



CALIFORNIA HEALTHCARE FOUNDATION



## **Gather Round:** Understanding How Culture Frames End-of-Life Choices for Patients and Families

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## About the Authors

R. Griffin Coleman, PhD, is an anthropologist and principal at the innovation consultancy Point Forward, Inc.

Judy Thomas, JD, is the executive director of the Coalition for Compassionate Care of California.

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## About the Foundation

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# Introduction

Health care providers who work with patients towards the end of life are sometimes surprised by the ways patients and their families approach care decisions. Wishes for care can appear unconnected to the facts of the patient's condition and often change over time. Families can get "stuck" and unable to arrive at consensus, and some avoid or delay making important decisions.

The research described in this report, funded by the California HealthCare Foundation, examines the process of learning and decisionmaking that patients and families often experience as they or their loved ones approach the end of life. Its purpose is to juxtapose those processes with the medical approach generally used by health care providers, in order to point to ways these professionals can work more collaboratively with patients and families. The aim is for genuine shared decisionmaking that results in effective, patient centered end-of-life care.

The findings are based on qualitative interviews with 24 sets of patients and their families — 50 individuals altogether — who were currently or recently entailed in an end-of-life experience. Conducted in 2012 and 2013, the interviews represented 17 recently deceased and 7 then-living patients; 14 were female and 10 male. Patients' ethnic breakdown was 7 White, 7 Asian, 6 African American, and 4 Hispanic. Of the deceased patients, 11 died at home, 2 in hospitals, and 1 in a nursing home.

The dramatic success of medical science in extending lives carries with it a latent danger that the scientific approach to caring for patients at the end of life can disregard the importance of patient input. The intense nature of the end-of-life experience often puts the medical framework for decisionmaking into stark contrast with the knowledge, values, and philosophy that patients and families bring to the table.

In fact, there is surprising sense, depth, and complexity to patient knowledge around death and dying. During this research, three insights emerged that may be useful to providers as they work with patients and families: (1) emotional learning occurs during the end-of-life experience for both patients and families; (2) "folk knowledge" or "folk philosophy" underpins individuals' approach to

## An Ethnographic, Cultural Approach

This research used a cultural anthropological perspective. Extended, qualitative, open-ended interviews were conducted in respondents' homes. The ideas, emotions, and actions of the individuals were placed at the center of the researchers' focus, and there was deliberate openness to many different kinds of facts as potentially having significant bearing on the end-of-life experience.

Minute attention was paid to language, style, and meaning, based on an assumption that the meanings inferred from respondent dialog hang together in subtle patterns that can be seen as "culture."<sup>1</sup>

death and dying; and (3) cultures vary subtly but fundamentally compared to the mainstream framework for decisionmaking.

## Emotional Learning

During an end-of-life experience, patients and families often find that intense feelings crowd out a more practical, problem-solving mindset. This is an unsettled, uncomfortable state, and people seek to return to a sense of normalcy by finding ways to compartmentalize their strong feelings. It is a learning process that requires time for people to notice, react to, and come to terms with their own feelings. It is very different from book learning. People cannot know ahead of time what their feelings will be as they go through an end-of-life experience.

One cancer patient, when asked about how she dealt with fear of death, referred to emotional compartmentalizing as "denial."



*"I think denial is a fabulous mechanism. I have thought about it for years. I used to have a blue rug in front of my couch, and if there was something that bothered me, I'd take a look at it — and shove it under the rug! It makes it easier. Pragmatic. I'm here. I'm going to try to enjoy it."*



Disregarding death is one of the most basic ways that humans organize experience. By not thinking about death in everyday life, we assume an infinite future. We are usually on our way to something better in the future. So recognizing and coming to terms with the absolute end — even for those who anticipate an afterlife — requires a major change of outlook. Making this change requires emotional learning. One respondent described her deceased mother's desire to get back to normal and her assumption that she would have a future.

Social interaction is indispensable for emotional learning during end-of-life experiences. It takes time and perspective for individuals to see which values have enduring meaning for them personally. Talking to other people and having those others give back their impressions enables this process of self-discovery. A patient's ideas about what matters to them, their values, can help them prioritize and re-arrange their feelings by giving them meaning and significance.

Emotional learning sometimes reaches an impasse that may not be resolved. When strong emotions continually block rational choices, patients and families get "stuck." This may happen when family members reach different



*"The importance of having dialog.... I'm just delighted when people want to talk about it because I'm still asking questions, in my own faith journey, for instance."*



emotional positions, which they cannot reconcile, about the real condition of the patient. This is an example of a family that got “stuck” in its emotional learning:

EB died of multiple causes including pneumonia at age 95 after spending his final year in a hospital bed intubated and mechanically ventilated. His eldest daughter worked as a hospital receptionist and often saw first-hand the suffering that frail old patients had to endure to be kept alive. She did not want that for her father, but was unable to persuade her younger sister and brothers to take him off life support because they were convinced EB still wanted to live. There were strong disagreements inside the family about EB’s care, complicating the family’s relationship with the hospital and resulting in a care approach the eldest daughter thought caused her father unnecessary suffering.

#### How Providers Can Support Emotional Learning

- ▶ Allow patients and families the time they need to accomplish their emotional learning.
- ▶ Assume that treatment wishes are an amalgam of facts and emotions that develops over time and during the end-of-life experience.
- ▶ Help patients and families recognize and express their emotions so they can compartmentalize them.
- ▶ Watch for patients and families who are “stuck” and help them learn about themselves through dialog that engages all key family members.

## Folk Knowledge of Care Wishes

The idea that most Americans enter an end-of-life experience completely unprepared to communicate their care wishes does not do justice to the common sense wisdom of patients and families. This research found surprising depth and power in a set of ideas that can be called a “folk philosophy” of care wishes — the informal, seemingly simple, verbal, barely organized, yet deeply significant, everyday knowledge of patients and families.<sup>2</sup>

These ideas include four areas of shared concern about end of life: (1) a handful of values about care, (2) a method for evaluating care scenarios, (3) two principles about the sanctity of life, and (4) what to do with my body. Patients will not articulate these ideas as a whole unprompted, but when asked will readily express a personal position on each. Taken together, patient ideas in these areas give them an informal framework for settling on care wishes in a way that is meaningful to them.

**Values about care.** There is widespread agreement about (a) not suffering too much pain, and (b) not being kept alive artificially.<sup>3</sup> The vast majority of people (c) want to die at home surrounded by loved ones. Most people readily agree that (d) they want to be resuscitated, if possible.

*“There are comfortable ways to die, and ways that aren’t so comfortable. My mother died of Parkinson’s when she was 70 years old. It came to where she could no longer swallow, and that was the end. So I’ve been through this once. But you know, there are ways to medicate [people] so they’re not in pain and not suffering.”*





*"I looked at my wife, with all those tubes running down her throat. And she can't talk. She just looked around without recognizing anything. It's pitiful. I tell you when God gets me like that, he's ready to take me. I don't want to be sitting up there suffering, waiting for everybody who's got to keep running and checking on me. Let somebody else that really could be helped."*



*"That was his fear. He didn't want to die in a hospital. He wanted to die at home, to be with family and see them smile. Emotionally he was probably just feeling, 'I don't want my family to come to this hospital one day and this bed is empty.' And then we would have had to feel 'Oh my God, we missed him. He went on without us.'"*

*"When you talked to her about the living will, you'd tell her what it was all about, whether to bring her back or not, and what it entailed...chest compressions...maybe breaking ribs. But she'd still want you to bring her back. I tried to explain how painful it would be. But if that's the way she wanted to do it, then that's the way it would be."*





**Evaluating care scenarios.** In thinking about which care scenarios would and would not be acceptable to them, patients imagine whether they can see themselves establishing some kind of new normal. This often goes to what routine, everyday, simple pleasures they would still be able to enjoy, often involving food and eating.



*"I look at these people down at the nursing home, and some of them are in wheelchairs. I've wondered what would it be like to live in a place like that and be stuck in a wheelchair. Would you rather be dead? I'm thinking probably not. If I can at least take care of myself somewhat. I wouldn't want to be a quadriplegic. I don't think I'd want to stay alive under those circumstances. I think if I was in D's shoes I'd just as soon be dead anyway....Yeah, I wouldn't want to be around like that."*

**The sanctity of life.** Patients and families all expressed belief in two closely related principles about death resulting from human action: (a) Do not take any proactive step to end someone's life; and (b) allow death to be

determined by God or nature.<sup>4</sup> Though the respondent quoted below provided a rationale from her Buddhist belief in reincarnation, she still clearly articulated the sanctity of life principles.



*"If you hasten your own demise, then you may have to come back earlier. You need a good rest in between. That's what I figure. And if you do anything to yourself to prevent that, like not eating, or suicide in some way, you're going to have to come back and take the whole lesson all over again."*



**Disposition of my body.** People generally have a notion about whether they want to be buried or cremated. Less widely shared is an opinion about donating one's organs or body to science.



*"We haven't had any advance directive. We do talk about, all of us, even the kids....When we die we want to be cremated. And I think we all made that decision as a family. You know, because one thing we know in life for sure is, we're going to die."*

Over the course of their lives, mostly in passing, patients have probably considered and spoken with loved ones about all of these four areas. This dialog rarely takes the form of a formal conversation, but the simplicity and brevity of these interactions should not be mistaken for ignorance or confusion. Folk knowledge is a mechanism people use to store, recall, and apply common sense knowledge in practical situations. It gives patients and families a resource for working through end-of-life decisions in a deep way that is truly linked to them.

## Contradictions Within Folk Knowledge

There are latent contradictions within the folk philosophy of care wishes, which can make it difficult to apply to real clinical choices. Working through these situations is where patients and families need the most help from care providers.

Two different perspectives implied in the sanctity of life principle may contradict each other: choosing not to actively prolong life may feel like a proactive step to end the patient's life, but on the other hand it is allowing God or nature to determine the outcome. The wish to be resuscitated could be seen as going against the wish to not be kept alive artificially. These contradictions hint at the ambiguity of the terms "natural" and "artificial."

In addition, the wish to minimize pain may come into conflict with the sanctity of life principle, where taking aggressive measures to keep a patient alive may cause them more pain or extend suffering. Individual patients and family members often struggle to explain why one of these principles should override the other.

There are no formulaic answers to these problems; patients and families need to arrive at their own answers in their own time.

### Using Folk Knowledge to Help Patients

- ▶ Elicit the patient's folk philosophy around care wishes and use it to frame patient-provider dialog. Explore how an individual patient "fills in" their own version of these ideas.
- ▶ Ask open-ended questions and allow the patient's point of view to frame the dialog about care wishes.
- ▶ Help patients try out applying their care beliefs to specific treatment scenarios so they can learn about the implications of their philosophy by confronting detailed cases.
- ▶ Iteratively confirm patient understanding of their documented care wishes. Keep checking back with them. Let patients change their mind. It's a learning process not a single decision event.



Because of the generality of the folk philosophy that patients start with, and its inherent ambiguities, they need the support of detailed, understandable information in order to create a stable viewpoint about their specific care wishes. Patients and families are unaware of and usually do not consider negative side effects of treatments. They tend to have a positive, optimistic view of care interventions over the short run and a negative, pessimistic view of long term care measures. There is a wide continuum between the patient's simple folk philosophy on one end, and the physician's clinical knowledge of possible outcomes of treatments on the other. Detailed stories or cases of other patients who were in similar circumstances may be the most effective way to bridge this gap.

## A Chinese American Variant of Folk Knowledge

The research sampled various racial/ethnic groups — African American, Hispanic, Chinese American, and Caucasian — in an attempt to detect cultural differences in their end-of-life experiences. The clearest pattern emerged with Chinese American respondents.<sup>5</sup>

Overall, the Chinese respondents did not accept that an individual patient or family caregiver can take responsibility for making a decision about care wishes, especially if in certain situations the follow-through would lead to

*"Going through this process, a learning for me is we cannot decide anything. Because we really don't know — we only know that day, but we don't know how the things follow it. The doctor told us many times he wanted us to stop the dialysis [for my mother]. But [my father] couldn't. He couldn't. He cannot do that. He just said the life is in God's hands. How can we decide how long she should live?"*

*"In our family, [my father] is always the anchor, deciding things. To us, the critical point is him, what he says. And my father always said we take care of the persons who are living. That's how he takes care of us too. That's why he's so considerate of other people...who are living. It's not just about the facts, how we see things. It's about how you feel about the facts. I need to take care of other people's feelings. It's not just according to what the best decision I can make. My father gave us some guidelines. 'Five of you need to be harmonious.' Of course maybe my mom was better off without the dialysis, at least no suffering of her physical body. But how about the people surrounding her? I cannot just say, 'OK the fact is she is better off; don't do the dialysis.' That would release our burden. No, I really need to think about the whole thing. That's why I'm saying I cannot decide based on the facts."*





*"To us, we just don't feel it's our position to decide, even we know she is suffering. We kind of had a little consensus if one day she cannot go [to dialysis] on her own, meaning I cannot get her into the car, then probably that's the time we need to really make a decision. And then, that happened on that Wednesday [when she died]. She just cannot go [to dialysis]. That's why we always say that she decided for us."*



the patient's death. This perspective seems to be based on two cultural factors. First, is the Chinese emphasis on the interdependence of family members, which differs from the mainstream American emphasis on the individual. For the Chinese respondents, the family group has precedence.<sup>6</sup> The second factor affecting decisionmaking is that the Chinese Americans preferred to respond to a context once it presented itself, and not presume to actively shape the flow of events.

Group dynamics, plus caution about taking proactive steps, can lead to an ambiguous situation where family members all wait for somebody else to suggest a

potentially controversial action to resolve a care dilemma, but social pressure prevents explicit communication and resolution.

Chinese respondents described being careful with information, not assuming that more is better. For example, one family never did tell the patient she had cancer because they thought if she knew, it would sap her will to live. Families were comfortable using implicit knowledge about the patient's wishes or tendencies in order to make choices on the patient's behalf. They are always very attuned to social context, which dictates which information to share and which to withhold.



*"I can tell you how Chinese think about death. I had a friend. He was in the hospital with a cancer diagnosis. The doctor already told him it was hopeless. All different types of machines kept his life ongoing. His family and friends were all around the patient. None of them would dare to say 'take out the machine.'*

*Death to Chinese is very heavy. As long as they are breathing, nobody would dare to say you should stop the life, neither family or friends. The group around the patient called me to the hospital, and the doctor said he can extend life for only a couple more hours. I said [to the group around the patient] 'You can just stop the machine. Just let it be.' All the people around the patient were relieved. I couldn't have said that if I had been part of that group sitting with him all along."*





*"Whom is it best to share certain information with and whom not to share it with, might be important for the doctor to learn about. Certain things maybe you would tell to the children but won't tell to the wife. If you are going to tell them, it could be better to say 'might' — just make it a little vague, because they take things very literally."*

Gish Jen, an American novelist of Chinese heritage has written a compelling autobiographical account of what social psychologists have called "the interdependent self" in Chinese culture.<sup>7</sup> The interdependent self is understood in contrast to the mainstream American "independent self." Jen distinguishes this Chinese notion of self as un-self-centered, collectivist, always situated in a context and sensitive to the roles it must play there. The individual self de-emphasizes its own uniqueness and is less concerned with its own interior state. Instead, it strives for harmony, valuing obligation, discipline, and effort on behalf of the group. This helps make sense of what was observed in the Chinese American end-of-life experience. There was a reticence to proactively take on responsibility for making care decisions; instead there was caution, indirectness, and awareness of social context in using information about the patient's condition and treatment. It explains several instances in which Chinese American patients were willing to make sacrifices themselves for the good of others in the family.

Decisionmaking for these families appeared to be located in a family group dynamic, with people being comfortable waiting as long as possible before taking concerted action. Information was employed selectively as a tool inside the family dynamics instead of being seen as a universal good.

Over the long history of Chinese culture, it has accumulated many specific beliefs and traditions related to death, and within its massive geographic area there are numerous regional and subcultural variations in these beliefs and traditions.

Interviewees described many examples of folk beliefs. For example, the color white and certain kinds of portraits are associated with funerals and therefore are off-limits. The word for "death" should not be spoken. A home where someone died may become unmarketable. The common thread is avoidance. One person observed, "Chinese don't like to talk about death," adding that bad luck ensues when this custom is violated. The respondents ascribed these sorts of beliefs mostly to older generations, implying that younger generations are far less superstitious. It is often difficult or impossible for family members to start a discussion of advance directives or care wishes with an elder. There may be concern that the conversation initiator wishes bad luck on the elder, perhaps to the end of inheriting the person's wealth.

The Chinese American end-of-life experiences examined in this research suggest at least three important differences from the mainstream folk philosophy described earlier.

First, woven through the mainstream-based interpretation of the end-of-life experience is an assumption that the patient is an independent self making decisions (or empowering a proxy to do so) based on an informed understanding of his or her options. This does not reflect the Chinese American attitudes and behaviors suggested by this research. Chinese Americans didn't seem to be evaluating care scenarios ahead of time and making advance decisions on that. Instead, this kind of consideration unfolds implicitly as a part of the family management of the care process as their shared experience goes forward.



*"The Chinese are ancient. They have a long history and over the years they developed all kinds of different concerns and superstitions. Like there's a death god always listening to you. [You want him to] focus on other people! Maybe he'll forget about you. But then when you mention death, he says 'Ohhh, there's somebody talking about me!' Old grannies have all kinds of little things to trick Yanluowang. Like they change their name. They don't use their real name to trick Yanluowang. [They say] 'No, no, no this person is not here!'"*



Second, a mainstream assumption is that it is humane to focus the care process entirely on the patient's needs. This inspires the general care wish for the patient not to suffer too much pain. But Chinese Americans expected dying patients to continue to value their role in, and obligations toward, the group right up until the end. It is more often the family group, not the individual patient, that makes the detailed determinations of how this is acted out.

#### **Working Effectively with Chinese American Patients and Families**

- ▶ Use the notion of the "interdependent self" to better empathize with patients and families.
- ▶ Recognize that the style of decisionmaking may be fundamentally different from mainstream American expectations: ambiguously located with the family group, seeming to ignore the centrality of patient wishes, oriented toward continuing treatment regimens until the care options resolve themselves.
- ▶ Expect that that patients and families will be cautious in sharing information inside their families; providers may need push them to the edge of their comfort zone to maximize their chances of making fully informed choices.
- ▶ Seek out young adults in the family to act as a cultural bridge, while keeping the family authority figures engaged in the dialog.

Third, the mainstream wish to die at home becomes more problematic for Chinese Americans. The personal desires of the patient can reasonably be overruled by the needs of the group.

## **Conclusion**

This research suggests that providers cannot make assumptions about what patients and families bring to interactions with the health care system without deeply listening to their ideas and personal stories related to death and dying.

Patients and doctors can have trouble reaching alignment on end-of-life care because of a mismatch of perspectives about time, information, and empathy. Insight about emotional learning can help providers understand the nature of the patient's and family's need for time, the difficulties they face in assimilating clinical information, and the emotional dynamics they experience.

Insight about folk knowledge and cultural variation can give providers a place to start and a method for having conversations about care wishes, bridging between patient and provider knowledge, and respectfully assuming patients bring with them a certain kind of competence and possibility for control.

Providers who fail to recognize and understand the perspectives of patients may seem insensitive. If patients or families then fixate on the doctor's poor social performance, their emotional learning is diverted and they may even lose trust in the institution the doctor represents.



In end-of-life interactions with patients and families, much of the doctor's job is to recognize the patient's different perspective and translate their expertise so it connects with the patient's way of understanding. By taking the concepts of emotional learning, folk knowledge, and cultural variability into account, providers can change the tenor of interactions that patients and families have with the health care system. In turn, patients and families would feel more respected and understood, and thereby drawn into a virtuous cycle of greater trust and engagement.

## Endnotes

1. Clifford Geertz provides perhaps the best example of this approach: "Religion As a Cultural System," *The Interpretation of Cultures*, New York: Basic Books, pp 87-125, 1973. Elsewhere Geertz calls culture "this acted document" ("Thick Description: Toward an Interpretive Theory of Culture," *The Interpretation of Cultures*, *ibid*, p10) and that it "consists of socially established structures of meaning in terms of which people do ... things" (*ibid*, p12).
2. D'Andrade, Roy "A Folk Model of the Mind," in *Cultural Models in Language and Thought*, D. Holland and N. Quinn (eds.), Cambridge: Cambridge University Press, pp 112-148, 1987; Keesing, Roger M. "Models, 'Folk' and 'Cultural': Paradigms Regained?" *ibid*, pp 369-393; Bernstein, Jay "Folk Concepts," [www.academia.edu](http://www.academia.edu), accessed 2014.
3. There are exceptions. Some patients feel that suffering redeems them. Some family members never agree to take a loved one off of life support. But these views are seen as outside the norm.
4. The movement in favor of assisted suicide represents a different principle. This is not yet a normal view.
5. Given the small research sample (6 African American individuals, 4 Hispanic individuals), confidence in making generalizations about experience differences for African Americans and Hispanics in California was lower because the differences observed with them were subtler. The account of emotional learning and folk knowledge presented above applies just as well to them as it does to the Caucasian respondents.  
  
Based on the limited sample, the Chinese American families studied were larger and characterized by more role structure than the other families in the study. The size of the care-engaged family group for Chinese individuals was 4.7, compared to 3.0 for non-Chinese. They maintained active ties with other extended family members who were still in Taiwan, Hong Kong, and mainland China. The average number of co-resident generations in family groups around the Chinese individuals was 2.7, compared to 1.9 for non-Chinese. There were widely accepted expectations that authority inside the family should be and was based on gender and seniority.
6. It is impossible to describe this cultural difference without invoking the implicit values of one perspective or the other. The authors chose to use the mainstream perspective. The term "independence" employs a concept and value from mainstream American culture. Saying the family group "has precedence" over the individual is rooted in the mainstream culture that places the individual in the center of understanding and legally regulating human behavior. Stating this from the Chinese perspective would probably stress the interdependence of the family group. It would be more 'other' than 'self' oriented.
- 7 *Tiger Writing: Art, Culture and the Interdependent Self*, Cambridge: Harvard University Press, 2012.