



RNAO comments on Draft – Palliative Health Services Delivery Framework: Recommendations for a Model of Care to Improve Palliative Care in Ontario – Part 1: Adults Receiving Care at Home

Submitted to the Ontario Palliative Care Network (OPCN)

February 26, 2018



Summary of RNAO Recommendations

Recommendation 1. Take a public health approach to palliative care emphasizing that it should be person-centered rather than disease-oriented.

Recommendation 2. Ensure consistency throughout the framework document, in recognizing RNs and NPs as vital members of the health-care team.

Recommendation 3. Alter the preamble of the framework to reflect that patient preference of where they wish to pass away must be revisited as required.

Recommendation 4. Include a recommendation in the framework to address the financial burden on the unpaid caregivers/family as part of the early identification process.

Recommendation 5. Clarify whether the centralized referral and navigation system, referenced in recommendation 2, is in place and how patients and their families access it.

Recommendation 6. To succeed in this role, care co-ordinators working with palliative patients should be a registered nurse working full-time to enable the attention necessary for the required caseloads.

Recommendation 7. Include the identification and engagement of substitute decision-makers (SDM) in the early identification and assessment process.

Recommendation 8. Include advanced care planning and the identification of the patient's wishes as part of the early identification process.

Recommendation 9. Move OPCN recommendation 24 to the early identification section as it addresses the assessment of legal, financial, and other social issues.

Recommendation 10. Incorporate the needs of the family at the end-of-life and include recommendations to address caregiver burden and respite care.

Recommendation 11. Integrate the recommendations for supports of family caregivers throughout the document, as their needs go hand in hand with that of the patient.

Recommendation 12. Integrate the needs of vulnerable and priority populations throughout the report using a health equity approach.

Introduction

The Registered Nurses' Association of Ontario (RNAO) is the professional association representing registered nurses (RN), nurse practitioners (NP), and nursing students in all roles and sectors across Ontario. Since 1925, RNAO has advocated for healthy public policy, promoted excellence in nursing practice, increased nurses' contributions to shaping the health system, and influenced decisions that affect nurses and the public they serve.

RNAO appreciates the opportunity to provide feedback to the Ontario Palliative Care Network (OPCN) on the draft *"Palliative Health Services Delivery Framework: Recommendations for a Model of Care to Improve Palliative Care in Ontario – Part 1: Adults Receiving Care at Home"*. RNAO's comments and recommendations are organized by the categories of recommendations contained in the report- Early identification, assessment of needs, and coordination; Palliative care team; Planning; Delivery of care; Supports for family and caregivers; and Palliative Care for First Nations, Inuit, and Metis population. Implementation considerations for each are also provided with the understanding that we will have further opportunity to comment.

General comments

RNAO supports OPCN's efforts to consolidate the multiple reports over the last decade that have highlighted persistent gaps in the delivery of palliative care services across Ontario.

Improving the care received at home starts with strengthening the primary care sector. RNAO has been a strong advocate for anchoring the health system in primary and community care, beginning with our 2012 report, *Enhancing Community Care for Ontarians (ECCO 1.0)*,¹ and again in *ECCO 2.0*.² This transformation is central to achieving a high performing health-care system. The benefits of community care are clear and include greater alignment with patient preferences, improved patient outcomes, and reduced system costs.^{3 4}

RNs and NPs play a vital role in delivering community palliative care services. RNAO's recently-released database, *70 Years of RN Effectiveness*,⁵ shows the positive impact RN care has on patient, organizational, and financial outcomes. This evidence demonstrates the importance of having RNs care for patients with complex care needs, such as those requiring palliative care.⁶ For more than four decades, NPs have delivered high quality patient care to meet the needs of Ontarians.⁷ Evidence collected over the last 50 years conclusively shows the positive value and impact NPs have on patient care and health system outcomes.^{8 9}

Given the important role that RNs and NPs have in the care of palliative patients in the home setting, RNAO insists that RNs and NPs are recognized consistently throughout the framework.

RNAO strongly encourages OPCN to take a public health approach to palliative care. This approach views the community as an equal partner in the provision of quality health care at the end of life.¹⁰ Addressing palliative care as a public health issue will ensure policy-makers view palliative care as an investment, rather than a burden. It will also help encourage a culture that honours those at the end of life.

For instance, creating compassionate communities is gaining support worldwide. Known for community development efforts that aim to accommodate death, dying, loss, and care into public health ideas, and creating supportive environments for those experiences, compassionate communities create an opportunity for person-centered care rather than one that is disease-orientated.¹¹

Recommendation 1. Take a public health approach to palliative care emphasizing that it should be person-centered rather than disease-oriented.

Recommendation 2. Ensure consistency throughout the framework document, in recognizing RNs and NPs as vital members of the health-care team.

Early identification, assessment of needs, and coordination

RNAO supports early identification, assessment of patient needs, and the co-ordination of care as an ongoing iterative process, as outlined in our Best Practice Guideline (BPG) *End-of-Life Care During the Last Days and Hours*,¹² hereafter referred to as the End-of-Life Care BPG.

An interprofessional approach to care is the foundation of quality palliative care. A comprehensive assessment identifies the need for physical, emotional, spiritual, cultural, psychosocial, and financial interventions provided by a team of relevant disciplines such as social work, physical therapy, occupational therapy, psychology, RNs, NPs, and palliative care physicians. Unfortunately, many of these disciplines are only located in hospices or in the acute care setting. There needs to be palliative care teams who are trained in a palliative approach to care in all health-care sectors. This should be included in the implementation considerations section of the next draft of the framework document.

As part of this early assessment, it is important that the patient's preference of where they wish to pass away is revisited as required. This should be contained in the preamble of the report.

Recommendation 3. Alter the preamble of the framework to reflect that patient preference of where they wish to pass away must be revisited as required.

In addition, the financial aspects incurred from care at home, such as the financial burden on the unpaid caregivers/family members, is absent. This is essential in the early identification of needs as a holistic approach to care for patients and their family/caregiver.

Recommendation 4. Include a recommendation in the framework to address the financial burden on the unpaid caregivers/family as part of the early identification process.

As introduced in our general comments and RNAO Recommendation 1, the draft framework's first recommendation should include NPs and RNs as vital members of the patient's care team who often complete the comprehensive, holistic assessments in addition to members of the interdisciplinary team.

All members of the interdisciplinary team, including RNs and NPs, should be provided with the tools necessary (e.g., RNAO's Assessment and Management of Pain BPG)¹³ to perform these palliative needs assessments.

While RNAO supports the draft framework's second recommendation, it should be clarified in the document if this service is in place or whether it needs to be created and implemented. In addition, how patients and their families' gain access to this service should be stated.

Recommendation 5. Clarify whether the centralized referral and navigation system, referenced in recommendation 2, is in place and how patients and their families access it.

In response to the draft framework recommendations 3, 4, 5 and 6, the framework document should clarify that care co-ordination will be a responsibility of primary care, and care co-ordinators will be located in primary care settings, as per the intent of *Patients First*, the direction of the minister of health to the LHINs, and the work of the Ontario Primary Care Council (of which RNAO is a founding member). This is also consistent with RNAO's recommendations in our ECCO reports, where we stress that care co-ordinators should play a comprehensive role for patients with complex care needs, including health system navigation.¹⁴
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In addition, it should be stated that care co-ordinators working with palliative patients will be a regulated health care professional – ideally an RN and social worker (SW) working in collaboration. The RN should work full time to ensure care continuity and be given lower caseloads due to the intensity of the role. A consistent care co-ordinator who can follow the patient throughout their illness trajectory - regardless of diagnosis or complexity - is ideal. RNs are well positioned to fulfill this role and there is a large body of evidence to support the effectiveness of RNs as care co-ordinators on patient and organizational outcomes.^{16 17}

Recommendation 6. To succeed in this role, care co-ordinators working with palliative patients should be a registered nurse working full-time to enable the attention necessary for the required caseloads.

Another area of consideration is the inclusion of substitute decision makers (SDM) in the early identification and assessment process. SDMs should be recognized as individuals who require the support of the interdisciplinary team when making decisions on behalf of a patient. This recommendation aligns with recommendations 2.1 and 2.2 in RNAO's End-of-Life Care BPG.

Recommendation 7. Include the identification and engagement of substitute decision-makers (SDM) in the early identification and assessment process.

The framework should emphasize that early discussion with patients and families about goals of care need to occur in the primary care setting. Moreover, GPs, RNs, and NPs in primary care need education and resources to engage patients and their families in these key discussions.

Consistency varies across the LHINs with regards to home care services. Patients in the early stages of the palliative care trajectory often do not qualify for interprofessional palliative care or community services. If patients do qualify, there is a waiting list for services or a delay in the delivery of services (e.g. pain relieving medications). As a consequence, patients have no choice but to return to the ER or the hospital for admission. This inconsistency should be considered in when thinking about implementation.

Palliative Care Team

The language in this section needs to be consistent in regards to the role of RNs and NPs (see RNAO Recommendation 1, above). For example, page 9 of the draft framework states "these recommendations envision that for long-term sustainability, the MRP will ideally be the patient's family physician". NPs also act as the most responsible provider (MRP) in all sectors of the health system and therefore must be included in the framework and recognized for the important work that they do.

RNAO supports the draft framework's recommendation 8, 9, 10, and 11. The current limitations on health-care infrastructure and funding will restrict the implementation of the framework's recommendation 8. For example, the current availability of 24/7 care is most likely to occur in the acute care setting and in residential hospice care whereas 24/7 care is least likely to occur in home care and long-term care. Lack of access to 24/7

care results in a high proportion of patients dying in hospital compared to home, where most patients wish to die.¹⁸ Access to care in remote areas is an important implementation consideration for these recommendations, as patients living in many areas of the province may not have a team of health-care professionals available to them.

RNAO supports recommendations 12 and 13. In order for the phone lines to be effective in reducing emergency department visits, patients and caregivers must be able to receive advice in pain and symptom management, have access to new or additional prescription medication if necessary, and have the option of a primary care after-hours visit by an RN, NP, or physician. Access to patient electronic medical records (EMRs) is a necessary prerequisite to effectively support patients and their loved ones. EMRs should be available to all clinicians in the patient's circle of care, including the phone line staff. Again, RNAO highlights that in many rural areas, patients do not have a palliative care physician or NP, and thus these recommendations also need to consider that a patient's death implications for where the patient's death may occur as a result needs to be considered in the implementation of these recommendations.

RNAO supports recommendation 14. An implementation consideration is that interpreters need to be available and trained in medical terminology so that family members and caregivers are not relied on for translation.

Planning

RNAO supports the recommendations in the planning section of the draft framework (recommendations 15 through 18). We recommend that the identification and engagement of SDMs should be included in the early identification, assessment of needs, and coordination section as mentioned previously.

Advanced care planning is missing from this section, and should also be included in the early identification process section.

Recommendation 8. Include advanced care planning and the identification of the patient's wishes as part of the early identification process.

Delivery of Care

RNAO supports the draft framework's recommendations in the delivery of care section (recommendations 19 through 32). Implementation considerations to the funding and the availability to accessing technology based services will be a barrier to implementing recommendation 19. Cultural considerations in the use of technology to provide services should be considered and alternative arrangements made where necessary.

Recommendation 24 should be moved to the early identification section as it addresses the assessment of legal, financial, and other social issues.

Recommendation 9. Move OPCN recommendation 24 to the early identification section as it addresses the assessment of legal, financial, and other social issues.

Recommendation 27 speaks to the needs of the patient nearing the end-of-life but should also include the needs of the family (i.e. what to expect, peace and comfort, treatment). The burden placed on the caregiver needs to be recognized and included in this section as well as a recommendation for respite care.

The role of volunteers and specially trained volunteer groups should be included in this section.

Recommendation 10. Incorporate the needs of the family at the end-of-life and include recommendations to address caregiver burden and respite care.

Supports for Family Caregivers

RNAO supports the recommendations in this section (recommendations 33 through 36), however the needs of the patient and family caregivers go hand in hand; therefore RNAO believes that this section should be integrated throughout the document in the early identification, planning, and delivery of care sections.

Recommendation 11. Integrate the recommendations for supports of family caregivers throughout the document, as their needs go hand in hand with that of the patient.

Palliative Care for First Nations, Inuit, and Metis (FNIM) Population

The palliative care needs for First Nations, Inuit, and Metis (FNIM) populations should be integrated throughout the document in the early identification, planning, and delivery of care sections. Furthermore, although the needs of FNIM are unique, taking a health equity approach “involves the fair distribution of resources needed for health, fair access to the opportunities available, and fairness in the support offered to people when ill”¹⁹ and thus should be inclusive of all socially and economically disadvantaged populations.

Recommendation 12. Integrate the needs of vulnerable and priority populations throughout the report using a health equity approach.

There are major gaps in the provision of faith-based and culturally competent services for patients in Ontario.^{20 21} In addition, specific funding should be allocated for developing and strengthening capacity to provide palliative care in rural and remote communities. For example, fly-in communities have limited or no access to the internet, which results in barriers to participating in telemedicine and webinars.

Conclusion

RNAO appreciates the opportunity to comment on the draft recommendations for a model of care to improve palliative care for adults receiving care at home. We look forward to providing continued input in the drafting of the Palliative Health Services Delivery Framework.

Appendix A: OPCN Recommendations for a Model of Care to Improve Palliative Care in Ontario

Early Identification of Needs for a Palliative Approach and Accessing Care

OPCN recommendation 1. All member of the patient's current care team (family physician, hospital team, home and community care providers, etc.) should use validated approaches to ensure early identification of patients who would benefit from a palliative approach to their care.

OPCN recommendation 2. Identified patients and their families/caregivers should be referred to a centralized referral and navigation system in order to initiate identification of needs, care planning and establishing their primary care team. The referral and navigation system may be housed in a variety of agencies depending on regional needs and resources.

OPCN recommendation 3. During the intake process, a coordinator is responsible for ensuring a detailed assessment of the needs of the patient and their family/caregivers, determining the MRP and allocating services. If services are not required at the time of assessment, the patient will remain registered to the program as case management only.

OPCN recommendation 4. The coordinator should ensure the assessment of family/caregiver circumstances to determine the level of their participation in patient care and identify the need for support, training, education, and information.

OPCN recommendation 5. A coordinator with expertise in managing care for vulnerable populations should assess the needs of the patient and connect with appropriate healthcare and social services.

OPCN recommendation 6. Upon assessing the needs of the patient and the family/caregivers, the coordinator will make referrals to appropriate services and teams. This will include identification and confirmation of the core primary care team (MRP, nurse and ongoing care coordinator) as well as the secondary level experts who will be available to that primary level team.

OPCN recommendation 7. When working with culturally diverse populations, every effort should be made to connect the patient and family/caregivers with interpreter services (French, First Nations, Inuit, and other), if needed, to ensure that the information is clear and understandable.

Palliative Care Team

OPCN recommendation 8. All patients with palliative care needs and their family/caregivers should have 24/7 access to a core primary level team. Every attempt will be made to find a primary care MD or NP for a patient who has a life limiting illness.

OPCN recommendation 9. Within the primary care palliative care team, the role of care coordination should be clearly identified. A designated Community Care Coordinator will be responsible to ensure that all elements of the care plan are implemented by the most appropriate team member and that team members understand each other's roles. Community Care Coordinator should engage members of the extended primary team as their services are required

OPCN recommendation 10. A specialist palliative care team should be available to support/consult the members of the primary level team. The primary level team will have 24/7 access to the specialist team for medical issues and support.

OPCN recommendation 11. Indicators which would suggest that the primary level team may need assistance from one or more members of the specialist level team include:

- a. One or more symptoms remain uncontrolled despite the use of best primary level practices to manage that symptom(s).
- b. Tertiary interventions are required to manage symptoms (e.g. radiation, surgery, interventional symptom management, and hospice or hospital admission for symptom management).
- c. Clinical syndromes or co-morbidities that require specialized expertise.
- d. Psychological distress for patients or caregivers that remains unresolved despite use of best practices at the primary level to address it.
- e. Complex social conditions that require additional expertise to manage and/or plan.
- f. Establishing goals of care or a care plan remains challenging despite best efforts to do so or is complicated by difficult ethical issues.
- g. Repeated ER visits and/or hospitalizations because of exacerbation of symptoms or other reasons for distress.
- h. Patient care needs exceed the physical or emotional capacity of the family and informal caregiver(s).

OPCN recommendation 12. The specialist team should provide consultation in-person or via telephone or other technologies (e.g. OTN, email, eConsult) across all of the domains of palliative care (or medical issues).

OPCN recommendation 13. Both the primary and specialist level palliative care teams will have access to the documentation of the patient's care plan and ongoing care details. They will also participate in a clear communication process to ensure good coordination and understanding of the care plan.

OPCN recommendation 14. Interpreter services should be available to First Nations, Inuit, Francophones, and representatives of other cultural/ethnic groups if requested.

Planning

OPCN recommendation 15. The primary level team should identify and confirm the Substitute Decision Maker with the patient. This may be based on a previously completed Power of Attorney for Personal Care or on the provincial hierarchy of Substitute Decision Makers.

OPCN recommendation 16. The physician/NP along with other members of the primary level team should engage the patient, family and substitute decision maker(s) in a discussion about goals of care. This will involve a discussion about the patient and family's understanding of the illness, prognosis and treatment options. This conversation will need to be sensitive to the patient's and family's readiness and for engaging in care planning. These conversations may need to be revisited at times when the patient's condition changes.

OPCN recommendation 17. Guided by the goals of care, the primary level team with the patient, family and caregivers will develop a plan of care.

OPCN recommendation 18. The MRP will be responsible for implementing the medical aspects of the care plan. The care plan will be documented and available to the patient, family and caregivers as well as all of the members of the primary level team. The care plan and documentation will be updated regularly.

Delivery of Care

OPCN recommendation 19. Where appropriate, technology-based healthcare services (e.g. OTN virtual services, PCVC9, e-shift) should be leveraged to bridge current service gap and improve access to services for rural and isolated communities.

OPCN recommendation 20. The primary level team RN should provide pain and symptom management in collaboration with the MRP.

- a. RN should provide day-to-day symptom assessment, management and monitoring.
- b. RN or RPN with RN supervision should conduct tasks associated with symptom management (e.g. management of tubes and infusion pumps, wound care) in collaboration of the primary level physician or NP. With appropriate training and education, family/caregiver, if willing and able, may carry out some tasks with guidance from the RN.
- c. MRP on the primary level core team should be responsible for prescribing medications and ordering treatments which require such an order. MRP may seek consultation on new medication orders from a specialist team (MD or NP).
- d. The primary team RN should regularly assess cognitive and functional needs of the patient. When issues cannot be addressed by the core team, the RN should consult with OT/PT or other appropriate extended team members and arrange service as needed.

OPCN recommendation 21. RN on the core team should assess and monitor and manage the patient's underlying illness(es) under the supervision of the family physician or NP. In cases when the primary level care team cannot meet the disease management needs, MD or NP should seek consultation with a specialist team member or with a disease-specific specialist (e.g. cardiologist, nephrologist).

OPCN recommendation 22. RN and or MD/NP on the primary level care team should provide culturally sensitive support and counselling for psychological and emotional needs (e.g. fear, anxiety, and depression) of the patient and their family/caregivers.

OPCN recommendation 23. When the psychological distress for patients or caregivers remains unresolved despite best efforts to address them, the member of the primary level team who has the function of care coordination should seek assistance from other members of the extended primary team such as a social worker, spiritual care provider, hospice staff or other providers of psychosocial/spiritual care.

OPCN recommendation 24. Where needed a Social Worker should assess legal, financial, and other social issues and consult or refer to financial/legal consultant, or other appropriate professionals.

OPCN recommendation 25. For complex social conditions that require additional resources to manage and/or plan (e.g. unstable housing, complex family dynamics), the Social Worker or a Community Care Coordinator should seek consultation with other appropriate professional and/or coordinate with specialized services such as shelters, flexible homes, etc.

OPCN recommendation 26. A member of the primary level palliative care team should assess spiritual needs of the patient and their family/caregivers, such as existential concerns, rites and rituals. Spiritual care providers, specific to the faith communities or beliefs of patients and families, should be engaged where needed. If needed, appropriate spiritual care providers should be engaged to address more complex needs.

OPCN recommendation 27. The needs of the patient, nearing end of life should be re-assessed and appropriate services, such as financial, psychological, legal and spiritual care should be organized to provide comfort to dying patient.

OPCN recommendation 28. Placeholder: Statement about the role of community hospice

OPCN recommendation 29. After assessing the needs for assistance with ADL and IADL, the Community Care Coordinator should connect with PT/OT, Personal Support Workers and volunteers. The intensity of personal support should be determined using the Levels of Care framework and re-assessed as the functional status of the patient continues to deteriorate, or as the patient's circumstances change.

OPCN recommendation 30. As the patient enters the end of life phase of illness, primary team members should revisit the conversation about goals of care in order to confirm or adjust the elements of the care plan that need to be adapted in recognition of a change in the patient's status.

OPCN recommendation 31. End of life care needs for the patient, family and caregivers need to be assessed by primary team members and services adjusted to meet those needs. Issues such as preferred place of death and plans for pronouncement of death should be discussed and planned at reasonable intervals, recognizing that the preferences may change nearing end of life.

OPCN recommendation 32. Bereavement support and loss and grief counseling should be provided to the family and caregivers throughout the journey and after the death of the patient, in a respectful and culturally sensitive manner. Bereavement information and education should be available, as well as one-on-one counseling and/or group sessions, which should be provided in accordance with the needs and preferences of the family/caregivers.

Supports for Family and Caregivers

OPCN recommendation 33. The primary team should provide information about informal caregiving to all identified caregivers; which includes but is not limited to what to expect/anticipate, as well as when and who to call for information services and/or support.

OPCN recommendation 34. The primary team members should regularly assess the needs of the family and caregivers. These needs may involve the domains of emotional, informational and practical needs. The ability

of the family and caregivers both physically and emotionally to care for the patient needs to be regularly assessed.

OPCN recommendation 35. The Community Care Coordinator will work with the patient and family to address and determine their needs, and provide access where possible to services to meet their needs.

OPCN recommendation 36. When patient care needs exceed the physical or emotional capacity of the caregiver(s), the Community Care Coordinator or RN should determine the levels and types of services necessary to provide respite and support to the family/caregivers. This could include pre planned process to access inpatient admission while avoiding the ER, additional respite services, access to paid providers for respite and additional care needs.

Palliative Care for First Nations, Inuit, and Metis (FNIM) Population

OPCN recommendation 37. In effort of harmonizing healthcare services, a collaborative approach should be used to bring together traditional and western medicine. Healers and Elders should be consulted for medical, psychosocial and spiritual needs, where requested by Aboriginal patients.

OPCN recommendation 38. Aboriginal Patient Navigators should play an important role in connecting the patient and the family/caregivers to culturally appropriate palliative care. Involving them early will contribute to better coordination and continuity of care. Patient Navigators' role includes helping with discharge planning, arranging language and cultural translation services, and connecting with traditional healers.

OPCN recommendation 39. Palliative care outreach teams should be used to provide home based palliative care. Comprised of Palliative MD/CNS, and psychosocial/bereavement worker, the outreach team works closely with the local primary care.

OPCN recommendation 40. Care coordinators should work closely with inpatient care settings and local health and social programs to ensure continuity of care for patients living on and off-reserve.

References:

- ¹ Registered Nurses' Association of Ontario (RNAO). (2012). Enhancing Community Care for Ontarians. ECCO 1.0. Retrieved: http://rnao.ca/sites/rnao-ca/files/RNAO_ECCO_WHITE_PAPER_FINAL_2.pdf.
- ² RNAO (2014). Enhancing Community Care for Ontarians. ECCO 2.0. Retrieved: http://rnao.ca/sites/rnao-ca/files/RNAO_ECCO_2_0.pdf.
- ³ RNAO. (2014). ECCO 2.0, p. 9.
- ⁴ RNAO. (2012). ECCO 1.0, p. 6.
- ⁵ RNAO. (2017). 70 Years of RN Effectiveness database. Retrieved: <http://rnao.ca/bpg/initiatives/RNEffectiveness>.
- ⁶ RNAO. (2014). ECCO 2.0. p. 31.
- ⁷ Government of Canada. (2007). Nursing issues: Primary health care nurse practitioners. Retrieved from <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/nursing/nursing-issues-primary-health-care-nurse-practitioners.html>.
- ⁸ Ibid.
- ⁹ Registered Nurses' Association of Ontario. (2015). Nurse practitioner utilization toolkit. Retrieved from <http://nptoolkit.rnao.ca/>.
- ¹⁰ Public Health Palliative Care International (2018). The Public Health Approach to Palliative Care. Retrieved from <http://www.phpci.info/public-health-approach/>
- ¹¹ Karapliagkou, A. & Kellehar, A. (2013). Public health approaches to end of life care: A toolkit. Retrieved: http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf.
- ¹² RNAO. (2011). End-of-life care during the last days and hours. Clinical best practice guidelines. Retrieved: http://rnao.ca/sites/rnao-ca/files/End-of-Life_Care_During_the_Last_Days_and_Hours_0.pdf.
- ¹³ RNAO. (2013). Assessment and management of pain. Clinical best practice guideline. Retrieved: <http://rnao.ca/sites/rnao-ca/files/AssessAndManagementOfPain2014.pdf>.
- ¹⁴ RNAO. (2012). ECCO 1.0, p. 11.
- ¹⁵ RNAO. (2014). ECCO 2.0, p. 18.
- ¹⁶ RNAO (2017). 70 Years of RN Effectiveness database. Retrieved: <http://rnao.ca/bpg/initiatives/RNEffectiveness>
- ¹⁷ Biernacki, P. J., Champagne, M. T., Peng, S., Maizel, D. R., & Turner, B. S. (2015). Transformation of Care: Integrating the Registered Nurse Care Coordinator into the Patient-Centered Medical Home. *Population Health Management*, 18(5), 330-336. doi:<http://dx.doi.org/10.1089/pop.2014.0131>
- ¹⁸ Health Quality Ontario (2016). Palliative Care at the End of Life. Retrieved: www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf
- ¹⁹ Whitehead M, Dahlgren G. Concepts and principles for tackling social inequities in health: Levelling up part 1. Geneva: World Health Organization; 2006 [cited 2012 Sept 21]. Retrieved: <http://apps.who.int/iris/bitstream/10665/107790/1/E89383.pdf>
- ²⁰ Ha-Redeye, O. (2017, May 7) Cultural competency in end of life care in Ontario. *Slaw*. Retrieved: <http://www.slaw.ca/2017/05/07/cultural-competency-in-end-of-life-care-in-ontario/>.

²¹ Fraser, J. (2016). Palliative and End-of-Life Care Provincial Roundtable Report, p. 10. Retrieved: http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf.