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# BMJ Open Which moral barriers and facilitators do physicians encounter in advance care planning conversations about the end of life of persons with dementia? A meta-review of systematic reviews and primary studies

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## ABSTRACT

**Importance and objective** Conducting advance care planning (ACP) conversations with people with dementia and their relatives contributes to providing care according to their preferences. In this review, we identify moral considerations which may hinder or facilitate physicians in conducting ACP in dementia.

**Design** For this meta-review of systematic reviews and primary studies, we searched the PubMed, Web of Science and PsycINFO databases between 2005 and 30 August 2019. We included empirical studies concerning physicians' moral barriers and facilitators of conversations about end-of-life preferences in dementia care. The protocol was registered at Prospero (CRD42019123308).

**Setting and participants** Physicians and nurse practitioners providing medical care to people with dementia in long-term and primary care settings. We also include observations from patients or family caregivers witnessing physicians' moral considerations.

**Main outcomes** Physicians' moral considerations involving ethical dilemmas for ACP. We define moral considerations as the weighing by the professional caregiver of values and norms aimed at providing good care that promotes the fundamental interests of the people involved and which possibly ensues dilemmas.

**Results** Of 1347 studies, we assessed 22 systematic reviews and 51 primary studies as full texts. We included 11 systematic reviews and 13 primary studies. Themes included: (1) beneficence and non-maleficence; (2) respecting dignity; (3) responsibility and ownership; (4) relationship and (5) courage. Moral dilemmas related to the physician as a professional and as a person. For most themes, there were considerations that either facilitated or hindered ACP, depending on physician's interpretation or the context.

**Conclusions** Physicians feel a responsibility to provide high-quality end-of-life care to patients with dementia. However, the moral dilemmas this may involve, can lead to avoidant behaviour concerning ACP. If these dilemmas are not recognised, discussed and taken into account,

## Strengths and limitations of this study

- This study exclusively focuses on moral barriers and facilitators to advance care planning to increase depth on reasons including moral dilemmas behind possible practical barriers and facilitators while other reviews have studied barriers and facilitators more generally.
- To further increase depth and to minimise chances of missing important barriers and facilitators, the review covered both systematic reviews and primary studies.
- We could not compare study quality in a valid manner as there was no good tool to appraise the quality of the evidence of the moral considerations we abstracted while the tools we used may be suboptimal for our purpose.

implementation of ACP as a process between physicians, persons with dementia and their family caregivers may fail.

## INTRODUCTION

Advance care planning (ACP) requires discussing medical, psychological, social, spiritual and existential issues, being aware of patients' norms and values, life events and what really matters to them in the last phase of life.<sup>1 2</sup> The patient's perspective may be lost when ACP is not discussed directly with patients themselves, not carried out in advance, or focuses mainly on preferred medical interventions, such as decisions around hospitalisation or withholding life-prolonging treatment.<sup>3 4</sup>

Although evidence on effectiveness in dementia is still limited, ACP may be particularly important for patients with dementia.<sup>5 6</sup>

Due to the cognitive decline and progression of the disease, patients with dementia will become less competent to express their values and preferences regarding the end of life (EOL),<sup>7</sup> and they become dependent on others to arrange their EOL care.<sup>1 3 8-11</sup> This increases the relevance of starting the conversation in the earliest phase of the disease.<sup>12 13</sup>

However, patients' interests may change over time, whether due to a change in personality as a result of the disease or not.<sup>1 3 6 8 14-17</sup> Despite physicians' aims to make decisions based on the patient's autonomy<sup>18-20</sup> and best interests,<sup>10 21</sup> a reserved and ambivalent attitude to ACP, specifically concerning patients with dementia,<sup>22</sup> is observed among physicians. Physicians may experience specific ethical dilemmas which may involve moral considerations such as those related to anxiety, hope and relationships,<sup>23 24</sup> which previous reviews did not address in depth as they mostly reported organisational and practical barriers. The aim of this meta-review of systematic reviews and primary studies is to better understand these moral considerations that present physicians and nurse

practitioners (further referred to as physicians) in long-term care (LTC) and primary care settings with ethical dilemmas regarding ACP with patients with dementia and their family caregivers.

## METHODS

We regard ACP in dementia—due to exclusion of persons with no capacity in general work around ACP<sup>25</sup>—as a communication process between physicians, patients if possible and family caregivers or other relatives to understand personal preferences for care goals, treatments and other wishes regarding the EOL. We define moral considerations as the weighing by the professional caregiver of values and norms aimed at providing good care that promotes the fundamental interests of the people involved and which possibly ensues dilemmas.<sup>26</sup>

## Search strategy

We systematically searched the PubMed, Web of Science and PsycINFO databases. We combined the search terms:

**Table 1** Search strategy and inclusion criteria

Search strategy	PubMed	Web of science	PsycINFO
	(“dementia”(mesh] OR neurocognit*(tiab] OR “cognitive”(tiab] OR “cognition”(tiab] OR “dementia”(tiab] OR “dementias”(tiab] OR “Alzheimer”(tiab] OR “Alzheimer’s”(tiab] OR “amnesia”(tiab] OR “amnesias”(tiab] OR “amnesic”(tiab)) AND (“Advance Care Planning”(Mesh] OR Advance Care Plan*(tiab))	(“dementia*” OR neurocognit* OR “cognitive” OR “cognition” OR “neurocognitive” OR “Alzheimer*” OR “amnesia*” OR “amnesic”) AND “Advance Care Plan”	(DE “Dementia” OR DE “Alzheimer’s Disease” OR neurocognit* OR TI “dementia*” OR TI “Alzheimer*” OR TI “cognitive” OR TI “cognition” OR TI “neurocognitive” OR “amnesia*” OR TI “amnesic” OR AB “dementia*” OR AB “Alzheimer*” OR AB “cognitive” OR AB “cognition” OR AB “neurocognitive” OR “amnesia*” OR AB “amnesic”) AND (DE “Advance Directives” OR TI “Advance Care Plan*” OR AB “Advance Care Plan”)
Inclusion and exclusion criteria			
<b>Inclusion criteria:</b>			
(1) Reporting on empirical data			
(2) A population or an identifiable subgroup diagnosed with dementia			
(3) ACP in the context of a long-standing relationship between the physician, the patient with dementia and his/her relatives			
(4) Care provided in long-term care (LTC) and primary care settings			
(5) Barriers to and facilitators of ACP on the part of the physician and described from various perspectives			
(6) Studies emphasising moral considerations as a barrier or facilitator for the physician			
<b>Exclusion criteria:</b>			
(1) Studies about consent for research participation			
(2) ACP limited to drawing up an advance directive that is not brought to the attention of a physician			
(3) Theoretical, legal and ethical issues that are not barriers to or facilitators of ACP for the Physician			
(4) Studies that exclusively consider advance decision making on euthanasia			

ACP, advance care planning.

dementia and ACP as MeSH terms, free-text words and equivalent index words (table 1). The search was limited to articles in English, Dutch, French and German and published in peer-reviewed journals between 1 January 2005 and 11 May 2018, and was updated on 30 August 2019. We checked the reference lists of included systematic reviews for additional primary studies and searched for relevant grey literature.

### Types of studies

We included systematic reviews, defined as reviews with a systematic search strategy, and additional primary studies that were not included in the systematic review and that met the criteria listed in table 1.

### Study selection

We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement for Reporting Systematic Reviews and Meta-Analyses of studies that Evaluate Health Care Interventions.<sup>27</sup> After removing duplicates, using Endnote X9 software, four researchers (AK-vL, MvT-dB, BT and JvdS) independently screened all remaining studies for possible eligibility by reading titles and abstracts. Disagreements were discussed in this team. The full text of studies that met the inclusion criteria was independently read and assessed for eligibility in pairs (AK-vL, MvT-dB, BT or DT). Disagreements were resolved through discussions with a third researcher (JvdS). For the process of data extraction, we refer to the Prospero protocol. (online supplemental file 1)

### Thematic analysis

The included studies were analysed using qualitative analysis software ATLAS.ti V.7. Through inductive coding,<sup>28</sup> 80% of these studies were independently coded by two researchers (DT, AK-vL). The codes were repeatedly compared and discussed to reach agreement. In the event of disagreement on the relevance of a code, the team discussed until consensus was reached and a set of codes was established. One researcher (AK-vL) subsequently coded the remaining 20%. Codes with similar content were merged while differentiating facilitators and barriers. Related groups of codes were subsequently combined into categories. Finally, we merged the categories into themes describing the main moral considerations.

### Methodological quality

The methodological quality of the primary studies was determined independently by two researchers (BT, AK-vL) using the Mixed-Methods Appraisal Tool (MMAT) range 0 (no quality criterion met) to 100 (all five criteria met). The systematic reviews—except for scoping reviews<sup>29</sup> were appraised independently by AK and HS using AMSTAR-2 (A Measurement Tool to Assess systematic Reviews) with no scoring as recommended for AMSTAR-2.<sup>30</sup>

## RESULTS

The search resulted in 11 systematic reviews,<sup>9 10 12 13 15–17 21 23 31 32</sup> and 13 primary studies<sup>1–3 6 8 11 22 33–38</sup> (figure 1). Check of the reference lists of the systematic reviews did not yield any relevant additional primary studies.

The 11 systematic reviews included qualitative or mixed-methods studies; none included quantitative studies only. Three were scoping reviews with systematic searches (table 2). Of the 13 primary articles, nine reported on qualitative research, two reported on quantitative research and two had a mixed-methods design (table 3). Most of the primary studies (9) were conducted in the UK, and settings varied (home, hospital, nursing home).

### Methodological quality

MMAT ratings for primary studies varied between 20 and 100 (see online supplemental table 1). The overall quality of five studies rated 80 or 100, six studies achieved ratings of 60, and two studies rated 40 or less. The quality of the eight assessed systematic reviews was rated critically low.

The thematic analysis identified five themes: (1) beneficence and non-maleficence; (2) respecting dignity; (3) responsibility and ownership; (4) relationship and (5) courage (table 4).

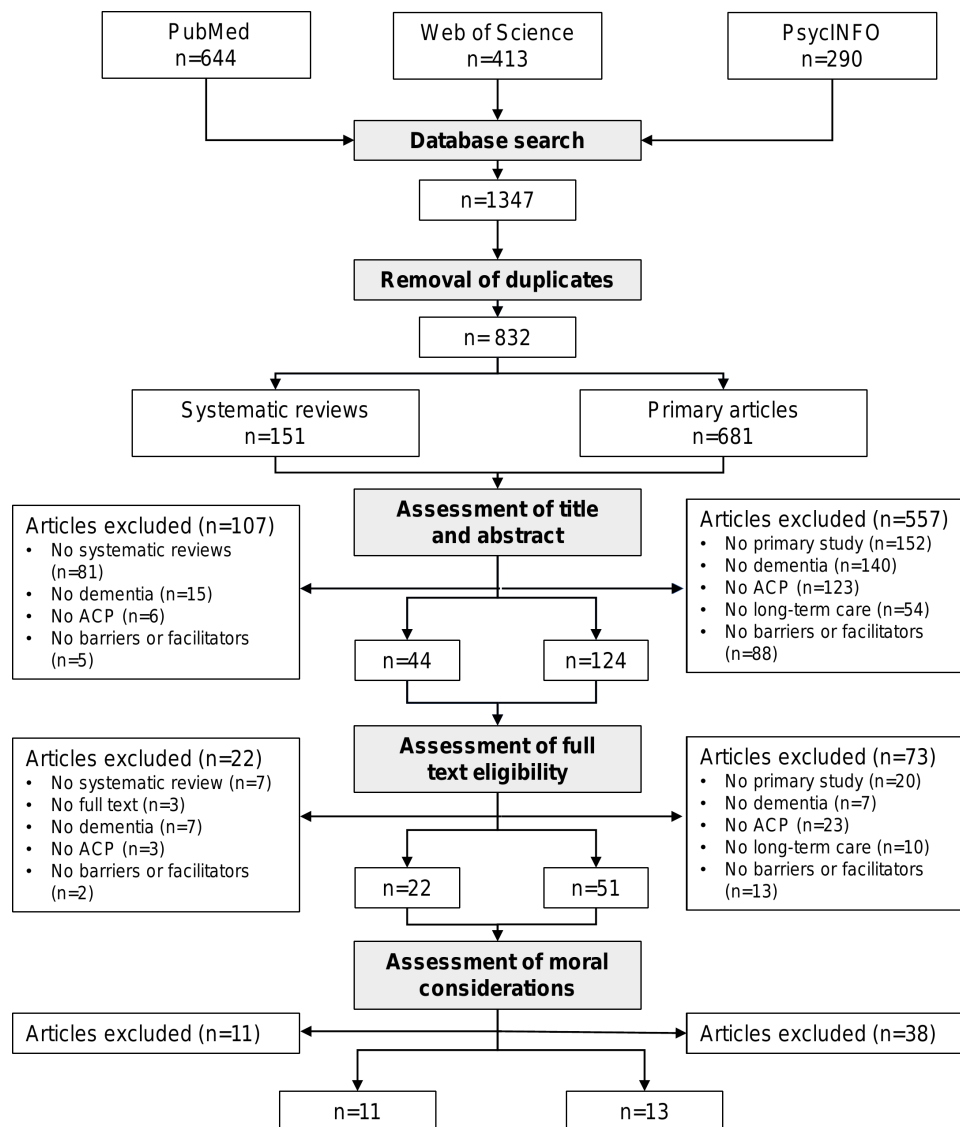
### Beneficence and non-maleficence

Physicians generally aim to provide care according the principles of beneficence and non-maleficence, and therefore, intend to act in patient's best interest from their own professional perspective and that of others including patients and family caregivers. In practice this intention facilitates ACP, promoting awareness of the patient's previous wishes. However, it can also create barriers and hence, dilemmas for conducting ACP.

### Category: providing good care and decision making at the EOL

Physicians aim to provide good care in the interest of the patient, particularly at the EOL,<sup>10 21</sup> and avoid unnecessary suffering.<sup>1 8 15 33 34</sup> Being aware of the patient's previous wishes helps physicians to resolve possible disagreement between patients and family caregivers and to avoid crises in decision making.<sup>16 23</sup> However, a dilemma emerges when he fears that discussing a patient's interest uncovers conflicting views,<sup>2 6 9 16 22 35</sup> or when discussing the implementation of earlier wishes is not in the actual best interest of the patient.<sup>2 6 8 9 16 22 35</sup> Another dilemma arises when the physician notices a shift in the patient's response in time, signifying that patient's preferences deviate from anticipatory beliefs.<sup>6</sup>

Physicians also aim to avoid adding emotional burden to the patient,<sup>1 3 8 9 21 31 33 35</sup> and provide emotional support to family caregivers.<sup>2 8–10 12 34</sup> These intentions will on the one hand motivate starting and conducting ACP conversations.<sup>2 6 9 10 12 34</sup> On the other hand, fear of inducing anxiety or emotional harm may induce reluctance to start conversations about the EOL.



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. ACP, advance care planning.

### Category: maintaining hope for the future

De Vleminck *et al*<sup>3</sup> and Lai *et al*<sup>21</sup> note that physicians in general aim to provide and maintain the patient's hope for the future, but fear that discussing the diagnosis and prognosis of dementia can take away hope.<sup>2 8 9 31 33</sup> This dilemma arises because physicians are aware of the uncertainties in prognoses and a future that can only be captured in hypothetical scenarios.<sup>11 13 16 17 36</sup> This may result in reluctance to make advance decisions.<sup>13 16</sup> A fear to induce anxiety by discussing the future can make the physician even more hesitant.<sup>3 8 9 33</sup>

Additionally, physicians observe that patients with dementia themselves often prefer not to initiate such discussions about future care, because they are unaware of the diagnosis and prognosis or because of diminished decision-making capacity.<sup>3 13 33</sup> A preference of people with dementia to focus on immediate rather than on future concerns<sup>3 8 10 13 15 21 23 31 33 37</sup> can create a dilemma when deemed at odds with the intention to provide hope for the future.

### Categories: physician's professional and personal attitude towards talking about death and dying

Despite findings that physicians who have more professional experience witnessing patients' illness or death are more motivated to conduct ACP,<sup>23</sup> many authors report that physicians feel uncomfortable discussing death or the approaching EOL with their patients.<sup>3 8 10 17 21 23 34 35</sup> This hesitation is reinforced by the patient or the family caregiver either actively or passively avoiding discussing dying.<sup>1-3 8 10 11 13 17 22 23 33-35</sup>

Patients may show active reluctance to face the EOL,<sup>23</sup> and avoid all conversations about their own death.<sup>8</sup> Passive avoidance of the conversation is observed when the patient puts all his faith in the physician,<sup>23</sup> or postpones talking about the future.<sup>17</sup> In addition, family caregivers may not want to discuss their relative's preferences because they do not want to think about, or accept their relative's EOL.<sup>2 10 11 23</sup>

Booij *et al*<sup>6</sup> emphasise that besides being a professional, the physician is also a 'fellow human being,' who may



**Table 2** Description of included systematic reviews

Author and year of publication	Type of systematic review	Study goal	Study design (qualitative, quantitative or mixed-methods)	Scope of the review	No of articles and setting	Themes relevant to moral considerations/perspective	AMSTAR-2
Beck <i>et al</i> <sup>9</sup> 2017	Narrative review	Overview of evidence on healthcare professionals' perspectives on ACP for people with dementia	Narrative literature review of qualitative and quantitative studies	4 databases searched for articles, published between 2002 and 2014	14 studies included. LTC settings	Healthcare professional's ethical and moral concerns regarding ACP. There were personal, professional and organisational challenges in implementation of ACP. Perspective: healthcare professionals	Critically low quality review
Birchley <i>et al</i> <sup>10</sup> 2014	Scoping review	To understand the challenges in securing good end-of-life care	Scoping review of qualitative and mixed-methods studies	6 databases searched for articles, published between 1945 and 2015	49 studies included. NH or hospitals	Process of decision making at the EOL, minimal medical intervention and a natural good death, difficulties in progressing the approach of ACP. Perspectives: frail older people and people with dementia	–
Barker <i>et al</i> <sup>12</sup> 2017	Scoping review	To explore evidence on decisional support needs of informal carers of people with end-stage dementia	Scoping review of literature reviews and primary studies. Quantitative, qualitative and mixed-methods studies	6 databases searched for articles published between 2000 and 2016	40 articles included. Healthcare settings and person's own home	Besides living well with dementia there is a need to plan for a good death. Perspectives: patients and informal carers of people with end-stage dementia	–
Brooke and Kirk <sup>13</sup> 2014	Literature review of empirical research	Barriers and facilitators with impact on healthcare professionals' engagement with ACP for people living with dementia and their families	Literature review of qualitative and quantitative studies	3 databases searched for articles published between 2013 and 2014	4 studies included. Primary care	Lack of ACP knowledge, understanding the right time and reluctance/avoidance of patients/relatives. Perspective: healthcare professionals	Critically low quality review
Junon <sup>15</sup> 2019	Scoping review	Synthesis of the research evidence on decision-making concerning EOL care for people with dementia	Scoping review of heterogeneous types of studies	9 databases searched for articles published between 1945 and 2015	25 studies included. Hospital, home and community	Decision making and who is involved, relevant systemic factors within agencies, and the quality of death vs withdrawal of treatment. Perspectives: person with dementia, healthcare professional and relative	–

Continued

Table 2 Continued

Author and year of publication	Type of systematic review	Study goal	Study design (qualitative, quantitative or mixed-methods)	Scope of the review	No of articles and setting	Themes relevant to moral considerations/perspective	AMSTAR-2
Lord <i>et al</i> <sup>16</sup> 2015	Systematic review	Review of barriers and facilitators of family carers of people with dementia and interventions for proxy decision making	Literature review of qualitative and quantitative studies	1 database searched without restrictions to date of publication up to 1 February 2014	30 papers included. LTC	Benefit of decision-making support provided by professionals to family caregivers. Development of decision aids. Perspective: informal caregivers: family and friends	Critically low quality review
Ryan <i>et al</i> <sup>17</sup> 2017	Systematic review, qualitative synthesis	Addressing the ACP experience of people with dementia, family caregivers and professionals	Literature review of qualitative studies	3 databases searched for articles published between 2007 and 2017	5 studies included. Primary healthcare	Scope of future planning, challenges to ACP, postponing ACP, confidence and making ACP happen. Perspective: people with dementia, family caregivers and professionals	Critically low quality review
Lai <i>et al</i> <sup>21</sup> 2019	Integrative review	Identify key factors for engagement in decision-making process	Review of qualitative, quantitative and mixed-methods studies	5 databases searched for articles published from 2012 to April 2018	20 articles included. Community	Six key factors identified: understanding dementia and decision making for the future, communication skills, timing and initiating, quality of the relationship, orientation on the future. Perspective: patients, family and physicians	Critically low quality review
van der Steen <i>et al</i> <sup>23</sup> 2014	Systematic review	Identify factors associated with initiation of ACP regarding issues in dementia	Literature review of qualitative and quantitative studies	5 databases searched for articles published up to 10 January 2013	33 studies included. Institutional and community LTC and hospice settings	A variety of factors related to initiating ACP on part of family, professional caregivers and healthcare system. Perspective: patients, family, professional caregivers	Critically low quality review
Tilburgs <i>et al</i> <sup>31</sup> 2018	Systematic integrative review	Determine the barriers and facilitators faced by GPs related to ACP with people with dementia and family carers	Literature review of qualitative, quantitative and one mixed-methods study	5 databases searched for articles published between January 1995 and December 2016	16 studies included. Primary healthcare	Four themes: timely initiation, stakeholder engagement, aspects of ACP conversation and prerequisites for ACP. Perspective: GP, people with dementia, family carers	Critically low quality review

Continued

Table 2 Continued

Author and year of publication	Type of systematic review	Study goal	Study design (qualitative, quantitative or mixed-methods)	Scope of the review	No of articles and setting	Themes relevant to moral considerations/perspectives	AMSTAR-2
Dening et al <sup>32</sup> 2011	Narrative review	Examine facilitators and inhibitors to ACP in people with dementia and themes that emerge from the literature	Literature review of quantitative, qualitative and mixed-methods studies	6 databases searched for articles published between 1950 and 2010	17 studies included. NH, primary care, community care and Alzheimer disease centre	Several themes revealing both barriers and facilitators for ACP. Perspectives: people with dementia, family carers and professionals	Critically low quality review

ACP, advance care planning; LTC, long-term care; NH, nursing home; EOL, end of life; GP, general practitioner.

experience a conflict of interests. Physicians' personal experiences with death can result in a moral conflict between the required professional role and private feelings.<sup>9 10 13 35</sup> Physicians who are motivated to follow the professional standards based on established guidelines can experience a dilemma when they feel that in a specific, individual case, following these guidelines is harmful.<sup>23 35</sup>

### Respecting dignity

Category: good death

Maintaining or improving quality of life at the EOL is often reported as an important goal for physicians to pursue. This involves a good death, dying with dignity,<sup>9 16 35</sup> and a process in accordance with a person's wishes and ethical standards.<sup>3</sup> However, being confronted with different views on what a good death means, reduces physicians' willingness to initiate ACP.<sup>1 9 10</sup> For example, physicians in favour of more active treatment show a more reserved attitude towards ACP.<sup>8 37</sup>

Family caregivers regard communication with and coordination of care by physicians in agreement with relatives as important conditions to achieve an EOL free from distress and suffering.<sup>1 3 8 15-17 21 33 34 36</sup> The planning of care and EOL choices,<sup>1 6 8 10 11 22</sup> for instance, concerning the place to die,<sup>19</sup> are seen as important aspects of a good death.

When a physician aims to increase the patient's and family caregiver's control over the EOL, he is more likely to initiate ACP.<sup>13</sup> An intention to ensure that patients with dementia have the same opportunities as anyone else,<sup>1</sup> also facilitates ACP. In practice, however, physicians report a gap between family caregivers' expectations concerning the dying process and reality, which creates dilemmas especially when decisions agreed on with the patient are reassessed.<sup>10</sup>

### Category: respecting cultural, spiritual and religious beliefs

Physicians who feel a responsibility to respect a patient's life story, religious beliefs, socio-cultural norms and personal values are motivated for ACP.<sup>1 8 9 11 16 33-35</sup> On the other hand, many authors also report that physicians' personal beliefs, especially when they differ from the patient's or relative's view, adversely affect the motivation for ACP and subsequent EOL decision making.<sup>8 9 15 23 35</sup>

Although concordance of values and beliefs facilitates decision making,<sup>23</sup> physicians with explicit personal beliefs report less perceived control in relation to ACP.<sup>8 34</sup> Differences in beliefs or ethnicity between physicians, patients or their families can act as a barrier to ACP for the physician.<sup>8 9 15 16 34</sup> This applies even more when such differences are observed between the physician and the nursing home's policy.<sup>23</sup>

### Category: respecting autonomy, wishes and preferences

Physicians who aim to maintain the patient's independence as long as possible, and those who promote self-determination and a person-centred approach,<sup>1 17 21 33 34 36</sup> regard ACP as a way of maintaining a person's individual



Table 3 Description of included primary studies reporting empirical research

Author, year of publication and country	Study goal	Study design: qualitative, quantitative or mixed-method	Participants and setting	Themes and findings: moral considerations as barriers to and facilitators of ACP, perspective	MMAT
Dempsey <sup>1</sup> 2013, UK	Highlight the benefits and challenges of ACP for individuals with dementia	Qualitative descriptive design	General practice. Physicians, patients and family or loved ones	Ethical and legal dilemmas for implementation ACP. Perspective: professionals, patients, loved ones	40
Saini <i>et al</i> <sup>2</sup> 2016, UK	Examine practices relating to EOL discussions with family members of people with advanced dementia residing in NH and to explore strategies for improving practice	Ethnographic study using framework approach: thematic analysis of fieldwork notes and observations, and data from in-depth interviews	NH. Residents, n=9; staff interviews, n=19; family members interviews, n=4	EOL discussions as an ongoing rather than a one-off task-driven conversation. Perspective: family members, GPs, nursing home staff and external physicians	60
De Vleminck <i>et al</i> <sup>3</sup> 2014, Belgium	Identify barriers to initiate ACP and gain insight into any difference in barriers between trajectories of patients with cancer, heart failure and dementia	Qualitative design, 5 focus groups, discussion analysed using the method of constant comparative analysis	Primary care. GP, n=36	Barriers to ACP relating to the GP, patient and family and the healthcare system. Perspective: GP	80
Booij <i>et al</i> <sup>6</sup> 2013, The Netherlands	Explore the role of the physician regarding talking about the EOL wishes.	Qualitative study, semi structured interviews	Primary care and elderly care physicians, n=15	Reasons for the physician to discuss EOL wishes from a legal, professional and moral point of view. Perspective: physicians	100
Beck <i>et al</i> <sup>8</sup> 2017, UK	Examine NH managers' knowledge, attitudes, beliefs and current practice regarding ACP	Cross-sectional postal survey, quantitative study	NH managers, n=116	Negative connotations regarding ACP among nurses. Role NH manager to actively engage and ensure facilitation of the process. Perspective: NH managers	20
Stewart <i>et al</i> <sup>11</sup> 2011, UK	Explore views on advance care planning in nursing homes	Individual semistructured interviews	NH. Staff, n=33; care assistants, n=29; nurses, n=18; family, n=8; friends, n=15	Benefits of, and barriers to ACP. Perspective: staff, care assistants, nurses, families and friends of residents	60
Brazil <i>et al</i> <sup>22</sup> 2015, Northern Ireland	GP's perception of ACP for patients living with dementia	Cross-sectional survey, using purposive, cluster sampling of GPs with registered dementia patients. Quantitative design	General practice. GP with registered dementia patients, n=133	Communication, ACP and decision making: optimal timing, initiated by the physician, importance of relationship, acceptance prognoses and limitations of life-sustaining therapy as barriers. Perspective: GP	80
Cheong <i>et al</i> <sup>33</sup> 2015, UK	Explore the perspectives of patients with early cognitive impairment regarding ACP	Mixed-methods study	Primary care. Patients diagnosed with early cognitive impairment, n=93	Patients decline ACP because of personal values, coping behaviours and sociocultural norms. Perspective: patients	100

Continued

Table 3 Continued

Author, year of publication and country	Study goal	Study design: qualitative, quantitative or mixed-method	Participants and setting	Themes and findings: moral considerations as barriers to and facilitators of ACP, perspective	MMAT
Livingston et al <sup>34</sup> 2013 UK	Improve EOL care for people with dementia in a nursing home by increasing documentation and implementation of advanced wishes	Mixed-methods study. Non-randomised study: comparing advance documentation and implementation and themes from after-death interviews, pre and postintervention	NH for people with dementia, providing care recognising Jewish traditions, beliefs and cultures. Patient records, n=98; interviews with relatives, n=20; staff, n=58	Increase in family satisfaction with reduction in hospital deaths. Staff members more confident about EOL planning and implementation wishes. Perspective: NH residents, family members and staff	60
Livingston et al <sup>35</sup> 2012 UK	Examine barriers and facilitators to care home staff delivering improved EOL care for people with dementia	Individual qualitative interviews	NH where staff and residents' ethnicity differed. Staff members, n=58	Barriers such as concern to upset, being blamed, inability to communicate Perspective: NH staff	60
Robinson et al <sup>36</sup> 2013, UK	Explore professionals' experiences on implementation of advance care planning in dementia and palliative care	Qualitative study, focus groups and individual interviews	Palliative care, primary care and dementia care services. Professionals: physicians, nurses, volunteers and legal professionals, n=95	Uncertainty about the value and usefulness of ACP, the definition, components and legal status of ACP and the practicalities of implementation. Perspective: professionals	80
Dickinson et al <sup>37</sup> 2013, UK	To investigate patients' and family caregivers' views on planning their future generally and ACP specifically	Qualitative study using semi-structured interviews	Local older people services People with mild to moderate dementia, n=17; and family caregivers, n=29	Participants' barriers to undertake ACP: knowledge and awareness, right time, informal plans, future care and lack of support. Perspective: patients and family caregivers	60
Palan Lopez et al <sup>38</sup> 2017, VS	Examine how decisions to transfer NH residents with advanced dementia are made	Qualitative descriptive method and semistructured, open-ended interviews	NH. Healthcare providers, n=20; nurses, n=14; physicians, n=6	ACP in the process of decision making in case of an acute event to ensure that goals of care are maintained. Perspective: nurses and physicians	60

ACP, advance care planning; EOL, end of life; GP, general practitioner; MMAT, Mixed-Methods Appraisal Tool; NH, nursing home.



**Table 4** Themes, categories and codes concerning moral barriers and facilitators physicians encounter in ACP

Themes	Categories	Facilitator codes for ACP	Barrier codes for ACP
1. Beneficence and non-maleficence	Decision making at the EOL based on the intention to provide good care	Aiming at decision making based on the patient's best interests <sup>10,21</sup> Avoiding prolongation of suffering <sup>1, 8, 15, 33, 34</sup>	Experiencing EOL decision making as difficult in case of conflicting interests <sup>2, 6, 8, 9, 16, 22, 35</sup>
		Diminishing emotional burden to patient <sup>6, 8, 33, 37</sup> Aiming to resolve a disagreement in favour of patient's wishes <sup>16, 23</sup>	Hesitating to discuss death because of fear to induce anxiety or emotional harm <sup>1, 3, 8, 9, 21, 31, 33, 35</sup>
		Aiming to provide emotional support to family <sup>8-10, 12, 34</sup>	
	Maintain hope for the future despite a future with inevitable decline	Providing hope for the future <sup>3, 21</sup>	Fearing to destroy patient's sense of hope for the future by conducting ACP <sup>2, 3, 8, 9, 31, 33</sup> Experiencing moral dilemmas around discussing future goals of care <sup>11, 13, 16, 17, 21, 36</sup> People with dementia focus on immediate concerns rather than on future concerns <sup>3, 8, 10, 13, 15, 21, 23, 31, 33, 37</sup>
	Physician's professional attitude towards talking about death and dying: intention and practice	Witnessing illness or death facilitates ACP <sup>23, 31</sup>	Experiencing discomfort in discussing death or EOL <sup>3, 8, 10, 17, 21, 23, 34, 35</sup> Experiencing patient's active avoidance of discussing death or EOL <sup>1-3, 8, 10, 11, 13, 17, 22, 23, 33-35</sup> Experiencing patient's passive avoidance of discussing death or EOL <sup>13, 17, 21, 23</sup> Experiencing reluctance of family caregivers to discuss death or EOL <sup>2, 10, 11, 23</sup>
Physician's personal attitude towards talking about death and dying	Perceiving the physician as a fellow human being, not just a professional <sup>6</sup>	Avoiding the conversation due to personal perspectives on death <sup>9, 10, 13, 35</sup> Experiencing a conflict between professional role and private feelings <sup>23, 35</sup> Experiencing a personal conflict of interest <sup>35</sup>	

Continued

Table 4 Continued

Themes	Categories	Facilitator codes for ACP	Barrier codes for ACP
2. Respecting dignity	Good death	Ensuring that patients with dementia have the same opportunities for EOL planning <sup>1</sup> Increasing patient's and family members' control over dying process <sup>13</sup> Physician's personal perspective on a good death <sup>1 9 10</sup>	Disregarding decisions agreed on due to families' poor understanding of how death happens, causing gaps between expectations and reality <sup>10</sup>  Opposite views among physicians on a good death <sup>8 10 12 15 16 23 37</sup>
	Respect cultural, spiritual and religious beliefs	Aiming to respect religious, cultural and life issues <sup>1 8 9 11 16 33-35</sup>	Family and professional caregivers holding different religious, spiritual and cultural beliefs regarding practicing ACP <sup>8 9 16 23 32 34 35</sup>
	Physician as a person: cultural, spiritual and religious beliefs	Impact of physician's personal religious beliefs on decision making <sup>8 9 15 23</sup>	Experiencing no concordance with physician's personal religious beliefs <sup>8 9 15 23 35</sup>
	Respect autonomy, wishes and preferences	Viewing ACP as a way of maintaining person's individual identity <sup>1 11 16 17 33 34 36</sup> ACP in regard to future communication inability and lack of decision making capacity <sup>3 13 33</sup>	Experiencing conflicts between personal and relational integrity, concerning patient's autonomy <sup>6 9 13 35</sup> Having moral and ethical concerns related to the effects of declining capacity of person with dementia <sup>13 8-11 13 31</sup> Undermining of physician's confidence in adhering to wishes when considering changing wishes as dementia progresses <sup>1 3 6 8 15-17 31</sup>
3. Taking responsibility and ownership	Obligation	Aiming to respect patient's healthcare or EOL wishes. <sup>1 6 8 10 11 16 17 21 22 34 36</sup>	Fearing substitute judgement being not truly reflective of wishes of person with dementia <sup>9-11 16 17 23 35 36</sup>
	Responsibility and ownership	Talking about the subject as a legal, professional and moral obligation <sup>6 33 36</sup> Feeling responsible for initiating the discussion given future lack of capacity/ ability of patients to take part in discussion <sup>12 13</sup> Feeling a professional responsibility for decision making based on patient's needs <sup>9 8 19 22 35 38</sup> Family caregiver requesting physician to bear responsibility for decision making <sup>12 16 23</sup>	Fearing litigation or fear of experiencing moral dilemmas regarding ACP <sup>3 6 15 21 23 31 34-36</sup> Feeling that initiating the discussion is inappropriate when patients don't initiate themselves. <sup>13 16 23 31 35</sup> Concern about timing <sup>3 8 17 23 31 33 36</sup> Being reluctant to assume responsibility for ACP and decision making <sup>2 8 13 15</sup> Being uncertain about who is responsible for discussing and decision making <sup>1-3 8 9 11 13 15 17 23 33 35 36</sup>

Continued



Table 4 Continued

Themes	Categories	Facilitator codes for ACP	Barrier codes for ACP
4. Relationship	Long-term relationship	Building conditions to maintain long-term relationships <sup>1 3 6 8 11 33 38</sup>	Not having a long-standing relation with family <sup>3 8 9 31</sup> Fearing to disturb the relationship. <sup>21</sup> Fearing attachment to the resident is unacknowledged, not allowed and less professional. <sup>9 23 35</sup>
	Trust and confidence	Having a good relationship with the person with dementia <sup>2 8 10-13 16 17 21 23 35</sup> Having a good relationship between physician and family generates confidence <sup>1 2 8 9 22 35</sup> Relationship of importance for decision making <sup>10 12 13 15 16 21 33 34 37 38</sup>	Not having a close relationship with staff, causing reluctance of family to discuss or to be involved in decision making <sup>1 2 8-11 13 15 16 21 33 34 37 38</sup> Physician experiencing lack of empathy and warmth in family-patient relationship <sup>1 8 9</sup>
5. Courage	Decision making in conflict and crisis	Physician experiencing a strong family attachment to resident <sup>1 21 23 35</sup> Aiming to reduce EOL crisis decision making <sup>8</sup> Prioritise patient's needs <sup>22 23</sup>	Experiencing dealing with conflicts about care as a challenge <sup>1 8 11 16 21 35</sup> Worrying about being blamed or litigation <sup>3 6 15 21 23 31 34-36</sup>
	Legal aspects		

ACP, advance care planning; EOL, end of life.

identity.<sup>1 11 16 17 21 33 34 36</sup> Honouring the patient's life story,<sup>16</sup> and respecting the patient's healthcare or EOL wishes,<sup>1 6 8 10 11 16 17 22 34 36</sup> is important to physicians who prefer individual decision making based on an existential view rather than collective decision making based on a communitarian view.<sup>1 16</sup> Because of future inability to communicate and lack of decision-making capacity in case of dementia, these physicians strongly prefer to conduct ACP.

However, physicians' personal integrity can conflict with their intention to respect the patient's autonomy,<sup>6 9 13 35</sup> especially when the aim to preserve life contradicts the patient's or family caregiver's wishes,<sup>8</sup> or when the fulfilment of the expressed wishes seems contrary to the patient's actual best interests.<sup>8</sup>

Lack of awareness of the diagnosis or prognosis impedes patients in making their own choices or even to be engaged in the conversation.<sup>3 13 33</sup> Preferences can change as time passes, which may cause difficulties specifically in the case of cognitive decline.<sup>1 3 6 8 15-17 31</sup> The patient will no longer be able to communicate new preferences, and changing one's mind can indicate loss of control, loss of self or loss of identity.<sup>1 8 9</sup> A perceived loss of personality enhances dilemmas for physicians,<sup>1 3 6 8 15-17</sup> for example, when confronted with the decision to either respect current wishes or to regard the patient's prior advance decisions. When the physician has doubts whether the relatives' view may truly be viewed as substituted judgement and adequately reflects the wishes of the patient,<sup>9-11 16 17 23 35 36</sup> his dilemma becomes even more obvious.

### Taking responsibility and ownership

#### Category: obligation

Physicians view talking about the EOL as a professional and moral obligation.<sup>6 33 36</sup> Subsequent agreement on future treatment is considered as a promise not to let the patient down.<sup>36</sup> Such an obligation can serve as a facilitator for ACP but also as a barrier.

#### Category: responsibility and ownership

The responsibility for initiating and conducting ACP<sup>12 13</sup> derives from the urgency of reaching decisions in line with the patient's needs or in accordance with his wishes<sup>6 8 16 22 35 38</sup> or at the request of the family caregiver as a substitute decision-maker.<sup>12 16 23</sup> Some studies show that physicians do not want to make decisions in advance at all, but prefer letting others serve as surrogate decision makers. They view ACP and decision making as the others' responsibility.<sup>11 23 33 36</sup>

The prognostic uncertainty in dementia increases physicians' concerns about the right timing.<sup>8 17 23 33</sup> Especially when patients do not initiate the conversation themselves, physicians may regard taking the initiative as inappropriate.<sup>13 16</sup> This uncertainty about who should start the discussion can make physicians reluctant to assume responsibility.<sup>1-3 8 13 15 17 23 35 36</sup>

### Relationship

#### Category: long-term relationship

Long-term relationships facilitate ACP through better understanding of patients' needs, preferences and fears, and of family dynamics.<sup>1-3 8 9 35 38</sup> However, personal integrity can be at stake when there is doubt about the appropriateness of a physician's personal relationship with the patient, especially if this attachment is considered less professional and therefore impedes ACP.<sup>9 23 35</sup> Other considerations include fear to disturb the relationship.

#### Category: trust and confidence

Both long-standing relationships and a professional relationship that is characterised by continuity, intensity and trust among all involved,<sup>2 11-13 16 17 23 35</sup> can lead to acceptance, understanding and sincerity.<sup>1</sup> Such experiences make physicians confident regarding ACP.<sup>1 2 8 9 22 35</sup> In the context of this relationship it is possible to share values and beliefs, which is important for a desirable level of trust.<sup>12 23</sup> When the physician-family relationship lacks trust,<sup>13 15 38</sup> physicians note passive avoidance or even reluctance on the side of the family to be involved in ACP.<sup>10 11 16</sup> This may also appear when there are different views between family caregiver and nursing staff.

Additionally, a strong family attachment,<sup>1 21 23 35</sup> and an involved family caregiver who encourages the patient, facilitate physicians, whereas a family-patient relationship lacking empathy and warmth serves as a barrier for physicians to take the initiative.<sup>1 8 9 23 35</sup>

### Courage

#### Category: decision making in conflict and crisis

According to Beck *et al*,<sup>8</sup> physicians refuse EOL decision making in a challenging relational crisis, whereas a medical crisis can even trigger tailored decision making.<sup>23</sup> When a family caregiver's view appears to conflict with the patient's own wishes, whether previously expressed or currently experienced, physicians perceive this as a serious barrier to ACP and hesitate to make decisions at the EOL.<sup>1 8 11 16 21 35</sup>

#### Category: legal aspects

Physicians express uncertainty about the legal status of ACP,<sup>15</sup> and may experience a conflict of duties.<sup>3 6</sup> They may be worried about being blamed or fear litigation or being viewed as less professional.<sup>3 6 15 21 23 31 34-36</sup> They may even fear being held legally accountable if the patient dies,<sup>2 8 15</sup> especially when patients change their mind,<sup>15 34 36</sup> or when the family caregiver has different views about care.

## DISCUSSION

This meta-review is unique in its focus on physician's moral considerations in ACP in dementia. We conclude that despite different stages of dementia and (cultural) context, physicians involved in providing medical care within the scope of a long-term relationship, generally



face the same dilemmas. Several moral considerations can either facilitate or hinder ACP, depending on the physician's personal interpretation or the context in which care is provided. This concerns, for instance, providing hope and comfort. ACP offers an opportunity to provide reassurance, but it could also take away hope for the future and induce anxiety. Also, professional experience with talking about death and providing care to patients with dementia at the EOL can facilitate ACP, while the same experience in private can make physicians hesitant. The same applies to the obligation to act according to patient's expressed wishes, which can function both as a facilitator and a barrier.

This review shows that physicians acknowledge their responsibility for decision making based on patients' autonomy and best interests. Therefore, a moral dilemma arises when striving to preserve patients' identity and autonomy is seen as contrary to the provision of care based on their actual best interests, especially when an observed change of patient's mind does not appear to be the result of a conscious revision of prior wishes. This may result in avoiding ACP in future cases. This main dilemma for physicians is evident from the perspective of physicians themselves, and is also witnessed by others including family caregivers.

Gillett<sup>39</sup> refers to two possible interpretations of autonomy: the evidentiary view and the integrity view, presented by Dworkin<sup>19</sup>. The evidentiary view states that autonomy means allowing competent patients to decide in their own best interests, as viewed at the moment. In Gillett's view, contemporary wishes should be respected, even if they conflict with a prior ACP and despite cognitive decline and the possibility of anosognosia, to safeguard the patient's sense of freedom. In contrast, in the integrity or existential view of autonomy, the patient's prior advance decision, formulated in the competent phase of their life, is leading. This leaves the physician with a dilemma regarding which course of action to take: to follow the prior wishes outlined in the context of ACP or to honour the patient's apparent wishes now, despite cognitive decline and change of personality and loss of self. Schenell *et al*<sup>40</sup> promote patients' self-determination by proposing a person-centred approach or, as defined by Wilson and Davies<sup>41</sup>, a relational model of autonomy. Understanding patients' life stories by conducting ACP allows for perceiving people with dementia as the person they were, as well as the person they are now. This will reduce a focus on patient's dependency and strengthen their selves. Making patients and relatives aware of this dilemma and discussing a possible effect of changing wishes on decision making, allows for sharing the responsibility with the patient.

Physicians have a professional responsibility to provide care in accordance with professional standards and norms, based on their patients' best interests and respect for their autonomy while also considering decision-making capacity. Talking about the EOL, as intended by ACP, is regarded as a legal, professional and moral obligation.

However, apart from professional norms, physicians also have their own, potentially conflicting, personal norms, values and feelings. The theory of planned behaviour (Ajzen<sup>42</sup>) may apply, describing behaviour predicted by perceived control over the behaviour, and intention. Physicians show a positive attitude and intention towards ACP. However, they encounter several barriers based on professional and personal moral considerations, which cause a serious impediment to physicians' practice of ACP. Despite positive attitudes and intentions, this may explain why physicians may be reluctant with regard to engaging in ACP in practice.

A third important complication relates to physician's doubts whether the relative who acts as a surrogate decision maker truly represents the patient's perspective, or even has the intentions to serve the patient's interests. The fear of being held legally accountable may discourage the physician to show leadership in ACP.

### Strengths and limitations

To increase depth and to decrease the risk of missing important ethical dilemmas and moral considerations that constitute barriers and facilitators to ACP, we analysed both systematic reviews and primary studies. Most studies reported research limited to western societies, but pointed out an influence of different cultural backgrounds and religious and spiritual beliefs on ACP. Nevertheless, they show that the observed dilemmas are consistent across studies. Additionally, we found that family caregivers' observations of physicians' moral considerations were generally consistent with the physicians' own perspectives.

The quality of the systematic reviews was rated critically low based on AMSTAR-2. However, this tool penalises reviews, for example, for not reporting funding sources while intellectual rather than financial conflicts of interests are probably relevant to our and other such reviews. In psychology, AMSTAR-2 had a profound floor effect, 95% rating critically low.<sup>43</sup> The quality of the primary articles in our review, however, was rated moderate to high, while findings were consistent with the systematic reviews supporting an explanation that the tools do not fit the purpose of our review on moral considerations.

### Recommendations for practice and research

Physicians regard timely initiation and a structural follow-up of ACP as beneficial for people with dementia, which indicates that barriers to implementation should be overcome. The fact that physicians, besides feeling obliged to conform to professional norms and standards, also encounter personal dilemmas, needs to be acknowledged by patients, relatives, society and by physicians themselves. Further research may study how conflict of personal norms concerning ACP with professional norms might be resolved.

An open, safe and honest discussion of the topic, including the detrimental effect it may have on the physician's job satisfaction in the long term, is needed. This is

a responsibility for the professional association and the healthcare team. The dilemmas we identified may also be addressed during ACP training. Raising awareness should be part of moral education within the context of a structurally provided peer discussions in practice. If these dilemmas are not recognised, discussed and taken into account, ACP will not be generally implemented. This may not only result in poor quality of care provided to the patient with dementia at the EOL, but may also negatively impact bereavement of relatives.

## CONCLUSION

Physicians feel a responsibility to provide high-quality EOL care to patients with dementia. However, the moral dilemmas they encounter may lead to avoidant behaviour concerning ACP practice. If these dilemmas are recognised, the implementation of ACP and, more importantly, physicians' aim to support an EOL in accordance with patient's wishes, may become successful.

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## REFERENCES

- Dempsey D. Advance care planning for people with dementia: benefits and challenges. *Int J Palliat Nurs* 2013;19:227–34.
- Saini G, Sampson EL, Davis S, et al. An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes. *BMC Palliat Care* 2016;15:55.
- De Vleminck A, Pardon K, Beernaert K, et al. Barriers to advance care planning in cancer, heart failure, and dementia patients: a focus group study on general practitioners' views and experiences. *J Palliat Care* 2014;30:218.
- Dixon J, Knapp M. Whose job? the staffing of advance care planning support in twelve international healthcare organizations: a qualitative interview study. *BMC Palliat Care* 2018;17:78.
- Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014;28:1000–25.
- Booij SJ, Engberts DP, Rödiger V, et al. A plea for end-of-life discussions with patients suffering from Huntington's disease: the role of the physician. *J Med Ethics* 2013;39:621–4.
- Davies N, Klapwijk MS, van der Steen JT. Palliative care in dementia. In: MacLeod RD, Van den Block L, eds. *Textbook of palliative care*. Berlin, Germany: Springer, 2018.
- Beck E-R, McIlpatrick S, Hasson F, et al. Nursing home manager's knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: a cross-sectional survey. *J Clin Nurs* 2017;26:2633–45.
- Beck E-R, McIlpatrick S, Hasson F, et al. Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: a narrative review of the literature. *Dementia* 2017;16:486–512.
- Birchley G, Jones K, Huxtable R, et al. Dying well with reduced agency: a scoping review and thematic synthesis of the decision-making process in dementia, traumatic brain injury and frailty. *BMC Med Ethics* 2016;17:46.
- Stewart F, Goddard C, Schiff R, et al. Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. *Age Ageing* 2011;40:330–5.
- Barker S, Lynch M, Hopkinson J. Decision making for people living with dementia by their carers at the end of life: a rapid scoping review. *Int J Palliat Nurs* 2017;23:446–56.
- Brooke J, Kirk M. Advance care planning for people living with dementia. *Br J Community Nurs* 2014;19:490–5.
- de Boer ME, Dröes R-M, Jonker C, et al. Advance directives for euthanasia in dementia: do law-based opportunities lead to more euthanasia? *Health Policy* 2010;98:256–62.
- Jones K, Birchley G, Huxtable R, et al. End of life care: a scoping review of experiences of advance care planning for people with dementia. *Dementia* 2019;18:825–45.
- Lord K, Livingston G, Cooper C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *Int Psychogeriatr* 2015;27:1301–12.
- Ryan T, Amen KM, McKeown J. The advance care planning experiences of people with dementia, family caregivers and professionals: a synthesis of the qualitative literature. *Ann Palliat Med* 2017;6:380–9.
- Dresser R. Treatment decisions and changing selves. *J Med Ethics* 2015;41:975–6.
- Dworkin R. Autonomy and the demented self. *Milbank Q* 1986;64:4–16.
- Jaworska A. Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philos Public Aff* 1999;28:105–38.
- Lai M, Jeon Y-H, McKenzie H. The key factors for the engagement of primary stakeholders in decision-making for the future care of people with dementia living in the community: a systematic integrative review. *Int Psychogeriatr* 2019;31:1731–46.
- Brazil K, Carter G, Galway K, et al. General practitioners perceptions on advance care planning for patients living with dementia. *BMC Palliat Care* 2015;14:14.
- van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, et al. Factors associated with initiation of advance care planning in dementia: a systematic review. *J Alzheimers Dis* 2014;40:743–57.





- 24 Rurup ML, Onwuteaka-Philipsen BD, Pasma HRW, *et al.* Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. *Patient Educ Couns* 2006;61:372–80.
- 25 Rietjens JAC, van der Heide A, Onwuteaka-Philipsen BD, *et al.* A comparison of attitudes towards end-of-life decisions: survey among the Dutch general public and physicians. *Soc Sci Med* 2005;61:1723–32.
- 26 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 7th ed. New York, Oxford: Oxford University Press, 2013: 20.
- 27 Liberati A, Altman DG, Tetzlaff J, *et al.* The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *J Clin Epidemiol* 2009;62:e1–34.
- 28 Whittmore R, Knafelz K. The integrative review: updated methodology. *J Adv Nurs* 2005;52:546–53.
- 29 Peters MDJ, Godfrey CM, Khalil H, *et al.* Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13:141–6.
- 30 Shea BJ, Reeves BC, Wells G, *et al.* AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *BMJ* 2017;358:j4008.
- 31 Tilburgs B, Vernooij-Dassen M, Koopmans R, *et al.* Barriers and facilitators for GPs in dementia advance care planning: a systematic integrative review. *PLoS One* 2018;13:e0198535.
- 32 Denning KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. *Int Psychogeriatr* 2011;23:1535–51.
- 33 Cheong K, Fisher P, Goh J, *et al.* Advance care planning in people with early cognitive impairment. *BMJ Support Palliat Care* 2015;5:63–9.
- 34 Livingston G, Lewis-Holmes E, Pitfield C, *et al.* Improving the end-of-life for people with dementia living in a care home: an intervention study. *Int Psychogeriatr* 2013;25:1849–58.
- 35 Livingston G, Pitfield C, Morris J, *et al.* Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *Int J Geriatr Psychiatry* 2012;27:643–50.
- 36 Robinson L, Dickinson C, Bamford C, *et al.* A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. *Palliat Med* 2013;27:401–8.
- 37 Dickinson C, Bamford C, Exley C, *et al.* Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *Int Psychogeriatr* 2013;25:2011–21.
- 38 Palan Lopez R, Mitchell SL, Givens JL. Preventing Burdensome transitions of nursing home residents with advanced dementia: it's more than advance directives. *J Palliat Med* 2017;20:1205–9.
- 39 Gillett G. Advance decisions in dementia: when the past conflicts with the present. *J Med Ethics* 2019;45:204–8.
- 40 Schenell R, Ozanne A, Strang S, *et al.* Balancing between maintaining and overriding the self: staff experiences of residents' self-determination in the palliative phases. *Int J Older People Nurs* 2019;14:e12255.
- 41 Wilson CB, Davies S. Developing relationships in long term care environments: the contribution of staff. *J Clin Nurs* 2009;18:1746–55.
- 42 Ajzen I. The theory of planned behaviour: reactions and reflections. *Psychol Health* 2011;26:1113–27.
- 43 Leclercq V, Beaudart C, Tirelli E, *et al.* Psychometric measurements of AMSTAR 2 in a sample of meta-analyses indexed in PsycINFO. *J Clin Epidemiol* 2020;119:144–5.