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Canadian Researchers at the End of Life Network (CARENET)



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Interview with Professor Daren Heyland

The [Canadian Researchers at the End of Life Network \(CARENET\)](#), directed by Professor Daren Heyland, brings together health professionals from across Canada. The network aims to understand and improve palliative and end-of-life (EOL) care through improving communication and decision making between patients, their families and health professionals. They have several projects evaluating different tools or strategies to improve communication and decision-making in all sectors of the healthcare system (primary care, long-term care, cancer care, ward-based care in hospital and the ICU). Current projects in critical care include Personalizing Death in the Intensive Care Unit (Cook et al. 2015) and Realities, Expectations and Attitudes to life support technologies in intensive care for Octogenarians: the Realistic 80 study (Heyland et al. 2015a; 2015b).

CARENET's goals include fostering research on palliative/EOL care with a focus on communication and decision-making. Why this focus?

Based on our lived experience as critical care practitioners, we saw that decision-making about the use or non-use of life-sustaining treatments was done poorly in many cases. We perceived that our patients and their families were ill prepared to engage with us in important EOL decisions and that oftentimes we were perhaps over treating or intensifying the dying experience in patients. We asked ourselves if we could do a better job and how. We set out to describe the dying experience and understand the conditions around which these decisions were made and then ultimately improve them through the use of various tools and training modules.

Has medical technology been ahead of communication in critical care?

The proliferation of technology and the ageing of society has created a clash. No older person can die now without passing through an intensive care unit and having technology applied at the end of life.

That's overstating the point somewhat, but the ageing society and explosion of medical technology has created a lot of challenges for those of us that work in the ICU with respect to the appropriateness of using life-sustaining technology. We wanted to drill into that and figure out how can we understand and improve communication and decision making related to use of life-sustaining treatments at the end of life.

Where do you see gaps in research into the end-of-life care in the ICU?

I think the biggest gaps are around engagement of health professionals. We know that patients say that they thought about the use of life-sustaining treatments, that they talked to their family members about their wishes (You et al. 2014a). But they had very little engagement with hospital professionals around treatment decisions at the end of life. That engagement comes too little too late and we are left with dealing with substitute decision makers or family members, who are badly prepared to step in to assist with the decision making that occurs. Patients and family members are ill prepared, and we as healthcare professionals are not active enough in asking patients about their wishes and helping them clarify their values and make decisions.

The Realistic 80 study addresses critical care for the very elderly, and you have found incongruity between family values and preferences for end-of-life care and actual care received. Was this a surprise?

The magnitude of the mismatch was surprising and the consequences of that on the prolongation on the dying experience (Heyland et al. 2015b). If a very elderly patient is admitted into the ICU and then dies, they spend an average of 12 days in an intensive care unit receiving life-sustaining treatments. This is in the context from a family's point of view that many of them didn't want this in the first place. Literature from other countries would suggest that either very elderly people are not admitted to the ICU, or if admitted at the end of life have one or two days in the ICU before life-sustaining treatments are withdrawn. So we still have real challenges related to communication and decision making that we are still struggling to fix.

Is provision of ICU beds in Canada quite generous in comparison to other countries?

Yes, our government's response over the last decade has been to increase critical care capacity rather than address the pressure on the system and question whether our resources are being appropriately utilised. Consequently, together with the ageing of society and progression of technology the attitude is that more is better, and we can reverse all of this and save lives. We end up with more and more older patients in the ICU receiving life-sustaining treatments. Please don't misunderstand, we are not opposed to admitting older patients to the ICU. We just want to make sure that it is consistent with their wishes, appropriate to the medical context and not prolonging the dying experience.

CARENET has developed resources for the public and for health professionals about starting the conversation about end-of-life care. How are these being disseminated and evaluated?

As well as describing the issues we are developing tools to improve the situation. There are a number of patient-facing tools to better prepare patients and their families and tools for health care professionals to help them engage patients and families in the conversation. We've developed several promotional campaigns to promote these tools:

ICU Workbook (myicuguide.com) is a novel website designed to support families of ICU patients so they can be better advocates of best practice in respecting the wishes of their loved one.

Speak Up (advancecareplanning.ca) is a public health campaign aimed to promote advance care planning in Canada. We hope to get lay people to think about, reflect on and speak up with respect to their wishes for end-of-life care to family members and healthcare practitioners. We have staff working on various communication strategies, and we have partnerships with agencies across Canada – cancer foundations, palliative care and hospice associations. Every April 16 we host a national advance care planning day that is government-endorsed. We have had great success in uptake particularly around the national advance care planning days. We have conducted public opinion polls to determine the level of awareness, engagement and advance care planning (Teixeira et al. 2015). We hope our activities will better prepare patients and their families to engage with healthcare professionals when it comes time to make serious end-of-life decisions.

Just Ask (thecarenet.ca/our-campaigns/justask-campaign) is intended to encourage healthcare professionals to ask their patients about their wishes and values and ask them to state their preferences (You et al. 2014b). We have some great tools on our website — a pathway, a conversation guide and some scripts as to how healthcare professionals might engage their patients in these conversations. The evaluation of this campaign is not as straightforward as for the public campaign. We are asking patients in various settings if they had these discussions with their healthcare practitioners about what their values and preferences are and if they trust that this is accurately put in the medical record. The novelty here is that we are reaching out to patients to audit the performance of healthcare professionals and the healthcare system. We audit if these conversations happened, and look at milestones in more detail, e.g. if the health professional talked to them about their prognosis etc. There are many gaps, and there is still a lot of work to be done. We felt this is a superior way of auditing performance compared to asking health professionals if they

discussed this with their patients. We have also surveyed healthcare professionals in terms of their level of engagement in conversations on advance care planning in relation to their level of comfort and in terms of their perceived barriers to further engagement (You et al. 2015). We believe we can have the greatest improvement on EOL care by improving communication and decision-making.

Further Information

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