# Dementia care model: Promoting personhood through co-production.

Alessandro Bosco[1], Justine Schneider[2], Donna Maria Coleston-Shields[1], Martin Orrell[1].

**Affiliation:** [1]Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham, Nottingham, United Kingdom; [2]School of Sociology and Social Policy, University of Nottingham, Nottingham, United Kingdom.

**Corresponding author:** Alessandro Bosco, Room A10, Institute of Mental Health, Innovation Park, University of Nottingham, Triumph Road, Nottingham NG7 2TU, United Kingdom. Email: Alessandro.bosco@nottingham.ac.uk Phone: (+44) 7453512212.

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## Abstract

**Background** Despite robust evidence on its effectiveness, current approaches that aspire to person-centred care (PCC) frequently locate people with dementia as passive recipients rather than as active agents in the care process. We define active involvement in care as 'co-production'. In order to investigate co-production, we set out to review the evidence concerning personhood and dignity in dementia care.

**Method** We adopted a meta-ethnographic approach to synthesise the predominantly-qualitative literature on personhood and dignity in dementia care using EMBASE, PsycINFO, and ASSIA databases. We also included relevant policy documents. Members of Patient and Public Involvement (PPI) group were consulted throughout.

**Results** A total of 14 empirical studies were subjected to content analysis. Three themes were identified: dignity and personhood, coping with dementia, and barriers to dignity in care. The findings suggest that positive strategies and coping mechanisms are associated with superior outcomes in relation to: sense of self, dignity and quality of care. The 22 policy documents yielded six themes pertaining to co-production: the part played by the person with dementia, family, environment, behaviour, governance and law, and health care partnership.

**Conclusion** Personhood in dementia care is enhanced through co-production, by actively participating in social, civic and political life. This is promoted through behavioural changes at the micro and macro levels of society, including providers of care being trained in co-producing care and policy makers creating opportunities with, rather than for people with dementia.

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**Keywords:** Person-centred care, dementia, personhood, integrated model, equal positioning.

## 1. Introduction

According to estimates, over 47 million individuals worldwide are living with dementia (WHO, 2017). Given the progressive cognitive impairment that dementia entails, people living with the condition have often been divested of their identities and their roles in society, even before the cognitive impairment disables them from self-expression and social participation (WHO, 2017). Consequently the entitlement of individuals with dementia receiving care to exercise autonomy and choice has frequently been overlooked.

Person-centred care (PCC) has become synonymous with high standards of care in dementia, promoting decision-making and user engagement in health care planning (Kitwood, 1997). PCC aims to promote the personhood of the person with dementia through an existentialist and humanistic consideration of their needs, values and beliefs (Kitwood, 1997). Successive models have tried to expand on Kitwood's framework, acknowledging the role of other agents in promoting personhood through care (i.e. the family or close social network) (Brooker, 2004). These models are grounded in the principles of social reciprocity, whereby all agents involved in the process of care influence each other and care outcomes through continuous social interaction. Despite the advances ensured by further development of the PCC framework, however, people with dementia have reported feeling passive recipients, rather than active agents, in the process of care (Armstrong, 2011). Examples of inadequate standards of care devaluing the self of the person with dementia and failing to meet their individual needs may be exacerbated in the context of hospital admissions, where staff may adopt a medical paradigm and objectify people with dementia in the process of care, thus failing to acknowledge their human rights:

*'Her family complained that their mother's care and treatment in hospital were inappropriate. They felt her care had been ignored due to her Alzheimer's and provided us with examples of her being treated with disrespect; these included being washed with the curtains drawn back and being left sitting in faeces during visiting time'.* (Armstrong & Byrne, 2011, p. 13).

The excerpt above reflects circumstances whereby, although the person with dementia was at the core in the delivery of care, as it is widely acknowledged in contemporary social and health care (Higgs & Gilleard, 2016), such centrality did not necessarily entail promotion of the person's dignity and personhood. This is also an example of the lack of autonomy and choice. A culture of care for people with dementia that permits such circumstances to occur points to a gross power imbalance between carers and cared-for, despite the lip-service paid to PCC. One challenge to redressing this imbalance is how to ensure that people with dementia are granted a truly active role and equal positioning in the delivery of care. In this review, we define active engagement of people with dementia in terms of co-production, which according to the definition suggested by the SCIE (2013) it is *'a meeting of minds coming together to find a shared solution'.* Ecological system theory provides the theoretical foundation to explain how personhood of the person with dementia can be promoted across different care systems as the person is enmeshed in different contexts or systems. Each system is not disjointed from the other, and the person finds her/himself simultaneously influenced by them. These systems represent different environments from the micro ecosystem of the home to the outward system of the community (e.g. Alzheimer’s café) moving towards more outward levels of societal involvement (e.g. government).

### *1.1 Study aims*

In this paper, we aimed to develop indicators for best PCC practice in dementia care through a synthesis of evidence on personhood in dementia.

## 2. Methods

As promoting personhood and dignity in dementia care has potential implications for research, policy and practice, it is of relevance to academics, policy makers, practitioners and members of the general public, so the research team felt that a holistic approach to the topic should be taken. The team, comprised researchers and clinicians operating in the health and social care sector who consulted with members of the public who volunteered to advise on the topic. Four phases of knowledge appraisal and theory development were undertaken: a systematic review on personhood and dignity in dementia that could explore examples of good and bad practice in dementia care (phase 1), a scoping review of policy documents around the preservation and promotion of either concepts (phase 2), the development of an integrated model of care ensuing from the findings of the two reviews  (phase 3), and the validation of the model through consultation with members of the patient and public involvement group (PPI) (phase 4).

### ***2.1 Phase 1. Systematic review on personhood in dementia care.***

The review complied with the PRISMA checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). We followed the PICO format to determine our search strategy (Sackett, Richardson, Rosenburg, & Haynes, 1997),

#### *2.1.1 Inclusion Criteria*

The study explores the concept of personhood and employs either a qualitative method or mixed method for data collection and analysis with direct quotes of participants. The study focuses on the positive factors (i.e. promoting/maintaining personhood) or negative factors (i.e. undermining personhood). The study is on dementia without comorbid organic disorders. Owing to the overlapping use of the terms ‘dignity’ and ‘personhood’, and their highly relatedness (Jacobsen, 2007), studies focusing on the preservation of dignity (both when reporting on how dignity helps support personhood and/or when exploring uniquely the promotion of dignity) were included when emerging from our search. Any language and publication year.

#### *2.1.2 Exclusion Criteria*

The Study is excluded if not empirical, (e.g. review, commentary, editorial, discussion paper), when not clearly reporting on personhood and/or dignity. The study is further excluded when is on palliative care, as the preservation of personhood and dignity may require more focussed and individualised strategies during the end of life care.

We ran searches on three databases, each from a relevant discipline: EMBASE (Medicine), PsycINFO (Psychology) and ASSIA (Social Sciences). The defining domains of our search were based on the concepts of dementia (i.e. dement* or Alzheimer*); personhood/dignity (i.e. personhood, self, selfhood, identit* or dignity); preservation (i.e. sustain* or maintain* or preserv*). We adapted the terms according to the characteristics of the individual databases. We further considered the first 100 hits on Google scholar and Google search to retrieve relevant grey literature.

The lead author (AB) undertook a two-stage process for the identification of articles to include in the review. The screening process was attained through the electronic databases used for the retrieval of the studies and comprised the following stages: 1) the titles and abstract of the articles were first screened against the inclusion/exclusion criteria of the review, 2) when the articles appeared relevant to the scope of the study, a second systematic screening was made and consisted in reading their full text against the inclusion/exclusion criteria. Upon completion of the screening process, for the included studies, information was extracted onto NVivo 11 (QSR International Pty Ltd., 2012) on study design, qualitative method and methodology, theoretical framework used for the concept of personhood, participants' demographics and area of investigation.

Although the search terms were in English and this may have automatically excluded studies published in other languages, we found that the majority of the articles we found in other languages were accompanied by an English abstract. This allowed us to include/exclude articles in the first screening process. A strategy was in place to involve foreign translators in case a study was found relevant for our review.

We conducted a quality appraisal of the articles through the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (CASP-UK, 2018). The first two items of the CASP checklist were used to exclude articles, if they did not clearly report on the aims of their investigation (item 1), and when the methodology they used was not appropriate for their research inquiry (item 2). The remaining eight items of the checklist were used for quality screening only.

***2.1.3 Data analysis.*** We used meta-ethnography for the extraction and synthesis of qualitative data and followed the seven steps by Noblit and Hare (1988) to reach third order interpretations deriving from the first and second order constructs reported in the studies. Meta-ethnography proves effective when developing theoretical models from interpretation of qualitative findings across studies (Atkins, Lewin, Smith et al., 2008), as it is in our interpretative analysis on the experience of people with dementia and their carers in regard to personhood and dignity in care.

As part of the analysis, the lead author (AB) extrapolated the relevant direct quotes from study participants (first order construct) and their interpretation as given by the authors (second order construct) and coded these into text units (by sentences). We then Employed constant comparative analysis to develop theme categories from first- and second-level interpretations. Constant comparative analysis enabled us to reach an understanding of social reality through generating concepts across studies (Charmaz, 2006).
The process of interpretation and synthesis was reviewed within the research team over several meetings, until consensus was reached. The research team included professionals with expertise in old age psychiatry, social care, and neuropsychology with a focus on dementia care. A final expressed synthesis, included a graphic representation for clarity in interpretation of our findings.

### *2.2 Phase 2. Scoping review on personhood and dignity in dementia – policy documents.*

We conducted a systematic search on governmental/policy documents (i.e. white papers, policy briefs) on dignity in care and personhood by searching for the terms ‘dignity’, ‘personhood’ and ‘dementia’ on the full databases on the NICE (National Institute for Health and Care Excellence), SCIE (Social Care Institute for Excellence), EUROPA (European Commission), UNECE, United Nations (Economic and Social Council), and Google web platforms. We further contacted members of the Global Action on Personhood (GAP) from participating countries (Italy, Canada, Japan, Norway, Singapore, and Spain) to ensure that existing relevant policies were not excluded from the search. A first screening was attained through the electronic databases and conducted by the lead author (AB). All policies were considered when meeting the inclusion criteria, be it issued at provincial level or national level. After the first screening, policies were screened against the inclusion/exclusion criteria and included if relevant to the scope of the review. When a policy at provincial/county level was found to replicate the national policy of the country in question, only the national policy was included. This did not apply to European and international Policies as we found they contained different or more comprehensive information compared to country-specific policies. However they were still screened against the inclusion/exclusion criteria.

#### *2.2.1 Inclusion Criteria*

The document is national guidance, a position statement such as a white paper or policy briefing (e.g. governmental report).  It concerns personhood, or dignity in dementia care and has been issued in the period 2007 to 2017, as policies and health care guidelines may change overtime. The document is in English and has been issued by any government with diplomatic recognition (United Nations, 2017).

#### *2.2.2 Exclusion Criteria*

The document is on palliative care, an adapted report from sources previously published from other governmental agencies, or a green paper. Updated versions of the same policy document were considered as secondary sources and were included only if adding new information.

***2.2.3 Data Analysis.*** We conducted a conventional inductive content analysis (Graneheim & Lundman, 2004), which is ideal in topic areas when the understanding of a phenomenon is fragmented and broad (Graneheim & Lundman, 2004), as it is the case of dignity and personhood in dementia care policy. The analysis comprised the following steps:

1) Familiarising with the content;
2) In-depth reading of the documents to generate meaning units;
3) Discussing within the research team the relevance and accuracy of the meaning units;
4) Developing themes and subthemes.

Any disagreement around themes and subthemes within the research team were resolved by consensus. We followed the criterion of credibility as described by Lincoln and Guba (1985) to reach study's rigour through the use of analyst triangulation by having members of the research team check the initial interpretations.

### *2.3 Phase 3. Development of an integrated model of care.*

Following findings from the reviews carried out in phase one and two, we developed an integrated model which aims at co-production in the delivery of care in dementia, where all agents involved are granted equal consideration of their personhood. The model takes into consideration human psychological needs as proposed by Kitwood (1997) and is grounded in Bronfenbrenner's framework of the self as situated in an ecological systemic parlance of life organisation (Bronfenbrenner, 1979). This theory was adopted for it helps describe the role of the person with dementia in society and helps factor in the different contexts whereby s/he operates.

### *2.4 Phase 4. Consultation with members of the PPI group.*

The study was discussed at two PPI sessions, comprising people with dementia and their carers who were already part of an established PPI group at the Institute of Mental Health, Nottingham. The first session involved the development of the questions that we later used in the second session to gather views on the relevance, feasibility and coherence of the model of care we developed. Examples of the questions discussed during the meeting were: 'do you think that these findings reflect the everyday life needs and preferences of people with dementia and their carers? If yes, in what ways?' A second meeting took place two weeks after to comment on the actual findings of the paper by means of the pre-developed questions.

# 3. Results

### *3.1 Phase 1. Systematic review and meta-ethnography on personhood in dementia.*

The systematic search initially retrieved 1,417 studies. We identified 11 additional records through Google. Of 1,428 records, we excluded 1,358 sources, which were clearly ineligible. The full texts of remaining 70 articles were assessed for eligibility against the inclusion/exclusion criteria. We excluded 55 articles with reason, thus including a final number of 15 articles for the quality appraisal. The selection process is reported in Figure 1 through a PRISMA flow diagram (Moher et al., 2009).

***3.1.1 Quality Appraisal*** Fifteen studies were appraised for their quality using CASP (Appendix A). One study was excluded as it did not clearly report the aims, the qualitative methods for data collection and information on data analysis. Overall, the 14 studies included were found to be of moderate-good quality (scores ranging 6-9 out of 10). We found it challenging to score the studies in relation to reporting bias (item 6) (e.g. the authors commenting on potential bias ensuing from their involvement in the study and in the development of questions for the interviews) as 11 out of 15 studies did not clearly report on this. In addition, discussing ethical issues (item 7) was the second least reported information across studies and this information was missing in 9 out of 15 studies.

***3.1.2 Study Characteristics.*** The studies selected were all published on peer reviewed journals from 2002 to 2017 (Appendix B for single study characteristics). Three studies were conducted in the UK, four in Canada, two in the USA, two in Norway and one each in Sweden, Australia and the Netherlands. A total of 251 participants were recruited (people with dementia: n=112, age=60+; carers: n=114, age=40+; health staff: n= 25, age=30+). Most studies approached their investigation from the perspective of personhood (n=12), and the remainder framed their enquiries with the concept of dignity (n=2). The studies varied in qualitative methodology: Most employed hermeneutic phenomenology (n=4), narrative (n=2), or constructivism (n=2). Less used were grounded theory (n=1) and ethnography (n=1). With respect to data collection, the most frequently-used methods were one-to-one interviews (n=12) and participant observations (n=3), the most used method for data analysis, was interpretative phenomenological analysis (n=4). Most studies explored the experience of residential care (n=7), community living (i.e. person accommodation) (n=5), only one study did not clearly report the setting and one included both participants from residential care and community living.

#### *3.1.3 Meta-ethnography*

Through the analysis we found preliminary themes around community belonging, activity involvement, and accessibility of the environment, the role of social networks, the function of interaction, active participation, and preservation of dignity. From these initial theme categories we then reached our third order constructs, which represented our interpretation of the material.

Three levels of third-order constructs emerged from the analysis of 14 studies (Table 1): (i) dignity and personhood, (ii) coping with dementia, (iii) barriers to dignity in care. The expressed synthesis of our findings is reported in Appendix C.

***Dignity and personhood.*** This theme pertains to a range of variables involved in the preservation of dignity and of strategies employed to promote personhood in the person with dementia.

*Dignity and its preservation.* Dignity is an abstract term and there is no consensus over its meaning. When inquired about how they conceive of dignity, people with dementia gave differing views based on their personal life experiences (VanGennip et al., 2016). Some attached a feeling of loss to the concept of dignity: *'Dignity means you can be yourself, you're still in control of your own thoughts, you can do what you want…But I'm not like that anymore.'* (person with dementia) (vanGennip et al., 2016, p. 494).

A sense of belongingness to family and a social role within the wider community seem to preserve dignity and a meaning to one's life, as much as engaging in meaningful activities: *'Yes, digging in the garden... It really does me good. I worked in the garden yesterday or the day before…And it makes me feel so much better'* (person with dementia) (vanGennip et al., 2016, p. 494).

*Strategies to promote personhood.* The environment plays an important role in promoting personhood in the person with dementia. For example, large spaces, low staffing or a noisy environment can be counterproductive (Hung & Chaudhury, 2011). On the contrary, large windows and natural light have been found to promote a sense of wholeness with nature and the outdoors, especially for those who are not able to spend time outside. When living in residential care, a home-like environment appears to be beneficial. Therefore, residents are encouraged to personalise rooms. The impact of environment is reported by several members of staff in care homes, who acknowledge that rooms where pleasant activities take place are favoured over others (Milte et al., 2015).

Family carers contend that behaviour and attitude on the part of the staff are also crucial to preserve dignity and personhood: *'They [people with dementia] need to be confirmed all the time, so that they may feel that they are individuals, and human beings'* (Carer) (Haggestad, Nortvedt, & Slettebø, 2015, p. 833). Family carers seem to appreciate when their loved ones are treated with respect: *'She's [a carer's mother] respected as the person she is; they don't treat her as a 'demented person' in a wheelchair who isn't able to move.'* (Carer) (Haggestad, Nortvedt, & Slettebø, 2015, p. 833).

An effective way for staff to promote dignity in care is promoting human connectedness with gestures of affection, which show heartfelt commitment to their emotional wellbeing (Hung & Chaudhury, 2011) or by behaving kindly while maintaining eye contact when speaking to the person, to show they are valued as human being (Hung & Chaudhury, 2011). Good interaction is further promoted by using positive statements during the conversation, as these may encourage the person with dementia to remain engaged.

***Coping with dementia.*** This theme relates to a series of mechanisms acted out by the person with dementia to cope with the condition, and a series of techniques used by the carers to improve the experience of dementia in their loved ones.

*Coping with one's own identity.* Being with peers was found to help some people with dementia safeguard a positive sense of identity: *'I've found that people here are like me, that aren't sure about what is going on... it makes me feel saner.'* (Person with dementia) (Nowell, Thornton, & Simpson, 2011, p. 403). However, residents may not always be willing to engage with peers, as they may feel a lack of empathy, given the highly subjective experience of the condition. Carers can also help promoting a positive sense of identity for the person with dementia by avoiding pointing out any inconsistencies between past and present events. In fact, the fluidity between past and present typical of dementia may prove beneficial for some people with dementia, who resort to the memories of past events to find strategies to cope with the issues of the 'here and now' (Phinney, Dahlke, & Purves, 2013).

Active engagement is also found to be instrumental in preserving one's own identity, as it gives continuity to life before and after the diagnosis of dementia (Milte et al., 2015). Given that the person with dementia may still be active, it is important to promote self-agency by finding suitable activities. A lack of stimulation may otherwise lead to apathy (Milte et al., 2015). Quite crucially, a person's condition may fluctuate over time and staff need to be prepared to grasp any opportunity for the person to get active (Zingmark, Sandman, & Norberg, 2002).

*Family carers' perspective.* The family carers reported feeling a duty of care towards the relative with dementia, especially in the presence of marital vows: *'Because I'm taking care of a person I feel I have to, because he's my husband. And it was a commitment I made.' 'So I'm bound by that commitment.'* (Carer) (Perry & O'Connor, 2002, p. 56).

The family carers felt that maintaining a positive view of the person by recollecting memories helps them deal with the present care duties: '*He was an excellent dancer… And the first five years of our marriage we danced every week…He always helped cook, he always helped.* (Carer) (Perry & O'Connor, 2002, p. 56).

In order to support the preservation of self-worth in their relative,  family carers sometimes justify the person's behaviours, making excuses for their diminished cognitive abilities or compensating for their lack of mental capacity (Perry & O'Connor, 2002). Another strategy is to operate on the environment, as explained by one carer: '*He's always wanting to wash dishes. Yesterday I let him wash a whole bunch of stuff that was already washed but [I just gave him the] plastics, you know.'* (Carer) (Perry & O'Connor, 2002, p. 58).

***Barriers to dignity in care.*** This theme includes negative intrapersonal and interpersonal factors which can negatively affect the personhood and dignity of residents with dementia.

*Internal factors.* Trying to fit in with the system's regime and rules of care homes may create barriers to expressing one's own identity and impact on the experience of care. A resident reported: *'You're living by their rules and regulations. You have to abide by their rules and regulations and I think that confines everybody in here to those aspects.'* (Resident) (Nowell, Thornton, & Simpson, 2011, p. 399). Another resident acknowledged that the rigidity of rules affected his self-determination: *'It's a lot of filling up time here, you have to do as you're told. You can't always have your own way.'* (Person with dementia) (Nowell, Thornton, & Simpson, 2011, p. 400).

*External factors.* The conduct of staff has consequences on the quality of care provided. For example, the members of staff may engage in mechanical behaviours which devalue the person's dignity: *'They are sitting and feeding a person… just mechanically put something into the resident's mouth. It's terrible!'* (Carer) (Haggerstad, Nortvedt, & Slettebø, 2015, p. 835).

Another example of negative behaviour includes members of staff showing no interest in engaging in conversation with the person, while carrying out daily tasks: *[Staff]: 'Are you finished? [Resident]: What? What? [Before the resident has finished asking the question, the staff left]* (Field notes) (Hung & Chaudhury, 2011, p. 5).

Quality of care is also negatively impacted by the patronising culture of some members of staff, which is reflected in the statement: *'To me, residents are like babies. I feed them, clean them, and put them to sleep.'* (Hung & Chaudhury, 2011, p. 7). A classic example of a patronising interaction with a person with dementia was reported by Hung and Chaudhury (2011): *[Resident]: I need to use the bathroom. [Staff]: No, you don't. You just went not long ago. Now, it's time to eat, you eat!* (Field notes) (Hung & Chaudhury, 2011, p. 5).

### *3.2 Phase 2. Scoping review and content analysis of health care policy documents on personhood and dignity in dementia.*

For our scoping review, we retrieved 482 documents. Based on our inclusion criteria, we selected 22 policy documents, which were published between 2009 and 2017 (table 2).

Three documents were issued by the NICE, two by the UK Department of Health (DoH), one by the European Commission, one by the Mental Welfare Commission for Scotland, one by the World Health Organisation (WHO), one by the U.S. Department of health & Human Services, one by the United Nation Economic Commission for Europe (UNECE), one by the Alzheimer's Europe, and one by the RTI International. One document was a collaboration between the National Institute of Health and Research (NIHR) and the UK DoH, and one between the NHS, AgeUK and the Local Government Association. We further retrieved one policy document from each of the following governmental offices: The Irish Department of

Health, one form the Norwegian Ministry of health and care services, the Maltese Parliamentary Secretariat for Rights of Persons with Disabilities and Active Ageing, the Italian Ministry of Health, the Flemish minister for welfare, public health, and family, the Ministry of Social Affairs and Health, the H M Government of Gibraltar, the Israeli Ministry of Health, and the Dutch Ministry of Health, Welfare and Sport.

International policy was the aim of 9.1% (n=2) of the documents, while 81.8% (n=18) aimed at national policy (6 at the UK, 2 at the USA, and one at Australia), and 9.1% (n=2) at European policy. The majority (n=21) were easy to read and accessible to a non-expert audience, whereas one was in accessible format for people with dementia (DH, 2009). The documents focused on the following topics: Dementia-friendly communities, health care needs in dementia, overview on dementia, quality care in dementia, dignity in dementia care, person-centred care in dementia.

### *3.2.1 Content analysis*

Seven themes emerged from the content analysis (participation, family, environment, behaviour, policy and law, health care partnership, autonomy) and most themes comprised a variety of subthemes (Appendix D). The frequency of the themes was evenly spread across documents, with the most frequent being ‘environment’, which was reported in 18 documents (81.8%). One theme, ‘health care partnership’ was reported in 16 documents (72.7%). Two themes (role to play and family) were reported with the same frequency (n=15; 68.1%). The themes ‘governance and law’ and ‘behaviour’ were retrieved in 13 documents (59.1%) and ten documents (45.4%) respectively.

***Participation.*** This theme refers to the active involvement of people with dementia in decision making and in the social, civic and political life (Irish Depart. of Health, 2014; Norwegian Min. of health, 2015; Maltese Parliamentary Secretariat; 2014; Flemish minister for welfare, 2016; H M Government of Gibraltar, 2015; Dutch Ministry of Health, 2009). It further describes their active participation in the development of health care plans. (Alzheimer Europe, 2015; DoH, 2009; DoH, 2014; Mental Welfare, 2013; NHS AgeUK, 2012; NICE, 2013, 2017; Flemish minister for welfare, 2016).

In people with dementia, dignity can be promoted through their engaging in meaningful roles in life, be it in the job market for those of working age, in advocacy projects (e.g. to promote emancipation, to fight off stigma), or helping in policy development. Examples of positive engagement included acting as volunteers in charities and advocacy groups, acting as representatives in the national, European Parliament, and international organisations, taking part in the development of programmes for ‘Alzheimer’s Cafes’ and being part of self-help groups (UNECE, 2015; Alzheimer Europe, 2015; NICE, 2017; Mental Welfare Commission for Scotland, 2013).

While participation at national or international level was possible for only a small number of people with dementia, there is potential for all to be actively involved in the planning of their own care. The type of involvement is different at different points in the progression of the cognitive impairment. Advance care planning is advisable for people in the early stages so that their wishes are known when they can no longer express themselves (WHO, 2012).

This point has been addressed prominently across policies, due to a lack of perceived involvement by people with dementia (NICE, 2013, 2017). There is also a strong need of involvement in the delivery and evaluation phases of services, which seems more possible when the providers of care are adequately supported by the local authorities and health commissioners (NICE, 2013, 2017).

***Health care partnership.*** This theme acts as an umbrella term to describe different types of partnerships: between health care professionals, between health care professionals and people with dementia and their families, between researchers and people with dementia and their carers (NICE, 2016, 2017; UNECE, 2015; DoH, 2014; DoH, 2009). The focus is on integrating geriatrics with primary care services to increase health literacy among health professionals around the bio-psychosocial determinants of dementia; developing care services targeting the needs of the person with dementia and their carers at the individual, community and societal levels; delivering dementia friendly programmes to increase awareness in the community and reduce social exclusion (U.S. Department of health & Human Services, 2016); creating partnership between advocacy agencies and people with dementia to promote equality and social justice among those who have decreased or no capacity for their rights to be upheld.

The involvement of people with dementia and their carers in research is of the utmost importance for the assessment and delivery of health care services (Irish DoH, 2014; Maltese Parliamentary Secretariat, 2014; Finnish Ministry of Social Affairs, 2013; H M Government of Gibraltar, 2015; Israeli Ministry of Health, 2013; Dutch Ministry of Health, 2009). Therefore, policies strongly advocate for private and public investment in research.

***Family.*** In most policies, dementia was regarded as a family condition owing to the negative implications it also has on the relatives. It is often the case that family members provide the most of care, thus being frequently exposed to increased burden and mental health problems (UNECE, 2015), which could all negatively impact on the quality of care provided for the person with dementia (Maltese Parliamentary Secretariat, 2014; Finnish Ministry of Social Affairs, 2013; Israeli Ministry of Health, 2013; Dutch Ministry of Health, 2009).

Strategies to support family carers in their journey into dementia are mainly focussed on support groups, information papers provided by local care agencies, engagement in advocacy and voluntary organisation, consultation with general practices, and on legal and financial information provided by advocacy groups (NICE, 2013, 2017).

Few policies (3 out of 22) have addressed the importance of care plans for carers to promote their dignity and preserve their identities. These plans comprise multiple elements based on group psychoeducational programs, peer support groups, easy access to web support programs through charities and voluntary organisations (e.g. Alzheimer's Europe), the involvement of other family members at health care meetings for people with dementia, and the employment of 'dementia buddies' for carers. Strategies to develop effective care plans for carers should be culture-sensitive (U.S. Department of health & Human Services, 2016; NICE, 2013, 2017).

***Environment.*** Policies have used the term 'environment' to report on the quality standards and strategies needed to design dementia friendly settings (i.e. care settings, transportation, support network, housing and outdoor space) which promote dignity and a positive sense of self in people with dementia (Irish DoH, 2014; Norwegian Ministry of health, 2015; Maltese Parliamentary Secretariat, 2014; H M Government of Gibraltar, 2015; Dutch Ministry of Health, 2009). Most strategies are based on accessibility (e.g. the use of sign posting, lighting, floor covering, and clutter-free rooms); in the delivery of activities in the home of the person with dementia; in the use of assistive technology based on the preferences and needs of the person with dementia. Strategies targeting community inclusion focus on social activity programmes (e.g. bridge club, writing groups, book clubs, choirs) which are run at Alzheimer's café, libraries, churches, or other community settings (NICE, 2017; UNECE, 2015; U.S. Department of Health & Human Services, 2016).

***Behaviour.*** This theme refers to the style of communication between health professionals and people with dementia and their carers, to their quality of relationship, and to a series of behaviours acted out by health professionals that promote normalcy and a sense of equality in people with dementia (Norwegian Min. of Health, 2015; H M Government of Gibraltar, 2015).

The behaviours of health staff may be at times stereotyping, when they inadvertently exhibit courtesy-stigma (e.g. not allowing the person with dementia to be in the community to avoid stigma from a non-friendly environment). In fact, this coping mechanism may lead to negative outcomes, including social exclusion. To change staff attitudes towards dementia and promote positive relationships, policies set strategies targeting communication, dementia awareness and positive interaction with people with dementia. These policies advocate that the health organisations where health staff operate, need to encourage positive behaviours, and implement good training and consistent monitoring of performance. Training should prepare health staff to attend to the needs and preferences of people with dementia (e.g. being warm and empathetic) (NICE, 2017; RTI International, 2014; WHO, 2012). The benefits of these techniques are maximised when there is co-operation between staff, and when the same health care staff are matched consistently with the person with dementia.

***Governance and law.*** This theme covers fundamental human rights warranting the attention of the general public, providers of care, and at a macro level, the attention of health commissioners and policy makers. This theme was used instrumentally across documents to differentiate the medical model from a 'human rights-centred approach', in which people with dementia are not divested of their rights to intimacy, self-agency, love and dignity in the care they co-produce (Irish DoH, 2014; Maltese Parliamentary Secretariat 2014; Flemish minister for welfare, 2016).

The documents further describe the key role of guardians in the late stages of dementia, setting principles for good practice in guardianship (e.g. the person with dementia should be able to nominate at an early stage of the condition the person they prefer to act as guardian and they should be able to handle financial assets until capacity is compromised) (NICE, 2017, 2016; UNECE, 2015; RTI International, 2014; WHO, 2012).

### *3.3 Phase 3. Development of an integrated model of care*

Owing to its complexity, the model consists of three sections informed by the ecological system theory by Bronfenbrenner (1979), by the concept of social reciprocity and dignity in care and by the indicators for the promotion of personhood ensuing form the findings of the systematic review on the qualitative evidence on personhood and dignity and the scoping review of policy documents on the promotion of personhood in dementia care. The model is illustrated in Figure 2.

***3.3.1 Dementia dyad living in an ecological system.*** We argue that the person with dementia, their carer, their social network and health staff are all situated in an ecological system based on Bronfenbrenner's idea of *'nested arrangement of structures, each contained within the next'* (Bronfenbrenner, 1979). In the model, the microsystem represents the immediate set of inter-relations existing between the person with dementia and the context, the carer and the context but also the dyad and the context (e.g. day care centre, neighbourhood). This also applies to members of the social network of the person with dementia and to health staff. We conceive of the personal dimensions of these four groups of agents as four inter-related circles, each agent bringing into the interaction their own biopsychosocial dimensions, cultural heritage, and biography.

In the mesosystem, we find the inter-relations between all the contexts and the experiences of the agents involved in the care. The exo-system, represents an extension of the previous system with the inclusion of other social structures that impact on the context (e.g. economic status, local charities, and governmental agencies). In the macrosystem, we find the cultural and societal values and beliefs impinging on the context and structures of the systems. In relation to dementia, a further system, the chronosystem, comes to play a central role, representing the development of the condition over time, which impacts on all the other systems.

When the Bronfenbrenner's ecological framework is applied to our model, a detailed description of the personal dimensions, levels of structural influences and systemic organisation of context-based experiences begins to emerge. The aim of this review though, is not to give a comprehensive description of all the variables influencing the systems in the model, as each individual is nested in a different social parlance, but to provide a heuristic to better understand how each agent operates and influences each other's ecological systems. This interpretation sets the basis for the following two blocks of the model and describes the context whereby co-production should occur.

***3.3.2 Social reciprocity and personhood.*** In line with Brooker's (2007) standpoint, we consider social reciprocity as a key function of personhood among actively interacting agents. In this regard, personhood is promoted through the social interaction between the person with dementia, carers and other influential agents providing care. The person with dementia therefore, plays an active role in promoting personhood through their own social behaviours (either verbal or non-verbal) enacted toward the other agents. The same applies to the other agents. Social reciprocity becomes therefore instrumental in meeting what Kitwood defined "psychological needs (Kitwood, 1997), which include occupation identity, inclusion, comfort and attachment. These all culminate in the need for love and meaning, that is intrinsic to all human beings.

### **3.3.3 *Standards to assess dignity in care and how personhood is promoted through co-production.***

In regard to dignity, in this model we applied the definition proposed in the Social Care Institute for Excellence (SCIE) guidelines whereby it is:

*'A state, quality or manner worthy of esteem or respect and self-respect. Dignity in care is therefore the care that promotes and does not undermine a person's self-respect irrespective of any difference'* (SCIE, 2006).

Although dignity remains a concept grounded in individual needs and life circumstances, what seems to be agreed on is that people know when they are not treated as such (SCIE, 2006). In our model, dignity in care is related to the promotion of personhood and is addressed through eight factors that we derived through interpretation and team discussion from the findings of the meta-ethnography and content analysis of the two reviews we undertook. Each factor contributes to positive personhood in the recipient of care and in the carer: behaviours, participation, support, recognition and respect, environment, personal space, relationship and communication, autonomy. These eight factors represent standards with each containing a number of indicators to assess/identify whether co-production is attained (Appendix E for standards and indicators to assess dignity in care).

### ***3.4 Phase 4. Consultation with members of the PPI group.***

The members of the PPI who volunteered to be involved in our research project had lived experience of dementia caring (e.g. hospitalisation, interaction with health staff, paid carers, GP, care home settings). Their views helped set the benchmarks for the promotion of personhood in dementia care. The first meeting lasted 45 minutes and the second meeting lasted 1:15 minutes. Each meeting included an initial 15 minutes debriefing session on what would happen during the day. Different participants attended the two meetings.

In the first meeting, the qualitative researcher (AB) met with 1 person with dementia to help refine the questions that were previously developed by the qualitative researcher (AB). In the second meeting, four people with dementia and two carers were present. They reported on the relevance of the integrated model of care and how well reflected their daily life experiences of social interaction with health staff. They commented on how it may be difficult at times to integrate the views of health professionals in their everyday life, especially in situations where complying with their suggestions means changing their routine (e.g. going to respite care, receiving care form social services).

They also commented on the important role of social networks for people with dementia. There was in fact consensus among PPI members on how the role of neighbours becomes crucial when the behaviour of the person with dementia is challenging and an extra support is needed. The group further advised that it would be important to gather the views of people with dementia, their carers and health staff with respect to how effectively promote co-production in dementia care. They reported on how the indicators of the model we developed (Appendix E) for the assessment of co-production can effectively help the person with dementia and their carers to assess (or have a sense of) whether their views are actively taken into consideration and their needs and preferences taken into account. The person with dementia also added on how the indicators may provide people with dementia with an instrument to use when receiving care and feedback to health staff or their carer to show points where co-production has not been promoted.  A carer felt that although some of the points are described in previous care guidance, these indicators well summarise the main areas to self-assess good quality of care.

## 4. Discussion

The current work aimed at the development of a theoretical model to strengthen the power of people with dementia in relation to their self-determination. The model was informed by the findings of a systematic review on personhood and dignity, and by findings of a scoping review of policy documents on personhood and dignity in dementia. The two reviews identified the factors that impinge on the quality of care when engaging with people with dementia and their social networks.  As evidenced in the literature and as also reported during the PPI meetings, people with dementia experience dissatisfaction with the way they are considered in the health care system, and in society at large, despite the delivery of PCC. For this reason, we created a model that was based on the ecological theory of social interaction across systems. The ecological system theory helped us situate the person with dementia and all the agents involved in their daily care at the centre of the system (microsystem).

Through social reciprocity the personhood of the agents is promoted or discouraged according to the quality of interaction and the level of co-production (partnership) experienced. It is through co-production that equal positioning and autonomy are preserved among agents.

Health care requires high degree of specialisation, and the context whereby care is delivered is becoming complex with time. The risk of power imbalance between agents is increased with the process of specialisation and this warrants a shift of positioning in which the person with dementia needs to be acknowledged as an active agent ‘citizen’ rather than patient. This means, that the person with dementia, as much as other individuals, needs to be able to operate in society, not only in health settings but in civic and political life and in other community contexts. The challenge is how to support active involvement in the face of a progressive neurodegenerative condition like dementia,

We found evidence that this can be achieved. In concert with what has been proposed by the Advanced Dementia Practice Model (Alzheimer Scotland, 2015), we found that it is important to promote social inclusion at any stages of the condition through creating opportunities for self-expression and socio-cultural partnership in community settings. In line with the findings from the Essence of Care report (Department of Health, 2010), we also found that elements of dignity promoting personhood are also important for the promotion of co-production. As evidenced in our model, personhood, dignity and co-production are inter-related concepts, hence it follows that the safeguard of personhood, for example, is crucial to fulfil also the degree of freedom in which the person with dementia operates (co-produces) in the system, and the level of dignity experienced during the delivery of care (Nuffield Council on Bioethics 2009). Similarly, partnership should also aim at the development of health care plans and at the creation of accessible places, as they can address some of the difficulties posed by the symptoms of dementia. A community survey found that there is fertile land in the community to accept co-operation with people with dementia (Reid et al., 2015). This feeling of solidarity may help situate people with dementia on a par with the rest of the community.

The strength of our review lies on the development of indicators that provide the agents involved in the care (i.e. health professionals, people with dementia and their carers) with a direct assessment of the quality of care delivered. They may use the indicators as parameters against which to assess whether their personhood and dignity have been promoted and whether co-production was discouraged or encouraged. Although the model may not be considered a systematic tool for the assessment of co-production, it may still provide the agents in care with an idea about the quality of care they received or delivered and about the domains that may require some more attention if not fully addressed.

As much as we consider important the preservation of the identity of people with dementia, we also need to take into consideration that because health professionals are still regarded as ‘the experts’, partnerships may represent a threat to their identities nonetheless (Nolan, Davis, Brown, Keady, & Nolan, 2004). Future studies may look into the experience of co-producing care with people with dementia and their carers from the point of view of health staff working in primary and secondary care settings, to explore what is key in the promotion of participatory care at organisational level (e.g. whether a training is necessary for them to receive or whether they feel that carers and people with dementia may require some more information on active participation in the delivery of care).

### *4.1 Limitations*

The current work has some limitations. In regard to the systematic review and meta-ethnography, the search of studies and the subsequent analysis has been conducted by one researcher and although a team of experts in dementia care and old age psychiatry checked the search strategy, retrieval of studies and analysis of findings, the absence of an independent researcher assessing the quality of the work may increase the experimenter bias in the results. For the scoping review, we searched our terms on English governmental databases, it may be the case that non-English speaking foreign countries could have policy documents that are relevant for the review, also they may have translated their original documents into English. As health policies are highly culture sensitive, it is required to consider the findings of our review with caution. Also, there are policies in which the involvement of stakeholders has not been made clear and therefore, they may not necessarily reflect the current needs or views of people with dementia and their carers. In regard to the model, we engaged with PPI members for validation, however they comprised individuals who shared similar socio-demographics characteristics (white British, aged between 60 and 70), thus further validation with people from different socio-cultural backgrounds is needed.

## 5. Conclusion

Our review has implications for change at the micro and macro levels of society. It highlights how behaviour of health and social care professionals can ideally promote normalcy and a sense of equality in people with dementia. Yet there may be needs for training to prepare professionals to work on a more equal basis with individuals with dementia in co-producing health care. The same may be true for policy makers whose task is to create opportunities with, rather than for, people with dementia. Our analysis highlights policy that promotes dignity and a positive sense of self in people with dementia living in the community, but this is far from universal. Person-centred care needs to incorporate the principle that people with dementia have human rights of autonomy and dignity throughout the course of dementia, and they should be empowered to engage in decision-making while they have capacity to do so.

Figure 1. Flow chart for selection of papers.

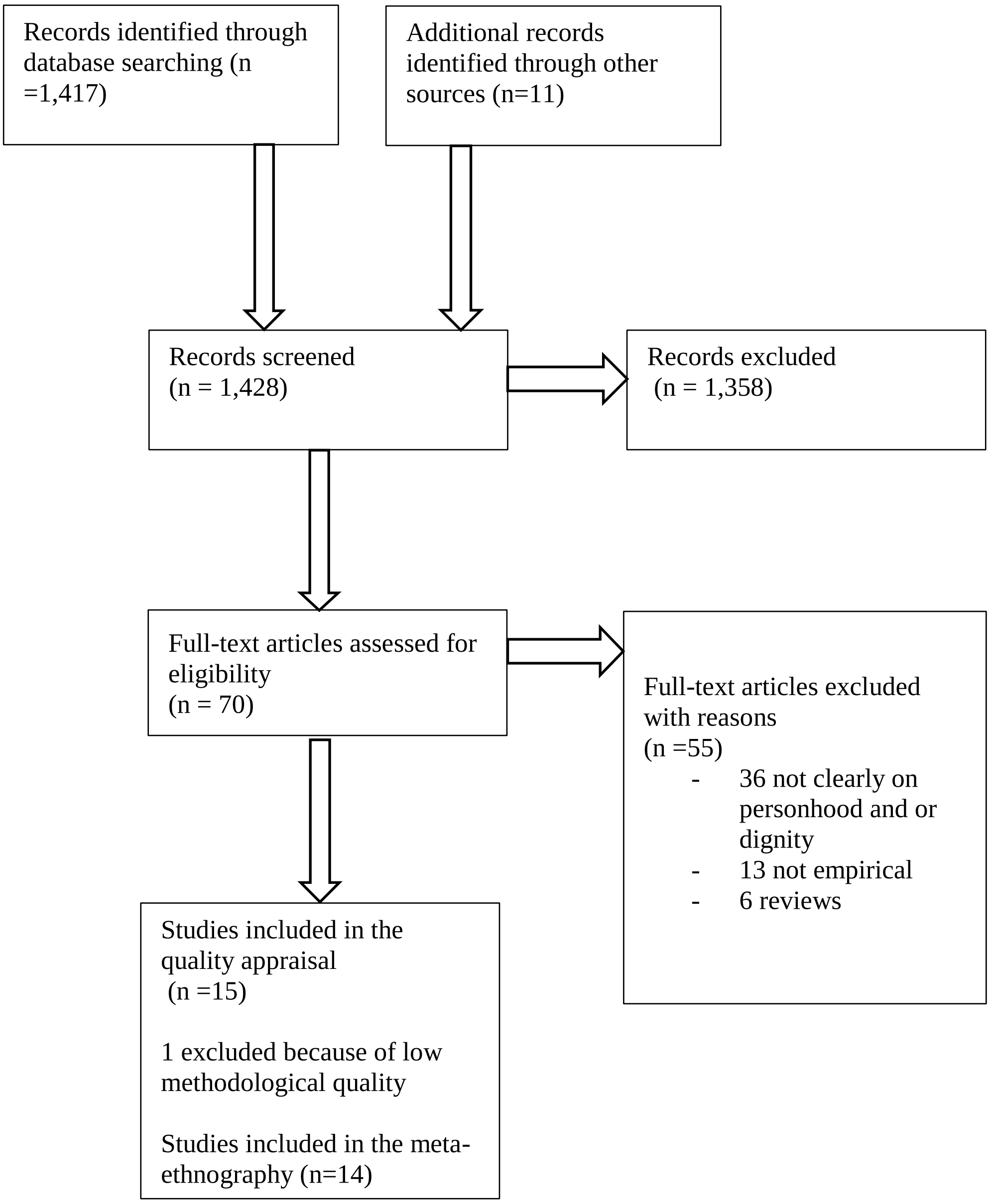


Table 1. Third order construct for the Meta-ethnography of the studies.

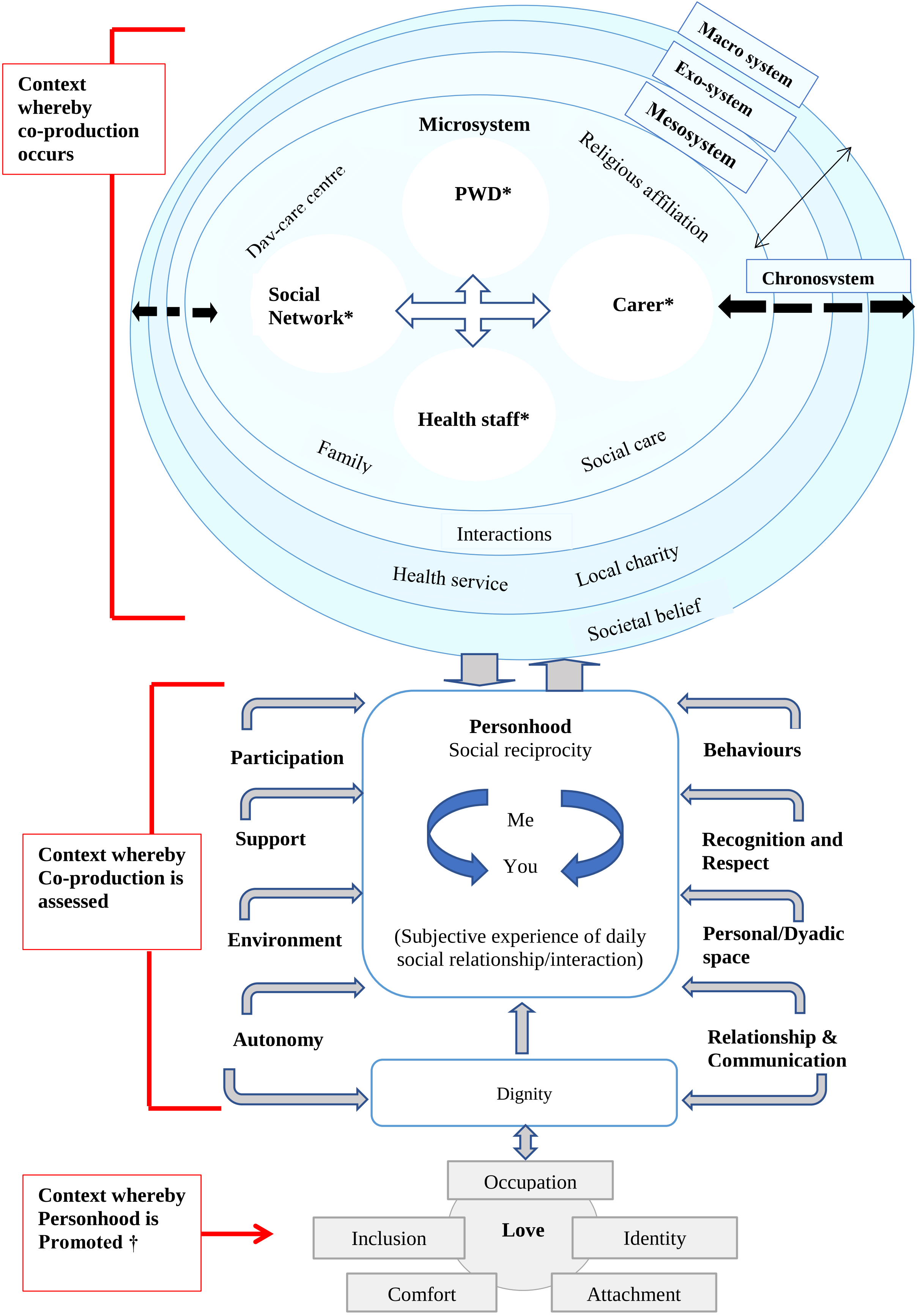
| Third order constructs | Categories | Themes |
|---|---|---|
| Dignity and personhood | Dignity and its preservation | • Community belongingness (vanGennip et al., 2016)<br>• Activity involvement (vanGennip et al., 2016) |
| | Strategies to promote personhood | • Environmental factor (Hung & Chaudhury, 2011; Milte et al., 2015; Zingmark, Sandman, & Norberg, 2002)<br>• Quality of interaction (Dran, 2008; Haggerstad, Nortvedt, & Slettebø, 2015; Hung & Chaudhury, 2011; Zingmark, Sandman, & Norberg, 2002)<br>• Social inclusion (Milte et al., 2015; Hung & Chaudhury, 2011; Haggerstad, Nortvedt, & Slettebø, 2015; Tolhurst & Weicht, 2017) |
| Coping with dementia | Coping with one's own identity | • Social network (Nowell, Thornton, & Simpson, 2011; Surr, 2006)<br>• Dealing with past/present roles (Dran, 2008; Nowell, Thornton, & Simpson, 2011; Phinney, Dahlke, & Purves, 2013; Tranvag, Petersen, & Naden, 2014)<br>• Active engagement (Milte et al., 2015; Palmer, 2013; Tolhurst & Weicht, 2017; Zingmark, Sandman, & Norberg, 2002) |
| | Family carers' perspectives | • Feeling a duty of care (Perry & O'Connor, 2002)<br>• Maintaining a positive view of the person (Perry & O'Connor, 2002)<br>• Justifying behaviours/cognitive decline in dementia (Vezina et al., 2011)<br>• Manipulating the physical environment (Perry & O'Connor, 2002) |
| Barriers to dignity in care | Internal factor | • Fitting in with the system (Nowell, Thornton, & Simpson, 2011) |
| | External factor | • Negative attitudes of health staff (Haggerstad, Nortvedt, & Slettebø, 2015; Hung & Chaudhury, 2011; Milte et al., 2015; Palmer, 2013; vanGennip et al., 2016) |

Table 2. Documents selected for the scoping review (n=22).

| Issuer | Document Title | Year | Type of document | Topic | Relevance |
|---|---|---|---|---|---|
| **Alzheimer Europe** | "Is Europe becoming more dementia friendly?" | 2015 | Dementia in Europe Yearbook 2015 | Dementia-friendly communities | European level |
| **Department of Health** | "Living well with dementia: A National Dementia Strategy" | 2009 | National Dementia Strategy Accessible Summary | Health care needs in dementia | National level (UK) |
| **Department of Health** | "Supporting people with dementia and their families and carers" | 2014 | Victorian dementia action plan 2014–18 | Health care needs in dementia | National level (Australia) |
| **European Commission** | "Implementation report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias" | 2014 | Commission staff working document | Overview on dementia | European level |
| **Flemish minister for welfare, public health, and family** | Flanders dementia strategy 2016-2019 (Update of 2015-2020 strategy plan) | 2016 | National strategy report | Dementia-friendly communities | National level (Belgium) |
| **H M Government of Gibraltar** | NATIONAL DEMENTIA VISION AND STRATEGY FOR GIBRALTAR | 2015 | National strategy report | Quality care in dementia | National level (Gibraltar) |
| **Irish Depart. of Health** | The Irish National dementia strategy | 2014 | National strategy report | Quality care in dementia | National level (Ireland) |
| **Israeli Ministry of Health** | Addressing Alzheimer's and other Types of Dementia: Israeli National Strategy | 2013 | Summary Document | Quality care in dementia | National level (Israel) |
| **Italian Ministry of Health** | The new Italian national strategy | 2014 | National strategy report | Overview on dementia | National level (Italy) |
| **Mental Welfare Commission for Scotland** | Dignity and respect: dementia continuing care visits | 2013 | Visit report | Quality care in dementia | National level (UK) |
| **Ministry of Health, Welfare and Sport** | Guideline for Integrated Dementia Care | 2009 | Governmental document | Quality care in dementia | National level (Netherlands) |
| **Ministry of Social Affairs and Health** | National Memory Programme 2012-2020 | 2013 | Policy brief | Dementia-friendly communities | National level (Finland) |
| **NHS, AgeUK, Local Government Ass.** | "Delivering Dignity" | 2012 | Report on dignity in care | Dignity in dementia care | National level (UK) |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| **NICE** | “Dementia: independence and wellbeing” | 2013 | Quality standard report | Quality care in dementia | National level (UK) |
| **NICE** | “Dementia: supporting people with dementia and their carers in health and social care” | 2016 | Clinical guidelines (2006) updated in 2016 | Quality care in dementia | National level (UK) |
| **NICE** | “Dementia overview” | 2017 | Governmental document | Quality care in dementia | National level (UK) |
| **Norwegian Ministry of health and care services** | Dementia plan 2020 | 2015 | National plan report | Dementia-friendly communities | National level (Norway) |
| **Parliamentary Secretariat for Rights of Persons with Disabilities and Active Ageing** | National dementia strategy 2015-2023 | 2014 | National plan report | Quality care in dementia | National level (Malta) |
| **RTI International** | “The Alzheimer’s Voice: Person-Centred and Person-Directed Dementia Care” | 2014 | Report on Person-centred care | Person centred care in dementia | National level (USA) |
| **UNECE** | “Dignity and non-discrimination for persons with dementia” | 2015 | Policy brief | Dignity in dementia care | International level |
| **U.S. Department of health & Human Services** | National Plan to Address Alzheimer’s Disease: 2016 Update | 2016 | National plan report | Health care needs in dementia | National level (USA) |
| **WHO** | “Dementia: A public health Priority” | 2012 | Policy report | Overview on dementia | International |

Figure 2. Dementia care model to promote personhood through co-production in dementia.



* Individual domains brought into interaction: Biopsychosocial, cultural heritage, biography.

† Personhood is promoted through interaction with all agents involved in the care (i.e. micro system)

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**Appendix A**. CASP Checklist – Quality appraisal of studies.

| **Studies** | **CASP** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** | **Include** | **Exclude** |
| Dran | Y | Y | Y | Y | Y | Can't tell | **N** | **N** | Y | **N** | X | |
| Haggerstad, Nortvedt, & Slettebø | Y | Y | Y | **N** | Y | Y | Y | Y | Y | Y | X | |
| Hung, Chaudhury | Y | Y | Y | Y | Y | **N** | **N** | Y | Y | Y | X | |
| Milte, Shulvera, Killingtona, Bradleya,, Ratcliffec, & Crotty | Y | Y | Y | Y | Y | **N** | **N** | Y | Y | Y | X | |
| Nowell, Thornton, & Simpson | Y | Y | Y | Y | Y | **N** | Y | Y | Y | Y | X | |
| Palmer | Y | Y | Y | Y | Y | **N** | **N** | **N** | Y | **N** | X | |
| Perry, & O'Connor | Y | Y | Y | Y | Y | **N** | **N** | **N** | Y | Y | X | |
| Phinney, Dahlke, & Purves, | Y | Y | Y | Y | Y | **N** | **N** | **N** | Y | Y | X | |
| Surr | Y | Y | Y | Y | Y | **N** | **N** | Y | Y | **N** | X | |
| Tolhurst &Weicht | Y | Y | Y | Y | Y | Y | Y | Y | Y | **N** | X | |
| Tranvag, Petersen, & Naden | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | X | |
| vanGennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen | Y | Y | Y | Y | Y | **N** | **N** | Y | Y | Y | X | |
| Vézinaa, Robichaudb, Voyerc, & Pelletier | Y | Y | Y | Y | Y | **N** | **N** | Y | Y | **N** | X | |
| Vittoria | **N** | Y | **N** | **N** | Y | **N** | Y | **N** | **N** | **N** | | X |
| Zingmark, Sandman, & Norberg | Y | Y | Y | Y | Y | **N** | Y | Y | Y | Y | X | |

**Appendix B.** Study characteristics (n=14).

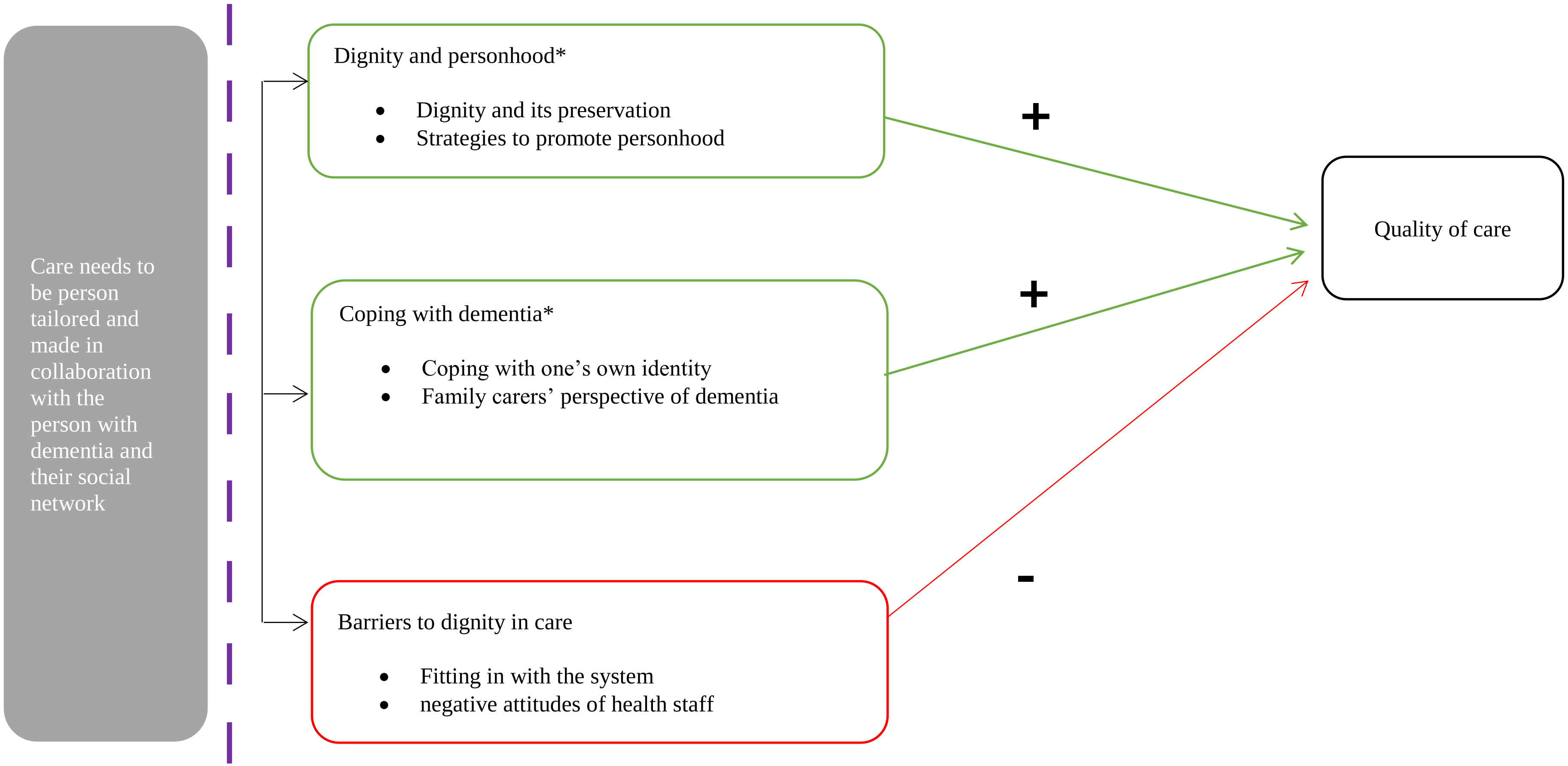
| **Author** | **Year** | **Country** | **Study design** | **Published venue** | **Theory on Personhood/dignity** | **Qualitative methodology** | **Qualitative methods of data collection** | **Qualitative methods of data analysis** | **Sample demographics** |
|---|---|---|---|---|---|---|---|---|---|
| Dran | 2008 | USA | Qualitative | Journal | Personhood (Kitwood 1997) | Narrative (descriptive) | One-to-one interviews | Narrative analysis (Vignette) | N=3 staff (residential care) |
| Haggerstad, Nortvedt, & Slettebø | 2015 | Norway | Qualitative | Journal | Person-centred approach and relationship cetred approach (Kitwood, 1997; Nolan, Davies, Ryan, and Keady, 2008) | Hermeneutic Phenomenology | Multi method<br>Participant observation<br>One-to-one semi structured interview | 3-steps of analysis (Kvale & Brinkmann, 2009) | N=22<br>PWD= 15<br>Aged 70+<br>Carers= 7<br>(Female=5)<br>(residential care) |
| Hung & Chaudhury | 2011 | Canada | Qualitative | Journal | Kitwood's (1997) approach | Ethnography | - participant observations,<br>-focus groups | integrated deductive–inductive approach* | N= 20 PWD<br>Aged 70+<br>(residential care) |
| Milte, Shulver, Killington, Bradley,, Ratcliffe, & Crotty | 2015 | Australia | Mix-method | Journal | Kitwood and Bredin (1992)<br>"Twelve indicators of well-being in dementia care, which are: (1) Assertion of desire or will, (2) the ability to experience and express a range of emotions, (3) initiation of social contact, (4) affectional warmth, (5) social sensitivity, (6) self-respect, (7) acceptance of other dementia | Not reported | -In-depth one-to-one semi structured interviews<br>- focus groups | Thematic analysis constant comparative analysis (Richards, 2005). | N=41<br>PWD=15<br>(Female=9)<br>Mean age=79(SD=11)<br>Carers=26<br>(Female=18)<br>Mean age=75(SD=9)<br><br>(residential care and community living) |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | sufferers, (8) humour, (9) creativity and self-expression, (10) showing evident pleasure, (11) helpfulness, and (12) relaxation.” | | | | |
| Nowell, Thornton, & Simpson | 2011 | UK | Qualitative | Journal | (Bradford Dementia Group, 1997; Kitwood, 1998) | Phenomenology | One-to-one semi-structured interviews | Interpretive Phenomenological analysis | N=7 PWD<br>Aged (60+; Mean=74)<br>(not clearly reported) |
| Palmer | 2013 | USA | Qualitative | Journal | Kitwood, (1997) | Hermeneutic Phenomenology | One-to-one open ended structured interviews | Interpretive phenomenology analysis* | N=15 carers<br>Aged 40+<br>(residential care) |
| Perry, & O'Connor | 2002 | Canada | Qualitative | Journal | Social constructionist perspective | Grounded theory* | One-to-one unstructured interviews | Constant comparative analysis (Strauss & Corbin, 1990) | N=38 carers<br>(Female=26)<br>(community living) |
| Phinney, Dahlke, & Purves, | 2013 | Canada | Qualitative | Journal | Kitwood 1997 | Interpretive phenomenology (Benner, 1994) | Multi method:<br>One-to-one in depth interviews<br>Dyadic interviews<br>Group interviews<br>Participant observation | Interpretive phenomenological analysis (IPA) | N=7<br>PWD=2 (all males)<br>Carers=5 (all female)<br>(community living) |
| Surr | 2006 | UK | Qualitative | Journal | socio-biographical theory of self * | Constructivism* | One-to-one unstructured interviews | interpretive biographical analysis | N=14 PWD<br>(Female=13)<br>Aged 70+<br>(residential care) |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Tolhurst &Weicht | 2017 | UK | Qualitative | Journal | Higgs & Gilleard, 2015. | Narrative (descriptive) | Semi structured dyadic interviews | Narrative analysis (Riessman, 2008) | N=14 dyads<br>(Aged 50+)<br>(1 same sex dyad)<br>(Female=13)<br>PWD=14 (all males)<br>(community living) |
| Tranvag, Petersen, & Na ˚den | 2014 | Norway | Qualitative | Journal | Dignity in care | Gadamer's (2010) hermeneutics | One-to-one semi structured interviews | Interpretive hermeneutic analysis Gaidys (2003) | N=11 PWD<br>(community living) |
| vanGennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen | 2016 | Netherlands | Qualitative | Journal | Kitwood and Bredin 1992* | Thematic analysis | One-to-one in-depth interviews | Thematic analysis Braun & Clarke, 2006<br>Constant comparison analysis (Strauss & Corbin, 1990). | N=14 PWD<br>Aged= 50+<br>(Female=6)<br>(community living) |
| Vézinaa,, Robichaudb, Voyerc, & Pelletier | 2011 | Canada | Qualitative | Journal | Kitwood 1997 | Constructivism | One-to-one semi directive interviews | Manifest content analysis* | N=21 carers and health care professionals<br>Carers=9<br>(Female=7)<br>(Aged 40+)<br>Health care professionals = 12<br>(Female=11)*<br>(residential care) |
| Zingmark, Sandman, & Norberg | 2002 | Sweden | Qualitative | Journal | Dignity in care | phenomenological hermeneutic | One-to-one semi structured interviews | Interpretive phenomenological analysis (Soderberg, 1999; Talseth et al., 1999) | N=10 staff<br>(Nurses)<br>(Aged 30+)<br>(residential care) |

*Not clearly stated/no further information was provided.

**Appendix C**. Expressed synthesis. Promoting dignity and personhood in dementia care.



*When positive strategies and coping mechanisms are present there is increased likelihood to experience better sense of self, dignity and have improved quality of care. Conversely, the more negative the barriers to dignity, the less positive the strategies and coping mechanisms, the less positive the quality of care experienced by the person with dementia and their carers.

**Appendix D**. Frequency of themes across documents.

| **Themes (n=6)** | **Issuer** | | | | | | | | | | | | | | | | | | | | | | **N (%)** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Subthemes (n=13)** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** | **11** | **12** | **13** | **14** | **15** | **16** | **17** | **18** | **19** | **20** | **21** | **22** | |
| Participation | x | x | x | | x | x | x | | x | x | x | | | x | x | x | | x | | x | | x | ***15 (68.1)** |
| - Active participation (social, policy) | x | x | x | | x | | x | | x | x | x | | | x | x | x | | x | | | | x | 13 (59.1) |
| - Self-agency (decision making, job, driving) | x | x | x | | | x | x | | x | x | x | | | x | | | | x | | x | | x | 12 (54.5) |
| - Co-production in care | x | x | x | | x | x | x | | x | | | | | | | | | x | | | | | 8 (36.3) |
| Family (e.g. carers' health) | | | x | | x | | x | x | x | | x | x | x | | x | x | | x | x | x | x | x | **15 (68.1)** |
| Environment | x | | x | x | x | x | x | x | x | | x | x | x | x | x | x | | x | x | x | | x | ***18 (81.8)** |
| - Care setting | | | x | x | x | | | | x | | x | | | x | x | x | | | | x | | x | 10 (45.4) |
| - Transportation | x | | | | x | x | x | x | x | | x | x | x | | | | | | | | | x | 10 (45.4) |
| - Support network | x | | x | x | | | | | | | | x | | x | x | x | | x | x | | | x | 10 (45.4) |
| - Housing | x | | x | x | x | | x | x | x | | x | x | | x | x | x | | x | x | x | | | 9 (41) |
| - Outdoor space | x | | x | x | x | | | | | | x | x | | | x | | | | | | | | 7 (31.8) |
| Behaviour | x | | x | | | x | x | | x | x | x | | x | | x | | | | | x | | | ***10 (45.4)** |
| - Communication | | | | | | x | x | | | x | | | x | x | x | | | | | | | | 6 (27.2) |
| - Relationship | x | | x | | | | x | | x | x | x | | x | x | x | | | | | | | | 10 (45.4) |
| - Normalcy/Equality | x | | | | | | | | x | x | | | x | x | x | | | | | x | | | 7 (31.8) |
| Governance and law | | | x | x | | x | | x | x | x | x | x | x | x | x | x | | x | | | | | ***13 (59.1)** |
| - Lack of capacity | | | x | x | | | | | x | x | x | x | x | x | x | x | | | | | | | 10 (45.4) |
| - Human rights (safety/independence) | | | | x | | x | | x | | | x | x | x | x | | x | | x | | | | | 9 (41) |
| Health care partnership | | x | x | x | x | x | | x | x | | x | x | | x | | x | x | | x | x | x | x | **16 (72.7)** |

*This was calculated by considering when any of the related subthemes was present without summing all their frequencies as to avoid multiple counting.

1) Alz. Europe (2015)
2) DoH (UK) (2009)
3) DoH (AU) (2014)
4) EU Comm. (2014)
5) Mental Welfare (2013)
6) NHS AgeUK (2012)
7) NICE (2013)
8) NICE (2016)
9) NICE (2017)
10) RTI Int. (2014)
11) UNECE (2015)
12) U.S. DoH & HS (2016)
13) WHO (2012)
14) Irish Depart. of Health (2014)
15) Norwegian Min. of health (2015)
16) Maltese Parliamentary Secretariat (2014)
17) Italian Ministry of Health (2014)
18) Flemish minister for welfare (2016)
19) Finnish Ministry of Social Affairs (2013)
20) H M Government of Gibraltar (2015)
21) Israeli Ministry of Health (2013)
22) Dutch Ministry of Health (2009)

Appendix E. Promoting positive personhood through dignity in care: Context whereby co-production is assessed.

| Variables | Standards for dignity in care | Indicators of dignity in care |
|---|---|---|
| **Behaviours** | People with dementia and their carers feel valued at all times during care.<br>The care people receive is considerate of their values and beliefs. The relationship with the carer is valued. | - Misconception of Dementia is challenged in favour of a holistic view of the individual situated in a social context (e.g. social interaction with the carers, friends).<br>- Staff views around dementia are challenged.<br>- Staff attitude toward people with dementia and their carers is adequate and respectful.<br>- Strategies are used to maintain adequate standards of behaviour with the person with dementia and their carer (e.g. eye contact, make sure everyone is introduced when talking to the person with dementia, treating the person with dementia as human not diagnosis, valuing the role of the carer at all time).<br>- Individual needs are acknowledged and met (people with dementia have unique needs especially for the behavioural psychological symptoms).<br>- Participants' preferences are accommodated.<br>- Relationship with the carer is acknowledged. |
| **Participation** | There is active involvement of people with dementia and their carers. | - People with dementia and their carer (when this is applicable) actively participate in decision making for health/social care.<br>- Carers' views are not collected on behalf of the person with dementia, yet rather they are gathered to complement their views when they lack capacity. |
| **Support** | For the dyad but also for each individual agent. | - Development and implementation of effective ways to support the relationship between the agents involved in the relationship (e.g. carer, people with dementia, dyad and health care services)<br>- Dynamic support that accommodates the needs of the person with dementia and the carer during the stages of dementia. |

| | | |
|---|---|---|
| | | - Support provided in an effective way whereby the needs of the person with dementia are reviewed and the views of the carers are considered.<br>- Encouragement in the promotion of activities that are inclusive of the carers as well as the person with dementia.<br>- Effective support is provided for vulnerable carers (e.g. young carers with little expertise in caring, old people caring for a person with dementia). |
| **Recognition and respect** | Of the carer and of the person with dementia. | - Relationships are acknowledged and respected irrespective of its nature (e.g. relationships between person with dementia and health care professionals, person with dementia and carer, person with dementia, carers and the community in general)<br>- Relationships change over time and their new status need to be respected at all time alongside the individual needs and the dyad’s needs.<br>- Relationship based on social reciprocity need to be valued and respected (e.g. promoting social interaction)<br>- Social interaction may change over time because of the severity of the condition and when this occurs it needs to be valued and promoted (e.g. body touch instead of spoken words may be needed in severe stages of cognitive decline)<br>- Recognition of the need to receive care from other agencies (outside the home) when applicable.<br>- Recognition of the role of the carer as fundamental for the daily support of the person with dementia and in promoting their life in the community.<br>- Recognition of the different perspectives of the person with dementia and their carer (they may be a dyad but not necessarily share the same belief and values).<br>- Search for and respect the expertise and knowledge of the carer with respect to the support delivered to the person with dementia. |

| | | |
|---|---|---|
| **Environment** | The care is provided in a way that the familiar environment of the person (and that of the carer when applicable) is respected. | - In case of residential accommodation, the layout of the bedroom is similar to the person’s own bedroom at home (e.g. person’s family pictures are displayed).<br>- Person’s hobbies are promoted (e.g. music, movies) as part of the care plan. |
| | The environment is experienced as safe throughout the care. | - The person with dementia feels safe and staff makes sure that this feeling is maintained during care (e.g. go somewhere quite as to avoid crowded and noisy places that could scare the person).<br>- Avoiding breaking the routine of the person without alerting her/him beforehand.<br>- The carer is actively involved in the daily activities of the person with dementia (e.g. they help develop new activity programs and are consulted frequently alongside the views of the person with dementia) |
| **Personal space/Dyadic space** | Individual needs of people with dementia and their carers are considered at all times during care. | - Person-centred care is respected along with a sense of personhood conceived of in terms of social reciprocity.<br>- Strategies are implemented with respect to entering the personal space of the person with dementia and their carers (e.g. avoiding physical contact, respecting the dyad’s privacy). |
| | People with dementia feel free to go to a private place during care and being on their own and or with the carer. | - The care plan (if any) takes into account the wish of the person with dementia to stay on their own and have their privacy respected.<br>- Topics that are potentially invasive of their privacy need to be approached sensibly with people with dementia and their carers (e.g. discussion about toiletry, sexuality). |
| **Relationship and communication** | The relationship with staff is experienced as effective during care. | - The care plan (if any) is explained to people with dementia and their carers (or social network) by including them in the conversation.<br>- Information about the care should be given in an accessible format (e.g. booklet with images).<br>- Communication between health professionals (in case of staff team) should be consistent and communication with the person with dementia and their carers not patronising (e.g. staff talk to |

| | | |
|---|---|---|
| | | the person like adults, avoid abstract concepts, avoid talking to the carer when referring to the person with dementia).<br>- Reciprocity (carers and staff benefit from delivering a dignified care as much as the person with dementia does).<br>- Time necessary to explain the care plan is divided in multiple visits if too much information needs to be taken in. |
| **Autonomy** | Strategies aiming at the promotion of independence/autonomy of the person with dementia need to be implemented | - The use of assistive technology that can support people with dementia in their daily tasks (e.g. navigation systems for orientation, calendar clocks). |
| | Autonomy needs to be promoted until capacity | - The role of guardians should only be supportive until the person with dementia lack capacity. The person with dementia has the right of engaging in decision making at all times. |