End-of-Life Conversations as a Legacy

ABSTRACT

Advance directives such as living wills and health care powers of attorney are important documents that offer patients ways to avoid unwanted care when they are unable to express their wishes. Although health care professionals have increased focus on advance care planning in recent years, approximately two thirds of American adults do not have advance medical directives. In addition, 90% of individuals believe that talking to loved ones about end-of-life wishes is important, but only 27% have done so. It is important for nurses to understand the complex factors that influence how individuals make health care decisions and identify ways to encourage conversations with family, friends, and health care providers to help clarify patients’ wishes for end-of-life care. [Journal of Psychosocial Nursing and Mental Health Services, 56(1), 32-35.]

“Too many people are dying in a way they wouldn’t choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. It’s time to transform our culture so we shift from not talking about dying to talking about it” (The Conversation Project, 2017, p. 1).

Ellen Goodman (2015) described how at age 25, she flew home for her father’s birthday after learning that his cancer had returned. Three months later, when he was 57, he died. Ellen vividly remembers the new suitcase her mother gave him as a birthday gift, demonstrating her mother’s denial of his imminent death. Carrying that psychic baggage with her for years, Ellen thought about how her family lost the chance to say goodbye. She wondered if her father felt alone in the silence surrounding him because of the family’s inability to talk about death (Goodman, 2015).
Research suggests that 90% of individuals believe that talking to loved ones about their end-of-life (EOL) wishes is important, but only 27% have done so (The Conversation Project National Survey, 2013). What responsibility do nurses and other healthcare professionals have to help individuals talk with loved ones about EOL wishes? Complex factors influence how individuals make decisions about EOL treatments, and an understanding of these factors is critical for nurses to translate patients’ goals, values, and preferences into actionable plans for EOL care (Schubart, Levi, Dellasega, Whitehead, & Green, 2014). Roberts (2016) suggested that as healthcare professionals who care for individuals from birth to death, nurses have a responsibility to ensure patients are empowered to discuss EOL choices with family and healthcare team members.

Advance directives such as living wills and healthcare powers of attorney are important documents that offer patients ways to avoid unwanted care when patients are incapable of expressing their wishes. Healthcare professionals have increased focus on advance care planning since Medicare approved reimbursement for advance care planning in January 2016. However, it is estimated that only one third of American adults have advance medical directives, and those who do may not have updated the directives to reflect changes in EOL wishes (Yadav et al., 2017). Barriers to advance care planning include lack of opportunity to have conversations about EOL care, determining the best time to initiate the conversation, reluctance to discuss death and dying, fear of removing hope, concerns about the impact of advance care planning on family dynamics, and time constraints for clinicians to facilitate advance care planning (Smith, 2017; Van Scoy, Green, et al., 2017). In addition, reluctance by individuals who are African American or of other minority groups to complete written advance directives may be caused by lack of trust in the medical system, including worry that directives will be used contrary to their wishes, such as for experimentation with their bodies (Grant, 2017). As treatments that Americans would choose near EOL are often different from treatments they receive (Yadav et al., 2017), nurses need to find ways to encourage conversations with family, friends, and healthcare providers to clarify EOL wishes.

THE CONVERSATION PROJECT

To address the need for individuals to discuss wishes related to EOL care, Ellen Goodman, a Pulitzer Prize-winning writer and former syndicated columnist for the Boston Globe, convened representatives from the media, clergy, and healthcare professions to share stories of “good deaths” and “bad deaths” within their circle of loved ones (Roberts, 2016). To expand this grassroots initiative to promote good rather than bad deaths, Goodman collaborated with the Institute for Healthcare Improvement (IHI) in 2011 to establish The Conversation Project, a nonprofit organization dedicated to helping individuals discuss wishes for EOL care (The Conversation Project, 2017; Roberts, 2016). The Conversation Project team includes five law, journalism, and media professionals who work pro bono with IHI to help individuals start important conversations that they previously avoided (The Conversation Project, 2017). The Conversation Project is founded on the assumption that only patients can be experts in EOL wishes, not nurses, physicians, or family members (Roberts, 2016).

Stories of good and bad deaths shared with The Conversation Project organizers demonstrated that individuals need help beginning the conversation about death. This realization led to creation of the Conversation Starter Kit, which serves as a “travel guide” to direct the conversation (Goodman, 2015). Developers of the starter kit designed a thoughtful guide for the living rather than a technical medical checklist for the dying. The kit encourages users to question: “What matters to me?” instead of “What is the matter with me?” Specific focus questions include:

- What is most important to you in the last phase of life?
- Whom do you want to make decisions for you?
- Where do you want to spend the last moments of life?
- Do you worry that you will not receive sufficient care?
- Do you worry that you will receive aggressive care?

The Conversation Starter Kit, available in 11 different languages, can be accessed for free at https://theconversationproject.org/starter-kits. The website includes guides on how to choose or be a health care proxy and how to talk to physicians about EOL issues, a starter kit for loved ones of individuals with dementia, and a pediatric starter kit to provide guidance for parents of seriously ill children.

The Conversation Project website contains stories of how individuals began conversations about EOL wishes, and how they avoided having these conversations too late. Stories revealed that the difference between good deaths and bad deaths hinged on whether patients could share wishes about how they wanted to live the end of their lives and whether these wishes were respected (Goodman, 2015). Patients who used the conversation starter kits reported feeling overwhelmed and fearful before starting the conversation, but ultimately experienced intimate and rewarding moments. The kits helped individuals think about values, share these values with others, and describe beliefs about potential decisions. Dying is not just a medical experience; it is a deeply human experience (Goodman, 2015).

In the Conversation Project Survey, the primary reason given for not
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and themselves. One participant stated that she avoided a discussion about the afterlife because of concern that it might cause uncertainty about an afterlife for her loved one who was dying. The study’s findings highlight the importance of providing opportunities for individuals to discuss EOL wishes while still healthy so that individuals make the best decisions for themselves, their families, and their relationships.

INITIATIVES TO ENCOURAGE END-OF-LIFE CONVERSATIONS

Recent studies have added to evidence that when patients and family members discuss values and beliefs about EOL care, outcomes are improved for both parties (Van Scoy, Green, et al., 2017). One innovative approach to encouraging these conversations uses games. Recent studies have demonstrated that games can be used to engage adults of all ages in discussing sensitive issues, as well as to stimulate behavior change in various health contexts (Van Scoy, Green, et al., 2017). In a pilot study with 68 volunteers ages 22 to 88, Van Scoy, Green, et al. (2017) engaged participants in a conversation card game, My Gift of Grace, that focused on EOL issues. A validated questionnaire was used to measure readiness to engage in four advance care planning behaviors: completing a living will, completing a health care proxy, discussing EOL wishes with loved ones, and discussing quality versus quantity of life with loved ones. A semi-structured phone interview was also used. Results showed that within 3 months of playing the game, 78% of participants engaged in at least one advance care planning behavior; the most common behavior change was initiating discussions with a family member or friend about EOL issues. The researchers concluded that a game format may be an effective strategy for motivating individuals to engage in important advance care planning.

As a follow up to the study described above, researchers implemented a mixed-methods study to assess whether the EOL conversation card game administered in a community setting would provide effective motivation for patients and their caregivers to engage in advance care planning behaviors (Van Scoy, Reading, et al., 2017). Participants (N = 93) included 49 patients with chronic illness and 44 unpaid caregivers or surrogate decision makers of patients with chronic illness. Community Game Day events (comprising 22 games) were held at 12 different venues that included libraries, senior centers, retirement communities, and churches. The study demonstrated that Community Game Day was a positive, well-received experience for participants. Within 3 months following the event, 75% of participants performed at least one advance care planning activity. Participants stated that playing the game empowered and prepared them to initiate advance care planning, and that they gained new understanding regarding death and dying (Van Scoy, Reading, et al., 2017).

An important group for advance care planning often overlooked is the young adult population. Although the Institute of Medicine recommends that individuals of all ages communicate about advance care planning, including young adults, strategies for guiding EOL discussions with young adults have received limited attention (Smith, 2017). To address this issue, Smith implemented a study with 18 nurses who used an advanced care document, Voicing My Choices, to engage standardized patients in EOL discussions in a simulation lab. The Voicing My Choices document is designed specifically for adolescents and young adults (Smith, 2017). Using a pretest–posttest design, Smith (2017) found that posttest scores showed significantly increased confidence among nurses regarding comfort in initiating EOL conversations with young patients. Using resources such as documents designed for young adults and simulation activities can help circumvent barriers and facilitate EOL conversations with adolescents and young adults (Smith, 2017).

Many health care providers are untrained and uncomfortable initiating conversations about EOL issues. To address this problem, the Florida Hospital Association partnered with IHI to provide hospitals and communities with training designed to encourage conversations about EOL issues while individuals are healthy (Karash, 2017). Training for hospital staff began in May 2017 and is expected to expand with community initiatives. Hospital training
includes a six-part series of call-ins and webinars focused on five principles for improving EOL care:

- Engage with patients and families to encourage them to share what matters most to them at the end of life;
- Preserve information about patients’ EOL care wishes as reliably as possible to maintain medical information such as allergies;
- Partner with patients and families to develop a patient-centered plan of care that reflects a respect for patients’ wishes for EOL care;
- Integrate principles into one’s own life to understand benefits and challenges of the process; and
- Connect with patients in a manner that is culturally and individually respectful (Karish, 2017).

CONCLUSION

It is estimated that 50% of older adults in hospitals cannot make informed EOL decisions for themselves (Goodman, 2015). It is important that nurses in hospitals, long-term care facilities, and the community become confident in initiating EOL conversations with individuals of various ages. Without these important conversations about life goals and wishes, patients across gender, ethnic, and age lines may receive unwanted treatments at the end of their lives (Grant, 2017). In addition, family members and patients may lose the chance to share the intimacy and peace of a goodbye. Thoughtful and respectful planning and conversations in which a provider or family member listens and attempts to understand individuals’ unique experiences, beliefs, and values can help break through the reluctance that has silenced these EOL conversations. Goodman (2015) noted that these conversations can serve as a legacy—maybe the last gift we can give to one another.

REFERENCES


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