Ontario
Palliative Care
Network

Patient and Family Advisor Journey Mapping Exercise Summary

January 12, 2018 (11:30 AM to 3:30 PM), YWCA Toronto Boardroom

Purpose

The purpose of the Journey Mapping exercise was to learn from the experiences of patients and families/caregivers in order to improve the delivery of hospice palliative care. Through a facilitated exercise, participants identified patient and family needs and discussed opportunities to address these needs. These needs pertained to five pre-determined elements of care: Accessing Palliative Care, Palliative Care Team, Planning, Delivery of Care, and Supports for Families/Caregivers[1]. Participants included patients, caregivers and family members. Findings from this exercise will be used to inform the Health Services Delivery Framework, which includes recommendations for the delivery of palliative care in Ontario.

The Palliative Care Health Services Delivery Framework

The Palliative Care Health Services Delivery Framework (HSDF) describes how care should delivered provincially, so that individuals with a life-limiting illness, and their family/caregivers, receive care from an interdisciplinary team at every point in their care trajectory. The goal is to deliver high quality, culturally sensitive, and needs-informed care that is able to be maintained over the long-term.

The first area of focus includes adults who are living at home (i.e. usual place of residence). Future areas of focus will include adults in a hospital setting and pediatric patients receiving palliative care.

The development of these recommendations involves wide consultation with patients and family advisors, health care providers, system planners, and a review of emerging research, and best practices in Ontario and abroad. A HSDF Working Group had been established to develop the recommendations. The final document will be published on the OPCN website (www.ontariopalliativecarenetwork.ca) in spring 2019.

Journey Mapping Exercise Activities

Dr. Robert Sauls, HSDF Working Group Co-Chair, led the introduction and overview of the exercise. Denis Charette, OPCN Patient and Family Advisor, shared his role with the OPCN and highlighted the importance of patient engagement in planning the delivery of care. Next, Naeema Tharani, CCO Senior Specialist in Strategy & Business Management, detailed the day's agenda and activities. Once the introduction and overview were complete, participants were asked to move into their assigned groups.

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[1] Adapted from the Canadian Hospice Palliative Care Association. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2013.

The 14 participants in attendance were assigned to one of three groups. To ensure diverse perspectives were represented, participants had been pre-assigned to their groups based on their role (patient or family/caregiver), geographical location, and life-limiting illness.

In their groups, participants reflected on the details of a patient scenario that had been provided and of their own personal experiences to identify the needs of patients and their families or caregivers. These needs were further discussed, enabling the group to brainstorm opportunities through which the delivery of palliative care can be improved. The exercise concluded with a member from each group sharing their key discussion points with the other participants.

Findings

Highlights

Throughout the exercise, participants identified the needs of patients and families/caregivers, as well as opportunities for improvement. Some of the opportunities could address and/or impact multiple needs. Key opportunities include:

1. Identifying and providing contact information for a designated individual (‘Navigator/Coordinator’)[2] to support the patient and family/caregiver throughout their journey.
2. Beginning discussions regarding palliative care and care planning early on in the patient’s illness journey.
3. Ensuring adequate palliative care services and resources are available to support the unique needs of patients and families/caregivers during care and after death.
4. Educating the public and healthcare providers about palliative care and related topics.
5. Integrating services and systems to enable seamless access to patient information, resources and services (e.g. primary care, hospital, home and community support services).

Needs & Opportunities

A complete account of the needs and opportunities discussed are detailed below. Grouped based on the element of care to which it best relates, the need is first described and followed by related opportunities.

A. Accessing Palliative Care

1. Identifying Needs:
To identify patient need for a palliative care approach earlier on in their illness journey.

- **Assess patient and family/caregiver needs** upon diagnosis. Health care providers should regularly review this assessment for patients and family/caregivers to be able to make informed decisions or seek out any supports they may benefit from.

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[2] This designated individual, also referred to as a Navigator or Coordinator, would be a member of the care team and a registered professional (e.g. Registered Nurse or Social Worker) who acts as a single point of contact for the patient and family/caregiver. This trained individual supports the patient and family/caregiver across all settings of care by sharing information, and acting as a liaison/facilitator among all healthcare providers and organizations who are part of their illness journey.

- **Apply the principles of a palliative approach to care** by enabling a continuum of services, rather than a sudden referral to palliative care services.

- **Provide a clear, concise and consistent definition** for ‘palliative care’ to clarify that a referral to palliative care services does not necessarily mean preparing for the end of life. This definition should reframe palliative care as more whole person care when one is diagnosed with a life limiting illness to address misconceptions and reduce stigma (e.g. holistic approach to pain and symptom management).

2. Accessing Services and Resources:

To have timely access to palliative care services and resources when needed.

- **Provide information** about services available to patients upon diagnosis of their life-limiting illness (e.g. hospice at home). The information should be presented in varying forms to accommodate preferences (e.g. print material and online information).
- **Develop a network of services** to facilitate access and navigation. Patients or families/caregivers can connect with this network through their designated Navigator/Coordinator and be immediately referred to a range of services.
- **Ensure 24/7 availability** of resources and services for patients and their families/caregivers, without any restrictions to the number of times they have been accessed (e.g. home care, palliative nurses on-call).
- **Enable patient and family/caregiver self-referral** to supportive services when access is needed.
- **Provide more community-based services** to support the palliative care needs of patients and families/caregivers, particularly services that support home-based care. There should also be recognition that not all individuals prefer home as a setting of care.
- **Enable health care provider knowledge** of services and resources that are available for the patient and their family/caregivers.
- **Review policies** to ensure they are not acting as a barrier to services for patients and are reflective of their needs. For example, policies to access palliative care home care services from the LHIN should be transparent on what services are available and when, so that the patient does not hear, “Are you sure the patient is near death? As I can only increase their nursing hours once”.

3. Supporting Transition:

To be supported in transitions during illness and bereavement.

- **Provide a designated Navigator/Coordinator who acts as a single point of contact**, and is available 24/7 to support the patient and family/caregiver with transitions by:
  - Driving the initiation of palliative care services in the hospital;
  - Ensuring regular communication between hospitals and home care services; and
  - Identifying next steps.

- **Better integrate processes** of different care settings (e.g. hospital and home care), through the use of technology. Healthcare providers in all settings should be able to access the patient's information in real-time to support continuity of care. In the longer term, patients/family members should have access to their information in real time (if they desire).

B. Palliative Care Team

1. Knowing the Members of the Care Team:

To know who are the members of the patient's palliative care team.

- **Provide clarity** about who the members of the palliative care team are by:
  - Assigning the responsibility of ensuring clarity to the designated Navigator/Coordinator on the team; and
  - Introducing the team to the patient and family/caregiver at diagnosis of the life-limiting illness or as early as possible.
- **Ensure the membership of the palliative care team is patient-driven and continuous.** It is suggested that the care team include, but is not limited to, the following:
  - Caregivers
  - Family doctor
  - Pharmacist
  - Psychologist
  - Spiritual Care Practitioners
  - Social Worker
  - Coordinator
  - Dietician
  - Nurse
- **Establish the role of the family doctor**. As a member of the care team, their role is to regularly check-in with the patient and family/caregiver to: review the patient's status, assess the patient and family/caregiver's need for services and make the appropriate referrals. They should also receive mandatory training to ensure they are prepared to support the patient and family/caregiver's needs arising from palliative care.

2. Participating as a Member of the Care Team:

To recognize and support patient and family/caregivers as part of the care team.

- **Enable the family/caregiver to understand their role as part of the care team** through discussions with the designated Navigator/Coordinator.
- **Provide available and dedicated space** in the hospital for the designated Navigator/Coordinator to sit with the family/caregiver and provide information or counselling (as needed). The Navigator/Coordinator should be afforded the flexibility to make home visits if requested.

3. Liaising between Healthcare Providers and Patients:

To share information related to the patient and their care.

- **Designate the responsibility for continuous exchange** with either the designated Navigator/ Coordinator or as a shared function that is spread evenly among the care team members. If the continuous exchange is a shared function, a designated member needs to ensure that the care team is sharing and collaborating with the patient and family/caregiver (e.g. an enhanced electronic medical record accessible to all members of the care team, the patient, and their family/caregivers).

C. Planning

1. Developing a Care Plan:

To ensure care plans are developed in consideration of patient's needs and updated as required.

- **Develop a care plan** at the time of the life-limiting illness diagnosis with the patient and family/caregiver, and regularly review and update. Any changes to the care plan needs to be effectively communicated to all healthcare providers. The use of electronic medical records can facilitate a common understanding of the patient's condition and care plan.
- **Ensure all care team members**, **including patients and family/caregivers, have the opportunity to contribute** to the development of the care plan. Provide patients and family/caregivers time to reflect, as they may not feel comfortable making decisions immediately.
- **Discuss potential considerations for care setting options** (e.g. home care) with the patient and family/caregiver.
- **Educate healthcare providers** on how to communicate with patients and family/caregiver about advance care planning, goals of care, and palliative care. Integrate palliative care training in the education of all healthcare providers to ensure their comfort in discussing sensitive topics related to palliative care (e.g. when discussing death and dying with patients).
- **Create a culturally safe environment** when discussing palliative care. Culture includes, but is not restricted to, age, sex, sexual orientation, race, gender identity or expression, creed, ethnicity, disability, or spiritual/religious beliefs. For example, moving the conversation from being about "how do you want to die" to "how do you want to live."

2. Ensuring Understanding of the Family/Caregiver:

To ensure the family/caregiver understands what is to be expected as part of the patient's palliative care journey.

- **Educate patient and family/caregiver** about what to expect as part of the palliative care journey. For example, understanding what physiological changes the family should expect to see and deal with if the patient chooses to die at home.
- **Engage a designated Navigator/Coordinator** to support the patient in understanding and thinking through their care options before having the discussion with their healthcare provider.
- **Ensure up-to-date resources** are available and accessible online to support the family/caregiver in understanding the care options.

3. Discussing Palliative Care:
To have provider-driven, proactive discussions related to palliative care and care planning.

- **Create a Just Ask! Campaign** to support healthcare providers in better communicating with patients to understand their needs. This includes asking patients questions about how they want to be involved in care, what their preferences are, and what they want to know.
- **Initiate advance care plan discussions early** on in the journey (e.g. in advance of needing palliative care and not during the time of crisis); consider having the discussion during the patient's annual physical exam.
- **Develop a checklist** detailing select discussion topics such as advance care planning, goals of care, and treatment plan to support primary care providers in having difficult conversations when acute changes occurs.

D. Delivery of Care

1. Receiving Person-Centred Care:
To receive care that is supportive to patient and family/caregiver needs and preferences.

- **Collaborate** with the patient and family/caregiver to develop a care plan by asking about and listening to what they want. This engagement process should be ongoing (i.e. patient and family/caregivers should be engaged whenever the care plan is revised).
- **Provide a copy of the care plan** to the patient and their family/caregiver, with the ability to make changes as needed.
- **Consult a cultural navigator** to ensure that services mitigate language and cultural barriers, patient's values are respected, and that needs are addressed.
- **Provide optional translation services** to the patient and their family/caregiver.
- **Enable support/training for healthcare providers in** real time.

2. Receiving Holistic Care:
To receive care that is holistic, and considers various aspects of the patient's illness journey.

- **Provide emotional support and mental health services** to the patient and family/caregiver early in the palliative care journey. These services are often left to the individual to identify a need and pay out of pocket for.
- **Recognize that health issues do not always occur in a linear/stepwise manner, may occur simultaneously, or at different times for different people**. Communication between specialists should take place when the patient has multiple chronic illnesses. This collaboration can help to avoid medication errors and manage expectations within their illness journey.
- **Include non-medical activities (e.g. recreational therapy)** to give the patient and family/caregiver some time to focus on things other than their illness.

3. Understanding Care Activities:
   To understand the activities the patient is undergoing as part of palliative care.

- **Ensure designated Navigator/Caregiver** is present during care activities to help the patient and family/caregiver understand what is happening and why it is happening (e.g. discussion about the removal of the patient’s IV). This Navigator/Coordinator should be available throughout the patient’s palliative care journey.

4. Ensuring Accountabilities:
   To be given the opportunity to provide feedback about the care received.

- **Create an ongoing feedback loop by establishing a real-time mechanism** for patients and family/caregivers to resolve their needs (e.g. informal checking in by healthcare providers on a regular basis; asking about the satisfaction with the process, what went well, what did not).
- **Determine system level measures** by developing process and outcome indicators for palliative care service delivery.

E. Supports for Families and Caregivers

1. Feeling Supported Prior to Death:
   To feel supported while the patient is receiving palliative care.

- **Provide supports** for the family/caregiver, which may include but are not limited to the following:
  - Financial and future planning support (e.g. development of a will)
  - Respite support
  - Spiritual support
  - Learning how to communicate with the patient
  - Peer counselling to discuss what to expect as part of the care journey
  - Proactive mental health support that acknowledges potential difficult or traumatic experiences (e.g. reviving their loved one)
  - Coping strategies for managing challenges, frustration, and burn-out
  - Knowledge of and access to services and resources through a community services database (e.g. 211 service for social services)
- **Assign a dedicated individual** whose primary focus is the needs of the family or caregiver, including medical and non-medical needs, and ensures they receive or have access to supporting services or resources.

2. Feeling Supported After Death:
   To feel supported after the death of the patient.

- **Provide supports** for the family/caregiver, which may include but are not limited to the following:
    - Continuity of services from time of death to bereavement, rather than an abrupt change or full stop in service
    - Mental health support to manage grief, loss and bereavement that is not time sensitive or limited to only the first year post loss.
    - In-person support to manage activities like police investigations or removal of the body from the home (if home was the preferred setting of death)
    - Peer support, to learn from someone else's experiences
    - Family doctor to acknowledge the loss of their loved one
    - Knowledge of and access to services and resources through a community services database (e.g. 211 service for social services).

F. Other

1. Creating Public Awareness of Palliative Care:
   To ensure understanding among the general public that 'palliative care' does not mean 'end of life'.

- **Develop an education campaign** to address the stigma associated with palliative care, recognizing it will become a more common form of care among the aging population. Ultimately, normalize palliative care services, advance care planning discussions, and discussions related to death and dying.

2. Addressing silos: To acknowledge the siloed operations of the various medical fields.

- **Change the funding structure** to alter the culture of how care is provided. Palliative care should be embedded in all aspects of care and not stand alone.
- **Publish clear guidelines on what palliative care services are available from LHIN home and community care.** This information will help families/caregivers understand the home care requirements of their loved ones, and determine if they are able to take on the caregiver role at home.

Next Steps

The needs and opportunities identified during the Journey Mapping Exercise will be used to inform the Health Services Delivery Framework, recommendations for the delivery of palliative care in Ontario.