## BMJ Open Person-centredness in dementia care: study protocol for an integrative review of theoretical approaches

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#### **ABSTRACT**

Introduction The concept of personhood is particularly important in person-centred dementia care because its overall aim is to maintain the personhood of people living with dementia despite disease progression. In a previous review on autonomy for people with dementia, two different underlying concepts of personhood were identified: a rationalistic and a social constructionist concept of personhood. The present integrative review aims to (1) identify existing theoretical approaches in person-centred dementia care, (2) describe the constitutive components for these theoretical approaches, (3) report the goals and/or outcomes to be achieved by person-centred care for people living with dementia and (4) identify the underlying concepts of personhood. Methods and analysis For our integrative review the search terms were derived from the research questions and clustered according to the 'PICo' (Population, Interest, Context) framework. A systematic literature search for theoretical approaches of 'person-centred dementia care' will be performed on MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycINFO (via EBSCO). The title/abstract and full-text screening will be performed independently by two researchers according to the inclusion criteria. The data analysis procedure will have two steps: (1) identification and extraction of general information (e.g., type of publication and name of theoretical approaches described) and (2) a qualitative content analysis to analyse the components, goals, outcomes and understanding of the respective underlying conceptions of personhood within the theoretical approaches. The extraction of general information (e.g., authors) will be performed by one researcher and qualitative content analysis will be performed independently by two researchers using MAXQDA software. Any disagreements will be resolved through discussion between the two researchers or, if no consensus can be reached, with all coauthors. Ethics and dissemination Due to the nature of a review, ethical approval is not required. We will disseminate our results in peer-reviewed journals and at (inter)national

# conferences.

#### INTRODUCTION

High-quality care is a prerequisite for people living with dementia to live well and for the families concerned to be supported. Highquality care for people living with dementia

#### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ By using a broad selection of electronic databases for our systematic search, we will be able to provide a comprehensive overview of theoretical approaches of person-centred dementia care.
- ⇒ For the identification of relevant theoretical approaches that may not be identified using the electronic database search, we plan to extend our systematic search by 'hand-searching' techniques, such as consulting experts, scanning specific journals and performing forward (via Google Scholar) and backward (via reference lists) citation tracking.
- ⇒ Due to our methodological approach and the related content analysis, we will be able to provide an indepth understanding about the different theoretical approaches of person-centred dementia care.
- ⇒ We expect that the reporting quality of the studies identified might be limited, it will therefore be challenging to analyse the various components, goals, and outcomes of theoretical approaches that are not clearly described.

is closely linked to the concept of 'person-centred care'. <sup>2-4</sup> In a recent integrative review, Byrne et al. concluded that there is no common understanding of what is meant by person-centred care.<sup>5</sup> In the context of person-centredness, the term goes back to Rogers<sup>6</sup> and his client-centred psychotherapy.<sup>7</sup> The term was first applied to the field of dementia care by Kitwood.<sup>3 4</sup> At the heart of person-centred care is the task of maintaining the personhood of people with dementia despite their cognitive decline.8 Accordingly, the concept of personhood is of particular importance in person-centred dementia care. In their thematic synthesis, Serbser-Koal et al. examined the concept of autonomy in the context of dementia within the literature on person-centred dementia care. The findings of this synthesis are in process for publication in an additional article. Based on that analysis, Serbser-Koal et al. identified two different conceptions



of personhood that underlie the research literature on dementia and autonomy. The rationalistic conception of personhood understands personhood as *dependent on a person's cognitive abilities*. Accordingly, whether an individual is assigned or recognised as a person depends on an understanding of he or she having the ability to act on a rational basis with recourse to his or her cognitive capacity. The social constructionist conception of personhood understands personhood as *constituted within social relations*. Accordingly, personhood results from reciprocal processes in interactions of at least two actors, which means that personhood is constituted by way of social embedding and not argued on the basis of cognitive abilities.

Considering these clarifications of personhood, the question arises of which understanding of personhood underlies theoretical approaches to person-centred dementia care. Specifically, which components and which objectives are pursued with the implementation of person-centred dementia care, which outcomes are to be achieved and which understanding of personhood underlies these theoretical approaches? Therefore, the aim of the integrative review is to identify existing theoretical approaches of person-centred dementia care and to analyse the defined aspects (e.g., components, goals/outcomes, underlying theoretical understanding of personhood), regardless of the publication quality or type. Theoretical approaches refer to explanations that specify (and/or operationalise) what is meant by personcentred dementia care. Brooker's VIPS framework can be understood as an example.

According to our research aim, we define the following research questions:

- 1. Which theoretical approaches to person-centred dementia care have been published?
- 2. What are the components of the identified theoretical approaches to person-centred dementia care, and which goals and/or outcomes can be identified?
- 3. What understanding of personhood underlies these theoretical approaches to person-centred dementia care?

To answer these research questions, we will conduct an integrative review that allows a comprehensive understanding of a phenomenon,<sup>9</sup> in our case, the published theoretical approaches on person-centred dementia care.

#### **METHOD**

For our integrative review (start: February 2022; planned end: December 2023), we choose the review approach of Whittemore and Knafl, which consists of the following five steps: (1) problem identification (see introduction), (2) literature search, (3) data evaluation, (4) data analysis and (5) presentation. For reporting the review protocol, we follow, whenever applicable, the PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) guideline and complement it with the abovementioned five steps of the integrative review approach.

Table 1 Inclusion 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	<ul><li>Care of people living with dementia.</li><li>All settings of care (e.g., nursing homes).</li></ul>		
Types of evidence sources	Any kind of literature, which describe theoretical approaches on 'person-centred dementia care'.		
Others	<ul><li>Languages: German and English.</li><li>Year: No restrictions.</li></ul>		

#### Literature search

#### Inclusion criteria

The inclusion criteria are based on our research aims and questions. The reporting of the inclusion criteria is performed according to the 'PICo' (Population, Interest, Context) framework<sup>11</sup> supplemented by the 'types of evidence source' and 'others' criteria (table 1).

#### Search strategies

We will conduct a literature search for theoretical approaches of 'person-centred dementia care' in the following electronic databases: MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycINFO (via EBSCO). The search terms were derived from our research questions and clustered according to 'population' and 'interest'. 11 With regard to the context, no search terms were formulated since the context 'care of people living with dementia' is represented by the phenomenon of interest (theoretical approaches of 'person-centred dementia care') and therefore does not require further specification. The search strings were developed first for MEDLINE via PubMed and then adopted for the two other databases (see online supplemental table 1) according to RefHunter V.5.0.<sup>12</sup> The systematic search will be supplemented by 'hand-searching' techniques, such as consulting experts, trawling specific journals and performing forwards (via Google Scholar) and backwards (via reference lists) citation tracking. 13 This procedure is considered particularly relevant for reviews of theoretical approaches. 13

#### Screening and eligibility process

The records identified in the literature search will be transferred to the reference manager EndNote<sup>14</sup> and then to the systematic review management system Covidence<sup>15</sup> and then will be automatically checked for duplicates. Titles and abstracts of records will be screened by two reviewers independently according to the inclusion criteria. All records assessed as potentially relevant will also undergo full-text screening for inclusion by the same reviewers independently. The reasons for excluding full



texts will be recorded. During the screening process, any disagreements between the two reviewers will be resolved through a discussion between them or, if no consensus can be reached, with all co-authors. The inclusion criteria will be pilot tested in the first 25 records and will be adjusted if necessary. Adjustment will be required if discrepancies between the two reviewers are greater than 25%. 16 If adjustments to the inclusion criteria become necessary in the screening process, these will be reported in the following publications.

#### **Data evaluation**

A review of the methodological quality of the included records is not planned, because the aim of the integrative review is to identify theoretical approaches to personcentred dementia care, regardless of the quality or type of publication, and to analyse them in relation to defined aspects. An assessment of relevance of the included records for answering the questions prior to the data analysis is not planned, as all included records will be integrated in the data analysis. If individual theoretical approaches are described in several publications, consolidation will be performed before data extraction since the theoretical approach and not a single report is the unit of interest. 17

#### **Data extraction and analysis**

The procedure related to the extraction and analysis of the data will have two independent phases:

In the first phase, general information will be identified and extracted with reference to the template for scoping reviews developed by the Joanna Briggs Institute. 16 General information includes (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 originate, (4) the type of publication and (5) the name of the theoretical approaches described/mentioned in the publication. The data will be extracted by one researcher and randomly checked by a second researcher. Deviations will be discussed, and if no consensus between the two researchers can be reached, the coauthors will be involved.

Within the second phase, a qualitative content analysis will be conducted to determine (1) the components, (2) the goals and/or outcomes and (3) the respective understanding of personhood of the theoretical approaches found in the literature. Referring to Schreier, 18 the procedure is planned to have the following steps: (a) familiarisation with the material; (b) deductions of the superordinate categories from the research question and based on the aforementioned conceptions of personhood identified in the examination of autonomy in a previous review; (c) determination of finding places and/ or coding units; (d) inductive development of subcategories (including category definition) through an iterative approach and coding of the whole material; and (e) presentation of the results (per theoretical approach and across theoretical approaches), interpretation and

Table 2 Data extraction template					
Authors	Year	Country	Type of publication	Identified theoretical approaches	
	_				

answering of the research questions. With regard to the analysis of the understanding of personhood in the identified theoretical approaches of person-centred dementia care (b), we will refer to two previously identified concepts of personhood (the rationalistic conception of personhood and the social constructionist conception of personhood). Based on these two concepts, we will analyse the extent to which these can be found in the theoretical approaches of person-centred dementia care. In case the theoretical approaches of person-centred dementia care do not correspond, the analysis will lead to the identification of additional understandings of personhood.

The coding of the material will be performed independently by two researchers using MAXQDA software. 19 The results from the two researchers will be checked for deviation. Deviations will be discussed. If no consensus between the two researchers can be reached, the coauthors will be involved. Based on the results of the comparison and consensus process, a final assignment of coding units to categories will be carried out. The results of the content analysis will be reviewed in extracts by one of the two researchers to ensure trustworthiness.<sup>20</sup>

#### **Data synthesis and presentation**

A PRISMA flowchart<sup>21</sup> will be used to illustrate the process of screening and eligibility. The general information (phase 1) will be presented in the form of a table

The results from phase two will be presented in an adequate narrative and/or visual form (e.g., tables or figures).

The results of this review will provide the first systematic, critical overview and comparison of existing theoretical approaches to person-centred dementia care related to components, goals and/or outcomes as well as the underlying conceptions of personhood. Based on the results of this integrative review, researchers will have the opportunity to further develop the identified theoretical approaches. Practitioners can use the results to make a reasoned choice of theoretical approaches to dementia care to improve the care of people living with dementia.

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#### Supplementary table 1: Search strategy

#### MEDLINE (via PubMed)

Population	#1 Dementia[MeSH Terms]			
i opulation	#2 Dement*[Title/Abstract]			
	#3 Alzheimer*[Title/Abstract]			
	#4 OR/ #1-3			
	#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			
Interest	#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		
Торошанон	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 AB client-cent* OR TI client cent OR AB client cent OR AB 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		