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Cross-Sectional Nutrition Profile of Palliative Home Care Clients in Ontario and Performance of the interRAI Palliative Care Nutrition Clinical Assessment Protocol

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Recommended Citation

Stevens T, Keller H, Williams N, Downar J, Guthrie DM. A cross-sectional nutrition profile of palliative home care clients in Ontario and performance of the interRAI Palliative Care Nutrition CAP. *Journal of Parenteral and Enteral Nutrition* 2021; 45: 183-192. doi: 10.1002/jpen.1827.

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**What should be measured to assess the quality of community-based palliative care?
Results from a collaborative expert workshop**

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Short title: Palliative home care workshop

Manuscript pages: 4,524

Number of tables: 2

Number of figures: 0

What should be measured to assess the quality of community-based palliative care? Results from a collaborative expert workshop

Abstract

Objectives: The need for palliative care (PC) will continue to increase in Canada with population aging. Many older adults prefer to ‘age in place’ and receive care in their own homes. Currently, there is a lack of standardized quality indicators (QIs) for PC delivered in the community in Canada. **Methods:** A one-day workshop collected expert opinion on what should be measured to capture quality PC. Three brainstorming sessions were focused on addressing the following questions: (1) what is important to measure to support quality PC, regardless of setting? (2) Of the identified measures, are any of special importance to care provided in the home? (3) What are the challenges, barriers and opportunities for creating these measures? The National Consensus Project (NCP) for Quality Palliative Care framework was used as a guide to group together important comments into key themes. **Results:** The experts identified four themes that are important for measuring quality, regardless of care setting, including access to care in the community by a multidisciplinary team, care for the individual with PC needs, support for the informal caregiver (e.g., family, friends) and symptom management for individuals with PC needs. Two additional themes were of special importance to measuring quality PC in the home, including spiritual care for individuals with PC needs and home as the preferred place of death. The challenges, barriers and potential opportunities to these quality issues were also discussed. **Significance of results:** PC experts, through this collaborative process, made a substantial contribution to the creation of a standardized set of QIs for community-based PC. Having a standardized set of QIs will enable health care professionals and decision makers to target areas for improvement, implement interventions to improve the quality of care, and ultimately, optimize the health and well-being of individuals with a serious illness.

Keywords: workshop; palliative care; expert opinion; home and community care

Introduction

Canada lacks a standardized method to collect information about the quality of community-based palliative care (PC) (Government of Canada, 2018). Unfortunately, the available evidence is inadequate to support clinical practice guidelines and individual/caregiver needs (Ahluwalia et al., 2018). The identification of appropriate and valid quality measures for PC is at a critical stage in the evolution of the assessment of quality in health care in Canada. The need for PC will increase in Canada with population aging. Many Canadians express a preference for dying at home (Canadian Hospice Palliative Care Association, 2013a). It is therefore a critical time to develop quality indicators (QIs) to assist in addressing possible gaps in care and inform where quality improvement efforts are most needed.

PC is intended to provide optimum quality of life for individuals with serious and life-limiting illnesses and to give support to their informal caregivers (World Health Organization, 2016). In some instances, PC initiatives have been shown to improve quality of life (Temel et al., 2010; Bakitas et al., 2009), but the evidence is mixed (Black et al., 2012; Curtis et al., 2013). To understand whether PC quality initiatives are making a difference, operational definitions are needed to identify the dimensions of PC quality and how they can be measured.

Quality indicators (QIs) are measurable aspects of care that address specific areas of care or a specific outcome. QIs examine the rates of potential issues for a group of individuals to allow for comparisons to be made between health care settings, care providers, or across geographic regions. QIs allow for better understanding of where improvements might be warranted and whether quality improvement strategies are working (Leemans et al., 2015; Bainbridge & Seow 2016). However, they are not definitive measures of quality, but rather serve as a proxy for the quality of care being provided. QIs are intended to support a variety of applications, including

internal continuous quality improvement, comparisons of regions and/or health care settings, external evaluation for accreditation, performance monitoring, and public reporting to enhance transparency for individuals and their families (Hirdes et al., 2004).

Several QIs have been proposed for PC services from a number of countries, including Canada (Grunfeld et al., 2006; Gagnon et al., 2015; Barbera et al., 2006), the United States (Wachterman et al., 2016; Dy et al., 2015), Italy (D'Angelo et al., 2012), and multiple countries in Europe (Woitha et al., 2012), including two systematic reviews (De Roo et al., 2013; Pasman et al., 2009). These QIs tend to use administrative data, focus on the structure/process of care rather than outcomes of care, and are primarily used for individuals with cancer. Consequently, there is a need to assess the applicability of existing QIs for use in community-based PC, and to develop additional measures where necessary to reflect the unique needs of individuals and their informal caregivers. The new QIs would broadly capture all of the key domains that represent what is important to measure when assessing care provided in the home and other community-based settings. Key domains for quality PC have been developed by The National Consensus Project (NCP) for Quality Palliative Care Guidelines in the US. These guidelines are intended to help guide health care organizations on how to improve access to quality PC for all individuals with a serious illness, regardless of prognosis, diagnosis, setting or age (Ferrell et al., 2018). There are eight domains in total, covering issues such as physical symptoms, spiritual, religious and existential issues, care for the individual nearing end-of-life and legal and ethical considerations. The guidelines can be used to in the development of new PC programs, to measure the effectiveness of current programs, to improve care and assist with educational and training programs.

To begin to address this gap, we held a one-day workshop to elicit input from experts

working in PC in order to better understand what is important to capture when thinking about providing good quality PC services in the community. The workshop was part of a larger three-year project, funded by the Canadian Institutes of Health Research (CIHR), aimed at developing and testing QIs for community-based PC. The insights gained from this expert consultation was used as the initial step in this project to create these QIs.

Methods

Design

A one-day workshop was held in Toronto in 2018. A workshop was chosen as the primary method of data collection as it is known to be effective for a large PC expert group (Payne et al., 2019; Stevinson et al., 2010). This event was designed to have PC experts from diverse backgrounds work collaboratively to identify what should be captured to measure quality PC delivered in the community. The workshop was held in Ontario, recognizing that additional phases of this project would include broad-based consultations with stakeholders from multiple provinces and territories. The general structure of the workshop included opening remarks from members of the research team, three brainstorming sessions where participants first worked in smaller groups to identify important quality measures and were then brought together to share their thoughts with the larger group. Finally, members of the research team and two international researchers gave presentations.

Qualitative validity of this research was established via: (1) an initial audit of the research methods; and (2) through an ongoing peer-review of the research process while planning and executing the workshop. These validity procedures were conducted by an external consultant, allowing for outside feedback into methodological processes from the beginning to the end of the data collection (Creswell, 2018). The consultant, with expertise in facilitating health stakeholder

collaborations across Canada (NaW), provided input throughout the planning of the workshop, acted as the event's moderator, and assisted with data analysis.

The workshop involved three brainstorming sessions. Participants were assigned by the research team to one of seven groups, with five to six people per group. This assignment was done in order to ensure that each group included at least one PC researcher and a balance of clinical, technical and administrative perspectives.

The brainstorming sessions were focused on answering the following questions:

1. What is important to measure to support quality PC, regardless of setting or current feasibility?
2. Of the measures identified in the first brainstorming session, are any of special importance in care provided in the home? Are there any new measures that are unique to the delivery of PC in the home?
3. What are the challenges, barriers, and potential opportunities for creating these measures?

This study was reviewed and approved by the Research Ethics Board at Wilfrid Laurier University (REB #5683).

Participants

Invitations were emailed to a sample of potential participants with the intent to recruit PC experts from a broad range of stakeholders (e.g., clinical leaders, researchers, front-line staff, health and information system administrators, and decision makers). At the time of the workshop, Ontario was divided geographically into 14 Local Health Integration Networks (LHINs) that were responsible for overseeing the delivery of health services within each region. Invitations were sent to the senior leaders of the 14 LHINs, the Ontario Ministry of Health and

Long-Term Care, as well as leaders representing an array of PC and other organizations (e.g., Hospice Palliative Care Ontario, Canadian Institute for Health Information). Senior leaders were invited to delegate an appropriate expert from their organization if they were unable to attend the workshop. Ultimately, invitation emails were sent to 70 individuals and follow-up emails were sent roughly two weeks later if no reply was received.

Of the 70 invitations sent, 30 experts consented to participate, representing 12 of the 14 LHINs, and 11 other organizations. The participants included registered nurses, nurse practitioners, social workers, researchers and decision makers. Time constraints and travel restrictions were noted as reasons why some individuals could not attend the workshop. Since we were interested in obtaining input from individuals in the PC community, several of the experts invited were members of the research team. Two international researchers also contributed to the workshop, providing information on how PC services and standardized assessments are being utilized in their home countries of Belgium and New Zealand and participated in the brainstorming sessions.

Data Collection

In each of the three brainstorming sessions, the moderator introduced the question and clarified the expectations for the group. Individuals initially worked alone to record their ideas on sticky notes and then collaboratively to cluster them into categories on their group's flipchart. Within each small group, a member of the research team was assigned to be a group facilitator to assure clarity of the notes, and to encourage participation from all group members. Each group chose one person to present their results to the larger group after each brainstorming session. As each group shared its findings, the moderator clarified the group's notes, solicited and recorded additional comments on a central flipchart, and then presented the information back to the room

in the form of a member check (Creswell, 2018). Due to the large number of participants working in close proximity to one another, audio recording was not performed. In between the second and third brainstorming session, the international researchers from Belgium and New Zealand both presented on research being done in PC in their home countries.

Data Analysis

Multiple methods of triangulation were used to establish credibility (Creswell, 2018). For all three brainstorming sessions, the flipchart notes from participants and the moderator were transcribed verbatim by NW. Important concepts and similar ideas were identified via content analysis of the two data sources (participant and moderate notes) and grouped together into themes. As mentioned, there are eight domains captured by the NCP guidelines. We used these eight domains as a guide when grouping together the comments from the workshop participants in order to create the key themes. Software was not used in this analysis. Instead, hand coding of the comments was completed by NW and reviewed by DMG. The categorized themes, along with the summary of the day, was sent to all participants. At a later date, review of all data and material pertaining to the workshop was completed by NB, NaW and NL as an additional form of research triangulation.

Results

Brainstorming session one

In the first session, participants were asked what they thought was important to measure to capture quality PC services, regardless of where this care was provided (i.e., community, hospital, etc.). Participants identified four key themes.

Theme 1: Access to care in the community by a multidisciplinary team

The access to care theme clearly aligns with the structure and process of care domain

developed by the NCP guidelines. This domain outlines that PC principles and practices can be integrated into any healthcare setting, and be delivered by members of a multidisciplinary team. Participants acknowledged that having access to multidisciplinary care providers in the community was a key component of PC, while also ensuring that this access was timely and available when the individual or their caregiver needed it. This also included appropriate and timely referrals, and ensuring continuity of care. Appropriate referrals also pertained to early identification of individuals who could benefit from a palliative approach to care as everyone agreed that only providing PC services in the last few weeks of life was not sufficient for most individuals with a life-limiting illness. Additionally, the participants thought it was important that health care professionals should have access to a standardized documentation system as well as the ability to access health records across the care team. Finally, participants felt it was important that individuals with PC needs had guaranteed access to the resources they needed to ensure the best quality of care was provided.

Theme 2: Care for the individual with PC needs

Participants highlighted that the care for the individual is not just about addressing their physical symptoms, but rather caring for all of the needs the individual may have including physical, spiritual, emotional, and psychosocial aspects. This idea captures two of the domains put forth by the NCP guidelines, namely, the social aspects of care and also care for the individual nearing end-of-life. Continual discussions with the individual around their preferred place of death was identified as important to measure when thinking about providing high quality palliative care. This included having the conversation early on in the disease trajectory, but also throughout the trajectory of the illness as the individual's wishes may change throughout their journey. Similarly, participants also agreed that it is important to have continual conversations

surrounding the individual's goals of care and around advance care planning. Finally, participants thought that a measure of quality PC was whether or not the individual was provided with information about death and how this might be unique for each individual.

Theme 3: Support for the informal caregiver (e.g., family, friends)

Participants noted that it was important to also ensure that their informal caregiver was supported, to enable them to continue in that role. This support may help mitigate the caregiver feeling burdened or distressed and therefore allow them to continue to provide support at home. It is imperative that the health care system continues to provide information and access to supportive services such as respite or other informal networks to help caregivers continue in their role. Additionally, the participants also agreed that good quality of care requires that health care professionals educate caregivers on how to best care for loved ones at home. Finally, the experts thought that offering access to bereavement services is important to consider when thinking about providing high quality PC to the individual and their caregiver. The NCP guidelines do not have a specific domain to capture support for the caregiver, however this idea is found throughout all eight domains as it is imperative that the caregiver is involved in all aspects of the care being provided to the individual with PC needs.

Theme 4: Symptom management for individuals with PC needs

High quality PC should view the individual as a whole person, and not simply focus on their physical symptoms. The physical aspects of care domain within the NCP guidelines supports the idea that it is important to address/relieve symptoms associated with their physical, functional, and emotional well-being in order to improve or maintain functional status and the individual's overall quality of life. The participants stressed that it is not enough to just treat the physical symptoms the individual may be experiencing. It is also important to have a person-

centered approach to care and manage both the physical symptoms, and any other issues (e.g., emotional, spiritual, cultural, goals of the individual, etc.) the individual may be experiencing, to help to improve the individual's quality of life. The participants also noted that it is imperative for those receiving PC to have access to after-hours supports (e.g., prescriptions, pain and symptom management), which would include timely responses to emergencies as well as access to a symptom management kit (includes medications and supplies for urgent medical care needs) that would assist the individual/caregiver for end-of-life emergencies (Table 1).

Brainstorming session two

In the second session, participants were asked to discuss which aspects of PC provided in the home were important to measure and whether these differed at all from services being provided in other locations. While everyone agreed that all four of the themes from the first brainstorming session were relevant to capture quality PC in the home, they also identified two themes that are of special importance to care being provided in the home, including spiritual care for individuals with PC needs and home as the preferred place of death.

Theme 5: Spiritual care for individuals with PC needs

Everyone agreed that it was important that the individual with PC needs and their family should be provided resources and have access to spiritual care, as appropriate, at the end-of-life. However, the participants did not specify what spiritual care should encompass, but in a general sense, everyone agreed that it was important when providing high quality PC. Within the NCP guidelines, spiritual, religious and existential aspects of care are a fundamental aspect of patient- and family-centered care and should be addressed.

Theme 6: Home as the preferred place of death

The participants thought it was important to capture issues around the home as the

preferred place of death. Even though an individual may be receiving PC services in their home, it does not necessarily imply that this is their preferred place of death. The feasibility of the individual with PC needs choosing to die at home should continually be evaluated with additional options being made available. While this theme could potentially fall under the structure and process of care domain within the NCP guidelines, it is important to highlight when the home is the preferred place of death as this may offer additional challenges to those caring for the individual at home. For example, the personal circumstances and the caregiver's ability to care for a dying person, who may have increasingly complex care needs, should be considered carefully in making this decision (Table 1).

Brainstorming session three

In the final session, the experts identified several challenges and areas of potential improvement associated with the delivery and measurement of quality PC (Table 2). Participants found it challenging to have multiple assessment tools being used simultaneously in PC across several organizations and suggested that integration of tools and having a standardized way of documentation could help mitigate this challenge. Similarly, the lack of shared health records and lack of communication across the PC team was identified as a challenge. However, having an open and collaborative approach established across PC teams could help mitigate this challenge. Finally, participants also acknowledged that everyone using the interRAI PC assessment may not know how to appropriately complete the assessment and could therefore lead to incomplete/inaccurate assessments. The interRAI PC is a comprehensive assessment instrument that was created by interRAI, a not-for-profit consortium of international researchers and clinicians (Smith et al., 2014). The assessment is used in Ontario for most individuals receiving palliative home care and identifies person-specific care preferences, symptoms and

needs, which assist health care professionals in the care planning process. In addition, many participants also expressed concern that the interRAI PC assessment is too long and quite repetitive, and suggested that more training on how to accurately complete the assessment would be beneficial for health care providers.

Discussion

This research represents an important initial step in the creation of QIs for palliative care in the community. The main finding of the workshop was that many of the themes identified by the experts as important to measure to capture quality of care were relevant for all care settings, while only two (spiritual care for individuals with PC needs and home as the preferred place of death) were of special importance to care provided in the home.

The six themes that were highlighted by our experts clearly align with the eight key domains developed by the National Consensus Project (NCP) for Quality Palliative Care Guidelines in the US (2018). These domains have been used as a benchmark for two systematic reviews from Europe examining the development of QIs for palliative care (De Roo et al., 2013; Pasma et al., 2009). Several of the key themes identified in the current study, clearly align with the domains put forth by the NCP such as the structure and process of care, the physical aspects of care, spiritual/religious aspects of care, continued care of the individual as they near the end-of-life and also the social aspects of care. The NCP guidelines also include domains around the cultural aspects of care, the psychological and psychiatric aspects of care, as well as the ethical and legal aspects of care. While our experts did touch on a number of these additional areas of care, they ultimately did not warrant their own theme as they tended to be captured within a larger theme. For example, ideas around the psychological and psychiatric aspects of care were captured in the “support for the informal caregiver (e.g., family, friends)” theme.

The majority of Canadians indicate that they would prefer to receive PC in their own homes and die at home surrounded by loved ones (Canadian Hospice Palliative Care Association, 2013a; Canadian Institute for Health Information, 2018). However, providing PC to individuals with a serious illness in their own homes offers an array of challenges. For example, care provided in the home is mainly delivered by non-paid individuals such as family members and friends who likely do not have any formal training on how to best care for individuals with a serious illness. As a result, informal caregivers have to deal with the physical, financial and emotional aspects of caring for their dying family member, while still trying to provide and coordinate their care. The additional stressors of caring for a loved one at home may increase the likelihood for a caregiver to experience burden (Guerriere et al., 2016; Hirdes et al., 2012). The experts in the workshop all agreed that it was vital to provide support and resources to the individual as well as their family support system (as captured in Themes 2 and 3). As highlighted in Theme 4 (symptom management for individuals with PC needs), it is essential that caregivers have access to after-hours supports and the necessary information on how to address both the physical symptoms and other issues (e.g., emotional, cultural, spiritual, etc.) the individual may be experiencing. Since a palliative approach to care is both individual- and family-centered, it is important that there are continuous discussions around care planning and the needs and wishes of the individual with PC needs and their family throughout the trajectory of the illness.

Regardless of care setting, the experts indicated in Theme 1 that access to PC in the community by a multidisciplinary team should be offered as early as possible for anyone who could benefit from a palliative approach to care. Currently in Canada, there are no standardized criteria for determining eligibility for PC and the initiation of PC services. The majority of individuals who receive PC have a cancer diagnosis and a much shorter prognosis (weeks or

months) (Paetkau et al., 2011). However, a recent shift in the PC community has been observed in multiple countries, including Canada (Canadian Hospice Palliative Care Association, 2013b), the United States (Ferrell et al., 2018), the United Kingdom (Shaw et al., 2010), Belgium (Maetens et al., 2019), New Zealand (Ministry of Health, 2001) and Australia (Australian Government, 2018), which has focused on providing PC to anyone who would benefit from a palliative approach to their care. Earlier access to PC has been found to be beneficial for individuals with a life-limiting illness as it has the potential to improve the overall quality of life for both the individual and their family (Paetkau et al., 2011), reduce symptom burden and may lead to reduced hospital admissions (Qureshi et al., 2019; Seow et al., 2018).

One of the main themes that the experts agreed was of special importance to the home setting was around the preferred place of death (Theme 6). There has been a shift in Canada away from hospital deaths, as discussions around location of death are becoming more common (Wilson et al., 2009; Wilson et al., 2017). The choice of where to receive care and where to die are extremely important to consider when providing good quality PC, as most individuals would prefer to remain at home (Skorstengaard et al., 2017). A recent retrospective cohort study of all decedents in Ontario found that increased community supports may lead to less hospital deaths (Tanuseputro et al., 2018). While it is not always reasonable for someone to remain at home, it is important to address these concerns as transitions in place of care/death can put an added stress on both the individual and their caregivers (Wilson & Birch, 2018; Cohen et al., 2015). Therefore, considerations and discussions around an individual's preferred place of death should be continually assessed and should address the feasibility of the wishes of the individual if they prefer to remain at home. The friend or family member who will take on the caregiver responsibilities at home must be prepared for the role (Garlo et al., 2010; Vellone et al., 2011;

Miller et al., 2012) as there are additional obstacles in providing care at home over other settings (e.g., medication management, monitoring vitals). Our experts agreed that this should be considered in the determination of the preferred place of death.

The importance of access to spiritual care resources for both the individual and their family at the end-of-life has been widely acknowledged in the literature (Ahluwalia et al., 2018; Wang et al., 2017), which was a key theme (Theme 5) that all experts agreed was important to measure when providing high quality PC. Despite the overwhelming evidence on the importance of availability of spiritual care resources, most QI lists have not adequately captured this concern as it can be quite subjective and therefore difficult to measure (Woitha et al., 2012; D'Angelo et al., 2012; Etkind et al., 2017; Barbera et al., 2015). Furthermore, the non-physical needs of individuals with PC needs and their families should be considerate of individual, cultural and religious beliefs (Mistry et al., 2015). Although these items may be difficult to measure, it is an important area that should be captured when providing good quality PC.

The NCP has identified how important it is that PC begins with the use of a comprehensive assessment and emphasizes the individual, their family, open communication and continuity of care across all care settings (Ferrell et al., 2018). One of the main challenges that our experts identified in delivering good quality PC was around communication either between care teams or with the individual/family. The experts expressed how important it is to use a standardized assessment to allow for continual and up-to-date sharing of information among health care teams. While this does not always happen in practice, the experts also expressed that having a standardized format for documentation, used by all health care providers providing PC in the community, could help lessen assessment burden.

Conclusion

The workshop was the first step in a larger multi-year project aimed at identifying and developing a standardized set of QIs for PC delivered in the community. Following the workshop, the research team conducted individual interviews and/or focus groups with individuals with PC needs, caregivers and decision makers from various parts of Canada. From these interviews, the research team has begun to create operational definitions (i.e., numerator and denominator) for a preliminary set of QIs, which will be able to be generated from existing interRAI assessment data. Several interRAI assessments are currently implemented in many parts of Canada, the US, multiple European countries, Australia and New Zealand. Therefore, the QIs that are developed through this work have the potential to be used in many regions around the world. Although this work is still underway, once completed, there will be a standardized set of QIs that are applicable to PC in the community for adults (18+). These indicators will enable health care professionals and decision makers to target areas for improvement, implement interventions to improve the quality of care, and ultimately, optimize the health and well-being of individuals with a serious illness.

Disclosures and Acknowledgements

This work was supported by a grant from the Canadian Institutes of Health Research (CIHR). [DG, Grant #: PJT-156359]

The last listed author is a Fellow with interRAI. All authors confirm that they have no conflicts of interest to disclose.

References

- Ahluwalia, S.C., Chen, C., Raaen, L., Motala, A., Walling, A.M., Chamberlin, M., O'Hanlon, C., Larkin, J., Lorenz, K., Akinniranye, O. & Hempel, S. (2018). A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition. *Journal of Pain and Symptom Management*, 56(6), 831-870.
- Australian Government (2018). National palliative care strategy 2018. Department of Health, Canberra, Australia.
- Bainbridge, D. & Seow, H. (2016). Measuring the Quality of Palliative Care at End of Life: An Overview of Data Sources. *Healthy Aging & Clinical Care in the Elderly*, 8, 9-15.
- Bakitas, M., Lyons, K.D., Hegel, M.T., Balan, S., Brokaw, F.C., Seville, J., Hull, J.G., Li, Z., Tosteson, T.D., Byock, I.R. & Ahles, T.A. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the project ENABLE II randomized controlled trial. *Journal of the American Medical Association*, 302(7), 741-749.
- Barbera, L., Paszat, L. & Chartier, C. (2006). Indicators of poor quality end-of-life cancer care in Ontario. *Journal of Palliative Care*, 22(1), 12-17.
- Barbera, L., Seow, H., Sutradhar, R., Chu, A., Burge, F., Fassbender, K., McGrail, K., Lawson, B., Liu, Y., Pataky, R. & Potapov, A. (2015). Quality of end-of-life cancer care in Canada: a retrospective four-province study using administrative health care data. *Current Oncology*, 22(5), 341-355.

- Black, B.S., Johnston, D., Morrison, A., Rabins, P.V., Lyketsos, C.G. & Samus, Q.M. (2012). Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Quality of Life Research, 21*(8), 1379-1389.
- Canadian Hospice Palliative Care Association (2013a). Fact Sheet: Hospice Palliative Care in Canada.
- Canadian Hospice Palliative Care Association (2013b). Palliative care in the community: an environmental scan of frameworks and indicators.
- Canadian Institute for Health Information (2018). Access to Palliative Care in Canada. Ottawa, ON.
- Cohen, J., Pivodic, L., Miccinesi, G., Onwuteaka-Philipsen, B.D., Naylor, W.A., Wilson, D.M., Loucka, M., Csikos, A., Pardon, K., Van den Block, L., Ruiz-Ramos, M., Cardenas-Turanzas, M., Rhee, Y., Aubry, R., Hunt, K., Teno, J., Houttekier, D. & Deliens, L. (2015). International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. *British Journal of Cancer, 113*(9), 1397-1404.
- Creswell, R. (2018). *Qualitative inquiry & research design: Choosing among five approaches*, Thousand Oaks, CA: Sage.
- Curtis, J.R., Back, A.L., Ford, D.W., Downey, L., Shannon, S.E., Doorenbos, A.Z., Kross, E.K., Reinke, L.F., Feemster, L.C., Edlund, B., Arnold, R.W., O'Connor, K. & Engelberg, R.A. (2013). Effect of Communication Skills Training for Residents and Nurse Practitioners on Quality of Communication With Patients With Serious Illness. *JAMA, 310*(21), 2271.

- D'Angelo, D., Mastroianni, C., Vellone, E., Alvaro, R., Casale, G., Latina, R. & Grazi De Marinis, M. (2012). Palliative care quality indicators in Italy. What do we evaluate? *Supportive Care in Cancer*, 20, 1983-1989.
- De Roo, M.L., Leemans, K., Claessen, S.J.J., Cohen, J., Pasman, R.W., Deliens, L. & Francke, A.L. (2013). Quality indicators for palliative care: update of a systematic review. *Journal of Pain and Symptom Management*, 46(4), 1-17.
- Dy, S.M., Kiley, K., Ast, K., Lupu, D., Norton, S., Mcmillan, S.C., Herr, K., Rotella, J.D. & Casarett, D.J. (2015). Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Palliative Nurses Association. *Journal of Pain and Symptom Management*, 49(4), 773-781.
- Etkind, S.N., Bone, A.E., Gomes, B., Lovell, N., Evans, C.J., Higginson, I.J. & Murtagh, F.E.M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, 15(1), 102.
- Ferrell, B.R., Twaddle, M.L., Melnick, A. & Meier, D.E. (2018). National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *Journal of Palliative Medicine*, 21(12), 1684-1689.
- Gagnon, B., Nadeau, L., Scott, S., Dumont, S., MacDonald, N., Aubin, M. & Mayo, N. (2015). The association between home palliative care services and quality of end-of-life care indicators in the province of Quebec. *Journal of Pain and Symptom Management*, 50(1), 48-58.

- Garlo, K., O'Leary, J.R., Van Ness, P.H. & Fried, T.R. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*, 58(12), 2315-2322.
- Government of Canada (2018). Framework on Palliative Care in Canada. Health Canada, Ottawa, Ontario.
- Grunfeld, E., Lethbridge, L., Dewar, R., Lawson, B., Paszat, L., Johnston, G., Burge, F., McIntyre, P. & Earle, C.C. (2006). Towards using administrative databases to measure population-based indicators of quality of end-of-life care: Testing the methodology. *Palliative Medicine*, 20, 769-777.
- Guerriere, D., Husain, A., Zagorski, B., Marshall, D., Seow, H., Brazil, K., Kennedy, J., Burns, S., Brooks, H. & Coyte, P.C. (2016). Predictors of caregiver burden across the home-based palliative care trajectory in Ontario, Canada. *Health and Social Care in the Community*, 24(4), 428-438.
- Hirdes, J.P., Freeman, S., Smith, T.F. & Stolee, P. (2012). Predictors of caregiver distress among palliative home care clients in Ontario: evidence based on the interRAI Palliative Care. *Palliative and Supportive Care*, 10(3), 155-163.
- Hirdes, J.P., Fries, B.E., Morris, J.N., Ikegami, N., Zimmerman, D., Dalby, D.M., Aliaga, P., Hammer, S. & Jones, R. (2004). Home care quality indicators (HCQIs) based on the MDS-HC. *The Gerontologist*, 44(5), 665-679.
- Leemans, K., Van den Block, L., Vander Stichele, R., Francke, A.L., Deliens, L. & Cohen, J. (2015). How to implement quality indicators successfully in palliative care services: perceptions of team members about facilitators of and barriers to implementation. *Supportive Care in Cancer*, 23(12), 3503-3511.

- Maetens, A., Deliens, L., Van den Block, L., Beernaert, K. & Cohen, J. (2019). Are We Evolving Toward Greater and Earlier Use of Palliative Home Care Support? A Trend Analysis Using Population-Level Data From 2010 to 2015. *Journal of Pain and Symptom Management*, 58(1), 19-28.
- Miller, E.A., Rosenheck, R.A. & Schneider, L.S. (2012). Caregiver burden, health utilities, and institutional service use in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 27(4), 382-393.
- Ministry of Health (2001). The New Zealand Palliative Care Strategy. Ministry of Health, Wellington, New Zealand.
- Mistry, B., Bainbridge, D., Bryant, D., Toyofuku, S.T. & Seow, H. (2015). What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators. *BMJ Open*, 5(6), 1-8.
- Paetkau, S., Switzer, G., Kasperki, J., Seow, H., Firth, R., Adler, L., Daub, S., Hirdes, J.P., Librach, L., Martin, A., MacLeod, B., Miles, M., Mottershead, M., Newman, C., Paech, G., Pilkington, K. & Thorning, S. (2011). Advancing high quality, high value palliative care in Ontario: declaration of partnership and commitment to action. Toronto, ON.
- Pasman, H.R.W., Brandt, H.E., Deliens, L. & Francke, A.L. (2009). Quality indicators for palliative care: a systematic review. *Journal of Pain and Symptom Management*, 38(1), 145-156.
- Payne, S., Hughes, S., Wilkinson, J., Hasselaar, J. & Preston, N. (2019). Recommendations on priorities for integrated palliative care: transparent expert consultation with international leaders for the InSuP-C project. *BMC Palliative Care*, 18(132), 1-8.

- Qureshi, D., Tanuseputro, P., Perez, R., Pond, G.R. & Seow, H. (2019). Early initiation of palliative care is associated with reduced late-life acute-hospital use: A population-based retrospective cohort study. *Palliative Medicine*, 33(2), 150-159.
- Seow, H., O'Leary, E., Perez, R. & Tanuseputro, P. (2018). Access to palliative care by disease trajectory: a population-based cohort of Ontario decedents. *BMJ Open*, 8(e021147), 1-9.
- Shaw, K.L., Clifford, C., Thomas, K. & Meehan, H. (2010). Improving end-of-life care: a critical review of the gold standards framework in primary care. *Palliative Medicine*, 24(3), 317-329.
- Skorstengaard, M.H., Neergaard, M.A., Andreassen, P., Brogaard, T., Bendstrup, E., Lokke, A., Aagaard, S., Wiggers, H., Bech, P. & Jensen, A.B. (2017). Preferred place of care and death in terminally ill patients with lung and heart disease compared to cancer patients. *Journal of Palliative Medicine*, 20(11), 1-8.
- Smith, T.F., Steel, K., Fries, B.E., Morris, J.N., Bellville-Taylor, P., Curtin Telegdi, N., Frijters, D., Hirdes, J.P., Ljunggren, G., Murphy, K.A., Nonemaker, S., Rabinowitz, T., Ribbe, M. & Topinkova, E. (2014). InterRAI palliative care (PC) assessment form and user's manual, 9.1., 1-145. Ann Arbor, MI.
- Stevinson, C., Preston, N. & Todd, C. (2010). Defining priorities in prognostication research: results of a consensus workshop. *Palliative Medicine*, 24(5), 462-468.
- Tanuseputro, P., Beach, S., Chalifoux, M., Wodchis, W.P., Hsu, A.T., Seow, H. & Manuel, D.G. (2018). Associations between physician home visits for the dying and place of death: A population-based retrospective cohort study. *PloS one*, 13(2), e0191322.
- Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., Dahlin, C.M., Blinderman, C.D., Jacobsen, J., Pirl, W.F., Billings, J.A. & Lynch, T.J. (2010).

- Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742.
- Vellone, E., Fida, R., Cocchieri, A., Sili, A., Piras, G. & Alvaro, R. (2011). Positive and negative impact of caregiving to older adults: A structural equation model. *Professioni Infermieristiche*, 64(4), 237-248.
- Wachterman, M.V., Pilver, C., Smith, D., Ersek, M., Lipsitz, S.R. & Keating, N. (2016). Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Internal Medicine*, 176(8), 1095-1102.
- Wang, C.W., Chow, A.Y. & Chan, C.L. (2017). The effects of life review interventions on spiritual well-being, psychological distress, and quality of life in patients with terminal or advanced cancer: A systematic review and meta-analysis of randomized controlled trials. *Palliative Medicine*, 31(10), 883-894.
- Wilson, D.M. & Birch, S. (2018). Moving from place to place in the last year of life: A qualitative study identifying care setting transition issues and solutions in Ontario. *Health and Social Care in the Community*, 26(2), 232-239.
- Wilson, D.M., Shen, Y. & Birch, S. (2017). New Evidence on End-of-Life Hospital Utilization for Enhanced Health Policy and Services Planning. *Journal of palliative medicine*, 20(7), 752-758.
- Wilson, D.M., Truman, C.D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Froggatt, K. & Justice, C. (2009). The rapidly changing location of death in Canada, 1994-2004. *Social Science and Medicine*, 68(10), 1752-1758.

- Woitha, K., Van Beek, K., Ahmed, N., Hasselaar, J., Mollard, J.M., Colombet, I., Radbruch, L.,
Vissers, K. & Engels, Y. (2012). Development of a set of process and structure indicators
for palliative care: the Europall project. *BMC Health Services Research*, 12(1), 381.
- World Health Organization (2016). WHO definition of palliative care. Vol. 2016.