

**Ontario
Palliative Care
Network**

Cancer Care Ontario
Action Cancer Ontario

Thematic Analysis Regional Palliative Engagement Report

A Summary of the Findings and Feedback from
Six Community Engagement Sessions in North Simcoe Muskoka

May-August, 2016

Introduction

Background

In March, 2016, the Ministry of Health and Long Term Care released their *Palliative and End-of-Life Care Provincial Roundtable Report* and formally announced the Ontario Palliative Care Network (OPCN). The *Report* and the establishment of the OPCN supports the development of a comprehensive strategy for palliative and end-of-life care, a key priority of the Ministry's *Patients First: A Roadmap to Strengthen Home and Community Care*.

In its role and mandate as the principal advisor to the government for quality, coordinated palliative care, the OPCN will support the development of 14 regional palliative care networks, jointly accountable to the Local Health Integration Networks (LHIN) and Cancer Care Ontario.

To help support the development of the North Simcoe Muskoka Palliative Care Network (NSMPCN), the North Simcoe Muskoka LHIN and Cancer Care Ontario engaged local stakeholders, including health service providers, community agencies and supports, patients and their caregivers, and members of the general public to provide an overview of the OPCN and seek feedback on local palliative care services and the development of a regional network and strategy. Six consultations, one in each sub-region and one for our First Nation Métis Inuit (FNMI) communities, occurred between May 30th and August 31st, 2016. A summary of the consultations is included below in Table 1.

Table 1 – Palliative Care Regional Engagement Sessions

Regional Engagement Session	Participant Representation	Number of Participants
Orillia Community	NSM LHIN, CCO, North Simcoe Muskoka Hospice Palliative Care Network, Simcoe Muskoka Regional Cancer Program, First Nation community members, Orillia Soldiers Memorial Hospital, Community Support Service agencies, Hospice Orillia, Central	44

	East Stroke Network, Couchiching Family Health Team, Information Orillia, family/caregivers, community members	
Collingwood Community	NSM LHIN, CCO, Hospice Georgian Triangle, North Simcoe Muskoka Hospice Palliative Care Network, Community Support Service agencies, spiritual care providers, community members	28
Midland/Penetanguishene Community	NSM LHIN, CCO, Hospice Huronia, Hospice Huntsville, NSM Community Care Access Centre, Entite 4, Georgian Bay General Hospital, North Simcoe Family Health Team, North Simcoe Muskoka Hospice Palliative Care Network, Barrie Area Native Advisory Circle, Georgian Bay Native Women's Association, Ontario Renal Network, Community Support Service agencies, Long Term Care and Retirement Homes, municipal leadership, spiritual care providers, community members	50
Muskoka Community	NSM LHIN, CCO, Hospice Huntsville, Hospice Muskoka, Andy Potts Foundation, Algonquin Family Health Team, Cottage Country Family Health Team, Muskoka Algonquin Healthcare, NSM Community Care Access Centre, North Simcoe Muskoka Hospice Palliative Care Network, Long Term Care homes, Community Support Service agencies	31
Barrie Community	NSM LHIN, CCO, Simcoe Muskoka Regional Cancer Program, Hospice Simcoe, Royal Victoria Regional Health Centre, NSM Community Care Access Centre, North Simcoe Muskoka Hospice Palliative Care Network, Barrie & Community Family Health Team, Long Term Care and Retirement	42

	Homes, Entite 4, spiritual care providers, community members	
FNMI Community	NSM LHIN, Barrie Area Native Advisory Circle, Enaahtig, North Simcoe Muskoka Hospice Palliative Care Network, Simcoe Muskoka Regional Cancer Program, Georgian Bay General Hospital, Georgian Bay Native Friendship Centre, community members	31

The input gathered from the engagement sessions was collected and reviewed by the NSM LHIN. The following will provide a summary of the feedback shared by the participants.

Methods

All responses were collected and a qualitative review of the feedback was done. The feedback received from the participants was reviewed and coded individually to identify emerging and consistent themes.

In regards to the local palliative care system, seven key themes emerged from the responses of the participants consistently across all six sessions. These themes reflected both successes and opportunities for the palliative care system in NSM. Within each sub-region/community in addition to the seven key themes identified, local nuances also emerged from the responses of the participants.

When asked to share their ideal vision for palliative care in a few words or phrases, five key concepts emerged from the feedback across all sub-regions.

Repeated key insights shared with the NSM LHIN and CCO by the participants, in respect of advice moving forward in the design and implementation of the regional palliative care system, and how to stay connected to the communities, has also been included. This feedback also includes responses received from the participants on the evaluation forms either completed at the conclusion of the sessions and/or those received electronically.

Results

Regional Themes Identified

A review of the feedback from the participants identified six key themes that were consistent across the six community engagements in NSM.

1. People

The strength of the people serving the local palliative care system was a key theme reflected by the participants across all six engagement sessions. Participants consistently reported the dedication and passion of their volunteers, health care providers, and community including spiritual care, when asked what contributed to the success of their local system.

We have people who are passionate about palliative care. A rich history of palliative care [Midland/Penetanguishene engagement session]

Dedicated people that are passionate about palliative care and service provision. [Barrie engagement session]

Strong pool of volunteers with professional and practical backgrounds. Strong sense of community, belonging [Collingwood engagement session]

We have access to wonderful family MDs, the vast majority provide palliative care across the palliative care trajectory [Muskoka engagement session]

Hospice volunteers are passionate and committed [Orillia engagement session]

(The community is) Accommodating and willing to help, knowledgeable when asked questions, and compassionate [FNMI engagement session]

In addition to reference to volunteers, health care providers and community members, participants in the five sub-regions spoke to the value of their local Hospice organization. Whether the local Hospice provided visiting hospice services and/or residential hospice services, their support was acknowledged as an integral component of the local palliative care system and key to moving forward to enhance quality palliative care.

Hospice Georgian Triangle [is a] leader, example of excellence [Collingwood engagement session]

Hospice Huronia deals with the network at a governance level, provides volunteers to help both patients and families. [They are] Specially trained for grief and bereavement support [Midland/Penetanguishene engagement session]

Strength in joint planning and mutual support between Hospice Huntsville and Hospice Muskoka. Overriding these strengths is the essential value of visiting Hospice volunteers [Muskoka engagement session]

2. Collaboration and Partnerships

Consistently across all six engagements, participants spoke to the community collaborations and partnerships as key to the success of their local palliative care system.

Within the sub-LHIN we work collaboratively and seamlessly to deliver services; [we have] excellent and dedicated leadership and mentorship of community partners by HOPE Huntsville to help ensure high quality care [Muskoka engagement session]

Highly skilled, collaborative team work [Barrie engagement session]

People willing to work together to support the patient/client/resident needs [Orillia engagement session]

Participants in all sessions spoke of the value of local interdisciplinary/multi-disciplinary palliative care rounds. These rounds are an example of the strength and value of local collaborations and partnerships in providing high quality palliative care.

Palliative care teams (hospital, hospice, CCAC, NSMHPNC, RN service provider, clergy) meet weekly to identify palliative patients and their needs. [Collingwood engagement session]

Weekly palliative rounds with community partners and the hospital providing early identification and early referrals [Midland/Penetanguishene engagement session]

Palliative care rounds (including GBGH and RVH) that includes the community, once a week [FNMI engagement session]

Specifically in our FNMI engagement session, participants recognized improvements to collaboration and partnerships between the medical service providers and the community's traditional practices/practitioners and cultural support.

GBGH is very accommodating for cultural ceremonies related to end-of-life. OSMH also supports ceremonies and other accommodations like having musicians come in to play. RVH CCO has spacious, peaceful, welcoming rooms to accommodate large families at end-of-life [FNMI engagement session]

Anishinabe Traditional Spiritual practices are being acknowledged. The medical community [has started] valuing traditional practices in end-of-life [FNMI engagement session]

Some primary care providers are respectful of the right to choose [FNMI engagement session]

3. Access to Education

Access to palliative care education and training for providers was consistently reported across all six engagement sessions, as a key to the success of their local palliative care system. Respondents spoke of the availability and easy access to this education and the organizations' support for participation.

Access to good palliative care education [Barrie engagement session]

Education opportunities from network accessible for all disciplines [Midland/Penetanguishene engagement session]

Access to education [FNMI engagement session]

Frontline providers are knowledgeable and caring because of the easy accessibility to education, supportive resources for providers [Orillia engagement session]

In addition to training for health service providers, access to training and education for volunteers was also noted in the responses. Participants referenced that the availability of this education enabled and supported a highly trained and skilled volunteer base to support local palliative care

Training program on palliation for volunteers and Board members-variety of sessions to ensure everyone has opportunity [Barrie engagement session]

Education provided to Presbyterian, well received, with good care provided to patient/caregiver as a result [Orillia engagement session]

4. Opportunity for Early Identification

Participants from all regions reiterated the need for early identification of palliative patients as an opportunity to improve the local palliative care system. They spoke of the value of early identification to facilitate the opportunity to connect patients and families with resources and supports throughout the palliative care continuum.

Earlier recognition and referral of life-limiting diagnosis [Collingwood engagement session]

Discussions of palliative care are happening too late in disease trajectory [Midland/Penetanguishene engagement session]

Aligned with early identification was feedback received throughout the region supporting the need to normalize conversations about death and dying to better support patients and their families through the care continuum.

More education along the 'journey'-in the language that people understand; normalize conversations about death, decrease crisis, trauma, honour good grieving and dying. [Orillia engagement session]

More truthful, clear Dr./Oncologist patient conversation re: need for palliative care [Muskoka engagement session]

Opportunities for doctors to become comfortable in discussing palliative care with their patients [Barrie engagement session]

5. Opportunity to Increase Capacity

Across North Simcoe Muskoka, participants provided feedback on the need to increase local and regional capacity to support improvements to the local/regional palliative care system. Capacity

was referenced in a number of examples including increased capacity for residential hospice and respite beds, technology that better shares and communicates information, and more service providers.

More support for nurses and staff in retirement and long-term care homes; more PSWs that are trained as they are the ones dealing with end-of-life clients [Barrie engagement session]

More beds and more hours [Collingwood engagement session]

Not enough staff to do palliative care, PSWs, nurse, consultants, counsellors, hospice volunteers, etc [Orillia engagement session]

Build stronger community members to support palliative patients in the community [FNMI engagement session]

Across North Simcoe Muskoka, participants reflected the need for funding to support increased capacity.

Funds for creating more Hospices. More government funding for palliative home care [Barrie engagement session]

More money needed to support palliative care in communities [FNMI engagement session]

More support for the caregiver at home for respite/PSW. OHIP funded services are focusing more on personal care beyond what Hospice volunteers can provide system limited resources [Midland/Penetanguishene engagement session]

Increased funding to frontline care of clients [Muskoka engagement session]

Aligned with enhancing capacity within the palliative care system, feedback from the participants yielded an interesting observation in regards to their reflection and comments on caregiver support. In a number of responses across the region, participants reflected on the availability of caregiver support, including grief and bereavement services, as a success of the local palliative system. Almost of equal frequency were the number of responses that reflected the need for greater caregiver support as an opportunity to improve the local palliative system. Certainly, caregivers were very much recognized throughout the engagement sessions and supporting them appropriately was identified as essential to a successful palliative care system.

Strong bereavement programs in North and South [including] caregiver respite overnight [Muskoka engagement session]

Supports/platforms exist in Aboriginal communities [FNMI engagement session]

Lack of respite care/support to prevent care provider burnout [Barrie engagement session]

Better support to caregivers-too many limitations on supports, caregivers have to collapse before support comes [Orillia engagement session]

Need more caregiver support if someone is to stay home. [We need] debriefing/specialized counselling for when they die.. [FNMI engagement session]

6. Improve Transitions and Coordination of Care

Reflected in the responses received from all six engagement sessions was the opportunity to improve transitions and/or coordination of care throughout the palliative care system. Respondents noted the challenges for patients and families as they transition across sectors and providers.

Defragment the system, connect the dots between providers [FNMI engagement session]

Improve coordination between communities-when discharge from one to another-to hospital and home, [prevent people from]“falling through the cracks” [Barrie engagement session]

People working in silos-not a smooth transition of care [Barrie engagement session]

Patients end up in emerge due to inability to have care streamlined [Barrie engagement session]

How can we best connect existing resources in a way that streamlines care to the family/patient [Muskoka engagement session]

The opportunity to improve coordination of care was also reflected in feedback regarding the need for greater clarification of roles and a decrease in the duplication/redundancies in the system.

Decrease duplication/increase efficiency of already available support. Clarity of roles- CCAC/NSMHPCN/Vising Nurse-decrease duplication [Barrie engagement session]

There are some redundancies in current community palliative care-how can we better use the resources and still get quality outcomes [Muskoka engagement session]

7. More Public Education

Responses across all six engagement sessions consistently reflected the need for more public education specifically on palliative care, what is available, and advance care planning. Participants reported that the general public needs to better understand what palliative care is and what it can offer across the continuum of care for an individual and their family.

Clear communication-avoid jargon. More public education re: what is “palliative”, “hospice”, etc [Collingwood engagement session]

Public health approach-compassionate communities [Midland/Penetanguishene engagement session]

More communication to the community about services and that palliative care is not just end of life care [Barrie engagement session]

Remove stigma of palliative care /death [Barrie engagement session]

Better promotion of what is available for the family, increased education for those who aren't aware of palliative care [FNMI engagement session]

In addition to a greater public understanding of palliative care, respondents also felt more education was required in regards to advance care planning. Aligned with this feedback, participants reflected on the importance of normalizing death and dying within our communities, and ensuring these conversations are happening. Respondents felt that more public education is required to support a cultural shift.

Advanced Care Planning-culture change regarding death and dying (What are the opportunities to improve palliative care in this community) [Collingwood engagement session]

More embracing of ACP and death/living rather than death denying culture—keep talking about ACP, death, continue the conversation cross culturally and socioeconomically [Orillia engagement session]

Get the word out about Advanced Care Planning! [Barrie engagement session]

More community education on palliative care and ACP [FNMI engagement session]

Community Themes Identified

In addition to these seven themes which were consistent across the regions, feedback from local communities suggested localized themes and observations of interest.

Orillia Community

Unique to the feedback received from participants in the Orillia community engagement session included repeated mention of the value of the local spiritual care providers as partners within the palliative care system. Respondents in Orillia also spoke to the strong bereavement and grief programs available to the community as another success of the local system. Participants from the Orillia engagement session repeatedly noted the need for local residential hospice beds as well as better support for caregivers as two key opportunities to improve the local palliative care system.

Collingwood Community

Participants in the Collingwood community engagement session repeatedly noted the strong partnerships with the chaplaincy/spiritual care community as well as funeral homes, in the provision of their local palliative care system. Respondents also noted the value of 2-1-1 as a resource to support the community in accessing palliative care services. From the participants in Collingwood, a number of responses reflected a palliative care navigator position as an opportunity to improve the local system. Respondents also noted the necessity for the palliative care system to be disease-agnostic.

Midland/Penetanguishene Community

The feedback provided by participants in the Midland/Penetanguishene community highlighted the value of the local spiritual care community as a key partner in the provision of palliative care.

Participants also noted the strong partnership and support they receive from the leadership of their local municipalities. Respondents from the Midland/Penetanguishene community repeatedly noted the need for residential hospice within their community as a key opportunity to improve their local palliative care system. Increased caregiver support as well as the provision of holistic, culturally safe care was also reflected as a key opportunity for improvement.

Muskoka Community

Engagement with the Muskoka community highlighted the local “grass-roots” system and solution, including the partnership between two community hospices, as key to the success of their local system. Respondents noted the strength of primary care leadership within the community, particularly HOPE Huntsville, and the value in implementing the EDITH protocol. Participants in Muskoka repeatedly noted the challenge in delivering equitable care across the geography and the need to work together to develop an appropriate strategy as a key opportunity for improvement of the local palliative care system. Many respondents noted the challenges in accessing equipment and medications in a timely fashion as a result of the logistics involved with the provider.

Barrie Community

Participants in the Barrie community engagement session reflected pediatric caregiver respite provided by Hospice Simcoe, as a strong success within the local palliative system. Participants also noted the value of the implementation of the EDITH protocol locally, as well as bereavement supports available. Access to pain management and symptom relief kits was also repeated as a strength in the local system. Respondents in Barrie have suggested increased support to long term care and retirement homes as a key opportunity to improve the system as well as offering more respite for caregivers.

FNMI Community

Participants at the FNMI engagement session reflected the significance and need for greater understanding, respect, and inclusion of cultural-based care within the delivery of hospice palliative care to urban and rural aboriginal people. Participants reiterated that palliative care is inherent within aboriginal culture; it is a part of the culture and what the community does naturally, supporting community members throughout their journey including end-of-life care. One group reinforced this understanding describing their ideal vision for palliative care as “Nigeewaymin”, going home. Participants spoke of the need for greater awareness by

mainstream providers for traditional and spiritual practices and practitioners and to include these providers within the care delivery, leveraging and engaging what is already available within the community. While they noted improvements from local health providers in working with aboriginal communities and collaborating with traditional practice and culture, they reflected the need for strengthened cultural sensitivity, awareness, and support by direct care providers and the system as a whole. Participants also spoke to the need to better support the family and caregivers with bereavement and respite.

Vision

In addition to soliciting feedback on successes and opportunities for the local palliative care system, participants were asked to share their vision of what an ideal palliative care system would be in their community, using simple words and/or phrases to describe it. Five key words and/or concepts were heard consistently across all six sessions;

1. **Equity**- Participants repeatedly reflected the need for the regional/local palliative care system to be equitable; to be provided in a culturally safe means that is inclusive and respectful of all individuals and their family members.
2. **Integrated**- Across all six engagement sessions, participants consistently envisioned a palliative care system that was coordinated and seamless with all partners collaborating across the care continuum.
3. **Patient-Family Centred**- A palliative care system that is patient and family-centred was a key theme that emerged from the responses of the participants. Participants also described the patient-family centred system as personalized, providing the patient and their family choices and respecting these decisions.
4. **Accessible**- Reported within all of our sub-regional engagement sessions, participants envision a palliative care system that is easy to access including all the supports and services across the continuum.
5. **Compassionate**- When describing the palliative care system, respondents repeatedly used the word "compassionate" to define the care provided by all those involved in the delivery of palliative care.

Staying in touch

At the conclusion of the engagement sessions, participants were asked for advice or insight for the NSM LHIN and CCO as they work together to structure the regional palliative care system moving forward. Although suggestions ranged, the following was consistently repeated;

- We want you to listen
- Communicate, be transparent and inclusive and stay connected with the communities
- Hang on to the strengths that have already been developed
- Have flexibility in the system, one size doesn't fit all
- Keep it simple
- Start with the patient; keep it patient-family centred

As the NSM LHIN and CCO move forward in the development of the NSM regional palliative care network, participants asked that contact be maintained using a variety of methods including emails and website updates/blogs.

Conclusion

Approximately 230 community members, health service providers, and other local stakeholders participated in the regional engagement sessions to share their thoughts and insights on their local palliative care system. This feedback depicted local palliative care systems built upon a number of strengths but also shared opportunities to improve upon the existing framework. Participants identified themes that were shared consistently across the region as well as those unique to the local community. The NSM LHIN and CCO would like to thank the participants for their time and willingness to share their understanding and insight. These engagement sessions were a true representation of the dedication and passion of the people involved within our local palliative care systems, the number one theme identified by participants across the region. The NSM LHIN and CCO will use this valuable feedback to inform the development of a regional palliative care system. To reiterate the communication from the engagement sessions, this was just a start of the conversations that we look forward to continuing with you as we move forward.