

A Research Agenda for Communication Between Health Care Professionals and Patients Living With Serious Illness

James A. Tulsky, MD; Mary Catherine Beach, MD, MPH; Phyllis N. Butow, PhD; Susan E. Hickman, PhD; Jennifer W. Mack, MD, MPH; R. Sean Morrison, MD; Richard L. Street Jr, PhD; Rebecca L. Sudore, MD; Douglas B. White, MD, MAS; Kathryn I. Pollak, PhD

IMPORTANCE Poor communication by health care professionals contributes to physical and psychological suffering in patients living with serious illness. Patients may not fully understand their illness, prognosis, and treatment options or may not receive medical care consistent with their goals. Despite considerable research exploring the role of communication in this setting, many questions remain, and a clear agenda for communication research is lacking.

OBSERVATIONS Through a consensus conference and subsequent activities, we reviewed the state of the science, identified key evidence gaps in understanding the impact of communication on patient outcomes, and created an agenda for future research. We considered 7 broad topics: shared decision making, advance care planning, communication training, measuring communication, communication about prognosis, emotion and serious illness communication, and cultural issues. We identified 5 areas in which further research could substantially move the field forward and help enhance patient care: measurement and methodology, including how to determine communication quality; mechanisms of communication, such as identifying the specific clinician behaviors that patients experience as both honest and compassionate, or the role of bias in the clinical encounter; alternative approaches to advance care planning that focus on the quality of serious illness communication and not simply completion of forms; teaching and disseminating communication skills; and approaches, such as economic incentives and other clinician motivators, to change communication behavior.

CONCLUSIONS Our findings highlight the urgent need to improve quality of communication between health care professionals and patients living with serious illness through a broad range of research that covers communication skills, tools, patient education, and models of care.

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Author Affiliations: Author affiliations are listed at the end of this article.

Corresponding Author: James A. Tulsky, MD, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, 450 Brookline Ave, Dana 2016A, Boston, MA 02215-5450 (jamesa_tulsky@dfci.harvard.edu).

Patients living with serious illness suffer both physically and psychologically. Although many factors contribute, including disease characteristics, quality of care, social determinants, and systems issues, wide consensus exists that poor communication by health care professionals plays a central role.^{1(pp117-219)} Physical and psychological suffering worsens when patients do not fully understand their illness, prognosis, and treatment options and when clinicians have not sufficiently elicited patients' values. Consequently, patients may receive medical care inconsistent with their goals.²

Inadequate communication also leads to higher use of invasive care near death, shorter hospice stays, lower patient quality of life at the end of life, and worse bereavement outcomes for family and caregivers.³ Poor-quality communication not only affects patients and families but also contributes to clinician burnout, a troubling outcome given current workforce shortages.⁴ Although

considerable research explores the effect of communication on these outcomes, many questions remain. Setting a clear research agenda would move the field forward.

Since the late 1980s, the primary approach to addressing poor communication and unwanted care for patients approaching the end of life has been to promote advance directive completion. Despite legislation encouraging advance directives and numerous dissemination efforts, the outcomes have been disappointing. Initiatives that focus on advance directives alone have changed little in the quality of the experience for seriously ill patients and families.¹ Many additional aspects of communication that mediate outcomes in serious illness are insufficiently addressed, including emotion, prognostic awareness, goals of care, spirituality and existential issues, and costs of care.⁵⁻⁸ Furthermore, effective interventions have not been disseminated widely into practice.

In response to these needs, in May 2015, we convened a conference at Duke University School of Medicine, Durham, North Carolina, that brought together the authors of this Special Communication.

The aims of the conference were to (1) review the state of the science in communication research on serious illness, (2) identify the key areas in which investment in research is likely to achieve the greatest returns, and (3) map out an agenda for communication research that includes the identification of potential stakeholders and funding sources. We defined serious illness as life-limiting disease for which most clinicians would not be surprised if the patient died within the year. The majority of research has focused on communication between prescribing clinicians (physicians, nurse practitioners, physician assistants) and their patients, perhaps because they are the clinicians most likely to deliver serious news and have conversations about treatment options toward the end of life.⁹ We also reviewed the empirical work on registered nurse and social worker communication in this setting.

Methods

We divided the field into 10 broad topic areas, and each expert presented a summary and a focused literature review of their assigned area. After these reviews and discussion, the group summarized what had been learned and created an initial list of research priorities. We used the nominal group technique, a structured iterative ranking process of problem identification, solution generation, and decision making, to develop a final set.¹⁰ In October 2015, we convened a workshop with additional palliative care and communication experts at the National Palliative Care Research Center Annual Foley Retreat, presented our findings, and received feedback.

Findings

After the 10 presentations, we organized the broad topic areas under 7 categories: shared decision making, advance care planning, communication training, measuring communication, communication about prognosis, emotion and serious illness communication, and cultural issues.

Shared Decision Making

Ethical, patient-centered care depends on shared decision making. This has been defined as “a collaborative process that allows patients (or their surrogates) and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences.”¹¹

By what criteria can we judge that shared decision making has been achieved? One perspective argues that evidence of a discussion of medical information that includes patients’ values and shared deliberation meets this standard.^{12,13} Alternatively, others posit that shared decision making has occurred only if there is a documented discussion about patient preferences for decision making, such as whether the patient prefers patient-driven, physician-driven, or shared approaches. This documentation allows for a determination of whether the patient’s preferences have been followed.^{14,15} Although both approaches have value, communication research

may benefit most from a substantive definition that includes specific elements of a conversation.

Given this understanding, does shared decision making occur in practice? Patients and surrogates may have variable role preferences.¹⁶ Furthermore, studies have shown that physicians frequently fail to discuss options robustly or elicit patients’ values in decision-making encounters.¹⁷ A further problem arises when patients with mild cognitive impairment who retain the ability to make decisions about their medical care are excluded. In addition, discordance between patients’ desired and actual roles in decision making may be associated with psychological distress.¹⁸ Finally, consensus is lacking on whether shared decision making should be evaluated on the basis of observed outcomes, such as audio recorded visits or medical record documentation of patient preferences, or patient self-report.

More research is needed to define shared decision making, observe how it unfolds within clinical encounters, and determine how patient attributes affect the shared decision-making process.

Advance Care Planning

Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.¹⁹ Although a broad concept that includes many steps, most advance care planning research has focused on tools used to document end-of-life treatment preferences, such as advance directives and POLST (Physician Orders for Life Sustaining Treatment) forms. Studies have explored various types of forms and facilitated processes in different age groups, diseases, and the general public. Results of these studies have been mixed. Advance directives are often not available when needed,²⁰ and their impact on both costs and care received is unclear.^{21,22} Disparities in literacy and culture compound the problem. Forms are usually written beyond the 12th grade level, only in English, and are oriented toward Western cultural norms about autonomy and decision making.²³(pp160-179)

Furthermore, little is known about the communication that occurs between patients, clinicians, and caregivers that leads to the creation of these documents and the clarification of patients’ preferences. Despite the completion of forms, patients may lack sufficient rapport with their clinician to discuss their wishes, patients’ affect may not be addressed, overall values and life goals may be unexplored, and patients may be poorly informed about their prognosis, medical condition, and choices.¹

Despite these limitations, some recent efforts have led to more effective advance care planning education, discussion, and completion. Patient videos that clearly describe potential outcomes have affected patient preferences, as have low-literacy forms and websites.^{24,25} Coordinated, comprehensive system-level efforts that enhance measurement and provide patient-facing tools, clinician training, and electronic health record documentation have demonstrated increased advance directive completion and documentation of patients’ preferences, better matches between preferences on the directives and treatments received, increased patient and family satisfaction, and lower surrogate anxiety and depression.^{26,27} Greater involvement by social workers and nurse practitioners may lead to greater advance directive completion rates.²⁸

For serious and advanced illness, the POLST paradigm is an approach for documenting treatment preferences as medical orders

that has become a standard component of advance care planning. The National POLST Paradigm Task Force was convened in 2004 to establish quality standards and to assist states in developing POLST paradigm programs.²⁹ This oversight body with representatives from each participating state program now endorses programs in 24 states and recognizes 24 others as developing. Although research suggests that POLST orders that reflect patients' choices to limit treatments are associated with lower rates of hospitalization, implementation at the patient level has been variable and the research is not definitive.³⁰

The literature on advance care planning leaves many unanswered questions. When should advance care planning be introduced? Who can best facilitate advance care planning, and can patients and their loved ones effectively do some planning on their own? How should advance care planning be documented in the medical record? Which approaches yield the greatest likelihood of goal-concordant care: purely patient-facing interventions, purely clinician-facing interventions, one-on-one facilitated discussions, counseling about advance care planning conducted in small groups of patients, or a combination of approaches tailored to patients' preferences? Finally, which outcomes of advance care planning communication are most important for clinical care?

Communication Training

There are multiple approaches to effectively train clinicians in serious illness communication skills, including face-to-face workshops, feedback on actual medical encounters both live and audiorecorded, online interactive courses, and innovative computerized simulation approaches.^{8,31-34} These approaches differ from traditional didactic training by ensuring that learners observe examples of high-quality communication, practice the skills, and receive feedback. Although successful in changing clinician behavior, little is known about the long-term effects of this training, the intensity of the interventions that are necessary for success, the value of follow-up skills training, how to engage unmotivated learners, and how to bring such programs to scale.

Several models have been shown, in small studies, to be effective. VitalTalk, of which one of us (J.A.T.) is a founder and director,³⁵ has created a structured model of communication skills teaching that allows for greater standardization of training. Hundreds of facilitators, trained in the method, now host their own local courses, and VitalTalk provides them with technical support. Kaiser Permanente has implemented the Four Habits model (not specifically targeted at serious illness), which uses a combination of small group courses and online tools to teach clinicians to adopt 4 habits in every encounter: invest in the beginning, elicit the patient's perspective, demonstrate empathy, and invest in the end.³⁶ This intervention has been credited with sustained improvement in patient satisfaction scores. The Serious Illness Communication Project³⁷ combines brief communication skills training with a discussion guide and other systems supports.³⁸ Respecting Choices offers advance care planning skills training primarily for nurses and social workers. Facilitator certification is provided through standardized courses in combination with systems change principles to promote a culture of person-centered care.^{27,39} Kaiser created its training for the benefit of its own health system; VitalTalk, the Serious Illness Communication Project, and Respecting Choices receive support from philanthropic foundations and also market their services to individuals

and health systems. Online approaches have also been shown to be effective in small individual trials⁸; the potential for wider dissemination requires evaluation.

Future directions include disseminating effective interventions through existing mechanisms, such as electronic health records that trigger and guide conversations or maintenance of certification for health professionals that provides an incentive for training in communications about serious illness. Another opportunity is to create quality measures for communication and to pay clinicians who achieve specified communication goals, such as documentation of the conversation, minimal scores on patient surveys, or even quality as determined by audiorecorded encounters. The Centers for Medicare & Medicaid Services decision in 2016 to pay for advance care planning visits is encouraging.⁴⁰ However, on the basis of prior evidence that advance directives alone do not change patient outcomes,¹ this effort is likely to increase goal-concordant care only if accompanied by skills training and health system support. Studies of the health system-level impact of communication skills training should be conducted using appropriate research methods, such as cluster randomized trials that account for the possibility of diffusion of an intervention throughout a clinical practice.

Measuring Communication

To improve the quality of communication, one must be able to measure it. In this domain, measurement includes both what occurs during a conversation (eg, actual words spoken) and how those words are perceived (eg, what patients and clinicians hear). Outcomes of communication include patient trust, satisfaction, decision quality, and health care use. There are several measures for coding actual utterances, including the Verona Coding Definitions of Emotional Sequences (VR-CoDES),⁴¹ the Roter Interactional Analysis System,⁴² the Street patient participation and physician partnership tool,⁴³ and a number of content coding systems for specific behaviors, such as shared decision making.^{8,44} These scientifically validated methods enable investigators to quantitatively and powerfully describe actual clinical interactions, yet their dependence on human manual coding makes them slow and cumbersome and not easily disseminated. For such methods to provide feedback to clinicians or reviewers on a mass scale, high-quality automated coding will be required. Nonverbal communication also affects patient outcomes, yet its measurement is less well developed.⁴⁵

Several challenges remain, however. Of the numerous survey measures about communication quality, it is not known which should be used for what patient populations and in what stage of illness. What is the role of measuring direct communication behavior as an outcome as compared with asking patients to report on communication quality? Moreover, many of these methods of measuring communications have not been fully validated with patient and family perceptions of communication.

Communication About Prognosis

Most clinicians are reluctant to talk about prognosis. They worry about causing distress and loss of hope.⁴⁶ As a result, some physicians discuss prognosis in vague or overly optimistic terms, avoid the topic unless the patient insists, or focus the discussion on treatment.⁹ Physicians' estimates of prognosis are often overly optimistic as compared with actual outcomes.^{47,48} Patients tend to be even more optimistic than their physicians; nevertheless, they say they want

prognostic information.^{49,50} Furthermore, with the exception of 1 recent study,⁵¹ the evidence suggests that prognosis communication does not take away hope, cause depression, increase anxiety, or harm the relationship with the clinician.^{3,6,7,51,52} In contrast, there is some evidence that communication about prognosis may support hope and peace of mind, even when prognosis is poor.⁵

Most data on communication about prognosis is in oncology; less is known about how prognosis is managed in other illnesses with longer and less certain disease trajectories. It is also not known how improving prognostic understanding affects decision making, particularly among patients who prefer not to even discuss the topic.

Emotion and Serious Illness Communication

Discussing serious illness can be frightening and overwhelming for patients and families. Clinicians worry about taking away patients' hope, must manage their own emotions, and often do not possess the tools to address strong emotional reactions during clinical encounters.⁸ Clinicians engaging in conversations about serious illness have 3 primary tasks—establishing connection; eliciting values, goals, and preferences; and delivering information.⁵³ Providing information works best when clinicians tailor the amount and type to the individual patient and to the patient's emotional state. Unfortunately, clinicians often share this information with patients who are already upset and may be unable to process what they are hearing.⁵⁴ Allowing patients to express their emotions and to be heard increases their sense of being cared for, conveys relationship, and facilitates understanding and decision making.⁵⁵

It is important to learn how much and what kinds of emotions affect decision making, and how the effect of emotions on decision making varies among patients. How do patient emotions change over time, and how does the quality of the communication influence these changes? And how can physicians facilitate patient emotional expression and involvement?

Cultural Issues

Cultural issues play an important role in how patients receive information and express emotion.⁵⁶ Research has provided insight into cultural differences in patient and clinician preferences, norms and traditions, and levels of trust in the health care system.⁵⁷ Furthermore, research has highlighted racial, ethnic, and language disparities in quality of care. For example, both African American patients and clinicians have documented preferences for more aggressive care at the end of life compared with their white counterparts. African American patients also are less likely to be enrolled in hospice, to have do not resuscitate orders,⁵⁸ and to use health care professionals as their primary source of advice.⁵⁹ Studies have also found that East Asian families more often have preferences for indirect or no disclosure to the patient directly in the face of serious chronic illness, and greater preferences for family engagement in decision making.⁶⁰

These observations have prompted recommendations for culturally appropriate communication that are not always evidence based, and it is not clear how cultural competency differs from patient-centered communication.⁶¹ It is not known how clinicians can best communicate with patients with various cultural and individual preferences. Nor is it known which communication strategies work best to assess patients' needs and tailor care to the individual patient within their cultural context.

Priorities for Communication Research in Serious Illness

Based on the review, we identified 5 areas in which further research and improvements in communications could substantially move the field forward and help to enhance patient care.

Measurement and Methodology

Greater consensus is needed on how to define and measure communication quality and outcomes. Coding systems should be more uniform, and investigators would benefit by knowing which tools are most efficient and serve which research questions best. Communication analysis tools should be more sensitive, more efficient (and thereby scalable), and better able to evaluate the impact of specific clinician words and expressions. There should be more evaluation of nonverbal communication and how it affects outcomes. Communication analysis should be more culturally and socioeconomically appropriate, and studies should include underrepresented populations in instrument development and validation. More research should be conducted in areas of medicine other than oncology. Other measurement needs include greater use of longitudinal assessments, evaluation of how large a "dose" of a communication approach is required to achieve an outcome, clarification of how many conversations are needed to assess an outcome, evaluation of communication with multiple parties (ie, patient, family, clinicians) present, and more multisite trials. Finally, to translate interventions into practice in a timely manner, rapid assessment and pragmatic trials that account for real-life challenges to implementation should be adopted for communication studies.

Mechanisms of Communication

Work in communication in serious illness is often atheoretical and focuses on blunt interventions without a specific understanding of the impact of discrete communication elements and behaviors. To develop more targeted interventions requires a broader understanding of the "basic science" of communication. Achieving this will require collaboration between clinical and communication science investigators to address questions at a more rudimentary level than are usually studied. Examples of such questions would be, "Is it possible to move patients away from an optimistic bias without causing harm?" "What clinician behaviors do patients experience as both honest and compassionate?" or "How does one promote clinician curiosity, resilience, and presence?" Broad topic areas include team-based communication, clinician communication capacities and motivation, management of bias in the medical encounter, tailoring communication to individual patients, and the effects of social media communication on the experience of serious illness.

Alternative Approaches to Advance Care Planning

Research on advance care planning and advance directives has not translated into a significant effect on outcomes. Systems approaches, such as POLST, hold promise but evidence is limited. Although documentation is important, future research should focus on the quality of advance care planning communication rather than just the completion of documents. Innovative ways to capture and share patient preferences should account for the trajectory of illness and readiness to engage in advance care planning. A focus should be preparing patients and surrogates for in-the-moment decision making, as well as documenting general preferences for care that may not be applicable when specific situations

arise. Finally, shared decision making in this context may need to be redefined with attention to the role of the family, the impact of emotion, what effective deliberation looks like, and clinician behaviors that enable expression of values and goals.

Teaching and Disseminating Communication Skills

There is little science about effective teaching methods to promote long-term change. Research should focus on whether feedback is an essential element, how methods can be scaled, and how best to incorporate decision aids into conversations. Furthermore, little is known about communication by and members of the interdisciplinary professional team (including physicians, nurses, social workers, chaplains, therapists), and how to train nonphysicians such as nurses, social workers, or chaplains to conduct specific tasks currently performed primarily by physicians, nurse practitioners, and physician assistants.

Identifying Approaches to Change Communication Behavior

Educating clinicians, nurses, and social workers is only one approach to improving communications for patients with serious ill-

ness. Research should explore the efficacy of multiple approaches that capitalize on other levers in the system. These might include payment approaches that incentivize the time spent on communication, or electronic health record prompts that remind clinicians of serious illness conversations and guide them through the discussion. Alternatively, clinicians may be motivated by sharing their adoption of communication behaviors with others in their practices.

Conclusions

Improving communication between clinicians and patients living with serious illness can alleviate physical and psychological suffering. There is an urgent need to improve quality of communication in serious illness through a broad range of research that covers communication skills, tools, patient education, and models of care. By focusing research in these identified priority areas, investigators and entities that sponsor research can make substantial strides toward an enhanced patient and clinician experience.

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Author Affiliations: Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts (Tulsky); Division of Palliative Medicine, Brigham and Women's Hospital, Boston, Massachusetts (Tulsky); Department of Medicine, Johns Hopkins School of Medicine, Baltimore, Maryland (Beach); Psycho-Oncology Co-Operative Research Group, Centre for Medical Psychology and Evidence-Based Medicine, School of Psychology, University of Sydney, New South Wales, Australia (Butow); School of Nursing, Indiana University, Indianapolis (Hickman); Department of Pediatric Oncology, Dana-Farber Cancer Institute, Boston, Massachusetts (Mack); Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York (Morrison); Michael E. DeBakey Veterans Affairs Medical Center, Houston, Texas (Street); Baylor College of Medicine, Houston, Texas (Street); Department of Communication, Texas A&M University, College Station (Street); Division of Geriatrics, Department of Medicine, University of California-San Francisco (Sudore); San Francisco Veterans Affairs Medical Center, San Francisco, California (Sudore); Department of Critical Care Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania (White); Cancer Control and Population Sciences, Duke Cancer Institute, Duke University, Durham, North Carolina (Pollak); Department of Community and Family Medicine, Duke University, Durham, North Carolina (Pollak).

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