Applied Nursing Research 50 (2019) 151198

Contents lists available at ScienceDirect

Applied Nursing Research

journal homepage: www.elsevier.com/locate/apnr

Challenges of older adults when a loved one was dying: Implications for nursing practice

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ARTICLE INFO

Keywords:
Older adults
Challenges
Dying loved one
Story-sharing
Nursing implications

ABSTRACT

Aims: To explore the challenge of losing a loved one who was hospitalized at end of life and identify approaches deemed most helpful by older adult family members to resolve this challenge.

Background: Nurses will be caring for a growing number of terminally ill older adults and their families. Research specific to older adults to address their needs when a loved one is dying is necessary to promote quality family-oriented care.

Methods: A qualitative descriptive exploratory study was conducted with a purposive sample of 15 older adult family members during July–August 2015. Methods for data collection and analysis included story theory inquiry and theory-guided content analysis.

Results: The dimensions of the challenge of losing a loved one include: moving from painful holding on to poignant letting go, uneasiness that permeates everyday living and precious memories, patterns of disconnect that breed discontent, and pervasive ambiguity that permeates perspectives about remaining time. Active engagement enabling exceptional care for loved ones, appreciating the rhythmic flow of everyday connecting and separating to get by, and embracing reality as situated in one's lifelong journey are the approaches to resolve this challenge.

Conclusions: Knowing a loved one was well cared for through nurses' compassionate caring was most important to older adults. Further research to address the self-care strategies of older adults as a loved one is dying is necessary. This study's nursing implications has the potential to enhance the quality of family-oriented care at end of life in diverse healthcare settings.

1. Introduction

Family members experience emotional turmoil when a loved one is dying (Adams et al., 2014; Cronin, Arnstein, & Flanagan, 2015), often enduring frequent and prolonged hospitalizations of loved ones in the last few months of life (Aldridge & Bradley, 2017). More than 60% of older adults (age 65 years and older) are hospitalized in the last three to six months of life (Aldridge & Bradley, 2017). Family members' distress and uneasiness intensifies when witnessing their loved one's suffering and deteriorating health and cognition (Meeker, McGinley, & Jezewski, 2019; Stephens et al., 2015). They feel helpless when unable to alleviate a loved one's suffering or halt disease progression in the last weeks of a loved one's life (Meeker et al.; Steinhauser, Voils, Bosworth, & Tulsky, 2015).

Family members often assume the burden of making difficult care decisions for loved ones who are dying since almost 50% of hospitalized older adults lack decisional capacity (Torke et al., 2014). Families describe decision-making as tormenting, knowing their decision may end a loved one's life (Schenker et al., 2012). Uncertainty about a loved one's prognosis, inability to process dismal news about a loved one's terminality, and conflicting, ambiguous conversations with multiple healthcare providers create decisional conflicts for families about a loved one's end of life (EOL) care in hospitals (Beckstrand, Hadley, Luthy, & Macintosh, 2017; Gutierrez, 2012) and long-term care (LTC) settings (Gonella et al., 2019; Stephens et al., 2015).

Unprepared for the death of a loved one, family members may experience emotional and physical health consequences (Stahl & Schulz, 2014) suggesting that their emotional needs remain unmet in EOL situations (Kisorio & Langley, 2016; Noome, Beneken genaarnd Kolmer, van Leeuwen, Dijkstra, & Vloet, 2016; Steinhauser et al., 2015). Older adults, in particular, due to existing age-related and chronic illnesses (Institute of Medicine [IOM], 2015) may be at an increased risk for developing physical and psychological health issues (Perng & Renz, 2018; Stahl & Schulz). Although many older adults have experienced the death of a significant other, this does not allay uncertainties and distress, or their ability to let go of a loved one who is dying (Perng & Renz; Stephens et al., 2015).

Nurses recognize the importance of encouraging intimate

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https://doi.org/10.1016/j.apnr.2019.151198
Received 18 February 2019; Received in revised form 30 May 2019; Accepted 18 October 2019
0897-1897/

connections with family members at EOL (Adams et al., 2014; Becker, Wright, & Schmit, 2017). However, working in institutionalized settings may desensitize nurses to the needs of family members. They may not understand fully the challenges that family members face and supportive measures desired to ease their emotional turmoil when a loved one is dying (Kisorio & Langley, 2016). Nurses, particularly in acute care settings, may inadvertently divert attention to care of patients to maintain their stability and have time-limited interactions with families (Beckstrand et al., 2017; Chan, Macdonald, Carnevale, & Cohen, 2018). Caregivers' rote work or inattentive behaviors escalates family members' stress and anguish (Lind, Lorem, Nortvedt, & HevrØy, 2012) and may hinder conversations about the quality of a loved one's care at EOL (Adams et al., 2014).

In spite of existing literature relevant to family's experiences in EOL situations, research specific to the needs and challenges of older adult family members and in healthcare settings is limited (IOM, 2015; Izumi & Van Son, 2016; Noome et al., 2016). This is significant to nursing practice since a majority of older adults die in hospitals and LTC facilities where almost 65% of nurses are employed (United States Department of Labor, 2018). Further research then is necessary to understand the nursing supportive measures that older adult family members deem most significant to ease their emotional vulnerabilities as a loved one is dying (Noome et al.; Stephens et al., 2015). The aim of this study was twofold: 1) To explore the dimensions of the health challenge of losing a loved one who had been hospitalized in an acute care setting within the last few months of life and 2) To identify approaches deemed most helpful by older adult family members to resolve this health challenge.

2. The study

2.1. Ethical considerations

Approval for this study was obtained from the Institutional Review Board of a Southeast (SE) Florida University and written permission to conduct the study at a SE Florida continuing care retirement community (CCRC) was received from the site's administrator. Each participant signed a consent form, agreed to be audio-recorded, and was assigned an identifier to maintain anonymity. Pseudonyms are used in all participant exemplars.

2.2. Methods

This study used a qualitative descriptive exploratory design guided by story inquiry method (Liehr & Smith, 2018) to understand the family heath challenge of losing a loved one. Story-sharing guided by story theory inquiry method (Liehr & Smith) provides individuals the opportunity to describe their EOL experiences and illuminate what really mattered as a loved one was dying. When an individual shares a story, insights about the past, present, and future circumstances surrounding a health challenge (story path approach) such as losing a loved one are described enabling an individual to gain insights on what approaches helped them to move through and resolve this complicating health challenge. Story inquiry method guided this study's data collection and analysis in line with the two research aims (Liehr & Smith). This inquiry method as described by Liehr and Smith (2018) includes five processes: 1) gather stories about a complicating health challenge (losing a loved one) through story-sharing; 2) begin deciphering the dimensions of the complicating health challenge; 3) describe the developing story plot (story path approach and what matters most to the story-sharer); 4) identify movement toward resolving (approaches); and 5) synthesize findings to address the research question (p. 255).

2.3. Sample/participants

This study's purposive sample included 15 independent-living older adults in a SE Florida CCRC. The recruitment process included three study information sessions, recruitment flyers, and snowballing technique with the help of a CCRC resident as an on-site contact. Each participant was a considered a family member defined in this study as a relative or significant other to a deceased individual. Of the 21 interested adults initially screened via telephone contact, 15 were eligible to participate. Eligibility for participation in this study included: 65 years of age or older; experienced the death of a loved one, no less than 1 month or, within the past 10 years at the time of interview; had a loved one hospitalized in an acute care facility (defined as a hospital or LTC facility such as a skilled nursing facility [SNF] or the CCRC's health care facility [HCF]) within the final 3 months of life (defined as EOL in this study), and was involved in making EOL decisions about a loved one's care. Participants were excluded from the study if they did not meet the inclusion criteria, and their loved one's death was due to a sudden violent event such as suicide or homicide. The time of a loved one's death was extended from the initial criteria of five years to 10 years to include two interested participants whose loved ones died 9 to 10 years ago.

2.4. Data collection

Two face-to-face interviews with each participant were prescheduled, audio-recorded, and conducted by the author in July and August of 2015. Second interviews occurred within 3 to 13 days after initial interviews to provide participants an additional opportunity for story-sharing about their loss and to clarify data generated in first interviews. Interviews were held in the participant's apartment, except for one participant who opted for a private room at the CCRC.

Following a story path approach in the first interview (Liehr & Smith, 2018), the dialogue began with a story guide sheet of paper with the title, your story of losing a loved one and this initial question, “Please think back to when your loved one died. Can you tell me how it is for you today?” After sharing what they wanted to about their present situation, gentle coaxing encouraged family members to recall a loved one's last hospitalization and EOL in an acute care facility prompted by questions such as, Can you tell me about your loved one's last hospitalization in an acute care facility; Can you tell me about your loved one's death; What do you recall about how it was like for you; and What was most helpful to you, to elicit the challenges faced and approaches that helped them through a loved one's illness and death. When participants had no further information to share about the present or their past loss, they were asked, Is there anything else that you would like to share about what was most important? Additional questions from a researcher-prepared questionnaire (past-present-future focus) were used, when necessary, to guide story-sharing in line with the research aims and open-ended questions assisted in clarifying ambiguities. First interview times ranged from 26 to 85 min and second interviews from 37 to 130 min. Field notes were recorded after each interview to capture researcher observations and non-verbal nuances to supplement the audio recordings.

2.5. Data analysis

Each interview was transcribed verbatim by the author in an iterative process using the pause/playback buttons on the audio-recorder and read line-by-line after transcription to ensure accuracy of the transcripts. Each participant's two transcripts were analyzed in the same manner by the author in an iterative process that included reading and re-reading transcripts prior to data abstraction to foster a meaningful understanding of the participant's entire story. Theory-guided content analysis (Hsieh & Shannon, 2005) was used to abstract data into categories and derive themes in line with the two research aims through a deductive-inductive process. First, words and phrases that explicitly or implicitly related to the dimensions of the challenge of losing a loved one were identified; then, approaches for resolving this challenge were grouped into meaningful clusters using the first six participant transcripts. Using an inductive analysis process, preliminary categories were derived for the dimensions (12) of the health challenge of losing a loved one and approaches used moving to resolve this challenge (15) in collaboration with an experienced qualitative nurse researcher from the six participant transcripts. Two of the 15 initial categories for approaches were later combined, for a total of 14 categories. The remaining nine participant transcripts were analyzed in the same manner using the preliminary categories. No new categories emerged. Finally, categories were interrelated and interpreted to elicit emerging themes related to the dimensions of the challenge of losing a loved one and approaches deemed most helpful by participants in resolving this challenge with the same experienced nurse researcher. Matrices listing the themes and respective categories were developed by the author to derive definitions for each theme, select participant phrases that best exemplified the themes, and explicate implications for nursing practice.

To address study rigor, Lincoln and Guba's (1985) four criteria for trustworthiness were applied. Data credibility was supported by prolonged engagement with participants, full immersion with the data during transcription and analysis, triangulation of written field notes, and peer debriefing with the experienced qualitative researcher. Data saturation was reached by participant 12 and verified by three additional interviews. Transferability was accomplished by providing rich descriptions of participants' experiences. Dependability was established through an audit inquiry by the same experienced researcher to promote confirmability, or objectivity in data interpretation. A journal was maintained to record the author's ongoing accounts and thoughts related to the research process and findings, including similar and divergent data that emerged during participant interviews. Participants' story details were consistent in both interviews substantiating data integrity.

3. Results

The mean age of participants was 84.5 years and loved ones (decedents) was 86.7 years. All decedents died in a SE Florida healthcare facility (6-hospital; 8-LTC facility) except for one who died at home in another US state. Three different local area hospitals were named by five of the six participants during the interviews. Eleven decedents (78.5%) of the 14 under hospice care had hospice stays of 30 days or less (Table 1). All participants self-reported that decedents had at least one chronic illness.

3.1. Dimensions of the health challenge of losing a loved one

This health challenge was described as facing a loved one's EOL where impending loss altered and disrupted an older adult's life patterns creating uneasiness in everyday living. This disruption was composed of four themes (dimensions).

Moving from painful holding on to poignant letting go is the arduous process of witnessing a loved one's unwavering physical and mental decline while struggling through the realization that a loved one is dying, facing the inevitable and moving to acceptance, or poignant letting go. Witnessing a loved one's decline is distressing for families. This theme is best illustrated by this participant who was struggling through the sudden decline of her husband in his last week of life.

> I saw him struggling. I still allowed it (life-support measures) to stay on for a while. Believing that he could make a turn for the better… He wanted his body to close down. And I didn't want that, but I did not want him to suffer…I witnessed the pain and suffering of such a good, decent man until my brain woke up and I said stop everything. Let him go.

At least half of the participants endured the gradual physical and cognitive deterioration of loved ones from chronic illness in LTC in the last months of life; some witnessed this decline for over a year. One recalled, “He couldn't walk, he didn't talk very much… Everything shuts down in the body step by step with Alzheimer's…it was just a very gradual declining. I watched it inch by inch. Not step by step, inch by inch…to die.”

Table 1

Summary of participant and decedent characteristics.

Characteristics	*N*	%
Participants (*n* = 15)		
Age (years)		
Mean (SD)	84.5 (7.2)	
Median/range	86/70–95	
Gender: male/female	5/10	33.3/67.7
Caucasian/Asian	14/1	93.3/6.7
Relationship to deceased		
Spouse	11	73.4
Friend	2	13.3
Sibling/parent	2	13.3
Time of decedent's death (months)		
3.5–8	6	40
12–13	2	13.3
26–42	2	13.3
54–59	3	20
105–120	2	13.3
Decedents (*n* = 15)		
Age at time of death (years)		
Mean/median/range	86.7/86/75–98	
Gender: male/female	6/9	40/60
Hospitalization and death		
Place of death[a]		
Hospital (intensive care stays)	6 (4)	40 (67)
Healthcare facility (HCF-CCRC)	7	46.7
Skilled nursing facility (SNF)	1	6.7
Home	1	6.7
Cause of death		
Brain tumor (1)/dementia (4)	5	33.3
Heart failure	2	13.3
Stroke	2	13.3
Pneumonia/pulmonary embolus	2	13.3
Cancer	1	6.7
Not specified/unsure	3	20
Length of time in facility prior to death		
Hospital (days)/median	5–14 days/7 days	
HCF/SNF (range)	2 weeks-2.75 yrs.	
2–6 weeks	2	25
9–13 months	3	37.5
2–3 years	3	37.5
Length of time in hospice to death (n = 14)		
Hospitalized decedents (*n* = 5)		
9 h-2 days	2	40
3 days–5 days	3	60
HCF/SNF decedents (*n* = 8)		
7 days or less	4	50
30 days	1	12.5
5 months	1	12.5
12 months	2	25
Death at home – 3 weeks	1	

[a] Place of death: LTC = Long term care facility = HCC-Healthcare facility at the Continuing Care Retirement Community and SNF-other skilled nursing facility in Southeast Florida.

Making definitive decisions about a loved one's care was difficult and a life haunting experience, as one participant in the hospital remembered, “But the minute, you make that decision, then you have to execute it. And it's saying to the doctors, let her go…That's the one thing I remember most of all. I'll remember that all my life, because that is tough.” Another participant, recalled the finality of signing her loved one's do not resuscitate (DNR) document in the LTC setting, “I was signing an execution” and “I was essentially signing his death warrant.”

Participants poignantly spoke of letting go of a loved one and how memories of a loved one's death linger on. Accepting the finality of a loved one's death was extremely difficult for participants as stated by this participant, “I think there's a reluctance to give up the body of a loved one…we just don't want it to ever end.” More than half of the participants showed photographs of once healthy loved ones perhaps to elicit fond memories of a past life.

Uneasiness that permeates everyday living and precious memories is the emotional turmoil that arises in the last few weeks of a loved one's life disrupting life's normalcy.

Most participants shared that dutiful vigilance and constant worry about a loved one created uneasiness and physical and emotional fatigue at EOL, making it difficult to care for self in day-to-day living as one participant related, “I got those frantic calls every morning at 5 am… I would stay there (hospital) until dark…and he'd (loved one) say, you need to hurry up, they're doing something to me…”.

Participants, particularly those whose loved ones resided in LTC, described an unrelenting uneasiness and being in limbo, facing a paradox of holding on and letting go in the last few weeks of a loved one's life, exemplified by this participant.

> There was a look of peace. And I was grateful for that. But by the same token, it was like, wait, stop don't do it so fast… I was annoyed with myself…But I'm not at peace, because I don't want him to go yet. …I resisted…But eventually you accept the fact that this is it.

Patterns of disconnect that breed discontent are the actions or behaviors of others that isolate and disjoin family members from others or the environment. Miscommunication, staff disengagement, lack of candid family-provider conversations, marginalization of family's concerns about loved ones, and a lack of empathy created family member discontentment and a family-staff disconnectedness for at least eight participants. This participant related his feelings about the lack of empathy from some of the nurses in the hospital.

> You know well it happens to all of us… but this is the way life is. You come and you go. It wasn't what I recall putting yourself in the person who had the loss in their sorta shoes. It was entirely a third party, distant relationship rather than a really close relationship… They (nurses) just didn't have the feelings, the closeness.

Participants in the hospital expressed that providing information about a loved one's care and prognosis was primarily a physician's role, although an arduous process with often brief family-physician over-the-counter conversations. Rote or inattentive behavior by nurses intensified a family member's discontentment expressed by this participant.

> How about giving us some information. How about letting us see … a smile, a kindness to the patient instead of just doing your job. I know they're (nurses) busy… But, the human contact is important. If they (nurses) saw the patient's wife sitting there… Just ask them a question. Is there anything I could do to relieve your mind? But that never happened.

Most participants (7 out of 8) whose loved ones were in LTC felt differently. They shared that the staff provided daily updates and showed love, respect, and concern to them and their loved ones. It was evident in their stories, that these participants shared a familiarity with LTC staff.

Pervasive ambiguity that permeates perspectives about remaining time is the uncertainty experienced by family members regarding a loved one's illness that distances them from death's inevitability and maintains hopefulness that a loved one's life will be sustained. Uncertainties materialized because of participants' ambiguous conversations with hospital providers about a loved one's illness trajectory or a loved one's recurrent rebounds from chronic disease exacerbations. One participant related:

> …Just chat, talk by the doctors…that they weren't, going to… They might have to… and this and that. And if I were to show any discontent it was a fact that we didn't ever get any more than ominous predictions for the future…and my wife would get into a little coughing fit. And it would sound like she was having real trouble and then she would get over it.

Finally, the slow and unpredictable trajectory of a loved one's chronic illness created uncertainties about a loved one's remaining time. A few participants, albeit stating that they felt informed about a loved one's status, shared that subtle signs of worsening health and impending death were missed because their loved ones' conditions and outward appearances to them remained relatively unchanged day-to-day, even at EOL. Subtle but significant changes/signs presaging a loved one's EOL may be less obvious to family members intimately involved, as shared by this participant:

> Molly had been ill for quite a while. And she had been back to the hospital, two or three times…With the last time …it knocked her out …it should have been explained to me a little more that she was failing. Because at a certain point, a loved one can be the same over and over again, but they're getting worse and you don't know it.

3.2. *Approaches to resolve the challenge of losing a loved one*

Resolving a challenge is defined as the ability to recognize alternative approaches and new possibilities in managing and moving forward through a challenge (Liehr & Smith, 2018). Three themes emerged to elucidate the approaches used by participants in this study.

Active engagement enabling exceptional care for loved ones is the compassion, caring, and competent actions of healthcare providers deemed most supportive by family members in transitioning through the emotionally challenging process of losing a loved one and the actions that family members engaged to facilitate and ensure that a loved one was being well cared for.

Knowing that their loved ones were well cared for and feeling cared for themselves by nursing staff helped participants move through the challenge of losing a loved one. Study participants identified attentiveness, compassion, presence, empathy, sympathy, cheerfulness, respect, and a loving spirit as qualities that encouraged family-nursing staff connectedness or compassionate caring. Knowing that a loved one was well cared through compassionate caring by nurses was most important to most, if not all participants. As one participant stated:

> They (nurses) have to really and truly deal with you and understand the stresses that you're under. So I thought that they were very, very excellent… they put their arm around you, and say, I know what you are going through. I think the main thing that they do for you is give the patient care and you know that. And you see it. And they are on top of everything. And that's what you need to see because you can't do anything.

It was apparent during participants' stories that compassionate care to family members by nursing staff was synonymous with competent care for loved ones. Nurses' lack of compassion to families raised doubts about the quality of a loved one's care as expressed by this participant, “you feel that they (nurses) just ignore you and then the next step, well then they definitely ignore your loved one.”

Despite the length of time since a loved one's death (3.5 months to 10 years), five participants specifically named caregivers who provided exceptional family-oriented care in the hospital and LTC setting. One participant in the LTC setting shared, “He (spouse) was getting worse. Karen who was the head nurse there helped me a lot. She was great. She'd get together and talk about it …We became kind friends…She had a great sense of humor too, that helped.”

Finally, enabling exceptional care for loved ones included participants' approaches to ensure that their loved one's needs were met such as seeking and finding out information about a loved one's condition from care providers and providing emotional support to loved ones. Performing small tasks to address a loved one's physical needs and comfort was important to many participants as one recalled: “I trimmed his hair. I didn't want to take him to the barber here (LTC facility)…And he turned his head… I said now you look good. I think he understood. They were rough times. I just wanted him to look nice."

Appreciating the rhythmic flow of everyday connecting and separating to get by are the actions of self and others that strengthen one's ability to face the day-to-day challenges of losing a loved one. Connecting with family or close friends helped participants transition through the challenge of losing a loved one, as shared by this participant, "Having the family there and all of us together was actually very peaceful death…we were able to sustain each other and we talked about different, all happy events in our lives with her (loved one)." For some participants (LTC), separating or a respite from loved ones helped to resolve some of the stress endured as a loved one's cognitive abilities and health continued to decline. Curtailing visit times and surrendering small care tasks helped some participants whose loved ones were in LTC. As one recalled:

> He was not responding to anything…he would sit there…they (LTC staff) told me don't come every day…but that's when I gave up the laundry…I would start going every second day… it was always a little bit of release… that I didn't go every day, because I didn't have it (loved one's declining health) in front of me.

Embracing reality as situated in one's lifelong journey is coming to grips with a loved one's demise in everyday living while relying on past and present circumstances to move along.

Knowledge about a loved one's chronic illness prepared some participants and their families for what was to come as this participant recalled, "We (family) were all so familiar with the case (loved one's illness) and the consequences, and the alternatives… it made us a little more at ease…I think we're as familiar with the case as anybody that is not a doctor would be."

Many participants realized that a loved one would not survive given their age and debilitating chronic illnesses. A loved one's death was more expected than unexpected amidst uncertainties about when it would occur as this participant shared:

> My wife had a long period of not being well and we realized that because of her age and her many ailments…and we would go along with some older friends who said it's a blessing when a person with all those difficulties and they can pass peacefully…it's the only logical thing that can be done and happen. We have a life cycle.

Many participants expressed hopes of comfort for loved ones at EOL exemplified by this participant, "…I realized that soon he (husband) will pass, because of all his illnesses…And I just kept praying that he won't last, and that he would go peacefully and pain free." Finally, most participants shared that being there and hopes that a loved one was aware of their presence provided comfort and helped them embrace the reality of a loved one's passing. As one offered, "I wanted him to just keep knowing how much I love him. I want to keep going there and being there (LTC facility). I want him always to know that I'm there… And I'll get through this…"

4. Discussion

While experiences of losing a loved one are unique for each person, commonalities among participants surfaced regarding the challenge of losing a loved one similar to existing research about family members' EOL experiences (Adams et al., 2014; Cronin et al., 2015; Jackson et al., 2012). This study provides additional insights regarding older adults' experiences in the hospital and LTC settings, family's perception of a loved one's health condition, and nurse's caring. Consistent with prior research, this study demonstrates the need to increase family care involvement (Adams et al.; Kisorio & Langley, 2016; Noome et al., 2016), improve care provider-family EOL communication (Beckstrand et al., 2017; Gonella et al., 2019; Gutierrez, 2012), encourage family bedside presence and visits of close family and friends (Becker et al., 2017; Naef, Ward, Mahrer-Imhof, & Grande, 2017; Williams, Lewis, Burgio, & Goode, 2012), and maintain consistent nurse staffing patterns (Beckstrand et al., 2017; Cronin et al., 2015; Jackson et al., 2012) to enhance family-oriented care at EOL (IOM, 2015).

Despite older adults acknowledging the probability of death, they, like other aged family members, vacillate between holding on and letting go of a loved one in the last few weeks of life (Schenker et al., 2012). Family members need time to work through their uneasiness and embrace new life meanings through this paradox, or the process of letting go, reflecting on memories of a past life, present circumstances surrounding a loved one's illness, and future life prospects without a loved one (Steinhauser et al., 2015). This reflective process highlights the value of story-sharing (Liehr & Smith, 2018) as a useful nursing approach to help families move to resolve this paradox of letting go at EOL (Naef et al., 2017; Noome et al., 2016).

This study illuminated that missing subtle signs of a loved one's worsening health and loved ones' apparent rebounds from chronic illness exacerbations complicate a family's perspectives about a loved one's EOL. Although nurses recognize that a loved one's deteriorating condition is past survival and determine that family members are in "denial" of a loved one's impending demise (Beckstrand, Mallory, Macintosh, & Luthy, 2018; Stephens et al., 2015), they should consider that some family members may not realize the severity of a loved one's illness due to missing subtle signs of a loved one's progressive decline from chronic illness over months. Robichaux and Clark (2006) suggest asking family members "Tell me what you see here," can enlighten nurses about their perceptions of a loved one's status (p. 486). This study questions if bedside photographs of once healthy loved ones, which may enhance family story-sharing and comfort, can paradoxically heighten family recognition of a loved one's instability and demise (Cronin et al., 2015); nonetheless further research is necessary.

Nurses should educate families about hospice services and the signs of EOL (Beckstrand et al., 2017; Izumi & Van Son, 2016) as 54% of patients enrolled in hospice nationally (78.5% in this study) receive care for 30 days or less (National Hospice and Palliative Care Organization, 2018). There is a need to expand EOL education in academia and clinical institutions to enhance nurses' and other clinicians' comfortability in communicating with families at EOL (Becker et al., 2017; IOM, 2015).

Ample research exists about the importance of fostering effective family-nurse communication affirming that family members often consider nurses as key information sources about a loved one's status (Gutierrez, 2012; Williams et al., 2012). Jackson et al. (2012) relate that family members of loved ones in LTC developed trust and confidence in caregivers when they interacted with the same nursing staff and were kept well-informed. This study, like Jackson et al., suggests that family familiarity with a consistent nursing workforce encourages fluent interactions and conversations, in turn, family-staff interconnectedness. Nonetheless, Lind et al. (2012) report that although nurses in the hospital were compassionate, nurse-family conversations about loved ones were ambiguous and limited; similar to this study's findings for family members in the hospital setting. Therefore, maintaining consistent nurse staffing patterns in EOL situations is recommended (Beckstand et al., 2017; Cronin et al., 2015; Jackson et al., 2012) and may enhance nurse-family EOL conversations.

Nurse and medical partnerships are essential to foster meaningful conversations with family members about the quality of care desired for loved ones at EOL (IOM, 2015). Healthcare institutions may want to consider scheduling interdisciplinary story-sharing sessions to raise awareness of the core components of quality EOL care and encourage mutual sharing of clinicians' EOL challenges. Sharing personal experiences may ignite nurse-medical partnerships to advance quality EOL care and support for families and their loved ones in EOL situations.

Finally, this study identified that compassionate care was synonymous with competent care suggesting that although a nurse is experienced, highly knowledgeable, and technically skilled, without

Table 2
Implications for nursing practice guided by participants' stories.

Nursing approaches	Supporting participant quotes
• Maintain a respectful and attentive presence to loved ones and family. Treat a person as person.	"You make that connection somehow, then, you just feel better. Because you know you've been seen as person. And not just something in the room." "They knew him by name and called him by name, even though he did not remember who he was."
• Provide empathetic and compassionate caring and a willingness to listen to what matters most to families as a loved one is dying. Encourage family guidance related to care needs and private time with loved ones and significant others.	"I think that not to intrude. You're (nurse) not to try to minimize the situation, or to give advice or anything…And so I've seen some nurses become over solicitous. They try to, not minimize the situation but to kinda gloss over it… he'll be in a better place… None of us want to believe that they're (loved ones) gonna be in a better place. That they're not gonna suffer anymore. Well, we (family) know that. We know all these things. So I think that letting the family guide you (nurse)…Every family has their own way of coping with the loss of a loved one. And there's no one rule… so you (nurse) have to let the family guide you."
• Consider that some family members may not realize that a loved one's life is ending. Explore family members' perspectives about a loved one's condition and what they want for their loved ones.	"Nobody (care providers) said, it looks like this is an EOL situation… If I hadda heard those words, I would have said, I want to put him on hospice. But nobody ever said They (care providers) all kept…building up the blocks of hope. Building this big tower of hope until it crashed… I was so sure from what I heard, from the few physicians that I did come in contact with, that he's gonna make it" "I wished I did, understand…I don't. Because when I left to go on vacation, he appeared to be the same that he had been for several months. So whatever happened with him after I left, I was not here… it evidently was very sudden. I did not expect it. I knew he was declining…but it had been such a long, slow process, I absolutely did not, did not anticipate it (death) at that time."
• Promote a comfortable, caring, and quiet environment to facilitate a story-sharing process. Story-sharing may be enhanced with pictures of loved ones to foster connectedness and revive special memories.	"And I could see the difference between **her** (a nurse) and the other nurses. She was much more showed tremendous empathy and understanding… It's not just looking after the patient but looking after the person that had suffered the loss. So, it was very comforting, it was just her general demeanor, her interest in what you're doing and is there any help we can give you and…It was really a change of emphasis that the others didn't have… it was with caring you know…" "I had the feeling that I would lose her (loved one), unless I had something visible for me that would be there to see. And so the pictures were very helpful. I can look at them and think of her, you know, the way she was. … We (family) want to remember when she was younger and vital, and telling jokes and laughing…"
• Promote a family-nurse partnership of caring for a loved one, emphasizing their involvement in small care tasks complements nursing care. Orient family members to the hospital environment and care.	"I feel very strongly that there should be, when someone goes into a facility that it's a good idea to sit down with the caregiver…And go through a protocol procedure, who do you talk to about this…I think that's very important especially for a caregiver's peace of mind… it would be very helpful to have like an orientation. And I firmly believe this for hospitals. He (husband) was in the hospital and I nearly lost my mind. We'll (family) do better and be less of a bother to the nurse, if we know what the protocol is. What you want me to do …Or if I can talk to you about what I need, whatever it is… But it would have been easier, far easier on me."
• Keep family members well informed in timely and frequent updates about a loved one's condition and procedures performed to ensure their comfort and stability.	"Suzie the charge nurse would always give me little updates or anything when I came in…he did this, he did that, or he didn't sleep well. They kept me up to date…I never felt out of the circle."
• Offer information about palliative and hospice services, depending upon family members' receptiveness or willingness to accept services.	"I saw the sign somewhere in that intensive care that reminded me of hospice. And people here (CCRC) have talked about hospice. So, then I said stop, I want him on hospice." "I don't think most people know what hospice does except, come and be present. And perhaps, the way hospice operates might be more, be more effective if people knew it better, how it operates."

compassionate presence, family members may lack confidence that a loved one is receiving competent care. Williams et al. (2012) report that families appreciate nurses who holistically met their needs and loved ones by showing genuine concern and thoughtfulness. Nurses' attentiveness to families encourages dedicated EOL conversations and family-guided caring actions, and therefore, strengthens nurse-family interconnectedness and enhances compassionate family-oriented care at EOL (Cronin et al., 2015; Jackson et al., 2012).

5. Limitations

This study's sample of Caucasian affluent older adults (14 out of 15 participants) residing in a CCRC limited inclusion of family members from diverse socioeconomic backgrounds and ages. However, the results of this study demonstrate that there are commonalities among family members related to the experience of losing a loved one similar to existing research findings as previously discussed. The emotional anguish experienced as a loved one is dying and exact details about the EOL experience may not be fully captured in participants' stories because of the length of time lapsed from a loved one's passing. Given that the death of a loved one is devastating, memories of what mattered most to family members at EOL remain. Although authenticity of data was maintained throughout the research process, unintentional biases in data interpretation may have arisen based on the researcher's prior knowledge of EOL research and extensive critical care work experiences in EOL situations.

6. Conclusion

Considering many issues that comprise the challenge of losing a loved one such as communication difficulties are similarly reported in existing literature indicates that further study is needed to enhance quality EOL care in all care settings. The unprecedented growth of older adults emphasizes that research relevant to their health needs and ability for self-care in EOL situations is essential. Policy changes to enhance respite care services and public awareness of palliative/hospice services are important which may help to mitigate the intense stress encumbering family members at EOL (IOM, 2015). Although interdisciplinary partnerships are essential to promote person-centered, family-oriented quality EOL care (IOM, 2015), a goal of this study was to derive a framework of nursing actions guided by participants' stories of what approaches they deemed most supportive as a loved one was dying. Implications for nursing practice (Table 2) include:

- Demonstrate respect and a willingness to listen to family's concerns and guidance regarding EOL care needs.
- Promote a caring and comfortable environment to facilitate story-sharing and an understanding of family's perspectives about a loved one's condition.
- Provide timely updates about a loved one's condition and education about the signs of EOL and hospice/palliative care services.

Funding statement

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of competing interest

No conflict of interest has been declared by the author.

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