

Not the Time: A Personal Reflection on Counseling Families on End-of-Life Decisions

"Not the Time" refers to my experience as a medical social worker in assisting families as they face decisions about removing life-supports of a terminal ill family member. This story comes out of: my struggle with these decisions; my strong disagreement with Dr. Kevorkian; and my concern with what I perceive as our "cultural obsession" with denying our own mortality. The unintentional outcome of writing this narrative resulted in resolving my ambivalence toward physician assisted suicide.

by
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Introduction

As a hospital social work director and medical social worker, I became interested in the use of narrative in working with profoundly ill and disabled clients. I found that an episode of illness typically constituted a significant chapter in people's life stories and, often, even the last chapter. Narrative techniques permitted me to assist patients in beginning to make sense of their illness, disability, and hospitalization. Because I was so impressed with the power of narrative in my clinical practice, I thought that narratives might be useful as a teaching tool for me in my part-time work as a social work instructor. As a result, I began to experiment with the use of practice narratives.

The impetus for my writing this particular narrative was two-fold. For some time, I had been struggling with my feelings about taking people off life supports and somehow I needed to find a way to deal with my feelings. In the past, it was very difficult to terminate life supports once they had been initiated and to do so often required a court order. However, the

medical, legal, and socio-political climate had shifted and now terminating life supports was being done with increasing regularity. My role as the medical social worker often involved approaching and guiding families through these kind of end-of-life decisions. I was becoming more and more troubled because it seemed that more often than not, my families would end up deciding to terminate life-sustaining care. While I almost always concurred with this decision at a personal level, I was concerned that perhaps I was influencing families in some way I was not aware of and would not consciously have intended.

Secondly, I had recently completed my doctorate and, after teaching as a part-time instructor for a number of years, was now prepared to move into academics full time. I was interviewing with a number of universities at CSWE's Annual Program Meeting, which is a narrative in itself. The Chair of one personnel committee had been a hospice worker for many years and repeatedly and quite forcefully asked my opinion of physician-assisted suicide. It was very awkward for me and I



can't remember what I said. The interviewer then enthusiastically indicated her support of assisted suicide and proclaimed, "In my book, Dr. Kevorkian is a saint!" Well, I may be ambivalent about assisted suicide, but I know for sure, Dr. Kevorkian ain't no saint. Being from Michigan, I hear regularly about his activities which seem to be spiraling out of control. I continue to be appalled at his practice of dumping off the body of his "patients" at some hospital emergency room, or worse yet, leaving it in the parking lot or in some sleazy motel room to be found.

Somehow, these two dynamics converged and I sat down one evening to write. The story was written in a single, cathartic sitting. I felt a tremendous sense of relief when it was completed. By describing a few of the families I have worked with through the years, I was again reminded of the strength and fortitude that characterizes so many families. I came to feel that it was unlikely that I was unintentionally "steering" families to specific treatment decisions, but I also resolved to never lose sight of the significance of this kind of case: terminating life supports will never become routine for me. And, like most good journeys, the story had an unintended conclusion when I found myself unexpectedly resolving my long-standing ambivalence regarding the issue of physician assisted suicide.

The title, "Not the Time," refers to what I perceive as our cultural obsession with denying our own mortality. We lack ad-

equate words and rituals to help us deal with our own impending deaths and the deaths of our loved ones. It seems as if it is never the time to talk about death and dying, even when staring it directly in the face. Through writing the story, I



came to realize that if we could only find the courage to talk openly about death and to question our values and the need to extend "life" at all costs, we would have little need for physician-assisted suicide.

There are typically many points throughout the progression of a chronic or terminal illness for the patient, family, and medical team to talk about death and dying, but more often than not, we seem to miss the opportunity. While no one has a crystal ball to predict the outcome of various medical interventions nowadays, there really is a level of sophistication in anticipating some consequences under certain conditions. For example, the prognosis is poor for a life-threatening event in a person of advanced age with multiple chronic diseases, perhaps in

conjunction with the failure of multiple body systems and coupled with likely hospital acquired infections.

But, unfortunately, so many families feel that they have failed their loved one if they have left any possible stone unturned. Patients, families, and physicians get caught up in a "let's try this, let's try that" mentality. They make isolated treatment decisions and avoid the larger questions. This strategy often takes on the characteristics of a defense mechanism, rigid and impenetrable. As long as the doctors are doing something, the family is permitted some hope and avoids acknowledging helplessness. Doing something, however intrusive, is better than nothing. This natural tendency is reinforced by our culture's unabashed and occasionally misplaced faith in the medical profession and the advances in medical technology.

Through writing the story, I came to realize my deep scepticism of contemporary health care. While I honestly admire and respect physicians at many levels, I consider the medical profession to be the equivalent of a contemporary theocracy. Like priest cultures and primitive civilizations of the past, physicians are a select and private group, representing the pinnacle of status in our society. They have a language of their own, and their practices seem "secret" and "mysterious" to the lay public. They consume public and private resources in the performance of their duties, but are notoriously resistant to public scrutiny. In short, they are

perceived as God and do all too little to dispel this myth. At the end of the story, I realized that, to my mind, it is simply just too dangerous to give these people further authority and power over our lives and deaths by way of legally permitting physician-assisted suicide.

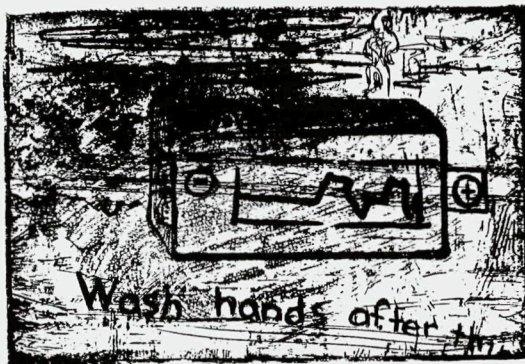
It is always a question of timing, always, and the time is almost always not yet. I have sat with these families, one after the other, like an assembly line, talking, talking, talking about the time.

Up at the intensive care unit, I look into each of the rooms through the glass window. I am looking for the young ones, the out-of-place ones. Up here, it is youth that is out of place amid the hissing and pumping machines, the endless yards of clear tubing and bags filled with colors, the colors of body fluids: the obvious reds and not-so-obvious browns and golds and greens. I look for the young ones because they are often here in failed suicide attempts, less often in accidents, and, thankfully, even less often in the end stages of terminal disease. I've stopped looking for the gray and balding heads of the older men and the blue-white hair of the older women because it is all right, even expected, that they be here at some time.

I worked with a really fine nurse who knew a lot about the breathing machines and the knobs and buttons that mixed

the proper amounts of oxygen and carbon dioxide and how fast and how hard the machines pumped to keep the lungs inflated. We had been doing this a long time and had seen the changes over the years. Not so long ago, the breathing machines were big and cumbersome and loud, not like they are now, small and compact like your dishwasher or some other functional appliance in the corner of your kitchen.

We would sit with these families and discuss whether or not this was the time and this nurse would explain all about the machines and what happens when they were turned off. She



would explain how we turned the machine down slowly, slowly, slowing the pumping and the flow of oxygen. As the carbon dioxide increases, it has a calming effect that creeps like a sleepy sedative. Then, at some point the machine is off. We're really just allowing nature to take its course. We say it's not up to the doctors anymore; it's in someone else's hands. We don't say who, leaving this up to the family. Sometimes the patients begin breathing on their own. Mostly they don't, because you don't usually start

talking about this, about "terminal weaning," unless you're pretty damn sure there isn't much hope, but sometimes they do keep breathing and it just goes to show you, you can never be really sure.

After the technical piece comes my part and, forgive me, but it never ceases to amaze me that people are so surprised and shocked to find themselves here, talking like this, even when the patient is 90 years old and has had half a dozen strokes or heart attacks or whatever it is, or is all curled up in a ball with some kind of dementia and has been in a nursing home for years—it is still a surprise to be here talking

like this. So I try to understand the family's history, the relationships, and what the patient would have wanted. Did they ever talk about this? Well, no, it was too soon, too unexpected, too difficult. It was not the time. Have they talked with their pastor or priest or

rabbi, because perhaps there are some permissions or prohibitions or answers on this somewhere, and I know I sure don't have any.

I ask about what the patient was like before all of this, trying to understand the part of the person that still remains, there in that bed. When I was younger, and there was more time to work with families in the hospital, I would ask for a picture of the patient when he or she was healthy. The families would inevitably bring in some carefully selected photograph,

like some secret code, telling me something they did not have the words for. My favorite picture was of a young guy, about fifty, who was dying of alcoholism. Now, this is a really bad way to go because all your organs shut down one by one, even your skin, until you look like some kind of dummy or mannequin with hair plastered on it and even the bones of your face show through, exaggerating every expression and smile into some grotesque caricature. The picture showed him at his son's graduation party, standing at the beer keg. We sent him home for the weekend, and we spent a lot of time with his wife teaching her how to take care of him. He couldn't swallow and needed to be fed by a tube, so we showed her how to do that. She had given up driving, so we taught her how to do that too, just so she could take him home.

He returns home and comes back with an aspiration pneumonia, which is what happens when food goes down the wrong pipe and ends up in the lung, which gets infected. His wife had fixed him all his favorite foods, including fried chicken, which he could not eat but did. He caught pneumonia and died.

There were three of them this day. It was a Thursday, because the doctors were getting antsy about doing something before the weekend in hopes of avoiding any excessive lengths of stay being logged in against their secret physician code numbers, which we're not supposed to know about but we

all do. So we got our computer printouts that day with our orders to discuss terminating treatment, hospice care, or 'do not resuscitate' orders with the families who did not think it was yet the time. The families are usually considered "unrealistic" at best and "difficult" at worst and the nurses give us the inside scoop on who's fighting with whom within the family and who wants and doesn't want what.

The first lady wasn't that old, maybe seventy, and every artery in her body was clogged up. There wasn't much we could do unless we could do a total body endarterectomy. This was kind of a joke at first because an endarterectomy is when they take a little tube and insert it into the carotid arteries in the neck to dislodge the fatty gunk that is preventing oxygen from getting to the brain. Trouble is sometimes the fatty gunk gets loose and goes to the brain or to the heart causing a stroke or something else, and, also, the surgeons don't do it as much as they used to. So a total body endarterectomy would be like 'blowing out' (that's what they call it) all the gunk in all the veins and arteries in the body, which would probably be impossible and certainly unwise.

So this nurse and I met with this family, it was a whole entourage. Someone had been drinking, and the smells of alcohol and of tobacco and of hard physical work filtered into my tiny, cluttered office. I opened the door, forsaking privacy for air, to dispel the smell. One daughter, extremely thin and

blonde, kept getting up to have a cigarette. The son sat shaking his head, silently and slowly. We gave them the pitch, about how there wasn't much that could be done and all, and how could we help them make the most of their mom's remaining time? Well, one of the daughters says that they have found a university hospital across the country that is doing this total body endarterectomy procedure on an experimental basis and would we please make all the arrangements to fly her mother there? The nurse and I have never heard of such a thing and we call the hospital and find out that they do in fact do this procedure and are expecting the patient. The hospital asks us to remind the family that this is an experimental procedure, and that the chances of surviving the operation are less than five percent, but that even if she dies she will have made her contribution to the advances of science and medicine and all that.

We go back into the room to talk to this family, this family, and tenderly I ask if this is what they really want, if this is what the patient would have really wanted, to be flown thousands of miles away from home for this highly experimental medical scheme. I am picturing this roly-poly, blue-white haired grandma on a stainless steel surgical table where it is so very cold and so far from home. But they are resolved, because if they leave one stone unturned they will have failed their mother, and they have to try everything, possible or not, in order to live with themselves.

So I do my job and make all the arrangements and the whole thing is going to cost about \$90,000 billed to Medicare and the U.S. taxpayer, but this is my job and it is not to judge and sometimes not even to think rationally. After I'm done and this woman is on the first and only helicopter ride of her life, this big son takes me gently aside and whispers his thanks, that he knows what I am trying to say, and that he knows his mother will probably die there on the operating table but that he is not strong enough to stand up to the rest of the family even though he wishes he could. I am again reminded that my lessons in humility come most often from sources unexpected. Later, this son is kind enough to call me back and tell me that, of course, she died there on the table, that it was her time, and that the family is so glad they gave her a last chance. I want to ask at what, but don't.

The second family is with a patient who has TB and it's eating up his brain now and they've already operated twice and taken out as much of the brain as they can but they can't take any more out or there won't be any left. Before this, I didn't even know that TB could eat out your brain. He's on a breathing machine and we have to give him big time drugs to force his heart to beat. The doctors finally stop the drugs believing that his heart will surely stop, but it doesn't, and he's been here in the hospital for five months in a persistent vegetative state. If you've ever admired the abso-

lute vulgarity of describing a human being as a vegetable, you can credit the medical profession with the term: persistent vegetative state.

We talk to the family about turning off the machine and we give them the standard counsel, but the sister starts getting really agitated. We stop and ask her to tell us what's wrong and she starts talking about us white folks trying to play God and determine when and how black folks are going to die. She says that God put her brother on that machine and for all she cares he can personally come down from on high and unplug him himself but this family is not ever going to let any white folks pull the plug on their brother. There isn't much more the nurse and I can say at this point, so the patient's still here and now he's got bedsores all over the hills of his vegetative flesh eating him from the outside in while the TB eats away at the inside.

The third family is one we have known for a long time because the patient has had cancer for many years and truly has fought it bravely and with dignity. Now it is all over his body, encroaching on his brain and liver and lungs, and he is on the machine and we can't get him off. So this nurse and I talk to the family, and we talk this time about how it is OK to give up the fight now, and we sincerely acknowledge this man's dignity and courage for fighting so long. The one daughter says there is another daughter who is a missionary somewhere in Brit-

ish Columbia and we need to talk to her too. So Saturday morning I call her from my home because she can't afford to call me and this is the only time we can talk. As I'm sitting on the floor of my kitchen behind the counter trying to cut down some of the noise from the cartoons that my seven year old is watching, I talk to this woman missionary about pulling the plug on her father. We spend nearly an hour on the phone (and I'm trying not to worry about the bill because I'm not sure the hospital will pay me for this) and I'm doing my best to explain all the technical stuff that this nurse usually does. Feeling really inadequate, I tell her it doesn't hurt, at least we don't think so. I hang up the phone, not sure what was accomplished, and forget about it until Monday morning when I go into work and find the family in my office, all ready to pull the plug.

I call this nurse and we talk to the doctor and we all go up to the room to do it. At this time, there aren't any forms or anything to sign because we're not all that sure that we want anyone to really know what we're up to. The Right to Life activists have been known around here to protest at hospitals and nursing homes and it's just better to be sort of quiet and unofficial about this. The doctor starts turning down the machine every fifteen minutes or so until it is completely stopped, and we admire the silence for a while. The whole thing takes about two hours and the whole time this gentleman looks like

he is sleeping instead of slipping. Usually, the patient doesn't start breathing on his own and he passes a few minutes after the procedure is done. I sit with the family the whole time, and sometimes they cry and sometimes they whisper and I am trying not to think of the two hours of work I am not getting to and force myself to think that this is probably the most important and serious event in the life of this family. Then I realize this is a pretty serious event in my life, too. I try to think of comforting things to say, feeling stupid doing things like offering coffee and tissues. Afterwards, I take the family down to the chapel and sit with them a bit longer, but I really can't sit here any more and have to go. The family thanks me profusely and even sends a thank you card and for days the nursing staff on the unit thanks me for being such a help and a comfort. I keep feeling like I didn't do anything but help pull the plug and I'm just not sure how I feel about all this.

In the meantime, Dr. Jack has killed ninety-something people in the back of a van or motel room, dumping the body off at the hospital down the street from here and I'm just glad it's not my hospital. I've decided that whether or not it turns out to be the time doesn't really matter. But if we stop talking about the time, we start driving around in beat up vans and end up in Motel Sixes with some crazy guy and his tubes. □



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