

## Editorial

### Communication, Trust, and Making Choices: Advance Care Planning Four Years On

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Discussions of advance directives and advance care planning are omnipresent in end-of-life literature. Most every organization provides some assistance with advance directives and is compliant with the 1990 Patient Self Determination Act (PSDA)<sup>1</sup> and accrediting standards. Despite all these activities we still do not have a consensus on what we mean when we talk about advance care planning nor what we take to be meaningful outcomes. Advance care planning is, at its most basic, a process of thinking ahead to treatment choices, goals of care, and/or choosing another person (a proxy) to speak for oneself at a point in the future.

In this issue of *Innovations*, we take as a starting point, the successful community-wide advance care planning program, *Respecting Choices*<sup>®</sup>, spotlighted in the inaugural issue of *Innovations* in January 1999, along with the articulate critique from five international experts<sup>2</sup> of this "American" approach to improving decisions near the end of life. We examine an array of current efforts to conduct meaningful advance care planning as a way to revisit how these questions are being framed today. The trajectory of the *Respecting Choices* effort foreshadows the evolution of the field from a legal, document-driven effort to one that privileges the process of engaging patients, families, and surrogates in conversations about hopes, wishes, values, and goals of care. *Respecting Choices* began as an advance directive, community-wide education project, which had a relational focus that made it stand out from other contemporaneous efforts. Today, it has broadened to include more focused planning for individuals with a life-limiting illness to help them live well with what time remains.

These conversations do not exist in a vacuum, however. Building a system that aims to expect, honor, and act on these preferences has been a second and equally distinctive feature of the *Respecting Choices* effort in La Crosse, Wisconsin.<sup>3</sup> The importance of thinking in terms of systems remains a distinctive and vital part of this approach. Since the inception of this program in the early 1990s, the La Crosse team has worked to identify the crucial elements of any effective advance care planning system as well as how to define the roles and responsibilities of various health professionals working as a team within such a system.

The gist of the international critique, as summarized by Mildred Solomon, EdD, in her 1999 editorial,<sup>4</sup> was that the American approach leaned too heavily on assumptions of autonomy, at the expense of the family and community values that surround a patient. This overemphasis on autonomy was perhaps natural, given that this movement emerged out of a series of court cases in

which the absence of documentation about patient wishes and preferences led to battles between families wishing to withdraw treatments and the state refusing to do so.<sup>5,6</sup> Documentation of wishes remains important. However, the international critique of the utility of advance directives was aimed at the unexamined assumptions underlying these tools as they had been implemented in the United States. Shimon Glick, MD, Linda Kristjanson, PhD, Juan Núñez Olarte, MD, PhD, Zbigniew Zylicz, MD, PhD, and Carla Ripamonti, MD, articulated alternate understandings of the context for end-of-life decision making.<sup>2</sup> Namely:

- In many societies, the family or larger group is the unit of care, not the patient alone. Decision making then becomes a more communal process rather than solely assessing what the patient wants. The most basic assumptions of disease cause and effect may not, in fact, be shared by some cultural groups. These cultural differences can create a canyon of misunderstanding between health care providers and families, especially when patient autonomy is emphasized.
- Even when patients, families, and health care providers share basic assumptions about disease and health, the detailed medical plans we make when healthy may change dramatically when we become ill. A document that reifies these earlier preferences may be of little use in guiding clinicians at a later time.
- Checklists that name acceptable vs. unacceptable procedures rarely accommodate the complexity of the real choices physicians and families face when a loved one is gravely ill.

The cross-cultural critiques of the value of advance directives that we published in our inaugural issue all pointed to the need for *judgment*, *ongoing planning/conversation*, and *interpretation*, in order to make appropriate treatment choices in real time, with real people. It is intriguing to note that the efforts we spotlight in this current issue of *Innovations* are all patient and family centered, i.e., they move these relationships to center stage and simultaneously require more interpretation, ongoing planning/conversation, and judgment in order to make treatment choices that reflect patient and family values as well as clinical realities and the likelihood of particular treatments having the desired outcomes.

Because of the range and quality of recent work on advance care planning, we are devoting two issues of *Innovations* to this topic. The papers included in these two issues each report on advance care planning (ACP) efforts taking place in a range of different settings (community, nursing home, outpatient clinic). Each sheds light on a particular aspect of advance care planning. The strengths and limitations of each effort, examined together in light of the work and commentary presented in the 1999 issue of *Innovations*, provide a real sense of the changing landscape of this topic. Taken together, this work demonstrates a greater focus on ACP models that privilege quality of communication, trust, and how family members and health care providers can function ethically in situations that are inherently ambiguous or even sometimes contradictory, rather than constructing checklists of to-do or not-to-do items. Advance care planning is being considered more than just planning for or against particular treatments. It embraces a broader, needs-based view of care, necessitating coordination of resources and services within a community or region by an individual or a palliative care team, rather than the tendency to see the patient and family in isolation from their communities.

Moving from an individualistic focus to a more community-based focus is an ambitious undertaking because it puts the onus of planning on the health care providers as well as the patient and family.

Considering what services might be needed when, advance care planning of this type is a more holistic, palliative approach to decision making, which includes time for considering alternative pathways, depending upon what stage of illness the patient is in and what the patient's goals of care are.

These efforts to make ACP more workable also shift medical care toward a much more family-centered<sup>7</sup>/relationship-centered model<sup>8</sup> of care. This move can allow for a figure-ground shift in the rationale for doing advance care planning. Instead of becoming an end, it becomes one vehicle or tool among many for enacting relationship-centered care, i.e., care that includes patient and family input and mutually negotiated and evolving treatment choices.

The current issue (Part 1, in vol. 5, no. 2, March-April 2003) updates readers about the evolution of *Respecting Choices* and some of the statewide efforts it has spawned, and focuses on two approaches to conceptualizing and creating a trusting relationship among the patient, proxy, and health care provider, so as to best elicit and be faithful to the patient's values and wishes about their future care. The next issue (Part 2, in vol. 5, no. 3, May-June 2003) features a community-wide effort to improve advance care planning as part of a continuum of care, which also involves mapping and coordinating resources to meet a patient's particular needs, and a promising approach to advance care planning that includes palliative care pathways in a nursing home setting.

### **Continuing the Conversation about Advance Care Planning: Part 1**

In the Featured Innovation in the current issue, "Shifting the Focus of Advance Care Planning: Using an In-Depth Interview to Build and Strengthen Relationships," Linda Briggs, RN, MS, MA, reports on evolving work to come out of the La Crosse program: the patient-centered advance care planning interview, constructed for use with persons suffering from chronic life-threatening illness and their surrogates. Ms. Briggs reflects on how this in-depth interview moves the focus of the intervention squarely onto what Kolarik et al. call the "social purposes"<sup>9</sup> of ACP—i.e., educating patients and families about the possible or likely illness trajectory, opening up a conversation and communication among the members of a triad: health care provider, patient, and surrogate. Listening is a key part of the process. The conversation only goes where the patient and surrogate want it to go, allowing health care providers to offer various "truths," as advised by the late Canadian researcher Dr. Benjamin Freedman,<sup>10</sup> but it does not require patients to discuss topics that do not feel relevant or that they are plainly not ready to discuss. This interview also includes attention to documentation. Ms. Briggs' reflective report on the development of the patient-centered advance care planning interview provides theoretical underpinnings for this approach and raises the question: What is the purpose of ACP for persons with chronic life-threatening illness? Ms. Briggs maintains that offering opportunities for patients who are living with chronic, difficult conditions to speak openly with loved ones about current quality of life and future wishes was the most valuable element of this intervention, although clearly there is also much value to documenting these decisions and entering them into the system.

However, this approach surfaces the potential for real differences to exist between providers and patients regarding the prognosis and its meaning, and therefore, what actions are reasonable to take, given what is known. In order for this approach to stay patient-centered, it will require the health professional to enter into a dialogue with the patient and surrogate and not simply to trump the beliefs and goals of those receiving care.

The Promising Practice in this issue further delineates the ways that all advance care planning

depend upon interpretation and judgment. Barbara Maltby, MA, and Joseph Fins, MD, FACP, have created a set of educational tools for communities to use,<sup>11</sup> based on Dr. Fins' argument for a patient-proxy relationship that has more in common with a covenant than a contract.<sup>12</sup> In "Informing the Patient-Proxy Covenant: An Educational Approach for Advance Care Planning," the authors describe the rationale for their interactive workbook. They summarize their earlier critiques of the proxy contractual model, one which they feel puts proxies in a straightjacket and cuts them off from the intimate, in-depth knowledge and variegated understanding of the patient that many proxies have. This covenantal model seeks to create a framework that can hold that deeper knowledge, and honor the trust in judgment that many wish to bestow on their proxies, unfettered by particular do's and don'ts to be applied against an unknowable future. The authors wish to acknowledge that entering into a patient-proxy relationship involves mutual responsibilities, and one of the goals of these materials is to create a context for patients and proxies to explore the obligations and burdens assumed by the proxies in advance of the need to make decisions. To do so, they have created a series of vignettes designed to illustrate a variable prognosis and to serve as triggers for in-depth discussion of end-of-life situations and what patients might wish for in those times. The materials include commentary and helpful hints, so that participants are not left facing these discussions with no one right answer, in a void. The aim of this intervention is that in the face of uncertainty, participants should enter into meaningful dialogue about goals for care and potential treatment, not about exact procedures to undertake or avoid. Ultimately, this dialogue aims to deepen the proxy's understanding of the patient and for the patient to understand what may be asked of the proxy, as well as to confirm the proxy's confidence in his or her ability to take on the covenantal role of decision maker on behalf of the patient at an unknown point in the future. Again, this effort requires trust, judgment, interpretation, and acceptance of a certain degree of "messiness" or a willingness to grapple with uncertainty—hallmarks of a relational approach.

This issue of *Innovations* also includes Dr. Cameron Bopp's review of *Long Goodbye: The Deaths of Nancy Cruzan* by William H. Colby (Hay House, 2002). It is important to keep sight of the tragedy that can and did ensue in the absence of documentation of patient wishes and beliefs. Revisiting this family's struggle to remove a feeding tube from their 28-year-old daughter who was in a persistent vegetative state as a result of a car accident is sobering. The Supreme Court decision that emerged from this case provided clarification that patients and their health care proxies have the right to refuse or withdraw treatment at the end of life, and that there is no rational difference between "extraordinary" treatments, such as ventilator support, and "ordinary" treatment, such as medically supplied nutrition and hydration.

Last, this issue includes an update on the progress made on *Respecting Choices* in La Crosse, Wisconsin and descriptions of two statewide efforts to adapt the *Respecting Choices* model. Since 1999, a great deal of work has occurred in La Crosse to develop the *Respecting Choices* model so it could be implemented in other communities and organizations. This required a more perceptive understanding of what aspects of the program contributed to success. It also required the development of print and teaching materials so the program could be disseminated to others. At this point, more than 25 groups in the United States and Australia are attempting to implement a *Respecting Choices* type of program in an organization, network, community, or across a whole state. Common barriers faced by these groups include a lack of resources (both time and money), difficulty in changing routines/medical cultures, and the lack of understanding of the value of effective advance care planning.

Two of the groups implementing a *Respecting Choices* type of advance care planning program are

doing so on a statewide basis. These include the New Hampshire Partnership for End-of-Life Care and the Carolinas Center for Hospice and End of Life Care. The reports from these two state projects describe the steps that have been taken to improve the quality and prevalence of advance care planning. These are ambitious programs that are attempting to change the culture around planning by creating educational materials that motivate and assist discussion, training advance care planning facilitators, and changing state policy and practice. The La Crosse program itself continues to evolve and develop as more effective and broader approaches to advance care planning are identified.

It is still too early to measure the full impact of the statewide programs. Perhaps the biggest concern is that these programs have not had as much success working directly with hospitals, clinics, and other health facilities. This lack of buy-in from health organizations is the result of approaching the problem from a statewide perspective. It is still to be seen if success at respecting patient choices can be achieved without significant buy-in from these health organizations or if these statewide approaches will eventually lead to changes in the routine of these health facilities. What does seem to be evident is that a more process-oriented, relational approach to advance care planning can be taught and implemented in other settings. It also seems that this approach to advance care planning can be reflected in community educational materials and state policies. In short, the approach pioneered by *Respecting Choices* does seem amenable to adoption by communities outside of western Wisconsin.

## **Continuing the Conversation about Advance Care Planning: Part 2**

In Part 2 (in the upcoming May-June 2003 issue of *Innovations*), "A Framework for Collaborative Consumer Centered Care" by Sally Okun, RN, BSN, MMHS, offers an example of a grassroots community effort to adapt the *Respecting Choices* materials in order to integrate the principles of advance care planning into the provision of health care across the community. Hospice and Palliative Care of Cape Cod (HPCCC) initiated a program called Lifecare Conversations<sup>®</sup>, which takes a community organizing model and assimilates the tools and message of La Crosse into Sally Okun's homegrown concept of CARETOGRAPHY, an assessment mapping tool that identifies the web of relationships and resources that may surround and support a person. The process of engaging in this mapping leads to uncovering both previously unrecognized needs as well as previously unknown resources. Ms. Okun's key message is that if you engage in advance care planning with someone, and view the person as embedded within a community or region that includes a range of resources, this conversation brings to the fore the potential for coordination across entities and reimbursement streams of those community resources, the health care provider, patient, and family members. Hospice and Palliative Care of Cape Cod created a palliative care service to address the needs uncovered by these community awareness-raising activities.

As the name implies, Lifecare Conversations does not limit ACP discussions to end-of-life issues, but seeks to help health care consumers and their providers become more skilled in exploring options and understanding choices for any health care decision as a routine component of quality care across the life span. The broad community-based focus of this effort was started from within HPCCC (which holds the rights to the name Lifecare Conversations), but the vision Ms. Okun describes is of a community coalition to embrace and enact these ambitious goals. The element of community transformation is innovative, yet may also make this approach difficult to implement and sustain. This HPCCC effort has thus far been dependent upon the charismatic and tireless leadership of Ms. Okun and several key actors, and HPCCC has fully supported its operational expenses with some limited philanthropic grants; now, however, responsibility for the effort is being

shifted to the organization's Community Advisory Board. Sustaining this kind of effort in tough economic times will be a challenge. However, the CARETOGRAPHY tools and vision that underlie this approach offer some liberating lessons about transforming end-of-life care: Make the person in need the center of your puzzle, and then identify their needs along with existing relationships and health care resources that might be coordinated to serve those purposes, regardless of reimbursement streams, and begin to construct meaningful plans for coordinating care. As with many examples of innovation highlighted in these pages, mindfulness is one of the core features of this effort.

Muriel Gillick, MD, in her article "Adapting Advance Medical Planning for the Nursing Home," moves us into the world of the nursing home, one she describes as a "wasteland" for advance care planning, in spite of the fact that as "home" to elderly frail residents, it is one of the health care settings patients are most likely to die in if they are not discharged to acute care settings. She describes a care pathway model that takes into account both patient and family goals of care, as well as evidence-based medicine and the likelihood that any given treatment would make a difference in patient quality of life. The care pathway model has both advantages and limitations. Similar to the work of Fins and Maltby, this model requires mindful judgment, in this case on the part of health care providers, because patients in this setting often cannot speak for themselves and families may be absent at critical times. Many of us would wish for practitioners who were authorized to use their best judgment, if we trusted that they understood our goals and values. However, risk taking, interpretation, and using best judgment thrive in systems characterized by trust, teamwork, and open communication, including feedback loops in which mistakes are characterized as opportunities for learning, rather than being penalized. Some nursing homes may live up to this high standard, but few institutions do across the board. One of the challenges of this model is how to create and sustain a system and culture that rewards mindful judgment and can tolerate anomalies.

Dr. Gillick describes the nursing home as a setting in which it would seem most challenging and perhaps most important to enact advance care planning, given that more than half of nursing home residents suffer from dementia and may not be able to articulate their own wishes. These conditions make it all the more compelling for health care providers to create a system that can take patients' earlier preferences and a family's ongoing wishes into account, yet allows the health care providers the opportunity to draw on their knowledge and expertise.

Melodie Heland, RN, MS, describes the impact of implementing the *Respecting Choices* program in Australia in her Personal Reflection in this issue. Her experience confirms the salutary effects of engaging health care professionals in relationship-centered care, as she describes the ways in which this program can buffer feelings of futility and burnout. She contrasts this with earlier experiences of providing care that felt like it betrayed the trust of one's patients; e.g., reverting to "doing everything" in the absence of advance care planning, in ways that cause patients pain and suffering, and diminish caregivers' sense of professionalism.

## **Conclusion**

Advance care planning is now moving into the uncharted territory of trust—continuing to discuss hopes, dreams, and assumptions of future care—but often with less focus on particular interventions. Instead, ACP is now offering a more global promise to follow through with a consistent quality and kind of care—care that engages patients who are gravely ill earlier in their illness, and opens difficult conversations about an uncertain future among patients, their loved ones, and health care providers. Trust must be present in order for this approach to work. As David

Barnard, PhD, notes, making a space for gravely ill persons to have these potentially meaningful conversations is in itself a valuable undertaking.<sup>13</sup> This slight shift in emphasis makes ACP a route to promoting patient-centered care.

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