Advance Care Planning (ACP) & Health Care Consent (HCC) Working Group Core Team Position Paper

Background

Current research has identified that there is a general lack of understanding and knowledge about Advance Care Planning and legislation in Ontario. Legislation varies from province to province which often results in confusion and questions related to health care treatment and health care consent.[1]

In keeping with the goals of the South East Hospice Palliative Care (SE HPC) Steering Committee, the South East Advance Care Planning (ACP) and Health Care Consent (HCC) Working Group was established to provide recommendations, assist in the implementation of the SE HPC Work Plan and collaborate with regional stakeholders in: promoting, educating, increasing awareness, understanding and implementation about ACP and HCC. This work will serve as the foundation to establish broader community engagement.

The ACP and HCC working group is represented by a CORE team tasked with developing and implementing the ACP and HCC initiative, and a broader membership to support the overall goals.

What is Advance Care Planning?

ACP is a process of reflection, consideration and communication in which a person plans for circumstances in which they cannot make personal or health care decisions for themselves at any time of their lives, especially at the end of their lives. This process involves determining the person's preferences and wishes based on their beliefs and values. These preferences and wishes are communicated to the individual's Substitute Decision Maker (SDM) and health care providers. As a result of these conversations, the individual(s) Substitute Decision Maker(s) will be more knowledgeable when making decisions and providing consent for health care when the individual is unable to speak for themselves.[2,3]

What is Health Care Consent?

"In Ontario, under the Health Care Consent Act, a health care provider (HCP) needs a person's informed consent or permission in order to deliver or withhold or withdraw any health care treatment or plan. To give informed consent, a person needs to be:

- capable of making the decision;
- and given information about:
  - their health condition;
  - the recommended treatment;
  - alternative options to the treatment;
  - and likely outcomes and risks of either accepting or refusing treatment.

In Ontario, capacity is defined by the Health Care Consent Act as: **understanding** the information that is needed to make a decision and the ability to **appreciate** the consequences and/or risks of that decision. "[4]

The Health Care Consent Act (HCCA), 1996, provides a way to obtain decisions from a SDM about health care such as treatment, admission to care facilities and services if an individual is unable to do so. In Ontario, a SDM may be identified in a Power of Attorney for Personal Care (POAPC). The legislation in Ontario provides a way of ensuring that an individual always has someone to speak on their behalf to give consent or refuse care or treatment by providing a hierarchy for determining an SDM if one has not been documented in a POAPC.

Why is Advance Care Planning Important?

There are times when a person may not be able to state his or her own wishes and if that person's Health Care Provider(s), loved ones or SDM don't know what those wishes are, the person may or may not receive the care that he or she would have chosen. Evidence suggests that ACP is often done poorly and at the very end of life or when a health care crisis occurs.[5] The following points clarify some of the issues, concerns and opportunities for improvement;

- A Canadian study revealed that 76% of palliative care patients or people receiving palliative care had considered their Advance Care Planning choices; of those only 30% had their end-of-life care preferences documented accurately. [6]
- "Studies show costly life-extending treatments that are not aligned with patient preferences result in patient and family dissatisfaction with care and higher costs"[7]
- "People with complex diseases are living longer and up to 50% of individuals are not able to give their own consent treatment or make decisions at the end of life."[8]
- "The Canadian Hospice Palliative Care Association (CHPCA) 2009 roundtable on ACP found that up to 50% of persons cannot make their own decisions at the end of life, and that health professionals and family members typically decide in favour of treatment when uncertain of treatment wishes."[9]
- The Ontario population includes a high number of seniors who have not expressed their wishes to their families, loved ones or health care providers. Current projections of demographics for the SE ON region along with the population health profile suggest a health care system crisis if improvements are not made. [10]
- ACP enhances patient / family / HCP relationships and can help reduce stress, anxiety and depression for patient's loved one and SDM. ACP also helps reduce HCP stress through minimizing ethical dilemmas.
- Reduces financial costs to the Health Care System by reducing unwanted medical interventions (i.e. avoiding hospitalization, emergency room visits or advance life safe measures)[11, 12]
- Research shows that people who have Advance Care Planning conversations with their families and HCP:
    - are more likely to be satisfied with their care
    - will require fewer aggressive interventions at the end of life [13]
- Assists in building system capacity to:
    - provide improved patient care and outcomes
    - encourage networking between organizations [14]
- Increases effectiveness and efficiency of health care resources [15]

Why do we need Advance Care Planning & Health Care Consent Education?

A number of gaps and barriers exist which negatively impact the ACP Process. Examples of these include:

- Individuals and families have expressed limited awareness, knowledge and confusion about the process
- Many people have conveyed discomfort and reluctance in talking about death and dying
- Many HCP and other professionals expressed uneasiness, lack of confidence and knowledge about engaging in ACP conversations [16, 17]
- There are a wide variety of resources readily available yet many are not relevant, application or compliant with Ontario legislation
- ACP conversations tend to be time consuming and many HCP lack information about applicable billing codes for this time

The following suggests that a high percentage of the Canadian population see the value in ACP, in starting the process when in good health and revising over time as appropriate. Health Care Providers could be much better prepared to assist people in the ACP process before a crisis situation emerges.

- A survey conducted by the SE Hospice Palliative Care Steering Group revealed that 77% of those providers surveyed expressed a need for education on ACP and HCC.
- "Although nearly all Canadians (96%) believe it is important to have a conversation with loved ones about their wishes for care, not many (34%) have actually had a discussion, and only 13% have completed an Advance Care Plan to communicate their wishes." [18]
- "The majority of Canadians (73%) would like to get more information from their doctors so that they can plan and begin these important conversations… most Canadians (80%) also feel these conversations should start when they are healthy or when they are diagnosed with a life-limiting disease."[19]
- Conversations regarding ACP are challenging, take time and likely require follow up conversations. The benefits of having these conversations before there is a medical crisis is an important element in the timing of HCP initiation.
- "In 2012, 80% of Canadians had no documentation of their ACP wishes, and only 46% had named a SDM."[20]
- A Canadian poll conducted in 2004 showed that even though Canadians expressed that discussing end of life care with a physician was important, a mere 9% of those polled had done so.[21]
- The Canadian Medical Association's National Dialogue on End of Life Care (June 2014) recommends:
  - "All Canadians should prepare advance care directives that are appropriate and binding for their jurisdiction in which they live."[22]
  - "Canadians should revisit their end-of-life care wishes periodically, recognizing that health care providers will interpret these wishes on the basis of a number of variables, including written advance care directives, conversations with loved ones and, input from a substitute decision-maker." [22]
  - "More education about palliative care approaches and as well as how to initiate discussions about advance care planning for medical students, residents and practising physicians." [22]

- A Canadian qualitative study of Advance Care Planning barriers with the seriously ill elderly illustrated the importance of providing patients, their SDM and families with the relevant medical information needed before asking questions about their wishes was critical to obtaining correct information. HCP ability to assess the readiness of patients and families in asking questions about ACP was also emphasized as important in making effective use of Provider and patient time. The study outlined the following suggestions to HCP:

"1. Helping a patient to acknowledge the personal relevance of ACP to him/her may improve the readiness to participate in ACP.
2. Normalising ACP conversations through routine clinic visits with the family doctor / general practitioner or family meetings during hospitalization may increase both the frequency of patient and family engagement in and their satisfaction with ACP.
3. Patients value sensitive, skilled communications when discussing ACP. **Education of health care providers (particularly doctors) should include a focus on developing communication skills for ACP**
4. Healthcare systems should ensure that the infrastructure is in place to support patients and healthcare providers engaging in ACP, for example, enabling access to appropriate documents and implementing processes to ensure that the output of prior ACP is available when patients are admitted to hospital." [23]

Goals of Advance Care Planning & Health Care Consent Education include:

- Provide the best quality of care to patients and their loved ones by ensuring patient's wishes are being respected and followed
- Enhance communication skills of Health Care Providers (HCPs) in initiating and participating in conversations about ACP and HCC
- Increase awareness of ACP and its benefits for all residents in SE ON region
- Increase knowledge and understanding of ACP and HCC legislation in Ontario
- Ensure that HCPs are providing correct information based on Ontario legislation therefore reducing risk of confusion and liability issues
- Reduce moral distress of HCP and patients' loved ones
- Increase awareness of HCP compensation for time related to ACP patient education
- Achieve deliverables set out by SE LHIN, MOH & LTC regarding ACP [24,25]
- Assist health care organizations to meet quality improvement and strategic goals
- Maximize inter-professional collaboration to better support patient and health care provider needs, enhance quality of care and patient outcomes
- Increase the use of standardized ACP tools and protocols that are consistent with Ontario legislation
- Meet the demand for ON relevant, user friendly resources on ACP and HCC in the SE LHIN

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