

An Analysis of Documents Guiding Palliative Care in Five Canadian Provinces*

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RÉSUMÉ

Cette étude avait pour but d'analyser le niveau de concordance et la portée du contenu en matière de soins palliatifs dans les documents directeurs de haut niveau visant les soins pour les personnes résidant en centres de soins de longue durée au Canada. Une recherche systématique a été menée en vue d'analyser les documents de niveau national et ceux provenant de cinq provinces (Alberta, Ontario, Saskatchewan, Manitoba, Québec). Vingt-cinq documents ont été sélectionnés en fonction des critères d'inclusion à partir de 273 documents identifiés dans la recherche systématique. La majorité de ces documents ont été créés sur le plan national (48 %) ou en Ontario (28 %). Les sujets abordés variaient en matière de soins palliatifs et les soins de longue durée n'étaient que minimalement traités. Un nombre restreint de documents directeurs sur les soins palliatifs ont été relevés. Aucun de ces documents ne traitait spécifiquement des soins de longue durée, et les documents identifiés manquaient d'uniformité en matière de soins palliatifs. Il est essentiel que les principes encadrant les soins palliatifs soient présentés et concordants dans les documents directeurs afin d'améliorer la qualité de vie et les soins pour les résidents en soins de longue durée à travers le Canada.

ABSTRACT

The purpose of this study was to analyse the consistency and extent of palliative content across high-level guiding documents related to the care of persons residing in Canadian long-term care homes. A systematic search was conducted examining documents at the national level and across five provinces (Alberta, Ontario, Saskatchewan, Manitoba, and Quebec). Twenty-five documents were selected based on inclusion criteria from 273 documents identified in the systematic search. The majority of these documents were created nationally (48%) or in Ontario (28%). Documents varied in palliative topics discussed, and long-term care was discussed minimally. A minimal number of palliative care guiding documents were found. Long-term care specific documents were absent, and all documents lacked consistency on palliative topics. It is imperative that palliative principles are present and consistent in high-level documents in order to improve the quality of life and care for long-term care residents across Canada.

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There is an increasing need for palliative care in Canada as our health care system responds to an aging and clinically complex population. As a result, there are a growing number of older Canadians entering long-term care (LTC) homes (Statistics Canada, 2016). LTC homes provide a range of services including nursing care and assistance with activities of daily living to the adults residing in them (Service Ontario, 2017).

As per the 2011 Canadian census, 4.5 per cent of the population over the age of 65 years was living in an LTC home (Statistics Canada, 2015). Many residents will live out their last days of life in LTC homes. Therefore, there is a need to ensure that these facilities have the capability to deliver quality palliative care to residents.

The provision of palliative care in Canada is guided by policies that exist at varying levels of government and within organizations. These policies provide a framework and guidelines for the delivery of palliative care in clinical practice. However, inconsistencies among palliative care guidelines in high-level guiding documents could result in suboptimal patient care, as further inconsistencies could be created in lower level documents (Venturato, Kellett, & Windsor, 2007). Documents need to ensure consistency across levels to avoid discrepancies in care and to ensure that optimal palliative care is provided to individuals residing in LTC homes throughout Canada.

The national model for hospice palliative care proposed by the Canadian Hospice Palliative Care Association (CHPCA) (Canadian Hospice Palliative Care Association, 2013) can be used as a guide to evaluate both the holistic nature of documents and whether the CHPCA model domains are maintained throughout varying levels of documentation. In this model, the Square of Care is a conceptual framework proposed by the CHPCA (Canadian Hospice Palliative Care Association, 2013) to reinforce the process of patient and family care in several essential palliative care domains.

Little is known about the characteristics of current Canadian palliative care guiding documents and whether they support the holistic nature of palliative care. By examining the extent to which documents address palliative care domains and the type of content covered, through use of the CHPCA Square of Care

model, key areas in need of further development can be identified and inconsistencies eliminated. This would help to guide future work when creating palliative care guiding documents. This would have the potential to improve palliative care for residents in LTC homes across Canada, as best practices are more likely to be clear and maintained throughout the varying levels of documentation (Venturato et al., 2007).

The purpose of this article is to provide an understanding of the current characteristics of Canadian national and provincial palliative care documents, address the provision of these documents in guiding palliative care in LTC homes, and evaluate if the domains of the conceptual Square of Care model are addressed and consistent throughout the varying levels of care guiding documentation.

Barriers to Delivering Palliative Care in LTC Settings

Literature suggests that there are several barriers that prevent LTC facilities from pursuing a palliative approach to care. For example, families of dying residents in LTC facilities have identified pain management and comfort care as the highest priority for care (Vohra, Brazil, Hanna, & Abelson, 2004). However, many family and resident needs are not met because of a lack of training/education, poor communication among interdisciplinary team members, and inadequate assessments (Estabrooks et al., 2015; Huskamp, Kaufmann, & Stevenson, 2012). Lack of training, knowledge, and communication leads to poor pain and symptom management as well as late implementation of palliative care strategies (Huskamp et al., 2012).

Organizational factors within LTC facilities also have a significant and direct impact on the quality of care (Estabrooks et al., 2015). Factors including leadership, management, and the culture of the environment all contribute to the quality of care given to residents at the end of life (EOL) (Estabrooks et al., 2015). Practical barriers, such as a lack of time, funding, staff, and other resources also hinder the ability of LTC facilities to identify palliative care needs among residents early on (Estabrooks et al., 2015; Huskamp et al., 2012; Kayser-Jones, Schell, Lyons, Kris, Chan, & Beard, 2003). Inadequate staffing and time constraints have led to

poor advance care planning (ACP) among LTC residents (Ampe, Sevenants, Smets, Declercq, & Van Audenhove, 2016, 2017; Huskamp et al., 2012). Literature suggests that health care professionals (HCP) engage in ACP discussions at the time of resident admission but fail to continue these conversations as the resident-care provider relationship progresses (Ampe et al., 2016). In cases in which ACP is discussed, the emotional and psychological state of patients and families is often unacknowledged (Ampe et al., 2016). A lack of clear guidelines and organizational policies, as well as the reluctance of HCPs to adhere to existing guidelines contribute to poor ACP engagement (Ampe et al., 2016; Silvester et al., 2013). Adjusting these modifiable organizational factors through the introduction of new policies, committed to delivering a palliative approach, can have positive effects on symptom management in chronic illness and at the EOL (Estabrooks et al., 2015). Therefore, it is evident that policies and procedures regarding ACP and other palliative care discussions need to be re-evaluated and standardized across sectors as well as strongly enforced by organizations to improve the quality of palliative care delivery.

Improving upon Palliative Care Delivery in LTC Homes

Problematic barriers influencing the provision of palliative care in LTC can be overcome through the implementation of a structured set of policies. For example, the implementation of a gold standard framework at local or provincial levels directing the provision of palliative care, especially in the LTC setting, can improve quality of life (Badger, Clifford, Hewison, & Thomas, 2009; Estabrooks et al., 2015; Kinley, Froggatt, & Bennett, 2013). A systematic review assessed the impact of implementing a gold standard framework and integrated care pathway for documents in LTC homes in the United Kingdom (Kinley et al., 2013). These tools were meant to guide the provision of palliative care specifically in the LTC setting. The implementation of these tools resulted in positive outcomes for HCPs and residents (Kinley et al., 2013). The tools helped identify resident needs, encouraged discussions regarding EOL preferences and supported a multidisciplinary approach. The implementation of such policies can also potentially increase the number of in-home deaths in LTC settings, facilitate the development of ACPs and decrease unnecessary hospital admissions or deaths (Badger et al., 2009; Finucane, Stevenson, Moyes, Oxenham, & Murray, 2013; Miller, Lima, & Mor, 2014; Miller, Tyler, & Shield, 2015). Furthermore, increasing the quality of care in LTC facilities is a more cost-effective strategy for the health care system (Holland, Evered, & Center, 2014; Ontario Health Technology Advisory Committee End-of-Life Collaborative, 2014). Overall, it is evident that the

integration and development of policies specific to the provision of palliative care in LTC facilities can lead to HCPs and teams being better trained in palliative care and enhance the quality of care provided in LTC homes (Kaasalainen et al., 2013; Radwany, Albanese, Hoiles, Hudak, & McGranahan, 2013).

Although there are many advantages to developing policies, guidelines and tools to address palliative care, these endeavors will be ineffective if the gap between policy and practice is not addressed (Venturato et al., 2007). Introducing new policies into practice, without consideration for the implementation process, resources, and training for staff can be met with resistance, rendering the effort unsuccessful (Venturato et al., 2007). Therefore, it is important to consider logistical factors and come to a consensus on a shared strategy for the improvement of palliative care. In recent years, new policies have been introduced in an attempt to improve and guide palliative care. However, the extent to which these policies are consistent across sectors and support one another in their vision and strategies for improving palliative care is unknown.

Methods

A document analysis was completed to describe current characteristics of national and provincial palliative care guiding documents and to gain an understanding of what domains of the Square of Care are addressed within current palliative care guiding documents pertaining to LTC. A document analysis involves completing a systematic process of retrieving and analysing documents (Bowen, 2009). Document analysis designs often utilize a content analysis methodology when analysing data. Therefore, this method of analysis was used in this study (Bowen, 2009; Elo & Kyngas, 2007). Content analysis is a process of data analysis, which provides a description and quantification of the data collected (Elo & Kyngas, 2007).

As part of a larger project, Strengthening a Palliative Approach in Long-Term Care (SPA-LTC), an analysis of documents pertaining to palliative care in LTC homes across five provinces in Canada (Ontario, Alberta, Saskatchewan, Manitoba, and Quebec) and nationally was undertaken. These provinces were chosen based on their connections with the overall SPA-LTC project. Further to this, the study design and methodology for this document analysis was informed by one of the lead authors (L.V.), who has previously created a structured approach to identifying and examining varied levels of documents and policies (Venturato, Moyle, & Steel, 2011).

Documentation Matrix and Analytical Framework

In this document analysis, high-level care guiding documents pertaining to palliative care were searched for

utilizing the Documentation Matrix and Analytical Framework created by Venturato et al. (2011). This framework was modified for this document analysis and can be found in Figure 1. This study is particularly concerned with Level 1 Guiding Documents and therefore searches targeted policy documents and palliative care guiding documents. Legislative documents were not included in this document analysis, as this study focuses on policy and palliative care guidelines applicable to LTC, whereas legislative documents are focused on written laws created by the government (Government of Canada, 2006). Although legislation was not analysed, government associations were included in searches for policy and palliative care guiding documents in LTC.

Square of Care and Identified Palliative Topics

All documents were assessed based on their content/discussion related to eight Square of Care “common issue” domains (i.e., complications typically experienced by patients and caregivers) including disease management; physical, psychological, social, spiritual, practical, and EOL/death management; and loss/grief (Canadian Hospice Palliative Care Association, 2013). A summary of the definition of these common issue domains can be found in Table 1.

Additional palliative care themes and topics emerged through researcher triangulation whereby three researchers completed a trial data extraction of an exemplary palliative care guiding document using

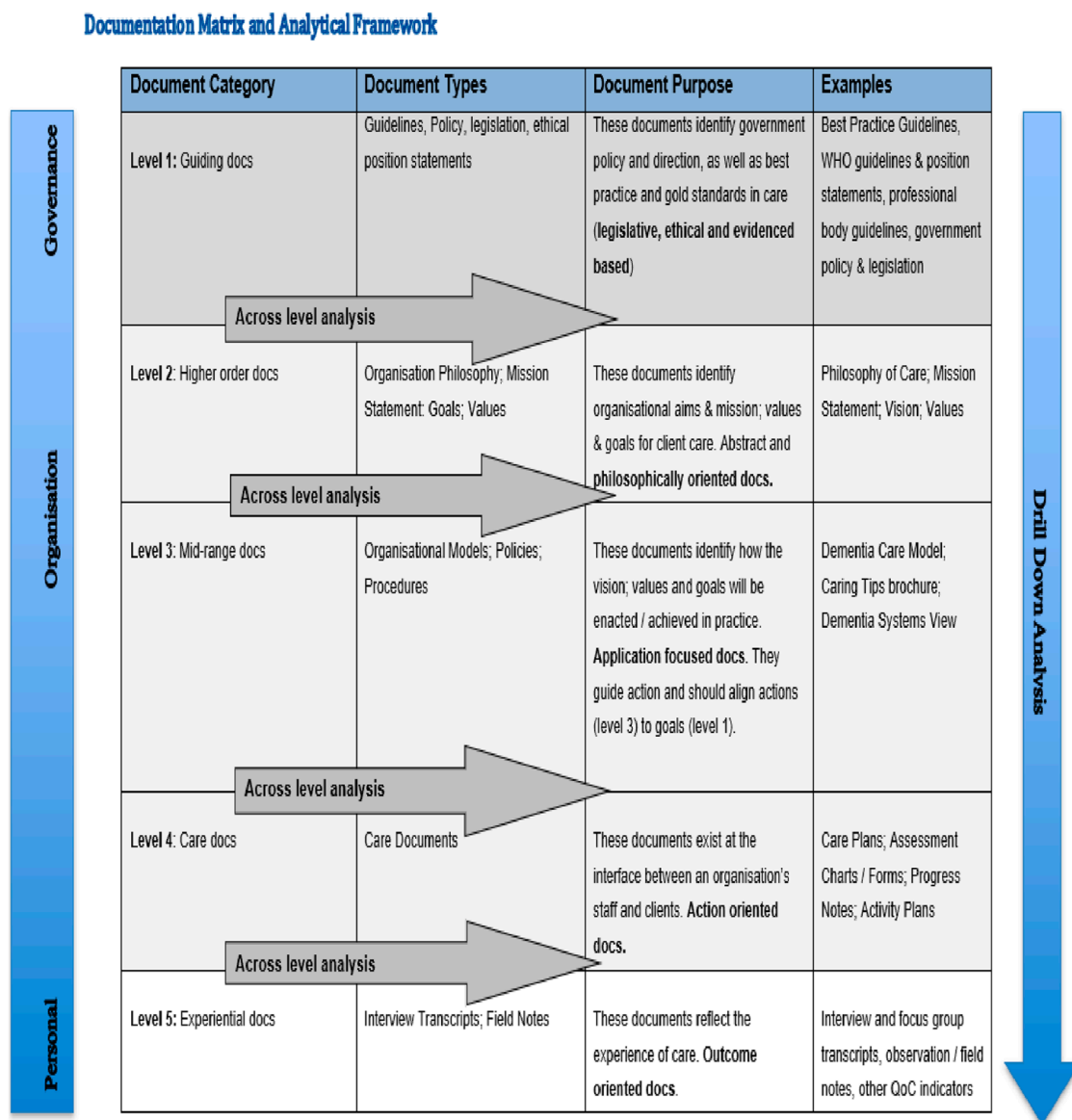


Figure 1: Depiction of the documentation matrix and analytical framework that defined various documents and guided searches in across level document analysis (Venturato et al., 2011)

Table 1: Canadian Hospice Palliative Care Association (2013) Square of Care Common Issue Domain definitions

Domain	Definition
Disease Management	Characterized by issues related to diagnosis, co-morbidities, and adverse events
Physical	Centers around pain and symptom management, maintaining cognition, and physical care
Psychological	Focuses on behaviour, emotional care, independence, conflict, and self-image
Social	Defined by cultural aspects of care, caregiver support, environment, privacy, and financial issues
Spiritual	Focuses on beliefs, patient values, and rites or rituals
Practical	Focuses on activities of daily living, dependence, and transportation
End of Life/Death Management	Revolves around life closures, management of physiological changes, and preparation for death
Loss/Grief	Focuses on the bereavement and mourning aspects of palliative care

Square of Care domains (Fraser, 2016). Emerging topics and themes agreed upon by the researchers were then included as categories on the data extraction template, supplementing the Square of Care domains. The topics that emerged from this process were assessed in the 25 documents identified in the literature search. These additional topics included policy and governance, quality management/accountability, rights/ethics (residents, families, staff), improving access and equity, developing caregiver supports, comprehensive palliative care program across sectors, and ACP. An “other” category was added to the additional palliative care topics to extract and describe content related to HCP education, policy issues, and EOL services, as these topics were addressed by multiple documents.

Search Strategy and Inclusion Criteria

To obtain guiding documents, a systematic search strategy was developed with the assistance of the McMaster University Health Sciences librarian. This strategy included searching two databases, the Canadian Health Research Collection and the Canadian Public Policy Collection. Following searches of these databases, further documents from palliative care associations, professional associations, and government organizations were accessed and screened. Professional associations pertained to social workers, registered nurses, physicians, and spiritual care practitioners. These were chosen as they are practitioners of regulated health professions most likely to be found in LTC. Searches were conducted using the same standardized search terms “palliative care”, “end of life”, and “long-term care”, and the same inclusion/exclusion criteria.

The inclusion criteria were developed by the research team and are listed here:

1. Created within the last 10 years (2007–17)
2. Palliative care focus
3. Applicable to LTC
4. High-level care guiding document
5. Canadian document
6. Applicable nationally or to one of the five included provinces

Documents published in the last 10 years were included because they were considered to be relevant, recent documents that were most likely to be currently in use. Documents were excluded if they did not meet inclusion criteria.

Professional associations, palliative associations, and government organizations were also contacted via e-mail to provide suggestions for possible high-level palliative care guiding documents. Those that were accessible via external Web sites and met the inclusion criteria were included. Palliative care experts were also approached for recommendations on high-level care guiding documents when documents could not be uncovered via the professional organization searches. Finally, associations and organizations for which documents were found that could not be accessed were e-mailed directly for assistance in accessing these identified documents.

Documents were initially collected and double-screened for inclusion criteria by two reviewers to ensure inter-rater reliability. A kappa calculated between the two reviewers based on the 206 documents demonstrated high consistency ($\kappa = .869$) in screening articles for inclusion. Reviewers then went on to screen additional documents independently. Any disagreements about documents to be included were resolved by a third reviewer.

Data Extraction and Directed-Content Analysis

Data were extracted and analysed from documents using a predetermined coding template for directed-content analysis (Hsieh & Shannon, 2005). Three research team members (C. H, S. K., P. D.) collaborated to create the template using categories from the CHPCA Square of Care Model to Guide Palliative Care (2013) as codes. The “common issues” section of the Square of Care was focused on because it highlights experiences that are typically experienced by patients and their families. Researchers trialed the template by coding an exemplary palliative care document by Fraser (2016) and added additional categories to fit the data (Hsieh & Shannon, 2005). A pre-extraction phase was completed with two

researchers coding the same 10 documents using the template to ensure agreement ($\kappa = .872$). Researchers then went on to code and extract data independently using the template. New codes were created to accommodate additional themes or categories as they emerged (Hsieh & Shannon, 2005; Patton, 2015).

Documents were coded “present” or “not present” and quotes from the documents were extracted as proof of this. Results were analysed utilizing a content analysis approach in which code frequency is calculated and patterns or themes are explored across documents (Hsieh & Shannon, 2005; Patton, 2015). Through researcher triangulation, team members further discussed and confirmed the emerging findings and their implications (Hsieh & Shannon, 2005; Patton, 2015).

Results

The literature search of the Canadian Health Research & Canadian Public Policy Collection databases resulted in 206 documents. Additionally, the literature search of the professional, palliative, and government organizations resulted in 145 documents. Following removal of duplicates, 273 records were initially screened for inclusion utilizing the identified inclusion criteria, and 33 documents were found to be eligible for inclusion. Documents were excluded when they did not fit inclusion criteria. A final total of 25 high-level palliative care guiding documents were included. A Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flowchart can be found in Figure 2 (Moher, Liberati, Tetzlaff, & Altman, 2009).

Characteristics of Documents

The 25 documents have varying characteristics based on origin, reason for creation, and whether the developer was a provincial or national association. The characteristics of these documents are outlined in Table 2. Eight of the 25 documents were created by government organizations, whereas 9 of these documents were created by professional organizations. Seven documents were created by palliative care associations and one document was attributed to the “other” category; this document was created by the Canadian Institute for Health Information (2007) and focused on EOL care in Western Canada.

Approximately half of the documents ($n = 12$) stem from national organizations. The remaining 13 documents were created provincially. Table 2 depicts descriptions of documents among the five provinces, with Ontario having the highest number of documents ($n = 7$). Fewer documents were found in Alberta ($n = 3$), Quebec ($n = 2$), and Manitoba ($n = 1$). No high-level palliative care guiding documents were

found in Saskatchewan that fit the inclusion criteria for this study, despite the comprehensive search and outreach to associations/organizations within the province.

Reasons for document creation varied among three pre-defined categories stemming from literature, including the need to address clinical issues arising in care ($n = 7$), new evidence ($n = 4$) and “other” reasons ($n = 19$). During analysis, these “other” reasons emerged and were found to consist of palliative care policy/guideline development ($n = 6$) and health care system issues ($n = 11$). Two documents were categorized as “other” and were created for such reasons as needing a framework to outline the steps needed to reach a palliative care vision and for quality improvement through health care professional education (Canadian Medical Association, 2014; Quality Hospice Palliative Care Coalition of Ontario, 2011). Further to this, in some cases documents were created for more than one reason.

Clinical issues that stimulated the development of new guiding documents included, for example, patients’ and families’ delayed access to palliative care until late in the illness trajectory, ineffective pain management, and the need for palliative education for HCPs (Canadian Hospice Palliative Care Association, 2010; Carstairs, 2010; Cooper et al., 2013). Documents were created in response to new evidence and trends surrounding hospital and pharmacy services during Canadians’ last year of life, place of death, and evolving best practice guidelines (Canadian Institute for Health Information, 2007; Ontario Health Technology Advisory Committee End-of-Life Collaborative, 2014; Registered Nurses Association of Ontario, 2011).

Table 3 depicts the number of documents addressing each Square of Care domain and the additional palliative care topics, as well as contrasting areas of focus among documents, based on their origin. Social issues were addressed in 19 (76%) of the documents, making this the most commonly discussed domain. The psychological and loss/grief domains closely followed and were touched on by 16 (64%) of the documents. The domains that were least addressed by these guiding documents were disease management and EOL/death management.

The additional palliative care topic of quality management and accountability was addressed most frequently in 21 (84%) documents. Examples of quality management and accountability topics are HCP knowledge and skills, setting provincial quality standards, and ensuring that quality palliative care is available to all Canadians (Canadian Hospice Palliative Care Association, 2010; Carstairs, 2010; Quality Hospice Palliative Care Coalition of Ontario, 2010). Supporting public

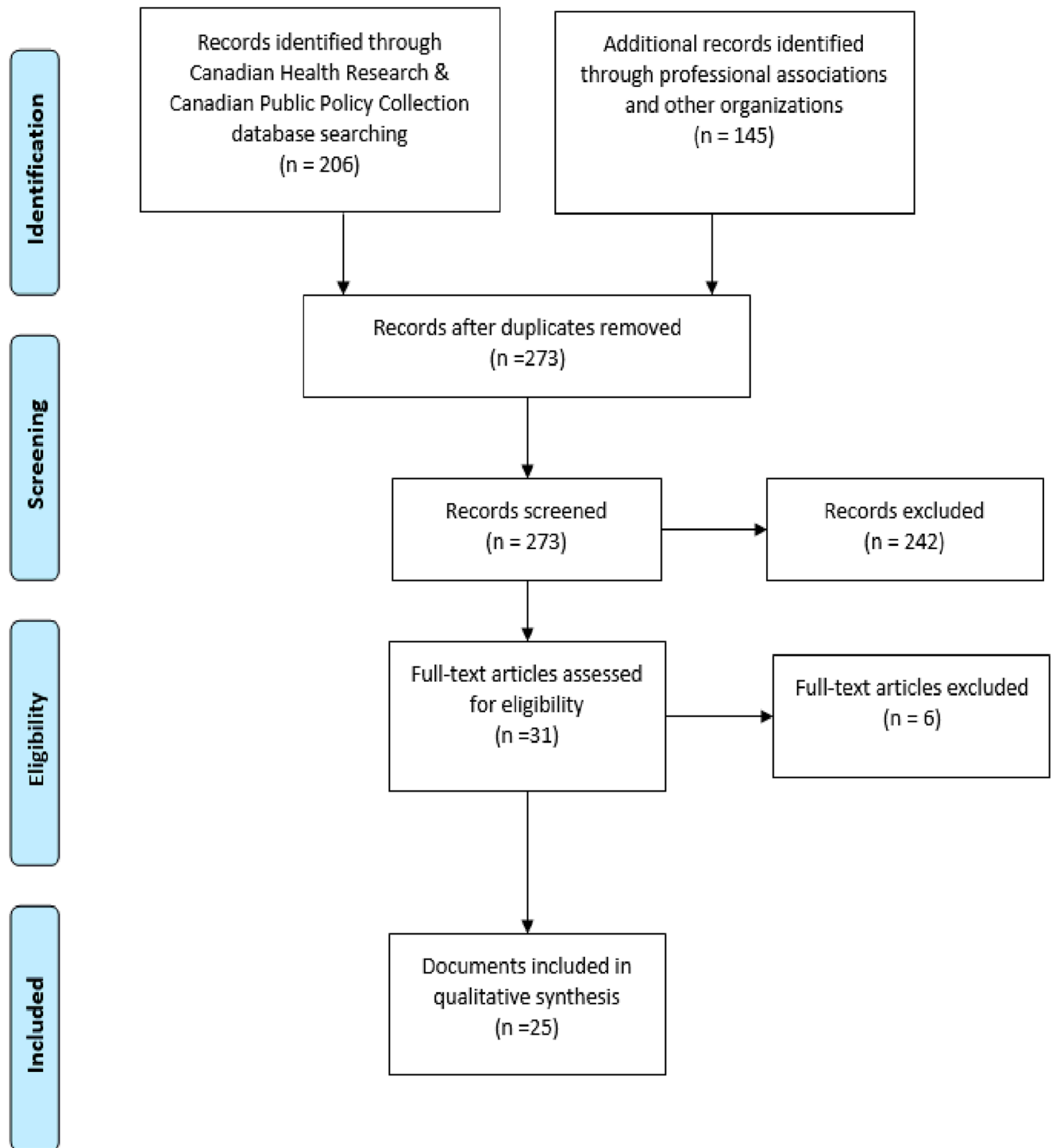


Figure 2: PRISMA flow chart depicting systematic search and selected documents (Moher et al., 2009)

education was the least frequently addressed additional palliative care topic with 10 (40%) documents touching on this topic. The ten documents that discussed supporting public education on palliative care proposed numerous strategies such as national public awareness campaigns and improving public awareness

of ACP (Canadian Medical Association, 2014; Parliamentary Committee on Palliative and Compassionate Care, 2011).

Table 3 also depicts differences in document content found among the three analysed categories of associations:

Table 2: Palliative care guiding documents characteristics

Characteristic		Documents n = 25
		n (%)
Origin/ Developer	Palliative care association	7 (28%)
	Government organization	8 (32%)
	Professional association	9 (36%)
	Other	1 (4%)
Provincial or national origin	Saskatchewan	0
	Manitoba	1 (4%)
	Quebec	2 (8%)
	Alberta	3 (12%)
	Ontario	7 (28%)
	National	12 (48%)
Reason for document creation	New evidence	4 (16%)
	Clinical issue	7 (28%)
	Palliative care policy/ guideline development	6 (24%)
	Health care system issue	11 (44%)
	Other	2 (8%)

Note. Reasons for document creation exceed a summative total of 100 per cent, as some documents were created for multiple reasons.

(1) palliative, (2) professional, and (3) government. Although these organizations all have different purposes, they all develop documents to guide care.

Examples of these associations include, respectively, the CHPCA, Registered Nurses Association of Ontario (RNAO), and Alberta Health Services. Overall, the palliative association documents addressed the additional palliative topics the most (75%), in comparison with the professional or government documents. Seven (100%) of the palliative association documents addressed the topics of quality management/accountability, improving access and equity, and comprehensive palliative care programs across sectors. Further to this, improving access and equity was also a focus in professional association documents, addressed by eight (88%) documents. Square of Care domains were addressed the least frequently (32%) by palliative associations, with disease management and EOL/death management only touched upon by one document each.

Professional associations focused on the Square of Care domains, addressing 63% of domains. In particular, eight (88%) of the professional association documents concentrated on social issues, and seven (77%) addressed the physical and psychological domains. Supporting public education and the practical domain were the least addressed topics by the professional associations. Overall, the government organizations' focus appeared to be on the additional palliative topics, addressing 72% of these areas. In particular, government organizations addressed the social domain and quality management/accountability in all eight (100%) documents. The least addressed topic by government

Table 3: Square of Care and additional palliative topics: Professional, palliative, and government documents n = 25

Square of Care Domain	Palliative Associations No. of Documents n = 7	Professional Associations No. of Documents n = 9	Government Organizations No. of Documents n = 8	Other Document n = 1 (%)	Total Documents Addressing Content n=25 (%)
Disease Management	1	4	2	1	8 (32%)
Physical	2	7	4	1	14 (56%)
Psychological	2	7	6	1	16 (64%)
Social	3	8	8	0	19 (76%)
Spiritual	2	5	4	0	11 (44%)
Practical	2	3	5	0	10 (40%)
End of Life/ Death Management	1	5	1	0	7 (28%)
Loss/ Grief	5	6	4	1	16 (64%)
Total domains addressed n (%)	18 (32%)	45 (63%)	34 (53%)	4 (50%)	
Additional Palliative Care Topics					
Support public education	4	3	3	0	10 (40%)
Policy and governance	6	5	6	1	18 (72%)
Quality management/ Accountability	7	6	8	0	21 (84%)
Rights/ Ethics (residents, families, staff)	3	6	4	0	13 (52%)
Improve access and equity	7	8	6	0	21 (84%)
Develop caregiver supports	5	5	7	0	17 (68%)
Comprehensive palliative care program across sectors	7	4	6	1	18 (72%)
Advance care planning	4	6	6	0	16 (64%)
Other	4	1	6	1	12 (48%)
Total addl. topics n (%)	47 (75%)	44 (54%)	52 (72%)	3 (33%)	

organizations was EOL/death management, with one document addressing this domain of the Square of Care.

Included Documents and LTC

All 25 documents were assessed as to whether LTC was addressed specifically, and with what frequency the term “long-term care” was mentioned. Table 4 provides a summary of the number of times LTC is mentioned in each document as well as the target audience, the purpose of the document, and, when substantive content was available, an example of the topics discussed related to LTC was provided. Twenty-three (92%) documents were found to mention LTC in the documents and the number of times LTC was mentioned varied significantly among documents. For example, five documents were found to only cite this term once (Canadian Hospice Palliative Care Association, 2013; Canadian Nurses Association, 2015; Cooper et al., 2013; Ministère de la Santé et des Services Sociaux, 2016; Ontario Medical Association, 2014). Four documents were found to cite LTC, 41, 45, 48, and 117 times (Canadian Hospice Palliative Care Association, 2014; Canadian Institute for Health Information, 2007; Parliamentary Committee on Palliative and Compassionate Care, 2011; Quality Hospice Palliative Care Coalition of Ontario, 2010). Although LTC was mentioned in most documents, its role in palliative care was discussed minimally. A typical citing is represented by the following quote. “At present, there is strong support for the development and implementation of an integrated palliative approach to care. Integration effectively occurs: throughout the disease trajectory; across care settings (primary care, acute care, **long-term** and complex continuing care, residential hospices, shelters, home); across professions/disciplines and specialties; between the health care system and communities; and with changing needs from primary palliative care through to specialist palliative care teams” (Canadian Medical Association, 2016, p. 4).

Documents that cited LTC at a higher frequency (i.e., 41, 45, 48, and 117 times) discussed in more detail the role of palliative care in LTC (Canadian Hospice Palliative Care Association, 2014; Canadian Institute for Health Information, 2007; Parliamentary Committee on Palliative and Compassionate Care, 2011; Quality Hospice Palliative Care Coalition of Ontario, 2010). One of these higher frequency documents, known as the “The Way Forward” document, outlined several key aspects to improving palliative care in LTC homes specifically, such as building connections with palliative care programs and changing staffing ratios when an individual is at the EOL (Canadian Hospice Palliative Care Association, 2014). Overall, very few documents specifically discussed in detail the role of palliative care in LTC.

Discussion

The purpose of this document analysis was to complete an across-level analysis of policy guiding documents pertaining to palliative care in LTC, nationally and across five provinces in Canada. In this analysis, documents were analysed for their characteristics, provision to guide palliative care in LTC, and ability to satisfy the “common issues” domains of the Square of Care, as well as commonly addressed palliative care topics (Canadian Hospice Palliative Care Association, 2013). Care guiding documents should be addressing the Square of Care domains, in particular, as these issues are typically experienced by residents and families. Furthermore, these documents aim to guide HCPs in providing high-quality care (Canadian Hospice Palliative Care Association, 2013).

Twenty-five documents that were palliative care guidelines and policy statements, from five provinces, were included in this review. This small number of guiding documents is of concern, as it indicates the lack of policy documents that exist across Canada on palliative care. Not only is there a low number of documents overall in Canada to guide palliative care in LTC, but this number also varies significantly depending on the province being analysed, as one province was found to have no guiding documents. This lack of policy documents in some provinces may be the result of there being fewer resources available. For example, some provinces appear to have fewer province-specific palliative associations when compared with Ontario (which had the highest number of documents provincially). Further to this, palliative care is a growing field in Canada that has often been set to the side in the health care system, which may be the cause of the lack of development of province-specific documentation (Williams et al., 2010). A final characteristic of these documents that stood out was the reason for the documents’ creation. Eleven (44%) of these 25 documents were created for the development of policies to address health care system issues. When guiding documents are created in response to issues, they are reactive and not proactive in guiding the development of palliative care in LTC. Although these documents appear to be created with a reactive intent, it is important that they are developed, as these health policies and guidelines are needed as a structure to accelerate palliative care development in Canada (Williams et al., 2010). The development of these few found documents to address these care issues is a step towards improving patient- and family-centred palliative care in Canada.

With regard to the Square of Care “common issues” domains, the documents were found to satisfy some aspects of these domains, but failed to address others. For example, the guiding documents addressed the

Table 4: Target audience, purpose, and number of times LTC was cited $n = 25$

Author	Target Audience	Purpose of Document	Number of Times LTC is Mentioned	Example
Bosma et al. (2008)	Health care professionals, educators, researchers	Outline practice guidelines for social workers within hospice palliative care	0	Not applicable
Canadian Hospice Palliative Care Association (2010)	Administrators, health care professionals, educators, researchers, policy makers	Encourage discussion and a systems approach to the issue of providing high quality end of life care	11	"Hospice palliative and end-of-life care will be integrated into all settings where people may die, including but not limited to: residential hospices, hospice palliative care units, acute care, long-term care facilities... and day hospice programs." (p. 4)
Quality Hospice Palliative Care Coalition of Ontario (2010)	Administrators, policy makers	To inform and advise policy makers (i.e., Ministry of Health and Long-Term Care [MOHLTC]) on the implementation of an integrated model for care, and continue to improve quality of palliative care	45	"A well-developed program of Hospice Palliative Care is required in all care settings where patients die... These care settings include acute care, complex continuing care, long term care, residential hospices as well as care in the patients' home." (p. 58)
Carstairs (2010)	Administrators, health care professionals, educators, researchers, policy makers	Outline goals for palliative care in Canada and make recommendations	6	"More and more, seniors are dying in long-term care facilities. Yet there is no consistency across the country in terminology, facilities, funding models, standards of care, education or training for long-term care facilities." (p. 13)
Canadian Institute for Health Information (2007)	Administrators, health care professionals, researchers, policy makers	Described aspects of care provided in the last year of life to residents who died in Canada's Western provinces	48	"Embark on a sustained quality improvement program to ensure that hospice palliative care services are working effectively in long-term care homes across Ontario." (p. 12)
Cooper et al. (2013)	Health care professionals, educators, researchers	Provide recommendations for standards on the practice of spiritual care at the end of life	1	"In long term care rituals are created for staff and other residents wishing to mark residents' deaths." (p. 52)
Ontario Health Technology Advisory Committee End-of-Life Collaborative (2014)	Health care professionals, educators	To improve end of life care and inform the development of interventions to improve end of life care	5	"This project emerged from a request by the Ministry of Health and Long-Term Care that HQO provide them with an evidentiary platform on strategies to optimize the care for patients with advanced disease, their caregivers (including family members), and providers." (p. 9)
Parliamentary Committee on Palliative and Compassionate Care (2011)	Administrators, health care professionals, educators, policy makers	Provide recommendations to improve care for vulnerable populations in areas of palliative care, pain control, funding for home, LTC services, caregiver support, suicide prevention, and elder abuse.	117	"We recommend the development of rural palliative care delivery within the primary health care system, utilizing home care services, and local long term care homes; allowing care to be delivered in or close to a person's home community." (p. 15)
Canadian Nurses Association (2015)	Administrators, health care professionals, educators, researchers	To provide guidance to nurses and to inform nursing practice	1	"Palliative care is provided in all primary care settings, including homes, ambulatory clinics and other community settings, and in all tertiary care settings, including hospitals, hospices and long-term care facilities." (p. 2)
Collège des Médecins du Québec (2016)	Health care professionals	Provide guidance to physicians when caring for patients in the last days of life	5	"When a patient is seen for an acute exacerbation of his pain, irrespective of the care setting (emergency department, home, long-term care facility, etc.), the patient must be given immediate relief if he is dying." (p. 19)
Fraser (2016)	Administrators, health care professionals, educators	To support the development of a comprehensive strategy for palliative and end of life care in Ontario; to improve access and equity of palliative care to all Ontarians	21	"In a palliative care system that values caring for patients where they live, more should be done to provide access to high-quality palliative care in long-term care homes." (p. 15)

Continued

Table 4: Continued

Author	Target Audience	Purpose of Document	Number of Times LTC is Mentioned	Example
Manitoba Health (2014)	Administrators, health care professionals, educators	A 5 year blueprint to support and build a sustainable health care system	7	"Based on past patterns, and considering the aging of the baby boomers (ex: those born between approximately 1946 and 1964), the demand for long term care will increase exponentially." (p. 3)
Canadian Hospice Palliative Care Association (2013)	Administrators, health care professionals, educators, researchers	A revision of the Model to Guide Hospice Palliative Care to reflect current practice and provide principles and norms of practice	1	Not applicable
Alberta Health Services (2014)	Administrators, health care professionals, educators, researchers, policy makers	Identify strategies to improve Palliative and End of Life Care (PEOLC) services	8	"At this time, many residents of long-term care will die within their facilities." (p. 26)
Canadian Medical Association (2014)	Health care professionals, educators, public, policy makers	To inform medical professionals on the public's view on palliative care	0	Not applicable
Provincial End of Life Care Network (2010)	Administrators, health care professionals, educators, policy makers	Provide guidelines that can be used to develop regional systems of hospice palliative care	9	"IT/IM considerations include central access to the same systems by all relevant health care workers...in all care settings (home/community, residential hospice, long term care and hospital)." (p. 14)
Alberta Health (2016)	Administrators, health care professionals	Set the standards on care for the continuing care system	15	"The continuing care system encompasses the Co-ordinated Home Care Program, Publicly Funded Supportive Living Facilities and Long-Term Care Facilities." (p. 3)
College and Association of Registered Nurses of Alberta (2013)	Administrators, health care professionals, educators, researchers	Identify care guiding principles for older adults in Alberta	13	"Continuing care services are delivered in three streams: home living, supportive living and facility living (long term care)." (p.12)
Quality End-of-Life Care Coalition of Canada (2010)	Health care professionals, educators, researchers	Develop a framework for action in Canada on end of life care issues	7	"High quality palliative and end-of-life care must be an integral part of health care, and available in all settings of care, including hospital, long-term/continuing care, residential hospices, shelters and individual homes." (p. 3)
Registered Nurses Association of Ontario (2011)	Administrators, health care professionals, educators, researchers, policy makers	Provide best practice guidelines for registered nurses and registered practical nurses on end of life care	10	"Consequently, health-care professionals may not associate a palliative approach to care to their particular setting on a busy acute unit or long-term care setting." (p. 15)
Ontario Medical Association (2014)	Administrators, health care professionals, educators, researchers, public, policy makers	Provide a framework to improve end of life care in Ontario	1	"Supportive services at home, like Meals on Wheels and home health aides, then institutional long-term care facilities are central to good care for this trajectory." (p. 3)
Quality Hospice Palliative Care Coalition of Ontario (2011)	Administrators, health care professionals, educators, researchers, public, policy makers	Outline and provide steps for advancing palliative care in Ontario	29	"There is a shortage of health care professionals and volunteers with training in palliative care, grief and bereavement support. This includes a lack of expertise and specialized resources for long-term care homes and primary care settings." (p. 19)
Canadian Medical Association (2016)	Health care professionals	Provide guidance on palliative care to physicians	2	Not Applicable
Canadian Hospice Palliative Care Association (2014)	Administrators, health care professionals, educators, researchers, policy makers	Provide guidance in integrating a palliative approach to care in Canada	41	"The services hospice palliative programs provide for people dying at home, such as volunteer visiting, should also be available for people in long-term care facilities." (p. 41)
Ministère de la Santé et des Services Sociaux (2016)	Health care professionals, educators, researchers	Outline strategies to improve the availability and delivery of palliative care in Quebec	1	Not applicable

social, physical, loss/grief, and psychological aspects of Square of Care in more than 50 per cent of all documents. However, disease management and EOL/death management were addressed the least. These findings are congruent with a similar study by Durepos et al. (2017) that explored the palliative content in dementia care guidelines utilizing the Square of Care model (Canadian Hospice Palliative Care Association, 2013). For example, Durepos et al. (2017) found that the physical, psychological, and social care domains of care were addressed often whereas EOL/death management and disease management were addressed the least (Durepos et al., 2017). Where our findings contrast with those of Durepos et al. (2017) is in the loss/grief and disease management domains. Durepos et al. (2017) found that the least-cited domain in the analysed guidelines was loss/grief, whereas the maximum available content on disease management appeared there. It is possible that disease management was addressed least in the high-level documents analysed for our study because they aim for broad applicability to multiple disease states, in contrast to Durepos' sample of documents, which focused entirely on dementia. Furthermore, it is possible that issues of disease management are more likely to be discussed in lower-level or organizational policies than in higher-level guiding documents.

Although the four domains of psychological, physical, social, and loss/grief were addressed more than 50 percent of the time in high-level care guiding documents, the four other common issue domains of spiritual, practical, EOL/death management, and disease management fell short. The Square of Care model is a nationally proposed strategy to address issues and provide high-quality palliative care (Canadian Hospice Palliative Care Association, 2013). Further to this, the Square of Care is built on national principles and practice standards, which should be addressed in order to ensure consistent and quality palliative care for residents (Canadian Hospice Palliative Care Association, 2013). The lack of attention to the four other domains of spiritual, practical, EOL/death management, and disease management could lead to inconsistencies in care, as lower levels of care guiding documentation will be inconsistent, resulting in unclear best practices (Venturato et al., 2007). It is necessary for future guiding documents to satisfy these domains so that no discrepancies arise, and consistency is maintained when developing more specific care guidelines and procedures at lower levels of documentation.

Within the three different types of associations analysed (palliative, professional, and government) inconsistencies in documents among associations were identified. For example, reviewed documents from professional associations (social work, nursing,

physicians, spiritual care) were found to meet the Square of Care domains more often than the additional palliative care topics when compared with the palliative and government association documents. These professional association documents addressed more clinical care issues (more documents addressed disease management, EOL/death management and physical domains of Square of Care) when compared with the reviewed documents created by government and palliative associations. Future research is necessary to explore the differences that may exist among high-level guiding documents within professions.

The palliative and government associations had a similar number of documents addressing additional palliative care topics of support for public education, policy and governance, quality management/accountability, rights/ethics, improving access and equity, and creating comprehensive palliative care programs across sectors. However, when examining the Square of Care domains, there is a difference in the number of documents that address these domains between palliative and government organizations. For example, government organizations have more documents addressing the disease management, physical, psychological, social, spiritual, and practical domains of the Square of Care than do palliative associations. These differences among the three different associations highlight inconsistencies existing across these high-level documents, which could greatly augment variations in future documents in lower levels of care guiding documentation. Consequently, this could affect HCPs' delivery of care, as there appear to be differences among palliative, professional, and government associations and their positions on what Square of Care domains are important when creating guiding palliative care documents for LTC (Venturato et al., 2011).

Finally, there was a significant lack of content found in reviewed documents addressing palliative care within the LTC setting. Although LTC was cited in nearly all documents, documents were found to be lacking in specific suggestions about how palliative care should be guided within LTC. Once again, this lack of content specific to LTC, similar to the domains that were addressed the least in the Square of Care, can open the door to inconsistencies in care as documents move from general policy to more specific procedural documents. Guiding documents include setting guidelines and policy pertaining to palliative care. If these documents are not suggesting gold standards of care for LTC residents (i.e., from the CHCPA Square of Care), it may result in sub-optimal care, as these gold standard frameworks and guidelines have been found to improve quality of life (Badger et al., 2009; Estabrooks et al., 2015; Kinley et al., 2013).

Strengths/Limitations

The strengths of this study included a systematic search strategy for both English and French documents, which was adherent to defined *a priori* inclusion and exclusion criteria. Further to this, when documents were unattainable, associations were contacted directly for access to documents or suggestions of available guiding documents. An additional strength of this study was that a kappa was completed during the screening and data extraction phases of the study to ensure inter-rater reliability.

Although there were many positive aspects of this study, there were some limitations as well. In this study, documents were only assessed at the higher guiding document level (excluding legislative documents) and more specific facility organizational and procedural documents were not assessed. Future research will be necessary to analyse inconsistencies with different types of legislative, organizational, and procedural documents. Finally, this study only looked at national documents and those within Ontario, Quebec, Manitoba, Alberta, and Saskatchewan, limiting the generalizability of the results to other Canadian provinces. Future research should be conducted for the purposes of evaluating palliative care documentation pertaining to LTC homes within the provinces and territories not included in this study.

Conclusion

In conclusion, this document analysis has identified new information pertaining to LTC and palliative care guiding documents. Information related to the characteristics of these documents has been outlined, and it has been identified that more province-specific palliative care documents are needed within Alberta, Saskatchewan, Quebec, and Manitoba, with Saskatchewan and Manitoba being in particular need of documents guiding palliative care. Creation of these documents is necessary in order to address province-specific palliative care issues and to ensure high quality palliative care for LTC residents.

A lack of consistency and structure was found among palliative, professional, and government organizations, resulting in inconsistencies among documents. This leaves room for misinterpretation of palliative principles and guidelines, as documents are created at lower levels of documentation, including procedural documents. Associations are challenged to improve this structure among each other, and to provide more consistent documentation, in order to avoid discrepancies in care.

The domains of EOL/death, practical, spiritual, and disease management were found to be addressed the least. Also, it was found that LTC-specific documents

are lacking across all provinces and nationally. It is necessary for organizations to address these lacking domains and to create specific LTC guiding documents to ensure consistency and help guide HCPs in the delivery of care to LTC residents. By ensuring consistent standards of practice through utilizing the Square of Care within policy documents, discrepancies in care should be reduced as more specific LTC home and practice documents are created, thus improving quality of life and care for residents receiving palliative care across Canada.

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