

Editorial

Why Are Advance Directives a Non-Issue Outside the United States?

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[Citation: Solomon MZ. Why are advance directives a non-issue outside the United States? *Innovations in End-of-Life Care*, 1999;1(1), www2.edc.org/lastacts/archives/archivesJan99/editorial.asp]

This first issue of *Innovations in End-of-Life Care* is doing two things that, to our knowledge, have not been done together. First, we are featuring an American innovation that has succeeded in promoting the completion of advance directives among a startlingly high proportion of people in one geographic area. The *Respecting Your Choices* program, spearheaded by Dr. Bud Hammes in La Crosse, Wisconsin, has achieved what no other community in the United States, or elsewhere, can claim: 81 percent of the people in their community have executed some form of advance directive and there is documentation of their wishes in the medical record.¹ Through a question and answer format in our Featured Innovations department, we present an in-depth analysis of the processes and strategies that led to that outcome.

However, advance directives are not in use in most other countries, and this issue of *Innovations in End-of-Life Care* has set out to explore why not. In our department, International Perspectives, we have asked palliative care experts from Australia, Israel, Italy, the Netherlands, and Spain to explain the ways in which health care decision making and end-of-life care are conceptualized and carried out in their countries. How is autonomy understood, and to what extent is it emphasized? What do the clinicians, patients and families in these countries see as the proper role of truth-telling? What advice can we glean about how best to communicate with patients and families near the end of life?

Our goal is three-fold: first, to let readers know of the most effective innovation, to date, that has succeeded in improving advance care planning in the United States; secondly, to shed light on the fundamental premises that have driven the emphasis on advance directives in the United States, with the hope that "unpacking" these assumptions can lead to the design of other, potentially complementary, strategies; and third, to inaugurate *Innovations in End-of-Life Care* as a place where contrasting perspectives are sought to ignite creative thinking and improve end-of-life care across very different cultures and health care delivery systems.

In the United States the focus on advance directives can be traced directly back to the American emphasis on autonomy and truth telling. Advance directives were conceived as a way to ensure that patients' wishes would guide the kind of treatments they received near the end of life. These

directives have come in two main forms: (1) highly specific documents, often called living wills or medical wills, that stipulate the sorts of treatments patients would or would not want, under various future medical circumstances; and (2) documents in which patients designate someone to serve as their health care agent, or proxy, for some time in the future, when the patient is no longer able to speak for herself.

Both living wills and the designation of health care agents have been highly promoted throughout the United States. Yet our international guests find them, at best, moot. Reading across their commentaries, several points emerge.

Self-determination or Access to Services?

In the United States, historically, the problem of end-of-life care has been framed as one of self-determination. In many other countries, the problem has been framed as one of providing services.

Beginning with the 1976 case of Karen Ann Quinlan, a young woman in a persistent vegetative state whose parents wanted her ventilator discontinued, end-of-life care in the United States has essentially been conceived as a process of ethical analysis and personal decision making. Until very recently, policy makers and bioethicists had framed the challenge of improving end-of-life care as one of getting better at ascertaining with as much precision as possible exactly what patients themselves would want. More recently, in the United States, and particularly with the publication of the Institute of Medicine report, *Approaching Death*,² the focus on advance directives has shifted to the broader, less document-driven, concept of advance care planning. There is also growing attention to the development of standards of care, care delivery, and clinician preparation.³⁻⁷ Nevertheless, the strong historical emphasis in the United States on self-determination has focused tremendous attention on making choices about what particular treatment modality someone does or does not want. This focus, in turn, has led down a highly legalistic path.

In other countries, the challenge has been framed, not as one of choice and self-determination, but as how best to provide a comprehensive set of services and how to prepare physicians, nurses and others with the skills necessary for delivering those services. I do not mean to over-romanticize the state of palliative care services outside the United States, nor to gloss over important variations in the quality of that care both within countries and between countries. However, it is helpful to acknowledge that fundamentally there have been very different conceptual frameworks for approaching what is, essentially, a common global problem.

The Importance of Relationships

Our commentators live in countries with a national public health system, a strong emphasis on primary care, and less geographic mobility among their patient population. A great deal of care is provided at home by general practitioner-nurse teams. As a consequence, patients are better known by their physicians and more trusting of the doctor-patient relationship. In this context, dying becomes a natural part of the continuum of care. Thus, strengths and weaknesses in communication and advance care planning are, to a very great extent, functions of how a health

care system is organized. As Dr. Zylicz of the Netherlands puts it, "You can not see communication separately from the system."

Long-term relationships between general practitioners, patients and families, coupled with the existence of palliative care services, solve many of the communication problems that, in the United States, advance care directives are intended to ameliorate. As Dr. Kristjanson of Australia explains, once the decision to accept palliative care is made, "people accept that certain things won't happen," the "resuscitation matter dissolves," and patient, family and health care team address each end-of-life question, such as tube feedings or the use of antibiotics, as they arise. In this context, she continues: "you know your patients, the relationship is very individualized, this [an advance directive] would be seen as a legalistic document that would be incongruent in the context of the relationship."

For Lack of a Crystal Ball

Furthermore, advance directives, particularly living wills which can suffer from too much specificity, assume that patients' wishes will be stable over time, as their health changes. As Dr. Zylicz points out, "patients create and sign living wills, when they are healthy. For us, it is important to find out what the patient wants at the moment when he or she is very ill." Zylicz's concerns are borne out empirically, since there is research suggesting that as people become more debilitated, they are willing to accept more limitations in their quality of life.

Is it possible to know what one would want in some future time, in a wholly different situation? As Dr. Núñez Olarte of Spain puts it, "We change marriages; we change political sides; we change religious convictions. And we expect when we are facing death, we are not going to change?"

Furthermore, many physicians point out that what was said in a specific treatment directive should not automatically be assumed to apply to the patient's current situation. Dr. Glick of Israel tells the story of a young Bedouin patient with a completely reversible pneumonia, but because he had an advance directive asking not to be intubated, he was allowed to die. Dr. Glick asks us to consider: Is this really what the patient would have wanted?

Concepts of Autonomy and Truth-telling Vary across Cultures

The apparent lack of truth-telling in countries, such as Italy and Spain, where patients are not routinely told their cancer diagnoses or prognoses of impending death, has been highly criticized. Yet, the commentaries by Drs. Ripamonti, Núñez Olarte and Glick shed light on the nature of truth-telling in their countries, and the story is more complex. For example, research Dr. Núñez Olarte and his colleagues have done on patients' attitudes demonstrates that a very significant number of patients either do not want to know their prognosis, or are ambivalent about it. The art of providing palliative care depends, in part, on understanding just how much information the patient wants, and modulating one's response to fit with that patient's needs and expectations. As Dr. Ripamonti of Italy says: "We have some patients who want to know their situation exactly and explicitly, so we speak exactly with them. And we give all our patients the opportunity to ask everything. We try to understand what, and how much, they want to know."

Our commentators' findings are similar to the findings that researchers have discovered among different cultural groups within the United States. Blackhall et al. [1995]⁸ as well as Koenig⁹, Koenig and Gates-William [1995]¹⁰ and others¹¹⁻¹² have found that many dying patients do not want to know the details of their prognosis, nor want to make their own autonomously derived decisions about their treatment options. For many such patients, family needs, obligations and responsibilities are of greater importance.

Such cross-cultural insights are helpful for articulating a more nuanced concept of autonomy. Dr. Glick says, "While I think one should tell the truth to patients in general, there are times when I don't, and I think there are times when patients don't want it, and they're very upset when you do."

"Autonomy," Dr. Núñez Olarte concludes, "does not mean assaulting them [patients] with truth, or assaulting them with informed consent, or assaulting them with advance directives." These sentiments echo advice that Dr. Benjamin Freedman, the late Canadian researcher, provided, when he suggested that health care providers "offer" truth, but not impose it.¹³

Kindness

Autonomy is not a command, but rather an invitation, a freeing of space for the possibility of self-fulfilling action. When autonomy is wielded like a club, it can be cruel and destructive. In contrast, Dr. Ripamonti talks about speaking in a *particular* way - a way that helps a patient arrive at his own sense of his prognosis. Furthermore, Ripamonti expects and accepts what others might merely dismiss, with frustration and exasperation, as "denial." "You could have a patient," she explains, "who clearly knows her prognosis, but when she feels better she believes that death is not near. One day we are able to accept death; the day after, we are not."

What all these commentators share is a commitment to individualizing decisions. Not through prior advance directives about a hypothetical time, but in the moment - a moment that is inevitably conflicted, uncertain, fraught with ambivalence. One that requires acts of human kindness, more than treatment directives.

And, in fact, if we look closely at what *Respecting Your Choices* accomplished in La Crosse, Wisconsin, it was exactly that -- better ways to ensure that conversations took place within families and among patients, families and health care providers. Dr. Hammes emphasizes that the goal is not to get people to fill out paperwork, but to use that task as an impetus to ensure that conversations take place. Most of the components in the *Respecting Your Choices* program involved helping family members talk amongst themselves and with their health care professionals. In the US health care system, we may need to work harder to ensure that that happens, because unfortunately we can not assume a long-standing relationship with our physicians or continuity of care as patients move across care settings. Dr. Hammes' group has demonstrated one very effective strategy for enhancing communication in a context where it is harder won.

I invite you to read about what he has achieved and to consider how it might be adapted for your community. Dr. Hammes will be available on-line to answer questions and interact with

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Innovations in End-of-Life Care, January-February 1999, Vol. 1, No. 1.

<http://www2.edc.org/lastacts/archives/archivesJan99/editorial.asp>

Innovations readers between January 20 and February 3, 1999. In the meantime, I hope you will begin the on-line discussion, by reacting to the featured innovation, this editorial and to our commentators' international perspectives. Please post your comments and questions in the "On-Line Discussion" section of this website. Our editorial board and other international participants will be joining in to make for a lively and provocative discussion.

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