm OR TI harms OR AB harms OR TI threatened OR AB threatened OR TI threats OR AB threats OR TI threat OR AB threat OR TI threateningly OR AB threateningly OR TI threatens OR AB threatens OR TI threatful OR AB threatful OR TI threat* OR AB threat* OR TI uncertain OR AB uncertain OR TI uncertain* OR AB uncertain* OR TI uncertainty OR AB uncertainty OR TI unsure OR AB unsure OR TI insecure OR AB insecure OR TI unsafe OR AB unsafe
3	454,077	(MH "Emotions+") OR TI emotion* OR AB emotion* OR TI emotion OR AB emotion OR TI emotions OR AB emotions OR TI feeling OR AB feeling OR TI feelings OR AB feelings OR TI feel OR AB feel OR TI feel* OR AB feel* OR TI emotional OR AB emotional OR TI socio-emotional OR AB socio-emotional OR TI

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Continued.

Step of search	Hits	Search terms
		psychological OR AB psychological OR TI psychosocial OR AB psychosocial OR TI psychical OR AB psychical OR TI experience OR AB experience OR TI experienced OR AB experienced OR TI experiences OR AB experiences
4	305,667	TI needs OR AB needs OR TI need OR AB need OR TI desire OR AB desire OR TI desires OR AB desires OR TI wish OR AB wish OR TI wishes OR AB wishes
5	151,193	(MH "Quality of Life+") OR TI "living well" OR AB "living well" OR TI "live well" OR AB "live well" OR TI "meaningful lives" OR AB "meaningful lives" OR TI "meaningful life" OR AB "meaningful life" OR TI "good life" OR AB "good life" OR ((TI "give meaning" OR AB "give meaning") AND (TI life OR AB life)) OR TI "quality of life" OR AB "quality of life" OR TI "life quality" OR AB "life quality" OR TI "health-related quality of life" OR AB "health-related quality of life" OR TI "health related quality of life" OR AB "health related quality of life" OR TI HRQoL OR AB HRQoL OR TI QoL OR AB QoL OR TI well-being OR AB well-being OR TI wellbeing OR AB wellbeing OR ((TI human OR AB human) AND (TI living OR AB living))
6	716	S1 AND S2 AND S3
7	1820	S1 AND S4 AND S3
8	363	S1 AND S2 AND S5
9	832	S1 AND S4 AND S5
10	2964	S6 OR S7 OR S8 OR S9
11	589	S1 AND S2 AND S4
12	1512	S1 AND S3 AND S5
13	2055	S11 OR S12
14	1797	S10 OR S13 (Limiters: Excluded Medline Records)
15	1256	S14 (Limiters: Exclude Medline Records AND Published Date: 20071101-20171031)

6. Search strategy "security" for CINAHL Plus (via EBSCOhost)
 Research period: 01 November 2007–31 October 2017
 Date of research: 26 January 2018

Step of search	Hits	Search terms
1	68,334	(MH "Dementia+") OR TI dementia OR AB dementia OR TI demen* OR AB demen* OR TI dementias OR AB dementias OR TI demented OR AB demented OR TI alzheimer OR AB alzheimer OR TI alzheimer's OR AB alzheimer's OR TI alzheimers OR AB alzheimers OR TI alzheimer* OR AB alzheimer* OR TI pwd OR AB pwd OR TI "lewy-body-dementia" OR AB "lewy-body-dementia" OR TI "lewy body disease" OR AB "lewy body disease" OR TI "lewy-body disease" OR AB "lewy-body disease" OR TI "binswanger disease" OR AB "binswanger disease"
2	15,083	TI insecurity OR AB insecurity OR TI security OR AB security OR TI securi* OR AB securi* OR TI insecuri* OR AB insecuri*
3	463,548	(MH "Emotions+") OR TI emotion* OR AB emotion* OR TI emotion OR AB emotion OR TI emotions OR AB emotions OR TI feeling OR AB feeling OR TI feelings OR AB feelings OR TI feel OR AB feel OR TI feel* OR AB feel* OR TI emotional OR AB emotional OR TI socio-emotional OR AB socio-emotional OR TI psychological OR AB psychological OR TI psychosocial OR AB psychosocial OR TI psychical OR AB psychical OR TI experience OR AB experience OR TI experienced OR AB experienced OR TI experiences OR AB experiences
4	313,110	TI needs OR AB needs OR TI need OR AB need OR TI desire OR AB desire OR TI desires OR AB desires OR TI wish OR AB wish OR TI wishes OR AB wishes
5	154,068	(MH "Quality of Life+") OR TI "living well" OR AB "living well" OR TI "live well" OR AB "live well" OR TI

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Continued.

Step of search	Hits	Search terms
		"meaningful lives" OR AB "meaningful lives" OR TI "meaningful life" OR AB "meaningful life" OR TI "good life" OR AB "good life" OR ((TI "give meaning" OR AB "give meaning") AND (TI life OR AB life)) OR TI "quality of life" OR AB "quality of life" OR TI "life quality" OR AB "life quality" OR TI "health-related quality of life" OR AB "health-related quality of life" OR TI "health related quality of life" OR AB "health related quality of life" OR TI HRQoL OR AB HRQoL OR TI QoL OR AB QoL OR TI well-being OR AB well-being OR TI wellbeing OR AB wellbeing OR ((TI human OR AB human) AND (TI living OR AB living))
6	34	S1 AND S2 AND S3
7	13	S1 AND S2 AND S5
8	41	S6 OR S7
9	33	S1 AND S2 AND S4
10	1797	S8 OR S9 (Limiters: Excluded Medline Records)
11	22	S10 (Limiters: Exclude Medline Records AND Published Date: 20071101-20171031)

7. Search strategy for PsycINFO & PSYINDEX (via EBSCOhost)
 Research period: November 2007 to October 2017
 Date of research: 02 November 2017

Step of search	Hits	Search terms
1	94,233	DE "Dementia" OR DE "Dementia with Lewy Bodies" OR TI dementia OR AB dementia OR TI demen* OR AB demen* OR TI dementias OR AB dementias OR TI demented OR AB demented OR TI alzheimer OR AB alzheimer OR TI alzheimer's OR AB alzheimer's OR TI alzheimers OR AB alzheimers OR TI alzheimer* OR AB alzheimer* OR TI pwd OR AB pwd OR TI "lewy-body-dementia" OR AB "lewy-body-dementia" OR TI "lewy body disease" OR AB "lewy body disease" OR TI "lewy-body disease" OR AB "lewy-body disease" OR TI "binswanger disease" OR AB "binswanger disease"
2	227,078	DE "Safety" OR DE "Patient Safety" OR DE "Risk Management" OR TI safe OR AB safe OR TI safe* OR AB safe* OR TI safeties OR AB safeties OR TI safety OR AB safety OR TI secure OR AB secure OR TI secure* OR AB secure* OR TI secureness OR AB secureness OR TI safeness OR AB safeness OR TI harm OR AB harm OR TI harms OR AB harms OR TI threatened OR AB threatened OR TI threats OR AB threats OR TI threat OR AB threat OR TI threateningly OR AB threateningly OR TI threatens OR AB threatens OR TI threatful OR AB threatful OR TI threat* OR AB threat* OR TI uncertain OR AB uncertain OR TI uncertain* OR AB uncertain* OR TI uncertainty OR AB uncertainty OR TI unsure OR AB unsure OR TI insecure OR AB insecure OR TI unsafe OR AB unsafe
3	1,144,032	DE "Emotions" OR TI emotion* OR AB emotion* OR TI emotion OR AB emotion OR TI emotions OR AB emotions OR TI feeling OR AB feeling OR TI feelings OR AB feelings OR TI feel OR AB feel OR TI feel* OR AB feel* OR TI emotional OR AB emotional OR TI socio-emotional OR AB socio-emotional OR TI psychological OR AB psychological OR TI psychosocial OR AB psychosocial OR TI psychical OR AB psychical OR TI experience OR AB experience OR TI experienced OR AB experienced OR TI experiences OR AB experiences
4	458,200	TI needs OR AB needs OR TI need OR AB need OR TI desire OR AB desire OR TI desires OR AB desires OR TI wish OR AB wish OR TI wishes OR AB wishes
5	149,870	(DE "Quality of Life") OR TI "living well" OR AB "living well" OR TI "live well" OR AB "live well" OR TI "meaningful lives" OR AB "meaningful lives" OR TI "meaningful life" OR AB "meaningful life" OR TI "good life" OR AB "good life" OR ((TI "give meaning" OR AB

(continued)

Continued.

Step of search	Hits	Search terms
		"give meaning") AND (TI life OR AB life)) OR TI "quality of life" OR AB "quality of life" OR TI "life quality" OR AB "life quality" OR TI "health-related quality of life" OR AB "health-related quality of life" OR TI "health related quality of life" OR AB "health related quality of life" OR TI HRQoL OR AB HRQoL OR TI QoL AB QoL OR TI well-being OR AB well-being OR TI wellbeing OR AB wellbeing OR ((TI human OR AB human) AND (TI living OR AB living))
6	908	S1 AND S2 AND S3
7	2367	S1 AND S4 AND S3
8	335	S1 AND S2 AND S5
9	988	S1 AND S4 AND S5
10	3753	S6 OR S7 OR S8 OR S9
11	622	S1 AND S2 AND S4
12	1933	S1 AND S3 AND S5
13	2514	S11 OR S12
14	3453	S10 OR S13 AND (Published Date: November 2007–October 2017)

8. Search strategy "security" for PsycINFO & PSYINDEX (via EBSCOhost)

Research period: November 2007 to October 2017

Date of research: 26 January 2018

Step of search	Hits	Search terms
1	95,582	DE "Dementia" OR DE "Dementia with Lewy Bodies" OR TI dementia OR AB dementia OR TI demen* OR AB demen* OR TI dementias OR AB dementias OR TI demented OR AB demented OR TI alzheimer OR AB alzheimer OR TI alzheimer's OR AB alzheimer's OR TI alzheimers OR AB alzheimers OR TI alzheimer* OR AB alzheimer* OR TI pwd OR AB pwd OR TI "lewy-body-dementia" OR AB "lewy-body-dementia" OR TI "lewy body disease" OR AB "lewy body disease" OR TI "lewy-body disease" OR AB "lewy-body disease" OR TI "binswanger disease" OR AB "binswanger disease"
2	34,119	TI insecurity OR AB insecurity OR TI security OR AB security OR TI securi* OR AB securi* OR TI insecurity* OR AB insecurity*
3	1,159,720	DE "Emotions" OR TI emotion* OR AB emotion* OR TI emotion OR AB emotion OR TI emotions OR AB emotions OR TI feeling OR AB feeling OR TI feelings OR AB feelings OR TI feel OR AB feel OR TI feel* OR AB feel* OR TI emotional OR AB emotional OR TI socio-emotional OR AB socio-emotional OR TI psychological OR AB psychological OR TI psychosocial OR AB psychosocial OR TI psychical OR AB psychical OR TI experience OR AB experience OR TI experienced OR AB experienced OR TI experiences OR AB experiences
4	465,563	TI needs OR AB needs OR TI need OR AB need OR TI desire OR AB desire OR TI desires OR AB desires OR TI wish OR AB wish OR TI wishes OR AB wishes
5	153,131	(DE "Quality of Life") OR TI "living well" OR AB "living well" OR TI "live well" OR AB "live well" OR TI "meaningful lives" OR AB "meaningful lives" OR TI "meaningful life" OR AB "meaningful life" OR TI "good life" OR AB "good life" OR ((TI "give meaning" OR AB "give meaning") AND (TI life OR AB life)) OR TI "quality of life" OR AB "quality of life" OR TI "life quality" OR AB "life quality" OR TI "health-related quality of life" OR AB "health-related quality of life" OR TI "health related quality of life" OR AB "health related quality of life" OR TI HRQoL OR AB HRQoL OR TI QoL AB QoL OR TI well-being OR AB well-being OR TI wellbeing OR AB wellbeing OR ((TI human OR AB human) AND (TI living OR AB living))
6	80	S1 AND S2 AND S3
7	31	S1 AND S2 AND S5
8	94	S6 OR S7
9	51	S1 AND S2 AND S4

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Continued.

Step of search	Hits	Search terms
10	111	S8 OR S9
11	65	S10 AND (Published Date: November 2007 – October 2017)

9. Search strategy for the Cochrane Library

Research period: November 2007 to October 2017

Date of research: 2 November 2017

Step of search	Hits	Search terms
1	12,566	[mh dementia] OR ("dementia" OR demen* OR "dementias" OR "demented" OR "alzheimer" OR "alzheimer's" OR "alzheimers" OR "alzheimer*" OR "pwd" OR "lewy-body-dementia" OR "lewy body disease" OR "lewy-body disease" OR "binswanger disease");ti,ab
2	150,557	[mh safety] OR [mh "safety management"] OR [mh "patient harm"] OR [mh "patient safety"] OR [mh "risk management"] OR ("safe" OR safe OR "safeties" OR "safety" OR "secure" OR secure OR "secureness" OR "safeness" OR "harm" OR "harms" OR "threatened" OR "threats" OR "threat" OR "threateningly" OR "threatens" OR "threatful" OR threat OR "uncertain" OR uncertain OR "uncertainty" OR "unsure" OR "insecure" OR "unsafe");ti,ab
3	103,023	[mh emotions] OR (emotion OR "emotion" OR "emotions" OR "feeling" OR "feelings" OR "feel" OR feel OR "emotional" OR "socio-emotional" OR "psychological" OR "psychosocial" OR "psychical" OR "experience" OR "experienced" OR "experiences");ti,ab
4	52,186	("needs" OR "need" OR "desire" OR "desires" OR "wish" OR "wishes");ti,ab
5	58,206	[mh "Quality of Life"] OR ("living well" OR "live well" OR "meaningful lives" OR "meaningful life" OR "good life" OR ("give meaning" AND "life") OR "quality of life" OR "life quality" OR "health-related quality of life" OR "health related quality of life" OR "HRQoL" OR "QoL" OR "well-being" OR "wellbeing" OR ("human" AND "living"));ti,ab
6	278	#1 AND #2 AND #3
7	249	#1 AND #4 AND #3
8	202	#1 AND #2 AND #5
9	197	#1 AND #4 AND #5
10	720	#6 OR #7 OR #8 OR #9
11	143	#1 AND #2 AND #4
12	459	#1 AND #3 AND #5
13	593	#11 OR #12
14	68	#10 OR #13 (Published Date: November 2007 – October 2017)

10. Search strategy "security" for the Cochrane Library

Research period: November 2007 to October 2017

Date of research: 26 January 2018

Step of search	Hits	Search terms
1	12,705	[mh dementia] OR ("dementia" OR demen* OR "dementias" OR "demented" OR "alzheimer" OR "alzheimer's" OR "alzheimers" OR "alzheimer*" OR "pwd" OR "lewy-body-dementia" OR "lewy body disease" OR "lewy-body disease" OR "binswanger disease");ti,ab
2	2595	("insecurity" OR "security" OR "secure*" OR "insecuri*");ti,ab
3	104,689	[mh emotions] OR (emotion OR "emotion" OR "emotions" OR "feeling" OR "feelings" OR "feel" OR feel OR "emotional" OR "socio-emotional" OR "psychological" OR "psychosocial" OR "psychical" OR "experience" OR "experienced" OR "experiences");ti,ab
4	53,105	("needs" OR "need" OR "desire" OR "desires" OR "wish" OR "wishes");ti,ab
5	59,519	[mh "Quality of Life"] OR ("living well" OR "live well" OR "meaningful lives" OR "meaningful life" OR "good life" OR ("give meaning" AND "life") OR "quality of life" OR "life quality" OR "health-related quality of life" OR

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Continued.

Step of search	Hits	Search terms
		"health related quality of life" OR "HRQoL" OR "QoL" OR "well-being" OR "wellbeing" OR ("human" AND "living"):ti,ab
6	4	#1 AND #2 AND #3
7	4	#1 AND #2 AND #5
8	6	#6 OR #7
9	3	#1 AND #2 AND #4
10	6	#8 OR #9
11	4	#10 (Published Date: November 2007 – October 2017)

11. Search strategy for Journals@Ovid (via Ovid)

Research period: Entry date last 10 years

Date of research: 2 November 2017

Step of search	Hits	Search terms
1	62,274	(dementia OR demen* OR dementias OR demented OR alzheimer OR alzheimers OR alzheimer* OR pwd OR lewy-body-dementia OR lewy body disease OR lewy-body disease OR binswanger disease).ti,ab.
2	328,735	(safe OR safe* OR safeties OR safety OR secure OR secure* OR secureness OR safeness OR harm OR harms OR threatened OR threats OR threat OR threateningly OR threatens OR threatful OR threat* OR uncertain OR uncertain* OR uncertainty OR unsure OR insecure OR unsafe).ti,ab.
3	583,167	(emotion* OR emotion OR emotions OR feeling OR feelings OR feel OR feel* OR emotional OR socio-emotional OR psychological OR psychosocial OR psychical OR experience OR experienced OR experiences).ti,ab.
4	283,606	(needs OR need OR desire OR desires OR wish OR wishes).ti,ab.
5	556,441	(live well OR well-being OR wellbeing OR (human AND living)).ti,ab.
6	405	1 AND 2 AND 3
7	914	1 AND 4 AND 3
8	563	1 AND 2 AND 5
9	712	1 AND 4 AND 5
10	2099	6 OR 7 OR 8 OR 9
11	327	1 AND 2 AND 4
12	1130	1 AND 3 AND 5
13	1418	11 OR 12
14	2052	10 OR 13 (limit last 10 years)

12. Search strategy "security" for Journals@Ovid (via Ovid)

Research period: Entry date last 10 years

Date of research: 26 January 2018

Step of search	Hits	Search terms
1	64,294	(dementia OR demen* OR dementias OR demented OR alzheimer OR alzheimers OR alzheimer* OR pwd OR lewy-body-dementia OR lewy body disease OR lewy-body disease OR binswanger disease).ti,ab.
2	17,984	(security OR insecurity OR secure* OR insecure*).ti,ab.
3	591,986	(emotion* OR emotion OR emotions OR feeling OR feelings OR feel OR feel* OR emotional OR socio-emotional OR psychological OR psychosocial OR psychical OR experience OR experienced OR experiences).ti,ab.
4	288,944	(needs OR need OR desire OR desires OR wish OR wishes).ti,ab.
5	564,154	(live well OR well-being OR wellbeing OR (human AND living)).ti,ab.
6	27	1 AND 2 AND 3
7	13	1 AND 2 AND 5
8	34	6 OR 7
9	28	1 AND 2 AND 4
10	45	8 OR 9
11	32	10 (limit 2007-2017)

Appendix B

Combinations of the five core components of the search terms

First combination	
dementia OR ...	
safety OR ... needs OR ...	AND
emotion OR ... well-being OR ...	
Second combination	
dementia OR ...	
safety OR ...	AND
needs OR ...	
Third combination	
dementia OR ...	
emotion OR ...	AND
well-being OR ...	

