

HUMANIZING END-OF-LIFE EXPERIENCES IN HEALTH CARE

Part 1 of 2

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A PERIODICAL FOR CONTINUUM OF CARE

PART 1

EXPLORING THE NEED TO HUMANIZE END-OF-LIFE CARE

In an age of increasing caseloads and growing emphasis on compliance and productivity, health care professionals, clients and their families face mounting stressors, making therapeutic and human interactions less frequent and more challenging to facilitate.

The desire to engage in the art of caring is a growing desire among patients, families and health care professionals. End-of-life care calls for an even greater sensitivity to the needs of all people involved as our cure oriented health care culture lacks the training and orientation that is called for as people enter the natural part of life, that is dying.

The following information comes from interviews and narration from the Solace Teachings: Life Awareness, End-of-Life Education documentary films, created by Camille Adair, RN.

In 2011, the first Baby Boomers turned 65. What we will experience in the next several decades has been termed by some as the Silver Tsunami. The aging population will change the way we live and will change the way we die.

The imbalance between the growing aging population, and the shrinking healthcare workforce will intensify over the next 30 years. The rapidly changing demographics are contributing to an Inverse Demographic Healthcare Change (IDHC) where health care workers are shrinking in proportion to the aging population, a population that will increasingly need care.

The modern world's aversion to the sick, elderly and dying has made these vulnerable populations the untouchables of the western world. Hypnotized by the media's focus on youth and glamor, America's integrity and intactness are threatened as society sacrifices the wisdom that comes with age. This disconnection is reflected not only in the quality of our lives but also in the cultural and economic realities that face the United States.
Camille Adair, RN

The proportion of older persons is projected to more than double worldwide over the next half century. New Mexico, in particular, faces the following challenges:

- Second highest poverty rate in the nation
- Second highest rate of uninsured
- Hispanic and American Indian adults are over twice as likely to be without health insurance coverage as whites.
- Native Americans lack a consistent health benefits package.

- The health workforce is neither diverse nor culturally competent. Minorities make up 59 percent of the population, but only 11 percent of the nursing workforce.
- Our rapidly changing environment, including demographic shifts, will have major implications in health for the people and communities of New Mexico.
- The largest percent increase (in the aging population) from 2000 to 2010 was among those 60 years to 64 years, at 5.8 percent. By 2030, the state will rank fourth in the nation in percentage of population age 65 and older; currently New Mexico is 39th.
- Thirty-two of the state's 33 counties are defined as Health Professional Shortage areas. Con Alma Health Equity Key Findings 2012. Conalma.org

WHERE DO WE GO FROM HERE? LEARNING FROM THE LEADERS WHO LISTEN

Many ancient cultures and wisdom traditions experience their relationship to death as a path for spiritual growth and awakening. The call of the contemporary world is to awaken those parts of ourselves that have an inherent understanding of the sacredness of birth and death and to work on ourselves so that we may discover meaning, compassion, forgiveness and love in our lives, which are also the human abilities that support quality end-of-life care.

The following are excerpts from the Solace Teachings documentary, *Humanizing Health Care: A Hospice & Palliative Care Perspective*. The physicians who were interviewed are devoted to care of the dying and leading a humanized approach to health care.

In my mind as I understand hospice history, mid-70s in this country, it was very much a counter-cultural movement, per se. It was a movement. I think that's a really accurate word, a philosophical underpinning, and was an answer to some of the problems of medicine. It was a non-medical model and sometimes even an anti-medical model. There was some tension.

So I was interested in revisiting that because I believe that was very relevant in the 1970s, 80s, and early 90s, but I also believe very strongly in what academic palliative care has done since the mid-90s. I think the field has grown up considerably. So I don't think it's as relevant to be anti-medical anymore. Certainly there's a point, counterpoint, but I think if we're trying to really serve the public, it's a futile argument. So I think in my mind, the time is right – either in my own development or historically, the time is right to bridge medicine with the more grassroots efforts of hospice.

So, in my mind, there is a third phase of hospice in this country; first, grassroots; then the medical model; and now some amalgam of the two. So my real goal with this in-hospice

project (Zen Hospice Project) is to bridge the social with the medical models of care and to open up the possibilities that death offers us, that our own mortality offers us, the re-prioritization that living with our own mortality offers us, the reexamination of our life as individuals but more important, in communion with each other. Bruce (BJ) Miller, MD

Any physician who's now in practice caring well – wanting to care well for people with a serious illness frankly needs to acknowledge that in all likelihood, their medical school training, their residency training, their fellowship did not fully prepare them to do the job that they're now expected to do, which is to bring the very best diagnostics, and command of the physiology and the biochemistry, and the physical and pharmacological treatments we have available while simultaneously holding in their minds that this is a whole person with a family, and that this person is scared, and does not want to die. Despite all of the power of our medical armamentarium, this person in front of us remains mortal and because they're mortal, at some point in time, more treatment will not be better care. At some point in time, more treatment will likely not be in their best interests

Therefore, our job, as physicians, is to give them the best care possible but to do that, we need to know what that means for the person, what their priorities are, what their values are, we also have to work with them in knowing how would this story of your rich life end so that if you were the reader rather than the protagonist, you would close the book feeling this life ended well. What does that look like? Help me understand so that I can be a better doctor for you.

But in fact, for some people, and I think more than we recognize, at some point in an advanced, progressive illness, something gets unhinged and to actually assess somebody's quality of life, you have to ask them.

I spent time in England in the early 90s studying hospice care. I went to Bath in England and spent a month at an in-patient hospice unit, and in the community, and a little time at St. Christopher's. When I was spending a day with a general practitioner, a GP, in the community in Bath, I heard this phrase. After we saw a patient who had advanced cancer, the doctor said, "How was your pain this week? How are you doing on the new morphine tablets? How are your bowels working?" He said, "I understand your family came down from the Cotswold's last weekend and you had a houseful. How did that go?" She kept saying, "Oh, fine, things went fine."

Then he leaned forward, and made eye contact, and very quietly said, "And how are you within yourself?" Wow. I'd never heard that phrase, and I heard him use it several times that day. I saw people who had been quite stoical begin to soften and sometimes break down. "Oh, Doctor, I don't know. If things get any worse, I just don't know what we're going to do. I don't know how we're going to hold it together."

At other times, I saw people who were dealing with substantial levels of symptom burden and psychosocial stress look straight at the doctor and say, "We're doing okay. I'm feeling okay. We're well. We're supporting one another. This is no fun, but we're going to get through this," and I thought, how do we measure that? That's what I'm interested in. I'm still asking that question, by the way, but working on it. Ira Byock, MD

So I think about really listening to where the patient is at, that's the piece that is so different in hospice, because so much of medicine has its own agenda. When you have a diagnosis, then a physician can so easily – or any healthcare provider – so easily walk in with a clear understanding of what needs to happen. Here, these are the things you need to do next. You need to go and get blood work. You need to go do this. It's a list. You could look it up in a book and there it would be.

Hospice is not like that, not that those things don't exist, but it's really about being in the presence of what is happening for the person and their community and family. It is a huge difference. It's such a fundamental difference that often, I think it takes people who are transitioning from primary care or other disciplines in medicine, transitioning to hospice a lot of working through their own internal pieces until they can grasp that and really be present to it. I find myself still going back there to this place of, "I know what we need to do. Oh, wait, that's not exactly what we need to do." Being here, that's really the piece.

I set myself the task of thinking what are the questions I could ask, or how could I be present to really hear what's going on? It's a huge piece. That's really a task and learning in itself. Most commonly by the time I come there, somebody already has a diagnosis. When I think to speak to people, one of the main things I try and do is just acknowledge how hard this is. I find I use that word a lot, how hard this must be, because really it may be many other things; it may be sad; it may make you angry, but it's certainly challenging and therefore hard. So I often just start there, how hard this must be.

It's always where we need to start is right where somebody's at. That may be about their family, or it may be about something so unrelated I could never have guessed it if I were just approaching it from my own perspective. So really trying my best to hear where the patient is at and whoever is with them also, because they often carry their own agenda, and that's really important to address, as well. Otherwise, you've missed something, and the patient knows it, and the other person in the room knows it, and you missed it, right? So really listening for anything that may be there that needs to be addressed before being able to move into the full implications of this diagnosis.

Karin Thron, MD

I really just want to take a few minutes, five or more minutes, not much, though, and find out a little bit about who you are as a person. I've been through your chart; I spent nearly an hour with your chart before coming down to see you today, and I know a lot about the diagnoses that you've had, the tests and previous treatments you've been

through, and you've been through a lot. The chart doesn't tell me much at all about who you are as a person.

I'd like to just pause and find out a little bit about who you are. I don't even know where you grew up. Can we start there? Where'd you grow up? I find that the more I can do that, when I don't start with the physiological or don't go right to the, "I understand that you're struggling about questions about whether to have the tumors in your liver excised or taken out at surgery, and that's a hard decision and we can talk about that. I'd love to know what you're feeling about that." That's premature. I first need to know who this person is and in doing so, frankly, first, it takes about five minutes. It doesn't take me a long time. When I say this in grand rounds or if I'm talking at a medical surgical conference, not uncommonly, a hand will go up and someone will say, "Dr. Byock, that's really good. You can do that, but we don't have the time to do that." Horse pucky, as if my pager isn't constantly going off. This takes five minutes.

In fact, all I'm really doing is doing a social history that in a complete evaluation is going to get done anyway 15 minutes down the line. I'm just putting it up front. In so doing, I find that I have re-contextualized this interaction and the relationship that is forming, not merely in the context of this hospitalization or the treatment of your condition now that it's metastasized or now that you know it's ALS but rather, in the context of your life. It makes a huge difference. It delivers people from anonymity and makes them a person, not merely a body with pathology.

I have actually become pretty strict with myself in doing a new consult; to introduce myself, explain who I am. I'm Dr. Byock. I'm from the palliative care service. You may not know what that is, but our team, we have a whole team, focuses on people's comfort and quality of life. We are often asked to meet people who are struggling with difficult diagnosis and maybe have serious questions and treatment decisions that they need to confront. I understand, unfortunately, you're in that situation.

First and foremost, frankly, I listen. It's such an incredibly difficult circumstance to meet people, in that I put out my tentacles and want to know how that person is doing. I do palliative care, and I want to palliate, provide comfort in the moment. So I'll often ask, "How can I help right now?" Ira Byock, MD

In many cultures, it's very common for families to make decisions together. I do a lot of teaching internationally, and it's not uncommon. You do need to talk to somebody in the family, so just asking people about how they traditionally make decisions, how they like to have their medical information handled. That's really critical.

I think the most important thing in starting those conversations is just to make sure that you really understand going in what the medical team has talked to them about but also when you sit down with the patient and family just to really understand what they know, where they're at, and not just knowledge-wise but I think also emotionally, making sure

the right people are in the room. I think starting off in the right way is critical to actually having the rest of the conversation, making sure that it's something that they are able to talk about at that particular point. I think one of the things that I learned as a hospice and palliative medicine physician that I didn't know in my training is to actually ask people permission if this an okay time to talk, or even how much information they wanted. That's not traditional teaching, even though it has served me very well because it's really allowed the patients to have more control over the conversation. Holly Yang, MD

In our fast paced health care system, the culture promotes action. It is easy to lose track of the fact that often, it is our human presence that is most needed in providing care for people facing the end of their physical lives. Listening is our greatest and most overlooked tool. Developing a practice of active listening is supportive in our personal and professional lives.

ACTIVE LISTENING PRACTICE

We often listen with partial attention and miss opportunities to connect. This exercise can help you express active interest in what another is communicating, allowing them to feel heard. This is especially helpful in difficult or vulnerable conversations. Research indicates that this helps people feel understood and can improve relationship satisfaction.

The time required is at least 10 minutes with a recommended practice frequency of at least one time per week.

Instructions: Find a quiet place to talk with someone who is close to you. It is important to create safety without interruption or distraction. Invite the other person to share with you, what is on their mind. As they do, practice following the steps listed below. The more closely you are able to follow the steps, the more effective your active listening is likely to be. This becomes easier with time and practice.

****It is important to allow yourself to feel natural and not forced. Perfectionism and criticism are great saboteurs of vulnerability. The art of presence, listening and relationship is an art that can be developed with time, intention and practice.**

1. **Reflect:** After the person is finished speaking, reflect back to them, beginning with, “what I heard you say is _____” or “I understood you to say _____.” Make sure what you heard is what they meant.
2. **Inquire:** When appropriate, ask questions to encourage the other person to elaborate on his or her thoughts and feelings. Be careful that you don’t make assumptions about what the other person means. Instead ask questions to clarify his or her meaning, such as, “When you say_____, do you mean_____”?
3. **Express Empathy:** If the other person expresses challenging feelings, strive to validate rather than question or defend against them.
4. **Use Engaged Body Language:** Communicate your engagement and interest by making eye contact, nodding, facing the other person and maintaining an open and relaxed body posture. Avoid distractions, such as checking your phone. Be aware of facial expressions that may communicate disapproval or disgust.
5. **Avoid judgment:** Active listening is meant to provide acceptance without judgment, even if you disagree with what the person is saying. Avoid interrupting or planning a counter-argument in your mind while the person is speaking.
6. **Avoid Advice Giving:** Problem-solving is likely to be more effective after both conversation partners understand one another’s perspective and feel heard. Giving advice to the other can be counter-productive.
7. **Reciprocate:** Practice taking turns. After engaging in the above steps, ask if it’s ok if you share your perspective. Be careful and use “I” statements, such as “I was frustrated.”

Active listening supports end-of-life communication in that people begin to feel understood and less threatened. When we improve communication, our relationships with patients, families and colleagues become more satisfying, leading to the development of trust.

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