

## Editorial

### **Listening to Patients and Families Moves Practice Toward Family-Centered Care**

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In the first issue of *Innovations of End-of-Life Care*, our international editors described how decisions about using or forgoing life-sustaining treatment are made in Israel, Australia, Italy, Spain and the Netherlands. As Mildred Solomon, EdD pointed out in her accompanying editorial, their descriptions revealed a more subtle interpretation of the concept of autonomy. In these countries, the focus seems to be on relationship building both with individual patients and their families. There is less interest in trying to document ahead of time precisely what patients think they will want under unknown future circumstances and more interest in understanding who the patient is, and what he or she wants in the present moment.

In this issue, we offer a range of pieces that extend this critique. Each of the innovators and researchers whose work we present has chosen to listen to patients and families carefully. In so doing, each has developed a more sophisticated understanding of autonomy, and as I will argue, moves us towards legitimizing a more family-centered ethic of care.

In this issue, we present two promising practices. Navah Harlow, MA, director of the Center for Ethics in Medicine at Beth Israel Medical Center in New York City, describes a process for bringing families, particularly those from minority cultural groups, back into the decision-making process for end-of-life care of their loved ones who have lost decision-making capacity. Ms. Harlow developed a process of family letter-writing, which has enabled families to communicate what they know of the patient's values, beliefs and wishes in their own words and often in their own languages. These letters are used to help the family clarify their own understanding, and to honor and respect what they know the patient would want. Because of the idiosyncrasies of New York State law, the letters are used to present the family's case to the hospital ethics committee where decisions about withdrawing treatment are often taken if patients have left no prior directions about their wishes.

Stuart Farber, MD and his colleagues at Multicare Regional Cancer Center in Tacoma, Washington are developing a workbook for patients and families to be used from the point of diagnosis with cancer forward, which aims to put patients and families back in the driver's seat in terms of decision making and informing their clinicians about who they are and how they want to proceed. What is distinctive about this project is that Dr. Farber and his colleagues are attempting to treat the family as the unit of care from the beginning -- a concept that derives from his initial focus group research

with surviving family caregivers. The serendipity here is that this project did not begin with an attention to "diverse" populations, but by really listening to what surviving family caregivers had to say about their experiences of end-of-life care. Taking family experiences as the starting point for this educational intervention, he and his colleagues came to the same insight suggested by the research on cultural diversity in end-of-life decision making:<sup>1,2,3</sup> when it comes to life and death issues, patients and families together need to be the unit of care.

In our International Perspectives department, we hear from two American physicians who have done cross-cultural research with patients, families and physicians around end-of-life issues. Recent research about the ways patients and families from different ethnic groups within and outside the United States understand end-of-life care and end-of-life decision making has made clear that assuming patients make decisions autonomously and out of the context of family, culture, community and the particulars of a given situation, has serious limits.<sup>4,5</sup> Each of our commentators shares how their respective research has challenged their own thinking and understanding about end-of-life care. Leslie Blackhall, MD describes the ways in which her research into the attitudes and beliefs of patients who were not white middle-class professionals like herself led her to develop a more subtle concept of autonomy. Really listening to the voices of her informants and going back to ask for clarification about these attitudes led her to discover the coherence in their stories and to reframe what she had initially seen as contradictory attitudes. Michael Fetters, MD, a family physician and researcher who has lived in Japan and studied how Japanese physicians work with patients and families around the question of disclosure of cancer diagnoses, reflects on what his research has taught him and then shares a real life example from his practice with Japanese expatriates in Ann Arbor, Michigan.

Family-centered care is a concept that has come out of pediatric literature and practice, but has not yet been widely translated into the care of adults.<sup>6</sup> Attention to issues of cultural diversity and attempts to learn from patients and families from ethnic groups other than white, middle-class Americans highlight the need for expanding current notions of patient-centered care to include the patient's family; however, he or she chooses to define "family". Taking questions of diversity seriously allows "mainstream" bioethics to see the holes in our theories and principles more clearly, i.e., interpret and understand principles such as autonomy in more nuanced ways, which in fact may benefit all patients and families.

We invite you to join the on-line discussion to share your experiences as well as any resources and tools you might be aware of for promoting family-centered care.

## References

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