

Effective communication regarding advanced care planning and end-of-life care options

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Advanced care planning is a process used by patients, caregivers, and healthcare providers (HCPs) to establish goals for end-of-life (EOL) care.¹ Patients who receive EOL care that is inconsistent with their wishes are likely to be dissatisfied with this care and consume large amounts of healthcare resources.² Studies have shown that many EOL care discussions are ineffective because of poor patient–HCP communication and the patient’s lack of sufficient understanding of EOL care options.¹ This article provides an overview of the consequences of poor communication and a guideline for nurse practitioners regarding the best evidence-based practices for discussing EOL care options most effectively with patients.

KEY WORDS: advanced care planning, end-of-life care, cardiopulmonary resuscitation, advance directive



The U.S. Census Bureau reports that by 2030, 72 million Americans will be aged 65 years or older; these individuals will represent 20% of the population.³ As a result, one might reasonably expect that more and more healthcare providers (HCPs), patients, and caregivers would be focusing their attention on advanced care planning (ACP) and end-of-life (EOL) care options. However, current research indicates that conversations about ACP and EOL care options are infrequent and that many HCPs lack sufficient training and/or experience to effectively communicate with patients about these topics.⁴

Many HCPs report difficulty in initiating EOL care discussions,¹ and many patients report that their HCPs display discomfort during these discussions.⁴ Patients want their HCPs to be honest with them.⁵ Most older persons are well prepared for the event of death (i.e., they have prepared a will), but not for the dying process (i.e., they have not completed ACP).⁴ Ineffective communication about EOL care options may lead to an overestimation of cardiopulmonary resuscitation (CPR) survival rates, decreased satisfaction among caregivers, and, ultimately, a dy-

ing experience that goes against the patient's wishes.

Consequences of ineffective communication

Inaccurate or inadequate information—Most HCPs use verbal descriptions to discuss ACP and EOL care, including terms such as *cardiopulmonary resuscitation* or *CPR*, *intubation*, and *mechanical ventilation*. These terms may be difficult for some patients to conceptualize.¹ Poor understanding about ACP and EOL care may prompt some patients to seek information elsewhere—for example, on television or on the Internet. As a consequence, some patients may make ACP and EOL decisions based on inaccurate information.⁶ Even if HCPs do engage in a conversation about ACP with their patients, these conversations may not take place early enough or often enough.⁴

According to the Pew Research Internet Project, 30% of adults aged 65+ and 54% of those aged 50-64 have looked online for health information in the past year (vs. 67% of adults aged 30-49 and 72% of adults aged 18-29).⁷ Other studies have shown that up to 92% of persons older than 62 years get health information from TV.⁶ In a classic study evaluating the influence of the media on healthcare decisions, investigators reviewed 97 episodes of medical TV dramas.⁸ In these episodes, 75% of "patients" undergoing CPR were successfully resuscitated. This fictional survival rate is a stark contrast to reality. The overall survival rate of intra-hospital CPR is only about 15% but can be as low as 0%-1% in seniors with terminal stages of cancer.⁸

The media's misinformation leads people to base decisions on inaccurate information. If HCPs have better communication skills and timing, patients will no longer need to rely on the media as a main source of health information.

Overestimation of CPR outcomes—When patients do not receive accurate information about CPR, they tend to overestimate rates of survival and retention of good neurologic function related to its performance. Most in-hospital patients with full

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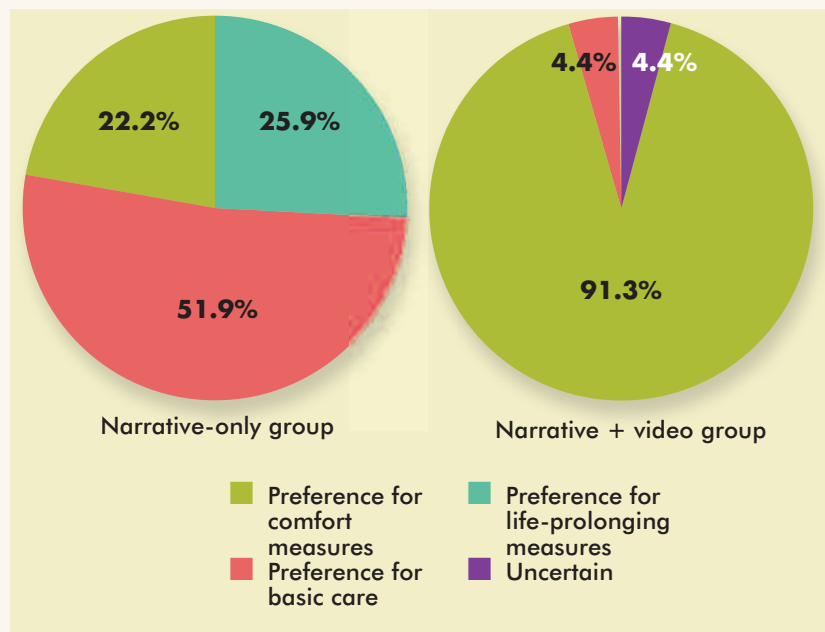
code status orders cannot identify the three steps of intra-hospital CPR: defibrillation, chest compressions, and intubation with mechanical ventilation.⁹ If patients are considered a full code, they are designated to receive all three of these components. Among 100 patients in a medical intensive care unit who were surveyed, only 4 could identify all three components of CPR.⁹ Patients were also asked about the overall likelihoods of surviving CPR and retaining good neuro-

logic function following CPR. They predicted an overall survival rate without loss of good neurologic function to be 71.8% (range, 10%-100%), even though the actual survival rate of in-hospital CPR is only 15%. The likelihood of leaving the hospital after CPR with good neurologic function is 14%.

In this study by Gehlbach et al,⁹ the higher the patients predicted the survival rate of CPR to be, the greater the likelihood that they would prefer to receive CPR. When patients were informed about actual survival rates and potential consequences of CPR, several were less interested in receiving CPR. After the interviews, patients' health records were assessed for documentation of code status. Ninety-eight of the 100 patients had documentation of code status in their chart. Of these, 16 discrepancies were found between code status preference expressed during the interview and the code status order in the chart; 10 of the 16 cases preferred less treatment and 6 preferred more.

Patients' inadequate knowledge of CPR and its possible outcomes leads to an excessively favorable view of potential outcomes. Few HCPs discuss success rates of CPR,⁹ an oversight that may lead to discrepancies between patients' wishes and actual code status orders. When patients are fully informed about CPR and its potential outcomes, they are less likely to prefer it. This same correlation has been noted among non-hospitalized patients. If HCPs educate their patients and are mindful of their learning preferences and needs, code status discrepancies might be avoided.

Figure 1. Use of a video to clarify end-of-life care options for patients with cancer: study results¹



Decreased satisfaction among caregivers—Many caregivers indicate that HCPs are not forthcoming enough with regard to the reality of a patient’s prognosis, and that the timing of the EOL care discussion is often not early enough.¹⁰ Caregivers ask that HCPs stop worrying about “failing” to cure patients’ incurable diseases and, instead, provide them with accurate and timely information so that they can prepare emotionally and physically for tending to patients’ EOL care needs (e.g., saying their goodbyes, preparing for funeral arrangements).^{10,11}

How to improve communication

Because communication with patients and their caregivers regarding ACP and EOL care is often ineffective, HCPs need to hone their communication skills.¹² Although many passive strategies are being implemented in undergraduate programs,

interactive approaches such as workshops for HCPs and videos for patients have proved to be more useful.

Workshops for HCPs—Participating in workshops that focus on communication skills may improve ACP and EOL care. In an illustrative study, a total of 115 medical oncology fellows participated in a workshop entitled Oncotalk that emphasized communication skills practice.¹³ The fellows were evaluated pre- and post-retreat with respect to their skills in conveying bad news to simulated cancer patients and transitioning these patients from curative to palliative care. Overall, the fellows gained 10 new communication skills, including the ability to remain silent for 10 seconds after delivering bad news and the ability to use empathetic statements. For example, after receiving bad news, the patient was cued to ask, “Is there any hope for a cure?” Prior to the retreat, fellows responded by immediately

offering new anticancer therapies, even if those therapies had no chance of working. After the retreat, fellows had learned how to express regret that no cure was available and wishing that there were a cure. Although this workshop was limited to oncology fellows, the authors of this article believe that the findings can be generalized to all patient populations for whom HCPs’ communication skills are needed to address bad news. However, additional studies are needed to confirm this belief.

Videos for patients—Verbal descriptions of complex health interventions may be difficult for patients to conceptualize. Use of videos can improve patients’ understanding of potential health situations, increase their preference for comfort measures when nearing the end of life, and decrease their uncertainty regarding EOL care decisions.¹ In a recent study, 50 patients with malignant glioma were randomized to either a verbal narrative of EOL care options (control) or a video after the same verbal narrative (intervention).¹ The 6-minute video depicted three levels of medical care: life-prolonging care (CPR, ventilation), basic care (hospitalization, no CPR), and comfort care (symptom relief). To depict these three respective levels of care, the video presented images of a patient on a ventilator and a simulated code, a patient receiving antibiotics through a peripheral intravenous line and oxygen via a nasal cannula, and a patient at home receiving pain medication and assistance from a nurse’s aide.

After the interventions, the two groups were asked which

level of care they would prefer when they were near the end of life (Figure 1). Among the controls, 25.9% preferred life-prolonging care, 51.9% preferred basic care, and 22.2% preferred comfort measures. Among the intervention group, none preferred life-prolonging care, 4.4% preferred basic care, 91.3% preferred comfort measures, and 4.4% were uncertain. Intervention group participants reported feeling very comfortable viewing the video, and they recommended that the video be shown to other patients with cancer. Results of this study verified that when patients have a better understanding of health-care options, they are more likely to choose less aggressive treatment. At the bottom of this page, readers can click on an example of the type of video on ACP that patients can view in the waiting room or the examination room.

Appropriate timing and setting

Fewer than 20% of patients with an impaired capacity for decision making have completed advance directives—the *written* portion of ACP. Many patients initially discuss ACP with an HCP during a hospital admission for an acute episode. Research suggests that anxiety related to hospitalization hinders patients' ability to make complex health-related decisions such as completing advance directives.⁴ In addition, patients feel uneasy when discussing ACP with HCPs (e.g., a hospitalist) other than their primary care practitioner (PCP).⁴

Initiating ACP discussions during well-patient visits with patients' PCP is preferable.⁴ Just as

Figure 2. Ways to enhance discussions with patients about advanced care planning and end-of-life care options



PCPs rely on milestones to initiate certain conversations in the pediatric population, PCPs can designate milestones that trigger the need for ACP discussions with adults—for example, when they reach a certain age or when they receive a diagnosis of a potentially life-threatening disease. Because patients may become incapacitated at any time and without warning, PCPs should have open and ongoing communication with patients about their EOL care wishes. These well-timed conversations might help patients avoid a dying experience that goes against their wishes.

Recognizing and responding to patients' emotional concerns

Patients may readily discuss their ACP concerns with their HCP, but it is often the HCP who is responsible for initiating this conversation. Communication techniques such as using open-ended questions, allowing adequate time for patients to speak, and showing empathy encourage patients to express their concerns. In addition, patients give cues that they have concerns about EOL care; for example, they may describe themselves as *unsure* or *fearful*. HCPs

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need to recognize these cues and understand that these patients may need more information and/or emotional support.⁵

Proposed guidelines

Based on the evidence presented, the authors suggest that HCPs seek out workshops focused on improving ACP and EOL communication with patients. Workshops have been shown to enhance HCPs' communication skills. In addition, HCPs should assess each patient's learning needs; patients may respond preferentially to audio-visual aids, repetition, or written information. EOL care discussions can occur during patients' annual visits beginning in adulthood or with the diagnosis of a potentially life-ending disease. These conversations can be revisited at regular intervals to ensure continuing understanding of patients' wishes. By using appropriate communication tools, HCPs can improve patient and family satisfaction, increase the public's general knowledge regarding ACP and EOL care options, and decrease the potential for unwanted dying experiences.

Conclusion

Evidence to date suggests that communication among patients, caregivers, and HCPs regarding ACP and EOL care options is inadequate. Many patients do not comprehend the language used when EOL care is described and they do not know the facts about CPR. However, once they learn about the steps involved in CPR and about possible complications resulting from this intervention, many individuals will choose to abstain from extreme

resuscitative measures.

Nurse practitioners' holistic approach to patient care, along with their eagerness to learning new communication skills, makes them ideal HCPs to lead discussions about ACP and EOL care with patients. Participating in workshops has been shown to improve communication with patients regarding ACP and EOL care. Using videos to enhance discussions with patients has also been shown to be beneficial. Utilizing empathetic communication techniques, asking open-ended questions, and giving patients adequate time to speak also promote effective communication regarding ACP and EOL care (Figure 2).

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