



“I Didn’t Know He Was Dying”

Missed Opportunities for Making End-of-Life Care Decisions for Older Family Members

Shigeko (Seiko) Izumi, PhD, RN ○ Catherine Van Son, PhD, RN, ANEF

Research is limited on end-of-life care decision-making for older adults with chronic conditions whose end-of-life trajectory is difficult to predict because of their complex and frail condition. Semistructured interviews were conducted with family members of 22 deceased older adults to explore their experiences with end-of-life decision-making with/for their loved ones. Participants did not identify a specific time they made an end-of-life care decision as they did not know the older adult was at the end of life, health care providers did not ask them to make a decision, or they had to make forced decisions, and subsequently they experienced regret about the end-of-life care their family member received. End-of-life care decisions were dependent on the awareness of approaching death by participants, their loved ones, and health care providers. Health care providers being aware of the possibility of approaching death and assisting family members to make decisions that would honor the older adult’s preference by explaining possible care options and what each care options would mean to them are key to providing quality end-of-life care for these individuals.

KEY WORDS

chronic conditions, decision making, end-of-life care, older adult

Decisions about end-of-life (EOL) care are difficult to make especially when the trajectory leading to death is unpredictable. Three distinct EOL trajectories are commonly noted in the literature: (1) steady progression with a clear terminal phase, which is seen mostly in cancer diagnoses; (2) gradual decline with repeated episodes of acute deterioration, recovery and

eventual death associated with life-limiting end-stage chronic illness (eg, organ failure); and (3) prolonged gradual decline with increasing frailty such as Alzheimer disease.¹⁻³ In the second and third trajectory, the terminal phase is not always clearly defined, and it is difficult to predict when death will occur. More than half of older adults have multiple chronic conditions resulting in a complex health status, placing them in the second or third trajectory.⁴⁻⁷ The lack of clarity as to whether older adults are reaching the end of their lives leads to repeated emergency room visits and hospital admissions without clear EOL care planning.⁸⁻¹⁰

Research on decision making related to the gradual EOL trajectory commonly experienced by older adults is limited.^{11,12} Most EOL decision-making research focuses on (1) known predictable life-limiting conditions, such as acute and progressive cancer,¹³ or (2) choices made at a specific time defined as a life-or-death situation, such as initiating or limiting cardiopulmonary resuscitation or withdrawing or withholding life-sustaining treatment such as mechanical ventilation.¹⁴⁻¹⁶ Direct application of findings from these studies is limited in the ability to assist decision making for older adults with chronic conditions whose EOL trajectory and life-or-death situation is not so clearly defined.^{13,17-19}

Furthermore, while the number of older adults with advanced directives (ADs) has risen to 72% as of 2010,²⁰ it is unknown how much of the EOL care older adults receive is concordant with the wishes expressed in their ADs.^{21,22} A gap exists in our understanding about how EOL decisions are made for older adults with a gradual and unpredictable trajectory and how ADs are used in their EOL decision making. Health care providers need a better understanding of EOL decision-making process for older adults with chronic conditions and an unpredictable trajectory.²³ The purpose of this qualitative descriptive study was to explore the EOL decision-making process for older adults with chronic conditions from family members’ perspectives.

METHODS

A qualitative descriptive approach was used to explore the family members’ perspectives of EOL decision making

Shigeko (Seiko) Izumi, PhD, RN, is assistant professor, School of Nursing, Oregon Health & Science University, Portland.

Catherine Van Son, PhD, RN, ANEF, is associate professor, College of Nursing, Washington State University, Vancouver.

Address correspondence to Shigeko (Seiko) Izumi, PhD, RN, School of Nursing, Oregon Health & Science University, 3455 SW US Veterans Hospital Rd, SN-6S Portland, OR 97239 (izumis@ohsu.edu).

This study was funded by the American Nurses Foundation and the Hospice and Palliative Nurses Foundation.

The authors declare no conflicts of interest.

DOI: 10.1097/NJH.0000000000000215



for older adults. Potential participants were identified from patient records in a large medical center located in the Pacific Northwest region of the United States. A nurse in the medical center's supportive care department maintained records of those individuals referred to their service regardless of whether they received care from their supportive care team. Referred patients were tracked after their discharge from the medical center. The nurse obtained information about their death in and outside the medical center through her formal and informal networks and the local obituary. Four to 12 weeks after an older adult's death, a letter was sent inviting family members to participate in the study if their deceased family member (1) was 70 years or older when he/she died, (2) received a diagnosis of more than 1 chronic condition, and (3) died of an exacerbation related to his/her chronic condition(s). Institutional review board approval was obtained from the researchers' institution and the medical center where the recruiting nurse worked.

Semistructured interviews were conducted by the authors, both of whom have hospice nursing experience. The participants were interviewed in a location of their choice; most chose their home. Initially, participants were asked to describe EOL care decision-making processes prior to the older adult's death. However, most of the participants found it difficult to identify specific decision-making events. Thus, to facilitate their recall of events, participants were asked to talk about the months, weeks, and days before their older family member's death. The participants began their narrative at a time when, upon reflection, they believed was the beginning of the older adult's end of life. As participants shared their journey, clarifying questions were asked regarding specific decisions that were made. These questions included where was the decision made, who was involved, what was the outcome, and what went well or did not go well in the process.

Interviews lasted 1 to 2 hours and were recorded using a digital audio recorder. The recordings were transcribed verbatim and analyzed using a conventional content analysis approach.²⁴ Analysis occurred simultaneously with data collection, allowing researchers to identify themes and saturation of data. Both researchers read the entire transcript of each interview independently, then reread word-by-word to create codes that highlighted key concepts using the qualitative data management software NVivo9 (QSR International, Doncaster, Victoria, Australia). Codes developed by the researchers were compared and contrasted and sorted into categories based on their relationship to each other in forming meaningful clusters. If researchers were in disagreement, transcripts were reviewed a third and fourth time in order to seek meaning and consensus with the narratives. In addition, member checks with participants were conducted informally by sharing them con-

tinued until no new codes were identified and data saturation was achieved.

RESULTS

Between January and July 2011, 187 letters were sent to family members of older adult decedents who met the study criteria. Of the 25 family members who responded to the letter (response rate, 13%), 23 family members were interviewed regarding 22 decedents. All interviews were with a single informant except for one where, by choice, both the spouse and daughter were interviewed together. Two family members who responded to the letter were not available at the phone number they provided, and interviews were not scheduled. Sampling criteria were inclusive to capture a broad range of variations in EOL care and the deceased older adults' health conditions (Table). Participants were spouses or adult children. Eight of the older adults (36%) had a history of a cancer diagnosis, but only one had a progressing cancer diagnosis during the EOL period. Fifteen of the older adults (68%) died in a hospital, including 3 who died while receiving palliative care services. Four died at home or in a skilled nursing facility where they lived (18%), including 3 who were receiving home hospice care. Three (14%) died at an inpatient hospice facility.

Retrospectively, most participants described how the journey into EOL care began with a trigger event requiring the older adult to seek health care services. The trigger event was usually not immediately life threatening. The older adult had similar events before, such as a fall or pneumonia, but recovered. Sometime after entering into the health care system, the focus of care shifted from treatment for trigger event to EOL care, but timing and process of the shift varied in each story.

Seventeen of the 22 deceased older adults (77%) had an AD, which had been completed years earlier. However, no distinct decision-making point of reviewing or honoring the AD was described as part of the family member's story. When interviewers asked about the use of AD, participants stated that they did not think to refer to an existing AD because they did not recognize that they were making EOL decisions at that moment, or providers did not ask about an AD. Being aware or not that the older adult was in the EOL phase was the key and overarching theme in which subthemes of how EOL care was discussed and how decisions were made emerged. The subthemes that emerged from the analysis are (1) explaining situations and care options, (2) inquiring about the older adult's preferences, and (3) guiding family members to make decisions to honor the older adult's preference. In the following section, 4 scenarios illustrating how overarching awareness and subthemes interrelate in EOL decision-making process are presented with exemplars.

**TABLE Participant Demographics**

Participants (n = 23)		
Age	Mean	56.0 y (range 39-81 y)
Gender	Men	4
	Women	19
Relationship	Spouses	9
	Adult children	14
Ethnicity	Non-Latino whites	22
	Other	1
Deceased older adults (n = 22)		
Age	Mean	73.1 y (range, 70-90 y)
Gender	Men	13
	Women	9
Diagnosis	Cancer	8
	Congestive health failure	7
	Pneumonia	6
	Urinary tract infection	4
	Organ failure other than heart	3
	Stroke	2
	Chronic obstructive pulmonary disease	2
	Fracture by fall	2
	Others	14
Location of death	Hospital	15
	Home/skilled nursing facility	4
	Hospice facility	3
Participants (n = 23)		
Age	Mean	56.0 y (range, 39-81 y)
Gender	Men	4
	Women	19
Relationship	Spouse	9
	Adult children	14
Ethnicity	Non-Latino whites	22
	Other	1

*Continued***TABLE Participant Demographics, Continued**

Deceased older adults (n = 22)		
Age	Mean	56.0 y (range, 39-81 y)
Gender	Men	13
	Women	9
Diagnosis ^a	Cancer	8
	Congestive heart failure	7
	Pneumonia	6
	Urinary tract infection	4
	Organ failure other than heart	3
	Stroke	2
	Chronic obstructive pulmonary disease	2
	Fracture by fall	2
	Others ^s	14
Location of death	Hospital	15
	Home/skilled nursing facility	4
	Hospice facility	3

Scenario 1: Family Was Made Aware of Approaching Death and Was Guided in Decision Making to Honor the Older Adult's Preferences

When study participants were aware of approaching death, and health care providers provided explanations and guidance on ways to integrate the older adult's preferences in EOL care, participants viewed EOL care as a positive experience.

Exemplar 1. A daughter shared her experience regarding her 85-year-old mother who was hospitalized because of a fall at home. Her mother was in remission from cancer, had emphysema, and was cognitively impaired. A palliative care physician explained what was occurring during hospitalization and helped the daughter sort out her mother's care needs.

The doctor did a great job. She came in and said, "Do you want me to talk to you about how long? Do you want to know?" I said, "Yes." She told me how many hours it was likely. It was great because I knew where I was going then. They did not play hide the ball. You had a period of time, and you wanted to plan for it.... I met with the doctor and the social worker in a quiet space to figure out



our plans. She told me that if this happens, these are your options; if this happens, these are your options. (Participant 5)

Years ago, this participant had discussed AD with her mother and knew what EOL care her mother wanted. However, the participant was not thinking of AD when her mother was hospitalized because she did not realize the situation as end of life until the palliative care physician explained her mother's status. Only when the participant became aware that death was approaching was she able to start thinking about the EOL care her mother would want. Her mother's AD and prior advanced care planning conversations were helpful. Yet, it was the palliative care physician's explanation that guided her in selecting EOL care options congruent with her mother's wishes.

Exemplar 2. Another participant talked about her 90-year-old father who had died of pneumonia in the hospital. She transferred her father from a nursing home to the hospital because she was concerned about his cough and fever.

They [intensive care unit staff] were great explaining. One of the doctors related his experience with his elderly parent, and staff showed us [his] x-rays. "This is what we are doing... We have reached the point [that] if you do something more, it is not going to bring about any effect, not make him comfortable. You're not going to be putting a tube down him." And they had a real nice way of explaining the situation in a caring way. I felt no pressure. My father was not able to make that kind of a decision. So my sister and I basically spoke. Everybody was good about explaining what was going on... that there was not anything [more] to be done. (Participant 18)

In this exemplar, the daughter wanted to have her father transferred to the hospital as a response to his acute symptoms; it was not an EOL care decision for her. However, the explanations by hospital staff made her realize that her father was dying. With the explanations of his condition and guidance as to potential treatment outcomes, the participant chose not to initiate life-sustaining treatments. Although her father had an AD, hospital staff never asked her about it, and the AD was not used in decision making, according to her. The daughter accepted the EOL care suggested by the health care providers because she believed it was what her father would want, and she was satisfied with the care provided.

Scenario 2: Family Was Told About Approaching Death, But No Explanation or Guidance Was Provided and the Older Adult's Preferences Were Not Respected

Exemplar 3. In contrast to the scenarios above, a daughter described EOL decision making where the wishes of her

father were at odds with the EOL care suggested by health care providers and her father's wishes were not honored. According to the daughter, her 75-year-old father had been living independently at home and was successfully managing his congestive heart failure and diabetes. A brief hospital stay to replace his pacemaker was the trigger event after which his diabetes became unstable. He alternated between the hospital and a nursing home to stabilize his diabetes and treat a urinary tract infection. The participant said that the hospital staff suggested a designation of do not resuscitate (DNR) after he was admitted to the hospital for the fifth time.

The nursing staff said, "Why is he full code?" And [they]... tried to talk to him. "Don't you want to change it?" And he would say, "No. I want a full code." He was waiting for the doctors to fix him. But when he got to the last hospital stay, in the intensive care unit, they wouldn't take no for an answer. A doctor went in... and talked and talked. After 10 or 15 minutes of hammering him, lying there, dying, my dad told him, "Fine! I am a DNR." (Participant 9)

The participant said her father became agitated and incoherent soon after this conversation. In her opinion, the health care providers communicated to her father that EOL was approaching and imposed the DNR option without inquiring or respecting his preferences for care. During the interview, the participant stated that she felt that her father was forced to choose DNR, and she continued to have doubts and regrets about the EOL care he received.

Exemplar 4. A husband and adult daughter shared their experience about their wife/mother who was admitted to the intensive care unit and died less than 3 days later from sepsis. The older woman did not have a written AD, but her husband said that they had discussed their EOL care wishes years before. At that time, he said his wife wanted all interventions available.

[Once we were in the hospital,] no one walked this journey with us.... That aspiration really upsets me. I kept asking when did that happen? No one told me about it. They put her on medications. No one asked us, "Is this the direction you want to go?" She had kidney shut down, this and that. No one explained that to us. We had no idea we were heading in that direction [death is approaching and using extreme life-sustaining measures]. We were blindsided. The nurse said, "We need to know whether to keep the extreme measures or not. Do you know the answer?" (Participant 19, daughter)

Everything happened so quickly. The nurse wanted us to make a decision "right now." (Participant 19, husband)



Both participants knew their wife/mother was sick, but were not aware that death was rapidly approaching. When they were asked to make an EOL care decision, they were blindsided and felt forced to make a rushed decision without sufficient explanation or guidance. The husband chose no extreme measure, which was different from what his wife previously expressed because, from his point of view, the options were presented in a way that made him believe there were no alternatives. During the interview, the participants reflected that health care providers might have provided them information about the patient's terminal condition or treatment, but neither he nor his daughter understood what the information meant. Therefore, when they were asked to make the EOL decision, they were caught off-guard and felt pushed to make decisions without time to consider the patient's preferences. During the interview, both participants expressed uncertainty and regrets about the decisions they made for their loved one.

Scenario 3: No Explanations or Guidance About EOL Were Provided, and Family Was Not Aware About Approaching Death

There were cases where family members did not know that death was approaching until hospital staff explained it. Most participants were informed that death was approaching only 24 to 48 hours in advance, and sometimes the fact that death might be imminent was not brought up at all.

Exemplar 5. In retrospect, 1 participant believed that the staff knew her husband was dying but did not share that information with her.

The last day, my husband was next to the nurses' station. It was very busy outside his room. One nurse said, "I have a room... that is bigger than this room... a nice room with a kitchen, tables, and couches..." They just moved his bed. They must know he had only hours left... but they didn't say that to us. Looking back, they knew; it was the dying room. (Participant 8)

Several participants talked about the palliative care team or hospice staff visiting, but they could not recall why they came or who called them. In these cases, the participants believed that the hospital staff members were aware that death was approaching and initiated EOL care, but family members were not told, and they found out only when the palliative care or hospice team arrived.

Exemplar 6. Another participant expressed his regret that he was not involved in his wife's EOL care because he was not aware that she was dying. This participant was told by a health care provider that his wife would be discharged to go home within a few days. Her condition declined after that conversation, but he did not recall anyone sharing this with him.

Many things were going on, but I didn't get this. So when I called her Friday night, I didn't understand any of this. So I said goodnight, she said goodnight [and hung up]. My daughter [who was staying with her mother in the hospital] said she talked for another few minutes with the niece and her husband who were there... laughing and having a good time. Then after a couple of minutes, she said "I need to go to sleep now." She went to sleep, and she never woke up again. My daughter called me early that morning and said, "You better come on down here." I'm still thinking I'm going to bring her home. So, I go down there... she was unconscious. She didn't respond in any fashion. (Participant 4)

His adult daughter was involved in his wife's care. He acknowledged that perhaps his daughter might have been informed about his wife's changing condition and was making decisions about her EOL care. However, he was not informed and did not feel included in her EOL care. Participants who were not aware that death was approaching and missed the opportunity to participate in the process of EOL care decision making shared that they experienced regret concerning the EOL care their loved one received. Thus, this is an example of the significance of involving all family members in the decision-making process.

Scenario 4: Family Became Aware of Approaching Death, But Health Care Providers Did Not Acknowledge It

In this study, all EOL care stories began with a trigger event as the participating family members recalled. Seeking health care for their older family member was in response to a trigger event such as a fall or infection, and EOL care was not the presenting concern. Yet, at a certain time, most participants became aware that they were facing the EOL because the health care providers or older adult told them or from observing subtle changes in the older adult's health status. Challenges emerged when the family members became aware of approaching death, but health care providers did not recognize the situation as EOL and continued to provide routine care for the admitting condition.

Exemplar 7. A participant shared that her 76-year-old mother, who lived independently at home despite complex comorbidities, fell and was hospitalized for an ankle fracture. According to the daughter, her mother became increasingly frail from several days of enforced bed rest in the hospital. Despite the woman's repeated requests to return home and the family's willingness to care for her, hospital staff insisted on discharging her to a nursing home. After 2 hospital readmissions from the nursing home, the participant said that her mother told her, "I did not want to die this way (in a hospital), but it looks like I am going to." The



daughter stated that her mother became adamant to stop all treatment except comfort care, which was congruent with her AD provided at an earlier admission. Her mother's request for comfort care was not granted until a panel of physicians evaluated her decision-making capacity. She died less than 2 days after the evaluation and initiation of hospice care (participant 3). In the daughter's opinion, the hospital staff did not realize that death was approaching, and throughout the multiple readmissions between the hospital and the nursing home, providers did not ask her care preference or honor her AD.

Exemplar 8. Similarly, in some situations, family members stated that they had to “fight” for their loved ones’ EOL preferences to be honored. They found themselves convincing the staff to acknowledge the situation as EOL and initiate the EOL care the older adult wanted instead of continuing care for the presenting problem. An 81-year-old woman who was cared for at home by her daughter was admitted to a hospital with pneumonia.

(After a few days) I could tell my mother was going down. So I was really stressing that I didn't want her to be in the hospital, I wanted her home. However, the health care providers insisted, “She should go to a nursing home and get intravenous antibiotics.” I told them “no,” and with a palliative care doctor's help, arrangements were made to take my mother home where she died the next day. I had to be very adamant about taking my mother home. (Participant 12)

The participant recalled that she had to “fight hard” against the hospital staff to bring her mother home. She believed that this would not have been possible without the help from the palliative care doctor. According to the participants, health care providers appeared to be following a standard course of treatment for the admitting condition and were not always open to or disregarded other care options desired by the older adult. Participants expressed that it was a challenge to convince providers to agree with care the older adults desired if it was not in accordance with the standard care.

DISCUSSION

Our data were limited to retrospective recall of EOL care from family members' perspectives. As a family member involved in and observing EOL care for older adults with chronic conditions, their perspective provides valuable insights on how EOL care decisions were made, although their accounts may not be accurate descriptions of what actually happened.

Key findings in this study were (1) the significant role the awareness of EOL played in decision making and (2) communication approaches to assist the older adult and family to

make EOL care decisions. For older adults with chronic conditions, the indication as to when to shift the focus of care from chronic conditions to EOL was found to be unclear. All of the EOL stories in this study started as a non-life-threatening health event. Therefore, the initial intention of care was to treat the presenting condition. Sometime during the treatment process, however, health care providers, family members, or the older adults became aware that they were facing an EOL situation. It then became the issue of how to make the EOL care decisions desired by the older adult. In this study, if awareness of EOL is absent by family members or health care providers, conversations about what EOL care the older adult desires were unlikely to happen.

Role of Awareness by Health Care Providers

If health care providers become aware of the EOL situation, but not family members and/or the older adults, health care providers need to explain what is occurring, helping the family members and patient be aware that this may be the EOL, and it is time to think about what EOL care the older adult wants. According to the participants, they needed to know that their loved one was dying in order to start EOL care decisions. Research is clear that timely, detailed information with explanations is needed in order for family members to prepare for the future.^{26,27} Upon reflection, as illustrated in scenario 3, participants regretted not knowing that the older adult was possibly dying and felt that they had missed a precious opportunity to honor their loved one's EOL preference. In some interviews (eg, exemplar 6) and through analysis, the researchers noticed that the situation the participants were describing indicated the clear signs of approaching death, yet the participants stated that they did not know their loved one was dying. Signs of approaching death may be present from the health care providers' perspective, but it may not be obvious to family members who may not know what the signs mean. Therefore, the explanations about changing conditions and signs of approaching death need to be communicated to all of the family members clearly in an honest and caring manner.

Role of Awareness by Older Adult and/or Family Member

When family members and/or older adults became aware that they were facing EOL but health care providers were not aware, family members and the older adults had to convince health care providers and fight to obtain the EOL care they wanted, as illustrated in scenario 4. In this study, 8 participants described that their older family member had a history of cancer, but only 1 died of cancer, following the first of the 3 EOL trajectories that has a predictable prognosis.^{1,3} All other participants' family members followed the second or third trajectory, in which death is typically difficult to predict. It might not be possible for health care providers to predict that an older adult hospitalized for a



non-life-threatening condition or repeated exacerbation of chronic condition was dying. However, multiple studies have shown that age, the number of comorbidities, and frailty are risk factors for frequent hospital admissions and eventual hospital death.²⁸⁻³⁰ There is evidence that non-life-threatening events such as falls and infections can trigger a sharp decline leading to death in frail older adults.³¹⁻³⁴ It is critical to increase awareness among health care providers about the possibility and need for EOL care for older adult patients with chronic conditions who sought health care service even for non-life-threatening trigger events.³⁵ According to the participants in this limited sample, when health care providers did not realize the situation as EOL and focused on the presenting health issue, they tended to provide usual care without exploring individual's preferences and goals of care. In fact, health care providers in these stories might have been aware of the possibility of EOL but still made a clinical judgement to pursue the standards of care for the presenting condition. A need exists for health care providers to be flexible in adapting the standards of care to include the possibility of EOL care needs for older adults with chronic conditions.

Communication Approaches

In addition to awareness of EOL was the importance of communication between the health care providers and family members about EOL care. As seen in exemplar 4, merely presenting a list of possible EOL care options is inadequate, because the patient and family members may not understand what each option entails. Health care providers need to explain not only the medical pros and cons of care options but also the downstream risks and benefits of the treatment that may have an impact on the older adult's values and quality of life.³⁵ Inquiring about the patient values, goals of care, and preferences in EOL care is important to determine how best to explain care options that are meaningful to the patient and assist the patient and families in making decisions. Advanced care planning conversations and ADs are useful guiding tools to facilitate the EOL care decision making. Interestingly, despite the majority of the older adults in this study having an AD completed, ADs were rarely used to guide EOL decisions, according to the participants. When asked why their AD was not used, most of participants responded because they did not know they were making EOL care decisions at that moment, therefore, they did not think to refer to the existing AD, and no health care provider asked for it. Awareness of EOL is important in making EOL care decisions and recognizing the appropriate time to inquire about a patient's preferences by referring to their AD.¹³ Health care providers should consider having a goals-of-care conversation before assuming standard care and encourage older adults and their family members to use an AD to facilitate EOL care decision making.^{11,14,18}

Guiding patient and family members to incorporate available care options with patient EOL care preference is the last piece of communication vital to EOL care decision making. In exemplar 4, the explanations of changing conditions and care options were missing from the family's perspective, and decision making was left to them without any guidance. In exemplar 3, as the participant observed, health care providers did not inquire about the patient's values and preferences. The patient's decision was coerced rather than guided. The participants who understood the care options and actively participated in decision making to choose the care option that would best fit with their family member's wishes were more satisfied with the EOL care that was provided (scenario 1). Research shows that inclusion of patient and family members in decision making, especially EOL decision making, reduces anxiety, increases care satisfaction and quality of life, and provides for better family member bereavement experiences.^{36,37}

Limitations of this study include convenience sampling in a small community, participants initially referred to palliative care, and retrospective reflections by family members. Larger studies exploring older adults' and health care providers' perspectives and facilitators and barriers of EOL care communication among this population are needed. To extend findings from this study, larger studies in other facilities and geographical locations are needed so that the findings are rigorous enough to design interventions to increase health care providers' awareness about chronic condition exacerbations that lead to death for older adults. In addition, increasing health care providers' skills for shared decision making and continuous exploration of care goals would improve the provision of quality end of life.

CONCLUSION

The EOL care experiences explored in this study represent family members' recollections of how EOL care occurred for older adults with multiple chronic conditions. Although ADs are a valuable tool for EOL decision making and may be readily available, their usefulness was limited if the presenting situation was not recognized as EOL. Older adults and family members need to be aware of the possibility of death approaching in order to make EOL care decisions congruent with the older adult's desires.^{13,38} Regardless of the immediate reason why an older adult is seen in a health care setting, health care providers should consider the patient's condition in the context of overall trajectory and have goals-of-care conversations with them. Nurses at the patient's bedside observing condition changes are a great asset to facilitate the communication of the signs and symptoms of approaching death and provide patients and family the time needed to prepare for EOL care decision making.³⁶ Nurses can also explore the



older adults' values and preferences and assist in integrating these into available care options to honor the older adult's wishes and create better EOL experiences for older adults and their families.

Acknowledgments

The authors thank the participants of the study and health care providers who assisted in participant recruitment.

References

- Gill T, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. *N Engl J Med*. 2010;362(13):1173-1180.
- Kendall M, Carduff E, Lloyd A, et al. Dancing to a different tune: living and dying with cancer, organ failure and physical frailty. *J Pain Symptom Manage*. 2015;50(2):216-224.
- Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc*. 2002;50(6):1108-1112.
- National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America. 2015. http://www.nhpc.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf. Accessed November 20, 2015.
- Goodlin SJ. Palliative care in congestive heart failure. *J Am Coll Cardiol*. 2009;54(5):386-396.
- Anderson G. Chronic care: making the case for ongoing care. 2010. <http://www.rwjf.org/content/dam/farm/reports/reports/2010/rwjf54583>. Accessed April 19, 2013.
- Freid VM, Bernstein AB, Bush MA. Multiple chronic conditions among adults aged 45 and over: trends over the past 10 years. *NCHS Data Brief*. 2012;(100):1-8.
- Lopez RP. Decision-making for acutely ill nursing home residents: nurses in the middle. *J Adv Nurs*. 2009;65(5):1001-1009.
- Naylor MD, Kurtzman ET, Pauly MV. Transitions of elders between long-term care and hospitals. *Policy Polit Nurs Pract*. 2009;10(3):187-194.
- Wennberg JE, Fisher ES, Goodman DC, Skinner JS. *Tracking the Care of Patients With Severe Chronic Illness*. The Dartmouth Institute for Health Policy & Clinical Practice; 2008. http://www.dartmouthatlas.org/downloads/atlas/2008_Atlas_Exec_Summ.pdf. Accessed November 20, 2015.
- Matlock DD, Keech TA, McKenzie MB, Bronsert MR, Nowels CT, Kutner JS. Feasibility and acceptability of a decision aid designed for people facing advanced or terminal illness: a pilot randomized trial. *Health Expect*. 2014;17(1):49-59.
- Müller-Mundt G, Bleidorn J, Geiger K, et al. End of life care for frail older patients in family practice (ELFOP)—protocol of a longitudinal qualitative study on needs, appropriateness and utilisation of services. *BMC Fam Pract*. 2013;14:52-61.
- Sharp T, Moran E, Kuhn I, Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *Br J Gen Pract*. 2013;63(615):e657-e668.
- Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in translation: the unintended consequences of advance directive law on clinical care. *Ann Intern Med*. 2011;154(2):121-128.
- Quinn JR, Schmitt M, Baggs JG, Norton SA, Dombeck MT, Sellers CR. Family members' informal roles in end-of-life decision making in adult intensive care units. *Am J Crit Care*. 2012;21(1):43-51.
- Wilson J. To what extent should older patients be included in decisions regarding their resuscitation status? *J Med Ethics*. 2008;34(5):353-356.
- Ditto PH, Jacobson JA, Smucker WD, Danks JH, Fagerlin A. Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Med Decis Making*. 2006;26(4):313-322.
- Drought TS, Koenig BA. "Choice" in end-of-life decision making: researching fact or fiction? *Gerontologist*. 2002;42(Spec No 3):114-128.
- Whellan DJ, Goodlin SJ, Dickinson MG; Quality of Care Committee, Heart Failure Society of America et al. End-of-life care in patients with heart failure. *J Card Fail*. 2014;20(2):121-134.
- Silveira MJ, Wiitala W, Piette J. Advance directive completion by elderly Americans: a decade of change. *J Am Geriatr Soc*. 2014;62(4):706-710.
- Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc*. 2010;58(7):1249-1255.
- Richardson DK, Fromme E, Zive D, Fu R, Newgard CD. Concordance of out-of-hospital and emergency department cardiac arrest resuscitation with documented end-of-life choices in Oregon. *Ann Emerg Med*. 2014;63(4):375-383.
- Schonfeld TL, Stevens EA, Lampman MA, Lyons WL. Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *Am J Hosp Palliat Care*. 2012;29(4):260-267.
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
- Whittemore R, Chase SK, Mandle CL. Validity in qualitative research. *Qual Health Res*. 2001;11(4):522-537.
- Torke AM, Petronio S, Purnell CE, Sachs GA, Helft PR, Callahan CM. Communicating with clinicians: the experiences of surrogate decision-makers for hospitalized older adults. *J Am Geriatr Soc*. 2012;60(8):1401-1407.
- Manson NC. Why do patients want information if not to take part in decision making? *J Med Ethics*. 2010;36(12):834-837.
- Dent E, Hoogendijk EO. Psychosocial factors modify the association of frailty with adverse outcomes: a prospective study of hospitalised older people. *BMC Geriatr*. 2014;14:108.
- DuGoff EH, Canudas-Romo V, Buttorff C, Leff B, Anderson GF. Multiple chronic conditions and life expectancy: a life table analysis. *Med Care*. 2014;52(8):688-694.
- Goodman DC, Fisher ES, Chang C-H. *After Hospitalization: A Dartmouth Atlas Report on Post-Acute Care for Medicare Beneficiaries*. The Dartmouth Institute for Health Policy & Clinical Practice; 2011.
- Archbald-Pannone LR, McMurry TL, Guerrant RL, Warren CA. Delirium and other clinical factors with *Clostridium difficile* infection that predict mortality in hospitalized patients. *Am J Infect Control*. 2015;43(7):690-693.
- Liu SW, Obermeyer Z, Chang Y, Shankar KN. Frequency of ED revisits and death among older adults after a fall. *Am J Emerg Med*. 2015;33(8):1012-1018.
- Lo JC, Srinivasan S, Chandra M, et al. Trends in mortality following hip fracture in older women. *Am J Manag Care*. 2015;21(3):e206-e214.
- Tan MP, Kamaruzzaman SB, Zakaria MI, Chin AV, Poi PJ. Ten-year mortality in older patients attending the emergency department after a fall. *Geriatr Gerontol Int*. 2015.
- Gabow P. The fall: aligning the best care with standards of care at the end of life. *Health Aff*. 2015;34(5):871-874.
- Walczak A, Butow PN, Clayton JM, et al. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ Open*. 2014;4(6):e005745.
- Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
- Institute of Medicine. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington DC: The National Academy Press; 2014.