

# Advance Care Planning for Seniors Diagnosed with Dementia: A Scoping Review of the Canadian Literature

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## Article

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## Résumé

La planification préalable des soins (PPS) est couramment recommandée aux personnes atteintes de démence. Le vieillissement et la progression incertaine de la maladie rendent cependant ce processus complexe. Un examen de la portée a été réalisé à partir de publications canadiennes en vue d'évaluer la faisabilité et l'acceptabilité de la PPS pour les personnes âgées (65 ans et plus) ayant reçu un diagnostic de démence, ainsi que pour formuler des recommandations liées à la pratique, à la politique et à la recherche sur la PPS, en tant que processus-clé dans un contexte de soins. Vingt-neuf publications ont été regroupées en cinq thèmes : 1) la faisabilité de la participation des patients à la PPS, 2) les opinions concernant l'aide médicale à mourir pour les patients inaptes, 3) l'application des connaissances pour soutenir les patients atteints de démence, les professionnels et les aidants, 4) les obstacles et les facilitateurs de la prestation de soins holistiques pour la démence, et 5) les considérations relatives à la santé des personnes Indigènes. Les recherches futures devront tenir compte de facteurs sociodémographiques et socioculturels associés à l'engagement des personnes âgées atteintes de démence dans la PPS. Une approche multidisciplinaire est requise lors de l'examen des aspects juridiques et des politiques qui seront élaborées. Enfin, l'application des connaissances en matière de PPS devrait être intégrée en tant que complément de routine dans les soins liés à la démence.

## Abstract

Advance care planning (ACP) is commonly recommended for persons living with dementia. Increasing age and uncertain disease trajectory add complexity to this process. A scoping review of the Canadian literature was completed to assess the feasibility and acceptability of ACP for seniors (≥ 65 years of age) diagnosed with dementia and to provide practice, policy, and research recommendations towards ACP as a critical aspect of care. Twenty-nine articles were grouped into five themes: (1) feasibility of patient engagement in ACP; (2) opinions regarding medical assistance in dying (MAiD) for incompetent patients; (3) knowledge translation to support persons living with dementia, professionals, and caregivers; (4) barriers to and facilitators of the delivery of holistic dementia care; and (5) Indigenous health considerations. Additional research should consider socio-demographic and social/cultural factors associated with older persons living with dementia's engagement in ACP. Future policies warrant a multidisciplinary approach when reviewing legalities. Finally, ACP knowledge translation should become a routine aspect of dementia care.

## Background

Dementia currently affects around 50 million people worldwide, and there are approximately 10 million new cases of dementia annually (World Health Organization, 2020). “Dementia” is an umbrella term encompassing any disorder which causes significant cognitive decline, leading to impairments in previous levels of functioning, including memory loss and the inability to perform daily tasks (Gale, Acar, & Daffner, 2018). In Canada, dementia affects an estimated 7.1 per cent of the senior population across the country (Government of Canada, 2017). Importantly, this statistic is accompanied by an increase in the prevalence of the disease, which doubles every 5 years among seniors (Government of Canada, 2017). This increase is attributable to an aging population, and therefore a growing senior population in Canada may present with a greater number of older adults impacted by dementia (Canadian

Institute for Health Information, n.d.). Given the growing burden of disease, the topic of dementia as it pertains to the well-being and quality of life (and death) of Canadian seniors becomes all the more pertinent. As there is currently no cure for the disease, and an often rapid mental, physical, and social decline leaves limited time for planning, it is important to understand the wishes of older adults while they are cognitively able to participate in those conversations.

### *Advance Care Planning (ACP)*

ACP is a proactive step that can be taken to prepare for the health complications which may accompany aging, and especially dementia. ACP is a process that allows a patient to have discussions with their health care provider (HCP) and/or family/friends regarding presumptive future health care plans in the face of potential diagnoses, cognitive decline, or health circumstances (deLima Thomas *et al.*, 2018). ACP is an interactive process, aimed at ensuring that decisions made in the future are in line with a patient's prerogatives, should the patient find themselves in a state in which they are unable to express their wishes, as is the case with dementia (Speak Up Canada, 2020).

Recent literature has investigated the various clinical barriers that exist and can impede completion of ACP. A systematic review conducted in 2019 found that the most common barriers to ACP were insufficient education and time to discuss or complete ACP processes (Blackwood, Walker, Mythen, Taylor, & Vindrola-Padros, 2019). Logistical factors, such as busy clinics, can present challenges to having thorough discussions about ACP and its elements. Successful completion of ACP also necessitates extensive training of HCPs, such that they can effectively hold relevant conversations and implement these plans (Blackwood *et al.*, 2019). In a 2015 study, HCPs expressed that forming a strong rapport with patients and their families offered them more opportunities to have productive conversations in a timely manner as well as to understand the nature of the decisions being made (Brazil, Carter, Galway, Watson, & van der Steen, 2015). Furthermore, the ACP process and the implementation of plans required support from a myriad of parties, both at the patient and system levels (Blackwood *et al.*, 2019). Patient-level aspects of ACP were particularly notable. During ACP, a patient would express their concerns, values, and goals for the care which they desire to be upheld in the future (Porteri, 2018). Uncertainty regarding the trajectory of the illness, potentially ensuring that a suitable surrogate was chosen, and making decisions that were aligned with the cultural beliefs of the patient, were all dilemmas that could arise in the context of ACP, particularly for cognitively impaired patients (deLima Thomas *et al.*, 2018).

ACP is commonly recommended for persons living with dementia, yet increasing age and an uncertain disease trajectory contribute a layer of complexity to this process. It is widely recognized that the neurological decline associated with the disease, coupled with precarious disease trajectories, poses a threat to the autonomy of the patient (Barbas & Wilde, 2001). A systematic review investigating ACP for people with dementia found that an early start to the process was imperative, in that it permitted the person living with dementia to be involved in decision making (Tilburgs *et al.*, 2018a). To this end, the review found that uncertainty regarding disease prognosis was the most common barrier that cognitively impaired patients experienced in trying to access ACP. To ameliorate this challenge, the authors suggested that HCPs follow up with patients and their families while providing

comprehensive knowledge about the situation and advocating for a timely start to the overall ACP process.

### *Patient Involvement*

The practice of having persons living with dementia participate in ACP has been gaining traction in the literature. A 2019 study conducted in the United States found that meaningful ACP tools and interventions could enable persons with dementia to articulate their end-of-life preferences coherently (Song *et al.*, 2019). Another study assessed the factors which impacted ACP and end-of-life decision-making preferences among persons living with dementia and their caregivers, as well as how race might affect these variables (Pettigrew *et al.*, 2020). Despite respondents being knowledgeable regarding dementia and hospice care – as well as demonstrating high engagement in ACP – there were racial differences. Black persons living with dementia had lower ACP completion and demonstrated less dementia knowledge than their White counterparts. Furthermore, a Belgian literature review sought to develop evidence-based clinical recommendations for the practical application of ACP in dementia care by professionals in varied settings (Piers *et al.*, 2018). Whereas it was found that no high-quality guidelines for ACP in dementia care were presently available, emphasis was placed on adequately educating HCPs to initiate and effectively perform all aspects of ACP. Similarly, cognizant of the practical limitations of form-based ACP procedures, other authors have explored alternative means of documenting care preferences and engaging stakeholders in ACP (Chan, 2020; Mollooy *et al.*, 2000). Changes from written to multimedia formats (such as video or audio recording) were not without their legal challenges, however (Chan, 2020).

Despite the availability of international studies on ACP for persons living with dementia, there is a paucity of Canadian literature investigating this topic. The current Canadian literature on ACP only offers a cursory overview of the basic attitudes and understandings that Canadians hold about ACP. An online opinion poll administered to elicit perspectives from the public concluded that Canadians had ACP discussions with family members rather than with HCPs; however, only a few respondents completed formal ACP documentation, opting instead for a substitute decision maker (Teixeira *et al.*, 2015). Likewise, a study by Howard *et al.* (2018) yielded similar results, revealing that many Canadians participated in certain ACP activities, yet few had ACP discussions with their family physicians. Despite these findings on ACP engagement, Heyland *et al.* (2015) observed that many individuals' values included being comfortable, minimizing suffering, spending time with family, not being connected to machines, and not prolonging death. Given the increasing prevalence of dementia and the importance of person-centred health care, a review of the Canadian literature is necessary to understand ACP for seniors ( $\geq 65$  years of age) living with dementia in a Canadian context, as well as to identify and fill the gaps in existing knowledge.

### *Objectives*

The primary objectives of this scoping review were to assess the feasibility and acceptability of ACP for Canadian seniors ( $\geq 65$  years of age) diagnosed with dementia. The secondary objectives were to offer recommendations for practice, policy, and research, such that ACP may become more widely recognized as an important aspect of accessible and equitable high-quality (hospice

palliative) care for persons living with dementia. Finally, we sought to determine knowledge gaps in order to formulate recommendations for improvement alongside future areas of investigation.

## Methods

To answer the question “*What is the feasibility and acceptability of advance care planning for older adults (≥65 years of age) diagnosed with dementia in Canada?*”, a scoping review of the Canadian literature was conducted following Arksey and O’Malley’s (2005) five-step framework. A scoping review was chosen given that this study design enables researchers to describe available literature in a field by mapping key concepts. In so doing, scoping reviews can identify research gaps in the current literature as well as summarize and disseminate information for diverse audiences, including professionals, policy makers, and lay persons. This methodology consists of five key procedures: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, synthesizing, and presenting the results (Arksey & O’Malley, 2005).

## Initial Review

We reviewed electronic databases in the health and social sciences. AgeLine, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, MEDLINE<sup>®</sup>, Proquest, PsycInfo, and Sociological Abstracts online databases were searched systematically, and Google (Scholar) was hand searched for relevant (grey) literature articles. Seniors and older adults were defined as individuals 65 years of age and older. The search strategy was developed in collaboration with a librarian from the University of Toronto. Search terms were related to “Canadians”, “older adults”, “advance care planning”, and “dementia” as listed in Table 1. Articles generated from database and hand searching were de-duplicated and initially reviewed by title and abstract by independent reviewers (B.K.A., A.K., M.K., S.M.). Articles were deemed suitable for full-text review if they: (1) examined ACP or components of ACP for older adults living with dementia or a similar cognitive impairment, (2) reported on a Canadian study population or context, (3) were published in English between the time period of 1 January 2000 and 31 December 2019, and (4) were available electronically in full text, without cost, through the University of Toronto Library System.

## Results

Database and hand searching yielded 6,645 studies, of which 29 were deemed acceptable for synthesis following the two-step review process described (Figure 1). Of these, 25 (86%) were original research articles. The remaining four articles (14%)

consisted of two case studies and two policy-related articles. Two pieces of grey literature were included overall (7%). A summary of study characteristics and findings can be found in Table 2. Articles were grouped according to the following five key themes, based on a thematic content analysis (Anderson, 2007):

1. Feasibility of patient engagement in ACP
2. Opinions regarding medical assistance in dying (MAiD) for incompetent patients
3. Knowledge translation (KT) to support persons living with dementia, professionals, and caregivers
4. Barriers to and facilitators of the delivery of holistic dementia care
5. Indigenous health considerations.

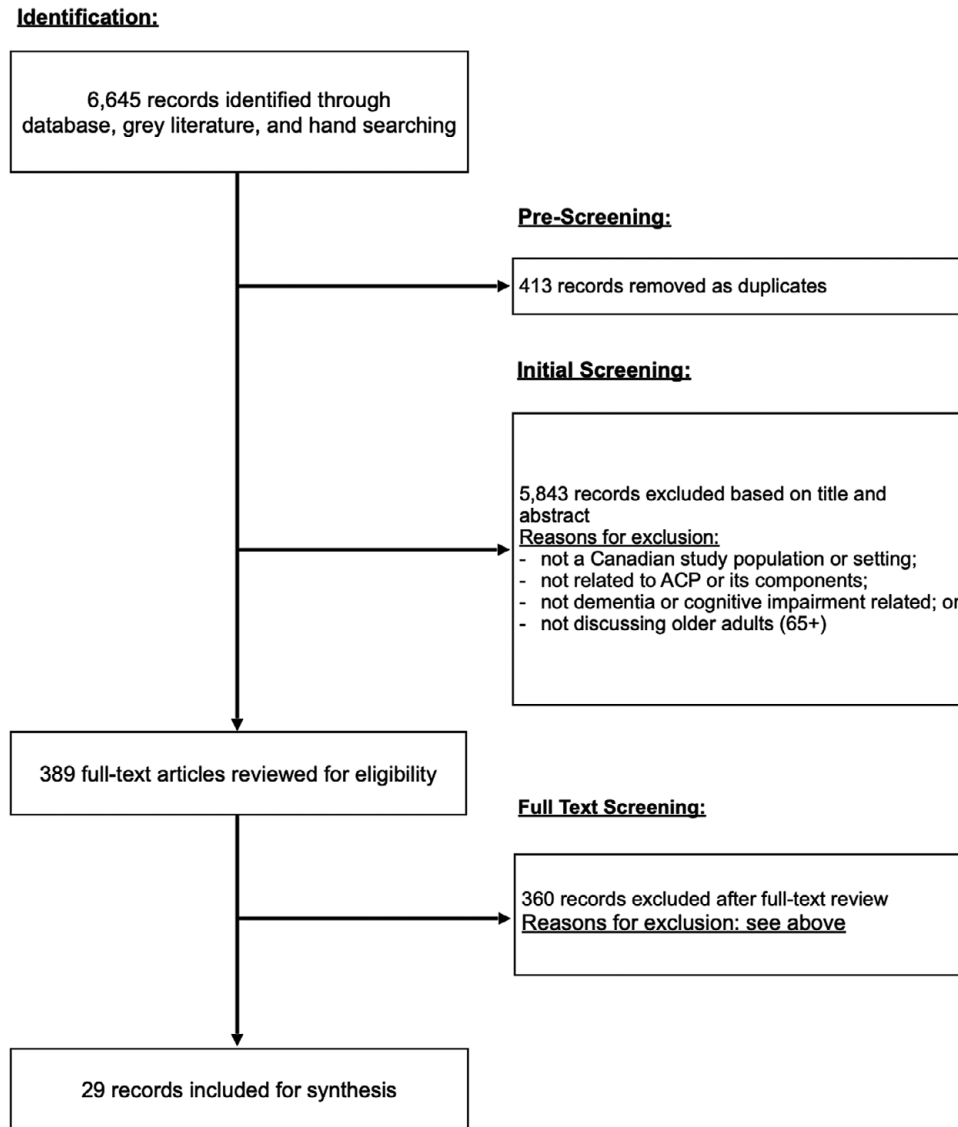
## Feasibility of Patient Engagement in ACP

A total of 12 of the 29 sources (41%) discussed the extent to which Canadian seniors and their caregivers engaged in ACP in the event of decisional incapacity (Bravo, Dubois, & Pâquet, 2003; Bravo et al., 2011; Bravo, Sene, & Arcand, 2017; Brink, Smith, & Kitson, 2008; Cramer, Tuokko, & Evans, 2001; Dyason Simon, & Martin, 2015; Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008; Goodridge, 2010; Huggins et al., 2019; Jeznach, Tuokko, Garcia-Barrera, & Stajduhar, 2015; Nuhn et al., 2018; Tanuseputro et al., 2019). Four studies examined the extent to which older adults considered or had already engaged in ACP (Bravo et al., 2003, 2011; Cramer et al., 2001; Garrett et al., 2008). Two studies by Bravo et al. (2003, 2011) examined the degree to which Canadians communicated their health care preferences should they become incapacitated. A majority of subjects had completed informal plans, such as sharing their preferences orally, as compared with formalized written documents (Bravo et al., 2003, 2011). Factors associated with ACP completion included cognitive impairment, higher age, knowing someone with a cognitive impairment, and being a woman. In one of these studies, married individuals who perceived their health as excellent had less often completed directives for health (Bravo et al., 2003).

Similarly, two studies explored the extent to which people thought about or formalized preferences for end-of-life care or substitute decision makers (Cramer et al., 2001; Garrett et al., 2008). A study from Vancouver, British Columbia investigated which types of end-of-life planning seniors were completing and whether a hierarchy existed, the types of surrogate decision makers selected by married versus unmarried seniors, and how seniors discussed health preferences with others (Cramer et al., 2001). Wills and powers of attorney for finances were most common; furthermore, cognitive disabilities and age were positively associated with the completion of powers of attorney for health. Higher education was the only statistically significant predictor for completion of the aforementioned documents. Moreover, daughters were generally preferred as surrogates – as compared to spouses and sons – by married and unmarried individuals living alone and with other family members. Another study found that, although many individuals thought about substitute decision makers and expressed their health preferences, few had completed formal ACP documents (Garrett et al., 2008). Notably, females were 1.46 times more likely to have considered a possible surrogate than were males; higher education and Ontario residence status were predictors of such behaviour. Unmarried participants were more likely to have a formal advance directive in place than married or

**Table 1.** Search terms

	Search Terms
1	Canad*
2	senior* OR older adult* OR elderly OR geriatric OR aged OR aging OR ageing
3	dementia OR Alzheimer’s OR cognit* OR impair* OR memory loss
4	advance care planning OR acp OR advance directive OR advance-care planning OR end of life OR end of life care OR end of life plan



**Figure 1.** Flow diagram of study results

common-law participants. Thinking about end-of-life preferences was predictive of sharing them with others; likewise, thinking about and discussing preferences were associated with formalizing them.

Multiple studies looked at ACP participation by cognitively impaired seniors (Brink *et al.*, 2008; Dyason *et al.*, 2015; Goodridge, 2010; Jeznach *et al.*, 2015). In their study, inclusive of participants from across Canada, Jeznach *et al.* (2015) found that older adults with cognitive impairments were more likely to have assigned a substitute decision maker and to have formalized legal documents for health care preferences or naming a decision maker. This group was also less likely to have discussed end-of-life care preferences. Patients who did not participate in ACP were less likely to die in a nursing home than in private residences, and there was no significant relationship between engaging in ACP and dying in a medical facility. Ultimately, it was noted that cognitively impaired persons experienced ACP differently than non-impaired persons. Similarly, a study of Western Canada's acute care hospitals reviewed the charts of deceased patients and noted patterns pertaining to documents, end-of-life orders, and cognitive status (Goodridge, 2010). Do not resuscitate (DNR) orders, compassionate terminal care,

cardiopulmonary resuscitation (CPR), end-of-life care, comfort measures, and no codes (i.e., do not initiate CPR protocol) were most frequently cited in patients' charts. The presence of an end-of-life order was positively associated with dementia and cancer diagnosis (Brink *et al.*, 2008; Goodridge, 2010). Moreover, patients accepting of their circumstances were 5.67 times more likely to have a formalized DNR, and persons with higher cognitive and functional impairments were more likely to have a recorded DNR than were unimpaired persons (Brink *et al.*, 2008). Similar results were also found in the context of Alberta long-term care (LTC) and assisted living facilities (Dyason *et al.*, 2015). The prevalence of cognitive impairments in LTC and assisted living facilities were 78 and 48 per cent, respectively, and a total of 272 ACP discussions were documented in the 166 charts reviewed and found to have documented ACP discussions. Residents were listed as being present in discussions about their preferences 47 per cent of the time, whereas 62 per cent of discussions had a family member in attendance. Only 20 per cent of cognitively impaired residents were documented as being present in such conversations; family members' attendance was more common. Nurses were most commonly

**Table 2.** Study characteristics

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France, and Japan (Arcand et al., 2013).	Québec and Ontario	Y	N	Observational cross-sectional survey design.	Evaluate nurses opinions regarding the acceptability of a booklet comprised of information on the course of dementia and palliative care options for families of people with late-stage dementia. Booklet content organized around core concepts: “the course of dementia, expected complications, the decision-making process, symptom management, dying, and grief.”	Surveys consisting of Likert scales, as well as ranking and open-ended questions.	Canadian (from long-term care facilities in Québec and Ontario), French and Japanese nurses. Total cohort size of 188.	<ul style="list-style-type: none"> <li>• A majority of nurses rated the booklet as useful for families of patients with advanced dementia.</li> <li>• 32% of Canadian nurses believed that spiritual orientation strongly included how they perceived the booklet.</li> <li>• A majority of nurses had educational needs pertaining to the comfort care approach in persons living with dementia end-of-life care.</li> <li>• A strong majority of Canadian nurses felt that content pertaining to ‘sensitive issues’ (i.e., life-prolonging care, etc.) was balanced.</li> <li>• Nurses who stated they were likely to provide the booklet to families in the near future (three months) noted events proximal to dementia such as diagnosis, hospital admission, and goals of care, and comfort care discussions as occasions to use the booklet.</li> </ul>	Knowledge translation to support persons living with dementia, professionals, and caregivers.
Development and implementation of dementia-related integrated knowledge translation strategies in rural home care (Bayly, Blake, Peacock, Morgan, & Forbes, 2018).	Alberta (rural)	Y	N	Longitudinal multiple case study (semi-structured interviews).	Evaluate the implementation of a knowledge broker on the development and implementation of knowledge translation (KT) strategies for dementia care in rural home care settings.	<ul style="list-style-type: none"> <li>• Semi-structured interviews.</li> <li>• Thematic content analysis.</li> </ul>	Persons living with dementia, family caregivers, and home care professionals (nurses, healthcare aides, managers, and other providers).	<ul style="list-style-type: none"> <li>• Themes included: facilitators and barriers of integrated knowledge translation (KT), the role of the knowledge broker, the perceived impact of the integrated KT strategies.</li> <li>• Barriers such as lack of time, limited resources, and the nature of the dementia trajectory were identified.</li> <li>• The knowledge broker was considered a valuable knowledge translation resource, and integrated KT strategies were identified in promoting community-specific solutions, improved professional knowledge and the abilities to make use of best practice information (in the context of dementia) and the capacity to act as knowledge brokers for families and clients (e.g., encourage further</li> </ul>	Knowledge translation to support persons living with dementia, professionals, and caregivers.

(Continued)

Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<p>discussions between staff, persons living with dementia, and their families).</p> <ul style="list-style-type: none"> <li>The knowledge broker role is especially valuable in rural settings, wherein staff may have less capacity to offer specialized KT services for persons with dementia.</li> <li>The knowledge broker is a way of ensuring that rural providers have the capability and confidence to deliver high quality care and supports to people with dementia, as well as their caregivers.</li> </ul>	
Improving Advance Medical Directives: Lessons from Québec (Bernier & Régis, 2019).	Québec	N	Y	Policy briefing/report.	Discuss the merits and limitations of a legally-binding standardized form for advance medical directives in Québec, which was implemented in 2015.	Comparative policy analysis.	N/A	<ul style="list-style-type: none"> <li>Québec's current advance medical directives (AMD) procedures have numerous limitations: 1) responsibility to be informed about the AMD procedures rests solely on the person completing the AMD, 2) a form-focused process is a barrier to making revisions and amendments, and 3) the current AMD process in Québec is based on individual autonomy, which fails to acknowledge the broader social context in which individuals make choices.</li> <li>Suggestions for improvement of AMD include: 1) adopting the strengths of other provincial AMD policies, such as foci on relational autonomy, and 2) offering resources for decision-making (e.g., bioethics mediation) or multi-modal knowledge translation and communication tools.</li> </ul>	Barriers and facilitators to the delivery of holistic dementia care.
Are Canadians providing advance directives about health care and research participation in the event of decisional incapacity? (Bravo et al., 2011).	Nova Scotia, Ontario, Alberta, and British Columbia.	Y	N	Observational cross-sectional survey design.	Estimate how frequently Canadians are communicating their health care and research wishes should they become incapacitated.	Surveys	Informal caregivers to cognitively impaired individuals, physicians, researchers working in aging, research ethics board	<ul style="list-style-type: none"> <li>69.1% of participants had expressed their wishes orally while 46.7% had expressed their wishes in written form.</li> <li>Of the respondents in these two groups, 91.2% had identified a substitute decision-maker.</li> </ul>	Feasibility of patient engagement in ACP.

(Continued)

Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
							members, and community-dwelling adults aged 65 years or more.	<ul style="list-style-type: none"> <li>80.9% and 19.5% had expressed their preferences for health care and research participation, respectively.</li> <li>Receiving advice to communicate their wishes was strongly predictive of having completed such processes.</li> <li>ACP was more frequently reported by informal caregivers to cognitively impaired individuals, suggestive, but not definitive, of higher prevalence of advance care planning amongst cognitively impaired individuals.</li> </ul>	
Advance directives for health care and research: prevalence and correlates (Bravo, Dubois, & Pâquet, 2003).	Québec	Y	N	Observational cross-sectional survey design.	“Estimate the prevalence of formal and informal advance directives (AD) for health care and research,” and characterize individuals who have communicated their preferences in these areas.	Surveys	Community-dwelling older adults, aged 65 years or greater.	<ul style="list-style-type: none"> <li>63.1% and 55.4% of respondents had completed informal and formal ADs, respectively.</li> <li>Financial and health care aspects were most commonly addressed, as compared to participation in research.</li> <li>Correlates of ADs for health included higher age, knowing someone with a cognitive impairment, and being a woman.</li> <li>Individuals who were married and perceived their health to be excellent were less likely to have completed directives for health.</li> </ul>	Feasibility of patient engagement in ACP.
Comparing the attitudes of four groups of stakeholders from Québec, Canada, toward extending medical aid in dying to incompetent patients with dementia (Bravo et al., 2019).	Québec	Y	N	Observational cross-sectional study.	Compare attitudes towards extending Medical Assistance in Dying (MAiD) to incompetent patients. In particular, older adults’ attitudes towards MAiD for incompetent patients.	Surveys	Older adults aged 65 years or older.	<ul style="list-style-type: none"> <li>317 individuals completed the survey, thereby achieving a response rate of 54%.</li> <li>In consideration of a diagnosis of dementia, 76% expressed being somewhat or extremely likely to write a request for MAiD and 74% expressed being just as likely to ask a physician to grant the MAiD request of a close relative diagnosed with the same disease.</li> <li>Physical pain that cannot be relieved was the most common trigger for such attitudes, while admission to a long-term care facility was the least common.</li> </ul>	Opinions regarding MAiD for incompetent patients.

(Continued)

Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
Québec physicians' perspectives on medical aid in dying for incompetent patients with dementia (Bravo et al., 2018a).	Québec	Y	N	Observational cross-sectional study.	Obtain physicians' attitudes towards MAiD for incompetent patients. Furthermore, to compare family physicians' attitudes with other medical specialists'.	Surveys	Physicians in family medicine, geriatrics, internal medicine, neurology, psychiatry, and intensive care.	<ul style="list-style-type: none"> <li>• Acceptance of MAiD, with or without an existing written request, was higher at the terminal stage of dementia than the advanced.</li> <li>• 44.2% of respondents had recorded their personal health care preferences should they become incapacitated.</li> </ul>	Opinions regarding MAiD for incompetent patients.
								<ul style="list-style-type: none"> <li>• 136 physicians completed the survey, thus achieving a response rate of 25.5%. There was variability in attitudes towards MAiD for incompetent patients, based on medical specialty.</li> <li>• In the context of dementia at an advanced stage, 45% and 14% of physicians were in support of providing MAiD to the patient with and without a written request, respectively.</li> <li>• In the context of dementia at the terminal stage, these percentages reached 71% and 43%, respectively; 79% and 52%, respectively for family physicians.</li> <li>• 18.5% and 60.3% of respondents agreed that "human life must be preserved in all circumstances," and that "every person has the right to choose how they will die," respectively.</li> <li>• 35.3% of respondents agreed and 18.4% were neutral that "the fear of living the advanced stages of Alzheimer's disease or related disorders should be considered as unbearable suffering for those at the early stage."</li> <li>• 65.9% of respondents disagreed that "the administration of a strong medication that would end life in a few minutes [...] should be prohibited because vulnerable individuals could receive it against their will."</li> </ul>	

(Continued)



Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
Nurses' perspectives on whether medical aid in dying should be accessible to incompetent patients with dementia: findings from a survey conducted in Québec, Canada (Bravo et al., 2018b).	Québec	Y	N	Observational cross-sectional study.	Assess the attitudes of nurses towards offering MAiD to incompetent patients, identify underlying reasons for their attitudes towards this issue, and evaluate the value attached to suggested safeguards. The secondary objective was to characterize nurses that are supportive of offering MAiD to incompetent patients under different circumstances.	Surveys	Registered nurses caring for patients with Alzheimer's disease or 'a related disorder' who work in geriatrics, gerontology, end-of-life care, or in the public health care network.	<ul style="list-style-type: none"> <li>Family physicians generally deemed MAiD more acceptable than other medical specialists.</li> <li>291 nurses completed the survey to achieve a response rate of 59%.</li> <li>19/22 nurses who did not wish to participate in the study expressed that the current legislation on MAiD is somewhat or totally acceptable.</li> <li>83% of respondents were in favour of offering MAiD to incompetent patients who are at the terminal stage of Alzheimer's disease, showing signs of distress and had made the request prior to losing capacity.</li> <li>A majority of nurses agreed with the notion of self-determination and attached high value to ADs.</li> <li>There was a significant difference in support for MAiD, based on the Alzheimer's patient not seeming uncomfortable versus being at the terminal stage of their disease and in distress.</li> <li>Three independent correlates of respondents' attitudes were identified through multiple logistic regression: "having accompanied a dying relative or friend through the dying process, being somewhat or totally likely to make a MAiD request should they be diagnosed with Alzheimer's disease, and being somewhat or totally likely to ask a physician to carry out the advance request made while incompetent by a now-incompetent relative diagnosed with Alzheimer's disease."</li> </ul>	Opinions regarding MAiD for incompetent patients.
Are Informal Caregivers of Persons With Dementia Open to Extending Medical Aid in Dying to Incompetent Patients? Findings from	Québec	Y	N	Observational cross-sectional study.	Investigate informal caregivers' attitudes towards MAiD for incompetent patients.	Surveys	Informal caregivers to Alzheimer's patients.	<ul style="list-style-type: none"> <li>306 individuals completed the survey, thereby achieving a response rate of 69%.</li> <li>A majority of respondents were the adult child or spouse of the person living with dementia.</li> </ul>	Opinions regarding MAiD for incompetent patients.

(Continued)

Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
a Survey Conducted in Québec, Canada (Bravo et al., 2018c).								<ul style="list-style-type: none"> <li>• 77.5% felt they would write an advance request for MAiD if diagnosed with Alzheimer's disease themselves.</li> <li>• Conditions under which they would want their request for MAiD to be accommodated were physical and psychological suffering that cannot be relieved, and complete dependence on others for basic needs.</li> <li>• Self-determination was the most common argument in support of rendering MAiD accessible to incompetent patients.</li> <li>• Religiosity was identified as a correlate, negatively associated with caregivers' positive attitudes towards MAiD for competent and incompetent patients.</li> <li>• 82% of respondents expressed that all persons have the right to choose how they will die and that preferences voiced ahead of losing capacity should be given equal merit as preferences expressed by a competent patient.</li> <li>• These same respondents were supportive of extending MAiD to incompetent persons living with dementia at the advanced and terminal stages of their disease, in the presence or absence of advance requests.</li> </ul>	
Reliability of health-related quality-of-life assessments made by older adults and significant others for health states of increasing cognitive impairment (Bravo, Sene, & Arcand, 2017).	Québec	Y	N	Longitudinal study.	Assess the extent to which QoL ratings of older adults and their designated proxies are consistent over time, in the context of increasing cognitive impairment.	Interviews using close-ended questions about health-related Quality of Life surveys.	Community-based older adults and their proxies.	<ul style="list-style-type: none"> <li>• 235 older adults and proxies participated in the study.</li> <li>• Health-related Quality of Life (QoL) ratings were consistent across time points and among dyads. This was increased under worsening implied cognitive function.</li> <li>• Findings emphasize the importance of considering QoL as part of advance care planning in the context of cognitive impairment, as well as engaging designated proxies in these deliberations.</li> </ul>	Feasibility of patient engagement in ACP.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
Determinants of do-not-resuscitate orders in palliative home care (Brink, Smith, & Kitson, 2008).	Ontario	Y	N	Retrospective cohort study.	Identify which palliative home care clients have a do-not-resuscitate order included in their ADs.	<ul style="list-style-type: none"> <li>Health information collected using the interRAI palliative care instrument, which collects information regarding clients' wishes as they pertain to do-not-resuscitate (DNR) status.</li> <li>Multivariate analysis.</li> </ul>	Palliative home care clients from a community care access centre.	<ul style="list-style-type: none"> <li>The desire to die at home, nearness to death, daily incontinence and sleep issues were associated with do-not-resuscitate orders.</li> <li>Clients who are accepting of their circumstances were 5.67 more likely to have a formalized DNR.</li> <li>Clients with higher cognitive and functional impairments were more likely to have a recorded DNR, as compared to unimpaired clients.</li> <li>Evidence on the association between delirium and completed DNR orders was weak.</li> <li>Females were more likely to be missing information regarding their preferred place of death, as compared to males.</li> </ul>	Feasibility of patient engagement in ACP.
The law and practice associated with advance directives in Canada and Australia: similarities, differences and debates (Brown, 2003).	N/A	N	N	Policy analysis.	Highlight the contexts in which seniors are encouraged to complete ADs, such as refusal of a healthcare intervention ahead of incompetence. Comparison of practices in Canada and Australia.	Policy analysis.	N/A	<ul style="list-style-type: none"> <li>There is a lack of consistency pertaining to the terminology used in the context of ADs.</li> <li>There is an emphasis on the concept of 'advance care planning' and ACP conversations, as opposed to the former focus being placed on ADs.</li> <li>The legislation in this area is, in many ways, confusing.</li> <li>There is increasing uptake in designating substitute decision-makers.</li> </ul>	Barriers and facilitators to the delivery of holistic dementia care.
Surrogate decision making: special issues in geriatric psychiatry (Cohen, 2004).	N/A	N	N	Presentation of a case vignette.	Identify surrogate decision-making issues that occur in geriatric psychiatry, specifically dementia care.	Case vignette.	N/A	<ul style="list-style-type: none"> <li>Many individuals are uncomfortable with personal care planning, despite being familiar with advance care planning such as for medical directives.</li> <li>There is a role for health care practitioners as well as legal and financial advisors to aid patients and prospective substitute decision-makers.</li> <li>Role clarification may assist surrogates with decision making in the future.</li> <li>It is common for family members to experience difficulty discerning when a loved one has</li> </ul>	Barriers and facilitators to the delivery of holistic dementia care.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<p>become incapable of making their own decisions.</p> <ul style="list-style-type: none"> <li>• Medical and social services for vulnerable seniors should be publicized such that family members can access them appropriately when needed.</li> <li>• Family members should have access to education, skills acquisition, and clear communication with professionals, so that they can make decisions for another member.</li> </ul>	
Extending autonomy for health care preferences in late life (Cramer, Tuokko, & Evans, 2001).	British Columbia	Y	N	Longitudinal study.	Evaluate which types of end-of-life planning seniors are using and whether or not a hierarchy relating to which documents are being completed exists; examine genre and relationships of chosen surrogates; and assess how seniors are discussing their health preferences with others.	In-person interviews using close-ended questions.	Seniors who receive public home supports.	<ul style="list-style-type: none"> <li>• Wills and power of attorney for finances were most commonly reported at 92% and 62% respectively.</li> <li>• 28% and 19% of participants reported having power of attorneys for health and living wills for health services.</li> <li>• Cognitive disabilities and age were associated with higher completion of powers of attorney for health.</li> <li>• Higher education was associated with having a will, power of attorney for health and a living will (this was the only significant predictor of the aforementioned documents being completed, after controlling for age).</li> <li>• Participants often wanted their daughters as future surrogate decision makers (32%), followed by sons (18%), and spouses (17%).</li> <li>• Women surrogates were preferred to men in most cases.</li> <li>• 53% of participants had discussed their health preferences. Of these, 22% had conversed with their daughters, followed by doctors (21%), and home support workers (18%).</li> <li>• This pattern was consistent with unmarried participants, unmarried participants with living children, married participants, and</li> </ul>	Feasibility of patient engagement in ACP.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<p>married participants with living children.</p> <ul style="list-style-type: none"> <li>Discussions of health care wishes amongst patients and preferred surrogates are warranted and require supports.</li> </ul>	
Advance care planning discussions among residents of long term care and designated assisted living: experience from Calgary, Alberta (Dyason, Simon, & Martin, 2015).	Alberta	Y	N	Retrospective cohort study.	Understand participation in ACP and decision-making for residents in long-term care (LTC) and assisted living, as well as identity which factors influence this activity.	Chart audit completed at three time points after policy implementation.	Calgary residents 50 years of age or older, who had endured a minimum length of stay of 45 days at a LTC centre or 90 days at a designated assisted living centre.	<ul style="list-style-type: none"> <li>200 charts were reviewed, of which 166 (83%) had documented ACP discussions.</li> <li>The prevalence of cognitive impairments in LTC and designated living was 78% and 46%, respectively.</li> <li>There were a total of 272 ACP discussions documented in the 166 charts.</li> <li>Residents were documented present in discussions about their preferences 47% of the time. 62% of discussions had a documented family member in attendance.</li> <li>Only 20% of cognitively impaired residents were documented as being present in such conversations, in which family members' attendance was more common.</li> <li>Nurses were most commonly present in conversations (67%).</li> <li>Physicians were more likely to be present in LTC than assisted living (43% versus 16%) for a total of 34% of all charts.</li> <li>Social workers, spiritual care and others (e.g., pharmacists, PT and OT) were present 16%, 2% and 15% of the times, respectively.</li> <li>Findings from this study support that ACP in LTC is based on relational autonomy, as opposed to solely patient autonomy.</li> </ul>	Feasibility of patient engagement in ACP.
Formal Dementia Care among First Nations in Southwestern Ontario (Finkelstein, Forbes, & Richmond, 2012).	Southwestern Ontario.	Y	N	Qualitative study, using interviews.	Understand how dementia care is delivered to Southwestern Ontario	<ul style="list-style-type: none"> <li>In-depth interviews using open-ended questions.</li> </ul>	Multidisciplinary health care providers (HCP).	<ul style="list-style-type: none"> <li>Dementia care can be understood through the care delivery framework and a knowledge framework. The first identifies goals of care, elements of care</li> </ul>	Indigenous health considerations.

(Continued)

Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
					First Nations communities.	<ul style="list-style-type: none"> <li>• Constructivist Grounded Theory approach.</li> <li>• Constant comparative data analysis.</li> </ul>		<p>being delivered, barriers to care, and strategies to overcome these obstacles. The second defines knowledge stakeholders, the knowledge they have, and how they share it.</p> <ul style="list-style-type: none"> <li>• Provider roles included assessing patients, managing symptoms and crises.</li> <li>• Barriers to care and accomplishing the aforementioned tasks included lacking resources, especially personnel, thereby taking away from tasks other than crisis management.</li> <li>• Few dementia resources and programs include First Nations knowledge, limiting the ability of professionals to share dementia knowledge with patients and families.</li> <li>• Other barriers included failure to collaborate with non-community workers, encountering mistrust from patients and community members, patients not accessing care, and burnout among providers.</li> <li>• There is a need for culturally appropriate dementia care and resources for First Nations peoples, maximizing resources, involving family members in the care of persons living with dementia, developing client and community relationships, investigating knowledge gaps, and supporting caregivers by accepting limitations.</li> </ul>	
Dementia Care Knowledge Sharing within a First Nations Community (Forbes et al., 2013).	Southwestern Ontario	Y	N	Qualitative study, using interviews.	Provide examples of dementia care knowledge exchange among HCPs, informal caregivers, and persons living with dementia in a First Nations community; determine barriers and facilitators to these processes and inform	<ul style="list-style-type: none"> <li>• In-person interviews conducted at multiple time points.</li> <li>• Constructivist Grounded Theory.</li> </ul>	Persons living with dementia, HCPs, and informal caregivers.	<ul style="list-style-type: none"> <li>• Three themes for dementia care knowledge sharing emerged: “developing trusting relationships, accessing and adapting information, and applying the information.”</li> <li>• There is a need to support collaboration between health care professionals, caregivers and persons living with dementia in</li> </ul>	Indigenous health considerations.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
					culturally sensitive applications of strategies for knowledge sharing in dementia care.			<p>care planning and discussions about the future.</p> <ul style="list-style-type: none"> <li>• There is a need to address stigma and sociocultural issues that underpin multi-ethnic societies and contribute to inequities in health and knowledge exchange.</li> <li>• Timely and accurate dementia diagnoses are integral in allowing patients and their caregivers to seek information about the disease trajectory, treatment options, viability of supports, and legal aspects of care planning, such as designating powers of attorney.</li> </ul>	
Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study (Forbes et al., 2012).	Southwestern Ontario (rural).	Y	N	Qualitative interpretive descriptive study.	Better enable HCPs, care partners and persons living with dementia to utilize dementia care information, by means of “examining their information needs, how these needs change over time, and how stakeholders access, assess, and apply the knowledge.”.	<ul style="list-style-type: none"> <li>• Interviews conducted at three time points.</li> <li>• Lubrosky’s thematic content analysis.</li> </ul>	Persons living with dementia, care partners, and HCPs.	<ul style="list-style-type: none"> <li>• There are six stages to the dementia care journey: “(1) recognizing the symptoms; (2) receiving a diagnosis; (3) loss of independence; (4) initiating and using home care and respite services; (5) LTC placement; and (6) decisions related to end-of-life care.”</li> <li>• Rural care partners noted that there are different knowledge needs per stage and persons living with dementia do not often recognize that they need dementia care information.</li> <li>• Facilitators of knowledge exchange included care partners with health care knowledge who seek information, building trust amongst providers, patients, and caregivers; and formalized programs for information sharing with rural community organizations.</li> <li>• Barriers included a paucity of rural community-based dementia care services, limited capacity among caregivers, and limited availability of integrated dementia services and supports.</li> </ul>	Knowledge translation to support persons living with dementia, professionals, and caregivers.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<ul style="list-style-type: none"> <li>Timely delivery of information and collaboration among patients, HCPs, and caregivers is warranted in order to ensure the appropriate provision of safe and quality dementia care, especially care planning, in rural settings.</li> </ul>	
Planning for end-of-life care: findings from the Canadian Study of Health and Aging (Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008).	Canada	Y	N	Retrospective cohort study.	Assess the frequency of individuals who have thought about a future surrogate decision maker, discussed preferences for end-of-life care with someone, and completed a formal legal document. Identify factors which affect the completion of the aforementioned measures. Assess the association between thinking about health preferences, discussing health preferences, and completing ADs.	Existing data which was collected through surveys and in-person examinations.	Adults who participated in the Canadian Study of Health and Aging, specifically the third wave.	<ul style="list-style-type: none"> <li>83.19% and 58.15% of participants had thought about prospective surrogate decision-makers and had discussed preferences with somebody, respectively.</li> <li>Of the 58.15%, however, only 66.73% had formalized an AD.</li> <li>Females were 1.46 times more likely to have thought about a possible surrogate, than males.</li> <li>Higher education and region of residence (Ontario) were predictive of this behaviour.</li> <li>Females were 1.51 times more likely to have discussed end-of-life preferences, than males; diagnostic status was predictive.</li> <li>Thinking about end-of-life preferences was predictive of sharing them with others; likewise, thinking about and discussing preferences were associated with formalizing them.</li> <li>Unmarried participants were more likely to have formal ADs in place, as compared to married or common law participants.</li> <li>The process of completing AD is multi-staged; interventions to promote planning for end-of-life care are warranted.</li> </ul>	Feasibility of patient engagement in ACP.
End-of-life care policies: Do they make a difference in practice? (Goodridge, 2010).	Western Canada	Y	N	Retrospective cohort study.	Answer the following question: "What effect do institutional policies relating to care at the [end-of-life] have on practice?".	<ul style="list-style-type: none"> <li>Retrospective chart review.</li> <li>Descriptive and analytical statistics.</li> </ul>	Patients who died in acute care hospitals.	<ul style="list-style-type: none"> <li>310 patient charts were reviewed. Up to three end-of-life orders found for 16.8% of patients.</li> <li>Few HCPs complied with policy directives for care plans, terminology, or recording conversations about treatment plans.</li> </ul>	Feasibility of patient engagement in ACP.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<ul style="list-style-type: none"> <li>Terminology of end-of-life (EOL) orders was extremely variable. These included “do not resuscitate, compassionate terminal care, no cardiopulmonary resuscitation, end-of-life care, comfort measures, no code.”</li> <li>The presence of an EOL order was positively associated with a dementia or cancer diagnosis.</li> <li>These orders were present for 60.9% of individuals who had documented ADs.</li> </ul>	
Advance Care Planning and Decision-Making in a Home-Based Primary Care Service in a Canadian Urban Centre (Huggins et al., 2019).	British Columbia	Y	N	Retrospective cohort study.	Describe the state of ACP for frail elderly people receiving home-based primary care.	Retrospective chart review.	Older adults. Mean age of participants was 87.7 (SD 7.1).	<ul style="list-style-type: none"> <li>54% of participants were living with dementia.</li> <li>79.5% and 63% of participants had documented a resuscitation status and named a substitute decision-maker, respectively.</li> <li>A dementia diagnosis and older age were positively associated with a documented do-not-resuscitate order.</li> <li>Older age, male sex and primary language being English were positively associated with a do-not-hospitalize order.</li> <li>The association between English as a main language and completion of ACP highlights the importance of cross-cultural considerations in ACP.</li> </ul>	Feasibility of patient engagement in ACP.
Findings on Advance Care Plans among Cognitively Impaired Older Adults (Jeznach, Tuokko, Garcia-Barrera, & Stajduhar, 2015).	Canadian data evenly distributed across Canada.	Y	N	Retrospective cohort study.	Assess the associations between demographic variables and the completion of ACP, as well as discern whether cognitively impaired or unimpaired patients differ according to making arrangements for surrogate decision-making before death, formalizing arrangements in legal documents, sharing end-of-life preferences with someone, and legally	Analysis of existing data.	Adults who participated in the Canadian Study of Health and Aging.	<ul style="list-style-type: none"> <li>Older adults with cognitive impairments were more likely to have assigned a substitute decision-maker and legally formalized their health care preference or named a decision maker (OR = 2.64 and 2.00, respectively).</li> <li>This group was also less likely to have shared end-of-life care preferences (OR = 0.62).</li> <li>There was no significant relationship between participating in ACP and dying in a medical facility.</li> </ul>	Feasibility of patient engagement in ACP.

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Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
					formalizing these preferences. Additionally, this study aimed to identify whether differences based on demographics and the completion of ACP affect outcomes such as location of death and respecting final wishes.			<ul style="list-style-type: none"> <li>Families that partook in end-of-life care discussions had higher ratings for respect for these preferences.</li> <li>Cognitively impaired seniors were less likely than unimpaired seniors to have shared their preferences with others.</li> <li>It is clear that cognitively impaired people experience ACP differently than unimpaired people.</li> </ul>	
A Call for Autonomy and Compassion: Insights from the Belgium Law on Euthanasia and propositions for future regulations of assisted death in Canada (Leduc, 2013).	N/A	Y	Y	Policy analysis.	Assess the merits and shortfalls of Belgium's Law on Euthanasia of 2002 and determine if a similar policy could be introduced in Canada.	Policy analysis.	N/A	<ul style="list-style-type: none"> <li>Regulating assisted death in Canada is recommended, based on compassion for patients.</li> <li>Dementia, a disease which causes progressive cognitive impairment, complicated the ability to test decisional capacity.</li> <li>Definitions of autonomy which focus on personal interaction and values may be richer than more rigid definitions.</li> <li>Following such definitions may help patients with cognitive impairments to make choices reflective of their values and preferences.</li> </ul>	Barriers and facilitators to the delivery of holistic dementia care.
Experiences and perspectives of people who pursued MAiD: Qualitative study in Vancouver, BC (Nuhn et al., 2018).	British Columbia	Y	N	Qualitative study, using semi-structured interviews.	Assess the "experiences, wishes, fears, and beliefs" of individuals who sought and were eligible for MAiD in the first year of its legalization.	<ul style="list-style-type: none"> <li>Semi structured interviews.</li> <li>Thematic content analysis.</li> </ul>	Patients who sought MAiD between 6 Feb 2016 and 17 Dec 2016; patients' family and friends.	<ul style="list-style-type: none"> <li>Only one patient included in the study was living with dementia.</li> <li>All patients were confident in their pursuit of MAiD.</li> <li>Common reasons for wanting MAiD were "loss of autonomy, loss of independence, loss of purposes and enjoyment, loss of physical and communication abilities, and suffering of fear of future suffering."</li> <li>Pain was infrequently cited as a reason for wanting MAiD.</li> <li>Patients reported feeling supported when sharing their decisions to seek MAiD.</li> <li>Most only told close friends and family, in avoidance of debate or needing to justify their choices.</li> </ul>	Feasibility of patient engagement in ACP.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<ul style="list-style-type: none"> <li>Patients varied in religious backgrounds, from 'atheist' to 'very spiritual.'</li> </ul>	
Whose life is it anyway? Capacity and consent in Canada (Straus & Stelfox, 2007).	N/A	N	N	Case study.	Showcase inconsistencies in approaches to assessing capacity and consent, according to the current legislation in Canada.	Case study.	N/A	<ul style="list-style-type: none"> <li>Physicians have a responsibility to inform patients of the capacity and consent legislations in their jurisdictions.</li> <li>Many patients who do not possess such information experience difficulties when transitioning between regions.</li> <li>Legislations which vary in including informal caregivers and family members result in health disparities for patients with capacity issues.</li> <li>The authors believe that legislation should reflect clear national standards which include caregivers in aspects of decision-making, as opposed to jurisdiction-specific policies.</li> </ul>	Barriers and facilitators to the delivery of holistic dementia care.
Barriers to Staff Involvement in End-of-Life Decision-Making for LTC Residents with Dementia (Sutherland, Wiersma, & Vangel, 2019).	N/A	Y	N	Interpretive descriptive design.	Evaluate barriers and facilitators to staff involvement in dementia-related decision-making in the context of LTC homes.	<ul style="list-style-type: none"> <li>Semi-structured in-person interviews.</li> <li>One focus group.</li> <li>Thematic analysis.</li> </ul>	Staff from two urban non-profit facilities; majority female.	<ul style="list-style-type: none"> <li>Four barriers to staff engagement emerged: "a) predominance of a bio-medical model of care; b) a varied understanding of a palliative approach; c) challenging relationships with families; and d) a discomfort with discussing death."</li> <li>Discomfort talking about death or sensitive topics, as well as fear of giving misinformation, hinders effective communication between staff and patients' family members.</li> <li>Policies in LTC homes should adopt a "humane, relational approach to dementia care."</li> <li>The bio-medical model, which is common, should honour relationships between residents, family, and staff.</li> </ul>	Barriers and facilitators to the delivery of holistic dementia care.
Do-Not-Resuscitate and Do-Not-Hospitalize Orders in Nursing Homes: Who Gets Them and Do They Make a	Ontario	Y	N	Retrospective cohort study.	"Describe the rate of do-not-resuscitate orders and do-not-hospitalize orders among residents	Retrospective chart review.	Admitted residents to all public long-term care facilities in Ontario during the time period	<ul style="list-style-type: none"> <li>60.7% and 14.8% of residents had a do-not-resuscitate order and do-not-hospitalize order, respectively.</li> </ul>	Feasibility of patient engagement in ACP.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
Difference? (Tanuseputro et al., 2019).					newly admitted into long-term care homes.”.		1 January 2010-1 March 2012.	<ul style="list-style-type: none"> <li>Variables associated with having one of the above forms of ACP included: older age, female sex, widowed, living in a rural facility, living in a higher income neighbourhood before entry to the facility, higher health instability or cognitive impairment, and speaking English or French.</li> </ul>	
A Family Booklet About Comfort Care in Advanced Dementia: Three-Country Evaluation. (van der Steen et al., 2012).	French-speaking Canada.	Y	N	Retrospective cohort study.	Evaluate a booklet discussing dementia comfort care in, as well as nursing home resident and family factors that are related to evaluations. The booklet content ranges from disease trajectory info to end-of-life decision-making, and conflict management among others.	8-item survey.	Canadians from five nursing homes. *	<ul style="list-style-type: none"> <li>Canadian respondents rated the quality of the booklet’s information highly.</li> <li>A majority of respondents (96–100%) thought the booklet was needed and useful ‘should they have had it earlier’.</li> <li>Reasons why the booklet was not perceived as useful were preferences for conversing rather than reading; reading would have augmented anxiety, and could have incited family conflicts, to name a few.</li> <li>Participants were accepting of having practitioners involved in providing the resource.</li> <li>Canadian families preferred the booklet to be offered upon diagnosis of dementia. 23% wished to have the resource offered at diagnosis or prior to nursing home admission.</li> </ul>	Knowledge translation to support persons living with dementia, professionals, and caregivers.
Impact of brief education on healthy seniors’ attitudes and health care choices about Alzheimer’s disease and associated symptoms (Waxman, Russell, lu, & Mulsant, 2018).	Ontario	Y	N	Mixed methods evaluation.	Assess if a brief education session on Alzheimer’s disease trajectory and symptoms affect healthy seniors’ treatment preferences; and moreover, evaluate if pharmacotherapy to reduce AD symptoms would be desired more than other restrictive interventions.	Pre- and post-intervention surveys.	Toronto patients older than 64 with no self-reported diagnosis of dementia.	<ul style="list-style-type: none"> <li>The session improved participants’ knowledge of Alzheimer’s disease.</li> <li>66% of participants already had a proxy decision-maker should they become incapable of making decisions regarding their treatment.</li> <li>As compared to individuals in complementary groups, having a designated proxy, knowing someone with Alzheimer’s disease, being born in Canada, and having a university education were associated with lower odds of wanting to receive treatment.</li> </ul>	Knowledge translation to support persons living with dementia, professionals, and caregivers.

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Table 2. Continued

Title and Authors	Setting	Original Research Article? (Y/N)	Grey Literature? (Y/N)	Study Design	Purpose	Methods	Participants	Key Results	Theme
								<ul style="list-style-type: none"> <li>• Participants chose less active treatments for moderate to severe stages of AD post-educational session.</li> <li>• Post-intervention, some participants preferred less intensive treatments due to new knowledge about symptoms, envisioning increasing family burden, or acknowledging treatments to be futile.</li> <li>• Some other participants preferred more active treatments after re-evaluating the dementia stages and “hope being ever present and life still mattering.”</li> <li>• Hospitalization was preferred by many, based on the belief that acute care hospitals have more means to improve patients’ circumstances.</li> <li>• Without being prompted by researchers, multiple participants expressed that they would seek MAiD should they develop Alzheimer’s disease, and hoped that MAiD be legalized soon.</li> <li>• Conversations on behavioural and psychological symptoms of dementia can impact a patient’s ADs and health care preferences; furthermore, dementia and ACP education initiatives should consider participants’ prior education and personal experiences.</li> </ul>	

\*This study also reports on results from The Netherlands and Italy, however only Canadian findings are presented here.

present in conversations, and physicians were more likely to be present in LTC than in assisted living facilities. Social workers, spiritual care providers and others (e.g., occupational therapists, pharmacists, and physiotherapists) were present 16, 2, and 15 per cent of the time, respectively, thereby reinforcing that ACP in LTC was based on relational autonomy. Likewise, studies from Huggins as well as Tanuseputro and colleagues reported that cognitive impairment, higher age, and primary language being French or English were positively associated with having completed a DNR or do-not-hospitalize order (Huggins *et al.*, 2019; Tanuseputro *et al.*, 2019). Their findings on the association between language and completion of ACP demonstrated the importance of considering cultural factors which hinder or promote engagement in ACP (Huggins *et al.*, 2019; Tanuseputro *et al.*, 2019).

Additionally, a Vancouver-based study assessed the “experiences, wishes, fears and beliefs” of patients who sought and were eligible for MAiD in the first year of its legalization (Nuhn *et al.*, 2018). Although only one participant out of 23 had dementia, the authors noted that all patients were confident in their pursuit of MAiD. Common reasons for wanting MAiD were the desire for autonomy, unacceptable quality of life, loss of independence and function, loss of physical ability, loss of ability to speak or communicate, and suffering or fear of future suffering (Nuhn *et al.*, 2018). It should be noted that pain was not frequently cited as a reason for wanting MAiD. Patients reported feeling supported when sharing their decisions to seek MAiD; most only told close friends and family, to avoid debate or the need to justify their actions. Patients’ religiosity varied from atheist to “very spiritual” (Nuhn *et al.*, 2018).

Finally, another study by Bravo *et al.* (2017) assessed the extent to which quality of life (QoL) ratings made by older adults in Québec were consistent with those of their designated proxies for health care, as well as consistent over time, in the context of increasing cognitive impairment. QoL ratings were persistent across time points and congruous between pairs of older adults and their proxies. This similarity was increased under worsening cognitive function, thereby suggesting the importance of conversations pertaining to QoL as part of ACP in the context of cognitive impairment as well as engaging designated proxies in these deliberations.

### *Opinions Regarding MAiD for Incompetent Patients*

Four studies (14%) focused on the opinions of various stakeholders regarding offering MAiD to cognitively impaired patients (Bravo *et al.*, 2018a, 2018b, 2018c, 2019). Two of these elicited the opinions of Québec physicians and nurses towards extending MAiD to incompetent patients and found that both groups were generally supportive (Bravo *et al.*, 2018b, 2018c). In the context of dementia at an advanced stage, 45 and 14 per cent of 136 physicians (including family, internal medicine, neurology, psychiatry, and intensive care physicians) were in support of providing MAiD to incompetent patients with and without a formal request, respectively (Bravo *et al.*, 2018c). In the context of dementia at a terminal stage, these percentages reached 79 and 52 per cent, respectively, for family physicians. Furthermore, 73 per cent of respondents agreed that health care preferences expressed before losing decisional capacity should carry the same weight as those expressed by a competent patient. Similarly, 83 per cent of surveyed nurses surveyed (including those working with patients with Alzheimer’s or a similar disorder, or working in geriatrics, gerontology, end-of-life care, or the public health care network) were in favour of offering MAiD to incompetent patients who were at the terminal stage of their

disease, showing signs of distress, and had made the request prior to losing capacity (Bravo *et al.*, 2018b). Generally, nurses agreed with the process of self-determination and attached high value to advance directives. Importantly, there was a significant difference in support for MAiD; this difference was contingent on factors such as the perceived comfort level of the patient or the patient being in the terminal stage of their disease (Bravo *et al.*, 2018b). Three independent correlates of respondents’ attitudes were identified through multiple logistic regression: “having accompanied a relative or friend through the dying process, being somewhat or totally likely to make a MAiD request should they be diagnosed with Alzheimer’s disease, and being somewhat or totally likely to ask a physician to carry out the advance request made while competent by a now-incompetent relative diagnosed with Alzheimer’s disease” (Bravo *et al.*, 2018b).

### *Lay Persons’ Perspectives*

Two studies assessed Québec lay persons’ perspectives towards extending MAiD to incompetent patients (Bravo *et al.*, 2018a, 2019). Seventy-eight per cent of informal caregiver survey respondents – a majority of whom were the adult child or spouse of an individual with dementia – felt that they would write an advance request for MAiD if personally diagnosed with Alzheimer’s disease (Bravo *et al.*, 2018a). Conditions under which they would want their request for MAiD to be accommodated were physical and psychological suffering that could not be relieved, as well as complete dependence on others to fulfil basic needs. Self-determination was the most common argument in favour of rendering MAiD accessible to incompetent patients, and religiosity was identified as a correlate negatively associated with caregivers’ positive attitudes towards MAiD for the same patients. Akin to surveyed physicians, 82% of respondents expressed that all persons should have the right to decide how they would die and that preferences voiced ahead of losing capacity should be assigned equal merit to preferences expressed by a competent patient. These same respondents were supportive of extending MAiD to incompetent persons living with dementia at the advanced and terminal stages of their disease, in the presence or absence of advance requests. Finally, another study by Bravo *et al.* (2019) elicited older adults’ opinions regarding MAiD for incompetent patients. In light of a dementia diagnosis, 76 per cent of the 317 respondents expressed being somewhat or extremely likely to write a request for MAiD and 74 per cent expressed being equally as likely to ask that a physician grant the MAiD request of a close relative diagnosed with the same disease. Physical pain that could not be relieved was the most common trigger for such positions, whereas admission to a LTC facility was the least common.

### *KT to Support Persons Living with Dementia, Professionals, and Caregivers*

Five studies (17%) discussed current KT and patient engagement initiatives designed to support cognitively impaired patients and their circle of care in ACP (Arcand *et al.*, 2013; Bayly, Blake, Peacock, Morgan, & Forbes, 2018; Forbes *et al.*, 2012; van der Steen *et al.*, 2012; Waxman, Russell, Iu, & Mulsant, 2018). Two studies examined the usefulness, quality, and acceptability of information booklets on dementia and end-of-life care (Arcand *et al.*, 2013; van der Steen *et al.*, 2012). These booklets were offered to patients – as well as family members and nurses – to inform them of dementia topics including disease trajectory, symptom management, end-of-

life decision making, and conflict management, among others. Broadly, the booklets from each study were well received. The booklet examined by Arcand et al. (2013) was generally acceptable in both French and English Canada, wherein a majority of surveyed nurses rated the booklet as a useful resource for families of persons living with advanced dementia, and had previously identified that the booklet contained information regarding the comfort care approach to dementia care at the end of life. Likewise, the booklet evaluated by van der Steen et al. (2012) was highly rated by survey respondents. These respondents were also in favour of having practitioners involved in providing the resources. Importantly, both studies found similar results regarding the timing of booklet delivery; recipients wished to receive the booklet close to the time of dementia diagnosis, during goals-of-care discussions, or prior to hospital admission if applicable (Arcand et al., 2013; van der Steen et al., 2012).

Another two studies examined the impacts of KT programs (Bayly et al., 2018; Waxman et al., 2018). Bayly et al. (2018) investigated the effects of a knowledge broker on the development and application of KT tactics for dementia care in Alberta rural home care settings. The knowledge broker, a dedicated team member, was deemed a valuable KT resource, particularly useful in rural settings where staff might have limited capacity to deliver specialized KT services to patients with dementia. The knowledge broker played a key role in facilitating knowledge exchange and negotiation, such as promoting further discussions among staff, persons living with dementia, and their families. By contrast, an intervention evaluated by Waxman et al. (2018) assessed whether an educational session on Alzheimer's disease affected healthy Toronto seniors' treatment preferences, while also examining the extent to which pharmacotherapy to reduce Alzheimer's disease symptoms was preferred over more restrictive interventions. The mean scores of correct answers on the Alzheimer's knowledge questionnaire were 72 per cent ahead of the educational intervention, 78 per cent immediately following, and 80 per cent a month later. Participants chose less active treatments for moderate to severe stages of the disease post-educational session. Without being prompted by researchers, multiple participants expressed that they would seek MAiD should they develop Alzheimer's disease, and that they hoped MAiD would be legalized soon. The authors affirmed the importance of considering patients' backgrounds and familiarity with dementia when planning and implementing education on advance directives. Conversations surrounding the behavioural and psychological symptoms of dementia could impact a patient's advance directives and health care preferences.

Finally, a study by Forbes et al. (2012) explored the information needs of multiple Southwestern Ontario stakeholders in dementia care as well as how these needs changed over time and how the aforementioned parties accessed, assessed, and applied dementia care knowledge. In this study, six stages to the dementia care journey were identified: "(1) recognizing the symptoms, (2) receiving a diagnosis, (3) loss of independence, (4) initiating and using home care and respite services, (5) LTC placement, and (6) decisions related to end-of-life care." Rural care partners communicated that each stage required unique knowledge and that persons living with dementia rarely recognized a personal need for dementia care information. Promoters of knowledge exchange included care partners with health care knowledge who sought information, building trust amongst HCPs, patients, and caregivers, and formalized programs for information sharing with rural community organizations. Notwithstanding these facilitators, barriers included a scarcity of rural community-based dementia care services, limited

capacity among caregivers, and limited availability of integrated dementia services and supports.

### *Barriers to and Facilitators of the Delivery of Holistic Dementia Care*

Six studies (21%) looked at factors hindering or promoting the effective delivery of dementia care, particularly in the area of patient and caregiver decision making (Bernier & Régis, 2019; Brown, 2003; Cohen, 2004; Leduc, 2013; Straus & Stelfox, 2007; Sutherland, Wiersma, & Vange, 2019). Confusion and discomfort discussing the end of life and ACP were cited multiple times (Cohen, 2004; Sutherland et al., 2019). Discomfort conversing about death or similar sensitive topics – as well as fear of giving misinformation – could hinder effective communication between HCPs and patients' family members, and ultimately prevent the initiation of ACP (Sutherland et al., 2019). It was also common for families to experience difficulty discerning when a loved one had become incapable of making their own decisions (Cohen, 2004). Uncertain disease diagnosis and prognosis, urgency about making decisions, and lack of understanding about care options were highlighted as factors complicating ACP processes. Consequently, these findings asserted the need for more comprehensive and publicly-advertised medical and social services for vulnerable seniors and their families, in addition to improved communication means and decision-making tools to engage prospective ACP participants, caregivers, and HCPs more effectively.

Moreover, some articles discussed system-level barriers to ACP (Bernier & Régis, 2019; Brown, 2003; Cohen, 2004; Straus & Stelfox, 2007; Sutherland et al., 2019). Factors preventing cognitively impaired older adults and their supports from accessing ACP effectively included, but were not limited to, inconsistencies in language, dominant biomedical approaches to care, lack of mandates for HCP involvement in supporting patients in ACP, form-focused policies, variable approaches to understanding autonomy, and jurisdiction-specific policies (Bernier & Régis, 2019; Cohen, 2004; Leduc, 2013; Straus & Stelfox, 2007). Furthermore, these articles emphasized the value of understanding ACP in dementia as a collaborative and iterative process which involved multiple individuals, not just the person with dementia (Bernier & Régis, 2019; Cohen, 2004; Sutherland et al., 2019). A relational approach – one taking into account the broader social contexts in which individuals make decisions – was warranted, as were diverse resources for knowledge exchange and communication in the patient's circle of care (Bernier & Régis, 2019; Cohen, 2004; Straus & Stelfox, 2007; Sutherland et al., 2019).

### *Indigenous Health Considerations*

Finally, two studies (7%) examined the intricacies of delivering high-quality dementia care in Canada's Indigenous communities (Finkelstein, Forbes, & Richmond, 2012; Forbes et al., 2013). A qualitative study by Forbes et al. (2013) assessed instances of dementia care knowledge exchange among HCPs, informal caregivers, and persons living with dementia in a First Nations community in Southwestern Ontario. Using a constructivist grounded theory approach, interviews were conducted with the aforementioned groups to inform culturally-sensitive applications of strategies for knowledge sharing in dementia care. Three themes for dementia care knowledge sharing emerged from this inquiry: "developing trusting relationships, accessing and adapting information, and applying the information." The need to support

collaboration among HCPs, informal caregivers, and persons living with dementia in planning and discussions about the future was evident. It was also clear that there was a need to address stigma and socio-cultural issues that underpinned multi-ethnic societies, particularly Indigenous ones, and contributed to inequities in health and knowledge exchange. Timely and accurate dementia diagnoses, as well as culturally-appropriate resources, were integral in enabling patients and their caregivers to seek information about the disease trajectory, treatment options, viability of supports, and legal aspects of care planning, such as designating powers of attorney. Similarly, another qualitative investigation, also performed in Southwestern Ontario, explored how dementia care was delivered to First Nations communities (Finkelstein et al., 2012). Here, in-depth interviews with HCPs revealed that dementia care for Indigenous persons could be understood through a care delivery framework and a knowledge framework. The first, identified goals of care, elements of care being delivered, barriers to care, and strategies to overcome these obstacles. The second, defined knowledge stakeholders, the knowledge they have, and how they share it. One of the key barriers to accomplishing these tasks was a lack of human resources for crisis management. There was a paucity of resources and programs including First Nations knowledge, thereby limiting HCPs in sharing dementia knowledge with Indigenous persons living with dementia and their caregivers, as well. Additionally, barriers such as failure of HCPs to collaborate with non-community workers, encountering mistrust from patients and community members, patients not accessing care, and burnout among providers were identified. There was a need to produce culturally-appropriate dementia care resources for Indigenous peoples, develop patient and community relationships, investigate knowledge gaps in this specific population, involve family members in the care of persons with dementia, and support caregivers by accepting their limitations.

## Discussion

To answer the question “*What is the feasibility and acceptability of advance care planning for older adults (≥65 years of age) diagnosed with dementia in Canada?*” we performed a scoping review of the Canadian literature published between 1 January 2000 and 31 December 2019. The results from this review elucidate the feasibility and acceptability of ACP for Canadian seniors (≥65 years of age) diagnosed with dementia. Many older Canadians have considered health care preferences in the event of decisional incapacity; numerous incompetent patients present with completed ACP such as advance directives. Despite positive levels of engagement in ACP, there are considerable barriers which restrict patients, especially those living with dementia, along with the members of their circle of care, from accessing ACP. Indigenous persons living with dementia, caregivers, and providers encounter distinct challenges in this area. Importantly, recent work also illuminates professional and lay opinions towards expanding MAiD access to include incompetent patients. Such findings support that the landscape of ACP and end-of-life care for Canadian seniors living with dementia is fluid.

The findings from this review demonstrate the usefulness of exploring how Canadian seniors living with dementia might be best enabled to partake in ACP, with the support of caregivers and HCPs alike. Importantly, our findings highlight the extent to which older Canadian adults have completed ACP or thought about their health care wishes in the event they became incapacitated (Bravo

et al., 2003, 2011, 2017; Brink et al., 2008; Cramer et al., 2001; Dyason et al., 2015; Garrett et al., 2008; Goodridge, 2010; Huggins et al., 2019; Jeznach et al., 2015; Nuhn et al., 2018; Tanuseputro et al., 2019). Although many individuals have thought about ACP or discussed their preferences informally, few have actually proceeded to formally documenting these wishes. Further, quite a few studies confirmed the existence of practical and emotional barriers preventing patients, caregivers, and HCPs from completing ACP (Bernier & Régis, 2019; Brown, 2003; Cohen, 2004; Leduc, 2013; Straus & Stelfox, 2007; Sutherland et al., 2019). Uniquely, this review also highlights the literature examining ACP considerations specific to persons living with dementia, as well as their caregivers and HCPs, in Indigenous communities. Finally, our findings showcase recent work assessing the potential for interventions such as MAiD to become more accessible regardless of cognitive status (Bravo et al., 2018a, 2018b, 2018c, 2019).

## Canadian Literature in the Context of International Findings

Much of the literature reviewed in our study echoes findings from international studies. First, results from studies such as Ashton and colleagues’ work from the United Kingdom support the value of engaging informal caregivers in the ACP process for persons living with dementia (Ashton, Roe, Jack, & McClelland, 2016). These individuals should be encouraged to seek information about the suitability of end-of-life care such as medical and nursing interventions (Ashton et al., 2016). Additional work from the United Kingdom also concluded that, despite awareness of ACP benefits, staff, such as nursing home managers, were often hesitant to engage in the process because of knowledge deficits (Beck, McIlfratrick, Hasson, & Leavey, 2017). Further training, education, and role clarification are required to target individual, organization, and system-level elements that prevent ACP for persons living with dementia (Beck et al., 2017). Beyond conveying the need to involve formal and informal caregivers in ACP, a study from The Netherlands also explored the ACP barriers and facilitators experienced by community-dwelling persons living with dementia (Tilburgs et al., 2018b). Similar to findings from Canada, successful ACP engagement by persons living with dementia was largely contingent on developing trust among involved parties and discussing both medical and non-medical topics during ACP discussions (Tilburgs et al., 2018b). Concerns, such as physician time constraints, were analogous with our review’s findings. Huang and colleagues’ findings from Taiwan similarly reported on the usefulness of an educational intervention for strengthening both persons living with dementia and their informal caregivers’ ACP knowledge (Huang, Lu, Liu, & Chang, 2020). Here, a family-centred ACP educational intervention conducted in the outpatient setting with persons living with mild dementia was effective in enhancing awareness and understanding of end-stage dementia care options and ACP, ultimately emphasizing the importance of making education a key component of dementia care (Huang et al., 2020).

## Policy Recommendations

There is a clear need to enhance and coordinate efforts to promote equitable access to, as well as delivery of, ACP for persons living with dementia, irrespective of age or their partners in care. As noted in the literature, several system-level barriers prevent cognitively impaired patients and their caregivers from actively and meaningfully engaging in ACP (Bernier & Régis, 2019; Brown, 2003; Cohen, 2004; Straus & Stelfox, 2007; Sutherland et al., 2019). Policies



should consider the practical limitations faced by those who will be most implicated, when developing means to implement policies. This may include rendering ACP language and terminology more suitable to lay persons, and/or introducing ACP processes that are not necessarily restricted to paper forms.

Moreover, positive attitudes from HCPs and lay persons surrounding access to ACP and MAiD for persons living with dementia suggest that MAiD should remain on the health policy agenda, if not be moved to the forefront. Given the support it is receiving in both professional and lay communities, more nuanced discussions should be held to ascertain and evaluate the legal and practical factors which may enable MAiD to become more widely accessible to patients regardless of cognitive status and decisional capacity, while still appreciating the differences in complex legal frameworks among jurisdictions. Multiple expert and lay stakeholders should be included in these deliberations to ensure that diverse viewpoints inform people-centred programs and policies. Some such conversations have already been initiated, for example, the extensive review of MAiD which was undertaken in 2016 included a “Call for Input” wherein Canadian groups and organizations could submit relevant information for panel consideration; as well as the recent forum which took place in Québec to engage multiple stakeholders in discussions about end-of-life care (Santé et Services sociaux Québec, 2020). Likewise, additional expert groups have recently offered recommendations pertaining to MAiD for persons living with mental disorders, spanning topics such as standards for clinical MAiD assessments and improved availability of social supports, to name a few (Council of Canadian Academies, 2018a, 2018b; Halifax Group, 2020). In October 2020, Bill C-7 An Act to Amend the Criminal Code (Assistance in Dying) was tabled in the House of Commons, to formalize exceptions to the existing criteria for final consent (Department of Justice, 2020). Whereas until the bill passed just recently, individuals receiving MAiD were required to provide final consent at the time of administration, a key goal of the new bill was to amend this criterion, among others, to include individuals “whose natural death is reasonably foreseeable and who have entered into an advance consent agreement” (Department of Justice, 2020). In other words, this new bill suggests that an individual who has formalized a request for MAiD as part of their advance care plan may be eligible to receive it whilst being incapacitated (with the safeguard that “MAiD would not be permitted on the basis of such an agreement if the person demonstrates – by words, sounds or gestures – refusal or resistance to the administration of a substance that would cause their death”). Formerly this was not possible and persons living with dementia remained excluded from accessing MAiD. These recent developments in MAiD policy making emphasize the importance of ensuring that ACP and MAiD are discussed with persons living with dementia early in their disease trajectory. Lastly, the broad support for MAiD evidenced in this review, and the apparent relevant political will at the federal level, make the importance of advocacy efforts in the areas of ACP, MAiD, (hospice) palliative care, and geriatric care increasingly salient.

### Practice Recommendations

In clinical practice, there is a need to acknowledge the bio-psychosocial contexts in which persons living with dementia and their circle of care conceptualize and formalize ACP. This review’s

findings note value in using relational autonomy as a basis for ACP and involving multiple parties in the process. Many of the studies synthesized in this review also illustrated knowledge gaps as barriers to participating in ACP (Bernier & Régis, 2019; Brown, 2003; Cohen, 2004; Leduc, 2013; Straus & Stelfox, 2007; Sutherland et al., 2019). Patients, caregivers, and HCPs are unable to fully participate in ACP when they lack the requisite information to navigate the intricacies of the process. Although an array of online resources exists for numerous dementia-related topics, for example those provided by the Alzheimer Society of Canada (2020), this review’s findings suggest a need for tools dedicated to ACP which can be implemented in diverse settings to support both HCPs and lay persons in the process. Such tools would include a holistic collection of information, pertaining not only to the disease trajectory of dementia or end-of-life care options, but also to the practical and emotional aspects of ACP. For example, the inclusion of recommendations for having difficult conversations, negotiating cultural beliefs, or navigating legal processes when formulating ACP may be incorporated. To optimize benefits at the patient, staff, and system levels, the timely introduction of these tools should become a routine aspect of the current standard of clinical dementia care.

### Research Recommendations

Certain groups may be prone to facing increased barriers to health care, particularly as a result of disparities in access to ACP. This has also been demonstrated in existing literature from outside of Canada (Pettigrew et al., 2020). Based on the sparseness of studies in this review, it is unambiguous that further research is vital to identify persons living with dementia who are at risk for marginalization and inadvertent exclusion from ACP discussions and processes. Little has been reported overall on Canadian socio-economic and socio-cultural factors which might be predictors of inclusion or exclusion from formal ACP. To this end, future studies could also consider how potential programs might be developed and implemented to foster guided discussions in a variety of settings where older adults may dwell. For example, such programs could be established in LTC and assisted living facilities, regardless of residents’ cognitive statuses. Lastly, the results of this study demonstrate the need for sustained funding to support research in the areas of dementia, ACP, and MAiD. The overall limitedness of Canadian literature exhibits the need for increased commitment to investigating these topics, so that the aforementioned policy and practice recommendations may be achieved.

### Strengths and Limitations

This scoping review of the literature is limited given that studies not published in English or available online through the University of Toronto Library System in full and free of charge were excluded. For these reasons, our results may be biased. Only articles which could be accessed through the university library system in full and without financial cost were included, because the project was unfunded and undertaken as university coursework (B.K.A.). Furthermore, multiple synthesized articles were published by the same authors or research teams. Despite these limitations, however, our methodology involved hand searching Google (Scholar) in attempts to capture a comprehensive collection of literature, with the literature search strategy itself refined through librarian support.

## Conclusions

This scoping review of the literature, as per Arksey and O'Malley's (2005) framework, assessed the feasibility and acceptability of ACP for Canadian seniors ( $\geq 65$  years of age) diagnosed with dementia. The review's findings contribute to the global literature on ACP for persons living with cognitive impairments, by surveying and synthesizing the state of the Canadian knowledge base on this topic. Importantly, this study highlights Canadian research findings that echo international literature on aspects of ACP such as engagement levels, barriers, and facilitators, as well as unmet patient and provider needs. In response to the results, this review provides propositions for policy, practice, and research, such that ACP may be emphasized as a critical aspect of equitable and high-quality dementia care for residents of Canada. There are numerous patient- and system-level barriers preventing seniors living with dementia, their caregivers, and providers from effectively engaging in ACP. Moreover, there is a range of lay and professional opinions towards extending access to interventions such as MAiD to incompetent patients. Future research should investigate socio-cultural and socio-demographic factors promoting or deterring seniors living with dementia – and their circle of care – from accessing ACP, practice should include the delivery of ACP KT tools, and policy deliberations should engage numerous stakeholders and adopt a multidisciplinary approach.

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