Briefing Note: Advance Care Planning – A Primer

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Abstract

Advance Care Planning (ACP) is the process by which individuals make decisions that can guide their future healthcare if they become incompetent. Creation of an Advance Care Plan should involve discussions with healthcare providers and substitute decision makers (SDM). ACP can assist individuals, their families, and healthcare professionals in planning for future and end-of-life (EOL) care. Recent research suggests that ACP can increase discussions about EOL preferences and improve the concordance between patient preferences and their EOL care.

More than 50% of Canadians have not completed an Advanced Care Plan. This may be due to a variety of reasons, however it is possible that the community does not have enough knowledge about healthcare options that can be provided in the hospitals. Current research is focused on identifying barriers and facilitators to ACP, as well as implementing methods for incorporating it during standard medical care. Various stakeholders have identified ACP as a priority, and in order to raise awareness, April 16th has been designated as National Advance Care Planning Day in Canada.

The Issue

The National Framework on Advance Care Planning (ACP) defines Advanced Care Planning as “a process of reflection and communication, in which a person with decision-making capacity makes decisions regarding their future health and/or personal care in the event that they become incapable of consenting to or refusing treatment”. In other words, ACP is a process where one plans for their future healthcare in the case that they become incompetent for making healthcare decisions. This planning process is completed while considering one’s beliefs and values and the process involves discussions with healthcare professionals and the substitute decision maker (SDM): the person that one chooses to make medical decisions on one’s behalf should they become unable to do so. ACP has been identified as a priority by health administrators, advocacy groups, policy leaders, and healthcare organizations.

End-of-life (EOL) care is defined as multifaceted care for those who have advanced, incurable disease and are likely to die within the next twelve months. It focuses on helping individuals live the way they want to as they approach death, instead of automatically resorting to aggressive and curative measures. About 40% of people become cognitively impaired as they approach EOL, and the need for a well-informed Advanced Care Plan becomes imperative. Creation of a patient-specific Advanced Care Plan allows for provision of healthcare according to the patients’ wishes and thus facilitates appropriate EOL care. This briefing note is based on scientific articles, literature reviews, and best practice literature available to the general public. It outlines the historical perspectives as well as current developments in the field of ACP in Canada.

Background

Recent surveys completed by Ipsos Reid have shown that 86% of Canadians have not heard of ACP. Less than half of those surveyed have had discussions about healthcare options for EOL care with their loved ones. 54% of Canadians have not designated a SDM to make decisions on their behalf should they become incapable of doing so. This issue becomes especially relevant when older adults become acutely ill and require emergency medical care. Healthcare teams are trained to provide aggressive medical care in emergency situations to sustain life, however this is not appropriate if it goes against a patients’ previously expressed wishes. Thus, it is crucial that healthcare practitioners are aware of an individual’s preferences regarding care at the point of contact, and this can be done through ACP. Inadequate information about personal wishes may lead to confusion and can add to grief and anxiety for their SDMs who may be forced to make difficult choices when their loved ones are critically ill.

Acute medical care in the 1950s was dominated largely by the principles of “beneficence” (under which
caregivers were expected to provide medical treatment to benefit patients) and “non-maleficence” (do no harm)\(^{11}\). Hospitals required that cardiopulmonary resuscitation (CPR) be performed on all patients with the assumption that such life-sustaining treatments were useful and wanted by most patients\(^{11}\). This paternalistic model of medical care became controversial with the legal decision on the cases of _Quinlan_\(^{12}\) and _Cruzan_\(^{13}\), which allowed these patients and their families to make all decisions about their healthcare, including those that were potentially lifesaving\(^{14}\). Thus, the next decade of patient care saw the ascendance of patient autonomy, the right to make decisions about one’s medical care without the influence of their healthcare provider. This model formed the basis of what is now considered a ‘shared’ model for medical decision-making. This model is defined as an approach where doctors and patients share the best available evidence when faced with the task of making decisions and where patients supported to consider options so that they can make informed choices\(^{15}\). It is followed rigorously for all medical decisions, especially for EOL care. Hence, it is crucial that personal preferences for healthcare options are well known since this would allow for preservation of ones’ autonomy, control, and dignity. Since most Canadians have not made choices regarding EOL care they are at risk of receiving healthcare that may not be consistent with their values.

Conversations about death and EOL can be difficult since it is a sensitive topic. However, it is also possible that the community does not have enough information about the healthcare options both in and out of hospitals that exist for those approaching EOL. Socio-demographic factors such as gender, ethnicity, age, income, education, and religion may play an overriding role in ones’ awareness, communication, and decision making about ACP. More importantly, it is possible that as integral parts of a death-denying and a death-defying society\(^{16}\), conversation about EOL care does not take precedence in our busy lives.

**Current Status**

In January 2012, the Canadian Hospice Palliative Care Association (CHPCA) published a national framework for ACP in Canada. As a part of this initiative, a website with various online tools has been created to engage the public and help them with online tools to formulate their own ACP\(^{17}\). Provincial health authorities, such as Fraser Health in British Columbia, have developed a formal ACP program; this has resulted in higher rates of awareness among residents compared to national rates\(^3\). In addition, April 16 is now being promoted as the National Advance Care Planning Day across Canada\(^{18}\).

Canadian physicians remain at the cutting edge of research in this area. For example, CARENET (Canadian Researchers at the End of Life Network)\(^{19}\) has established a multi-institutional research team to guide the conceptualization and implementation of research in EOL decision making and quality care assessments. Expert opinion suggests that discussion of patient preferences with regards to appropriate life-sustaining treatments should take place with the SDM and physician prior to hospital admission\(^{20}\). A recent landmark study of over 1250 clinicians in five Canadian provinces highlighted barriers to goals of care discussions near EOL. Major obstacles included family members’ and patients’ lack of knowledge about life-sustaining treatments as well as difficulty in accepting poor prognoses\(^{21}\). The authors of this article propose that improving communication skills amongst clinicians and decision aids for ACP may help patients and their SDMs make healthcare decisions at the EOL. It has also been suggested that all healthcare workers who care for patients approaching EOL should routinely integrate conversations about goals of care into their clinical care processes\(^{21}\).

It is not known whether local communities are knowledgeable of ACP or if there are any local barriers that prevent ACP activities. ACP is a dynamic process and people may have go through stages of behavior change before they can engage in meaningful ACP\(^{22}\). While it is logical that the seniors should be thinking about ACP, it would also be interesting to know how the younger community perceives this concept and if they can help their elders in the decision making process. Furthermore, the CHPCA National Framework recommends that family physicians should have end-of-life conversations with their patients\(^1\), but it is not known if this happens routinely. The i-GAP study, a CARENET initiative, is geared towards understanding the barriers and facilitators for ACP in the primary care setting\(^{23}\).

A recent meta-analysis has shown that ACP interventions increase discussions about EOL preferences and improve concordance between patient preferences and their EOL care\(^{24}\). This is not associated with any adverse effects on psychological wellbeing, or increased anxiety or depression. Further research is needed to determine the
best method of implementing ACP in standard healthcare and determine if ACP results in reduced utilization of healthcare resources.

**Conclusion**

Most Canadians have not heard of ACP. While it is true that a conversation on this subject can be emotional, depressing, and perhaps taboo, it is crucial for individuals to be knowledgeable about healthcare options available at EOL in order to make well-informed choices. It is also imperative for individuals to discuss their values and wishes with their loved ones regarding future healthcare choices. Furthermore, there is a continued need for quality improvement initiatives involving healthcare workers that provide frontline medical care to the aging population. Current research suggests that ACP interventions are associated with increased discussions about EOL preferences and improved concordance between patient preferences and EOL care.

Further work is needed to raise awareness about ACP and to formalize processes that ensure prompt retrieval of that information by SDMs and various healthcare teams. Failure of the elders within the community to make decisions for healthcare options in advance may lead to inappropriate treatment and resource use. Most importantly, it may also lead to unnecessary pain and suffering with added responsibilities for their SDM at their EOL.

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**References**


