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Earlier Hospice Referrals among Recommendations to Improve End-of-Life Care

Nationwide efforts to improve the quality of care delivered to dying patients have a nearly four-decade history, spanning the establishment of individual patients' rights, identification of clinical barriers to progress, and improvement of delivery systems. But if progress in improvement is to continue, more work is needed in all of these areas, including overcoming barriers to timely hospice referral, according to an article published in *The New England Journal of Medicine*.

"Nearly 40 years of intensive work to improve care at the end of life has shown that aligning care with patients' needs and preferences in order to ease the dying process is surprisingly difficult," write the authors, who also authored the updated 2013 edition of the 1987 groundbreaking ethical guidelines on the topic from the Hastings Center.

"More work is needed at all levels — to protect patients' rights to choose care options, to improve the quality of clinical care and clinicians' responsiveness to patients and families, and to create well-functioning health care finance and delivery systems that make high-quality care genuinely available."

The authors identify stages in the history of the nation's end-of-life care improvement efforts, assessing the impact of each, and propose strategies for continued progress.

"This history has demonstrated the need to attack the problem at all levels, from individual rights, to family and caregiving relationships, to institutional and health systems reform," write the authors. "Facing death will never be easy, and controversial cases are inevitable. Yet, too large a gulf remains between the theory and the practice of end-of-life care."

RECOMMENDED STRATEGIES FOR CONTINUED PROGRESS

- 1. Communication skills training** for all professionals caring for patients and their surrogates facing critical treatment decisions can help them support informed decision making under stressful conditions.
- 2. Systemic improvements** can be designed to assist all professions caring for patients who are nearing the end of life and/or confronted with decisions about life-sustaining treatment.
- 3. Financing reforms** should be enacted to counter current "misaligned financial incentives," which work against patients' preferences and safety. Problems caused by existing incentives include: referrals of dying patients for dialysis or to intensive care units; insertion of feeding tubes in patients with Alzheimer's disease; transfers of dying nursing home residents to hospitals to shift the cost; and late hospice referrals for cancer patients.

Source: "Forty Years of Work on End-of-Life Care — From Patients' Rights to Systemic Reform," *The New England Journal of Medicine*; February 12, 2015; 372(7):678-682. Wolf SM, Berlinger N, Jennings B; Consortium on Law and Values in Health, Environment, and the Life Sciences, University of Minnesota, Minneapolis; the Hastings Center, Garrison, New York; and the Center for Humans and Nature, Dobbs Ferry, New York.

Hospital Clinicians Identify Patient and Family Factors as Chief Barriers to Goals of Care Discussions

Physicians see greater role for nurses and other health care professionals

Hospital-based clinicians consider that family-related and patient-related issues pose the greatest obstacles to discussing goals of care (GOC) decisions with seriously ill patients and their families, more so than any clinician or system factors, Canadian researchers have found. Difficulty accepting a poor prognosis or understanding treatment options, family disagreement about GOC, and lack of decision making capacity were cited as the most important barriers.

Further, physicians are in favor of the inclusion of other members of the health care team in conducting certain aspects of end-of-life care discussions, according to a report on the findings of the large national study, which was published in the *Journal of the American Medical Association*.

“All study participants viewed staff physicians and residents as the most acceptable professional groups to engage in communication and decision making about goals of care,” write the authors. However, “they also believed that a range of clinician groups could play a role in several other key activities, including initiating goals of care discussions and acting as a decision coach.”

Because two aspects of end-of-life care found to be of crucial importance to seriously ill hospitalized patients are communication and decision making about GOC, the researchers hope their findings aid efforts to improve end-of-life care by tailoring interventions to address existing barriers, in this case from the perspective of clinicians.

Investigators analyzed survey responses of 1256 clinicians who were on a medical teaching unit in one of 13 hospitals across seven Canadian provinces from September 2012 to March 2013. Participants were staff physicians (n = 260), internal medicine residents (n = 484), and nurses (n = 512). Respondents rated the

importance of each barrier to GOC discussions on a 7-point scale, with 1 being “extremely unimportant” and 7 indicating “extremely important.”

All three clinician groups consistently identified family- and patient-related factors as being the greatest barriers (“somewhat” to “very” important) to conducting GOC discussions.

BARRIERS TO DISCUSSING GOC DECISIONS

- Family members’ difficulty in accepting a poor prognosis (mean score, 5.8 [\pm standard deviation, 1.2])
- Patients’ difficulty in accepting a poor prognosis (5.6 [1.3])
- Family members’ or patients’ difficulty in understanding the limitations and/or complications of life-sustaining treatments (5.8 [1.2] for both groups)
- Lack of agreement among family members about GOC (5.8 [1.2])
- Incapacity of patients to make GOC decisions (5.6 [1.2])

Only two clinician factors were rated as being “somewhat” important barriers: prognostic uncertainty (5.1 [1.2]) and lack of time (5.1 [1.5]), with nurses rating these factors higher than did staff physicians or residents. “Clinicians perceived their own skills and system factors as relatively less important barriers,” note the authors. Desire to maintain hope (4.2 [1.5]) and fear of litigation (3.5 [1.8]), were viewed as the least important barriers.

Staff physicians indicated the most willingness to engage in communication and decision making about GOC, with residents only slightly less willing. However, a higher percentage of residents reported having formal training in GOC discussions than did staff physicians (34.9% vs 28.5%). Nurses, who had the lowest group percentage of formal training in end-of-life care discussions (9.6%)

were neutral about feeling supported in the role of communicating about GOC, but willing to initiate discussions and act as GOC coaches.

STUDY IMPLICATIONS

“Our study has implications for the future development of interventions aimed at improving communication about goals of care among clinicians, patients, and families,” state the authors. “Promising interventions include more and better communication skills training for clinicians, conversation guides for discussion of prognosis, decision aids to support advance care planning, and greater involvement of the interprofessional health care team in this important process of care.”

CLINICIAN TRAINING AND TOOLS

The finding that family/patient difficulty in accepting prognosis was seen as a key barrier to GOC discussions may be a reflection of the high levels of anxiety and denial often experienced in the hospital setting by seriously ill patients and their families, note the authors. Navigating discussions involving strong feelings requires effective communication skills.

The authors recommend more clinician training in communication skills and improved tools to aid them in supporting patients/families through the decision-making process by enhancing clinicians’ ability to build rapport, listen with empathy, and discuss prognosis.

PATIENT DECISION AIDS

Decision aids should be developed to improve patient and family preparedness to discuss GOC, suggest the authors. Such aids would assist patients with advance care planning and increase their knowledge about life-sustaining treatments prior to an acute event and hospitalization.

“It is crucial, however, that such tools

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Clinician Resources: Having ‘The Conversation’ Can Help Improve Quality of Life for Dying Patients

“Much of the medical care that is delivered at the end of life to patients in the advanced stages of a disease would largely be rejected if patients and families had a better sense of what it involved,” writes Angelo E. Volandes, MD, MPH, in his book arguing that all patients, families, and physicians should be talking about death.

Volandes, a staff physician at Massachusetts General Hospital in Boston, believes that the fallout from the giant advances made in medical technology in recent decades has led to an “assault of medical interventions at the very end of life,” most of which are unwanted and could be avoided if patients talked to their families and physicians about how they want to die.

In his book, entitled *The Conversation: A Revolutionary Plan for End-of-Life Care*, Volandes urges all parties to establish “a new standard of care” for those facing the end of life, and provides lists of questions as guides for starting the dialogue.

“Patients can drive change by having greater knowledge of their options, while doctors can drive change by communicating and advocating for those choices,” Volandes writes. “Doctors have good reason to be the catalysts of change; every doctor knows that in the end, we all find ourselves on the patient’s side of the stethoscope.

“When patients have honest exchanges and have the tools necessary to understand their choices at the end of life, then

Questions All Physicians Should Ask Their Patients

- What kinds of things are important to you in your life?
- If you were not able to do the activities you enjoy, are there any medical treatments that would be too much?
- What fears do you have about medical care or getting sick?
- Do you have any spiritual, religious, philosophical, or cultural beliefs that guide you when you make medical decisions?
- If you had to choose between living longer or having a higher quality of life, which would you pick?
- How important is it for you to be at home when you die?

— Adapted from A.E. Volandes
The Conversation: A Revolutionary Plan for End-of-Life Care

they — not the health care system — remain in charge of decisions about how they want to live,” states Volandes, who is also an assistant professor of medicine at Harvard Medical School.

The book is published by Bloomsbury USA, 2015; ISBN-13: 978-1620408544 (Hardcover); 240 pp.

Goals of Care Discussions (from Page 2)

not be considered as a replacement for meaningful communication among clinicians, patients, and families,” caution the authors. “Rather, use of decision support tools can precede, facilitate, and support subsequent goals of care discussions that clinicians need to have with their patients and their families.”

EXPANDED ROLES FOR OTHER CLINICIAN GROUPS

Future interventions to improve end-of-life care could support the involvement of many other health care professionals in certain aspects of GOC discussions, such as initiating discussions and acting as GOC coaches. “[T]here is growing interest in improving the quality of health care and shared decision making through greater interprofessional collaboration within multidisciplinary

health care teams,” the authors observe.

EDUCATION IS THE FIRST STEP

“These findings suggest a way to improve goals of care discussions that is in line with the recent Institute of Medicine report ‘Dying in America’ and the work of many others: empower and even task nurses and other non-physician health care professionals to explore goals of care with patients and families,” writes James N. Kirkpatrick, MD, assistant professor of medicine at the Hospital of the University of Pennsylvania in Philadelphia, in his commentary accompanying the report.

From as early as the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) findings, first reported 20 years ago in the U.S., research has consistently shown that seriously ill patients, even if they have

completed an advance directive, rarely communicate their end-of-life preferences to physicians, Kirkpatrick notes.

Because nurses usually spend more time with patients, they are more likely than physicians to have an idea of a patient’s goals and values, and thus would be well placed to initiate discussions, act as decision coaches, and administer decision aids. Physicians would then exchange information and assist patients and families in making final decisions. “A clear first step, however, must be education,” Kirkpatrick states.

Source: “Barriers to GOC Discussions with Seriously Ill Hospitalized Patients and Their Families: A Multicenter Survey of Clinicians,” *Journal of the American Medical Association*; April 1, 2015; 175(4):549-556. You JJ et al, *McMaster University, Hamilton, Ontario*. “GOC Discussion: How Hard It Can Be,” *ibid.*, pp. 557-558. Kirkpatrick JN; *Cardiovascular Division, Department of Medicine, University of Pennsylvania, Philadelphia*.



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When life expectancy can be measured in weeks or months, hospice is usually the best option.

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- Arrhythmias resistant to treatment
- Ejection fraction < 20%

Call us any time, any day.

Geoffrey Coleman, MD
Medical Director
Montgomery Hospice



Earlier Support Reduces Risk for Depression among Caregivers

Initiating a telehealth palliative care intervention — along with a parallel caregiver intervention — soon after a patient’s advanced cancer diagnosis was found to lower depression and the emotional/stress burden experienced by family caregivers, according to a report published in the *Journal of Clinical Oncology*.

“Recognizing that palliative support for patients and families is often initiated late in the illness trajectory, we sought to determine whether providing this extra layer of support further upstream would result in a greater benefit,” write the authors. “[Our] findings suggest that providing caregiver support at the time of advanced cancer diagnosis may be the essential ingredient to achieving positive outcomes.”

In a randomized controlled trial conducted from 2010 to 2013, patients who were newly diagnosed with advanced-stage recurrent or progressive metastatic cancer (n = 207) and their family caregivers (n = 122) were randomly assigned to either an early (immediately after assignment) or a delayed (3 months after diagnosis) intervention group.

The telehealth caregiver intervention consisted of three weekly structured coaching sessions, monthly follow-up, and a bereavement call. In the one-on-one coaching sessions, advanced practice palliative care nurses provided caregivers

with informational, emotional, and problem-solving support. Key findings:

- Between-group differences in depression at 3 months (before the delayed group received the intervention) were significantly better in the early group compared with delayed group (mean difference, -3.4 on a 0–60 scale; standard error [SE], 1.5; $P = .02$).
- Terminal-decline differences in depression (using data from the last 36 weeks of the decedent’s life) between groups favored the early-intervention group (mean difference, -3.8 on a 0–60 scale; SE, 1.5; $P = .02$).
- Terminal-decline differences in stress burden also favored the early group (mean difference, -1.1 on a 0–20 scale; SE, 0.4; $P = .01$).

“Future work should continue to devise ways to alleviate the number of tasks and hours individuals spend caregiving and focus on optimizing their physical health,” the authors conclude.

Source: “Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients with Advanced Cancer: Outcomes from the ENABLE III Randomized Controlled Trial,” *Journal of Clinical Oncology*; Epub ahead of print, March 23, 2015; pii: LCO.2014.58.7824. Dionne-Odom JN et al; University of Alabama at Birmingham, Birmingham; and Dartmouth College, Hanover, New Hampshire.