

Readers' Forum

New Directions in End-of-Life and Palliative Care

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Reaching for reassurance at the end of life

CHAPEL HILL—"What would you do?" I've been asked this question hundreds of times since I started medical school in 1983. I was asked it as a medical student, as a surgical resident, as a trauma surgeon, a critical care specialist, and as the director of an ICU in a rural North Carolina hospital. I've been asked it about a variety of issues, but most commonly I've been asked it by families who were making end-of-life decisions about their loved ones.

Should they put a feeding tube in their grandmother, now too demented to eat? Should they donate the organs of their brain-dead son? And what about their father and his massive stroke—should they disconnect him from the ventilator?

"What would you do?"

For years, this question made me nervous. It was a relic of the old days, before I came along, when doctors had all the answers, when we simply went ahead and did what we thought was right without much input from patients and their families. I didn't train in the era of paternalism. I trained in the era of patient autonomy, so when families asked, "What would you do," I thought that they were asking me what they should do, as if there were some kind of objectively right answer, separate from the wishes of the people for whom they were speaking.

For years, I sidestepped this question. I told families that I didn't know what I would do in their situation. I said you never knew what you would do until you were the one that was having to do it. In fact, however, this was often a lie. Generally, I knew what I would have done: I wouldn't have put in the feeding tube, I would have donated the organs, I would have turned off the ventilator.

But for years I didn't tell people that. I didn't want them to do what I wanted them to do. I wanted them to do what the patient would have wanted. I thought that injecting my own opinion would make them think more about me and less about the patient, that the possibility of doing something their doctor disagreed with would only make their decision more difficult.

Over time, though, I began to notice something. I wasn't



the only person hearing "What would you do?" Families asked nurses too, and they asked the nursing assistants whose job it was to bathe the patients, change their sheets, empty their catheters, turn them side to side to prevent them from developing pressure sores. When I moved to rural North Carolina, the family meetings at which we discussed all this expanded to include "church family" and the patients' ministers. They faced the question too: "What would you do, Reverend?"

After a while, I began to realize that the families weren't actually asking what they should do. In fact, most of them already had an idea about what they should do. Most of them felt they should withdraw life support, because the majority of my families knew that somewhere along the line, the patient had told his brother or his wife or his daughter or his mother something about not wanting to be kept alive by tubes and machines.

And so I came to understand that the families weren't asking what they should do. Instead they were asking us all for permission to actually do it—permission to withdraw life support and allow the patient to die. They weren't asking for legal permission—they knew it was legal. But they were asking for true social sanction. They wanted to know that other families did this, that people from the church wouldn't think of them as murderers, that their neighbors wouldn't fault them when the word got out.

Families were also asking for reassurance that the patient wouldn't suffer. They needed to believe that if they elected to withdraw support, we could continue to comfort patients and alleviate their suffering as they moved toward death.

Families asked nurses and nursing assistants as often as they asked me, because they knew the nursing staff well. They had seen the nurses rub lotion on the patient's dry feet. They had seen the aide comb out the patient's matted hair. They had watched techs readjust tape and bandages and tubes and IV lines so they didn't tug and tear at the patient's fragile skin. Family members, watching this, were touched by the staff who cared the most for their family member. When they asked staff members what they would do, they chose the ones that they trusted most. They chose ones that they knew would never have done anything that would have increased the suffering of the patient.

I am dismayed that the president and Congress, particularly the physician members of Congress, have elected to intervene in the Terri Schiavo case. The physicians above all should understand the delicate, carefully wrought relations of trust that are an essential part of patient care and decision-making, especially at the end of life. The name-calling and grandstanding

that have accompanied this case will only make it more difficult for families in the future to make end-of-life decisions.

Just as sadly, I think, they will cause families who have already had to make these painful decisions to question themselves and the decisions for which they so plaintively begged reassurance.

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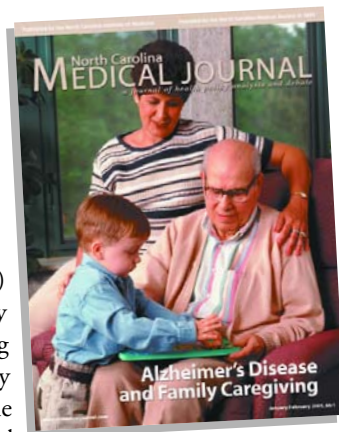
Alzheimer's Disease and Family Caregivers

To the Editor

Your January/February 2005 issue (66:1) of the *North Carolina Medical Journal* is truly overwhelming because of: the staggering numbers of us who will have one day, by current projections, Alzheimer's Disease; the depiction of the incredible amount of sad work involved in care giving; the financial burdens families must bear; the description of the pathos/grieving associated with being around these patients; and because of the paucity of policy options available to North Carolina or the United States.

Sixteen million people afflicted with dementia by 2050 will clearly require a carefully planned/well-funded system of organized, standardized care. Such a system can only be achieved by the design/construction of a very large number of Alzheimer domiciliaries patterned after the concept of tuberculosis in sanatoria as built in the late 1800s-early 1900s. Patchwork of respite options, as in the table from Karisa Derence's commentary will not suffice and almost certainly would not prevent bankruptcies within families, churches, or governmental agencies. Of course building a multitude of structures for patient's with TB had the notions of "healthy" food/air contributing positively to the treatment of and the need for isolation to prevent contagion as a powerful force to get the policymakers to act.

For Alzheimer's dementia, the impeti are the logistics of financing such care, defining the care to be provided, and the recruitment of an adequate sized army of caregivers. Remember, some of the requirements of these 16 to 50 million folk will be: housing; feeding; protection from cold/heat; prevention of injury to self/others while permitting maximum freedom to pace, wander, or babble early on in the disease; preserving some activities of daily living for as long as possible; cleanliness; and dignity; however society chooses to define it by then. Such requirements extrapolate into the need for unique interiors/furnishings for this kind of housing. Then, there are the matters of: choking/feeding for many who can't chew or swallow or have lost the ability to use knife/fork/spoon; air handling of odors, washability of repeatedly soiled every day items (beds, bedding, chairs, walls, floors, etc.), and an endless supply of diapers, diaper changers/diaper disposals to mention



just a few. Finally, in the last trimester of the illness our hosts and their staff will have to make hard decisions about how/whether to treat malnutrition, dehydration, skin breakdown, urinary tract infections with resistant organisms, pneumonia, sepsis; exacerbations of the other chronic medical conditions that were on the problem list before the onset of dementia or developed during the dementia; and the occasional intercurrent acute surgical event.

No matter how such "hotels" are financed, whether at the state or federal level, there will still be a need for volunteerism beyond any exhibited in this country to-date. As an aside, we must not limit such volunteerism by requiring bureaucratic certification in feeding, bathing, dressing, or walking with these cognitive invalids. Indeed, perhaps we will need a form of universal subscription (say between the junior and senior years of high school) to swell the ranks of caregivers.

There are, of course, many objections to this proposal, such as: how much dare we spend on a structured solution lest we siphon funds away from the promise of a cure by research or from the cost of a truly effective chronic treatment; the unfair requirement in some less populated states that visitors might have to travel for a day to visit a relative or loved one; and the logistical problem of who will and how to decide about eligibility for admission. Perhaps a happy long-term concern will be what to do with all that new construction once the disease joins the list of easily preventable or successfully treatable disorders. If we're optimistic, then we should plan on multipurpose structures and consider geography accordingly.

Be assured that despite the anticipated letters and outcry by social scientists, politicians, clergy, and ethicists to what appears to be a calloused practical solution to a challenge of staggering proportions, there will be millions of relatives clamoring to get a loved one admitted when the institution is as conceptualized in my mind and as it could/should be.

"If we build them, they shall come!"

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