

Research Priorities for Geriatric Palliative Care: Goals, Values, and Preferences

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Abstract

Older patients and their families desire control over health decisions in serious illness. Experts recommend discussion of prognosis and goals of care prior to decisions about treatment. Having achieved longevity, older persons often prioritize other goals such as function, comfort, or family support—and skilled communication is critical to shift treatment to match these goals.

Shared decision making is the ideal approach in serious illness. Older patients desire greater family involvement; higher rates of cognitive impairment mean greater dependency on surrogates to make decisions. Despite the importance of communication, fewer than half of older patients or families recall treatment discussions with clinicians, and poor quality communication adversely affects family satisfaction and patient outcomes.

Direct audiorecording of clinical encounters and longitudinal studies of communication and treatment decisions have yielded important insights into the quality of clinical communication. Current clinical practice rarely meets standards for shared decision making. Innovative methods to record and use patient preferences show promise to overcome the limitations of traditional advance directives. Decision aids, intensive clinician training, and structured interpersonal communication interventions have all been shown to be effective to improve the quality of communication and decision making. Priorities for geriatric palliative care research, building on these insights, now include empirical testing of communication approaches for surrogates and for diverse populations, exploration of meaningful ways to communicate prognosis, and expansion of intervention research.

What Defines Quality in Health Care Communication?

CONTROL OVER HEALTH DECISIONS is important to older patients, to ensure treatment in serious illness is driven by patient and family values, rather than by social norms or economic imperatives.^{1,2} Shared decision making is the model of communication for serious illness, when optimal treatment is uncertain and risks of treatment are high.^{3,4} This ideal of health care communication elevates patient autonomy when the stakes are highest, moving beyond advance care planning to define quality communication for real-time decisions.

Experts recommend the process of shared decision making begin with clarification of prognosis and goals of care in serious illness.⁵ In an elegant review, Kaldjian organized a framework of six major goals of health care: (1) curing disease, (2) living longer, (3) improving or maintaining function, (4) being comfortable, (5) achieving life goals, and (6) providing support for family.⁶ When cure is not possible, the remaining medical goals—prolonging life, maintaining function, or promoting comfort—are still relevant. Empirically studied in

PACE and in nursing home care, this approach matches the needs of older patients.^{7,8} Having achieved longevity, older and seriously ill persons often prioritize other goals such as function, comfort, or family support—and skilled communication is critical to shift treatment to match these goals.⁹

High quality communication is necessary for meaningful exercise of patient autonomy, but it also affects patient outcomes.^{10,11} After death, surviving family members report concerns about poor quality communication adversely affecting care.^{12–15} Shared decision making improves patient knowledge, reduces conflict, improves adherence, and improves alignment of treatment with preferences.^{16,17,18,19,20,21,22} Research to improve health care communication is a promising way to improve outcomes in geriatric palliative care.

How Can We Study Health Care Communication?

To open the “black box” of actual clinical communication, palliative care investigators have recorded and analyzed hundreds of real-world clinical encounters. These compelling

studies show the distinct importance of informational and affective elements of communication. Analysis of recorded communication provides conclusive evidence that shared decision making is rare.^{23,24,25} Minority populations are particularly disadvantaged, as race and ethnicity adversely affect communication quality, and medical interpretation to bridge language barriers also results in a high rate of alterations in key elements of medical information.^{26,27}

Longitudinal studies describe how often communication affects downstream outcomes of treatment decisions, quality of care, and quality of life. The Coping with Cancer Study enrolled 325 advanced cancer patients and their family caregivers. Two-thirds of patients received end-of-life care consistent with preferences, and patients who understood their prognosis were more likely to transition to palliative care. Treatment was more often concordant with preferences if the patient discussed them with a physician; however, only 39% of patients reported having this discussion.²⁸ The Choices, Attitudes and Strategies for Care of Advanced Dementia at End-of-Life (CASCADE) study examined the impact of surrogate health care provider communication on care in advanced dementia. Only 38% of surrogates for persons with advanced dementia recalled involvement in medical decisions, and less communication was associated with poor quality end-of-life care.²⁹⁻³¹

How Can Patients' Goals and Preferences Be Used to Influence Quality of Care?

Exercise of autonomy becomes more complicated as patients age. Older patients are more often affected by conditions limiting decisional capacity, such as dementia or delirium, and their exercise of autonomy will more often depend on advance directives and the actions of surrogate decision makers.³² Older patients vary in their desire for autonomy, and many seek to balance their needs with those of their family.³³ Traditional legalistic advance directives are completed by less than half of older persons, and used less often by vulnerable elders with less education and low health literacy.³⁴ Novel tools to document patient goals and preferences have been developed to reach persons with low health literacy.^{35,36}

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm began with a particular focus on frail, chronically ill elders in long-term care. POLST documents improve on traditional advance directives. First, they can be completed by authorized surrogates when patients lose this capacity. Second, they activate patient preferences in the form of physician orders. Developed in Oregon, POLST documentation is currently endorsed in 16 states and 27 have policies in development.³⁷ Tracking this innovation as a natural experiment, investigators have found evidence that POLST is effective to facilitate care consistent with preferences for older patients in nursing homes, PACE, and hospice.³⁸⁻⁴⁰

Can Interventions Improve the Quality of Decision Making?

Decision aids provide evidence-based information to support patient decision making. Numerous randomized trials support their effectiveness in outpatient care.⁴¹⁻⁴⁸ By informing patients prior to communication they also improve time efficiency for clinicians. Decision aids have only recently begun to be studied

for older and more seriously ill patients. Volandes has found that varied versions of a video decision aid on advance care planning will increase geriatric or oncology patients' interest in comfort care.⁴⁹⁻⁵² Only one randomized trial tested a decision aid for surrogates, developed to provide decision support in nursing homes for the choice between tube feeding and assisted feeding in advanced dementia.⁵³ This decision aid reduced increased knowledge, reduced conflict, and increased frequency of communication with health care providers.⁵⁴

Other interventions have been effective at changing provider behavior. Using highly structured and interactive educational methods, providers can learn new communication skills, and this training changes patient care.^{55,56} In the intensive care setting, investigators have tested a variety of ways to enhance informed and structured clinical communication. Interventions have included printed information, family meeting protocols, and scheduled communication with either the primary intensive care clinicians or with specialty clinicians from medical ethics or palliative care.⁵⁷ These studies show that printed information and structured communication can improve knowledge and reduce emotional distress for family.⁵⁸⁻⁶⁰ These interventions also reduced ICU length of stay and resource use; evidence for effects on patient-centered outcomes was lacking. Communication clinical trials are examples of behavioral intervention, and design may benefit from further insights from human psychology, behavioral economics, and health literacy research.^{61,62}

What Are Communication Research Priorities for Geriatric Palliative Care?

1. Shared decision making and goals of care language are widely endorsed concepts, yet they have had little empirical testing, and these approaches may or may not fit the needs of diverse populations. Research should expand empiric study of communication for racial, ethnic, and religious minorities.
2. Surrogate decision making raises new challenges to shared decision making based on the ethical principal of autonomy, yet surrogates make a majority of healthcare decisions in geriatric care.^{63,64} Future communication research should expand empiric study of the ethical, emotional, and practical concerns of surrogate decision makers.
3. Prognostic indices provide information relevant to older adults.^{65,66} Patients, surrogates, and clinicians filter prognostic information with optimism, limiting effective information sharing.⁶⁷⁻⁷⁰ Research is needed to examine new and effective methods to share prognostic information with patients and their families.
4. Communication interventions—decision aids, structured communication, and intensive clinician training—have been shown to improve the quality of communication and decision making. Despite strong evidence for efficacy, these interventions are rarely disseminated.⁷¹ Future research should include implementation science, with creative attention to communication technology and cost-effective dissemination.

Communication and shared decision making will remain the primary palliative care procedure, and the clinical skill upon which ethical practice depends. While these skills are highly individualized for clinicians, research will provide new words to use, compassionate approaches to reach more vulnerable

populations, and new intervention tools to empower older patients and their surrogate decision makers.

Acknowledgments

This work was supported by The National Institute on Aging (NIA), Claude D. Pepper Older Americans Independence Center at the Icahn School of Medicine at Mount Sinai [5P30AG028741], and the National Palliative Care Research Center. Funding Source: NIA R01AG037483 (Hanson).

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