


REVIEW ARTICLE

# Social inclusion of people with dementia – an integrative review of theoretical frameworks, methods and findings in empirical studies

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## Abstract

The social inclusion of people with dementia (PwD) is recognised as a global goal of legislation, societal initiatives and service provision. Ensuring the social inclusion of PwD in these areas implies that its dimensions and domains are clear and unambiguous. However, the concept of social inclusion as it is currently used by researchers and practitioners is often vague or acts as a container concept for a variety of different approaches. This paper reports on an integrative review that analysed qualitative and quantitative studies on social inclusion and exclusion of PwD. It focused not only on the empirical results of the included studies but also on the theoretical embedding and methodological approaches to the concept of social inclusion and exclusion. We find that empirical studies on the social inclusion of PwD are scarce and largely characterised by a lack of or inconsistent conceptualisation. Against this background, the operationalisation of the concept and the assessment of the individual aspects of social inclusion with standardised instruments seem to be premature. Substantial theoretical and methodological work is needed to guide research on the social inclusion of PwD. The empirical results show that relationships with other people and being integrated into social networks are essential aspects of social inclusion. Likewise, the strategies and attitudes of caring persons can help to create or reinforce exclusion.

**Keywords:** dementia; social inclusion; integrative review; social exclusion

## Introduction

For many years, research on dementia has focused primarily on the pathophysiological changes of the brain that lead to symptoms such as impaired memory, reasoning and comprehension (Plum, 1986: 2). This ‘standard paradigm’ was criticised by Kitwood (1997: 20) for neglecting changes in the social-psychological environment. He emphasised the changes that dementia brings in terms of relationships and interactions. Therefore, Kitwood (1997) developed a framework of a person-centred paradigm to depathologise dementia and to focus more on the person than on the disease. The ability to adapt socially to the changes of dementia and to manage to have a good quality of life despite some limitations is one of the dimensions of social health as proposed by Huber *et al.* (2011). Social health ‘can be regarded as a dynamic balance between opportunities and limitations, shifting through life and affected by external conditions such as social and environmental challenges’ (Huber *et al.*, 2011: 2). The social consequences of dementia, such as limitations of the ability to live independently or to engage in social activities, deserve as much scientific attention as the cognitive consequences (Dröes *et al.*, 2017). Currently, the social inclusion of people with dementia (PwD) is recognised as a global goal of legislation, societal initiatives and service provision (World Health Organization (WHO), 2012). To what extent social inclusion is already the subject of empirical dementia-related research is unclear.

## Social policies on social inclusion

The concept of social inclusion became prominent through the disability rights movement. In this movement, people with disabilities – especially younger people – made their personal experience of discrimination and social inequality a political issue (WHO, 2011; Sabatello and Schulz, 2013). A broad social debate about people with disabilities being excluded from mainstream society led to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which was passed by the United Nations in 2006 (United Nations, 2006). This convention marked a paradigm shift from exclusionary public welfare to the unrestricted participation and inclusion of people with disabilities in society (Martin and Cobigo, 2011). The main principles of the CRPD are the safeguarding of human rights, the avoidance of discrimination and the acceptance of people with disabilities as part of human diversity.

The simultaneous global rise of the human rights movement with its demands for ‘recognition of the interdependence of democracy, economic development, and human rights’ (Sabatello and Schulz, 2013: 14) supported the efforts of the disability rights movement in shifting the emphasis from the inabilities of persons with disabilities to their rights (Sabatello and Schulz, 2013). The Vienna Declaration and Programme of Action (United Nations, 1993), which was adopted by the World Conference on Human Rights, reaffirmed the universality of human rights that unreservedly apply to people with disabilities. The Declaration emphasises that all ‘socially determined barriers which exclude or restrict full participation in society’ (United Nations, 1993) should be eliminated.

### **Social inclusion in the context of disability and mental health**

Huxley *et al.* (2006) identified two schools of thought concerning social inclusion. They called one approach the rights-based approach, and it emphasises the rights of people as citizens or members of the society. The second approach is based on the assumption that 'social inclusion is the opportunity to participate in key functions or activities of the society in question' (Huxley *et al.*, 2006).

In the context of disability and mental health, the issue of social inclusion has been a subject of research and policy for many years. The focus in relation to health is on barriers to health care, health inequality and rehabilitation. While in relation to social aspects, topics such as work, education and enabling environments are relevant (WHO, 2011). These may not be of similar relevance, at least for the majority of PwD, as the disease predominantly affects older people beyond the age of employment.

Several conceptual reviews aimed to illuminate the meaning of the concept of social inclusion (Morgan *et al.*, 2007; Martin and Cobigo, 2011; Bigby, 2012; Cobigo *et al.*, 2012). They evidenced no consensus in the definition of 'social inclusion', the interchangeable use of terms such as 'social integration', the insufficient theoretical underpinning of the social inclusion concept, and a country- and cultural-specific use of the concept. It is not known how dementia research meets these challenges.

Further research focuses on the investigation of social inclusion as an outcome. To this end, various measurement tools that aim to test the effectiveness of interventions have been developed and examined. In a literature review, O'Donnell *et al.* (2018) examined 22 different instruments for measuring social inclusion in health-care settings. The large number of instruments shows the importance of the concept of 'social inclusion' in health research. However, a close look at the instruments also reveals their heterogeneity in relation to the definition of 'social inclusion' and in relation to the domains included. The instruments also varied in the allocation of scores and in the way they were administered (O'Donnell *et al.*, 2018). Other reviews criticise the limited adaption of instruments for cross-cultural use (Baumgartner and Burns, 2014) and note a lack of sufficient psychometric testing (Coombs *et al.*, 2013). The applicability of these instruments in dementia research is unclear.

### **Social inclusion and dementia**

Dementia is increasingly recognised as a disability, *e.g.* it is recognised under the CRPD. Therefore, the social inclusion of PwD is gaining more attention. For example, the WHO recently called for a 'Global Action Against Dementia' (WHO, 2015) that includes efforts to promote 'a better understanding of dementia, raising public awareness and engagement, including respect for the human rights of people living with dementia, reducing stigma and discrimination and fostering greater participation, social inclusion and integration' (WHO, 2015: 2). In recent years, a number of initiatives have already reflected the recognition of the rights and participation of PwD in social and political contexts. For example, the development of national dementia policies or strategies (*e.g.* WHO, 2012) or public and political campaigns to raise awareness for PwD (*e.g.* Dementia Friends in the UK, [www.dementiafriends.org.uk/](http://www.dementiafriends.org.uk/)) are indications of efforts to make dementia

a major public health issue. To ensure the social inclusion of PwD through legislation and care provision, research that focuses on this concept is needed.

### **Aim of the study**

The authors of this review are dementia researchers focusing on health-care services. The aim of our research is to develop and evaluate strategies to support PwD and their families, and social inclusion is one objective of our research (Bartholomeyczik *et al.*, 2010). To investigate how social inclusion of PwD has been researched, this paper reports on an integrative review that analysed qualitative and quantitative studies on social inclusion and exclusion of PwD.

With this review, we aim to describe the use of the concept of ‘social inclusion of people with dementia’ in empirical studies. We sought to determine whether the researcher used consistent theories and definitions of the concept and whether they applied comparable methods to assess or explore the concept. The review should enhance the critical discussion about the current use of the concept of social inclusion and encourage researchers to contribute to theory building in the field of dementia.

Because social inclusion may be better understood by taking the counterpart of social exclusion into account, we enclose the concept of social exclusion in the review.

The review addresses the following research questions:

- (1) How are social inclusion and/or social exclusion of people with dementia defined and theoretically embedded in the included studies?
- (2) How are social inclusion and/or social exclusion of people with dementia methodologically approached in the included studies?
- (3) What are the relevant findings of the included studies with regard to social inclusion and/or social exclusion of people with dementia?

## **Methods**

### **Design**

An integrated review was conducted to examine the use of the concepts of social inclusion and social exclusion in empirical studies. This type of review allows ‘the simultaneous inclusions of experimental and non-experimental research in order to more fully understand a phenomenon of concern’ (Whittemore and Knafl, 2005: 547). This integrated review is based on the strategies proposed by Whittemore and Knafl (2005): problem identification, literature search, data evaluation, data analysis and presentation. The authors decided not to evaluate the quality of the included studies because of the small number of relevant studies and their heterogeneous methodologies. Furthermore, the focus of this review is the underlying theoretical frameworks and identifying concept of social inclusion.

### **Problem identification**

Social inclusion seems to be an important concept in the field of dementia care and research. However, it is unclear what theoretical models and definitions are used in

dementia research and how they may be operationalised. This integrated review focused not only on the empirical results of the included studies but also on the theoretical embedding and methodological approaches to the concept of social inclusion and exclusion. Other terms such as participation or integration were not considered because of their suspected divergent meaning.

### **Literature search**

To answer our research questions, in July 2016 we conducted a literature search in five electronic databases (Medline (PubMed), CINAHL, PsychInfo, PsychArticles, and Psychology and Behavioral Science Collection (EBSCO)). We defined three search terms: 'dementia', 'social inclusion' and 'social exclusion'. For each database, a separate search strategy using defined key words was used. The terms describing the key categories 'social inclusion' and 'social exclusion' were combined with an OR operator; next, the key categories were combined with an AND operator with 'dementia'. In addition to the databases, we identified other sources through an internet search using the meta-database Google Scholar. The search protocol can be found in the online Appendix.

The publications found with this search strategy were screened in two steps: (a) title/abstract and (b) full text. Screening was conducted independently by two researchers (RP, MvK). In cases of disagreement, consensus was reached through discussion. The screening for inclusion was based on pre-defined criteria: only papers that reported in German or English on an empirical study and that focused explicitly on social inclusion/social exclusion of PwD were included. Theoretical texts or literature reviews were excluded. Following the inclusion decision, the reference lists of the included studies were also checked for other relevant publications. The flow chart documents this process (Figure 1).

### **Data analysis**

First, a code system covering the objectives of the review (study design, methods, aim/research question, theoretical framework, definitions, key concepts, findings) was defined and then used to deductively code the corresponding text passages of the studies.

To answer Research Question 1, 'How are social inclusion and/or social exclusion of people with dementia defined and theoretically embedded in the included studies?', the theoretical frameworks were grouped based on their different traditions of thought and scientific disciplines. Those approaches that focus on social life were assigned to the social sciences. Studies that focus on philosophical or cultural phenomena were attributed to the humanities. Furthermore, definitions of social inclusion or exclusion were identified wherever available and placed in relation to the theoretical perspective.

To answer Research Question 2, 'How are social inclusion and/or social exclusion of people with dementia methodologically approached in the included studies?', we identified the design characteristics of the included studies. The studies were grouped according to their methodological approaches (qualitative, quantitative and mixed methods) and the heterogeneity of their methods of data collection.

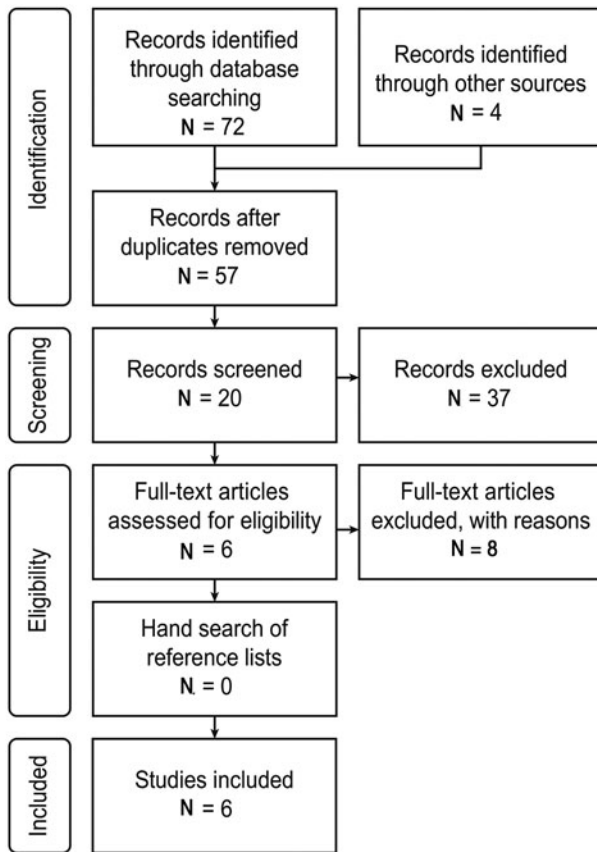


Figure 1. Literature search.

Research Question 3, ‘What are the relevant findings of the included studies with regard to social inclusion and/or social exclusion of people with dementia?’, was answered via a thematic analysis (Braun and Clarke, 2006) of the study results (both qualitative and quantitative). Therefore, inductive codes were assigned to the text as sub-themes of the initial codes. By this means, themes such as *influencing factors*, *subjective experiences* or *strategies* were identified. The software MAXQDA 12 (VERBI Software, Berlin, Germany) supported the management of data.

The analysis of each part was performed in groups of two authors. The results were discussed in the whole group and merged in the final analysis.

## Results

The results are presented according to the three research questions for this review. First, a description of the theoretical frameworks and definitions of social inclusion/social exclusion is provided. It is followed by the examination of the methodological

characteristics of the included studies. The section ends with the presentation of the analysed empirical findings of the included studies. In total, six publications were analysed: five journal articles and one PhD thesis (three qualitative, two mixed methods and one quantitative study). An overview of the study characteristics is provided in [Table 1](#).

### **Theoretical frameworks**

The theoretical frameworks that guided the included research are derived from the social sciences and humanities. Within the social sciences frameworks, Bartlett's publications have a socio-political character (Bartlett, 2003, 2007). Critical gerontology is the leading approach in the work of Forbes *et al.* (2011). The research of Camic *et al.* (2014), which used art pedagogy as a theoretical underpinning, is counted among the humanities. Wolf-Ostermann *et al.* (2017) and Dow *et al.* (2011) did not refer to a theoretical framework (see [Table 2](#)).

The included studies focus either on social exclusion or on social inclusion. Some authors used an explicit definition to guide their research. This was the case in the studies that focused on social exclusion (Bartlett, 2003, 2007; Forbes *et al.*, 2011). The other three studies (Dow *et al.*, 2011; Camic *et al.*, 2014; Wolf-Ostermann *et al.*, 2017) examined whether and how social inclusion was experienced by the PwD or their carers and did not refer to an explicit definition. Therefore, we tried to elaborate an implicit definition.

### **Characteristics and methodological approaches of included studies**

With regard to the research methods used, the studies can be clustered into three groups: (a) qualitative studies with a single method or multi-method approach, (b) mixed-method studies combining qualitative and quantitative methods, and (c) quantitative studies. The characteristics of the included studies are displayed in detail in [Table 1](#).

### **Empirical findings**

Data analysis of the study findings revealed four themes with several sub-themes: (a) social inclusion/exclusion as a multi-dimensional phenomenon, (b) factors influencing social inclusion/exclusion, (c) subjective experiences and perspectives regarding social inclusion/exclusion, and (d) strategies to live with/manage dementia. However, there is an overlap with regard to content, and some of the codes could be assigned to more than one theme or sub-theme. In fact, the themes were revealed to be closely intertwined.

#### ***Social inclusion/exclusion as a multi-dimensional phenomenon: dimensions and levels***

Data analysis showed that social inclusion/exclusion is multi-dimensional. Bartlett (2007) argued that a definition of the phenomenon based on a binary opposition, such as inclusion or exclusion, does not cover its complexity. She described the experience of inclusion/exclusion as heterogeneous and highly individual. In her

Table 1. Characteristics of the included studies

Author	Source	Country	Year	Study design	Method of data collection	Method of data analysis	Setting	Participants and sampling strategy	Sample size	Study aim
Qualitative study – single-method approach:										
Forbes <i>et al.</i>	Journal article (peer reviewed)	Canada	2011	Qualitative study; secondary analysis	Qualitative in-depth interviews; field notes; several time-points over 19 months	Luborsky's thematic analysis	Rural community	PwD, family care-givers, home care providers; recruitment through Community Care Access Centres	N = 18 interviews from three care networks (PwD, their spousal care-givers and others)	To determine how best to support dementia care networks in rural settings and to illuminate the care work of paid and unpaid care-givers
Qualitative studies – multi-method approach:										
Bartlett	PhD thesis	UK	2003	Qualitative study	Focus groups with care workers, in-depth interviews with residents with and without dementia, home care managers. In-depth interviews: with PwD and home care managers. Case study: unstructured interviews with PwD; semi-structured interviews with relatives; semi-structured interviews with key workers; contextual information and private care records, environmental observations	Thematic techniques (Luborsky's thematic analysis)	Five care homes (respectively specialist care unit)	Recruitment was carried out within a larger study; people working in the care homes selected interview partners. Sampling groups were PwD, other residents of the care homes, care workers, professional staff	Three focus groups with care workers (N = 19 participants); three rounds of in-depth interviews (N = 15 residents without dementia, 12 residents with dementia, 4 home care managers, 4 individual case studies)	To explore the meaning of social exclusion in relation to older people with dementia in care homes
Bartlett	Journal article (peer reviewed)	UK	2007	Qualitative study (single case study); secondary analysis	Unstructured interviews with PwD; semi-structured interviews with relatives; semi-structured interviews with key workers; contextual information and private care records, environmental observations	Framework approach (Ritchie and Spencer, 1994)	One care home (respectively specialist care unit)	PwD; relatives; key workers; purposive sampling strategy within a sample of a larger study; recruitment strategy not reported	N = 1 PwD	To explore how men with dementia experience, and deal with, nursing home life



Mixed-method studies:										
Camic <i>et al.</i>	Journal article (peer reviewed)	UK	2014	Mixed-methods pre-post design	Semi-structured interviews; standardised measures (QOL = DEMQOL-4; carer burden = Zarit Burden Interview; ADL = Bristol Activities of Daily Living Scale)	Thematic analysis; parametric and non-parametric statistical tests	Community: two art galleries	PwD and their carers; recruitment through Alzheimer's society, Extra Care Charitable Trust, host galleries	N = 24 (12 with dementia)	To explore the experience of an art gallery-based intervention for PwD and their carers; impact of intervention on social inclusion, carer burden, quality of life and ADLs
Dow <i>et al.</i>	Journal article (peer reviewed)	Australia	2011	Mixed-methods design evaluation study	Focus groups and surveys (self-developed questionnaire) with PwD and their carers, staff consultation, semi-structured and in-depth interviews with service providers, researcher observation	Content and thematic analysis (Miles and Huberman, 1994), descriptive statistics	Community: Memory Lane Cafés	PwD and carers: recruited from the Australia Vic Memory Lane Café mailing list; visitors of the café were invited by researcher. Staff: all staff members of the café. Service providers: purposeful selection through researchers; categorisation of service providers into seven categories, random selection of one person from each category	Focus groups: 37 PwD and their carers (three groups). Survey: N = 139. Staff consultation: N = 8 staff members. Service provider consultation: N = 24. Researcher observation: N = 3	To describe an evaluation of the Memory Lane Café service run by Alzheimer's Australia Vic.
Quantitative study:										
Wolf-Ostermann <i>et al.</i>	Journal article (peer reviewed)	Germany	2017	Observational study (cross-sectional)	Standardised questionnaires: dementia severity = Functional Assessment Staging (FAST); challenging behaviour = Cohen-Mansfield Agitation Inventory (CMAI); depression = Geriatrische Depressionsskala (GDS); Instrumental activities of daily living = (IADL); social inclusion = UCLA Loneliness Scale + Sense of Acceptance in Community Activities (SACA)	Linear mixed models	Community	Dyads of PwD and their care-givers; sampling strategy not reported	560 dyads	To describe perceived social participation and inclusion

Notes: PwD: people with dementia. UK: United Kingdom. QOL: quality of life. ADL: activities of daily living.

**Table 2.** Theoretical frameworks and definitions

Author	Approach	Explicit definitions of social inclusion/exclusion	Implicit definitions of social inclusion/exclusion
Social sciences:			
Bartlett (2003)	Socio-political	'Social exclusion is a process whereby people gradually lose their status in the social world. It is characterized by a lack of meaningful opportunities and sense of identity and belonging. A complex range of factors including societal attitudes and health status influences the process' (p. 47)	
Bartlett (2007)	Socio-political	Social exclusion is defined as 'an experience characterized by deprivation and the lack of social networks, activities and services that results in a poor quality of life' (Social Exclusion Unit, 2006: 18, quoted on p. 17)	
Forbes <i>et al.</i> (2011)	Critical gerontology	Social exclusion means 'the dynamic process of being shut out, fully or partially, from any of the social, economic, political and cultural systems which determine the social integration of a person in society' (Walker, 1997: 8, quoted on p. 28)	
Humanities:			
Camic <i>et al.</i> (2014)	Art pedagogy		Social inclusion is seen as active social contacts and social engagement
No reported theoretical framework:			
Dow <i>et al.</i> (2011)	Not reported		Social inclusion is seen as being promoted by fostering peer support and expanding social networks beyond existing care arrangements
Wolf-Ostermann <i>et al.</i> (2017)	Not reported		Social inclusion is seen as comprising sense of loneliness and acceptance as key aspects

work, she identified four dimensions of social inclusion/exclusion that we also found in our data: an *environmental dimension* (locality, configuration of internal spaces, level of access to places), an *economic dimension* (funding of long-term care, income of care receiver), an *emotional dimension* (comfort, mood, self-assurance) and a *cultural/societal dimension* (routines and regulations, language, attitudes, power dynamics) (Bartlett, 2003). These dimensions can gain relevance on different levels. Forbes *et al.* (2011) characterised social inclusion as a complex phenomenon shaped by interconnected factors and processes on a *micro-level* (the subjective experience of the PwD), *meso-level* (the immediate interactional environment) and *macro-level* (the broader socio-cultural context).

We identified findings related to the specific dimensions of social inclusion/exclusion (as introduced by Bartlett, 2003, 2007) and related them to the three different levels (as introduced by Forbes *et al.*, 2011).

*Dimensions on the micro-level.* On the micro-level, dimensions directly rely on the PwD and their experiences. Wolf-Ostermann *et al.* (2017) referred to the micro-level by assuming that feelings of loneliness and feelings of acceptance are linked with social inclusion/exclusion. Bartlett (2003) emphasised that to maintain continuity of the self, PwD reflect on the type of person they once were and try to stay connected with their pre-dementia identity. These aspects are primarily related to the *emotional dimension*. PwD claim a right to participate in their care, social activities and work (Forbes *et al.*, 2011), and the opportunity to choose among different options (Bartlett, 2003). These aspects could be subsumed within the *cultural/societal dimension*.

*Dimensions on the meso-level.* The dimensions related to the meso-level correspond to the prominent concept of relationship. Forbes *et al.* (2011) identified quality relationships among family members, friends and health-care professionals, and Dow *et al.* (2011) identified socialising with others as pivotal elements of social inclusion. All of these aspects are related to the *cultural/societal dimension*. Failing social relationships can lead to exclusionary processes such as isolation, discrimination (referring to the *cultural/societal dimension*) or emotional misuse of the PwD (referring to the *emotional dimension*) (Bartlett, 2003, 2007).

*Dimensions on the macro-level.* On the macro-level, we found two dimensions of inclusion/exclusion: an *environmental* and an *economic dimension*. The environment promotes social exclusion, e.g. by PwD being restricted to a nursing home (Bartlett, 2003, 2007). Furthermore, PwD experience social exclusion in an economic sense that excludes them from certain societal groups (e.g. from those who can afford their housing option of choice) (Bartlett, 2007).

#### *Factors influencing social inclusion/exclusion*

In sum, the dimensions of social inclusion/exclusion derived from the empirical results of the included studies are multifarious. The influencing factors, subjective experiences and strategies analysed below correspond to these dimensions and add further aspects that are closely related.

In the analysed studies, we identified numerous factors that either challenge or promote the social inclusion of PwD. There is a clear focus on factors that foster exclusionary processes, and less attention is paid to factors that support social inclusion. We differentiated among influencing factors related to the PwD, to their informal carer(s), to health-care professionals, to the health-care system, to the environment and to society/culture. Four of the included studies primarily investigate the situation of PwD living in the community; the two publications of Bartlett (2003, 2007) study the inclusion/exclusion of PwD living in a nursing home. Therefore, her findings deliver the most information related to institutional living and the health-care professionals who work in such institutions. Some of the influencing factors that we summarise are valid in both settings; others are specific either to the community or to the institutional setting.

*Factors related to the person living with dementia.* Influencing factors related to the PwD illuminate aspects of the disease itself, such as the severity of cognitive impairment (Bartlett, 2003; Wolf-Ostermann *et al.*, 2017), challenging behaviour (Bartlett, 2003; Forbes *et al.*, 2011; Wolf-Ostermann *et al.*, 2017), affected ability to speak (Bartlett, 2003) and physical restrictions due to incontinence or visual impairment (Bartlett, 2003; Forbes *et al.*, 2011) that may be part of the ageing process. These factors usually lead to social exclusion. Additionally, the experienced dependency (*i.e.* reliance on the help of others and/or exclusion from decisions) (Bartlett, 2003; Forbes *et al.*, 2011) makes the involvement of PwD in social life or the organisation of care difficult. Wolf-Ostermann *et al.* (2017) found that PwD who were supported by urban dementia care networks felt more excluded than PwD in rural networks. When people had the opportunity to spend quality time with friends and to keep friendships alive, this opportunity was experienced as promoting social inclusion (Bartlett, 2003; Dow *et al.*, 2011; Camic *et al.*, 2014).

*Factors related to informal carers.* Regarding informal carer(s), the influencing factors refer mostly to relationship and interaction. Often, families experience dementia as causing changes in family relationships to the point that the PwD is no longer perceived as the same person with whom the family members were familiar. Therefore, the PwD is rarely involved in care decisions, although family members can have a strong commitment to marriage vows or feel pleased to support the PwD. Furthermore, the ability of informal carer(s) to cope with daily challenges and to manage dementia care, for example, by focusing on the person instead of the disease and using a non-verbal, caring and consistent approach, seems to contribute to the inclusion of the PwD. Strong promotive factors for social inclusion are the involvement of the PwD in social and community networks, and a focus on the person instead of the symptoms of dementia (Dow *et al.*, 2011; Forbes *et al.*, 2011).

*Factors related to health-care professionals.* Influencing factors related to health-care professionals are the relationship between professionals and their clients with dementia, their perceptions regarding PwD, and their expertise or failure in offering care that supports inclusive processes (Bartlett, 2003). Factors that could be attributed to a person-centred care approach, such as treating PwD as equals or supporting the maintenance of the unique identity of the PwD (Bartlett, 2003: 40), serve as

the main promotive factors of social inclusion (Bartlett, 2003). A care approach focused primarily on physical care and the avoidance of risk may lead to social exclusion (Bartlett, 2007; Forbes *et al.*, 2011).

*Factors related to the health-care system.* Regarding aspects of the health-care system, the identified influencing factors bundle aspects of financing, including (public) perceptions of what should or should not be financed, and staffing in terms of sufficient resources and staff qualifications. Furthermore, the attitude towards dementia inherent in the care system promotes or challenges the choices and participation of nursing home residents concerning their care (Bartlett, 2003).

*Factors related to the environment.* Influencing factors related to the environment can be divided into factors associated with the community setting and with the nursing home setting. On the one hand, the community may be helpful when the connections remain, and PwD value the involvement with their social network. Especially in rural communities, a lack of anonymity or stigma may become a matter of concern for PwD and their families (Forbes *et al.*, 2011). In that case, familiarity with the community setting constitutes a barrier to social inclusion.

Regarding institutional settings, the authors of the included studies discussed the links of nursing homes to the local community. When PwD are admitted to nursing homes located at a distance from their friends, visitors play an important role in connecting them to the outside world (Bartlett, 2003; Forbes *et al.*, 2011). Furthermore, Bartlett (2003) addressed the architectural design and environmental standards of nursing homes. When there is enough private space and a sufficient level of access to communal space for PwD and others, the design can facilitate the inclusion of PwD. Some nursing homes tend to separate PwD from residents without dementia or restrict their freedom of movement, *e.g.* by having a locked front door (Bartlett, 2003). The difficult accessibility of such places by public transport is also discussed for people living in nursing homes and those living at home (Bartlett, 2003; Dow *et al.*, 2011).

*Factors related to society and culture.* Finally, regarding society and culture, the authors contrast exclusion processes such as stigmatisation, ageism and the perceived inability of PwD to reciprocate socially (Forbes *et al.*, 2011) with inclusion approaches such as enhancing relations between the local community and the nursing home (Bartlett, 2003).

#### *Subjective experiences and perspectives regarding social inclusion/exclusion*

Another theme identified in the analysis was the subjective experiences of PwD and the perspectives of professional carers regarding social inclusion/exclusion. Most of the quotes were related to aspects of social exclusion. We expected to also find insights into the views of informal carers. However, this perspective was not represented in the included studies.

*Subjective experience of people living with dementia.* People living in an institutional setting reported a range of experiences, many of them as a result of exclusionary care practices or attributed to the care home as an exclusionary setting *per se*.

Apart from these setting-specific exclusionary experiences, people felt excluded from the outside world and from social interactions due to their restricted ability to express themselves verbally or due to their old age. The results in Bartlett (2007) referred to the subjective experience related to the dimension of social exclusion in an economic sense. In contrast, being part of an extended social network while not being labelled 'demented' and being treated as a 'normal' person make people experience social inclusion (Dow *et al.*, 2011). Additionally, being able to support each other (Dow *et al.*, 2011) and not only feeling dependent on others but also being an active part of society led to the experience of social inclusion (Camic *et al.*, 2014).

*Perspectives of professional carers.* In the study of Bartlett (2003), the perspective of professional carers on issues and the dynamics of social inclusion/exclusion became apparent. Nursing home care practices rather than the care setting were seen as most critical to exclusion/inclusion by professional carers in this setting. The role and potential of care homes were evaluated as contradictory: while residents may miss aspects of everyday life, some might have been very isolated before entering the nursing home and gain more social contact after they are institutionalised. Nevertheless, a generally exclusionary view was attributed to nursing homes as an environment based on the general perception that this institutional setting symbolises dependence, inability to control one's own affairs and reliance on others. Professionals reported the observance that the nursing home environment keeps relatives, especially younger family members, from visiting. In reflecting on their own care practices, professionals perceived enabling nursing home-dwelling PwD to go out as important to promote social inclusion. However, professionals stated a lack of resources (staff) to do so. Care homes are experienced not only as physical places but also as social systems involving other people and relationships. Care staff definitely attributed some responsibility to residents for their own social inclusion or exclusion in terms of their general attitude. Some residents view a nursing home as more like a hotel than a home in which they would normally be active and autonomous, making it difficult to involve them in activities.

#### *Strategies to live with/manage dementia*

PwD do not undergo the disease passively but rather develop (constructive) strategies to cope with dementia and the associated challenges. Three of the included studies (Bartlett, 2003, 2007; Forbes *et al.*, 2011) revealed a range of strategies that PwD themselves or their family carers applied to live with dementia, including exclusionary experiences, or to manage dementia. We grouped these strategies into proactive, self-preserving strategies, and strategies of avoidance or denial. Care strategies of professionals that are relevant in the context of social inclusion/exclusion can be found in Bartlett's (2003) study. These strategies can be differentiated as integrative *versus* segregative care strategies.

*Strategies of persons living with dementia.* Most strategies applied by PwD, as found in the included studies, were *proactive*, and many of them directly addressed experiences of social exclusion. Bartlett (2003: 267) argued that 'the core meaning of social exclusion is loss of identity'. Consequently, maintaining and evoking one's

(sense of) identity seemed to be the main impetus for many of the strategies found in this study. Bartlett (2003) found five different strategies used to counter exclusionary processes: (a) distancing oneself from others, (b) aligning oneself with others, (c) recounting past pleasures and routines, (d) using individual resources to manage everyday life, and (e) thinking rebellious thoughts to create an inner resistance to the disabling influences and exclusionary experiences that they face.

A strategy of avoidance and denial is described in the study by Bartlett (2003) as complex and not only attributable to individual coping but also a symptom of societal or cultural norms and values: PwD sometimes tend to explain away exclusionary experiences by defining themselves as belonging to the social category 'old' and therefore not expecting much in this regard.

*Strategies of informal carers.* Maintaining routines and familiar activities to maintain normalcy is a central endeavour not only of PwD but also of informal carers. Some carers cope with the new situation by accepting the change, particularly within their relationship with the PwD, and adapting their everyday routines.

In the study by Forbes *et al.* (2011), the quality of the relationships among network members was an important theme. One strategy reported by informal carers attempting to adjust their changing relationship with the PwD and the changing appearance and behaviour of the PwD was to understand these changes and discuss them within the family. However, these efforts seemed to be aimed primarily at supporting the informal care-givers. The families made substantive efforts in the belief that the family home was the best place for the PwD. Similar efforts were not as apparent in terms of attempting to understand the perspective of the PwD.

*Strategies of professional carers.* The majority of care strategies found among professional carers were derived from Bartlett (2003) and reflected the policies and care concepts of nursing homes and their implementation in everyday care. Most strategies are rooted in an integrative attitude that involves trying to value the personhood of residents with dementia and their rights, as citizens as well as empowering and motivating them to stay as independent as possible. Furthermore, professionals tried to tackle the marginalisation and stigmatisation of PwD, in general, and their residents, in particular, by raising awareness of their behaviour, which in their environment is sometimes perceived as challenging.

Among the strategies characterised as integrative, only one concerned family carers. Professionals stated that they explicitly valued informal carers and treated them as care partners, and they emphasised the essential importance of including them in decision-making processes, such as the admission process into an institution.

In addition to the integrative care strategies applied in residential care, we found strategies that can be termed segregative. Segregation occurs between residents with and without dementia or on the basis of dementia severity. In the study by Bartlett (2003), we found an example of spatial segregation as well as examples of how professionals naturally tended to exclude PwD from common internalised social practices, such as experiencing attentive and caring interactions with other residents and (physically) helping them.

## Discussion

The aim of this review was to examine the use of the concepts of social inclusion and social exclusion in empirical studies in terms of definitions and theoretical frameworks (Research Question 1), methodological approaches (Research Question 2) and relevant findings (Research Question 3).

The analysis of theoretical frameworks and *a priori* definitions of social inclusion/exclusion shows a heterogeneous picture. Only three of the six included studies are based on explicit definitions of social inclusion/exclusion. In line with recent reviews in the field of mental health (Morgan *et al.*, 2007; Baumgartner and Burns, 2014), one can criticise the lack of a clear and widely accepted definition of social inclusion/exclusion in dementia research. The conceptual review of literature concerning social exclusion and mental health by Morgan *et al.* (2007) noted a lack of conceptual clarity and the use of indistinguishable and overlapping concepts such as poverty and social capital. In the context of dementia research, ambiguity of the concepts of social inclusion/exclusion can also be assumed.

The explicit and implicit definitions of social inclusion/exclusion analysed in this review suggest that these concepts are recognised in some studies as a process (Bartlett, 2003) and in others as a state (Camic *et al.*, 2014; Wolf-Ostermann *et al.*, 2017). Conceptual reviews of social inclusion/exclusion in mental health research mainly emphasise the dynamic and relational aspects of social inclusion/exclusion (Morgan *et al.*, 2007; Cobigo *et al.*, 2012). They describe interacting factors, such as personal and contextual factors, that lead to inclusion and exclusion as well as different levels of inclusion/exclusion that 'vary across roles, environments, and over time' (Cobigo *et al.*, 2012: 82). An individual may be included in one group while at the same time being excluded from another group. These conclusions correspond to our dementia-specific integrative review.

Although the authors of this review specifically searched only for studies in the context of dementia, the definitions found in the included studies are not specific to dementia. This issue raises the question of whether a dementia-specific definition is necessary and possible. Regarding the first research question of our integrative review, one can state a conceptual uncertainty owing to different definitions from diverse theoretical perspectives, which poses problems in adequately researching social inclusion.

The methodological approaches are dominated by qualitative designs used to examine the meaning and experience of living with dementia from the perspective of PwD, their informal carers and/or health-care professionals. This approach could be rationalised by the fact that little is known about the phenomena of social inclusion/exclusion of PwD and the lack of studies focusing on this topic. For this reason, researchers might focus on qualitative research to obtain a better and more in-depth understanding of the phenomenon. This understanding could forward further theorising about the phenomenon and also support service planning and delivery.

Quantitative approaches are used to investigate the effects of interventions such as dementia networks (Wolf-Ostermann *et al.*, 2017), art gallery interventions (Camic *et al.*, 2014) or a Memory Lane Café (Dow *et al.*, 2011), which aimed to promote social inclusion. The effects were evaluated by measuring satisfaction with the intervention (Dow *et al.*, 2011) or quality of life (Camic *et al.*, 2014).



The operationalisation of the phenomenon of social inclusion/exclusion is conducted by measuring loneliness and acceptance (Wolf-Ostermann *et al.*, 2017). Morgan *et al.* (2007: 482) concluded in their methodological review that 'direct measures of social exclusion are in their infancy'. The conceptual uncertainty and the lack of distinction between direct and indirect factors or between indicators and causes of exclusion, such as stigma or discrimination, have made the interpretation of the findings difficult. Furthermore, these authors criticised most studies for using data that were already available, *e.g.* case records or population registries, and therefore not specific to social inclusion. In summary, they stated a 'pressing need for further conceptual and methodological work' (Morgan *et al.*, 2007: 482).

Recent reviews of social inclusion measures (Coombs *et al.*, 2013; Baumgartner and Burns, 2014) examined several instruments for use in mental health. While Coombs *et al.* (2013) identified ten candidate social inclusion measures, Baumgartner and Burns (2014) found five instruments to measure social inclusion. After a sound examination of all instruments, only two instruments were classified as potentially appropriate after further testing: the APQ-6 (Activity and Participation Questionnaire; Stewart *et al.*, 2010) and the SCOPE (Social and Community Opportunities Profile; Huxley *et al.*, 2012). The authors of these two reviews provided valuable recommendations for the development of sound and valid instruments to measure social inclusion/exclusion. Such measures should cover different life domains such as housing, employment and education; incorporate objective and subjective elements of social inclusion; include indicators that can be measured on a population level as well as on an individual level; be brief, inexpensive and simple to administer; meet psychometric criteria such as validity, reliability and sensitivity to change; be based on theory or a framework; reflect the values of the affected persons; and be adaptable for cross-cultural use.

The analysis of the methodological approaches of the studies included in this review indicates that little is known about the different dimensions and indicators of social inclusion/exclusion of PwD (Research Question 2). Therefore, qualitative approaches were predominantly used to elucidate the concept.

In addition to the focus on the theoretical and methodological approaches of the studies included in this review, empirical findings concerning the experience of social inclusion/exclusion from the perspective of PwD, their family and professional carers were analysed. These empirical results provide insight into the complexity of the phenomenon of social inclusion and show in what dimensions and on what levels social inclusion is experienced and influenced.

The dynamic nature of the phenomenon found in the analysed studies is also described in the mental health literature (Morgan *et al.*, 2007; Cobigo *et al.*, 2012). Factors such as the interaction between persons and the environment and the change over time suggest that inclusion is not a fixed state. Additionally, the multi-dimensional composition of social inclusion/exclusion is described, *e.g.* in the context of research on developmental disabilities (Simplican *et al.*, 2015). Simplican *et al.* (2015) developed an ecological model of social inclusion to conceptualise variables that influence social inclusion in different domains. While the authors of this review grouped together the findings related to three levels – the micro-, meso- and macro-level – according to Forbes *et al.* (2011), the model developed by Simplican *et al.* (2015) consists of five domains with enabling or disabling

conditions in the individual, interpersonal, organisational, community or socio-political domains. Despite these different categorisations, factors such as self-esteem, level of functioning and loneliness, family culture or type of living accommodation are similar in each approach. Only the socio-political issues, *e.g.* 'whether social inclusion affects political change' or how 'political level conditions ... have negatively influenced organizational cultures and staff behaviour' (Simplican *et al.*, 2015: 26) are not examined in the studies concerning PwD that we analysed for this integrative review.

The empirical findings in the studies included in this review reveal the experiences, perspectives and strategies concerning the social inclusion/exclusion of PwD and their families and professional care-givers. Currently, there is a growing amount of dementia research that takes into account the experiences of PwD themselves. These studies reveal aspects such as quality of life, identity, relationship, and feelings of uncertainty and loss or lack of control as central elements of the lived experience or as (unmet) needs of PwD (Clare *et al.*, 2008; Bunn *et al.*, 2012; von Kutzleben *et al.*, 2012). Among the studies analysed for this review, only the thesis of Bartlett (2003) focuses on the meaning of social inclusion/exclusion from the perspective of PwD in residential care. Thus, her findings contribute most to the findings of this review. The results represent the experience of exclusion as feelings of isolation and loneliness or exclusion from social interaction. Research concerning isolation and loneliness is ambiguous (Alzheimer's Society, 2013). Some studies conclude that isolation and loneliness are predictors of dementia, as they result from the deterioration of social skills that can be observed as the disease progresses. Others view the association of isolation and loneliness as an indication of the difficulty of PwD in engaging in social interaction and therefore as a consequence of dementia (Holwerda *et al.*, 2014). In contrast to this pathophysiological view, the findings of Bartlett (2003, 2007) suggest that PwD who live in nursing homes experience isolation and loneliness due to exclusionary care practices, physical exclusion from the 'outside world', or fewer opportunities and choices resulting from lacking economic resources. From the perspective of professional carers, exclusion is attributed to the PwD and his or her decreasing ability to reciprocate socially or to the institutional restrictions of nursing homes.

The potential for the exclusionary impact of institutions on people is discussed in detail in sociology and especially in the field of mental health. It is debatable whether institutional care is always exclusive, while home care *per se* enables or maintains social inclusion. Whereas the segregation of PwD, for example, in special care units, may serve their needs for activity, autonomy and participation (Müller-Hergl, 2014), care for people at home may lead to 'increasing isolation and individual institutionalization within the home' (Milligan and Wiles, 2010: 746). However, there is much agreement that the relationships between the places of care and the experiences and practices of care are complex (Milligan and Wiles, 2010).

The analysed studies reveal important findings in relation to Research Question 3. They show that relationships with other people and being integrated into social networks are essential aspects of social inclusion. In addition, it has become clear that PwD themselves as well as informal and professional carers can promote social inclusion. Likewise, the strategies and attitudes of caring persons can help to create or reinforce exclusion. However, the results are insufficient to clarify what social

inclusion means to PwD and how to approach this concept methodologically in research. An application of knowledge from other scientific contexts, e.g. mental health research, has not yet taken place but is an important next step to take.

### Limitations

There are limitations that should be taken into account. We chose a narrow search with social inclusion or social exclusion as search terms in research articles. As this review aimed to perform not a concept analysis but rather a review of the literature concerning the use of and findings regarding the experience of 'social inclusion/exclusion of PwD' in empirical studies, we exclude studies that focus on assumed different concepts as well as theoretical texts. Therefore, we might have missed important articles that in fact used different key words, such as social integration or social participation, but were about the same concept.

### Conclusion

Empirical studies on the social inclusion of PwD are scarce and largely characterised by a lack of or inconsistent conceptualisation. Against this background, the operationalisation of the concept and the assessment of the individual aspects of social inclusion with standardised instruments seem to be premature. The simple adoption of instruments developed for use in the mental health context seems not to be constructive. Substantial theoretical and methodological work is needed to guide research on the social inclusion of PwD. The findings of this review concerning the experience of social inclusion/exclusion from the perspective of PwD and their informal and professional carers should inform service planning that meets the needs of PwD.

The results of this review are comparable to mental health or disability research findings. Therefore, it is questionable whether the social inclusion of PwD in fact differs from the social inclusion of people with mental health conditions or disabilities in terms of definition and meaning. It could be argued that the exclusions experienced by PwD are social barriers that are related more to the social relationships between people with and without dementia than to the cognitive effects of dementia. This position is consistent with the social model of disability (Oliver and Sapey, 1983). However, the binary opposition on which this model is based (medical–social) seems to be 'too simplistic for understanding the complex and fluid relationships, that the people with dementia ... had with their social world (Bartlett, 2003: abstract i). Future research on this topic should at least be inspired by the debate and approaches of the mental health and disability context.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S0144686X19001338>.

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