



Palliative and End-of-Life Care: Issues, Ethics and Technology
A Think Research Thought Piece

Aging affects us all; as patients, families, caregivers and clinicians. In fact, as revealed by the Hospice Palliative Care Association, 3 out of 4 Canadians report having thought about end-of-life care. It's a topic that's gaining traction in the agendas of our governments, as revealed by recent Ministry of Health and Long Term Care initiatives.

Hospice palliative care is universally relevant across disciplines and sectors of healthcare, yet it's riddled with complexity, nuances and ethical issues. To assist with the ongoing improvement of care in this challenging field, Think Research recently hosted a Clinical Workshop involving palliative care specialists, including nurses, nurse practitioners and other leading researchers and physicians. The aim was to foster an interprofessional discussion that would help us gain a better understanding of the day-to-day challenges of palliative care. By combining shared field inputs with our evidence-based clinical research, we hoped to improve our palliative care Patient Order Sets and End-of-Life and Palliative Care assessment tools – making them more practical for facilities to implement and clinicians to use.

During this engaging workshop, a number of recurring themes and issues emerged. As the process of standardizing care is an evolving effort, those themes are summarized and explored in more detail throughout these pages. What issues resonate for your practice? How can technology help address these concerns? How can we standardize care and improve outcomes? These questions will be answered when we have a better understanding of the current hospice palliative care landscape.

1 Defining the Two Types of Care: Palliative vs End-of-Life

There is often a lack of understanding between the two types of care, and while concepts are similar, it's important to know why they aren't the same.

Palliative Care	End-of-Life Care
Care provided for those living with (or at risk of developing) a life-threatening illness	Care provided specifically in the last weeks and days of life
Not restricted to the last months of life	Often connected with hospice and palliative care facilities

Hospice palliative care and end-of-life care are terms that have been used interchangeably, yet there are differences between the two. In 2002, the World Health Organization defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

According to Health Quality Ontario, palliative care is the broad approach to providing comfort and dignity for patients and families who are living with, or at risk of developing, a life-threatening illness.

End-of-life care, as defined by the Registered Nurses' Association of Ontario, refers to care provided when residents/patients are in the last weeks and of day of life, and is most often associated with specialized settings, such as hospice and palliative care units. Palliative care is not restricted to care during the last months or days of life and "can be used in conjunction with curative treatments" (13;15). End-of-life care usually begins days before death, yet this varies with each individual and condition, although end-of-life care can last for up to 6 months.

2 The Importance of Advance Care Planning

Advance Care Planning (ACP) was another theme of the workshop. ACP refers to the discussion between family and care providers about the resident's wishes, preferences and goals of care. The conversation around those goals of care needs to happen early in individuals' illness trajectory and providers are becoming increasingly aware of this. Individuals are encouraged to share their values and wishes with their 'substitute' decision maker (the person who will speak for them if they can't speak for yourself). The earlier on in the patient's journey that these conversations take place, the better equipped providers will be when making important decision that reflect each person's wishes.

A 2016 study by the Law Commission of Ontario also revealed that the demand for patient planning about future healthcare decisions has dramatically increased (Wahl et al 2016). In Canada, part of the decision-making process requires health practitioners to obtain informed consent before providing any life-saving treatment (although the process varies between provinces). This push for pre-planning has extended across the many settings where health services are provided, including hospitals, primary care, long-term care (LTC) and home care. While a diversity of forms have been developed in Ontario, there is limited research and statistics evaluating their use.

Some tools have been created to help educate physicians and other care practitioners on the definitions and interrelated nature between Advance Care Planning, Goals of Care discussions and decision-making discussions. A 2016 study by the Law Commission of Ontario has examined this topic in detail. Dr. Nadia Incardona and Dr. Jeff Myers have explored the relationship between the discussions that contribute to what's known as "informed consent". In ACP conversations, the information gathered acts as a guideline for future decisions. Later on in the process, this information informs the treatment decisions made in the "goals of care" and then finally, the "consent" conversations. The common theme that underpins all three discussions is an individual's values and preferences around their care (Wahl et al 2016; 4).

However, definitions of these various discussions can often be subject to emotional bias and contradicting opinion at the point of care. Ultimately, our clinical workshop participants felt that a greater emphasis should be placed on an individual patient's needs, not on overarching definitions and semantics. For example, addressing a 30-year-old palliative care patient (as opposed to a 90-year-old patient with an end-of-life condition) requires a customized consideration and a different 'checklist' of approaches.

3 Do Not Resuscitate (DNR): What You Need to Know

Cardiopulmonary resuscitation (CPR) is a treatment choice. Individuals or their substitute-decision makers may elect to choose no CPR, or what's known as a Do Not Resuscitate (DNR) option, which is recorded in the individual's chart.

The Clinical Workshop discussions revealed that DNR requests are variably tracked in Canada. Currently, DNR is only addressed upon a patient's admission and discharge, and there are often differing approaches to how DNR requests are managed outside of a hospital setting. According to Dr. Moser at Baycrest Health Services, DNR is an evolving concept that should be brought into discussion recurrently, because a patient might "want DNR yesterday and CPR today."

In September of 2017, CBC News investigated the DNR protocol in Canada, revealing a lack of a centralized database for documentation of individuals' wishes. This revelation, shocking to many, provoked 67-year-old Shahnaz Azarbehi to wear her DNR request in a pouch around her neck. The story illustrates the need for a standardized approach to storing and accessing personal directives (a set of complex nuances based on individual situations). It requires more robust care procedures and options at the bedside, but it ultimately respects individual choice.

Ethical Issues: End-Of-Life Hydration

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Providing hydration is an intervention that may support individuals at end of life. Hypodermoclysis refers to a method of slow, continuous hydration, using a subcutaneous infusion of fluids. This hydration technique is an effective non-invasive method of artificial hydration that can be used under specific circumstances. In hospices, where staff are experienced in palliative and end-of-life care, artificial hydration is viewed less favourably, and should only be offered if it's in the patient's best interests (Bowen et al 2013).

During this Clinical Workshop, knowing when to use this treatment was a topic of discussion amongst clinicians. In patients who require hospice palliative care, hypodermoclysis should be used to reverse another symptom. For example, if a patient has opioid toxicity, this treatment would be more appropriate than administering a standard IV fluid. However, at the very end of life, hypodermoclysis is not appropriate, as the body naturally will reject these fluids, and they won't be of any benefit to the patient.

To ensure proper actions are taken for hydration, individualized assessment that values the wishes of the patient and family were recommended.

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How Technology Can Support Palliative and End-of-Life Care

Here are some of the key points underscored as we learned from palliative and end-of-life experts:

- Advance Care Planning (ACP); establish patient's goals of care
- Ensure your patient is aware of these goals
- Identify substitute decision maker (early in care)
- Educate decision makers/caregivers so they can make informed decisions on behalf of their loved one
- Understand what DNR (Do Not Resuscitate) means and how to get proper consent from your patient
- Ask open-ended questions
- Use the Symptom Management Tool to detect early signs
- Utilize the support of PSW's

To overcome the various issues associated with end-of-life and palliative care, providers need solutions that bring evidence-based content to the point of care for clinical decision making.

Our tools for long term care reflect clinical practices to promote best care. For example, Think Research's **Palliative and End-of-Life Management Clinical Support** Tool assists nurses and long term care facilities by providing guidance and best practices along this difficult healthcare journey. The Palliative and End-of-Life Management Clinical Support Tool is intended to be used by nursing staff and is designed to provide evidence-based decision support by incorporating hospice palliative care best practice evidence, while documenting it in the resident's EMR in PointClickCare.

This tool helps long term care facilities to integrate a number of evidence-based tools [to replace the 'Edmonton Symptoms Assessment System (ESAS)] into their workflow based on symptoms and severity, whether daily or weekly. The Palliative and End-of-Life Management Clinical Support Tool is meant to prompt palliative care best practices early on in the process. This tool is currently used in nursing homes across all of Ontario, and we are working directly with clinicians to perfect its use for a seamless and accurate user experience and outcome.

To learn more about our Palliative and End-of-Life Management Clinical Support Tool, please click contact Stephanie Buchanan, Clinical Education Specialist at Think Research.

About Think Research

Think Research (TRC) develops knowledge-based tools that empower clinicians to deliver the best evidence-based care to patients, driving better patient outcomes. We're connecting clinicians, facilities and entire health care systems with the highest quality clinical content and the technologies to put it into practice.

To learn more about company news, health care and technology trends, visit our website.

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