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

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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. Physical and psychological suffering worsens when patients do 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.

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.

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.

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.

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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

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. 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.10

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.37,39 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 trials35; 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.59,52 Furthermore, with the exception of 1 recent study,57 the evidence suggests that prognosis communica-
tion 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 sup-
port hope and peace of mind, even when prognosis is poor.55

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, par-
ticularly 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 Pro-
viding 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 relation-
ship, 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 infor-
mation 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 Further-
more, research has highlighted racial, ethnic, and language dispari-
ties in quality of care. For example, both African American patients
and clinicians have documented preferences for more aggresive
care at the end of life compared with their white counterparts.
African American patients also are less likely to be enrolled in hos-
pice, to have do not resuscitate orders,58 and to use health care pro-
fessionals 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 seri-
ous chronic illness, and greater preferences for family engagement
in decision making.60

These observations have prompted recommendations for cul-
turally appropriate communication that are not always evi-
dence 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 strat-
egy works 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 substan-
tially move the field forward and help to enhance patient care.

Measurement and Methodology

Greater consensus is needed on how to define and measure com-
mutation 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. Communi-
cation analysis tools should be more sensitive, more efficient (and
thereby scalable), and better able to evaluate the impact of spe-
cific clinician words and expressions. There should be more evalu-
ation of nonverbal communication and how it affects outcomes.
Communication analysis should be more culturally and socio-
economically appropriate, and studies should include underrepre-
sented 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 longi-
itudinal assessments, evaluation of how large “a dose” of a commu-
nication approach is required to achieve an outcome, clarification
of how many conversations are needed to assess an outcome, evalu-
ation of communication with multiple parties (ie, patient, family,
clinicians) present, and more multisite trials. Finally, to translate in-
terventions into practice in a timely manner, rapid assessment and
pragmatic trials that account for real-life challenges to implementa-
tion 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 under-
standing 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 pos-
sible to move patients away from an optimistic bias without caus-
ing 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, tailor-
ing 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 cap-
ture and share patient preferences should account for the trajec-
tory 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 prefer-
ences 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 illness. 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.

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