


SPECIAL CONTRIBUTION

The Practice of Emergency Medicine

Addressing end-of-life care in the chronically ill: Conversations in the emergency department

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Funding and support: By *JACEP Open* policy, all authors are required to disclose any and all commercial, financial, and other relationships in any way related to the subject of this article as per ICMJE conflict of interest guidelines (see www.icmje.org). The authors have stated that no such relationships exist.

Abstract

Patients present to the emergency department in various stages of chronic illness. Advance directives (ADs) aid emergency physicians in making treatment decisions, but only a minority of Americans have completed an AD, and the percentage of those who have discussed their end-of-life wishes may be even lower. This article addresses the use of common ADs and roadblocks to their use from the perspectives of families, patients, and physicians. Cases to examine new approaches to optimizing end-of-life conversations in patients who are chronically ill, such as the Improving Palliative Care in Emergency Medicine Project, a decision-making framework that opens discussion for patients to gain understanding and determine preferences, and the Brief Negotiated Interview, a 7-minute, scripted, motivational interview that determines willingness for behavior change and initiates care planning, are used.

KEYWORDS

advance directives, brief negotiated interview, do not resuscitate orders, durable power of attorney, end-of-life, illness trajectories, improving palliative care in emergency medicine project, living will, physician orders for life-sustaining treatment, shared decision-making

1 | INTRODUCTION

Patients may present to the emergency department (ED) in various stages of chronic illness, from those in whom disease is diagnosed during their ED visit to those in the final hours of life. Common advance directives (ADs) aid emergency providers in treating patients with chronic illnesses. We discuss AD limitations and family, patient, and physician perspectives on ADs. We conclude by using cases to examine

several recent approaches designed to help providers address end-of-life care issues with ED patients.

2 | WHAT COST, AT END OF LIFE?

Historically, life expectancy in the United States increased as a result of advances in healthcare technology, and the location of death moved from the home to the hospital. With the improvement of this technology and the idea that “everything be done,” the cost to implement this

Supervising Editor: David Wampler, PhD, LP.

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technology increased as well. In the United States, the share of Medicare payments in an individual's last year of life was 25.1% in 2006.¹ A total of \$205 billion was devoted to the care of individuals in the last year of their lives in 2011.² With increased life expectancy, the quality of that extended life came into question. There is a clear need to mitigate not only the financial impact of prolonging life but also to improve the quality of life near its end. Herein is the benefit of the modern AD: documentation of patient preferences and wishes to direct care at the end of life.

3 | ADVANCE DIRECTIVES

ADs are intended to provide guidance to assist providers in directing patient care and treatment in cases where the patient lacks decision-making capacity. Some types of ADs are patient-completed directives and others are provider-completed directives. As of 2017, only 36.7% of the American population had completed any AD.³ The percentage of people who have shown their AD to a trusted proxy may be even lower, as conversations between patients and their families concerning end-of-life care can be uncomfortable and difficult. In addition, there is a knowledge gap among providers regarding how this documentation should be interpreted and validated.⁴ Approximately 85% of Americans have at least one chronic medical condition, and one study determined that, during a 15-year period, >50% of the study participants aged 65 years or older had visited an ED in the month before their deaths.^{5,6} This offers emergency clinicians a unique position to begin or refocus discussions about end-of-life care that can continue with other members of the patient's healthcare team. Descriptions of various ADs and their limitations are provided in the next sections.

3.1 | Living will

The living will allows patients to specify interventions they wish to receive or forgo in different medical conditions, including life support measures such as cardiopulmonary resuscitation (CPR), defibrillation, ventilation, dialysis, and artificial hydration and nutrition. Through living wills, patients attempt to strike a balance between their interests in prolonging life and preserving the quality of life. Unfortunately, living wills are often written from the patient's perspective and not in medical terms; therefore, they can be difficult to interpret.⁷ Patients with limited medical knowledge are often unable to specify the precise treatment desired for all the possible end-of-life scenarios that may arise. This is especially true of the acute presentations routinely seen by emergency providers. When family members are called on to be a surrogate decision maker, their ability to understand the complexities of all management options provided by the clinician immediately is unlikely. In addition, these family members are often unfamiliar with the patient's wishes, leading to stress, guilt, and doubt about their choices.⁸ Given the limitations of medical language in living wills, they can be difficult for emergency physicians to use during crises in which decision-making time is limited. Similarly, errors in family understand-

ing of patient wishes compromise their ability to be surrogates during these stressful and timely conversations.

3.2 | Do not resuscitate

The do not resuscitate (DNR) order is perhaps the most well-known AD. It varies by state and even between health facilities, leading to differences in language and potential confusion. Some states offer minimally descriptive language, such as the form for the state of New York, which reads simply, "Do not resuscitate the person named above,"⁹ whereas the state of Ohio offers options for DNR: Comfort Care (DNR-CC) as well as for DNR-Comfort Care Arrest (DNR-CCA).¹⁰ As the Cleveland Clinic's Patient Guide to Personal Medical Decision's section titled "DNR and Code Status Information" describes, "DNR-CCA orders permit the use of life-saving treatments before your heart or breathing stops [while] DNR-CC orders require that only comfort measures be administered before, during, or after the time your heart or breathing stops."¹¹ Implementation of DNR orders typically occurs in the following 3 scenarios: (1) patients or surrogates clearly understand and communicate they do not want advanced cardiovascular life support protocol if the heart or breathing stops; (2) patients or surrogates follow the recommendations of physicians to forgo CPR through the process of informed consent; and (3) when patients are incapacitated, lack an AD or a surrogate, and the physician determines that resuscitation efforts will likely be unsuccessful. Institutional mechanisms may exist for such situations. Alternatively, attending physicians may unilaterally or in collaboration with a patient's primary physician enact a DNR on behalf of the patient because of medical futility. The third scenario was enacted during the COVID-19 pandemic. In these situations, despite maximal interventions, their condition of acute cardiopulmonary failure worsened.¹² It became evident that CPR was non-beneficial to these patients. In the context of medical futility of end-of-life care, a type of "informed assent" in which family may defer to a clinician's judgment about withholding or withdrawing life-sustaining therapy allows the weight of the decision to be largely in the hands of the physician as opposed to the patient or family.¹³

Patients, families, and even physicians can be confused by variations in terminology and treatment specified by the different orders. Without standard language or location for resuscitation orders, physicians may inadvertently violate those orders when acute care is required.¹⁴ Limitation of DNR documentation also extends into the prehospital setting, where access to orders is often inadequate. Even if resuscitative care is not indicated in a patient who is terminally ill, EMS providers must provide the full scope of care if a DNR order is not present and accessible.

3.3 | Physician's Orders for Life-Sustaining Treatment Advance Directive

The Physician's Orders for Life-Sustaining Treatment Advance Directive (POLST; sometimes referred to as POST (Physician Orders on

Scope of Treatment), MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders on Scope of Treatment), etc) provides patients with a transportable end-of-life directive that can be used by all care providers in states that recognize them.¹⁵ POLST orders contain sections with detailed instructions regarding CPR, medical interventions, surrogate information, and the reasons for the orders contained therein. POLST orders focus on goals of care, from aggressive resuscitation to treatments focused on comfort. POLST orders have increased accuracy of care consistent with the patient's wishes, and quality of end-of-life care over other ADs and DNRs.¹⁰ Despite this effectiveness, their novelty in the medical world may result in misinterpretation for providers who are more familiar with other ADs.¹⁶

3.4 | Healthcare power of attorney

The healthcare durable power of attorney, also known as a healthcare proxy or proxy directive, is a legal document in which another individual is granted the authority to make healthcare decisions on behalf of the signer (ie, the patient). It is only implemented when the patient becomes incompetent or unable to make decisions as a result of illness or injury. In the event the patient has not named a legal proxy, family members are called on to become the surrogate decision-maker to make medical decisions on behalf of the patients, representing what the patients would have wanted if they were able to make the decisions for themselves. State-defined hierarchies typically include the patient's spouse, followed by children and then siblings. Arkansas and Ohio are the only states in which it is required that an attending physician specifically certify that a patient is end stage/chronic or permanently unconscious before a surrogate can withhold or withdraw life-sustaining treatment, even with an AD.¹⁷ However, there is much variation in this law from state to state.

3.5 | Nonstandard ADs

Finally, some patients may present to the ED with nonstandard ADs in the form of tattoos or medallions. It is generally agreed that these nonstandard ADs are not acceptable as true, legally binding ADs and should at most be seen as a guide to patient wishes.¹⁸⁻²⁰

4 | ROADBLOCKS AND OPPORTUNITIES TO CARE

Conversations regarding end-of-life wishes, chronic illness, and death are sometimes considered taboo in the United States, leading to a lack of AD completion. Those who are chronically ill must grapple with friends and family in communicating their diagnosis, care plans, and changing quality of life. Also, expressing treatment wishes and goals in documents that cover different clinical scenarios can be difficult. In one study aimed at identifying patient perspectives on the use of ADs

in unanticipated clinical scenarios, 64% of participants believed that a DNR order should not apply in the setting of cardiac arrest, meaning that these patients believed that someone with a DNR order in cardiac arrest could still receive life-saving care.²¹ Similarly, 80.36% of respondents believed that a DNR order does not apply in the setting of pneumonia, 60.99% for a pulmonary embolus, and 56.25% for cancer causing a collapsed lung,²¹ all of which are common cases brought to the ED.

Confusion and unfamiliarity over ADs felt by families and patients are echoed by physicians. In the ED specifically, current literature demonstrates that the greatest roadblocks to using ADs appropriately in medical emergencies include imprecise language, mismatch of protocols, lack of understanding by patients/families, and difficulty accessing the AD.²² The Realistic Interpretation of Advance Directives Research Series found significant differences in application regarding the use of POLST in patients who are critically ill.²³ Physicians were provided scenarios of patients who are critically ill with POLST documents who are in cardiopulmonary arrest and were asked to determine code status and treatment decisions for the cases. When a POLST form specified DNR, decisions to resuscitate ranged from 25% to 74%, and it was only when POLST aligned with a consistent treatment picture (DNR/comfort care only vs CPR/full treatment) that correct treatment responses were 90% to 95%.¹⁶ Similar studies in Oregon, California, and Delaware have led to changes to their POLST documents because of inappropriate use.²⁴⁻²⁷ General statements about treatment preferences in living wills can also be difficult to interpret and apply to specific clinical scenarios. Surrogate decision-makers may not make decisions that reflect patient preferences. The relationship between living wills, surrogate decisions, and portable physician orders may also be unclear.²³ The current literature demonstrates that even when physicians are presented with POLST documentation, there remains confusion on how to enact these end-of-life preferences.

Emergency physicians find themselves in a unique position to explain ADs to their patients in acute settings. To this end, awareness of religious and cultural differences is essential to prevent misunderstandings. Physicians should ask their patients if they wish to consult with a religious leader regarding end-of-life choices. Furthermore, physicians must recognize what social determinants of health may be at hand, contributing to the patient's presentation. Patients may have limited medical literacy, so speaking in plain terms is encouraged. In addition, acknowledging and preventing bias is an ever-present challenge for physicians. Because emergency physicians are both gatekeepers for hospital resources and information providers for patients, AD education for physicians as well as patients can promote both patient autonomy and appropriate care.

5 | OPTIMIZING END-OF-LIFE DISCUSSIONS

Although end-of-life care discussions may not be ideal in the ED setting, this might be the only time a patient can form a realistic clinical picture of his or her illness, its treatment, and its prognosis. One group of authors created a roadmap for trajectories in major types of chronic

illnesses seen in EDs that warrant advance care planning conversations. Outlining 3 main trajectories of chronic illness (Appendix A),²⁸ they demonstrate and provide context for the advance care conversations and ethical decision-making. These visits become important moments to discuss the patient's goals of care regarding palliative treatment, life-sustaining care, and end-of-life care (Appendix B).²⁸ Discussions with family at primary care visits are preferred; it is important for patients to have the time and space to consider and digest factors that affect their definition of quality of life and how this frames their goals of care. It can be particularly difficult for patients to make decisions in the ED if it is the first time they are considering any of these concepts. However, previous advance care planning conversations need to be put into context and revisited later, when the patient presents to the ED.²⁸ For example, when a patient with cancer is currently in the ED with refractory symptoms, this ED visit can be an opportunity for the patient to consider quality of life, values, and wishes regarding his or her future care.

Based on these timelines and illness trajectories, the following 2 types of conversations can occur once the patient is in the ED: hyperacute and subacute. Hyperacute conversations take place during an acute decompensation (eg, pulmonary edema from heart failure), requiring rapid decision-making. In subacute situations, patients come to the ED with worsening symptoms of chronic illness, but no emergent treatment needs (eg, a late-stage cancer patient experiencing declining quality of life or refractory symptoms despite outpatient treatments; Appendix B).²⁸ Use of these models can help physicians guide end-of-life care conversations in the ED with greater delicacy and skill.

5.1 | Improving Palliative Care in Emergency Medicine Project

Shared decision-making is a collaborative process in which physicians and patients, through discussions of goals of care and treatment, come to a consensus for a healthcare plan. This type of decision-making framework acknowledges the physician's role in providing diagnostic and prognostic information while encouraging patients to understand and voice their own genuine preferences. The Improving Palliative Care in Emergency Medicine Project provides the following model for ED end-of-life care communication after acute illness:²⁹

1. Determine a patient's decision-making capacity.
2. Identify legal surrogate.
3. Elicit patient values expressed in completed ads.
4. Determine patient/surrogate understanding of life-limiting event and expectant treatment goals.
5. Convey physician understanding of the illness, including prognosis, treatment options, and recommendations.
6. Share decisions regarding withdrawing or withholding of resuscitative efforts using available resources and considering options for organ donation.
7. Revise treatment goals as needed.

5.2 | Brief Negotiated Interview

The Brief Negotiated Interview (BNI) technique, similar to motivational interviewing, has been adapted for ED-specific end-of-life AD discussions.^{30–32} This BNI intervention is based on the social cognitive theory and transtheoretical model. It provides a 7-minute, scripted, motivational interview in which a clinician explores health behavior change in patients,³² with the goal of increasing patient motivation to initiate advance care planning conversations.³⁰ The following are key components to the BNI intervention:

1. opening
2. rapport building
3. information and feedback
4. readiness
5. summary
6. action

The BNI uses effective communication skills, including the following:

- appropriate language
- reflective listening
- use of empathetic language
- assessing mutual understanding
- listening for cues
- redirects when needed³⁰

Some limitations to the BNI include the need for professional training in conducting an effective motivational interview and the need for urgent or emergent treatment. The "acceptability" of the intervention by patients may reflect attributes of any shared decision-making process: time taken for meaningful conversation, the emergency physician's comforting approach, and the informative nature of the discussion.³² In addition, time limitations with patients in a fast-moving, scheduled-restrained ED can be a challenge for an emergency provider performing a complete BNI. Therefore, emergency physicians can use the BNI motivational interviewing framework to initiate a discussion that is continued with inpatient providers if the patient is admitted or family care providers at a discharge follow-up. Introduction of the end-of-life planning concepts in emergent settings allows for baseline awareness that may encourage patients to broach the topic with other providers and possibly reevaluate interests.

Although such conversations may be time-consuming, physicians can bill for them as part of critical care time or separately under CPT coding for "Advanced Care Planning." Such discussions may include the following:

- discussion of goals and preferences for care
- complex medical decision-making regarding life-threatening or life-limiting illness

- explanation of relevant ADs, including (but not requiring) completion of ADs
- engaging patients, family members, and/or surrogate decision makers as the clinical situation requires³³

5.3 | Other resources

End-of-life circumstances are challenging for patients and family members. With so many unknowns at the moment of death, family members are often overwhelmed with which way to proceed to best care for their loved one who is nearing the end of life. Spiritual figures such as pastors, rabbis, imams, and other religious authorities can often fill this gap. Their presence allows family members and decision makers to receive another viewpoint about death and dying. Many hospitals do have religious affiliations and have on-call pastors and religious figures to help pacify, calm, and be with the patient's family members. This makes the overall experiences for doctors, nurses, staff, and family easier to process in a time-sensitive situation.

In addition, emergency physicians may obtain consults from palliative care services or their hospital's ethics committee when facing complex decisions. Although time factors may not always allow for this, physicians should become acquainted with the local resources available to them. Also, familiarity with state laws and hospital policies will assist the physician when offering suggestions and options to patients and families.

5.4 | Case 1

A 72-year-old man presents to the ED with right-sided chest pain for 1 month and increasing dyspnea during the past week. He reports no past medical history and states he has not seen a doctor in years. Your workup includes a computed tomography scan of the chest, which demonstrates stage IV lung cancer with metastasis to the ribs and liver. A long-time smoker, he tells you that he suspects that he might have lung cancer and "just wanted to be sure." He insists that he does not wish to pursue treatment and wants to go home.

5.5 | Case 1 resolution

This patient has chronic illness with acute exacerbation in long-term decline (Appendix A) in which "the visit serves as an inflection point in the illness trajectory, portending a worsening course."²⁸ This patient's diagnosis puts him on a likely rapid decline within the next weeks to months. The patient has not had goals-of-care conversations, so this ED visit can be the first time to discuss all of his options, values, and goals.

The physician employs elements of the BNI intervention, including reflective listening, use of empathetic language, and assessing mutual understanding. After capacity is determined, goals-of-care are discussed and the patient expresses desires to forgo future aggressive treatments and clearly expresses his values and reasons for going

home. The patient is encouraged to talk with family and about his wishes and to put his preferences in writing. Pastoral care is notified at the patient's request. He is offered consultation with oncology and palliative care to ensure that he understands all of his options.

5.6 | Case 2

A 48-year-old man with stage IV melanoma presents with worsening back pain. His cancer has spread to multiple organs as well as his spine. He is undergoing radiotherapy to lessen the tumor burden but notes that he is losing weight and is more tired and in increasing pain. Despite this, he and his wife insist that "he's going to beat this" and request help in managing his pain. You are concerned that their treatment goals are unrealistic. At this time, he is "full-code" status.

5.7 | Case 2 resolution

Similar to the previous case, this is an acute exacerbation in the setting of long-term functional decline. This case, unfortunately, is not unusual, as 1 study found that among a population of 1193 patients, 69% of patients with lung cancer and 81% of those with colorectal cancer did not understand that chemotherapy was palliative rather than curative for their cancer.³⁴ This ED visit offers an opportunity to help this patient understand his illness and treatment options more fully. Here, the patient has full capacity, as does his potential surrogate (his wife), but it is not clear that they understand that the treatment is meant to be palliative rather than curative. It is key that the physician clarify the patient's condition, prognosis, and treatment options. The clinician confirms patient understanding of his illness and explains in clear terms what the metastases mean and why he is getting the treatment he is receiving. Through a series of questions and answers, the patient explains what he would do if the outcome were different from what he believes it will be. His oncologist may need to be further consulted if the patient is having difficulty understanding his prognosis and if there are changes in goals of treatment and care after these conversations. The physician's ultimate goal is to elicit genuine patient understanding of his illness and ensure that his wishes are followed.

5.8 | Case 3

A 56-year-old woman with advanced chronic obstructive pulmonary disease is brought to the ED by ambulance for pain and difficulty breathing. Her family tells you that she is a patient in hospice, but that the medications they have been using are not sufficient to manage her pain. The family contacted the hospice nurse on call, who gave them advice on medication adjustment, but when pain continued, they came to the ED. The patient cannot answer questions because of confusion, dyspnea, and pain. She appears to be in respiratory distress with an oxygen saturation of 78% on room air. With supplemental oxygen via non-rebreather mask, her oxygen saturation improves to 93%, but her

mental status is unchanged. You assure the family that you will treat her shortness of breath and pain acutely but are uncertain about pursuing laboratory and radiographic testing given her hospice status.

5.9 | Case 3 resolution

This scenario describes a goals-of-care conversation that requires rapid decision-making between diverging treatment strategies and outcomes. In this case, the provider is working with a surrogate, and the patient's wishes are known. She is a patient in hospice, and the surrogate and family are aware of her prognosis. Care needs to reflect the evolving state of the patient's condition and provide an opportunity for shared decision-making between the family and the physician regarding future goals of care. The physician explains to the family the severity of the patient's condition. She is a patient in hospice, and the primary focus is on comfort care. Further X-rays and laboratory tests are usually not indicated. The emergency physician consults the hospice nurse to help adjust the patient's pain medications, and the patient is discharged home in the care of family.

5.10 | Case 4

A 90-year-old woman arrives from home via ambulance after activating her medical alarm, complaining of increased dyspnea and leg edema. You are unable to reach any family. The patient is frail but normally performs her activities of daily living. She is fiercely independent and eschews any mention of an extended care facility. She indicates that she has never created any documentation of her end-of-life wishes. Her workup reveals a non-ST-segment-elevation myocardial infarction with worsening congestive heart failure. The cardiologist feels the risk of cardiac catheterization outweighs its benefits, but you are concerned that she is a "good 90-year-old" and worry about forgoing intervention.

5.11 | Case 4 resolution

Similar to cases 1 and 2, this case demonstrates an acute exacerbation in the setting of long-term decline. Here, however, there is no family with whom to communicate, and your patient wishes to maintain her independence. You discuss the patient's end-of-life wishes with her. You explain that the potential harms of cardiac catheterization outweigh their benefits. Together you devise a plan to optimize her medical management with the understanding that she will not receive intubation or CPR. These wishes are formalized using the POLST and DNR forms available to you.

6 | CONCLUSION

Patients with chronic illness often present to the ED. Because patients and families frequently lack full understanding of chronic illnesses,

their prognoses, and options for ADs, emergency physicians are in a unique position to facilitate goals of care and advance care planning conversations. Through measures such as the Improving Palliative Care in Emergency Medicine Project, the BNI, and shared decision-making in general, emergency physicians may help patients optimize their plan of care, enabling them to receive care that aligns with their genuine wishes. Religious leaders may be asked to participate in these discussions, in accordance with a patient's desires.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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How to cite this article: Hughes K, Achauer S, Baker EF, et al. Addressing end-of-life care in the chronically ill: Conversations in the emergency department *JACEP Open.* 2021;2:e12569. <https://doi.org/10.1002/emp2.12569>