

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

Laura C. Hanson, MD, MPH and Gary Winzelberg, MD

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).

References

- Singer PA, Martin DK, Kelner M: Quality end-of-life care: Patients' perspectives. *JAMA* 1999;281(2):163–168.
- Steinhauser KE, Christakis NA, Clipp EC, et al.: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284(19):2476–2482.
- Whitney SN, McGuire AL, McCullough LB: A typology of shared decision making, informed consent, and simple consent. *Ann Intern Med* 2003;140:54–59.
- Braddock CH III, Fihn SD, Levinson W, Jonsen AR, Pearlman RA: How doctors and patients discuss routine clinical decisions: Informed decision making in the outpatient setting. *J Gen Intern Med* 1997;12:339–345.
- Cassell EJ: *The Nature of Suffering and the Goals of Medicine*. Oxford: Oxford University Press, 1991.
- Kaldjian LC, Curtis AE, Shinkunas LA, Cannon KT: Goals of care toward the end of life: A structured literature review. *Am J Hosp Palliat Care* 2008;25:501–511.
- Schamp R, Tenkku L: Managed death in a PACE: Pathways in present and advance directives. *J Am Med Dir Assoc* 2006;7:339–344.
- Gillick M, Berkman S, Cullen L: A patient-centered approach to advance medical planning in the nursing home. *J Am Geriatr Soc* 1999;47:227–230.
- Quill T, Norton S, Shah M, Lam Y, Fridd C, Buckley M: What is most important for you to achieve? An analysis of patient responses when receiving palliative care consultation. *J Pall Med* 2006;9:382–388.
- Hanson LC: Communication is our procedure. *J Pall Med* 2011;14:1084–1085.
- Tulsky JA: Beyond advance directives: Importance of communication skills at the end of life. *JAMA* 2005;294:359–365.
- Hanson LC, Danis M, Garrett J: What is wrong with end of life care? Opinions of bereaved family members. *J Am Geriatr Soc* 1997;45:1339–1344.
- Teno JM, Clarridge BR, Casey V, et al.: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291(1):88–93.
- Birch D, Draper J: A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *J Clin Nursing* 2008;17:1144–1163.
- Sloane PD, Zimmerman S, Williams CS, Hanson LC: Dying with dementia in long-term care. *Gerontologist* 2008;48:741–751.
- Charles C, Gafni A, Whelan T: Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Soc Sci Med* 1999;49:651–661.
- Kaplan SH, Greenfield S, Ware JE: Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care* 1989;27:S110–S127.
- Golin C, DiMatteo R, Duan N, Leake B, Gelberg L: Impoverished diabetic patients whose doctors facilitate their participation in medical decision making are more satisfied with their care. *J Gen Intern Med* 2002;17:866–875.
- Gattellari M, Butow PN, Tattersall MHN: Sharing decisions in cancer care. *Soc Sci Med* 2001;52:1865–1878.
- Schonberg MA, Silliman RA, McCarthy EP, Marcantonio ER: Factors noted to affect breast cancer treatment decisions of women aged 80 and older. *J Am Geriatr Soc* 2012;60:538–544.
- Hack TF, Pickles T, Ruether JD, Weir L, Bultz BD, Mackey J, Degner LF: Predictors of distress and quality of life in patients undergoing cancer therapy: Impact of treatment type and decisional role. *Psychooncology* 2010;19:606–616.
- Bakitas M, Kryworuchko J, Matlock DD, Volandes AE: Palliative medicine and decision science: The critical need for a shared agenda to foster informed patient choice in serious illness. *J Pall Med* 2011;14:1109–1116.
- Tulsky JA, Chesney MA, Lo B: How do medical residents discuss resuscitation with patients? *J Gen Intern Med* 1995;10:436–442.
- Tulsky JA, Fischer GS, Rose MR, Arnold RM: Opening the black box: How do physicians communicate about advance directives? *Ann Intern Med* 1998;129:441–449.
- White DB, Braddock CH, Bereiknyei S, Curtis JR: Toward shared decision making at the end of life in intensive care units: Opportunities for improvement. *Arch Intern Med* 2007;167:461–467.
- Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR: Patient-centered communication, ratings of care, and concordance of patient and physician race. *Ann Intern Med* 2003;139:907–915.
- Pham K, Thornton JD, Engelberg RA, Jackson JC, Curtis JR: Alterations during medical interpretation of ICU family conferences that interfere with or enhance communication. *Chest* 2008;134:109–116.
- Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG: End-of-life discussions, goal attainment and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203–1208.
- Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB: The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529–1538.
- Givens JL, Kiely DK, Carey K, Mitchell SL: Healthcare proxies of nursing home residents with advanced dementia: Decisions they confront and their satisfaction with decision-making. *J Am Geriatr Soc* 2009;57:1149–1155.
- Engel SA, Kiely DK, Mitchell SL: Satisfaction with end of life care for nursing home residents with advanced dementia. *J Am Geriatr Soc* 2006;54:1567–1572.
- Silveira MJ, Kim SY, Langa KM: Advance directives and outcome of surrogate decision making before death. *N Engl J Med* 2010;362:1211–1218.
- Winzelberg GS, Hanson LC, Tulsky JA: Beyond autonomy: Diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc* 2005;53:1046–1050.
- Sudore RL, Mehta KM, Simonsick EM, Harris TB, Newman AB, Satterfield S, Rosano C, Rooks RN, Rubin SM, Ayonayon HN, Yaffe K, for the Health, Aging and Body Composition Study: Limited literacy in older people and disparities in health and healthcare access. *J Am Geriatr Soc* 2006;54:770–776.
- Sudore R: Prepare for Your Care. www.prepareforyourcare.org. (Last accessed June 29, 2013.)
- Sudore RL, Schillinger D: Interventions to improve care for patients with limited health literacy. *J Clin Outcomes Manage* 2009;16:20–29.

37. National POLST Paradigm Task Force: www.ohsu.edu/polst/programs/state+programs.htm. (Last accessed January 16, 2013.)
38. Tolle SW, Tilden VP, Nelson Ca, Dunn PM: A prospective study of the efficacy of the physician order form for life-sustaining treatment. *J Am Geriatr Soc* 1998;46:1097-1102.
39. Lee MA, Brummel-Smith K, Meyer J, Drw N, London MR: Physician orders for life-sustaining treatment (POLST): Outcomes in a PACE program. *J Am Geriatr Soc* 2000;48:1343-1344.
40. Hickman SE, Nelson CA, Moss AH, Hammes BJ, Terwilliger A, Jackson A, Tolle SW: Use of the Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in the hospice setting. *J Palliat Med* 2008;12:133-141.
41. O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, Homes-Rovner M, Barry M, Jones J: Decision aids for patients facing health treatment or screening decisions: A systematic review. *BMJ* 1999;319:731-734.
42. Whelan T, Levine M, Willan A, Gafni A, Sanders K, Mirsky D, Chambers S, O'Brien AM, Reid S, Dubois S: Effects of a decision aid on knowledge and treatment decision making for breast cancer surgery. *JAMA* 2004;292:235-441.
43. Pignone M, Harris R, Kinsinger L: Videotape-based decision aid for colon cancer screening: A randomized controlled trial. *Ann Intern Med* 2000;133:761-769.
44. Kennedy ADM, Sculpher MJ, Coulter A, Dwyer N, Rees M, Abrams KR, Horsely S, Cowley D, Kidson C, Kirwin C, Naish C, Stirrat G: Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: A randomized controlled trial. *JAMA* 2002;288:2701-2708.
45. Green MJ, Peterson SK, Baker MW, Harper GR, Friedman LC, Rubinstein WS, Mauger DT: Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility. *JAMA* 2004;292:442-452.
46. Barry MJ: Health decision aids to facilitate shared decision making in office practice. *Ann Intern Med* 2002;136:127-135.
47. Frosch DL, Kaplan RM: Shared decision making in clinical medicine: Past research and future directions. *Am J Prev Med* 1999;17:285-294.
48. Molenaar S, Sprangers MAG, Postma-Schuit FCE, Rutgers EJR, Noorlander J, Hendriks J, DeHaes HCJM: Feasibility and effects of decision aids. *Med Decis Making* 2000;20:112-127.
49. Volandes AE, Paasche-Orlow MK, Barry MJ, Gillick MR, Minaker KL, Chang Y, Cook EF, Abbo ED, El-Jawahri A, Mitchell SL: Video decision support tool for advance care planning in dementia: A randomized controlled trial. *BMJ* 2009;338:b2159.
50. El-Jawahri A, Podgurski LM, Eichner AF, Plotkin SR, Temel JS, Mitchell SL, Chang Y, Barry MJ, Volandes AE: Use of video to facilitate end-of-life discussions with patients with cancer: A randomized controlled trial. *J Clin Oncol* 2010;28:305-310.
51. Volandes AE, Brandeis GH, Davis AD, Paasche-Orlow MK, Gillick MR, Chang Y, Walker-Corkery ES, Mann E, Mitchell SL: A randomized controlled trial of a goals of care video for elderly patients admitted to skilled nursing facilities. *J Palliat Med* 2012;15:805-811.
52. Volandes A, Davis AD: Advance Care Planning Decisions. www.acpdecisions.org/about-us/. (Last accessed June 29, 2013.)
53. Hanson L. Improving Decision Making about Feeding Options in Advanced Dementia. www.med.unc.edu/pcare/resources/feedingoptions. (Last accessed June 29, 2013.)
54. Hanson LC, Carey TS, Caprio AJ, Lee TJ, Ersek M, Garrett J, Jackman A, Gilliam R, Wessell K, Mitchell SL: Improving decision-making for feeding options in advanced dementia: A randomized controlled trial. *J Am Geriatr Soc* 2011;59:2009-2016.
55. Ersek M, Grant MM, Kraybill BM: Enhancing end-of-life care in nursing homes: Palliative care educational resource team (PERT) program. *J Pall Med* 2005;8:556-566.
56. Back AL, Arnold RM, Baile WF, Fryer-Edwards KA, Alexander SC, Barley GE, Gooley TA, Tulsy JA: Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* 2007;167:453-460.
57. Scheunemann LP, McDevitt M, Carson S, Hanson LC: Randomized, controlled trials to improve communication in intensive care: A systematic review. *Chest* 2011;139:143-154.
58. 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;356:469-478.
59. Schneiderman LJ, Gilmer T, Teetzel HD, et al.: Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: A randomized controlled trial. *JAMA* 2003;290(9):1166-1172.
60. Azoulay E, Pochard F, Chevret S, et al.: Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: A multicenter, prospective, randomized, controlled trial. *Am J Respir Crit Care Med* 2002;165(4):438-442.
61. Halpern SD: Shaping end-of-life care: Behavioral economics and advance directives. *Semin Respir Crit Care Med* 2012;33:393-400.
62. Epstein RM, Alper BS, Quill TE: Communication evidence for participatory decision making. *JAMA* 2004;291:2359-2366.
63. Torke AM, Alexander GC, Lantos J: Substituted judgement: The limitations of autonomy in surrogate decision making. *J Gen Intern Med* 2008;23:1514-1517.
64. Kiely DK, Prigerson H, Mitchell SL: Health care proxy grief symptoms before the death of nursing home residents with dementia. *Am J Geriatr Psychiatry* 2008;16:664-673.
65. Yourman LC, Lee SJ, Schonberg MA, Widera EW, Smith AK: Prognostic indices for older adults: A systematic review. *JAMA* 2012;307:182-192.
66. Glare PA, Sinclair CT: Palliative medicine review: Prognostication. *J Palliat Med* 2008;11:84-103.
67. Robinson TM, Alexander SC, Hays M, Jeffreys AS, Olsen MK, Rodriguez KL, Pollak KI, Abernethy AP, Arnold R, Tulsy JA: Patient-oncologist communication in advanced cancer: Predictors of patient perception of prognosis. *Support Care Cancer* 2008;16:1049-1057.
68. Zier LS, Sottile PD, Hong SY, Weissfield LA, White DB: Surrogate decision makers' interpretation of prognostic information: A mixed methods study. *Ann Intern Med* 2012;156:360-366.
69. Weeks JC, Catalano PJ, Cronin A, Finkelman MD, Mack JW, Keating NL, Schrag D: Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med* 2012;367:1616-1625.

70. Lee Char SJ, Evans LR, Malvar GL, White DB: A randomized trial of two methods to disclose prognosis to surrogate decision makers in intensive care units. *Am J Respir Crit Care Med* 2010;182:905-909.
71. Graham ID, Logan J, Bennett CL, Presseau J, O'Connor AM, Mitchell SL, Tetroe JM, Cranney A, Hebert P, Aaron SD: Physicians' intentions and use of three patient decision aids. *BMC Medical Informatics and Decision Making* 2007; 7:20.

Address correspondence to:
Laura C. Hanson, MD, MPH
Division of Geriatric Medicine
UNC Palliative Care Program
CB 7550, 5003 Old Clinic Building
University of North Carolina
Chapel Hill, NC 27599-7550
E-mail: lhanson@med.unc.edu

This article has been cited by:

1. Kelley Amy S., Langa Kenneth M., Smith Alexander K., Cagle John, Ornstein Katherine, Silveira Maria J., Nicholas Lauren, Covinsky Kenneth E., Ritchie Christine S.. Leveraging the Health and Retirement Study to Advance Palliative Care Research. *Journal of Palliative Medicine*, ahead of print. [[Abstract](#)] [[Full Text HTML](#)] [[Full Text PDF](#)] [[Full Text PDF with Links](#)]