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Person-centredness in dementia care: an integrative review of theoretical approaches

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ABSTRACT

Objectives This review identifies and examines theoretical approaches (components and objectives) to person-centred dementia care in order to obtain a better understanding of what is meant by the concept of person-centred dementia care.

Design Following the approach of Whittemore and Knafl, an integrative literature review was conducted to answer the following questions: (1) Which theoretical approaches to person-centred dementia care have been published? (2) What are the components of the theoretical approaches to person-centred dementia care thus identified, and which objectives can be identified?

Data sources MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycINFO (via EBSCO) were searched through to 26 April 2021.

Eligibility criteria We included any kind of published literature that describes theoretical approaches to person-centred dementia care and that was written in German or English.

Data extraction and synthesis Two independent reviewers extracted data. Data were pooled using a data extraction form developed by the Joanna Briggs Institute. A qualitative content analysis was conducted.

Results The analysis revealed heterogeneous perspectives within the identified approaches to person-centred dementia care. Statements pertaining to the components and objectives could be assigned to three different subcategories (microlevel, macrolevel and application level). This analysis enabled an enhanced understanding of how person-centred dementia care is currently described and whether and how the theoretical approaches differ in terms of their orientations and their focus on the individual and/or on sociality, which allows conclusions regarding the underlying conceptual idea of personhood.

Conclusions There is a clear challenge for future research to overcome the dominance of the focus on the individual and to consider aspects of sociality to be at least equally important. This is needed in order to understand dementia as a multifaceted phenomenon that demands a differentiated consideration of theoretical notions of how to understand personhood in this context.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Our integrative review provides a systematic overview of international theoretical approaches to person-centred dementia care.
⇒ The analytical approach offers a way to operationalise theoretical approaches through inductive categorisation and thus contributes to a better understanding of what is meant by person-centred dementia care.
⇒ The inclusion of literature written in English or German languages only, as well as the inclusion only of publications that described an approach to person-centred dementia care explicitly, might have biased the results of our review.
⇒ As the differentiation between aims and outcomes was not always clearly described, we had to merge these categories in the analysis (with regard to potential changes in practice), making it difficult or even impossible to make plausible statements about measurably effective outcomes of person-centred dementia care.

INTRODUCTION

The idea of person-centred care can be traced back to, among other sources, Rogers[1] and his client-centred psychotherapy.[2] In the context of dementia care, the term was first used by Kitwood,[3 4] to identify the task of maintaining the personhood of people living with dementia as the central focus of person-centred care.[5] High-quality care is a precondition for the ability of people living with dementia to live well and for their families and care partners to be supported.[6] Since the 1990s, when Kitwood published descriptions of the fundamental aspects of person-centredness in dementia, the concept has been viewed as a point of reference in dementia care. What constitutes high-quality care for people living with dementia is closely linked to the concept of person-centred care.[3 4 7] Subsequently, the concept has been widely expanded and used as a basis for care guidelines, conceptions of nursing homes (NH) and practice models for dementia care[8–13]; it has even been called the gold standard for dementia care practice.[14 15] Nevertheless, at least from

a theoretical-conceptual perspective, the extent to which person-centredness can be understood as a unified concept is questionable, as there also seems to be a lack of clarity regarding how the personhood of people living with dementia can be conceptualised and understood in this context.[13 16–20] In a recent integrative review, Byrne *et al*[21] concluded that no common understanding of what is meant by person-centred care has yet been developed.

Considering the lack of such a common understanding, the aim of this integrative review is to identify theoretical approaches to person-centred dementia care and to analyse their components, pursued objectives and outcomes.

In accordance with this research aim, we address the following research questions:

1. Which theoretical approaches to person-centred dementia care have been published?
2. What are the components of the theoretical approaches to person-centred dementia care thus identified, and which objectives can be identified?

Here, theoretical approaches refer to explanations that specify or operationalise what is meant by person-centred dementia care. With regard to the second research question, we define components as the described content-related aspects which are offered within the approaches to differentiate or operationalise person-centred dementia care in terms of content. For identifying the objectives, we focus on what the approach is aimed at and what is to be achieved with the content components.

To answer these research questions, an integrative review of relevant literature was conducted. This approach offers a comprehensive understanding of the phenomenon under investigation, which in our case focuses on theoretical approaches to person-centred dementia care.

METHODS

The methodological approach used for the integrative review was described in a previously published review protocol.[22] Following the suggestions of Pieper *et al*,[23] we reuse the text of our review protocol in the methods section of this publication while making necessary changes in cases in which the process differed between the planned methodological approach and the approach that was actually implemented. There were no substantial changes to the study protocol, but there were two changes in total with regard to the research questions. The aspects of aims and outcomes of the second research question as originally stated in the protocol were combined to emphasise the objectives of the different approaches as a result of this integrative review. In addition, based on the literature included, it was decided to address the third research question on underlying concepts of personhood from the study protocol in another publication. However, the classification of the approaches to person-centred dementia care still allows to draw conclusions about the underlying concept of personhood in each case.

Table 1 Eligibility criteria

Criteria	Definition
Population	People living with dementia
Interest	Theoretical approaches (in the sense of theoretical/conceptual descriptions) describing/defining 'person-centred dementia care'
Context	Care of people living with dementia All settings of care (eg, nursing homes)
Types of sources	Any kind of literature, which describes theoretical approaches to 'person-centred dementia care'
Others	Languages: German and English Year: No restrictions

For our integrative review, we choose the review approach developed by Whittemore and Knafl,[24] which comprises the following five steps: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis and (5) presentation.

Literature search

To answer our research questions, we conducted a systematic literature search regarding the theoretical approaches to person-centred dementia care by using three literature databases (MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycINFO (via EBSCO)). The search terms as well as the inclusion criteria were based on our research aims and questions and were developed in accordance with the PICo (Population, Interest, Context) framework[25] and supplemented with the additional categories types of sources and others (table 1). The search terms were clustered according to population and interest. We formulated no search terms pertaining to the context since the context of care for people living with dementia is also represented by the phenomenon of interest (ie, theoretical approaches to person-centred dementia care) and does not require further specification. The search strings were developed first for the database MEDLINE (via PubMed) and subsequently adopted for the other databases (see online supplemental table S1) according to RefHunter V.5.0.[26] We supplemented the systematic search by using handsearching techniques, such as trawling specific journals and performing forwards (via Google Scholar) and backwards (via reference lists) citation tracking,[27 28] as this procedure is considered to be particularly relevant for reviews of theoretical approaches.[29]

Publication selection

For the screening process, the records, thus, identified were transferred to the reference manager EndNote[30] and then to the systematic review management system Covidence,[31] where all records were first automatically checked for duplicates. Title and abstract screening were performed by three reviewers (JS-K (100% of all records), DP (50% of all records) and MR-M (50% of

all records)) independently according to the defined inclusion criteria. The same reviewers performed a full-text screening of all records that were assessed as potentially relevant. The reasons for the exclusion of certain full texts were recorded. Any disagreements among the reviewers throughout the screening process were resolved through discussion between the specific reviewers who disagreed or, in cases in which consensus could not be reached, among all coauthors.

Data evaluation

With regard to possible data evaluation, no review of the methodological quality of the included records was planned and conducted, as the aim of the integrative review was to identify the theoretical approaches to person-centred dementia care regardless of the quality or type of the publications in question and to analyse those approaches in relation to the defined aspects. Additionally, no assessment of relevance[24] of the included records with regard to answering the questions prior to the data analysis was planned because all included records were integrated into the data analysis. If certain theoretical approaches were described in several publications (eg, Kitwood or Brooker), we consolidated this material before the data extraction since the overall theoretical approach was the unit of interest rather than a single report.[32]

Data extraction

Our data extraction form was based on a template developed by the Joanna Briggs Institute.[33 34] We considered general information, including (1) the names of the authors, (2) the year in which the publication was published, (3) the country to which the publication refers/from which the authors originated, (4) the type of publication and (5) the name of the theoretical approaches described in/mentioned by the publication. The data were extracted by one researcher (JS-K) and checked by a second researcher (MR-M). Deviations were discussed, and in case of disagreement, the coauthors were consulted.

Analysis

To analyse the person-centred dementia care approaches, we conducted a qualitative content analysis to determine (1) the components and (2) the objectives according to the identified publications. According to the approach developed by Schreier,[35] content analysis comprises the following steps: (1) familiarisation with the material, (2) deductions of superordinate categories based on the research question, (3) determination of finding places and/or coding units, (4) inductive development of subcategories (including category definition) using an iterative approach and coding of the entirety of the material and (5) presentation of the results (both for each theoretical approach and across theoretical approaches), interpretation and answering of the research questions. We conducted the content analysis in a deductive-inductive mixed method. In a first step, we deductively derived our main categories ('components' and 'objectives') from our research questions and coded the included literature based on these categories. In a second step, we carried out an inductive coding process in the form of open coding with the aim of forming subcategories and abstracting through the mapping process in order to create inductively constructed subcategories within the main categories. For this purpose, the identified text passages were read intensively and checked for their fit with the deductive main categories (components, objectives), and subcategories were formed with the help of generated notes and headings. Similar subcategories were grouped depending on whether they could be assigned to certain dimensions of the main categories. An example of the analytical inductive process is provided in figure 1.

The analysis and coding of the material were performed independently by two researchers (JS-K and MR-M) using qualitative data analysis software MAXQDA.[36] The results of the coding process were checked for deviation, discrepancies were discussed and in cases in which no consensus was reached, the coauthors were consulted. A final assignment of coding units to categories was performed on the basis of a process of comparison and consensus between these researchers. An excerpt review of the results of the

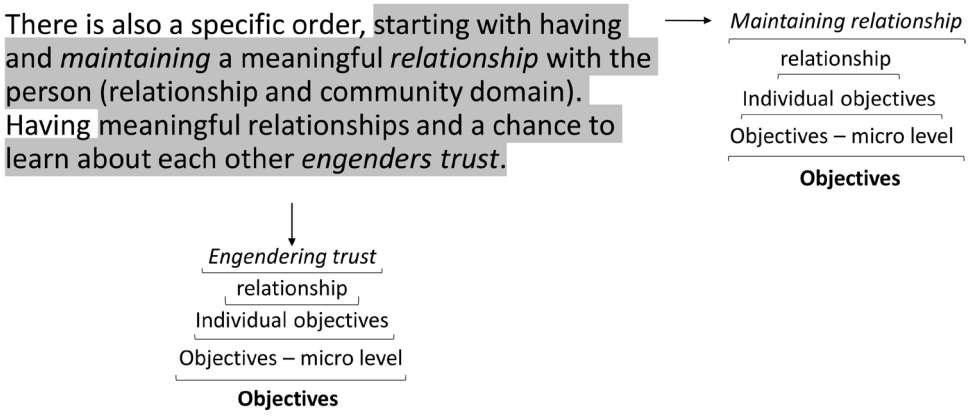

Figure 1 Example of analytical inductive process.

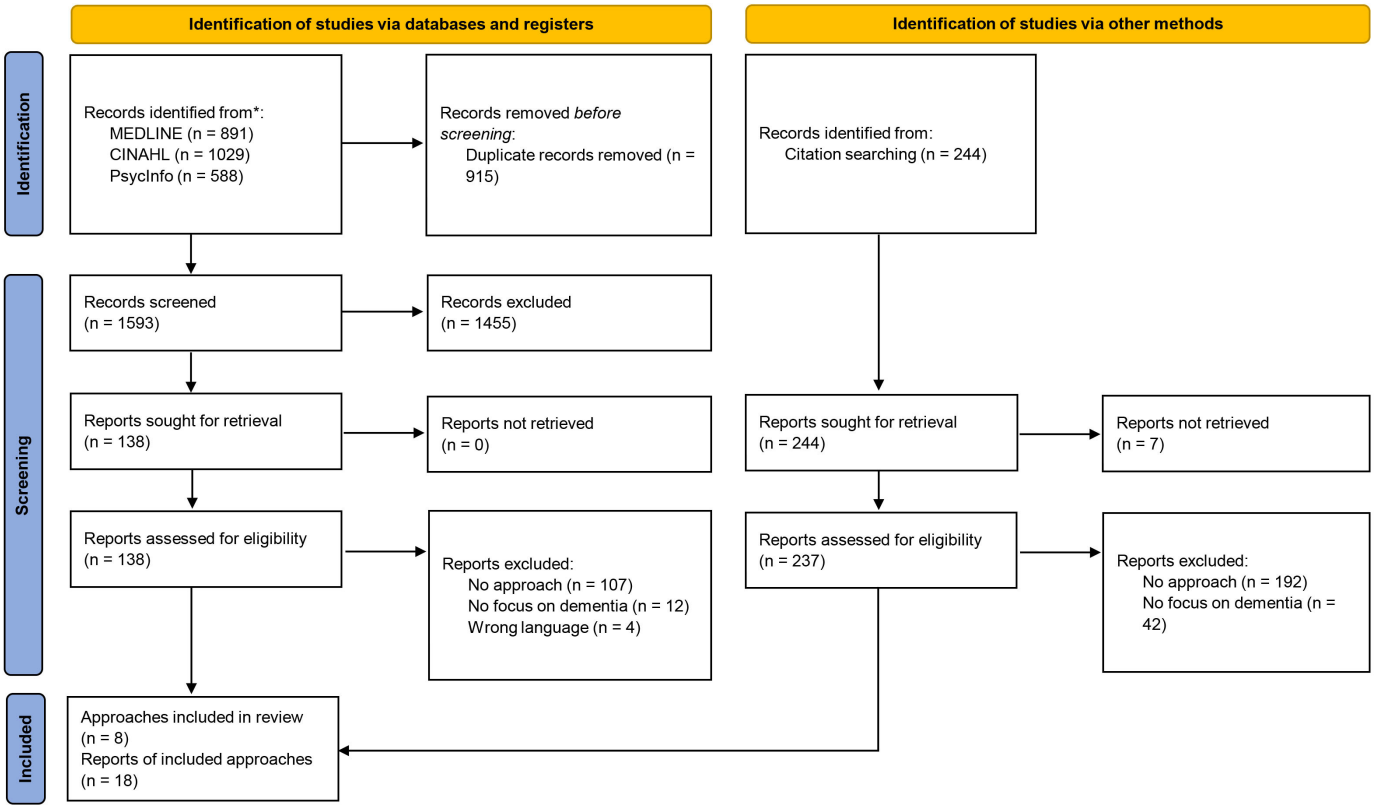

Figure 2 PRISMA 2020 flow diagram demonstrating the identification, screening and eligibility assessments of records preceding scoping review inclusion.[49] PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

content analysis performed by one of the two researchers ensured trustworthiness.[37]

RESULTS

We identified a total of 2508 records through database retrieval and other methods. After checking for duplicates, 1593 titles and abstracts were screened for inclusion, and the full texts of 138 publications were then screened. Exclusions made through the full-text screening were mostly due to the fact that these reports did not focus on theoretical approaches addressing person-centred dementia care. Ultimately, we included 8 person-centred approaches to dementia care reported in 18 reports (figure 2).

Descriptive characteristics of person-centred dementia care approaches

Most person-centred care approaches were found in research articles,[38–42] followed by two books[2 43] and one practice article.[44] Notably, only two articles were published within the past 5 years,[41 42] and the publication of the other texts lies further in the past. We included person-centred dementia care approaches described by authors originated from the UK (n=2), the USA (n=3), the USA/China (n=1), Canada (n=1) and Australia (n=1).

Descriptions of the theoretical approaches to person-centred dementia care were mostly found in literature reviews, in syntheses of results aimed at developing a framework,[43] in definitions and discussions of the model,[38] in discussions of the results of consensus-based workshops[40] and in combinations of results into an overarching model.[42] Moreover, we found one fundamental, theoretical discussion of person-centred care,[2] one editorial that discussed the appropriateness of westernised person-centred care approaches with respect to Indigenous people,[39] one qualitative study that conducted interviews with staff and family members to explore their experiences with the Namaste Care programme[41] and one practice-oriented description of the different Butterfly Care Home projects included within the practice article.[44]

With regard to our aim, search strategy and inclusion criteria the following approaches were identified: *Person-Centred Dementia Care*,[2] *The VIPS-Framework*,[43] *Personhood Model of Dementia Care*,[38] *The Butterfly Approach*,[44] *The Dementia Initiative's Person-Centered Dementia Care Framework*,[40] *Namaste Care: A Person-Centered Care Approach for Alzheimer's and Advanced Dementia*,[41] *Model of Person-Centred Care in the context of Indigenous cultures*[39] and *The Model of Person-Centered Dementia Care in China*.[42]

A detailed illustration of all the approaches included in this research is provided in table 2.

Analytical description of person-centred dementia care approaches

During the analysis and coding process, we inductively identified three different subcategories providing descriptions of person-centred dementia care: microlevel,

Table 2 Study characteristics

General information	Study design/methods	Identified theoretical approach
Primary publication: Brooker[43] Additional publication: Brooker,[4] Brooker and Snaedal[50] Publication type: Book Year: 2007 Country: UK	Study design/methods: ► Literature review ► Synthesising the results in a framework	► The VIPS framework – The book offers a definition of person-centred dementia care through four key elements comprising the VIPS model: A values base that asserts the absolute value of all human lives regardless of age or cognitive ability (V); an individualised approach, recognising uniqueness (I); Understanding the world from the perspective of the person with dementia (P); Providing a positive social environment that supports the person living with dementia experiencing relative well-being (S). Emphasising practical application, the book contains recommendations for effective implementation of person-centred dementia care.
Primary publication: Buron[38] Additional publication: Buron[51] Publication type: Journal article Year: 2008 Country: USA	Study design/methods: ► Literature review ► Definition and discussion of the model	► Personhood model of dementia care – The personhood model for dementia care (1) provides a framework for person-centred care in the nursing home setting, (2) organises existing person-centred interventions and (3) guides the development of future interventions in the nursing home setting. Specifically, the model proposes 3 levels of dementia care based on 3 identified levels of personhood: (1) biological personhood, (2) individual personhood and (3) sociologic personhood.
Primary publication: DeSantis[44] Additional publication: Knocker,[52] Williams[53] Publication type: Practice article Year: 2015 Country: Canada	Study design/methods: ► Descriptions of the different Butterfly Care Home projects	► The Butterfly approach – The approach provides various recommendations for nursing homes and nursing home staff to create a positive and person-centred environment for people living with dementia. These include liberating staff from only doing tasks, developing emotional intelligence in staff so they can develop an emotional connection with the cared for, transforming the physical places to make them engaging places that actually feel like home, eliminating separateness between staff and residents, relaxing the routines to give staff the freedom to just 'be' with people and assisting them in drawing on a variety of ways to engage and occupy residents 'in the moment', understanding the meaning behind behaviours and train the staff to connect with their own feelings (emotions) which leads to more successful outcomes for the cared for, possessing an understanding of the 'lived experience' of the person living with dementia, determined to improve the minute-by-minute experience in the reality they presently live in, prioritising of feelings, when responding to 'expressive' behaviours of people living with dementia and interpreting the meaning behind the behaviour by searching for it in the person's past.

Continued

Table 2 Continued

General information	Study design/methods	Identified theoretical approach
Primary publication: Kitwood[2] Additional publication: Kitwood[45] Publication type: Book Year: 1997 Country: UK	Study design/methods: ► Theoretical principles with recommendations for practice	► Person-centred care for people living with dementia – The author outlines the theoretical principles of the person-centred approach to dementia care which was developed in the 1980s by the author and the Bradford Dementia Group. Drawing on the psychological theory of client-centred therapy by Carl Rogers the author adapt his concept to the complex phenomenon of dementia care by putting the person living with dementia in the focus and highlighting the principles of empathy (understanding), acceptance (appreciation) and congruence (authenticity) which at the same time provide practical recommendations for the care of people living with dementia.
Primary publication: Love and Pinkowitz[40] Additional publication: Publication type: Journal article Year: 2013 Country: USA	Study design/methods: ► Literature review ► Consensus-based Workshops	► The Dementia Initiative's person-centred dementia care framework – The authors present a person-centred model of care that reorients the medical disease-dominated model of care towards holistic well-being which encompasses all four human dimensions: biopsychosocialspiritual. Every person has his or her meaning of life, authenticity (personality, spirit and character), history, interests and need to continue to experience life throughout the stages of dementia and the condition is understood as only one aspect of their current being. The authors provide eight domains for person-centred dementia care: relationships, community (belonging), governance, leadership, care partners or workforce services, meaningful life and engagement, environment and accountability. The authors provide care practices (eg, providing interesting, purposeful and meaningful things to do as part of daily life) and individual ways of interaction (eg, supporting and honouring the person's unique interests, preferences and needs).
Primary publication: McNiel and Westphal[41] Additional publication: Magee *et al*[54] Publication type: Journal article Year: 2018 Country: USA	Study design/methods: ► Qualitative study ► Conducting interviews with staff and family members to explore the experience with Namaste Care programme	► Namaste Care: A Person-Centered Care Approach for Alzheimer's and Advanced Dementia – The article aims to explore the experience of residents, staff and family involved in the Namaste Care programme which provides a person-centred care approach for people living with dementia. Six themes emerged from qualitative interviews with staff members in response to personal experience with the programme: peaceful sanctuary (specially designed environment), relating their way (engagement in meaningful interaction), transforming experiences (changing experience of interaction and care), connections (to residents, the environment and of support for families) and community (between residents, staff and families), positive moments (changes for resident's moments and behaviours) and awakened to the possibilities (how to reach and engage residents within their unique capabilities).

Continued

Table 2 Continued

General information	Study design/methods	Identified theoretical approach
Primary publication: McMillan *et al*[39] Additional publication: Du Toit *et al*,[55] Nguyen[56] Publication type: Journal article Year: 2010 Country: Australia	Study design/methods: ► Editorial ► Discussion about appropriateness of westernised person-centred care approaches for Indigenous people	► Model of person-centred care in the context of Indigenous cultures – The authors aim to raise a deeper awareness about some assumptions and the appropriateness of Westernised person-centred care approaches in the context of Indigenous peoples. They call for the importance of Westernised person-centred care approaches of not repeating the fundamental errors of the Western biomedical approach to dementia care by: (1) assuming universality of models and frameworks, (2) assuming this is the only and dominant discourse, (3) valuing individuality over collectivism and (4) imposing existing Westernised frameworks on Indigenous communities.
Primary publication: Wang *et al*[42] Additional publication: Wang *et al*[57] Publication type: Journal article Year: 2019 Country: USA/China	Study design/methods: ► Literature review ► Results were combined in an overarching model	► Model of person-centred dementia care in China – The authors aim to develop a person-centred care model with specific relevance to China. Their literature review revealed three overarching themes: (1) Chinese cultural relevance of person-centred care, (2) perceived need for person-centred care for older adults in China, (3) implementation and measurement of person-centred care in China. These findings are combined in an overarching model of person-centred care in China which consists of different layers: (1) person with dementia, thriving in interactions with all the persons involved in care; (2) person-centred process, which supports the partnerships between persons with dementia and their care partners and is (3) influenced by the shared understanding of core values and philosophies of person-centred care; (4) coordinated community, where all persons involved in the care of a person with dementia openly communicate with one other; (5) supportive sociocultural context, as values and attitudes in the culture can serve as facilitators but also barriers to the implementation of person-centred care.

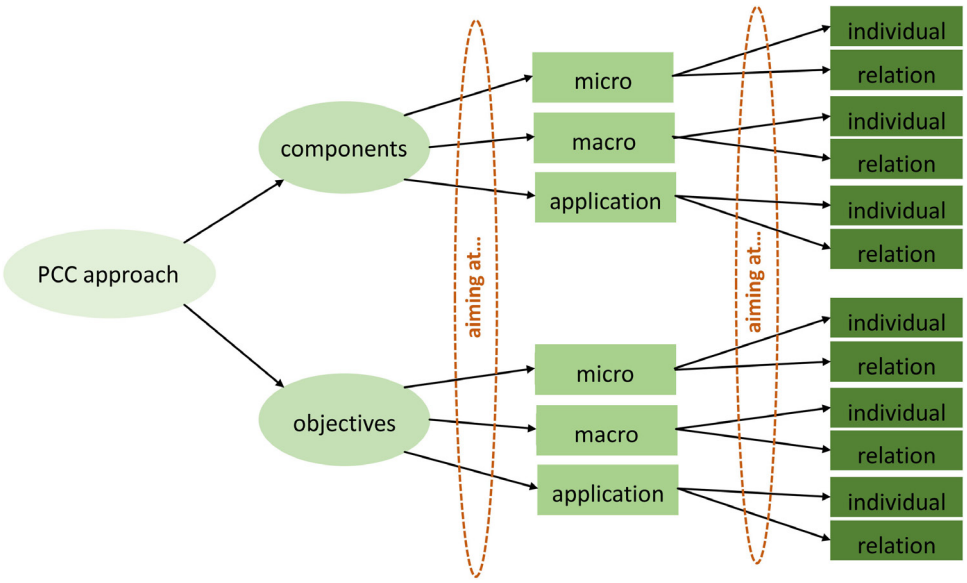

Figure 3 Explanatory model of the individual steps of operationalisation of the theoretical approaches to person-centred dementia care.

macrolevel and application level. This differentiation served as an orderly aid to these descriptions. The different subcategories describe different levels with regard to what is to be addressed and were defined in terms of content as follows. The subcategory microlevel comprises descriptions regarding the individual or situations featuring direct social interaction. The subcategory macrolevel focuses on more abstract or supra-individualised aspects pertaining to the caring organisation or societal attitudes. The subcategory application level includes examples drawn from caring practice regarding what should be done to implement and ensure person-centred dementia care practice as well as how these tasks should be accomplished. In our view, these three subcategories represent the characteristics of the person-centred dementia care approaches identified in this research that could further be operationalised. A complete overview of the reported components and objectives of these approaches, including their assignment to the different subcategories, is presented in online supplemental tables S2 and S3.

Figure 3 presents the components and objectives of the included person-centred dementia care approaches in accordance with the inductively identified subcategories: first the components that relate to the respective subcategory (microlevel, macrolevel, application level) and then the same for the identified objectives.

The following sections present statements pertaining to the components and objectives of person-centred dementia care are presented in accordance with the definitions of the three different subcategories: microlevel, macrolevel and application level.

Components aiming at the microlevel (individual or situations featuring direct social interaction)

As noted, the microlevel comprises statements made regarding the components of person-centred dementia care approaches that pertain to the individual as well as to situations of direct social interaction. The category 'components aiming at the microlevel' can be described more precisely in terms of the following characteristics, which were assigned to the individual parts of the texts: focus on the individual living with dementia, staff to individual living with dementia, individual living with dementia to social environment, relationship and social environment to individual living with dementia.

The focus on the individual living with dementia could be achieved through the enhancement of self-esteem and the confirmation of agency or by increasing social confidence and sustaining hope.[45] Moreover, the concept of positive person work was mentioned, according to which four types of positive interaction in particular direct the focus of this process towards the individual: recognition, negotiation, play and relaxation.[2] Satisfying preferences, desires and needs were also mentioned,[2 43] as was a focus on strengths rather than diminished abilities[40] and the provision of meaningful activities.[41] One important point pertains to the concept of empathy or the notion of 'entering the world' on the part of people living with dementia with the goal of promoting better understanding, communication and interpretation and highlighting the possibility of providing care on an individualised basis.[2 40 42 43]

Concrete recommendations concerning the attitude of staff to individuals living with dementia with the aim of establishing a reciprocal relationship were offered. These recommendations included recognition without stereotyping and pathologising, negotiating without ready-made assumptions, collaboration without the use of power or any form of imposition or coercion, facilitation through the shared creation of meaning and supporting relationships that can help the person receiving care

remain socially involved.[2 43 45] To accomplish this task, it is important to be able to adopt the perspective of the other person and to develop an understanding of the meaning underlying the other person's behaviours and the lived experience.[2 43 44] Forms of good and open communication[42 43] are just as important as the possibility of being fully present, which is facilitated by the liberation of staff from a sole focus on completing tasks and their freedom to stop their active work.[2 44] With regard to actively establishing a reciprocal relationship, it is also essential for staff to keep their own needs in mind, to be at ease with their own sensuality and to be able to accept kindness and support from those to whom they provide care.[2]

How the individual living with dementia relates to his or her social environment is addressed in terms of reciprocity, as it is important that people living with dementia also play the leading role in interaction. In the context of person-centred care, this goal is accomplished by framing creation as a spontaneous offer to the social setting and understanding giving as, for example, an expression of concern, affection or gratitude, an offering of help or the presentation of a gift.[2] As noted, our definition of the subcategory microlevel comprises not only statements pertaining to the individual but also to situations of direct social interaction. Accordingly, in contrast to the focus directly on the individual living with dementia, the importance of a relationship has been emphasised in the literature. Related components of person-centred dementia care include collaboration through sharing tasks and working together towards definite aims, 'timalation' in the form of sensual interaction that provides contact, reassurance and pleasure and celebration as an intrinsically joyful experience.[2] Additionally, a link between a close attachment or strong relationship with a feeling of well-being has been highlighted.[2 38] Structural components of person-centred care frameworks include relationships, community, meaningful life and engagement and accountability[40] as well as family relationships as the core of a community that facilitates thriving interactions and partnerships.[42] The importance of how the social environment relates to the individual living with dementia has been highlighted by the argument that a positive social environment is key to maintaining the personhood of people living with dementia.[43]

Components aiming at the macrolevel (organisation or societal attitudes)

In addition to the statements made on the microlevel, we identified the subcategory macrolevel which focus on the individual towards more superordinate or abstract conceptions pertaining to the caring organisation or societal attitudes. This subcategory can be described more precisely in terms of the following components: values—individual living with dementia, valuing individual living with dementia—professional environment, values—community, spirituality and space and time.

In the literature, we found statements that emphasised a common value base as an essential requirement of person-centred dementia care. Some of these statements described values that were directed towards the individual living with dementia. These societal values emphasised the overall importance of valuing people living with dementia regardless of their age or cognitive abilities and recognising their uniqueness and personal identity.[40 43] Moreover, the establishment of a social environment that supports psychological needs, accountability and a sympathetic presence and creates a feeling of belonging to the community[40 42 43] was highlighted. Additionally, the necessity of understanding the world from the perspective of people living with dementia was emphasised, as was the need to ensure that these persons have the possibility of living a meaningful life and experiencing engagement, shared decision-making and the prioritisation of well-being.[40 42 43] This aspect of valuing the individual was expanded to the professional environment by the argument that such a value must be made explicit in value statements made by the professionals throughout the organisational level.[43]

In contrast to the statements that highlighted valuing the individual living with dementia as a component of person-centred dementia care, other authors offered a culturally influenced perspective that emphasised the importance of values that are directed towards the community. These values described the role of kin and family relationships, a holistic understanding of the person's connection to his or her country, a shared history and mutual responsibility[39 42] as central to models of person-centred dementia care from different cultural perspectives.

The aspect of spirituality was mentioned in the comparison made between celebration (as one component of person-centred dementia care) and understanding spirituality as a form of interaction in which the division between caregiver and cared-for vanished.[2] Moreover, the Namaste Care approach highlighted spirituality, as it was based on the premise, that the spirit of the person living with dementia remains even during advanced stages of the disease.[41]

The importance of time and space can be illustrated based on a perspective that views time as an important factor in understanding the experience of dementia; furthermore, this perspective posits the understanding and influence of this factor depends on the cultural background in question.[39]

Components aiming at the application level (care practises and implementation)

In addition to the categorisation of statements pertaining to components into the microlevels and macrolevels, we also found statements concerning components that were more closely related to direct application and care practice. The subcategory 'components aiming at the application level', as noted above, includes examples drawn from caring practice concerning what must be done to implement and ensure person-centred dementia care practice as well as how this goal should be accomplished. This subcategory can be described more precisely in terms of

the components: intervention—caregiver to individual living with dementia, intervention—staff to 'biological personhood', intervention—focus on individual living with dementia, intervention—environment to individual living with dementia and intervention—day structure.

In the literature, we found descriptions regarding how the caregiver could relate to and actively support the individual living with dementia in a person-centred way. We found references to dementia care interventions—such as memory books, snoezelen and individualised interventions involving social activity—that targeted the sustaining and retention of personhood through improved communication as well as behaviour and sleep patterns.[38] Other descriptions highlighted opportunities to create a feeling of togetherness by liberating staff from organisational routines and eliminating the separation between staff and residents[44] or operational practices that could be used to support person-centred care and the task of promoting meaningful life and engagement.[40]

A way in which staff could respond to a biological understanding of personhood (whereby 'biological personhood' is a specific formulation of Buron, which we have understood to mean meeting essential physical needs or dissatisfaction with care in light of communication problems) was presented based on consideration of the ways in which non-verbal interventions such as touch could be used for communication and confirmation, and awareness and sensitivity on the part of caregivers were recommended to enable them to uncover explanations for behaviours and other forms of communication.[38]

An opportunity to develop an active focus on the individual living with dementia was presented in terms of individualised, practices. These practices include forms of tailored interaction that can support individual interests, preferences and needs in several ways, such as initiating projects of interest or taking the time to talk.[40] Additionally, a day structure was mentioned as an opportunity for caregivers to provide active support, as the individualised development of such a structure offers room for recovery and recreation.[2]

Possible effects of the environment with regard to the individual living with dementia were discussed by some recommendations pertaining to interventional approaches that focused on the idea of changing the environment to ensure a person-centred surrounding. These changes were described in terms of a transformation of the physical environment to ensure the presence of engaging, home-like places that could stimulate conversation and activity[44] or the establishment of specially designed rooms for individual sessions, the provision of personal care, the setting aside of time for reminiscence and multisensory stimulation.[41]

Objectives aiming at the microlevel (individual or situations featuring direct social interaction)

As noted, the microlevel contains statements concerning objectives that should directly affect the individual living with dementia or situations featuring social interaction. The subcategory 'objectives aiming at the microlevel' includes the most identified descriptions (38 descriptions, the other categories featured 5 or 4 descriptions) and includes statements pertaining to physical, psychological and social aspects of the individual living with dementia and addresses—besides the individual living with dementia—also NH staff as well as leaders and responsible within the caring organisations. Due to the relatively high number of codes contained in this category, we decided to present only those in which statements from at least two or more different authors could be assigned to one code. For further information, the detailed categories and subcategories can be found in online supplemental table S3. These objectives could be described more precisely in terms of the following five aspects: (1) QoL (quality of life), (2) preservation of personhood (general statement), (3) well-being—recognition of personhood for well-being, (4) participation—individual living with dementia as active member and (5) security.

One prominent objective of the process of putting person-centred dementia care concepts into practice with regard to the individual living with dementia is the improvement of the QoL of people living with dementia.[2 40 41 44] Additionally, the preservation of personhood or, as alternatively discussed in the literature, the retention and maintenance of personhood throughout the process of dementia was identified as an important objective.[2 38] Another objective mentioned that pertained to the individual living with dementia focused on the aspect of well-being, which can be achieved by recognising personhood in person-centred care practice.[40 45] Furthermore, person-centred care aims to offer the opportunity for participation. One author focused on the opportunity to improve the psychological foundations underlying the possibility of social participation,[45] whereas another author emphasised the opportunity to become an active member of the community by implementing the concept of sociological personhood.[38] Two authors identified the achievement of a sense of security as an objective of person-centred care.[42 45]

Objectives aiming at the macrolevel (organisation or societal attitudes)

Similar to the differentiation of the components into different levels, we found that some statements regarding objectives could also be assigned to the subcategory macro level. The objectives comprise statements that address more superordinate or super-individual aspects such as the environment, the community or the quality of care. These objectives could be described more precisely in terms of the following four aspects: (1) quality of care, (2) NH as community, (3) family as community and (4) engaging environment (aim)/feeling like home (outcome).

Improving the quality of care through the use of non-verbal interventions (such as the use of touch for communication and confirmation in response to limited abilities)

was viewed as one part of one conception of person-centred care.[38] Another formulated objective focused on the NH as a community, arguing that promoting 'higher sociological personhood' aims at advanced community building despite cognitive and communication barriers.[38] The objective of establishing a coordinated community was also highlighted by another author with reference to the incorporation of families and the support of family caregiving.[42] The idea of an active transformation of the physical environment, which was described as a component of person-centred care, aims at offering the opportunity to create engaging places and a homelike atmosphere.[44]

Objectives aiming at the application level (care practises and implementation)

In the literature, we found statements concerning objectives that also referred to the level of application and care practice and that we assigned to the subcategory 'objectives aiming at the application level'. These objectives could be described more precisely in terms of these four aspects: (1) engaging in activity—social engagement, (2) engaging in activity—individual meaningfulness, (3) creating a feeling of humanity, providing time for activity and (4) providing pleasure.

The objective of fostering conversation and activity by actively engaging people living with dementia in activities associated with daily living in various ways through social engagement was highlighted in the literature.[44] Similarly—although with a stronger focus on the individual—the argument for active engagement in activities associated with daily living for the purpose of creating individual meaningfulness was also mentioned.[40] The same authors indicated that certain individualised practices associated with person-centred care aim to create a feeling of being human and convey worth and value.[40] Providing time for activity was presented as one aim of the Namaste Care programme that offered the opportunity for an unhurried experience of the activities.[41] Another objective of the Namaste Care programme, in contrast to the typical care routine, was the provision of pleasure on a sensual basis to residents living with dementia.[41]

DISCUSSION

As described in the introduction, the starting point of this research was to shed light on the identified research gap that person-centred care is seen as a point of reference in dementia care and has been widely expanding on the one hand and on the other hand there seems to be no common or unified theoretical understanding of the concept, as there also seems to be a lack of clarity regarding how personhood can be understood in this context. In order to develop a better understanding of what is meant by the concept of person-centred care, we aimed to conduct an integrative review in which we examined theoretical approaches to person-centred dementia research and care in terms of their components and objectives.

Our integrative review provides a comprehensive and systematic overview of extant theoretical approaches describing person-centred dementia care in terms of their components and objectives. Furthermore, our analysis synthesises these aspects in the form of an explanatory model of operationalisation (see figure 3) based on inductively defined subcategories (microlevel, macrolevel and application level). This review enables us to obtain a better understanding how person-centred dementia care is currently described and specifically whether and how the theoretical approaches differ in terms of their orientations and their focus on the individual and/or on sociality. The latter point allows conclusions to be drawn regarding the underlying conceptual idea of personhood.

The identified components of the described theoretical approaches highlight the strong focus on the individual living with dementia observed at the micro level. However, this subcategory also contains a perspective on sociality that is associated with statements concerning the importance of (reciprocal) relationship and the ways in which the social environment relates to and impacts the individual. Two statements pertaining to the attitude of staff to individual living with dementia and how the individual living with dementia relates to the social environment cannot be distinguished quite as clearly and lie between these two perspectives. The main focus of these statements is on the individual living with dementia, but they also address the perspective of sociality in terms of prerequisites of reciprocal relationships. At the macrolevel, we also found a strong emphasis on the individual living with dementia through the description of values that prioritise the individual. In contrast, we also found a perspective on sociality that was represented by statements concerning the importance of values directed towards the community and by the aspect of spirituality, which was, on the one hand, compared with the component of celebration and, on the other hand, understood as an equal form of interaction. Once again, we found aspects that could not be clearly distinguished. The aspect of valuing the individual living with dementia, when expanded to a professional environment, focuses on the individual living with dementia but refers to the broader context of the caring organisation. The aspect of time and space refers, on the one hand, to an understanding of the experience of dementia and, on the other hand, to the dependence of such an experience on the cultural background.

The focus on the individual is particularly clear at the application level, as every aspect (caregiver support, responding to biological personhood, individualised practices, environmental influences and day structure) is directed towards the individual. In addition to the components of person-centred dementia care, some objectives are reflected in these person-centred dementia care approaches. A similar distribution can be observed here in terms of the representations of the foci, although

objectives are not as clearly described as in the application level of the components.

Overall, it became apparent that the focus primarily lies on the individual and is therefore the dominant perspective within the (sub)categories of the person-centred dementia care approaches identified in this review. At the same time, the conceptual perspective on sociality and its relevance for person-centred dementia care is underrepresented and/or not discussed. In this context, for example, approaches that adopt a distinct cultural perspective (ie, the Model of Person-Centred Care in the context of Indigenous cultures[39] and the Model of Person-Centred Dementia Care in China[42]) provide a different focus on personhood (and thus person-centred dementia care) and emphasise the importance of (family) relationships, communities, country and society in their operationalisations of person-centred dementia care. A recent published review points out that dementia care services lack cultural and diversity sensitivity.[46] Another review criticises that the intersection of culture in the provision of dementia care is missing.[47] We, therefore, need to reflect on the range of the identified reports since concepts such as diversity in the perception of dementia (individual/societal) and/or cross-cultural communication (individual/organisational) and/or diversity sensitive experiences are not addressed during the application of person-centred dementia care and are not equally represented in the identified person-centred dementia care approaches.

From our point of view, this highlights a huge gap in research on person-centred dementia care concepts. Dementia is a multifaceted phenomenon that is difficult to understand mainly through a focus on the individual. Future research should pay more attention to the perspective of sociality and consider this aspect to be at least equally important for understanding the phenomenon of dementia. The debate on social health in dementia[48] represents a strong effort in this direction. Furthermore, it was particularly notable that at the application level, reference was made exclusively to the individual. This one-sided focus was not the case with regard to any other subcategory. Although some approaches considered the perspective of sociality theoretically, it was not present in the examples of application. In our opinion, this situation might highlight a gap in person-centred dementia care practice, as the transfer from theory to practice seems to have not yet been fully implemented.

With regard to our integrative review, we must consider potential limitations pertaining to the area of search and to the application of the inclusion criteria, to one of the inductively identified subcategories and to the interpretation of the results regarding the second of our initial research question on aims and outcomes of person-centred approaches in dementia care.

We decided to include only publications in the English and German languages. This decision might have narrowed the search strategy and thus have been problematic, especially with regard to grey literature or practice literature, which is often written in authors' native languages. It is possible that this is why we were only able to include one practice article and might have missed relevant publications on the topic.

Furthermore, we included only publications that included an explicitly described approach to person-centred dementia care. To limit the results of the search from the outset and ensure their feasibility in terms of resources, we interpreted the inclusion criteria we defined very narrowly. Accordingly, only publications that explicitly mentioned the term 'person-centred dementia care approach' (or similar terms such as 'theoretical model') were considered for inclusion. Publications that did not use these terms explicitly were excluded, which might have biased the results by overlooking similar concepts that merely used different descriptive terms that might have emerged.

One point should be mentioned regarding the inductively identified subcategory of application level. This subcategory, in contrast to the two other identified subcategories (microlevel and macrolevel), could be further differentiated in another analysis, as it seems quite possible that the statements relating to the application level could also be assigned to a micro and macro level. Conceivable here, for example, would be statements on care interventions aimed either at the individual or at social situations (micro) or at a change in attitudes towards organisational or societal values (macro). In our view, the differentiation identified in our analysis was sufficient to make our results comprehensible, but nevertheless, we see this point as an interesting subject of a possible further investigation.

The second of our initial research questions focused on the identification of aims and outcomes of person-centred approaches in dementia care. With regard to the statements made concerning the aims and outcomes of the person-centred approaches identified in this research, it should be noted restrictively that the differentiation of aims and outcomes was often difficult to discern. The difficulty in distinguishing between aims and outcomes was partly due to the fact that the authors did not clearly delineate this distinction in their publications, but also to the fact that we did not include any classical intervention studies in our literature sample, which may have measured certain outcomes and made statements about effectiveness. We, therefore, decided to combine the categories of this research question in the presentation of the findings to highlight the objectives that the different approaches were trying to achieve. This was our solution to deal with the problem of differentiating between aims and outcomes in the presentation of the result, but this is of course also open to debate and shared opinion.

CONCLUSION

Through this integrative review, we provided a systematic overview of international approaches to person-centred dementia care. As expected, we found heterogeneous characteristics and aspects pertaining to the components and

objectives of the approaches to person-centred dementia care included in this research. Our analysis offers a way to categorise these findings by synthesising the components and objectives thus identified into different subcategories. This approach contributes to a better understanding of what is meant by person-centred dementia care as well as a conceptual differentiation among the approaches. A point that became clear in the results is the dominance of the focus on the individual perspective within the identified subcategories. Alternative approaches are generated, for example, from different cultural perspectives, which shift the focus towards a perspective on sociality by emphasising (family) relationships, communities, country and society.

On the one hand, the dominance of the individual perspective highlights a gap in research, such that more attention should be given to the perspective of sociality. On the other hand, this situation might refer to a gap in practice that occurs when the dominance of the individual perspective, especially with regard to the subcategory of application, indicates an ineffective transfer from theory to practice. Future research may explore both gaps, the one in research and the one in theory practice transfer, by focusing more on the perspective of sociality, and regard this perspective on sociality to be equally important to the perspective of the individual in understanding the phenomenon of dementia. Dementia, as a multifaceted phenomenon, demands a differentiated consideration of theoretical notions of how to understand the person in that context. This consideration serves as the foundation for a truly holistic approach to person-centred dementia care.

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Table S1: search strategy

MEDLINE (via PubMed)

Population	#1 Dementia[MeSH Terms] #2 Dement*[Title/Abstract] #3 Alzheimer*[Title/Abstract] #4 OR/ #1-3
Interest	#5 person-cent*[Title/Abstract] #6 person cent*[Title/Abstract] #7 client-cent*[Title/Abstract] #8 client cent*[Title/Abstract] #9 resident-cent*[Title/Abstract] #10 resident cent*[Title/Abstract] #11 patient-cent*[Title/Abstract] #12 patient cent*[Title/Abstract] #13 OR/ #5-12 #14 #4 AND #13
	#15 frame*[Title/Abstract] #16 model*[Title/Abstract] #17 theor*[Title/Abstract] #18 concept*[Title/Abstract] #19 approach*[Title/Abstract] #20 Guide*[Title/Abstract] #21 nursing models[MeSH Terms] #22 nursing theories[MeSH Terms] #23 theoretical models[MeSH Terms] #24 OR #15-23
	#25 #4 AND #13 AND #24 #26 #4 AND #13 AND #24 AND (english[Filter]) #27 #4 AND #13 AND #24 AND AND (english[Filter] OR german[Filter])

CINAHL (via EBSCO) and PsycInfo (via EBSCO)

Population	S1 MW dementia OR TI Dement* OR AB Dement* OR TI Alzheimer* OR AB Alzheimer*
Interest	S2 TI person-cent* OR AB person-cent* OR TI person cent* OR AB person cent* OR TI client-cent* OR AB client-cent* OR TI client cent OR AB client cent OR TI resident-cent* OR AB residentcent* OR TI resident cent* OR AB resident cent* S3 TI patient-cent* OR AB patient-cent* OR TI patient cent* OR AB patient cent*

	S4 TI frame* OR AB frame* OR TI model* OR AB model* OR TI theor* OR AB theor* OR TI concept* OR AB concept* OR TI approach* OR AB approach* OR TI guide* OR AB guide* S5 MW nursing models OR MW nursing theories OR MW theoretical models
	S6 S2 OR S3 S7 S1 AND S6 S8 S4 OR S5 S9 S7 AND S8

Table S2: reported components of the included approaches on PCDC

Coding components	Kitwood (1997, 1993)	Brooker (2007)	Buron (2008)	DeSantis (2015)	Love & Pinkowitz (2013)	McMillan (2010)	McNiel (2018)	Wang (2019)	N=
Micro level – social environment to individual		X							1
Micro level – individual to social environment	X								1
Micro level – focus on individual	X	X			X		X	X	5
Micro level – staff to individual	X	X		X				X	4
Micro level – relationship	X		X		X			X	4
Macro level – Valuing individual – prof. environment (organisational level)		X							1
Macro level – spirituality	X						X		2
Macro level – space and time						X			1
Macro level – values – community						X		X	2
Macro level – values – individual		X			X			X	3
Application level – intervention – day structure	X								1
Application level – intervention – focus on individual					X				1
Application level – intervention – environment to individual				X			X		2
Application level – intervention – staff to biologic personhood			X						1
Application level – intervention – carer to individual			X	X	X				3
N=	6	5	3	3	5	2	3	5	32

Table S3: reported objectives of the included approaches on PCDC

Coding objectives	Kitwood (1997, 1993)	Brooker (2007)	Buron (2008)	DeSantis (2015)	Love & Pinkowitz (2013)	McMillan (2010)	McNiel (2018)	Wang (2019)	N=
Micro level – individual – social confidence	X								1
Micro level – individual – self-respect	X								1
Micro level – individual – priority of the person		X							1
Micro level – individual – rementing (nerve function, neuroregeneration)	X								1
Micro level – individual – improving physiological status	X								1
Micro level – individual – resilience	X								1
Micro level – individual – neurological growth (biological)	X								1
Micro level – individual – person-centred death	X								1
Micro level – individual – fulfilment of psychological needs	X								1
Micro level – individual – preservation of personhood (general statement)	X		X						2

Micro level – individual – preservation of autonomy			X						1
Micro level – individual – QoL	X			X	X		X		4
Micro level – individual – well-being – relative well-being	X								1
Micro level – individual – well-being – recognition of personhood for well-being	X				X				2
Micro level – individual – well-being – relationships with others for feeling of well-being	X		X						2
Micro level – individual – participation							X		1
Micro level – individual – participation – individual as active member	X		X						2
Micro level – individual – relationship – establishing relationship	X								1
Micro level – individual – relationship – engendering trust					X				1
Micro level – individual – relationship – maintaining relationship					X				1
Micro level – individual – relationship – emotional connection				X					1
Micro level – individual – positive social interaction				X					1
Micro level – individual – providing best lived experience				X					1
Micro level – individual – security	X							X	2
Micro level – individual – belonging								X	1
Micro level – individual – purpose								X	1
Micro level – individual – achievement								X	1
Micro level – individual – continuity								X	1
Micro level – individual – significance								X	1
Micro level – individual – open mindedness	X								1
Micro level – organization – organisational development		X							1
Micro level – organization – evidence and benchmark		X							1
Micro level – staff – inspiring the team				X					1
Micro level – staff – PCC as staff capability				X					1
Micro level – staff – emotional intelligence				X					1
Micro level – staff – merging clinical practice and PCC				X					1
Micro level – staff – QoS				X					1
Micro level – leaders/responsibles – strategy of attachement prior to system requirements				X					1
Macro level – engaging environments (aim), feeling like home (outcome)				X					1
Macro level – community building – family as community								X	1
Macro level – community building – NH as community			X						1
Macro level – QoC			X						1
Application level – creating a feeling of humanity					X				1
Application level – engaging in activity – individual meaningfulness					X				1
Application level – engaging in activity – social engagement				X					1
Application level – providing time for activity							X		1
Application level – providing pleasure							X		1
N=	17	3	6	12	6	0	4	7	55