

## Featured Innovation

### The Lessons from *Respecting Your Choices*:

#### An Interview with Bernard "Bud" Hammes, PhD from La Crosse, Wisconsin

*Bernard Hammes, PhD, Director of Medical Humanities at Gundersen Lutheran Medical Center and his colleagues on the La Crosse Area Medical Center's Task Force on Advance Directives wanted to make sure that patient and family values and preferences would guide end-of-life treatment decisions in La Crosse Wisconsin. The result of their efforts is Respecting Your Choices (RYC), a community-wide advance directive education project. An evaluation of this multi-dimensional intervention revealed that a full 81 percent of decedents in the community had documentation in the medical record indicating their treatment preferences and values or their choice of a health care agent who could speak for them when they were no longer able to speak for themselves<sup>1</sup>. This finding stands in stark contrast to all other efforts in the United States to promote advance directives. Nationwide, only between 15-25 percent of outpatients in the United States have reported completing an advance directive and even fewer patients actually have their documents in the medical record<sup>2</sup>.*

*Equally impressive, chart review and retrospective interviews with family members demonstrated that nearly all the deceased patients received treatments that were consistent with their expressed wishes<sup>3</sup>. Other American studies have documented extremely poor concordance between patients' preferences and the treatments that their physicians<sup>4</sup> and their spouses thought they wanted<sup>5</sup>.*

*The contrast between the La Crosse experience and other efforts to promote advance directives in the United States is so sharp that we invited Dr. Hammes to discuss with us how he and his colleagues instigated such a comprehensive cultural change in the practice of medicine in their community. One feature that stands out here is that four local health care systems that compete in other domains chose to work together in the service of this educational venture and, as a result, developed a program that has its own community identity. The four health systems whose staff worked together to spawn this effort were Franciscan Health System, Gundersen Clinic, Ltd., Lutheran Health System-Lacrosse, and Skemp Clinic, Ltd. These organizations have now consolidated into Franciscan Skemp Healthcare and Gundersen Lutheran. [Citation: Hammes B, Romer AL. The lessons from Respecting Your Choices: An interview with Bernard Hammes. *Innovations in End-of-Life Care*, 1999;1(1), [www2.edc.org/lastacts/archives/archivesJan99/featureinn.asp](http://www2.edc.org/lastacts/archives/archivesJan99/featureinn.asp)]*

### ***Respecting Your Choices* and Its Goals**

*What is the innovation you developed?*

BH: *Respecting Your Choices* is a comprehensive advance directive education program formulated by the La Crosse Area Medical Centers' Task Force on Advance Directives, of which I'm a member. The components are:

- locally developed patient education materials

- availability of these materials throughout the community
- training agendas and resources for educating a large core group of nonphysician educators
- access to advance directive educators at all health care organizations in the community
- [common policies](#) and practices of maintaining and using advance directive documents, including broad physician involvement
- documentation of advance directives in the patient's medical record and systems in place to ensure that this information "travels" with the patient across care settings

*What were your goals in designing this innovation? What did you hope to achieve?*

BH: From the very beginning, there were a few things we felt were very important: One was not just to focus on the technical completion of documents, but that we really wanted to engage patients and their families, as a unit. Our approach was to engage the patient, along with those who are close to the patient. It could be friends, it could be a religious group. It could be anyone. The question we asked was, "Who would be those people the patient would want at the bedside making decisions and supporting the patient?" We felt that should really be the locus of education.

The goal of education would be first of all to help these people understand what options and decisions might be faced, help them reflect on those decisions, work through those issues, and then both make a decision and communicate that decision to each other and ultimately to the health professionals. How that was communicated was probably best in writing, but we left it open to some variation. The main thing that was important was that whatever was written down clearly reflected and communicated the patient's preferences.

Now there are obvious advantages of completing a legal document, and particularly a [power of attorney for health care](#). But even that might vary from place to place, depending on what state statutes require and other kinds of rules and regulations of the law.

*Other goals?*

BH: In addition to these primary goals, we wanted to assure patients and families that our systems would be able to track and make use of these documents and preferences. We wanted to be able to promise that any documents that they then generated, through our assistance or on their own, would reliably be put into the medical record and would be retrievable and available. And then, finally, that those documents would be carefully considered in any decision making—we needed to have health professionals who understood how to implement those preferences and decisions.

From the very beginning of *Respecting Your Choices* that we didn't want to do just a lot of exposure and education. We wanted to make sure that we could follow through on the implicit promise

one makes when one solicits patient and family input. We wanted to be able to stand behind that promise, basically saying, "We want you to think about this, and we'll help you think about this, and if you do think about it, and tell us what your preferences are, we will look at that, and we will take it into account when making decisions."

### **Pilot Program that led to RYC**

*What steps did you take to initiate this innovation at your institution?*

BH: The project was informed by a pilot program that we ran in La Crosse between 1986 and 1991 called, *If I Only Knew....* The pilot program was an effort to develop a curriculum and education for chronic dialysis patients. We hoped to elicit from them their ideas about when they would want treatment withheld. Or under what circumstances they would want treatment withheld, particularly focusing on CPR [cardiopulmonary resuscitation] and of course, dialysis.

So we did the typical things: what kind of material would we have to use; who would do the education; when would it be done; how would it be done. The pilot really helped us understand how to integrate that kind of advance care planning program into patient care.

*How did you finance the pilot?*

BH: We got a small grant from one of the local hospital foundations, and we got permission from both the dialysis unit and the hospital to use staff time to do this. Basically, we said, "We educate patients on nutrition, we educate them about all other kinds of things, don't we need to educate them about these kinds of decisions? Because many of these patients are going to face them. Why is this different than any other kind of education we do for patients We convinced administrators that this kind of education was a responsible thing to do for patients, and something that we should offer patients. So we got permission to use staff and we got some extra money from the hospital foundation to pay for some of the materials.

*How many patients were you working with in the pilot?*

BH: At that time, I believe, we had a constant population of about 60 to 80 hemodialysis patients. It's a nice population to work with, because these patients are in one sense, outpatients. And yet, they're on life support, and they are interacting with health professionals frequently and over lengthy periods of time. So the kind of relationship and opportunity are there to do these kinds of things, which gets a little bit trickier with other groups of patients, simply because the exposure and interaction may not be as frequent.

*And was there an evaluation component of that pilot?*

BH: The simple evaluation was just to do a pre- and post-test of the number of advance directives that we did. Prior to the program, only 2 percent of our dialysis patients had written advance directives. After two years, 46 percent of our dialysis patients had advance directives. We looked in their record and counted what they had. Physicians reported that they just had a much easier time making these decisions with the patient or family than they had before the

program.

*An easier time-- can you say more?*

BH: We found that particularly with the dialysis patients, even with patients whose written advance directive doesn't become necessary to use because they remain competent, these previous discussions about values and preferences put patients and families in a better position to consider those issues when they faced decisions to withhold or stop treatment as competent patients.

*Can you give me an example of what you mean?*

BH: Actually, it touched my family because my stepfather was one of the dialysis patients involved in the pilot. He made, as a competent patient, a decision to stop dialysis. And I was a little bit surprised, because this was a man who typically deferred decisions to my mother, and prior to that, to his former wife. He was a rather passive man, in decision-making anyway. So when he himself made this decision quite quickly, I was very surprised and later asked my mom if she could give me any insight into this decision. She referred back to some of the things that had happened in the dialysis unit, discussing issues like CPR and other patients stopping treatment. These things helped him reflect on what he would or would not want in the future. And I can only conjecture, because I was never able to ask him, but my conjecture was that because of those experiences he had previously thought through what he would or would not want. Then when he was actually confronted with that decision, he was able to reach a conclusion and make a decision very quickly.

*How did the pilot inform your process, in designing Respecting Your Choices, the community-wide intervention?*

BH: One reason we were able to make that big step is that our pilot served as evidence that this could be done, and how. We used that as a basis to explain to physicians and other health professionals what we did in a small population of people and how it worked.

It was particularly helpful, since one of the nephrologists was the president of one of the largest organizations, and he was willing to say to his physician colleagues, "It's a lot better to talk with patients and their families who have thought about these issues in advance; we have a lot less conflict and people feel more confident about their decisions." We also had data from the dialysis program to share with physicians. Data are always helpful when talking with medical groups -- to say, "Here's what we did, how we did it, and the outcome." So, that kind of success on a small scale really helped convince skeptics or people who weren't so sure that there was value in doing this.

There's another thing that I didn't really understand until it happened. Our educational goals—understanding, reflection, communication and discussion, rather than the advance directive document itself—were very positively received by physicians. That wasn't anything we planned—it wasn't a strategy—but when I started to talk about the program I realized two things very quickly. First, we have physicians who say "Documents don't help me" but who

supported the concept of the program. And when you can, at least , mostly deliver on that— patients and families are better prepared because of the process they've been through— physicians can support that. Second, even physicians who still oppose advance directives have a hard time publicly objecting to our goals since they are such an accepted part of informed consent.

## **The Importance of Training**

*Other features that were important to your success?*

BH: One thing we learned in the pilot and carried through, was the importance of having trained staff to do these conversations. We developed a day and a half training in-service and only nonphysicians who've done the in-service are allowed to do advance directive education. We developed an educator manual, *Respecting Your Choices Training Manual*, with 12 chapters that we use in those trainings, and that can later serve as resources to our counselors<sup>6</sup>.

*Who gets trained at these in-services?*

BH: I would say the largest group of people are social workers, who work in hospitals, nursing homes, hospices, home health care, county health departments, and a few in ambulatory care. And then it probably gets evenly divided between the next two groups, between chaplains and nurses. The fourth group are a variety of people from the general community, who serve as volunteers for hospitals or other kinds of organizations.

*Do they all get the same training?*

BH: They all get the same training. Generally, the volunteers are people who are college educated, who have other kinds of professional training and experience, in terms of communication and human relations.

*You're building on their existing skills. What happens in the training?*

BH: The first morning, we lay out the general concepts and go into the psychology of end-of-life planning, language issues, what kinds of medical issues are most important to talk about. We attempt to broaden the idea of what should be in this conversation, and really focus on this as a process with goals of understanding, reflection, and communication and discussion. One key piece is that we recommend that the counselors to go home and talk about their values and preferences for end-of-life care with their family members as part of the training, because we believe that grappling with these tough issues oneself is a prerequisite for facilitating that discussion with others. In the afternoon, the educators focus on their own knowledge, values and beliefs in small and large group discussions. The goal is to reflect on what they heard in the morning, to integrate personal and professional beliefs and to resolve and clarify their questions.

One week elapses between the first and second days of training and during that time, educators complete a take-home exam, read the training manual and complete a power of attorney for health care document for themselves or for a fictitious character. During the second half day of training, the take-home exam is corrected, the power of attorney for health care document is

reviewed, but most of the morning is spent in role playing advance care planning discussions. The training ends with a final exam which requires educators to outline how they would deal with three cases.

*And how many people are you training each year now?*

BH: We train probably anywhere from 50 to 60 people a year. To date we've trained over 300 people as advance directive educators. Now, we're talking about just our local geographic area. And I liken it to kind of a CPR training or advanced cardiac life support training. We just finished our last training for 1998, and we'll sit down and develop a training schedule for 1999 and make a brochure and send it out and then we do at least one additional in-service or update every year.

*And the update is primarily for?*

BH: For people who have already been trained. Because there are new things -- changes, new ideas. So we keep a list of people who have been trained, their names and addresses, and we stay in contact with them through letters and correspondence, articles that may be helpful to them. Most recently, we just developed a new power of attorney for health care form, and we did a two-hour in-service on that, in which they were allowed as educators to comment on the proposed draft, and we made additional changes.

### **Sustaining the Program**

*It sounds as though you had extensive physician support and input from early on that was key to getting the program going. What else is necessary to build and sustain the program over time? Are there things that you can think of besides success breeding success?*

BH: I think one of the things people need to understand and I feel painfully, sometimes every day, is that this is a program that needs to be managed. It's a very large system, and it requires constant attention and improvement. We have done a number of quality improvement projects, which really has been very important in making sure that a good program, in fact, works. This is something I probably can't emphasize too much. My experience has taught me that no matter how well designed a program is, implementing it is never smooth or perfect.

*What quality indicators do you employ to assess the impact of your program?*

Five years ago we sat down and looked at how advance directive education worked at our hospital. And we identified two big areas where we felt the system was not working properly.

**Decision Tree Script.** One system was the conversation that was occurring between the nurse and the patient when the patient got into a particular unit in the hospital. We felt that there were problems there, so we did some surveying of nurses regarding their practice and knowledge. We found a wide variation of practice and knowledge among nurses in talking with patients about advance directive documents and their treatment preferences. While some nurses were very good, others were clearly inadequately prepared to conduct this kind of communication, despite

prior training.

So, that was something we felt we needed to correct, and we had to come up with a strategy. Rather than going through another round of in-services and education for the hospital nursing staff we developed a script with a [decision tree](#) for nurses to use.

And then we went back after nine months of implementing this script and decision tree, and used the same tool to measure practice and knowledge, and what we found was a fairly consistent pattern of knowledge and practice.

**The "Green Sleeve"**. The other example is much simpler. One of our practices is we put the advance directive document and our [education record](#) in a "green sleeve", and when a patient is hospitalized, those materials are supposed to be brought into the unit record. (This is literally a translucent, green plastic envelope that holds 8 by 11 inch sheets of paper.)

So if you can imagine your hospital chart being down in a file room, in a folder, and if you were brought into the hospital, that folder would be brought up to the place in the hospital where your bed was in the nursing unit, and if you had an advance directive, it would be in the "green sleeve". That green sleeve's now supposed to go in the ring binder that is your active chart while you're in the hospital.

*So the "green sleeve" itself moves?*

BH: It moves to the patient, so to speak, from the file folder; it now becomes part of your immediate hospital record so that it's available and obvious to the health professionals caring for you during that hospitalization.

Well, that was the procedure outlined in our policy, and one question that came up is, "Do we do that all the time?" And what we found is that, again, there was a lot of variation in practice. This time, it was based on individual misunderstandings, so in a particular unit, one unit secretary might be very good at it and another secretary in the same unit may not do it at all. So the system only worked part of the time. What we found is that the policy was written in such a way that it led to misunderstanding. It was a simple matter of rewriting the policy in less ambiguous terms and then doing a little more education. We then went back and measured compliance and had nearly 100 percent compliance.

## **Potential Barriers**

*Were there other barriers to implementing this advance care planning program?*

BH: Well, one of the things that very much concerned people was how this would be perceived by the community. One potential concern was that there would be a perception that we were doing this program for economic reasons, since it was being developed and promoted by health organizations.

Our answer, ultimately, was, "Look, if a patient doesn't want care, and they tell us they don't want care, that's the primary motivation here. If that saves money, that saves money. If it doesn't

save money, it doesn't save money." That consequence, the economic consequence, is irrelevant to what's the right thing to do. And again, I think emphasizing the respect of the individual's values really became a very strong message, that people saw the overwhelming guiding ethical principle of the program. So that broke down those kind of community concerns and barriers.

*Other concerns or barriers to implementing the program?*

The other concern was about religious communities just objecting or opposing this kind of program on theological, moral grounds, that what we were after was something akin to killing people.

*So how did you address that?*

BH: Well, we did have a member of the clergy serve on our task force, and she became a liaison to the religious community. We have two bishops in our city, one a Roman Catholic bishop and the other a Lutheran bishop, and we approached both of them and talked with them about the program, what we were trying to do, and asked them to give support for the program. In fact, we asked them to encourage clergy in their denominations to come to the training we were providing so that this kind of education could be conducted and carried out in churches throughout our area.

*And how did they respond to that invitation?*

BH: They responded positively and they issued a joint letter to their clergy indicating their support for this program, in helping patients and their families think about end-of-life issues, and encouraged their clergy to think about participating in this training.

*Now, were there already relationships in place here? This sounds too smooth to be true.*

BH: (Laughs) Well, yes, there are. The other facility, the other major health care facility is a Catholic facility.

*One of the four facilities that made up the team?*

BH: Right. So that was clearly an important factor in the support, and the hospitals and health institutions in this community are in fact, the biggest employers. They are major institutions in this city, and because of that, they have close and frequent contact with other institutions, and the churches are one of those. So, I don't want to say that this happened in a matter of a few minutes. This took months to negotiate and consider and think through, but I think it's part of the way the program was simply constructed, which is, we were really focused on trying to elicit from individuals their desires and their values.

*So it sounds like you came to them early enough in the process.*

BH: We certainly had a very good idea of what we were going to do. The theme that we kept hammering at was that this really was an effort on the part of the hospitals, to respect the values that individuals and families hold.

When we ran into certain people who held strong views on withdrawal of treatment, that is, they felt, for example, nutrition should never be withheld -- our response was, "We're not trying to promote any particular value or view here about this, except the value of respecting the individual's choice. And so if people feel very strongly about certain kinds of decisions, we want to know that, and we want clinicians to be able to respect those values."

I think we were able to deflect any major criticism of the health organizations or the program by focusing on our objective -- to respect individuals' choices.

Our major concern as health professionals is to know when an individual does want us to do that and when they don't want us to do that, particularly if they can't tell us. We don't want to make that kind of mistake for an individual. So, we deflect it and say, "Look, if you have objections and think that withholding of nutrition and hydration should be made illegal, then you need to take that up with the state legislators or you need to take that up with the courts. It's not something we can solve; we can only do as much as we can to make sure that we make a good decision for each individual patient we care for."

*How about the barrier of past research that shows that advance directives don't matter, don't influence practice or family members or clinicians' understandings of what patients would have wanted?*

BH: One of the questions that often comes up about advance directives is, "Well, you know, patients write these things down, but that's not what families actually do, and then physicians always follow the family." And I think that experience is actually pretty accurate.

So then the question is, "So why should I write these things down in a document when my family may not even follow these things, or the physician may not follow these things because the family doesn't support them or is anguishing over them, anyway?" And I think that is a huge question, so at least part of our experience is that in one sense, just the intellectual clarification of values doesn't necessarily lead to the kind of decision making that might be implied.

So, I think there's a central issue here of how do you get people to act on their values, as opposed to just recognizing them? And it has struck us, at least in La Crosse, that when families are anguishing about what is the right thing to do, that in their gut, what they're really saying is, "How can I be a good person, a loving son or daughter or whatever in making this kind of decision?" And that question hasn't been answered in the process of advance care planning.

### **Focus on Relationships, Not Abstract Values**

*How do you get people to go to that 'place'?*

BH: We reframe the conversation a bit and make it a more personal conversation. We say, "You know, if something were to happen to you, that you had a massive brain injury, what would you want your son or daughter to do for you? What would it mean for them to be good care providers and loving sons and daughters, if you could never recover from that brain injury?" In this way the focus is really on relationships and not on abstract values.

*How do people respond to that kind of approach?*

BH: You need to have someone who can create an emotionally safe environment. That allows a group of people who love each other, ("family" here is, I think, a placeholder rather than anything else) to discuss these questions. This is why I think the training of people to have these conversations is so important. We call the people we train counselors or educators -- but in a sense, they're guides -- guides and facilitators. This trained person has to make the family or patient comfortable and feel safe and then help them frame the questions in a way which are, in this sense, very personal.

*Your thinking is so different from the usual language and sets of assumptions that I think underlie many conversations about advance directives.*

BH: Right. One of the things that we notice, and again, this is more anecdotal in a sense, but one of the contrasts that we found in our advance directive study <sup>7</sup>, was that about 15 percent of the documents were done with attorneys. And there's this curious phenomenon that often those documents lead us to indecision. It's not because the documents are done improperly. It's because the documents are done by attorneys who haven't had this kind of a discussion with patients and families.

Just recently, I was asked to come and talk with a family that had a power of attorney for health care, which even had some fairly good instructions in it. It was done 8 years ago, so there's been plenty of time for family discussion, but when I asked the family what kind of conversation they had had about these issues with the author, who was now a patient, they said, "Well, we never talked about this." Some of them, even though they were named in the document, weren't really familiar with the document at all. So here we have this legal document, which provides minimal assistance in making decisions because this conversation had never occurred.

*So this brings us back to your first stated goal of promoting understanding, reflection and communication about values and preferences, rather than completing a document.*

## **International Applicability**

*How would what you've done be useful in countries where there are no laws legalizing advance directives and where there isn't such an emphasis on individual autonomy, but families might have need for some guidance around these communication issues? Can you speak to that?*

BH: Well, first of all, I'm not sure that advance care planning is necessary everywhere. We have minority cultural groups in our own community on which, after a lot of thought, we decided we would not really focus any education. In particular, we have a group of H'mong from Southeast Asia and we have another relatively distinct group of Amish. These are two fairly sizable, identifiable, cultural groups in our immediate geographic area. We had some conversations about what our obligations were to provide education about advance care planning to these groups. And our ultimate conclusion was that it would almost be disrespectful.

*Why?*

BH: Because advance care planning, at least as we approach it in this country, is really predicated on individual autonomy. And these cultures don't seem to hold that as a central value. I'm not saying they don't have it at all, it's just that it's not central value for them the way it is for kind of the more predominant culture in the United States. And so to go in and say, "You know, we want to respect your choices as individuals," is a little bit disrespectful of the fact that there is a different way of making decisions within this group of people. It's very hierarchical, and very patriarchal, and you know, each of us may have views on whether that's a good or a bad thing, but people within that system value that, and accept that, and work within that. So that's one part of it.

The other part of it is they have fairly well-established views about death and dying that guide them, from a value point of view, in knowing when to continue and when to stop medical care. So unlike many of us in the dominant American culture who say, "Gee, what are our values about this?" they kind of *know* what their values are as a group.

*So you haven't run into problems of decision making with members of these groups?*

BH: No. We have not seen members of either of these cultures struggle greatly with these issues as family members approach death. To impose another system on them, and say, "You should change your system and now adapt ours..." would be disrespectful. I reviewed some educational material done by a group, which had developed a video tape on advance care planning and advance directives, and they did the video in English, Spanish and H'mong. And my comment was that you're taking a very specific, predominantly American, United States culturally-bound concept and you're developing a scripted educational program to be provided through a video format, and you're simply translating the words and the concepts into H'mong, but that's not going to be intelligible. They'll understand the words, but the concepts and the values that you're promoting here are foreign. So, I had objections to that approach.

Now, making end-of-life decisions is still always hard because it's inherently filled with grief and sadness, and complexity about what the choices are. I mean, those things are hard and there's nothing anyone can do about that.

### **Advance Care Planning**

What advance care planning does is to lay out a set of relationships, values and processes, of knowing how to approach these decisions for individual people who live in a culture like ours, in which these things are not well understood or where there may be a lot of differences in opinion. That doesn't necessarily mean that every culture has those problems, and where this isn't an issue, advance care planning may be less germane.

The other comment I would have is that, nevertheless, we have to be sensitive to the fact that even within cultures where end-of-life decision making is well-established, there can be variation...or change. And so, for example, we have many H'mong now who have become quite Westernized, and, in some sense, have given up many of their traditional values and

relationships. Here, then, for someone who may have H'mong ancestry and family ties, it may become quite appropriate to do advance care planning.

*Thus far, you have been describing advance care planning as setting up a process and making values more transparent for people who live in a heterogeneous culture where things are less clear and where these values haven't been explicit. This brings up the whole issue of families knowing -- the issue of people actually knowing what dying looks like. "How will I know when my relative is actually dying?" Do you think of that as part of advance care planning, helping people anticipate and know, or is that something else? Is that just being a good doctor?*

BH: Well, in one sense, if you think about our current dilemma with technological care, fitting into the category of someone who's dying is, in some cases, a choice. And so it is part of the advance care discussion.

So, for example, if I told my family, "If I reach a point where I'm largely unconscious and unresponsive, and I will never recover..." When I tell them not to treat me, what I'm really saying is, "I want you to treat me as a dying person at that point." When, in fact, it may technically be possible to sustain biological life for long periods of time. So, my values about what is important and not important help define, in that particular instance, whether my family in a loving relationship, should treat me as a dying person or a person who has some life yet to life. So I'm setting up a perspective of reality that is really driven by values and not by, say, some science.

And it's really an interesting, kind of philosophic, question. This is where my background does come into play. There are different cultural definitions and understandings of when people are dead. In some cultures, death doesn't occur for many, many days after the heart stops, because they believe that the soul inhabits the body and stays there for periods of time. So, one of the things that we need to understand and sometimes we forget, is that our science doesn't give us answers to these questions. They are not arbitrary, but they are ultimately realities that we create through a host of information and perspectives, and some of those perspectives are values. And by that, I'm separating them from something you scientifically go out and determine. They are driven by values and personal experiences, and not by objective, scientific measure.

## **Truth-telling**

*And so, in some of these cultures that you described where you thought advance care planning might be disrespectful, does this notion connect with the concern about being too blunt, informing patients that they are dying?*

BH: Just a quick thought on that, my perspective is, that there may be and can be tremendous variation within cultures -- that what could happen in cultures where patient self-determination and autonomy are not generally well-accepted or valued -- there could at least be the openness to check and see if an individual patient, in fact, buys into their dominant culture, or whether they don't.

In my own teaching, I've been telling physicians more and more, "Look, check in with your patient." And it's reasonable to say, "There are some things I would like to share with you. How

much do you want to know?" And if a patient says, "You know, doctor, I really don't want you to tell me these things..." That would be an unusual patient in our US culture, but by checking in, you know that that patient doesn't want to be told, and then you can say, "Well, how do you want me to make decisions?" "I want you to talk with my son, and tell him everything." In this country, that would be the exception, but that would be respectful, rather than forcing that person to live by the dominant culture. I don't know why you couldn't do the opposite in other cultures, and simply give the opportunity for the exceptional patient, i.e., the patient who may not share the dominant values, to say, "I do want to make these plans. I do run my life differently."

## What To Do Differently

*What would you do differently if you were starting Respecting Your Choices now?*

I think I'd change the wording of the name of the program (*Respecting Your Choices*, An Advance Directive Education Program), and delete the word advance directive. Instead I'd want to talk about advance care planning. What we've found is that the words "advance directive" always take people back to the document, and the document is just an outcome of the process we're interested in. What is essential is the conversation and all it entails -- reflection, understanding, communicating with loved ones and health care practitioners about values and preferences. Advance care planning and advance directives are not about death, but are about living well near the end of life. You can reformulate advance care planning to focus on the following kinds of questions. How do you want to live when you may be very ill and may not recover? In what way would medicine and medical treatment be helpful? Are there kinds of medical treatment that might interfere with respecting who you are, and your dignity? I think grounding the conversation in people's lives puts a slightly different perspective on what we're thinking about. I'd like to see greater focus on what it means to provide good care for someone we love near the end of that person's life. In that way, advance care planning is as much about relationships as it is about values and medical treatment.

## References.

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