

How hospice staff members prepare family caregivers for the patient's final days of life: An exploratory study

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Abstract

Background: There is widespread agreement that the families of hospice patients need to be prepared for the final days of life, yet current practices preparing families are not well described. Examining the gap between family needs and current practice will inform the development of effective preparatory interventions.

Aim: The purpose of the study was to describe how hospice clinicians prepare family for the final days of life, including (1) the content of the preparatory information, (2) strategies and timing of preparation, and whether the preparation is tailored, and (3) who prepares families.

Design: Conventional content analysis guided this study. Individual interviews using semi-structured questions were conducted.

Setting/participants: In all, 19 hospice clinicians who provided care in the home setting from two hospice agencies in the United States participated.

Results: Preparatory messages included information on signs of impending death, symptoms, implications of the symptoms, what to expect next, and instructions on what to do. Commonly used strategies included listening, engendering trust, repetition, collaboration with other disciplines, and demonstrations. Staff tailored content and delivery of messages on patient, family, and hospice factors. Preparation usually occurred over time. All hospice staff provided preparatory information, but there are some differences by discipline.

Conclusions: Most content previously identified as necessary for preparedness is part of the current preparation. The knowledge of the current practice in preparing families can be used to develop systematic means of assessing the factors related to timing and tailoring, which may assist in developing preparatory messages that are effective and timely.

Keywords

Family, caregivers, hospices

What is already known about the topic?

- Family preparation for death improves caregiver outcomes such as perceived competence, having informational needs met, family satisfaction, and hope.
- Lack of preparedness is associated with caregiver fear, anxiety, anger, fatigue, lack of adjustment, feelings of helplessness, lack of confidence about caregiving abilities, and depression.
- Caregiver knowledge and information from hospice staff and volunteers, spiritual beliefs or practices, social connections, respite availability, prior caregiving experience, bearing witness to suffering, and being aware of impending death support preparedness.

What this paper adds?

- Content of preparation includes information on (1) symptoms and signs of impending death, (2) implications of the signs and symptoms, (3) what to expect next including symptoms and expected time to death, and (4) instructions on what to do.

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- Strategies used in preparing families include the following: listening, engendering trust, repetition, collaboration with other disciplines, demonstration, and presence.
- Content, delivery, and timing of preparation are tailored based on patient, family, and hospice factors.

Implications for practice, theory, or policy

- Comparing the current practice to family needs, there is a need to include information about family spiritual beliefs, social connections, and unmet financial needs when tailoring information to prepare family members for caregiving in the final days.
- There needs to be coordinated efforts between disciplines to assure that the multidimensional needs of the family are met.

Introduction

Preparing families for the end of the patient's life is central to the mission of hospice. Family caregivers who are prepared for caregiving and for the patient's death exhibit positive outcomes such as perceived competence, having informational needs met, and family satisfaction¹⁻³ and describe higher levels of hope than those who are not prepared.⁴ Lack of preparedness is associated with caregiver fear,⁵ anxiety,⁴⁻⁷ anger,⁶ fatigue,⁶ lack of adjustment,^{5,8} feelings of helplessness,⁶ lack of confidence about their caregiving abilities,^{5-7,9} and depression.¹⁰⁻¹²

Family preparation for death includes knowing patient preferences and having someone designated to make decisions,¹³ knowing what to expect about the dying person's physical condition and symptoms,¹³⁻²⁰ and having sufficient finances.^{13,15} Family preparedness is multidimensional and includes medical, psychosocial, spiritual, and practical dimensions.^{13,21} Communication,^{14,18,20,22} including knowing that clinicians are comfortable talking about dying,¹³ is also necessary for preparedness. Other elements that support preparedness in family caregivers include caregiver knowledge^{13,15,18,19,21,23} and information from hospice staff and volunteers,^{15,22-24} spiritual beliefs or practices,^{15,21,23} social connections,¹⁵ respite availability,¹⁵ prior caregiving experience,^{22,23} bearing witness to suffering,^{23,25} and being aware of impending death.²⁰

In contrast to the literature on family preparation for death, there is much less research specifically examining family preparedness for caregiving in the final days. It is important to know more about the gap between family member needs and current practice, so effective preparatory interventions can be developed. Knowing which hospice clinicians are involved in family preparation can help us develop interdisciplinary interventions that meet the multidimensional needs of family and informal caregivers during active dying.

Given the limited evidence about how families are prepared for the final days and the documented negative consequences of poor preparation, there is a need for further research.⁹ The questions guiding this study were as follows:

(1) What is the content of the preparatory information hospice clinicians provide to families? (2) How are families prepared for the patient's final days especially in regards to the strategies and timing of the preparation, and whether the preparation is tailored to the patient and family? and (3) Who prepares families for the end of life?

Methods

A qualitative descriptive study was conducted. Study procedures were reviewed and approved by the University of Wisconsin-Madison, Social and Behavioral Science Review Board. One of the hospice organizations had a research committee that granted approval. The other hospice did not have a research committee and approval was obtained from the CEO.

Participants

In all, 19 hospice staff members who provided direct care in the home setting were recruited from three offices of two hospice organizations in south-central Wisconsin, USA, between July 2007 and September 2008. The researcher described the study at hospice staff meetings. A total of 40 staff members volunteered, gave written consent for participation, and completed demographic data forms. The participants were purposefully selected for maximum variation²⁶ based on variations in discipline, experience, age, gender, ethnicity, location of office, and job title. All the selected individuals completed a single interview. The researcher previously worked as an on-call nurse for one of the hospices and had worked with four of the nurses. All participants were aware of the researcher's background as a hospice nurse and current role as a researcher.

Data collection and analysis

Participants were interviewed individually by the author during working hours in a private room at the hospice.

Interviews lasted approximately 50 min and were audio-recorded and transcribed. Notes were recorded during and immediately after each interview. The interview questions were developed by the researcher and reviewed for content validity by a hospice nurse and social worker (SW), who were not interviewed for the study. All participants were asked the following questions: (1) Do you think that families can be prepared for the final hours of life? (2) What is the content of your preparation, what do you tell them? (3) How do you prepare the family? (4) When do you prepare them? and (5) Do you give the same message to everyone? If not, what do you do differently? Additional probe questions were asked, if needed.

Conventional content analysis was used and began with the first interview. Conventional content analysis is used to describe a phenomenon, in this case hospice staff preparation of families for caregiving in the final days, when there is limited prior research. Following a protocol for conventional content analysis,²⁷ each transcript was reviewed and coded by the researcher at least three times. Transcriptions were compared to the audio-recording to assure accuracy. Microsoft Word 2007 was used for transcription and coding. Transcripts were first read for data immersion. Then, transcripts were thoroughly reviewed and key words were highlighted. Codes were derived from the key words. Codes were separated into categories and themes based on the relationship between the coded concepts, supported by interview data. After the coding tree was complete, the transcripts were re-read and recoded. Finally, the transcripts were reviewed again to verify the coding and mark passages for quotation. Content was compared within each interview and across interviews for similarities and differences.

When thematic saturation was reached, no further interviews were scheduled. To enhance the rigor of the analysis and trustworthiness of the findings, the following strategies were used:²⁸ (1) careful documentation of each step of the analytic process, (2) recoding the data to verify reliability, and (3) member checking with participants reviewing the transcripts and analysis notes and discussing their perceptions of the analysis with the researcher. During member checking, there were no disagreements with the analysis.

Results

Participants included Registered Nurses (RNs), Licensed Practical Nurses (LPNs), a Certified Nursing Assistant (CNA), SWs, bereavement counselors (BERs) who provided pre-death counseling, and a chaplain (Table 1). They had a wide range of experience (<1 year to >25 years). Education varied with 55% holding a bachelor's degree or higher. The participants were primarily female (80%). All participants were non-Hispanic and White. The sample was similar to the employee demographics in the agencies involved and roughly similar to demographics of the Hospice and Palliative Nurses Association, which is 95%

Table 1. Demographics of participants in hospice staff interviews concerning preparation of families for death.

Discipline	N= 19
Registered Nurse	Nine (two on-call, two per diem, and five case managers with on-call duties)
Licensed Practical Nurse	3
Certified Nursing Assistant	1
Clinical social worker	3
Bereavement	2
Chaplain	1
Years of healthcare experience	
0–3	2
>3–5	3
>5–10	4
>10–15	2
>15–20	1
>20–25	2
>25	5
Years of hospice experience	
0–1	3
>1–2	8
>2–5	1
>5–10	3
>10–15	2
>15–20	2
Age (years)	
26–30	2
31–35	2
36–40	4
41–45	5
46–50	4
51–55	1
56–60	0
>60	1
Education	
Certificate program	1
Associate degree	8
Bachelor's degree	6
Masters' degree	4
Religion	
Christian	18
None	1
Marital status	
Married	16
Not married	3
Gender	
Male	3
Female	16

female and 87% White. The demographics of the region indicate a population that is 91.1% White.

The hospices represent the range of sizes and locations of agencies in the region. Both hospices are non-profit and serve both urban and rural families. One hospice is large,

Table 2. Themes and distribution of discussion by discipline.

Themes	Nursing			Counseling		
	RN, n=9	LPN, n=3	CNA, n=1	SW, n=3	BER, n=2	CH, n=1
<i>Content of preparation</i>						
Physical signs of impending death and/or symptoms that occur in the final days	X	X	X	X		
Emotional changes that occur in the patient and caregiver	X					X
Anticipated time to death	X	X	X	X	X	
What to expect next	X	X		X	X	
Instructions on what to do	X			X		
<i>Strategies for preparing families</i>						
Listening to the family	X	X			X	X
Engendering trust	X			X	X	
Repetition	X			X		
Collaboration with other disciplines	X	X	X	X	X	
Demonstration	X	X				
Presence	X			X		X
<i>Tailoring of content and delivery—based on</i>						
<i>Patient factors</i>						
Symptoms exhibited	X					
Time to death	X	X	X	X		
<i>Family factors</i>						
Healthcare or caregiving experience	X					
Education	X	X		X	X	
Culture	X	X			X	X
Desire for knowledge about dying process	X	X		X	X	
<i>Hospice factors</i>						
Continuity	X	X				
Staff training	X			X	X	
<i>Timing</i>						
Over time	X			X	X	
Start early	X	X				
<i>Timing tailored based on patient factors</i>						
Condition changes—escalation of symptoms, rapid condition changes	X	X				
Medication changes	X	X				
<i>Timing tailored based on family factors</i>						
Assessment of family needs		X		X	X	
Family readiness to accept death	X	X		X	X	
Family request for information	X	X		X		

RN: Registered Nurse; LPN: Licensed Practical Nurse; CAN: Certified Nursing Assistant; SW: social worker; BER: bereavement counselor; CH: chaplain.

has two offices, and an average daily census of around 400 patients. The other hospice is small with an average daily census of about 40 patients. At the time of data collection, there were no for-profit hospices operating in the area. Both hospices have a majority of White patients but did not provide specific demographic information.

Content of preparatory messages

The content of preparatory messages included the following: (1) symptoms and signs of impending death, (2) implications

of the signs and symptoms, (3) what to expect next including symptoms and expected time to death, and (4) instructions on what to do. A summary of the themes derived from the analysis is in Table 2.

Signs of impending death and symptoms that occur in the final days. Staff discussed signs and symptoms most frequently and at the most length. All the nursing staff included information about signs and symptoms. A wide variety of signs and symptoms at the end of life were described (Table 3):

Table 3. Signs of impending death and symptoms at the end of life included in hospice staff preparation of families.

Breathing changes
Changes in appetite and eating
Restlessness or delirium
Patient not taking fluids
Skin changes
Mottling
Jaundice
Urinary changes
Incontinence
Concentrated urine
Congestion or audible secretions
Dysphagia
Visions or nearing death awareness
How the patient smells
Pain
Possibility of hemorrhage
Body temperature
Cool extremities
Vacant look/looking past you
Vomiting
Weakness
Weight loss
Emotional changes
Bowel changes
Involuntary bowel movements
Decreased volume of bowel movements
Constipation
Vital sign changes
Blood pressure changes
Changes in pulse
Decreased activity
How they look
Social withdrawal

I talk about the breathing, probably first. Because I think they're going to notice that before they're going to notice mottling. People don't know to look for mottling. And not everybody mottles, or the same. Not everybody's toes get dusky. Not everybody's body cools. But almost everybody has a respiratory change. So I focus on that more than I do anything else I guess. I also focus on the pain and restlessness. The restlessness, be it pain or be it near death experience, whatever it may be, those people are uncomfortable whether it be emotionally, spiritually, physically, whatever; they're uncomfortable. (LPN 3)

Hospice clinicians discussed signs and symptoms as a way of normalizing the experience:

I prepare them by doing the teaching, giving the hand-outs, trying to normalize it for them as much as possible by telling them what signs and symptoms they might be seeing, that they might have, you know, they might start talking to things or people that aren't there in the room with them, the restlessness, all those things. (SW 17)

Implications of the signs and symptoms. The timing and implications of the symptoms were considered important in the preparatory process:

I tell them is what's happening now and what it means. What the physical thing is saying and what it means in terms of their dying process. What is and is not painful to them, especially when we're talking days to hours. (RN 10)

How long until death is expected. Staff said that families usually want information about what to expect next and how long it will be until death is likely to occur:

I will say, "Well it will be more like hours to days rather than days to weeks." Or I'll say, "It will be days to weeks rather than weeks to months." And that's a real uninfinitive [sic] answer but it's kind of—it appeases them, typically. And the other thing I think they want to know at that moment is, "Are they going to die tonight?" And I will say, "You know, I really don't see death as imminent, but I've had people make liars out of me too. Do what you've got to do with the time you've got left. Because I cannot guarantee if I walk out this door that he's not going to go. I can't guarantee that he'll be here three days from now. I just cannot." (LPN 3)

Instructions on what to do. Along with information on recognizing signs and symptoms, nurses often provide instructions on what to do when the signs or symptoms occur.

How to prepare families

Strategies used in preparing families. Strategies used by clinicians include listening, engendering trust, repetition, collaboration with other disciplines, demonstration, and presence. Both nursing and counseling staff discussed the importance of careful listening:

And you can't teach a family without knowing, I mean, by listening to them you're going to learn how they learn or, you know, I mean, you may have a family member who needs to have everything on paper, everything written down. But you may have another family that you need to go and physically show them what they have to do. You know, things like that. You can't without listening—basically you learn from the families. (RN 12)

Engendering trust was considered a key component in family acceptance of the staff messages:

It makes death easier for them because they know that trusted one who they can trust who will always tell them the truth will be there. (LPN 9)

Clinicians work to build trust and develop relationships with family members:

They weren't comfortable with me. And, so, what I did was just basically I said, you know, I'm going to go and take care of the patient right now, get the symptoms under control and

then when I was done I went back to the loved one that was taking care of them and just talked and explained and we ended up sitting and talking for a really long time and that built their trust. (RN 12)

Another commonly used strategy is repetition. As RN 12 said, “you probably won’t say it once, you’re going to say it a zillion times.”

Presence was also an important strategy discussed by both nurses and counselors (SW, chaplain, and bereavement). This RN talked about the differences between education and presence:

Education and taking away some of the fear of the unknown helps make it easier . . . helping them understand what’s going on in the disease process and the dying process. But also I think just being a presence for them and knowing that we’re there and knowing that we will be there for them and allowing them to sort of say good-bye and to say what’s in their heart and what they need to say so hopefully we can take away some of the what-ifs, I should have done this, the regrets. (RN 14)

Collaboration with other disciplines was considered necessary to provide a broader picture of the family situation:

And there’s kind of some different perspectives from different disciplines and IDT [interdisciplinary team meeting] revealed that. (BER 19)

Demonstration was only mentioned by nursing staff, who know how seeing and participating in care helps family prepare:

You can talk and try to prepare them all you can, but it’s actually more of the hands-on learning that I think that they seem to deal with better. (LPN 5)

Tailoring of preparation. Most staff said that they tailor preparation, but what was tailored varied. Content, delivery, and timing of preparation were tailored based on patient, family, and hospice factors. Patient factors were primarily mentioned by nursing staff and include symptoms exhibited and anticipated time to death. Family factors included healthcare or caregiving experience, family education, culture, and desire for knowledge about dying. While both nurses and counselors mentioned family education, culture, and desire for knowledge, only nursing staff mentioned healthcare or caregiving experience. This hospice nurse used both the family’s experience in caregiving and the patient’s symptoms to tailor the message:

I would first I think ask you if you have ever had experience before taking care of someone who is nearing the end of their life. And then if you’d say, “No,” I’d say, “Well here are some

changes I’m seeing, I’m noticing that from last I was here their breathing is different, they’re not eating as much, they seem weaker,” and just kind of go by the symptoms I’m seeing and explain why that’s happening. (RN 1)

Continuity of staff assignment and staff training were hospice factors. Continuity was seen as a factor in building trust, “I do like the continuity because when I go back they know who I am. They build a trust” (LPN 9). Staff training was needed to have consistent family preparation.

Timing of preparation. Another aspect of tailoring the preparation concerned timing. Some of the strategies discussed, such as incrementally preparation and repetition, were also related to timing. Tailoring the timing was based on patient and family factors. Nurses focused on patient factors, including medication and condition changes. Escalation of symptoms precipitating a crisis in care was also a factor in timing of preparation:

Sometimes you have to do it all at once if the patient is nearing very quickly or changing very quickly. (SW 16)

Family factors related to the timing included family readiness to accept the inevitability of the patient’s death and family requests for information:

Sometimes they’re just so grateful for anybody coming in there and helping that they’ll absorb whatever you can tell them as soon as you can. They want it laid out immediately. Other people are like, “We’re going to get better. We’re going to take some time.” They’re not in that frame where they want to talk about the dying yet. But, yes, absolutely, I go from where the patient or where that family is at. (SW 13)

Many of the nurses said that preparation should begin at admission:

I think the one thing I feel really strongly about is from the minute we admit someone, is that’s when we start preparing them. So that as we see things change, that’s the norm for the family, so when it happens it’s not a panic situation. They can just say, “Oh yeah, we talked about this was going to happen” and so it’s normal for them. (RN 1)

However, one nurse explained that preparation can be started too early. This staff nurse talked about the effects of trying to prepare the family too soon:

I don’t think they will absorb it all. I think they will absorb what they can. And you just—and I don’t know if repeating it is going to help. I mean, you know, because you can repeat and you can repeat. Maybe it helps once the person is in the more active stage of dying. That you can say, “Now see how this is?” This is—you know, there’s more a visual with your words. (RN 19)

Both nurses and counselors provided preparation over time. This more gradual preparation allowed for reinforcement and repetition of the preparation. It also gave family members time to process their experiences:

Pretty much, I would say, 99% of the time we do it over time. There's no way you can do it in one visit. I mean, every time you go in there it may be a different symptom or it may be a different situation going on and it's an ongoing teaching process every time. (RN 12)

Who prepares families

All the disciplines participated had a role in preparation. Nursing staff and SWs were most involved in preparation. There was a great deal of similarity in content, strategies, timing, and tailoring across disciplines, but there are some notable exceptions (Table 2). There were no themes that were discussed only by counseling staff. SWs included more elements in regards to content and strategies than other counselors. Nursing staff were alone in identifying a number of tailoring factors including the patient's symptoms, the family's caregiving experience, and the hospice's continuity of care. Nurses also discussed the need to start preparation early and to tailor the timing based on changes in the patient's condition or medications.

Discussion

While little attention has been paid to the strategies used in preparing families, better knowledge of preparation strategies is needed to build effective preparatory interventions. Some of the strategies, such as careful listening to the family and interdisciplinary collaboration, have been accepted as keys to quality care at the end of life.^{29,30} Patient and family trust in nurses has been considered a key element in the relationship between the nurse and the family,³¹ particularly in hospice,^{32,33} but the impact of engendering trust on the ability of staff to prepare families has not been explored, nor have techniques to engender trust been tested in this population. Other strategies such as repetition and demonstration are common elements of professional practice, but the impact of these strategies on preparing families for caregiving in the final days should be explored.

Most participants tailored their preparation by altering the content, strategies, delivery, or timing of preparation. Tailoring is based on patient, family, and hospice agency variables. While most participants stressed the importance of assessing the family member's readiness and desire for information about impending death, they did not discuss how they make that assessment. Because family members may respond to preparation differently, it is important to assess understanding of what will happen and each person's preferences as caregiving changes in the final days. Additional research is needed to understand which caregiver

characteristics affect the ability to be prepared so that assessment guides can be developed.

There was a lack of consensus about optimal timing of preparation. Previous research has indicated that the best time to prepare caregivers may be highly individual.²² Assessing the family member's response to preparatory information to determine the frequency of preparation is necessary. Repetition is also important to facilitate acceptance of preparation.

Much of the comparison of content, strategies, timing, and tailoring across disciplines produced expected results. It is not surprising the nursing staff focus on physical signs of impending death, what to expect next, and what to do. Nor is it surprising that nurses focus on physical indicators such as symptoms and medications when tailoring preparatory messages. It is notable that all disciplines except the chaplain included content on the anticipated time to death, which indicates the importance of this issue. Collaboration with other disciplines was similarly important.

However, there are a number of surprises in the disciplinary comparison. SWs have more of a focus on physical signs of impending death or symptoms and the time to anticipated death than might be expected. They also include content on what to expect next and instructions on what to do in their preparatory messages. If this information is focused on the caregivers' reactions and responses to the dying process, this is appropriate, but the specifics of the content were not discussed. It would be expected that SWs would prepare family for the emotional changes that are likely to occur in the patient and the caregiver, but this was addressed by the nurses and the chaplain in this sample. It may be that the SWs thought this was obvious, but this gap requires additional scrutiny. Similarly, one might expect nurses to base their timing of preparation on an assessment of family needs, which was mentioned by the LPNs, SWs, and BERs, but not the RNs. Nurses need be performing assessments of family needs related to preparation for caregiving in the final days and using this information to develop the messages and timing of preparation for families.

Identifying gaps in the current preparation of family for caregiving at the end of life begins with comparing how hospice clinicians prepare family with what families need to be prepared (Table 4). Most of the content that is considered necessary is part of the current preparation. In addition to the previously identified needs, this study describes inclusion of information on the emotional changes that occur in the patient and caregiver. In this study, knowing the patient's treatment preferences was not discussed. This may be because discussion of advance care planning usually takes place before or during hospice admission. But further exploration of patient preferences particularly regarding symptom monitoring and management, who should be present and providing care, and preferred location of death would be beneficial.

Table 4. Comparison of previously identified needs for family caregiver preparation and what is currently included in hospice staff member preparation of families.

Previously identified need	Content	Included in current preparation
Caregiver knowledge, ^{13,15–19,21,23} including <ul style="list-style-type: none"> • Knowing what to expect about the patient’s physical condition¹⁴ • Symptoms¹⁴ • Recognizing signs of imminent death¹⁴ 		<ul style="list-style-type: none"> • Physical signs of impending death • What to expect next including signs and symptoms
Prognosis ^{13,15–19,21,23}		Anticipated time to death
Having the patient’s treatment preferences in writing/ACP/ knowing patient preferences? ^{13,21}		Emotional changes that occur in the patient and caregiver
Instructions on what to do for <ul style="list-style-type: none"> • Physical care¹⁴ • Symptom monitoring and management¹⁴ 		Instructions on what to do
Good communication with healthcare professionals about dying ^{14,20} <ul style="list-style-type: none"> • Careful listening^{13,15–19,34} • Demonstration²² 	Strategies	<ul style="list-style-type: none"> • Listening • Engendering trust • Repetition • Demonstration • Presence
Prognosis ^{13,15–19,21,23}	Tailoring factors—patient	Time to death
Prior caregiving or life experiences ^{11,22,23}	Tailoring factors—family	Healthcare or caregiving experience
Awareness of death ^{20,23}		Family readiness to accept death
Spiritual beliefs or practices ^{15,21,23}		
Social connections ¹⁵		
Financial needs met ^{13,15}		
Bearing witness to suffering ^{22,23,25}		
Cultural concerns ²¹		Culture
		Education
Information given by hospice staff and volunteers ^{15,22–24}	Tailoring factors—hospice	Staff training
Respite availability ¹⁵		Continuity of care

The most notable gaps concern family factors that affect tailoring. Patient and family spiritual beliefs or practices and social connections are important issues when preparing families,^{10,13} which were not well addressed in this study. Awareness of whether the family’s financial needs are met is another important element that was not discussed. Finally, bearing witness to suffering is a factor in family preparation according to a previous research, with the patient’s suffering sometimes being the trigger to the family member’s openness to preparatory knowledge.²²

The findings of this study are meant to begin the description of home hospice staff perceptions of preparing family for the final days and are not intended to be generalized to other care settings or providers. The sample included staff from three offices of two hospice organizations in one geographic region and it is possible that

participants were describing experiences with some of the same patients and families. Both nursing assistants and chaplains were represented by a single interview, which makes it difficult to determine whether the variations are related to the individual or the discipline. The coding and content analysis were done by a single researcher, whose previous experience as a hospice staff nurse and researcher informed her perspective. Both the hospice staff and the patient population were White. While the sample is representative of the population of hospice staff and hospice patients in this region, it does mean that the results are culturally limited.

This study provides initial evidence of differences in approach to preparation of family members by discipline, with nurses focusing on symptoms and tailoring messages on previous caregiving experience. While repetition of key

elements by both counselors and nursing staff assists in preparation, preparatory messages should be planned so that key elements are addressed by the appropriate clinician. A simple way to assure such coverage would be to develop a checklist of key elements that could be used to document preparation by all disciplines.

The gaps between family needs and the current practices can be addressed immediately by hospice clinicians. Assessing additional factors such as family spiritual beliefs and social connections will assist in more effective tailoring of preparatory messages, as will assessing the adequacy of finances and family response to the patient's suffering. Understanding the current practice in preparing families can also be used to develop systematic means of assessing the factors related to timing and tailoring. This may lead to development and testing of assessment instruments and preparatory messages that are more effective and timed so that families have the information when it is needed and when it can be absorbed.

Declaration of conflicting interests

The author declares that there is no conflict of interest.

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References

1. Stajduhar K, Funk L, Toye C, et al. Part 1: home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998–2008). *Palliat Med* 2010; 24(6): 573–593.
2. Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *ANS Adv Nurs Sci* 2000; 23(2): 82–97.
3. Hudson P, Quinn K, Kristjanson L, et al. Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *Palliat Med* 2008; 22(3): 270–280.
4. Henriksson A and Arestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: a correlational, cross-sectional study. *Palliat Med* 2013; 27(7): 639–646.
5. Kalnins I. Caring for the terminally ill: experiences of Latvian family caregivers. *Int Nurs Rev* 2006; 53(2): 129–135.
6. Oldham L and Kristjanson LJ. Development of a pain management programme for family carers of advanced cancer patients. *Int J Palliat Nurs* 2004; 10(2): 91–99.
7. Cain R, MacLean M and Sellick S. Giving support and getting help: informal caregivers' experiences with palliative care services. *Palliat Support Care* 2004; 2(3): 265–272.
8. Broback G and Bertero C. How next of kin experience palliative care of relatives at home. *Eur J Cancer Care* 2003; 12(4): 339–346.
9. Funk L, Stajduhar K, Toye C, et al. Part 2: home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). *Palliat Med* 2010; 24(6): 594–607.
10. Hebert RS, Dang Q and Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *J Palliat Med* 2006; 9(3): 683–693.
11. Hebert RS, Schulz R, Copeland VC, et al. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J Pain Symptom Manage* 2009; 37(1): 3–12.
12. Houts PS, Nezu AM, Nezu CM, et al. The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Educ Couns* 1996; 27(1): 63–73.
13. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001; 22(3): 727–737.
14. Bee PE, Barnes P and Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 2009; 18(10): 1379–1393.
15. Cagle JG and Kovacs PJ. Informal caregivers of cancer patients: perceptions about preparedness and support during hospice care. *J Gerontol Soc Work* 2011; 54(1): 92–115.
16. Zapart S, Kenny P, Hall J, et al. Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care. *Health Soc Care Community* 2007; 15(2): 97–107.
17. Osse BH, Vernooij-Dassen MJ, Schade E, et al. Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nurs* 2006; 29(5): 378–388; quiz 389–390.
18. Jansma FF, Schure LM and de Jong BM. Support requirements for caregivers of patients with palliative cancer. *Patient Educ Couns* 2005; 58(2): 182–186.
19. Angelo JK, Egan R and Reid K. Essential knowledge for family caregivers: a qualitative study. *Int J Palliat Nurs* 2013; 19(8): 383–388.
20. Loke AY, Li Q and Man LS. Preparing family members for the death of their loved one with cancer: a review of literature and direction for future research. *J Hosp Palliat Nurs* 2013; 15(2): E1–E11.
21. Hebert RS, Prigerson HG, Schulz R, et al. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *J Palliat Med* 2006; 9(5): 1164–1171.
22. Stajduhar KI, Funk L and Outcalt L. Family caregiver learning—how family caregivers learn to provide care at the end of life: a qualitative secondary analysis of four datasets. *Palliat Med* 2013; 27(7): 657–664.
23. Hovland-Scafe C. *Preparedness for death: the experience of family caregivers of elders with dementia*. PhD Dissertation, University of Wisconsin-Madison, Madison, WI, 2013.

24. Kehl KA, Kirchhoff KT, Finster MP, et al. Materials to prepare hospice families for dying in the home. *J Palliat Med* 2008; 11(7): 969–972.
25. Kehl KA, Kirchhoff KT, Kramer BJ, et al. Challenges facing families at the end of life in three settings. *J Soc Work End Life Palliat Care* 2009; 5(3): 144–168.
26. Patton MQ. Designing qualitative studies. In: Patton MQ (ed.) *Qualitative research & evaluation methods*. 3rd ed. Thousand Oaks, CA: SAGE, 2002, pp. 209–258.
27. Hsieh HF and Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; 15(9): 1277–1288.
28. Creswell JW. Standards of quality and verification. In: Creswell JW (ed.) *Qualitative inquiry and research design*. Thousand Oaks, CA: SAGE, 1998, pp. 193–218.
29. Andershed B. Relatives in end-of-life care—part 1: a systematic review of the literature the five last years, January 1999–February 2004. *J Clin Nurs* 2006; 15(9): 1158–1169.
30. Beckstrand RL, Collette J, Callister L, et al. Oncology nurses' obstacles and supportive behaviors in end-of-life care: providing vital family care. *Oncol Nurs Forum* 2012; 39(5): E398–E406.
31. Bell L and Duffy A. A concept analysis of nurse-patient trust. *Br J Nurs* 2009; 18(1): 46–51.
32. Mok E and Chiu PC. Nurse-patient relationships in palliative care. *J Adv Nurs* 2004; 48(5): 475–483.
33. Wu HL and Volker DL. Living with death and dying: the experience of Taiwanese hospice nurses. *Oncol Nurs Forum* 2009; 36(5): 578–584.
34. Yates P and Stetz KM. Families' awareness of and response to dying. *Oncol Nurs Forum* 1999; 26(1): 113–120.