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# BMJ Open

## Social networks, social capital and end-of-life care for people with dementia: a realist review

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## ABSTRACT

**Objectives:** (i) To develop an understanding of how social capital may be conceptualised within the context of end-of-life care and how it can influence outcomes for people with dementia and their families with specific reference to the context and mechanisms that explain observed outcomes. (ii) To produce guidance for healthcare systems and researchers to better structure and design a public health approach to end-of-life care for people with dementia.

**Design:** A realist review

**Data sources:** Medline, EMBASE, Cinhal and grey literature

**Analysis:** We conceptualised social capital as a complex intervention and, in order to understand how change is generated, used realist evaluation methods to create different configurations of context, mechanism and outcomes. We conducted an iterative search focusing on; social capital, social networks and end-of-life care in dementia. All study designs and outcomes were screened and analysed to elicit explanations for a range of outcomes identified. Explanations were consolidated into an overarching programme theory that drew on substantive theory from the social sciences and a public health approach to palliative care.

**Results:** We identified 118 articles from 16 countries ranging from 1992 to 2018. A total of 40 context-mechanism-outcome configurations help explain how social capital may influence end-of-life care for people with dementia. Such influence was identified within 5 key areas. These included; (i) socially orientating a person with dementia following diagnosis; (ii) transitions in the physical environment of care; (iii) how the caregiving experience is viewed by those directly involved with it; (iv) transition of a person with dementia into the 4th age; (v) the decision making processes underpinning such processes.

**Conclusion:** This review contributes to the dispassionate understanding of how complex systems such as community and social capital might be viewed as a tool to improve end-of-life care for people with dementia.

## Strengths and limitations of this study

- A broad search to avoid missing major concepts.
- Using a realist methodology allows us to focus on how contexts influence outcomes whilst identifying generative mechanisms.
- The programme theory generated by this approach is therefore applicable to multiple interventions across different settings.
- Social networks and social capital was often studied from a narrow perspective.
- A lack of empirical evidence meant that context-mechanism-outcome configurations could not fully explore specific functions of social networks or social capital.

## BACKGROUND

The dementias are a group of incurable, progressive illnesses with uncertain clinical trajectories. Globally there are 35.6 million people living with dementia, figures are projected to triple by 2050.<sup>1</sup> The need for care, especially at the end-of-life, is an international public health priority.<sup>2</sup>

Dementia changes social relationships.<sup>2,3</sup> These relationships are fundamental to improving access to services and delivery of care. Relational changes are often portrayed negatively, meaning people affected by dementia may experience social isolation and prejudice.<sup>3,4</sup>

Attempts to address this have sought to shift the focus in care towards a person's environment and the wider societal and organisational practices that shape it.<sup>5,6</sup> How these concepts operate at the end-of-life, a time of heightened vulnerability and dependency, is of profound social and ethical importance yet relatively under researched.

Fraught with uncertainty and unpredictability,<sup>7,8</sup> the end-of-life with dementia is often depicted as 'tragic' and 'untimely'.<sup>9</sup> Unsurprisingly, residential care is often recommended. Whilst a positive experience for some, this process can bring further distress in the form of guilt, family discord and loss of identity.<sup>10,11</sup>

Specialist palliative care professionals have expertise and experience working with such complexity.<sup>12-14</sup> However, comparatively few people with dementia are referred.<sup>15</sup> In the UK, hospices have limited capacity, whilst cuts to social service budgets mean professional home care is diminishing.<sup>16,17</sup>

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3 With these issues in mind, a public health approach to end-of-life care has been proposed.<sup>18</sup>

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5 <sup>19</sup> The movement aims to pre-empt issues such as social isolation and stigma, by promoting  
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7 supportive networks of community members. There is a growing evidence base for this  
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9 approach, yet how it relates to the specific challenges of dementia is unknown.<sup>20 21</sup>

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11 The concept of social capital links the relational component to dementia with a public health  
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13 approach to palliative care. Social capital takes many forms, is not uniformly accessible, and  
14  
15 its sources and consequences are plural.<sup>22</sup> Definitions are multiple and dependent on the  
16  
17 context and complexity associated with its operationalisation.<sup>22-24</sup> Unifying themes focus on  
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19 social capital being inherent in the structure of human relationships. To possess social  
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21 capital one must therefore be held in connection with others and an advantage is realised  
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23 through these other people. Positive consequences may exist at the level of the individual  
24  
25 and the community.<sup>22</sup>

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27 How social capital impacts on healthcare is gaining academic interest and a range of positive  
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29 outcomes have been described.<sup>20 25-27</sup> However, at the level of the individual, the processes  
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31 involved in acquiring social capital cut both ways. For example, social-ties may provide  
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33 access to resource, but can also restrict individual freedoms and bar outsiders from access.<sup>22</sup>  
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35 For this reason social capital in relation to health must be studied in all its complexity rather  
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37 than as an example of value.

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39 Previous systematic reviews have looked at factors including, caregiver and family  
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41 characteristics that influence transitions in care and the various interventions to support or  
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43 delay this process.<sup>28</sup> Less attention has been paid to exploring the underlying causal  
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45 processes that occur during this process and how transitions in care fit into the broader  
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47 picture of end-of-life care.

## 48 **EVALUATION QUESTIONS AND OBJECTIVES**

### 49 **Research questions**

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1. What are the mechanisms by which social capital is believed to impact on relevant outcomes for people with dementia at the end-of-life?
  2. What are the important contexts which determine whether different mechanisms produce intended outcomes?
  3. In what circumstances and for who is social capital an effective intervention?

## Objectives

1. To develop theory around the interaction between social capital, end-of-life care and dementia.
2. To develop an understanding of how social capital may be defined and conceptualised within the context of end-of-life care and how it can influence outcomes for people with dementia and their families with specific reference to the context and mechanisms that explain observed outcomes.
3. To produce guidance for healthcare systems and researchers to better structure and design a public health approach to end-of-life care for people with dementia.

## METHODS

To address the complexity presented by the research questions, we drew on critical realist philosophy.<sup>29</sup> This approach follows an interpretative, theory driven process of synthesising evidence from heterogeneous data.<sup>30</sup> The main strength is to produce findings that explain how and why social practices have the potential to cause change. Findings are described in terms of context-mechanism-outcome configurations (CMOCs). Causation is therefore not to be understood in relation to an 'intervention', i.e. to see if social capital 'works' or 'doesn't work'. Instead causation is thought to be generative through the release of 'mechanisms' or underlying causal powers of individuals and communities.<sup>30</sup>

To account for the pan-disciplinary interest in social capital, our search was not restricted to one definition. Through immersion in the literature, we chose to focus on how the nature and existence of human relationships, within social structures such as healthcare, community and 'the home', were introduced or excluded from an evolving network of care, and how this appeared to influence outcomes at a series of key decision points. Instead of focusing on barriers or facilitators to the development of social capital, we focused on what happens in the presence of challenges faced by people with dementia.

The review is registered on PROSPERO (CRD42018084524) and ran for 17 months (Oct 17 to Feb 19). It is reported according to the RAMASES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) publication standards.<sup>31</sup> The review followed Pawson's five iterative stages as described below.<sup>32</sup> With reference to Papoutsi et al,<sup>33</sup> and in order to

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3 develop a more accessible narrative beyond CMOCs, we sought to engage with substantive  
4 theory in what became the sixth step.  
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### 7 **(i) Locating existing theories and programme theory development**

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10 Prior to formal literature searching, JS devised an initial programme theory to act as a  
11 reference point. This was based on prior knowledge and an initial scoping search. The  
12 scoping search used key terms and recognized authors in the field across MEDLINE/Pubmed  
13 and Google. Additional literature was accessed through citation tracking and eliciting key  
14 studies from experts.<sup>34</sup> Relevant theories such as Bartlett and O'Connor's model of 'social  
15 citizenship',<sup>5</sup> Kitwood's ideas on personhood,<sup>6 35 36</sup> and Kellehear's 'compassionate cities'  
16 model<sup>18 37</sup> were reviewed in conjunction with established literature on social capital.<sup>22-24 38</sup>

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18 Findings were combined with the experiential, professional and content knowledge of the  
19 research team (JS – clinical research fellow in palliative care, LS – consultant in palliative  
20 care, senior clinical lecturer in new public health approaches, NK – senior research fellow in  
21 dementia, PS clinical academic in palliative care and ELS- clinical reader in old age  
22 psychiatry, expert in dementia and end-of-life care). The resulting programme theory acted  
23 as a guide for refining assumptions against data from the main search. Group consultations  
24 continued during data analysis in order to refine the programme theory.  
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### 36 **(ii) Searching for evidence**

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38 Two distinct formal literature searches were conducted through the databases MEDLINE,  
39 EMBASE and CINAHL. For the main search, terms included; dementia OR Alzheimer's disease  
40 OR multi-infarct dementia OR vascular dementia; social capital OR social network OR social  
41 support OR community development OR community participation OR social integration;  
42 palliative therapy OR terminal care OR palliative care OR end-of-life OR Death OR dying. Full  
43 terms are available in the supplementary file. Terms were piloted and refined to increase  
44 sensitivity. Grey literature was searched using Google and the data base OpenGrey.  
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54 References within included documents were screened for relevance.

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56 The search was run in December 2017 and repeated in October 2018 to capture newly  
57 published articles. Databases were searched from inception. We included all studies on  
58 dementia relating to any aspect of social capital identified in step (i). All study designs were  
59 included across all settings. We excluded studies focusing on old-age and frailty.  
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3 Following analysis of the literature from the main search, and discussions within the  
4 research team, an additional search was undertaken to focus the review on emerging  
5 themes. This looked at the influence of social networks and social capital on 'transitions in  
6 care'. This was intended to provide more detail to the contextual influences identified as  
7 important from the main search. There were no pre-specified exclusion criteria, all study  
8 types and settings were included.  
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14 Results from both searches were exported to Endnote X8 referencing software. Duplicates  
15 were removed using automated and manual checking. All citations were reviewed by JS  
16 against the inclusion criteria and a 10% random subsample reviewed by NK.  
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### 20 **(iii) Selecting articles**

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22 All titles and abstracts were screened by JS and included if they were judged to contain data  
23 relevant to the programme theory. Studies did not need to contain all components of the  
24 programme theory so as not to exclude important concepts. Only studies in English were  
25 included. The purpose of selecting and appraising full text articles was not to create an  
26 exhaustive set of studies, but rather to reach conceptual saturation in which sufficient  
27 evidence could be collated to meet the stated aims.<sup>39</sup> At the point of inclusion, based on  
28 relevance, judgments on the rigor and trustworthiness of each source was addressed (see  
29 supplementary file for details). There was significant overlap between relevance and rigor as  
30 data was only selected to modify the programme (i.e. relevant to the research question)  
31 theory when adherent to the chosen methodology (i.e. rigorously conducted).  
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### 42 **(iv) Extracting and organizing data**

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44 Study characteristics were tabulated in Microsoft Word. Sections of text, including  
45 participant quotes, author interpretations and conclusions, relevant to the programme  
46 theory were highlighted in PDF format. Broad themes relating to the highlighted text were  
47 recorded in an Excel spreadsheet. Repeating themes were developed into codes inductively.  
48 Codes were also developed deductively (originating from the initial programme theory). The  
49 codes were refined based on emerging concepts throughout the analysis period. Codes  
50 were developed by asking if the identified information was referring to context, mechanism  
51 or outcome. Upon coding, the original text would be revisited and the highlighted text  
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3 reviewed before making a decision. A sample 10% of the coded papers was independently  
4 reviewed by LS for consistency.  
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#### 7 **(v) Synthesizing the evidence and drawing conclusions**

9 Highlighted excerpts, which had then been coded, were transferred into a word document.  
10 This was printed and annotated as themes developed iteratively. As data came to represent  
11 either context, mechanism or outcome it was labelled as such and transferred into  
12 PowerPoint. This was to provide a more flexible work space to construct CMOCs. To develop  
13 an overall programme theory, we moved iteratively between the analysis of particular  
14 examples, discussion within the research team, refinement of programme theory and  
15 further iterative searching from within the existing data set.  
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18 A realist logic of analysis was applied to synthesize data, this process involves the constant  
19 movement from data to theory to refine explanations for observed patterns. Explanations  
20 were built at a level of abstraction that would cover a range of observed behaviors in  
21 different settings. In order to achieve this, inferences were made about which mechanism  
22 may be triggered in specific contexts. This was necessary as mechanisms were often not  
23 explicitly stated within the literature. The data set was then reviewed to find data to  
24 corroborate, refute or refine developing CMOCs.  
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27 Relationships between context, mechanism and outcomes were sought from within the  
28 same article to which relevant data appeared, but also across sources. Thus it was not  
29 uncommon for a mechanism inferred from one article to explain the way contexts  
30 influences outcomes in a different article.  
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#### 33 **(vi) Writing and engaging with substantive theory**

34 The process of writing helped develop the final programme theory. Narrative is used to  
35 explain the data which in turn enabled us to fine tune our interpretations of meaning and  
36 relevance. Formal theory identified during the search was used to assist in programme  
37 theory refinement by substantiating the inferences made about contexts, mechanism and  
38 outcomes thus enhancing plausibility and coherence.<sup>5 18 40-42</sup>  
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#### 41 **Patient and Public Involvement**

42 Patients and the public were not involved in this research  
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## RESULTS

### Search results

A total of 3199 titles and abstracts were screened leading to a full text review of 182 articles. Seventy-four articles were excluded after assessment for relevance and rigor and 10 added via citation analysis and expert opinion leaving a total of 118 included references (Figure 1). Of these, 55 used qualitative methods, 28 used quantitative and 5 used mixed methods. There were 11 reviews and 19 references that included book chapters, editorials or commentaries (full characteristics available in the supplementary information).

### Programme theory and CMOCs

The following sections provide a narrative overview of the programme theory that explains how social capital may influence end-of-life care for people with dementia. Impact is evaluated under 5 categories; (i) socially orientating a person with dementia following diagnosis; (ii) the process of decision making; (iii) transitions in the physical environment of care; (iv) how the caregiving experience is viewed by those directly involved with it; (v) transition of a person with dementia into the 4<sup>th</sup> age. These five categories emerged following analysis and clustering of the data from the literature. Due to space constraints only a selection of CMOCs are presented in narrative form.

#### (i) Socially orientating a person with dementia following diagnosis

We found the impact of structural social capital, that is the properties of a social system and its networks of relations,<sup>38</sup> was pronounced in socially orientating a person following diagnosis. To explain this, we draw on the sociological concept of liminality; a state of 'inbetweenness and ambiguity' that often occurs following a serious diagnosis.<sup>43 44</sup> Birt et al describe movement to a 'post-liminal' state in dementia, a state characterized by interdependency that allows for the expression of a new identity that can exert influence on the surrounding environment.<sup>45</sup> This process reflected themes developed from key sources<sup>5 6 45</sup> and the data set at large.<sup>46-52</sup>

For example, we found evidence that where cohesive support networks surround a person with dementia,<sup>53 54</sup> people are able to live with a sense of purpose<sup>53 55</sup> whilst members of the network are able to advocate for their perceived wishes through the exchange of knowledge with other community members.<sup>56-62</sup> Cohesive support networks developed

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3 knowledge or 'expertise' relating to the person with dementia.<sup>49 63</sup> This was accumulated  
4 through the provision of care and equated to 'longitudinal monitoring'.<sup>64-66</sup> Knowledge was  
5 then conveyed through narrative<sup>67 68</sup> to help develop a person's role as an active citizen.<sup>5 45</sup>  
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11 We also found evidence that with progressive dementia, social networks dwindle.<sup>53 69-71</sup> The  
12 decline in social connections gave rise to people living in a period of extended liminality<sup>45 47</sup>  
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72 73 where uncertainty as to what the future may hold was the generative mechanism.<sup>48-52 60</sup>  
Periods of extended liminality were also noted to be a product of the public and bio-  
medically fuelled discourse that depicts dementia as 'death in the realm of the living'.<sup>3 72</sup>  
This was also noted in situations where people, conscious of their diagnosis, experienced  
uncertainty as to how their views would be interpreted, again leading to a state of extended  
liminality.<sup>45 48-50 73 74</sup> Figure 2 shows a complete set of CMOCs for this section. Detailed  
examples of CMOCs with supporting evidence are shown in table 1. A full list is available in  
the supplementary file.

**Table 1:** Examples of key CMO configuration's with supporting evidence for 'transition to a post liminal state'.  
The full list is available in the supplementary file

Context (C)-Mechanism (M)- Outcome(O)	Example of supporting evidence from the literature
CMO: In the context of dementia being perceived as 'death in the realm of the living' (C), people with dementia and their wider social network experience fear and trepidation (M) that moves people into a state confined by the shadow of the '4 <sup>th</sup> age' (O)	<p><b>Death in the realm of the living:</b> "Dementia confronts because it seems to bring death into life, implicitly questioning what life, relationship, and death are about."<sup>3</sup></p> <p><b>Fear</b> "people with dementia are often thought of as tragic, robbed of life, and having lost their personhood."<sup>3</sup></p> <p><b>The 4<sup>th</sup> age</b> "It is when people are no longer "getting by", when they are seen as not managing the daily round, when they become third persons in others' age-based discourse, within others' rules, that they become subjects of a fourth age"<sup>75</sup></p>
CMO: In communities of identity (C), people with dementia have a sense of purpose (M) which allows them to grow and maintain a role as an active citizen (O)	<p><b>Communities of identity</b> "This centre provides day care for those living with dementia but instead of playing games or receiving passive entertainment the main program is about the design and production of the mid-day meal. Seniors with dementia are asked to jointly design the meal, then to go out shopping together to buy the ingredients, and then return to help prepare the meals. Shopkeepers are briefed on the program and willingly participate in the program, learning and experiencing the complexities of communicating with seniors with dementia and also Compassionate communities gaining insight into the complexities of their care while sharing this in a small way."<sup>55</sup></p>
CMO: As dementia progresses a person may change their perceptions and views on various issues (including	<p><b>Changing perceptions:</b> "Relatives and staff need to be aware that the person's attitude to death may evolve during their dementia. When a comparison was made between participants' attitudes to</p>

<p>death) (C), they maintain their role as an active citizen (O) by conveying these views through their agentic influence (M)</p>	<p><i>death and those ascribed to them by their family carers, for some people they appeared to have changed.”<sup>67</sup></i></p> <p><i>“(Husband) had a bit of a health crisis about 12 months ago...when he came out of this acute crisis, he said to me he was afraid people that people would turn off the switch. So there was a complete change of his limited understanding...(now) I don't know whether I'm actually fulfilling his wishes.”<sup>54</sup></i></p>
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## (ii) Decision making processes

The decision making process acted as a vehicle to move between outcomes and was heavily influenced by ‘cognitive social capital’. Cognitive social capital relates to the shared representations and interpretations of meaning held by involved parties.<sup>38</sup>

This was particularly evident in the context of advance care planning.<sup>54 68 76-78</sup> Here decision making processes are influenced by a family’s power as a surrogate decision maker.

Mechanisms included the maintenance of a historic identity,<sup>77 79</sup> growth of a new identity,<sup>67 76 80</sup> discrimination against a person with reduced agency,<sup>52 76 78</sup> compassion towards a person affected by dementia and ‘knowledge exchange’ between caregivers and professionals.<sup>19 61 67 69 76 77 79 80</sup>

Decision making was facilitated by ‘case based theory’ rather than ‘principal theory’<sup>79</sup> i.e. when faced with a ‘what’s best scenario’, families use factors important to the individual as opposed to humanity in general. Here narrative relating to the person with dementia is of prime importance. Depending on how the caring network developed this narrative, i.e. through mechanisms such as identity growth, knowledge exchange, paternalism or identity maintenance, the outcome would vary.<sup>41 49 60 61 68 79 81 82</sup>

The influence of supportive care networks, both professional and lay, were not uniformly positive. Decision making was found to be subject to the independent agendas of a care network or the paternalistic actions of professionals. These mechanisms lead to discrimination against the person with dementia in certain contexts.<sup>52 57 59 71 72 76 78 79</sup> Figure 3 shows a complete set of CMOCs with detailed examples described in table 2.

When considering the decision making process from the perspective of the family or main carers, we found the same contexts and mechanism were in operation. The CMO configurations are configured to outcomes relevant to the care network in figure 4.

**Table 2:** Examples of key CMO configuration's for the 'decision making process' with supporting evidence. The full list is available in the supplementary file

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
<p>CMO: Families used 'case based theory' rather than 'principal theory' when making decisions. Here narrative relating to the person with dementia is of prime importance (C). A more rewarding care experience occurs (O) with the use of agency (M), identity growth (M), and knowledge exchange (M).</p>	<p><b>Primacy of narrative:</b> "The ethical approach implicit in these families' descriptions are consistent with a case-based theory, rather than a principle theory. When these family decision-makers utilized an abstract concept such as human dignity, they did so in a limited manner by discussing the factors that were important for the dignity of their relative, rather than for human dignity in general. They did not invoke patterns or principles from beyond their own experience."<sup>79</sup></p> <p><b>Identity growth:</b> "She had always been shy and didn't want to entertain people. Yet, when her inhibitions were lost because of the Alzheimer's, she would get excited when people visited. She enjoyed the Bible study in our home every Friday evening. One day I was late getting her up from a nap, and students were already arriving. I woke her, asking if she wanted to see the students coming. She jumped out of bed, replying, "I think they'll want to see me." Indeed, she did have a special relationship with the students."<sup>61</sup></p> <p><b>Knowledge exchange:</b> "Inclusion was facilitated in other ways such as knowing the preferences of the person through previous interviews with them and their family, or by asking family members about what those preferences might be, building a biographical understanding of the person and being informed by that."<sup>81</sup></p> <p><b>Fluid decision making leading to a more rewarding experience:</b> "I think whatever you do, you've got to do it with a relatively good grace. If you feel that you've been pushed into it, or you're obliged to do it, then I think it won't work."<sup>60</sup></p>
<p>CMO: Where there is interaction with professional care services (C) the decision making process can be facilitated to increase a persons role as an active citizen (O). Mechanisms include compassion, knowledge exchange, and confidence/autonomy (M).</p>	<p><b>Knowledge exchange:</b> "I was able to tell the doctor what was going on with my mom. And he was grateful for the knowledge. He told me what to expect and when to call the clinic. I felt better prepared after that."<sup>49</sup></p> <p><b>Confidence/autonomy:</b> "So they're sort of pre-empting what they know is going to happen. [Yes] See I don't necessarily know that's gonna happen so they're kind of giving me that information. "Look, you know, you're gonna be heading down this road soon so you may wanna do this, this and this." So it's helping me to future plan [Yep] which I find very helpful".<sup>82</sup></p>
<p>CMO: In a state of liminality characterised by indecision and uncertainty (C), medical paternalism and authority (M) can provide some direction allowing the decision making process to proceed with more fluidity but maintain a state of liminality and loss of control (O)</p>	<p><b>Paternalism/authority:</b> "So long as you say... 'doctor' in the sentence . . . she will go along with that, she will listen to that authority so that's been good actually." (daughter)<sup>60</sup></p> <p>My mother was asked what she thought and said, "Whatever the doctor thinks is best."<sup>47</sup></p> <p>"The second strongest influence affecting the decisions of both groups...was the advice of the physician..."<sup>83</sup></p> <p>"You accept it because it's easy...I think to meself [sic] 'they are only trying to help you so let them do what they think is best'."<sup>73</sup></p>
<p>CMO: Where relationships with a caring network become strained (C) a sense of guilt (M), failure (M) and uncertainty (M) in addition to</p>	<p><b>Strained relationships:</b> "It's a different thing when Mum (person with dementia) was living with us. He (participant's husband) just didn't handle things, and I was between the devil and the deep. I didn't want to -Mum</p>

<p>the paternalistic actions of professional care networks (M) can cause the caregiving experience to become overwhelming (O)</p>	<p><i>needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly"</i> <sup>72</sup></p> <p><b>Guilt:</b> <i>"The doctor said my mom could not live alone. You know, I love my mom, but she could not come and live with us. It would have disrupted my whole family. I know it is terrible to call your mother a disruption. What a guilt trip."</i> <sup>84</sup></p> <p><b>Paternalism:</b> <i>"...healthcare professionals unfamiliar with the family and the resident's individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact."</i> <sup>71</sup></p> <p><b>Uncertainty:</b> <i>"...thus, critical issues of personhood, identity, agency, and control were embedded in our moms' experiences and reflected in our experiences as families as we struggled to "do what was right."</i> <sup>50</sup></p> <p><b>Overwhelming:</b> <i>"I had no one to look after mum, so I couldn't go to work, and I do believe that that impacted and I do believe that that's one of the reasons that they fired me. Because I couldn't attend work because I had to look after mum"</i> <sup>63</sup></p>
<p>CMO: Where powerful structures of care become involved (C), feelings of failure (M) and a loss of autonomy (or paternalism from healthcare professionals) (M) can lead to a care experience that feels overwhelming (O)</p>	<p><b>Professionalised care:</b> <i>"Dementia starkly reveals the Cartesian biomedical model's incomplete understanding of "health," through its inability, even unwillingness, to develop effective (non-biomedical) interventions to address a range of experiences of disease in their social, relational context."</i> <sup>3</sup></p> <p><i>"...carers experience in receiving formal services is inherently ambiguous, for whilst formal services are providing support to family carers, they can also be undermining their sense of identity and control over their circumstances..."</i> <sup>63</sup></p> <p><b>Loss of control/autonomy in the care role:</b> <i>"Oh God no, they did everything, all I had to do was go and visit and feed her. Didn't even have to feed her but I liked to."</i> <sup>58</sup></p>

### (iii) Transitions in care

Much of the data focused on transitions for people into hospital or long term care as a primary outcome.<sup>56 84-87</sup> To understand the influence of social capital in this setting we drew upon Bourdieu's work that implies social capital is deeply reliant on the context of a particular social space.<sup>23</sup>

The data revealed that transitions in the care environment occur as a function of progressive illness, often as a necessity rather than something to be prevented.<sup>88 89</sup> We found that transitions in the care environment were therefore operating as context as opposed to an outcome. The full CMO configurations are available in figure 5.

Transitions occurred within a person's home as professionals entered and changed the physical space. They also occurred when a person moved out of the home into an alternate care environment.<sup>90-92</sup> The process of physical transition acted as an interface upon which

supportive networks of care would convene along with the person with dementia and professional care services. The outcomes of this process contribute to the post-liminal states previously described but also help define the care experience for those within the main care network. Rather than being mutually exclusive endpoints, people would move between outcomes based on the contexts and mechanism described. Table 3 gives further examples of CMOs with supporting evidence.

**Table 3:** CMO configurations with supporting evidence for ‘transitions in the care environment’

<b>Context (C)-Mechanism (M)-Outcome(O)</b>
<p>CMO: As dementia progresses and manifest as changes in behaviour and social relationships transitions occur to the care environment, these might involve the person moving or objects moving into what was previously the home environment. Either way, the space as it previously was, transitions to something new (a hybrid space in the home) or an entirely new space in some form of institutional care (nursing home, hospital, sheltered accommodation). These transitions (C) have outcomes relating to the individual: Living in extended liminality; living as an active citizen; living in the shadow of the 4<sup>th</sup> age, and to the individuals care network; rewarding care experiences; overwhelming care experiences and transfer of acquired skills outside of care network (O). Mechanisms identified include duty, paternalism, compassion, routineisation, reciprocity, narrative, resilience, discrimination, teamwork, identity growth, identity maintenance, grief, loneliness and knowledge exchange (M)</p>
<b>Example of supporting evidence from the literature</b>
<p><b>Transitions:</b> <i>“I tend to think that people with dementia do want familiar; it’s the change that is difficult to cope with and the familiar things are personal things, if we’re talking about residential care, to bring in personal things of theirs, whether it was his music, I know my husband did a lot of photography as a hobby... and he had the photographs there...and when he did go into respite, we took the same pictures, I think, that was important to him.”<sup>91</sup></i></p> <p><b>Transitions in the home:</b> <i>“Although all the care recipients and their family caregivers indicated a strong preference for home care over institutional care, their experiences and practices within their homes were disrupted and reconfigured by the insertion of logics emanating from the healthcare field”<sup>90</sup></i></p> <p><b>Duty:</b> <i>“Another difference was in the sense of obligation for family members to provide care for their next of kin through the course of the disease...”<sup>93</sup></i></p> <p><b>Guilt:</b> <i>“I visit here many times, but every time I am so ashamed. This place is like a dumpster where you throw away things, a place for well-off daughters’ in-law to throw away their parents-in-law. I felt so guilty in front of the nursing assistants to be a child of one of these elderly people. I don’t even dress nice when I come here because I’m afraid of what people will say of me since I’ve brought my parents over here.”<sup>94</sup></i></p> <p><b>Reciprocity:</b> <i>“Mom also taught me more about love. I learned to express my love. Because I knew she would easily forget, I would remind her many times a day that I loved her. Each time I did, she would light up with a smile. It brought me much joy to see her receive my love. Often when I was helping her, she would kiss me on the arm, whisper “I love you,” or say “Thank you.” .... I realized the more I said, “I love you,” the more love grew”<sup>61</sup></i></p> <p><b>Resilience:</b> <i>“It is surprising that behavioural disturbances are one of the major reasons for admission in RUD (rehabilitation unit for dementia), but they are not risk factors for institutionalization after discharge. The process mediating the association between BPSD (behavioural and psychological symptoms of dementia) and placement may be the ability of the caregiver to tolerate such behaviours and not BPSD by themselves.”<sup>95</sup></i></p> <p><b>Growth and liminality:</b> <i>“... participants show an orientation to the present and the future that contains growth on the one side and vulnerability on the other. Growth concerns personal growth and developing new ways in which to organize their lives. Aspects of vulnerability include declining health, possible dependence, coping with growing older, and being concerned with finitude.”<sup>46</sup></i></p>



**Grief:** "This transition (to long term care) can also highlight the sadness that marks the end of a long-standing relationship."<sup>96</sup>

"I had to keep reminding myself that the disease took away the dad I once knew"<sup>97</sup>

**Loneliness:** "I don't actually call them that much, but just knowing they are there is a tremendous source of help..."<sup>98</sup>

**Knowledge exchange:** A lack of communication or information sharing appeared to be a key reason why older adults and caregivers felt ignored, forgotten or unimportant"<sup>86</sup>

**Conflict:** "You tell him that I absolutely refuse for them to do anything with my father. Unless a doctor calls and tells me that I have to do something, it's gonna stay the way it is now'. And I said, 'If he doesn't like it, and he thinks he's gonna cause you trouble, you tell him that I'm gonna go get me a lawyer, and I'm gonna call Channel 5...'"<sup>79</sup>

#### (iv) The care-givers experience

The care-givers experience brought up themes relating to the concept of relational social capital, that is aspects such as trust, trustworthiness and norms.<sup>38</sup>

Much of the empirical data focused on the negativity associated with care.<sup>11 48 49 59 63 64 99-101</sup>

However, we found evidence of the positive aspects of caregiving which was noted as an important outcome. For example, where relationships with a caring network become strained,<sup>11 63 72 102</sup> the exchange of knowledge and trusting relationships<sup>57 58 71 99</sup> generated rewarding aspects to the care experience.<sup>5 51 103-105</sup>

In certain conditions there was also evidence of the skills acquired through the caregiving process being transferred to wider community networks. For example, when a person with dementia died, the void in reciprocity experienced during caregiving, and a sense of duty, can drive people to transfer their skills to the community.<sup>55 61 82 89 93 106-109</sup> The full list of mechanisms and associated contexts are shown in figure 6 with selected CMO configurations described in table 4.

**Table 4:** CMO configurations with supporting evidence for the 'caregiver's experience'

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
CMO: When a person with dementia dies (C), the void in reciprocity experienced during the care giving relationship (M) and a sense of duty (M) can drive members of the caring network to transfer their skills to the community (O)	<p><b>Reciprocity:</b> "...yet many aspects of my experience were positive. My father and I had conversations about his memories of his older relatives that I doubt we would have had otherwise. Sharing the ups and downs of caregiving with my sister also brought us closer together. It was the first time that we had discussed our values about caregiving (despite having witnessed our mother's experience), money, and ultimately, end-of-life care..."<sup>105</sup></p> <p><b>Duty:</b> "As a son, taking care of my parents is my responsibility. Sometimes, my sisters come back home to care for my father, but they have already married out [of the family]. They are guests. It's not their responsibility. I appreciate their</p>

	<p>assistance though. However, my brother and I have the ultimate responsibility to take care of our parents.”<sup>110</sup></p> <p>“I just took it as that was part of my life goal, to take care of them... It’s stressful, but sometimes it’s rewarding.”<sup>104</sup></p> <p>“...if you have to have something bad happen to you, to be able to turn it into something positive that helps other people, it’s a good thing to do... I like to say when I go out to speak that I have a lot of passions, that I have passions for gardening and for hiking and for quilting... I chose those passions, and then I have a passion that chose me, and that’s what Alzheimer’s is... I think there are ways to give of yourself that sort of replace that caregiving role... working with the Alzheimer’s Association and that work that I do- I think that’s filled the void.”<sup>104</sup></p>
<p>CMO: Where relationships with a caring network become strained (C), the exchange of knowledge (M) and trusting relationships (M) generated positivity and rewarding aspects to the care experience (O)</p>	<p><b>Strain:</b> “Initially life seemed unbearable. My mother was incontinent, hallucinating, and disoriented. At one point she stayed awake for 40 hours seeing people, places, and things that weren’t there. We were exhausted. But in time, she showed signs of improvement.”</p> <p><b>Knowledge exchange:</b> “I think just their reassurance...there is nothing physically they can do...they just reassure you.... That you are doing the right thing, more than anything, because sometimes you do doubt yourself”<sup>62</sup></p> <p><b>Trust:</b> “External support resources from the community or charitable organizations were a key feature for some. Specifically, reliance on neighbours or being members of a close community gave reassurance of their relative’s safety when they were not present...”<sup>71</sup></p> <p><b>Rewarding aspects to care:</b> “When my mother died from a fall, I reflected on the satisfaction and peace I had not anticipated I would feel. I knew what it was to “give back” to my mother. It seems incredible that caregiving can be so satisfying. I look into her bedroom now and I can feel her presence...and I am thankful for the final gift she gave me.”<sup>103</sup></p>
<p>CMO: Where powerful structures of care become involved (C), feelings of failure (M) and a loss of autonomy (or paternalism from healthcare professionals) (M) can lead to a care experience that feels overwhelming (O)</p>	<p>“Hospitalisation of the person with dementia was also described as a challenging time. Carers may have taken responsibility for all of the caring, believed they knew the person and their needs most intimately and taken responsibility for decision-making; however, when the person with dementia is admitted to hospital, the carer is usually no longer primarily responsible for these things and he/she can experience an acute loss of control. In addition, vulnerable family caregivers can feel disempowered by the health care system, especially when they are not recognised as the expert in the care of their relative and not appropriately included in decision-making”<sup>72</sup></p>

(v) Dementia progression and the 4<sup>th</sup> age

The final aspect of our programme theory investigates the role of social capital in the context of entry into a state of complete dependency known as the ‘4<sup>th</sup> age’.<sup>75</sup> At this point, a person’s ability to influence their surroundings is reduced, social networks have diminished and pre-formed close contacts hold a narrative that is referred to during decision making.<sup>53 69-71 82 108 109</sup> Where social networks have diminished, the routinization of

paternalistic care and the ignominy of this can lead to people entering the 4<sup>th</sup> age,<sup>59 70 75 108</sup>

<sup>111</sup> see figure 7 for complete CMO and table 5 for evidenced examples.

The 4<sup>th</sup> age has been theorized as a ‘black hole’ into which the effort and energy of caring falls into.<sup>75</sup> We found no evidence of the reciprocity associated with dyadic caring relationships. There was however evidence of people transferring their acquired caring skills to the community. We hypothesize that this would result in the acquisition of network members that may contribute to care. Ultimately this may begin to bring a shift in how society views someone dying with dementia, thus contributing to the way a person becomes a ‘person with dementia’ in the first instance. We did not find empirical data to corroborate this theory.

Figure 8 provides an overarching programme theory that depicts the relationship between each of the 5 subsections. Links represented by a dashed line represent unsubstantiated theory. The multiple contexts explored through the results section are situated in our programme theory under the umbrella terms; ‘liminal state –figure 2’; relevant decision making – figure 3 and 4; caregiving – figure 6; progressive illness – figure 7.

**Table 5:** CMO configurations with supporting evidence for transitioning to the 4<sup>th</sup> age

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
CMO: Where there is a public failure of self-management (C), a person enters the 4 <sup>th</sup> age (O) via mechanisms including institutionalisation (M), ignominy (M) routinisation of care (M).	<p><b>Public failure of self-management:</b> reflections from a paid carer, “Not being able to take responsibility, not knowing that things (food) are mouldy or at the expiration date. Not knowing when you need to clean up (the house) and also not knowing how to perform certain actions.”<sup>70</sup></p> <p><b>Ignominy and routineisation:</b> “this condition was devastating to watch, to [wife’s name] who was always rather coy, shy about the activities of bodily functions, to have her more or less on a timeslot and put into a machine, ‘cos they’d had lunch, lifted up and wheeled into the toilet – that was very devastating . . . I didn’t like to see her suffering these sorts of indignities.”<sup>59</sup></p> <p>“She passes stool and handles the faecal matter. Makes a mess and this then cannot be cleaned. The whole household stinks. There is smell of faeces always. Nobody will help. Even my husband, that is her own brother, does not want to be at home. He cannot stand the bad smell.”<sup>111</sup></p>
CMO: Where communities of identity exist (C), people with dementia are seen to go about their business, their growth and development is then visually acknowledged so people develop an understanding of their needs	<p><b>Communities of identity:</b> ...where people living with dementia are normalized not only in terms of their day care activity—by not being treated as passive consumers of ‘treatments’ or ‘services’ but as active agents of their own preferences and activities—but also as people to be publicly seen going about their usual business. Furthermore, people not directly involved with care for people living with dementia are encouraged to participate in that care and to obtain basic understandings of both the challenges of living with dementia and also the challenges in its daily care. Thus the levels of</p>

and daily challenges. Through compassion (M) this may aid community development (O)

*public education about living with dementia and its care are significantly raised....*<sup>55</sup>

## DISCUSSION

### Summary of findings

This realist review of 118 studies has begun to uncover the complex relationships involved in the end-of-life journey. We have shown that human relationships, at an interpersonal, community and professional level, help shape decision making thus bringing about change through key transitional states. Importantly these relationships have the power to dictate outcomes yet their influence is not uniformly positive.

The review acknowledges the importance of the multiple contexts within which end-of-life care is played out. In doing so we do not aim to produce evidence about the relative advantages or disadvantages of interventions that improve end-of-life care. We instead argue that the complexity inherent in the process requires in-depth understanding and multifaceted solutions. By exploring the underlying mechanisms that occur within certain contexts, we have developed a provisional theory that may act as a starting point on which to build, whilst helping public health interventions to be tailored more effectively.

### Comparisons with existing literature

Despite a growing evidence base on the role of social networks and social capital in healthcare there is still significant emphasis on professionally enacted interventions.<sup>48 99 100</sup>  
<sup>112</sup> This emphasis is underpinned by a culture that seeks immediately recognizable outcomes of mutual benefit to care receivers and providers. We found that where care is disjointed from how it has evolved in the home, it is less likely to bring meaningful results or be valued by those involved in the day-to-day care of a person with dementia.

A public health approach to palliative care promotes the development of communities that share responsibility for the care of the terminally ill and the bereaved.<sup>55</sup> Dementia however is an illness like no other, the cognitive changes can outstrip the physical leading to a rapid dissolution of social capital on which this theory is dependent. In addition, the public discourse and fear that surrounds dementia, reinforces the polarized view that caring for

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3 these people is primarily the responsibility of immediate family or of health and social care  
4 services.  
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7 Our results suggest that as people affected by dementia take a more active role in society,  
8 there is potential for growth and change to the broader sociopolitical dynamic and  
9 structures that influence public perception of dementia. Whilst the individuals' social  
10 networks may dwindle, there is potential for community growth through the transference  
11 of skills acquired. This concept is recognized by Bartlett's social citizenship theory and its  
12 implications for social and health care practices.<sup>5</sup>  
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### 18 **Recommendations for policy and practice**

#### 19 (i) Making death, dying and dementia everyone's business

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21 Our findings stress the importance of human relationships across a range of interlinking  
22 networks that impact on care outcomes. Given this, it would not be adequate to implement  
23 interventions that target one specific group (lay or professional). Rather a cultural shift is  
24 required across wider societal and organisational practices that contribute to notions of  
25 responsibility and duty of care.  
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#### 32 (ii) Promote the message that health and illness can and do co-exist

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34 We found numerous anecdotes of joy within the literature. Joy involved in the caregiving  
35 process, joy felt at life events experienced by people living with dementia. Acknowledging  
36 that life continues as illness progresses is key to engaging people from all backgrounds in  
37 the care process.  
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#### 43 (iii) Create a platform for mutual knowledge exchange between professionals, people 44 with dementia and lay members of their care network

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46 We found that where care is provided in a routine, top down manner, irrespective of a  
47 person's evolving identity and the knowledge and expertise held by their care network, the  
48 process becomes fraught with conflict. In order to harness the therapeutic potential of  
49 caring relationships we should instead foster an environment of mutual knowledge  
50 exchange whilst appreciating that limitations exist on either side of the professional - lay  
51 divide.  
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3 (iv) Acknowledge and value the skills developed through caregiving as tools for  
4 community development  
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7 We found that people develop a unique skill set through caregiving in certain contexts there  
8 is potential for the transference of these skills to the community. This may aid community  
9 development thus contributing to the wider cultural shift outlined in (i).  
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### 13 **Strengths and limitations**

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15 This review has been conducted in accordance with the methodological guidance for realist  
16 reviews as described in the RAMESES quality standards.<sup>31</sup> The use of a broad search strategy  
17 was particularly helpful when evaluating an often ambiguous term such as social capital. The  
18 iterative nature of both the search and analysis has allowed us to contextualize our  
19 definition of social capital. Realist methodology has also allowed us to focus on how  
20 contexts influence the variety of outcomes seen in end-of-life care. By identifying generative  
21 mechanisms we hope to have articulated findings that are relevant across a range of  
22 settings.  
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31 Naturally our findings are limited by the quality, breadth and specificity of available  
32 literature. We found social networks were often studied from a narrow perspective and  
33 defined as a set of dyadic relationships rather than communities of individuals. Social  
34 networks were often examined from professionally centered perspectives meaning they  
35 were used as a metaphor for 'lay' or 'informal' caring. Social networks therefore became  
36 synonymous with a rather generic approach (e.g. partner, family or friends) which were  
37 rarely differentiated or compared. End points were frequently studied from a medical  
38 perspective (e.g. hospital admission, nursing home transfer) leading to the assumption that  
39 medically defined priorities match those of the individual and their care network. The lack of  
40 empirical evidence suggests that whilst human relationships can be demonstrated to impact  
41 on care trajectories, the specific functions and their relationships with specific community  
42 or network structures could not be explored in any detail.  
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53 In using a systematic realist approach we hope that our programme theory can be applied  
54 across a range of populations. At the same time we recognize that inferences drawn from  
55 the data are subject to the lead researcher's perspective. Reflexivity is key in conducting  
56 such work and therefore the context and personal assumptions of the main researcher were  
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3 considered when reviewing references. Regular review of the emerging programme theory  
4 within the research team was also helpful in addressing this. We did not have a lay person  
5 affected by dementia to review gaps and inconsistencies with CMOCs. This combined with  
6 gaps in the empirical data mean our programme theory is likely to need modification as our  
7 knowledge of the topic expands.  
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## 12 **CONCLUSIONS**

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15 Comparatively few interventions and or end-of-life policies are designed to address the  
16 complexities highlighted by the multiple contexts and mechanisms identified in this review.  
17 As a public health approach to palliative care gathers pace it is important that 'community'  
18 or 'social capital' is not viewed as a universal solution to the mounting public health crisis.  
19 This study highlights the need to take a more dispassionate approach, studying its potential  
20 in all its complexity in order to further understand what works for whom and in what  
21 circumstances.  
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32

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36

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40

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43 **Data availability statement:** All additional data available via the supplementary file  
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45

## 46 **Figure legends**

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48 **Figure 1:** PRISMA diagram  
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50 **Figure 2: Context–mechanism–outcome configuration for 'transition to a post liminal state':** Rectangular  
51 node = context; Grey node = mechanism; Double border node = outcome; Broken line = Maps CMO to the  
52 relevant context where a mechanism produces multiple outcomes

53 **Figure 3: Context–mechanism–outcome configuration for decision making from the perspective of a person  
54 with dementia:** Rectangular node = context; Grey node = mechanism; Double border node = outcome; Broken  
55 line = Maps CMO to the relevant context where a mechanism produces multiple outcomes

56 **Figure 3: Context–mechanism–outcome configuration for decision making from the perspective of a person  
57 with dementia:** Rectangular node = context; Grey node = mechanism; Double border node = outcome; Broken  
58 line = Maps CMO to the relevant context where a mechanism produces multiple outcomes  
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3 **Figure 4: Context–mechanism–outcome configuration for decision making from the perspective of the**  
4 **caregiver:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

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6 **Figure 5: Context–mechanism–outcome configuration for ‘transitions in the care environment’:** Rectangular  
7 node = context; Grey node = mechanism; Double border node = outcome

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9 **Figure 6: Context–mechanism–outcome configuration for the ‘caregiver’s experience’;** Rectangular node =  
10 context; Grey node = mechanism; Double border node = outcome; Broken line = Maps CMO to the relevant  
11 context where a mechanism produces multiple outcomes

12 **Figure 7: Context–mechanism–outcome configuration for dementia progression & transitioning to the 4<sup>th</sup>**  
13 **age;** Rectangular node = context; Grey node = mechanism; Double border node = outcome

14 **Figure 8: Overarching programme theory:** Rectangle = outcome; Rounded edge rectangle = context; Broken  
15 border = umbrella term for multiple contexts identified in corresponding figure; Arrow = signifies CMO  
16 configuration; Broken Arrow = unsubstantiated theory without supplementary CMO data  
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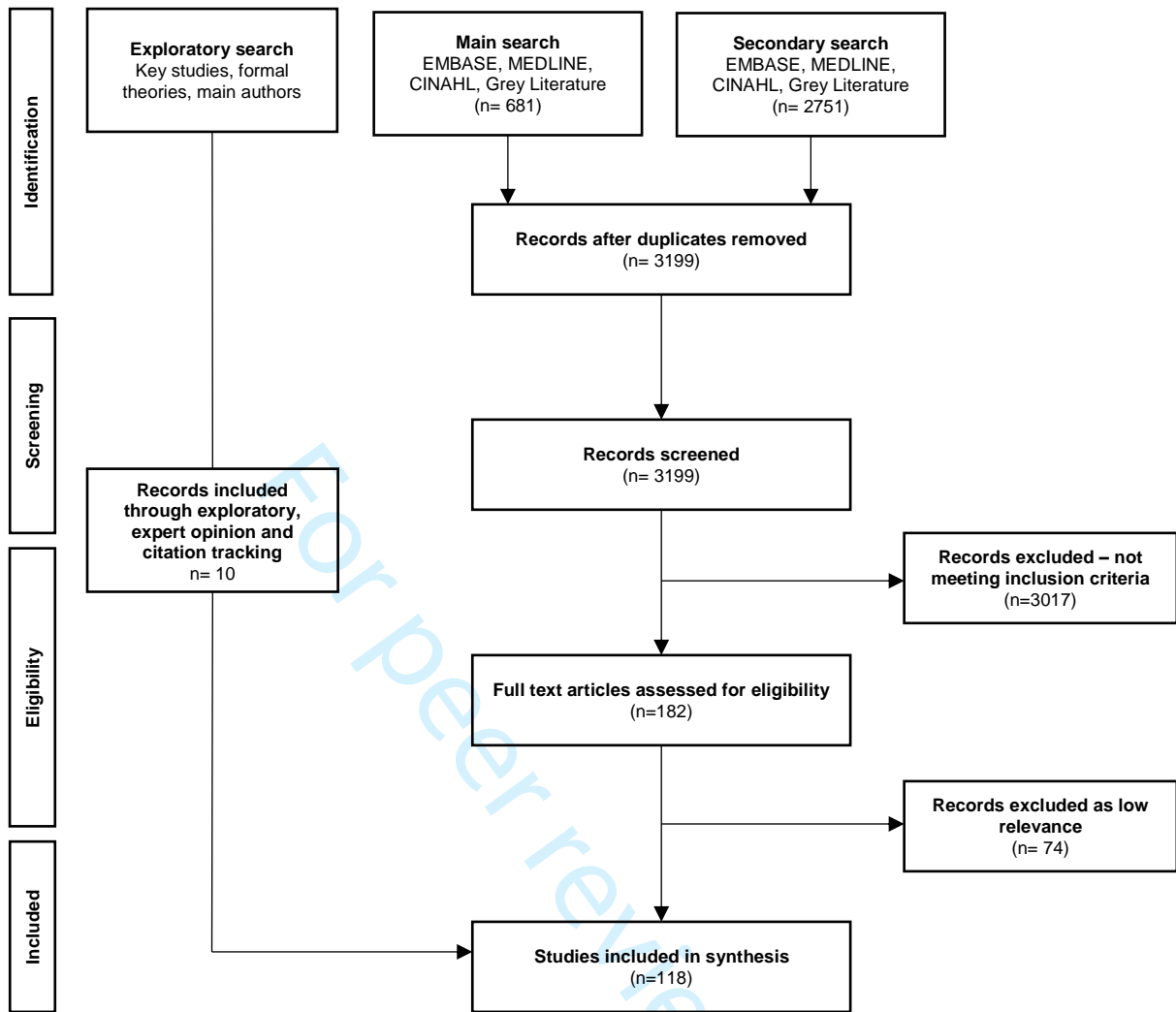
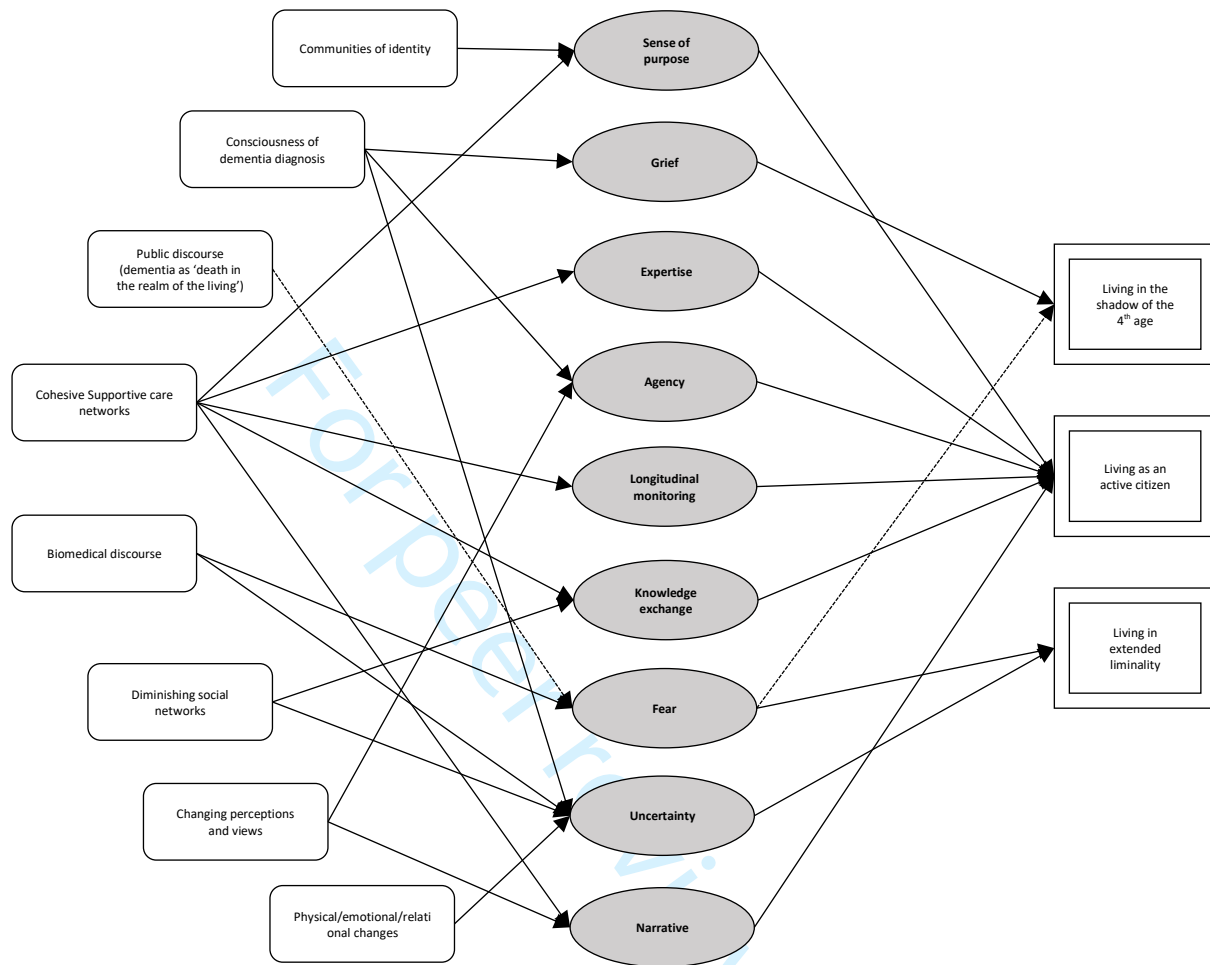
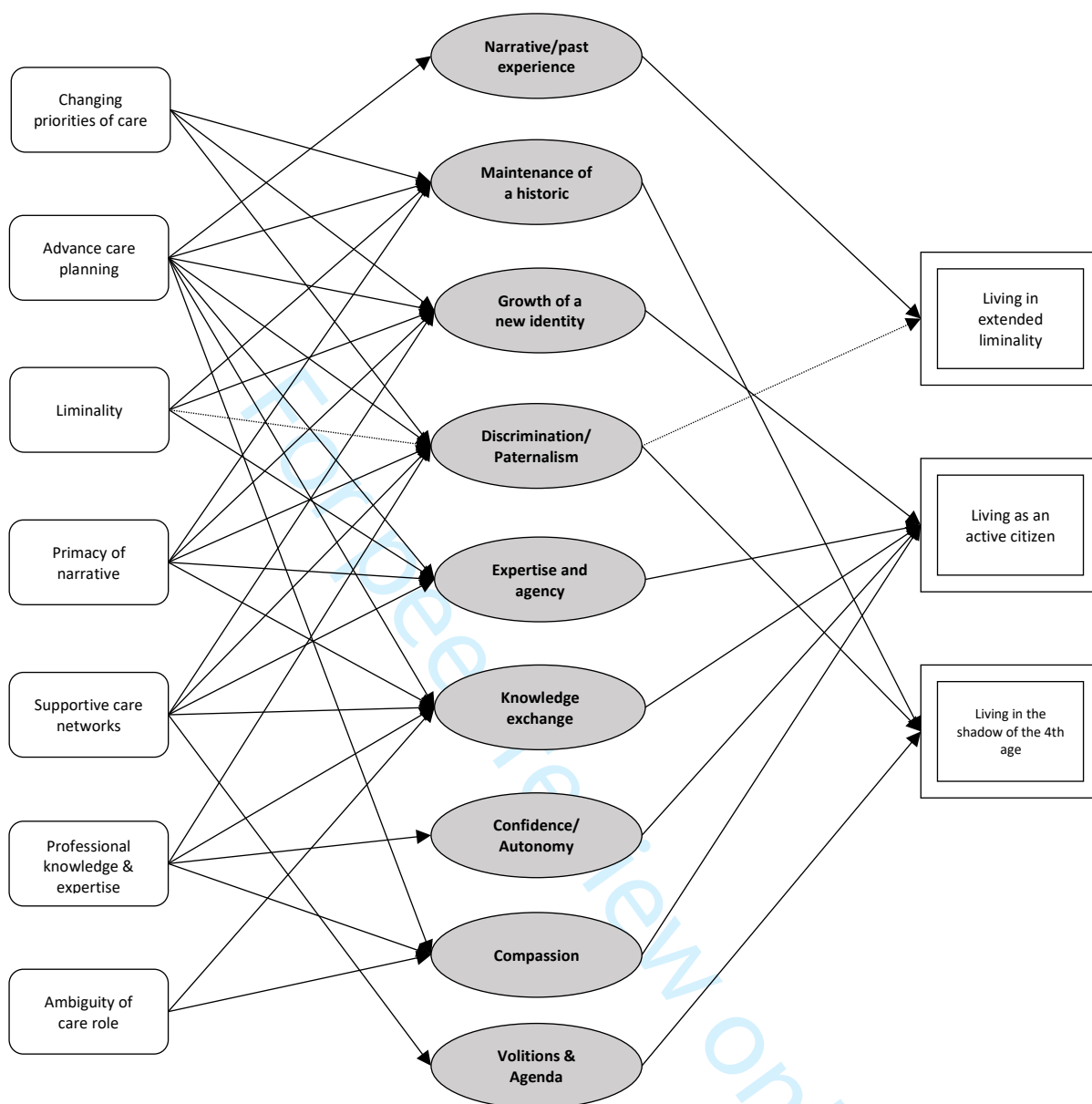


Figure 1: PRISMA diagram



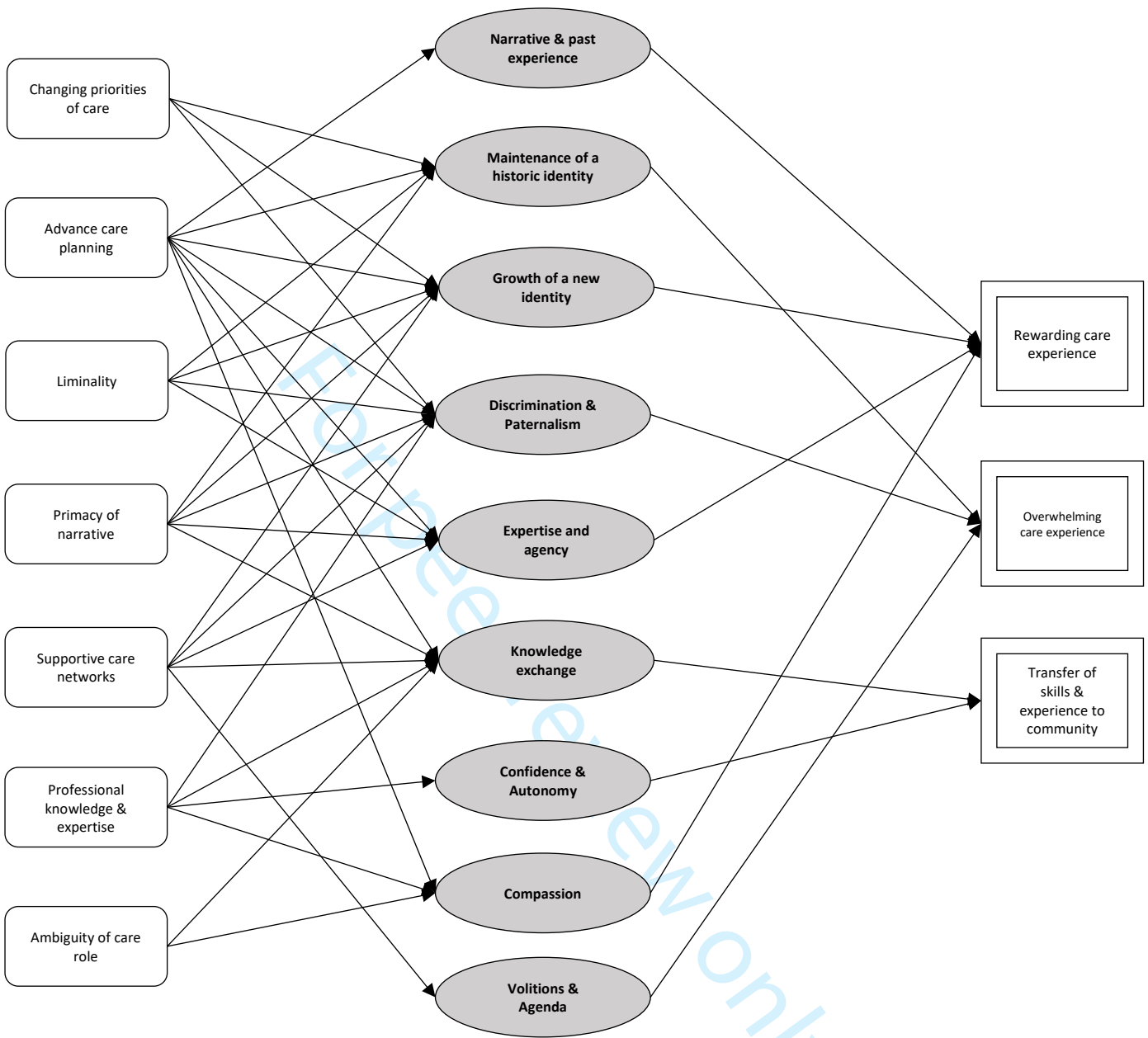


**Figure 2: Context–mechanism–outcome configuration for “transition to a post liminal state”:**  
 Rectangular node = context; Grey node = mechanism; Double border node = outcome; Broken line = Maps CMO to the relevant context where a mechanism produces multiple outcomes

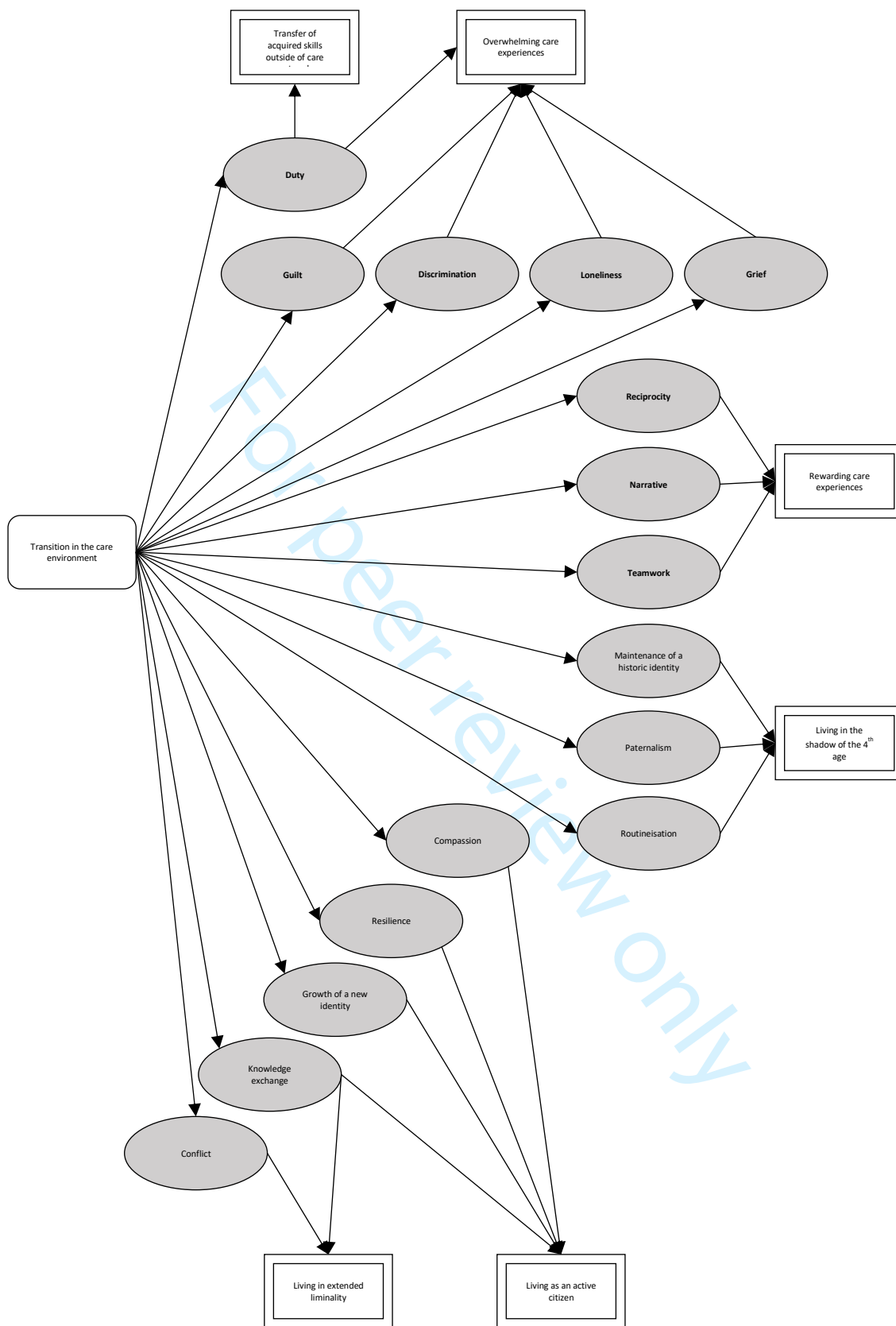


**Figure 3: Context–mechanism–outcome configuration for decision making from the perspective of a person with dementia:** Rectangular node = context; Grey node = mechanism; Double border node = outcome; Broken line = Maps CMO to the relevant context where a mechanism produces multiple outcomes

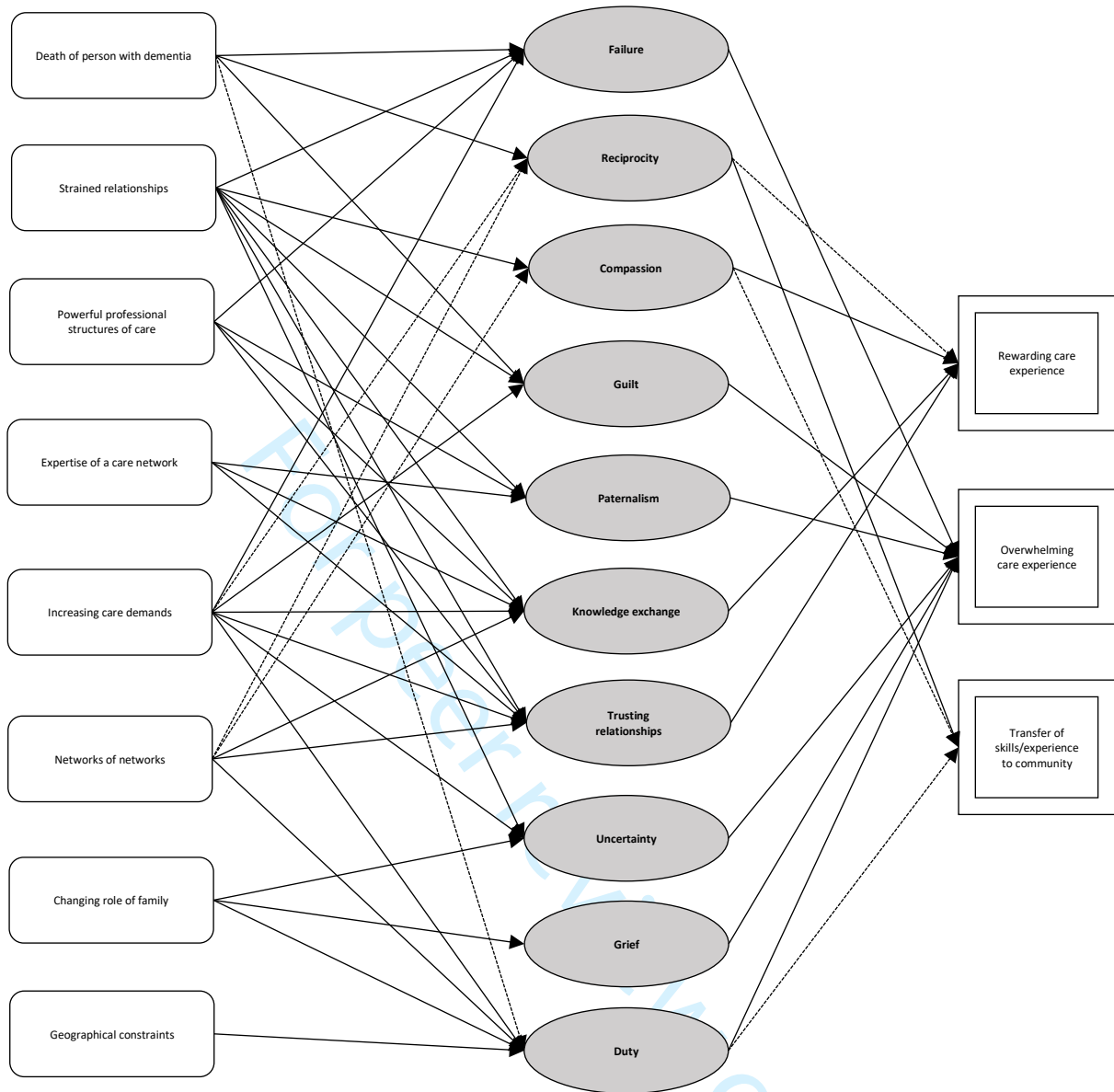
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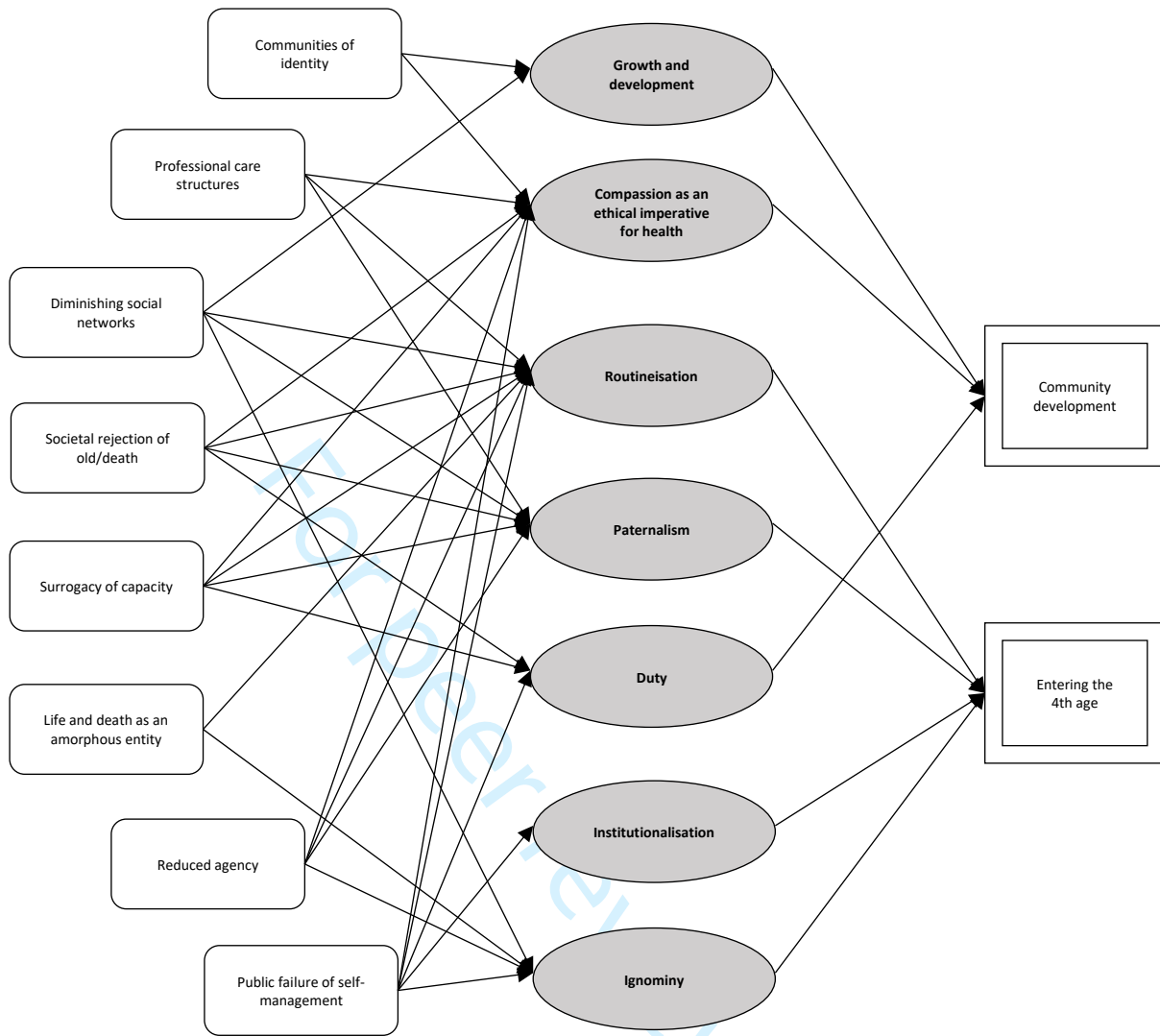
**Figure 4: Context–mechanism–outcome configuration for decision making from the perspective of the caregiver:** Rectangular node = context; Grey node = mechanism; Double border node = outcome



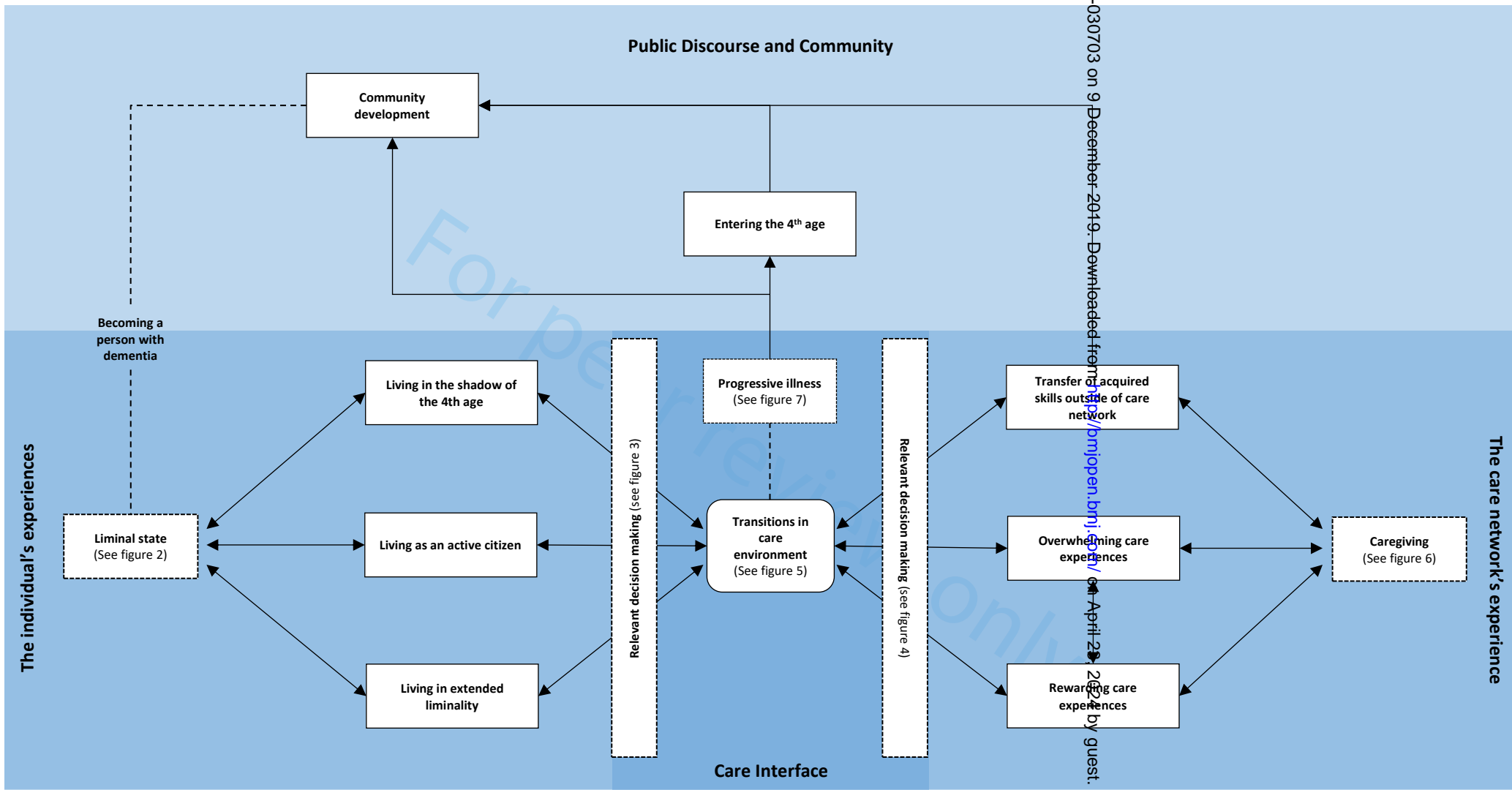
**Figure 5: Context–mechanism–outcome configuration for “transitions in the care environment”:**  
 Rectangular node = context; Grey node = mechanism; Double border node = outcome



**Figure 6: Context-mechanism-outcome configuration for the 'caregiver's experience';** Rectangular node = context; Grey node = mechanism; Double border node = outcome; Broken line = Maps CMO to the relevant context where a mechanism produces multiple outcomes



**Figure 7: Context–mechanism–outcome configuration for dementia progression & transitioning to the 4<sup>th</sup> age; Rectangular node = context; Grey node = mechanism; Double border node = outcome**



**Figure 8: Overarching programme theory:** Rectangle = outcome; Rounded edge rectangle = context; Broken border = umbrella term for multiple contexts identified in corresponding figure; Arrow = signifies CMO configuration; Broken Arrow = unsubstantiated theory without supplementary CMO data

## Supplementary data

### Part 1 - Glossary

Inductive analysis: Inductive analysis refers to an approach to reading raw data to derive concepts or themes through interpretations made from the raw data by the researcher

Deductive analysis: Deductive analysis refers to data analyses that tests whether data are consistent with prior assumptions or theories constructed by the researcher

Contexts: settings, structures, environments, public discourse, conditions or circumstances that trigger behavioural and emotional responses (i.e. mechanisms) for those affected.

Mechanisms: the way in which individuals respond to and reason about the resources, opportunities or challenges offered by a particular process. Mechanisms are triggered in specific contexts and lead to changes in behaviour.

Outcomes: impacts or behaviours resulting from the interaction between mechanisms and contexts.

Context-Mechanism-Outcome Configurations (CMOCs): relationships between the building blocks of realist analysis, i.e. how mechanisms are triggered under specific contexts to result in particular outcomes.

Programme theory: a set of theoretical explanations or assumptions about how a particular, process is might be expected to work

Social capital: the influence of human relationships that exist through the caregiving process and within social structures such as healthcare, community and 'the home'. How these relationships are introduced or excluded from an evolving network of care and how this appeared to influence outcomes at a series of key decision points.

Primary care network: Members of lay people who are involved in the day to day care and decision making for a person with dementia

### Part 2 - Search strategies

#### Exploratory search

**Example keywords in different arrangements:** Dementia, Alzheimer's disease, multi-infarct dementia, vascular dementia, cognitive impairment, social capital, community networks, community care, end-of-life care, palliative care, systematic reviews.



**Example author based searches:** Allan Kellehear, Alejandro Portes, Pierre Bourdieu, Ruth Bartlett, Deborah O'Connor, James Coleman, Robert David Putnam

### Main search strategy

Database: EMBASE

Host: Ovid

Date searched 15/12/2017, updated 4/12/18

Searcher: JS

Hits 399 when limited to the English language

Strategy:

1. Exp dementia/ OR dementia.mp OR exp alzheimers disease/ OR alzheimers.mp OR exp multi-infarct demnientia/ OR mult-infarct dementia.mp OR vascular dementia.mp  
AND
2. Exp Social capital/ OR social capital.mp OR exp social network/ OR social network.mp OR exp Social support/ OR social support.mp OR community development.mp OR exp community care/ OR community care.mp OR exp community participation OR community participation.mp. OR exp family relation/ OR family relati\*.mp OR social integration.m  
AND
3. Exp Palliative therapy/ OR exp terminal care/ OR terminal care.mp OR palliative care.mp OR end-of-life.mp OR exp Death/ OR death.mp OR dying.mp Or end-of-life.mp

Database: MEDLINE

Host: Ovid

Date searched 15/12/2017, updated 4/12/18

Searcher: JS

Hits 198 when limited to the English language

Strategy:

1. Exp dementia OR Dementia.mp OR exp vascular dementia or vascular dementia.mp OR exp multiinfarct dementia OR multi-infarct dementia.mp OR exp Alzheimer's disease or Alzheimer's disease.mp  
AND
2. Exp Social capital/ OR social capital.mp OR exp social network/ OR social network.mp OR exp Social support/ OR social support.mp OR community

development.mp OR exp community care/ OR community care.mp OR exp  
 community participation OR community participation.mp. OR exp family relation/  
 OR family relati\*.mp OR social integration.mp  
 AND

3. Exp Palliative therapy/ OR exp terminal care/ OR terminal care.mp OR palliative  
 care.mp OR end-of-life.mp OR exp Death/ OR death.mp OR dying.mp Or end-of-  
 life.mp

Database: CINAHL

Date searched 15/12/2017, updated 4/12/18

Searcher: JS

1. Exp dementia vascular dementia, senile dementia, alzheimers disease, vascular  
 dementia, ulti-infarct dementia  
 AND
2. Social captital, social networks, social network analysis, community development,  
 communities, community care, community networks, MH "Community Networks")  
 OR (MH "Communities") OR "community care", community participation, family  
 relationships, patient-family relations  
 AND
3. Palliative care OR terminal care OR end-of-life care OR dying or dying process or  
 terminally ill patients OIR terminally ill patients OR dying process OR dying care

Hits 91 when limited to the English language

Total of 681 – 138 duplicates = 583 papers

### Secondary search strategy

1. Dementia OR dementia, vascular OR dementia, multi infarct OR alzheimer disease OR  
 dementia, lewy body OR tauopathies  
 AND
2. social support OR care networks, community OR loneliness OR family relationships  
 OR friendships OR loneliness OR social support OR social isolation OR social  
 participation OR social engagement OR social disengagement OR social integration  
 OR personal network\* OR social network\* OR social relation\* OR social capital OR  
 social contact OR social embeddedness OR family relation\*

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5 3. Discharge OR transfer OR exit OR move OR transition OR admission OR placement  
6  
7 OR long term care OR nursing home  
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9 **Part 3 - Characteristics of the studies included in the review**

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11 Table 1: Study characteristics main search (n=74)

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13 Table 2: Study characteristics additional search (n=34)

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15 Table 3: Study characteristics of papers identified separately (n=10)

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17 Table 1: Study characteristics (literature from main search n=74).

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Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Albinsson, L. Strang, P.	2003	Sweden	Research	Open ended question with thematic analysis	Participants in national course on dementia	To investigate what staff working in close contact with patients perceive as good support of families in dementia care as compared with support of families in palliative cancer care.
Angus, Jan Kontos, Pia Dyck, Isabel McKeever, Patricia Poland, Blake	2005	Canada	Research	Ethnography	Home care in 16 homes across urban, rural and remote locations Ontario Canada	To examine the physical, symbolic and experiential aspects of receiving long-term care are examined
Arruda, Elizabeth H. Paun, Olimpia	2017	USA	Research	Integrative review	family caregivers of individuals diagnosed with ADRD who died either at home, in the hospital, or in LTC	To examine and synthesize the evidence on grief and bereavement in Alzheimer's disease and related dementias caregivers

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Ashton, S. E. Roe, B. Jack, B. McClelland, B	2016	UK	Research	Interviews with thematic analysis	12 family caregivers from a specialist dementia unit	To explore the experiences of advance care planning amongst family caregivers of people with advanced dementia.
Ashworth, V. A.	2009	USA	Editorial	NA	End of life care with person with dementia	Reflecting on the use of compassion at the end of life in someone with dementia
Bartlett, Ruth O'Connor, Deborah	2010	UK	Book chapter	NA	People with dementia and their role in society	To broaden the debate on how people with dementia are viewed in society
Belle, S. H. Burgio, L. Burns, R. Coon, D. Czaja, S. J. Gallagher-Thompson, D. Etc...	2006	USA	Research	Randomised control trial	Caregivers for people with dementia	To test the effects of a structured multicomponent intervention on quality of life and clinical depression in caregivers and on rates of institutional placement of care recipients in 3 diverse racial or ethnic groups.
Bennett, D. A. Schneider, J. A. Tang, Y. Arnold, S. E. Wilson, R. S.	2006	USA	Research	Longitudinal cohort study	Elderly people with dementia	To measure the effect of social networks in reducing the risk of cognitive impairment in old age
Birchley, G. Jones, K. Huxtable, R. Dixon, J. Kitzinger, J. Clare, L.	2016	UK	Research	Scoping review and thematic synthesis	Frail older people, people with dementia and people with severe traumatic brain injury	Understanding challenges in accessing palliative care

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Birt, L. Poland, F. Csipke, E. Charlesworth, G.	2017	UK	Research	reviewing the role of society and culture in repositioning dementia	People with dementia and their families	To understand dementia through the sociological lens of citizenship
Bokberg, C. Ahlstrom, G. Leino-Kilpi, H. Soto-Martin, M. E. Cabrera, E. Verbeek, H. Saks, K. Stephan, A. Sutcliffe, C. Karlsson, S.	2015	Pan Europe	Research	Descriptive cross country survey	People with dementia and their families	To describe available and utilized formal care and service at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries.
Brannelly, T.	2011	New Zealand	Research	Non-participant observation	People with dementia and their families	To examine the constructed facilitation of participation in care by community mental health nurses and social workers for people with dementia and their families.
Broadly, T. R. Saich, F. Hinton, T.	2018	Australia	Research	Scoping literature review	Family members or friends providing unpaid care to people with dementia	To identify what is known about carers' experiences of providing end-of-life care to a family member or friend with dementia.
Carter, G. McLaughlin, D. Kernohan, W. G. Hudson, P. Clarke, M. Froggatt, K. Passmore, P. Brazil, K.	2018	UK	Research	Descriptive qualitative	Family carers of nursing home residents with advanced dementia	To explore experience and preparedness of family carers in their care giving role as best interest decision makers of a relative with advanced dementia

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Chambaere, K. Cohen, J. Robijn, L. Bailey, S. K. Deliens, L.	2015	Belgium	Research	Survey	People with advanced dementia and their families	To describe the prevalence and characteristics of end-of-life decisions in individuals dying with dementia in Belgium.
Colbert, S.	2003	USA	Editorial	NA	Carer for dementia with Christian faith	To reflect on the care process of a close relative with advanced dementia
Corey, K. L. McCurry, M. K.	2018	USA	Research	Semi structured interviews	Former family caregivers for people with dementia	To examine the health of former family caregivers and describe their experiences following the death of a care recipient with dementia.
D'Astous, V. Abrams, R. Vandrevala, T. Samsi, K. Manthorpe, J.	2017	UK	Research	Systematic review	Homecare workers caring for people with dementia	explores the perspectives and experiences of homecare workers providing care for people with dementia living at home up to the end of life
Edwards, H. B. Ijaz, S. Whiting, P. F. Leach, V. Richards, A. Cullum, S. J. Cheston, R. I. Savovic, J.	2018	UK	Research	Systematic review	People and their families with advanced dementia	To evaluate the association between the quality of relationship between a person with dementia and their family carer and outcomes for the person with dementia.
Elliott, B. A. Gessert, C. E. Peden-McAlpine, C.	2009	USA	Research	Focus groups	Family members of people affected with severe dementia	To describe and understand the ethical thinking used in end-of-life decision-making by family surrogates on behalf of their cognitively impaired elders.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Espino, D. V. Mouton, C. P. Del Aguila, D. Parker, R. W. Lewis, R. M. Miles, T. P.	2001	USA	Research	Case study	Hispanic people with dementia and their caring networks	Understanding unique cultural influences in a cohort of Hispanic people with dementia
Fleming, R. Kelly, F. Stillfried, G.	2015	Australia	Research	Focus groups	Recently bereaved family carers	To explore the views of people with dementia, family carers and professionals on what aspects of the physical environment would be important to support a good quality of life to the very end.
Forbes, D. A. Finkelstein, S. Blake, C. M. Gibson, M. Morgan, D. G. Markle-Reid, M. Culum, I. Thiessen, E.	2012	Canada	Research	Interviews with thematic analysis	Rural dementia care networks	To enable HCPs, care partners, and PWD to use dementia care information more effectively by examining their information needs, how these change over time, and how they access, assess, and apply the knowledge.
Francis, L. P.	2001	USA	Book chapter	NA	Legalities of decision making in dementia	NA
Fredman, L.	2017	USA	Opinion	NA	Reflections from the care journey from a son caring for his father with dementia	Interconnections between a researcher and his experience as a caregiver

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Garner, J.	1997	UK	Research	Case study	Person with dementia and their family	How does the loss of intimacy and mutuality impact on care
Gaugler, J. E. Kane, R. L. Newcomer, R.	2007	USA	Research	Logistic regression	People with dementia moving to care homes	To test resilience as a factor that may contribute to care transitions for people with dementia
Gerritsen, D. Kuin, Y. Steuerink, N.	2004	Netherlands	Research	Semi-structured interviews	Children of parents with dementia	To investigate whether adults with a parent with dementia experience their personal aging differently than adults whose parents do not have dementia.
Gessert, C. E. Elliott, B. A. Peden-McAlpine, C.	2006	USA	Research	Retrospective cohort study	Minnesota and Texas nursing homes – residents with severe dementia	To identify factors associated with the use of selected medical services near the end-of-life
Gilleard, C. Higgs, P.	2010	UK	Opinion	NA	NA	Theorizing the 4 <sup>th</sup> age
Godwin, B. Waters, H.	2009	UK	Research	Non participant observation	Hospital wards, nursing home, residential homes and hospices	To explore the opinions of people with advanced dementia their family and professional carers



Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Goodman, Claire Amador, Sarah Elmore, Natasha Machen, Ina Mathie, Elspeth	2013	UK	Research	Qualitative guided conversation	People with dementia living in a care home	To explore how older people with dementia discuss their priorities and preferences for end-of-life care.
Goodman, C. Froggatt, K. Amador, S. Mathie, E. Mayrhofer, A.	2015	UK	Research	Qualitative	Care home residents with dementia	This paper draws on findings from three studies to develop a framework for understanding the essential dimensions of end of life care delivery in long-term care settings for people with dementia.
Gott, M. Wiles, J. Moeke-Maxwell, T. Black, S. Williams, L. Kerse, N. Trussardi, G	2018	New Zealand	Research	Interviews	People with old age and frailty including those with dementia and their families	To explore the role of community at end of life for people dying in advanced age from the perspective of their bereaved family caregivers.
Hickner, J.	2015	USA	Editorial	NA	NA	Advice on general management for people with dementia
Hurley, A. C. Volicer, L.	2002	USA	Research	Case study	People with advanced dementia	To examine the role of the physician in advancing illness for people with dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Jennings, L. A. Palimaru, A. Corona, M. G. Cagigas, X. E. Ramirez, K. D. Zhao, T. Hays, R. D. Wenger, N. S. Reuben, D. B.	2017	USA	Research	Focus group interviews	People with dementia and their caregivers	To elicit patient-centred goals for dementia care
Jones, P. S. Martinson, I. M.	1992	USA	Research	Interviews	Recently bereaved care givers	To analyse the bereavement experience for caregivers involved with people with dementia
Jotkowitz, A. Clarfield, A. Glick, S.	2005	Israel	Editorial	NA	A modern Jewish ethical perspective	To describe a Jewish ethical approach to care for people with dementia
Kaldjian, L. C. Shinkunas, L. A. Bern-Klug, M. Schultz, S. K.	2010	USA	Research	In depth interviews	Surrogate decision makers for people with dementia	To increase our knowledge about surrogates' understanding and articulation of goals of care, as well as the foundational beliefs and ethical values that may underlie their goals
Kellehear, A.	2013	Australia	Overview	NA	NA	To theorize a public health approach to end of life care
Laakkonen, M. L. Pitkala, K.	2009	Finland	Editorial	NA	NA	To outline ethical constructs to help facilitate the care of people with dementia
Large, S. Slinger, R.	2015	UK	Research	Qualitative synthesis	Grief in caregivers of people with Alzheimer's disease	To provide a detailed and contextualised account of caregiver grief when caring for someone with AD or related dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Lewin, T.	1996	USA	Newspaper article	NA	Parent with advanced dementia and loss of capacity	To describe the fraught decision making process that can occur in the advanced stages of dementia
Lawrence, V. Samsi, K. Murray, J. Harari, D. Banerjee, S.	2011	UK	Research	In depth interviews	Bereaved family carers and health care professionals recruited from care homes, the community and hospitals	To define good end-of-life care for people with dementia and identify how it can be delivered across a range of care settings in the UK
Lindsay, S.	2010	Australia	Research	Case study	Rural community in New South Wales	Identify how to support carers and people with dementia in their own home
Livingston, G. Leavey, G. Manela, M. Livingston, D. Rait, G. Sampson, E. Bavishi, S. Shahriyarmolki, K. Cooper, C.	2010	UK	Research	Focus group and individual interviews	Community settings in London UK	To identify common difficult decisions made by family carers on behalf of people with dementia, and facilitators of and barriers to such decisions, in order to produce information for family carers about overcoming barriers.
Lombardo, S.	2003	USA	Comment	NA	Care home in USA	To describe the potential positive aspects to caregiving for people with dementia
Macdonald, G.	2018	Australia	Comment	NA	Dementia care in Australia	To analyse how to end one's life well with dementia, a social commentary

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Masuchi, Y. Jylha, M. Raitanen, J. Aaltonen, M.	2018	Finland	Research	Logistic regression	All people who had died with dementia aged >70	To determine how place of death has changed in Finland
McCleary, L. Thompson, G. N. Venturato, L. Wickson-Griffiths, A. Hunter, P. Sussman, T. Kaasalainen, S.	2018	Canada	Research	Focus group interviews	Family and staff experiences of end of life care for people with dementia	To explore understanding of staff and family experiences of dying and bereavement in long term care
Michael, N. O'Callaghan, C. Sayers, E.	2017	Australia	Research	Focus group interviews	Older people and their offspring in Australian city and rural setting	To examine the awareness, attitudes, and experiences of advance care planning amongst older people and unrelated offspring/caregivers of older people residing in the community
Mitchell, S. L. Morris, J. N. Park, P. S. Fries, B. E.	2004	USA	Research	Retrospective cohort study.	Persons 65 years or older with advanced dementia who died within 1 year of admission to a nursing home	To describe and compare the end-of-life experience of persons dying with advanced dementia in the nursing home and home care settings.
Mogan, C. Lloyd-Williams, M. Harrison Denning, K. Dowrick, C.	2018	UK	Research	Narrative synthesis of mixed methods data	End of life care for people with dementia	To identify and understand the challenges and facilitators of providing end-of-life care at home for people with dementia.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Monroe, B. Hansford, P.	2010	UK	Editorial/ review	NA	Specialist palliative care at home	To describe a model of specialist palliative care at home and the challenges and opportunities it presents
Mullard, A.	2015	UK	Editorial	NA	NA	Review of a film and its influence on the public discourse that shapes opinion on dementia
Obisesan, T. O. Gillum, R. F.	2009	USA	Research	Longitudinal follow up	Older people some with diagnosis of dementia	To determine whether social integration and cognitive function are independently associated with subsequent mortality
Pecanac, K. E. Wyman, M. Kind, A. J. H. Voils, C. I.	2018	USA	Research	Scoping review	Treatment decision making in the acute care setting	To summarize the evidence regarding the factors and processes of treatment decision making involving a person with dementia (PWD) in the acute care setting.
Petriwskyj, A. Parker, D. Robinson, A. Gibson, A. Andrews, S. Banks, S.	2013	Australia	Research	Review	People with dementia in residential care	to identify and appraise the existing quantitative evidence about family involvement in decision making for people with dementia living in residential aged care
Powell, T. Powell, Tia	2011	USA	Editorial	NA	Reflections on caring for a parent with dementia	To describe the decision making process for people and their families with advanced dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Rodriguez, G. De Leo, C. Girtler, N. Vitali, P. Grossi, E. Nobili, F.	2003	Italy	Research	Survey	All primary caregivers of 120 patients with a diagnosis of AD	To examine stress levels amongst carers for people with dementia
Rosenwax, L. Spilsbury, K. Arendts, G. McNamara, B. Semmens, J.	2015	Australia	Research	Retrospective population based cohort study	Western Australia, people with dementia who had died within a 2 year window	To describe patterns in the use of hospital emergency departments in the last year of life by people who died with dementia and whether this was modified by use of community-based palliative care.
Russell, C. Middleton, H. Shanley, C.	2008	Australia	Research	In depth semi-structured interviews	Australia New South Wales	To document the views of family caregivers of persons with dementia about quality of life for their relative during the late and terminal stages of the disease.
Saini, G. Sampson, E. L. Davis, S. Kupeli, N. Harrington, J. Leavey, G. Nazareth, I. Jones, L. Moore, K. J.	2016	UK	Research	Ethnography	Nursing home residents with dementia	To examine practices relating to end-of-life discussions with family members of people with advanced dementia residing in nursing homes and to explore strategies for improving practice.
Shaji, K. S. Smitha, K. Praveen Lal, K. Prince, M. J.	2003	India	Research	Qualitative study	Caregivers for people with dementia in south India	To understand care arrangements for people with dementia and strain experienced by the family
Shanley, C Fetherstonhaugh, D McAuliffe, L Bauer, M Beattie, E	2017	Australia	Research	Semi-structured interviews	Carers in Victoria Australia	To learn from surrogate decision-makers for PWD can be most effectively supported in this role

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Shanley, C Russell, C Middleton, H Simpson-Young, V	2011	Australia	Research	In-depth interviews	Family carers for PWD	To understand the experiences and needs of family carers of people with end-stage dementia
Sundquist, J. Hamano, T. Li, X. Kawakami, N. Shiwaku, K. Sundquist, K.	2014	Sweden	Research	Cohort study	Swedish men and women	To see if there is an association between linking social capital and drug prescription (including anti-dementia drugs)
Thompson, G. N. Roger, K.	2014	Canada	Research	Review	Dementia family caregivers	To describe the domains of dementia friendly caregivers needs and their impact on the delivery of palliative care services.
Collins, Clare Liken, Michelle King, Sharon Kokinakis, Candance	1993	USA	Research	Interviews	Family caregivers of relatives with dementia	To describes family caregiver perceptions of the experience of loss and grief as it occurs prior to and following the death of a relative with dementia
Van Der Steen, J. T. Van Soest-Poortvliet, M. C. Onwuteaka-Philipsen, B. D. Deliens, L. De Boer, M. E. Van Den Block, L. Hertogh, C. M. P. M. De Vet, H. C. W.	2014	Netherlands	Research	Systematic review	Factors related to initiation of ACP defined as starting a discussion, starting the decision making, or having a documented patient-written advance directive.	To identify factors associated with initiation of advance care planning (ACP) regarding end-of-life issues in dementia.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Vlachogianni, A. Efthymiou, A. Potamianou, D. Sakka, P. Orgeta, V.	2016	Greece	Research	In depth interviews	Carers taking part were recruited from a day care centre, providing specialist services to people with dementia.	To explore the key psychological changes associated with carers' adjustment to bereavement and "life after care."
You, E. C. Dunt, D. R. White, V. Vander Hoorn, S. Doyle, C.	2014	Australia	Research	Survey	Community-dwelling older people living with dementia in Australia	To determine risk factors for time to death or hospital admission (combined)



Table 2: Study characteristics (literature from additional search n=34).

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Afram, Basema Verbeek, Hilde Bleijlevens, Michel H. C. Challis, David Leino-Kilpi, et al	2015	USA	Research	Cohort study with qualitative data	Informal caregivers of people with dementia who made a transition to institutional long-term care.	To investigate agreement between expected reasons and actual reasons for admission of people with dementia according to informal caregivers
Amuah, J. Maxwell, C. Cepoiu-Martin, M. Soo, A. Gruneir, A. Et al.	2012	Canada	Research	Interviews with family caregivers at 1 year intervals	Older adults with dementia residing in Designated Assisted Living	To identify resident- and facility- level predictors of (first-event) hospitalization over 1-year
Armstrong, M.	2000	UK	Research	Semi-structured interviews	Carers of relatives with dementia before and after placement into residential care	To find out the reasons why carers might decide that they could not continue caring for a relative with dementia at home
Banerjee, S. Murray, J. Foley, B. Atkins, L. Schneider, J. Mann, A. Banerjee, S. Murray, J. Foley, B. Atkins, L. Schneider, J. Mann, A.	2003	UK	Research	Longitudinal cohort study	People with dementia under old age psychiatry in London	To identify what patient and carer characteristics influence transition into residential care for people with dementia.
Bloomer, M. Digby, R. Tan, H. Crawford, K. Williams, A.	2016	Australia	Research	In depth interviews	Family caregivers for people with dementia who had been admitted to hospital	To explore the carer's experience when the person he/she cares for is an inpatient in hospital.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Caldwell, Lauren Low, Lee-Fay Brodaty, Henry	2014	Australia	Research	Semi-structured interviews	Caregivers for people with dementia on waiting lists or living in a nursing home	to investigate the decision-making process for placing a person with dementia on a waiting list for a nursing home
Chiu, L. Shyu, W. Liu, Y. Wang, S. Chang, T.	2001	Taiwan	Research	Telephone survey	Primary caregivers in two metropolitan areas of Taiwan	To determine the factors that influence the attitudes of family caregivers of dementia patients toward nursing home placement
Cloutier, D. S. Penning, M. J.	2017	USA	Research	Administrative data triangulated with personal narrative	Women with dementia in British Columbia, Canada	To explore the interplay between personal narratives and quantitative research on the experiences of older women with dementia in long-term care
Coehlo, D. P. Hooker, K. Bowman, S.	2007	USA	Research	multivariate design using a combination of longitudinal and cross-sectional data	Persons diagnosed with dementia and evaluated for behavioural changes	To determine the key variables that affect the occurrence and timing of institutional placement for families caring for an individual with dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Cox, C.	1996	USA	Research	Interviews	Caregivers of dementia patient	To understand factors influencing discharge outcomes of African American and white hospitalized dementia patients
Cox, C. B.	1996	USA	Research	Interviews	Caregivers of hospitalised people with dementia	What factors determine caregiver satisfaction with the discharge plan
Digby, R. Moss, C. Bloomer, M.	2012	Australia	Research	Interviews	Older patients with mild to moderate dementia	To understand the experienced of transfer from acute to subacute care
Ducharme, F. Couture, M. Lamontagne, J.  <b>??Substantive theory???</b>	2012	Canada	Research	Grounded theory	Caregivers of cognitively impaired relatives	To develop a model of the family caregiver decision making process
Fields, N. L. Richardson, V. E. Schuman, D.	2017	USA	Research	Cox regression	People with dementia in assisted living	To determine whether marital status influenced length of stay
Fisher, L. Lieberman, M. A.	1999	USA	Research	Logistic regression	Patients and their families seen during 1993 and 1994 at Alzheimer's and Memory Clinics	To understand characteristics of the multi-generation family that predict nursing home placement

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Gaugler, J. E. Edwards, A. B. Femia, E. E. Zarit, S. H. Stephens, M. P. Townsend, A. Greene, R.	2000	USA	Research	Cox proportional hazard model	Caregivers for people with dementia	To examine the type and amount of family assistance offered to caregivers prior to institutionalization
Gaugler, J. E. Zarit, S. H. Pearlin, L. I.	1999	USA	Research	Repeated measures ANOVA	Family caregivers to people with dementia placed into institutional care	To examine the impact of family conflict and socio-emotional support among caregivers who institutionalize their relative
Giebel, C. Bleijlevens, M. Soto, M. E. Chester, H. Meyer, G. Stephan, A. Et al.	2017	Pan Europe	Research	Cross sectional study with logistic regression	People with dementia at risk of admission to long term care across 8 European countries	To explore associations between carer burden and characteristics of (1) the informal carer, (2) the person with dementia, and (3) the care support network
Hagen, B.	2001	Canada	Research	Qualitative interviews	Family caregivers of elderly family members with dementia	To explore the decision-making process of whether or not to place a family member in a nursing home.
Kao, H. Stuifbergen, A. K.	1999	Taiwan	Research	Semi-structured interviews	Family members caring for people with dementia in Taiwan	To explore the decision making process for families caring for someone with dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Liken, M. A.	2001	USA	Research	Interviews	family caregivers who had moved their relatives with AD to an ALF within the past 6 months	The experience of moving a relative with Alzheimer's disease (AD) to an assisted living facility
Maxwell, C. J. Amuah, J. E. Hogan, D. B. Cepoiu-Martin, M. Gruneir, A. Patten, S. B. Soo, A. Le Clair, K. Wilson, K. Hagen, B. Strain, L. A.	2015	Canada	Research	Interviews and linkage with hospital discharge database	Assisted living residents with dementia and their carers	To determine the incidence of hospitalization over 1 year for dementia residents of assisted living facilities, compared with long-term care facilities
Park, M. Butcher, H. K. Maas, M. L.	2004	Korea	Research	Interviews	Korean family caregivers'	To provide an in-depth description of experiences in making the decision to place a family member with dementia in a long term care
Parke, Belinda Hunter, Kathleen F. Strain, Laurel A. Marck, Patricia Beryl Waugh, Earle H. McClelland, Ashley J.	2013	Canada	Research	Interviews, narrative journal	Community dwelling older adults with dementia in Canadian emergency departments	To understand ED transitional processes relating to people with dementia
Pot, A. M. Deeg, D. J. Knipscheer, C. P.	2001	Netherlands	Research	Logistic regression	Community based caregivers for people with dementia	To understand the role for caregiver characteristics on institutionalisation

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Rozzini, L. Cornali, C. Chilovi, B. V. Ghianda, D. Padovani, A. Trabucchi, M.	2006	Italy	Research	Multivariate logistic regression	People with dementia admitted to a dementia rehab unit in northern Italy.	To identify the patient's and the caregiver's characteristics that influence discharge to a nursing home
Sadak, T. Foster Zdon, S. Ishado, E. Zaslavsky, O. Borson, S.	2017	USA	Research	Semi-structured phone interviews	Family caregivers of people with dementia who experienced a recent hospitalization due to an ambulatory care sensitive condition or fall-related injury	To describe the lived experience of dementia family caregivers whose care recipients had a recent unplanned admission
Sharpp, Tara J. Young, Heather M.	2016	USA	Research	Interviews Comparison of demographic data between groups	Family members of people with dementia and incident reports relating to people with dementia in assisted living	To describe the health care incidents and experiences of residents and their family members who are transferred from assisted living to an emergency department
Shinnichi, Tochimoto Maki, Kitamura Shoryoku, Hino Tatsuru, Kitamura	2015	Japan	Research	Multiple logistic regression analysis	People with dementia admitted to hospital for behavioural and psychological symptoms	To identify predictors of home discharge
Singh, Prabhjot Hussain, Rafat Khan, Adeel Irwin, Lyn Foskey, Roslyn	2014	Australia	Research	Interviews	Family caregivers for people with dementia across Australia	To explore the intersection of informal family caregiving and the formal care systems from the perspective of the primary family carers

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Smith, G. E. Kokmen, E. O'Brien, P. C.	2000	USA	Research	Demographic, medical, social, and functional predictors were examined as static and time-dependent risk factors for nursing home placement	People with onset of dementia between 1980 and 1984.	To examine risk factors for nursing home placement in a population-based dementia cohort.
Spruytte, N. Van Audenhove, C. Lammertyn, F.	2001	Belgium	Research	Multiple logistic regression and qualitative interviews	Partners, children and children in law caring for a relative suffering with dementia	To identify risk factors for nursing home placement of cognitive impaired elderly
Stevens, A. Owen, J. Roth, D. Clay, O. Bartolucci, A. Haley, W.	2004	USA	Research	Cox proportional hazard models used to analyse predictors of nursing home placement	Primary family caregiver and an individual with Alzheimer's disease or other progressive dementia	To examine the influence of racial group identification on nursing home placement for individuals with dementia
Thoma-Lurken, T. Bleijlevens, M. Lexis, M. De Witte, L. Hamers, J.	2018	Netherlands	Research	A qualitative explorative study by means of six focus group interviews with	Formal caregivers of community-dwelling people with dementia	To gain insight into problems which directly threaten people with dementias potential to stay at home

Table 3: Study characteristics of papers identified separately (n=10)

Name	Year	Country	Type of paper	Study design/methods	Sample /setting	Objectives
Abel, J Kingston, H Scally, A Hartnoll, J Hannam, G Thomson-Moore, A Kellehear, A	2018	UK	Research	Cohort retrospective study	Rural setting involving people with frailty and cause for concern	To evaluate a population health complex intervention of an enhanced model of primary care and compassionate communities on population health improvement and reduction of emergency admissions to hospital.
Angus, J. Kontos, P. Dyck, I. McKeever, P. Poland, B.	2005	Canada	Research	Ethnography	Home care	To understand the personal significant of home in the context of place of care
Bird-David, Nurit Israeli, Tal	2010	Israel	Research	Ethnography	Institutional care	To address the personhood of patients in a permanent vegetative state (PVS), who fall outside categories of “alive” or “dead” and “subject” or “object.
Bourdieu, Pierre	1986	France	Book	NA	NA	Theoretical outline
Pitkin Derose, Kathryn Varda, Danielle M	2009	Canada	Research	Systematic review	NA	To assess the rigor with which social capital has been empirically applied in research on health care access, a systematic review was conducted
Higgs, P Gilliard, C	2015	UK	Book	NA	NA	Theoretical overview
Kaufman, S. R.	2000	USA	Research	Ethnography	Care home	To address the permanent or persistent comatose condition and the



						institutions and practices that enable this life form to exist.
Kellehear, A	2012	UK	Book	NA	NA	Theoretical outline
Reeves, D Blickem, C Vassilev, I Brooks, H Kennedy, A Richardson, G Rogers, A	2014	UK	Research	Longitudinal study	People with chronic long term conditions	To determine how the social networks of people with long-term conditions (diabetes and heart disease) are associated with health-related outcomes and changes in outcomes over time.
Vassilev, I. Rogers, A. Sanders, C. Kennedy, A. Blickem, C. Protheroe, J. Bower, P. Kirk, S. Chew-Graham, C. Morris, R.	2011	UK	Research	Realist review	People with chronic long term conditions	To explore the theoretical and empirical links between social networks, social capital and the self-care practices associated with chronic illness work and management in the context of people's everyday lives.

#### Part 4 - Analysis and synthesis processes

During the analytic phase we developed and refined the programme theory by drawing on coding that was developed over the data set as a whole. Coding occurred within and outside Excel (e.g. Word document coding reports, pdf documents, and memos) to configure relationships between contexts, mechanisms and outcomes. This entailed asking a series of questions and making judgements about the relevance and rigour of content. The process is outlined below.

Relevance:

- Are the contents of a section of text referring to data that is relevant to the programme theory development?

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3 1. Judgements about trustworthiness and rigour:  
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5 - Is this data sufficiently trustworthy to warrant changing to the programme theory?  
6  
7
- 8 2. Interpretation of meaning:  
9  
10 - If the section of text is relevant and trustworthy, do the contents provide data that  
11 may be interpreted as being context, mechanism or outcome?  
12  
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- 14 3. Interpretations and judgements about Context-Mechanism-Outcome-Configurations:  
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16 - What is the Context-Mechanism-Outcome-Configuration (CMOC) (partial or  
17 complete) for the data?  
18  
19 - Is there data to inform CMOCs contained within this document or other included  
20 documents? If so, which other documents?  
21  
22 - How does this CMOC relate to CMOCs that have already been developed?  
23  
24
- 25 4. Interpretations and judgements about programme theory:  
26  
27 - How does this (full or partial) CMOC relate to the programme theory?  
28  
29 - Within this same document is there data which informs how the CMOC relates to  
30 the programme theory? If not, is there data in other documents? Which ones?  
31  
32 - In light of this CMOC and any supporting data, does the programme theory need to  
33 be changed?  
34  
35  
36

37 The process of evidence synthesis was achieved by the following analytic processes

38  
39 a) Juxtaposition of data sources – comparing and contrasting between data presented in  
40 different articles. For example, where data relating to the decision to move someone with  
41 dementia into long term care in an-depth qualitative source enabled insights into how outcomes  
42 are achieved as described in a quantitative study.  
43  
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45  
46 b) Reconciling ‘contradictory’ or ‘outlying’ data – where outcomes differ in what may seem to  
47 be similar circumstances, further investigation is necessary to find an adequate explanations  
48 for this. This involved a closer consideration of context and what counts as context for different  
49 types of ‘problems’, in order to understand how the mechanisms triggered can explain  
50 differences in outcomes.  
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3 c) Consolidation of sources of evidence – where there are similarities between findings  
4 presented in different sources, a judgment needs to be made about whether these similarities  
5 are adequate to form patterns in the development of CMOCs and programme theory, or whether  
6 there are nuances that need to be highlighted, and to what end.  
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## Part 5 - Full lists of CMOCs developed from the literature with illustrative data

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMOC 1: In the context of people being conscious of their dementia diagnosis (C), people with dementia experience uncertainty (M) that their views will be acknowledged leading to a state of extended liminality (O).</p>	<p><b>Consciousness of diagnosis:</b> <i>‘Knowing that they had dementia affected confidence in expressing opinions, self-esteem and whether they thought their views were worth listening to and if expressed that they would be noted or trusted. Derogatory terms were used, one called herself a “mouldy oldie”, another “going potty” to describe her situation:(1)</i></p> <p><b>Consciousness of diagnosis</b> <i>“Yes oh and I’ve got my. . . What’s it called? See I think you may have picked the wrong person cos I’m going potty, can’t remember everything. . . I don’t like it being like this, but there’s nothing I can [do] about it really, I don’t think.” (1)</i></p> <p><b>Uncertainty:</b> <i>“[I] do feel that it’s a bit of a fiasco when people decide ‘no, no, I want to still have an intervention’ and it’s chaos towards the end. .... It would be very nice to have a very clear treatment and to have everything crystal clear but I don’t think that is ever going to happen...” (2)</i></p> <p><b>Extended liminality</b> <i>“She drew attention to both social and emotional liminal states experienced when people received a diagnosis of dementia, drawing out the sense of uncertainty inherent in liminality. While in her later work Kelly (2010: 7) reports people as ‘learning to live with liminality’, rather than seeing the liminal state as a transitory state on the route to new roles and status. This has resonance with Bruce et al.’s (2014) description of pervasive liminality.”(3)</i></p>
<p>CMOC 2: In the context of people being conscious of their dementia diagnosis (C), people can use ‘Agency’ (M) to maintain their position as an active citizen (O)</p>	<p><b>Agency:</b> <i>“The way agency is exerted—sometimes subversively—by older people who are deemed to lack the ability to formally make decisions has been noted by anthropologists, who document the rebellion against resented authority that manifests in soiling or refusing food [76]. Such a lens seems absent from the literature reviewed, but suggests that mentally incapacitated patients might more realistically be viewed as participants in the decision-making process, exerting influence in a multitude of ways.” (4)</i></p> <p><b>Agency in advanced dementia:</b> <i>“Right after she got into a nursing home they notes she had a lot of difficulty eating. She would push food away or refuse to swallow it. At that time the family discussed goals of care with the physician...”(5)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>“My experience of going into nursing homes is that I will often think that non-verbally someone is indicating to me that they have got pain, but because the person can’t tell the nurse looking after them that they have got pain the nurse doesn’t recognise it.” (6)</i></p> <p><b>The active citizen:</b> <i>The narratives of deficit presented above are countered by narratives from people with dementia articulating and defending positive accounts of living well, engaging in loving relationships, preserving identity and self, and living as recognised citizens in their communities (Bartlett 2014, Beard et al. 2009). (3, 7)</i></p>
<p>CMO 3: In the context of dementia being perceived as ‘death in the realm of the living’ (C), people with dementia and their wider social network experience fear and trepidation (M) that moves people into a state confined by the shadow of the ‘4<sup>th</sup> age’ (O)</p>	<p><b>Death in the realm of the living:</b> <i>“Dementia confronts because it seems to bring death into life, implicitly questioning what life, relationship, and death are about.”(8)</i></p> <p><b>Fear</b> <i>“people with dementia are often thought of as tragic, robbed of life, and having lost their personhood.” (8)</i></p> <p><b>The 4<sup>th</sup> age</b> <i>“It is when people are no longer ‘getting by’, when they are seen as not managing the daily round, when they become third persons in others’ age-based discourse, within others’ rules, that they become subjects of a fourth age” (9)</i></p>
<p>CMO 4: Where cohesive care networks surround a person with dementia (C), the individual has a sense of purpose (M) that enables them to function as an active citizen (O)</p>	<p><i>“[My mother had a steady stream of visitors] ... from the village, from the church, from the Catholic Women’s League which she belonged to. She had a brother and sister-in-law living over there just over the next street. They would pop in and their children would pop in, her ex-daughter in law would pop in. She did have a lot of visitors and a lot of friends. Because she was a very social woman, relatives would drop in or stay, visit or whatever.” (10)</i></p>
<p>CMO 5: In communities of identity (C), people with dementia have a sense of purpose (M) which allows them to grow and maintain a role as an active citizen (O)</p>	<p><b>Communities of identity</b> <i>“This centre provides day care for those living with dementia but instead of playing games or receiving passive entertainment the main program is about the design and production of the mid-day meal. Seniors with dementia are asked to jointly design the meal, then to go out shopping together to buy the ingredients, and then return to help prepare the meals. Shopkeepers are briefed on the program and willingly participate in the program, learning and experiencing the complexities of communicating with seniors with dementia and also Compassionate communities gaining insight into the complexities of their care while sharing this in a small way.” (11)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 6: In a society where concepts of health are shaped by a biomedical discourse great value is placed upon the cognitive faculties (C), the prospect of dementia therefore invokes fear (M) that can paralyse causing people to live in an extended period of liminality (O)</p>	<p><i>“They’re telling her things and she doesn’t understand. He says ‘the doctor’s come in and told me this’ and she says ‘I don’t know what’s going on’”. She said, “They should be telling you”. She said, “My brain’s gone”, which it has. So I think that’s caused more stress, to be honest, because you’re thinking to yourself ‘I’m not being told what’s going on’” (12)</i></p>
<p>CMO 7: As dementia progresses a person may change their perceptions and views on various issues (including death) (C), they maintain their role as an active citizen (O) by conveying these views through their agentic influence (M)</p>	<p><b>Changing perceptions:</b> <i>“Relatives and staff need to be aware that the person’s attitude to death may evolve during their dementia. When a comparison was made between participants’ attitudes to death and those ascribed to them by their family carers, for some people they appeared to have changed.” (13)</i></p> <p><i>“(Husband) had a bit of a health crisis about 12 months ago...when he came out of this acute crisis, he said to me he was afraid people that people would turn off the switch. So there was a complete change of his limited understanding... (now) I don't know whether I'm actually fulfilling his wishes.” (14)</i></p>
<p>CMO 8: As dementia progresses a person may change their perceptions and views on various issues (including death) (C), they maintain their role as an active citizen (O) through the use of narrative which may be stored within social capital (M)</p>	<p><i>“the report suggests that professionals involved in advance care planning should consider both the patient’s past and present interests because their view may change during the course of their illness.” (15)</i></p>
<p>CMO 9 Where cohesive support networks surround a person with dementia (C), they are able to advocate for their perceived wishes through the exchange of knowledge (M). Knowledge or expertise (M) relates to the person with dementia and is accumulated through longitudinal monitoring (M) and conveyed through narrative (M) to help maintain a person’s role as an active citizen (O)</p>	<p><b>Support networks:</b> <i>“support from healthcare professionals, carer resilience and extended social networks, support with medications and symptom management, and appropriate equipment and home adaptations all facilitated dying at home with dementia.” (16)</i></p> <p><b>Expertise:</b> <i>“Especially when you’re the caregiver and you’re used to dealing with the one person and you’re the person they deal with mostly, you start to build a routine and also know when something is off.” (17)</i></p> <p><i>“That they will not really listen to you when you understand the person better than they do. They’re telling her things and she doesn’t understand. She says ‘the doctor’s come in and told me this’ and she says ‘I don’t know what’s going on’”. She said, “They should be telling you”. She said, “My brain’s gone”, which it has. So I think that’s caused more</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p data-bbox="864 196 2045 264"><i>stress, to be honest, because you're thinking to yourself 'I'm not being told what's going on' (12)</i></p> <p data-bbox="864 304 2045 411"><i>"Several of the carers quoted one of the community workers who was involved in local support groups who used to say to them 'I am the professional, you people are the experts!' This was a positive and empowering message that the carers appreciated." (18)</i></p> <p data-bbox="864 451 2045 671"><i>"Results of this study show that informal caregivers are, for the most part, quite able to provide good indications of what will cause admission of PWD to ILTC. When directly asked for the expected reasons for admission, approximately two thirds of the sample was able to identify what will cause the admission of their loved one with dementia, although the degree of accuracy between the expected and actual reasons for admission varied." (19)</i></p> <p data-bbox="864 711 2045 858"><b>Knowledge exchange:</b> <i>"When I get a new client on I get a diagnosis that just gives me dementia, or this client has Alzheimer's with no follow up, no follow through of any information whatsoever. I go in half the time blind as to what level of dementia they have, form that they have, what stage they're in. (6C1-1, HCP) (20)</i></p> <p data-bbox="864 898 2045 967"><i>"With people with dementia it's important to have some kind of continuity' and stressed the value of 'familiarity and to know what that person needs.' (21)</i></p> <p data-bbox="864 1007 2045 1075"><i>"Carers wished that health care professionals would listen to their input more and value their personal history with care recipients." (22)</i></p> <p data-bbox="864 1118 2045 1302"><b>Longitudinal monitoring:</b> <i>"The finding that the care recipient's behaviour change score influenced institutional placement emphasizes the importance of longitudinal monitoring of behavioural changes in persons with dementia and support for caregivers' in coping and adapting to problem behaviours. This is also supported by the caregivers' reports of aggressive behaviour being a factor in choosing institutional care for their relative." (23)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p>“You have to get to know them personally... and obviously as you get to know that person, then I think you can provide that compassionate care because you know what their needs are. (Family ID 1)” (24)</p> <p>“Evidence widely supported the benefits of continuity of care and support in the face of significantly changing life circumstances. Considering the extended nature of end-of life care in dementia, and the non-linear progression of symptoms, palliative care services would benefit from explicitly encouraging carers to include wider support networks for themselves and their care recipients, and formally recognising them.”(22)</p> <p><b>Narrative:</b> “As in Sidell’s study, at least some interviewees seemed to have accepted the inevitability of death with equanimity. At first, we had low expectations of achieving useful responses to the question of participants’ attitudes to death. However, these low expectations were not completely substantiated and similarly to Killick and Allan, we were surprised by participants’ ‘humour, fellow-feeling, insightfulness and honesty’. People with dementia provided a range of responses.” (13)</p>
<p>CMO 10: With advancing age and progressive dementia social networks dwindle (C), where this occurs, knowledge exchange (M) relating to the person with dementia, between members of the care networks can allow people to exert influence and maintain a role as an active citizen (O)</p>	<p><b>Diminished social networks:</b> “An active withdrawal from people outside of the immediate family/whānau in the period preceding death was frequently reported. As one daughter recounted, her non-Māori mother ‘wasn’t allowing people near her’ towards the end of her life ‘... there was just me’.” (10)</p> <p>“Returning to his room, I asked Walter if he was warm enough. Instead of answering, he became very agitated, moving from side to side, swearing, and spitting on the floor. Sarah, a tiny woman, sat in a corner of the room, gripping a big black purse in her lap as if it could protect her.” (25)</p> <p>“Aggressive behavior against other people, which causes those people to visit them less frequently and for that reason, probably are also unable to provide support (for the person with dementia).” (FG62) (26)</p> <p>“Loss of social contacts, this is very important. I think that it is not necessarily caused by behavioral problems. If, during a birthday party, a person asks “when are we going home”</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p>20 times, this is not aggressive behavior, but perhaps this is a reason for the informal caregiver to decide to no longer go there” (26)</p> <p>“It’s painful to watch someone completely change. And he’s isolating because...we’d a big circle of friends and slowly but surely everything just disappeared. People came, kept calling for a little while and then one by one they faded away”(27)</p>
<p>CMO 11: With changing physical, emotional and behavioural characteristics (C), people with dementia and their families experience uncertainty for what the future holds and the timescales changes may occur within (M). This uncertainty is characteristic of a state of liminality (O)</p>	<p><b>Changing physical, emotional and behavioural states:</b> <i>‘I just consider myself to be living with an old man who I never knew’ (Sanders et al., 2002 p. 13). ‘She was always very well dressed and very polite. Now she doesn’t thank people . . . She was never like that’ ” (28)</i></p> <p><b>Uncertainty for the future:</b> <i>“Even telling family members that the pathways ahead will be rocky and unpredictable would be more helpful than silence or limited guidance, education, or instruction” (29)</i></p> <ul style="list-style-type: none"> <li>• <i>Wife: “Guessing, always guessing. I want to do right by him, but he has not been able to tell me when he is ill or hurting for over a year now, so I have to be vigilant.” (17)</i></li> </ul> <p><i>“If it comes to me and I don’t know, can’t comprehend this, I don’t know what’s going on, don’t know what to do and she’s complaining about it, that’s more of a crisis of not being able to deal with things that Alzheimer’s presents through the patient, through the caregiver, not know what’s going on with the patient.” (7)</i></p> <p><b>Liminality:</b> <i>“During the liminal state people are often structurally invisible, without status: ‘no longer classified and not yet classified” (3)</i></p> <p><i>“Nobody else is going to make decisions for me because they don’t know what I want – I’ll do what I like’. Dan was apprehensive about the possibility of residential care.” (30)</i></p>
<p>CMO 12: The priorities of care may change as dementia progresses and relationships change (C). This may lead to a decision making process (O), the nature of the outcome (fraught or fluid) is mediated through acknowledging growth of a new identity (M), maintenance of a historic</p>	<p><b>Changing priorities of care:</b> <i>“It’s very hard to set in stone goals because they change...so you have to change with them and adapt, add or subtract from your goals or your plan depending on where they (person with dementia) are at.” (nephew)” (31)</i></p> <p><b>Fraught decision making:</b> <i>“I said, ‘The next time that he calls, you give him my telephone number’, and I said, ‘You tell him that I absolutely refuse for them to do anything with my</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>identity now lost (M), or by active discrimination and manipulation of a person with reduced agency (M)</p>	<p><i>father. Unless a doctor calls and tells me that I have to do something, it's gonna stay the way it is now'. And I said, 'If he doesn't like it, and he thinks he's gonna cause you trouble, you tell him that I'm gonna go get me a lawyer, and I'm gonna call Channel 5...'. (32)</i></p> <p><i>"Should we stay with her earlier wishes or go with her contemporaneous neutrality? The group was passionately divided. We had agonizing conversations." (33)</i></p> <p><b>Fluid decision making:</b>  <i>"a sense of the existential self, suggests that care givers ability to derive meaning in their lives and sense of self apart from the caregiving situation" (34)</i></p> <p><i>"Me, too, I'm not what I used to be. So, when you see that the situation is deteriorating. . . . If it's for their own good, between you and me, even though they don't see it that way at first. Maybe in the beginning she'll say: "No, I'm not going." But I think she'll come around in time." (35)</i></p> <p><b>Growth of a new identity:</b> <i>"...at lunchtime, when the researcher tried to help her, she refused to eat. When staff warned her that she would 'waste away', she replied emphatically 'I don't want to be . . .'. This sentence definitely sounded unfinished. Perhaps she did not want to be fed, or was she saying 'I don't want to be alive any more'? Anecdotally, nurses reported similar conversations with people with advanced dementia who confirmed their decision not to eat or who refused essential medication, apparently 'fully' aware of the consequences of this choice, and died soon afterwards" (13)</i></p> <p><i>"Despite her profound dementia, she can still play the piano and read music." (36)</i></p> <p><b>Maintenance of historic identity:</b> <i>"We have been saying goodbye to grandma for over 10 years because my grandma's gone! You get little glimpses of her but she's not there anymore. You know? She doesn't play her music anymore she doesn't play her Black Sabbath at full volume and dance round the kitchen like she used to . . . and that's at 80 . . . She can't get on the back of the boys bikes anymore . . . 'She's not there'. Which is sad?" (37)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><b>Maintenance of a historic identity:</b> “And they said something one time, and I just told ‘em, I said, ‘Hey, I’m doing what [Dad] wanted, and if you don’t like it, that’s your problem, because this is what he wanted” (32)</p> <p>“There are those who say he is such a gentle, nice man, he would never do this. But before he had Alzheimer’s, he was pro-choice; he performed abortions. He is a wonderful man, and I love him. But he has positions I think are morally reprehensible.” (38)</p> <p>“We become ridiculous, incapable, comic. But this is not who we are. This is our disease...Please do not think that I am suffering. I am not suffering. I am struggling to be a part of things, to stay connected to who I once was.” (39)</p> <p><b>Discrimination/manipulation:</b> “My mom and my uncle have been managing her finances, because there was some concern around that, where some family members may be taking advantage of that. So they’ve been managing that for my grandmother.” (40)</p>
<p>CMO 13: Where people with dementia and their families enter into advance care planning (C), the decision making process (O) is influenced by a family’s power as a surrogate decision maker. Here mechanisms (M) include the maintenance of a historic identity, the growth of a new identity, discrimination of a person with reduced agency, compassion towards a person (and family) with dementia, knowledge exchange between caregivers and professionals</p>	<p><b>Growth of a new identity:</b> “While seeking information from families is clearly necessary in many cases (including to ascertain applicable past wishes of patients who lack written statements), the views of proxies should be balanced with the past and – importantly– the present voices of incapacitated patients” (4)</p> <p><b>Paternalism/Discrimination:</b> “Both dementia and frailty studies report advance decisions being overridden where there had been an antecedent rejection of artificial nutrition and hydration and hospitalisation.”(4)</p> <p>“There were also instances when caregivers pursued more aggressive treatment than what the patient had wanted. Some caregivers explained that even when the wishes were known, they had a reluctance to “let the person go,” [9] or they experienced uncertainty, which contributed to the weight of those decisions.” (41)</p> <p>“While some studies indicate moderate agreement between surrogate reports (of advanced care planning) and documented patient wishes, the instructions may be nonspecific, fail to address common end-of-life dilemmas” (4)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p>“...a variety of factors were involved in initiating ACP. Family factors dominated, with family’s initiative or lack of it, and willingness or reluctance identified in a series of studies... ”(42)</p> <p>“But it was just a couple of the nurses that screamed at him so, so, so bad. I do think that they should try to understand the person. They’re elderly, you know, even different ones in there, the way they are. Look, I know the nurses have got to have enormous amount of patience. But the way that he was screamed at was terrible...”(12)</p> <p>“An important issue that emerged in many of the interviews was the carers’ role in understanding what the person with dementia may be experiencing, and advocating for what they would want if they could speak for themselves – as opposed to what the carer themselves thought would be a good thing to do.” (43)</p> <p><b>Agency:</b> My brother-in-law fell . . . and they said to his wife ‘do you want us to resuscitate him?’ and she said ‘I can’t tell you to let him die!’ So they kept him going. . . he came to at one stage . . . and he shook his head like that and my sister-in-law said ‘I’m so sorry, I should have said to them don’t resuscitate him’ and I thought, ‘I’m not going to let my husband suffer in that way’.”(44)</p> <p><b>Compassion:</b> “So you really have to really think about the journey that your gonna take with your loved one, and I always say, ‘How would I want to be treated? Will someone be there for me?’ So I put myself in that role, and I’m really acting it out, and so, so far it’s been working.” (32)</p> <p>“Because rationalizing usually made her angrier, I would hold her in my arms and tell her over and over, “I love you.” She melted in my arms, feeling secure and peaceful. I believe that as Mom grew more secure in my love, she was able to transition to the third stage with a deep sense of satisfaction and contentment.” (45)</p> <p><b>Knowledge exchange:</b> “When I have plenty of time and sometimes talk to family members for well over an hour, we don’t usually get to a point where they are ready to complete an</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>ACP or change goals of care...requires ongoing discussions...reflections...perhaps some involvement from the GP.”(46)</i></p> <p><i>“There was a lot of discussion... about dementia...diagnosis process...acceptance of dementia amongst family and...society...how this hindered the diagnosis process... early part about dementia identification, diagnosis, symptoms...family inheritance” (46)</i></p> <p><i>“Help and advice was sought from friends and family, caregiver support groups, general practitioners, social workers, and aged care assessment teams.” (47)</i></p> <p><i>“...physicians mostly discuss end-of-life questions with long-term family caregivers. The high degree of consultation with caregivers is a positive finding in itself, and the input of family as proxy decision-makers is indispensable...” (48)</i></p> <p><i>“Surrogates’ answers revealed considerable variety regarding goals and the beliefs and values that may underlie them. This variability underscores the importance of clear communication between surrogates and clinicians so that treatment decisions can be guided by agreed upon goals of care within a context of shared decision making” (49)</i></p>
<p>CMO 14: In a state of liminality (C), decision making processes may be fraught (O), due to families or social networks clinging to a historic identity (M), or engaging in paternalistic patterns of behaviour (M).</p>	<p><b>Liminality:</b> <i>“During the liminal state people are often structurally invisible, without status”(3)</i></p> <p><b>Historic identity:</b> <i>“The maintenance of the image of the whole person, to keep alive their personal history, was expressed as being very important by study participants and was an important feature of ACP discussions” (37)</i></p> <p><b>Paternalism:</b> <i>“In particular, two people were not provided with the opportunity to participate in their care, even though they were competent to participate” (50)</i></p> <p><i>“only about one-third of the caregivers in either group consulted the patient regarding discharge”(51)</i></p> <p><b>Fraught decision making process:</b> <i>“all of a sudden you’ll be faced with a decision, it would be at a time perhaps when you’re not emotionally prepared for it, and it would be a bit too much at that stage.” (37)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 15: In a state of liminality (C), decision making is fluid (O), due to the recognition of a person with dementia having a new identity (M) and ongoing agency (M)</p>	<p><i>“The cardiologist showed up at her bedside, shower cap on his head; two of my siblings were there with my mother. “What are you doing here?” asked my mother. “I’ve come to take you for a pacemaker,” he replied. “I don’t want a pacemaker. You doctors do too much stuff to old people.” My siblings asked my mother the same question in as many ways as they could: “Do you understand you might not live as long without the pacer?” “Yes. I’ve lived a good long time.” And so forth. The pacemaker insertion was cancelled.” (33)</i></p>
<p>CMO 16: Families used ‘case based theory’ rather than ‘principal theory’ when making decisions. Here narrative relating to the person with dementia is of prime importance (C). Fluid decision making processes occur (O) with the use of agency (M), identity growth (M), and knowledge exchange (M).</p>	<p><b>Primacy of narrative:</b> <i>“The ethical approach implicit in these families’ descriptions are consistent with a case-based theory, rather than a principle theory. When these family decision-makers utilized an abstract concept such as human dignity, they did so in a limited manner by discussing the factors that were important for the dignity of their relative, rather than for human dignity in general. They did not invoke patterns or principles from beyond their own experience.” (32)</i></p> <p><b>Identity growth:</b> <i>“She had always been shy and didn’t want to entertain people. Yet, when her inhibitions were lost because of the Alzheimer’s, she would get excited when people visited. She enjoyed the Bible study in our home every Friday evening. One day I was late getting her up from a nap, and students were already arriving. I woke her, asking if she wanted to see the students coming. She jumped out of bed, replying, “I think they’ll want to see me.” Indeed, she did have a special relationship with the students.” (45)</i></p> <p><b>Knowledge exchange:</b> <i>“Inclusion was facilitated in other ways such as knowing the preferences of the person through previous interviews with them and their family, or by asking family members about what those preferences might be, building a biographical understanding of the person and being informed by that.” (50)</i></p> <p><b>Fluid decision making:</b> <i>We’ve made arrangements through a chaplain to be prepared for her death if it happens when we’re not here. I mean, we would come back quickly, you know that kind of thing, and my sister realizes that she could also have to come out quickly. So, while we feel that obligation, yet we feel that our lives have to go on too. (32)</i></p> <p><i>“I think whatever you do, you’ve got to do it with a relatively good grace. If you feel that you’ve been pushed into it, or you’re obliged to do it, then I think it won’t work.” (44)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<i>See above entries for data supporting repeated mechanisms</i>
CMO 17: Where there is interaction with professional care services (C) the decision making process can be facilitated to give greater fluidity (O). Mechanisms include compassion, knowledge exchange, and confidence/autonomy (M).	<p><b>Knowledge exchange:</b> “It’s really hard to get advice on how to find out what is the best way to approach, you know, these sorts of situations. And people are in them all the time, more and more. I mean people are having to look after ageing parents with failing faculties and, as a society, we don’t seem to have any structure in place to manage that process or support it.” (52)</p> <p>“I was able to tell the doctor what was going on with my mom. And he was grateful for the knowledge. He told me what to expect and when to call the clinic. I felt better prepared after that.” (17)</p> <p>“Three variables, patient satisfaction with the plan as perceived by the caregiver, caregiver satisfaction with involvement in the plan, and patient satisfaction with involvement in the plan as perceived by the caregiver significantly contributed to caregiver satisfaction” (51)</p> <p>“I wish the doctor had told me what was in store for us when we got the diagnosis. He just said, “She has Alzheimer’s and there’s nothing we can do for her.” If we had known that she’d get worse and we’d have to eventually place her in a facility, we could have prepared a little for what was ahead of us.” (53)</p> <p><b>Confidence/autonomy:</b> “So they’re sort of pre-empting what they know is going to happen. [Yes] See I don’t necessarily know that’s gonna happen, so they’re kind of giving me that information. “Look, you know, you’re gonna be heading down this road soon so you may wanna do this, this and this.” So it’s helping me to future plan [Yep] which I find very helpful”.(52)</p> <p>“The report broadens the concept of autonomy. In dementia care, autonomy should not only be the freedom to make decisions but should also be considered in “relational” terms—when patients cannot make decisions for themselves their closest family members should help (joint decision making)” (15)</p>
CMO 18: Where there is interaction with professional care services (C), the decision	<p><b>Paternalism:</b> she’s literally out of the house, she’s out of my sight, she’s out of my control. . .and I find that really difficult (27)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>making process can be fraught or undermined (O) by paternalistic or dismissive attitudes.</p>	<p><i>“Carers wished that health care professionals would listen to their input more and value their personal history with care recipients.”(22)</i></p> <p><i>“Carers were critical of health care professionals’ unwillingness or inability to deviate from protocol, such as health and safety regulations, which negatively affected the quality of care services.<sup>37</sup> While some conflict may therefore have existed between carers and individual health care professionals, conflict between carers and broader service systems was also apparent.” (22)</i></p> <p><i>“Caregivers consistently reported limited involvement in planning the hospital care, and they did not receive the communication they felt was necessary to fulfil their role...” (41)</i></p> <p><i>“I’m most upset with my mom’s doctor. He was rude to me, told me my mom was his patient, and he couldn’t talk to me about her. He told me to butt out when I asked him to help me with my mom’s memory problems. I think what he did is malpractice.” (53)</i></p>
<p>CMO 19: In a state of liminality characterised by indecision and uncertainty (C), medical paternalism and authority (M) can provide some direction allowing the decision making process to proceed with more fluidity (O)</p>	<p><b>Paternalism/authority:</b> <i>“So long as you say... ‘doctor’ in the sentence . . . she will go along with that, she will listen to that authority so that’s been good actually.” (daughter) (44)</i></p> <p><i>My mother was asked what she thought and said, “Whatever the doctor thinks is best.” (33)</i></p> <p><i>The second strongest influence affecting the decisions of both groups...was the advice of the physician...”(51)</i></p> <p><i>‘You accept it because it’s easy...I think to meself [sic] they are only trying to help you so let them do what they think is best’. (30)</i></p>
<p>CMO 20: Where members of a caring network feel lost in the ambiguity of their role (C), compassionate care (M) and knowledge exchange (M) can provide fluidity in the decision making (O).</p>	<p><b>Role ambiguity:</b> <i>“Research has begun to highlight the substantial contribution that homecare workers make towards meeting not only the needs of people with dementia at end of life but also their families...their contributions to caring for people dying at home may be overshadowed by the ambiguity of their role and their unmet need for preparation and ...misunderstandings of the role of homecare workers have been described by older people, their family members, and by health care professionals.”(54)</i></p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 21: When a person with dementia dies (C), the void in reciprocity experienced during the care giving relationship (M) and a sense of duty (M) can drive members of the caring network to transfer their skills to the community (O)</p> <p>When a person with dementia dies (C), guilt experienced (M) can drive an overwhelming care experience (O)</p>	<p><b>Reciprocity:</b> “...yet many aspects of my experience were positive. My father and I had conversations about his memories of his older relatives that I doubt we would have had otherwise. Sharing the ups and downs of caregiving with my sister also brought us closer together. It was the first time that we had discussed our values about caregiving (despite having witnessed our mother’s experience), money, and ultimately, end-of-life care...” (55)</p> <p>“This experience of caring for her, brought me closer to my mother. I can now see my strengths as a person.” (56)</p> <p>On bereavement: “The majority of carers reported that no longer being able to provide care for their loved one was associated with feelings of loss...”(56)</p> <p>“For those reporting caring for another dependant or engaging in caring duties, feelings of altruism were described as a central part of their post-caring life.” One daughter mentioned: “Giving to other people is very important in life, it makes you feel useful.” (56)</p> <p><b>Duty:</b> “As a son, taking care of my parents is my responsibility. Sometimes, my sisters come back home to care for my father, but they have already married out [of the family]. They are guests. It’s not their responsibility. I appreciate their assistance though. However, my brother and I have the ultimate responsibility to take care of our parents.” (57)</p> <p>“I just took it as that was part of my life goal, to take care of them... It’s stressful, but sometimes it’s rewarding.” (58)</p> <p><b>Transfer of skills:</b> “Consistent with the general caregiving literature, carers reported finding other or new carer-related volunteer activities (Arksey, 2003; Larkin, 2009), during which they contributed and supported their local community” (56)</p> <p>“...for me, it is my way to honor Gloria. I couldn’t do anything for her in terms of saving her or changing the progression of her illness, but if I can do something that will help some other family not have to go through what I’ve gone through, what she’s gone through, then that’s what I can do for her.” (58)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><b>Guilt:</b> "For some caregivers, relief was tinged with feelings of guilt that stemmed from various sources. Some felt guilty simply for feeling relieved by the death of their family member. Others felt guilty about decisions made during the caregiving period, especially the decision to institutionalize the family member, or for having expressed anger and frustration when the going was tough." (59)</p>
<p>CMO 22: Where relationships with a caring network become strained (C) a sense of guilt (M), failure (M) and uncertainty (M) in addition to the paternalistic actions of professional care networks (M) can cause the caregiving experience to become overwhelming (O)</p>	<p><b>Strained relationships:</b> "Overall, family conflict and socioemotional support have important implications among caregivers who institutionalize their relatives" (60)</p> <p>"It's a different thing when Mum was living with us. He just didn't handle things, and I was between the devil and the deep. I didn't want to - Mum needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly" (12)</p> <p><b>Guilt:</b> "since they gradually become unable to care for the patient, feelings of guilt easily arise"(61)</p> <p>"Retrospectively, former caregivers often expressed feelings of regret and guilt surrounding decisions they made while caregiving..."(58)</p> <p>"The doctor said my mom could not live alone. You know, I love my mom, but she could not come and live with us. It would have disrupted my whole family. I know it is terrible to call your mother a disruption. What a guilt trip. (62)</p> <p>"feelings of guilt, obligation, and regret can emerge at various points along the disease trajectory. However, the majority of these feelings arise when the person must be institutionalized" (63)</p> <p>"Sometimes I wonder how much she must hate me inside for doing this to her. I feel guilty because I feel she's saying "How could you abandon me here?" (64)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><b>Failure:</b> “For others, this placement was seen as a personal failure, illustrating a belief that care should be a family responsibility and that admission into a facility was an abandonment of this responsibility” (22)</p> <p><b>Paternalism:</b> “...healthcare professionals unfamiliar with the family and the resident’s individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact.” (27)</p> <p>“...we had to deal with numerous health and care-related issues...; unapproved chemical restraints; repeated falls; a fractured hip; facility unwillingness to follow up on the surgeon’s recommendations regarding physiotherapy following surgery; confinement to a wheelchair for most of the day; and requests that we designate mom for ‘comfort care’ only in case of medical emergency). As I recount selected aspects of mom’s LTC journey, I receive an email from my brother, informing me that mom has been rushed to hospital for the second time in two weeks....”(29)</p> <p><b>Uncertainty:</b> “...thus, critical issues of personhood, identity, agency, and control were embedded in our moms’ experiences and reflected in our experiences as families as we struggled to “do what was right.” (29)</p> <p><b>Overwhelming:</b> “I had no one to look after mum, so I couldn’t go to work, and I do believe that that impacted and I do believe that that’s one of the reasons that they fired me. Because I couldn’t attend work because I had to look after mum.”(65)</p> <p>“...families that experience negative feelings among members institutionalize their ill elders more frequently than families that do not experience such feelings. Negative affect among family members often leads to conflict, distress, and frustration that can intensify over time. Family members may decide on NHP because of the emotional difficulties that result from ongoing, painful family interactions and the interpersonal difficulties that emerge when attempting to coordinate patient care...”(66)</p>
CMO 23: : Where relationships with a caring network become strained (C), the exchange of knowledge (M) and trusting relationships (M)	<p><b>Strain:</b> “Initially life seemed unbearable. My mother was incontinent, hallucinating, and disoriented. At one point she stayed awake for 40 hours seeing people, places, and things that weren’t there. We were exhausted. But in time, she showed signs of improvement.”</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>generated positivity and rewarding aspects to the care experience (O)</p>	<p><b>Knowledge exchange:</b> “I think just their reassurance...there is nothing physically they can do...they just reassure you.... That you are doing the right thing, more than anything, because sometimes you do doubt yourself” (46)</p> <p><b>Trust:</b> “External support resources from the community or charitable organizations were a key feature for some. Specifically, reliance on neighbours or being members of a close community gave reassurance of their relative’s safety when they were not present...” (27)</p> <p><b>Rewarding aspects to care:</b> “When my mother died from a fall, I reflected on the satisfaction and peace I had not anticipated I would feel. I knew what it was to “give back” to my mother. It seems incredible that caregiving can be so satisfying I look into her bedroom now and I can feel her presence...and I am thankful for the final gift she gave me.” (67)</p> <p>“Although caring for patients with AD can be challenging and involves many different decisions, good endings are possible. By encouraging patient discussions regarding care preferences early in the course of the disease and educating family and caregivers about what to expect and how to deal with each stage of the disease, physicians can ease the transition for patients and families.” (5)</p>
<p>CMO 24: Where powerful structures of care become involved (C), feelings of failure (M) and a loss of autonomy (or paternalism from healthcare professionals) (M) can lead to a care experience that feels overwhelming (O)</p>	<p><b>Professionalised care:</b> “Dementia starkly reveals the Cartesian biomedical model’s incomplete understanding of “health,” through its inability, even unwillingness, to develop effective (non-biomedical) interventions to address a range of experiences of disease in their social, relational context.” (8)</p> <p>“...carers experience in receiving formal services is inherently ambiguous, for whilst formal services are providing support to family carers, they can also be undermining their sense of identity and control over their circumstances...” (65)</p> <p><b>Loss of control/autonomy in the care role:</b> “Oh God no they did everything, all I had to do was go and visit and feed her. Didn’t even have to feed her but I liked to.” (18)</p> <p>“That they will not really listen to you when you understand the person better than they do”(12)</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p data-bbox="864 233 2029 376"><i>“There was no people feeding them and I went, I used to go in and feed her and they said, “Oh no, she’s here to be rehabilitated, you shouldn’t feed her, it’s spoiling her, she can do it herself,” well . . . she couldn’t do it at all and as I say her eating was getting worse and worse at that stage.”</i> (6)</p> <p data-bbox="864 416 2007 520"><i>“Sarah experienced separation anxiety, had concerns about relinquishing her role as primary carer and worried that the facilities would not be able to meet Derek's needs...”</i> (68)</p> <p data-bbox="864 560 2040 855"><i>“Hospitalisation of the person with dementia was also described as a challenging time. Carers may have taken responsibility for all of the caring, believed they knew the person and their needs most intimately and taken responsibility for decision-making; however, when the person with dementia is admitted to hospital, the carer is usually no longer primarily responsible for these things and he/she can experience an acute loss of control. In addition, vulnerable family caregivers can feel disempowered by the health care system, especially when they are not recognised as the expert in the care of their relative and not appropriately included in decision-making”</i> (12)</p> <p data-bbox="864 895 2040 1070"><i>“I thought that was really nice because I still had some control over the situation. They sort of asked, ‘What clothes do you want him to have on today?’, so I wasn’t doing the nitty-gritty showering and toileting I was sitting there pushing a button and they’d come and toilet him and shower him and dress him, but I still had a say in when it was done and how it was done, which was really nice.”</i> (18)</p>
<p data-bbox="203 1086 819 1222"><b>CMO 25:</b> Where powerful structures of care become involved (C), knowledge exchange (M) and trusting relationships (M) create an environment for a rewarding care experience</p>	<p data-bbox="864 1086 2018 1150"><b>Trust:</b> <i>“If you don’t feel you can trust them or something, you’re more apt to just sit there and listen and not interact.”</i> (40)</p> <p data-bbox="864 1190 1995 1326"><i>“One of the difficulties many carers discussed was having to trust that paid workers will provide a good quality of care to their loved one. Some carers were constantly at the nursing home either providing direct care themselves or else making complaints to the management about the standard of care.”</i> (18)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 26: Where a social network has amassed expertise in caring for a person with dementia (C), knowledge exchange (M) and trusting relationships with professionals (M) allow for a more rewarding care experience. Whereas paternalism and disregard of this expertise can mean carers are devalued (O).</p>	<p><i>“A number of carers mentioned that the clinicians didn’t seek their opinion about the care of the patient although the carer considered himself/herself to be expert in the care of that patient.” (12)</i></p> <p><b>Expertise:</b> <i>“it doesn’t matter how many university degrees and that people do, they don’t know until they’re a carer...what it really involves.” (65)</i></p>
<p>CMO 27: As care demands increase (C), people struggle to keep afloat. Feelings of duty (M) combine with feelings of failure (M) and guilt (M) that makes caregiving overwhelming (O).</p>	<p><b>Duty with increased care demands:</b> <i>“...the children must ensure that the parent is cared for in a ‘manner that is appropriate to them.’ The child’s obligation does not end once the patient is transferred but continues as an ongoing responsibility to oversee the care of the parent...” (69)</i></p> <p><i>“Most caregivers did not have a regular job; three said that they had had to give up their jobs, as their caring role became more demanding.”(70)</i></p> <p><i>“In Kaohsiung most respondents attributed their unwillingness to use nursing homes to filial piety: in contrast, only 22.5% of respondents in Taipei had the same response”(71)</i></p> <p><i>“My sisters-in-law and brothers-in-law opposed bringing my mother-in-law here. It was very hard to persuade them. They wouldn’t listen to me, and the only thing they did was to blame me.”(64)</i></p> <p><i>“I panic and shut down, sometimes I just want to go to my room and close the door and pretend he is not there, but I need to be there for him. I frequently feel that I cannot do one more thing, make one more decision, take one more breath.” (17)</i></p> <p><i>“I had no one to look after mum, so I couldn’t go to work, and I do believe that that impacted and I do believe that that’s one of the reasons that they fired me. Because I couldn’t attend work because I had to look after mum.” (65)</i></p>
<p>CMO 28: As care demands increase (C), people utilise knowledge exchange (M), reciprocity (M) and trusting relationships (M) between formal</p>	<p><i>“The neighbours were all good and if I was worried I would ring the neighbours and they’d say no, he’s out in the garden or we can see him from here, he’s up a ladder or on the roof, or something.” (10)</i></p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
and informal care networks to maintain care and an overall positive outlook (O).	
CMO 29: Where networks of networks develop (C), reciprocity (M), compassion (M), knowledge exchange (M), trusting relationships (M) provide mechanisms for a more rewarding care experience (O).	<p><b>Networks of networks:</b> “Indeed, several mechanisms have been discovered by means of which the interdependence between different networks or network layers may help to resolve social dilemmas beyond the potency of traditional network reciprocity” (72)</p> <p>“A final important but unsurprising result is that decision-making for individuals with dementia typically happens without their input, because they are usually completely dependent on their caregivers and no longer able to interact with their environment in a meaningful way, to address treatment concerns, or to provide consent. Instead, physicians mostly discuss end-of-life questions with long-term family caregivers.”(48)</p>
CMO 30: As the role of the family changes in response to increased care demands uncertainty (M), a sense of duty (M) and grief (M) for lost relationships (M) can impact on each member of the care network to create an overwhelming care experience (O).	<p><b>Changing role of the family:</b> <i>In an ancient model of assistance, the family has always been a central point in taking care of elderly people, but modern medicine has prolonged life expectancy while families are becoming smaller and women, traditionally devoted to the care of its members, are often professionally employed”(73)</i></p> <p><b>Duty:</b> “The family members render the majority of pre- and post-institutional care, usually a daughter or daughter-in-law. Although other family members may be available, the bulk of the care support falls to this individual. The significant caregiver burden may be related to the caregiving role of the daughter combined with the enhanced severity of the disease prior to institutionalization” (74)</p> <p><b>Duty and uncertainty:</b> “three years after placement of the feeding tube, her daughters expressed dismay at her condition but felt unable to discontinue the tube feedings.” (5)</p> <p><b>Grief for lost relationships:</b> “Some role changes were so significant leading one caregiver to remark, ‘I don’t call her mum anymore’ (Dupuis, 2000, p. 104). Overall, caregivers began to grieve the losses whilst concurrently attempting to continue a meaningful relationship with their loved one.” (28)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
CMO 31: Where geographical constraints exist (C) (i.e. a family member lives far away and can not get time off to attend) the care experience may feel overwhelming (O) due to the sense of duty felt (M)	<p><b>Geographical constraints:</b> “In multivariable logistic regression analyses (all Po.05), feeding tube use was more common in urban nursing home residents, whereas rural nursing home residents were at greater risk for hospitalisation.” (75)</p> <p>“The bivariate analyses indicated that caregivers expressed a higher preference for institutionalisation when they were living apart from the patient”(76)</p>
CMO 31: Where professional structures of care become involved (C), care can be routinized (M) and subject to paternalistic ideas (M) leading to a person entering the 4 <sup>th</sup> age (O). Where compassion is harnessed as an ethical imperative for health there is potential for community development (O)	<p><b>Compassion as an ethical imperative for health:</b> “These are, first, that compassion is an ethical imperative for health. Compassion is the human response, the tender response aroused by the distress and suffering of others. It is the moral, social, political, and physical basis of our attempts to give aid and support in a time of difficulty. A healthy person without compassion is a potentially dangerous person to the health and safety of other people.” (77)</p> <p><b>Community development:</b> Palliative care must develop a public health approach to end-of-life care if it is to embrace health promotion activities that draw it towards community partnerships beyond volunteer programs and towards broader collaborations such as compassionate cities. (77)</p>
CMO 32:where care networks have diminished (C) there is potential for growth and development of networks (M) that can aid community growth (O)	<p><b>Potential for growth:</b> “Various local people said, you know, ‘We’ll come in and sit with him, for an hour’, but, it didn’t sort of work out – people are busy in the middle of the day.(10)</p>
CMO 33: Where social networks have diminished (C), the routinisation of paternalistic care (M) and the ignominy of this (M) can lead to people entering the 4 <sup>th</sup> age (O)	<p>“We also heard accounts of older people actively resisting community support, with reasons related to shame about bodily decline, concerns about being a burden, an inability to reciprocate and difficulties maintaining engagement in the face of deteriorating health (most notably dementia).”(10)</p>
CMO 34: In the context of a society that rejects death (C), ethical constructs such as compassion (M) and duty (M) have the potential to aid community development (O). Routinisation (M) and paternalism (M) feed into the 4 <sup>th</sup> age (O)	<p><b>Routinization:</b> “Technology and the clinical routine now acknowledge life, though it is a life without subjectivity, produced entirely through technology, clinical care, and surveillance” (78)</p>
CMO 35: Where capacity is held by a surrogate (C), care can be protocolised or routinized leading to the 4 <sup>th</sup> age (O). There is potential to	<p><b>Surrogacy of care:</b> “I want my agent to consider the relief of suffering and the quality as well as the extent of the possible extension of my life in making decisions concerning life-sustaining treatment.”(78)</p>



CMOCs	Illustrative examples of supporting data extracted from the literature
harness ethical constructs such as compassion and duty to aid community development (O).	
CMO 36: where life and death become an amorphous entity (C) routinization in the care of the body (M) leads to the 4 <sup>th</sup> age (O)	<p><i>“The caregivers’ daily routine involves washing the patient’s body, tube-feeding her, collecting her urine, causing her to empty her bowels into disposable diapers, dressing her, rubbing creams into the skin so that it does not shrivel, combing her hair, brushing her teeth, turning her over in bed a few times a day to avoid bedsores, taking her to the veranda in a wheelchair...”</i> (79)</p>
CMO 37: Where a person has reduced agency (C), care is routinized (M) and fraught with ignominy (M) to the point of entering the 4 <sup>th</sup> age (O)	<p><b><i>Ignominy and routineisation:</i></b> <i>“this condition was devastating to watch, to [wife’s name] who was always rather coy, shy about the activities of bodily functions, to have her more or less on a timeslot and put into a machine, ‘cos they’d had lunch, lifted up and wheeled into the toilet – that was very devastating . . . I didn’t like to see her suffering these sorts of indignities.”</i> (43)</p> <p><i>“She passes stool and handles the faecal matter. Makes a mess and this then cannot be cleaned. The whole household stinks. There is smell of faeces always. Nobody will help. Even my husband, that is her own brother, does not want to be at home. He cannot stand the bad smell.”</i> (70)</p>
CMO 38: Where there is a public failure of self-management (C), a person enters the 4 <sup>th</sup> age (O) via mechanisms including institutionalisation (M), ignominy (M) routinisation of care (M). Mechanisms such as compassion and duty have the potential to develop communities to support such people (O)	<p><b><i>The 4<sup>th</sup> age:</i></b> <i>“It is the combination of a public failure of self-management and the securing of this failure by institutional forms of care that a key boundary is passed.”</i> (9)</p> <p><b><i>Public failure of self-management:</i></b> <i>reflections from a paid carer, “Not being able to take responsibility, not knowing that things (food) are moulded or at the expiration date. Not knowing when you need to clean up (the house) and also not knowing how to perform certain actions.”</i> (26)</p> <p><b><i>Ignominy:</i></b> <i>“But it’s ignominious to have strangers come and dress you, shower you, and I think that’s one of the most humiliating things. It was for my father as well. That’s why I tended to do it myself and latterly with the help of one of the staff – who was very good, the only one who would do it. But I think that’s very ignominious and I think that’s one of the things, and there’s no way around it I suppose...”</i> (43)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 39: Where communities of identity exist (C), people with dementia are seen to go about their business, their growth and development is then visually acknowledged so people develop an understanding of their needs and daily challenges. Through compassion (M) this may aid community development (O)</p>	<p><b>Communities of identity:</b> ...where people living with dementia are normalized not only in terms of their day care activity—by not being treated as passive consumers of ‘treatments’ or ‘services’ but as active agents of their own preferences and activities—but also as people to be publicly seen going about their usual business. Furthermore, people not directly involved with care for people living with dementia are encouraged to participate in that care and to obtain basic understandings of both the challenges of living with dementia and also the challenges in its daily care. Thus the levels of public education about living with dementia and its care are significantly raised....”(11)</p>
<p>CMO 40: As dementia progresses and manifest as changes in behaviour and social relationships transitions occur to the care environment (C), these might involve the person moving or things moving into what was previously the home environment. Either way, the space as it previously was, transitions to something new (a hybrid space in the home) or an entirely new space in some form of institutional care (nursing home, hospital, sheltered accommodation). These transitions (C) have multiple outcomes for both the individual and members of their care networks. Mechanism identified include duty, paternalism, compassion, routinisation, reciprocity, narrative, resilience, discrimination, teamwork, identity growth, identity maintenance, grief, loneliness and knowledge exchange (M)</p>	<p><b>Transitions:</b> “...there is an important connection for Bourdieu between the social or material dimensions associated with specific positions in social space and the body and its dispositions.” The environment as an extension of social capital (80)</p> <p>“I tend to think that people with dementia do want familiar; it’s the change that is difficult to cope with and the familiar things are personal things. If we’re talking about residential care, to bring in personal things of theirs, whether it was his music, I know my husband did a lot of photography as a hobby... and he had the photographs there...and when he did go into respite, we took the same pictures, I think, that was important to him.”(81)</p> <p>“More than 70% of both the dementia and comparative cohorts attended hospital emergency departments in the last year of life... Decedents with dementia who were not receiving community-based palliative care attended hospital emergency departments more frequently than people receiving community-based palliative care” (82)</p> <p><b>Transitions in the home:</b> “Although all the care recipients and their family caregivers indicated a strong preference for home care over institutional care, their experiences and practices within their homes were disrupted and reconfigured by the insertion of logics emanating from the healthcare field”(80)</p> <p><b>Duty:</b> Another difference was in the sense of obligation for family members to provide care for their next of kin through the course of the disease, which was apparent, for example, in Spain and Estonia (83)</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p data-bbox="864 196 1928 264">“...our study showed that end-of-life care for people with dementia is moving from institutional care to non-institutional LTC in Finland....” (84)</p> <p data-bbox="864 304 1995 448">“The demands of patient choice and cost appear to create an overwhelming case for the drive to increase the numbers of people dying at home. We support this endeavour but would also emphasise that not every admission for in-patient care should be seen as a failure to provide effective community services” (85)</p> <p data-bbox="864 488 2018 632">“As in previous studies, demented older people cared for by non-spouses were more likely to be institutionalized in the first year after baseline measurement as compared to those cared for by spouses. This is in agreement with the assumption that non spouses are less strongly committed to the caregiving relationship as compared to spouses” (86)</p> <p data-bbox="864 671 2029 855"><b>Guilt:</b> “I visit here many times, but every time I am so ashamed. This place is like a dumpster where you throw away things, a place for well-off daughters’ in-law to throw away their parents-in-law. I felt so guilty in front of the nursing assistants to be a child of one of these elderly people. I don’t even dress nice when I come here because I’m afraid of what people will say of me since I’ve brought my parents over here.”(64)</p> <p data-bbox="864 895 2029 1078"><b>Reciprocity:</b> “Mom also taught me more about love. I learned to express my love. Because I knew she would easily forget, I would remind her many times a day that I loved her. Each time I did, she would light up with a smile. It brought me much joy to see her receive my love. Often when I was helping her, she would kiss me on the arm, whisper “I love you,” or say “Thank you.” .... I realized the more I said, “I love you,” the more love grew” (45)</p> <p data-bbox="864 1118 2029 1262"><b>Resilience:</b> “Following control for the various resilience covariates, resilience remained a significant predictor of transitions from dementia caregiving. Those caregivers in the low-resilience category at baseline were 0.62 times less likely than those in the high-resilience category to experience a care recipient death (<math>p &lt; .01</math>)” (87)</p> <p data-bbox="864 1302 2018 1406">“It is surprising that behavioural disturbances are one of the major reasons for admission in RUD (rehabilitation unit for dementia), but they are not risk factors for institutionalization after discharge. The process mediating the association between BPSD</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>(behavioural and psychological symptoms of dementia) and placement may be the ability of the caregiver to tolerate such behaviours and not BPSD by themselves.” (88)</i></p> <p><b>Growth and liminality:</b> “... participants show an orientation to the present and the future that contains growth on the one side and vulnerability on the other. Growth concerns personal growth and developing new ways in which to organize their lives. Aspects of vulnerability include declining health, possible dependence, coping with growing older, and being concerned with finitude.” (89)</p> <p><b>Grief:</b> “This transition can also highlight the sadness that marks the end of a long-standing relationship.” (63)</p> <p>“I had to keep reminding myself that the disease took away the dad I once knew” (90)</p> <p>Loneliness: “I don’t actually call them that much, but just knowing they are there is a tremendous source of help...”(91)</p> <p>“I think it has something with me being the only girl in the family...there’s my three older brothers, but like I said before they really haven’t helped that much. If anything I have to protect my mother from them...”(91)</p> <p><b>Knowledge exchange:</b> A lack of communication or information sharing appeared to be a key reason why older adults and caregivers felt ignored, forgotten or unimportant” (92)</p> <p><b>Conflict:</b> “I said, ‘The next time that guy calls, you give him my telephone number’, and I said, ‘You tell him that I absolutely refuse for them to do anything with my father. Unless a doctor calls and tells me that I have to do something, it’s gonna stay the way it is now’. And I said, ‘If he doesn’t like it, and he thinks he’s gonna cause you trouble, you tell him that I’m gonna go get me a lawyer, and I’m gonna call Chanel 5...’.” (32)</p>

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## Part 6 – Example of CMOC development

To provide an example of the process of interpreting data to develop CMOCs from the papers reviewed we are drawing Kellehear's model of compassionate cities.

Kellehear argues that the responsibility of care at this point should not be left alone with families or professional care services. Instead end of life care is a form of social, psychological, spiritual and even physical support that extends through to the point of death and beyond. The care process facilitates community development, helping society to reclaim death as a social problem where reciprocity is transferred from the dyadic relationship of caregiver and care receiver to a more complex phenomena articulated through networks of networks, community or social capital.

We found data to support elements of this theory, and community development became a repeating code across the data set. In order to develop a CMOC we needed a number of elements to substantiate our theory. This led us to look in more detail at the role of social networks surrounding the nodal person with dementia in search of specific contexts and mechanisms that would lead to this outcome. The data uncovered conflicting information, that social networks would dwindle with no evidence of expansion, in fact that people with dementia would in some cases actively seek to detach themselves from community.

This led us to Gilliard's and Higgs theory on the 4<sup>th</sup> age. Higgs and Gilliard argue that the 4<sup>th</sup> age emerges from the 'institutionalisation of infirmities of old age'. Through the combination of a public failure of self-management and the securing of this failure by institutional forms of care a key boundary is passed. Beyond this boundary a person may fade from the social world much in the way a black hole may distort the gravitational field surrounding it – not observable other than in the traces of its effects. Institutionalized health and social care practices help demarcate the 'event horizon'. Beyond which a person is stripped of any social or cultural capital which is valued and allows for the articulation of choice.

As we analysed the data set empirical evidence was found that served to act as a context and mechanisms leading with 'entry into the 4<sup>th</sup> age' or 'community development'. These appeared to be the most relevant and overarching outcomes. After theoretical saturation of combinations of CMOC that lead to each of these outcomes the next task was to see how the 2 groups of CMOCs related to one another.

True to Gilliard and Higgs theory of the 4<sup>th</sup> age acting as a black hole, (one into which data is lost and can therefore not be studied directly but within its impact on the discourse that surrounds and orientate themselves to it) we found a lack of subject relevant data relating to what happens after entry into the 4<sup>th</sup> age. It was on the impact of this transition, in studies relating to the grieving process, that we found evidence of reciprocity being achieved and not within dyadic relationships but through mechanism such as duty and compassion which prompted engagement with people outside of the care networks and back into the community. Thus linking the 2 CMOC configurations together as one aspect of the programme theory.

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**RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) publication standards for meta-narrative/realist reviews**

Section:	Topic	Explanation	Page number
Introduction	Rationale for review	Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area.	p3-4
	Objectives and focus of review	State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review.	p4-5
Methods	Changes in the review process	Any changes made to the review process that was initially planned should be briefly described and justified.	p6
	Rationale for using meta-narrative review	Explain why meta-narrative review was considered the most appropriate method to use.	p5
	Evidence of adherence to guiding principles of meta-narrative review	Where appropriate show how each of the six guiding principles (pragmatism, pluralism, historicity, contestation, reflexivity and peer review) have been followed.	p5-7
	Scoping the literature	Describe and justify the initial process of exploratory scoping of literature	p6
	Searching processes	While considering specific requirements of the journal or other publication outlet state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include (for example) name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected.	p5-7
	Selection and appraisal of documents	Explain how judgements were made about including and excluding data from documents, and justify these.	main document p7, supplementary file p26-27
	Data extraction	Describe and explain which data or information were extracted from the included documents and justify this selection.	main document p7-8, supplementary file p26-27
	Analysis and synthesis processes	Describe the analysis and synthesis processes in detail. This section should include information on the constructs analysed and describe the analytic process.	Main document p8 Supplementary file p54
Results	Document flow diagram	Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example,	Figure 1 and p9

		from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification to suit the data) that are provided.	
	Document characteristics	Provide information on the characteristics of the documents included in the review	Main document p9 Supplementary file p4-26
	Main findings	Present the key findings with a specific focus on theory building and testing.	p9-17
Discussion	Summary of findings	Summarise the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s)	p18
	Strengths, limitations and future research directions	Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed	p20
	Comparison with existing literature	Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic.	p18-19
	Conclusion and Recommendations	List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice.	p19-21
	Funding	Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers.	p21

# BMJ Open

## Social networks, social capital and end-of-life care for people with dementia: a realist review

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## ABSTRACT

**Objectives:** (i) To develop an understanding of how social capital may be conceptualised within the context of end-of-life care and how it can influence outcomes for people with dementia and their families with specific reference to the context and mechanisms that explain observed outcomes. (ii) To produce guidance for healthcare systems and researchers to better structure and design a public health approach to end-of-life care for people with dementia.

**Design:** A realist review

**Data sources:** MEDLINE, EMBASE, CINAHL and grey literature

**Analysis:** We conceptualised social capital as a complex intervention and, in order to understand how change is generated, used realist evaluation methods to create different configurations of context, mechanism and outcomes. We conducted an iterative search focusing on; social capital, social networks and end-of-life care in dementia. All study designs and outcomes were screened and analysed to elicit explanations for a range of outcomes identified. Explanations were consolidated into an overarching programme theory that drew on substantive theory from the social sciences and a public health approach to palliative care.

**Results:** We identified 118 articles from 16 countries ranging from 1992 to 2018. A total of 40 context-mechanism-outcome configurations help explain how social capital may influence end-of-life care for people with dementia. Such influence was identified within 5 key areas. These included; (i) socially orientating a person with dementia following diagnosis; (ii) transitions in the physical environment of care; (iii) how the caregiving experience is viewed by those directly involved with it; (iv) transition of a person with dementia into the 4th age; (v) the decision making processes underpinning such processes.

**Conclusion:** This review contributes to the dispassionate understanding of how complex systems such as community and social capital might be viewed as a tool to improve end-of-life care for people with dementia.

## Strengths and limitations of this study

- A broad search to avoid missing major concepts.
- Using a realist methodology allows us to focus on how contexts influence outcomes whilst identifying generative mechanisms.
- The programme theory generated by this approach is therefore applicable to multiple interventions across different settings.
- Social networks and social capital was often studied from a narrow perspective. This lack of empirical evidence meant that context-mechanism-outcome configurations could not fully explore specific functions of social networks or social capital.

## BACKGROUND

The dementias are a group of incurable, progressive illnesses with uncertain clinical trajectories. Globally there are 35.6 million people living with dementia, figures are projected to triple by 2050.<sup>1</sup> The need for care, especially at the end-of-life, is an international public health priority.<sup>2</sup>

Dementia changes social relationships.<sup>2,3</sup> These relationships are fundamental to improving access to services and delivery of care. Relational changes are often portrayed negatively, meaning people affected by dementia may experience social isolation and prejudice.<sup>3,4</sup>

Attempts to address this have sought to shift the focus in care towards a person's environment and the wider societal and organisational practices that shape it.<sup>5,6</sup> How these concepts operate at the end-of-life, a time of heightened vulnerability and dependency, is of profound social and ethical importance yet relatively under researched.

Fraught with uncertainty and unpredictability,<sup>7,8</sup> the end-of-life with dementia is often depicted as 'tragic' and 'untimely'.<sup>9</sup> Unsurprisingly, residential care is often recommended. Whilst a positive experience for some, this process can bring further distress in the form of guilt, family discord and loss of identity.<sup>10,11</sup>

Specialist palliative care professionals have expertise and experience working with such complexity.<sup>12-14</sup> However, comparatively few people with dementia are referred.<sup>15</sup> In the UK, hospices have limited capacity, whilst cuts to social service budgets mean professional home care is diminishing.<sup>16,17</sup>



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3 With these issues in mind, a public health approach to end-of-life care has been proposed.<sup>18</sup>

4  
5 <sup>19</sup> The movement aims to pre-empt issues such as social isolation and stigma, by promoting  
6  
7 supportive networks of community members. There is a growing evidence base for this  
8  
9 approach, yet how it relates to the specific challenges of dementia is unknown.<sup>20 21</sup>

10  
11 Close association between the disciplines of public health and palliative care represents a  
12  
13 shift from more traditional public health measures towards embracing the social  
14  
15 determinants of health and the influence of communities in the development of health. The  
16  
17 actual articulation of such an approach focusses on 'health promotion' and emphasises  
18  
19 notions such as promoting community engagement and adopting progressive asset based  
20  
21 and social capital orientated interventions.

22  
23 Social capital is therefore a potential target for public health interventions operating in the  
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25 context of end-of-life care. Social capital is however a controversial concept. This stems  
26  
27 from a diverse literature where definitions are multiple and dependent on the context and  
28  
29 complexity associated with its operationalisation.<sup>22-24</sup> It follows that social capital may take  
30  
31 many forms, is not uniformly accessible, whilst its sources and consequences are pleural.<sup>23</sup>  
32  
33 Unifying themes focus on social capital being inherent in the structure of human  
34  
35 relationships. To possess social capital, one must therefore be held in connection with  
36  
37 others and an advantage is realised through these other people. Positive consequences may  
38  
39 exist at the level of the individual and the community.<sup>23</sup>

40  
41 In order to better understand such a broad concept Nahapiet and Ghoshal have  
42  
43 distinguished between structural, cognitive and relational social capital. <sup>25</sup> Structural social  
44  
45 capital refers to the presence of a network of access to people and resources. Cognitive  
46  
47 social capital relates to subjective interpretations of shared understandings whilst relational  
48  
49 social capital includes feelings of trust shared by people within a social context (e.g. a  
50  
51 community).

52  
53 A public health approach to palliative care seeks to operationalise social capital and its  
54  
55 varying components. In a relationship that is new and constantly evolving, a range of  
56  
57 positive outcomes have been described.<sup>20 26-28</sup> However, at the level of the individual, the  
58  
59 processes involved in acquiring social capital cut both ways. For example, social-ties may  
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61 provide access to resource, but can also restrict individual freedoms and bar outsiders from

1  
2  
3 access.<sup>23</sup> For this reason social capital in relation to health must be studied in all its  
4 complexity rather than as an example of value.  
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7 Previous systematic reviews have looked at factors including, caregiver and family  
8 characteristics that influence transitions in care and the various interventions to support or  
9 delay this process.<sup>29</sup> Less attention has been paid to exploring the underlying causal  
10 processes that occur during this process and how transitions in care fit into the broader  
11 picture of end-of-life care.  
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## 16 17 **EVALUATION QUESTIONS AND OBJECTIVES**

### 18 19 **Research questions**

- 20 1. What are the mechanisms by which social capital is believed to impact on relevant  
21 outcomes for people with dementia at the end-of-life?  
22
- 23 2. What are the important contexts which determine whether different mechanisms  
24 produce intended outcomes?  
25
- 26 3. In what circumstances and for who is social capital an effective intervention?  
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### 30 31 **Objectives**

- 32 1. To develop theory around the interaction between social capital, end-of-life care and  
33 dementia.  
34
- 35 2. To develop an understanding of how social capital may be defined and conceptualised  
36 within the context of end-of-life care and how it can influence outcomes for people with  
37 dementia and their families with specific reference to the context and mechanisms that  
38 explain observed outcomes.  
39
- 40 3. To produce guidance for healthcare systems and researchers to better structure and  
41 design a public health approach to end-of-life care for people with dementia.  
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## 49 50 **METHODS**

51 To address the complexity presented by the research questions, we drew on critical realist  
52 philosophy.<sup>30</sup> This distinguishes between three aspects of the world that co-exist yet remain  
53 distinct. The 'empirical', what we actually experience; the 'actual', events that occur and the  
54 'real'; generative mechanisms that are often hidden. This distinction implies any singular  
55 event can be perceived differently when influenced by different mechanisms or that the  
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3 same mechanism may lead to a different event depending on the context. Critical realist  
4 approaches follow an interpretative, theory driven process of synthesising evidence from  
5 heterogeneous data.<sup>31</sup> The main strength is to produce findings that explain how and why  
6 social practices have the potential to cause change. Findings are described in terms of  
7 context-mechanism-outcome configurations (CMOCs). We conceptualized social capital as a  
8 complex intervention. This was done in order to understand the challenges faced by a  
9 growing trend for public health interventions that seek to build social capital as a means of  
10 improving end-of-life care. Causation was not to be understood in relation to social capital  
11 per se, i.e. to see if social capital 'works' or 'doesn't work'. Instead causation is thought to  
12 be generative through the release of 'mechanisms' or underlying causal powers of  
13 individuals and communities.<sup>31</sup>

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15 To account for the pan-disciplinary interest in social capital, our search was not restricted to  
16 one definition. Through immersion in the literature, we chose to focus on how the nature  
17 and existence of human relationships, within social structures such as healthcare,  
18 community and 'the home', were introduced or excluded from an evolving network of care,  
19 and how this appeared to influence outcomes at a series of key decision points. Instead of  
20 focusing on barriers or facilitators to the development of social capital, we focused on what  
21 happens in the presence of challenges faced by people with dementia.

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23 The review is registered on PROSPERO (CRD42018084524) and ran for 17 months (Oct 17 to  
24 Feb 19). It is reported according to the RAMASES (Realist And Meta-narrative Evidence  
25 Syntheses: Evolving Standards) publication standards.<sup>32</sup> The review followed Pawson's five  
26 iterative stages as described below.<sup>33</sup> With reference to Papoutsis et al,<sup>34</sup> and in order to  
27 develop a more accessible narrative beyond CMOCs, we sought to engage with substantive  
28 theory in what became the sixth step.

### 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 **(i) Locating existing theories and programme theory development**

Prior to formal literature searching, JS devised an initial programme theory to act as a  
reference point. This was based on prior knowledge and an initial scoping search. The  
scoping search used key terms and recognized authors in the field across MEDLINE/Pubmed  
and Google. Additional literature was accessed through citation tracking and eliciting key  
studies from experts.<sup>35</sup> Relevant theories such as Bartlett and O'Connor's model of 'social

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3 citizenship',<sup>5</sup> Kitwood's ideas on personhood,<sup>6 36 37</sup> and Kellehear's 'compassionate cities'  
4 model<sup>18 38</sup> were reviewed in conjunction with established literature on social capital.<sup>22-25</sup>  
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7 Findings were combined with the experiential, professional and content knowledge of the  
8 research team (JS – clinical research fellow in palliative care, LS – consultant in palliative  
9 care, senior clinical lecturer in new public health approaches, NK – senior research fellow in  
10 dementia, PS clinical academic in palliative care and ELS- clinical reader in old age  
11 psychiatry, expert in dementia and end-of-life care). The resulting programme theory acted  
12 as a guide for refining assumptions against data from the main search. Group consultations  
13 continued during data analysis in order to refine the programme theory.  
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## 20 **(ii) Searching for evidence**

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22 Two distinct formal literature searches were conducted through the databases MEDLINE,  
23 EMBASE and CINAHL. For the main search, terms included; dementia OR Alzheimer's disease  
24 OR multi-infarct dementia OR vascular dementia; social capital OR social network OR social  
25 support OR community development OR community participation OR social integration;  
26 palliative therapy OR terminal care OR palliative care OR end-of-life OR Death OR dying. Full  
27 terms are available in the supplementary file. Terms were piloted and refined to increase  
28 sensitivity. Grey literature was searched using Google and the data base OpenGrey.  
29 References within included documents were screened for relevance.  
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38 The search was run in December 2017 and repeated in October 2018 to capture newly  
39 published articles. Databases were searched from inception. We included all studies on  
40 dementia relating to any aspect of social capital identified in step (i). All study designs were  
41 included across all settings. We excluded studies focusing on old-age and frailty.  
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46 Following analysis of the literature from the main search, and discussions within the  
47 research team, an additional search was undertaken to focus the review on emerging  
48 themes. This looked at the influence of social networks and social capital on 'transitions in  
49 care'. This was intended to provide more detail to the contextual influences identified as  
50 important from the main search. There were no pre-specified exclusion criteria, all study  
51 types and settings were included.  
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3 Results from both searches were exported to Endnote X8 referencing software. Duplicates  
4 were removed using automated and manual checking. All citations were reviewed by JS  
5 against the inclusion criteria and a 10% random subsample reviewed by NK.  
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### 9 **(iii) Selecting articles**

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11 All titles and abstracts were screened by JS and included if they were judged to contain data  
12 relevant to the programme theory. Studies did not need to contain all components of the  
13 programme theory so as not to exclude important concepts. Only studies in English were  
14 included. The purpose of selecting and appraising full text articles was not to create an  
15 exhaustive set of studies, but rather to reach conceptual saturation in which sufficient  
16 evidence could be collated to meet the stated aims.<sup>39</sup> At the point of inclusion, based on  
17 relevance, judgments on the rigor and trustworthiness of each source was addressed (see  
18 supplementary file for details). There was significant overlap between relevance and rigor as  
19 data was only selected to modify the programme (i.e. relevant to the research question)  
20 theory when adherent to the chosen methodology (i.e. rigorously conducted).  
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### 30 **(iv) Extracting and organizing data**

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32 Study characteristics were tabulated in Microsoft Word. Sections of text, including  
33 participant quotes, author interpretations and conclusions, relevant to the programme  
34 theory were highlighted in PDF format. Broad themes relating to the highlighted text were  
35 recorded in an Excel spreadsheet. Repeating themes were developed into codes inductively.  
36 Codes were also developed deductively (originating from the initial programme theory). The  
37 codes were refined based on emerging concepts throughout the analysis period. Codes  
38 were developed by asking if the identified information was referring to context, mechanism  
39 or outcome. Upon coding, the original text would be revisited and the highlighted text  
40 reviewed before making a decision. A sample 10% of the coded papers was independently  
41 reviewed by LS for consistency.  
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### 51 **(v) Synthesizing the evidence and drawing conclusions**

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53 Highlighted excerpts, which had then been coded, were transferred into a word document.  
54 This was printed and annotated as themes developed iteratively. As data came to represent  
55 either context, mechanism or outcome it was labelled as such and transferred into  
56 PowerPoint. This was to provide a more flexible work space to construct CMOCs. To develop  
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3 an overall programme theory, we moved iteratively between the analysis of particular  
4 examples, discussion within the research team, refinement of programme theory and  
5 further iterative searching from within the existing data set.  
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9 A realist logic of analysis was applied to synthesize data. This process involves the constant  
10 movement from data to theory to refine explanations for observed patterns. Explanations  
11 were built at a level of abstraction that would cover a range of observed behaviors in  
12 different settings. In order to achieve this, inferences were made about which mechanism  
13 may be triggered in specific contexts. This was necessary as mechanisms were often not  
14 explicitly stated within the literature. The data set was then reviewed to find data to  
15 corroborate, refute or refine developing CMOCs.  
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18 Relationships between context, mechanism and outcomes were sought from within the  
19 same article to which relevant data appeared, but also across sources. Thus it was not  
20 uncommon for a mechanism inferred from one article to explain the way contexts  
21 influences outcomes in a different article.  
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#### 24 **(vi) Writing and engaging with substantive theory**

25 The process of writing helped develop the final programme theory. Narrative is used to  
26 explain the data which in turn enabled us to fine tune our interpretations of meaning and  
27 relevance. Formal theory identified during the search was used to assist in programme  
28 theory refinement by substantiating the inferences made about contexts, mechanism and  
29 outcomes thus enhancing plausibility and coherence.<sup>5 18 40-42</sup>  
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#### 32 **Patient and Public Involvement**

33 Patients and the public were not involved in this research  
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## 36 **RESULTS**

### 37 **Search results**

38 A total of 3199 titles and abstracts were screened leading to a full text review of 182  
39 articles. Seventy-four articles were excluded after assessment for relevance and rigor and 10  
40 added via citation analysis and expert opinion leaving a total of 118 included references  
41 (Figure 1). Of these, 55 used qualitative methods, 28 used quantitative and 5 used mixed  
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3 methods. There were 11 reviews and 19 references that included book chapters, editorials  
4 or commentaries (full characteristics available in the supplementary information).  
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### 7 **Programme theory and CMOCs**

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10 The following sections provide a narrative overview of the programme theory that explains  
11 how social capital may influence end-of-life care for people with dementia. The impact of  
12 social capital is evaluated under 5 categories; (i) socially orientating a person with dementia  
13 following diagnosis; (ii) the process of decision making; (iii) transitions in the physical  
14 environment of care; (iv) how the caregiving experience is viewed by those directly involved  
15 with it, and (v) transition of a person with dementia into the 4<sup>th</sup> age. These five categories  
16 emerged following analysis and clustering of the data from the literature. They represent  
17 areas in which social capital was observed to have significant influence and which may  
18 therefore be targeted for further study and the development of public health interventions  
19 that are specifically seeking to harness the influence of social capital. Due to space  
20 constraints only a selection of CMOCs are presented in narrative form. Definitions of key  
21 terms can be found in table 1.  
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32 **Table 1:** Definition of key terms as used in this review  
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34 <b>Term</b>	35 <b>Definition</b>
36 Context	37 Context was viewed as the backdrop to a person's progressive journey following a 38 diagnosis of dementia. More specifically they were settings, structures, environments, 39 public discourse, conditions, circumstances or specific universally experienced events 40 (such as transitions in the care environment) where social relationships could be seen to 41 directly influence outcomes either positively or negatively. Contexts triggered 42 behavioural and emotional responses (i.e. mechanisms) for both the individual with 43 dementia and those people within their immediate social network (e.g. family and 44 friends).
45 Mechanisms	46 The way in which people with dementia and those involved in their care (both 47 professional and lay) respond to and reason about challenges presented by the 48 progression of dementia. Mechanisms were triggered in specific contexts and led to 49 changes in behaviour and decision making.
50 Outcome	51 Observed points from the literature that resulted from an interaction between specific 52 mechanism and contexts. These points represent outcomes that were observed to be 53 directly influenced by social capital and as such are potential targets for interventions 54 that seek to harness the role of social capital in end-of-life care.
55 Agency	56 Is the capacity of individuals to act independently, to make their own choice and thus 57 bear influence upon their surroundings
58 Agentic influence	59 This is the influence exerted by the agent in question
60 Cognitive social capital	Subjective interpretations of shared understandings held by a close network or group of people
Structural social capital	The presence of a network of access to people and resources both professional and lay
Relational social capital	Feelings of trust shared by people within a social context

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3 (i) Socially orientating a person with dementia following diagnosis  
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5 We found the impact of structural social capital, that is the properties of a social system and  
6 its networks of relations,<sup>25</sup> was pronounced in socially orientating a person following  
7 diagnosis. Structural social capital was therefore viewed as a naturally occurring  
8 intervention that influenced how a person with dementia orientates themselves within the  
9 world. This influence of structural social capital is explained as a function of generative  
10 mechanisms in combination with specific and recurring contexts as seen within the data.  
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12 To explain this, we draw on the sociological concept of liminality; a state of 'inbetweenness  
13 and ambiguity' that often occurs following a serious diagnosis.<sup>43 44</sup> Birt et al describe  
14 movement to a 'post-liminal' state in dementia, a state characterized by interdependency  
15 that allows for the expression of a new identity that can exert influence on the surrounding  
16 environment.<sup>45</sup> This process reflected themes developed from key sources<sup>5 6 45</sup> and the data  
17 set at large.<sup>46-52</sup>

18 For example, we found evidence that where cohesive support networks surround a person  
19 with dementia,<sup>53 54</sup> people are able to live with a sense of purpose<sup>53 55</sup> whilst members of  
20 the network are able to advocate for their perceived wishes through the exchange of  
21 knowledge with other community members.<sup>56-62</sup> Cohesive support networks developed  
22 knowledge or 'expertise' relating to the person with dementia.<sup>49 63</sup> This was accumulated  
23 through the provision of care and equated to 'longitudinal monitoring'.<sup>64-66</sup> Knowledge was  
24 then conveyed through narrative<sup>67 68</sup> to help develop a person's role as an active citizen.<sup>5 45</sup>  
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We also found evidence that with progression of dementia, social networks dwindle.<sup>53 69-71</sup>  
The decline in social connections gave rise to people living in a period of extended liminality  
<sup>45 47 72 73</sup> where uncertainty as to what the future may hold was the generative  
mechanism.<sup>48-52 60</sup> Periods of extended liminality were also noted to be a product of the  
public and bio-medically fuelled discourse that depicts dementia as 'death in the realm of  
the living'.<sup>3 72</sup> This was also noted in situations where people, conscious of their diagnosis,  
experienced uncertainty as to how their views would be interpreted, again leading to a state  
of extended liminality.<sup>45 48-50 73 74</sup> Figure 2 shows a complete set of CMOCs for this section. A  
summary overview of this section shown in table 2. Detailed examples of CMOCs with  
supporting evidence are shown in table 3. A full list is available in the supplementary file.



**Table 2:** Summary of findings

Context
People enter a state of ‘inbetweenness’ or liminality following a diagnosis of dementia
Influence of social capital as an intervention
Social capital, in particular structural social capital influenced the coming to terms with a diagnosis and set the path moving forward
Context specific outcomes
Depending on the context, which would trigger specific mechanisms, people with dementia were found to move into one of three states; (i) Living as an active citizen (ii) living in a state of extended liminality (iii) living in the shadow of the 4 <sup>th</sup> age

**Table 3:** Examples of key CMO configuration’s with supporting evidence for ‘transition to a post liminal state’. The full list is available in the supplementary file

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
CMO: In the context of dementia being perceived as ‘death in the realm of the living’ (C), people with dementia and their wider social network experience fear and trepidation (M) that moves people into a state confined by the shadow of the ‘4 <sup>th</sup> age’ (O)	<p><b>Death in the realm of the living:</b> “Dementia confronts because it seems to bring death into life, implicitly questioning what life, relationship, and death are about.”<sup>3</sup></p> <p><b>Fear</b> “people with dementia are often thought of as tragic, robbed of life, and having lost their personhood.”<sup>3</sup></p> <p><b>The 4<sup>th</sup> age</b> “It is when people are no longer “getting by”, when they are seen as not managing the daily round, when they become third persons in others’ age-based discourse, within others’ rules, that they become subjects of a fourth age”<sup>75</sup></p>
CMO: In communities of identity (C), people with dementia have a sense of purpose (M) which allows them to grow and maintain a role as an active citizen (O)	<p><b>Communities of identity</b> “This centre provides day care for those living with dementia but instead of playing games or receiving passive entertainment the main program is about the design and production of the mid-day meal. Seniors with dementia are asked to jointly design the meal, then to go out shopping together to buy the ingredients, and then return to help prepare the meals. Shopkeepers are briefed on the program and willingly participate in the program, learning and experiencing the complexities of communicating with seniors with dementia and also Compassionate communities gaining insight into the complexities of their care while sharing this in a small way.”<sup>55</sup></p>
CMO: As dementia progresses a person may change their perceptions and views on various issues (including death) (C), they maintain their role as an active citizen (O) by conveying these views through their agentic influence (M)	<p><b>Changing perceptions:</b> “Relatives and staff need to be aware that the person’s attitude to death may evolve during their dementia. When a comparison was made between participants’ attitudes to death and those ascribed to them by their family carers, for some people they appeared to have changed.”<sup>67</sup></p> <p>“(Husband) had a bit of a health crisis about 12 months ago...when he came out of this acute crisis, he said to me he was afraid people that people would turn off the switch. So there was a complete change of his limited understanding...(now) I don’t know whether I’m actually fulfilling his wishes.”<sup>54</sup></p>

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3 (ii) Decision making processes  
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5 The decision making process acted as a vehicle to move between outcomes and was heavily  
6 influenced by 'cognitive social capital'. Cognitive social capital relates to the shared  
7 representations and interpretations of meaning held by involved parties.<sup>25</sup>  
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11 Cognitive social capital was viewed as an intervention that became influential at times of  
12 decision making. Its influence is explained as a function of generative mechanisms in  
13 combination with specific and recurring contexts as seen within the data.  
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17 This process was particularly evident in the context of advance care planning.<sup>54 68 76-78</sup> Here  
18 decision making processes are influenced by a family's power as a surrogate decision maker.  
19 Mechanisms included the maintenance of a historic identity,<sup>77 79</sup> growth of a new identity,<sup>67</sup>  
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23 <sup>76 80</sup> discrimination against a person with reduced agency,<sup>52 76 78</sup> compassion towards a  
24 person affected by dementia and 'knowledge exchange' between caregivers and  
25 professionals.<sup>19 61 67 69 76 77 79 80</sup>  
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29 Decision making was facilitated by 'case based theory' rather than 'principal theory' <sup>79</sup> i.e.  
30 when faced with a 'what's best scenario', families use factors important to the individual as  
31 opposed to humanity in general. Here narrative relating to the person with dementia is of  
32 prime importance. Depending on how the caring network developed this narrative, i.e.  
33 through mechanisms such as identity growth, knowledge exchange, paternalism or identity  
34 maintenance, the outcome would vary.<sup>41 49 60 61 68 79 81 82</sup>  
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40 The influence of supportive care networks, both professional and lay, were not uniformly  
41 positive. Decision making was found to be subject to the independent 'volitions and  
42 agendas' of a care network or the paternalistic actions of professionals. These mechanisms  
43 lead to discrimination against the person with dementia in certain contexts.<sup>52 57 59 71 72 76 78 79</sup>  
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48 Table 4 provides a summary of findings for this section. Figure 3 shows a complete set of  
49 CMOs with detailed examples described in table 5.  
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52 When considering the decision making process from the perspective of the family or main  
53 carers, we found the same contexts and mechanism were in operation. The CMO  
54 configurations are configured to outcomes relevant to the care network in figure 4.  
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**Table 4:** Summary of findings

Context
As dementia progresses decisions relating to all aspects of life present challenges that come thick and fast.
Influence of social capital as an intervention
Shared representations and interpretations of meaning held by social networks influenced decision making
Context specific outcomes
(i) Living in extended ambiguity; (ii) Living as an active citizen; (iii) Living in the shadow of the 4 <sup>th</sup> age

**Table 5:** Examples of key CMO configuration’s for the ‘decision making process’ with supporting evidence. The full list is available in the supplementary file

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
CMO: Families used ‘case based theory’ rather than ‘principal theory’ when making decisions. Here narrative relating to the person with dementia is of prime importance (C). A more rewarding care experience occurs (O) with the use of agency (M), identity growth (M), and knowledge exchange (M).	<p><b>Primacy of narrative:</b> “The ethical approach implicit in these families’ descriptions are consistent with a case-based theory, rather than a principle theory. When these family decision-makers utilized an abstract concept such as human dignity, they did so in a limited manner by discussing the factors that were important for the dignity of their relative, rather than for human dignity in general. They did not invoke patterns or principles from beyond their own experience.” <sup>79</sup></p> <p><b>Identity growth:</b> “She had always been shy and didn’t want to entertain people. Yet, when her inhibitions were lost because of the Alzheimer’s, she would get excited when people visited. She enjoyed the Bible study in our home every Friday evening. One day I was late getting her up from a nap, and students were already arriving. I woke her, asking if she wanted to see the students coming. She jumped out of bed, replying, “I think they’ll want to see me.” Indeed, she did have a special relationship with the students.” <sup>61</sup></p> <p><b>Knowledge exchange:</b> “Inclusion was facilitated in other ways such as knowing the preferences of the person through previous interviews with them and their family, or by asking family members about what those preferences might be, building a biographical understanding of the person and being informed by that.” <sup>81</sup></p> <p><b>Rewarding experience:</b> “I think whatever you do, you’ve got to do it with a relatively good grace. If you feel that you’ve been pushed into it, or you’re obliged to do it, then I think it won’t work.” <sup>60</sup></p>
CMO: Where there is interaction with professional care services (C) the decision making process can be facilitated to increase a persons role as an active citizen (O). Mechanisms include compassion, knowledge exchange, and confidence/autonomy (M).	<p><b>Knowledge exchange:</b> “I was able to tell the doctor what was going on with my mom. And he was grateful for the knowledge. He told me what to expect and when to call the clinic. I felt better prepared after that.” <sup>49</sup></p> <p><b>Confidence/autonomy:</b> “So they’re sort of pre-empting what they know is going to happen. [Yes] See I don’t necessarily know that’s gonna happen so they’re kind of giving me that information. “Look, you know, you’re gonna be heading down this road soon so you may wanna do this, this and this.” So it’s helping me to future plan [Yep] which I find very helpful”.<sup>82</sup></p>
CMO: In a state of liminality characterised by indecision and uncertainty (C), medical	<p><b>Paternalism/authority:</b> “So long as you say... ‘doctor’ in the sentence . . . she will go along with that, she will listen to that authority so that’s been good actually.” (daughter) <sup>60</sup></p>

<p>paternalism and authority (M) can provide some direction allowing the decision making process to proceed with more fluidity but maintain a state of liminality and loss of control (O)</p>	<p><i>My mother was asked what she thought and said, “Whatever the doctor thinks is best.”<sup>47</sup></i></p> <p><i>“The second strongest influence affecting the decisions of both groups...was the advice of the physician...”<sup>83</sup></i></p> <p><i>“You accept it because it’s easy...I think to meself [sic] ‘they are only trying to help you so let them do what they think is best’.”<sup>73</sup></i></p>
<p>CMO: Where relationships with a caring network become strained (C) a sense of guilt (M), failure (M) and uncertainty (M) in addition to the paternalistic actions of professional care networks (M) can cause the caregiving experience to become overwhelming (O)</p>	<p><b>Strained relationships:</b> <i>“It’s a different thing when Mum (person with dementia) was living with us. He (participant’s husband) just didn’t handle things, and I was between the devil and the deep. I didn’t want to -Mum needed the care. I felt that she wasn’t ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly”<sup>72</sup></i></p> <p><b>Guilt:</b> <i>“The doctor said my mom could not live alone. You know, I love my mom, but she could not come and live with us. It would have disrupted my whole family. I know it is terrible to call your mother a disruption. What a guilt trip.”<sup>84</sup></i></p> <p><b>Paternalism:</b> <i>“...healthcare professionals unfamiliar with the family and the resident’s individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact.”<sup>71</sup></i></p> <p><b>Uncertainty:</b> <i>“...thus, critical issues of personhood, identity, agency, and control were embedded in our moms’ experiences and reflected in our experiences as families as we struggled to “do what was right.”<sup>50</sup></i></p> <p><b>Overwhelming:</b> <i>“I had no one to look after mum, so I couldn’t go to work, and I do believe that that impacted and I do believe that that’s one of the reasons that they fired me. Because I couldn’t attend work because I had to look after mum”<sup>63</sup></i></p>
<p>CMO: Where powerful structures of care become involved (C), feelings of failure (M) and a loss of autonomy (or paternalism from healthcare professionals) (M) can lead to a care experience that feels overwhelming (O)</p>	<p><b>Professionalised care:</b> <i>“Dementia starkly reveals the Cartesian biomedical model’s incomplete understanding of “health,” through its inability, even unwillingness, to develop effective (non-biomedical) interventions to address a range of experiences of disease in their social, relational context.”<sup>3</sup></i></p> <p><i>“...carers experience in receiving formal services is inherently ambiguous, for whilst formal services are providing support to family carers, they can also be undermining their sense of identity and control over their circumstances...”<sup>63</sup></i></p> <p><b>Loss of control/autonomy in the care role:</b> <i>“Oh God no, they did everything, all I had to do was go and visit and feed her. Didn’t even have to feed her but I liked to.”<sup>58</sup></i></p>

### (iii) Transitions in care

Much of the data focused on transitions for people into hospital or long term care as a primary outcome.<sup>56 84-87</sup> To understand the influence of social capital as an intervention in this setting, we drew upon Bourdieu’s work that implies social capital is deeply reliant on the context of a particular social space.<sup>22</sup>

The data revealed that transitions in the care environment occur as a function of progressive illness, often as a necessity rather than something to be prevented.<sup>88 89</sup> We found that transitions in the care environment were therefore operating as context as opposed to an outcome. The full CMO configurations are available in figure 5.

Transitions occurred within a person’s home as professionals entered and changed the physical space. They also occurred when a person moved out of the home into an alternate care environment.<sup>90-92</sup> The process of physical transition acted as an interface upon which supportive networks of care would convene along with the person with dementia and professional care services. The outcomes of this process contribute to the post-liminal states previously described but also help define the care experience for those within the main care network. Rather than being mutually exclusive endpoints, people would move between outcomes based on the contexts and mechanism described. Table 6 gives a summary of the findings from this sections and table 7 gives detailed examples of CMOs with supporting evidence.

**Table 6:** Summary of findings

Context
Transitions occur as a function of progressive illness. Transitions are often a necessity rather than something to be prevented.
Influence of social capital as an intervention
Social capital bore great influence not on whether the transition occurred or not but more how the process unfolded and was perceived by the person with dementia and their wider social network
Context specific outcomes
(i) Overwhelming care experience; (ii) Rewarding care experience; (iii) Living in shadow of 4th age , (iv) living as an active citizen; (v) Living in extended ambiguity

**Table 7:** CMO configurations with supporting evidence for ‘transitions in the care environment’

Context (C)-Mechanism (M)-Outcome(O)
CMO: As dementia progresses and manifest as changes in behaviour and social relationships transitions occur to the care environment, these might involve the person moving or objects moving into what was previously the home environment. Either way, the space as it previously was, transitions to something new (a hybrid space in the home) or an entirely new space in some form of institutional care (nursing home, hospital, sheltered accommodation). These transitions (C) have outcomes relating to the individual: Living in extended liminality; living as an active citizen; living in the shadow of the 4 <sup>th</sup> age, and to the individuals care network; rewarding care experiences; overwhelming care experiences and transfer of acquired skills outside of care network (O). Mechanisms identified include duty, paternalism, compassion, routinisation,

reciprocity, narrative, resilience, discrimination, teamwork, identity growth, identity maintenance, grief, loneliness and knowledge exchange (M)

**Example of supporting evidence from the literature**

**Transitions:** "I tend to think that people with dementia do want familiar; it's the change that is difficult to cope with and the familiar things are personal things, if we're talking about residential care, to bring in personal things of theirs, whether it was his music, I know my husband did a lot of photography as a hobby... and he had the photographs there...and when he did go into respite, we took the same pictures, I think, that was important to him."<sup>91</sup>

**Transitions in the home:** "Although all the care recipients and their family caregivers indicated a strong preference for home care over institutional care, their experiences and practices within their homes were disrupted and reconfigured by the insertion of logics emanating from the healthcare field"<sup>90</sup>

**Duty:** "Another difference was in the sense of obligation for family members to provide care for their next of kin through the course of the disease..."<sup>93</sup>

**Guilt:** "I visit here many times, but every time I am so ashamed. This place is like a dumpster where you throw away things, a place for well-off daughters' in-law to throw away their parents-in-law. I felt so guilty in front of the nursing assistants to be a child of one of these elderly people. I don't even dress nice when I come here because I'm afraid of what people will say of me since I've brought my parents over here."<sup>94</sup>

**Reciprocity:** "Mom also taught me more about love. I learned to express my love. Because I knew she would easily forget, I would remind her many times a day that I loved her. Each time I did, she would light up with a smile. It brought me much joy to see her receive my love. Often when I was helping her, she would kiss me on the arm, whisper "I love you," or say "Thank you." .... I realized the more I said, "I love you," the more love grew"<sup>61</sup>

**Resilience:** "It is surprising that behavioural disturbances are one of the major reasons for admission in RUD (rehabilitation unit for dementia), but they are not risk factors for institutionalization after discharge. The process mediating the association between BPSD (behavioural and psychological symptoms of dementia) and placement may be the ability of the caregiver to tolerate such behaviours and not BPSD by themselves."<sup>95</sup>

**Growth and liminality:** "... participants show an orientation to the present and the future that contains growth on the one side and vulnerability on the other. Growth concerns personal growth and developing new ways in which to organize their lives. Aspects of vulnerability include declining health, possible dependence, coping with growing older, and being concerned with finitude."<sup>46</sup>

**Grief:** "This transition (to long term care) can also highlight the sadness that marks the end of a long-standing relationship."<sup>96</sup>

"I had to keep reminding myself that the disease took away the dad I once knew"<sup>97</sup>

**Loneliness:** "I don't actually call them that much, but just knowing they are there is a tremendous source of help..."<sup>98</sup>

**Knowledge exchange:** A lack of communication or information sharing appeared to be a key reason why older adults and caregivers felt ignored, forgotten or unimportant"<sup>86</sup>

**Conflict:** "You tell him that I absolutely refuse for them to do anything with my father. Unless a doctor calls and tells me that I have to do something, it's gonna stay the way it is now'. And I said, 'If he doesn't like it, and he thinks he's gonna cause you trouble, you tell him that I'm gonna go get me a lawyer, and I'm gonna call Channel 5...'"<sup>79</sup>

(iv) The care-givers experience

The care-givers experience brought up themes relating to the concept of relational social capital, that is aspects such as trust, trustworthiness and norms.<sup>25</sup> Here relational social

capital is conceptualised as the intervention that works to define a care givers experience through combinations of observed contexts and mechanisms.

Much of the empirical data focused on the negativity associated with care.<sup>11 48 49 59 63 64 99-101</sup>

However, we found evidence of the positive aspects of caregiving which was noted as an important outcome. For example, where relationships with a caring network become strained,<sup>11 63 72 102</sup> the exchange of knowledge and trusting relationships<sup>57 58 71 99</sup> generated rewarding aspects to the care experience.<sup>5 51 103-105</sup>

In certain conditions there was also evidence of the skills acquired through the caregiving process being transferred to wider community networks. For example, when a person with dementia died, the void in reciprocity experienced during caregiving, and a sense of duty, can drive people to transfer their skills to the community.<sup>55 61 82 89 93 106-109</sup> The full list of mechanisms and associated contexts are shown in figure 6. A summary of this section is in table 8 and selected CMO configurations described in table 9.

**Table 8:** Summary of findings

Context
Positive and negative aspects to caregiving are reported in the literature
Influence of social capital as an intervention
Shaped how the caregiving experience was viewed aspects are under-researched
Context specific outcomes
(i) Rewarding care experience; (ii) Overwhelming care experience; (iii) Transferring of skills to the community

**Table 9:** CMO configurations with supporting evidence for the 'caregiver's experience'

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
CMO: When a person with dementia dies (C), the void in reciprocity experienced during the care giving relationship (M) and a sense of duty (M) can drive members of the caring network to transfer their skills to the community (O)	<p><b>Reciprocity:</b> "...yet many aspects of my experience were positive. My father and I had conversations about his memories of his older relatives that I doubt we would have had otherwise. Sharing the ups and downs of caregiving with my sister also brought us closer together. It was the first time that we had discussed our values about caregiving (despite having witnessed our mother's experience), money, and ultimately, end-of-life care..."<sup>105</sup></p> <p><b>Duty:</b> "As a son, taking care of my parents is my responsibility. Sometimes, my sisters come back home to care for my father, but they have already married out [of the family]. They are guests. It's not their responsibility. I appreciate their assistance though. However, my brother and I have the ultimate responsibility to take care of our parents."<sup>110</sup></p>

	<p><i>"I just took it as that was part of my life goal, to take care of them... It's stressful, but sometimes it's rewarding."</i> <sup>104</sup></p> <p><i>"...if you have to have something bad happen to you, to be able to turn it into something positive that helps other people, it's a good thing to do... I like to say when I go out to speak that I have a lot of passions, that I have passions for gardening and for hiking and for quilting... I chose those passions, and then I have a passion that chose me, and that's what Alzheimer's is... I think there are ways to give of yourself that sort of replace that caregiving role... working with the Alzheimer's Association and that work that I do- I think that's filled the void."</i> <sup>104</sup></p>
<p>CMO: Where relationships with a caring network become strained (C), the exchange of knowledge (M) and trusting relationships (M) generated positivity and rewarding aspects to the care experience (O)</p>	<p><b>Strain:</b> <i>"Initially life seemed unbearable. My mother was incontinent, hallucinating, and disoriented. At one point she stayed awake for 40 hours seeing people, places, and things that weren't there. We were exhausted. But in time, she showed signs of improvement."</i></p> <p><b>Knowledge exchange:</b> <i>"I think just their reassurance...there is nothing physically they can do...they just reassure you.... That you are doing the right thing, more than anything, because sometimes you do doubt yourself"</i> <sup>62</sup></p> <p><b>Trust:</b> <i>"External support resources from the community or charitable organizations were a key feature for some. Specifically, reliance on neighbours or being members of a close community gave reassurance of their relative's safety when they were not present..."</i> <sup>71</sup></p> <p><b>Rewarding aspects to care:</b> <i>"When my mother died from a fall, I reflected on the satisfaction and peace I had not anticipated I would feel. I knew what it was to "give back" to my mother. It seems incredible that caregiving can be so satisfying. I look into her bedroom now and I can feel her presence...and I am thankful for the final gift she gave me."</i> <sup>103</sup></p>
<p>CMO: Where relationships with a caring network become strained (C) a sense of guilt (M), failure (M) and uncertainty (M) in addition to the paternalistic actions of professional care networks (M) can cause the caregiving experience to become overwhelming (O)</p>	<p><b>Strained relationships:</b> <i>"It's a different thing when Mum (person with dementia) was living with us. He (participant's husband) just didn't handle things, and I was between the devil and the deep. I didn't want to [move to a care home]-Mum needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly"</i> <sup>72</sup></p> <p><b>Guilt:</b> <i>"The doctor said my mom could not live alone. You know, I love my mom, but she could not come and live with us. It would have disrupted my whole family. I know it is terrible to call your mother a disruption. What a guilt trip."</i> <sup>84</sup></p> <p><b>Paternalism:</b> <i>"...healthcare professionals unfamiliar with the family and the resident's individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact."</i> <sup>71</sup></p> <p><b>Uncertainty:</b> <i>"...thus, critical issues of personhood, identity, agency, and control were embedded in our moms' experiences and reflected in our experiences as families as we struggled to "do what was right."</i> <sup>50</sup></p> <p><b>Overwhelming:</b> <i>"I had no one to look after mum, so I couldn't go to work, and I do believe that that impacted and I do believe that that's one of the reasons that they fired me. Because I couldn't attend work because I had to look after mum"</i> <sup>63</sup></p>



<p>CMO: Where powerful structures of care become involved (C), feelings of failure (M) and a loss of autonomy (or paternalism from healthcare professionals) (M) can lead to a care experience that feels overwhelming (O)</p>	<p><i>“Hospitalisation of the person with dementia was also described as a challenging time. Carers may have taken responsibility for all of the caring, believed they knew the person and their needs most intimately and taken responsibility for decision-making; however, when the person with dementia is admitted to hospital, the carer is usually no longer primarily responsible for these things and he/she can experience an acute loss of control. In addition, vulnerable family caregivers can feel disempowered by the health care system, especially when they are not recognised as the expert in the care of their relative and not appropriately included in decision-making”<sup>72</sup></i></p>
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(v) Dementia progression and the 4<sup>th</sup> age

The final aspect of our programme theory investigates the role of social capital in the context of entry into a state of complete dependency known as the ‘4<sup>th</sup> age’.<sup>75</sup> At this point, a person’s ability to influence their surroundings is reduced, social networks have diminished and pre-formed close contacts hold a narrative that is referred to during decision making.<sup>53 69-71 82 108 109</sup> Where social networks have diminished, the routinisation of paternalistic care and the ignominy of this can lead to people entering the 4<sup>th</sup> age,<sup>59 70 75 108</sup> <sup>111</sup> see figure 7 for complete CMOC, table 10 for a summary and table 11 for evidenced examples.

The 4<sup>th</sup> age has been theorized as a ‘black hole’ into which the effort and energy of caring falls into.<sup>75</sup> We found no evidence of the reciprocity associated with dyadic caring relationships. There was however evidence of people transferring their acquired caring skills to the community. We hypothesize that this would result in the acquisition of network members that may contribute to care. Ultimately this may begin to bring a shift in how society views someone dying with dementia, thus contributing to the way a person becomes a ‘person with dementia’ in the first instance. We did not find empirical data to corroborate this theory.

Figure 8 provides an overarching programme theory that depicts the relationship between each of the 5 subsections. Links represented by a dashed line represent unsubstantiated theory. The multiple contexts explored through the results section are situated in our programme theory under the umbrella terms; ‘liminal state –figure 2’; relevant decision making – figure 3 and 4; caregiving – figure 6; progressive illness – figure 7.

**Table 10:** Summary of findings

Context
A person's ability to influence their surroundings is markedly reduced and social networks have diminished
Influence of social capital as an intervention
Can impact on how caregiving skills are transferred to the community
Context specific outcomes
(i) Rewarding care experience; (ii) Overwhelming care experience; (iii) Transferring of skills to the community

**Table 11:** CMO configurations with supporting evidence for transitioning to the 4<sup>th</sup> age

Context (C)-Mechanism (M)-Outcome(O)	Example of supporting evidence from the literature
CMO: Where there is a public failure of self-management (C), a person enters the 4 <sup>th</sup> age (O) via mechanisms including institutionalisation (M), ignominy (M) routinisation of care (M).	<p><b>Public failure of self-management:</b> <i>reflections from a paid carer, "Not being able to take responsibility, not knowing that things (food) are mouldy or at the expiration date. Not knowing when you need to clean up (the house) and also not knowing how to perform certain actions."</i> <sup>70</sup></p> <p><b>Ignominy and routinisation:</b> <i>"this condition was devastating to watch, to [wife's name] who was always rather coy, shy about the activities of bodily functions, to have her more or less on a timeslot and put into a machine, 'cos they'd had lunch, lifted up and wheeled into the toilet – that was very devastating . . . I didn't like to see her suffering these sorts of indignities."</i> <sup>59</sup></p> <p><i>"She passes stool and handles the faecal matter. Makes a mess and this then cannot be cleaned. The whole household stinks. There is smell of faeces always. Nobody will help. Even my husband, that is her own brother, does not want to be at home. He cannot stand the bad smell."</i> <sup>111</sup></p>
CMO: Where communities of identity exist (C), people with dementia are seen to go about their business, their growth and development is then visually acknowledged so people develop an understanding of their needs and daily challenges. Through compassion (M) this may aid community development (O)	<p><b>Communities of identity:</b> <i>...where people living with dementia are normalized not only in terms of their day care activity—by not being treated as passive consumers of 'treatments' or 'services' but as active agents of their own preferences and activities—but also as people to be publicly seen going about their usual business. Furthermore, people not directly involved with care for people living with dementia are encouraged to participate in that care and to obtain basic understandings of both the challenges of living with dementia and also the challenges in its daily care. Thus the levels of public education about living with dementia and its care are significantly raised...."</i> <sup>55</sup></p>

## DISCUSSION

### Summary of findings

This realist review of 118 studies has begun to uncover the complex relationships involved in the end-of-life journey. We have shown that human relationships, at an interpersonal,

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3 community and professional level, help shape decision making thus bringing about change  
4 through key transitional states. Importantly these relationships have the power to dictate  
5 outcomes yet their influence is not uniformly positive.  
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9 The review acknowledges the importance of the multiple contexts within which end-of-life  
10 care is played out. In doing so we do not aim to produce evidence about the relative  
11 advantages or disadvantages of interventions that improve end-of-life care. We instead  
12 argue that that the complexity inherent in the process requires in-depth understanding and  
13 multifaceted solutions. By exploring the underlying mechanisms that occur within certain  
14 contexts, we have developed a provisional theory that may act as a starting point on which  
15 to build, whilst helping public health interventions to be tailored more effectively.  
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### 22 **Comparisons with existing literature**

23  
24 Despite a growing evidence base on the role of social networks and social capital in  
25 healthcare there is still significant emphasis on professionally enacted interventions.<sup>48 99 100</sup>  
26  
27 <sup>112</sup> This emphasis is underpinned by a culture that seeks immediately recognizable outcomes  
28 of mutual benefit to care receivers and providers. We found that where care is disjointed  
29 from how it has evolved in the home, it is less likely to bring meaningful results or be valued  
30 by those involved in the day-to-day care of a person with dementia.  
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36 A public health approach to palliative care promotes the development of communities that  
37 share responsibility for the care of the terminally ill and the bereaved.<sup>55</sup> Dementia however  
38 is an illness like no other, the cognitive changes can outstrip the physical leading to a rapid  
39 dissolution of social capital on which this theory is dependent. In addition, the public  
40 discourse and fear that surrounds dementia, reinforces the polarized view that caring for  
41 these people is primarily the responsibility of immediate family or of health and social care  
42 services.  
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49 Our results suggest that as people affected by dementia take a more active role in society,  
50 there is potential for growth and change to the broader sociopolitical dynamic and  
51 structures that influence public perception of dementia. Whilst the individuals' social  
52 networks may dwindle, there is potential for community growth through the transference  
53 of skills acquired. This concept is recognized by Bartlett's social citizenship theory and its  
54 implications for social and health care practices.<sup>5</sup>  
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## Recommendations for policy and practice

### (i) Making death, dying and dementia everyone's business

Our findings stress the importance of human relationships across a range of interlinking networks that impact on care outcomes. Given this, it would not be adequate to implement interventions that target one specific group (lay or professional). Rather a cultural shift is required across wider societal and organisational practices that contribute to notions of responsibility and duty of care. Below are a series of practical points as to how this might be achieved.

#### *Promote early engagement with existing social networks and social structures*

When cohesive networks of people form around a person with dementia it is more likely they will be empowered to live as an active citizen. This is more likely to occur and have lasting benefits if it is done at an early stage.

To achieve this outcome employers of people with dementia, and of people who care for someone with dementia, need to accommodate for their needs. Families, and those lay people directly involved with care, need to acknowledge that dementia may lead to a change in identity. Allowing this identity to grow rather than trying to maintain a historical identity can facilitate a person with dementia becoming an active citizen and allow a more positive care giving experience that focusses less on grief and loss. At the same time professional bodies must work to change the frequently encountered discourse that dementia is simply 'death in the realm of the living'. This must be done at every level of our medical institutions not least in the way dementia is taught at undergraduate level.

#### *Facilitate decision making*

We must facilitate decision making processes by shining a light on how cognitive social capital influences decision making. For example, advance care planning should not be prescribed for all as a measure of ubiquitous value. Instead we must use the information from this review which outlines how decisions are made and their potential to sometimes marginalize the expressed wishes of someone with dementia. Using this, more tailored public health interventions can be built to ensure decision making upholds a person's role as an active citizen.

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3 *Understand transitions in the care environment as a process to be influenced rather than an*  
4 *outcome to be avoided.*

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7 When transitions occur, the outcome is more likely to be positive when professionals and  
8 lay networks of care convene around themes of narrative and identity growth relating to the  
9 person with dementia. Understanding the influence of social capital in determining how this  
10 process unfolds is likely to yield more positive results than focussing on preventing  
11 transitions in care.  
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17 (ii) Promote the message that health and illness can and do co-exist

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19 We found numerous anecdotes of joy within the literature. Joy involved in the caregiving  
20 process, joy felt at life events experienced by people living with dementia. Acknowledging  
21 that life continues as illness progresses is key to engaging people from all backgrounds in  
22 the care process. Greater publicity and acknowledgement of the skills acquired in care  
23 giving and the rewards of this role are needed.  
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29 (iii) Create a platform for mutual knowledge exchange between professionals, people  
30 with dementia and lay members of their care network

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33 We found that where care is provided in a routine, top down manner, irrespective of a  
34 person's evolving identity and the knowledge and expertise held by their care network, the  
35 process becomes fraught with conflict. In order to harness the therapeutic potential of  
36 caring relationships we should instead foster an environment of mutual knowledge  
37 exchange whilst appreciating that limitations exist on either side of the professional - lay  
38 divide. This needs to be better incorporated into training for professionals looking after  
39 people with dementia.  
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46 (iv) Acknowledge and value the skills developed through caregiving as tools for  
47 community development

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50 We found that people develop a unique skill set through caregiving. In certain contexts  
51 there is potential for the transference of these skills to the community. This may aid  
52 community development thus contributing to the wider cultural shift outlined in (i).  
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### Strengths and limitations

This review has been conducted in accordance with the methodological guidance for realist reviews as described in the RAMESES quality standards.<sup>32</sup> The use of a broad search strategy was particularly helpful when evaluating an often ambiguous term such as social capital. The iterative nature of both the search and analysis has allowed us to contextualize our definition of social capital. Realist methodology has also allowed us to focus on how contexts influence the variety of outcomes seen in end-of-life care. By identifying generative mechanisms we hope to have articulated findings that are relevant across a range of settings.

Naturally our findings are limited by the quality, breadth and specificity of available literature. We found social networks were often studied from a narrow perspective and defined as a set of dyadic relationships rather than communities of individuals. Social networks were often examined from professionally centered perspectives meaning they were used as a metaphor for 'lay' or 'informal' caring. Social networks therefore became synonymous with a rather generic approach (e.g. partner, family or friends) which were rarely differentiated or compared. End points were frequently studied from a medical perspective (e.g. hospital admission, nursing home transfer) leading to the assumption that medically defined priorities match those of the individual and their care network. The lack of empirical evidence suggests that whilst human relationships can be demonstrated to impact on care trajectories, the specific functions and their relationships with specific community or network structures could not be explored in any detail.

In using a systematic realist approach we hope that our programme theory can be applied across a range of populations. At the same time we recognize that inferences drawn from the data are subject to the lead researcher's perspective. Reflexivity is key in conducting such work and therefore the context and personal assumptions of the main researcher were considered when reviewing references. Regular review of the emerging programme theory within the research team was also helpful in addressing this. We did not have a lay person affected by dementia to review gaps and inconsistencies with CMOCs. This combined with gaps in the empirical data mean our programme theory is likely to need modification as our knowledge of the topic expands.

## CONCLUSIONS

Comparatively few interventions and or end-of-life policies are designed to address the complexities highlighted by the multiple contexts and mechanisms identified in this review. As a public health approach to palliative care gathers pace it is important that 'community' or 'social capital' is not viewed as a universal solution to the mounting public health crisis. This study highlights the need to take a more dispassionate approach, studying its potential in all its complexity in order to further understand what works for whom and in what circumstances.

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**Data availability statement:** All additional data available via the supplementary file

## Figure legends

**Figure 1:** PRISMA diagram

**Figure 2: Context–mechanism–outcome configuration for ‘transition to a post liminal state’:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

**Figure 3: Context–mechanism–outcome configuration for decision making from the perspective of a person with dementia:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

**Figure 4: Context–mechanism–outcome configuration for decision making from the perspective of the caregiver:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

**Figure 5: Context–mechanism–outcome configuration for ‘transitions in the care environment’:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

**Figure 6: Context–mechanism–outcome configuration for the ‘caregiver’s experience’:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

**Figure 7: Context–mechanism–outcome configuration for dementia progression & transitioning to the 4<sup>th</sup> age:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

**Figure 8: Overarching programme theory:** Rectangle = outcome; Rounded edge rectangle = context; Broken border = umbrella term for multiple contexts identified in corresponding figure; Arrow = signifies CMO configuration; Broken Arrow = unsubstantiated theory without supplementary CMO data



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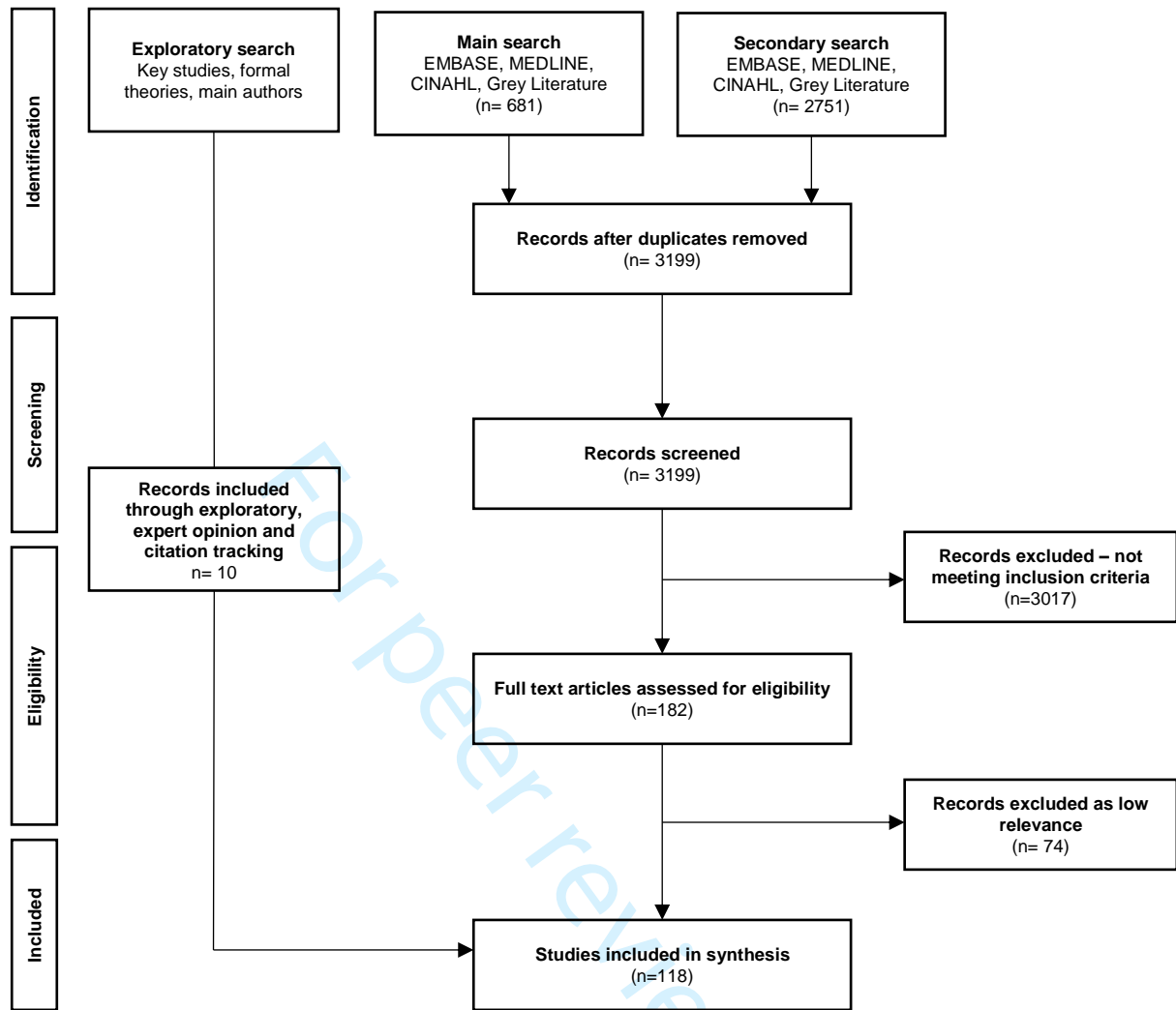
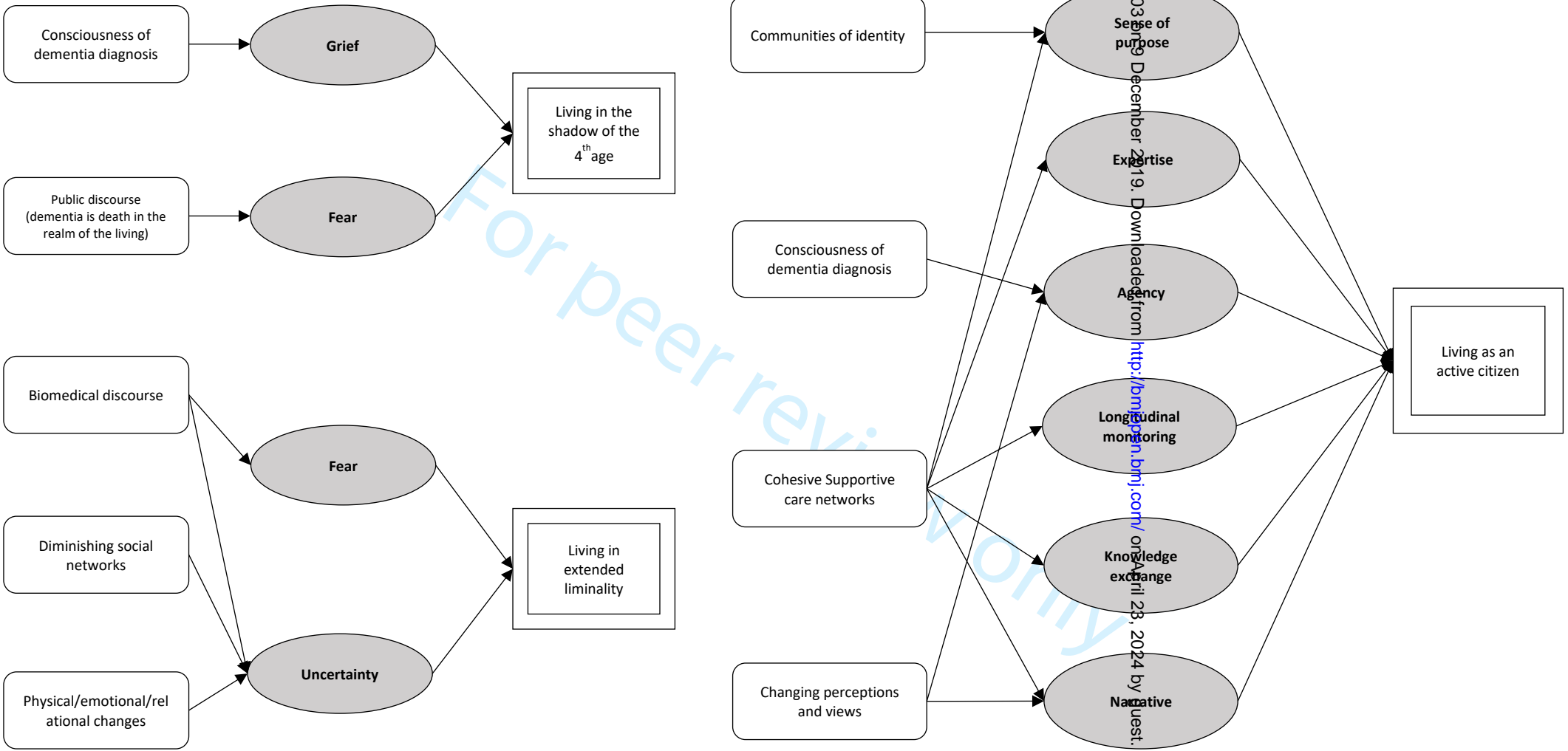


Figure 1: PRISMA diagram

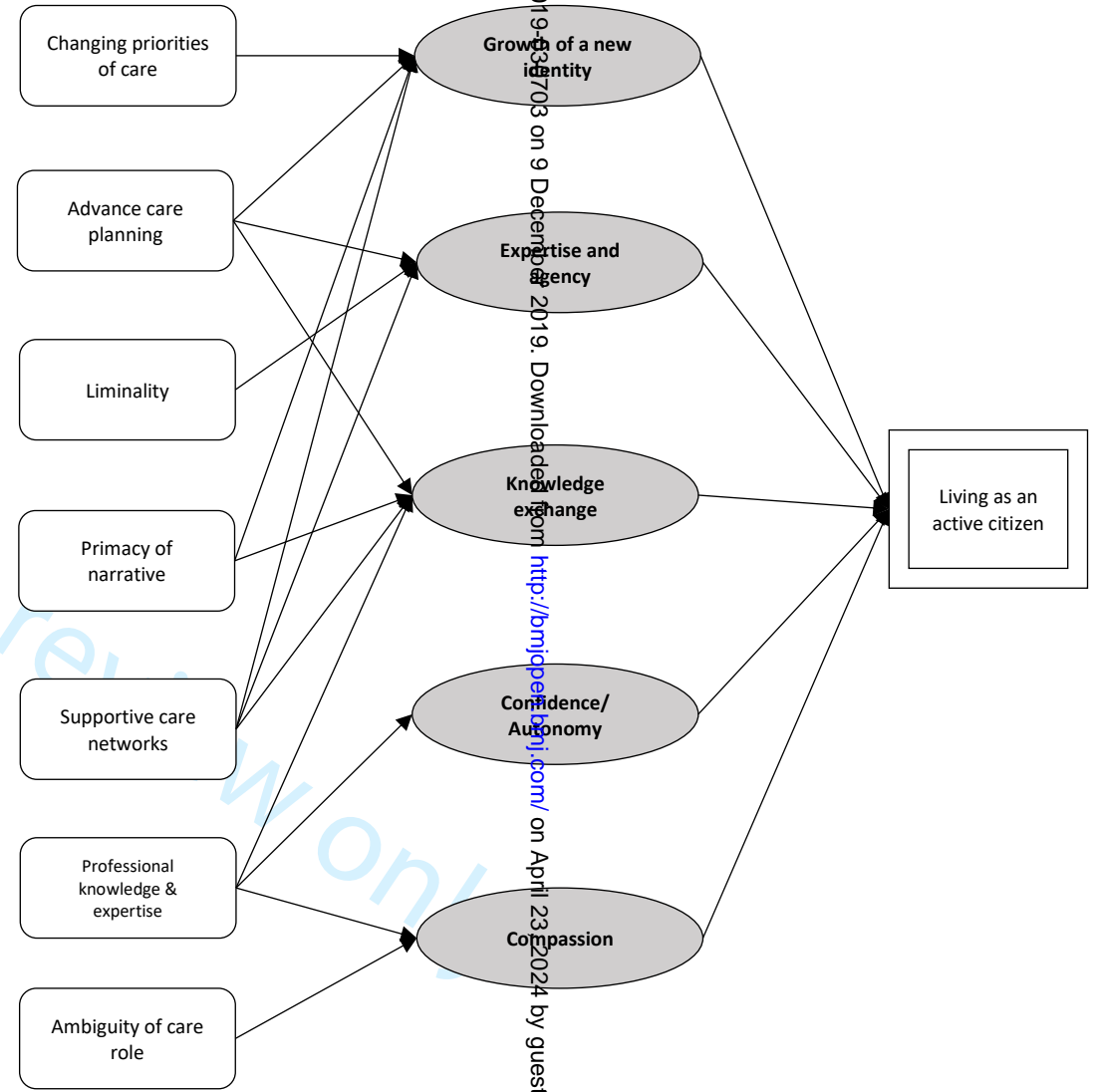
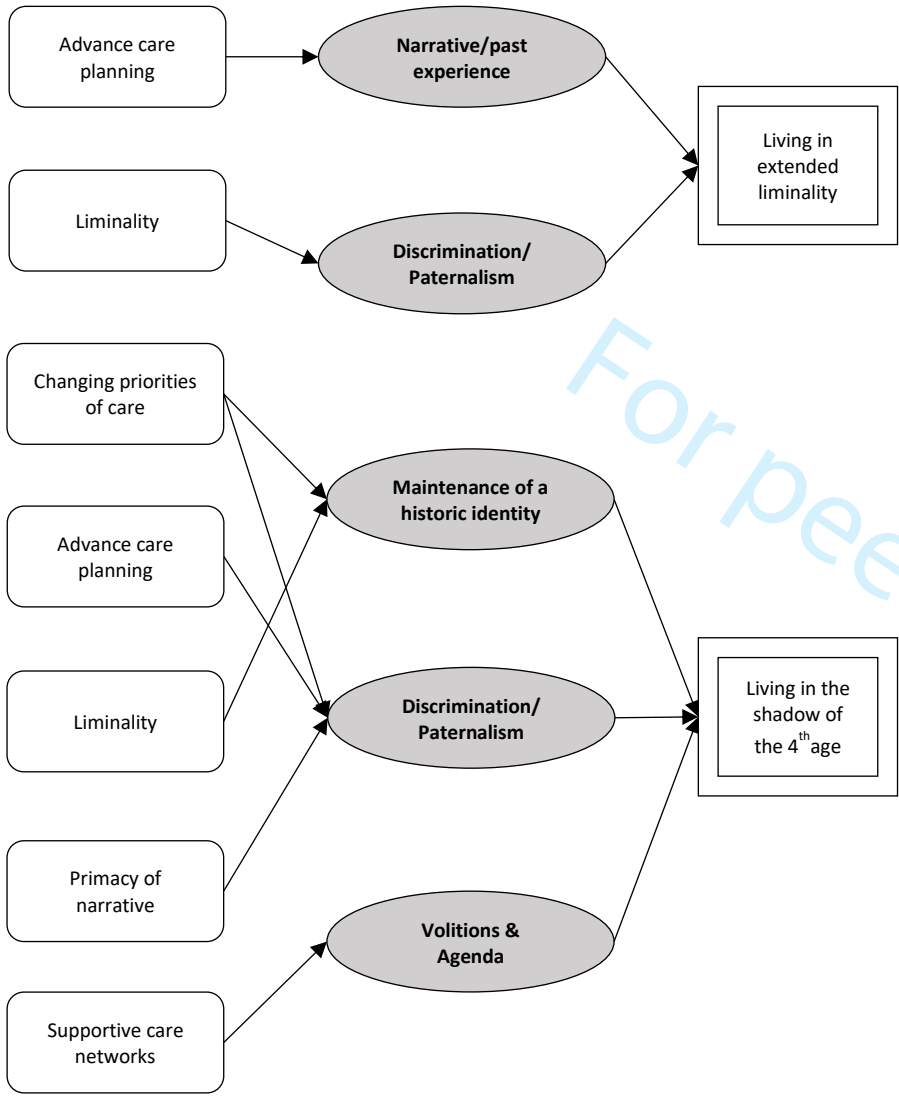




**Figure 2: Context-mechanism-outcome configuration for 'transition to a post liminal state':** Rectangular node = context; Grey node = mechanism; Double border node = outcome

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**Figure 3: Context–mechanism–outcome configuration for decision making from the perspective of a person with dementia:** Rectangular node = context; Grey node = mechanism; Double border node = outcome

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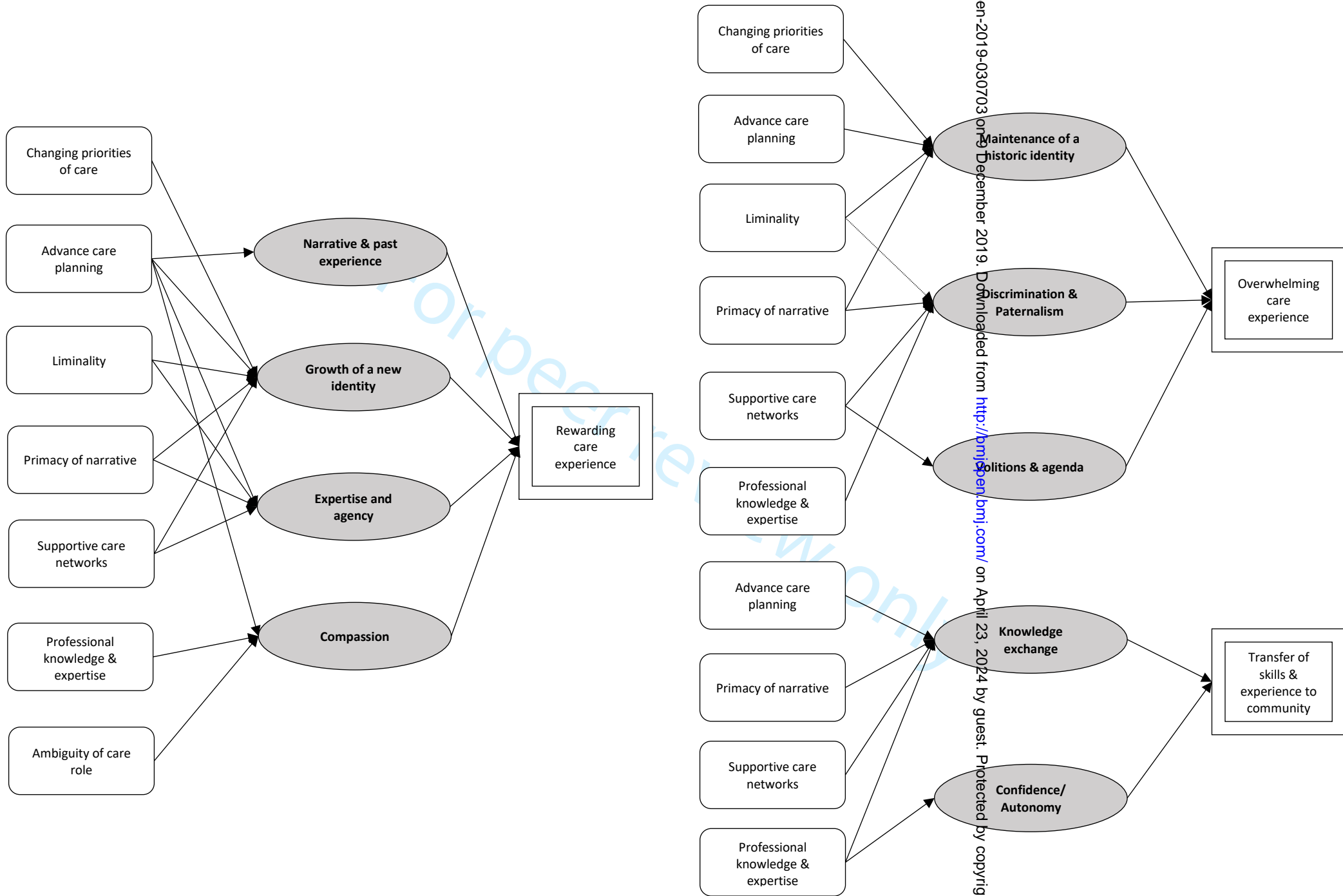
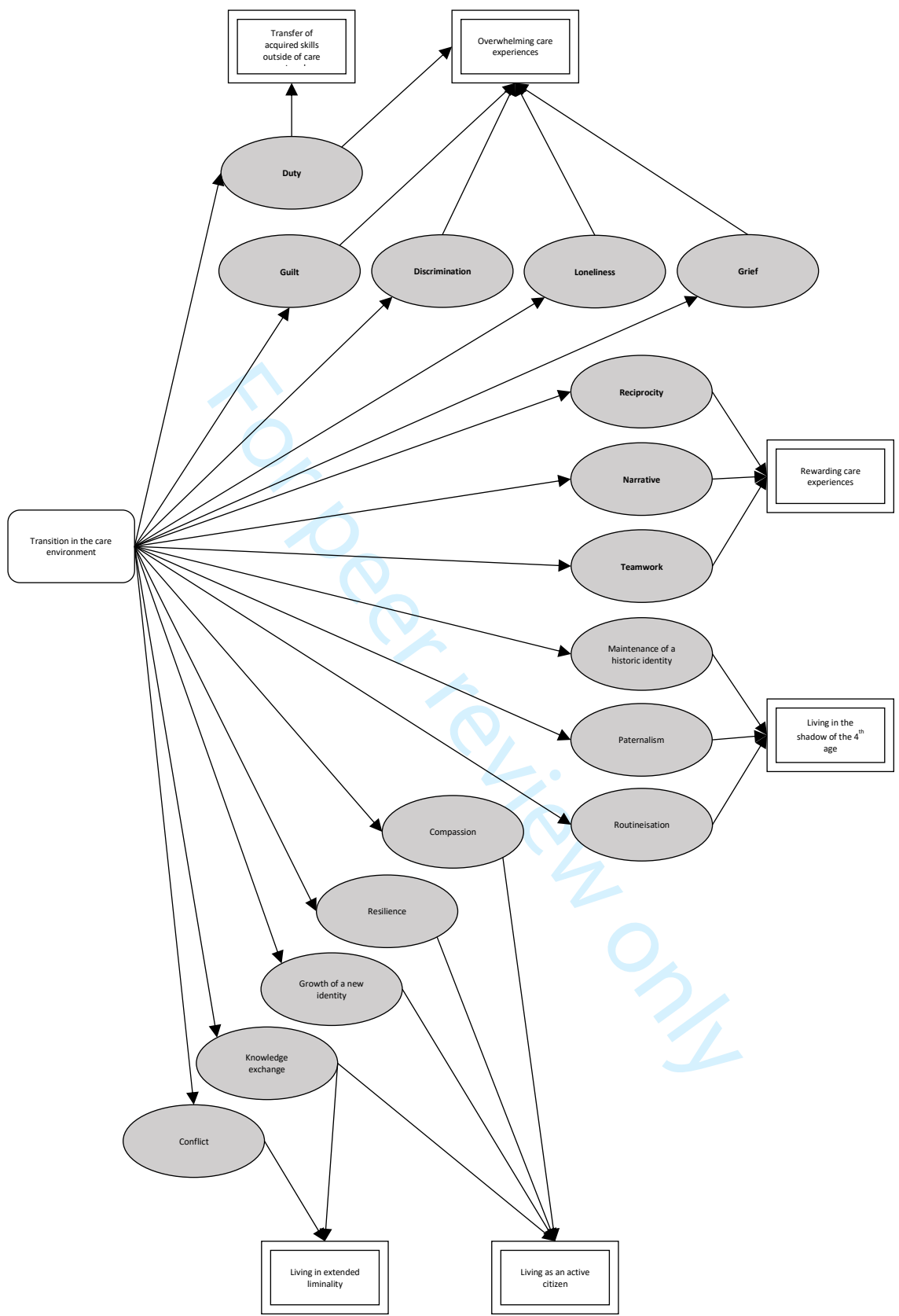


Figure 4: Context–mechanism–outcome configuration for decision making from the perspective of the caregiver. Rectangular node = context; Grey node = mechanism; Double border node = outcome

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**Figure 5: Context–mechanism–outcome configuration for “transitions in the care environment”:**  
 Rectangular node = context; Grey node = mechanism; Double border node = outcome

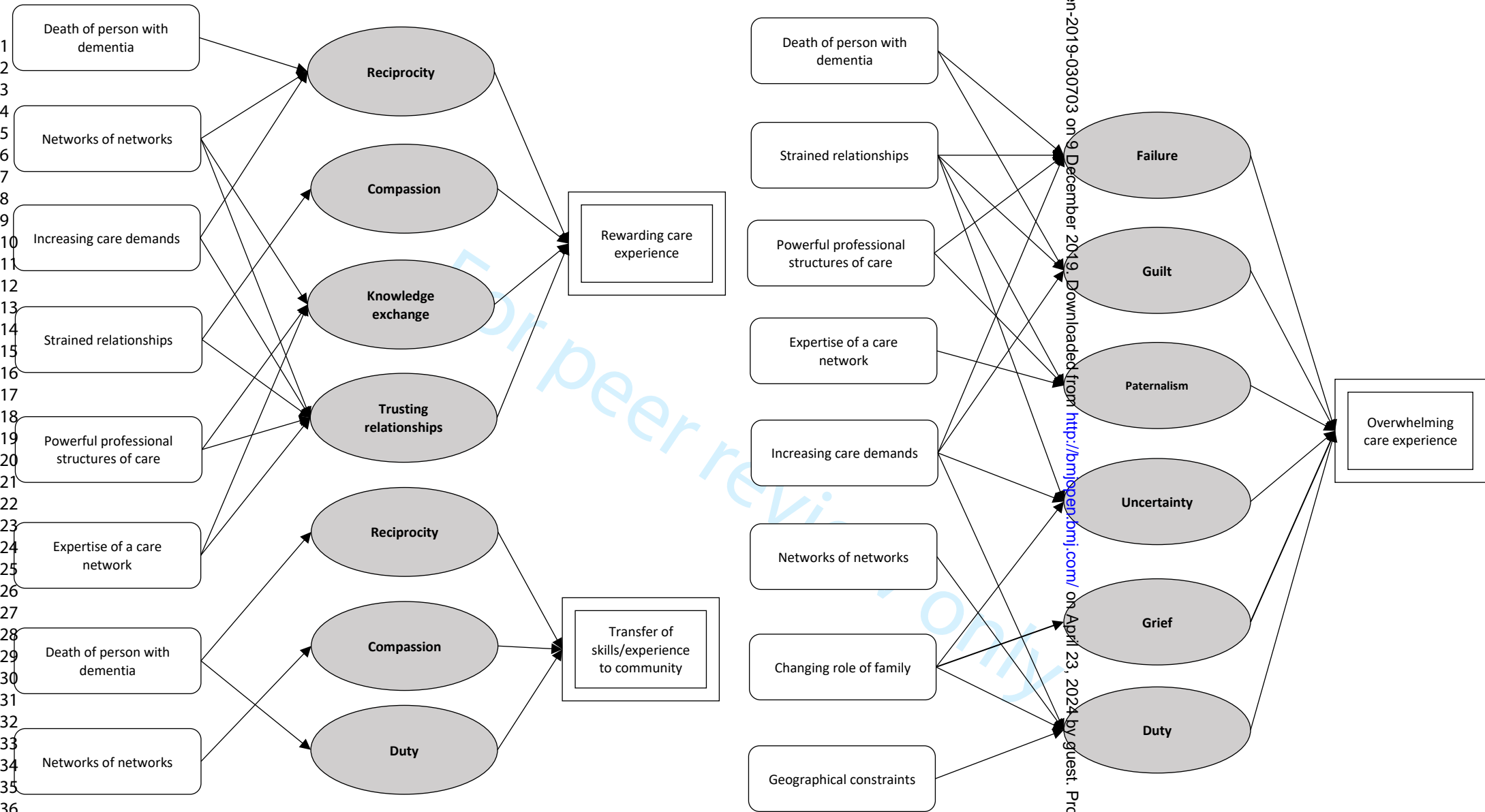
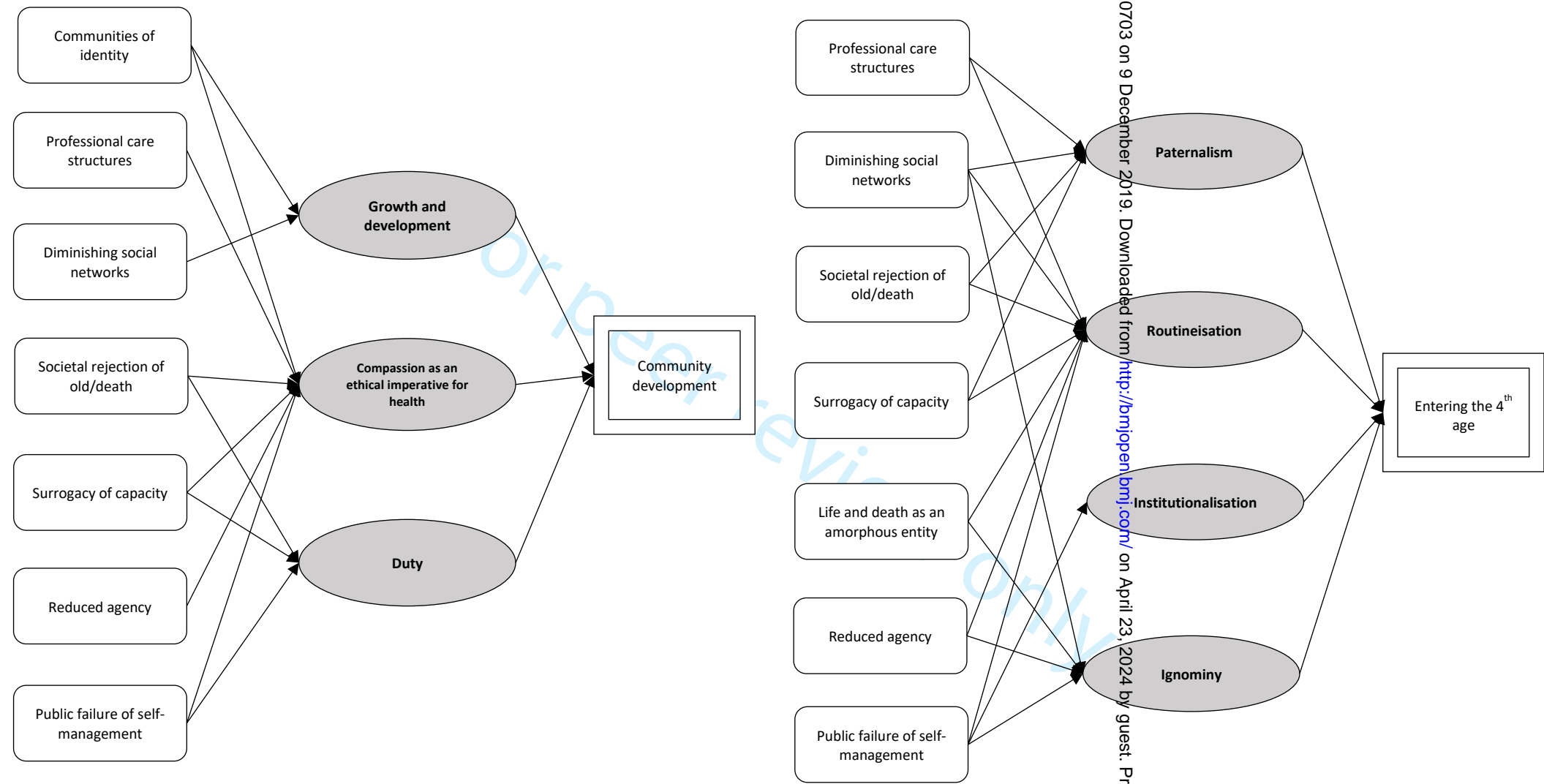


Figure 6: Context-mechanism-outcome configuration for the 'caregiver's experience'; Rectangular node = context; Grey node = mechanism; Double border node = outcome

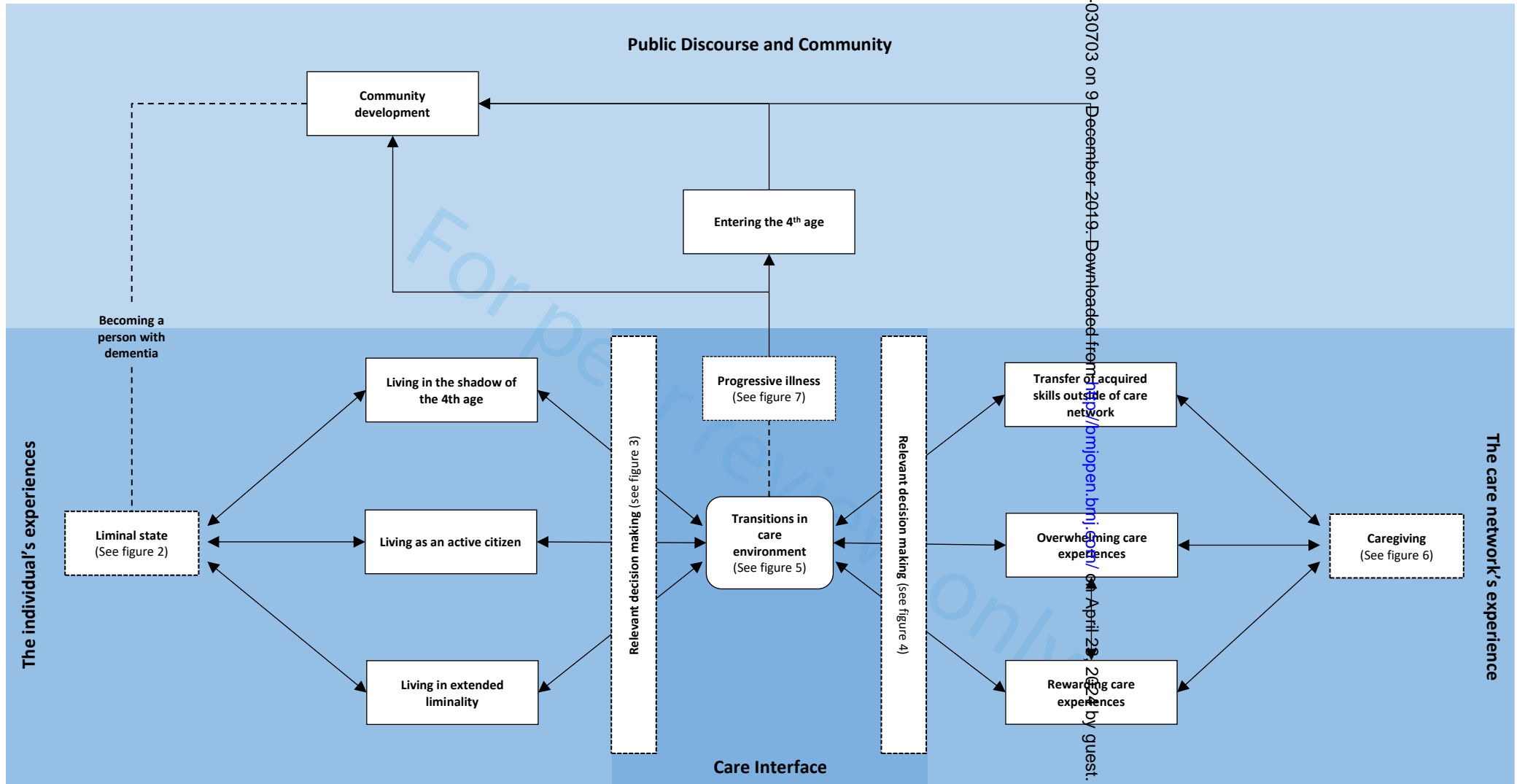
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**Figure 7: Context–mechanism–outcome configuration for dementia progression & transitioning to the 4<sup>th</sup> age;** Rectangular node = context; Grey node = mechanism; Double border node = outcome



**Figure 8: Overarching programme theory:** Rectangle = outcome; Rounded edge rectangle = context; Broken border = umbrella term for multiple contexts identified in corresponding figure; Arrow = signifies CMO configuration; Broken Arrow = unsubstantiated theory without supplementary CMO data

## Supplementary data

### Part 1 - Glossary

Inductive analysis: Inductive analysis refers to an approach to reading raw data to derive concepts or themes through interpretations made from the raw data by the researcher

Deductive analysis: Deductive analysis refers to data analyses that tests whether data are consistent with prior assumptions or theories constructed by the researcher

Contexts: settings, structures, environments, public discourse, conditions or circumstances that trigger behavioural and emotional responses (i.e. mechanisms) for those affected.

Mechanisms: the way in which individuals respond to and reason about the resources, opportunities or challenges offered by a particular process. Mechanisms are triggered in specific contexts and lead to changes in behaviour.

Outcomes: impacts or behaviours resulting from the interaction between mechanisms and contexts.

Context-Mechanism-Outcome Configurations (CMOCs): relationships between the building blocks of realist analysis, i.e. how mechanisms are triggered under specific contexts to result in particular outcomes.

Programme theory: a set of theoretical explanations or assumptions about how a particular, process is might be expected to work

Social capital: the influence of human relationships that exist through the caregiving process and within social structures such as healthcare, community and 'the home'. How these relationships are introduced or excluded from an evolving network of care and how this appeared to influence outcomes at a series of key decision points.

Primary care network: Members of lay people who are involved in the day to day care and decision making for a person with dementia

### Part 2 - Search strategies

#### Exploratory search

**Example keywords in different arrangements:** Dementia, Alzheimer's disease, multi-infarct dementia, vascular dementia, cognitive impairment, social capital, community networks, community care, end-of-life care, palliative care, systematic reviews.



**Example author based searches:** Allan Kellehear, Alejandro Portes, Pierre Bourdieu, Ruth Bartlett, Deborah O'Connor, James Coleman, Robert David Putnam

### Main search strategy

Database: EMBASE

Host: Ovid

Date searched 15/12/2017, updated 4/12/18

Searcher: JS

Hits 399 when limited to the English language

Strategy:

1. Exp dementia/ OR dementia.mp OR exp alzheimers disease/ OR alzheimers.mp OR exp multi-infarct demnientia/ OR mult-infarct dementia.mp OR vascular dementia.mp  
AND
2. Exp Social capital/ OR social capital.mp OR exp social network/ OR social network.mp OR exp Social support/ OR social support.mp OR community development.mp OR exp community care/ OR community care.mp OR exp community participation OR community participation.mp. OR exp family relation/ OR family relati\*.mp OR social integration.m  
AND
3. Exp Palliative therapy/ OR exp terminal care/ OR terminal care.mp OR palliative care.mp OR end-of-life.mp OR exp Death/ OR death.mp OR dying.mp Or end-of-life.mp

Database: MEDLINE

Host: Ovid

Date searched 15/12/2017, updated 4/12/18

Searcher: JS

Hits 198 when limited to the English language

Strategy:

1. Exp dementia OR Dementia.mp OR exp vascular dementia or vascular dementia.mp OR exp multiinfarct dementia OR multi-infarct dementia.mp OR exp Alzheimer's disease or Alzheimer's disease.mp  
AND
2. Exp Social capital/ OR social capital.mp OR exp social network/ OR social network.mp OR exp Social support/ OR social support.mp OR community

development.mp OR exp community care/ OR community care.mp OR exp  
community participation OR community participation.mp. OR exp family relation/  
OR family relati\*.mp OR social integration.mp

AND

3. Exp Palliative therapy/ OR exp terminal care/ OR terminal care.mp OR palliative  
care.mp OR end-of-life.mp OR exp Death/ OR death.mp OR dying.mp Or end-of-  
life.mp

Database: CINAHL

Date searched 15/12/2017, updated 4/12/18

Searcher: JS

1. Exp dementia vascular dementia, senile dementia, alzheimers disease, vascular  
dementia, uli-infarct dementia  
AND
2. Social captital, social networks, social network analysis, community development,  
communities, community care, community networks, MH "Community Networks")  
OR (MH "Communities") OR "community care", community participation, family  
relationships, patient-family relations  
AND
3. Palliative care OR terminal care OR end-of-life care OR dying or dying process or  
terminally ill patients OIR terminally ill patients OR dying process OR dying care

Hits 91 when limited to the English language

Total of 681 – 138 duplicates = 583 papers

### Secondary search strategy

1. Dementia OR dementia, vascular OR dementia, multi infarct OR alzheimer disease OR  
dementia, lewy body OR tauopathies  
AND
2. social support OR care networks, community OR loneliness OR family relationships  
OR friendships OR loneliness OR social support OR social isolation OR social  
participation OR social engagement OR social disengagement OR social integration  
OR personal network\* OR social network\* OR social relation\* OR social capital OR  
social contact OR social embeddedness OR family relation\*

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5 3. Discharge OR transfer OR exit OR move OR transition OR admission OR placement  
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7 OR long term care OR nursing home  
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10 **Part 3 - Characteristics of the studies included in the review**

11 Table 1: Study characteristics main search (n=74)

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13 Table 2: Study characteristics additional search (n=34)

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15 Table 3: Study characteristics of papers identified separately (n=10)

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17 Table 1: Study characteristics (literature from main search n=74).

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Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Albinsson, L. Strang, P.	2003	Sweden	Research	Open ended question with thematic analysis	Participants in national course on dementia	To investigate what staff working in close contact with patients perceive as good support of families in dementia care as compared with support of families in palliative cancer care.
Angus, Jan Kontos, Pia Dyck, Isabel McKeever, Patricia Poland, Blake	2005	Canada	Research	Ethnography	Home care in 16 homes across urban, rural and remote locations Ontario Canada	To examine the physical, symbolic and experiential aspects of receiving long-term care are examined
Arruda, Elizabeth H. Paun, Olimpia	2017	USA	Research	Integrative review	family caregivers of individuals diagnosed with ADRD who died either at home, in the hospital, or in LTC	To examine and synthesize the evidence on grief and bereavement in Alzheimer's disease and related dementias caregivers

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Ashton, S. E. Roe, B. Jack, B. McClelland, B	2016	UK	Research	Interviews with thematic analysis	12 family caregivers from a specialist dementia unit	To explore the experiences of advance care planning amongst family caregivers of people with advanced dementia.
Ashworth, V. A.	2009	USA	Editorial	NA	End of life care with person with dementia	Reflecting on the use of compassion at the end of life in someone with dementia
Bartlett, Ruth O'Connor, Deborah	2010	UK	Book chapter	NA	People with dementia and their role in society	To broaden the debate on how people with dementia are viewed in society
Belle, S. H. Burgio, L. Burns, R. Coon, D. Czaja, S. J. Gallagher-Thompson, D. Etc...	2006	USA	Research	Randomised control trial	Caregivers for people with dementia	To test the effects of a structured multicomponent intervention on quality of life and clinical depression in caregivers and on rates of institutional placement of care recipients in 3 diverse racial or ethnic groups.
Bennett, D. A. Schneider, J. A. Tang, Y. Arnold, S. E. Wilson, R. S.	2006	USA	Research	Longitudinal cohort study	Elderly people with dementia	To measure the effect of social networks in reducing the risk of cognitive impairment in old age
Birchley, G. Jones, K. Huxtable, R. Dixon, J. Kitzinger, J. Clare, L.	2016	UK	Research	Scoping review and thematic synthesis	Frail older people, people with dementia and people with severe traumatic brain injury	Understanding challenges in accessing palliative care

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Birt, L. Poland, F. Csipke, E. Charlesworth, G.	2017	UK	Research	reviewing the role of society and culture in repositioning dementia	People with dementia and their families	To understand dementia through the sociological lens of citizenship
Bokberg, C. Ahlstrom, G. Leino-Kilpi, H. Soto-Martin, M. E. Cabrera, E. Verbeek, H. Saks, K. Stephan, A. Sutcliffe, C. Karlsson, S.	2015	Pan Europe	Research	Descriptive cross country survey	People with dementia and their families	To describe available and utilized formal care and service at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries.
Brannelly, T.	2011	New Zealand	Research	Non-participant observation	People with dementia and their families	To examine the constructed facilitation of participation in care by community mental health nurses and social workers for people with dementia and their families.
Broadly, T. R. Saich, F. Hinton, T.	2018	Australia	Research	Scoping literature review	Family members or friends providing unpaid care to people with dementia	To identify what is known about carers' experiences of providing end-of-life care to a family member or friend with dementia.
Carter, G. McLaughlin, D. Kernohan, W. G. Hudson, P. Clarke, M. Froggatt, K. Passmore, P. Brazil, K.	2018	UK	Research	Descriptive qualitative	Family carers of nursing home residents with advanced dementia	To explore experience and preparedness of family carers in their care giving role as best interest decision makers of a relative with advanced dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Chambaere, K. Cohen, J. Robijn, L. Bailey, S. K. Deliens, L.	2015	Belgium	Research	Survey	People with advanced dementia and their families	To describe the prevalence and characteristics of end-of-life decisions in individuals dying with dementia in Belgium.
Colbert, S.	2003	USA	Editorial	NA	Carer for dementia with Christian faith	To reflect on the care process of a close relative with advanced dementia
Corey, K. L. McCurry, M. K.	2018	USA	Research	Semi structured interviews	Former family caregivers for people with dementia	To examine the health of former family caregivers and describe their experiences following the death of a care recipient with dementia.
D'Astous, V. Abrams, R. Vandrevala, T. Samsi, K. Manthorpe, J.	2017	UK	Research	Systematic review	Homecare workers caring for people with dementia	explores the perspectives and experiences of homecare workers providing care for people with dementia living at home up to the end of life
Edwards, H. B. Ijaz, S. Whiting, P. F. Leach, V. Richards, A. Cullum, S. J. Cheston, R. I. Savovic, J.	2018	UK	Research	Systematic review	People and their families with advanced dementia	To evaluate the association between the quality of relationship between a person with dementia and their family carer and outcomes for the person with dementia.
Elliott, B. A. Gessert, C. E. Peden-McAlpine, C.	2009	USA	Research	Focus groups	Family members of people affected with severe dementia	To describe and understand the ethical thinking used in end-of-life decision-making by family surrogates on behalf of their cognitively impaired elders.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Espino, D. V. Mouton, C. P. Del Aguila, D. Parker, R. W. Lewis, R. M. Miles, T. P.	2001	USA	Research	Case study	Hispanic people with dementia and their caring networks	Understanding unique cultural influences in a cohort of Hispanic people with dementia
Fleming, R. Kelly, F. Stillfried, G.	2015	Australia	Research	Focus groups	Recently bereaved family carers	To explore the views of people with dementia, family carers and professionals on what aspects of the physical environment would be important to support a good quality of life to the very end.
Forbes, D. A. Finkelstein, S. Blake, C. M. Gibson, M. Morgan, D. G. Markle-Reid, M. Culum, I. Thiessen, E.	2012	Canada	Research	Interviews with thematic analysis	Rural dementia care networks	To enable HCPs, care partners, and PWD to use dementia care information more effectively by examining their information needs, how these change over time, and how they access, assess, and apply the knowledge.
Francis, L. P.	2001	USA	Book chapter	NA	Legalities of decision making in dementia	NA
Fredman, L.	2017	USA	Opinion	NA	Reflections from the care journey from a son caring for his father with dementia	Interconnections between a researcher and his experience as a caregiver

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Garner, J.	1997	UK	Research	Case study	Person with dementia and their family	How does the loss of intimacy and mutuality impact on care
Gaugler, J. E. Kane, R. L. Newcomer, R.	2007	USA	Research	Logistic regression	People with dementia moving to care homes	To test resilience as a factor that may contribute to care transitions for people with dementia
Gerritsen, D. Kuin, Y. Steверink, N.	2004	Netherlands	Research	Semi-structured interviews	Children of parents with dementia	To investigate whether adults with a parent with dementia experience their personal aging differently than adults whose parents do not have dementia.
Gessert, C. E. Elliott, B. A. Peden-McAlpine, C.	2006	USA	Research	Retrospective cohort study	Minnesota and Texas nursing homes – residents with severe dementia	To identify factors associated with the use of selected medical services near the end-of-life
Gilleard, C. Higgs, P.	2010	UK	Opinion	NA	NA	Theorizing the 4 <sup>th</sup> age
Godwin, B. Waters, H.	2009	UK	Research	Non participant observation	Hospital wards, nursing home, residential homes and hospices	To explore the opinions of people with advanced dementia their family and professional carers



Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Goodman, Claire Amador, Sarah Elmore, Natasha Machen, Ina Mathie, Elspeth	2013	UK	Research	Qualitative guided conversation	People with dementia living in a care home	To explore how older people with dementia discuss their priorities and preferences for end-of-life care.
Goodman, C. Froggatt, K. Amador, S. Mathie, E. Mayrhofer, A.	2015	UK	Research	Qualitative	Care home residents with dementia	This paper draws on findings from three studies to develop a framework for understanding the essential dimensions of end of life care delivery in long-term care settings for people with dementia.
Gott, M. Wiles, J. Moeke-Maxwell, T. Black, S. Williams, L. Kerse, N. Trussardi, G	2018	New Zealand	Research	Interviews	People with old age and frailty including those with dementia and their families	To explore the role of community at end of life for people dying in advanced age from the perspective of their bereaved family caregivers.
Hickner, J.	2015	USA	Editorial	NA	NA	Advice on general management for people with dementia
Hurley, A. C. Volicer, L.	2002	USA	Research	Case study	People with advanced dementia	To examine the role of the physician in advancing illness for people with dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Jennings, L. A. Palimaru, A. Corona, M. G. Cagigas, X. E. Ramirez, K. D. Zhao, T. Hays, R. D. Wenger, N. S. Reuben, D. B.	2017	USA	Research	Focus group interviews	People with dementia and their caregivers	To elicit patient-centred goals for dementia care
Jones, P. S. Martinson, I. M.	1992	USA	Research	Interviews	Recently bereaved care givers	To analyse the bereavement experience for caregivers involved with people with dementia
Jotkowitz, A. Clarfield, A. Glick, S.	2005	Israel	Editorial	NA	A modern Jewish ethical perspective	To describe a Jewish ethical approach to care for people with dementia
Kaldjian, L. C. Shinkunas, L. A. Bern-Klug, M. Schultz, S. K.	2010	USA	Research	In depth interviews	Surrogate decision makers for people with dementia	To increase our knowledge about surrogates' understanding and articulation of goals of care, as well as the foundational beliefs and ethical values that may underlie their goals
Kellehear, A.	2013	Australia	Overview	NA	NA	To theorize a public health approach to end of life care
Laakkonen, M. L. Pitkala, K.	2009	Finland	Editorial	NA	NA	To outline ethical constructs to help facilitate the care of people with dementia
Large, S. Slinger, R.	2015	UK	Research	Qualitative synthesis	Grief in caregivers of people with Alzheimer's disease	To provide a detailed and contextualised account of caregiver grief when caring for someone with AD or related dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Lewin, T.	1996	USA	Newspaper article	NA	Parent with advanced dementia and loss of capacity	To describe the fraught decision making process that can occur in the advanced stages of dementia
Lawrence, V. Samsi, K. Murray, J. Harari, D. Banerjee, S.	2011	UK	Research	In depth interviews	Bereaved family carers and health care professionals recruited from care homes, the community and hospitals	To define good end-of-life care for people with dementia and identify how it can be delivered across a range of care settings in the UK
Lindsay, S.	2010	Australia	Research	Case study	Rural community in New South Wales	Identify how to support carers and people with dementia in their own home
Livingston, G. Leavey, G. Manela, M. Livingston, D. Rait, G. Sampson, E. Bavishi, S. Shahriyarmolki, K. Cooper, C.	2010	UK	Research	Focus group and individual interviews	Community settings in London UK	To identify common difficult decisions made by family carers on behalf of people with dementia, and facilitators of and barriers to such decisions, in order to produce information for family carers about overcoming barriers.
Lombardo, S.	2003	USA	Comment	NA	Care home in USA	To describe the potential positive aspects to caregiving for people with dementia
Macdonald, G.	2018	Australia	Comment	NA	Dementia care in Australia	To analyse how to end one's life well with dementia, a social commentary

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Masuchi, Y. Jylha, M. Raitanen, J. Aaltonen, M.	2018	Finland	Research	Logistic regression	All people who had died with dementia aged >70	To determine how place of death has changed in Finland
McCleary, L. Thompson, G. N. Venturato, L. Wickson-Griffiths, A. Hunter, P. Sussman, T. Kaasalainen, S.	2018	Canada	Research	Focus group interviews	Family and staff experiences of end of life care for people with dementia	To explore understanding of staff and family experiences of dying and bereavement in long term care
Michael, N. O'Callaghan, C. Sayers, E.	2017	Australia	Research	Focus group interviews	Older people and their offspring in Australian city and rural setting	To examine the awareness, attitudes, and experiences of advance care planning amongst older people and unrelated offspring/caregivers of older people residing in the community
Mitchell, S. L. Morris, J. N. Park, P. S. Fries, B. E.	2004	USA	Research	Retrospective cohort study.	Persons 65 years or older with advanced dementia who died within 1 year of admission to a nursing home	To describe and compare the end-of-life experience of persons dying with advanced dementia in the nursing home and home care settings.
Mogan, C. Lloyd-Williams, M. Harrison Denning, K. Dowrick, C.	2018	UK	Research	Narrative synthesis of mixed methods data	End of life care for people with dementia	To identify and understand the challenges and facilitators of providing end-of-life care at home for people with dementia.

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Monroe, B. Hansford, P.	2010	UK	Editorial/ review	NA	Specialist palliative care at home	To describe a model of specialist palliative care at home and the challenges and opportunities it presents
Mullard, A.	2015	UK	Editorial	NA	NA	Review of a film and its influence on the public discourse that shapes opinion on dementia
Obisesan, T. O. Gillum, R. F.	2009	USA	Research	Longitudinal follow up	Older people some with diagnosis of dementia	To determine whether social integration and cognitive function are independently associated with subsequent mortality
Pecanac, K. E. Wyman, M. Kind, A. J. H. Voils, C. I.	2018	USA	Research	Scoping review	Treatment decision making in the acute care setting	To summarize the evidence regarding the factors and processes of treatment decision making involving a person with dementia (PWD) in the acute care setting.
Petriwskyj, A. Parker, D. Robinson, A. Gibson, A. Andrews, S. Banks, S.	2013	Australia	Research	Review	People with dementia in residential care	to identify and appraise the existing quantitative evidence about family involvement in decision making for people with dementia living in residential aged care
Powell, T. Powell, Tia	2011	USA	Editorial	NA	Reflections on caring for a parent with dementia	To describe the decision making process for people and their families with advanced dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Rodriguez, G. De Leo, C. Girtler, N. Vitali, P. Grossi, E. Nobili, F.	2003	Italy	Research	Survey	All primary caregivers of 120 patients with a diagnosis of AD	To examine stress levels amongst carers for people with dementia
Rosenwax, L. Spilsbury, K. Arendts, G. McNamara, B. Semmens, J.	2015	Australia	Research	Retrospective population based cohort study	Western Australia, people with dementia who had died within a 2 year window	To describe patterns in the use of hospital emergency departments in the last year of life by people who died with dementia and whether this was modified by use of community-based palliative care.
Russell, C. Middleton, H. Shanley, C.	2008	Australia	Research	In depth semi-structured interviews	Australia New South Wales	To document the views of family caregivers of persons with dementia about quality of life for their relative during the late and terminal stages of the disease.
Saini, G. Sampson, E. L. Davis, S. Kupeli, N. Harrington, J. Leavey, G. Nazareth, I. Jones, L. Moore, K. J.	2016	UK	Research	Ethnography	Nursing home residents with dementia	To examine practices relating to end-of-life discussions with family members of people with advanced dementia residing in nursing homes and to explore strategies for improving practice.
Shaji, K. S. Smitha, K. Praveen Lal, K. Prince, M. J.	2003	India	Research	Qualitative study	Caregivers for people with dementia in south India	To understand care arrangements for people with dementia and strain experienced by the family
Shanley, C Fetherstonhaugh, D McAuliffe, L Bauer, M Beattie, E	2017	Australia	Research	Semi-structured interviews	Carers in Victoria Australia	To learn from surrogate decision-makers for PWD can be most effectively supported in this role

Name	Year	Country	Type of paper	Study design/methods	Sample/setting	Objectives
Shanley, C Russell, C Middleton, H Simpson-Young, V	2011	Australia	Research	In-depth interviews	Family carers for PWD	To understand the experiences and needs of family carers of people with end-stage dementia
Sundquist, J. Hamano, T. Li, X. Kawakami, N. Shiwaku, K. Sundquist, K.	2014	Sweden	Research	Cohort study	Swedish men and women	To see if there is an association between linking social capital and drug prescription (including anti-dementia drugs)
Thompson, G. N. Roger, K.	2014	Canada	Research	Review	Dementia family caregivers	To describe the domains of dementia friendly caregivers needs and their impact on the delivery of palliative care services.
Collins, Clare Liken, Michelle King, Sharon Kokinakis, Candance	1993	USA	Research	Interviews	Family caregivers of relatives with dementia	To describes family caregiver perceptions of the experience of loss and grief as it occurs prior to and following the death of a relative with dementia
Van Der Steen, J. T. Van Soest-Poortvliet, M. C. Onwuteaka-Philipsen, B. D. Deliens, L. De Boer, M. E. Van Den Block, L. Hertogh, C. M. P. M. De Vet, H. C. W.	2014	Netherlands	Research	Systematic review	Factors related to initiation of ACP defined as starting a discussion, starting the decision making, or having a documented patient-written advance directive.	To identify factors associated with initiation of advance care planning (ACP) regarding end-of-life issues in dementia.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Vlachogianni, A. Efthymiou, A. Potamianou, D. Sakka, P. Orgeta, V.	2016	Greece	Research	In depth interviews	Carers taking part were recruited from a day care centre, providing specialist services to people with dementia.	To explore the key psychological changes associated with carers' adjustment to bereavement and "life after care."
You, E. C. Dunt, D. R. White, V. Vander Hoorn, S. Doyle, C.	2014	Australia	Research	Survey	Community-dwelling older people living with dementia in Australia	To determine risk factors for time to death or hospital admission (combined)



Table 2: Study characteristics (literature from additional search n=34).

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Afram, Basema Verbeek, Hilde Bleijlevens, Michel H. C. Challis, David Leino-Kilpi, et al	2015	USA	Research	Cohort study with qualitative data	Informal caregivers of people with dementia who made a transition to institutional long-term care.	To investigate agreement between expected reasons and actual reasons for admission of people with dementia according to informal caregivers
Amuah, J. Maxwell, C. Cepoiu-Martin, M. Soo, A. Gruneir, A. Et al.	2012	Canada	Research	Interviews with family caregivers at 1 year intervals	Older adults with dementia residing in Designated Assisted Living	To identify resident- and facility- level predictors of (first-event) hospitalization over 1-year
Armstrong, M.	2000	UK	Research	Semi-structured interviews	Carers of relatives with dementia before and after placement into residential care	To find out the reasons why carers might decide that they could not continue caring for a relative with dementia at home
Banerjee, S. Murray, J. Foley, B. Atkins, L. Schneider, J. Mann, A. Banerjee, S. Murray, J. Foley, B. Atkins, L. Schneider, J. Mann, A.	2003	UK	Research	Longitudinal cohort study	People with dementia under old age psychiatry in London	To identify what patient and carer characteristics influence transition into residential care for people with dementia.
Bloomer, M. Digby, R. Tan, H. Crawford, K. Williams, A.	2016	Australia	Research	In depth interviews	Family caregivers for people with dementia who had been admitted to hospital	To explore the carer's experience when the person he/she cares for is an inpatient in hospital.

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Caldwell, Lauren Low, Lee-Fay Brodaty, Henry	2014	Australia	Research	Semi-structured interviews	Caregivers for people with dementia on waiting lists or living in a nursing home	to investigate the decision-making process for placing a person with dementia on a waiting list for a nursing home
Chiu, L. Shyu, W. Liu, Y. Wang, S. Chang, T.	2001	Taiwan	Research	Telephone survey	Primary caregivers in two metropolitan areas of Taiwan	To determine the factors that influence the attitudes of family caregivers of dementia patients toward nursing home placement
Cloutier, D. S. Penning, M. J.	2017	USA	Research	Administrative data triangulated with personal narrative	Women with dementia in British Columbia, Canada	To explore the interplay between personal narratives and quantitative research on the experiences of older women with dementia in long-term care
Coehlo, D. P. Hooker, K. Bowman, S.	2007	USA	Research	multivariate design using a combination of longitudinal and cross-sectional data	Persons diagnosed with dementia and evaluated for behavioural changes	To determine the key variables that affect the occurrence and timing of institutional placement for families caring for an individual with dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Cox, C.	1996	USA	Research	Interviews	Caregivers of dementia patient	To understand factors influencing discharge outcomes of African American and white hospitalized dementia patients
Cox, C. B.	1996	USA	Research	Interviews	Caregivers of hospitalised people with dementia	What factors determine caregiver satisfaction with the discharge plan
Digby, R. Moss, C. Bloomer, M.	2012	Australia	Research	Interviews	Older patients with mild to moderate dementia	To understand the experienced of transfer from acute to subacute care
Ducharme, F. Couture, M. Lamontagne, J.  <b>??Substantive theory???</b>	2012	Canada	Research	Grounded theory	Caregivers of cognitively impaired relatives	To develop a model of the family caregiver decision making process
Fields, N. L. Richardson, V. E. Schuman, D.	2017	USA	Research	Cox regression	People with dementia in assisted living	To determine whether marital status influenced length of stay
Fisher, L. Lieberman, M. A.	1999	USA	Research	Logistic regression	Patients and their families seen during 1993 and 1994 at Alzheimer's and Memory Clinics	To understand characteristics of the multi-generation family that predict nursing home placement

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Gaugler, J. E. Edwards, A. B. Femia, E. E. Zarit, S. H. Stephens, M. P. Townsend, A. Greene, R.	2000	USA	Research	Cox proportional hazard model	Caregivers for people with dementia	To examine the type and amount of family assistance offered to caregivers prior to institutionalization
Gaugler, J. E. Zarit, S. H. Pearlin, L. I.	1999	USA	Research	Repeated measures ANOVA	Family caregivers to people with dementia placed into institutional care	To examine the impact of family conflict and socio-emotional support among caregivers who institutionalize their relative
Giebel, C. Bleijlevens, M. Soto, M. E. Chester, H. Meyer, G. Stephan, A. Et al.	2017	Pan Europe	Research	Cross sectional study with logistic regression	People with dementia at risk of admission to long term care across 8 European countries	To explore associations between carer burden and characteristics of (1) the informal carer, (2) the person with dementia, and (3) the care support network
Hagen, B.	2001	Canada	Research	Qualitative interviews	Family caregivers of elderly family members with dementia	To explore the decision-making process of whether or not to place a family member in a nursing home.
Kao, H. Stuifbergen, A. K.	1999	Taiwan	Research	Semi-structured interviews	Family members caring for people with dementia in Taiwan	To explore the decision making process for families caring for someone with dementia

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Liken, M. A.	2001	USA	Research	Interviews	family caregivers who had moved their relatives with AD to an ALF within the past 6 months	The experience of moving a relative with Alzheimer's disease (AD) to an assisted living facility
Maxwell, C. J. Amuah, J. E. Hogan, D. B. Cepoiu-Martin, M. Gruneir, A. Patten, S. B. Soo, A. Le Clair, K. Wilson, K. Hagen, B. Strain, L. A.	2015	Canada	Research	Interviews and linkage with hospital discharge database	Assisted living residents with dementia and their carers	To determine the incidence of hospitalization over 1 year for dementia residents of assisted living facilities, compared with long-term care facilities
Park, M. Butcher, H. K. Maas, M. L.	2004	Korea	Research	Interviews	Korean family caregivers'	To provide an in-depth description of experiences in making the decision to place a family member with dementia in a long term care
Parke, Belinda Hunter, Kathleen F. Strain, Laurel A. Marck, Patricia Beryl Waugh, Earle H. McClelland, Ashley J.	2013	Canada	Research	Interviews, narrative journal	Community dwelling older adults with dementia in Canadian emergency departments	To understand ED transitional processes relating to people with dementia
Pot, A. M. Deeg, D. J. Knipscheer, C. P.	2001	Netherlands	Research	Logistic regression	Community based caregivers for people with dementia	To understand the role for caregiver characteristics on institutionalisation

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Rozzini, L. Cornali, C. Chilovi, B. V. Ghianda, D. Padovani, A. Trabucchi, M.	2006	Italy	Research	Multivariate logistic regression	People with dementia admitted to a dementia rehab unit in northern Italy.	To identify the patient's and the caregiver's characteristics that influence discharge to a nursing home
Sadak, T. Foster Zdon, S. Ishado, E. Zaslavsky, O. Borson, S.	2017	USA	Research	Semi-structured phone interviews	Family caregivers of people with dementia who experienced a recent hospitalization due to an ambulatory care sensitive condition or fall-related injury	To describe the lived experience of dementia family caregivers whose care recipients had a recent unplanned admission
Sharpp, Tara J. Young, Heather M.	2016	USA	Research	Interviews Comparison of demographic data between groups	Family members of people with dementia and incident reports relating to people with dementia in assisted living	To describe the health care incidents and experiences of residents and their family members who are transferred from assisted living to an emergency department
Shinnichi, Tochimoto Maki, Kitamura Shoryoku, Hino Tatsuru, Kitamura	2015	Japan	Research	Multiple logistic regression analysis	People with dementia admitted to hospital for behavioural and psychological symptoms	To identify predictors of home discharge
Singh, Prabhjot Hussain, Rafat Khan, Adeel Irwin, Lyn Foskey, Roslyn	2014	Australia	Research	Interviews	Family caregivers for people with dementia across Australia	To explore the intersection of informal family caregiving and the formal care systems from the perspective of the primary family carers

Name	Year	Country	Type of paper	Study design/ methods	Sample/ setting	Objectives
Smith, G. E. Kokmen, E. O'Brien, P. C.	2000	USA	Research	Demographic, medical, social, and functional predictors were examined as static and time-dependent risk factors for nursing home placement	People with onset of dementia between 1980 and 1984.	To examine risk factors for nursing home placement in a population-based dementia cohort.
Spruytte, N. Van Audenhove, C. Lammertyn, F.	2001	Belgium	Research	Multiple logistic regression and qualitative interviews	Partners, children and children in law caring for a relative suffering with dementia	To identify risk factors for nursing home placement of cognitive impaired elderly
Stevens, A. Owen, J. Roth, D. Clay, O. Bartolucci, A. Haley, W.	2004	USA	Research	Cox proportional hazard models used to analyse predictors of nursing home placement	Primary family caregiver and an individual with Alzheimer's disease or other progressive dementia	To examine the influence of racial group identification on nursing home placement for individuals with dementia
Thoma-Lurken, T. Bleijlevens, M. Lexis, M. De Witte, L. Hamers, J.	2018	Netherlands	Research	A qualitative explorative study by means of six focus group interviews with	Formal caregivers of community-dwelling people with dementia	To gain insight into problems which directly threaten people with dementias potential to stay at home

Table 3: Study characteristics of papers identified separately (n=10)

Name	Year	Country	Type of paper	Study design/methods	Sample /setting	Objectives
Abel, J Kingston, H Scally, A Hartnoll, J Hannam, G Thomson-Moore, A Kellehear, A	2018	UK	Research	Cohort retrospective study	Rural setting involving people with frailty and cause for concern	To evaluate a population health complex intervention of an enhanced model of primary care and compassionate communities on population health improvement and reduction of emergency admissions to hospital.
Angus, J. Kontos, P. Dyck, I. McKeever, P. Poland, B.	2005	Canada	Research	Ethnography	Home care	To understand the personal significant of home in the context of place of care
Bird-David, Nurit Israeli, Tal	2010	Israel	Research	Ethnography	Institutional care	To address the personhood of patients in a permanent vegetative state (PVS), who fall outside categories of "alive" or "dead" and "subject" or "object.
Bourdieu, Pierre	1986	France	Book	NA	NA	Theoretical outline
Pitkin Derose, Kathryn Varda, Danielle M	2009	Canada	Research	Systematic review	NA	To assess the rigor with which social capital has been empirically applied in research on health care access, a systematic review was conducted
Higgs, P Gilliard, C	2015	UK	Book	NA	NA	Theoretical overview
Kaufman, S. R.	2000	USA	Research	Ethnography	Care home	To address the permanent or persistent comatose condition and the



						institutions and practices that enable this life form to exist.
Kellehear, A	2012	UK	Book	NA	NA	Theoretical outline
Reeves, D Blickem, C Vassilev, I Brooks, H Kennedy, A Richardson, G Rogers, A	2014	UK	Research	Longitudinal study	People with chronic long term conditions	To determine how the social networks of people with long-term conditions (diabetes and heart disease) are associated with health-related outcomes and changes in outcomes over time.
Vassilev, I. Rogers, A. Sanders, C. Kennedy, A. Blickem, C. Protheroe, J. Bower, P. Kirk, S. Chew-Graham, C. Morris, R.	2011	UK	Research	Realist review	People with chronic long term conditions	To explore the theoretical and empirical links between social networks, social capital and the self-care practices associated with chronic illness work and management in the context of people's everyday lives.

#### Part 4 - Analysis and synthesis processes

During the analytic phase we developed and refined the programme theory by drawing on coding that was developed over the data set as a whole. Coding occurred within and outside Excel (e.g. Word document coding reports, pdf documents, and memos) to configure relationships between contexts, mechanisms and outcomes. This entailed asking a series of questions and making judgements about the relevance and rigour of content. The process is outlined below.

Relevance:

- Are the contents of a section of text referring to data that is relevant to the programme theory development?

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2  
3 1. Judgements about trustworthiness and rigour:  
4  
5 - Is this data sufficiently trustworthy to warrant changing to the programme theory?  
6  
7
- 8 2. Interpretation of meaning:  
9  
10 - If the section of text is relevant and trustworthy, do the contents provide data that  
11 may be interpreted as being context, mechanism or outcome?  
12  
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- 14 3. Interpretations and judgements about Context-Mechanism-Outcome-Configurations:  
15  
16 - What is the Context-Mechanism-Outcome-Configuration (CMOC) (partial or  
17 complete) for the data?  
18  
19 - Is there data to inform CMOCs contained within this document or other included  
20 documents? If so, which other documents?  
21  
22 - How does this CMOC relate to CMOCs that have already been developed?  
23  
24
- 25 4. Interpretations and judgements about programme theory:  
26  
27 - How does this (full or partial) CMOC relate to the programme theory?  
28  
29 - Within this same document is there data which informs how the CMOC relates to  
30 the programme theory? If not, is there data in other documents? Which ones?  
31  
32 - In light of this CMOC and any supporting data, does the programme theory need to  
33 be changed?  
34  
35  
36

37 The process of evidence synthesis was achieved by the following analytic processes

38  
39 a) Juxtaposition of data sources – comparing and contrasting between data presented in  
40 different articles. For example, where data relating to the decision to move someone with  
41 dementia into long term care in an-depth qualitative source enabled insights into how outcomes  
42 are achieved as described in a quantitative study.  
43  
44

45  
46 b) Reconciling ‘contradictory’ or ‘outlying’ data – where outcomes differ in what may seem to  
47 be similar circumstances, further investigation is necessary to find an adequate explanations  
48 for this. This involved a closer consideration of context and what counts as context for different  
49 types of ‘problems’, in order to understand how the mechanisms triggered can explain  
50 differences in outcomes.  
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3 c) Consolidation of sources of evidence – where there are similarities between findings  
4 presented in different sources, a judgment needs to be made about whether these similarities  
5 are adequate to form patterns in the development of CMOCs and programme theory, or whether  
6 there are nuances that need to be highlighted, and to what end.  
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## Part 5 - Full lists of CMOCs developed from the literature with illustrative data

CMOCs	Illustrative examples of supporting data extracted from the literature
CMOC 1: In the context of people being conscious of their dementia diagnosis (C), people with dementia experience uncertainty (M) that their views will be acknowledged leading to a state of extended liminality (O).	<p><b>Consciousness of diagnosis:</b> <i>‘Knowing that they had dementia affected confidence in expressing opinions, self-esteem and whether they thought their views were worth listening to and if expressed that they would be noted or trusted. Derogatory terms were used, one called herself a “mouldy oldie”, another “going potty” to describe her situation:(1)</i></p> <p><b>Consciousness of diagnosis</b> <i>“Yes oh and I’ve got my. . . What’s it called? See I think you may have picked the wrong person cos I’m going potty, can’t remember everything. . . I don’t like it being like this, but there’s nothing I can [do] about it really, I don’t think.” (1)</i></p> <p><b>Uncertainty:</b> <i>“[I] do feel that it’s a bit of a fiasco when people decide ‘no, no, I want to still have an intervention’ and it’s chaos towards the end. .... It would be very nice to have a very clear treatment and to have everything crystal clear but I don’t think that is ever going to happen...” (2)</i></p> <p><b>Extended liminality</b> <i>“She drew attention to both social and emotional liminal states experienced when people received a diagnosis of dementia, drawing out the sense of uncertainty inherent in liminality. While in her later work Kelly (2010: 7) reports people as ‘learning to live with liminality’, rather than seeing the liminal state as a transitory state on the route to new roles and status. This has resonance with Bruce et al.’s (2014) description of pervasive liminality.”(3)</i></p>
CMOC 2: In the context of people being conscious of their dementia diagnosis (C), people can use ‘Agency’ (M) to maintain their position as an active citizen (O)	<p><b>Agency:</b> <i>“The way agency is exerted—sometimes subversively—by older people who are deemed to lack the ability to formally make decisions has been noted by anthropologists, who document the rebellion against resented authority that manifests in soiling or refusing food [76]. Such a lens seems absent from the literature reviewed, but suggests that mentally incapacitated patients might more realistically be viewed as participants in the decision-making process, exerting influence in a multitude of ways.” (4)</i></p> <p><b>Agency in advanced dementia:</b> <i>“Right after she got into a nursing home they notes she had a lot of difficulty eating. She would push food away or refuse to swallow it. At that time the family discussed goals of care with the physician...”(5)</i></p>

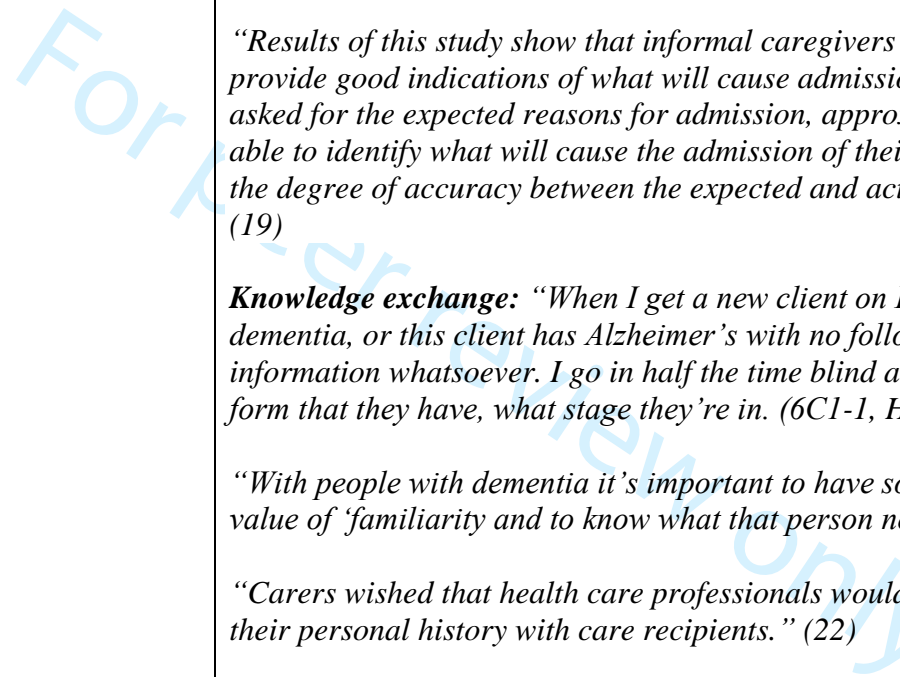
CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>“My experience of going into nursing homes is that I will often think that non-verbally someone is indicating to me that they have got pain, but because the person can’t tell the nurse looking after them that they have got pain the nurse doesn’t recognise it.” (6)</i></p> <p><b>The active citizen:</b> <i>The narratives of deficit presented above are countered by narratives from people with dementia articulating and defending positive accounts of living well, engaging in loving relationships, preserving identity and self, and living as recognised citizens in their communities (Bartlett 2014, Beard et al. 2009). (3, 7)</i></p>
<p>CMO 3: In the context of dementia being perceived as ‘death in the realm of the living’ (C), people with dementia and their wider social network experience fear and trepidation (M) that moves people into a state confined by the shadow of the ‘4<sup>th</sup> age’ (O)</p>	<p><b>Death in the realm of the living:</b> <i>“Dementia confronts because it seems to bring death into life, implicitly questioning what life, relationship, and death are about.”(8)</i></p> <p><b>Fear</b> <i>“people with dementia are often thought of as tragic, robbed of life, and having lost their personhood.” (8)</i></p> <p><b>The 4<sup>th</sup> age</b> <i>“It is when people are no longer ‘getting by’, when they are seen as not managing the daily round, when they become third persons in others’ age-based discourse, within others’ rules, that they become subjects of a fourth age” (9)</i></p>
<p>CMO 4: Where cohesive care networks surround a person with dementia (C), the individual has a sense of purpose (M) that enables them to function as an active citizen (O)</p>	<p><i>“[My mother had a steady stream of visitors] ... from the village, from the church, from the Catholic Women’s League which she belonged to. She had a brother and sister-in-law living over there just over the next street. They would pop in and their children would pop in, her ex-daughter in law would pop in. She did have a lot of visitors and a lot of friends. Because she was a very social woman, relatives would drop in or stay, visit or whatever.” (10)</i></p>
<p>CMO 5: In communities of identity (C), people with dementia have a sense of purpose (M) which allows them to grow and maintain a role as an active citizen (O)</p>	<p><b>Communities of identity</b> <i>“This centre provides day care for those living with dementia but instead of playing games or receiving passive entertainment the main program is about the design and production of the mid-day meal. Seniors with dementia are asked to jointly design the meal, then to go out shopping together to buy the ingredients, and then return to help prepare the meals. Shopkeepers are briefed on the program and willingly participate in the program, learning and experiencing the complexities of communicating with seniors with dementia and also Compassionate communities gaining insight into the complexities of their care while sharing this in a small way.” (11)</i></p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 6: In a society where concepts of health are shaped by a biomedical discourse great value is placed upon the cognitive faculties (C), the prospect of dementia therefore invokes fear (M) that can paralyse causing people to live in an extended period of liminality (O)</p>	<p><i>“They’re telling her things and she doesn’t understand. He says ‘the doctor’s come in and told me this’ and she says ‘I don’t know what’s going on’”. She said, “They should be telling you’’. She said, “My brain’s gone”, which it has. So I think that’s caused more stress, to be honest, because you’re thinking to yourself ‘I’m not being told what’s going on’” (12)</i></p>
<p>CMO 7: As dementia progresses a person may change their perceptions and views on various issues (including death) (C), they maintain their role as an active citizen (O) by conveying these views through their agentic influence (M)</p>	<p><b>Changing perceptions:</b> <i>“Relatives and staff need to be aware that the person’s attitude to death may evolve during their dementia. When a comparison was made between participants’ attitudes to death and those ascribed to them by their family carers, for some people they appeared to have changed.” (13)</i></p> <p><i>“(Husband) had a bit of a health crisis about 12 months ago...when he came out of this acute crisis, he said to me he was afraid people that people would turn off the switch. So there was a complete change of his limited understanding... (now) I don't know whether I'm actually fulfilling his wishes.” (14)</i></p>
<p>CMO 8: As dementia progresses a person may change their perceptions and views on various issues (including death) (C), they maintain their role as an active citizen (O) through the use of narrative which may be stored within social capital (M)</p>	<p><i>“the report suggests that professionals involved in advance care planning should consider both the patient’s past and present interests because their view may change during the course of their illness.” (15)</i></p>
<p>CMO 9 Where cohesive support networks surround a person with dementia (C), they are able to advocate for their perceived wishes through the exchange of knowledge (M). Knowledge or expertise (M) relates to the person with dementia and is accumulated through longitudinal monitoring (M) and conveyed through narrative (M) to help maintain a person’s role as an active citizen (O)</p>	<p><b>Support networks:</b> <i>“support from healthcare professionals, carer resilience and extended social networks, support with medications and symptom management, and appropriate equipment and home adaptations all facilitated dying at home with dementia.” (16)</i></p> <p><b>Expertise:</b> <i>“Especially when you’re the caregiver and you’re used to dealing with the one person and you’re the person they deal with mostly, you start to build a routine and also know when something is off.” (17)</i></p> <p><i>“That they will not really listen to you when you understand the person better than they do. They’re telling her things and she doesn’t understand. He says ‘the doctor’s come in and told me this’ and she says ‘I don’t know what’s going on’”. She said, “They should be telling you’’. She said, “My brain’s gone”, which it has. So I think that’s caused more</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>stress, to be honest, because you're thinking to yourself 'I'm not being told what's going on'' (12)</i></p> <p><i>"Several of the carers quoted one of the community workers who was involved in local support groups who used to say to them 'I am the professional, you people are the experts!' This was a positive and empowering message that the carers appreciated." (18)</i></p> <p><i>"Results of this study show that informal caregivers are, for the most part, quite able to provide good indications of what will cause admission of PWD to ILTC. When directly asked for the expected reasons for admission, approximately two thirds of the sample was able to identify what will cause the admission of their loved one with dementia, although the degree of accuracy between the expected and actual reasons for admission varied." (19)</i></p> <p><b>Knowledge exchange:</b> <i>"When I get a new client on I get a diagnosis that just gives me dementia, or this client has Alzheimer's with no follow up, no follow through of any information whatsoever. I go in half the time blind as to what level of dementia they have, form that they have, what stage they're in. (6C1-1, HCP) (20)</i></p> <p><i>"With people with dementia it's important to have some kind of continuity' and stressed the value of 'familiarity and to know what that person needs.' (21)</i></p> <p><i>"Carers wished that health care professionals would listen to their input more and value their personal history with care recipients." (22)</i></p> <p><b>Longitudinal monitoring:</b> <i>"The finding that the care recipient's behaviour change score influenced institutional placement emphasizes the importance of longitudinal monitoring of behavioural changes in persons with dementia and support for caregivers' in coping and adapting to problem behaviours. This is also supported by the caregivers' reports of aggressive behaviour being a factor in choosing institutional care for their relative." (23)</i></p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p data-bbox="864 196 2024 304">“You have to get to know them personally... and obviously as you get to know that person, then I think you can provide that compassionate care because you know what their needs are. (Family ID 1)” (24)</p> <p data-bbox="864 344 1995 528">“Evidence widely supported the benefits of continuity of care and support in the face of significantly changing life circumstances. Considering the extended nature of end-of life care in dementia, and the non-linear progression of symptoms, palliative care services would benefit from explicitly encouraging carers to include wider support networks for themselves and their care recipients, and formally recognising them.”(22)</p> <p data-bbox="864 568 2040 783"><b>Narrative:</b> “As in Sidell’s study, at least some interviewees seemed to have accepted the inevitability of death with equanimity. At first, we had low expectations of achieving useful responses to the question of participants’ attitudes to death. However, these low expectations were not completely substantiated and similarly to Killick and Allan, we were surprised by participants’ ‘humour, fellow-feeling, insightfulness and honesty’. People with dementia provided a range of responses.” (13)</p>
<p data-bbox="203 786 837 1042">CMO 10: With advancing age and progressive dementia social networks dwindle (C), where this occurs, knowledge exchange (M) relating to the person with dementia, between members of the care networks can allow people to exert influence and maintain a role as an active citizen (O)</p>	<p data-bbox="864 786 2040 935"><b>Diminished social networks:</b> “An active withdrawal from people outside of the immediate family/whānau in the period preceding death was frequently reported. As one daughter recounted, her non-Māori mother ‘wasn’t allowing people near her’ towards the end of her life ‘... there was just me’.” (10)</p> <p data-bbox="864 975 2024 1123">“Returning to his room, I asked Walter if he was warm enough. Instead of answering, he became very agitated, moving from side to side, swearing, and spitting on the floor. Sarah, a tiny woman, sat in a corner of the room, gripping a big black purse in her lap as if it could protect her.” (25)</p> <p data-bbox="864 1163 2024 1272">“Aggressive behavior against other people, which causes those people to visit them less frequently and for that reason, probably are also unable to provide support (for the person with dementia).” (FG62) (26)</p> <p data-bbox="864 1311 2024 1374">“Loss of social contacts, this is very important. I think that it is not necessarily caused by behavioral problems. If, during a birthday party, a person asks “when are we going home”</p>



CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>20 times, this is not aggressive behavior, but perhaps this is a reason for the informal caregiver to decide to no longer go there” (26)</i></p> <p><i>“It’s painful to watch someone completely change. And it’s isolating because...we’d a big circle of friends and slowly but surely everything just disappeared. People came, kept calling for a little while and then one by one they faded away”(27)</i></p>
<p>CMO 11: With changing physical, emotional and behavioural characteristics (C), people with dementia and their families experience uncertainty for what the future holds and the timescales changes may occur within (M). This uncertainty is characteristic of a state of liminality (O)</p>	<p><b>Changing physical, emotional and behavioural states:</b> <i>‘I just consider myself to be living with an old man who I never knew’ (Sanders et al., 2002 p. 13). ‘She was always very well dressed and very polite. Now she doesn’t thank people . . . She was never like that ’” (28)</i></p> <p><b>Uncertainty for the future:</b> <i>“Even telling family members that the pathways ahead will be rocky and unpredictable would be more helpful than silence or limited guidance, education, or instruction” (29)</i></p> <ul style="list-style-type: none"> <li>• <i>Wife: “Guessing, always guessing. I want to do right by him, but he has not been able to tell me when he is ill or hurting for over a year now, so I have to be vigilant.” (17)</i></li> </ul> <p><i>“If it comes to me and I don’t know, can’t comprehend this, I don’t know what’s going on, don’t know what to do and she’s complaining about it, that’s more of a crisis of not being able to deal with things that Alzheimer’s presents through the patient, through the caregiver, not know what’s going on with the patient.” (7)</i></p> <p><b>Liminality:</b> <i>“During the liminal state people are often structurally invisible, without status: ‘no longer classified and not yet classified” (3)</i></p> <p><i>“Nobody else is going to make decisions for me because they don’t know what I want – I’ll do what I like’. Dan was apprehensive about the possibility of residential care.” (30)</i></p>
<p>CMO 12: The priorities of care may change as dementia progresses and relationships change (C). This may lead to a decision making process (O), the nature of the outcome (fraught or fluid) is mediated through acknowledging growth of a new identity (M), maintenance of a historic</p>	<p><b>Changing priorities of care:</b> <i>“It’s very hard to set in stone goals because they change...so you have to change with them and adapt, add or subtract from your goals or your plan depending on where they (person with dementia) are at.” (nephew)” (31)</i></p> <p><b>Fraught decision making:</b> <i>“I said, ‘The next time that he calls, you give him my telephone number’, and I said, ‘You tell him that I absolutely refuse for them to do anything with my</i></p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
identity now lost (M), or by active discrimination and manipulation of a person with reduced agency (M)	<p><i>father. Unless a doctor calls and tells me that I have to do something, it's gonna stay the way it is now'. And I said, 'If he doesn't like it, and he thinks he's gonna cause you trouble, you tell him that I'm gonna go get me a lawyer, and I'm gonna call Channel 5...'. (32)</i></p> <p><i>"Should we stay with her earlier wishes or go with her contemporaneous neutrality? The group was passionately divided. We had agonizing conversations." (33)</i></p> <p><b>Fluid decision making:</b>  <i>"a sense of the existential self, suggests that care givers ability to derive meaning in their lives and sense of self apart from the caregiving situation" (34)</i></p> <p><i>"Me, too, I'm not what I used to be. So, when you see that the situation is deteriorating. . . . If it's for their own good, between you and me, even though they don't see it that way at first. Maybe in the beginning she'll say: "No, I'm not going." But I think she'll come around in time." (35)</i></p> <p><b>Growth of a new identity:</b> <i>"...at lunchtime, when the researcher tried to help her, she refused to eat. When staff warned her that she would 'waste away', she replied emphatically 'I don't want to be . . .'. This sentence definitely sounded unfinished. Perhaps she did not want to be fed, or was she saying 'I don't want to be alive any more'? Anecdotally, nurses reported similar conversations with people with advanced dementia who confirmed their decision not to eat or who refused essential medication, apparently 'fully' aware of the consequences of this choice, and died soon afterwards" (13)</i></p> <p><i>"Despite her profound dementia, she can still play the piano and read music." (36)</i></p> <p><b>Maintenance of historic identity:</b> <i>"We have been saying goodbye to grandma for over 10 years because my grandma's gone! You get little glimpses of her but she's not there anymore. You know? She doesn't play her music anymore she doesn't play her Black Sabbath at full volume and dance round the kitchen like she used to . . . and that's at 80 . . . She can't get on the back of the boys bikes anymore . . . 'She's not there'. Which is sad?" (37)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><b>Maintenance of a historic identity:</b> “And they said something one time, and I just told ‘em, I said, ‘Hey, I’m doing what [Dad] wanted, and if you don’t like it, that’s your problem, because this is what he wanted” (32)</p> <p>“There are those who say he is such a gentle, nice man, he would never do this. But before he had Alzheimer’s, he was pro-choice; he performed abortions. He is a wonderful man, and I love him. But he has positions I think are morally reprehensible.” (38)</p> <p>“We become ridiculous, incapable, comic. But this is not who we are. This is our disease...Please do not think that I am suffering. I am not suffering. I am struggling to be a part of things, to stay connected to who I once was.” (39)</p> <p><b>Discrimination/manipulation:</b> “My mom and my uncle have been managing her finances, because there was some concern around that, where some family members may be taking advantage of that. So they’ve been managing that for my grandmother.” (40)</p>
<p>CMO 13: Where people with dementia and their families enter into advance care planning (C), the decision making process (O) is influenced by a family’s power as a surrogate decision maker. Here mechanisms (M) include the maintenance of a historic identity, the growth of a new identity, discrimination of a person with reduced agency, compassion towards a person (and family) with dementia, knowledge exchange between caregivers and professionals</p>	<p><b>Growth of a new identity:</b> “While seeking information from families is clearly necessary in many cases (including to ascertain applicable past wishes of patients who lack written statements), the views of proxies should be balanced with the past and – importantly– the present voices of incapacitated patients” (4)</p> <p><b>Paternalism/Discrimination:</b> “Both dementia and frailty studies report advance decisions being overridden where there had been an antecedent rejection of artificial nutrition and hydration and hospitalisation.”(4)</p> <p>“There were also instances when caregivers pursued more aggressive treatment than what the patient had wanted. Some caregivers explained that even when the wishes were known, they had a reluctance to “let the person go,” [9] or they experienced uncertainty, which contributed to the weight of those decisions.” (41)</p> <p>“While some studies indicate moderate agreement between surrogate reports (of advanced care planning) and documented patient wishes, the instructions may be nonspecific, fail to address common end-of-life dilemmas” (4)</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p data-bbox="864 233 1984 336">“...a variety of factors were involved in initiating ACP. Family factors dominated, with family’s initiative or lack of it, and willingness or reluctance identified in a series of studies... ”(42)</p> <p data-bbox="864 379 2022 523">“But it was just a couple of the nurses that screamed at him so, so, so bad. I do think that they should try to understand the person. They’re elderly, you know, even different ones in there, the way they are. Look, I know the nurses have got to have enormous amount of patience. But the way that he was screamed at was terrible...”(12)</p> <p data-bbox="864 566 1984 710">“An important issue that emerged in many of the interviews was the carers’ role in understanding what the person with dementia may be experiencing, and advocating for what they would want if they could speak for themselves – as opposed to what the carer themselves thought would be a good thing to do.” (43)</p> <p data-bbox="864 753 2029 928"><b>Agency:</b> My brother-in-law fell . . . and they said to his wife ‘do you want us to resuscitate him?’ and she said ‘I can’t tell you to let him die!’ So they kept him going. . . he came to at one stage . . . and he shook his head like that and my sister-in-law said ‘I’m so sorry, I should have said to them don’t resuscitate him’ and I thought, ‘I’m not going to let my husband suffer in that way’.”(44)</p> <p data-bbox="864 971 2018 1115"><b>Compassion:</b> “So you really have to really think about the journey that your gonna take with your loved one, and I always say, ‘How would I want to be treated? Will someone be there for me?’ So I put myself in that role, and I’m really acting it out, and so, so far it’s been working.” (32)</p> <p data-bbox="864 1158 2033 1302">“Because rationalizing usually made her angrier, I would hold her in my arms and tell her over and over, “I love you.” She melted in my arms, feeling secure and peaceful. I believe that as Mom grew more secure in my love, she was able to transition to the third stage with a deep sense of satisfaction and contentment.” (45)</p> <p data-bbox="864 1345 2018 1410"><b>Knowledge exchange:</b> “When I have plenty of time and sometimes talk to family members for well over an hour, we don’t usually get to a point where they are ready to complete an</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>ACP or change goals of care...requires ongoing discussions...reflections...perhaps some involvement from the GP.”(46)</i></p> <p><i>“There was a lot of discussion... about dementia...diagnosis process...acceptance of dementia amongst family and...society...how this hindered the diagnosis process... early part about dementia identification, diagnosis, symptoms...family inheritance” (46)</i></p> <p><i>“Help and advice was sought from friends and family, caregiver support groups, general practitioners, social workers, and aged care assessment teams.” (47)</i></p> <p><i>“...physicians mostly discuss end-of-life questions with long-term family caregivers. The high degree of consultation with caregivers is a positive finding in itself, and the input of family as proxy decision-makers is indispensable...” (48)</i></p> <p><i>“Surrogates’ answers revealed considerable variety regarding goals and the beliefs and values that may underlie them. This variability underscores the importance of clear communication between surrogates and clinicians so that treatment decisions can be guided by agreed upon goals of care within a context of shared decision making” (49)</i></p>
<p>CMO 14: In a state of liminality (C), decision making processes may be fraught (O), due to families or social networks clinging to a historic identity (M), or engaging in paternalistic patterns of behaviour (M).</p>	<p><b>Liminality:</b> <i>“During the liminal state people are often structurally invisible, without status”(3)</i></p> <p><b>Historic identity:</b> <i>“The maintenance of the image of the whole person, to keep alive their personal history, was expressed as being very important by study participants and was an important feature of ACP discussions” (37)</i></p> <p><b>Paternalism:</b> <i>“In particular, two people were not provided with the opportunity to participate in their care, even though they were competent to participate” (50)</i></p> <p><i>“only about one-third of the caregivers in either group consulted the patient regarding discharge”(51)</i></p> <p><b>Fraught decision making process:</b> <i>“all of a sudden you’ll be faced with a decision, it would be at a time perhaps when you’re not emotionally prepared for it, and it would be a bit too much at that stage.” (37)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
CMO 15: In a state of liminality (C), decision making is fluid (O), due to the recognition of a person with dementia having a new identity (M) and ongoing agency (M)	<p><i>“The cardiologist showed up at her bedside, shower cap on his head; two of my siblings were there with my mother. “What are you doing here?” asked my mother. “I’ve come to take you for a pacemaker,” he replied. “I don’t want a pacemaker. You doctors do too much stuff to old people.” My siblings asked my mother the same question in as many ways as they could: “Do you understand you might not live as long without the pacer?” “Yes. I’ve lived a good long time.” And so forth. The pacemaker insertion was cancelled.” (33)</i></p>
CMO 16: Families used ‘case based theory’ rather than ‘principal theory’ when making decisions. Here narrative relating to the person with dementia is of prime importance (C). Fluid decision making processes occur (O) with the use of agency (M), identity growth (M), and knowledge exchange (M).	<p><b>Primacy of narrative:</b> <i>“The ethical approach implicit in these families’ descriptions are consistent with a case-based theory, rather than a principle theory. When these family decision-makers utilized an abstract concept such as human dignity, they did so in a limited manner by discussing the factors that were important for the dignity of their relative, rather than for human dignity in general. They did not invoke patterns or principles from beyond their own experience.” (32)</i></p> <p><b>Identity growth:</b> <i>“She had always been shy and didn’t want to entertain people. Yet, when her inhibitions were lost because of the Alzheimer’s, she would get excited when people visited. She enjoyed the Bible study in our home every Friday evening. One day I was late getting her up from a nap, and students were already arriving. I woke her, asking if she wanted to see the students coming. She jumped out of bed, replying, “I think they’ll want to see me.” Indeed, she did have a special relationship with the students.” (45)</i></p> <p><b>Knowledge exchange:</b> <i>“Inclusion was facilitated in other ways such as knowing the preferences of the person through previous interviews with them and their family, or by asking family members about what those preferences might be, building a biographical understanding of the person and being informed by that.” (50)</i></p> <p><b>Fluid decision making:</b> <i>We’ve made arrangements through a chaplain to be prepared for her death if it happens when we’re not here. I mean, we would come back quickly, you know that kind of thing, and my sister realizes that she could also have to come out quickly. So, while we feel that obligation, yet we feel that our lives have to go on too. (32)</i></p> <p><i>“I think whatever you do, you’ve got to do it with a relatively good grace. If you feel that you’ve been pushed into it, or you’re obliged to do it, then I think it won’t work.” (44)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<i>See above entries for data supporting repeated mechanisms</i>
<p>CMO 17: Where there is interaction with professional care services (C) the decision making process can be facilitated to give greater fluidity (O). Mechanisms include compassion, knowledge exchange, and confidence/autonomy (M).</p>	<p><b>Knowledge exchange:</b> “It’s really hard to get advice on how to find out what is the best way to approach, you know, these sorts of situations. And people are in them all the time, more and more. I mean people are having to look after ageing parents with failing faculties and, as a society, we don’t seem to have any structure in place to manage that process or support it.” (52)</p> <p>“I was able to tell the doctor what was going on with my mom. And he was grateful for the knowledge. He told me what to expect and when to call the clinic. I felt better prepared after that.” (17)</p> <p>“Three variables, patient satisfaction with the plan as perceived by the caregiver, caregiver satisfaction with involvement in the plan, and patient satisfaction with involvement in the plan as perceived by the caregiver significantly contributed to caregiver satisfaction” (51)</p> <p>“I wish the doctor had told me what was in store for us when we got the diagnosis. He just said, “She has Alzheimer’s and there’s nothing we can do for her.” If we had known that she’d get worse and we’d have to eventually place her in a facility, we could have prepared a little for what was ahead of us.” (53)</p> <p><b>Confidence/autonomy:</b> “So they’re sort of pre-empting what they know is going to happen. [Yes] See I don’t necessarily know that’s gonna happen, so they’re kind of giving me that information. “Look, you know, you’re gonna be heading down this road soon so you may wanna do this, this and this.” So it’s helping me to future plan [Yep] which I find very helpful”.(52)</p> <p>“The report broadens the concept of autonomy. In dementia care, autonomy should not only be the freedom to make decisions but should also be considered in “relational” terms—when patients cannot make decisions for themselves their closest family members should help (joint decision making)” (15)</p>
<p>CMO 18: Where there is interaction with professional care services (C), the decision</p>	<p><b>Paternalism:</b> she’s literally out of the house, she’s out of my sight, she’s out of my control. . .and I find that really difficult (27)</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
<p>making process can be fraught or undermined (O) by paternalistic or dismissive attitudes.</p>	<p><i>“Carers wished that health care professionals would listen to their input more and value their personal history with care recipients.”</i>(22)</p> <p><i>“Carers were critical of health care professionals’ unwillingness or inability to deviate from protocol, such as health and safety regulations, which negatively affected the quality of care services.<sup>37</sup> While some conflict may therefore have existed between carers and individual health care professionals, conflict between carers and broader service systems was also apparent.”</i> (22)</p> <p><i>“Caregivers consistently reported limited involvement in planning the hospital care, and they did not receive the communication they felt was necessary to fulfil their role...”</i> (41)</p> <p><i>“I’m most upset with my mom’s doctor. He was rude to me, told me my mom was his patient, and he couldn’t talk to me about her. He told me to butt out when I asked him to help me with my mom’s memory problems. I think what he did is malpractice.”</i> (53)</p>
<p>CMO 19: In a state of liminality characterised by indecision and uncertainty (C), medical paternalism and authority (M) can provide some direction allowing the decision making process to proceed with more fluidity (O)</p>	<p><b>Paternalism/authority:</b> <i>“So long as you say... ‘doctor’ in the sentence . . . she will go along with that, she will listen to that authority so that’s been good actually.”</i> (daughter) (44)</p> <p><i>My mother was asked what she thought and said, “Whatever the doctor thinks is best.”</i> (33)</p> <p><i>The second strongest influence affecting the decisions of both groups...was the advice of the physician...”</i>(51)</p> <p><i>‘You accept it because it’s easy...I think to meself [sic] they are only trying to help you so let them do what they think is best’.</i> (30)</p>
<p>CMO 20: Where members of a caring network feel lost in the ambiguity of their role (C), compassionate care (M) and knowledge exchange (M) can provide fluidity in the decision making (O).</p>	<p><b>Role ambiguity:</b> <i>“Research has begun to highlight the substantial contribution that homecare workers make towards meeting not only the needs of people with dementia at end of life but also their families...their contributions to caring for people dying at home may be overshadowed by the ambiguity of their role and their unmet need for preparation and ...misunderstandings of the role of homecare workers have been described by older people, their family members, and by health care professionals.”</i>(54)</p>



CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 21: When a person with dementia dies (C), the void in reciprocity experienced during the care giving relationship (M) and a sense of duty (M) can drive members of the caring network to transfer their skills to the community (O)</p>	<p><b>Reciprocity:</b> “...yet many aspects of my experience were positive. My father and I had conversations about his memories of his older relatives that I doubt we would have had otherwise. Sharing the ups and downs of caregiving with my sister also brought us closer together. It was the first time that we had discussed our values about caregiving (despite having witnessed our mother’s experience), money, and ultimately, end-of-life care...” (55)</p>
<p>When a person with dementia dies (C), guilt experienced (M) can drive an overwhelming care experience (O)</p>	<p>“This experience of caring for her, brought me closer to my mother. I can now see my strengths as a person.” (56)</p>
	<p>On bereavement: “The majority of carers reported that no longer being able to provide care for their loved one was associated with feelings of loss...”(56)</p>
	<p>“For those reporting caring for another dependant or engaging in caring duties, feelings of altruism were described as a central part of their “post-caring life.” One daughter mentioned: “Giving to other people is very important in life, it makes you feel useful.” (56)</p>
	<p><b>Duty:</b> “As a son, taking care of my parents is my responsibility. Sometimes, my sisters come back home to care for my father, but they have already married out [of the family]. They are guests. It’s not their responsibility. I appreciate their assistance though. However, my brother and I have the ultimate responsibility to take care of our parents.” (57)</p>
	<p>“I just took it as that was part of my life goal, to take care of them... It’s stressful, but sometimes it’s rewarding.” (58)</p>
	<p><b>Transfer of skills:</b> “Consistent with the general caregiving literature, carers reported finding other or new carer-related volunteer activities (Arksey, 2003; Larkin, 2009), during which they contributed and supported their local community” (56)</p>
	<p>“...for me, it is my way to honor Gloria. I couldn’t do anything for her in terms of saving her or changing the progression of her illness, but if I can do something that will help some other family not have to go through what I’ve gone through, what she’s gone through, then that’s what I can do for her.” (58)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><b>Guilt:</b> "For some caregivers, relief was tinged with feelings of guilt that stemmed from various sources. Some felt guilty simply for feeling relieved by the death of their family member. Others felt guilty about decisions made during the caregiving period, especially the decision to institutionalize the family member, or for having expressed anger and frustration when the going was tough." (59)</p>
<p>CMO 22: Where relationships with a caring network become strained (C) a sense of guilt (M), failure (M) and uncertainty (M) in addition to the paternalistic actions of professional care networks (M) can cause the caregiving experience to become overwhelming (O)</p>	<p><b>Strained relationships:</b> "Overall, family conflict and socioemotional support have important implications among caregivers who institutionalize their relatives" (60)</p> <p>"It's a different thing when Mum was living with us. He just didn't handle things, and I was between the devil and the deep. I didn't want to - Mum needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly" (12)</p> <p><b>Guilt:</b> "since they gradually become unable to care for the patient, feelings of guilt easily arise"(61)</p> <p>"Retrospectively, former caregivers often expressed feelings of regret and guilt surrounding decisions they made while caregiving..."(58)</p> <p>"The doctor said my mom could not live alone. You know, I love my mom, but she could not come and live with us. It would have disrupted my whole family. I know it is terrible to call your mother a disruption. What a guilt trip. (62)</p> <p>"feelings of guilt, obligation, and regret can emerge at various points along the disease trajectory. However, the majority of these feelings arise when the person must be institutionalized" (63)</p> <p>"Sometimes I wonder how much she must hate me inside for doing this to her. I feel guilty because I feel she's saying "How could you abandon me here?" (64)</p>

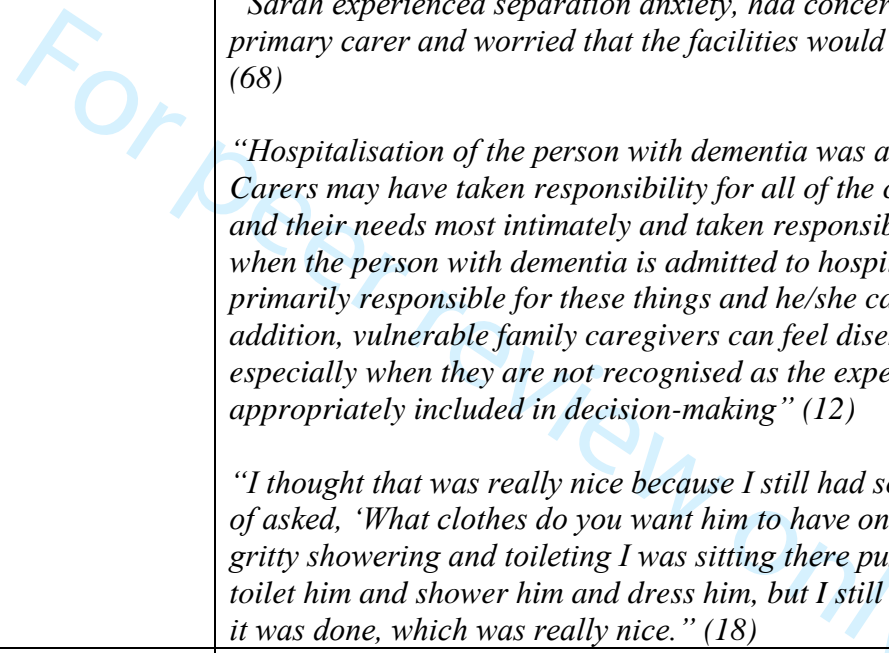
CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><b>Failure:</b> “For others, this placement was seen as a personal failure, illustrating a belief that care should be a family responsibility and that admission into a facility was an abandonment of this responsibility” (22)</p> <p><b>Paternalism:</b> “...healthcare professionals unfamiliar with the family and the resident’s individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact.” (27)</p> <p>“...we had to deal with numerous health and care-related issues...; unapproved chemical restraints; repeated falls; a fractured hip; facility unwillingness to follow up on the surgeon’s recommendations regarding physiotherapy following surgery; confinement to a wheelchair for most of the day; and requests that we designate mom for ‘comfort care’ only in case of medical emergency). As I recount selected aspects of mom’s LTC journey, I receive an email from my brother, informing me that mom has been rushed to hospital for the second time in two weeks....”(29)</p> <p><b>Uncertainty:</b> “...thus, critical issues of personhood, identity, agency, and control were embedded in our moms’ experiences and reflected in our experiences as families as we struggled to “do what was right.” (29)</p> <p><b>Overwhelming:</b> “I had no one to look after mum, so I couldn’t go to work, and I do believe that that impacted and I do believe that that’s one of the reasons that they fired me. Because I couldn’t attend work because I had to look after mum.”(65)</p> <p>“...families that experience negative feelings among members institutionalize their ill elders more frequently than families that do not experience such feelings. Negative affect among family members often leads to conflict, distress, and frustration that can intensify over time. Family members may decide on NHP because of the emotional difficulties that result from ongoing, painful family interactions and the interpersonal difficulties that emerge when attempting to coordinate patient care...”(66)</p>
<p>CMO 23: : Where relationships with a caring network become strained (C), the exchange of knowledge (M) and trusting relationships (M)</p>	<p><b>Strain:</b> “Initially life seemed unbearable. My mother was incontinent, hallucinating, and disoriented. At one point she stayed awake for 40 hours seeing people, places, and things that weren’t there. We were exhausted. But in time, she showed signs of improvement.”</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
<p>generated positivity and rewarding aspects to the care experience (O)</p>	<p><b>Knowledge exchange:</b> “I think just their reassurance...there is nothing physically they can do...they just reassure you.... That you are doing the right thing, more than anything, because sometimes you do doubt yourself” (46)</p> <p><b>Trust:</b> “External support resources from the community or charitable organizations were a key feature for some. Specifically, reliance on neighbours or being members of a close community gave reassurance of their relative’s safety when they were not present...” (27)</p> <p><b>Rewarding aspects to care:</b> “When my mother died from a fall, I reflected on the satisfaction and peace I had not anticipated I would feel. I knew what it was to “give back” to my mother. It seems incredible that caregiving can be so satisfying. I look into her bedroom now and I can feel her presence...and I am thankful for the final gift she gave me.” (67)</p> <p>“Although caring for patients with AD can be challenging and involves many different decisions, good endings are possible. By encouraging patient discussions regarding care preferences early in the course of the disease and educating family and caregivers about what to expect and how to deal with each stage of the disease, physicians can ease the transition for patients and families.” (5)</p>
<p>CMO 24: Where powerful structures of care become involved (C), feelings of failure (M) and a loss of autonomy (or paternalism from healthcare professionals) (M) can lead to a care experience that feels overwhelming (O)</p>	<p><b>Professionalised care:</b> “Dementia starkly reveals the Cartesian biomedical model’s incomplete understanding of “health,” through its inability, even unwillingness, to develop effective (non-biomedical) interventions to address a range of experiences of disease in their social, relational context.” (8)</p> <p>“...carers experience in receiving formal services is inherently ambiguous, for whilst formal services are providing support to family carers, they can also be undermining their sense of identity and control over their circumstances...” (65)</p> <p><b>Loss of control/autonomy in the care role:</b> “Oh God no they did everything, all I had to do was go and visit and feed her. Didn’t even have to feed her but I liked to.” (18)</p> <p>“That they will not really listen to you when you understand the person better than they do”(12)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>“There was no people feeding them and I went, I used to go in and feed her and they said, “Oh no, she’s here to be rehabilitated, you shouldn’t feed her, it’s spoiling her, she can do it herself,” well . . . she couldn’t do it at all and as I say her eating was getting worse and worse at that stage.”</i> (6)</p> <p><i>“Sarah experienced separation anxiety, had concerns about relinquishing her role as primary carer and worried that the facilities would not be able to meet Derek's needs...”</i> (68)</p> <p><i>“Hospitalisation of the person with dementia was also described as a challenging time. Carers may have taken responsibility for all of the caring, believed they knew the person and their needs most intimately and taken responsibility for decision-making; however, when the person with dementia is admitted to hospital, the carer is usually no longer primarily responsible for these things and he/she can experience an acute loss of control. In addition, vulnerable family caregivers can feel disempowered by the health care system, especially when they are not recognised as the expert in the care of their relative and not appropriately included in decision-making”</i> (12)</p> <p><i>“I thought that was really nice because I still had some control over the situation. They sort of asked, ‘What clothes do you want him to have on today?’, so I wasn’t doing the nitty-gritty showering and toileting I was sitting there pushing a button and they’d come and toilet him and shower him and dress him, but I still had a say in when it was done and how it was done, which was really nice.”</i> (18)</p>
<p><b>CMO 25:</b> Where powerful structures of care become involved (C), knowledge exchange (M) and trusting relationships (M) create an environment for a rewarding care experience</p>	<p><b>Trust:</b> <i>“If you don’t feel you can trust them or something, you’re more apt to just sit there and listen and not interact.”</i> (40)</p> <p><i>“One of the difficulties many carers discussed was having to trust that paid workers will provide a good quality of care to their loved one. Some carers were constantly at the nursing home either providing direct care themselves or else making complaints to the management about the standard of care.”</i> (18)</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 26: Where a social network has amassed expertise in caring for a person with dementia (C), knowledge exchange (M) and trusting relationships with professionals (M) allow for a more rewarding care experience. Whereas paternalism and disregard of this expertise can mean carers are devalued (O).</p>	<p><i>“A number of carers mentioned that the clinicians didn’t seek their opinion about the care of the patient although the carer considered himself/herself to be expert in the care of that patient.” (12)</i></p> <p><b>Expertise:</b> <i>“it doesn’t matter how many university degrees and that people do, they don’t know until they’re a carer...what it really involves.” (65)</i></p>
<p>CMO 27: As care demands increase (C), people struggle to keep afloat. Feelings of duty (M) combine with feelings of failure (M) and guilt (M) that makes caregiving overwhelming (O).</p>	<p><b>Duty with increased care demands:</b> <i>“...the children must ensure that the parent is cared for in a ‘manner that is appropriate to them.’ The child’s obligation does not end once the patient is transferred but continues as an ongoing responsibility to oversee the care of the parent...” (69)</i></p> <p><i>“Most caregivers did not have a regular job; three said that they had had to give up their jobs, as their caring role became more demanding.”(70)</i></p> <p><i>“In Kaohsiung most respondents attributed their unwillingness to use nursing homes to filial piety: in contrast, only 22.5% of respondents in Taipei had the same response”(71)</i></p> <p><i>“My sisters-in-law and brothers-in-law opposed bringing my mother-in-law here. It was very hard to persuade them. They wouldn’t listen to me, and the only thing they did was to blame me.”(64)</i></p> <p><i>“I panic and shut down, sometimes I just want to go to my room and close the door and pretend he is not there, but I need to be there for him. I frequently feel that I cannot do one more thing, make one more decision, take one more breath.” (17)</i></p> <p><i>“I had no one to look after mum, so I couldn’t go to work, and I do believe that that impacted and I do believe that that’s one of the reasons that they fired me. Because I couldn’t attend work because I had to look after mum.” (65)</i></p>
<p>CMO 28: As care demands increase (C), people utilise knowledge exchange (M), reciprocity (M) and trusting relationships (M) between formal</p>	<p><i>“The neighbours were all good and if I was worried I would ring the neighbours and they’d say no, he’s out in the garden or we can see him from here, he’s up a ladder or on the roof, or something.” (10)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
and informal care networks to maintain care and an overall positive outlook (O).	
CMO 29: Where networks of networks develop (C), reciprocity (M), compassion (M), knowledge exchange (M), trusting relationships (M) provide mechanisms for a more rewarding care experience (O).	<p><b>Networks of networks:</b> “Indeed, several mechanisms have been discovered by means of which the interdependence between different networks or network layers may help to resolve social dilemmas beyond the potency of traditional network reciprocity” (72)</p> <p>“A final important but unsurprising result is that decision-making for individuals with dementia typically happens without their input, because they are usually completely dependent on their caregivers and no longer able to interact with their environment in a meaningful way, to address treatment concerns, or to provide consent. Instead, physicians mostly discuss end-of-life questions with long-term family caregivers.”(48)</p>
CMO 30: As the role of the family changes in response to increased care demands uncertainty (M), a sense of duty (M) and grief (M) for lost relationships (M) can impact on each member of the care network to create an overwhelming care experience (O).	<p><b>Changing role of the family:</b> <i>In an ancient model of assistance, the family has always been a central point in taking care of elderly people, but modern medicine has prolonged life expectancy while families are becoming smaller and women, traditionally devoted to the care of its members, are often professionally employed”(73)</i></p> <p><b>Duty:</b> “The family members render the majority of pre- and post-institutional care, usually a daughter or daughter-in-law. Although other family members may be available, the bulk of the care support falls to this individual. The significant caregiver burden may be related to the caregiving role of the daughter combined with the enhanced severity of the disease prior to institutionalization” (74)</p> <p><b>Duty and uncertainty:</b> “three years after placement of the feeding tube, her daughters expressed dismay at her condition but felt unable to discontinue the tube feedings.” (5)</p> <p><b>Grief for lost relationships:</b> “Some role changes were so significant leading one caregiver to remark, ‘I don’t call her mum anymore’ (Dupuis, 2007, p. 104). Overall, caregivers began to grieve the losses whilst concurrently attempting to continue a meaningful relationship with their loved one.” (28)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
CMO 31: Where geographical constraints exist (C) (i.e. a family member lives far away and can not get time off to attend) the care experience may feel overwhelming (O) due to the sense of duty felt (M)	<p><b>Geographical constraints:</b> “In multivariable logistic regression analyses (all Po.05), feeding tube use was more common in urban nursing home residents, whereas rural nursing home residents were at greater risk for hospitalisation.” (75)</p> <p>“The bivariate analyses indicated that caregivers expressed a higher preference for institutionalisation when they were living apart from the patient”(76)</p>
CMO 31: Where professional structures of care become involved (C), care can be routinized (M) and subject to paternalistic ideas (M) leading to a person entering the 4 <sup>th</sup> age (O). Where compassion is harnessed as an ethical imperative for health there is potential for community development (O)	<p><b>Compassion as an ethical imperative for health:</b> “These are, first, that compassion is an ethical imperative for health. Compassion is the human response, the tender response aroused by the distress and suffering of others. It is the moral, social, political, and physical basis of our attempts to give aid and support in a time of difficulty. A healthy person without compassion is a potentially dangerous person to the health and safety of other people.” (77)</p> <p><b>Community development:</b> Palliative care must develop a public health approach to end-of-life care if it is to embrace health promotion activities that draw it towards community partnerships beyond volunteer programs and towards broader collaborations such as compassionate cities. (77)</p>
CMO 32: where care networks have diminished (C) there is potential for growth and development of networks (M) that can aid community growth (O)	<p><b>Potential for growth:</b> “Various local people said, you know, ‘We’ll come in and sit with him, for an hour’, but, it didn’t sort of work out – people are busy in the middle of the day.(10)</p>
CMO 33: Where social networks have diminished (C), the routinisation of paternalistic care (M) and the ignominy of this (M) can lead to people entering the 4 <sup>th</sup> age (O)	<p>“We also heard accounts of older people actively resisting community support, with reasons related to shame about bodily decline, concerns about being a burden, an inability to reciprocate and difficulties maintaining engagement in the face of deteriorating health (most notably dementia).”(10)</p>
CMO 34: In the context of a society that rejects death (C), ethical constructs such as compassion (M) and duty (M) have the potential to aid community development (O). Routinisation (M) and paternalism (M) feed into the 4 <sup>th</sup> age (O)	<p><b>Routinization:</b> “Technology and the clinical routine now acknowledge life, though it is a life without subjectivity, produced entirely through technology, clinical care, and surveillance” (78)</p>
CMO 35: Where capacity is held by a surrogate (C), care can be protocolised or routinized leading to the 4 <sup>th</sup> age (O). There is potential to	<p><b>Surrogacy of care:</b> “I want my agent to consider the relief of suffering and the quality as well as the extent of the possible extension of my life in making decisions concerning life-sustaining treatment.”(78)</p>



CMOCs	Illustrative examples of supporting data extracted from the literature
harness ethical constructs such as compassion and duty to aid community development (O).	
CMO 36: where life and death become an amorphous entity (C) routinization in the care of the body (M) leads to the 4 <sup>th</sup> age (O)	<p><i>“The caregivers’ daily routine involves washing the patient’s body, tube-feeding her, collecting her urine, causing her to empty her bowels into disposable diapers, dressing her, rubbing creams into the skin so that it does not shrivel, combing her hair, brushing her teeth, turning her over in bed a few times a day to avoid bedsores, taking her to the veranda in a wheelchair...” (79)</i></p>
CMO 37: Where a person has reduced agency (C), care is routinized (M) and fraught with ignominy (M) to the point of entering the 4 <sup>th</sup> age (O)	<p><b><i>Ignominy and routineisation:</i></b> <i>“this condition was devastating to watch, to [wife’s name] who was always rather coy, shy about the activities of bodily functions, to have her more or less on a timeslot and put into a machine, ‘cos they’d had lunch, lifted up and wheeled into the toilet – that was very devastating . . . I didn’t like to see her suffering these sorts of indignities.” (43)</i></p> <p><i>“She passes stool and handles the faecal matter. Makes her mess and this then cannot be cleaned. The whole household stinks. There is smell of faeces always. Nobody will help. Even my husband, that is her own brother, does not want to be at home. He cannot stand the bad smell.” (70)</i></p>
CMO 38: Where there is a public failure of self-management (C), a person enters the 4 <sup>th</sup> age (O) via mechanisms including institutionalisation (M), ignominy (M) routinisation of care (M). Mechanisms such as compassion and duty have the potential to develop communities to support such people (O)	<p><b><i>The 4<sup>th</sup> age:</i></b> <i>“It is the combination of a public failure of self-management and the securing of this failure by institutional forms of care that a key boundary is passed.” (9)</i></p> <p><b><i>Public failure of self-management:</i></b> <i>reflections from a paid carer, “Not being able to take responsibility, not knowing that things (food) are moulded or at the expiration date. Not knowing when you need to clean up (the house) and also not knowing how to perform certain actions.” (26)</i></p> <p><b><i>Ignominy:</i></b> <i>“But it’s ignominious to have strangers come and dress you, shower you, and I think that’s one of the most humiliating things. It was for my father as well. That’s why I tended to do it myself and latterly with the help of one of the staff – who was very good, the only one who would do it. But I think that’s very ignominious and I think that’s one of the things, and there’s no way around it I suppose...” (43)</i></p>

CMOCs	Illustrative examples of supporting data extracted from the literature
<p>CMO 39: Where communities of identity exist (C), people with dementia are seen to go about their business, their growth and development is then visually acknowledged so people develop an understanding of their needs and daily challenges. Through compassion (M) this may aid community development (O)</p>	<p><b>Communities of identity:</b> ...where people living with dementia are normalized not only in terms of their day care activity—by not being treated as passive consumers of ‘treatments’ or ‘services’ but as active agents of their own preferences and activities—but also as people to be publicly seen going about their usual business. Furthermore, people not directly involved with care for people living with dementia are encouraged to participate in that care and to obtain basic understandings of both the challenges of living with dementia and also the challenges in its daily care. Thus the levels of public education about living with dementia and its care are significantly raised....”(11)</p>
<p>CMO 40: As dementia progresses and manifest as changes in behaviour and social relationships transitions occur to the care environment (C), these might involve the person moving or things moving into what was previously the home environment. Either way, the space as it previously was, transitions to something new (a hybrid space in the home) or an entirely new space in some form of institutional care (nursing home, hospital, sheltered accommodation). These transitions (C) have multiple outcomes for both the individual and members of their care networks. Mechanism identified include duty, paternalism, compassion, routinisation, reciprocity, narrative, resilience, discrimination, teamwork, identity growth, identity maintenance, grief, loneliness and knowledge exchange (M)</p>	<p><b>Transitions:</b> “...there is an important connection for Bourdieu between the social or material dimensions associated with specific positions in social space and the body and its dispositions.” <i>The environment as an extension of social capital</i> (80)</p> <p>“I tend to think that people with dementia do want familiar; it’s the change that is difficult to cope with and the familiar things are personal things. If we’re talking about residential care, to bring in personal things of theirs, whether it was his music, I know my husband did a lot of photography as a hobby... and he had the photographs there...and when he did go into respite, we took the same pictures, I think, that was important to him.”(81)</p> <p>“More than 70% of both the dementia and comparative cohorts attended hospital emergency departments in the last year of life... Decedents with dementia who were not receiving community-based palliative care attended hospital emergency departments more frequently than people receiving community-based palliative care” (82)</p> <p><b>Transitions in the home:</b> “Although all the care recipients and their family caregivers indicated a strong preference for home care over institutional care, their experiences and practices within their homes were disrupted and reconfigured by the insertion of logics emanating from the healthcare field”(80)</p> <p><b>Duty:</b> Another difference was in the sense of obligation for family members to provide care for their next of kin through the course of the disease, which was apparent, for example, in Spain and Estonia (83)</p>

CMOCs	Illustrative examples of supporting data extracted from the literature
	<p data-bbox="862 196 1933 264">“...our study showed that end-of-life care for people with dementia is moving from institutional care to non-institutional LTC in Finland....” (84)</p> <p data-bbox="862 304 1995 451">“The demands of patient choice and cost appear to create an overwhelming case for the drive to increase the numbers of people dying at home. We support this endeavour but would also emphasise that not every admission for in-patient care should be seen as a failure to provide effective community services” (85)</p> <p data-bbox="862 491 2022 638">“As in previous studies, demented older people cared for by non-spouses were more likely to be institutionalized in the first year after baseline measurement as compared to those cared for by spouses. This is in agreement with the assumption that non spouses are less strongly committed to the caregiving relationship as compared to spouses” (86)</p> <p data-bbox="862 678 2033 858"><b>Guilt:</b> “I visit here many times, but every time I am so ashamed. This place is like a dumpster where you throw away things, a place for well-off daughters’ in-law to throw away their parents-in-law. I felt so guilty in front of the nursing assistants to be a child of one of these elderly people. I don’t even dress nice when I come here because I’m afraid of what people will say of me since I’ve brought my parents over here.”(64)</p> <p data-bbox="862 898 2033 1078"><b>Reciprocity:</b> “Mom also taught me more about love. I learned to express my love. Because I knew she would easily forget, I would remind her many times a day that I loved her. Each time I did, she would light up with a smile. It brought me much joy to see her receive my love. Often when I was helping her, she would kiss me on the arm, whisper “I love you,” or say “Thank you.” .... I realized the more I said, “I love you,” the more love grew” (45)</p> <p data-bbox="862 1118 2033 1265"><b>Resilience:</b> “Following control for the various resilience covariates, resilience remained a significant predictor of transitions from dementia caregiving. Those caregivers in the low-resilience category at baseline were 0.62 times less likely than those in the high-resilience category to experience a care recipient death (<math>p &lt; .01</math>)” (87)</p> <p data-bbox="862 1305 2022 1410">“It is surprising that behavioural disturbances are one of the major reasons for admission in RUD (rehabilitation unit for dementia), but they are not risk factors for institutionalization after discharge. The process mediating the association between BPSD</p>

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CMOCs	Illustrative examples of supporting data extracted from the literature
	<p><i>(behavioural and psychological symptoms of dementia) and placement may be the ability of the caregiver to tolerate such behaviours and not BPSD by themselves.” (88)</i></p> <p><b>Growth and liminality:</b> “... participants show an orientation to the present and the future that contains growth on the one side and vulnerability on the other. Growth concerns personal growth and developing new ways in which to organize their lives. Aspects of vulnerability include declining health, possible dependence, coping with growing older, and being concerned with finitude.” (89)</p> <p><b>Grief:</b> “This transition can also highlight the sadness that marks the end of a long-standing relationship.” (63)</p> <p>“I had to keep reminding myself that the disease took away the dad I once knew” (90)</p> <p>Loneliness: “I don’t actually call them that much, but just knowing they are there is a tremendous source of help...”(91)</p> <p>“I think it has something with me being the only girl in the family...there’s my three older brothers, but like I said before they really haven’t helped that much. If anything I have to protect my mother from them...”(91)</p> <p><b>Knowledge exchange:</b> A lack of communication or information sharing appeared to be a key reason why older adults and caregivers felt ignored, forgotten or unimportant” (92)</p> <p><b>Conflict:</b> “I said, ‘The next time that guy calls, you give him my telephone number’, and I said, ‘You tell him that I absolutely refuse for them to do anything with my father. Unless a doctor calls and tells me that I have to do something, it’s gonna stay the way it is now’. And I said, ‘If he doesn’t like it, and he thinks he’s gonna cause you trouble, you tell him that I’m gonna go get me a lawyer, and I’m gonna call Chanel 5...’.” (32)</p>

## Part 6 – Example of CMOC development

To provide an example of the process of interpreting data to develop CMOCs from the papers reviewed we are drawing Kellehear's model of compassionate cities.

Kellehear argues that the responsibility of care at this point should not be left alone with families or professional care services. Instead end of life care is a form of social, psychological, spiritual and even physical support that extends through to the point of death and beyond. The care process facilitates community development, helping society to reclaim death as a social problem where reciprocity is transferred from the dyadic relationship of caregiver and care receiver to a more complex phenomena articulated through networks of networks, community or social capital.

We found data to support elements of this theory, and community development became a repeating code across the data set. In order to develop a CMOC we needed a number of elements to substantiate our theory. This led us to look in more detail at the role of social networks surrounding the nodal person with dementia in search of specific contexts and mechanisms that would lead to this outcome. The data uncovered conflicting information, that social networks would dwindle with no evidence of expansion, in fact that people with dementia would in some cases actively seek to detach themselves from community.

This led us to Gilliard's and Higgs theory on the 4<sup>th</sup> age. Higgs and Gilliard argue that the 4<sup>th</sup> age emerges from the 'institutionalisation of infirmities of old age'. Through the combination of a public failure of self-management and the securing of this failure by institutional forms of care a key boundary is passed. Beyond this boundary a person may fade from the social world much in the way a black hole may distort the gravitational field surrounding it – not observable other than in the traces of its effects. Institutionalized health and social care practices help demarcate the 'event horizon'. Beyond which a person is stripped of any social or cultural capital which is valued and allows for the articulation of choice.

As we analysed the data set empirical evidence was found that served to act as a context and mechanisms leading with 'entry into the 4<sup>th</sup> age' or 'community development'. These appeared to be the most relevant and overarching outcomes. After theoretical saturation of combinations of CMOC that lead to each of these outcomes the next task was to see how the 2 groups of CMOCs related to one another.

True to Gilliard and Higgs theory of the 4<sup>th</sup> age acting as a black hole, (one into which data is lost and can therefore not be studied directly but within its impact on the discourse that surrounds and orientate themselves to it) we found a lack of subject relevant data relating to what happens after entry into the 4<sup>th</sup> age. It was on the impact of this transition, in studies relating to the grieving process, that we found evidence of reciprocity being achieved and not within dyadic relationships but through mechanism such as duty and compassion which prompted engagement with people outside of the care networks and back into the community. Thus linking the 2 CMOC configurations together as one aspect of the programme theory.

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### RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) publication standards for meta-narrative/realist reviews

Section:	Topic	Explanation	Page number
Introduction	Rationale for review	Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area.	p3-5
	Objectives and focus of review	State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review.	P5-6
Methods	Changes in the review process	Any changes made to the review process that was initially planned should be briefly described and justified.	p6-7
	Rationale for using meta-narrative review	Explain why meta-narrative review was considered the most appropriate method to use.	p5-6
	Evidence of adherence to guiding principles of meta-narrative review	Where appropriate show how each of the six guiding principles (pragmatism, pluralism, historicity, contestation, reflexivity and peer review) have been followed.	p5-9
	Scoping the literature	Describe and justify the initial process of exploratory scoping of literature	p6-7
	Searching processes	While considering specific requirements of the journal or other publication outlet state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include (for example) name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected.	P7-8
	Selection and appraisal of documents	Explain how judgements were made about including and excluding data from documents, and justify these.	main document p8, supplementary file p26-27
	Data extraction	Describe and explain which data or information were extracted from the included documents and justify this selection.	main document p8-8, supplementary file p26-27
	Analysis and synthesis processes	Describe the analysis and synthesis processes in detail. This section should include information on the constructs analysed and describe the analytic process.	Main document p8-9 Supplementary file p54
Results	Document flow diagram	Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example,	Figure 1 and p9-10

		from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification to suit the data) that are provided.	
	Document characteristics	Provide information on the characteristics of the documents included in the review	Main document p9 Supplementary file p4-26
	Main findings	Present the key findings with a specific focus on theory building and testing.	p9-22
Discussion	Summary of findings	Summarise the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s)	P21
	Strengths, limitations and future research directions	Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed	p25
	Comparison with existing literature	Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic.	p22
	Conclusion and Recommendations	List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice.	p23-26
	Funding	Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers.	p26