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Improving End-of-Life Care

The following summaries of recent peer-reviewed studies, non-peer-reviewed articles, and resources describe factors that enhance end-of-life care and reduce patient suffering. Citations are linked to full-text articles when available. **[PG]** denotes Press Ganey research.

Peer-Reviewed Studies

Study	Objective	Conclusion
Hudak, C. D., & von Gunten, C. (2016). "The Talk:" Discussing hospice care. *Current Oncology Reports, 18*(7), 46.	To frame a communication approach that any oncologist can incorporate into his/her practice to facilitate the timely referral of appropriate patients for hospice care.	▪ The following model can facilitate conversations with patients about hospice: 1. Establish a setting – Schedule a meeting with the patient and family members to discuss overall goals of care 2. Assess patient understanding – Ask open-ended questions to find out what the patient understands about her/his health situation and how much information s/he wants to know 3. Identify patient expectations – Ask the patient what s/he wants the future to look like and reflect back the words the patient uses. Use the opportunity to educate patients who have inaccurate or exaggerated fears 4. Discuss hospice – Review patient's goals and, if fitting, suggest that hospice is the best way to meet those goals. Offer an informational hospice visit. 5. Respond to emotions – Respectful silence on the part of the physician can be a powerful initial response to the variety of emotions patients may express 6. Establish a plan – If the patient is agreeable, arrange the hospice informational visit and schedule a follow-up call or visit with the patient
Bomba, P. A., & Orem, K. (2015). Lessons learned from New York's community approach to advance care planning and MOLST. *Annals of Palliative Medicine, 4*(1), 10-21.	To review the lessons learned from New York's community approach to advance care planning as a wellness initiative.	▪ Effective advance care planning models promote culture change through professional training, community education, system implementation, and continuous performance improvement. ▪ Community engagement through education and empowerment promotes awareness and readiness for advance care planning discussions. ▪ Health care and community collaborative partnerships can be formed by engaging individuals with faith-based, patient advocacy, community, and professional organizations to help achieve the goal of advance care planning as a wellness initiative.
Cagle, J. G., Pek, J., Clifford, M., Guralnik, J., & Zimmerman, S. (2015). Correlates of a good	To identify correlates of a good death and provide evidence on the	▪ The perceived knowledge and expertise of providers has a direct effect on quality of death. ▪ Oncology providers should strive to stay informed

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death and the impact of hospice involvement: Findings from the national survey of households affected by cancer. *Supportive Care in Cancer, 23*(3), 809-818.	impact of hospice on quality of death.	about best practices for end-of-life care—including ways to improve communication about end-of-life matters, enhance bedside compassion, manage pain and other distressing symptoms, and attend to non-medical factors like coping and social support. ▪ Hospice is strongly associated with quality of death, and high-quality pain management is the leading reason. Providers should be vigilant about tailoring treatments to patient wishes and timely referrals to hospice.

Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C., . . . Casarett, D. J. (2015). Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain and Symptom Management, 49*(4), 773-781.	To recommend a concise portfolio of valid, clinically relevant, cross-cutting indicators for internal measurement of hospice and palliative care.	▪ Meeting the following 10 quality measures can help providers reduce avoidable physical and emotional suffering in palliative care patients:
		  − Comprehensive assessment
		  − Screening for physical symptoms
		  − Pain treatment
		  − Dyspnea screening and management
		  − Discussion of emotional/psychological needs
		  − Discussion of spiritual/religious concerns
		  − Documentation of surrogate
		  − Treatment preferences
		  − Care consistency with care preferences
		  − Global indicator of patient/family perceptions

Keary, S., & Moorman, S. M. (2015). Patient-physician end-of-life discussions in the routine care of Medicare beneficiaries. *Journal of Aging and Health, 27*(6), 983-1002.	To explore correlates of doctor-patient end-of-life discussions.	▪ Patients who have end-of-life discussions with their doctors have significantly greater trust in their physicians than patients who do not have such discussions. ▪ Patients whose physicians have end-of-life discussions with them are significantly more likely to complete advance care planning with their family members than those who do not.
Nathaniel, J. D., Garrido, M. M., Chai, E. J., Goldberg, G., & Goldstein, N. E. (2015). Cost savings associated with an inpatient palliative care unit: Results from the first two years. *Journal of Pain and Symptom Management, 50*(2), 147-154.	To compare cost saving of Mount Sinai Hospital's specialized palliative care unit (PCU) to those of the palliative care consultation services (PCCS).	▪ Transferring patients to the PCU is associated with decreasing direct costs. ▪ The PCU provides more cost savings than PCCS for patients who die in the hospital.
Singer, A. E., Meeker, D., Teno, J. M., Lynn, J., Lunney, J. R., & Lorenz, K. A. (2015). Symptom trends in the last year of life from 1998 to 2010: A cohort study. *Annals of Internal Medicine, 162*(3), 175-183.	To describe changes in pain intensity and symptom prevalence during the last year of life from 1998 to 2010.	▪ Between 1998 and 2010, reports of serious pain and other distressing symptoms became more common near the end-of-life. ▪ Some patients may not have consistent access to services that reduce suffering such as palliative services in outpatient, home, and long-term facility settings (where most of the course of a terminal illness

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		takes place). ▪ Patients who have short hospice stays may not be able to realize the full benefits of suffering reduction through symptomatic relief.

Virdun, C., Luckett, T., Davidson, P. M., & Phillips, J. (2015). Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine, 29*(9), 774-796.	To ascertain the most important elements of inpatient end-of-life care as identified by patients with palliative care needs and their families.	▪ The most important elements of inpatient end-of-life care as identified by patients with palliative care needs and their caregivers has remained consistent for over two decades:
		   – Effective communication and shared decision making to limit futile treatments and enable end-of-life preparation
		   – Expert physical care, symptom management and integrated care
		   – Respectful and compassionate care to preserve dignity
		   – Trust and confidence in clinicians
		   – Adequate environment for care
		 ▪ Minimizing burden and the importance of financial affairs

Zadeh, S., Pao, M., & Weiner, L. (2015). Opening end-of-life discussions: How to introduce Voicing My CHOiCES, an advance care planning guide for adolescents and young adults. *Palliative and Supportive Care, 13*(3), 591-599.	To introduce the Voicing My CHOiCES™ guide to health care providers to help them incorporate end-of-life planning with terminally ill adolescents and young adults.	▪ Adolescents and young adults want to discuss end-of-life issues with health care providers they trust. ▪ Health care providers must delicately balance the need to respect and maintain hope while promoting meaningful conversations throughout the illness trajectory, including when death approaches. ▪ Voicing My CHOiCES™ can potentially be a "blueprint" and legacy document that reaffirms the child's self-worth and fulfills their final wishes.

Abdul-Razzak, A., You, J., Sherifali, D., Simon, J., & Brazil, K. (2014). "Conditional candour" and "knowing me:" An interpretive description study on patient preferences for physician behaviours during end-of-life communication. *BMJ Open, 4*(10), e005653.	To understand patients' preferences for physician behaviors during end-of-life communication.	▪ Patients prefer a nuanced approach to truth-telling when having end-of-life discussions with physicians.
		 ▪ Two types of physician behaviors are beneficial during end-of-life conversations:
		   – Attentiveness to a patient's background, social, and family roles (i.e., "knowing me")
		   – An evaluation of a patient's readiness to engage in end-of-life conversations, being invited to the conversation, and attentiveness to contextual factors, such as appropriate timing and sensitive word choice (i.e., "conditional candor")

Brinkman-Stoppelenburg, A., Rietjens, J. A., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine, 28*(8), 1000-1025.	To present an overview of studies on the effects of advance care planning and gain insight in the effectiveness of different types of advance care planning.	▪ Advance care planning positively impacts the quality of end-of-life care. ▪ Complex advance care planning interventions (e.g., use of palliative care consultation teams) may be more effective in meeting patients' preferences than written documents alone.

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Houben, C. H., Spruit, M. A., Groenen, M. T., Wouters, E. F., & Janssen, D. J. (2014). Efficacy of advance care planning: A systematic review and meta-analysis. *Journal of the American Medical Directors Association, 15*(7), 477-489.	To systematically review the efficacy of advance care planning interventions in different adult patient populations.	▪ Advance care planning interventions increase the completion of advance directives, the occurrence of discussions about end-of-life care preferences, and the concordance between patients' preferences and end-of-life care received in different adult populations. ▪ Advance care planning interventions are likely to improve other outcomes for patients and their loved ones, such as quality of communication. ▪ Advance care planning interventions seem to have no detrimental effect on anxiety, depression, and psychological well-being.
Parry, R., Land, V., & Seymour, J. (2014). How to communicate with patients about future illness progression and end-of-life: A systematic review. *BMJ Supportive & Palliative Care, 4*(4), 331-341.	To synthesize observational evidence about how people communicate about sensitive future matters.	▪ Posing hypothetical questions strongly encourages patients to discuss end-of-life feelings and plans. ▪ Indirect references to difficult issues are a more gentle way of introducing end-of-life topics compared with posing hypothetical questions, but some patients will respond readily and others will deflect.
Ranganathan, A., Gunnarsson, O., & Casarett, D. (2014). Palliative care and advance care planning for patients with advanced malignancies. *Annals of Palliative Medicine, 3*(3), 144-149.	To detail the importance of advance care planning and demonstrate the role of palliative care specialists in early communication with advanced cancer patients.	▪ Delayed advance care planning discussions frequently result in unwanted care that does not improve or extend a patient's life. ▪ Early introduction of palliative care improves mood, quality of life, and patient satisfaction. It also reduces emergency department visits, hospital, and intensive care admissions and can improve overall survival. ▪ Early initiation of palliative care achieves many of the desired outcomes of early advance care planning and may represent the most effective modality of supporting patients through early discussions of their personal treatment preferences.
Doll, K. M., Stine, J. E., Van Le, L., Moore, D. T., Bae-Jump, V., Brewster, W. R., . . . Kim, K. H. (2013). Outpatient end-of-life discussions shorten hospital admissions in gynecologic oncology patients. *Gynecologic Oncology, 130*(1), 152-155.	To determine whether prior outpatient exposure to hospice discussion altered the inpatient course and end-of-life care among patients ultimately discharged to hospice.	▪ Patients exposed to a hospice discussion have significantly shorter overall survival suggesting that providers are accurate in identifying patients nearing the end-of-life. ▪ Patients exposed to outpatient hospice discussions have a shorter length of stay and increased utilization of palliative care resources.
Motley, M. (2013). Improving patient-centered care through advance care planning. *Journal of the American Academy of Physician Assistants, 26*(6), 38-43.	To describe how discussing end-of-life issues can reduce overtreatment and undertreatment and improve patient satisfaction with care.	▪ Communication between patients and surrogates before a medical crisis is crucial to in-the-moment decision making. ▪ Advance care planning meetings are a medium through which the clinician can clarify the patient's questions, fears, and values. ▪ An increased frequency of clinician-guided end-of-life discussions of all levels of care can lead to improved patient-centered care.

Study	Objective	Conclusion
Green, M. J., & Levi, B. H. (2012). The era of "E": The use of new technologies in advance care planning. *Nursing Outlook, 60*(6), 376-383.	To review developments in technology that can help patients, their loved ones, and health care providers engage in more effective advance care planning.	▪ E-resources for advance care planning represent an increasingly valuable set of tools for improving care when patients cannot speak for themselves. ▪ Well-designed e-resources can help better inform individuals about decisions that might need to be made; challenge them to think deeply about what matters to them and why; encourage dialogue with loved ones, health care providers, and others; and promote greater access to a variety of advance care planning materials and methods.
Hanratty, B., Lowson, E., Holmes, L., Grande, G., Jacoby, A., Payne, S., . . . Whitehead, M. (2012). Breaking bad news sensitively: What is important to patients in their last year of life? *BMJ Supportive & Palliative Care, 2*(1), 24-28.	To understand how to mitigate suffering by improving the practice of communicating bad news to patients.	▪ The pace and clarity of communication are particularly important to patients when they are receiving bad news from their care provider. ▪ More time to build up giving bad news is required, especially for new patients where a relationship with the care provider has not already been established. ▪ Planning is needed to meet the practical and emotional aspects of breaking bad news, for example, suggesting that a relative accompany the patient receiving results or having a counselor available.

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Non-Peer-Reviewed Articles

Article	Overview	Highlights
Aronczyk, A. (2015, February 10). Cancer patients and doctors struggle to predict survival. *NPR.*	To discuss the shortcomings of providing accurate prognoses to terminally ill patients and share a role-playing approach for training physicians to talk about prognoses with their patients.	▪ Doctors consistently overestimate how long terminally ill patients have to live which can prevent patients from fulfilling key goals before they die. ▪ To train physicians to effectively discuss prognoses with patients, role play using the following format: – Set an agenda for the discussion – Ask the "patient" what he or she wants from the session – Present the prognosis as a best-case, worst-case, and most-likely scenario
Gabow, A. (2015). The fall: Aligning the best care with standards of care at the end of life. *Health Affairs, 34*(5), 871-874.	To discuss how health care systems must better align standards of care with end-of-life goals.	▪ Standards of care are essential in reducing unwanted variability in the care of patients with similar clinical problems, but they need to be adapted for the patient population and the individual patient being treated. ▪ Standards of care, particularly at the end-of-life, should be adapted to be more flexible with branch points reflecting—for example—a patient's age, overall condition, and desires. ▪ Health policies and our health care system should evolve to keep what is good about standards of care in reducing inappropriate variability, while learning to align them with patients' goals and values, particularly at the end-of-life.
Gawande, A. (2014, October 6). No risky chances: The conversation that matters most. *Slate.*	To examine how medicine often fails patients at end-of-life and what can be done to help patients have meaning until the end of life.	▪ Without a coherent view of how people might live successfully until death, the fates of patients at end-of-life are often controlled by medicine, technology, and strangers. ▪ The medical profession needs to refashion our institutions, culture, and conversations to transform the possibilities for end-of-life care. ▪ Clinicians can gain insights into patients' end-of-life priorities—beyond being safe and living longer—by asking about their fears, concerns, goals, and about the sacrifices they are willing to make.
Gawande, A. (2015, May 11). Overkill. *The New Yorker.*	To explore the repercussions of overtesting and overtreatment in the U.S. health care system.	▪ Millions of people are receiving drugs that are not helping them, operations that are not going to make them better, and scans and tests that do nothing beneficial for them, and that often cause harm. ▪ Overtesting is a by-product of the many new technologies available for examining the human body. ▪ Overtesting is problematic because some diagnostic studies are harmful in and of themselves. Overtesting also leads to overdiagnosis (i.e., the correct diagnosis of a disease that will never pose a problem to the patient in his or her lifetime).

Article	Overview	Highlights
Minnier, T. (2015, April 16). "Tell me who is important to you" - Opening the door to end-of-life discussions. *Institute for Innovation.*	To share how the University of Pittsburgh Medical Center (UPMC) deepened the patient-clinician relationship by expanding the practice of asking patients about their emergency contacts.	▪ In addition to asking patients for emergency contact information upon admission, UPMC floor nurses also say, "Tell me who is important to you." This demonstrates that the nurse wants to know about patients' unique relationships and circumstances. ▪ Nurses can follow up with the question, "Is that the person you'd want to make decisions if you couldn't?" to create an opportunity to offer an advance directive choice form.
[PG] Mylod, D. (2015, March 4). Encouraging end-of-life discussions to improve care, enhance patient decision making and reduce suffering. *Institute for Innovation.*	To summarize key approaches to promoting good end-of-life discussions and documentation.	▪ Put training programs in place to help staff know when and how to broach the topic of end-of-life planning with patients. ▪ Encourage clinicians to address their own end-of-life planning as part of their training in order to become more comfortable with the process and to have authentic personal experience to share with patients. ▪ Standardize questions, discussion, and documentation for all patients—not just those in decline—to remove some of the emotional intensity and help clinicians become more comfortable with the topic.

Reddy, S. (2015, May 18). How doctors deliver bad news. *The Wall Street Journal.*	To discuss new approaches to help physicians deliver bad news to patients.	▪ If physicians don't balance the physiological basis of disease and treatment of disease with the psychosocial side of medicine, they risk alienating patients and their families.
		▪ Breaking bad news is an opportunity to deepen the patient-doctor relationship.
		▪ SPIKES is one mnemonic physicians use to help break bad news to patients:
		  – Setting
		  – Patient perspective
		  – Information
		  – Knowledge
		  – Empathize/explore emotions
		  – Strategize/summarize

Volandes, A. (2015, April 15). End-of-life care needs an overhaul. *The Boston Globe.*	To discuss how conversations about end-of-life care are essential and empower patients to receive the type of end-of-life medical care they desire.	▪ Patients can have more control over how to spend their final days if doctors fully explain to seriously ill patients all of the options for medical care as the end-of-life approaches—including the choice to forgo countless interventions in advanced illness.
		▪ When discussing end-of-life options, physicians need to ask 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 getting sick or

		medical care?
		− Do you have any spiritual, religious, philosophical, or cultural beliefs that guide you when you make medical decisions?
Volandes, A. (2015, January 11). Prescribing the end-of-life conversation: Is saving the life of a terminal patient always the best medicine? *The Boston Globe.*	To identify the disadvantages of written advance directives and propose video advance directives as an alternative.	▪ A disadvantage to written advance directive forms is that most patients do not complete them and—even if they do—physicians do not have access to them. ▪ The legalistic language of written advance directives makes them difficult to integrate into clinical care and often do not help clarify patients' values. ▪ Video advance directives allow caregivers and others to hear patients' emotional inflections and see their facial expressions—nonverbal information that could help both the health care team and families understand the patient's desires.
Gawande, A. (2014, October 5). The best day possible. *The New York Times.*	To examine the deficiencies of how the medical profession manages mortality and how it can improve.	▪ Payment systems should enable health professionals to take sufficient time to have end-of-life discussions with their patients and tune care accordingly. ▪ Successful end-of-life discussions involve three important questions: − What is the patient's understanding of their health or condition? What are their goals if their health worsens? − What are their fears? − What are the trade-offs they are willing to make and not willing to make? ▪ End-of-life discussions must be repeated over time because patients' answers change and their evolving priorities should be known and respected.

Resources

Organization / Individual	Resource	Description
AARP	Caregiving Resource Center: End-of-life	Information, tools, and tips on end-of-life concerns (e.g., palliative care, pain management, hospice) for individuals caring for someone during the final stages of life.
Advance Care Planning (ACP) Decisions	ACP Decisions	ACP Decisions is a non-profit foundation that seeks to empower patients and families with video support tools for end-of-life care planning.
American Academy of Hospice and Palliative Medicine (AAHPM)	AAHPM	AAHPM is dedicated to advancing hospice and palliative medicine and improving the care of patients with serious illness through education and training, resources, networking, and advocacy.
American Hospital Association (AHA)	Scanning the Headlines: End-of-Life Care	The AHA's bibliography on the topic of end-of-life care.
Center to Advance Palliative Care (CAPC)	CAPC	CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness.
Coda Alliance	The Go Wish Game	The Go Wish card game helps individuals learn how to best comfort loved ones if their lives were shortened by serious illness. A deck of 36 cards describe factors that people often say are important when they are very sick or dying (e.g., how they want to be treated, who they want near them, what matters to them). Individuals sort the cards into three categories: Very Important to Me, Somewhat Important to Me, and Not Important to Me to facilitate discussions with loved ones about end-of-life priorities.
Compassion & Choices	Compassion & Choices	Compassion & Choices is a non-profit organization committed to helping individuals have the best death possible. It offers free consultation, planning resources, referrals and guidance, and work to protect and expand options at the end-of-life.
Engage with Grace	Engage with Grace: The One Slide Project	Engage with Grace: The One Slide Project has created one publicly-available slide with five questions that are designed to help start conversations about end-of-life priorities. The slide can be shared during presentations, at dinner, at a book club meeting, at a conference, or in any venue desired to encourage people to begin talking with each other about their end-of-life preferences.
Gawande, MD, Atul	Being Mortal: Medicine and What Matters in the End	Dr. Gawande, a practicing surgeon, addresses his profession's ultimate limitation, arguing that quality of life is the desired goal for patients and families. He offers examples of freer, more socially fulfilling models for

Organization / Individual	Resource	Description
		assisting the infirm and dependent elderly, and explores the varieties of hospice care to demonstrate that a person's last weeks or months may be rich and dignified.
Gunderson Health System	Respecting Choices® Advance Care Planning	Respecting Choices® is an advance care planning system that includes a person-centered, ongoing process of communication that facilitates individuals' understanding, reflection and discussion of their goals, values and preferences for future health care decisions.
Institute of Medicine (IOM)	Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life	This IOM report presents recommendations in the areas of care delivery, clinician-patient communication and advance care planning, professional education and development, policies and payment systems, and public education and engagement to offer a roadmap for progress in the nation's approach to end-of-life care and management.
Institute of Medicine (IOM)	Vital Signs: Core Metrics for Health and Health Care Progress	This IOM report identifies a set of 15 core measures that constitute the most vital signs for the nation's health and health care. Alternative measures considered by the committee include use of shared decision making, patient ratings of providers, end-of-life care, and likelihood of recommending. The report concludes that end-of-life care is an area in need of significant development in terms of both care and its measurement, and one in which patient and family views and perspectives play a critical role.
Massachusetts Medical Orders for Life-Sustaining Treatment	MOLST	MOLST is a standardized medical order form for use by clinicians caring for patients diagnosed with serious illnesses throughout Massachusetts.
Minnesota Medical Association	Provider Orders for Life-Sustaining Treatment (POLST) Communications	POLST is a standardized medical order form for use by clinicians caring for patients diagnosed with serious illnesses throughout Minnesota.
National Healthcare Decisions Day (NHDD)	NHDD	NHDD is an initiative to encourage patients to express end-of-life health care wishes and for providers and facilities to respect those wishes.
PBS VIDEO	FRONTLINE: Being Mortal	The film follows *New Yorker* writer and Boston surgeon Atul Gawande as he investigates the practice of caring for the dying, and shows how doctors are often untrained, ill-suited, and uncomfortable talking about chronic illness and death with their patients.

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Organization / Individual	Resource	Description
PREPARE	PREPARE	The PREPARE website is designed to help individuals prepare for medical decision making including: − Choosing a medical decision maker − Deciding what medical care matters most − How much flexibility to allow the decision maker − Telling others about medical wishes − Formulating the right questions to ask physicians
The Conversation Project	The Conversation Project	The Conversation Project is dedicated to helping individuals talk about their wishes for end-of-life care. The interactive, online starter kit allows users to type their answers, save a personalized version, and email it to family and friends.
Vital Talk	Vital Talk	VitalTalk is a non-profit specializing in developing and facilitating advanced fee-based communication skills courses and faculty training courses focused on balancing honesty with empathy when discussing serious illness and end-of-life care. It also provides short videos and one-page guides on its website, free of charge.
Volandes, MD, Angelo E.	*The Conversation: A Revolutionary Plan for End-Of-Life Care* Book Overview Video (00:01:55) Book Follow-Up Video (00:05:12) Talks at Google Video (01:00:16)	Through the stories of seven patients and seven different end-of-life experiences, Dr. Volandes argues for a re-envisioning of the patient-doctor relationship and offers ways for patients and their families to talk about this difficult issue to ensure that patients will be at the center and in charge of their medical care.