

## Commentary

# Should research be part of advance care planning?

Alexandra M Easson

Lecturer, University of Toronto, Department of Surgical Oncology, Princess Margaret Hospital, Toronto, Ontario, Canada

Corresponding author: Alexandra M Easson, Easson.Alexandra@uhn.on.ca

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### Abstract

Advance care planning is a process to help people to formulate and communicate their preferences regarding future care during critical illness. Reviews of the advance care planning process in its current form have been disappointing. Improvements in care at the end of life and palliative care are necessary for the provision of modern medical care. Medical research has led to many improvements at the physiological and technological levels. It is only by applying the same rigour of scientific study and research ethics that improvements in the advance care planning process can be made.

**Keywords** advance care planning, critical illness, palliative care, research ethics

Advance care planning is a process to help people formulate and communicate their preferences regarding future medical care in anticipation of a time when they are unable to express those preferences because of incapacity due to critical illness or injury [1,2]. In our current medical system, the result of these deliberations is generally expressed when the patient prepares an advance directive. This directive, either oral or written, may be an attempt to predict and direct care in the event of specific and unfortunate future situations (e.g. it may pertain to whether life support should be prolonged) or it may designate a specific person to speak on the patient's behalf. The premise of this process is that when the patient can no longer make decisions, the physician who is caring for them will be able to use this directive to guide care that is compatible with the patient's unique values and characteristics.

In theory, effective advance care planning should directly improve the quality of medical care. Most people in the developed world die at an advanced age after a protracted chronic illness, more often in an institution after a crisis than peacefully at home. Without this anticipatory discussion, medical decisions in the case of patient incapacity must be made without knowledge of the level of care that the patient would have preferred. This potentially could result in unfortunate and costly over- or under-treatment, and conflicts between health care professionals and the patient's family and friends.

Reviews of the advance care planning process in its current ethical, moral and legal form have been disappointing [1,2]. Despite introduction of the Patient Self Determination Act in

the USA in 1990, the majority of patients with chronic illnesses do not have advance directives in place on admission to hospital [2]. When they do exist, advance directives are often difficult for families and physicians to follow because they may not apply to the situation at hand [1]. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) trial [3] was a multicentre attempt to improve end-of-life decision making and to reduce the frequency of a mechanically supported and prolonged process of dying by increasing the frequency and effectiveness of patient-physician communication. However, despite the best intentions of the clinicians involved, the introduction of an advance care planning process neither had an impact on clinical care nor reduced consumption of hospital resources.

There can be no doubt that care at the end of life is an important issue. Medical advances are proving to be very expensive, with the greatest resources spent during the last 6 months of life. During this period, patients are often subjected to prolonged stays in a critical care unit, undergoing aggressive interventions of unclear benefit, and are prescribed many drugs, perhaps with unlicensed indications. Researchers have shown that aggressive therapy aimed at prolonging life with little attention given to relief from suffering and the experience of illness has resulted in suboptimal care being provided at the end of life [3,4]. Patients and families are suffering because of inadequate pain and symptom control, inappropriate prolongation of dying, loss of control, and distance from loved ones caused

by the medicalization of dying [5]. Major improvements in end-of-life care are needed at the clinician, organization and health system levels.

Perhaps the advance care planning process is too sensitive and complex a subject for scientific study. Some (albeit fewer than in the past) wonder whether, '[research questions] should ever be asked by the living of the dying... To research at all could be ... an affront to the dignity of [terminally ill] people and an expression of profound disrespect for the emotional and physical state of such patients' [6]. Research in advance care planning may be a low priority during critical and stressful phases of illness; clinicians may not want to 'bother the patients and their families at such a time' [7]. The focus on cure as the only valid goal of medical care may result in a belief that study participation is only beneficial if it holds out hope of longer survival; in such a culture, studies looking to improve the process of a patient's dying have been disdainfully referred to as 'salvage studies' [8].

In fact, research in this area is exactly what is needed. What distinguishes modern medical practice is the attempt to understand disease by the application of rigorous ethical systematic research to determine what works and what does not, and to apply it to change clinical practice. We have been very good at studying and applying physiological and technological advances in critical illness, changing culture such that many physicians have come to believe that the only acceptable therapeutic goal is the absolute cure of the patient [9]. This belief is inadequate in the face of modern medical reality. An emerging consensus recognizes that extension of biological life cannot be the only goal of medicine; comfort and dignity are appropriate goals when cure is no longer possible, and should be pursued at reasonable financial and human costs. Grounded in the ethical principle of beneficence central to the traditional medical value of doing what is best for the patient [10], the increased focus on improvement and quality of end-of-life care has been called 'the most important recent advance in medical ethics' [5]. Patients with a terminal illness should not be deprived of the benefits of research; in fact, there is a great clinical need to improve their care.

The current problem with our understanding of advance care planning probably represents the complexity inherent in the process. The domains that we wish to understand represent new horizons in medical research, and require the incorporation of nonquantitative research techniques such as qualitative research and quality-of-life measurement theory. Unlike history taking, a process that has evolved over decades and is well taught in medical schools, methods of inquiry for advance care planning and shared decision-making are just beginning to be systematically described, studied and taught [11]. Recent research is suggesting that, for patients, advance care planning is more than the one-time completion of a form. Rather, decisions about preferences in advance

care planning emerge from a complex process of preparation for death, with an emphasis on relationships with loved ones, maintaining control, and relief from the burden of difficult decision-making for others, and occurs in the context of not just the physician-patient relationship but also the relationship with loved ones [12]. Other research recognizes that, although patients are individuals, common patient preferences within disease sites exist that may help providers to understand disease-specific advance care planning, such as for heart disease [13] and dialysis patients [14]. In addition, an emphasis on advance care planning research in the context of quality improvement rather than strict therapeutic research may increase acceptance of study in this area.

The only way to improve the advance care planning process is to study the process and to evolve it in response to this work. Research will increase the likelihood of solutions being found. The advance care planning process of the future may be very different from what it is today. The only way to develop an effective process is to study it, applying the same rigour to the research process that has so successfully led to our improved understanding in biochemical and physiological systems, culminating in the medical successes that we enjoy today.

## Competing interests

The author(s) declare that they have no competing interests.

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