



STANFORD
CENTER ON
LONGEVITY



Family Decision-Making Surrounding Life-Threatening Illness

APRIL 16-17, 2015
CONFERENCE PROCEEDINGS
STANFORD, CA

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CONFERENCE AGENDA

Day 1: Thursday, April 16, 2015

3:00 Convene

3:00 – 3:45 Welcome, Introductions, and Goals of the Meeting

- Jim Johnson
- Laura Carstensen

3:45 – 5:30 Topic #1: The Decision-Making Process in Families Discussion
moderated by John Rother

What conditions maximize quality of high stakes and high stress decisions for families? What are the biggest obstacles/problems/greatest challenges? Why are bad decisions being made? What do we need to know (and what don't we know) about this process of decision-making?

Opening comments:

- Frank Furstenberg
- Dan McFadden
- Laura Carstensen
- Craig Fox
- VJ Periyakoil

5:30 – 6:00 Happy Hour in Courtyard

6:00 – 8:00 Dinner with Panel Discussion:
The Decision Process from Multiple Perspectives
Moderated by Tom Rando

Panelists:

- Jennifer Brokaw
- Bob Gregg
- Bill Novelli
- Paul Brest

8:15 Adjourn

Day 2: Friday, April 17, 2015

8:00 – 8:15 Breakfast

8:15 – 10:00 Topic #2: The Societal and Medical Context of Family Decision-Making
Discussion moderated by John Rother

What are the strengths and weaknesses of current decision aids and tools like advance directives? What is working and what is not? How can past regrets (families' previous experiences that did not have the outcome they wanted for their loved one) inform and guide future decisions? Could studies of regret help guide change?

Opening comments:

- Diana Dooley
- Phil Pizzo
- James Hallenbeck
- Jay Bhattacharya
- Naomi Karp
- Arnie Milstein

10:00–11:30 Topic #3: Imaging the End of Life Under Ideal Conditions
Discussion moderated by John Rother

Is there a model program anywhere that we can learn from? What would ideal family decision-making look like, even in non-ideal circumstances? Who are the players in creating this utopian system? How do we get there from here?

Opening comments:

- Harriet Warshaw
- Gretchen Addi
- Bill Novelli

11:30–11:45 Break

11:45–12:30 Topic #4: Setting the Research Agenda
Discussion moderated by John Rother

Opening comments:

- Laura Carstensen

12:30 Lunch and Adjourn

INTRODUCTION: THE DILEMMA OF FAMILY DECISION-MAKING SURROUNDING LIFE-THREATENING ILLNESS



A Growing and Urgent Problem

Public policies and guidelines have not kept pace with the emerging complexity that families confront in the face of life-threatening illness, leaving individuals and families without sufficient support and guidance to make the most important of family decisions: how best to manage care for loved ones approaching the end of life.

Medical Advances Fuel the Complexity of Managing Life-Threatening Illness

Medical advances present individuals and families with unprecedented opportunities to defy death in the face of life-threatening illness, but they also may pose significant trade-offs and risks to quality of life. Dying with dignity, with minimal pain, in a setting of one's choosing may be preferable to the longest possible life. In fact, among older people, illness and the loss of independence are feared more than death itself. Seventy percent of those surveyed say that they want to die in their own homes, but only 32 percent do.

A Difficult Task for Families

Understanding your loved one's wishes requires extensive family conversation that can be difficult to initiate. Cultural restrictions around topics of medical intervention, relief of suffering, death and dying, and financial implications can be uncomfortable, and even taboo in some cultures. Circumstances often demand that decisions are made with great haste, and in the majority of cases, surrogates may be uncertain about the nuances of the patient's wishes. In a recent survey by the California Health Care Foundation, a majority indicated that ensuring their families are not burdened by decisions about their care is "extremely important." Yet most have not communicated their express wishes to the loved ones who will make decisions on their behalf. Another recent survey conducted by the Conversation Project found that more than 9 in 10 Americans think it's important to talk about their own and their loved ones' wishes for care at the end of life, yet fewer than 3 in 10 have held these discussions.

It is ironic that prolonged and painful medical care, which patients often fear more than death, comes at enormous financial cost. The cost of care in the last year of life consumes more than a quarter of the Medicare budget and too often depletes family resources. The United States spends twice as much per capita on health care as any other country. Cancer costs alone are expected to rise from \$125 billion in 2010 to \$173 billion in 2020 largely due to the aging of the population.

Setting the Research and Policy Agendas

In cases of serious illness, the series of decisions demanded can pose great challenges to family members. Basic do-not-resuscitate orders, though useful in a limited way, fail to answer scores of questions about specific treatments or alternatives to hospital care. Family members often disagree over the desirability of treatment options, and different family members may experience emotional and financial consequences differently. Some deaths follow prolonged periods of pain and suffering, while others are peaceful and relatively serene.

Research suggests that decisions are especially difficult when there is uncertainty about options, when emotions are intense, and when the stakes are high. Patient and family choices are influenced not only by what information is provided, but also by how it is presented. Moreover, patients may change their wishes as their diseases progress, seeking more intervention than they had anticipated they would want when they were healthy.

The palliative care model, in which a team of trained specialists works closely with families to understand and deliver services based on the values and beliefs of the patient, may offer guidance.

FURTHERING THE CONVERSATION: A CONFERENCE CONVENED BY THE STANFORD CENTER ON LONGEVITY



In 2015, the Stanford Center on Longevity launched a program to identify and explore the key unanswered questions about decision-making surrounding life-threatening illness and end of life. The aim was to characterize critical turning points and decision contexts that optimize the likelihood of individuals, families, and loved ones to manage care in accordance with patient goals. As part of this work, the Center plans to survey the public, and cultivate ideas from academics, thought leaders, health care providers, policy makers and religious scholars in an effort to develop and communicate guidelines.

On April 16 and 17, 2015, the Center convened a group of distinguished experts representing the disciplines of sociology, medicine, ethics, health economics, law, health policy, and psychology to articulate key issues, compile existing evidence, and identify questions to which answers are needed in order to inform policies and improve programs surrounding life-threatening disease.

This meeting of experts launched a research and policy program that addresses questions such as:

- What forms of collaborative decision-making do families now use? How does palliative care inform family decision-making? Do some approaches to end-of-life care entail less regret among survivors than others?
- What conditions maximize quality of high-stakes and high-stress decisions?
- Can advanced directives be expanded to address a broader range of issues?
- What are key cultural considerations for decision-making in an ethnically diverse society?
- What kind of training is needed for professionals in various fields to provide patients with serious illness (and their families) quality medical support, including discussions of patient goals and objectives?
- What might the United States learn about best practices from other countries around the world?

Following the meeting, the project plans to pilot research on identified topics and to convene practitioners, family members, and other stakeholders to develop a strategic plan that will improve decision-making near the end of life.

CONFERENCE PROCEEDINGS APRIL 16-17, 2015

WELCOME AND GOALS OF THE MEETING



Jim Johnson, Chairman of the Stanford Center on Longevity Advisory Council and CEO of Johnson Capital Partners welcomed attendees and introduced Founding Director Laura Carstensen, Professor of Psychology. Professor Carstensen along with colleagues Frank Furstenberg, Professor of Sociology at the University of Pennsylvania; Jack Rowe, Professor of Health Policy and Aging at the Columbia University Mailman School of Public Health; and Dana Goldman, Professor and Director of the USC Schaeffer Center for Health Policy and Economics, proposed the conference to identify a research and policy agenda by which to approach end-of-life issues. Craig Fox, Professor of Management, Psychology and Medicine and Director of the Interdisciplinary Research Group on Behavioral Decision Making at the University of California, Los Angeles invited conference participants to submit articles for a special section of the *Journal of Behavioral Science and Policy Association*.

The conference was organized around four topics:

- **The decision-making process in families.** A sociological perspective on the changing demographics and increased complexities of today's families, offering multiple perspectives about the decision process during the end of life.
- **The societal and medical contexts of family decision-making.** A broad overview of the current state of the health care system, economic and cultural factors, and policies at all levels that influence end-of-life choices and decisions.
- **Imagining the end of life under ideal conditions.** A discussion of best practices around end-of-life decision-making and care
- **Setting the research agenda.** Identifying and prioritizing future research and intervention programs

THE DECISION-MAKING PROCESS IN FAMILIES



Moderator: John Rother, President and CEO, National Coalition on Health Care

Panelists:

Frank Furstenberg, Professor of Sociology, University of Pennsylvania

Dan McFadden, Professor of Economics, University of California, Berkeley, Nobel Laureate

Laura Carstensen, Professor of Psychology, Stanford University, Director, Stanford Center on Longevity

Craig Fox, Professor of Management, Psychology, and Medicine, UCLA

VJ Periyakoil, Clinical Associate Professor, Stanford University Medical Center

Decision-making conditions near the end of life are as poor as they could possibly be: Families have to make important, often life-or-death choices when they are extremely fatigued, inexperienced with making group decisions, inexperienced in medical and economic implications, fearful, and facing critical outcomes with immense uncertainty under extreme time pressure. Family dynamics also play a role: Family members who disagree with one another tend to state their positions more strongly than they believe in them, which can lead to suboptimal, even undesired outcomes. Even when families have discussed end-of-life care, patient goals can change as disease progresses. Advance directives are necessary but not sufficient: While such legal documents deal with specific and limited circumstances, they do not address the many shades of gray that families confront when a loved one is dying.

End-of-life communication is not a single conversation, but rather many conversations held over time, preferably under less stressful conditions, focused on values, what matters, what limitations or loss of capacity are acceptable, and which are unacceptable. Americans tend to approach end-of-life with an expectation that the medical establishment can cure all ills. Increasing understanding that death is as natural as all other aspects of life could lift some of the onus from families trying to make critical care decisions. Quality of life as well as length of life are important, personal considerations.

A range of professionals can help families as they plan for the inevitable, including accountants, attorneys, social workers, clergy, and medical personnel. At present, there is no system in place to bring all of them together in service to families: Families must assemble their networks ad hoc. How to bring the right professionals to the table, and how to facilitate their interactions are important, so far unaddressed priorities. Palliative and/or hospice care may provide a model.

For professionals, understanding cultural differences and building trust are essential. For example, the American response to diagnosis is vastly different than that in Europe. When asked, “If your physician said you had a life-threatening illness, would you accept it or seek a second opinion?” only 6 percent of U.S. patients accepted the diagnosis; 75 percent of Europeans did.

For further exploration:

Having lost one loved one to life-threatening illness, are families better equipped to optimize decision-making with regard to a second and/or subsequent loved one? Further research is recommended.

What models exist, and which might be developed, to assist families in collective decision-making? What are the “right” questions to ask?

What drives physician communication and how can it be improved? Do doctors fear legal repercussions? Do they face economic pressures from the insurance industry and/or medical establishment? Are they aware that the way they present information affects how it is understood? (Anecdotally, when presented with the statement, “You have a 10 percent chance of remission, most focus on remission. Similarly, patients presented with a 10 percent change of malignancy focus on the continued cancer, not the small percentage.) Experiments designed to frame communications so that families can understand the information presented would be useful in developing more effective decision-making skills.

Did you know...

- *more than 60 percent of decisions made by physicians were contrary to the patients’ documented preferences?*
- *between 65 and 76 percent of physicians were not aware their patients had advance directives on file with the medical office/hospital?*

PANEL: THE DECISION PROCESS FROM MULTIPLE PERSPECTIVES



Moderator: Tom Rando, Professor of Neurology and Neurological Sciences, Stanford University, Deputy Director, Stanford Center on Longevity

Panelists:

Jennifer Brokaw, Founder and Physician, Good Medicine Consult and Advocacy

Bob Gregg, Professor of Religious Studies (Emeritus), Stanford University

Bill Novelli, Professor, Georgetown University McDonough School of Business, Co-chair, Coalition to Transform Advanced Care

Paul Brest, Professor of Law and Former Dean of Stanford University School of Law

Panelists:

Jennifer Brokaw, Founder and Physician, Good Medicine Consult and Advocacy

Robert Gregg, Professor of Religious Studies (Emeritus), Stanford University

Bill Novelli, Professor, Georgetown University McDonough School of Business; Co-chair, Coalition to Transform Advanced Care

Paul Brest, Professor of Law and Former Dean of Stanford University School of Law

Two conversations are critical to making effective end-of-life decisions: One among family members, preferably at a time when everyone is healthy; and one between doctor and patient to clarify goals and wishes. Family agreement on the professionals to be engaged in caring for a loved one at the end of life – notably doctors and caregivers – and understanding options and patient preferences go a long way toward achieving desired outcomes.

Most individuals say that at the end of life, they want to be at home, connected with their families, free of pain, and spiritually nourished. They do not want to impoverish their families by choosing expensive solutions. Nor do they want to exhaust their loved ones who are thrust into the position of caregiver. But too often, people die in isolation and in pain while imposing great burden. The false belief that all family members share the same beliefs and desires for end-of-life decisions is clarified when families discuss wishes in advance of a crisis.

For further exploration:

- How can families and practitioners be encouraged to conduct these conversations before it is time to make a critical decision?
- How can families learn to address patients' changing wishes as they decline?
- What policies might ease the burden on family members caring for loved ones at the end of life, and what changes might be contemplated in the status of paid caregivers?

Did you know...

- *Ira Byock's Four Things that Matter Most recommends four things to say when a loved one is dying: I love you. Thank you. I forgive you. I am sorry.*
- *Icebreaker questions can help start family conversations. Ask loved ones if they have written out plans for their memorial services. Do they want to be cremated or buried? Is there a family burial place? Often such practical questions lead to deeper discussions of beliefs and values.*

THE SOCIETAL AND MEDICAL CONTEXT OF FAMILY DECISION-MAKING



Moderator: John Rother, President and CEO, National Coalition on Health Care

Panelists:

Diana Dooley, Secretary, California Health and Human Services

Phil Pizzo, Professor of Medicine and Former Dean of Stanford University School of Medicine

Jay Bhattacharya, Professor of Medicine and Health Research and Policy, Stanford University, Senior Fellow at SIEPR

Jim Hallenbeck, Associate Professor, Stanford University School of Medicine, Palo Alto Veterans Affairs Health Care System

VJ Periyakoil, Clinical Associate Professor, Stanford University Medical Center

Naomi Karp, Policy Advisor, Consumer Financial Protection Bureau, Office of Older Americans

Arnie Milstein, Professor of Medicine, Stanford University Medical Center

The good news: California is providing a model for achieving better health care at lower cost. Since the passage of the Affordable Care Act, 80 percent of Californians are enrolled in managed care systems, served through community clinics that coordinate care. California's Health and Human Services Department is collecting data to measure 39 wellness indicators, including reduced hospitalization during the end of life, increased palliative care and hospice care use, and increased use of advance directives and end-of-life planning.

The bad news: Some 99.99 percent of physicians report that they struggle to conduct end-of-life conversations with their patients. Particularities exacerbate the challenge: Physicians' gender, ethnicity, and specialty influenced the likelihood that they would initiate conversations about advance directives. Moreover, many people do not have sufficient information to prepare an advance directive. That is, they don't know their options, and they don't know what they will want. The fact that patient wishes change as illness progresses only complicates the scenario in which the initial conversation is a struggle, let alone subsequent, regular discussions.

Although electronic medical records offer the best way to document patient wishes and doctor-patient/family conversations, privacy issues continue to be a barrier to implementation. Another barrier is balancing the expense of desired, reasonable care with the wish to leave an inheritance for one's family.

For further exploration:

- Physicians want what a majority of respondents say they want – to be with their loved ones in a comfortable place when they die. So why do they choose something else for their patients?
- How can public policy create a mechanism to serve the wishes of patients who have no family members or surrogates?
- Could development of a "911 Hospice" provide doctors and patients with instant, accurate information to help make effective end-of-life decisions?

Did you know...

- *The individual has the right to make a decision, even if unconscious, cognitively impaired, or under heavy medication.*
- *People who wanted a Do Not Resuscitate order were more likely to have advance directives and organ donation plans in place.*
- *Patients who were encouraged to write letters to their physicians outlining their care goals and needs were able to launch effective doctor-patient conversations about end-of-life care.*

IMAGINING THE END OF LIFE UNDER IDEAL CONDITIONS



Moderator: John Rother, President and CEO, National Coalition on Health Care

Panelists:

Harriet Warshaw, Executive Director, The Conversation Project

Gretchen Addi, Associate Partner, IDEO

Bill Novelli, Professor, Georgetown University McDonough School of Business, Co-chair, Coalition to Transform Advanced Care

What constitutes a good death and what are the best systems to achieve it?

The Conversation Project is shattering taboos and increasing awareness about the importance of communicating end-of-life wishes among patients, family members, and caregivers, including physicians. A free online toolkit available in seven languages assists individuals, their loved ones, and their doctors in experiencing the end of life they wish. Media is paying more attention, and Baby Boomers, now facing older age, are initiating conversations.

The Coalition to Transform Advanced Care (C-TAC), comprising 110 organizations from healthcare companies to AARP, health systems, faith-based organizations, and many others, utilizes four strategies to help close the gap between what patients say they want, and what the healthcare system delivers:

- Improved consumer understanding of the healthcare system in order to make informed choices
- Improved physician communication through education
- Implementing best practices to scale across the country
- Policy advocacy at the state and federal levels

For further exploration:

- How do we think about death and dying in a way that respects the healthcare system?
- If families cannot serve in the surrogate decision maker role, could having a “private medical advocate” or “bodyguard” be a better solution? All patients need an advocate to represent their wishes, but there isn’t yet a way to pay for it. The “bodyguard” needs to be someone who is medically trained and who is respected, and ideally is not a family member.
- What metrics might be useful in reaching end-of-life decisions?
- In what ways might Medicare enrollment be maximized to generate end-of-life conversations while people are in relatively good health?

Did you know...

- Some 90 percent of people in the U.S. say they want to have an end-of-life conversation, but only 30 percent have.
- Individuals with income less than \$50,000 are half as likely to have communicated end-of-life choices.
- Families tend to over-value immediate rewards at the expense of long-term goals when making decisions for a loved one. Balancing quality of life with length of life might lead families to make different decisions in support of their loved one’s wishes.
- A good experience with death and dying requires
 - agreement from all parties (physician, patient, and family) to support the patient’s wants and needs;
 - a clear understanding that there isn’t any treatment that could restore the patient to good health;
 - safety, comfort, and family involvement.

SETTING THE RESEARCH AGENDA



Moderator: John Rother, President and CEO, National Coalition on Health Care

Laura Carstensen, Professor of Psychology, Stanford University, Director, Stanford Center on Longevity

A robust brainstorming session generated practical applications and suggestions for further research involving patients, families, professionals, and the media. Practical Applications:

- Develop a practice or profession of consultants to offer expertise in end-of-life decision-making.
- Generate and distribute a toolkit to help patients, families, and professionals identify the information they want and need to make suitable collective decisions.
- Produce a film that would serve as a conversation starter for families dealing with end-of-life decision-making.

Research Ideas:

- Develop a national survey to generate data examining perspectives on end-of-life issues. Survey patients, family members, and professionals including physicians, financial advisors, lawyers, and clergy. Such a broad survey would provide a benchmark on the current state of practice and trigger national conversations.
- Initiate longitudinal studies with patients newly diagnosed with terminal illnesses. Track conversations to analyze outcomes and assess differences between those who have end-of-life conversations and those who don't, as well as how the conversations change over time.
- Study how families make decisions in a hospital setting. How does the patient's participation, or lack thereof, affect decision-making? How do physicians make decisions, with and without information from the patient?
- Role play family decision-making in the lab under professional observation. How does ambiguity affect decision-making? Given more time to make decisions, does the quality of the decision-making improve?

For further consideration:

- The default medical decision today is to prolong life, but that often has negative implications on quality of life. What if factors such as quality of life, financial implications, and length of life all were considered in formulating a new default, end-of-life medical practice?
- How do costs of care affect decision-making? Would patients and their families make different decisions if they were fully informed about costs, and what is the best way to deliver financial information in a crisis setting?
- How do we talk about end-of-life choices without imposing bias toward a particular decision?
- Does the death of a loved one serve to educate the family to make better end-of-life decisions when the next family member is dying? Do attitudes shift?

Did you know...

- There is a 30 percent gap between the number of people who say they want to die at home and those who do.
- Even when advance directives have been signed, they don't seem to be followed. Why not?

CONCLUSIONS



Conference Themes and Recommendations:

Several key topics emerged with regard to family decision-making surrounding life-threatening illness, including:

- Recognizing the important roles that cultural factors, trust, practice and experience play in decision-making;
- Creating awareness of the family dynamics and the surrogate decision-making styles that influence decisions;
- Reimagining decision aids and tools and the involvement of a variety of community professionals to support educated and informed decisions;
- Improving EOL literacy and language (including media) to facilitate improved communication and updating of social norms;
- Fostering collaborations to share and scale best practices and create standards of care.

Next Steps:

The Stanford Center on Longevity and the Stanford School of Medicine are currently seeking funding for five projects:

- A national survey of patients, their families, health care providers, attorneys, and financial advisors about their views, practices and experiences with end-of-life decision-making;
- A “Close the Gap” challenge to fuel innovation in developing end-of-life solutions to reduce the gap between people who say they want to die at home and those who actually do;
- A measurement project to determine the best and most relevant questions to ask individuals who have dealt with end-of-life events, to be certain that experienced patient voices contribute to the development of improved end-of-life care.
- A large-scale, multi-ethnic, multi-lingual study to improve public awareness of advance care planning to increase demand for good end-of-life care; and
- The development of a diverse, multi-level, multi-disciplinary, multi-ethnic end-of-life learning community.

In addition, Laura Carstensen and Craig Fox are collaborating on a special issue of the Behavioral Science and Policy Association journal on end-of-life decision-making.

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“To the extent that people arrive at old age mentally sharp, physically fit, and financially secure, long-lived societies will thrive.”

Laura Carstensen
Founding Director



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