Canadian Home Care
Association
canadienne de soins
et services à domicile

Building Operational Excellence
Home-Based Palliative Care

Mapping the Palliative Care Experience

Multi-phase stakeholder engagement

December 2018

ABOUT THE OPERATIONAL EXCELLENCE IN HOME-BASED PALLIATIVE CARE PROJECT

Operational Excellence in Home-Based Palliative Care is a 19-month project that builds on The Way Forward: An Integrated Palliative Approach to Care. The goal is to identify innovative operational practices that address specific service gaps and improve the quality, efficiency and accessibility of home and community palliative care. The project is a catalyst to improve operational infrastructure in home-based palliative care and enhance access to better home care as outlined in the Common Statement of Principles on Shared Health Priorities for federal, provincial and territorial governments. Visit https://cdnhomecare.ca/operational-excellence-in-home-based-palliative- care/ for more information.

This project was supported by a health funding contribution agreement from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

ABOUT THE CANADIAN HOME CARE ASSOCIATION

Established in 1990, the Canadian Home Care Association (CHCA) is a national non-profit membership association dedicated to advancing excellence in home and community care. Through our diverse membership base, the CHCA represents public and private organizations that fund, manage and provide services and products in the home and community. In partnership with our members, the CHCA advances initiatives that address national priorities in home and community care. As a recognized authority, the CHCA facilitates knowledge sharing, creates connections, informs policy and practices, and advocates for integrated home and community care for all Canadians.

EXECUTIVE SUMMARY

Supported through a Health Canada funding contribution, CHCA is leading a 19-month project which builds on the **"The Way Forward: An Integrated Palliative Approach to Care"** by identifying innovative operational practices to address specific service gaps and improve the quality, efficiency and accessibility of home-based palliative care.

Surveys of Canadians show that most would prefer to die at home if they could get the support they need.

Across all sectors of care, but particularly in the home setting, there is a lack of data on the basket of palliative services patients receive, and on what patients and their families experience. Plus, variations in provincial and territorial policies, strategies, frameworks and funding models affect the organization and delivery of home-based palliative care services across the country. There are also variations within jurisdictions.

This project is a catalyst to improving operational infrastructure in home-based palliative care and enhancing access to better home care as outlined in the **Common Statement of Principles on Shared Health Priorities**, endorsed by federal, provincial, and territorial governments.

Based on gaps identified in the *Way Forward* study, this project focused on the following four areas for improvement:

1. inclusion of advance care plans into the delivery of care in the home;
2. assessment and care planning;
3. effective communication strategies and tactics, and
4. supplies, equipment and medication management.

Beginning in the June 2018, the Canadian Home Care Association (CHCA) conducted a multi-phased stakeholder engagement process to help identify innovative operational practices to address the service gap areas noted above.

The results of this comprehensive engagement process have provided a rich landscape of palliative care experiences across the country and opportunities for innovations in operational processes. Key findings for each of the focus areas are summarized next:

Inclusion of advance care planning into care delivery

- Hold early and ongoing conversations about end of life wishes and values
- Understand and consistently communicate end of life wishes
- Ensure care plans, documentation and other legal requirements reflect wishes and values

Assessment and Care Planning

- Use a palliative approach to care in identifying and responding to patient needs
- Involve patients and caregivers and providers in developing and updating care plans
- Understand and use assessment and planning tools for comprehensive awareness of patient needs

Effective Communication Strategies and Tactics

- Recognize and communicate with all members of palliative care team members
- Consistently communicate changes in the patient's condition and needs
- Communicate with patients, family and caregivers in a manner that is appropriate, timely and practical

Effective Communication Strategies and Tactics

- Ensure medications and supplies and equipment are available without duplication and delay
- Organize and manage use of supplies and medications
- Ensure removal of supplies, equipment and medications from the home

This report outlines the overall design of the engagement process and a summary of the results of the engagement process.

Overall Design of Engagement Process

This multi-phased engagement process consisted of four main activities:

a) regional stakeholder workshops;
b) key informant interviews with cultural groups;
c) key informant interviews and an online survey with patients and caregivers, and
d) E-Delphi process with 2 rounds.

REGIONAL WORKSHOPS

During the summer of 2018, four invitational stakeholder workshops were held across the country to develop Palliative Care Experience Maps. Each workshop addressed one of four areas of focus.

Edmonton	INCLUSION OF ADVANCE CARE PLANS INTO THE DELIVERY OF CARE IN THE HOME
Vancouver	ASSESSMENT AND CARE PLANNING
Charlottetown	EFFECTIVE COMMUNICATION STRATEGIES AND TACTICS
Ottawa	SUPPLIES, EQUIPMENT AND MEDICATION MANAGEMENT

The purpose of these workshops was to develop palliative care experience maps of the current operational procedures, policies and processes for home-based palliative care. Through a facilitated dialogue process, participants representing a range of stakeholder organizations provided feedback on what is taking place currently as well as identifying potential solutions or innovations.

INTERVIEWS WITH CULTURAL GROUPS

CHCA identified a range of cultural, religious and LGBTQ organizations as potential stakeholders. Through direct contact, representatives were invited to participate in one-on-one interviews to provide insights into barriers and considerations for delivering culturally respectful home-based palliative care.

The interviews were conducted over the telephone using an interview guide. A total of four organizations participated in the interviews.

INTERVIEWS AND SURVEY WITH PATIENTS AND CAREGIVERS

A flexible approach was used to capture the voice of patients and their caregivers to accommodate their needs and circumstances. It was important to recognize their health condition, schedules and responsibilities. To accomplish this, the CHCA engaged patients and caregivers through scheduled telephone interviews and an online survey aimed at caregivers who had supported a loved one to die at home. This engagement phase identified several areas of improvement and innovative practices specific to the operational gaps in home-based palliative care.

A total of 15 patients and caregivers participated in 30-minute one-on-one telephone interviews following an interview guide. These participants came from Ontario, Alberta, BC and PEI. The online survey for caregivers resulted in 61 completed surveys covering experiences in seven provinces.

E-DELPHI PROCESS

Based on the input from the workshops, interviews and online survey, an E-Delphi process was undertaken with a group of experts to validate and prioritize the key areas of improvement. The results of the e-Delphi were used to finalize the Palliative Care Experience Maps which highlight priorities for leading practices and will help to inform policies, programs and practices. The objectives of the E-Delphi process were to:

- Share the initial considerations from the first phase of engagement and consultation.
- Validate key areas for operational improvement.
- Identify other significant issues and areas for improvement in operational processes.
- Inform the Palliative Care Experience Mapping.
- Determine stakeholders' ranking of priority areas of improvement.

This electronic consultation was carried out by a web-based survey over a period of approximately 44 days. It was an iterative process, with two rounds, involving 2 questionnaires, building on the results of the previous one.

- E-DELPHI ROUND 1 FEEDBACK – A set of questions was developed to help validate the areas for improvement and to identify any areas that were missed and are significant. The online questionnaire was sent to a panel of home care leaders and subject matter experts for a period of 2 weeks.
- E-DELPHI ROUND 2 FEEDBACK – The questionnaire was modified based on the feedback from Round 1 and circulated to the panel for final input and comments with the goal to identify priorities for operational improvement.
- E-DELPHI ROUND 1 REPORT – A report on the results from Round 1 was circulated with the Round 2 survey. Both the consolidated and a summary of open-ended responses were included in this report. All responses were kept anonymous, so participants could see only the overall feedback.
- REVISED AREAS OF FOCUS – The areas of focus statements were modified based on the feedback received from the Round 1 of the e-Delphi and ordered by ranking of importance from Round 1. In addition, new statements were added based on comments from Round 1 survey.
- FINAL AREAS OF FOCUS – A final version of the areas of focus was developed. These findings helped to finalize the Experience Maps and will provide input to CHCA and the Project Advisory Committee to assist with the selection of innovations for further development into High Impact Practices.

In this Delphi process, a wide range of "experts" were recruited as the panel. This included all participants from the four regional workshops, representatives of leading home care provider organizations, relevant non-governmental organizations, and government agencies. Interested caregivers from the engagement phase were also invited to participate. Invitations to participate in the Delphi process were sent to 92 experts. For Round 1, a total of 36 responded to the survey and for Round 2, 26 responded to the survey.

Feedback from Regional Workshops – Areas for Operational Improvement

Each of the regional workshops focused on one the key areas of focus for the overall project which were based on the gaps identified through The Way Forward: An Integrated Palliative Approach to Care project. The locations were selected to build on regional expertise and experience with the topic area. The summary provided below highlights the touchpoints in the palliative care experience which were discussed by the participants, the key gaps that they identified, and some of the innovations or best practices currently in place in the province or region.

Inclusion of advance care planning into care delivery – Edmonton

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Thinking and talking about values and wishes	- Tools exist to help with discussions, but these are not always part of the home care admission process	- Central Zone has a pilot project to include this in-home care admission process - Tool" What matters to you" being implemented in Calgary
Individual Care Plans and Goals of Care	- Gaps between rural and urban - Recognition that home care service does not provide enough time for conversations and development of care plans - These discussions need to happen earlier in the process	- Rural In-Home Program in Calgary promotes home-based care
Reviewing and Updating plans	- More resources needed to support use and updating of Greensleeves tool	- Alberta is developing additional resources to support use of Greensleeves
Communications	- Gaps exist at transition points and between family members - All members of team need access to tools and documentation	- Simulation training on "Serious Illness Conversations" in Calgary - Potential use of Community Liaison Officer to improve communications
Integration	- More use of interdisciplinary teams to work collaboratively and provide continuity of care	- Paramedic Services -Assess, Treat and Refer Program (unique and best practice) - Programs and processes to reduce acute care admissions

Assessment and Care Planning – Vancouver

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Person & Family Needs Identification	- Tools exist, but they come too late - Need to shift to palliative care approach	- Fraser Health Advance Care Planning Framework - Centralized intake and registry
Assessment	- Rural and urban gaps in care - More effective assessment tools (quality of life, etc.)	- Interior Region Circle of Care Program - Research underway on Quality of Life Assessment
Developing a Care Plan	- Lack of awareness of why this is important – more communication	- Translation of Serious Illness Guide into 10 languages (including context interpretation for cultural groups) - Fraser Health Conceptual Model (under development)
Inclusion of patients and carers	- Better education for patients and carers needed – lack of awareness on options - Provide services designed for needs populations segments	
Inclusion of all members of team	- Disconnects with primary care - Better inclusion of paramedics - Better sharing of care plan	- Interior Weekly Rounds Program - Job aids for new nurses - Telephone consults with Palliative Care Specialists - Palliative clinics
Review and updating	- Guidelines for discharge and de-registering - Lack of good measurement and metrics	
Communications	- Rural and remote access - More community awareness and public understanding	- Virtual consults for remote patients

Effective Communication Strategies and Tactics – Charlottetown

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Overall Strategy	- No overall strategy exists – just info on projects - Systems do not talk to each other	- More funding for systems upgrades
Teamwork and Communications	- Lack of role clarity - Inefficient communications	
Communication across settings and transitions	- Poor communication leads to safety risks - No interoperability – need work arounds to function - Need more integration and information sharing	- Paramedic 24-hour care plans - Case conferences and collaborative care rounds
Communication tools for patients and caregivers	- Caregivers need to be at the centre - Resources need to meet the needs of caregivers – not the system - Information overload can be a problem – need right info at the right time	- Medication tracker - Home Care binders - 24/7 home care

Management of Equipment, Supplies and Medication – Ottawa

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Overall Strategy	- No overall strategy exists – just info on projects - Systems do not talk to each other	- More funding for systems upgrades
Teamwork and Communications	- Lack of role clarity - Inefficient communications	
Communication across settings and transitions	- Poor communication leads to safety risks - No interoperability – need work arounds to function - Need more integration and information sharing	- Paramedic 24-hour care plans - Case conferences and collaborative care rounds
Communication tools for patients and caregivers	- Caregivers need to be at the centre - Resources need to meet the needs of caregivers – not the system - Information overload can be a problem – need right info at the right time	- Medication tracker - Home Care binders - 24/7 home care

Feedback from Cultural Group Engagement

The diversity of Canadian society and the influence of an individual's culture, values and beliefs has a tremendous impact on the care they wish to receive and how care is experienced. An aspect of care delivery the Canadian Home Care Association (CHCA) explored was the significance and recognition of an individual's culture, personal relationships, gender, values and beliefs

The results of the key informant interviews showed that palliative care experiences can be variable for those patients and caregivers who identify with specific cultural groups. Sometimes this can be due to geography, but it is also due to the following factors:

- Language and literacy barriers
- Treatment protocols have improved for some chronic diseases such as HIV and Cystic Fibrosis – resulting in an aging demographic of these patients and changing requirements for palliative care
- Move to more patient-centred or holistic approach to care delivery
- Trauma experiences (e.g. refugee population)
- Assumptions about cultural needs and expectations

Inclusion of advance care planning into care delivery

Our interviewees strongly advocated for a person and caregiver-centred approach to the development and use of advance care plans. Members of the palliative team need to be non-judgmental and allow for flexibility in care delivery so that the wishes of the patient and their loved ones can be accommodated and respected

WHAT WE HEARD:

"In order for a person's Advance Care Plan to be incorporated into their care it is important to engage people in conversations about their wishes. And it is about the how again – not so much about the content piece"

"Don't presume that the family knows what the dying person wants. They may not have had the conversations either"

"There is a history of incredible self-reliance within the HIV community. This led to the development of incredible sources of support out of necessity when no one else would provide care that was compassionate, and non-judgemental."

Assessment and Care Planning

A person-centred approach for assessment and care planning was seen as the most important issue. Our interviewees recommended that it was critical to reduce language and literacy barriers though better access to translation services and availability of resources in multiple languages, where required. One recommendation from the transgender community was that assessments should address gender surgical reassignment so that those receiving care are respected and those providing care can be prepared properly.

WHAT WE HEARD:

"It's important to maintain cultural humility. Don't presume to understand everything about that patient, everything they want and need. Go in being open to learn and without preconceived notions."

"Refugee populations face some of the greatest challenges. There is a lack of literacy, they don't know and understand the system. They may fear repercussion. Knowing what to do and how to access the system is a huge problem."

"Once you approach care planning with an emphasis and understanding of the whole person – the spiritual, their values and beliefs and wishes you move away from standardized care planning and towards person-centred care."

"As a same sex couple, I can say I felt respected and the relationship was valued for what it was. Just like every other couple in home care."

Effective Communication Strategies and Tactics

It is important that communication strategies and tactics consider not just the message, but also the delivery. Our interviewees stressed that members of the palliative care team need to ensure that there is a clear understanding of confidentiality and acceptance of everyone, regardless of religion, culture, sexual identity, gender, or race. Representatives of the LGBTQ community recommended that patients should be encouraged to identify the pronouns and terminology that would like to have used in communications.

WHAT WE HEARD:

"It's important to maintain cultural humility. Don't presume to understand everything about that patient, everything they want and need. Go in being open to learn and without preconceived notions."

"Culturally safe conversation means that there are no preconceptions or stigma attached to whatever they want or say, however they want to act, what their wishes are or how they interact with family, their caregivers or care providers."

"There was a PSW who showed difficulty accepting the relationship between R. and myself as a couple. She referred to us 'as very good friends'. We would explain that we were not just friends, but without malice, the 'good friends' continued to be how we were referred to by this one particular PSW. It didn't impact on the care we received or compassion shown, it was just one of those things that people still struggle with."

"In the larger cities, there is less engagement, a get in, get out approach to care, task oriented care."

Management of Equipment, Supplies and Medication

This area of focus did not generate a lot of feedback from the interviews with the cultural groups. However, one specific issue was identified by the transgender community who pointed out that there is a lack of awareness and understanding about the impact of medications (e.g. pain meds) on hormone treatments. It was recommended that pharmacists play a more active role in helping to ensure that the palliative care medications are compatible with the patient's current therapies.

WHAT WE HEARD:

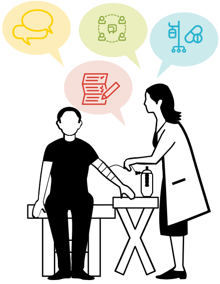
"I would have to say the experience of the LGBTQ community is mixed, and that likely depends on where people live."

"It would seem the experience of individuals living in more rural, less urban settings, is more compassionate, and I think that may be a reflection of the local culture, sense of community and community reliance."

"We've seen people who choose to return or sent to their home country, leaving spouses and family in Canada, so they can receive the extended family support they need and care in a language they understand." things that people still struggle with."

"In the larger cities, there is less engagement, a get in, get out approach to care, task oriented care."

Feedback from Patient and Caregiver Engagement



The experiences and perspectives of patients and caregivers were essential to informing this project. To capture the voice of patients receiving palliative care in the home, and their caregivers, both one on one interviews were used, supplemented by an online survey. This approach resulted in rich data on all of the four focus areas.

Inclusion of advance care planning into care delivery

Overall, the patients and caregivers who participated in the project understood the importance of advance care plans and were positive about the process.

Over 60% of the survey respondents reported that they were satisfied with how their loved one's ACP wishes were respected and acted upon by home care providers and that these wishes were reflected in the care plan. However, the biggest concern expressed by caregivers was that these conversations only happen when diagnosis is terminal (versus integrated palliative approach) or at crisis points (acute deterioration in care). The caregivers felt that there is little public awareness about the existing tools and resources available to help with these conversations and in many cases these tools are not being used. Caregivers reported that in some situations, they had to be very forceful advocates to get their loved ones wishes carried out.

Jurisdictional differences mean that advance care plan and integration of wishes into a person's care plan varies across the country. Another area of great variation is the range of people who are involved in having these conversations with patients and caregivers. Experiences show that some members of the team do this very well and others lack the necessary skills to conduct these conversations.

WHAT WE HEARD:

"I feel sometimes they used scare tactics. Was it what they thought would be best?" "We knew what we wanted, but we didn't know how to make everyone else know." "I just didn't know what could be done. I'd never done anything at all like this before."

"The plan was developed very well. The problem is in the implementation of the plan. Companies providing the care do not follow the care plan and are not accountable to anyone within the Ministry when they provide poor or nonexistent services"

"More time should be taken at the beginning of the palliative care journey to get to know the patient, his wishes and values, his cultural origin. This would permit the development of a care plan that reflects who that patient really is, the whole person, his likes and dislikes. The person needs to be valued, respected, celebrated at his life's end just as his entry into the world was celebrated by family and friends."

"I think more information needs to be provided around what end of life can look like, what the options for care are, what supports are available. How can people make informed choices without a full picture? More education and understanding of wish planning."

"We had most of the conversations with the palliative care team from our hospital. Home care workers played minor role and care coordinators were virtually non-existent and unhelpful. As a hindrance, we chose to simply not engage with them when it came to any planning"

"One sister had an oncologist that was very well linked to the Palliative Care team and seemed to remain in touch. There was an understanding of her wishes and it went forward. With my other sister, when the Oncologist was done, he was done, she was sent back to the Primary Care doctor who had no experience in palliative care or understanding of resources, and it got worse from there. The first conversations about wishes for care were with someone who really didn't know what to do, what could be done or what was needed.

Assessment and Care Planning

72% of survey respondents reported that the results of assessments were shared with them and 67% of them were asked to provide input into the development of the care plan. The interviews with patients and caregivers highlighted challenges with communication and awareness of the supports and services available for home-based palliative care. Caregivers recommended the use of navigators to help with understanding assessment processes, care planning and how to access services.

Patients and caregivers complained about having to constantly answer the same questions. There were also significant variations in the care provided by members of the team and across teams. Respondents noted significant variations in processes between rural, remote and urban settings. Caregivers stressed the importance of having specialized/trained staff to provide this service in the home.

While caregivers and patients recognize the reality of resource constraints in the home-based setting, they strongly expressed a need for full scope care (nursing and personal support) during evenings and nights. This is particularly important as the trajectory of a patient's end-of-life care needs dramatically increase. Caregivers require overnight support to maintain their own well-being and return to the role of family member, spouse, and friend in the final weeks and days.

WHAT WE HEARD:

"Every visit started with 'How is your day today? What can do or work on and make it better?' I had a real sense that they were there to give Sam what she needed to turn the day around. It was knowing that things weren't great, but let's try to change today."

"Include the patient in conversations. My dad felt we were talking about him when discussions happened without him. The many meetings and telephone contacts to coordinate care, deliveries, and pharmacy took time away from essential care giving and

"I don't know if it is possible but having a community-based extension of the Palliative care team in the hospital deliver and provide the care for those who wish to die at home, would have allowed for consistency of the level of care. This would also ensure those that are providing the care, have the required education spending quality time together near end of life. Process can be simplified."

"There was so much confusion about what was available, what was not. If we stayed home, we could get this or that. Then someone else would say something different."

"At night is when I needed the most help. Dementia doesn't sleep. Literally. And neither did I. And I needed to work. And have a life with my family. Round the clock care support would have saved the relationship with my mother."

and "orientation" towards palliative care that is required."

"It was only by trial and error that I discovered what services were available - they were not explained or introduced to me by anyone. Having to work with four different individuals coming to assist each day was a nightmare – So, I hired a private agency."

"More time should be taken at the beginning of the palliative care journey to get to know the patient, his wishes and values, his cultural origin. This would permit the development of a care plan that reflects who that patient really is, the whole person, his likes and dislikes. The person needs to be valued, respected, celebrated at his life's end."

"An information session with detail offered to other family members. At times there was conflict with siblings who did not understand the process. It can be draining when you are caring for someone in this state to explain and defend yourself."

Effective Communication Strategies and Tactics

Communication is one of the greatest challenges for caregivers. Suddenly, they are expected to be the hub for communication, even though this role is rarely explained to them at the beginning. Plus, they are often overwhelmed with information or do not have the information they need at the right time.

Home-based palliative care is a complex network. The patients and caregivers recommended that one point of contact would be the optimum solution to a very fragmented system where they are not included in the communications between other members of the palliative team. The caregivers reported serious gaps in communication and frustration with systems do not support effective and timely communication. The patients and caregivers stressed the importance of trust with providers for effective communication. The survey responses show that communication is largely a hit and miss situation for patients and caregivers – it is a constant challenge to get timely answers to urgent questions and support in crisis situations. While technology may exist to improve communications, the feedback from most of the caregivers was that the telephone is still regarded as the most efficient, reliable and personal.

WHAT WE HEARD:

“More effective sharing of up to date information and being clear about urgency of care needs. Our family was not included in the conversations between providers which led to poor communication and decisions that were not in line with needs or care we required. Make the family part of the conversation. Always.”

“What would have been helpful for us was a communication sheet that everyone had access to, where everyone could write questions or comments, including me, and everyone was expected to check, read, sign off every time they came into the house.”

“We needed to be the middleman in all of it because it wasn’t a team-based approach. It was very much the nurses did this, the OT did this, the PSW did this.”

“Written information is critical. I was so overwhelmed at the beginning. The information overload was incredible. I needed more information that was written out so that I could go back later and go over it and digest it when I could.”

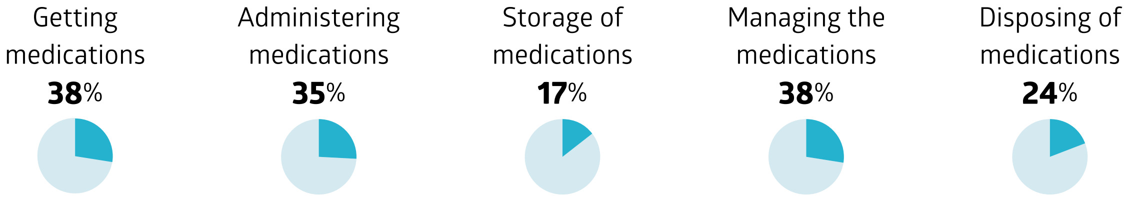
“One electronic portal. One provider service per family. We were forced to deal with several care agencies. No transfer of care conversations ever happened. We were accountable for ensuring all agencies had status updates. They even suggested plan of care could be better if WE documented more. Unfortunately, we were busy providing 24 7 care. I didn’t realize it was our job to document for the agency as well.”

“I think more information needs to be provided around what end of life can look like, what the options for care are, what supports are available. How can people make informed choices without a full picture? More education and understanding of wish planning.”

Management of Equipment, Supplies and Medication

This area of focus highlighted the variations across the country in terms of funding, access and processes. This was also an area that had one of the biggest financial burdens on patients and caregivers depending on the jurisdiction. The caregivers interviewed also expressed a high degree of concern about the amount of waste there is in home-based palliative care. 63% of the survey respondents reported that they were satisfied with access to supplies and medications.

When asked about where improvements could be made in medication management in the home, survey respondents provided the following rankings:



Issues with supplies and equipment depends a lot of where you live. Removal of expensive equipment can create a burden on families. Plus, caregivers are often challenged with knowing what equipment and supplies are needed, particularly as the patient's needs change.

WHAT WE HEARD:

"The O.T. would arrange to meet us at the supplier. She would help us, make suggestions, size the equipment, and help us try it out. And then she would be there when it was delivered."

"It was part of the home care service agreement that patients are responsible for purchasing equipment and supplies. The next part of that has to be some information on where to purchase things. It would be helpful to have a list of recommended supplies with sources and availability."

"There was an overabundance of supplies. The deliveries were constant. Every time the door was opened it was another delivery. It was so wasteful. And none of it went back."

"We got them, but they weren't always available when we needed them. The red tape was excessive and to be fair, the staffing was insufficient, they were mostly doing their best."

"No one in the family was comfortable giving her the morphine. I did it, just because I was the nurse in the family. A bit of a burden when you can't leave because no one else will do it."

"I experienced some confusion related to use of different meds for similar symptoms. For example, where my husband was experiencing mild anxiety, one RPN used midazolam and another diazepam. Since I was alone all day, I wondered what I should administer but chose diazepam because of what I read about when best to use midazolam. Better education needed for home care staff and for caregivers in terms of symptom management."

"My experience was good however more sensitivity to my non-health professional status would have helped. An example "increase the does if she is uncomfortable". How do I know, how much etc."?

"It was terribly emotional making the house our home again afterwards. No one prepares you or is there to help taking things down, bringing it back to how it was before."

"After my husband's death, no one seemed the least bit interested in the fact that I still had some very dangerous prescription medications in my home. They were very concerned about what was here while he was alive and audited it regularly, but once he died, they did not seem at all interested. I was also left with an over-abundance of bandages and wound care products (lotions and antiseptics) that filled a closet. No one would take them back despite still being in packages."

"All medications needed for my mom's end of life care were delivered to the house in a safe box. They were accessible to the nurse for anytime they were needed. I was trained by the nurse on delivering some of the med that were always prepared. The nurse took care of disposing all of the meds on mom's passing."

Feedback from E-Delphi Process

The use of a modified Delphi technique allowed a participative and inclusive approach that encouraged a wide range of experts to validate priority areas for ways to improve home-based palliative care. It led to the identification of **20** areas of improvement from a variety of stakeholders' perspectives that included consideration of their context of practice and experiences of service delivery.

It is clear that the topic areas identified through the workshops, interviews the following areas of improvement:

1. Ways to support early and ongoing conversations about end of life wishes with patients are caregivers
2. Processes to ensure that the necessary medications are onsite in the home without duplication or delay
3. Processes for early identification and response to the needs of individuals with life-limiting illness and survey of caregivers and patients and cultural groups were strongly supported by the expert panel through the E- Delphi online survey rounds. The process also helped to identify 6 additional areas for consideration. The top three scores were for

Overall, the E-Delphi process validated the original feedback received during the initial engagement phase and helped to identify several additional issues for consideration. The following tables show the results of Round 2 on the most important areas for improvement in operational processes for home-based palliative care.

Focus Area 1: Inclusion of advance care planning into care delivery

PRIORITY	AREA FOR IMPROVEMENT	SCORE (out of 5)
1	Ways to support early and ongoing conversations about end of life wishes with patients and caregivers	4.72
2	Ways to support early and ongoing conversations about end of life wishes which involve front line staff	4.44
3	Processes that help frontline staff understand and respond to an individual's wishes at end of life	3.92
4	Structured care planning that incorporate advance care wishes	3.08
5	Processes that sensitive to spiritual, cultural, gender and other considerations	2.65
6	Structured documentation of all wishes and identification of legal documents and sharing across sectors and jurisdictions	2.46

Focus Area 2: Assessment and Care Planning

PRIORITY	AREA FOR IMPROVEMENT	SCORE (out of 4)
1	Processes for early identification and response to the needs of individuals with life-limiting illness	3.00
2	Processes to make sure the patient and caregiver are included in the development and updating of care plan	2.46
3	Constant review of care plans and assessment that includes family coping, distress and resiliency	2.42
4	Assessment tools that provide a comprehensive understanding of patient's needs	2.12

Focus Area 3: Effective Communication Strategies and Tactics

PRIORITY	AREA FOR IMPROVEMENT	SCORE (out of 5)
1	Processes to rapidly and effectively share information between home care, acute care, primary care, palliative specialists and community paramedics	3.92
2	Ways to share information and communicate changes in the patient's condition to the individual, the caregiver and all the members of the team	3.54
3	Information and resources designed for family caregivers that are user-friendly, practical and timely	2.69
4	Single point of access such as palliative care nurse navigator	2.65
5	Communications that culturally sensitive and use respectful language about individual's identity	2.28

Focus Area 4: Management of Equipment, Supplies and Medication

PRIORITY	AREA FOR IMPROVEMENT	SCORE (out of 5)
1	Processes to ensure that necessary medications are onsite in the home without duplication or delay	4.38
2	Processes to ensure that necessary equipment and supplies are onsite in the home without duplication or delay	3.92
3	Systems to organize supplies and medications in the home for quick and easy access and effective inventory management	2.72
4	Protocols for returning and or recycling of supplies, equipment and medications that cost-effective and user-friendly	2.04
5	Processes for safe disposal or diversion of narcotics such as opioids	2.04

Verbatim comments

Respondents were asked to provide any additional ideas and suggestions about how to improve the quality, efficiency and accessibility of home-based palliative care. These are summarized below:

Significant overlap in categories and if some done well the others may simply follow. While common documentation would be nice, common terminology may be more realistic given the numerous EMRs etc. Also some risk to including the "wishes" as these need to be reviewed in context with the SDM. (for healthcare providers in Ontario, they provide a way to monitor if SDM making decisions consistent with patient wishes but cannot be used alone by healthcare team.)

Around the clock nursing for the final days/hours.

More emphasis on non-medical processes in supporting home care. And the palliative journey can not be too structured because everyone is different and that won't allow for true compassion to come forth. Also, I have been involved with families at home and the administration of medication has become so complicated with the high numbers of drugs being prescribed. We have created a great palliative care system, and improvements are necessary without making it more complicated.

I would like to ensure we are not interchanging the correct term Advance Care Planning with Advanced Care Plans that are not recognized in Ontario Law

Training for the informal caregiver

EMS palliative and end of life assess treat and refer program has proven to keep patient at home in symptom crisis 80-90% of the time https://www.albertahealthservices.ca/info/Page14899.aspx

For ACP, I just realized that it talks mostly about 'End of life'. but EOL is a very small part of palliative care and ACP. It involves getting to know patient's values and wishes, decision making preference. and therefore, helping them with all aspects of medical care (including decision to continue chemo, decision to go to hospital). that's more than just end of life. Please expand this to the true definition of palliative care (from moment of diagnosis of life-threatening illness, as per WHO definition). Otherwise, there's a huge risk of perpetuating myth of palliative care = End of life care.

More help for the caregiver. For those with a life limiting illness, a mediator who can help guide a couple in talking about important things, so the surviving spouse has less regrets.

Had great difficulty ranking these as each one should be rated 1....and if they are then patient and caregiver would be well taken care of

one single site for intake that covers the province. care coordinators with reasonable caseloads that follow patients through all transitions -- medical leadership within home care palliative care.

review and "leaning" process of admission to pall caseloads.