



STUDY PROTOCOL

The experiences and perceptions of personhood for people living with dementia: A qualitative evidence synthesis protocol [version 1; peer review: 2 approved]

Niamh Hennelly ¹, Adeline Cooney², Catherine Houghton ³, Eamon O'Shea ¹

¹Centre for Economic and Social Research on Dementia, National University of Ireland, Galway, Ireland

²Centre for Teaching & Learning, Maynooth University, Maynooth, Ireland

³School of Nursing and Midwifery, National University of Ireland, Galway, Galway, Ireland

v1 First published: 05 Jun 2018, 1:18 (<https://doi.org/10.12688/hrbopenres.12845.1>)

Latest published: 05 Jun 2018, 1:18 (<https://doi.org/10.12688/hrbopenres.12845.1>)

Abstract

Background: Personhood in dementia is concerned with treating people living with dementia with dignity and respect, in a manner that supports their sense of self. It focuses on treating the person living with dementia as a person first and foremost. Supporting personhood in dementia is the key goal of person-centred care. Existing qualitative research examines what personhood means to the person living with dementia and explores what is important to their personhood and sense of self. However, to date little work has focused on synthesising these studies.

Methods: This is a protocol for a qualitative evidence synthesis of personhood in dementia. The review examines qualitative peer-reviewed research of the perspectives and experiences of personhood for people living with dementia. A systematic search will be carried out on eight electronic databases and supplemented by other purposeful literature search methods. Title and abstract screening, and full text screening will be carried out by two authors independently. Included studies will be critically appraised. Thematic synthesis will be conducted on all of the included studies. Confidence in the review findings will be assessed using GRADE CERQual.

Discussion: The findings from this synthesis will be useful to health care providers and policy makers seeking to understand what personhood means for people living with dementia. The findings will also inform optimal service provision, as well as outcome measures in dementia.

PROSPERO registration: [CRD42017076114](https://doi.org/10.1186/1745-6215-21-11) (21/11/2017)

Keywords

Dementia, personhood, self-identity, systematic review, qualitative synthesis



This article is included in the [Ageing Populations](#) collection.

Open Peer Review

Reviewer Status

	Invited Reviewers	
	1	2
version 1 published 05 Jun 2018	 report	 report

1 **Steven R. Sabat** , Georgetown University, Washington, USA

2 **Deborah O'Connor**, University of British Columbia (UBC), Vancouver, Canada

Any reports and responses or comments on the article can be found at the end of the article.

Corresponding author: Niamh Hennesly (N.HENNELLY2@nuigalway.ie)

Author roles: **Hennesly N:** Conceptualization, Methodology, Project Administration, Writing – Original Draft Preparation, Writing – Review & Editing; **Cooney A:** Investigation, Methodology, Writing – Review & Editing; **Houghton C:** Formal Analysis, Investigation, Methodology, Validation, Writing – Review & Editing; **O'Shea E:** Conceptualization, Formal Analysis, Funding Acquisition, Methodology, Supervision, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: Health Research Board Ireland [RL-2015-1587]. This work was also supported by the Irish Research Council. *The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.*

Copyright: © 2018 Hennesly N *et al.* This is an open access article distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

How to cite this article: Hennesly N, Cooney A, Houghton C and O'Shea E. **The experiences and perceptions of personhood for people living with dementia: A qualitative evidence synthesis protocol [version 1; peer review: 2 approved]** HRB Open Research 2018, 1:18 (<https://doi.org/10.12688/hrbopenres.12845.1>)

First published: 05 Jun 2018, 1:18 (<https://doi.org/10.12688/hrbopenres.12845.1>)

Introduction

In 2015, the number of people living with dementia was estimated at 46.8 million globally. This is predicted to increase significantly to 131.5 million by 2050 (Prince *et al.*, 2015). Dementia impacts profoundly on the person living with dementia but also has significant social effects, not least on family and friends. Until very recently, the biomedical model has dominated our thinking on dementia (Cahill, 2018). It viewed people living with dementia as lacking rationality and capacity and by consequence having lost personhood (Baldwin *et al.*, 2007; Caddell & Clare, 2010; Small *et al.*, 1998; Surr, 2006). Kitwood (1997) posits that treating the person living with dementia as if they are no longer a person, as if they had lost personhood, exacerbates the impact and the progression of the dementia.

Research from social psychology into the self in dementia concurs with Kitwood's theory and shows the critical role that people around the person living with dementia play in supporting their sense of self and social roles (Sabat & Harré, 1992; Sabat & Collins, 1999). The implications of these findings on dementia care have resulted in a gradual paradigm shift from a biomedical model to a biopsychosocial model of dementia care (O'Shea & Carney, 2016). This model takes a whole-person approach to understanding dementia and examines a wide range of factors likely to impact on the person's subjective experience, including influences from biology, society, economics, psychology and the environment.

Person-centred care is firmly rooted in the biopsychosocial model and is centred on recognising and supporting personhood in dementia (Brooker, 2007; Edvardsson *et al.*, 2008; Hughes & Beatty, 2013). McCormack *et al.* (2012) argue that evidence and research into personhood is critical to the application of best practice in person-centred care. While there are existing studies on personhood in dementia and in the related areas of sense of self and self-identity, very little of that research has been systematically reviewed and synthesised. Moreover the voice of the person living with dementia in relation to personhood has not been heard as strongly as one might expect. This review aims to systematically search the literature to examine what personhood means to people living with dementia and, in particular, what they define as its most important constituent parts.

Personhood in dementia

Primarily, personhood in dementia is concerned with how the person living with dementia perceives themselves (Sakamoto *et al.*, 2017) and how this can be supported by those around them in relation to their own being and identity. For example, Leibling (2008) explains how personhood is concerned with "that which really matters" to us as people and how important it is for people living with dementia that care practices does not "diminish someone's 'humanness'" (2008, p.183). Selfhood and self-identity are intrinsically linked with, and viewed as, core elements of personhood. McCormack *et al.* define personhood as "a sense of self-identity maintained by relationships" (2012, p.286). Personhood in dementia is predominantly conceptualised as relational and socially constructed placing it within the domain of roles, relationships and social interaction (Tolhurst *et al.*, 2014).

Hennelly & O'Shea (2017), found synonyms for personhood to encompass an even wider range of terms such as connection, dignity, holistic, identity, person-centred, relationships, role, respect and self.

There are a number of existing reviews and syntheses on the experiences of people living with dementia (Ablitt *et al.*, 2009; Eriksen *et al.*, 2016; Górska *et al.*, 2018; La Fontaine & Oyebode, 2014; Steeman *et al.*, 2006; von Kutzleben *et al.*, 2012; Wadham *et al.*, 2016; Wolverson *et al.*, 2016). However, there are few reviews of personhood in dementia, particularly ones that focus exclusively on the direct experiences of the person living with dementia. Caddell & Clare (2010) conducted a comprehensive systematic review of both qualitative and quantitative research to investigate self and identity in dementia, but they did not include any type of synthesis. They found that the majority of studies supported the persistence of self in people living with dementia, including people with severe dementia. Our review will build on their work by synthesising existing qualitative research on personhood from the perspective of the person living with dementia, exploring their experiences and perceptions of personhood, self-identity, sense of self and selfhood. However, the review will not seek to examine the evidence in relation to the existence of self, as Caddell & Clare (2010) have already examined this issue.

Rationale

In his theorising about personhood in people living with dementia, Kitwood (1997) identified five psychological needs experienced by people living with dementia, namely the need for comfort, attachment, identity, occupation and inclusion. He also talked about the relationship aspect of dementia and the importance of inter-personal relations in building and maintaining personhood. Maintaining personhood in the face of declining cognitive powers presents a huge challenge to care systems in all countries. Brooker's (2004) response was to set out a person-centred care approach comprising of four key elements: a value base; an individualised approach emphasising uniqueness; adopting the perspective of the individual; and providing a supportive social environment.

Reviews of person-centred care in dementia have been undertaken (Chenoweth *et al.*, 2015; Houghton *et al.*, 2016; Kim & Park, 2017). However, there are few reviews of research on personhood. In carrying out this review we will assess how much research has been conducted on personhood, what the quality of this work is, what the results of those studies tell us and, if feasible, we will synthesise these studies to provide a more comprehensive view of personhood in dementia. The findings from the synthesis will be useful in designing, implementing and assessing future work on personhood, in relation to person-centred care for people living with dementia in all care settings. Findings will also be useful in informing future practice, regulation and policy in dementia care, including the measurement of personhood-related outcomes.

Protocol

Aims and objectives

This review aims to examine the experiences and perceptions of personhood for people living with dementia

in various dementia care settings using qualitative evidence synthesis. The objectives of the review are to:

1. Describe the experiences and perceptions of personhood for people living with dementia living at home and across home, community and long-stay care settings.
2. Examine the potential implications of this synthesis for practice, regulation and policy in dementia care.

Methods

Eligibility criteria

Inclusion criteria.

Types of studies:

Primary research studies which are qualitative and mixed-methods will be considered for inclusion. The design methods (e.g. semi-structured interviews or observation) and the analysis (e.g. thematic analysis or grounded theory) must be clearly reported and must be qualitative to be included in the review. Mixed-methods studies will be included if the qualitative element is clearly reported. All studies must be peer-reviewed articles.

Types of participants:

Study participants are people with any type of dementia, including Alzheimer’s disease, Lewy Body dementia, vascular dementia, Pick’s Disease, Huntington Disease, Frontotemporal Dementia, or Creutzfeldt-Jakob disease. Studies focusing on people with early to late-onset dementia of all ages will be included. A formal diagnosis of dementia will not be necessary. Studies will be included once the study author(s) have stated that the participants have dementia. If the study also contains participants who do not have dementia, then it must be possible to extract the views and expressions of the participants with dementia within such studies. Otherwise, these studies will be excluded.

Phenomenon of interest:

The phenomenon of interest in this study are the experiences and perceptions of personhood for people living with dementia which includes studies of the self, self-identity, selfhood and sense of self. If studies examine personhood along with another concept in dementia then it must be possible to extract the information specific to personhood in order for the study to be included in the synthesis.

Comparison:

Perspectives of personhood in dementia will be solely from people living with dementia. There is the potential for subgroup analysis within this population, for example, analysis of personhood in relation to care provided in different care settings.

Evaluation:

The results of this synthesis will be useful in guiding practice and policy which aim to support personhood in dementia. The results will be useful for both implementation of such practices and examining outcomes in dementia.

Settings:

Studies will be in three types of settings: home care, day care and long-stay care. This review will include studies from any country and in any language.

Exclusion Criteria.

Types of studies:

- Quantitative research
- Mixed-methods studies that do not report their qualitative methods nor present qualitative findings
- Literature reviews and editorials
- Non-peer reviewed items including: grey literature, reports and theses
- Studies which collect data qualitatively and analyse it quantitatively (e.g. descriptive analysis) will also be excluded.
- Studies where the full text is not available

Types of participants:

- Studies where the person living with dementia is not a participant
- Studies where the participants have a mild cognitive impairment
- Studies where it is not possible to extract the views of the person living with dementia

Phenomenon of interest:

- Research on artistic expressions of personhood including interpretation of texts, art or film
- Studies which examine interventions to support personhood including for example, reminiscence, person-centred care interventions, self-management interventions, art therapies etc.
- Studies which examine other elements of subjective experiences in dementia such as coping, social relationships, dignity and meaning-making along with personhood where it is not possible to extract the data on personhood

Search methods for identification of studies

This review will use a combination of systematic searching of the literature using electronic databases and other search methods including purposive sampling of papers using key citations and hand searching of references (Booth, 2016).

It will search the electronic databases listed in [Table 1](#).

Table 1. Electronic databases.

1.	Scopus
2.	Web of Science
3.	EBSCO – CINAHL and AgeLine
4.	Sociological Abstracts
5.	PsycINFO
6.	Medline
7.	Embase
8.	Cochrane

These databases have been selected, in consultation with an expert librarian, in order to source peer-reviewed articles across a number of disciplines including nursing, psychology, social care and social gerontology. The search will be conducted by one author (NH) in all databases over one day. In addition, this review will use the Google Scholar's *Cited by* option to include all papers referencing [Kitwood & Bredin \(1992\)](#) and [Sabat & Harré \(1992\)](#) which are two seminal works on personhood in dementia. Reference searches of the included papers will also be conducted. This involves both manual backward searching of their references and forward searches using Google Scholar's *Cited by* option ([Booth, 2016](#)). The search will not be limited to particular geographic locations and will include papers in any language. The search will cover from 1985 to present, starting several years prior to the publication of [Kitwood & Bredin \(1992\)](#) and [Sabat & Harré \(1992\)](#).

Electronic Search. A summary of the electronic search strings is presented in [Table 2](#).

Certain terms will be truncated, for example dement* or Lewy Bod*, to ensure all spellings are captured. MeSH terms will be used for Medline. The use of title and abstract will depend on the individual databases. This review will report results of searching, screening and included studies using the PRISMA flowchart ([Moher et al., 2009](#)).

Screening

All references will be imported into Endnote and duplicates removed. Two authors (NH and AC) will screen titles and abstracts independently, using [Covidence](#). When there is no abstract or it is not possible to determine whether to include an article or not, the full text of the article will be retrieved. One author (NH) will review all full-text articles, two other authors (CH and EOS) will share second screening of all full-text articles. Disagreement between authors will be discussed and if required, in consultation with all authors. If necessary, we will contact authors of potential included studies for further clarification and information. If the review retrieves more than 40 eligible papers then the CART framework will be used to determine what articles to include ([Aslam et al., 2017](#); [Tennison, 2013](#)). This encompasses examining the completeness, accuracy, relevance and timeliness of the studies ([Aslam et al., 2017](#); [Tennison, 2013](#)).

Data extraction and management

Full text articles will be imported and managed within [NVivo](#). Data extraction and the thematic synthesis will be facilitated within NVivo ([Houghton et al., 2017](#)). The data extraction form will be created within NVivo using categories such as: author, year, location, methodology, ethics, data collection, results/findings including participant quotes etc.

Assessment of methodological limitations in primary studies.

The included studies will be assessed for quality using the [Critical Appraisal Skills Programme tool](#). This includes examining: the aims of the study, methodology, research design, recruitment strategy, data collection, relationship between researcher and participant, ethics, data analysis, findings and the value of the research. How the study is reported may not be reflective of how the study was conducted and therefore this assessment will not be used to exclude any studies from the synthesis ([Dixon-Woods et al., 2007](#)). The appraisal will be carried out by one author (NH) and reviewed by a second (EOS).

Data synthesis

The field of qualitative evidence synthesis is wide and varied ([Barnett-Page & Thomas, 2009](#)). Qualitative synthesis differs to narrative and systematic literature reviews as it aims to go beyond solely describing qualitative studies to developing new interpretations or explanations of these studies' findings ([Barnett-Page & Thomas, 2009](#)). This review will synthesise the included qualitative studies using thematic synthesis ([Thomas & Harden, 2008](#)). This is a three step process which starts with line by line coding of primary data from the included studies in order to develop descriptive themes and generate broader analytical themes ([Thomas & Harden, 2008](#)). This process will be conducted within NVivo with guidance from a previous synthesis on how best to use the coding software ([Houghton et al., 2017](#)). Thematic synthesis was chosen because the final result is particularly useful for providing information for policy and practice ([Barnett-Page & Thomas, 2009](#)). One author (NH) will carry out the thematic synthesis with continuous input from the other three authors at each stage. Using NVivo to carry out the whole process from line by line coding to analytical themes provides for transparency and clarity in the synthesis process. All of the authors will read and make contributions to the final paper. As this is a qualitative evidence synthesis, no statistical analysis is planned on the papers selected for the review.

Table 2. Search strings.

	personhood OR person*hood OR selfhood OR self*hood OR self-identity OR self*identity OR identity OR "sense of self" OR self (Title and abstract)
AND	dementia OR Alzheimer* OR "Lewy Bod*" OR "vascular dementia" OR pick* OR Huntington* OR frontotemporal OR Creutzfeldt-Jakob OR "cognitive impairment"(Title and abstract)
AND	qualitative OR "mixed*method*" OR narrative OR phenomenol* OR ethnograph OR ethnonursing OR ethnological OR questionnaire OR "grounded*theory" OR "case*stud*" OR "action*research" OR "focus*group*" OR thematic OR construction* OR hermeneutic OR heurist* (Title and abstract)

Sub group analysis and heterogeneity. Given the significant impact of setting on the dementia experience, a sub group analysis between home and residential care settings will be carried out. Other sub group analysis many include experience of personhood in formal care provision, people with young onset dementia, gender or ethnicity. Such groups will be determined inductively through the synthesis.

Assessment of confidence in the review findings

Appraisal of review findings. This review will use the [GRADE CERQual](#) approach, to appraise the review findings, which involves examining four main elements: the limitations of included studies, how relevant the studies are to the review question, the coherence of the review finding and how adequate that data is in supporting the review finding. This will include a sensitivity analysis to examine the contribution of the poorer quality studies to the overall findings ([Houghton et al., 2017](#); [Thomas & Harden, 2008](#)). The appraisal of review findings will be carried out by one author (CH) and reviewed by a second (NH).

Reporting. This review will be reported in line with the ENTREQ guidelines ([Tong et al., 2012](#)). A completed PRISMA-P checklist is available as [Supplementary File 1](#).

Dissemination of findings. Findings will be submitted to a peer-reviewed journal for publication. The findings will also be integrated into a wider study being conducted at NUI Galway, also funded by the Health Research Board of Ireland (HRB), on resource allocation processes in dementia care provision. The findings will also be shared with stakeholders, including people with dementia, as part of the commitment to Public Patient Involvement (PPI) at the Centre for Economic and Social Research on Dementia in NUI Galway.

Study status. This study is currently underway. Title and abstract screening has taken place. Full-text screening is ongoing. Data extraction has not yet taken place.

Discussion

Personhood, and its realisation in person-centred care, is nowadays part of the narrative, if not always the reality, of care for people living with dementia. While it appears that we have come a long way from [Kitwood's \(1993\)](#) early theorising about personhood to a clearer understanding of the practical application of the model, personhood remains a contested space within the dementia literature. Moreover, an absence of clarity with respect to the conceptualisation and actualisation of personhood within policy documents, for example the Irish National Dementia Strategy ([Hennelly & O'Shea, 2017](#)),

makes it difficult to assess how person-centred care can be enhanced for people living with dementia through changes in current practice. The challenge is to provide the information, knowledge, incentives and resources for personhood to take hold in dementia care across all care settings. The purpose of this protocol is to systematically assess peer-reviewed qualitative studies of personhood in dementia from the perspective of people living with dementia themselves. This will help give direct voice and influence to people living with dementia in shaping the narrative with respect to personhood and person-centred care in dementia. The outcomes of the planned synthesis will be useful as an aid to developing an experience-led appreciation and understanding of the key elements of personhood in dementia. The results will be important in planning care and supports for people living with dementia that focus on, and support, personhood-focused care, as interpreted by people living with the disease. Structuring person-centred care around what matters to people living with dementia increases the potential of enhancing their care and quality of life. Additionally, these results will be useful for evaluation, regulation and outcome assessment in dementia care. They will also act as a benchmark for people living with dementia and their family carers in relation to personhood ideals and attributes.

Protocol registration

Registered with International Prospective Register of Systematic Reviews (PROSPERO) no. [CRD42017076114](#) on the 21st November 2017. The following amendments were made to the original protocol: the electronic search string was edited and the expected completion date of the review was extended. Both versions of the protocol are available on [www.crd.york.ac.uk/prospere](#). Any further amendments to the protocol will be updated on PROSPERO.

Data availability

No data is associated with this article

Competing interests

No competing interests were disclosed.

Grant information

Health Research Board Ireland [RL-2015-1587].

This work was also supported by the Irish Research Council.

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Supplementary material

Supplementary File 1 – Completed PRISMA-P checklist.

[Click here to access the data.](#)

References

- Ablitt A, Jones GV, Muers J: **Living with dementia: a systematic review of the influence of relationship factors.** *Ageing Ment Health.* 2009; **13**(4): 497–511.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Aslam RW, Hendry M, Booth A, *et al.*: **Intervention Now to Eliminate Repeat Unintended Pregnancy in Teenagers (INTERUPT): a systematic review of intervention effectiveness and cost-effectiveness, and qualitative and realist synthesis of implementation factors and user engagement.** *BMC Med.* 2017; **15**(1): 155.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Baldwin C, Capstick A, Phinney A, *et al.*: **Conceptualizing personhood in dementia.** In: BALDWIN, C. & CAPSTICK, A. (eds.) *Tom Kitwood on dementia: A reader and critical commentary.* Berkshire, UK: Open University Press, 2007.
- Barnett-page E, Thomas J: **Methods for the synthesis of qualitative research: a critical review.** *BMC Med Res Methodol.* 2009; **9**: 59.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Booth A: **Searching for qualitative research for inclusion in systematic reviews: a structured methodological review.** *Syst Rev.* 2016; **5**: 74.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Brooker D: **What is person-centred care in dementia?** *Rev Clin Gerontol.* 2004; **13**(3): 215–222.
[Publisher Full Text](#)
- Brooker D: **Person-centred dementia care: making services better.** London, UK: Jessica Kingsley Publishers. 2007.
[Reference Source](#)
- Caddell LS, Clare L: **The impact of dementia on self and identity: A systematic review.** *Clin Psychol Rev.* 2010; **30**(1): 113–126.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Cahill S: **Dementia and human rights.** Policy Press, 2018.
[Reference Source](#)
- Chenoweth L, Stein-parbury J, Lapkin S, *et al.*: **Organisational interventions for promoting person-centred care for people with dementia.** *Cochrane Database Syst Rev.* 2015.
[Publisher Full Text](#)
- Dixon-woods M, Sutton A, Shaw R, *et al.*: **Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods.** *J Health Serv Res Policy.* 2007; **12**(1): 42–47.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Edvardsson D, Winblad B, Sandman PO: **Person-centred care of people with severe Alzheimer's disease: current status and ways forward.** *Lancet Neurol.* 2008; **7**(4): 362–367.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Eriksen S, Helvik AS, Juvet LK, *et al.*: **The Experience of Relations in Persons with Dementia: A Systematic Meta-Synthesis.** *Dement Geriatr Cogn Disord.* 2016; **42**(5–6): 342–368.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Górska S, Forsyth K, Maciver D: **Living With Dementia: A Meta-synthesis of Qualitative Research on the Lived Experience.** *Gerontologist.* gnw195. 2018; **58**(3): e180–e196.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Hennelly N, O'Shea E: **Personhood, dementia policy and the Irish National Dementia Strategy.** *Dementia (London).* [Accessed 29/09/2017]. 2017; 1471301217729232.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Houghton C, Murphy K, Brooker D, *et al.*: **Healthcare staffs' experiences and perceptions of caring for people with dementia in the acute setting: Qualitative evidence synthesis.** *Int J Nurs Stud.* 2016; **61**: 104–16.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Houghton C, Murphy K, Meehan B, *et al.*: **From screening to synthesis: using nivo to enhance transparency in qualitative evidence synthesis.** *J Clin Nurs.* 2017; **26**(5–6): 873–881.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Hughes JC, Beatty A: **Understanding the person with dementia: A clinicophilosophical case discussion.** *Adv Psychiatr Treat.* 2013; **19**(5): 337–343.
[Publisher Full Text](#)
- Kim SK, Park M: **Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis.** *Clin Interv Aging.* 2017; **12**: 381–397.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Kitwood T: **Towards a theory of dementia care: the interpersonal process.** *Ageing Soc.* 1993; **13**(1): 51–67.
[Publisher Full Text](#)
- Kitwood T: **Dementia Reconsidered: The person comes first.** Buckingham, UK: Open University Press, 1997.
[Reference Source](#)
- Kitwood T, Bredin K: **Towards a theory of dementia care: Personhood and well-being.** *Ageing Soc.* 1992; **12**(3): 269–287.
[PubMed Abstract](#) | [Publisher Full Text](#)
- La Fontaine J, Oyebode JR: **Family relationships and dementia: a synthesis of qualitative research including the person with dementia.** *Ageing Soc.* 2014; **34**(7): 1243–1272.
[Publisher Full Text](#)
- Leibing A: **Entangled Matters—Alzheimer's, interiority, and the 'unflattening' of the world.** *Cult Med Psychiatry.* 2008; **32**(2): 177–193.
[PubMed Abstract](#) | [Publisher Full Text](#)
- McCormack B, Roberts T, Meyer J, *et al.*: **Appreciating the 'person' in long-term care.** *Int J Older People Nurs.* 2012; **7**(4): 284–294.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Moher D, Liberati A, Tetzlaff J, *et al.*: **Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement.** *PLoS Med.* 2009; **6**(7): e1000097.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- O'Shea E, Carney P: **Paying Dividends: A Report on The Atlantic Philanthropies Investment in Dementia in Ireland.** Galway, Ireland: Centre for Economic and Social Research on Dementia. 2016.
[Reference Source](#)
- Prince M, Wimo A, Guerchet M, *et al.*: **World Alzheimer Report 2015. The global impact of dementia. An analysis of prevalence, incidence, cost and trends.** London: Alzheimer's Disease International. 2015.
[Reference Source](#)
- Sabat SR, Collins M: **Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease.** *Am J Alzheimers Dis Other Demen.* 1999; **14**(1): 11–19.
[Publisher Full Text](#)
- Sabat SR, Harré R: **The Construction and Deconstruction of Self in Alzheimer's Disease.** *Ageing Soc.* 1992; **12**(4): 443–461.
[Publisher Full Text](#)
- Sakamoto ML, Moore SL, Johnson ST: **"I'm Still Here": Personhood and the Early-Onset Dementia Experience.** *J Gerontol Nurs.* 2017; **43**(5): 12–17.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Small JA, Geldart K, Gutman G, *et al.*: **The discourse of self in dementia.** *Ageing Soc.* 1998; **18**(3): 291–316.
[Reference Source](#)
- Steeman E, de Casterlé BD, Godderis J, *et al.*: **Living with early-stage dementia: a review of qualitative studies.** *J Adv Nurs.* 2006; **54**(6): 722–738.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Surr CA: **Preservation of self in people with dementia living in residential care: a socio-biographical approach.** *Soc Sci Med.* 2006; **62**(7): 1720–1730.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Tennison B: **Understanding data, information, and knowledge.** In: GUEST, C., RICCIARDI, W., KAWACHI, I. & LANG, I. (eds.) *Oxford Handbook of Public Health Practice.* 3rd ed. Oxford, UK: Oxford University Press, 2013.
- Thomas J, Harden A: **Methods for the thematic synthesis of qualitative research in systematic reviews.** *BMC Med Res Methodol.* 2008; **8**: 45.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Tolhurst E, Bhattacharyya S, Kingston P: **Young onset dementia: the impact of emergent age-based factors upon personhood.** *Dementia (London).* 2014; **13**(2): 193–206.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Tong A, Flemming K, McInnes E, *et al.*: **Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ.** *BMC Med Res Methodol.* 2012; **12**: 181.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- von Kutzleben M, Schmid W, Halek M, *et al.*: **Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia.** *Ageing Ment Health.* 2012; **16**(3): 378–390.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Wadhwa O, Simpson J, Rust J, *et al.*: **Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood.** *Ageing Ment Health.* 2016; **20**(5): 463–473.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Wolverson EL, Clarke C, Moniz-cook ED: **Living positively with dementia: a systematic review and synthesis of the qualitative literature.** *Ageing Ment Health.* 2016; **20**(7): 676–699.
[PubMed Abstract](#) | [Publisher Full Text](#)

Open Peer Review

Current Peer Review Status:  

Version 1

Reviewer Report 28 June 2018

<https://doi.org/10.21956/hrbopenres.13907.r26259>

© 2018 O'Connor D. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Deborah O'Connor

School of Social Work, University of British Columbia (UBC), Vancouver, BC, Canada

Thank you for inviting me to review this proposed study. As the authors note, there is a growing body of research now linked to how people with dementia experience dementia, much of which is grounded within the personhood literature. However, to the best of my knowledge, this literature has not been synthesized. Certainly, as a researcher, I would welcome this and look forward to seeing the end results of this study.

Generally, I see this proposed study as well-developed and straight-forward. I do have a few relatively minor questions/comments for the authors to consider:

Criteria for inclusion/exclusion:

1. The authors note that: "Studies focusing on people with early to late-onset dementia of all ages will be included. A formal diagnosis of dementia will not be necessary". I have two questions here. First, how will the authors ascertain that this research has indeed focused on persons with dementia? Second, while the authors note here they will include early to late-onset, later in the protocol they indicated that studies where participants have a mild cognitive impairment will be excluded. Can these two, potentially conflicting statements, be clarified? Perhaps the authors are referencing MCI as a diagnosis? If so, how does this align with not requiring a diagnosis of dementia?
2. In terms of selection, the authors indicate that they will examine "all papers referencing Kitwood & Bredin (1992) and Sabat & Harré (1992) which are two seminal works on person- hood in dementia". I would suggest expanding this to include Kitwood 1997 as often this is cited in lieu of the 1992 paper. As well, anything referencing Sabat is probably relevant as well.
3. The authors indicate they will only address peer-reviewed publications. While on the one hand I understand this, it would be useful to explicate why other sources are being excluded and to recognize the limitations associated with this decision to exclude. This is particularly pertinent to the decision to exclude autobiographical accounts (which arguably, a case could be made for them

to be considered case studies). Similarly, there are a number of policy papers that have attempted to bring forward the perspectives of those with dementia, can the authors explain why these will be excluded including acknowledging the limitations of their exclusion.

Analysis and Synthesis

When asked if sufficient details about methodology were provided that this study would be replicable, I responded 'partly'. The rationale behind my hesitant response is related to three issues that I think could usefully be further developed to increase replicability:

1. Initially I wondered if only studies in English would be considered, but later noted that non-English papers will also be included. How do the authors intend to handle non-English papers?
2. In terms of developing a protocol that is replicable, it would be useful if the author's identified the questions or topics that they will use to insure a systematic reading of each paper. I recognize that some broad questions have been identified (i.e. Study quality) and I suspect there are some implicit questions, but as a reader it would be helpful if these were more explicitly operationalized into some sort of a reading protocol. This would facilitate contrast and comparison?
3. Picking up on my previous comment: I think there are some aspects related to a synthesis of this body of research that would be of particular value to address. One of these is culture: for example, how does culture inform each study including sense-making of perceptions/experiences of personhood? I note that the authors' state that "Other sub group analysis many[*] include experience of personhood in formal care provision, people with young onset dementia, gender or ethnicity". Personhood has been critiqued for it's cultural relevance. From my perspective, some incorporation of culture into this synthesis would increase its value. Hence, I would recommend that the tentative '*may*' be changed to a more intentional '*will*' be included as a sub-group analysis. I would also encourage broadening beyond ethnicity to consider for example, race and sexual orientation.

I hope these comments are helpful and as previously noted, I look forward to reading this synthesis!

* Note need to edit this sentence as this is a direct quote: I'm assuming the 'many' is supposed to read 'may'.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 21 June 2018

<https://doi.org/10.21956/hrbopenres.13907.r26262>

© 2018 Sabat S. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

**Steven R. Sabat** 

Georgetown University, Washington, DC, USA

I indicated that the study is "partly" appropriate for the research question because it appears to be limited to peer reviewed work. Even though there is a statement to the contrary within the protocol, there seems to be an omission of important references. For example, the voices of people with dementia, such as those of Kate Swafford, Richard Taylor, and Christine Bryden, for example, who have written books on their experience of dementia are omitted in this study, but should not be. The fact that their work is not peer reviewed should not disqualify their voices from the study because, after all, their voices are precisely those that the authors seek to hear. Likewise, books such as Snyder's *Speaking Our Minds: What it's Like to have Alzheimer's* should be included as well for the same reasons as mentioned above. All modesty notwithstanding, my own work in book form is germane as well. The perspective of people with dementia can be found in great detail in sources other than peer reviewed journals and although the authors have noted that non-peer reviewed items are included, the above authors' works are not included in the reference section and, I believe, inclusion of those works would add to the authors' protocol especially because they are so clearly and correctly concerned with the perspective of people living with dementia (see Discussion section).

Having said that, it is excellent that the studies reviewed will include the settings of home care, day care, and long-term care. This is especially important and a potential source of valuable information as are studies using a variety of methods (quantitative, qualitative, mixed, etc.). Likewise, I think that the "Phenomenon of Interest" is excellent for its inclusivity of a variety of expressions of personhood, such as art and social relationships, dignity, and meaning making for example. The authors are to be congratulated for the breadth of their protocol in this respect as well as exploring contributions from a number of different disciplines and databases and geographic locations. This, too, is evidence of the authors' understanding that knowledge can be gained from using a wide-angle lens, as it were, so as to include a variety of methods and venues of reporting information. The inclusion of a variety of data bases is also admirable.

I appreciate the authors' intention to assess methodological limitations in primary studies. The assets and liabilities of methods of investigation is an important contribution to the study. The same is true of subgroup analysis involving people living in a variety of settings and people with varied gender and ethnicity. This is especially important because the "one size fits all" variety of understanding is terribly flawed in light of the idea of person-centered care.

I agree wholeheartedly with the authors' goal of improving person-centered care by including the perspective of those very people. In the words of Christine Bryden, there should be "nothing about us without us" and this, as the authors clearly note, needs to be applied in all care settings so that it can be shown that doing so is not only beneficial for those diagnosed and their care partners, but also

economically and socially beneficial for the country itself. The protocol is especially important and timely and I am very impressed with its scope and, of course, with the rather important rationale for improving further person-centered care for people living with dementia.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Partly

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

No

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.
