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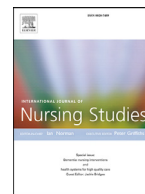
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## Practical nursing recommendations for palliative care for people with dementia living in long-term care facilities during the COVID-19 pandemic: A rapid scoping review

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### ABSTRACT

**Background:** The acute nature of COVID-19 and its effects on society in terms of social distancing and quarantine regulations affect the provision of palliative care for people with dementia who live in long-term care facilities. The current COVID-19 pandemic poses a challenge to nursing staff, who are in a key position to provide high-quality palliative care for people with dementia and their families.

**Objective:** To formulate practice recommendations for nursing staff with regard to providing palliative dementia care in times of COVID-19.

**Design and method:** A rapid scoping review following guidelines from the Joanna Briggs Institute. Eligible papers focused on COVID-19 in combination with palliative care for older people or people with dementia and informed practical nursing recommendations for long-term care facilities. After data extraction, we formulated recommendations covering essential domains in palliative care adapted from the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care.

**Data sources:** We searched the bibliographic databases of PubMed, CINAHL and PsycINFO for academic publications. We searched for grey literature using the search engine Google. Moreover, we included relevant letters and editorials, guidelines, web articles and policy papers published by knowledge and professional institutes or associations in dementia and palliative care.

**Results:** In total, 23 documents (7 (special) articles in peer-reviewed journals, 6 guides, 4 letters to editors, 2 web articles (blogs), 2 reports, a correspondence paper and a position paper) were included. The highest number of papers informed recommendations under the domains 'advance care planning' and 'psychological aspects of care'. The lowest number of papers informed the domains 'ethical care', 'care of the dying', 'spiritual care' and 'bereavement care'. We found no papers that informed the 'cultural aspects of care' domain.

**Conclusion:** Literature that focuses specifically on palliative care for people with dementia in long-term care facilities during the COVID-19 pandemic is still largely lacking. Particular challenges that need addressing involve care of the dying and the bereaved, and ethical, cultural and spiritual aspects of care. Moreover, we must acknowledge grief and moral distress among nursing staff. Nursing leadership is needed to safeguard the quality of care and nursing staff should work together within an interprofessional care team to initiate advance care planning conversations in a timely manner, to review and document advance care plans, and to adapt goals of care as they may change due to the COVID-19 situation.

**Tweetable abstract:** The current COVID-19 pandemic affects people living with dementia, their families and their professional caregivers. This rapid scoping review searched for academic and grey literature

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to formulate practical recommendations for nursing staff working in long-term care facilities on how to provide palliative care for people with dementia in times of COVID-19. There is a particular need for grief and bereavement support and we must acknowledge grief and moral distress among nursing staff. This review exposes practice and knowledge gaps in the response to COVID-19 that reflect the longstanding neglect and weaknesses of palliative care in the long-term care sector. Nursing leadership is needed to safeguard the quality of palliative care, interprofessional collaboration and peer support among nursing staff.

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### What is already known about the topic?

- Palliative care for people with dementia is complex and involves responding to physical, psychological, social and spiritual needs, discussing wishes and care preferences, and supporting families before and after bereavement.
- Nursing staff working in long-term care facilities have a key role in providing person-centered and compassionate palliative care.
- Ideally, palliative care should be in place in times of humanitarian crises or pandemics to meet end-of-life care needs and to facilitate a peaceful death.

### What this paper adds

- The global response to the COVID-19 pandemic regarding palliative care for people with dementia reflects the longstanding neglect and weaknesses of palliative care in the long-term care sector. This paper formulates practical nursing recommendations based on 23 documents to inform palliative dementia care during this crisis.
- The unprecedented COVID-19 situation raises a particular need for grief and bereavement care to mitigate adverse outcomes such as complicated grief and trauma. Moreover, we need to acknowledge grief experiences and moral distress in nursing staff.
- The pandemic emphasizes the need for nursing leadership to safeguard the quality of palliative care, to establish effective interprofessional collaboration and to maintain a peer support system among nursing staff members.

## 1. Introduction

In recognition of the global outbreak of COVID-19, the World Health Organization (WHO) declared a COVID-19 pandemic on March 11, 2020 (World Health Organization, 2020). The world population is at risk due to the rapid spread of the virus. As of July 15th, over 580,000 deaths have been reported from 215 countries (Worldometers, 2020). The case fatality rate is highest among frail older adults (Onder et al., 2020; Shams et al., 2020). Current estimates of the case fatality rate from COVID-19 are below 0.2% for people aged under 60, and up to 9.3% among people aged over 80 years (Ferguson et al., 2020). Older people with dementia are generally frail and they are more likely to have comorbid conditions such as cardiovascular disease, diabetes and pneumonia compared to older individuals without dementia (Bauer et al., 2014). Hence, they constitute a particularly vulnerable group that is at risk for negative health outcomes of COVID-19 (Clarfield et al., 2020). The population of people living with dementia is expected to show more severe illness and higher mortality as a result of COVID-19, due to their comorbidities and other characteristics of dementia (Brown et al., 2020). Even as an independent risk factor, Atkins and colleagues found that pre-existing dementia was the strongest risk diagnosis for developing severe symptoms of COVID-19 in community-dwelling adults aged over 65 (Atkins et al., 2020). Although this may be different for older people living in facilities, once a virus enters a facility, it is difficult to control and likely to

spread rapidly (Gardner et al., 2020). Residents with dementia may be more at risk of contracting and transmitting COVID-19 resulting from difficulties to understand and remember infection prevention regulations such as isolation, social distancing and general hygiene regulations such as hand sanitizing (Brown et al., 2020; Livingston et al., 2020).

In most western countries, the majority of people living in long-term care facilities have some form of dementia (Doupe et al., 2011; Froggatt et al., 2016; Seitz et al., 2010). The institutional nature of long-term care facilities facilitates the spread of the virus and adds to the risk of COVID-19 among residents (Clarfield et al., 2020). The double challenge of dementia combined with the COVID-19 pandemic raises concerns for residents living with dementia, their families and their caregivers (Brown et al., 2020; Wang et al., 2020a). In addition to the increased risk of COVID-19, societal regulations and the organization of healthcare in response to COVID-19 affect the usual provision of care for all people with dementia living in long-term care facilities. Social distancing regulations and visiting restrictions compromise their social contacts and engagement with other residents, physical exercise and meaningful or joint activities undertaken within facilities. These changes may elicit anxiety, agitation and depression in residents with dementia, as well as loneliness, distress and confusion (Velayudhan et al., 2020). Loneliness and social isolation are linked to poorer mental and physical health outcomes and a higher mortality risk (Leigh-Hunt et al., 2017; Sutin et al., 2018). In addition, reduced sensory stimulation due to social isolation and physical distancing from others may lead to boredom, sedentary behavior or behavioral disturbances such as agitation or apathy in people with dementia (Brown et al., 2020; Kolanowski et al., 2017). Non-pharmacological treatments of neuropsychiatric behaviors such as distraction, engagement in activities or going out for a walk are more difficult to apply due to contagion prevention regulations (Canevelli et al., 2020). This may increase the risk of use of physical restraints and inadequate psychotropic medications in long-term care facilities to manage isolation and distancing regulations, particularly in the case of wandering behaviors (Canevelli et al., 2020; Velayudhan et al., 2020; Zuidema et al., 2010).

Maintaining quality of life and optimizing comfort are important goals of care for people with moderate to severe dementia (van der Steen et al., 2014). In many western countries, the most common place of death of people with dementia is a long-term care facility (Reyniers et al., 2015), which highlights the need for palliative and end-of-life care for people with dementia who live in these facilities. Palliative care aims to improve the quality of life by responding to physical, psychosocial and spiritual needs. Early end-of-life conversations and advance care planning are cornerstones of high-quality palliative care, as are the management of pain and other burdensome symptoms, the pursuit of a comfortable death, and support for families before and after bereavement (van der Steen et al., 2014). There is increasing recognition of the need for the integration of palliative care with care for people with dementia. Nonetheless, palliative care for people with dementia is challenging even in more stable circumstances. For instance, peo-

**Table 1**

Key subjects and their search terms.

Subject	Search terms
<b>People with dementia</b>	Dementia; Alzheimer's disease; Alzheimer; cognitive impairment; cognitively impaired
<b>Palliative care</b>	Palliative care; terminal care; end-of-life care; comfort care; nursing home; aged care; long-term care; bereavement; grief
<b>COVID-19</b>	Covid-19; Corona; Coronavirus; 2019-nCoV; SARS-CoV-2

**Table 2**

In- and exclusion criteria for selecting articles.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>Peer-reviewed articles or reviews of primary research.</li> <li>Grey literature including policy papers, guides or guidelines, letters and editorials, newspaper or web articles.</li> <li>Informing (implicitly or explicitly) recommendations for nursing staff (<i>population</i>) providing palliative care for people with dementia living in long-term care facilities (<i>concept</i>) during the COVID-19 crisis (<i>context</i>).</li> </ul>	<ul style="list-style-type: none"> <li>Not written in Dutch or English.</li> <li>Not relevant to the current COVID-19 crisis in relation to palliative care for older people, or care for people with dementia, in long-term care facilities.</li> </ul>

ple with dementia are more likely to have unmet needs, to receive poor treatment of pain and other symptoms, to face inappropriate aggressive medical treatments and to be transferred to acute care at the end of life (Birch and Draper, 2008). Professional caregivers such as nurses and physicians report difficulties in palliative dementia care related to lacking or fragmented palliative care services, pain management, psychosocial needs and challenging behaviors, and end-of-life communication and (shared) decision-making (Bolt et al., 2019; Davies et al., 2014; Ryan et al., 2012).

During the COVID-19 pandemic, providing palliative care for long-term care residents with dementia (with or without COVID-19) is even more complex. The pandemic particularly challenges nursing staff working in long-term care, who have an important role in providing palliative care for people with dementia and their families. While they need to deliver medical and physical care to the current standard, they also need to preserve human contact, dignity and comfort for people with dementia with or without COVID-19. Physical touch and social interactions are important to enhance the wellbeing of people with severe dementia, particularly if other forms of communication become difficult (Nicholls et al., 2013). Social distancing regulations and personal protective equipment deprive people with dementia at the end of life from intimacy and being touched gently by their family members or caregivers (Lapid et al., 2020). Moreover, personal protective equipment may be frightening and confusing for people with dementia (Lapid et al., 2020; Velayudhan et al., 2020). It is particularly challenging to respond to psychological symptoms such as anxiety and depression, and to deal with challenging behaviors, as people with dementia are likely to have difficulties understanding their current situation (Velayudhan et al., 2020). Palliative care for people with dementia also involves compassionate advance care planning conversations. However, as COVID-19 unfolds rapidly and visiting of families is restricted, there may be insufficient time and occasions for elaborate and personal conversations with persons with dementia and their families (British Geriatrics Society, 2020). Families as proxy decision-makers may face difficult and ethically challenging decisions, for instance, concerning the desirability of hospitalization (Livingston et al., 2020; Moore et al., 2020a, 2020b). Overall, families must be involved in end-of-life care for people with dementia, which is hindered due to the widespread lockdown regulations in long-term care facilities (Gordon et al., 2020). Caring for a person with dementia who is dying of COVID-19 or its complications may raise additional challenges for families and nursing staff. Rapid deterioration of health and a lack of personal protective equipment in long-term care facilities may compromise family

involvement in the last phase. These situations may be stressful for families and for nursing staff (Brown et al., 2020; Moore et al., 2020a, 2020b), who have often cared for a person with dementia and their family for a long period.

The current COVID-19 crisis poses multiple challenges for nursing staff, who are key professionals providing high-quality palliative care for people with dementia residing in long-term care facilities. This paper describes a rapid scoping review to inform practice recommendations for nursing staff with regard to providing palliative dementia care in long-term care facilities in times of COVID-19.

## 2. Methods

This rapid scoping review is part of the overarching research project 'DEDICATED: Desired Dementia Care Towards End of Life'. The goal of DEDICATED is to improve palliative care for people with dementia and their families. To structure this review, we used the framework proposed by the Joanna Briggs Institute (Peters et al., 2015). The framework builds upon the original framework for scoping reviews by Arksey and O'Malley (2005), taking into account earlier enhancements by Levac et al. (2010). Thereby, the Joanna Briggs Institute's framework provides a detailed and explicit description for conducting systematic and rigorous scoping reviews. It is a leading source for guiding the conduct of scoping reviews (Lockwood et al., 2019) and it informed the development of the PRISMA Extension for Scoping Reviews checklist (Tricco et al., 2018).

### 2.1. Search strategy

We performed weekly literature searches between April and May 2020, with a last search on May 18th. The search strategy included four steps, following the Joanna Briggs Institute manual (Peters et al., 2015). In step one, we searched the databases of PubMed, CINAHL, PsycINFO and the search engine Google (Scholar) to identify relevant keywords related to the subjects (Table 1, view details of the search in Supplementary material 1). In step two, we used these keywords to build elaborated search strings for searching the databases of PubMed, CINAHL and PsycINFO. We used various combinations of search terms to either broaden or narrow down the search, depending on the results in a specific database. The search string focused on keywords in titles and abstracts. We searched for papers written in English or Dutch and published from December 2019 onwards, as this review focusses on the COVID-19 period. In step three, we hand-searched the

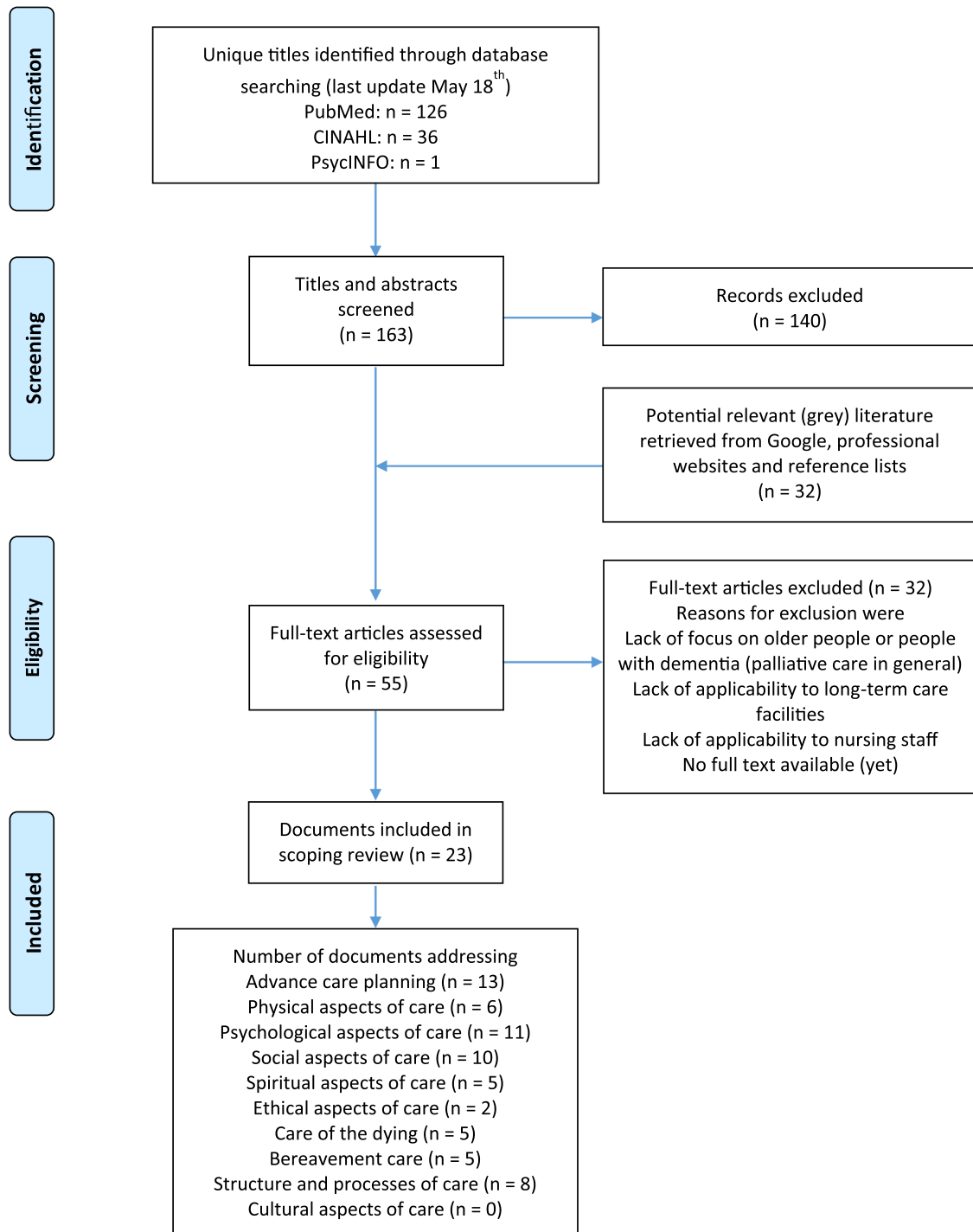


Fig. 1. Flowchart of the search and selection process.

reference lists of articles that we considered eligible. Finally, in step four we searched for grey literature using the search engine Google. Furthermore, we searched for relevant letters and editorials, guides, web articles and policy papers published by knowledge and professional institutes or associations in dementia and palliative care. These included: The European Association for Palliative Care, Alzheimer's Disease International, The Gerontological Society of America, International Psychogeriatric Association, The Society for Post-Acute and Long-Term Care Medicine, International Long-Term Care Policy Network, Marie Curie, Dutch professional

nurses organization, Palliaweb (Dutch online platform), Dutch Palliative Care Cooperation, Dutch Association of Elderly Care Physicians Verenso.

## 2.2. Study selection process

Table 2 displays the inclusion criteria for selecting articles and grey literature. Initially, we screened titles and abstracts or summaries and we excluded articles and papers that were irrelevant or beyond the scope of this review. After screening titles and abstracts



or summaries, we obtained articles and papers that we deemed eligible as full texts and further scanned them for eligibility. Authors JM and SB contributed to the study selection process by both performing title–abstract and summary screening and full-text screening independently on all potential titles. Afterwards, the authors discussed any discrepancies and reached full agreement on which articles and papers to include in the review.

### 2.3. Data synthesis and analysis

Three authors (JM, SB and IM) extracted data from the included papers. First, IM and SB extracted descriptive information from the articles to fill in a data extraction form. Extracted descriptive information included authors, date of publication, country, source or organization, type of article, setting and focus relevant to the review. Further, JM and SB read the included papers thoroughly to become acquainted with the content. Thereafter, JM listed initial relevant findings related to the research question that could inform recommendations for nursing staff working in long-term care facilities. The two authors (JM and SB) discussed the findings and SB formulated practical recommendations using the extracted information from included sources, adapted to our specific goal.

The recommendations were initially categorized according to the domains of palliative care as proposed by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (Ferrell et al., 2018). These domains include physical aspects of care, psychological aspects of care, social aspects of care, spiritual aspects of care, cultural aspects of care, care for the dying, ethical aspects of care, and structure and processes of care. We discussed the recommendations that followed from this process iteratively throughout the analysis. We placed them under what we considered the most appropriate domain. Based on inductive findings from the included articles, we included recommendations on advance care planning and bereavement care. After JM and SB set up a complete list of recommendations, these were discussed with all authors integrating each team member's expertise for further interpretation, practical application and fine-tuning. The team's areas of expertise cover palliative care (for people with dementia and/or frailty), advance care planning, elderly care medicine, transmural nursing home care, and long-term care and (community) nursing. This process resulted in a final overview of recommendations for nursing staff on how to provide palliative care for people with dementia during the COVID-19 crisis.

### 3. Results

Searching CINAHL, PsycINFO and PubMed databases and searching (non-scientific) websites for eligible grey literature yielded 163 unique titles (Fig. 1). Eventually, we obtained full texts from 55 documents based on title/abstract screening, by hand searching eligible articles and by searching for grey literature. Of these full texts, 23 were eligible.

Table 3 shows the included articles and other documents, and their focus relevant to this review. Among the included documents, there were 7 (special) articles published in peer-reviewed journals (Borasio et al., 2020; Brown et al., 2020; D'Adamo et al., 2020; Kunz and Minder, 2020; Lapid et al., 2020; Moore et al., 2020a, 2020b; Wallace et al., 2020), 6 guides (British Geriatrics Society, 2020; Dementia Australia, 2020; Kaserer and Hofland, 2020; The Irish Hospice Foundation, 2020; The Scottish Government, 2020; Victoria State Government, 2020), 4 letters to editors (Eghtesadi, 2020; Husebo and Berge, 2020; Padala et al., 2020; Wang et al., 2020b), 2 web articles (blogs) (Bauer, 2020; Russell, 2020), 2 reports (Bauer et al., 2020; European Academy of Neurology, 2020), one correspondence paper (Wang et al., 2020a), and one position paper (Livingston et al., 2020). The documents

(first authors) were from the UK and Ireland ( $n = 7$ ), Europe ( $n = 6$ ), the USA ( $n = 3$ ), Australia ( $n = 2$ ), Canada ( $n = 2$ ), and Asia ( $n = 2$ ). One was an international paper.

From the included information sources, we extracted original content that informed a list of specific recommendations for nursing staff regarding the provision of palliative care for people with dementia living in long-term care facilities during the COVID-19 pandemic (Table 4). We categorized recommendations under a number of key domains in palliative care adapted from the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (Ferrell et al., 2018). Some would fit under multiple domains, though we chose what we considered the most appropriate domain. The domains with the highest number of articles that informed recommendations are 'advance care planning' and 'psychological aspects of care' (Fig. 1). The domains with the lowest number of articles that informed recommendations are 'ethical care', 'care of the dying', 'spiritual care' and 'bereavement care'. We did not find information on 'cultural aspects of care'.

### 4. Discussion

This paper describes a rapid scoping review to formulate practice recommendations for nursing staff with regard to providing palliative dementia care in long-term care facilities in times of COVID-19. The recommendations that followed from the review touch upon most of the key elements of palliative care for people with dementia. Initially, we found papers that mainly addressed advance care planning and physical or medical care of COVID-19 patients. At the time of our first searches, articles on psychological, social and spiritual care and on nursing care were scarce. However, over time, more papers appeared that described these other domains and the impact of the COVID-19 pandemic on (caring for) people living with dementia. Although we found an increasing number of papers to inform palliative care given to people with dementia in times of COVID-19, papers that explicitly discussed palliative care in dementia specifically in relation to COVID-19 were limited. This illustrates that, although over the past two decades there has been increasing attention for palliative care in dementia (Hashimie et al., 2020; van der Steen, 2010), it is not a top priority when a crisis strikes. The current literature emphasizes specific challenges in times of COVID-19 related to advance care planning, family involvement and management of psychosocial needs that may aggravate due to social isolation and residents' limited understanding of the situation. To a lesser extent, the literature addressed the spiritual aspects of care and grief and bereavement. So far, ethical and cultural aspects of palliative dementia care in times of COVID-19 remain under-reported. The available literature on the current pandemic reflects the need for holistic palliative care for people with dementia in long-term care facilities as well as for their families before and after bereavement. Besides improved experiences of people with dementia and their families, a palliative approach to care may contribute to better use of healthcare resources. For instance, advance care planning and setting palliative care goals may reduce hospitalizations and futile medical treatments, and education of healthcare staff may reduce medication administration and costs (Senderovich and Retnasothie, 2019). Adequate allocation of healthcare resources is imperative in times of COVID-19 (Barclay, 2020).

Although previous papers emphasize the important role of palliative care in times of humanitarian crises and pandemics (Downar and Seccareccia, 2010; Powell et al., 2017; Rosoff, 2006), the global response to COVID-19 exposes a lack of efficient pandemic palliative care plans and gaps in palliative care training and literature (Etkind et al., 2020). In long-term care facilities, which are generally understaffed and under-resourced with regard to providing palliative care, the current pandemic poses particular chal-

**Table 3**  
Descriptive information of the included articles and other documents.

No.	Author(s)	Publication date, Country	Source or organisation	Type of article	Setting	Focus of the article relevant to the review
1	Victoria State Government	18 March 2020, Australia	Victoria State Government	Guide	Long-term care facilities	Guidance for residential aged care staff regarding recognizing and responding to residents at the end of life
2	Borasio et al.	24 March 2020, Switzerland	Swiss Medical Weekly (peer-reviewed journal)	Special article	Various settings	Palliative care for vulnerable groups receiving palliative or long-term care
3	Kunz & Minder	24 March 2020, Switzerland	Swiss Medical Weekly (peer-reviewed journal)	Special article	Home and long-term care facilities	Palliative care for frail older people in long-term care facilities
4	D'Adamo, Yoshikawa & Ouslander	25 March 2020, USA	Journal of the American Geriatrics Society (peer-reviewed journal)	Special article	Long-term care facilities	Care for frail older people living in long-term care facilities
5	Kaserer & Hofland	25 March 2020, The Netherlands	Curinamiae	Guide	Various settings	Advice on how to arrange rituals at the end of life and enable families to say goodbye (from a distance)
6	Russell	26 March 2020, UK	British Geriatrics Society	Web article (blog)	Long-term care facilities	Advice on how to deal with challenges due to lockdowns in long-term care facilities
7	British Geriatrics Society	30 March 2020, UK	British Geriatrics Society	Guide	Long-term care facilities	Decision-making and palliative care for residents in long-term care facilities
8	Wang et al.	30 March 2020, China	The Lancet (peer-reviewed journal)	Correspondence (letter)	Long-term care facilities	Challenges and requirements in care and support for people living with dementia
9	Bauer	31 March 2020 Switzerland	International Long-Term Care Policy Network	Web article (blog)	Various settings	Palliative care for vulnerable groups with pre-existing conditions and those receiving long-term care
10	The Irish Hospice Foundation	April 2020 Ireland	The Irish Hospice Foundation	Guide	Various settings	Advice for family members on how to deal with a loss due to COVID-19
11	European Academy of Neurology	3 April 2020, European countries	European Academy of Neurology	Report	Various settings	Advice for care providers on how to support people with dementia in times of social isolation and lockdown
12	Livingston & Weidner	9 April 2020, UK	Alzheimer's Disease International	Position paper	Various settings	Difficult palliative care decisions for people with dementia and their families
13	Eghtesadi	11 April 2020, Canada	Journal of the American Geriatrics Society (peer-reviewed journal)	Letter to editor	Long-term care facilities	Tips for using modern technology in long-term care facilities to avoid acute care services
14	Wallace et al.	13 April 2020, USA	Journal of Pain and Symptom Management (peer-reviewed journal)	Clinical practice article	Hospital and long-term care facilities	Dealing with (complicated) grief, considerations for palliative care providers
15	Brown et al.	18 April 2020, Canada	The American Journal of Geriatric Psychiatry (peer-reviewed journal)	Special article	Various settings	Challenges in the care for people with dementia due to the impact of the COVID-19 pandemic in different (long-term) care settings
16	Wang et al.	20 April 2020, Singapore	Journal of Palliative Medicine (peer-reviewed journal)	Letter to editor	Various settings	Advice for care providers to support older COVID-19 patients at the end of life and their families in grief and bereavement
17	Husebo & Berge	22 April 2020, Norway	American Journal of Geriatric Psychiatry (peer-reviewed journal)	Letter to editor	Long-term care facilities	The challenge of restricted visits in long-term care facilities and the importance of advance care planning
18	Padala, Jendro & Orr	23 April 2020, USA	Psychiatry Research (peer-reviewed journal)	Letter to editor	Long-term care facilities	An example of managing behavioral disturbances in a resident with dementia
19	Moore et al.	30 April 2020, UK	International Psychogeriatrics (peer-reviewed journal)	Journal article	Various settings	Support needs of family caregivers of older people with dementia at the end of life and after bereavement
20	Dementia Australia	April 2020, Australia	Dementia Australia	Guide	Long-term care facilities	Guidance for long-term care staff caring for people with dementia
21	Bauer, Dixon & Comas-Herrera	1 May 2020, UK	International Long-Term Care Policy Network	Report	Long-term care facilities	Provision of palliative care for older people residing in long-term care facilities
22	Lapid et al.	11 May 2020, International	International Psychogeriatrics	Special article	Various settings	Providing end-of-life care for older people (with dementia)
23	The Scottish Government	15 May 2020 (update), Scotland	The Scottish Government	Guide	Long-term care facilities	Practical advice for long-term care staff providing palliative care for residents

**Table 4**

Recommendations for nursing staff on providing palliative care for people with dementia in long-term care facilities in times of COVID-19.

Advance care planning
<ul style="list-style-type: none"> <li>Nursing staff should collaborate with geriatricians and family doctors to review (existing) advance care plans of people with dementia. In particular, discuss and evaluate appropriate actions together to anticipate potential COVID-19 (for instance, whether or not life-sustaining treatments and hospital admission are desired).<sup>1,7,21</sup></li> <li>Note that, ideally, advance care planning starts before a diagnosis of COVID-19 and before the person with dementia loses cognitive capacity.<sup>1,3,17,19</sup> Nursing staff may provide information and guidance to people with dementia and their families to facilitate the discussions of wishes and care preferences.<sup>2,3,9,12,19,22</sup> Consider using decision aids as a practical tool to support (proxies in) making difficult decisions.<sup>19</sup></li> <li>Aim to facilitate timely advance care planning conversations by thoughtfully introducing the COVID-19 subject.<sup>15</sup> Nurses could explain that in the context of COVID-19, it is advisable to discuss potential (realistic) scenarios and end-of-life care options proactively to avoid undesirable treatment (such as unwanted hospital admission, life-sustaining treatments or hospitalization).<sup>2,3,16,19,22</sup></li> <li>Be aware that, in case advance care planning conversations did not take place before, initiating first conversations in times of COVID-19 may be colored by fears or emotions induced by the current pandemic.<sup>22</sup> Without in-depth reflection or repeated discussions, certain decisions may be particularly difficult to make.</li> <li>Consider using advance care planning conversations to identify anticipatory grief and to provide information on bereavement preparation in times of COVID-19.<sup>14,16,19</sup></li> <li>For optimal support concerning advance care planning, a follow-up conversation or call is recommended to respond to psychosocial or spiritual needs or questions that may arise from discussing care plans.<sup>16</sup></li> <li>Make sure to document wishes clearly in transferable (digital) files that should be available and accessible at all times for different care agencies and care personnel (such as emergency physicians) in acute situations.<sup>2,3</sup></li> <li>During this pandemic, nursing staff may discuss the preferred place of death with persons with dementia, before potential infection. Keep in mind that a familiar environment is likely preferred over a hospital.<sup>3,12,19</sup></li> </ul>
<p><i>Additional recommendations for people with dementia who have COVID-19</i></p> <ul style="list-style-type: none"> <li>Complex decisions about hospitalization related to COVID-19 should be discussed jointly within the interprofessional care team (including nurses, family doctors or elderly care physicians, paramedics, palliative care specialists).<sup>2,7</sup></li> <li>For people with dementia who have COVID-19, discuss goals of care with the patient and within the interprofessional care team as soon as possible and revise care goals as the situation changes (involve the person's family or surrogate decision-maker).<sup>21</sup></li> <li>Be sensitive to family members and proxy decision-makers, who may have to make hasty, difficult and emotive decisions on behalf of their relative.<sup>19</sup></li> </ul>
Physical aspects of care
<ul style="list-style-type: none"> <li>Try to stimulate people with dementia to stay active by encouraging movement and (small, at-home) exercises (walking around the room, ward, or outside if possible, changing position (sitting, standing or lying down) regularly).<sup>1,11</sup></li> <li>Provide additional support and explanation to residents with dementia, to help them to maintain proper hand hygiene.<sup>20</sup> Consider the following tips: <ul style="list-style-type: none"> <li>Place dementia friendly instruction boards or signs in bathrooms or elsewhere as a reminder to wash one's hands with soap for 20 seconds.</li> <li>Demonstrate how to execute thorough hand washing.</li> <li>Use hand sanitizer or anti-bacterial hand wipes as an alternative for people with dementia who cannot easily get to a sink to wash their hands.</li> <li>Encourage people with dementia to sneeze and cough into a tissue (and discard afterwards) or into their elbow instead of their hands.</li> <li>Remind them about social and physical distancing and encourage them to stay in their room, for instance by tempting them with indoor hobbies (of their own, or something new that they find interesting).</li> </ul> </li> <li>Note that other health issues might mask manifestations of COVID-19 in people with dementia or infection may appear asymptotically (reported symptoms include sudden cough and fever, presence of diminished taste or smell, nausea and diarrhoea, shortness of breath, falls, dehydration, delirium or confusion, disordered sleep).<sup>23</sup></li> <li>Careful identification, documentation and discussion of changes in health status, mood or behavior as potential indicators for infection is advisable,<sup>23</sup> taking into account that people with dementia may not self-report such changes.<sup>4,11</sup></li> </ul>
<p><i>Additional recommendations for people with dementia who have COVID-19</i></p> <ul style="list-style-type: none"> <li>Pay attention to oral hygiene; this is particularly important for those who contract COVID-19, which may cause a dry mouth.<sup>3</sup></li> <li>Nursing staff may advocate for person-centered procedures to isolate people with dementia who have COVID-19 (especially with behavioral disturbances), that do not involve physical or medical (antipsychotics, sedatives) restraining measures.<sup>7,11</sup> (see 'Psychological care'). Instead of isolation on one's own room, consider arranging COVID-19 cohort units, allowing for freedom of movement.</li> </ul>
Psychological aspects of care
<ul style="list-style-type: none"> <li>Be mindful that regulations of social isolation and distancing followed by experienced loss of social connections and the sight of personal protective equipment on staff may instigate feelings of anxiety, depression, grief and trauma in people with dementia.<sup>1,15,22</sup></li> <li>Try to reduce heightened anxiety about COVID-19 among people with dementia.<sup>1,11,20</sup> Consider the following tips: <ul style="list-style-type: none"> <li>Minimize access and exposure to media information.</li> <li>Provide information and explanation to persons with dementia if they express concerns.</li> <li>Use simple reminders and visual instructions to explain the current situation.</li> <li>Use reassuring language and gestures to help people with dementia to follow safety regulations.</li> <li>Interact with persons with dementia frequently, ask how they are doing and take time to listen. Validate the person's feelings and provide reassurance.</li> <li>Avoid using negative language (words such as 'crisis', 'pandemic', 'lockdown' or 'isolation') and do not argue with colleagues about COVID-19 regulations in front of persons with dementia.</li> </ul> </li> <li>Spend sufficient time with persons with dementia and encourage them to engage in everyday activities and routines to reduce boredom and confusion.<sup>20</sup></li> <li>Report and respond to behaviors that may pose a risk to persons themselves or others (such as ignoring or resisting safety instructions).<sup>20</sup></li> <li>Look for psychosocial interventions to manage such behaviors.<sup>7,11</sup> Consider the following tips:<sup>11,18</sup>: <ul style="list-style-type: none"> <li>Use old photographs, objects or songs from the past for distraction.</li> <li>Stimulate movement, exercise and (creative or household) activities (such as painting, cooking, folding towels).</li> <li>Keep a regular schedule and routine.</li> <li>Be mindful about the effect of social isolation on people with dementia and that it may worsen symptoms of dementia. Take time to talk to them regularly and thoughtfully explain the situation, taking into account cognitive difficulties, and try not to submit your own anxiety.<sup>11</sup></li> <li>Reach out for family members who may (video)call to reduce distress and confusion in their relative with dementia through interaction.<sup>18</sup></li> </ul> </li> <li>Nursing staff should collaborate with mental health professionals and social workers to deliver adequate mental health care.<sup>8</sup></li> </ul>
<p><i>Additional recommendations for people with dementia who have COVID-19</i></p> <ul style="list-style-type: none"> <li>Report and respond to behaviors that may pose a risk to others (such as wandering behavior during isolation).<sup>20</sup></li> <li>Nursing staff should collaborate with mental health and dementia teams to manage wandering behavior of residents who need to be isolated due to infection.<sup>7</sup></li> <li>Pay attention to anticipatory grief work by preparing persons with dementia and their families in case of a nearing death due to COVID-19. Communicate and address anticipatory grief by recognizing and validating emotions. Preferably, use a direct approach and do not avoid or shy away from talking about emotions and grief.<sup>14,19</sup></li> <li>Consider providing (written) information about bereavement preparation in relation to COVID-19 to people with dementia and their families.<sup>16</sup></li> </ul>



**Table 4**  
continued

Social aspects of care
<ul style="list-style-type: none"> <li>• Be mindful of the potential adverse effects of isolation from others and the outside world for people with dementia (for instance, loneliness, anxiety, depression and worsening symptoms of dementia).<sup>13</sup></li> <li>• Although COVID-19 patients should be isolated, infection control regulations affect all people living with dementia, in terms of social isolation. When a person is nearing the end of life or when there is an acute need for companionship, staff should weigh the importance of a visit against infection risk.<sup>1,17,21</sup></li> <li>• Reduce social isolation and loneliness.<sup>11,20</sup> Consider the following tips: <ul style="list-style-type: none"> <li>- Encourage families and friends to drop off letters, drawings or other packages.</li> <li>- Encourage participation in everyday activities (such as listening to music or audiobooks).</li> <li>- Encourage (individual, at a distance) singing, walking outside, doing exercises.</li> <li>- Maintain social support by arranging regular check-ins by family members.</li> <li>- Maintain (small) group activities when possible; play interactive games via overhead speakers, eat in turns at mealtimes.<sup>1</sup></li> <li>- Encourage the use of technology, such as tablets or smartphones to facilitate online social engagement (with relatives). Note that the use of technology may require additional explanation and support, and may not be suitable for everyone.<sup>15,19</sup></li> </ul> </li> <li>• Invest in creative solutions and alternatives for the restricted visiting.<sup>1,22</sup> Consider using advanced technology such as Virtual Reality to offer people with dementia in isolation the opportunity to meet with their family in a simulated, trusted place or to visit special environments (such as music concerts, nature expeditions).<sup>13,17</sup></li> <li>• Virtual networks can also be used as platforms for joint activities and as a virtual visiting lounge for social contacts.<sup>5</sup></li> <li>• Nursing staff may advocate for offering family caregivers the opportunity to move in during the COVID-19 period.<sup>5</sup></li> </ul>
Spiritual aspects of care
<ul style="list-style-type: none"> <li>• During advance care planning conversations, it is advisable to pay attention to personal values, desired ritual or spiritual practices surrounding the end of life (which may also include funeral or memorial plans) to enable choosing a suitable course of action.<sup>14,19</sup></li> <li>• Connect people with dementia and their families to resources that may support them in their spiritual needs or needs surrounding postdeath planning and that may provide additional (grief) support using telehealth services.<sup>1,14</sup></li> <li>• Consider calling in a chaplain or spiritual caregiver to support people with dementia at the end of life and their families during the dying process.<sup>5</sup> Spiritual support is particularly essential in the complex times of COVID-19, regardless of whether the person with dementia is dying from COVID-19.</li> </ul> <p><i>Additional recommendations for people with dementia who have COVID-19</i></p> <ul style="list-style-type: none"> <li>• Be mindful of the burden of decision-making for people with dementia who contract COVID-19 themselves, their families and their formal caregivers. Feelings of abandonment and moral distress may arise, which may cause complicated grief in families and burnout in nursing staff.<sup>2</sup></li> </ul>
Care of the dying
<ul style="list-style-type: none"> <li>• It is important that nursing staff can identify when a person's death is imminent.<sup>1,17</sup> Three or more of the following symptoms likely indicate a terminal phase in persons with COVID-19: <ul style="list-style-type: none"> <li>- Experiencing rapid day to day and irreversible deterioration</li> <li>- Completely bedbound, requiring frequent interventions</li> <li>- Becoming less conscious, with lapses into unconsciousness, diminished or absent response to voices</li> <li>- Unable to swallow</li> <li>- Diminished or no urine secretion</li> <li>- An acute event happened that required revision of care goals</li> <li>- Profound weakness</li> <li>- Changing breathing pattern</li> <li>- Gurgling or rattly breathing</li> <li>- Changing body temperature (hot and clammy, or cold)</li> <li>- Pale or mottled skin</li> </ul> </li> <li>• If a person with dementia approaches the end of life, nursing staff may advocate for offering families the opportunity to say goodbye in person, despite potential visiting bans due to COVID-19.<sup>3,21</sup> In the terminal phase, talk to the person and his or her family and address the person's comfort.<sup>1</sup></li> <li>• If family members are unable to visit in-person, use technology to enable a connection between the dying person and his or her family.<sup>5</sup></li> <li>• Involve families as much as possible if a person with dementia is nearing the end of life (regardless of whether they have COVID-19), also if they cannot be present in-person. Provide information every step of the way and ask for ideas on how to arrange a peaceful death, tailored to the dying person.<sup>5</sup></li> <li>• In times of COVID-19, be mindful of rituals that may enable persons with dementia and their families to say goodbye properly (either in person or at a distance).<sup>5</sup> Nursing staff can contribute to a peaceful death, even in complex times. Consider the following tips: <ul style="list-style-type: none"> <li>- Rituals for saying goodbye at the end of life should be tailored to the individual to be meaningful. Try to align with the specific life view or religion of the dying person.</li> <li>- You may speak to the dying person, even if they have advanced cognitive impairments and are unaware of the situation. For instance, explain to the person that the moment has come to say goodbye, while trying to maintain a sense of calm and peace.</li> <li>- Consider lighting a candle, investing in a moment of silence.</li> <li>- You may speak to the dying person about their family members and others with whom the person had a connection. For instance, ask the dying person to think of or imagine these others. You may ask the dying person what he or she wants to say to them. If a person cannot speak, consider sharing your own thought and feelings. By doing this, you may foster feelings of connectedness, even when family is not present.</li> <li>- If family members are present, either in-person or via a video call, you may stimulate a joint feeling of connectedness (for instance, by reading a poem, being silent together, saying prayers together, singing or humming, listening to music).</li> </ul> </li> </ul>
Bereavement care
<ul style="list-style-type: none"> <li>• After the death of a person with dementia, inform family members (if they were not present at the moment of death) about the dying process and rituals that were used to foster a peaceful goodbye.<sup>5</sup> Tell them about any meaningful last words or gestures of their relative. This may enable them to grieve their loss in a healthy way.</li> <li>• Consider sharing a dignified photograph of the person with dementia after death with the bereaved family (with their permission). As families may not be present at the time of death, this might be the only visual evidence of the person's death and it may enable emotional relief.<sup>16</sup></li> <li>• Nursing staff may advocate for accessing and sharing tools and resources that are needed to mitigate (complicated) grief of families, and to help nursing staff cope with their own grief. For instance, think of communication tools, telehealth services, and nursing staff self-care.<sup>14</sup></li> <li>• Be mindful that families bereaved of someone with dementia in times of (and sometimes due to) COVID-19, may feel a range of negative emotions such as abandonment, anger, isolation and loneliness. Families who have not been able to spend time with their relative before death or those who felt unprepared for the loss may have difficulties to come to terms with their loss.<sup>10,14,19</sup></li> <li>• Be aware that complicated grief may follow from adverse experiences surrounding the loss. In times of COVID-19, adverse experiences are likely to arise due to the sudden and rapid nature of the infection.<sup>10,19</sup></li> <li>• Complicated grief involves recurring intrusive thoughts about the loss, preoccupation with sorrow, ruminating behavior, excessive bitterness, alienation of social contacts, difficulties accepting the loss and losing perceived purpose in life.<sup>14</sup> Pay attention to families' signs of grief and point out that they should seek information or contact their family doctor if they are concerned about their coping with the loss.<sup>10</sup></li> <li>• However, note that not every bereaved family member during the COVID-19 pandemic will experience complicated grief.<sup>14</sup> Nursing staff should explain to families that grieving is normal and that it generally takes time.</li> <li>• Tell bereaved family members to look after themselves by considering the following tips<sup>10</sup>: <ul style="list-style-type: none"> <li>- Think of the basics: eat well, stay hydrated, exercise regularly, try to maintain your usual routine.</li> <li>- Stay connected (digitally) and talk to others about how you are doing.</li> <li>- Allow yourself to experience negative emotions: it takes time to come to terms with a loss and the grieving process may fluctuate over time.</li> </ul> </li> </ul>

**Table 4**  
continued

Ethical aspects of care
<ul style="list-style-type: none"> <li>• Be aware that in the context of COVID-19, decision-making can be particularly challenging, which may induce moral distress. Moral distress arises when internal or external constraints prevent us from doing what we think is morally right.<sup>14</sup> Moral and emotional distress may lead to burnout and unresolved grief in professional caregivers and families.<sup>14,19</sup></li> <li>• Nurses are often trained to place the patients' well-being above their own feelings. However, self-awareness in care staff and dealing with one's own emotions and thoughts during care provision in times of the COVID-19 pandemic is imperative to the provision of care that meets ethical standards for persons with dementia and their families.<sup>14</sup></li> <li>• To deal with stress and loss during the COVID-19 pandemic, consider the following tips for self-care<sup>14</sup>: <ul style="list-style-type: none"> <li>- Disconnect from the disaster event by allowing yourself to take breaks (and deep breaths) occasionally.</li> <li>- Facilitate your own role during COVID-19 by making sure you feel prepared and informed.</li> <li>- Make sure you know local resources and services to which you may refer for additional support.</li> <li>- Join or arrange peer support and ask for adequate supervision to facilitate your decisions and responses.</li> </ul> </li> </ul>
Structure and processes of care
<ul style="list-style-type: none"> <li>• The health condition may deteriorate quickly in COVID-19 patients and people with and without COVID-19 may have unmet palliative care needs as professionals may be unable to prescribe in times of limited resources. It is advisable to consider anticipatory prescription: arrange and document prescriptions in advance. Nursing staff may advocate for collaboration with family doctors and local pharmacists to ensure timely availability of required palliative medication and equipment and to keep anticipatory stocks.<sup>3,7</sup></li> <li>• Note that residents with symptoms of COVID-19 must be isolated in a separate room or on a COVID-19 cohort unit immediately.<sup>22</sup> Nursing staff may advocate for the implementation of strict infection prevention measures in their organization (such as wearing personal protective equipment including masks, goggles, a gown and gloves).<sup>14,15</sup></li> <li>• It is advisable for nursing staff who have been in contact with infected persons to be tested if they experience symptoms and to self-quarantine in case they test positive.<sup>4</sup></li> <li>• To reduce the chances of viral outspread, it is advisable that nursing staff do not work in multiple facilities and restrict movement between facilities.<sup>1</sup></li> <li>• Nursing staff may collaborate with specialized (mobile) palliative care teams, if available, to provide the necessary support and care for persons with dementia.<sup>3</sup> Consider consulting a palliative care physician or geriatrician via phone or telehealth to assist the identification of the terminal phase.<sup>1</sup></li> <li>• Nursing staff may advocate for or contribute personally to the tailoring of information materials (such as guidelines and information sheets) developed for the general population to those who have cognitive and behavioral impairments.<sup>12</sup></li> <li>• During this pandemic, it is important to have supportive and visible nursing leadership in long-term care.<sup>1</sup> Nurses should advocate for their role as leaders and supervisors to optimize the quality of care, to increase adherence to prevention and control measures and to support their peers.</li> <li>• Nursing staff should address their needs with regard to specific information about risks and guidelines on protective measures when providing palliative and end-of-life care under COVID-19.<sup>9</sup></li> <li>• Nursing staff may advocate for setting up a 24-h palliative care hotline, to give advice and answers to people with dementia and their families.<sup>21</sup></li> </ul>

\*Referencing numbers correspond with the overview of included documents in Table 3.

lenges by further increasing the workload and potential distress of staff (Arya et al., 2020). At this early point, it is difficult to map the adequacy of palliative care in long-term care facilities in the context of COVID-19. However, Bauer and colleagues wrote that many people at the end of life may have unmet palliative care needs in times of COVID-19, particularly the frail population residing in long-term care facilities (Bauer et al., 2020). The COVID-19 pandemic raises concerns as it induces a strain on health providers who are under-resourced to provide safe and effective palliative care (The Lancet, 2020). As the number of infected individuals has increased, the potential seriousness and mortality of the infection is becoming more clear, for vulnerable groups and for people with dementia in particular (Atkins et al., 2020). Moreover, social isolation regulations may have a detrimental effect on the psychosocial and physical wellbeing of residents with dementia in long-term care facilities (Velayudhan et al., 2020). These challenges highlight the necessity of adequate palliative care to relieve suffering of people with dementia on the physical, psychological, social and spiritual domain (The Lancet, 2020). Expectations are that COVID-19 will continue to be a long-lasting global health problem, which underlines the need to provide simultaneous COVID-sensitive and dementia-sensitive care as we transition back from emergency care to regular care (Canevelli et al., 2020). The current scoping review adds to the knowledge base by providing an overview of relevant literature and practical recommendations.

Over the past few months, the initial response to the pandemic crisis was focused on curing those infected, containing extensive outspread and preventing intensive care facilities from being overwhelmed by demand. This also reflects the more general, long-standing neglect of the long-term care sector (Lapid et al., 2020) and weaknesses in its palliative care capacities (Bauer et al., 2020). Although the initial response focused on the hospital setting and less on long-term care setting, initiatives that address the psychosocial and spiritual consequences of the pandemic for older people with dementia are on the rise. Long-term care organizations are thinking of innovative ways to deal with social isolation and quarantine regulations to avoid loneliness and social exclusion of older people and persons with dementia (Dementia Aus-

tralia, 2020). Nursing staff working in long-term care facilities have a key role in providing psychosocial and spiritual care, especially when face-to-face meetings between families and their relatives with dementia are prohibited.

Literature that addresses domains of palliative dementia care other than the physical domain is increasing. However, a gap remains on some important aspects. The included documents in our review most often addressed advance care planning and psychological care, whereas practical information on spiritual care, care of the dying and the bereaved, and ethical aspects of care was sparse. The recommendations that we formulated related to these aspects are underpinned by a smaller body of literature, which suggests that (practical) knowledge on these aspects needs to be expanded. Currently, the most prominent literature gap is in cultural aspects of care, despite the global impact of COVID-19. Another recent review of worldwide guidance documents on palliative care in long-term care facilities also shows that several key aspects, such as holistic symptom management, decision-making and end-of-life and bereavement care remain under-reported (Gillissen et al., 2020). Although the recommendations that we formulated provide an initial basis for palliative care provision for people with dementia in times of COVID-19, they are limited to the currently available literature. Ideally, the recommendations should be updated regularly to provide ongoing support and information for nursing staff in long-term care facilities. This should inform contemporary COVID-sensitive and dementia-sensitive practice in long-term care facilities and add to the knowledge base for anticipating possible future crises.

#### 4.1. Ethical issues in decision-making

An important, yet under-reported issue is how to deal with people for whom life-sustaining measures may be inappropriate in the context of COVID-19. In a paper responding to a previous influenza pandemic, Downar and colleagues describe ethical issues related to scarce healthcare resources and medical decision-making (Downar and Seccareccia, 2010). Triage systems and decision-making in times of scarcity may deprive seriously ill people from

potentially life-sustaining treatments and cause physical and emotional suffering for patients, their families and care staff. Advance care planning is a process between healthcare professionals, an individual patient and his or her loved ones. Advance care planning and shared decision-making are core processes in establishing care goals for the end of life of persons with dementia (van der Steen et al., 2014) and may prevent unwanted life-sustaining treatments, which is paramount during this pandemic. Advance care planning conversations are particularly important in times of COVID-19 so that individual wishes for end-of-life care can be discussed in a timely manner and to inform people with dementia and their families about potential risks of hospitalization with the infection (Livingston et al., 2020). Families may feel more confident and less guilty about making end-of-life care decisions on behalf of their loved one with dementia if they know the person's wishes (Sellars et al., 2019). Particularly in times of COVID-19, it may be difficult and emotive for families of people with dementia who have not previously discussed their wishes to make such decisions (Moore et al., 2020a, 2020b). Although discussing care preferences may help to reduce chances of potentially futile and burdensome treatments and hospitalization, discussions concerning triage for intensive-care treatment under resource scarcity should not be included in the advance care planning process. However, during this pandemic, the autonomy to opt for life-prolonging treatments or a preferred place of death is possibly challenged because of public health directives and scarce resource accessibility (Brown et al., 2020).

Lack of a palliative care plan in times of a pandemic raises concerns about the provision of care that is in line with individual wishes of people facing life-limiting conditions and their families. A pandemic palliative care plan should facilitate palliative care services and health organizations to respond quickly and flexibly in times of scarce resources (Etkind et al., 2020). As Downar and colleagues described: we need "stuff" (for instance, stockpile medications), staff (education, expertise), space (special wards and units) and systems (triage systems, updated care plans) to provide comprehensive palliative care during a crisis (Downar and Seccareccia, 2010). In times of COVID-19 specifically, older and vulnerable people with cognitive impairment may not receive mechanical ventilation due to their prognosis, even if they wish to (Parsons and Johal, 2020). Residents with COVID-19 may be confined to a room or a special COVID-19 ward that is not of their choosing and regulations of social isolation and quarantine may hamper involvement of family members in the last phase of life of people with dementia (Radbruch et al., 2020). Even if people with dementia may not qualify for life-sustaining measures or acute care admission, it is a human right that they are not denied palliative care and adequate relief of suffering, regardless of whether they have COVID-19 (Brennan, 2007; Clarfield et al., 2020; Downar and Seccareccia, 2010). Stigma increases the risk of certain groups being denied access to health and social services (Brown et al., 2020). In dementia, stigmatization is a pervasive and widespread problem and there have been reports on stigmatization of older people who are at risk for contracting COVID-19 (Fraser et al., 2020). Hence, people with dementia may face double stigmatization (Brown et al., 2020). Nursing staff have an important role in advocating for people with dementia to shelter them from the negative consequences of stigmatization. During this pandemic, it is a global, public health urgency to apply palliative care knowledge to its best to provide equitable, compassionate and dignified care, to alleviate suffering and to mitigate the impact on caregiver grief and distress (Radbruch et al., 2020). In this review, we added advance care planning as a key domain for nursing recommendations. Nursing staff are essential stakeholders advocating for the provision of dignified palliative care for people with dementia. To achieve high-quality palliative care in times of this

pandemic, it is crucial to review care plans within the interprofessional care team and to update goals of care through advance care planning conversations with people with dementia and their families (Borasio et al., 2020; British Geriatrics Society, 2020; Kunz and Minder, 2020).

Nursing staff should collaborate diligently with families, and with physicians and other healthcare professionals to provide timely and adequate care that is tailored to individual wishes. Vice versa, healthcare professionals from other disciplines must acknowledge and support nursing staff to facilitate their role. The current pandemic emphasizes the need for nursing leadership in long-term care settings. Especially registered nurses should have a recognized leading role in the delegation and oversight of care tasks, initiation and evaluation of care plans and assessment of their effectiveness (McGilton et al., 2016). They should also function as mentors and supervisors for other care personnel. In the context of COVID-19, decision-making and care provision may be challenging due to strained resources, which can induce moral distress. Moral distress arises when constraints prevent us from doing what we think is morally right, and it may induce unresolved grief and burnout in families and nursing staff (Wallace et al., 2020). It is important that nursing staff engage in open communication with their (interprofessional) colleagues and with families about the experience of distress. Nursing staff and family members often place the wellbeing of the person with dementia above their own feelings. Nonetheless, we need to stimulate self-care and increase self-awareness of families and nursing staff about (negative) emotions and thoughts during care provision in times of the COVID-19 pandemic. Again, this requires leadership skills among nurses to provide peer support and facilitate self-reflection and peer-to-peer coaching.

#### 4.2. Grief and bereavement

In the context of the COVID-19 pandemic, experiences of grief and anticipatory grief are subject to change, which stimulates the need for adapting usual approaches to grief support (Wallace et al., 2020). Anticipatory grief is an emotional reaction to imminent losses and occurs before the actual death of oneself or a relative (Wallace et al., 2020). Anticipatory grief in relation to dementia is prevalent and complex (Moore et al., 2020a, 2020b), given the uncertain and sometimes lengthy illness trajectory, which is accompanied by serial losses on different domains (cognition, autonomy, social relationships) (Chan et al., 2013). Severe symptoms of anticipatory grief and low preparedness for the death of a relative are part of a complex network of risk factors for adverse bereavement outcomes, such as complicated grief (Nielsen et al., 2016; Stroebe et al., 2006; Wallace et al., 2020).

In this review's recommendations, we included bereavement care as a separate domain, given the unusual circumstances under which people are currently facing the loss of a relative. Given the sudden and rapid decline that a COVID-19 infection may cause, families and nursing staff may feel unprepared for the loss of a person (Moore et al., 2020a, 2020b; Wallace et al., 2020). Along with the possible inability of families to see or have physical contact with their relative at the end of life, this may increase the risk of complicated grief (Moore et al., 2020a, 2020b). It is important to note that nursing staff may equally suffer from grief or moral distress following the deaths of their residents (Bauer et al., 2020; Lapid et al., 2020). They may have to communicate distressing news to loved ones, which may be particularly disturbing for care staff who often consider residents (whom they have cared for over an extended period) as a part of their own family. Not being able to say goodbye properly relates to post-bereavement depression and complicated grief (Moore et al., 2020a, 2020b; Otani et al., 2017). Moreover, the world population is facing multiple potential

or actual losses in several other areas due to the COVID-19 pandemic, including the loss of jobs and financial income security, of social, physical and spiritual connections, of physical or mental health, and of autonomy and freedom. A lack of social support relates to increased pre-death grief among family caregivers of people with dementia (Moore et al., 2020a, 2020b). Moreover, social distancing regulations force those who are bereaved in times of COVID-19 to suspend funerals or to arrange an online service instead, with no physical attendance of family members and friends. Thus, bereaved individuals may lack support in terms of physical touch from and closeness to others ('a shoulder to cry on', literally) (Moore et al., 2020a, 2020b). All these factors may increase the risk of trauma, posttraumatic stress disorder, feelings of abandonment or loneliness and a lack of social support to enable coping with the loss of a relative.

The complexity of grief and bereavement in times of COVID-19 emphasizes the role of nursing staff in adequately recognizing and addressing anticipatory grief, in preparing families for bereavement, and in helping families come to terms with their loss as a part of palliative care (Shore et al., 2016; Wallace et al., 2020). We need to optimize the quality of palliative care to reduce potential risk of adverse outcomes for those bereaved of a relative or friend with dementia during the COVID-19 pandemic. To achieve this, it is important that nurses pay attention to possible unmet psychosocial needs of people with dementia and their families, spiritual needs, rituals and family involvement towards the end of life, and signs of anticipatory or complicated grief. Moreover, grief and moral distress among nursing staff in times of COVID-19 should be acknowledged (Moore et al., 2020a, 2020b) and long-term care organizations should facilitate (peer) support structures.

Ultimately, humane and empathetic provision of palliative care including grief and bereavement support should prevail, even in times of the COVID-19 pandemic. As Dame Cecily Saunders once said, "how people die remains in the memory of those who live on." Despite the tragedy of the COVID-19 pandemic, its worldwide impact may raise public death literacy and awareness with regard to the need to prioritize integration of palliative care into global health to ensure relief of suffering both before and after death (Lapid et al., 2020; Radbruch et al., 2020).

#### 4.3. Limitations

This rapid scoping review has a few limitations. The goal of this review was to gather relevant information from various resources regarding palliative care and dementia care during the COVID-19 pandemic at short notice. The conduct of the searches was not fully systematic. Relevant documents may have been omitted due to oversight of relevant search terms and due to the rapid increase of both academic and grey literature focusing on COVID-19. Moreover, this review only included documents that were written in English or Dutch. The recommendations were not ranked on their importance. We did not perform a structured quality assessment of the included documents. However, this is in line with the conduct of scoping reviews (Peters et al., 2015).

#### 5. Conclusion

In times of COVID-19, a pressing need arises for high-quality palliative care for people with dementia living in long-term care facilities and their families. Literature that informs how we should address this need increased over the last months. Nonetheless, an explicit focus on palliative dementia care is still largely lacking in the current academic and grey literature. Although medical and physical care are crucial in times of this pandemic, we need to address spiritual care, and culturally sensitive and ethical care. The COVID-19 outbreak and its ensuing societal impact emphasizes a

particular need for care of the dying and the bereaved. We must acknowledge grief and moral distress that may arise among staff caring for residents in long-term care facilities. Currently, literature on the spiritual, cultural and ethical aspects and on care of the dying and the bereaved is scarce. The current pandemic raises the need for nursing leadership. Nursing staff should collaborate with their interprofessional teams to establish and document suitable goals of care, tailored to the wishes of patients and their families as these may change in times of COVID-19. Nursing staff are essential to providing palliative care across all domains of care for people with dementia and their families to safeguard a peaceful death and a worthy farewell in these unsettling times.

#### Conflict of Interest

None to declare.

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#### Supplementary materials

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