

1 **Dementia care model: Promoting personhood through co-production.**

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50 **Abstract**

51

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

57

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

62

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

69

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

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76 Word count: 236/250

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

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96 **1. Introduction**

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

104

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

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

126

127 The excerpt above reflects circumstances whereby, although the person with dementia was at
128 the core in the delivery of care, as it is widely acknowledged in contemporary social and
129 health care (Higgs & Gilleard, 2016), such centrality did not necessarily entail promotion of
130 the person’s dignity and personhood. This is also an example of the lack of autonomy and
131 choice. A culture of care for people with dementia that permits such circumstances to occur
132 points to a gross power imbalance between carers and cared-for, despite the lip-service paid
133 to PCC. One challenge to redressing this imbalance is how to ensure that people with
134 dementia are granted a truly active role and equal positioning in the delivery of care. In this
135 review, we define active engagement of people with dementia in terms of co-production,
136 which according to the definition suggested by the SCIE (2013) it is *‘a meeting of minds*
137 *coming together to find a shared solution’*. Ecological system theory provides the theoretical
138 foundation to explain how personhood of the person with dementia can be promoted across
139 different care systems as the person is enmeshed in different contexts or systems. Each

140 system is not disjointed from the other, and the person finds her/himself simultaneously
141 influenced by them. These systems represent different environments from the micro
142 ecosystem of the home to the outward system of the community (e.g. Alzheimer’s café)
143 moving towards more outward levels of societal involvement (e.g. government).
144

145 1.1 Study aims

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

148 **2. Methods**

149 As promoting personhood and dignity in dementia care has potential implications for
150 research, policy and practice, it is of relevance to academics, policy makers, practitioners and
151 members of the general public, so the research team felt that a holistic approach to the topic
152 should be taken. The team, comprised researchers and clinicians operating in the health and
153 social care sector who consulted with members of the public who volunteered to advise on
154 the topic. Four phases of knowledge appraisal and theory development were undertaken: a
155 systematic review on personhood and dignity in dementia that could explore examples of
156 good and bad practice in dementia care (phase 1), a scoping review of policy documents
157 around the preservation and promotion of either concepts (phase 2), the development of an
158 integrated model of care ensuing from the findings of the two reviews (phase 3), and the
159 validation of the model through consultation with members of the patient and public
160 involvement group (PPI) (phase 4).
161

162 **2.1 Phase 1. Systematic review on personhood in dementia care.**

163 The review complied with the PRISMA checklist (Moher, Liberati, Tetzlaff, & Altman,
164 2009). We followed the PICO format to determine our search strategy (Sackett, Richardson,
165 Rosenburg, & Haynes, 1997),

166 *2.1.1 Inclusion Criteria*

167 The study explores the concept of personhood and employs either a qualitative method or
168 mixed method for data collection and analysis with direct quotes of participants. The study
169 focuses on the positive factors (i.e. promoting/maintaining personhood) or negative factors
170 (i.e. undermining personhood). The study is on dementia without comorbid organic disorders.
171 Owing to the overlapping use of the terms ‘dignity’ and ‘personhood’, and their highly
172 relatedness (Jacobsen, 2007), studies focusing on the preservation of dignity (both when
173 reporting on how dignity helps support personhood and/or when exploring uniquely the
174 promotion of dignity) were included when emerging from our search. Any language and
175 publication year.
176

177 *2.1.2 Exclusion Criteria*

178 The Study is excluded if not empirical, (e.g. review, commentary, editorial, discussion
179 paper), when not clearly reporting on personhood and/or dignity. The study is further

180 excluded when is on palliative care, as the preservation of personhood and dignity may
181 require more focussed and individualised strategies during the end of life care.

182

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

190

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

201

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

207

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

214

215 **2.1.3 Data analysis.** We used meta-ethnography for the extraction and synthesis of
216 qualitative data and followed the seven steps by Noblit and Hare (1988) to reach third order
217 interpretations deriving from the first and second order constructs reported in the studies.
218 Meta-ethnography proves effective when developing theoretical models from interpretation
219 of qualitative findings across studies (Atkins, Lewin, Smith et al., 2008), as it is in our
220 interpretative analysis on the experience of people with dementia and their carers in regard to
221 personhood and dignity in care.

222

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

234

235 ***2.2 Phase 2. Scoping review on personhood and dignity in dementia – policy documents.***

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

252

253 *2.2.1 Inclusion Criteria*

254

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

260

261 *2.2.2 Exclusion Criteria*

262

263 The document is on palliative care, an adapted report from sources previously published from
264 other governmental agencies, or a green paper. Updated versions of the same policy

265 document were considered as secondary sources and were included only if adding new
266 information.

267

268 **2.2.3 Data Analysis.** We conducted a conventional inductive content analysis (Graneheim &
269 Lundman, 2004), which is ideal in topic areas when the understanding of a phenomenon is
270 fragmented and broad (Graneheim & Lundman, 2004), as it is the case of dignity and
271 personhood in dementia care policy. The analysis comprised the following steps:

272

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

277

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

282

283 **2.3 Phase 3. Development of an integrated model of care.**

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

292

293 **2.4 Phase 4. Consultation with members of the PPI group.**

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

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306 **3. Results**

307

308 **3.1 Phase 1. Systematic review and meta-ethnography on personhood in dementia.**

309

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

316

317 **3.1.1 Quality Appraisal** Fifteen studies were appraised for their quality using CASP
318 (Appendix A). One study was excluded as it did not clearly report the aims, the qualitative
319 methods for data collection and information on data analysis. Overall, the 14 studies included
320 were found to be of moderate-good quality (scores ranging 6-9 out of 10). We found it
321 challenging to score the studies in relation to reporting bias (item 6) (e.g. the authors
322 commenting on potential bias ensuing from their involvement in the study and in the
323 development of questions for the interviews) as 11 out of 15 studies did not clearly report on
324 this. In addition, discussing ethical issues (item 7) was the second least reported information
325 across studies and this information was missing in 9 out of 15 studies.

326

327 **3.1.2 Study Characteristics.** The studies selected were all published on peer reviewed
328 journals from 2002 to 2017 (Appendix B for single study characteristics). Three studies were
329 conducted in the UK, four in Canada, two in the USA, two in Norway and one each in
330 Sweden, Australia and the Netherlands. A total of 251 participants were recruited (people
331 with dementia: n=112, age=60+; carers: n=114, age=40+; health staff: n= 25, age=30+). Most
332 studies approached their investigation from the perspective of personhood (n=12), and the
333 remainder framed their enquiries with the concept of dignity (n=2). The studies varied in
334 qualitative methodology: Most employed hermeneutic phenomenology (n=4), narrative
335 (n=2), or constructivism (n=2). Less used were grounded theory (n=1) and ethnography
336 (n=1). With respect to data collection, the most frequently-used methods were one-to-one
337 interviews (n=12) and participant observations (n=3), the most used method for data analysis,
338 was interpretative phenomenological analysis (n=4). Most studies explored the experience of
339 residential care (n=7), community living (i.e. person accommodation) (n=5), only one study
340 did not clearly report the setting and one included both participants from residential care and
341 community living.

342 **3.1.3 Meta-ethnography**

343

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

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

352

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

356

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

363

364 A sense of belongingness to family and a social role within the wider community seem to
365 preserve dignity and a meaning to one's life, as much as engaging in meaningful activities:
366 *'Yes, digging in the garden... It really does me good. I worked in the garden yesterday or the*
367 *day before...And it makes me feel so much better'* (person with dementia) (vanGennip et al.,
368 2016, p. 494).

369

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

379

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

387

388 An effective way for staff to promote dignity in care is promoting human connectedness with
389 gestures of affection, which show heartfelt commitment to their emotional wellbeing (Hung
390 & Chaudhury, 2011) or by behaving kindly while maintaining eye contact when speaking to
391 the person, to show they are valued as human being (Hung & Chaudhury, 2011). Good

392 interaction is further promoted by using positive statements during the conversation, as these
393 may encourage the person with dementia to remain engaged.

394

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

398

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

409

410 Active engagement is also found to be instrumental in preserving one's own identity, as it
411 gives continuity to life before and after the diagnosis of dementia (Milte et al., 2015). Given
412 that the person with dementia may still be active, it is important to promote self-agency by
413 finding suitable activities. A lack of stimulation may otherwise lead to apathy (Milte et al.,
414 2015). Quite crucially, a person's condition may fluctuate over time and staff need to be
415 prepared to grasp any opportunity for the person to get active (Zingmark, Sandman, &
416 Norberg, 2002).

417

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

422

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

427

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

434

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

437

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

446

447 *External factors.* The conduct of staff has consequences on the quality of care provided. For
448 example, the members of staff may engage in mechanical behaviours which devalue the
449 person's dignity: *'They are sitting and feeding a person... just mechanically put something*
450 *into the resident's mouth. It's terrible!'* (Carer) (Haggerstad, Nortvedt, & Slettebø, 2015, p.
451 835).

452

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

457

458 Quality of care is also negatively impacted by the patronising culture of some members of
459 staff, which is reflected in the statement: *'To me, residents are like babies. I feed them, clean*
460 *them, and put them to sleep.'* (Hung & Chaudhury, 2011, p. 7). A classic example of a
461 patronising interaction with a person with dementia was reported by Hung and Chaudhury
462 (2011): *[Resident]: I need to use the bathroom. [Staff]: No, you don't. You just went not long*
463 *ago. Now, it's time to eat, you eat!* (Field notes) (Hung & Chaudhury, 2011, p. 5).

464

465 **3.2 Phase 2. Scoping review and content analysis of health care policy documents on** 466 **personhood and dignity in dementia.**

467

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

470

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

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

484

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

492

493 **3.2.1 Content analysis**

494 Seven themes emerged from the content analysis (participation, family, environment,
495 behaviour, policy and law, health care partnership, autonomy) and most themes comprised a
496 variety of subthemes (Appendix D). The frequency of the themes was evenly spread across
497 documents, with the most frequent being ‘environment’, which was reported in 18 documents
498 (81.8%). One theme, ‘health care partnership’ was reported in 16 documents (72.7%). Two
499 themes (role to play and family) were reported with the same frequency (n=15; 68.1%). The
500 themes ‘governance and law’ and ‘behaviour’ were retrieved in 13 documents (59.1%) and
501 ten documents (45.4%) respectively.

502

503 **Participation.** This theme refers to the active involvement of people with dementia in
504 decision making and in the social, civic and political life (Irish Depart. of Health, 2014;
505 Norwegian Min. of health, 2015; Maltese Parliamentary Secretariat; 2014; Flemish minister
506 for welfare, 2016; H M Government of Gibraltar, 2015; Dutch Ministry of Health, 2009). It
507 further describes their active participation in the development of health care plans.
508 (Alzheimer Europe, 2015; DoH, 2009; DoH, 2014; Mental Welfare, 2013; NHS AgeUK,
509 2012; NICE, 2013, 2017; Flemish minister for welfare, 2016).

510

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

519

520 While participation at national or international level was possible for only a small number of
521 people with dementia, there is potential for all to be actively involved in the planning of their

522 own care. The type of involvement is different at different points in the progression of the
523 cognitive impairment. Advance care planning is advisable for people in the early stages so
524 that their wishes are known when they can no longer express themselves (WHO, 2012).

525

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

531

532 **Health care partnership.** This theme acts as an umbrella term to describe different types of
533 partnerships: between health care professionals, between health care professionals and people
534 with dementia and their families, between researchers and people with dementia and their
535 carers (NICE, 2016, 2017; UNECE, 2015; DoH, 2014; DoH, 2009). The focus is on
536 integrating geriatrics with primary care services to increase health literacy among health
537 professionals around the bio-psychosocial determinants of dementia; developing care services
538 targeting the needs of the person with dementia and their carers at the individual, community
539 and societal levels; delivering dementia friendly programmes to increase awareness in the
540 community and reduce social exclusion (U.S. Department of health & Human Services,
541 2016); creating partnership between advocacy agencies and people with dementia to promote
542 equality and social justice among those who have decreased or no capacity for their rights to
543 be upheld.

544

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

550

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

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

561

562 Few policies (3 out of 22) have addressed the importance of care plans for carers to promote
563 their dignity and preserve their identities. These plans comprise multiple elements based on
564 group psychoeducational programs, peer support groups, easy access to web support

565 programs through charities and voluntary organisations (e.g. Alzheimer’s Europe), the
566 involvement of other family members at health care meetings for people with dementia, and
567 the employment of ‘dementia buddies’ for carers. Strategies to develop effective care plans
568 for carers should be culture-sensitive (U.S. Department of health & Human Services, 2016;
569 NICE, 2013, 2017).

570

571 **Environment.** Policies have used the term ‘environment’ to report on the quality standards
572 and strategies needed to design dementia friendly settings (i.e. care settings, transportation,
573 support network, housing and outdoor space) which promote dignity and a positive sense of
574 self in people with dementia (Irish DoH, 2014; Norwegian Ministry of health, 2015; Maltese
575 Parliamentary Secretariat, 2014; H M Government of Gibraltar, 2015; Dutch Ministry of
576 Health, 2009). Most strategies are based on accessibility (e.g. the use of sign posting,
577 lighting, floor covering, and clutter-free rooms); in the delivery of activities in the home of
578 the person with dementia; in the use of assistive technology based on the preferences and
579 needs of the person with dementia. Strategies targeting community inclusion focus on social
580 activity programmes (e.g. bridge club, writing groups, book clubs, choirs) which are run at
581 Alzheimer’s café, libraries, churches, or other community settings (NICE, 2017; UNECE,
582 2015; U.S. Department of Health & Human Services, 2016).

583

584 **Behaviour.** This theme refers to the style of communication between health professionals and
585 people with dementia and their carers, to their quality of relationship, and to a series of
586 behaviours acted out by health professionals that promote normalcy and a sense of equality in
587 people with dementia (Norwegian Min. of Health, 2015; H M Government of Gibraltar,
588 2015).

589

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

602

603 **Governance and law.** This theme covers fundamental human rights warranting the attention
604 of the general public, providers of care, and at a macro level, the attention of health
605 commissioners and policy makers. This theme was used instrumentally across documents to
606 differentiate the medical model from a ‘human rights-centred approach’, in which people
607 with dementia are not divested of their rights to intimacy, self-agency, love and dignity in the

608 care they co-produce (Irish DoH, 2014; Maltese Parliamentary Secretariat 2014; Flemish
609 minister for welfare, 2016).

610 The documents further describe the key role of guardians in the late stages of dementia,
611 setting principles for good practice in guardianship (e.g. the person with dementia should be
612 able to nominate at an early stage of the condition the person they prefer to act as guardian
613 and they should be able to handle financial assets until capacity is compromised) (NICE,
614 2017, 2016; UNECE, 2015; RTI International, 2014; WHO, 2012).

615

616

617

618 ***3.3 Phase 3. Development of an integrated model of care***

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

625

626 ***3.3.1 Dementia dyad living in an ecological system.*** We argue that the person with dementia,
627 their carer, their social network and health staff are all situated in an ecological system based
628 on Bronfenbrenner's idea of '*nested arrangement of structures, each contained within the*
629 *next*' (Bronfenbrenner, 1979). In the model, the microsystem represents the immediate set of
630 inter-relations existing between the person with dementia and the context, the carer and the
631 context but also the dyad and the context (e.g. day care centre, neighbourhood). This also
632 applies to members of the social network of the person with dementia and to health staff. We
633 conceive of the personal dimensions of these four groups of agents as four inter-related
634 circles, each agent bringing into the interaction their own biopsychosocial dimensions,
635 cultural heritage, and biography.

636

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

645

646 When the Bronfenbrenner's ecological framework is applied to our model, a detailed
647 description of the personal dimensions, levels of structural influences and systemic
648 organisation of context-based experiences begins to emerge. The aim of this review though,
649 is not to give a comprehensive description of all the variables influencing the systems in the

650 model, as each individual is nested in a different social parlance, but to provide a heuristic to
651 better understand how each agent operates and influences each other's ecological systems.
652 This interpretation sets the basis for the following two blocks of the model and describes the
653 context whereby co-production should occur.

654
655 **3.3.2 Social reciprocity and personhood.** In line with Brooker's (2007) standpoint, we
656 consider social reciprocity as a key function of personhood among actively interacting agents.
657 In this regard, personhood is promoted through the social interaction between the person with
658 dementia, carers and other influential agents providing care. The person with dementia
659 therefore, plays an active role in promoting personhood through their own social behaviours
660 (either verbal or non-verbal) enacted toward the other agents. The same applies to the other
661 agents. Social reciprocity becomes therefore instrumental in meeting what Kitwood defined
662 "psychological needs (Kitwood, 1997), which include occupation identity, inclusion, comfort
663 and attachment. These all culminate in the need for love and meaning, that is intrinsic to all
664 human beings.

665 **3.3.3 Standards to assess dignity in care and how personhood is promoted through co-**
666 **production.**

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

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

672
673 Although dignity remains a concept grounded in individual needs and life circumstances,
674 what seems to be agreed on is that people know when they are not treated as such (SCIE,
675 2006). In our model, dignity in care is related to the promotion of personhood and is
676 addressed through eight factors that we derived through interpretation and team discussion
677 from the findings of the meta-ethnography and content analysis of the two reviews we
678 undertook. Each factor contributes to positive personhood in the recipient of care and in the
679 carer: behaviours, participation, support, recognition and respect, environment, personal
680 space, relationship and communication, autonomy. These eight factors represent standards
681 with each containing a number of indicators to assess/identify whether co-production is
682 attained (Appendix E for standards and indicators to assess dignity in care).

683
684 **3.4 Phase 4. Consultation with members of the PPI group.**

685
686 The members of the PPI who volunteered to be involved in our research project had lived
687 experience of dementia caring (e.g. hospitalisation, interaction with health staff, paid carers,
688 GP, care home settings). Their views helped set the benchmarks for the promotion of
689 personhood in dementia care. The first meeting lasted 45 minutes and the second meeting
690 lasted 1:15 minutes. Each meeting included an initial 15 minutes debriefing session on what
691 would happen during the day. Different participants attended the two meetings.

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

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

714 **4. Discussion**

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

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

730 Health care requires high degree of specialisation, and the context whereby care is delivered
731 is becoming complex with time. The risk of power imbalance between agents is increased
732 with the process of specialisation and this warrants a shift of positioning in which the person

733 with dementia needs to be acknowledged as an active agent ‘citizen’ rather than patient. This
734 means, that the person with dementia, as much as other individuals, needs to be able to
735 operate in society, not only in health settings but in civic and political life and in other
736 community contexts. The challenge is how to support active involvement in the face of a
737 progressive neurodegenerative condition like dementia,

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

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

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

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773 **4.1 Limitations**

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

789 **5. Conclusion**

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

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809 Figure 1. Flow chart for selection of papers.

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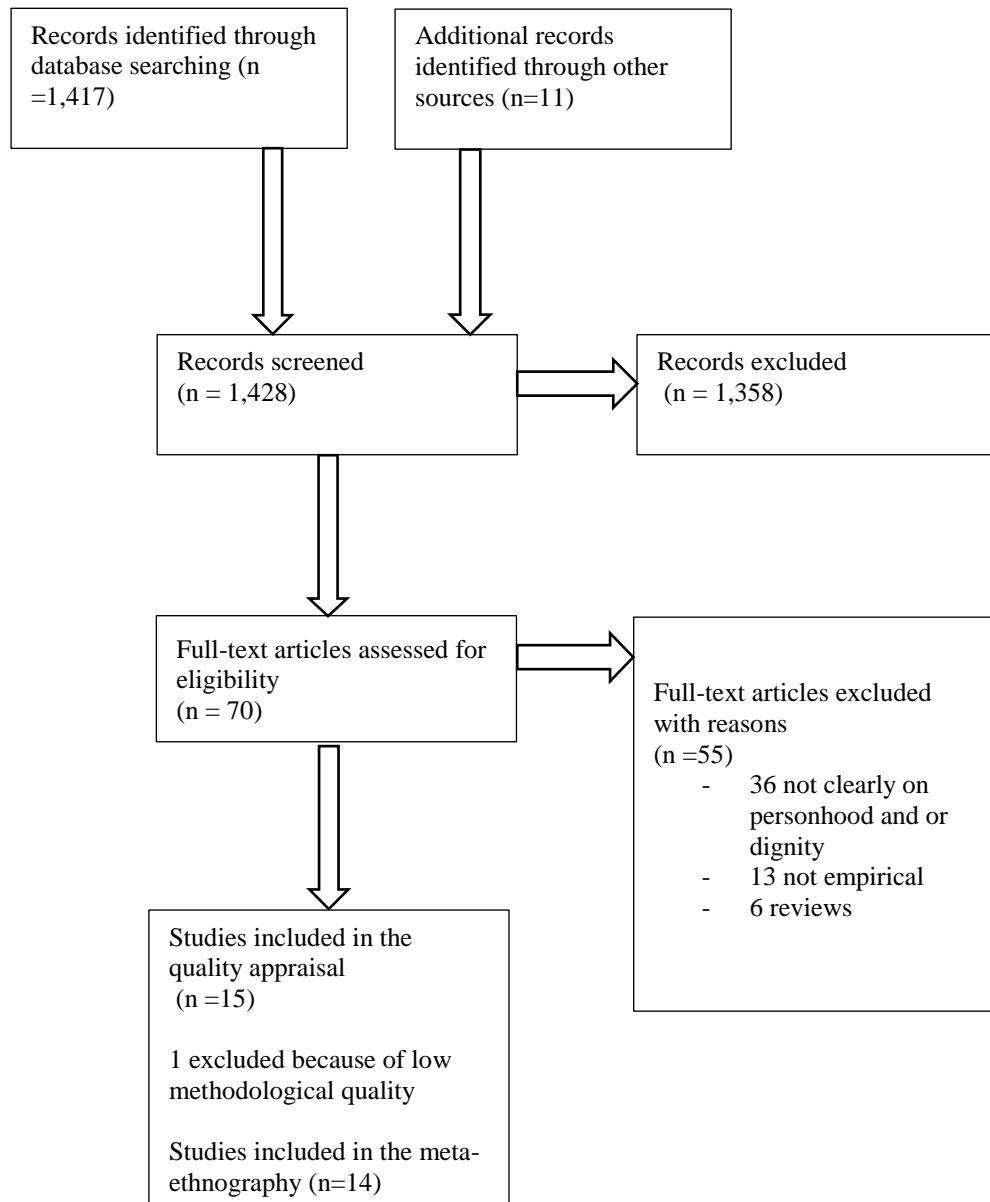


Table 1. Third order construct for the Meta-ethnography of the studies.

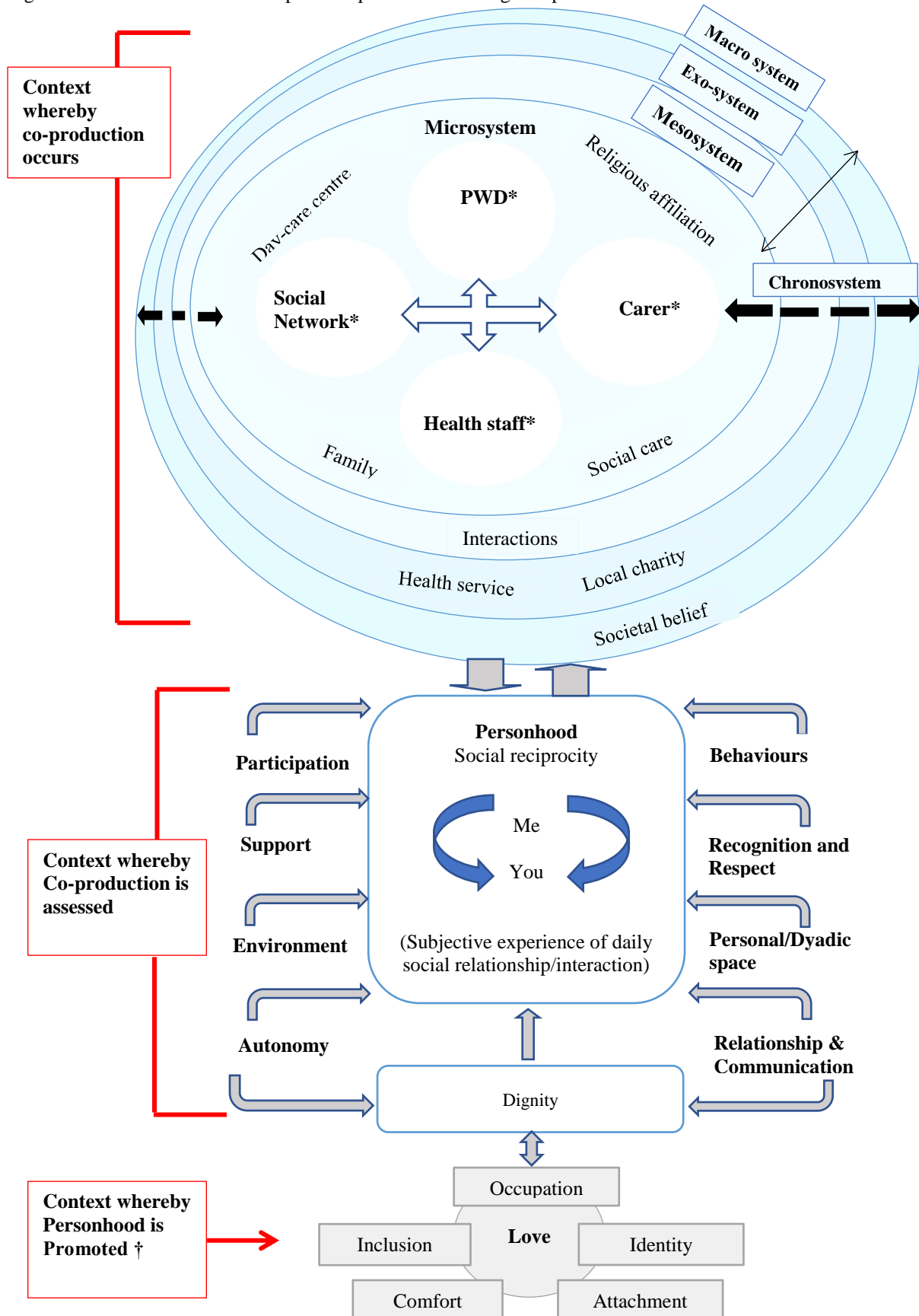
Third order constructs	Categories	Themes
Dignity and personhood	Dignity and its preservation	<ul style="list-style-type: none"> • Community belongingness (vanGennip et al., 2016) • Activity involvement (vanGennip et al., 2016)
	Strategies to promote personhood	<ul style="list-style-type: none"> • Environmental factor (Hung & Chaudhury, 2011; Milte et al., 2015; Zingmark, Sandman, & Norberg, 2002) • Quality of interaction (Dran, 2008; Haggerstad, Nortvedt, & Slettebø, 2015; Hung & Chaudhury, 2011; Zingmark, Sandman, & Norberg, 2002) • Social inclusion (Milde et al., 2015; Hung & Chaudhury, 2011; Haggerstad, Nortvedt, & Slettebø, 2015; Tolhurst & Weicht, 2017)
Coping with dementia	Coping with one's own identity	<ul style="list-style-type: none"> • Social network (Nowell, Thornton, & Simpson, 2011; Surr, 2006) • Dealing with past/present roles (Dran, 2008; Nowell, Thornton, & Simpson, 2011; Phinney, Dahlke, & Purves, 2013; Tranvag, Petersen, & Naden, 2014) • Active engagement (Milde et al., 2015; Palmer, 2013; Tolhurst & Weicht, 2017; Zingmark, Sandman, & Norberg, 2002)
	Family carers' perspectives	<ul style="list-style-type: none"> • Feeling a duty of care (Perry & O'Connor, 2002) • Maintaining a positive view of the person (Perry & O'Connor, 2002) • Justifying behaviours/cognitive decline in dementia (Vezina et al., 2011) • Manipulating the physical environment (Perry & O'Connor, 2002)
Barriers to dignity in care	Internal factor	<ul style="list-style-type: none"> • Fitting in with the system (Nowell, Thornton, & Simpson, 2011)
	External factor	<ul style="list-style-type: none"> • 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).

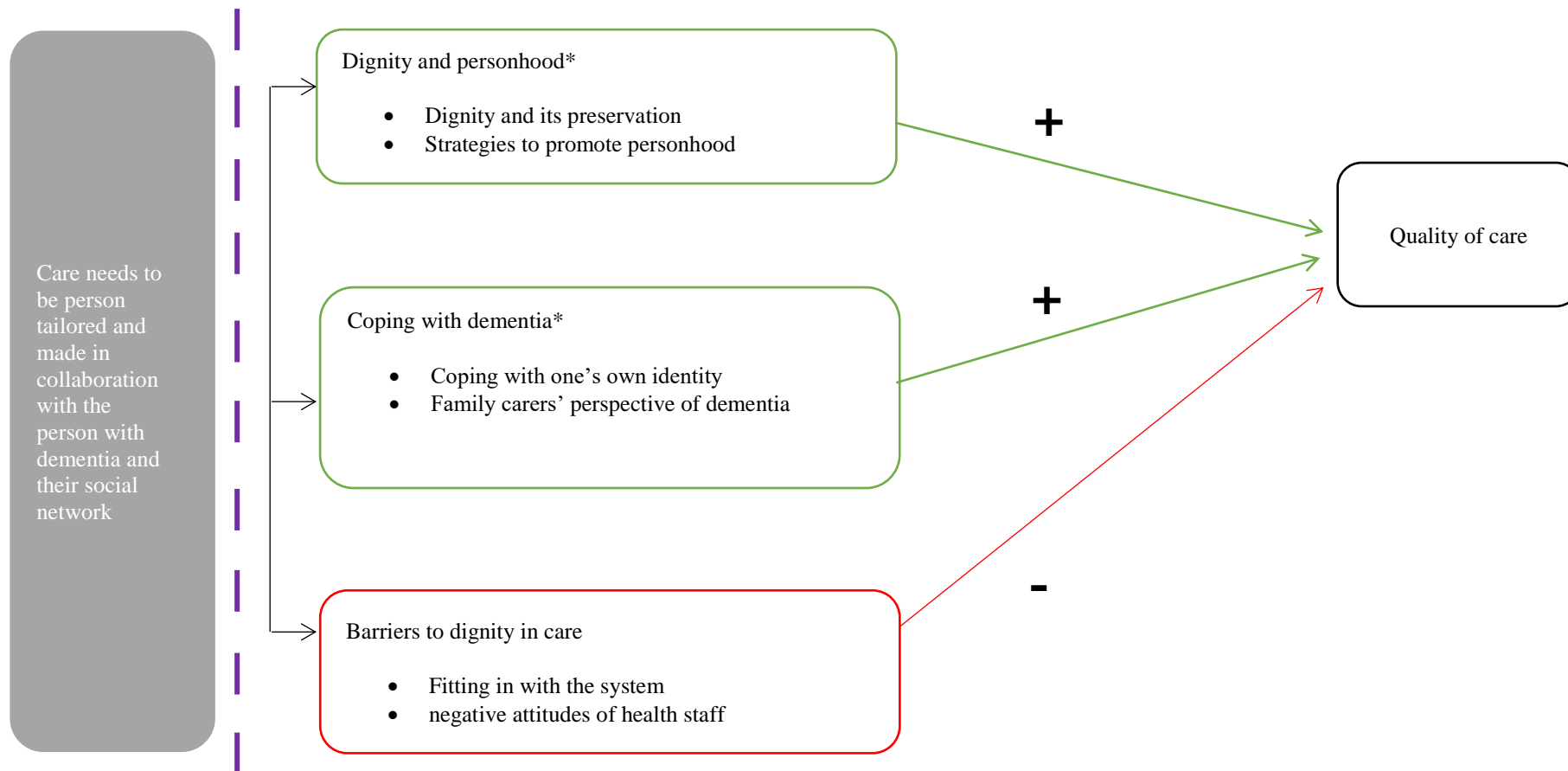
Author	Year	Country	Study design	Published venue	Theory on Personhood/dignity	Qualitative methodology	Qualitative methods of data collection	Qualitative methods of data analysis	Sample demographics
Dran	2008	USA	Qualitative	Journal	Personhood (Kitwood 1997)	Narrative (descriptive)	One-to-one interviews	Narrative analysis (Vignette)	N=3 staff (residential care)
Haggerstad, Nortvedt, & Slettebø	2015	Norway	Qualitative	Journal	Person-centred approach and relationship centred approach (Kitwood, 1997; Nolan, Davies, Ryan, and Keady, 2008)	Hermeneutic Phenomenology	Multi method Participant observation One-to-one semi structured interview	3-steps of analysis (Kvale & Brinkmann, 2009)	N=22 PWD= 15 Aged 70+ Carers= 7 (Female=5) (residential care)
Hung & Chaudhury	2011	Canada	Qualitative	Journal	Kitwood's (1997) approach	Ethnography	- participant observations, -focus groups	integrated deductive– inductive approach*	N= 20 PWD Aged 70+ (residential care)
Milte, Shulver, Killington, Bradley,, Ratcliffe, & Crotty	2015	Australia	Mix-method	Journal	Kitwood and Bredin (1992) “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 - focus groups	Thematic analysis constant comparative analysis (Richards, 2005).	N=41 PWD=15 (Female=9) Mean age=79(SD=11) Carers=26 (Female=18) Mean age=75(SD=9) (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 Aged (60+; Mean=74) (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 Aged 40+ (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 (Female=26) (community living)
Phinney, Dahlke, & Purves,	2013	Canada	Qualitative	Journal	Kitwood 1997	Interpretive phenomenology (Benner, 1994)	Multi method: One-to-one in depth interviews Dyadic interviews Group interviews Participant observation	Interpretive phenomenological analysis (IPA)	N=7 PWD=2 (all males) Carers=5 (all female) (community living)
Surr	2006	UK	Qualitative	Journal	socio-biographical theory of self *	Constructivism*	One-to-one unstructured interviews	interpretive biographical analysis	N=14 PWD (Female=13) Aged 70+ (residential care)

Tolhurst & Weicht	2017	UK	Qualitative	Journal	Higgs & Gilleard, 2015.	Narrative (descriptive)	Semi structured dyadic interviews	Narrative analysis (Riessman, 2008)	N=14 dyads (Aged 50+) (1 same sex dyad) (Female=13) PWD=14 (all males) (community living)
Tranvag, Petersen, & Naden	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 (community living)
vanGennip, Pasma, 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 Constant comparison analysis (Strauss & Corbin, 1990).	N=14 PWD Aged= 50+ (Female=6) (community living)
Vézina, Robichaud, 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 Carers=9 (Female=7) (Aged 40+) Health care professionals = 12 (Female=11)* (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 (Nurses) (Aged 30+) (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 (%)
	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	*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	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					*13 (59.1)
- Lack of capacity			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) | 5) Mental Welfare (2013) | 9) NICE (2017) | 13) WHO (2012) | 17) Italian Ministry of Health (2014) | 21) Israeli Ministry of Health (2013) |
| 2) DoH (UK) (2009) | 6) NHS AgeUK (2012) | 10) RTI Int. (2014) | 14) Irish Depart. of Health (2014) | 18) Flemish minister for welfare (2016) | 22) Dutch Ministry of Health (2009) |
| 3) DoH (AU) (2014) | 7) NICE (2013) | 11) UNECE (2015) | 15) Norwegian Min. of health (2015) | 19) Finnish Ministry of Social Affairs (2013) | |
| 4) EU Comm. (2014) | 8) NICE (2016) | 12) U.S. DoH & HS (2016) | 16) Maltese Parliamentary Secretariat (2014) | 20) H M Government of Gibraltar (2015) | |

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	<p>People with dementia and their carers feel valued at all times during care.</p> <p>The care people receive is considerate of their values and beliefs. The relationship with the carer is valued.</p>	<ul style="list-style-type: none"> - 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). - Staff views around dementia are challenged. - Staff attitude toward people with dementia and their carers is adequate and respectful. - 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). - Individual needs are acknowledged and met (people with dementia have unique needs especially for the behavioural psychological symptoms). - Participants' preferences are accommodated. - Relationship with the carer is acknowledged.
Participation	<p>There is active involvement of people with dementia and their carers.</p>	<ul style="list-style-type: none"> - People with dementia and their carer (when this is applicable) actively participate in decision making for health/social care. - 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	<p>For the dyad but also for each individual agent.</p>	<ul style="list-style-type: none"> - 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) - Dynamic support that accommodates the needs of the person with dementia and the carer during the stages of dementia.

		<ul style="list-style-type: none"> - Support provided in an effective way whereby the needs of the person with dementia are reviewed and the views of the carers are considered. - Encouragement in the promotion of activities that are inclusive of the carers as well as the person with dementia. - 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.	<ul style="list-style-type: none"> - 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) - Relationships change over time and their new status need to be respected at all time alongside the individual needs and the dyad's needs. - Relationship based on social reciprocity need to be valued and respected (e.g. promoting social interaction) - 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) - Recognition of the need to receive care from other agencies (outside the home) when applicable. - 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. - 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). - Search for and respect the expertise and knowledge of the carer with respect to the support delivered to the person with dementia.

Environment	<p>The care is provided in a way that the familiar environment of the person (and that of the carer when applicable) is respected.</p> <p>The environment is experienced as safe throughout the care.</p>	<ul style="list-style-type: none"> - 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). - Person's hobbies are promoted (e.g. music, movies) as part of the care plan. - 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). - Avoiding breaking the routine of the person without alerting her/him beforehand. - 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	<p>Individual needs of people with dementia and their carers are considered at all times during care.</p> <p>People with dementia feel free to go to a private place during care and being on their own and or with the carer.</p>	<ul style="list-style-type: none"> - Person-centred care is respected along with a sense of personhood conceived of in terms of social reciprocity. - 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). - 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. - 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	<p>The relationship with staff is experienced as effective during care.</p>	<ul style="list-style-type: none"> - The care plan (if any) is explained to people with dementia and their carers (or social network) by including them in the conversation. - Information about the care should be given in an accessible format (e.g. booklet with images). - 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

		<p>the person like adults, avoid abstract concepts, avoid talking to the carer when referring to the person with dementia).</p> <ul style="list-style-type: none"> - Reciprocity (carers and staff benefit from delivering a dignified care as much as the person with dementia does). - Time necessary to explain the care plan is divided in multiple visits if too much information needs to be taken in.
Autonomy	<p>Strategies aiming at the promotion of independence/autonomy of the person with dementia need to be implemented</p> <p>Autonomy needs to be promoted until capacity</p>	<ul style="list-style-type: none"> - The use of assistive technology that can support people with dementia in their daily tasks (e.g. navigation systems for orientation, calendar clocks). - 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.