Speak Up
Start the conversation about end-of-life care

CARENET
Canadian Researchers at the End of Life Network

TECH VALUE NET
BETTER HEALTH CARE FOR AN AGING POPULATION

Advance Care Planning Evaluation in Elderly Patients: The ACCEPT Study

Improving health care outcomes and patient care at the end of life

Advance care planning is a process of reflection and communication about personal care preferences in the event that an individual becomes incapable of consenting to or refusing treatment or other care. ACP practices result in greater adherence to patient's wishes, and greater improvements in-patient and family member quality of life and ratings of quality of care.[1] Investing in ACP is perhaps the single most important thing we can do as a society and a health care system to improve outcomes for care and to facilitate patient-centered communication.

Importantly, there are also suggestions from published research that ACP can significantly lower healthcare costs during the final week of life.[2,3] Studies have shown that patients who have documented plans spend 10 fewer days in hospital in their final months compared to those who do not. In patients who had terminal cancers, those who reported end of life (EOL) discussions underwent a less resource intensive final pathway (less use of Intensive Care and more use of hospice, for example) that resulted in approximately $1000 less per case compared to those that did not have an EOL conversation. At a system level, based on the number of deaths per year, this could translate into over $200 million of savings per year.

The ACCEPT study

The ACCEPT Study is a Canadian, multi-year, multi-centre, prospective audit of current ACP practices in elderly patients at high-risk for dying. This three-year project is funded by the Canadian Institutes of Health Research, the Michael Smith Foundation and Alberta Innovates Health Solutions. In Year 1, the study evaluated the quantity and quality of ACP from the perspective of over 500 patients and family members in 12 acute care institutions in British Columbia, Alberta, Ontario and Québec. Using validated questionnaires, ACCEPT examined whether respondents had reflected about their attitudes towards life-sustaining treatments, had discussed these issues with family members or healthcare providers, had formally designated a decision maker and had written a care plan. The study also evaluated patients' and family members' satisfaction with EOL care.

Patient participants were, on average, 80 years old and had significant illnesses. Year 1 findings demonstrate that there is considerable opportunity for improving end of life care, particularly in this high risk, elderly patient population:

- More than 75% of participants had thought about the care they would want in the final stages and more than 90% had discussed their preferences with other family members.
- But less than 30% had discussed their preferences for EOL care with doctors.
- And, only about 20% had been informed by their doctors about their prognosis.
- Before their hospitalization, 70% of these elderly patients had formally designated a representative concerning treatment decisions and approximately 55% had filled out an advance directive.
- Ratings of satisfaction with EOL care show considerable opportunity for improvement. The proportion of patients indicating their overall rating of care as 'completely satisfied' was 40% with a range from 12-75% across all sites.

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Areas of greatest dissatisfaction from a patient point of view related to discussions about location of care at the EOL and what to expect in the future, and 46% indicated dissatisfaction with their lack of knowledge of comfort measures. One patient stated:

> *"I didn't know what he (MD) was saying when asking me when I was in the ER. Do I want CPR? He asked with no explanation. I said 'sure if it works.' He put down YES on the form, but then told me it probably wouldn't work and I would have brain function problems. Good God! I don't want that! Give the information first, then ask the question!"*

- Family members were most dissatisfied about location of care at the EOL and the use of life sustaining treatments in their loved ones. One family member stated:

> *"I don't have enough information about his condition, what to expect or how long he has. I am trying my best but I don't have a medical background and I am alone in all this decision making and feel overwhelmed. They asked me about CPR and I said to try and if it doesn't work then let him go. He wouldn't want to suffer."*

- The patients' expressed preferences from the study questionnaire agreed with documented goals of care order only 1/3 of the time with the majority of the disagreement being that the patient preferred comfort care (no resuscitation in event of cardiac arrest) but documents in the chart stated that patients were to receive full resuscitation in the event of a cardiac arrest.

The Impact

A 2008 Study clearly shows that failure to address these deficiencies in EOL communication and decision making will lead to poor quality of care at the end of life, negative health consequences for both patients and family members, and excessive waste of scarce health care resources, particularly given our aging population.[4] It's clear that we need more investment in ACP activities so that we can develop strong and supportive practices that make best use of valuable health care resources, while providing the quality EOL experience that all Canadians deserve.

What can you do?

We are soliciting your support for directing existing and/or new health care resources and personnel to lead and implement ACP in your hospital or health region. Scientific studies demonstrate greater patient-centered care and reduced health care expenditures in regions with a greater investment in ACP activities.[3, 5]

Please consider joining our "Speak UP" campaign (for more information, see www.advancecareplanning.ca) and joining our national ACP quality improvement initiative, The ACCEPT study (for more information see www.thecarenet.ca/ACCEPT). All sites participating in the ACCEPT study will receive a free benchmarked report of ACP activities enabling them to see their strengths and opportunities for improvement.

Joining the campaign and the ACCEPT study will provide you with many benefits. You will have the opportunity to efficiently apply knowledge into practice. You will have access to tools and processes that have already been developed. You will have the opportunity to share knowledge and learn from others.

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