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# Book Review

***Conversations on the Edge: Narratives of Ethics and Illness***
By Richard M. Zaner. 2004. Georgetown University Press. Washington, D.C. 141 pages.
Reviewed by Frederic W. Platt, MD

Richard Zaner was professor of Medical Ethics at Vanderbilt University. This memoir recounts the terminal illnesses of six patients in whose care Zaner was involved and some of their last conversations. His cases include two very premature infants in the Newborn Intensive Care Unit, a young man suffering with congenital neurologic disease who now needs but refuses renal dialysis, an elderly woman dying of respiratory and renal failure whose husband seems unable to come to grips with the situation, a patient with Alzheimer's disease, an adolescent who was brain dead after an automobile accident, and finally Zaner's own mother who died of end stage obstructive lung disease and the loss of her will to live.

I found Zaner's last chapter to be the best place to start. The story of his mother's illness and of Zaner and his brother's struggle to deal with the illness, with their irascible mother who eventually probably suicided, and with the unresponsive and unhearing medical team – would have been a good place to start rather than finish this book. In fact, I'd suggest just that for the reader—start with the last chapter. One gains a great deal of respect and liking for Zaner in that chapter and one comes to understand that even a lifetime of work in medical ethics, huge experience dealing with dying patients and their families, still leaves one suffering when the case is that of a loved relative.

Zaner understands and details for us the relationship between our patient's vulnerability and neediness and our own responses to that patient. The patient's vulnerability behooves us to act in a fashion that we might not choose if the patient were more competent to fend for himself. Zaner calls it "the patient's awesome vulnerability," an appropriate adjective. He understands that we take over the lives of our patients and that we invade their rooms, their lives, even their hopes. Here is a bit of his discussion of Tom's case, a patient with congenital spina bifida, many hospitalizing infections, and now renal failure:

> *Vulnerability augurs temptation but at the same time evokes – seems even to awaken – concern, a wanting to care. ... Tom, like most any sick person, awakens an otherwise mostly dormant moral sense.…These feelings propel me beyond myself, take me out of myself, beyond my own concerns of the moment, towards Tom. They are an elemental and literal ec-stasis; to be myself before Tom is to be beyond myself, always already with him. I find myself busied with him, not me. Being myself, as it were, is something I have to accomplish within these very circumstances: it is with Tom that I am brought to myself; "self" more a prize won through complex developmental experiences than some "inside" entity brooding in me. Thus is understandable that otherwise odd sense of gratitude one feels in being able to help someone like Tom, even if it is merely to have placed a full glass of water next to him as he asked.*

Zaner's perspective and professional field of philosophy leads some of his writing to be jargonesque for physicians, but he has great respect and empathy for the clinicians he works with. And as a reader, I came to have considerable respect for Zaner, for his sensitivity, his intellect, and his concern.

Much of the book consists of partial dialogues – between Zaner and clinicians, Zaner and the families, Zaner and the patients themselves. And it is there, in the recorded dialogues that one wonders whether we are simply not being shown enough or whether Zaner follows the typical clinician pattern of talking too much and listening too little. He might say to a patient, "What I wanted to discuss …" and then proceed to tell a lot but not ask enough, even when he is puzzled by the patient's or family member's demeanor. Several times I found myself hoping he would soon say to the patient, "I am still confused. Can you tell me how you feel about this? Can you tell me what is most important to you in this process? Can you tell me what your thoughts are about this?" Only knowing what he tells us, only hearing the parts of the dialogues he presents, we might find ourselves wondering if he explains too much, wonders enough, but asks too little. With that single caveat, I recommend this book to fellow clinicians. It helps to hear about our work from a compassionate, empathetic, thoughtful person such as Zaner. I will not quickly forget his concept of the awesome vulnerability of my patients.□

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## Nurses as Patient Advocates: Making it Easier for Nurses to 'Do the Right Thing'

With their medical knowledge and the time they spend with patients in a medical setting, nurses are often in an excellent position to serve as advocates for those patients. Sometimes that advocacy is a relatively simple matter, such as communicating a patient's wishes to appropriate persons. Other times it may involve confronting colleagues, physicians, or administrators, when the patient's safety or wellbeing is being compromised, for example. Undoubtedly, many nurses fulfill their professional role in this regard, but it is not always easy to do so.

Serious barriers stand in the way of advocating for patients when it requires that nurses take a stand and point out deficiencies. These barriers may include personal levels of assertiveness, conflicting loyalties to colleagues and the healthcare facility in which they are employed; the uneven balance of power in the nurse-physician relationship; an institutional culture that does not support such actions; and, consequently, feelings of futility along with fears of risking one's job.[1]

What, for instance, should an office nurse do if the surgeon she works for does not encourage a newly diagnosed patient, with advanced cancer, to explore his options – instead recommending an approach that, she thinks, will virtually guarantee a greatly shortened lifespan? If she feels it appropriate, she might want to suggest he visit a cancer care center. How easy will it be for this nurse to do that? Overtly?

What would be the effect on a nurse when, after suggesting to a patient's family that they ask about certain treatments, he is "read the riot act", by the patient's doctor – declaring that he had no authority to do so?[2] And how easy would it be to intercede when it will stir up a hornet's nest of bad feelings among colleagues?

What might make it easier? Taking a page from North Shore University Hospital, in Manhasset, NY might help. That institution, cited in 2002 as the nation's top metropolitan hospital by Consumer's Checkbook, empowers its staff to speak up when they feel it is warranted.[3] Ensuring that nurses are "…given a voice with which to advocate for their patients…" and have full administrative support when they use that voice are essential ingredients for encouraging nurses to act as patient advocates.[4] For such policies to work, however, attention to communication and relationship building should also take place. In-services and team meetings may be two ways to help medical personnel build these skills. When combined with a culture that does not instantly seek to blame and punish, health administrators can effectively promote patient advocacy.□

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[1] George Allen, "Maximizing Nurses' Advocacy Role to Improve Patient Outcomes," *AORN Journal* 71(5): 1038 (May 2000); Marie B. Andrews, "Nurse's plea: 'Can we talk?', *Medical World News* 31(12): 39 (June 25, 1990); Rosalind Bull and Mary Fitzgerald, "Nurses' advocacy in an Australian operating department," *AORN Journal* 79(6): 1275 (June 2004); Kathryn Schroeter, "Ethics in perioperative practice – patient advocacy," *AORN Journal* 75(5): 941 (May 2002); L. Schwartz, "Is there an advocate in the house? The Role of Healthcare professionals in patient advocacy," *Journal of Medical Ethics* 28 (1): 37 (February 2002);

[2] Demetria Anderson, "On Being an Advocate," *RN* 61(9): 96 (Sept. 1998).

[3] Joe Bargmann, "The Top Hospital in America," *AARP* 44-53, 77-8 (May/June 2002).

[4] See Kathryn Schroeter, note 1.

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## Talking With Patients About Advance Directives

If you are a physician, nurse, or other healthcare professional, chances are you are well aware of the various problems that can arise when family or friends are called upon to make healthcare decisions for once-competent patients who never prepared advance directives. If you've actually been part of such situations, you've likely experienced, first hand, the emotional toll it takes on family and, perhaps, involved professionals. How much easier this difficult situation would be if patients would only think ahead, prepare advance directives and talk about their wishes with family, friends, and physicians.

While many, if not all, hospitals provide admitted patients with a packet that includes some type of healthcare directive, that does not work for those patients who have lost their ability to make decisions prior to admission. How helpful it might be, then, for physicians to speak with their patients about this matter. This is, of course, a difficult subject to broach. Not only is this a topic that many people find difficult to face, but patients may interpret the suggestion to prepare an advance directive as another way of saying they don't have long to live. One way around this is for doctors to bring the subject up by saying something like:

> *I've been talking to all my patients about advance directives and how important it is for everyone, young and old, to have them. Advance directives are important because…*

By emphasizing the fact that you are bringing the matter up to all your patients and, perhaps, indicating that you have prepared such documents for yourself (if you have), you may be able to prevent misinterpretations, on their part, and create an atmosphere conducive to their consideration of preparing advance directives.□