

Public Perceptions of Advanced Illness Care: *How Can We Talk When There's No Shared Language?*



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Selected Findings from Consumer Research on Advance Planning and Care for Serious Illness

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The Coalition to Transform Advanced Care (C-TAC) is a nonprofit, nonpartisan organization dedicated to transforming advanced illness care by empowering consumers, changing the health care delivery system, improving public and private policies and enhancing provider capacity.

Gaps in Our Understanding

Much consumer research is designed to look at a particular issue, such as advanced planning, advanced directives, palliative care, end-of-life care, the culture of death in America or hospice. But research that begins with the **consumer's own frame of reference** is more likely to provide **unbiased responses about his/her values, attitudes and decision-making**, based on his/her life experience.

Some groups are in fact conducting studies that are more consumer-oriented. The methodology of the SCAN Foundation, the Center to Advance Palliative Care, AARP Services Inc. and the National Journal are designed so that the **consumer provides the starting point**.¹ Their studies use an array of research techniques (qualitative, ethnographic, survey) to understand the events, questions and decision making that occur in relation to advanced illness care.

From such research, it appears that more information is needed on:

- the **decision-making process** that patients, their families, caregivers and medical teams undertake;
- how the public thinks about the **costs of care**, in regard to both the health care system and to their personal finances; and
- the effectiveness of **communication** between patients and clinicians and how to improve it.

Communication

A **common language of health and medical terms is lacking** among patients, families and caregivers and even among health professionals, who often assign different meanings and interpretations to the same words. The lack of common terminology is a **critical, multilayered problem**, cutting across and within population segments:

The public: As noted earlier, many studies start from the researcher's point of view on a defined topic such as advance directives or palliative care, without considering the consumer's perspective, knowledge and vocabulary.

¹ UHG-AARP Services Advance Care Planning Roundtable in DC, April 2010. 2011 Public Opinion Research on Palliative Care. Center to

Public Perceptions of Advanced Illness Care: *How Can We Talk When There's No Shared Language?*

- People generally have little awareness or understanding of such topics—for instance, 78 percent do not know what palliative care is. The problem is compounded when similar words are interpreted differently. In surveys of adults over age 25, "serious illness" connotes terminal illness to 18 percent, while "advanced illness" signifies terminal illness to 36 percent.²

Among medical professionals: While efforts are underway to distinguish, for example, “palliative care” from “end-of-life” and “hospice care,” many physicians appear to believe that palliative care *is* end-of-life care, offered only when curative attempts are no longer viable.

- As a result, physicians might be unwilling to refer a patient still undergoing curative treatment to a palliative care specialist.

Between the public and health providers: For the majority (76 percent) of people, physician and other health providers appear to remain the most trusted source for information on care options for serious illness.³ Even so, considerable miscommunication between clinicians and the public can occur.

- When a physician tells a patient that a treatment has "X percent likelihood of success," she presumably means that X percent of the time the desired medical outcome is achieved—say, three more months of remission for a cancer patient. But the patient hearing "X percent chance of success" may interpret "success" as a cure and a lifetime free of disease.

Without clear communication, how do consumers tell providers what they want? How does a patient even know what to ask for? If clinicians do not correctly interpret the request, how do they translate it into patient-centered care?

One approach to this problem may be to focus on articulating **what people experience** rather than on developing a shared language and helping the public understand terminology. Despite the work done to help patients recognize quality medical care, consumers often measure “quality” using such factors as the doctor’s demeanor and time spent with the patient rather than on treatment and outcomes.⁴ Studies show that patients can have high levels of satisfaction with their pain treatment, even if suboptimal by clinical standards, because of the relationship with their care provider.⁵

Consumers gain an understanding of their health care from their experiences and the emotional bonds formed with their physicians. **Strategies that connect directly with those experiences and emotions** may be effective in bridging communication gaps. Research shows promising results in patient-clinician interaction in advanced illness care and related areas such as pain management⁶ when professionals use narratives and storytelling,⁷ metaphors and analogies,⁸ and video and other media.⁹ Some researchers caution that while these methods can

² 2011 Public Opinion Research on Palliative Care. Center to Advance Palliative Care and American Cancer Society Action Network.

³ Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.

⁴ Murray Ross, PhD. (Winter). From Our Lips To Whose Ears? Consumer Reaction to Our Current Health Care Dialect. *The Permanente Journal*, 13(1), 8-16.

⁵ Dawson R, Spross JA, Jablonski ES, et al. Probing the paradox of patients’ satisfaction with inadequate pain management. *J Pain Symptom Manage*. 2002;23(3):211-220. The Dartmouth Atlas found that patients reported higher wait times and worse access to care in higher spending regions of the country, yet indicated no difference in terms of satisfaction of the care received. See Wennberg JE, Fisher ES, Goodman DC, et al.: *The Dartmouth Atlas of Health Care 2008*, Executive Summary, April 2008.

⁶ Cepeda MS, Chapman CR, Miranda N, et al. Emotional Disclosure Through Patient Narrative May Improve Pain and Well-Being: Results of a Randomized Controlled Trial in Patients with Cancer Pain. *Journal of Pain and Symptom Management*. 2008;35(6):623-631. Krahn M, Naglie G. The Next Step in Guideline Development. *JAMA: The Journal of the American Medical Association*. July 23;300(4):436-438.

⁷ UHG-AARP Services Advance Care Planning Roundtable in DC, April 2010

⁸ Casarett, D., Pickard, A., Fishman, J. M., Alexander, S. C., Arnold, R. M., Pollak, K. I., & Tulsky, J. A. (2010). Can Metaphors and Analogies Improve Communication with Seriously Ill Patients? *Journal of Palliative Medicine*, 13(3), 255-260.

⁹ Volandes AE, Paasche-Orlow MK, Barry MJ, et al. Video decision support tool for advance care planning in dementia: randomized controlled trial.

Public Perceptions of Advanced Illness Care: *How Can We Talk When There's No Shared Language?*

convey complex, emotionally weighted information, they can also lead to confusion about care decisions. The stories can describe *why* and *how* the system of care can work, but they also need to explain the *action* that needs to be taken by the listener – in this case, the patient or caregiver.

Finally, consumers want **information to be presented in positive ways**.¹⁰ They do not want to hear horror stories, problems or what happens without advance planning. They tend to look ahead and are interested in better health care and supportive communities so they can live as healthy and independent as they can.

Attitudes Toward Advanced Illness and Care

The aging of the boomer generation (the first of some 78 million boomers turned 65 in 2011) is projected to have a tremendous impact on health care in the United States. The system will face not only a burgeoning older population but also patients whose views on aging are very different from past generations. **Age does not seem to be a relevant frame of reference** for many boomers. They are less likely to define their lives by age, life stages or events than as a **continuum to build upon**. They focus not on their potential decline but on the future, on what's next and what else needs to be done.¹¹

Recent research indicates that people want care that enhances their quality of life.¹² Most would choose a shorter, higher-quality life over a longer, lower-quality life. They also want to avoid being a burden to their family and to have adequate information about treatment for advanced illness.¹³ For chronic and late-stage illness, the majority says¹⁴ they prefer to stay in their homes, rather than in other settings, with the support of their families, who are their most trusted caregivers.¹⁵

Adults say they find deep satisfaction in caring for family members experiencing serious illness, despite the significant emotional, physical and financial burdens, especially during the last year of a patient's life when family care averages nearly 66 hours per week.¹⁶ Increased support, especially from employers and professional care teams, will be necessary for caregivers even as they themselves age and struggle with their own health conditions.

Attitudes on Planning for Advanced Illness

Research shows that preparation for potential advanced illness is often not undertaken when consumers are healthy.¹⁷ Those 65 and older are more likely to talk with their children about what to do with their possessions than their preferences for care in a medical emergency.¹⁸ Why is this?

¹⁰ 2011 Public Opinion Research on Palliative Care. Center to Advance Palliative Care and American Cancer Society Action Network. Long-term Care Study conducted Lake Research Partners, December 18-23, 2010. The SCAN Foundation.

¹¹ Unpublished, proprietary data on aging Americans, 2005.

¹² Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.

¹³ Ibid

¹⁴ Majority of Americans Agree "There's No Place Like Home" for Care of Elderly Family Members. (2010) Harris Interactive Poll conducted for Amedisys.

¹⁵ Whitlatch, CJ and Feinberg, LF, "Family care and decision making," in Cox, C (ed.) *Dementia and Social Work Practice: Research and Interventions* (New York: Springer, 2007).

¹⁶ Rhee, Y, Degenholtz, HB, Lo Sasso, AT, and Emanuel, LL. "Estimating the quantity and economic value of family caregiving for community-dwelling older persons in the last year of life," *Journal of the American Geriatrics Society*, 2009; 57:1654-1659. The estimated economic value is in 2002 dollars.

¹⁷ Advance Care Planning: Preferences for Care at the End-of-Life (2003). Agency for Healthcare Research and Quality. Research in Action, 12.

¹⁸ Pew Research Center, *Growing Old in America: Expectations vs. Reality* (Washington, DC: Pew Research Center, June 29, 2009).

Public Perceptions of Advanced Illness Care: *How Can We Talk When There's No Shared Language?*

First, many adults are **reluctant to plan for a time when they may be ill or dependent and may need help**, even though they worry about these things.¹⁹

- People feel they have enough to deal with right now and consequently resist serious discussions about planning ahead.²⁰
- Interestingly, an AARP survey among boomer women showed that even direct experience with advanced illness—such as caring for a seriously ill family member—was not an inducement to prepare for decline; rather, it was more likely to boost the determination to lead a full life. The survey found that only 16 percent of these women with caregiving experience were likely to have a plan. In any case, many of the women felt that planning is fruitless given the state of the country's medical system or the lack of support for caregiving.²¹
- The desire to avoid even thinking about advanced illness in old age is captured in one caregiver's words: *I don't even want to think about it. I want to pass in my sleep of old age. It's an ugly time of life—the last few years of suffering. I would rather die in a car wreck than put anyone through what I had to go through taking care of my mother.*²²

Secondly, many do **not know how to plan or even where to begin**.²³ Consumers are unaware of where to turn for help when they need care, what advanced illness care services are available in their communities and which are covered by Medicare or insurance. Research shows, for instance, that many people are unaware of what services hospice provides, how to access these services and how they are financed.²⁴

Some research indicates that **financial planning**—by addressing difficult life choices—may overcome consumer resistance to preparing for future health crises.²⁵ And the wider availability of resources to help people plan may help, too. Preliminary studies have shown that a new online tool, [Making Your Wishes Known](#), has received favorable reviews from both patients and physicians in generating easy to follow, accurate care plans and advance directive forms.²⁶ Little has been done, however, to promote wider access to this program among consumers or to identify the benefits they may derive.

Given the barriers that people face in planning for advanced illness and the need for care during serious illness, a growing number of medical professionals want to redefine advance planning and medical directives. They recommend that planning for care be separated from documenting treatment preferences for specific medical conditions because, too often, these advance directives provide little support in the actual care decisions that have to be made. Instead, efforts around advanced illness care should focus on ensuring that the **proper**

¹⁹ Survey of California Voters 40 and Older conducted by Lake Research Partners and American Viewpoint. The SCAN Foundation and UCLA Center for Health Policy Research, August 16, 2011.

²⁰ Ibid.

²¹ AARP *Planning for Long-Term Care: A Survey of Midlife and Older Women*, Oct 2010

²² The Elder Care Study: Everyday Realities and Wishes for Change. (2008). Families and Work Institute. Retrieved from http://familiesandwork.org/site/research/reports/elder_care.pdf

²³ Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation.

²⁴ Sofaer S, Hopper SS, Firminger K, Naierman N, Nelson M. Addressing the need for public reporting of comparative hospice quality: a focus group study. *Jt Comm J Qual Patient Saf.* 2009;35(8):422-429.

²⁵ For more on the use of non-medical advance planning models, see: Fried, T. R., Redding, C. A., Robbins, M. L., Paiva, A., O'Leary, J. R., & Iannone, L. (2010). Stages of Change for the Component Behaviors of Advance Care Planning. *Journal of the American Geriatrics Society*, 58(12), 2329-2336. doi:10.1111/j.1532-5415.2010.03184.x

²⁶ Presentation by Levi B and Green M, Pennsylvania State University, June 1, 2011. See also: Levi B, Green M. Too Soon to Give up: Re-Examining the Value of Advance Directives. *The American Journal of Bioethics.* 2010; 10(4):3.

Public Perceptions of Advanced Illness Care: *How Can We Talk When There's No Shared Language?*

mechanisms are in place for shared discussion and decision-making among the triad of patients, family members and physicians **at the time care decisions need to be made.**²⁷

Approaches for Providers to Discuss Advance Illness

In caring for the seriously ill, medical professionals are challenged as they grapple with difficult questions on *how* and *when* to share information with patients, families and even with their fellow professionals.²⁸

Underscoring this challenge is the fact that "**communicating bad news**" (along with "**improving pain control**") is one of the most requested topics for physician training programs on advanced illness/end-of-life care.²⁹

While they remain a trusted source of information, recent ethnographic research found that physicians need not be the primary focal point for supporting patient and surrogate decision-making.³⁰ Programs involving physician assistants, nurse practitioners and other professionals have shown their potential to integrate decision-making support as a natural element of patient-centered care.

The success of conversations and decision making during advanced illness appears to be best supported by an informed professional care team that removes barriers, manages expectations and provides resources and planning tools to use *before* the onset of advanced illness.

Cost Concerns & Advanced Illness

Consumer perspectives on health care costs fall into two different but overlapping areas.

The first, and most compelling by far, relates to their **personal costs for care**, including insurance premiums and other out-of-pocket expenses.

- The cost of treatment, according to a 2011 poll by the Cambia Foundation (formerly Regence Foundation),³¹ ranked as the highest concern of Americans when they thought about advanced illness. It was of greater concern than being unprepared spiritually for dying. Another recent poll found that the financial burden on family members ranked as the highest concern of Californians when thinking about serious illness.³²

There is significant—and not unjustified—fear among individuals that their life savings and way of life can be swiftly destroyed by a serious illness. They have seen it happen to other families.

- **According to a recent study, 25 percent of seniors lose their entire assets during the last five years of life because of the costs of advanced illness care; 41 percent lose all of their assets, with the**

²⁷ Sudore RL, Fried TR. Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making. *Annals of Internal Medicine*. 2010;153(4):256-261. Nicholas L, Langa K, Iwashyna T, Weir D. Regional Variation in the Association Between Advance Directives and End-of-Life Medicare Expenditure. *JAMA*. 2011;306(13):1447-1453. Tulsky JA. Beyond Advance Directives: Importance of Communication Skills at the End of Life. *JAMA*. 2005; 294 (3).

²⁸ Solomon, M.Z., Browning, D.M., Dokken, D.L., Merriman, M.P., Rushton, C.H. Learning that Leads to Action: Impact and Characteristics of a Professional Education Approach to Improve the Care of Critically Ill Children and Their Families. *Arch Pediatr Adolesc Med*. 2010 Apr;164(4):315-22.

²⁹ Robinson K, Sutton S, Gunten C.F. von, et al. Assessment of the Education for Physicians on End-of-Life Care (EPECTM) Project. *Journal of Palliative Medicine*. 2004;7(5):637-645.

³⁰ UHG-AARP-AARP Services Advance Care Planning Roundtable in DC, April 2010; Meier DE, Spragens LH, Sutton S: A Guide To Building A Hospital-Based Palliative Care Program. Center to Advance Palliative Care & Mount Sinai School of Medicine, New York NY, 2004.

³¹ Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.

³² Final Chapter: Californians Attitudes and Experiences with Death and Dying (2012, February). California Healthcare Foundation

Public Perceptions of Advanced Illness Care: *How Can We Talk When There's No Shared Language?*

exception of housing benefits.³³ 31 percent of families and individuals facing serious illness lose their savings each year because of the costs of care.³⁴ The out-of-pocket expenses of care can vary tremendously. One study shows that families pay an average of \$11,618 for care in the last year of life; in some cases those costs can reach close to \$95,000 during that time.³⁵

People tend to overestimate how much private insurance or Medicare will help them and therefore are unlikely to plan for the costs of advanced illness. During advanced illness, over 80 percent of patients and families ask about the cost implications of their care; unfortunately, most physicians feel that they have had inadequate training when it comes to the costs and finances for advanced illness care.³⁶ Patients and families are shocked when they learn that many needs they consider "health and medical," such as help for bed-ridden patients, are not classified as such by the system and therefore are not covered by Medicare. They are also worried about the cost of long-term care and are unaware of their options.³⁷

The second area of concern is how cost affects **the country and the health care system**. People realize that costs are out of control and will worsen as the boomers age. At a policy level, the focus is on what these spiraling costs are doing to the country's economy and competitiveness. And while consumers acknowledge these concerns, they are apt to become more engaged—and impassioned—when the talk turns to cost cutting. They fear cuts will affect their right to medical care and a loss of control over their care. Various parties who are battling over policy changes often capitalize on these fears, causing greater consumer confusion about the system, solutions and credible information sources.

Going Forward

The American public clearly has the will to change the current approach to advanced illness care. Ninety-three percent say it should be a top priority for our health care system; eighty-six percent want a public discussion about it.³⁸ Now is the time to find a common language that will close the communications gap among consumers, health professionals, members of the media and policymakers, so the conversation can begin.

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³³ Kelley, A., McGarry, K., Fahle, S., Marshall, S., Du, Q., & Skinner, J. (2012). Out-of-Pocket Spending in the Last Five Years of Life. *Journal of General Internal Medicine*, 1–6. doi:10.1007/s11606-012-2199-

³⁴ Kenneth E. Covinsky et al., "The Impact of Serious Illness on Patients' Families," *JAMA* 272, no. 23 (December 21, 1994): 1839 -1844.

³⁵ Marshall S, McGarry KM, Skinner JS. The Risk of Out-of-Pocket Health Care Expenditure at End of Life. National Bureau of Economic Research Working Paper Series. 2010;No. 16170. Available at: <http://www.nber.org/papers/w16170>.

³⁶ Living Well at the End of Life: a National Conversation. (2011, November). National Journal and the Regence Foundation.

³⁷ Survey of California Voters 40 and Older conducted by Lake Research Partners and American Viewpoint. The SCAN Foundation and UCLA Center for Health Policy Research, August 16, 2011.

³⁸ Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.