



# Integration of a Palliative Approach in the Care of Older Adults with Dementia in Primary Care Settings: A Scoping Review

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Shirin Vellani<sup>1,2</sup> , Martine Puts<sup>1</sup> , Andrea Iaboni<sup>2,3</sup> , Christine Degan<sup>4</sup> and Katherine S. McGilton<sup>1,2</sup>

## Article

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### Corresponding author:

La correspondance et les demandes de tiré-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to: Dr. Shirin Vellani, Ph.D., NP, KITE-Toronto Rehabilitation Institute, University Health Network, 550 University Avenue, Toronto, Ontario Canada, M6K 2R7 ([shirin.vellani@mail.utoronto.ca](mailto:shirin.vellani@mail.utoronto.ca))

<sup>1</sup>Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada, <sup>2</sup>Knowledge, Innovation, Talent, and Everywhere (KITE)-Toronto Rehabilitation Institute, University Health Network, Toronto, Ontario, Canada, <sup>3</sup>Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada, and <sup>4</sup>Geriatric Assessment and Intervention Network (GAIN) Clinic, Senior Persons Living Connected, Scarborough, Ontario, Canada

## Résumé

L'approche palliative vise à répondre aux besoins des patients ayant certaines maladies chroniques et à ceux de leurs aidants tout au long de la trajectoire de soins. Elle peut être dispensée par des spécialistes non palliatifs. Une lacune importante subsiste dans la compréhension des perspectives et des expériences des prestataires de soins de première ligne pour ce qui est de l'approche palliative en soins intégrés pour les personnes atteintes de démence, ainsi que concernant l'impact des programmes et des modèles existants. Pour y remédier, nous avons réalisé une revue de la portée. Cinq bases de données ont été consultées et des approches descriptives numériques et de synthèse narrative ont été utilisées pour l'analyse des données. Nous avons constaté que : 1) les difficultés associées à la détermination du pronostic et le manque de collaboration interdisciplinaire et intersectorielle constituent des obstacles à l'utilisation d'une approche palliative dans les soins de première ligne ; 2) l'approche palliative a un impact statistiquement et cliniquement significatif sur les personnes avec démence vivant dans la communauté, particulièrement à un stade avancé. Des recherches de haute qualité sont requises sur les modèles de l'approche palliative intégrée et sur leur implantation à des stades moins avancés de la maladie, pour les personnes vivant dans la communauté et souffrant de démence précoce ou légère.

## Abstract

A palliative approach to care aims to meet the needs of patients and caregivers throughout a chronic disease trajectory and can be delivered by non-palliative specialists. There is an important gap in understanding the perspectives and experiences of primary care providers on an integrated palliative approach in dementia care and the impact of existing programs and models to this end. To address these, we undertook a scoping review. We searched five databases; and used descriptive numerical summary and narrative synthesizing approaches for data analysis. We found that: (1) difficulty with prognostication and a lack of interdisciplinary and intersectoral collaboration are obstacles to using a palliative approach in primary care; and (2) a palliative approach results in statistically and clinically significant impacts on community-dwelling individuals, specifically those with later stages of dementia. There is a need for high-quality research studies examining the integrated palliative approach models and initiation of these models sooner in the care trajectory for persons living with mild and moderate stages of dementia in the community.

## Background

Dementia is a terminal illness; however, the disease trajectory is highly unpredictable, making prognostication difficult (Smith & Ferguson, 2017). Dementia is typically complicated by the presence of multiple chronic diseases, increasing the risk for frequent hospitalizations and emergency department visits (Mondor et al., 2017). As cognitive abilities and decision-making capacity worsen, caregivers are expected to make care decisions on behalf of the persons living with dementia, which may exert increased caregiver burden (Gofton, Jog, & Schulz, 2009) and care that may be discordant with wishes of the care recipients. As a result, in the last year of their life, people with advanced dementia may receive burdensome medical interventions such as enteral nutrition, and suboptimal management of pain (Cintra, de Rezende, de Moraes, Cunha, & da Gama Torres, 2014).

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A “palliative approach” has been suggested as a way to conceptualize care for people with non-cancer chronic illnesses – such as dementia – who may not require the formal palliative care services (Kristjanson, Toye, & Dawson, 2003) that are usually delivered by palliative specialists. A palliative approach utilizes the principles of palliative care, which involve the physical, social, emotional, and spiritual aspects of holistic care (Gamondi, Larkin, & Payne, 2013), to meet the needs of the person and their caregivers at all stages of chronic diseases, not just at the end of life (Canadian Hospice Palliative Care Association, 2013a, 2015), and which can be delivered by health care practitioners regardless of their training, role, and work setting (Touzel & Shadd, 2018). In this scoping review, the conceptualization of a palliative approach in the care of older adults with dementia was drawn from the work by Maciver and Ross (2018), the Canadian Hospice Palliative Care Association (2013b), Touzel and Shadd (2018), and van der Steen et al. (2014). The four consistent components within each of the above works include (1) advance care planning (ACP), (2) pain and symptom management, (3) psychosocial and spiritual support, and (4) the process of shared decision making. Advance care planning is defined as “a process that supports adults at any age or stage of health in understanding and sharing their values, life goals, and preferences regarding future medical care” (Sudore et al., 2017). Pain and symptom management are interventions instituted to maximize comfort to optimize the quality of life (Canadian Hospice Palliative Care Association, 2015), whereas psychosocial and spiritual care provide emotional support, boost hope, address stress, and increase the quality of life of patients and caregivers coping with chronic medical conditions (Canadian Hospice Palliative Care Association, 2015; Reyes-Ortiz, 2015). The process of shared decision making is proactive and iterative (Maciver & Ross, 2018) and involves evidence-informed decision making among practitioners, patients and care partners (Elwyn et al., 2010; van der Steen et al., 2014).

The majority of people with dementia live in the community (Alzheimer’s Association, 2018; Dudgeon, 2010; Wertman, Brodsky, King, Bentur, & Chekhir, 2007), and these numbers are projected to increase exponentially (Dudgeon, 2010). The supply of geriatric practitioners is insufficient to meet the demands of the rising number of older adults (Canadian Nurses Association, 2016; Warshaw & Bragg, 2014). Furthermore, only about 15 per cent of persons with dementia receive any specialist palliative care services in the community in the last year of their life, and less than 1.9 per cent of these receive physician home visits (Seow, O’Leary, Perez, & Tanuseputro, 2018). As such, most people with dementia, including those approaching the end of life, are cared for by primary care providers in community settings (Shadd et al., 2013). Hence, primary care providers, both nurse practitioners (NP) and physicians, should be well situated to integrate a palliative approach when caring for older adults with dementia in their practice.

Authors in previous studies have examined how a palliative care approach was perceived and operationalized by nurses and physicians working in primary care settings, who cared for patients with life-limiting chronic illnesses (Reimer-Kirkham, Sawatzky, Roberts, Cochrane, & Stajduhar, 2016; Rewegan et al., 2019). The authors found that in caring for these patients, these clinicians were employing strategies that are aligned with the principles of palliative care, yet, clinicians tended to meld a palliative approach with specialist palliative services that are mostly limited to the end-of-life period as opposed to having an upstream focus. There remains an important gap in understanding the perspectives and experiences of primary care providers (nurses and physicians) on an integrated palliative approach in dementia care, as well as the

impact of existing programs and models of care in primary care using an integrated palliative approach in dementia.

Past reviews have specifically examined outcomes of a integrated palliative approach in caring for individuals with dementia with most studies involving institutional care settings (Hines et al., 2011; Sampson, Ritchie, Lai, Raven, & Blanchard, 2005). No review, to our knowledge, has specifically focused on health care providers (nurses and physicians) in primary care/community settings and the integration of a palliative approach throughout the dementia trajectory. To address this gap, we aim to examine the literature guided by the following questions:

1. What are the nurses’ and physicians’ perspectives and experiences regarding the integration of a palliative approach in the care of older adults with dementia in primary care settings?
2. What are the impacts of the integration of a palliative approach in the care of older adults with dementia in primary care settings on patients, caregivers, and health care utilization outcomes?

A scoping review was selected because it aligned with the goal of exploring the topic’s breadth and depth in the available literature (Colquhoun et al., 2014). Furthermore, it allowed us to examine the broad scope of different community-based programs aimed at integrating a palliative approach into the care of older adults with dementia. It also explores a wide variety of perspectives and experiences of practitioners in primary care settings, including nurses and physicians, pertaining to an integrated palliative approach. This examination of empirical literature has important implications for enhancing the practice of primary care practitioners in the delivery of quality dementia care in primary care settings. This review also highlights gaps in current knowledge and the need for more research in this area.

## Methods

We developed the review protocol according to the framework outlined by Arksey and O’Malley (2005), and advanced by Levac, Colquhoun, and O’Brien (2010), and followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) statement (Tricco et al., 2018) (Supplement A). MEDLINE<sup>®</sup>, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo, Embase, and Ageline databases were searched for studies between 1990 and February 2018, as significant seminal work was done in the early 1990s on palliative care (Mohanti, 2011). The search strategy was updated in October 2019. Based on the descriptive aims of the review, three key concepts made up the search strategy, “older adults”, “dementia”, and “palliative approach”, which was developed in consultation with an information specialist at the University of Toronto libraries. The search strategy was translated according to each database platform’s command language, controlled vocabulary, and appropriate search fields. For example, the search terms for the broad concept of palliative approach included palliative care, palliat\*.tw,kf., palliat\* adj3 (care or approach or utiliz\* or method\*).tw,kf. Supplement B presents an example of the MEDLINE search strategy.

## Criteria

The inclusion criteria were

- Original research studies using quantitative, qualitative, and mixed-methods research designs
- Studies published in English and addressing the integration of palliative care principles and practices (Sawatzky et al., 2016) for

people with dementia in primary care settings even though the term “palliative approach” may not have been explicitly used

- Studies in which the mean age of the study population was  $\geq 65$  years
- Studies that addressed the perspectives and experiences of nurses and physicians working in primary care settings on the integration of a palliative approach for older adults with dementia in their care; and/or that reported on the impact of an integrated palliative approach on older adults, caregivers, and/or health care utilization outcomes.

The exclusion criteria were

- Editorials, reviews, expert opinions, and materials that did not include original data
- Publications about medical assistance in dying (MAID), withdrawal of care, euthanasia, and assisted suicide
- Studies involving settings other than primary care; for example, acute care and/or long-term care
- Studies with the exclusive focus on end-of-life care

### Data Analysis

We used the EndNote reference manager to collate 2,945 retrieved records. After systematic de-duplication, a final unique set of 2,153 records were imported into Covidence. This Web-based software program streamlines the screening, study selection, and data extraction for the literature reviews ([www.covidence.org](http://www.covidence.org)). Article screening, selection, data extraction, and quality assessment were completed independently by two reviewers (S.V. and C.D.) for each of the included studies, and consensus was reached through discussion. Cases of disagreement between reviewers were resolved by a third reviewer (K.M.). In the first stage of study selection, titles and abstracts of each article were screened, whereas in the second stage, full-text screening was completed for 70 articles that were deemed relevant. We also screened the reference lists of all the included studies. Where results of a study were reported in more than one publication, they were grouped.

The data were extracted by two authors (S.V. and C.D.) for each of the included studies and then compared and amalgamated, using a pre-piloted form on the details of the study type (quantitative, qualitative, report); physicians' and nurses' characteristics (specialty type, years of experience, additional educational preparation); patient and/or caregiver characteristics (age, gender, ethnicity, number of chronic conditions, dementia stage); features of a palliative approach; impact of integration of a palliative approach in dementia care; and categories/themes – if used; as well as nurses' and physicians' perspectives and experiences in integrating a palliative approach in the care of older adults with dementia in primary care settings, referring back to the research questions as a guide (Levac *et al.*, 2010) (sample data abstraction form available from the corresponding author upon request). We used the Mixed Methods Appraisal Tool (MMAT) to critically appraise diverse designs in this review, with quality criteria specific to each design (Hong *et al.*, 2018). It allowed us to summarize the quality of the evidence, as well as to guide the design of high-quality studies in future. However, no study was excluded based on the MMAT scores, to be consistent with the goals of the scoping reviews (Joanna Briggs Institute, 2015).

We followed Arksey and Malley's as well as Levac *et al.*'s suggestion to analyze the extracted data in the context of each objective using a descriptive numerical summary to describe the

characteristics of the study, participants, and interventions (Colquhoun *et al.*, 2014; Daudt, van Mossel, & Scott, 2013; Levac *et al.*, 2010). We used a narrative synthesizing approach guided by the definition of a palliative approach in the care of older adults with dementia operationalized for this review (Popay *et al.*, 2006). This served as a common analytical framework for organizing and synthesizing standard information from each study to support mapping the data. As a result, it not only helped frame a nebulous concept that was useful in organizing the data synthesis but stands a higher likelihood of being useful in clinical practice.

## Results

### Characteristics of the Included Studies

Figure 1 describes our PRISMA flow diagram and the study selection process. Of 2,153 studies, 17 (21 articles) met inclusion criteria. Of the 17 studies, 8 addressed the perspectives of physicians and/or nurses, whereas, 9 studies reported on the impact of a palliative approach in the care of older adults with dementia in primary care settings (Carduff *et al.*, 2016; Clevenger, Cellar, Kovaleva, Medders, & Hepburn, 2018; Daaleman *et al.*, 2019; Holley, Gorawara-Bhat, Dale, Hemmerich, & Cox-Hayley, 2009; Hum *et al.*, 2018; London, McSkimming, Drew, Quinn, & Carney, 2005; Nakanishi, Hirooka, Morimoto, & Nishida, 2017; Sternberg *et al.*, 2019; Treloar, Crugel, & Adamis, 2009). Eight of nine studies involved persons with late stage of dementia, whereas one study did not report the dementia stage (Daaleman *et al.*, 2019). No study addressed both the research questions. Supplement C describes the summary of the included studies. The selected articles included 7 (41%) qualitative, 8 (47%) quantitative, and 2 (11.7%) mixed-method studies. No randomized control trial was identified. Ten studies were conducted in Europe, four in the United States, and three in Asia (Singapore, Israel, and Japan).

The sample size in eight studies (Beernaert *et al.*, 2014; Brazil, Carter, Galway, Watson, & van der Steen, 2015; Carduff *et al.*, 2016; Davies *et al.*, 2014; De Witt Jansen *et al.*, 2017; Evans *et al.*, 2014; Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012; Vleminck *et al.*, 2014) involving physicians and nurses, varied from 1 (Carduff *et al.*, 2016) to 188 (Brazil *et al.*, 2015) with a total sample size of 459 primary care physicians and 195 nurses. Of six studies in which response rate was applicable (Brazil *et al.*, 2015; Evans *et al.*, 2014; Holley *et al.*, 2009; London *et al.*, 2005; Nakanishi *et al.*, 2017; Treloar *et al.*, 2009), five reported it. It ranged from 25.6 per cent (Nakanishi *et al.*, 2017) to 100 per cent (Treloar *et al.*, 2009). Details on the characteristics of the health care practitioners are provided in Supplement D.

Table 1 summarizes the features of a palliative approach addressed in the included studies based on our operationalized definition. Ten of the 17 studies highlighted all four features; that is, ACP, pain and symptom management, psychosocial and spiritual support, and shared decision making (Brazil *et al.*, 2015; Clevenger *et al.*, 2018; Daaleman *et al.*, 2019; Davies *et al.*, 2014; Evans *et al.*, 2014; Holley *et al.*, 2009; Hum *et al.*, 2018; London *et al.*, 2005; Ryan *et al.*, 2012; Treloar *et al.*, 2009), whereas the remaining studies, except one (Carduff *et al.*, 2016), addressed at least two. No study reported a feature that is not captured in our definition.

### Quality Assessment

The quality assessment result is presented in Supplement E based on the MMAT. The authors of MMAT discourage calculating the

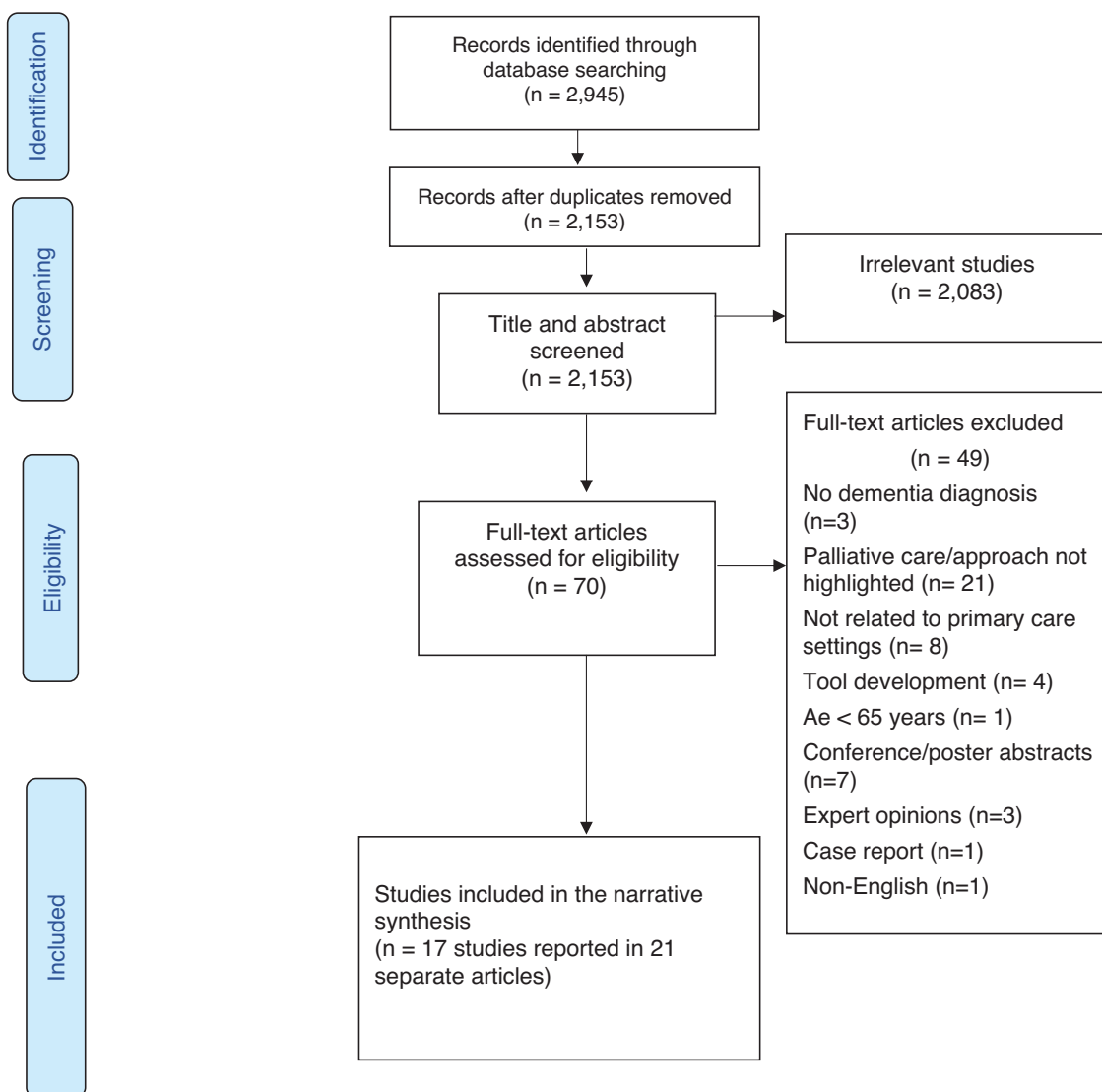


Figure 1: PRISMA flow diagram

overall score of the included studies (Hong et al., 2018), however, the majority ( $n = 8$ ) of the studies only met 40 per cent of the quality criteria. Quality assessment using MMAT enabled us to provide a comprehensive overview of the methodological quality of the available evidence (Pluye, 2014). Studies measuring the impact of a palliative approach had small sample sizes and sources of bias, leading to questions about the generalizability of the results. Nonetheless, it is crucial to conduct further research with rigorous methods to accumulate findings related to the effectiveness of this approach in dementia care.

Among the quantitative studies, in which response rates were indicated, only one was below 30 per cent (Nakanishi et al., 2017). The primary author of this study clarified that the low response rate of 25.6 per cent is comparable to other surveys in Japan. For most of the qualitative studies, issues concerning reflexivity and positionality were not discussed; hence, they may influence the interpretation of data. The qualitative studies were mainly descriptive without theoretical or paradigmatic foundations.

### Question 1: Perspectives and Experiences of Nurses and Physicians

Table 2 presents a summary of nurses' and physicians' perspectives on integration of a palliative approach in the care of older adults with dementia in community settings. The next section presents the details on each of the four components of the definition of a palliative approach as operationalized for this review.

#### ACP

Six of the eight studies highlighted ACP as part of a palliative approach (Beernaert et al., 2014; Brazil et al., 2015; Davies et al., 2014; Evans et al., 2014; Ryan et al., 2012; Vleminck et al., 2014). The findings were mixed regarding the appropriate timing of conducting ACP discussions. Many physicians agreed that early discussions promote the person's role in the decision-making process and provide the opportunity to express their wishes while they can

**Table 1.** Features of a palliative approach in dementia care addressed in the studies

First Author Publication Year	Shared Decision Making	Advance Care Planning	Psychosocial and Spiritual Support	Pain and Symptom Management
Studies Addressing Perspectives and Experiences of Nurses and Physicians				
<sup>a</sup> Brazil et al., 2017 Brazil et al., 2015 Carter et al., 2017 van der Steen et al., 2016			✓	
<sup>a</sup> Beernaert et al., 2014, 2015		✓	✓	✓
Davies et al., 2014			✓	
De Witt Jansen et al., 2017			✓	
Evans et al., 2014			✓	
Ryan et al., 2012 (UK)			✓	
Toivonen et al., 2017			✓	
Vleminck et al., 2014	✓	✓		
Studies Addressing Impact of a Palliative Approach in Dementia Care				
Carduff et al., 2016			✓	
Clevenger et al., 2018	✓	✓	✓	✓
Daaleman et al., 2019	✓	✓	✓	✓
Holley et al., 2009	✓	✓	✓	✓
Hum et al., 2018	✓	✓	✓	✓
London et al., 2005	✓	✓	✓	✓
Nakanishi et al., 2017			✓	✓
Sternberg et al., 2019	✓		✓	✓
Treloar et al., 2009	✓	✓	✓	✓

Note. <sup>a</sup>Denotes study presented in more than one article.

communicate them (Beernaert et al., 2014; Davies et al., 2014; Ryan et al., 2012; Vleminck et al., 2014). Conversely, some physicians had reservations about early ACP discussions, believing that the caregivers need to experience the decline in the advanced stages to help with treatment decisions (Brazil et al., 2015; Vleminck et al., 2014). Many participants raised the concern that ACP discussions may cause anxiety among patients and caregivers and take away hope (Beernaert et al., 2014; Brazil et al., 2015; Vleminck et al., 2014). Furthermore, physicians underlined that their lack of training leads to challenges with diagnosing a person in the early stages and projecting its trajectory, serving as a barrier to ACP discussions (Beernaert et al., 2014; Brazil et al., 2015; Vleminck et al., 2014).

### *Pain and symptom management*

This was highlighted in all studies except one (Vleminck et al., 2014). Concerning challenges in managing pain and other symptoms, physicians expressed difficulty in identifying and assessing distressing symptoms in persons with advanced dementia (Davies et al., 2014; De Witt Jansen et al., 2017; Ryan et al., 2012). These challenges result from a person's lack of communication abilities to describe troubling symptoms, which sometimes result in responsive behaviours. Physicians expressed difficulty identifying the etiology of behavioural symptoms and concern that they do not want to medicate patients for the wrong reasons (Davies et al., 2014; De Witt Jansen et al., 2017; Ryan et al., 2012; Toivonen et al., 2017).

Practitioners, therefore, emphasized the role of caregivers for the assessment of distressing symptoms as well as response to treatments (De Witt Jansen et al., 2017; Ryan et al., 2012).

Participants indicated a lack of resources and personnel to optimize symptom management in the community (Brazil et al., 2015). They highlighted that caring for persons with dementia requires collaboration and open channels of communication among various specialists including palliative, psychogeriatric, and hospice care, as well as sectors for consultation and seamless care transitions (Beernaert et al., 2014; Davies et al., 2014; De Witt Jansen et al., 2017; Ryan et al., 2012).

### *Psychosocial and spiritual care*

Seven of the eight studies related to practitioners' perspectives identified psychosocial support as an essential feature of a palliative approach in dementia care, whereas only two studies explicitly mentioned the importance of spiritual care (Brazil et al., 2015; Toivonen et al., 2017).

Participants in one study reported that persons with dementia should be treated with basic nursing skills that include psychosocial and emotional support (Ryan et al., 2012). Whereas participants in several other studies indicated that it is the role of the physicians to address the needs requiring psychosocial support (Beernaert et al., 2014; Brazil et al., 2015; Ryan et al., 2012). Physicians also pointed to a lack of funding for interdisciplinary teams to complement their

**Table 2.** Perspectives and experiences of nurses and physicians regarding integration of palliative approach

First Author, Publication Year (Country)	HCP	Key Findings
<sup>a</sup> Brazil et al., 2015 Brazil et al., 2017 Carter et al., 2017 van der Steen et al., 2016 (Europe- Netherlands & Northern Ireland, UK)	The Netherlands Elder-care physicians provided primary care for patients with dementia for years including at the EOL UK/NI: GPs with responsibility for patients with dementia	<ul style="list-style-type: none"> <li>• A large number of GPs agreed that early discussion about dementia trajectory will facilitate decision making in the later stages of dementia by family members. Most agreed that these discussions can cause anxiety for patients and family</li> <li>• Some respondents agreed that early discussion with patients and families is not needed, as family will witness decline and this will sufficiently aid in decision making</li> <li>• Physicians from both countries attested that it is the role of physicians to initiate the ACP conversation</li> <li>• A wide variability was seen between the physicians from two countries about the initiation of ACP on EOL care at diagnosis. In the UK almost as many physicians agreed (39.8%) as disagreed (45.9%), whereas a majority of Dutch physicians (60.8%) agreed to it; however, a substantial minority (25.3%) disagreed to it</li> <li>• 90.2% GPs felt that there is a need for an accepted format for ACP</li> <li>• Patients are inappropriately sent to hospital via ambulance, where they receive aggressive interventions which are inappropriate. The also identified that physicians send patients to hospital even in cases in which there is ACP in place, which is usually the result of family members' changing their mind</li> <li>• Physicians are reluctant to de-prescribe unnecessary medications</li> <li>• 79.7% of GPs felt that they need improved knowledge to involve family members in caregiving at the EOL</li> <li>• Lack of knowledge and understanding about dementia among HCPs, family, and the public are barriers to providing PC to patients with dementia</li> <li>• Difficulty in prognosticating dementia and identifying when PC should take over also serve as barriers in the provision of PC</li> <li>• There is a lack of resources in terms of time and staff to provide care to these patients and available services</li> <li>• There is a lack of interdisciplinary approach in the provision of PC in dementia, and specialist support such as for PC and psychogeriatrics is sporadic and there is a long waitlist</li> <li>• One of the reasons for a lack of access to the PC team is that their care is mostly focused on patients with cancer</li> <li>• GPs also pointed out that they do not have a consistent support from family members and fellow IP team members such as SWs to complement their care</li> <li>• 96.3% of GPs agreed that shared decision making involving patients and their family members as partners should be a goal of clinical practice</li> <li>• Lack of support for family members such as for respite, results in transferring patients to the hospital</li> </ul>
<sup>a</sup> Beernaert et al., 2014, 2015 (Europe)	Community nurses, FPs	<ul style="list-style-type: none"> <li>• FPs should have sufficient time to contact and communicate with patients when providing PC</li> <li>• Collaboration and open channels of communication among various providers/caregivers about medical and non-medical matters is very valuable</li> <li>• FPs should assess the capacity of family members to provide care to their loved ones</li> <li>• Symptoms as well as adverse effects of treatment management is a task of FPs; FPs should be available to manage emergencies and acute changes in condition, including home visits, urgent treatment, and assistance with decision making around treatment options including transfer to ED</li> <li>• FPs have the role of providing psychological support as patients are stressed as a result of multifactorial causes</li> <li>• FPs should discuss future care including treatments options, place of care, and help with EOL decision making</li> <li>• Psychosocial and existential care in the terminal phase is the role of other professionals</li> <li>• FPs should be able to initiate appropriate referrals and do not need to take care of every issue personally</li> <li>• Patients with cancer would benefit from specialist PC, however those with dementia do not require it</li> <li>• FPs identified that discussing imminent death with patients and families is a difficult task to perform; however, they should not ignore this discussion</li> <li>• FPs should keep up with the latest development in caring for patients with life-limiting illnesses and PC</li> <li>• Some FPs feel incompetent in providing PC as it is not a part of their basic medical training, and those who do provide PC are doing so based on their level of comfort</li> </ul>

(Continued)

Table 2. Continued

First Author, Publication Year (Country)	HCP	Key Findings
Davies et al., 2014 (Europe)	Nurse, $n = 11/77$ ; physician, $n = 23$ ; researcher, $n = 10$ ; management/policy professional, $n = 28$ ; SW, $n = 2$ ; psychologist, $n = 2$ ; volunteer $n = 1$	<ul style="list-style-type: none"> <li>It is important to discuss disease trajectory, especially with relatives and caregivers, and that dementia is the disease that their loved one will die of</li> <li>The concept of PC is applicable to all kinds of conditions and not only to cancer patients</li> <li>There was an expressed need to get clarity on different definitions, such as PC, supportive care, or EOL care</li> <li>PC is usually understood by people as care provided to cancer patients, which leads to misunderstandings when discussed in the context of dementia, as dementia is not considered life-limiting and hence pain management is suboptimal</li> <li>Lack of funding affects the development of outpatient PC</li> </ul>
De Witt Jansen et al., 2017 (Europe- Northern Ireland)	Physicians	<ul style="list-style-type: none"> <li>Collaboration among providers in primary, secondary, and tertiary care settings in terms of consultation and exchange of expertise, was appreciated</li> <li>Because of the lack of overt physical symptoms and loss of communication ability, pain assessment is difficult at the EOL</li> <li>Some participants mentioned looking for non-verbal and behavioural symptoms for the presence of pain, and also expressed apprehension that behavioural symptoms could be suggestive of another etiology such as fear and anxiety</li> <li>Participants identified that “neuropsychiatric symptoms” can hamper the ability to accurately assess pain and that they may unnecessarily treat for pain</li> <li>Many physicians follow the “start low and go slow” principle and trial the mildest form of analgesia to see the response and also referred to the WHO ladder for pain management</li> <li>GPs felt validated seeking consultation from specialists in areas such as PC, hospice, and psychogeriatric services for guidance on pain management</li> <li>GPs felt that families played an important role in providing collateral information and identifying if the treatments were working, including identification of side effects</li> </ul>
Evans et al., 2014 (Europe- Netherlands)	GPs	<ul style="list-style-type: none"> <li>GPs were more frequently aware of EOL care wishes including wishes regarding place of death and proxy decision makers mostly for their cancer patients and those with organ failure than those with dementia</li> <li>More cancer patients receive PC from a GP (75%) than do old age/dementia patients (64%) and organ failure patients (38%)</li> <li>Prevalence of EOL topic discussion by GPs with patients was higher in oncology patients and lowest in followed by old age/dementia patients</li> <li>GPs’ odds of discussing PC options, EOL, and ACP with old age/dementia patients was much lower than the odds of discussion these with organ failure and cancer patients, after controlling for differences in patients’ characteristics</li> </ul>
Ryan et al., 2012 (Europe-UK)	Consultant: 4 Junior physician, 9 GP, 6 Practice nurse, 4 CNS, 11 Other nurses, 19 Allied health professional, 5	<ul style="list-style-type: none"> <li>GPs informed that specialist PC is generally offered to oncology patients and they are unsure of the criteria for PC referral in patients with dementia</li> <li>Patients with dementia should be treated with basic nursing skills, including emotional support and care provision with dignity. However, dementia patients do not need specialist PC, particularly around pain management, as they may not have the same symptoms as cancer patients</li> <li>Patients with dementia do need hospice/palliative care; however, they do not get PC services and mostly get transferred to geriatric units as opposed to hospice</li> <li>The participants agreed on engaging in ACP and PC early on in the disease process proactively and respecting patients’ role in the decision-making process</li> <li>Participants pointed to the UK Mental Capacity Act, that since enacted, has “made people think” and engage patients with dementia in the decision-making process</li> <li>Participants felt that their skills and competencies were insufficient around assessment and management of challenging behaviours, as well as pain assessment when patients are unable to provide subjective data in the late stages</li> <li>Some GPs expressed that dementia is not identified as a terminal disease like COPD, cancer, and HF</li> <li>Some physicians expressed that dementia is the result of old age and that people get confused when old</li> </ul>

(Continued)

Table 2. Continued

First Author, Publication Year (Country)	HCP	Key Findings
		<ul style="list-style-type: none"> <li>• Palliative team staff in the community expressed concerns about having stretched in terms of resources to deliver PC services to cancer patients, the fact that it is difficult to extend it to patients with other diagnoses such as dementia, and that persons with dementia can have EOL in a nursing home, whereas oncology patients do not have this option</li> <li>• Caring for persons with dementia in the late stages requires collaborating with various specialists</li> </ul>
Toivonen et al., 2017 (Europe- Southern Finland)	9 RNs 8 assistant nurses	<ul style="list-style-type: none"> <li>• Addressing the spiritual needs of the patients is a part of basic nursing care and follows a person-centred framework</li> <li>• Spiritual needs may be addressed by giving comfort and hope and being present, and addressing them promotes a sense of value</li> <li>• Patients may express their spiritual needs through request for praying for/with them and/or reading scriptures for them. However, patients who may not be able to express spiritual needs, may present with responsive behaviours; e.g., restlessness</li> </ul>
Vlemingck et al., 2014 (Europe-Belgium)	GPs	<ul style="list-style-type: none"> <li>• GPs had a general opinion that ACP discussions were important in their practice, yet many were not familiar with the term ACP</li> <li>• No GP had a formal ACP process in place, and they said that it usually happens informally and at times in an indirect way</li> <li>• Physicians with more experience in PC and those with previous positive outcomes in response to ACP conversations were more willing to initiate these discussions.</li> <li>• GPs with more experience in EOL care identified that having this conversation earlier in the disease process is important to identify future care wishes when they can communicate with the patient</li> <li>• Lack of time served as a barrier in initiating ACP discussions in the GPs' practice</li> <li>• Physicians alluded to having no "key moments" to initiate ACP in patients with dementia as they could with cancer patients e.g., at the time of cancer diagnosis or when a patient became unresponsive to treatment</li> <li>• Some GPs had less familiarity with identifying the terminal phases of dementia and HF than they had with the terminal phases of cancer</li> <li>• Some GPs were not clear about the terminal nature of dementia; hence, ACP conversation did not ensue</li> <li>• Conversation about ACP can lead to "anxiety and depression", as patients are not usually aware of their diagnosis and related prognosis; and telling them about them losing their mental capacity in coming years is a "taboo"</li> <li>• With dementia, there was apprehension related to patients' capacity in making these decisions and concerns about potential medical lawsuits</li> </ul>

Note. <sup>a</sup>Denotes study presented in more than one article.

ACP = advance care planning; CNS = clinical nurse specialist; COPD = chronic obstructive pulmonary disease; ED = emergency department; EOL = end of life; FP = family physician; GP = general practitioner; HCP = health care practitioner; HF = heart failure; NI = Northern Ireland; PC = palliative care; PCP = primary care provider; WHO = World Health Organization; IP = interprofessional; SW = social worker.



**Table 3.** Studies addressing the impact of palliative approach in dementia care

First Author, Year (Country)	Patient Characteristics					Impact of Palliative Approach
	Average Age	% of Participants with Dementia	Dementia Stage when PA Implemented	Features of PA	% Female	
Carduff et al., 2016 (UK)	X	40	Terminal	<ul style="list-style-type: none"> <li>• PSS</li> <li>• PSM</li> </ul>	X	Impact on healthcare utilization <ul style="list-style-type: none"> <li>• X</li> </ul> Impact on Patient-related outcomes <ul style="list-style-type: none"> <li>• X</li> </ul> Impact on CG-related outcomes using Carer Support Needs Assessment Tool (CSNAT) and interview <ul style="list-style-type: none"> <li>• Identification of carers who needed support; their number was small</li> <li>• Problematic to identify carer because of associated paperwork</li> </ul>
Clevenger et al., 2018 (North America-Atlanta, USA)	78.6	100	Mean MOCA score:12.6	<ul style="list-style-type: none"> <li>• SDM</li> <li>• ACP</li> <li>• PSS</li> <li>• PSM</li> </ul>	63.3	Impact on healthcare utilization <ul style="list-style-type: none"> <li>• Ambulatory-sensitive hospital admissions declined from 6.7% to 0.8%</li> <li>• Less-fragmented continuity of care, better management of BPSD, and tailored optimized medication management</li> <li>• Increased connection to adult day programs (21%), home care services (35%), and assisted living homes (19%)</li> </ul> Impact on patient-related outcomes <ul style="list-style-type: none"> <li>• No deceased patient (<math>n = 4</math>) experienced burdensome transitions in the last 3 days of life, only 1 hospitalization in the last 90 days of life</li> <li>• Optimal management of chronic conditions including hypertension, depression, and diabetes</li> <li>• Non-significant but improved neuropsychiatric symptoms (<math>p = 0.07</math>).</li> <li>• 38.1% of patients and CGs identified advanced directive, a medical power of attorney, or a living will</li> </ul> Impact on CG-related outcomes <ul style="list-style-type: none"> <li>• 28.1% of CGs participated in psychoeducational or support group</li> <li>• Although statically non-significant, authors speculate promising reduction in CG stress (<math>p = 0.69</math>) and improvement in competence (<math>p = 0.18</math>) as a result of better management of BPSD at home by the team</li> </ul>
Daaleman et al., 2019 (North America-USA)	70.3	32	X	<ul style="list-style-type: none"> <li>• SDM</li> <li>• ACP</li> <li>• PSS</li> <li>• PSM</li> </ul>	56	Impact on healthcare utilization <ul style="list-style-type: none"> <li>• 43% reduction in hospitalization and 25% reduction in ED visits</li> <li>• Increased referral (25% participants) to hospice care services</li> <li>• Increased number of referrals for personal care services (53%)</li> <li>• 81% of participants received home health referrals</li> <li>• Receipt of durable medical equipment (15% participants)</li> </ul> Impact on patient-related outcomes <ul style="list-style-type: none"> <li>• Participants reported a high-quality care experience measured by items from the HCSCM-CM13</li> <li>• Very high quality of communication except for subjects related to prognosis and spiritual care needs</li> </ul> Impact on CG-related outcomes <ul style="list-style-type: none"> <li>• X</li> </ul>
Holley et al., 2009 (North America-Chicago, USA)	85	64	X, however, had limited life expectancy	<ul style="list-style-type: none"> <li>• SDM</li> <li>• ACP</li> <li>• PSS</li> <li>• PSM</li> </ul>	86	Impact on health care utilization <ul style="list-style-type: none"> <li>• &gt;2/3 patients died at home or inpatient hospice setting</li> <li>• None of the patients with primary dementia died at a LTC</li> <li>• Smooth transition to the next level of care; e.g., home to hospice</li> </ul> Impact on patient-related outcomes <ul style="list-style-type: none"> <li>• Decreased suffering because of pain and symptom management at home</li> <li>• Decreased anxiety associated with visiting outpatient clinics</li> <li>• Increased feeling of comfort by staying home</li> </ul> Impact on CG-related outcomes <ul style="list-style-type: none"> <li>• Relief and reassurance for CGs and patients because of 24-h access to a practitioner trained in geriatrics, palliative care, and EOL</li> </ul>

(Continued)

Table 3. Continued

First Author, Year (Country)	Patient Characteristics					Impact of Palliative Approach
	Average Age	% of Participants with Dementia	Dementia Stage when PA Implemented	Features of PA	% Female	
						<ul style="list-style-type: none"> <li>13/14 CGs were satisfied with the place of death being home, only 1 person was not satisfied with the location of death.</li> <li>100% CGs expressed satisfaction with PATCH practitioners</li> </ul>
Hum et al., 2018 (Asia-Singapore)	X	100	Late stage, FAST 7	<ul style="list-style-type: none"> <li>SDM</li> <li>ACP</li> <li>PSS</li> <li>PSM</li> </ul>	X	<p>Evaluation of patient outcomes, health care utilization and cost effectiveness will be presented in future articles. However, the following outcomes were assessed:</p> <ul style="list-style-type: none"> <li>PAINAD; NPI-Q; MNA; QUALID; CAD-EOLD; ZBI</li> <li>Preliminary review reveals: decreased rate of hospitalization because of symptom management at home 24/7</li> <li>Direct admission to hospital without waits in ED</li> <li>Direct transition to hospice from home if necessary</li> </ul>
London et al., 2005 (North America-USA)	74	22	Late stage, FAST 6–7	<ul style="list-style-type: none"> <li>SDM</li> <li>ACP</li> <li>PSS</li> <li>PSM</li> </ul>	62	<p>Impact on health care utilization</p> <ul style="list-style-type: none"> <li>Of 92 people who died during the CALL project; 38% died at home, 35% in hospital, and 27% in LTC</li> <li>Decreased utilization of inpatient hospitalization to 29% and critical care to 7%</li> <li>Increased utilization of hospice</li> </ul> <p>Impact on patient-related outcomes using Modified City of Hope Patient Questionnaire</p> <ul style="list-style-type: none"> <li>Patients found symptoms less problematic at the time of the last questionnaire in 6 out of 8 areas: sleep changes, dry mouth, change in food tastes, drooling, or appetite changes, intestinal problems of constipation or diarrhea, shortness of breath or difficulty breathing, aches or pain, and current pain (<math>p &lt; 0.05</math> for each). There were no statistically significant changes in fatigue or nausea</li> </ul> <p>Impact on Caregiver related outcomes: Modified City of Hope Caregiver Outcomes</p> <ul style="list-style-type: none"> <li>X</li> </ul>
Sternberg et al., 2019 (Asia-Israel)	83.5	100	Late stage, FAST 7	<ul style="list-style-type: none"> <li>SDM</li> <li>PSS</li> <li>PSM</li> </ul>	70	<p>Impact on health care utilization</p> <ul style="list-style-type: none"> <li>4 patients died during the program: 3 at home and 1 in hospital.</li> <li>Two patients left the program because of aggressive treatment request by the family. 1 later died in hospital and 1 was admitted to a nursing home</li> <li>At the culmination of the 6-month pilot project, 13 of 20 participants moved back to usual home care services</li> <li>11% of physician's and nurses' home visits and 28% of their telephone consultation with family were outside of the regular working hours to address urgent, emergent issues.</li> <li>On average, 33 hospitalizations were averted, including: 11 cases of aspiration pneumonia, 6 of urinary tract infection, and 6 of cellulitis in 15/20 participants</li> <li>Preliminary cost analysis revealed the program to be cost neutral</li> </ul> <p>Impact on patient-related outcomes</p> <ul style="list-style-type: none"> <li>Significant improvement in symptoms such as pain, skin issues, and agitation, from an average pre-program score of 33.8, to 38.3 at the end (<math>p &lt; 0.001</math>)</li> <li>Family reported decreased suffering because of symptom management at home</li> <li>On average 2.1 (SD 1.4) medications/person were de-prescribed</li> </ul> <p>Impact on CG-related outcomes</p> <ul style="list-style-type: none"> <li>Significant improvement in family's satisfaction with care from an average score of 27.5 to 35.3 (<math>p &lt; 0.001</math>)</li> <li>Decrease in CG burden from 12.1 to 1.4 (<math>p &lt; 0.001</math>)</li> <li>Family described team's high level of professionalism and around the clock access to be very valuable and stated that it gave them a "sense of support" as well as increased their knowledge of the dementia trajectory</li> <li>Involvement of social worker and spiritual care provider positively impacted their well-being and reduced care-giving burden</li> </ul>

(Continued)

Table 3. Continued

First Author, Year (Country)	Patient Characteristics					Impact of Palliative Approach
	Average Age	% of Participants with Dementia	Dementia Stage when PA Implemented	Features of PA	% Female	
Treloar <i>et al.</i> , 2009 (Europe-UK)	80.64	100	Late stage, FAST 6	<ul style="list-style-type: none"> <li>• SDM</li> <li>• ACP</li> <li>• PSS</li> <li>• PSM</li> </ul>	57	<p>Impact on health care utilization</p> <ul style="list-style-type: none"> <li>• Care at home cost £0 to approximately £650/week, whereas in a nursing care facility it would cost approximately £700/week</li> <li>• Total spending on care provision by health social services on these 14 patients was £337,670 whereas the cost of care at a nursing care facility for them would have been &gt; £1,034,600, leading to a saving of approximately £696,930</li> <li>• 6/14 died in hospital, where they stayed for a short period, most likely because service was not accessible after hours</li> </ul> <p>Impact on patient-related outcomes</p> <ul style="list-style-type: none"> <li>• Comfortably stayed at home, as hospital beds not considered comfortable by participants</li> <li>• Comfort feeding as opposed to enteral feeding offered with flavorsome and nutritious food choices</li> <li>• Smart medication; i.e., ones with low volume options used for antipsychotics, opiates, and antibiotics</li> </ul> <p>Impact on CG-related outcomes</p> <ul style="list-style-type: none"> <li>• Quality time with loved ones at home</li> <li>• Daytime access to the professional expertise of psychiatrist, district nurses, and a social worker was considered “indispensable” for symptom management including behaviours</li> </ul>
Nakanishi <i>et al.</i> , 2017 (Japan, Asia)	85	100	Advanced stage	<ul style="list-style-type: none"> <li>• PSS</li> <li>• PSM</li> </ul>	75.4	<p>Impact on patient-related outcomes</p> <p>Patients-QLDJ: Rated by formal CGs, 24 items categorized into three dimensions: interaction with surroundings, self-expression, and exhibition of minimum negative behaviour</p> <ul style="list-style-type: none"> <li>• Patients’ quality of life (measured as interaction with surroundings, self-expression, and exhibition of minimum negative behaviour in patients with dementia) was observed to be significantly higher when professional CGs exhibited greater knowledge/positive attitudes regarding palliative care for dementia, relative to that observed when CGs exhibited less knowledge or negative attitudes</li> <li>• Total scores observed for “interaction with surroundings” significantly higher when professional CGs held positive attitudes regarding palliative care (coefficient 5.18 95% CI 2.96–7.41) than when CGs held negative views (coefficient 3.10 95% CI 1.18–5.01)</li> <li>• Scores for “exhibition of minimum negative behaviour” were significantly higher when professional CGs possessed greater knowledge regarding palliative care for dementia (coefficient 2.45 95% CI 0.58–4.32), relative to those observed when CGs possessed less knowledge</li> <li>• Scores for “self-expression” were significantly higher when professional CGs possessed greater knowledge (coefficient 2.92 95% CI 0.97–4.87) and held positive attitudes (coefficient 4.26 95% CI 2.15–6.37), relative to those observed when CGs possessed less knowledge and held negative attitudes</li> <li>• Physical restraint use: Restraint use was not associated with knowledge and attitudes regarding palliative care for advanced dementia. Higher use of restraints seen in patients with more severe ADL impairment (odds ratio 2.98 95% CI 2.37–3.74)</li> <li>• Antipsychotic use: Not associated with knowledge and attitudes regarding palliative care in advanced dementia</li> </ul>

Note. ✓ = Yes; X = not mentioned/reported

ACP = advance care planning; ADL = activities of daily living; BPSD = Behavioral and Psychological Symptoms of Dementia; CAD-EOLD = Comfort Assessment in Dying With Dementia; CALL Project = Comprehensive, Adaptable, Life-Affirming, Longitudinal (CALL) palliative care project; CG = caregiver; CI = confidence interval; ED = emergency department; EOL = end of life; FAST = Functional Assessment Staging; HCSMCM13: Home Care Satisfaction Measure-Care Management Service; LTC = long-term care; MNA: Mini Nutritional Assessment; MOCA = Montreal Cognitive Assessment; NPI-Q: Neuropsychiatric Inventory Questionnaire, severity domain; caregiver distress domain; PAINAD: Pain Assessment in Advanced Dementia; PATCH = Palliative Access Through Care at Home; PSM = pain and symptom management; PSS = psychosocial and spiritual support; QLDJ = Japanese QOL instrument for older adults experiencing dementia; QUALID = Quality of Life in Late-Stage Dementia; SDM = Shared Decision Making; ZBI = Zarit Burden Interview to assess impact of caregiving.

care in supporting persons with dementia and caregivers at home (Brazil et al., 2015; Davies et al., 2014; Ryan et al., 2012). Physicians expressed frustration about the difficulty of acquiring community support for informal caregivers such as respite care to relieve their stress, resulting in unnecessary hospital transfers (Brazil et al., 2015; Carduff et al., 2016). One study also highlighted the need for the integration of health and social care services for the optimal delivery of a palliative approach (Davies et al., 2014).

### *The process of shared decision making*

The shared decision-making process was highlighted in six of eight studies addressing the perspectives and experiences of physicians and nurses (Brazil et al., 2015; Davies et al., 2014; De Witt Jansen et al., 2017; Evans et al., 2014; Ryan et al., 2012; Vlemminck et al., 2014). Participants recognized that shared decision making involving patients and their caregivers as partners should be a goal of clinical practice (Brazil et al., 2015; Ryan et al., 2012). They perceived that persons with dementia should be engaged in the conversation about their future care because of the impending loss of decisional capacity, hence acknowledging the patients' role in decision making (Brazil et al., 2015; Ryan et al., 2012; Vlemminck et al., 2014). Shared decision making also involved engaging caregivers in the late stages for the purpose of identifying treatment options according to the best interests of the person living with dementia (Davies et al., 2014; De Witt Jansen et al., 2017; Evans et al., 2014; Ryan et al., 2012).

### *Question 2: Impact of a Palliative Approach in Dementia Care*

Of the 17 studies, 9 reported on the impact of a palliative approach in the care of older adults with dementia in primary care settings and examined a variety of interventions and outcome measures (Carduff et al., 2016; Clevenger et al., 2018; Daaleman et al., 2019; Holley et al., 2009; Hum et al., 2018; London et al., 2005; Nakanishi et al., 2017; Sternberg et al., 2019; Treloar et al., 2009) (See Table 3 for details on these outcomes). Eight of nine studies involved patients in the advanced stage of the disease, whereas one did not report the dementia stage (Daaleman et al., 2019). The outcomes describing the impact of a palliative approach were focused on the impacts on patient-related outcomes, most of which were reported by caregivers and/or assessed by health care practitioners, as described in the following paragraphs (Clevenger et al., 2018; Holley et al., 2009; London et al., 2005; Nakanishi et al., 2017; Sternberg et al., 2019; Treloar et al., 2009); caregiver-related outcomes (Carduff et al., 2016; Clevenger et al., 2018; Holley et al., 2009; Sternberg et al., 2019; Treloar et al., 2009); and health care utilization (Clevenger et al., 2018; Daaleman et al., 2019; Holley et al., 2009; Hum et al., 2018; London et al., 2005; Sternberg et al., 2019; Treloar et al., 2009). Table 3 presents significant findings from the studies related to the impact of this approach.

### *Impact of a palliative approach on patient-related outcomes*

Several researchers focused on patient-related outcomes such as a decrease in suffering, increased ability to stay home (Clevenger et al., 2018; Holley et al., 2009; Hum et al., 2018; London et al., 2005; Treloar et al., 2009), and improvement in the quality of life (Hum et al., 2018; Nakanishi et al., 2017). Overall, investigators reported that optimization of pain and symptom management including the use of oral feeding as opposed to enteral nutrition (Treloar et al., 2009) at home in the advanced stages led to a reduction in overall suffering (Clevenger et al., 2018; Holley et al., 2009; London et al.,

2005; Sternberg et al., 2019; Treloar et al., 2009). Only one study reported on medication de-prescribing (Sternberg et al., 2019).

Clevenger et al. (2018) examined the Integrated Memory Care Clinic (IMCC) led by advanced practice nurses that delivered interdisciplinary comprehensive primary and behavioural care management around the clock at home. The program led to the identification and management of chronic diseases, identification of advanced directives (38%), and non-significant improvement in neuropsychiatric symptoms severity ( $p = 0.07$ ) as well as caregiver distress ( $p = 0.69$ ) related to behavioural symptoms. Sternberg and colleagues examined a home hospice program offered to older adults with advanced dementia, which also included after-hour service (Sternberg et al., 2019). The program led to statistically significant improvement in participants' symptom management scores ( $p \leq 0.001$ ) at the end of the program when compared with the baseline scores; also, the program led to an average medication de-prescribing of 2.1 (standard deviation [SD] 1.4) unnecessary medications per person.

One study used a patient self-reported tool called the Modified City of Hope questionnaire to assess the improvement in physical symptoms ( $p \leq 0.05$ ) over time with interventions provided through a palliative care program at home (London et al., 2005). Participants included patients in the advanced stages of various diseases, including dementia. However, authors do not provide details on how data were acquired from these individuals, given that loss of communication abilities is inevitable in advanced dementia (Fazel, Hope, & Jacoby, 2000). Hence, there is a concern related to the threat to internal validity in terms of how the patients completed the questionnaire, and it is challenging to contextualize the findings. In their qualitative analysis, Holley et al. found that a decrease in suffering and an increase in comfort resulted from the optimal management of issues at home, such as sleep problems, dry mouth, constipation or diarrhea, breathing concerns, and pains, as well as decrease in psychological and physical distress associated with attending outpatient clinic appointments, because care was provided at home (Holley et al., 2009). Nakanishi and colleagues measured quality of life as an interaction with surroundings, self-expression, and exhibition of minimum negative behaviour in patients with dementia (Nakanishi et al., 2017). The participants were professional caregivers to community-dwelling older adults with advanced dementia; for example, nurses and nursing assistants, who completed these measures. Researchers found that patients' quality of life was significantly higher ( $p \leq 0.05$ ) when professional caregivers exhibited greater knowledge of dementia or possessed positive attitudes regarding palliative care in dementia. Conversely, the investigators also found that the use of physical restraints was higher in patients with severe impairment in the activities of daily living regardless of the professional caregivers' knowledge and attitudes regarding palliative care for advanced dementia (Odds ratio 2.98 95% confidence interval [CI] 2.37–3.74).

### *Impact of a palliative approach on caregiver outcomes*

Five studies reported on caregiver outcomes (Carduff et al., 2016; Clevenger et al., 2018; Holley et al., 2009; Sternberg et al., 2019; Treloar et al., 2009). Main outcomes measured included: identification of carers needing support ( $n = 1$ ), caregivers' participation in psychoeducation ( $n = 1$ ), caregiver stress ( $n = 2$ ), caregiver competence ( $n = 1$ ), caregivers' satisfaction with care at home ( $n = 3$ ), and quality time

spent at home ( $n = 1$ ). The investigators in one United Kingdom-based study developed a model to identify, assess, and support carers in primary care practice (Carduff *et al.*, 2016). They found that carers valued the connection with their primary care practice. However, because of time-consuming paperwork to acquire support, only 36 per cent of the eligible carers participated in this program, whereas Clevenger and colleagues (2018) provided caregivers opportunities to engage in psychoeducation and support groups, where 38.1 per cent of caregivers participated. Although statistically non-significant, there was a reduction in caregiver stress ( $p = 0.69$ ) and an improvement in caregiver competence ( $p = 0.18$ ) in managing responsive behaviours in consultation with the IMCC team (Clevenger *et al.*, 2018).

Caregivers reported a sense of relief and support because of the 24-hour access to practitioners with training in geriatrics, palliative care, and end-of-life care for symptom management (Holley *et al.*, 2009; Sternberg *et al.*, 2019), and also reported an increase in their knowledge of the dementia trajectory (Sternberg *et al.*, 2019). In another study, caregivers found that access to professionals, including a social worker and spiritual care provider, had a positive impact on their well-being and lessened their caregiving burden (Sternberg *et al.*, 2019; Treloar *et al.*, 2009).

#### *Impact of a palliative approach on health care utilization*

Seven studies reported an impact on health care utilization, where specific outcomes included: death at home versus in hospital and/or long-term care homes (Holley *et al.*, 2009; London *et al.*, 2005; Sternberg *et al.*, 2019; Treloar *et al.*, 2009), decrease in emergency department visits and hospitalization (Clevenger *et al.*, 2018; Daaleman *et al.*, 2019; London *et al.*, 2005; Sternberg *et al.*, 2019), reduction in health care costs (Treloar *et al.*, 2009), smooth care transitions including to hospice (Clevenger *et al.*, 2018; Daaleman *et al.*, 2019; Holley *et al.*, 2009; Hum *et al.*, 2018), and care coordination for the receipt of appropriate services such as day programs (Clevenger *et al.*, 2018).

Two studies reported that the majority of patients died at home as a result of optimal symptom management (Clevenger *et al.*, 2018; Holley *et al.*, 2009; Treloar *et al.*, 2009). Two studies reported on the cost of the program; one reported considerable savings when the cost of care was compared between home and a nursing care facility for the 14 participants in the program (Treloar *et al.*, 2009), whereas one reported that preliminary cost analysis revealed the program to be cost neutral (Sternberg *et al.*, 2019). Authors reported a decrease in hospitalization rate and improved care transitions because of optimal symptoms management at home (Hum *et al.*, 2018; London *et al.*, 2005; Sternberg *et al.*, 2019) including after hours (Hum *et al.*, 2018; Sternberg *et al.*, 2019). For example, in one study, the rate of hospitalization decreased to 29 per cent, and critical care admission decreased to 7 per cent among the participants when compared with the much higher national averages of 71 and 36 per cent, respectively (London *et al.*, 2005), whereas in another study, hospital admissions declined to 0.8 per cent from 6.7 per cent (Clevenger *et al.*, 2018). In comparison, in one study, 6 of the 14 participants died in the hospital following a short hospitalization (Treloar *et al.*, 2009). The authors speculated that the symptoms could have been alleviated had the service been available after hours. Interestingly, Sternberg *et al.* reported a 6-month mortality of 20 per cent in the participants in their pilot hospice program, declaring that this was less than predicted in the literature, suggesting that existing survival prognosis tools for persons living with advanced dementia have inconsistent predictive validity of 6-month mortality (Sternberg *et al.*, 2019).

## **Discussion**

The review included 17 studies, the majority of which were published recently, pointing to the relevance and the growing awareness of an integrated palliative approach in caring for persons living with dementia in primary care settings. No studies were found that looked at the integration of a palliative approach in persons with mild to moderate dementia. As such, the findings in this article relate to the integration of a palliative approach in advanced dementia, which appears to be most common. Primary care providers are reluctant to initiate ACP discussions because of the barriers related to the unpredictable and protracted trajectory of dementia, leading to difficulty in prognostication and concerns about stripping hope and causing psychological distress, as well as lack of training and experience in caring for the persons with dementia (Beernaert *et al.*, 2014; Brazil *et al.*, 2015; Vleminck *et al.*, 2014). Primary care physicians worry about the ability to offer appropriate symptom management and psychosocial support to patients and caregivers (Brazil *et al.*, 2015; Davies *et al.*, 2014; Ryan *et al.*, 2012). This is because of a lack of interdisciplinary approach, collaboration among specialties and sectors (Beernaert *et al.*, 2014; Davies *et al.*, 2014; De Witt Jansen *et al.*, 2017; Ryan *et al.*, 2012), and integration of health and social services (Davies *et al.*, 2014).

In this review, we have operationalized a definition of a palliative approach in the context of dementia and used this definition to scope the existing literature in this area. There is variability in the literature regarding what constitutes an integrated palliative approach to care for older adults with dementia at various stages within their trajectory from the perspective of non-palliative specialists. Therefore, setting out the four main components of a palliative approach; that is, ACP, pain and symptoms management, psychosocial and spiritual support, and the process of shared decision making, was a necessary first step. Given the lack of clarity as to the core components of a palliative approach in the care of older adults with dementia in primary care settings, future investigation is required to test this definition.

The uncertainty related to the appropriate timing of the integration of a palliative approach in dementia care was a prominent theme identified in this review. It is recommended that a palliative approach should be integrated early with chronic disease management to enhance the quality of life of patients and their caregivers throughout the disease trajectory and not just at the end of life (Canadian Hospice Palliative Care Association, 2015; Durepos *et al.*, 2017; Hines *et al.*, 2011). However, there remain substantial gaps in integrating a palliative approach with chronic disease management, resulting in aggressive treatment and investigations at the end of life leading to compromised care experiences (Durepos *et al.*, 2017). Persons with mild to moderate dementia can evaluate, interpret, and derive meaning in their lives (Cheong *et al.*, 2015; Hegde & Ellajosyula, 2016), making early stages a highly appropriate time for engaging patients and their care partners in discussions about dementia trajectory, care approaches, goals, and wishes for ongoing and future care. Nevertheless, how early after the diagnosis should these discussions commence remains a question that requires further exploration.

Advance care planning can promote patients' autonomy and prepare their caregivers for future care decisions. We found that primary care practitioners are concerned about causing anxiety and destroying a person's hope with the integration of a palliative approach in dementia care, specifically when discussing ACP. However, in other populations, early integration of palliative care that included ACP improved quality of life and reduced depression

symptoms in participants (Hoerger et al., 2018; Temel et al., 2010). Participants in these studies received less aggressive care at the end of life than those in the standard care group (Temel et al., 2010). Such prospective studies are also needed for persons with early stages of dementia, to examine the short-term and long-term impact on clinically significant outcomes.

A significant finding of our review was related to a lack of access to community agencies to enhance psychosocial support for patients and caregivers. Community-dwelling older adults with dementia live with informal caregivers and receive more care from them than from paid caregivers (Alzheimer's Association, 2014). Although anticipatory grief was not specifically examined in any of the included studies, it is frequently experienced by informal caregivers of persons with dementia throughout the course of the disease, and it is associated with an increased level of caregiving burden and depression (Garand et al., 2012). As previously identified, one of the main components of an integrated palliative approach is psychosocial and spiritual support for the patients and caregivers. Therefore, lack of identification and supports for their unmet needs could lead to burnout and portend unnecessary hospitalizations. Hence, it is crucial that primary care practitioners have access to interprofessional teams, including social workers and spiritual care providers throughout the dementia trajectory, to establish a comprehensive and coordinated plan of care. It is also imperative to recognize that an integrated care approach requires aligning the health and social care systems, as health and social care needs are inextricably connected (McGilton et al., 2018). Hence, an unmet psychosocial need may potentially minimize the effect of a well-planned health intervention.

The process of shared decision making was identified as an essential feature to actualize an integrated palliative approach in dementia care. Shared decision making requires building rapport with patients and caregivers, as well as respecting a person's capacity and dependence on others (Elwyn et al., 2012). Decision-making capacity worsens as dementia progresses, making it more critical to engage the caregivers at the outset of dementia, as their role is instrumental and dynamic in optimizing care for persons with dementia through its progression. By means of the opportunities to engage in the process of shared decision making, caregivers can learn about the care wishes and values of the older adults they care for, which can potentially result in increased decision-making confidence when the person with dementia loses their ability to make personal care decisions, as well as during the periods of crisis.

We identified nine studies that examined the integration of a palliative approach in the care of older adults with dementia in primary care settings. The outcomes were related to impact on the patients, such as a decrease in suffering as a result of pain and symptom management at home (Clevenger et al., 2018; Holley et al., 2009; Hum et al., 2018; London et al., 2005; Sternberg et al., 2019; Treloar et al., 2009), on the caregivers, such as satisfaction with care (Holley et al., 2009; Sternberg et al., 2019; Treloar et al., 2009), and on health care utilization, such as a decrease in inpatient hospitalization (Clevenger et al., 2018; Daaleman et al., 2019; London et al., 2005; Sternberg et al., 2019). The synthesis of outcomes for a palliative approach in dementia care presented methodological challenges. This was noted in another systematic review that evaluated randomized controlled trials examining the efficacy of a palliative approach in advanced dementia (Sampson et al., 2005). The investigators in this review found that in advanced dementia, validated measures, including pain scales and caregiver reports of symptom control and satisfaction, may be inaccurate. Furthermore, patients with late stages of dementia have verbal

difficulty, and scales measuring satisfaction with care usually have positive responses, resulting in skewed distribution (Volicer, Hurley, & Blasi, 2001). Our findings also raise questions about the use and efficacy of tools to measure outcomes in studies of impact, as eight of nine studies addressing the impacts of this approach recruited patients in the advanced stage. There remains a need to identify and validate appropriate measures sensitive to palliative approach interventions throughout the trajectory of the illness; for example, using behaviour-based tools when verbal communication is no longer accessible. Sternberg et al. reported a lack of survival tools with consistent predictive validity of 6-month mortality for advanced dementia; as a result, over 60 per cent of participants in the study were transferred back to regular home care service at the culmination of the pilot home-based hospice project (Sternberg et al., 2019). This is likely related to the unpredictable and protracted trajectory of dementia, complicated by the presence of multi-morbidities and a high level of frailty. Hence, placing a person with dementia in a numerical range of prognosis for the receipt of optimal care in the community does not seem to provide patient-centred care. Therefore, it is vital to acknowledge the terminal and progressive nature of dementia at the outset to customize care per unique individual needs and circumstances, regardless of the dementia stage.

It is important that primary care clinicians mindfully incorporate each of the four components of palliative approach laid out in this review in caring for persons living with dementia in community throughout the course of the disease. This would also acknowledge the definition of palliative care by the World Health Organization (WHO), which asserts that it is applicable early with the management of life-limiting conditions and aims to improve the quality of life of patients and caregivers by addressing their physical, psychosocial, and spiritual care needs (World Health Organization, 2020). The specific interventions for each of the four components of a palliative approach will differ with the progression of dementia, level of frailty, and individual needs of patients and caregivers. Also, the integrated palliative approach goes beyond the person's death to providing for the bereavement care needs of the caregivers (Schulz et al., 2003). As our findings suggest, clinicians will need to advance their knowledge and expertise on the complexity of dementia care, including communication skills to broach difficult topics with patients and caregivers such as the terminal and progressive nature of dementia, inevitable loss of communication abilities, and need for early ACP discussions.

### *Recommendations for Future Research and Clinical Practice*

Future research should focus on longitudinal studies to establish the benefits of a palliative approach integrated over the trajectory of dementia, including for those persons in the early stage. Specific interventions with appropriate outcome measures need to be identified and validated. Also, there is a need to determine the timing at which a palliative approach should be integrated with dementia management that is tailored to individual preferences and values. Typically, older adults with dementia, especially those who are recipients of home and community care services (Mondor et al., 2017), also have multiple chronic conditions. As it is, persons with dementia have an increased likelihood of hospitalizations with 3.68 times higher odds than those without dementia (Bynum et al., 2004). With each additional chronic disease, there is an even higher risk of frequent hospitalizations and visits to emergency departments (Mondor et al., 2017). These exposures to the health care system can serve as opportune times for hospital and community-

based clinicians to broach the subject of ACP, assess the need for psychosocial and spiritual support for patients and caregivers, and optimize pain and symptom management through the process of shared decision making.

Our findings suggest that health care providers in primary care practice must be trained and available to manage patients at home for an effective, integrated palliative approach in caring for their patients at all stages of dementia. Physicians in primary practice already have a lack of primary care resources and heavy workloads. Therefore, there is a need to innovate community-based interdisciplinary models of care delivery that address care and symptom management at home. These models should have the capacity to amalgamate health care provided by various sectors while coordinating services provided by health and social services; and optimizing support for patients as well as for informal caregivers (Cohn *et al.*, 2017). Furthermore, primary care clinicians should be able to know the components of the integrated palliative approach with dementia care to be able to measure its delivery and effectiveness in their setting in order to highlight their role in the delivery of palliative care at the system level and be recognized by the system planners (Shadd *et al.*, 2013). Hence, future research should be designed by looking at indicators of an integrated palliative approach in caring for community-dwelling individuals with dementia in primary care.

In light of the growing number of older adults, the health care systems are presented with challenges whereby there is a shortage of practitioners who are well versed in caring for older adults. A large number of those who are providing care to this group of patients are critically underprepared to serve the needs of their older patients (Institute of Medicine Committee, 2008). Hence, there is tremendous potential to design and evaluate interdisciplinary models of care that may involve advanced practice nurses such as NPs. Studies examining the outcomes related to the care provided by NPs to residents of long-term care homes have revealed greater family satisfaction with end-of-life care (Liu, Guarino, & Lopez, 2012) and reduction in the cost of care (Bauer, 2010).

Given the fact that the majority of community-dwelling older adults with dementia receive assistance with the activities of daily living from unpaid caregivers (Kasper, Freedman, Spillman, & Wolff, 2015), future work should also involve an exploration of the perspective and experiences of caregivers related to this approach. Longitudinal studies need to be designed to explore the sources of anticipatory grief at different stages of dementia and specific interventions to address them. Finally, one of the barriers to the integration of a palliative approach in the care of older adults with dementia was primary care practitioners' lack of education and experience in caring for this group of individuals. This is a concern and calls for the design and implementation of educational and capacity-building strategies included as part of the basic professional education, which should also be mandated as part of continuing education activities.

### Strengths and Limitations

There is not a single agreed-upon conceptual framework of a palliative approach for persons with dementia through the illness trajectory, including the early stages, the strength of our study is that we consolidated and synthesized a model that focused on four consistent components. The scoping review results showed that the model we proposed was relevant, as most of the studies we found had at least three of the four features embedded in them; that is., ACP, pain and symptom management, psychosocial and spiritual support; and the process of shared decision making. Developing the

definition of an integrated palliative approach from the existing literature was an important step to guide our search strategy, data extraction, and synthesis, because of a lack of clarity as to what constitutes this approach for persons living with dementia throughout the trajectory, and not just at the late stage. Our study had several limitations. We excluded studies involving other settings such as acute care or long-term care because of our inclusion criteria that the study needed to address palliative care principles for persons with dementia in primary care settings. Hence, of 2,153 abstracts, we only identified 17 that met the inclusion criteria. Although the review sheds light on the state of evidence on the topic of inquiry, it only includes studies published in English, potentially missing out on literature that may be available in other languages. Also, to capture all the relevant studies from the selected databases, we did not exclude studies based on the quality. This allowed us to present results that include lower quality studies, to be able to summarize the breadth of the available literature.

### Conclusion

To our knowledge, this review is the first to operationalize the definition of a palliative approach in the care of older adults with dementia throughout the disease trajectory in primary care, which was necessary based on existing work which had focused on persons in the late stages of dementia or was developed for palliative experts. The findings of the review indicate that there is a lack of studies dealing with older adults with dementia in primary care settings, particularly in the early stages. Future research is needed to confirm whether the integration of a palliative approach early on in the dementia trajectory offers the opportunity to understand and honour a person's wishes for present and future health care, prepare caregivers for making future care decisions, and increase the likelihood of receiving goal-concordant end-of-life care.

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### References

- Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, **10**(2), e47–e92. <https://doi.org/10.1016/j.jalz.2014.02.001>
- Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, **14**(3), 367–429. <https://doi.org/10.1016/j.jalz.2018.02.001>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, **8**(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Bauer, J. C. (2010). Nurse practitioners as an underutilized resource for health reform: Evidence-based demonstrations of cost-effectiveness. *Journal of American Academy of Nurse Practitioners*, **22**(4), 228–231. <https://doi.org/10.1111/j.1745-7599.2010.00498.x>
- Beernaert, K., Deliëns, L., Vleminck, A., Devroey, D., Pardon, K., Van Den Block, L., *et al.* (2014). Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients. *Palliative Medicine*, **28**(6), 480–490. <https://doi.org/10.1177/0269216314522318>
- Beernaert, K., Van den Block, L., Van Thienen, K., Devroey, D., Pardon, K., Deliëns, L., *et al.* (2015). Family physicians' role in palliative care throughout

- the care continuum: Stakeholder perspectives. *Family Practice*, **32**(6), 694–700. <https://doi.org/10.1093/fampra/cmz072>
- Brazil, K., Carter, G., Galway, K., Watson, M., & van der Steen, J. T. (2015). General practitioners' perceptions on advance care planning for patients living with dementia. *BMC Palliative Care*, **14**, 14. <https://doi.org/10.1186/s12904-015-0019-x>
- Brazil, K., Galway, K., Carter, G., & van der Steen, J. T. (2017). Providing optimal palliative care for persons living with dementia: A comparison of physician perceptions in the Netherlands and the United Kingdom. *Journal of Palliative Medicine*, **20**(5), 473–477. <https://doi.org/10.1089/jpm.2015.0274>
- Bynum, J. P. W., Rabins, P. V., Weller, W., Niefeld, M., Anderson, G. F., & Wu, A. W. (2004). The relationship between a dementia diagnosis, chronic illness, medicare expenditures, and hospital use. *Journal of the American Geriatrics Society*, **52**, 187–194. <https://doi.org/10.1111/j.1532-5415.2004.52054.x>
- Canadian Hospice Palliative Care Association. (2013a). A model to guide hospice palliative care. Retrieved 20 November, 2017 from [www.chpca.net/media/319547/norms-of-practice-engweb.pdf](http://www.chpca.net/media/319547/norms-of-practice-engweb.pdf).
- Canadian Hospice Palliative Care Association. (2013b). Innovative models of integrated hospice palliative care. Retrieved 20 November, 2017 from <http://hpcintegration.ca/media/40546/TWF-innovative-models-report-Eng-webfinal-2.pdf>.
- Canadian Hospice Palliative Care Association. (2015). The way forward national framework: A roadmap for an integrated palliative approach to care. Retrieved 20 November, 2017 from <http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf>.
- Canadian Nurses Association. (2016). Dementia in Canada: Recommendations to support care for Canada's aging population. Retrieved 10 October 2017 from [https://cna-aiic.ca/~media/cna/page-content/pdf-en/dementia-in-canada\\_recommendations-to-support-care-for-canadas-aging-population.pdf?la=en](https://cna-aiic.ca/~media/cna/page-content/pdf-en/dementia-in-canada_recommendations-to-support-care-for-canadas-aging-population.pdf?la=en).
- Carduff, E., Jarvis, A., Highet, G., Finucane, A., Kendall, M., Harrison, N., et al. (2016). Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: A feasibility study. *BMC Family Practice*, **17**, 18. <https://doi.org/10.1186/s12875-016-0414-2>
- Carter, G., Van der Steen, J. T., Galway, K., & Brazil, K. (2017). General practitioners' perceptions of the barrier and solutions to good quality palliative care in dementia. *Dementia (London)*, **16**(1), 79–85.
- Cheong, K., Fisher, P., Goh, J., Ng, L., Koh, H. M., & Yap, P. (2015). Advance care planning with early cognitive impairment. *BMJ Supportive and Palliative Care*, **5**, 63–69.
- Cintra, M. T., de Rezende, N. A., de Moraes, E. N., Cunha, L. C., & da Gama Torres, H. O. (2014). A comparison of survival, pneumonia, and hospitalization in patients with advanced dementia and dysphagia receiving either oral or enteral nutrition. *The Journal of Nutrition, Health & Aging*, **18**(10), 894–899. <https://doi.org/10.1007/s12603-014-0487-3>
- Clevenger, C. K., Cellar, J., Kovaleva, M., Medders, L., & Hepburn, K. (2018). Integrated memory care clinic: Design, implementation, and initial results. *Journal of the American Geriatrics Society*, **66**(12), 2401–2407. <https://doi.org/10.1111/jgs.15528>
- Cohn, J., J. Corrigan, J. Lynn, D. Meier, J. Miller, J. She-ga, et al. (2017). *Community-based models of care delivery for people with serious illness*. Discussion Paper, National Academy of Medicine, Washington, DC. Retrieved 8 March 2019 from <https://nam.edu/wp-content/uploads/2017/04/Community-Based-Models-of-Care-Delivery-for-People-with-Serious-Illness.pdf>.
- Colquhoun, H. L., Levac, D., O'Brien, K. K., Straus, S., Tricco, A. C., Perrier, L., et al. (2014). Scoping reviews: Time for clarity in definition, methods, and reporting. *Journal of Clinical Epidemiology*, **67**(12), 1291–1294. <https://doi.org/10.1016/j.jclinepi.2014.03.013>
- Daaleman, T. P., Ernecoff, N. C., Kistler, C. E., Reid, A., Reed, D., & Hanson, L. C. (2019). The impact of a community-based serious illness care program on healthcare utilization and patient care experience. *Journal of American Geriatric Society*, **67**, 825–830. <https://doi.org/10.1111/jgs.15814>
- Daudt, H.M., van Mossel, C. & Scott, S.J. (2013). Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology*, **13**(48). <https://doi.org/10.1186/1471-2288-13-48>
- Davies, N., Maio, L., van Riet Paap, J., Mariani, E., Jaspers, B., Sommerbakk, R., et al. (2014). Quality palliative care for cancer and dementia in five European countries: Some common challenges. *Aging & Mental Health*, **18**(4), 400–410. <https://doi.org/10.1080/13607863.2013.843157>
- De Witt Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., McIlfatrick, S. J., et al. (2017). 'There's a Catch-22' – The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians' perspectives. *Palliative Medicine*, **31**(8), 734–742. <https://doi.org/10.1177/0269216316673549>
- Dudgeon, S. (2010). Rising tide: The impact of dementia on Canadian Society. Retrieved 10 October 2017 from [https://alzheimer.ca/sites/default/files/files/national/advocacy/asc\\_rising\\_tide\\_full\\_report\\_e.pdf](https://alzheimer.ca/sites/default/files/files/national/advocacy/asc_rising_tide_full_report_e.pdf).
- Durepos, P., Wickson-Griffiths, A., Hazzan, A. A., Kaasalainen, S., Vastis, V., Battistella, L., et al. (2017). Assessing palliative care content in dementia care guidelines: A systematic review. *Journal of Pain and Symptom Management*, **53**(4), 804–813. <https://doi.org/10.1016/j.jpainsymman.2016.10.368>
- Elwyn, G., Coulter, A., Laitner, S., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *British Medical Journal*, **341**(c5146), 971–973.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., et al. (2012). Shared decision making: A model for clinical practice. *The Journal of General Internal Medicine*, **27**(10), 1361–1367. <https://doi.org/10.1007/s11606-012-2077-6>
- Evans, N., Pasman, H. R. W., Donker, G. A., Deliens, L., Van den Block, L., & Onwuteaka-Philipsen, B. (2014). End-of-life care in general practice: A cross-sectional, retrospective survey of 'cancer', 'organ failure' and 'old-age/dementia' patients. *Palliative Medicine*, **28**(7), 965–975. <https://doi.org/10.1177/0269216314526271>
- Fazel, S., Hope, T., & Jacoby, R. (2000). Effect of cognitive impairment and premorbid intelligence on treatment preferences for life-sustaining medical therapy. *The American Journal of Psychiatry*, **157**(6), 1009–1011. <https://doi.org/10.1176/appi.ajp.157.6.1009>
- Gamondi, C., Larkin, P., & Payne, S. (2013). Core competencies in palliative care: An EAPC white paper on palliative care education - Part 1. *European Journal of Palliative Care*, **20**(2), 86–91.
- Garand, L., Lingler, J. H., Deardorf, K. E., DeKosky, S. T., Schulz, R., Reynolds, C. F., 3rd, et al. (2012). Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. *Alzheimer Disease and Associated Disorders*, **26**(2), 159–165. <https://doi.org/10.1097/WAD.0b013e31822f9051>
- Gofton, T. E., Jog, M. S., & Schulz, V. (2009). A palliative approach to neurological care: a literature review. *Canadian Journal of Neurological Sciences*, **36**(3), 296–302. <https://doi.org/10.1017/s0317167100007010>
- Hegde, S., & Ellajosyula, R. (2016). Capacity issues and decision-making in dementia. *Annals of Indian Academy of Neurology*, **19**(5), 34–39. <https://doi.org/10.4103/0972-2327.192890>
- Hines, S., McCrow, J., Abbey, J., Foottit, J., Wilson, J., Franklin, S., et al. (2011). The effectiveness and appropriateness of a palliative approach to care for people with advanced dementia: A systematic review. *JBI Library of Systematic Reviews*, **9**(26), 960–1131.
- Hoerger, M., Greer, J. A., Jackson, V. A., Park, E. R., Pirl, W. F., El-Jawahri, A., et al. (2018). Defining the elements of early palliative care that are associated with patient-reported outcomes and the delivery of end-of-life care. *American Society of Clinical Oncology*, **36**(11), 1096–1102. <https://doi.org/10.1200/JCO.2017.75.6676>
- Holley, A. P. H., Gorawara-Bhat, R., Dale, W., Hemmerich, J., & Cox-Hayley, D. (2009). Palliative access through care at home: Experiences with an urban, geriatric home palliative care program. *Journal of the American Geriatrics Society*, **57**(10), 1925–1931. <https://doi.org/10.1111/j.1532-5415.2009.02452.x>
- Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., et al. (2018). Mixed methods appraisal tool (MMAT), version 2018 (Registration of Copyright (#1148552)). Retrieved 30 August 2018 from [http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/attach/127916259/MMAT\\_2018\\_criteria-manual\\_2018-08-01\\_ENG.pdf](http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/attach/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf).
- Hum, A. Y. M., Wu, H. Y., Ali, N. B., Leong, I. Y. O., Chin, J. J., Lee, A. O. K., et al. (2018). The dignity in advanced dementia (diadem) study: Developing an integrated geriatric palliative homecare program. *Progress in Palliative Care*, **26**(2), 65–72. <https://doi.org/10.1080/09699260.2018.1442286>



- Institute of Medicine Committee on the Future Health Care Workforce for Older Americans. (2008). *Retooling for an aging America: Building the health care workforce*. Washington, DC: National Academies Press (US).
- Joanna Briggs Institute. (2015). Joanna Briggs Institute reviewers' manual: 2015 edition/supplement. Joanna Briggs Institute. Retrieved 15 November 2017 from <https://nursing.isuhsc.edu/JBI/docs/ReviewersManuals/Scoping-pdf>.
- Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs*, *34*(10), 1642–1649. <https://doi.org/10.1377/hlthaff.2015.0536>
- Kristjanson, L. J., Toye, C., & Dawson, S. (2003). New dimensions in palliative care: A palliative approach to neurodegenerative diseases and final illness in older people. *Medical Journal of Australia*, *179*(Suppl. 4), S41–S43.
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*(1), 69. <https://doi.org/10.1186/1748-5908-5-69>
- Liu, L. M., Guarino, A. J., & Lopez, R. P. (2012). Family satisfaction with care provided by nurse practitioners to nursing home residents with dementia at the end of life. *Clinical Nursing Research*, *21*(3), 350–367. <https://doi.org/10.1177/1054773811431883>
- London, M. R., McSkimming, S., Drew, N., Quinn, C., & Carney, B. (2005). Evaluation of a comprehensive, adaptable, life-affirming, longitudinal (CALL) palliative care project. *Journal of Palliative Medicine*, *8*(6), 1214–1225. <https://doi.org/10.1089/jpm.2005.8.1214>
- Maciver, J., & Ross, H. J. (2018). A palliative approach for heart failure end-of-life care. *Current Opinion in Cardiology*, *33*(2), 202–207. <https://doi.org/10.1097/HCO.0000000000000484>
- McGilton, K. S., Vellani, S., Yeung, L., Chishtie, J., Comisso, E., Ploeg, J., et al. (2018). Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: A scoping review. *BMC Geriatrics*, *18*(1), 231. <https://doi.org/10.1186/s12877-018-0925-x>
- Mohanti, B. K. (2011). Research focus in palliative care. *Indian Journal of Palliative Care*, *17*(Suppl.), S8–S11. <https://doi.org/10.4103/0973-1075.76231>
- Mondor, L., Maxwell, C. J., Hogan, D. B., Bronskill, S. E., Gruneir, A., Lane, N. E., et al. (2017). Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: A retrospective analysis of a population-based cohort. *PLoS Medicine*, *14*(3), e1002249. <https://doi.org/10.1371/journal.pmed.1002249>
- Nakanishi, M., Hirooka, K., Morimoto, Y., & Nishida, A. (2017). Quality of care for people with dementia and professional caregivers' perspectives regarding palliative care in Japanese community care settings. *International Journal of Geriatric Psychiatry*, *32*(12), 1342–1351. <https://doi.org/10.1002/gps.4620>
- Pluye, P., & Hong, Q. N. (2014). Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. *Annual Review of Public Health*, *35*, 29–45. <https://doi.org/10.1146/annurev-pubhealth-032013-182440>
- Popay, J., Roberts, H., Sowden, A. J., Petticrew, M., Arai, L., Rodgers, M., et al. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme. Version 1*. Lancaster, UK: University of Lancaster.
- Reimer-Kirkham, S., Sawatzky, R., Roberts, D., Cochrane, M., & Stajduhar, K. (2016). 'Close to' a palliative approach: Nurses' and care aides' descriptions of caring for people with advancing chronic life-limiting conditions. *Journal of Clinical Nursing*, *25*(15–16), 2189–2199. <https://doi.org/10.1111/jocn.13256>
- Rewegan, A., Danho, S., White, J., Winemaker, S., Hansen, N., MacLennan, A., et al. (2019). How do physicians and nurses in family practice describe their care for patients with progressive life-limiting illness? A qualitative study of a palliative approach. *Primary Health Care Research & Development*, *20*, e95. <https://doi.org/10.1017/S1463423619000252>
- Reyes-Ortiz, C. A. (2015). Psychological and spiritual supports in coronary disease. *Journal of the American Geriatrics Society*, *45*(11), 1412–1412. <https://doi.org/10.1111/j.1532-5415.1997.tb02950.x>
- Ryan, T., Gardiner, C., Bellamy, G., Gott, M., & Ingleton, C. (2012). Barriers and facilitators to the receipt of palliative care for people with dementia: The views of medical and nursing staff. *Palliative Medicine*, *26*(7), 879–886.
- Sampson, E. L., Ritchie, C. W., Lai, R., Raven, P. W., & Blanchard, M. R. (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*, *17*(1), 31–40.
- Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., et al. (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliative Care*, *15*, 5.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., et al. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, *349*(20), 1936–1942.
- Seow, H., O'Leary, E., Perez, R., & Tanuseputro, P. (2018). Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents. *BMJ Open*, *8*(4), e021147. <http://doi.org/10.1136/bmjopen-2017-021147>
- Shadd, J. D., Burge, F., Stajduhar, K. I., Cohen, S. R., Kelley, M. L., & Pesut, B. (2013). Defining and measuring a palliative approach in primary care. *Canadian Family Physician Medecin de Famille Canadien*, *59*(11), 1149–1150.
- Smith, L., & Ferguson, R. (2017). Artificial nutrition and hydration in people with late-stage dementia. *Home Healthcare Now*, *35*(6), 321–325. <https://doi.org/10.1097/nhh.0000000000000550>
- Sternberg, S. A., Sabar, R., Katz, G., Segal, R., Fux-Zach, L., Grofman, V., et al. (2019). Home hospice for older people with advanced dementia: A pilot project. *Israel Journal of Health Policy Research*, *8*(1), 42. <https://doi.org/10.1186/s13584-019-0304-x>
- Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., et al. (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management*, *53*(5), 821–832.e821. <https://doi.org/10.1016/j.jpainsymman.2016.12.331>
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine*, *363*, 733–742. <https://doi.org/10.1056/NEJMoa1000678>
- Toivonen, K., Charalambous, A., & Suhonen, R. (2017). Supporting spirituality in the care of older people living with dementia: A hermeneutic phenomenological inquiry into nurses' experiences. *Scandinavian Journal of Caring Sciences*, *32*(2), 880–888. <https://doi.org/10.1111/scs.12519>
- Touzel, M., & Shadd, J. (2018). Content validity of a conceptual model of a palliative approach. *Journal of Palliative Medicine*, *21*(11), 1627–1635. <https://doi.org/10.1089/jpm.2017.0658>
- Treloar, A., Crugel, M., & Adamis, D. (2009). Palliative and end of life care of dementia at home is feasible and rewarding: Results from the 'Hope for Home' study. *Dementia*, *8*(3), 335–347.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., et al. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, *169*(7), 467–473. <https://doi.org/10.7326/M18-0850>
- van der Steen, J. T., Galway, K., Carter, G., & Brazil, K. (2016). Initiating advance care planning on end-of-life issues in dementia: Ambiguity among UK and Dutch physicians. *Archives of Gerontology and Geriatrics*, *65*, 225–230.
- van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., et al. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, *28*(3), 197–209. <https://doi.org/10.1177/0269216313493685>
- Vlemminck, A. D., Pardon, K., Beernaert, K., Deschepper, R., Houttequier, D., Audenhove, C. V., et al. (2014). Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on general practitioners' views and experiences. *PLoS One*, *9*(1), e84905. <https://doi.org/10.1371/journal.pone.0084905>
- Volicer, L., Hurley, A. C., & Blasi, Z. V. (2001). Scales for evaluation of end-of-life care in dementia. *Alzheimer Disease & Associated Disorders*, *15*(4), 194–200.
- Warshaw, G. A., & Bragg, E. J. (2014). Preparing the health care workforce to care for adults with Alzheimer's disease and related dementias. *Health Affairs*, *33*, 633–641.
- Wertman, E., Brodsky, J., King, Y., Bentur, N., & Chekhir, S. (2007). An estimate of the prevalence of dementia among community-dwelling elderly in Israel. *Dementia and Geriatric Cognitive Disorders*, *24*(4), 294–299. <https://doi.org/10.1159/000107593>
- World Health Organization. (2020). Palliative care: Key facts. Retrieved 30 May 2020 from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.