



Consumer Perceptions and Needs Regarding Advanced Illness Care: *Are We Listening?*

Selected Findings, Conclusions and Indicated Action to Improve Public Engagement

February 2014

Introduction

In 2011, the Coalition to Transform Advanced Care (C-TAC) issued a research brief -- ***Public Perceptions of Advanced Illness Care: How Can We Talk When There's No Shared Language*** -- that highlighted the substantial communication gap between patients/families with advanced illness and their health care providers. This gap and related issues were discussed at the January 2013 [C-TAC National Summit](#) and further examined at a [Consumer Research Symposium](#), co-hosted by Gallup and C-TAC on June 27, 2013. This second C-TAC paper: updates the 2011 brief; provides additional learning; and adds to the discussion on communication to improve advanced illness care.

Public Knowledge and Attitudes on Advanced Illness

The first research brief (2011) reported on the absence of a meaningful, shared vocabulary among patients/families and providers that could enable more effective communication on advanced illness. Not only does this barrier impede discussions between providers and patients, but appears to often limit the actual medical care that is provided and received.

Confusion on Advanced Illness Terminology

- People generally have little awareness or understanding of advanced illness topics—for instance, 78% 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%, while "advanced illness" signifies terminal illness to 36%.¹
- Even among medical professionals there is confusion around these terms. While efforts are underway to distinguish, for example, "palliative care" from "end-of-life"

¹ 2011 Public Opinion Research on Palliative Care. Center to Advance Palliative Care and American Cancer Society Action Network.

and “hospice care,” many physicians appear to consider that palliative care *is* end-of-life care, offered only when curative attempts are no longer viable.

- There is considerable variability in the terminology used to refer to a family member or other lay person who provides care for someone with a serious illness. In a study looking at naming concepts, when asked the term they use for “loved ones who care for [an individual] at the end of their lives,” nearly half of the respondents said that they didn’t know how they would refer to a person in this role; 24% said “family,” and 25% said “caregiver” or “caretaker.” When asked the term they use to refer to the “person they designate to make healthcare decisions on their behalf,” 30% of respondents didn’t know, 32% said “family,” 15% “power of attorney,” 11% “beneficiary/executor,” and 10% “caregiver.”²
- The same study found that awareness and understanding of advanced illness and end of life care terms and services are low. Less than one in five have heard the terms palliative care (17%) and POLST (Physicians Orders for Life Sustaining Treatment) (13%). Hospice (73%) and do-not-resuscitate (DNR) orders (63%) are more familiar terms.
- Variability also exists in understanding of the term “long-term care,” and in perceptions of who requires these services. In one study, 48% of respondents say that just about everyone, even if they do not become seriously ill, will require long term care services.³ One-third hold the view that it is not likely they would require long-term care someday.

The terminology that the health care system uses and the way information is presented is often not aligned with what consumers use and seek. For example, information about Medicare often focuses on the services that are covered, when what may be even more useful to consumers is a clear description of what is not covered.

[Attitudes on Aging and Advanced Illness](#)

The aging of the boomer generation (the oldest of some 78 million boomers will turn 68 in 2014) is projected to have a large-scale impact on health care in the United States. The health system will face not only a burgeoning older population, but also patients whose views on aging appear to be 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 so much on their potential decline as on the future -- on what's next and what else needs to be done.⁴

² Calabrese-Eck, L. Understanding consumer attitudes, barriers, and word-strings around advanced care. Presented June 27, 2013, at the Consumer Research Symposium. Washington, DC.

³ Tompson, T., Benz, J., Agiesta, J., Junius, D., Nguyen, K, and Lowell, K. 2013. Long-term care: perceptions, experiences, and attitudes among Americans 40 or older. The Associated Press-NORC Center for Public Affairs Research.

⁴ Unpublished, proprietary data on aging Americans, 2005.

Recent research indicates that people want care that enhances their quality of life.⁵ Most would choose a shorter, higher-quality life over a longer, lower-quality life. They also want to avoid being a burden to their families and to have adequate information about treatment for advanced illness.⁶ For chronic and late-stage illness, the majority says ⁷ they prefer to stay in their homes, rather than in other settings, with the support of their families, who are their most trusted caregivers.⁸

For most people (76%), physicians and other health providers appear to remain the most trusted source for information on care options for serious illness.⁹ However, consumers tend to 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 seem to look ahead and are interested in better health care and supportive communities, so they can live as healthy and independently as possible.

Attitudes on Planning for Advanced Illness and Care

Research shows that preparation for potential advanced illness is rarely undertaken when consumers are healthy.¹¹ 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.¹² Some have suggested that those who undertake financial planning may be open to discuss future health crises, since financial planning can include preparation of Advance Directives (AD) and selecting health surrogates.¹³

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.¹⁴ People feel they have enough to deal with right now and consequently resist serious discussions about planning ahead.¹⁵

⁵ Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.

⁶ Ibid

⁷ Majority of Americans Agree “There’s No Place like Home” for Care of Elderly Family Members. (2010) Harris Interactive Poll conducted for Amedisys.

⁸ 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)

⁹ Ibid

¹⁰ Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

¹¹ Advance Care Planning: Preferences for Care at the End-of-Life (2003). Agency for Healthcare Research and Quality. Research in Action, 12.

¹² Pew Research Center, Growing Old in America: Expectations vs. Reality (Washington, DC: Pew Research Center, June 29, 2009).

¹³ 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

¹⁴ Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

¹⁵ Ibid.

A survey of Boomer women (born between 1946 and 1964) showed that even caring for a seriously ill family member was not an inducement to prepare for their own decline. Rather, it was more likely to boost their determination to lead a full life. The survey found that only 16% of these women with caregiving experience were likely to have a plan. Instead many expressed the opinion that planning is fruitless, given the state of the country's medical system or the lack of support for caregiving.¹⁶

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."*¹⁷

Cost Concerns and 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,¹⁸ 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 poll found that the financial burden on family members ranked as the highest concern of Californians when thinking about serious illness.¹⁹

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% of seniors lose their entire assets during the last five years of life because of the costs of advanced illness care; 41% lose all of their assets, with the exception of housing benefits.²⁰ Thirty-one percent of families and individuals facing serious illness lose their savings each year because of the costs of care.²¹ The out-of-pocket expenses of care can vary tremendously. One study shows

¹⁶ AARP Boomer Women's Long-Term Care Planning: Barriers And Levers, August 2009. Retrieved from http://assets.aarp.org/rgcenter/health/boomer_women_ltc.pdf

¹⁷ 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

¹⁸ Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.

¹⁹ Final Chapter: Californians Attitudes and Experiences with Death and Dying (2012, February). California Healthcare Foundation. Retrieved from <http://www.coalitionccc.org/documents/FinalChapterDeathDying.pdf>

²⁰ 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

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

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.²²

- People tend to overestimate how much private insurance or Medicare will help them. 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 largely unaware of their options.²³
- A recent survey of Americans 40 or older demonstrated the confusion around the cost and availability of long-term care services. Many overestimate the long-term care services that Medicare will cover. For example, 37% believe that Medicare pays for ongoing care in a nursing home and 44% believe that it pays for ongoing home care by a home health aide. On the other hand, they underestimate the cost of nursing home care (58%). Only 35% of respondents have set aside money to pay for long-term care services and very few report planning for their long-term care needs.²⁴

When families are dealing with advanced illness there is significant interest in cost. During such a time, over 80% of patients and families ask about the cost implications of their care; unfortunately, most physicians feel that they have had inadequate training for discussing the costs and finances of advanced illness care.²⁵

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.

Rather than developing a shared language or educating the public on terminology, some have suggested that effective communication needs to be linked to the subjective experience of patients, families and providers. Research has shown that the assessment of quality medical care²⁶ and levels of patient satisfaction are strongly related to subjective

²²Marshall 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>.

²³Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

²⁴Tompson, T., Benz, J., Agiesta, J., Junius, D., Nguyen, K, and Lowell, K. 2013. *Long-term care: perceptions, experiences, and attitudes among Americans 40 or older*. The Associated Press-NORC Center for Public Affairs Research.

²⁵Living Well at the End of Life: a National Conversation. (2011, February). National Journal and the Regence Foundation. <http://syndication.nationaljournal.com/communications/NationalJournalRegenceToplines.pdf>

²⁶Murray Ross, PhD. (Winter). From Our Lips To Whose Ears? Consumer Reaction to Our Current Health Care Dialect. *The Permanente Journal*, 13(1), 8-16.

views and experience rather than actual benchmarks for care.²⁷ While most think of advanced illness in physical terms, illness occurs within a social and cultural environment that also affects how the patient, family and physician experience advanced illness. It is clearly important to have a better understanding of public attitudes and consumers within this context for effective communication on advanced illness.

Audiences for Advanced Illness Care

Beyond the general public, communication research on advanced illness focuses on three broad groups: 1) the patient living with advanced illness; 2) their families and loved ones²⁸ who are involved in their care; and 3) physicians. Those represented by the first two consumer audiences are diverse on many attributes, but they share common characteristics when placed in these roles. Physicians are not the only professionals involved in advanced illness care, but given the central role they play in patients' minds and treatment, they are the focus of much communication research. However, research frequently suggests that the physician may not be the best communicator for a number of reasons, and that effective communication in advanced illness care must be practiced by the entire clinical team.

Patients

There are common interests across all demographic groups of patients suffering with advanced illness. A research review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness showed that, at the time of diagnosis, patients and families wanted to discuss the illness itself, likely future symptoms and their management, clinical treatment options and life expectancy. In these discussions, the content and level of detail needed to be negotiated with the provider.²⁹

The desire for concurrent curative and palliative care is high across race/ethnicity,³⁰ gender, educational level, and cancer diagnosis.³¹ Unfortunately, the minority of patients who have knowledge of palliative care services link it to hospice and the mandate to stop curative treatment. Most seriously ill patients want:

- To spend quality time with family and friends;
- To have their pain managed;

²⁷ 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.

²⁸ Those who are involved in a patient's care are determined by the patient and may not be actual family members. However, the term "families" is used here to describe those individuals who participate closely in decisions and caregiving.

²⁹ Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage.* 2007 Jul;34(1):81-93. Epub 2007 May 25.

³⁰ Santiago, K.C. *Palliative Care & Hospice Care – Attitude & Usage Trends Among African American and Hispanic Populations*. Presented June 27, 2013, at the Consumer Research Symposium. Washington, DC.

³¹ 2011 Public Opinion Research on Palliative Care. Center to Advance Palliative Care and American Cancer Society Action Network.

- To have their spiritual wishes and needs respected;
- To be assured that loved ones are not emotionally and financially devastated;^{32 33 34}

Some variations in preferences for discussing advanced illness, completing Advance Directives, involving family members and sharing decision making have been linked to cultural and ethnic backgrounds.³⁵

Most advanced illness patients have considerable difficulty making care decisions as illness progresses. A major reason for this appears to be that the majority of those with advanced illness cannot determine if they are actually nearing the end of their life. More than 80% of those dying are over 65 and suffering from one or more chronic conditions.³⁶ For example, the decline of those patients with congestive heart failure, COPD, and diabetes is slow and marked by sudden, severe episodes of illness requiring hospitalization, from which they often recover. This pattern can repeat itself for many years until the final time when the patient fails to recover. Elderly patients suffering from frailty of old age, stroke or dementia also follow an unpredictable trajectory of dying. It is only the 22% of elderly patients dying of cancer who tend to follow an expected course of dying. Those without cancer are rarely told that their condition is terminal and so they may not think they are dying until the very end.^{37 38}

Families and Caregivers

Family caregivers have increasingly expanded roles and responsibilities in caring for those with advanced illness. During the last year of a patient's life family care averages nearly 66 hours per week.³⁹ As illness progresses, the information needs of patients and their families tend to diverge; families need more information while patients want less.⁴⁰ The need for more information on the part of the families may reflect their growing role as caregivers and the increased complexity of the decisions and tasks they must carry out.

³² Living Well at the End of Life: a National Conversation. (2011, March). National Journal and the Regence Foundation.

³³ Final Chapter: Californians Attitudes and Experiences with Death and Dying (2012, February). California Healthcare Foundation. Retrieved from <http://www.coalitionccc.org/documents/FinalChapterDeathDying.pdf>

³⁴ Allshouse, KD. Treating patients as individuals. In: Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care, Gerteis, M, Edgman-Levitan, S, Daley, J, Delbanco, TL (Eds), Jossey-Bass Publishers, San Francisco 1993.

³⁵ Santiago, K.C. Palliative Care & Hospice Care – Attitude & Usage Trends Among African American and Hispanic Populations. Presented June 27, 2013, at the Consumer Research Symposium. Washington, DC.

³⁶ Hogan C, Lynn J, Gabel J, et al. Medicare beneficiaries' costs and use of care in the last year of life. Final Report to MedPAC. Washington (DC); 2000.

³⁷ Lynn J. Serving patients who may die soon and their families. JAMA 2001;285(7):925-32

³⁸ Lynn J, Schall MW, Milne C, et al. Quality improvements in end of life care: insights from two collaboratives. Jt Comm J Qual Improve 2000;26(5):254-67

³⁹ 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.

⁴⁰ Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. J Pain Symptom Manage. 2007 Jul;34(1):81-93. Epub 2007 May 25.

While caregivers say they find deep satisfaction in caring for family members experiencing serious illness, caregiving causes significant emotional, physical and financial burdens.⁴¹ Increased support, especially from employers and professional care teams, is important for caregivers as they themselves age and struggle with their own health conditions.

Traditionally, caregivers have assisted with personal care and household work. Increasingly, they are becoming the primary care coordinator and are often providing complex, technical care that only skilled clinicians provided, such as: managing medications, helping with assistive devices for mobility, preparing food for special diets, and providing wound and ostomy care.⁴² There is insufficient training and support for this shift of medical care from the nurse to the caregiver. In many cases, caregivers had no training to perform these tasks and learned on their own.⁴³

A recent panel survey found that 46% of caregivers provide medical tasks (e.g., managing medications, including IV and injections, wound care, oxygen, tube feeding) in addition to providing support for daily living (e.g., bathing, dressing, toileting and shopping, managing finances, and handling transportation).⁴⁴ Medical tasks are difficult, time-consuming, and stress-inducing, and caregivers fear making a mistake or harming the person they are caring for.

As the paradigm of care delivery shifts from in-patient to out-patient settings,⁴⁵ family caregivers need significant support. Many consumers do not know where to begin when faced with advanced illness. They are unaware of where to turn for help with needed care, what advanced illness care services are available in their communities and which are covered by Medicare or insurance.⁴⁶ Research shows, for instance, that many people are unaware of what services hospice provides, how to access these services and how they are financed.⁴⁷

A recent report issued a call for collective action, from across professions, to support family caregivers.⁴⁸

⁴¹ 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.

⁴² Reinhard, S.C., Levine, C., and Samis, S. 2012. *Home alone: family caregivers providing complex chronic care*. AARP Public Policy Institute. Washington, DC.

⁴³ Reinhard, S., Levine, C., and Samis, S. Family Caregivers Providing Complex Chronic Care, AARP & UHF

⁴⁴ Reinhard, S., Levine, C., and Samis, S. Family Caregivers Providing Complex Chronic Care, AARP & UHF

⁴⁵ *Next Generation of Palliative Care: Community Models Offer Services Outside the Hospital*. Larry Beresford and Kathleen Kerr (2012, California HealthCare Foundation). Accessed: <http://www.chcf.org/publications/2012/11/next-generation-palliative-care#ixzz2TTzjFUPO>

⁴⁶ Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

⁴⁷ 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.

⁴⁸ Home Alone: Family Caregivers Providing Complex Chronic Care (AARP, 2012)

Physicians

Within the complex health care system, physicians are often playing smaller roles and may feel (and be) less connected to their patients. Doctors may be seen as distant, while at the same time they are seeking to find the human side of care that drew many of them to practice medicine. Within the chaos that often describes advanced illness care, their patients increasingly send messages that question physicians' motives and quality of care.⁴⁹

Healthcare providers appear to often underestimate the amount of information patients want and overestimate their understanding of provided information.⁵⁰ Even if patients do not want to discuss every detail of their advanced illness, most want honest, accurate information about what clinicians think is wrong with them, what treatment they recommend, and what outcomes to expect. Many clinicians often perceive that they lack the time for this communication.⁵¹ However, physicians are considered to be in the best position to initiate and guide discussions with patients and families.⁵²

Physicians are often challenged as they grapple with difficult questions on how and when to share information with patients, families and even with their fellow professionals.⁵³ "Communicating bad news" (along with "improving pain control") is one of the most requested topics for physician training.⁵⁴ Physicians are also reluctant to communicate fully on options and outcomes, fearing that patients will make poor decisions. Patients may disagree with what is an acceptable risk, side effect, or unavoidable disability. Many physicians appear to have difficulty accepting that informed, rational patients may hold a different opinion than their own as to what is in the patient's best interest.^{55 56}

A major communication challenge for providers is dealing with patients from different ethnicities and other social distinctions. But even when the patient and physician come from similar backgrounds, the most important disparity is the lack of a shared-understanding concerning medicine. Differences in knowledge of physiology, disease, treatment and the health system affect how the physician and patient think about and respond to advanced illness. The gulf between the culture of medicine and the patient's

⁴⁹ Up To Date A patient-centered view of the clinician-patient relationship Tom Delbanco, MD Margaret Gerteis, PhD

⁵⁰ Hancock K, Clayton JM, Parker SM, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. Discrepant perceptions about end-of-life communication: a systematic review. *J Pain Symptom Manage.* 2007 Aug;34(2):190-200. Epub 2007 Jun 4.

⁵¹ Up To Date A patient-centered view of the clinician-patient relationship Tom Delbanco, MD Margaret Gerteis, PhD

⁵² Emanuel LL, Danis M, Pearlman RA, et al. Advance care planning as a process: structuring discussions in practice. *J Am Geriatr Soc* 1995;43(4):440-6.

⁵³ 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.

⁵⁴ Robinson K, Sutton S, Gunten C.F. von, et al. Assessment of the Education for Physicians on End-of-Life Care (EPEC™) Project. *Journal of Palliative Medicine.* 2004;7(5):637-645.

⁵⁵ O'Connor AM, Légaré F, Stacey D. Risk communication in practice: the contribution of decision aids. *BMJ* 2003; 327:736.

⁵⁶ Politi MC, Han PK, Col NF. Communicating the uncertainty of harms and benefits of medical interventions. *Med Decis Making* 2007; 27:681.

cultural experience of illness is not easily bridged without specific communication strategies and training for providers.⁵⁷

Physicians want and need support in dealing with family members and their participation in shared decision making with the patient.⁵⁸ This can help providers and patients come to terms with treatment options, outcomes, risks and values.

Improving Communication for Advanced Illness

Research has shown that effective communication among providers, patients and their families can improve medical outcomes, increase patient and family satisfaction and reduce burden on the health care system.^{59 60 61 62 63} Achieving these results necessitates ongoing conversation over the course of an illness because the situation is constantly changing – including the status of the patient, prognosis, treatment options, available resources and participants.

Current State

There is a heavy burden placed on patients and their families to clearly understand and wisely navigate the systems of care, especially when they are facing a serious illness. Despite the growing emphasis on patient-centered care, there is little evidence that new approaches are meeting the needs of those suffering with advanced illness and their families trying to provide support. All too often the systems seem designed to benefit the professionals and working within the institution.

For example, there have been serious unintended consequences from the Health Insurance Portability and Accountability Act (HIPAA). The law does not restrict communication between medical staff and family members concerning patient care or payment for that care.⁶⁴ However, HIPAA has generated significant concern among physicians with regard to privacy regulations and is misunderstood on the part of many clinicians, making meaningful conversation more difficult.⁶⁵ While "patient engagement" and "person- and

⁵⁷ Up To Date A patient-centered view of the clinician-patient relationship Tom Delbanco, MD Margaret Gerteis, PhD

⁵⁸ Alston, C. et al. 2012. *Communicating with Patients on Health Care Evidence*. Discussion Paper, Institute of Medicine, Washington, DC.

⁵⁹ *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*, Gerteis, M, Edgman-Levitan, S, Daley, J, Delbanco, TL (Eds), Jossey-Bass Publishers, San Francisco 1993.

⁶⁰ Lilly CM, De Meo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. *Am J Med* 2000; 109:469.

⁶¹ Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007; 356:469.

⁶² Curtis JR, Treece PD, Nielsen EL, et al. Integrating palliative and critical care: evaluation of a quality-improvement intervention. *Am J Respir Crit Care Med* 2008; 178:269.

⁶³ Mosenthal AC, Murphy PA, Barker LK, et al. Changing the culture around end-of-life care in the trauma intensive care unit. *J Trauma* 2008; 64:1587.

⁶⁴ A health care provider's guide to the HIPAA privacy rule: Communicating with a Patient's Family, Friends, or Others Involved in the Patient's Care, Department of Health and Human Services, Office of Civil Rights

⁶⁵ Michael W. Rabow, MD; Joshua M. Hauser, MD; Jocelia Adams, RN, Supporting Family Caregivers at the End of Life "They Don't Know What They Don't Know" *JAMA*. 2004;291(4):483-491.

family-centered care" are today's trends, the reality is that HIPAA is another barrier that patients with advanced illness and their family members must overcome to participate in coordinated care.

Another example of expert-driven communication is the ongoing effort around advance planning -- usually defined as completion of an Advance Directive (AD) and family conversations about patient preferences. Campaigns promoting advanced planning prior to the actual period when a patient and family are dealing with serious illness provides only limited, if any, benefits to the patient – and in some cases can be detrimental⁶⁶. However, public engagement campaigns to promote advance planning are the primary focus of the major investments in advanced illness communication. This misalignment appears to be based on expert assumptions that a population that has “planned in advance” or lives in a culture that “accepts death” could better deal with the process of dying.

For example, Robert Wood Johnson Foundation funded a national communication campaign (1995-2005) that involved over 1,000 health and consumer groups. The campaign's primary goals were: (1) to improve medical communication and decision making for consumers; (2) to change the culture of care for the dying in health care institutions; and (3) to change American culture and attitudes about death and dying. Their evaluation found that the campaign attracted little public interest and may have benefited coalition partners, rather than its intended audience, the public.⁶⁷

Research indicates that emphasis on advanced planning is misguided. First, people do not imagine themselves as seriously ill or dying, nor can they predict ahead of time what their wants and needs will be, since they change as the situation changes.⁶⁸ Second, communication on advance planning lacks relevance for those not facing a life-threatening illness. Public engagement on end of life cannot compete with more powerful messages offering personal benefits for dealing with daily life.^{69 70 71} The research base documenting consumer resistance and lack of interest in planning ahead of time for terminal illness continues to grow.^{72 73 74 75 76} Thus, the question arises as to whether communicators understand and/or are listening to their audience.

⁶⁶ Susan Shapiro, PhD, Advance Directives: The Elusive Goal Of Having The Last Word, NAELA Journal, Volume VIII, Number 2, Fall 2012, pp 205-232.

⁶⁷ Balch Associates. Assessment of Last Acts Program Provides Recommendations for Future Direction. <http://www.rwjf.org/reports/grr/038049.htm>. Accessed March 22, 2007.

⁶⁸ Lynn J, Arkes HR, Stevens M, et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. J Am Geriatr Soc 2000;48(5):S214-21.

⁶⁹ Advance Care Planning: Preferences for Care at the End-of-Life (2003). Agency for Healthcare Research and Quality. Research in Action, 12.

⁷⁰ Pew Research Center, *Growing Old in America: Expectations vs. Reality* (Washington, DC: Pew Research Center, June 29, 2009).

⁷¹ Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

⁷² Advance Care Planning: Preferences for Care at the End-of-Life (2003). Agency for Healthcare Research and Quality. Research in Action, 12.

⁷³ Pew Research Center, *Growing Old in America: Expectations vs. Reality* (Washington, DC: Pew Research Center, June 29, 2009).

Research also indicates that preparing ADs and general conversations prior to serious illness are ineffective.^{77 78} When ADs exist, they often have little effect on treatment decisions that occur during the course of the illness once patients have lost the ability to make their own decisions, including decisions to resuscitate.⁷⁹ There is concern that the current evolution of ADs to POLST (Physician Orders for Life Sustaining Treatment) may actually pose a barrier to accessing early palliative care since the timing focuses physicians on people likely to die soon and not on the important earlier care decisions affecting patient priorities or quality of life.⁸⁰

Planning in advance and changing the culture of death may appear to offer help to some – but these efforts do not seem to address the real problems facing the large population with advanced illness.

[The Need to Refocus Communication for Advanced Illness](#)

While there is strong evidence that generally healthy people do not want to discuss their “end of life” treatment until there is a need and benefit to doing so, this is in stark contrast to patient and family behavior during serious illness. Patients and their families tend to have high levels of information needs at all stages of the serious illness process regarding: the nature of the illness, what to expect in the future, likely symptoms and their management, treatment options and their pros and cons, and potential outcomes.⁸¹ There are many issues that are not specific to a particular disease that also become critical to the majority of those who die from chronic illness. These include such topics as goals of medical treatment in the last phase of life, cardiopulmonary resuscitation, ventilators, dialysis, antibiotics, artificial hydration and nutrition, and others. Serious illness brings on needs that become pressing when an illness diminishes independent function. They can only be addressed when ongoing communication about changing priorities is an integral part of the treatment plan. Challenges to clinicians providing this support are significant and include:

⁷⁴ Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

⁷⁵ AARP Boomer Women’s Long-Term Care Planning: Barriers And Levers, August 2009

⁷⁶ 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.

⁷⁷ U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, *ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS*, August 2008

⁷⁸ Advance Care Planning: Preferences for Care at the End of Life, Research in Action, AHRQ, Issue #12, March 2003

⁷⁹ Fagerlin A, Schneider C. Enough: the failure of the living will. *Hastings Cent Rep* 2004; 34: 30-42.

⁸⁰ Charles P. Sabatino, The Evolution of Health Care Advance, Planning Law and Policy, *The Milbank Quarterly*, Vol. 88, No. 2, 2010 (pp. 211-239)

⁸¹ Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage*. 2007 Jul;34(1):81-93. Epub 2007 May 25.

- There are few guidelines on the amount of information physicians are obligated to disclose to the patient on risks/benefits of different courses of treatment to obtain informed consent; where there are guidelines, these vary state-to-state.⁸²
- Patients' treatment preferences can vary significantly⁸³, often by race and ethnicity,⁸⁴ and clinicians are not good at predicting what these preferences might be.⁸⁵ Clinicians often appear to underestimate the amount of information patients want and overestimate patients' understanding of provided information.⁸⁶ Patients may either not have strongly formed preferences or not adequately understand the effects of different treatment options near the end of life.⁸⁷
- There appears to be poor utilization of decision-making resources. Many clinicians claim that they lack the time for adequate communication with patients.⁸⁸ Among patients and clinicians there is lack of awareness of and access to clear, relevant, and trustworthy decision-making resources.

Patients and families also face substantial information gaps outside of the hospital. They are unclear as to how best to care for themselves, what help is needed and available, whom to ask, and lack knowledge of care services covered by Medicare or insurance. Research shows, for instance, that most people are unaware of home health and hospice services, what they provide, how to access these services and how they are financed.^{89 90}

Changes in Advanced Illness Communication

Given the need for care during serious illness, a growing number of medical professionals want to redefine "communication and advanced illness." Some suggest that Advance Care Planning (ACP) should refer to communication occurring "throughout the life cycle and as they approach the end of life." Since ACP is often linked to Advance Planning and Advance Directives, patient-physician conversations during a serious illness should be called by a

⁸² King, Jaime Staples, and Benjamin W Moulton. "Rethinking Informed Consent: The Case for Shared Medical Decision-Making." *American Journal of Law & Medicine* 32, no. 4 (2006): 429–501.

⁸³ Feldman-Stewart, Deb, Michael D. Brundage, Beth A. McConnell, and William J. MacKillop. "Practical Issues in Assisting Shared Decision-Making." *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy* 3, no. 1 (March 2000): 46–54.

⁸⁴ Bullock, Karen. "The Influence of Culture on End-of-life Decision Making." *Journal of Social Work in Endoflife Palliative Care* 7, no. 1 (2011): 83–98.

⁸⁵ Joan Teno et al., *Preferences for Cardiopulmonary Resuscitation: Physician-Patient Agreement and Hospital Resource Use*, 10 J. Gen. Internal Med. 179, 180 (1995)

⁸⁶ Hancock K, Clayton JM, Parker SM, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. Discrepant perceptions about end-of-life communication: a systematic review. *J Pain Symptom Manage.* 2007 Aug;34(2):190-200. Epub 2007 Jun 4.

⁸⁷ Halpern, Scott D., George Loewenstein, Kevin G. Volpp, Elizabeth Cooney, Kelly Vranas, Caroline M. Quill, Mary S. McKenzie, et al. "Default Options In Advance Directives Influence How Patients Set Goals For End-Of-Life Care." *Health Affairs* 32, no. 2 (February 1, 2013): 408–417. doi:10.1377/hlthaff.2012.0895.

⁸⁸ Up To Date A patient-centered view of the clinician-patient relationship Tom Delbanco, MD Margaret Gerteis, PhD

⁸⁹ Perry, M. Long-term Care Study conducted by Lake Research Partners, December 18-23, 2010. The SCAN Foundation. Presented June 2011 at the C-TAC Consumer Research Meeting, Washington, DC.

⁹⁰ 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.

different name.⁹¹ Others recommend that planning for care be separated from documenting treatment preferences for specific medical conditions. Instead, efforts around advanced illness care should focus on ensuring that the proper mechanisms are in place for shared discussion and decision-making among the triad of patients, family members and physicians and other clinicians at the time care decisions need to be made.^{92 93}

Unlike public engagement campaigns on advance planning, there has been strikingly little investment in improving the quality or increasing the level of effective clinician /patient-family communication during illness. Research on communication among patients, families and providers during the course of a serious illness seems limited and fragmented. Many small studies have been done within an academic and medical framework, often without the benefit of professional communication and/or educational support. And the quality messaging and educational materials that exist are not systematically used, if used at all.⁹⁴

Internal medicine residency training now includes “Interpersonal and Communication Skills” as a key competency. Physicians will be trained and assessed on their ability “to communicate effectively with patients, families, and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds.”⁹⁵ The advancements in palliative medicine have greatly increased the focus and support for communications. An early example is the EPEC and ELNEC efforts to educate physicians and nurses on end-of-life care. There are clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness and their caregivers. These guidelines contain practical strategies for health professionals, with examples of useful words and phrases that can be used.⁹⁶

There are quality materials available – ranging from printed items to interactive computer applications -- to help clinicians better communicate with patients, but providers often do not appear to have the time and systems in place to take advantage of them. Some examples are: decision aid communication tools such as [When Cancer Returns](#) (free government publication and online content); [Making Choices: Feeding Options for Patients with Dementia](#) (video and print); [Prepare for Your Care](#) (interactive website); [Advance Care Planning Decisions](#) (patient educational videos); and [Decision Aid for Families of](#)

⁹¹ IOM Committee discussion on EOL

⁹² 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

⁹³ Tulskey JA. Beyond Advance Directives: Importance of Communication Skills at the End of Life. *JAMA*. 2005; 294 (3).

⁹⁴ California HealthCare Foundation – shared internal research.

⁹⁵ Michael L. Green, MD, MSc, Eva M. Aagaard, MD, Kelly J. Caverzagie, MD, Davoren A. Chick, MD, Eric Holmboe, MD, Gregory Kane, MD, Cynthia D. Smith, MD, and William Iobst, MD, “Charting the Road to Competence: Developmental Milestones for Internal Medicine Residency Training,” *J Grad Med Educ*. 2009 September; 1(1): 5-20.

⁹⁶ Josephine M Clayton, Karen M Hancock, Phyllis N Butow, Martin H N Tattersall and David C Currow, “Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers,” *Med J Aust* 2007; 186 (12): 77.

[Patients with Prolonged Mechanical Ventilation](#) (web-based decision aid with provider reporting).

In addition to proper clinician training, there is a need for mechanisms such as triggers from electronic health records, and checklists that remind clinicians and make it easier to engage in patient and family discussions.

For-profit enterprises offer products to fill these needs, but they may not be accepted within the medical community and/or prohibitively expensive. Free promotional materials from pharmaceutical and medical companies are available to fill some patient-education and communication gaps. All this may be changing, with the explosion of medical information databases, electronic medical record systems and on-line decision tools and the involvement of for-profit companies such as UpToDate and Google.

For example, UpToDate, a service used by more than 340,000 physicians reporting over 120 million page views per year,⁹⁷ offers physicians information for their patients. Basic materials are written in plain language at the 5th and 6th grade level, along with more sophisticated pieces written at the 10th to 12th grade level. These materials focus on specific conditions but do not address many common issues and procedures faced by most patients with serious illness. While physicians turn to UpToDate to fact check it is not known if or how they use this resource for their patients. Policies that support creation of consumer-based health communication and incentivize their use could be beneficial.

Google has enormous consumer reach and resources to apply to the communication challenges within the health care system. It has the capacity to analyze health data and the power to redefine not only provider-patient communication but perhaps even the practice of medical care. Although big data in healthcare is expanding quickly, it is still largely limited by both HIPAA and a tradition of paper records. Many say that these opportunities mean that it is time “for HIPAA to go.”⁹⁸ This is supported by research suggesting that the public is more interested in having access to their medical records and communication with their providers than it is concerned with privacy.⁹⁹

Going Forward

Given the criticality that patient-provider interactions can have during serious illness on care quality and patient/family satisfaction, while reducing the cost burden for society, effective communication must be a foundation of patient-centered, competent care. The need to focus on in-the-moment shared discussions and decision-making is clear. Advanced illness communication must be realigned and directed to the timeframe and place where

⁹⁷Attention Health Policy Makers: How To Win Docs And Influence Patients, Dr. Val Jones in Health Policy, Opinion, February 25th, 2009

⁹⁸ Josh Stevens, CEO at Keas, <http://www.informationweek.com/healthcare/mobile-wireless/what-googles-calico-means-for-healthcare/240161883>

⁹⁹ Josh Stevens, CEO at Keas, <http://www.informationweek.com/healthcare/mobile-wireless/what-googles-calico-means-for-healthcare/240161883>

⁹⁹ HIPAA Privacy Rule: Focus Group Exploration of Patient/Caregiver Perspectives, National Health Council May 2012

patients and families are desperately looking for help. This is when decisions are made that can improve medical care and family support for the seriously ill and dying. The American public is seeking changes to improve the system. An emphasis on effective communication between patients and providers is clearly an essential step.

C-TAC, along with numerous partners, is undertaking a program to improve informed, shared decision-making. This will include an assessment of current practices, expert analysis, the development of best practices guidelines and tools and the dissemination and promotion of results to both consumers and clinicians.

There must be a health professional, public, and policy commitment to funding and taking to scale research-based training of health professionals in effective communication, and a system that proactively integrates ongoing, quality conversation among patients, family members and physicians into the evolving treatment plan. Now is the time to find a common language that will close the communications gap among consumers, health professionals, the media and policymakers, so that Americans with advanced illness receive comprehensive, high-quality, person-and family-centered care that is consistent with their goals and values and that honors their dignity.

Sharyn Sutton, PhD, is the principal author of this paper, with assistance from C-TAC staff. The Coalition to Transform Advanced Care (C-TAC) is a national, non-profit, non-partisan alliance of patient and consumer groups, health care professionals and providers, private sector stakeholders, faith-based organizations and health care payers. Visit <http://thectac.org/> for more information on C-TAC and slides and research presented at the June 27, 2013 Consumer Research Meeting. Follow us at @CTACorg.

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