Mapping empirical experiences of Tom Kitwood’s framework of person-centred care for persons with dementia in institutional settings.

A scoping review

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Abstract

Introduction: Tom Kitwood’s theoretical framework of person-centred care is extensively and internationally referred to in health care services. However, despite the broad use of Kitwood’s approach in clinical practice, the research examining experiences with the approach has not been mapped.

Aim: To map the available literature on current empirical experiences in clinical practice of Kitwood’s approach to person-centred care for people with dementia, living in institutional settings in primary health care.

Methods: 154 studies concerning the experiences of people with dementia and their formal caregivers’ use of Kitwood’s framework of person-centred care for residents living in institutional settings in primary health care, were compiled from scientific databases. All three authors engaged in a systematic selection process, leading to nineteen articles being included in the review.

Results: The results showed an overall tendency towards positive experiences gained from applying person-centred approaches in clinical practice influenced by Kitwood’s theoretical framework. Through the synthesis of data from the selected studies, six categories related to our research aim were identified: “Theoretical evaluation of Tom Kitwood’s model of care”, “Models and frameworks”, “Interventions”, “Communication”, “Dementia Care Mapping”, and “Environment”.

Conclusion: The present review included nineteen studies published from 1998 to 2016 and consisted mainly of peer-reviewed scientific articles, followed by dissertations, conference posters, and non-peer-reviewed articles. All studies were undertaken in Western countries. The vast majority of the studies considered Kitwood’s theoretical framework to be beneficial and useful in practice.
Keywords: Kitwood; dementia; person-centred care; experiences; institutional settings.
Introduction

Kitwood’s approach to person-centred care is widely known and implemented in dementia care in the past few decades (1,2,3). However, despite the extensive use of Kitwood’s approach in clinical practice, research examining clinical experiences with this approach has not been undertaken. This scoping review aims to map the available literature on current empirical experiences of Tom Kitwood’s approach to person-centred care, for people with dementia living in institutional settings in primary health care.

Dementia, which is defined as, “a syndrome in which there is deterioration in memory, thinking, behaviour, and the ability to perform everyday activities” (4), and is considered as an umbrella term for a number of complex illnesses often involving symptoms such as, declining cognition, emotional control, and social behaviour, has become a matter of growing concern on a worldwide level (3,5). In 2017, it was estimated that close to 50 million people were living with dementia globally (6). Approximately 35,000 Danes above 65 years of age have been diagnosed with dementia, but the Danish Dementia Research Centre estimates that more than 80,000 Danish people currently suffer from the illness. Moreover, today, 42% of residents in Danish nursing homes and sheltered care in primary health care have a diagnosis of dementia. Nevertheless, the total number may even be higher as not all residents living with dementia have been diagnosed (7).

Dementia encompasses numerous complex, progressive illnesses with various symptoms and appearances, depending on the type of dementia and the state of the illness. The differences entail wide variation in the care and support needed by the individual person with dementia, and the care and support given are often of crucial importance for those persons’ everyday quality of life. For that reason, Prof Thomas (Tom) Kitwood’s (1937 – 1998) theory of person-centred care is extensively and internationally referred to in health care services. Its main theoretical contribution encompasses a coherent and dynamic model of interaction between psychosocial and neurological factors in the course of the illness, a conceptual understanding of personhood, and the concept of malignant social psychology. Kitwood criticised the biomedical approach for its understanding, treatment, and care of people with dementia illnesses. Thus, Kitwood considered the biomedical approach to represent a narrow and insufficient understanding of the person’s mental and emotional state. In this approach, the illness was mainly reduced to neurological impairments in the brain and seen as independent of the person’s life story and situation. Which, in Kitwood’s interpretation, causes the person’s life experiences to be treated as insignificant (8).
Consequently, he advocated for a paradigm shift towards a person-centred approach, which he considered was already used in dementia care practices at an intuitive level. Kitwood (8) concluded that a humanistic ethical approach was vital for the person and that the illness did not become the centre of attention.

Kitwood provided groundwork for an approach to health care that makes use of interactive approaches and humanistic ethics more than medical interventions, aiming to support and strengthen the experience and feeling of sustained personhood (9,10). Thus, in Kitwood’s work, it is repeatedly stressed that the development of dementia varies from person to person and that the process of the illness is affected by the social and psychological environment of the individual person. Moreover, Kitwood saw the person-centred paradigm as a way to frame an interactional, multisided causality (8). Although Kitwood left his work unfinished, his theoretical frameworks have made a significant impact on the way that dementia and its care have been viewed. Many health professionals consider the approach very useful in providing a theoretical conceptual framework for person-centred care and support for people with dementia. As a result, there has been a growth of person-centred practices in dementia care in the past few decades (2,3).

Kitwood’s approach to person-centred care is also broadly known and implemented in Danish health care (1). However, despite the extensive use of Kitwood’s approach in clinical practice, the research examining clinical experiences with this approach has not been mapped and discussed.

**Aim**

This scoping review aims to map the available literature on current empirical experiences in clinical practice of Kitwood’s approach to person-centred care, for people with dementia living in institutional settings in primary health care.

**Methods**

The methodological framework of the present scoping review was underpinned by The Joanna Briggs Institute Reviewers’ Manual – Methodology for JBI Scoping Reviews (11), which builds on the framework introduced by Arksey and O’Malley (12) and further improvements by Levac et al. (13). Scoping reviews are especially useful when research-based literature has not yet been comprehensively reviewed, or if it exhibits a heterogeneous nature not suitable for a systematic review. Hence, scoping reviews often have a broad approach, generally with the aim of mapping the available literature and addressing a broad research question (14). The scoping review was conducted using four steps: a thorough literature search, a study selection process, a data extraction procedure, and a synthesis of the data.
Inclusion criteria

Participants
The participants considered in this scoping review were people of any age diagnosed with dementia and living in institutional settings in primary health care and/or their formal caregivers, such as nursing staff and care assistants. All available literature concerning the experiences of people with dementia and their formal caregivers using Kitwood’s framework of person-centred care was included in the results.

Context
Institutional facilities in primary health care such as nursing homes were included, because influence of the context in which the framework of person-centred care is used, was considered important.

Exclusion criteria
As Kitwood’s approach is primarily aimed at people with dementia living in an institutional setting in primary health care, literature describing Kitwood’s framework of person-centred care and associated empirical experiences, general attitudes, and considerations for people with dementia living in their own homes and in hospitals was excluded.

Kitwood’s framework was mentioned in the literature for the first time in 1993, therefore, literature published before 1993 was excluded. Moreover, literature in languages other than English, Danish, Norwegian and Swedish was excluded.

Literature search
Together with two experienced librarians, all three authors discussed search terms relevant to the research question and undertook a systematic block search of the health databases: Medline (via PubMed), CINAHL Complete, and PsycINFO (via EBSCO), using the search terms ‘Kitwood’, ‘Kitwood’s’, ‘Kitwoods’, and ‘dementia’ and associated terms such as ‘Alzheimer’s’. The searches were conducted from September to October 2017. After a two-block search yielded satisfactory results, other relevant health and sociological databases were searched as well, namely, Embase, Cochrane, SveMed+, Danish Medical Journal, Idunn, SocINDEX, and Sociological Abstracts. Additional literature was found through the databases Academic Search Premier, Web of Science, and Scopus. Furthermore, the databases OpenGrey, Google Scholar, Bibliotek.dk, and the Danish National Research Database were explored in search of unpublished literature.

The literature identified through the databases PubMed, CINAHL Complete, PsycINFO, Academic Search Premier, SocINDEX, EMBASE, Scopus, Cochrane, Web of Science, and Idunn was transferred to RefWorks 2017, and duplicates were removed.

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Selection process
In the first step of selection, two independent authors reviewed the titles and abstracts and eliminated studies on the basis of the inclusion and exclusion criteria and in accordance with the aim of the review. Subsequently, in the second step of selection, the included papers from step one were retrieved in full text and screened for relevance by one author working independently, while a second author analysed half of the full text articles. Moreover, the reference lists of all included articles were examined for any that were missed during the first step of the search process. At both the title/abstract and full-text level, any inconsistencies between the two authors regarding which literature to deem eligible for final inclusion were resolved through discussion with the third author.

Data extraction
To provide an overview of the characteristics of the literature included in the scoping review and the findings of each study, we extracted those data and formatted them in two tables (Table 1 and 2). Before any data extraction occurred, the authors each read three different articles and discussed which study characteristics and which findings were relevant to include in the tables.

One author initially extracted data from all the included full-text literature, while the second reader of the full-text literature undertook the same procedure with the first half of the included full-text literature in alphabetic order. Any disagreements in relation to the extracted data were resolved through discussion with a third author.

Synthesis of the data
Following the recommendations of Levac et al. (13), the analytical stage resembled qualitative data analytical techniques. We used a deductive content analysis, which required analysis and simplification of data, forming categories that reflected the aim of the study in a reliable manner and results that described the contents of conceptually and empirically grounded categories (15). In the analysis, a categorisation matrix was developed, and data was coded according to the chosen concepts (see Figure 2). The key concepts reflected the aim of the review and included personhood, person-centred care, and malignant social psychology from the theoretical framework by Tom Kitwood, as well as the caregivers’ experiences, attitudes, and considerations regarding Tom Kitwood’s framework of person-centred care.

Please insert Figure 2.
Results

Literature search

Arksey and O’Malley described the need to provide a descriptive, numerical summary and characteristics of included studies (12). In this scoping review, the search for relevant literature in the 17 databases returned a total of 203 records, from CINAHL Complete (n=53), PsycINFO (n=52), PubMed (n=36), Academic Search Premier (n=15), SocINDEX (n=13), EMBASE (n=11), Scopus (n=10), Cochrane (n=8), Web of Science (n=4), and Idunn (n=1) (Figure 1). Of these records, 49 were removed because they were duplicates transferred from two or more databases. The remaining 154 records were screened by title and abstract, and 124 of those records were excluded because they did not meet the inclusion criteria. The full texts of the 30 eligible records were read. Nine articles were excluded because they were not relevant to the research question, and another two articles were excluded because they were not written in English or a Scandinavian language. Thus, nineteen full-text articles were ultimately included in the review.

Study characteristics

The characteristics of the studies are presented in Table 1. The included literature (n=19) was published from 1998 to July 2016. No studies prior to 1998 and after July 2016 were considered relevant. The studies consisted mainly of peer-reviewed scientific articles (n=13), followed by dissertations (n=3), conference posters (n=2), and non-peer-reviewed articles (n=1). The studies were undertaken in Europe (n=10), the US (n=4), Canada (n=4), and Australia (n=1) (Table 1).

Six studies were observational (qualitative n=5, quantitative n=1), six were interventional (qualitative n=2, quantitative n=3, mixed methods n=1), five were evaluation studies (qualitative n=2, quantitative n=2, mixed methods n=1), and two were case studies (qualitative n=1, quantitative n=1) (Table 1).

Consistent with our inclusion criteria, the included literature referred to people with dementia (n=8 studies), their formal caregivers (n=3 studies), or a combination of those two groups (n=8) (Table 1).

Aims, conclusions and recommendations for practice from included literature

The results showed an overall tendency towards positive experiences gained from applying person-centred approaches in clinical practice influenced by the theoretical framework, although substantially different

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factors, concepts and approaches were explored. The aim, conclusion and recommendations for practice from each included study are presented in Table 2. Through our synthesis of data, we identified six categories related to our research aim: “Theoretical evaluation of Tom Kitwood’s framework”, “Models and frameworks”, “Interventions”, “Communication”, “Dementia Care Mapping”, and “Environment”.

**Theoretical evaluation of Tom Kitwood’s theoretical framework**

Theoretical evaluations of Tom Kitwood’s framework were conducted in studies by Hunter et al. (16) and Kaufmann and Engel (17). In both studies, the theories and concepts of Tom Kitwood provided empirical evidence and relevance, although the study by Kaufmann and Engel (17) called for a change. Through a series of three studies, Hunter et al. (16) stated that health providers’ care decisions were positively influenced by their knowledge about patients’ personhood as assessed through the Personhood in Dementia Questionnaire. The questionnaire was considered a useful tool for measuring person-centred attitudes towards people with advanced dementia (16). Kaufmann and Engel (17) stated that Kitwood’s model of psychological needs and well-being in dementia had empirical relevance but needed extension. Specifically, several differences were found between Kitwood’s definitions of psychological needs and well-being and the subjective experiences of the individuals with dementia.

**Models and frameworks**

Two different models and frameworks were described and evaluated in the studies by Hadley et al. (18) and Rosvik et al. (19). The models and frameworks were generally considered useful, but with mixed results regarding their implementation in daily practice. The VIPS model provided a common base of knowledge and was able to convert the concept of the person-centred approach into daily care (19), while the Positive Response Schedule, on the other hand, reduced some of the limitations of DCM but was too detailed for use in daily practice (18).

**Interventions**

Five studies examined the effect of interventions. The experiences gained using the person-centred approach influenced by Tom Kitwood in interventions were generally positive. People with dementia experienced occupational tasks as meaningful and reported increased well-being, while formal caregivers reported an increase in confidence and work satisfaction (20, 21, 22). However, Kelly (21) also found that formal caregivers not being influenced by the person-centred approach, led to ill-being for people with
dementia. A study by Buron (23) found that person-centred Life History Collages based on Tom Kitwood’s concept of personhood increased formal caregivers’ knowledge and perceptions of the residents with dementia. Additionally, in a study by Theurer et al. (24), the concept of personhood inspired weekly discussions of themes in mutual support groups, leading to a decrease in loneliness and an increase in friendship, coping, and understanding among people with dementia.

Communication
The category, “Communication”, was identified in four studies. Those four studies mainly supported Kitwood’s approach to successful communication. Tom Kitwood suggested that successful communication had a positive influence on the well-being and quality of life of people with dementia (25). Acton et al. (25) supported this idea, finding that individual communication prescriptions encouraged people with dementia to better communicate their needs, preferences and ideas. Amstrup (26) found that people with dementia and severe dementia used social, emotional and cognitive resources when interacting with other people. In those interactions, they demonstrated humour, creativity and fellow-feeling, all of which are indicators of relative well-being as defined by Tom Kitwood. Skovdahl et al. (27) found that Kitwood’s idea of positive interactions, or ‘power to’, was the most suitable approach for formal caregivers managing aggressive behaviour in people with dementia. On the other hand, Schindel (28) called for more guidelines, education and research in order for caregivers to interact in a person-centred way when communicating with people with dementia.

Dementia Care Mapping
Dementia Care Mapping (DCM) as a category was identified in three studies. The three studies were positive about DCM as a tool for quality assurance or evaluation, or as part of an intervention. Brooker et al. (29) and Campbell and Davis (30) used DCM as a tool for assessing the care process in a dementia care setting. Brooker et al. (29) found DCM very useful as an audit tool, reporting that it resulted in improved quality of care for people with dementia. Brooker et al. (29), evaluating the care process using DCM, reported an increased possibility for formal carers to maintain the personality of the demented and their well-being. As a tool for improving non-verbal communication for people with dementia, DCM was very useful, resulting in a decreased number of drug prescriptions for people with dementia (31).

Environment
The environment was identified as a category in three studies (32,33,34). Both Chaudhury et al. (32) and Hiroto (33) had a favourable view of the effect of physical environments influenced by Kitwood’s
framework of person-centred care, while Sharpp (34) called for an environmental change at the assisted living facility examined in the study. According to Chaudhury et al. (32), environmental renovations inspired by the concept of person-centred care improved the mealtime experience for people with dementia, and formal caregivers provided a more person-centred form of care. However, more staff was needed to fully deliver person-centred care after the renovation (32). Using stimuli to change the wandering behaviour of people with dementia in a study by Hiroto (33), was greatly influenced by interactions between staff and residents. Staff acted in a person-centred way by facilitating residents’ interests in stimuli, thus revealing residents’ personal identities and preferences (33). In the study by Sharpp (34), the challenges of providing person-centred care consisted of an administrative conflict of providing quality care versus making a profit; untrained caregivers who lacked knowledge of person-centred care; and lack of consistency in monitoring, assessing and communicating residents’ health care needs. To overcome these challenges, Sharpp (34) advocated for employment of gerontological nurses at the assisted living facility to teach caregivers person-centred care, thereby improving the environment and the quality of life for residents with dementia.

Please insert Table 2
Discussion

The six synthesised categories all provided knowledge on current empirical experiences of Kitwood’s framework for approaches to high quality health care, aiming to support and strengthen the experience and feeling of sustained personhood among people with dementia.

Personhood as a core concept in Tom Kitwood’s theoretical framework

Several of the studies in this review evaluated the concept of personhood (16,17,20,21,22,23,24). Kitwood stressed the consolidation of personhood as an ongoing process, deeply influenced by social relationships and their interactions. Hence, Buron (23) attached special importance to health professionals knowing the person with dementia in detail and to staff understanding the person with dementia through empathy. Hunter et al. (16) also emphasised the importance of social interactions between health professionals and people with dementia. In this study, the concept of personhood was operationalised as a status by assessing health providers’ beliefs about the abilities and rights of people with dementia. Another perspective was employed by Theurer et al. (24), where the interaction among people with dementia was in focus. Kitwood’s understanding of personhood was here used to develop a weekly discussion group. The overall study findings supported Kitwood’s concept of personhood in the context of these relationships, suggesting that the social engagement among people with dementia may have also increased the sense of belonging and feelings of connectedness. The importance of positive relations is in agreement with Tolhurst et al. (35), who stressed the significance of interconnectedness and interdependencies of relationships in the maintenance of personhood and argued for these dynamics as a focus for further research in dementia care.

Kitwood based his research mainly on persons with moderate to severe dementia living in institutional care. The understanding of how psychosocial environmental factors may affect the person was developed mainly on the basis of close relatives’ and professionals’ perspectives (3). Moreover, in Kitwood’s theoretical framework, personhood is seen as a state endorsed by others and not a state maintained and shaped by people with dementia themselves (35). The study by Kaufmann and Engel (17) was the only study in this review that empirically investigated the subjective experiences of people with dementia. The findings suggested that all the domains in the model of needs developed by Kitwood were empirically supported. However, the analysis revealed a number of differences between Kitwood’s definitions and the experiences among people with dementia. Comments on comfort showed that some of the included persons with dementia were able to help themselves. Moreover, the findings suggested adding a new
domain, labelled “agency” and summarised in three components: self-determination, freedom of action, and independence.

Although understanding the world of experience of people with dementia is deeply influenced by the theoretical work of Kitwood, more current explanatory models of experiencing the world with dementia also emphasise psycho-social aspects and approaches (Zweijsen, van der Ploeg, & Hertogh, 2016). Here, the subjective experiences of feeling respected and being seen as a fellow human being, in particular by healthcare professionals, in order to be able to practice self-determination, are stressed. The ability to have everyday choices in relation to having own ideas taken into account by professional carers are also valued. The notions of accomplishing something meaningful, feeling of use and therefore of value, were considered important. Moreover, freedom to get around on ones’ own, having personal space and control over that space, were associated with respect and was deeply appreciated. These findings are in line with other current studies of people with dementia (O’Rourke et al., 2015; Stewart-Archer et al., 2016; Martyr, Nelis, Quinn, Wu, Lamont, Henderson, Clarke, Hindle, Thom, Jones, Morris, Rusted, Victor, & Clare, 2018). In the study by O’Rourke et al. (36), a person’s ability to express his or her sense of self and to experience autonomy and independence in day-to-day living, e.g., to be in control of the direction of daily life, to produce, to achieve, or to have a meaningful effect on others or society, was found to enhance the subjective experience of quality of life. The growing population of people with dementia living in institutional settings require support to achieve high quality of life, accentuates the importance of gaining a deeper insight into subjective perspectives. Therefore, in order to target factors that matter to people today, these findings suggest that concepts of quality of life and personhood may also need to include the persons’ subjective perspectives, to ensure the relevance and value of the person-centred dementia care offered.

**Successful communication and interactions**

Although Kitwood emphasised that engaging communication positively influenced the well-being and quality of life of people with dementia, little empirical evidence has supported these assumptions (25). On this subject, several of the included studies stressed the need to explore how best to increase and qualify social communication between people with dementia and health professionals in clinical practice (25,26, 27,28). More successful communication interactions were expected to increase the ability of health professionals to meet the needs of persons with dementia, potentially decrease problematic behaviours and thereby improve the relationship between persons with dementia and health professionals. The results of the included studies implied that the development of strategies for successful communication might be a suitable way to improve clinical practice. Skovdahl et al. (27) emphasised that it might be difficult to generate and sustain suitable amounts of support from health professionals to maintain the autonomy of
the people with dementia. Reflective clinical reasoning and formal clinical knowledge and competencies might reduce the risk of the professionals becoming trapped in routines and adopting stereotyped attitudes in daily clinical practice (27). Acton et al. (25) concluded that the intervention strategies they had employed to promote meaningful conversation interactions were inexpensive and at the same time, easily taught and implemented. Amstrup (26) also advocated for engaged and empathetic communication and stressed this process as a window to detailed knowledge of the individual person with dementia. Furthermore, Schindel (28) highlighted the need to change organisational cultural perspectives through guideline development, educational initiatives, and further research in order for clinical culture to come into alignment with a person-centred approach, that acknowledges the dignity and quality of life of people with dementia.

**Useful models and tools to improve quality of care**

Several studies in this review employed DCM to assess and evaluate quality of care or as an integrated tool in clinical interventions (29,30,31). Brooker et al. (29) employed DCM in several dementia care settings over three annual evaluations. The results reflected improvements in the quality of dementia care and were considered very positive. Although DCM was based on observations and might affect the practice of health professionals, DCM was deemed appropriate for use in formal dementia care settings (29). In the study by Campbell and Davis (30), the assessments were completed by trained mappers within seven dementia care settings. The overall results showed an increasing potential for health professionals to meet the psychological needs, sustain the personhood, and enhance the well-being of people with dementia living in the included dementia care settings (30). DCM was also recently found by Leners (31) to be a useful tool for improving non-verbal communication in people with dementia, as DCM might help health professionals understand unusual behaviour in persons in advanced stages of dementia. As an alternative to DCM, Hadley et al. (18) employed the Positive Response Schedule, which was developed by Perrin for persons with severe dementia. They determined that although the tool by Perrin was a labour-intensive measure, it overcame some of the limitations of DCM. According to Hadley et al. (18), DCM lacks the sensitivity to detect changes in the well-being of people with severe dementia, especially changes that are sustained only for short time periods. Hadley et al. (18) concluded that the PRS extended the range of people whose care could be evaluated by instruments designed within the scope of person-centred care, as defined by Kitwood. Rosvik et al. (19) employed another alternative to DCM by implementing a well-structured and person-centred care framework called VIPS (Values people, Individual’s needs, Perspective of service user, Supportive social psychology) based on the work of Kitwood. The results of the study indicated that well-supervised facilitating roles based on the context are crucial for implementation (19).
Environmental factors affecting person-centred care

In contrast to other, more contemporary theoretical frameworks within health care, Kitwood’s framework does not consider the impact of the physical environment (2). However, this factor is receiving growing attention in an effort to comply with existing expectations for modern everyday life.

There seems to be a growing recognition of environmental factors as unacknowledged resources in long-term care for people with dementia. Chaudhury et al. (32) noted the existing gap in the understanding of how the physical environment might support person-centred care as part of a change in the culture of care practice. Their study investigated the impact of environmental changes in dining spaces in a long-term care setting. The study concluded that although the physical environment might play an influential role in enhancing the experience of people with dementia, the variability in staff practices underlined the importance of a systemic approach in implementing meaningful culture changes (32). Hiroto (33) accentuated the movement of creating homelike environments for people with dementia as a mark of the conceptual shift towards recognising people with dementia. In his study, he investigated how interactions between personal and environmental characteristics impacted the experience and use of space (33). Hence, the studies by Chaudhury et al. (32) and Hiroto (33) both drew attention to the dialectical dynamics between people and their environments, which is of increasing relevance in current dementia care. The qualifications and experiences of care staff in institutional settings may also affect the environment. Thus, in order to change the mental environment in an assisted living facility, Sharpp (34) called for a change in the administrative practices of the facility, as well as further education of care staff.

Limitations

The results in the present scoping review are subject to certain limitations. First, the review focused only on institutional settings in primary health care; thus, its conclusions should be interpreted cautiously in other settings. Second, only English and Scandinavian-language sources were reviewed; any relevant studies that may have been produced in other languages were disregarded. Third, the findings of the review were subjectively included and interpreted by the authors, albeit under rigorous procedures, and if any individual author had doubts about a study’s suitability or outcome, the other authors were consulted. Finally, the review did not assess the methodological quality of the included studies, but merely mapped the evidence to provide a scientific overview of the topic. Consequently, critical reflections should be employed when the findings are translated into policy and practice.
Conclusion and implications
The present review included nineteen studies published from 1998 to 2016 and consisted mainly of peer-reviewed scientific articles, followed by dissertations, conference posters, and non-peer-reviewed articles. All studies were undertaken in Western countries. Although the included literature diverged in terms of their approaches, research designs and methods, the vast majority of the included studies considered Kitwood’s theoretical framework beneficial and useful in practice. More studies are warranted in order to strengthen the existing knowledge base and to further expand the understanding of practical empirical experiences based on Kitwood’s theoretical framework.

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Declaration of conflicting interests
The authors declare that there is no conflict of interest.

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References


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Figure 1 Modified PRISMA flow diagram illustrating the article selection process for the scoping review (Moher et al., 2009)
Figure 2: Key concepts and synthesized categories

Key concepts related to research aim:
- Tom Kitwood’s theoretical framework
- Personhood
- Person-centred care
- Malignant social psychology
- Caregivers’ experiences, attitudes and considerations

Synthesized categories identified:
- Theoretical evaluation of Tom Kitwood’s framework
- Models and frameworks
- Interventions
- Communication
- Dementia Care Mapping
- Environment
### Table 1: Study characteristics (N=19)

<table>
<thead>
<tr>
<th>Author(s), year</th>
<th>Title</th>
<th>Source</th>
<th>Country</th>
<th>Design/method</th>
<th>Participants</th>
</tr>
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<td>Acton, Yauk, Hopkins, &amp; Mayhew, 2007</td>
<td>Increasing social communication in persons with dementia</td>
<td>Research &amp; Theory for Nursing Practice</td>
<td>US</td>
<td>Intervention study; quantitative</td>
<td>10 persons with dementia residing in the same nursing home</td>
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<tr>
<td>Amstrup, 2007</td>
<td>Exploit the resources of elderly dementia sufferers</td>
<td>Sygeplejersken</td>
<td>Denmark</td>
<td>Observational study; qualitative</td>
<td>Demented (7 women and 2 men)</td>
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<td>Brooker, Foster, Banner, Payne, &amp; Jackson, 1998</td>
<td>The efficacy of Dementia Care Mapping as an audit tool: report of a 3-year British National Health Service evaluation</td>
<td>Aging &amp; Mental Health</td>
<td>UK</td>
<td>Evaluation; quantitative</td>
<td>National Health Service staff</td>
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<tr>
<td>Buron, 2009</td>
<td>Promoting personhood among nursing home residents living with dementia</td>
<td>Dissertation</td>
<td>US</td>
<td>Intervention study; quantitative</td>
<td>36 nursing staff</td>
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<td>Campbell &amp; Davis, 2011</td>
<td>The value of dementia care mapping in evaluation</td>
<td>Conference poster publication</td>
<td>Australia</td>
<td>Evaluation study; quantitative</td>
<td>Residents and staff at 11 residential aged-care facilities</td>
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<td>Chaudhury, Hung, Rust, &amp; Wu, 2017</td>
<td>Do physical environmental changes make a difference? Supporting person-centred care at mealtimes in nursing homes</td>
<td>Dementia</td>
<td>Canada</td>
<td>Intervention study; qualitative</td>
<td>10 residents and survey responses from 17 care aides and nurses</td>
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<td>Hadley, Brown &amp; Smith, 1999</td>
<td>Evaluating interventions for people with severe dementia: using the Positive Response Schedule</td>
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<td>Case study; quantitative</td>
<td>2 older adults diagnosed as having severe dementia</td>
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<td>Harvey, 2016</td>
<td>Can staff education reduce the occupational deprivation of people with dementia?</td>
<td>British Journal of Occupational</td>
<td>UK</td>
<td>Case study; qualitative</td>
<td>Persons with dementia and 1 carer</td>
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<tr>
<td>Hiroto, 2011</td>
<td>Engaging the senses: Creating a multisensory environment to alter how residents with dementia use space</td>
<td></td>
<td>Dissertation</td>
<td>UK</td>
<td>Intervention study, qualitative and quantitative</td>
</tr>
<tr>
<td>Hunter, Hadjistavropoulos, Smythe, Malloy, Kaasalainen &amp; Williams, 2013</td>
<td>The Personhood in Dementia Questionnaire (PDQ): establishing an association between beliefs about personhood and health providers' approaches to person-centred care</td>
<td></td>
<td>Journal of aging studies</td>
<td>Canada</td>
<td>Intervention and evaluation studies; a series of three studies; qualitative and qualitative</td>
</tr>
<tr>
<td>Kaufmann &amp; Engel, 2016</td>
<td>Dementia and well-being: A conceptual framework based on Tom Kitwood’s model of needs</td>
<td></td>
<td>Dementia</td>
<td>Germany</td>
<td>Evaluation study; qualitative</td>
</tr>
<tr>
<td>Kelly, 2010</td>
<td>Recognising and supporting self in dementia: A new way to facilitate a person-centred approach to dementia care</td>
<td></td>
<td>Ageing &amp; Society</td>
<td>UK</td>
<td>Observational study; qualitative</td>
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<tr>
<td>Leners, 2016</td>
<td>Dementia care mapping: A tool to improve non-verbal communication for people with dementia</td>
<td></td>
<td>Conference poster publication</td>
<td>Luxembourg</td>
<td>Observational study; quantitative</td>
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<tr>
<td>Rosvik, Kirkevold, Engedal, Brooker, &amp; Kirkevold, 2011</td>
<td>A model for using the VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study</td>
<td></td>
<td>International Journal of Older People Nursing</td>
<td>Norway</td>
<td>Evaluation study; qualitative</td>
</tr>
<tr>
<td>Schindel Martin, 2004</td>
<td>Exploding the culture of censorship, repression and silence: a critical ethnographic study of response to sexual behaviour in persons with dementia living in long-term care</td>
<td></td>
<td>Dissertation</td>
<td>Canada</td>
<td>Observational study; qualitative</td>
</tr>
<tr>
<td>Sharpp, 2008</td>
<td>An ethnography of dementia care in an assisted living facility</td>
<td></td>
<td>Dissertation</td>
<td>US</td>
<td>Observational study; qualitative</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Journal</td>
<td>Country</td>
<td>Study Design</td>
<td>Participants</td>
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<tr>
<td>Skovdahl, Kihlgren, &amp; Kihlgren, 2003</td>
<td>Dementia and aggressiveness: video recorded morning care from different care units</td>
<td>Journal of Clinical Nursing</td>
<td>Sweden</td>
<td>Observational study; qualitative</td>
<td>Nine caregivers and two residents</td>
</tr>
<tr>
<td>Theurer, Wister, Sixsmith, Chaudhury, &amp; Lovegreen, 2014</td>
<td>The development and evaluation of mutual support groups in long-term care homes</td>
<td>Journal of Applied Gerontology</td>
<td>Canada</td>
<td>Evaluation and observational study; qualitative</td>
<td>Six resident groups, individual resident interviews (N=65), and staff interviews (N=7) in three long-term care homes</td>
</tr>
<tr>
<td>van Weert, van Dulmen, Spreeuwenberg, Bensing &amp; Ribbe, 2006</td>
<td>Nursing assistants’ behaviour during morning care: effects of the implementation of snoezelen, integrated in 24-hour dementia care</td>
<td>Journal of Advanced Nursing</td>
<td>Netherlands</td>
<td>Intervention study; quantitative</td>
<td>Certified assistant nurses and older mentally infirm patients at six nursing homes</td>
</tr>
</tbody>
</table>
Table 2 Aims, conclusions and recommendations for practice from the included literature (N=19)

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study aim</th>
<th>Authors’ conclusion</th>
<th>Authors’ recommendations for practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acton, Yauk, Hopkins, &amp; Mayhew, 2007</td>
<td>This study aimed to determine whether individualised communication prescriptions (ways interviewers might facilitate collaborative communication) would be effective in successful collaborative communication and increasing well-being and quality of life in persons with dementia.</td>
<td>Systematic, individualised communication strategies may encourage persons with dementia to express their needs, preferences, and ideas. These strategies may also help institutional caregivers manage problematic behaviour, resulting in lower care costs and increased quality of life for residents.</td>
<td>Intervention strategies promoting meaningful conversation interactions are inexpensive and easy to teach and implement.</td>
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<td>Amstrup, 2007</td>
<td>This study explored the mental resources of older adults with severe dementia.</td>
<td>The study showed that the elderly had insight into themselves and their situation, assertive capacity, perseverance, fellow-feeling, humour and creativity. The study confirmed the indicators of relative well-being in dementia identified by the British dementia researcher Tom Kitwood.</td>
<td>Take dementia sufferers words and actions seriously. Follow the emotional rhythm of the elderly. Acknowledge dementia sufferers’ cultural competence in thought and deed. Acknowledge dementia sufferers’ need for active development in thought and deed. Involve the dementia sufferers in decisions about, as well as participation in, daily care and other activities. Focus on the relation rather than the task. (Translated from Danish.)</td>
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<tr>
<td>Brooker, Foster, Banner, Payne, &amp; Jackson, 1998</td>
<td>This paper reported on the experience of using Dementia Care Mapping (DCM) over three annual Quality Assurance cycles on nine formal dementia care</td>
<td>Dementia Care Mapping was successfully incorporated into a large-scale British NHS Quality Assurance Programme with obvious benefits to service users.</td>
<td>A significant minority of staff found DCM anxiety provoking. Mechanisms need to be built into the process to decrease this anxiety. Training a large number of</td>
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</table>
units. Specifically, the aims of this study were to assess the efficacy of DCM as part of a Quality Assurance strategy for people with dementia within the NHS and to assess the acceptability of the method to nursing and care staff as an audit of quality.

Buron, 2009

The study evaluated the effect of individualised, or person-centred, Life History Collages on (1) changes in nursing staff knowledge of individual residents and (2) nursing staff perceptions of (a) knowing the person, (b) staff-to-resident communication, and (c) staff-to-staff communication.

On the basis of Kitwood's theory of personhood, improved knowledge and perceptions of residents living with dementia may lead to improved personhood status.

Elevated personhood status has strong implications for caregiving practices in the National Health setting.

Campbell & Davis, 2011

This poster focused on the value of DCM as part of the evaluation process. Outcome indicators included levels of psychotropic drug use, frequency of behaviours of concern and reported incidents, measures of individualised care practices, well-being, quality of life and family involvement.

Overall, across participating facilities, DCM results showed that the proportion of personal enhancers increased by 40%, thereby increasing the potential for staff to sustain residents' personhood, meeting residents' psychological needs and enhancing well-being. The proportion of personal detractors decreased.

No recommendations

Chaudhury, Hung, Rust, & Wu, 2017

Drawing on therapeutic physical environmental design principles and Kitwood's theoretical view of person-centred care, this study examined the impact of environmental renovations in the dining spaces of a long-term care facility on residents' mealtime experience and staff practice in two care units.

Increased staff on the unit and addition of a dedicated kitchen staff were important contributing factors in increasing the staff's capacity to provide personal attention to the residents and to work effectively as a team.

Although the physical environment can play an influential role in enhancing the dining experience of residents, the variability in staff practices reveals the complexity of the mealtime environment and points to the necessity of a systemic approach to foster meaningful culture change.

Physical environmental
interventions, such as adding an open kitchenette and creating a more homelike dining atmosphere with appropriate interior design changes, can enhance the quality of residents’ dining experience and create positive work environment for staff to deliver person-centred care.

Organisational and staff culture change needs to be addressed in a systemic approach, in conjunction with making improvements to the physical environment.

| Hadley, Brown, & Smith, 1999 | The Positive Response Schedule (PRS) was used in this study to assess the impact of short, individualised interventions on the well-being of two older adults diagnosed as having severe dementia. | The PRS is a labour-intensive measure that overcomes some limitations of Dementia Care Mapping and extends the range of people whose care can be evaluated by instruments designed within the scope of person-centred care as defined by Kitwood (e.g., 1997). It helps detect component, rather than composite, behaviours. | Since direct care staff could rarely spare the considerable time required solely for observation, the PRS is mainly a research tool. |
| Harvey, 2016 | The case analysis considered the impact that a dementia training course had on the occupational engagement of people with dementia. | The carer reported an increase in meaningful occupation taking place, such as laying the table, leisure activities, socialising, and singing. The course had also improved the carer’s confidence and work satisfaction and influenced day-service culture. The education of one person increased the occupational engagement of several people with dementia. The training also appeared to break down the wider socio-environmental barriers that had restricted No recommendations were set forth. |
This article explored how interactions between personal and environmental characteristics impacted the experience and use of space among 10 residents living in a unit for persons with dementia. This study demonstrated the importance of conceptualising the personhood of both residents and staff members beyond the level of personal characteristics (e.g., their sense of time, use of home/work space) in order to provide a deeper level of person-centred care. Moreover, the results from this exploratory study suggested that the construct of the person-environment fit needs to consider the multiple interactions between the resident with dementia, their care provider(s), and their objective and subjective experiences of this shared care environment.

Hunter, Hadistavropoulos, Smythe, Malloy, Kaasalainen & Williams, 2013

Although Kitwood (1997) emphasised that personhood, a status extended by others, is at the heart of person-centred care, to our knowledge, no one has demonstrated empirically that beliefs about patient status influence how care is provided. The purpose of this series of studies was to investigate how provider beliefs about patient status are related to the care provider's use of psychosocial strategies. Our results indicated that having stronger positive beliefs about personhood in dementia increased the likelihood that health providers would select analgesics and non-pharmacological interventions, and decreased the likelihood of selecting psychotropic medication, compared to other measures of person-centeredness, the Personhood in Dementia Questionnaire (PDQ) is unique in two main ways. First, no other measure of person-centeredness relies solely on self-reports of attitudes. This feature makes the PDQ particularly well suited for use in long-term care communities wishing to enhance their environment with engaging stimuli should consider including a diverse collection of stimuli that engage multiple domains of residents’ lives (e.g., personal, work, hobbies). Stimuli should be placed within areas where residents tend to congregate (e.g., dining room, lounge). This placement would also fit with staff members’ use of their work space. Despite the multiple precautions taken to create secure and safe environments for persons with dementia (e.g., secured doors, overhead security cameras), staff remained concerned that residents might find ways of leaving. Considering the degree of anxiety around this concern, staff members would benefit from further education on the low potential for this risk. The amount of time that staff members spend redirecting residents from exit doors to avoid departure could then be redistributed to other responsibilities and activities.
Three studies was to operationalizes Kitwood’s definition of personhood in order to test this hypothesis. In response to the vignettes. Thus, these results provide the first direct empirical evidence of Kitwood’s (1997) theory that beliefs about patient personhood have the potential to influence health providers’ care decisions, including decisions about pain management.

<table>
<thead>
<tr>
<th>Kaufmann &amp; Engel, 2016</th>
<th>The study aimed to examine Tom Kitwood’s model of psychological needs and well-being in dementia through the self-reports of individuals with moderate or severe dementia and to differentiate and elaborate this model in the light of the empirical qualitative data.</th>
<th>The study was able to find indications that Kitwood’s model has empirical relevance. Nevertheless, it needs to be extended by the addition of agency as a domain. Furthermore, the study suggests that individuals with dementia are important informants on their own subjective well-being.</th>
<th>Kitwood’s conceptual framework needs to be extended. The suggested domain is called agency because Kitwood himself describes agency as one of four global sentient states of well-being.</th>
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<tr>
<td>Kelly, 2010</td>
<td>This paper reported findings from a three-year project that integrated Kitwood’s (1997) person-centred and Sabat’s (2001) selfhood approaches in the design, fieldwork and analysis of a multimethod observational study exploring the social worlds of 14 people with dementia in continuing care.</td>
<td>The findings indicate that staff interactions in the wards were often limited and sometimes abusive and that participants experienced ill-being, whereas during creative sessions, interactions were generally facilitatory and celebratory, with the participants experiencing well-being.</td>
<td>There is scope for incorporating this developed selfhood framework into staff training, for it has the potential to transform practice and the experiences of people with dementia in receipt of care. I therefore recommend a shift in focus, from examining elements of the care interaction to looking outwards towards those for whom we care. If practitioners are taught to recognise and support verbal and visual expressions of the self of the</td>
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<tr>
<td>Reference</td>
<td>Summary</td>
<td>Evidence</td>
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<td>Leners, 2016</td>
<td>Leners sought to determine whether non-verbal communication improved after person-centred care was implemented for 6 months.</td>
<td>DCM is a useful tool for geriatricians to understand the unusual behaviour of persons in advanced stages of dementia. Through this positive attitude, the physician is less susceptible to negative attitudes about his or her patient and will prescribe less. No recommendations were made.</td>
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<tr>
<td>Rosvik, Kirkevold, Engedal, Brooker, &amp; Kirkevold, 2011</td>
<td>This study conducted an initial evaluation of a model aimed at facilitating the application of the VIPS (Values people; Individual’s needs; Perspective of service user; Supportive social psychology) framework.</td>
<td>The model worked best in wards organized with a leading registered nurse who could support an auxiliary nurse responsible for the facilitating function. The model offers a way of translating the concepts of person-centred care into daily care in nursing homes. The model can build a shared base of knowledge and instil the values of person-centred care in the team. The model requires little change in the organisation and fits within normal resources.</td>
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<tr>
<td>Schindel Martin, 2004</td>
<td>This dissertation was undertaken to scrutinise the positions of professional and family care givers in response to the sexual behaviours of persons living with dementia in three long-term care facilities. In keeping with the tenets of critical ethnography and critical social theory, the intent was to identify response patterns that might need to be altered to reflect a person-centred philosophy of dementia care.</td>
<td>All three sites had limited in-house resources, poorly developed or non-existent practice guidelines, and management strategies based on highly conservative and restrictive risk management philosophies. As a result, sexual expression for persons with dementia exists in these facilities within a vacuum that would preclude formal exploration of ways to promote their sexual health. Since practice response appears to be highly influenced by personal value and belief systems, it is essential that as many front-line staff and families as possible are involved with the development of guidelines and the evaluation of their implementation. &quot;Care unit champions&quot; should be assigned to act as liaisons between their colleagues and the team assembled to develop guidelines. Guidelines need to be reflective of the potential for relationships developing between residents of the same gender and need to acknowledge the sexual needs of transgendered individuals.</td>
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<tr>
<td>Author(s)</td>
<td>Purpose of the Study</td>
<td>Findings</td>
<td>Implications</td>
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<td>Sharpp, 2008</td>
<td>The purpose of this study was to examine how care is provided to residents with dementia in an assisted living facility (ALF).</td>
<td>This study illuminates the role gerontological nurses could play if they were employed in an ALF. First, gerontological nurses could improve the care of older adults with dementia by educating caregivers. Nurses have unique insights into the needs of residents with dementia and could teach caregivers about those needs by offering formal classes and by working alongside caregivers, demonstrating proper methods. Second, gerontological nurses know the common illnesses that afflict older adults in long-term care facilities and could assess and monitor residents for those illnesses, possibly preventing hospital and emergency department admissions. Finally, nurses could show caregivers how to communicate and interact with residents with dementia, and they could show caregivers how to deliver person-centred care to them, thus improving a facility’s environment and, most importantly, the quality of life of its residents.</td>
<td>In order to make the needs of residents a consistent priority, the delivery of person-centred care requires cooperation between caregivers and their administration. In addition, it requires that the employees know how to monitor and assess the unique health needs of residents with dementia, which the employees in the studied facility did not have. While this study was conducted in just one ALF, the findings, if replicated, have policy implications. In particular, the current regulations for medication administration, while minimal, were violated by the caregivers and administrative staff, which has multiple clinical and ethical implications. Additionally, the staffing in the facility was not adequate, as caregivers were frequently responsible for showering, dressing, and feeding 8 residents each. Caregivers working the night shift were responsible for 15 residents each but often slept during their shifts.</td>
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<td>Skovdahl, Kihlgren, &amp; Kihlgren, 2003</td>
<td>The aim of the study was to characterise, from video-recorded sequences, the interactions of individuals with dementia and aggressive behaviour.</td>
<td>Our conclusion is that caregivers should use power ‘to’ when they have to help persons with dementia and aggressive behaviour. When caregivers must help a resident, they should act in a sensitive and reflective manner by using their power ‘to’. In other words, caregivers should be able to use power ‘to’ when it is necessary to help a resident.</td>
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This article describes the development of a new mutual support group intervention for long-term care homes (LTCH); evaluates the processes, structure, and content of the intervention; and addresses replication and sustainability.

Introducing mutual support groups as a part of a system of care within LTCH has a number of potential benefits. The format creates a group dynamic that encourages individual participation. With a positive support structure in place, more residents will be empowered to engage in decision making. Given the disparity between the unmet needs of residents and the costs of individual care, offering opportunities for residents to engage regularly in mutual support groups could provide cost savings. Finally, although further research on outcomes is needed, mutual support groups represent tremendous therapeutic potential for decreasing the loneliness, helplessness, and depression currently prevalent in care homes.

A number of recommendations for programme refinement were identified by staff, and these recommendations included the following: revision of the recordings to lower keys, use of a decorated talking stick to help residents with higher cognitive impairment identify its purpose, increased usage of the photographs, optimal group sizes (8 to 10 residents), use of the word assistant rather than leader, and the use of a volunteer to help with setup and clean-up.

This paper reports an investigation of the effects of the implementation of snoezelen, or multisensory stimulation, on the quality of nursing assistants’ behaviour during morning care.

Certified nursing assistants succeeded in improving the quality of their behaviour during morning care by employing a more person-centred approach. It seems likely that this change was the cause of the improved levels of well-being for nursing home residents suffering from dementia as found in a parallel study (van Weert, van Dulmen, Spreeuwenberg, Bensing & Ribbe, 2006).

The intervention offered in the present study included a well-evaluated education programme, with follow-up meetings and coaching or supervision. Use of snoezel care plans, the increase of mutual consultations, structural evaluations, adaptations in daily schedules and investments in snoezel materials for successful...
implementation of the new care model.
Figure 1 Modified PRISMA flow diagram illustrating the article selection process for the scoping review (Moher et al., 2009)

Records identified through database searches ($n=203$)
- CINAHL Complete: 53
- PsycINFO: 52
- PubMed: 36
- Academic Search Premier: 15
  - SocINDEX: 13
  - EMBASE: 11
  - Scopus: 10
  - Cochrane: 8
  - Web of Science: 4
  - Idunn: 1

Records screened by title and abstract ($n=154$)

Full-text articles assessed for eligibility ($n=30$)

Records excluded by title and abstract ($n=124$)

Duplicate records removed ($n=49$)

Records identified ($n=154$)

Full-text articles excluded ($n=11$)
- Full text not available in English or Scandinavian languages: 2
- Not relevant: 9

Full-text articles included ($n=19$)
Figure 2 Key concepts and synthesized categories

<table>
<thead>
<tr>
<th>Key concepts related to research aim</th>
<th>Synthesized categories identified</th>
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<tbody>
<tr>
<td>Tom Kitwood's theoretical framework</td>
<td>Theoretical evaluation of Tom Kitwood's framework</td>
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<td>Personhood</td>
<td>Models and frameworks</td>
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<td>Person-centred care</td>
<td>Interventions</td>
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<td>Malignant social psychology</td>
<td>Communication</td>
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<tr>
<td>Tom Kitwood's framework of person-centred care</td>
<td>Dementia Care Mapping</td>
</tr>
<tr>
<td>Caregivers' experiences, attitudes and considerations</td>
<td>Environment</td>
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