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For Their Patients

A Study of Hospice Nurses' Responses to Patient Suffering

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The purpose of this study was to develop an inductive theory describing the process that hospice nurses use to identify and respond to their patients' suffering. In addition, the study sought to describe the coping strategies that hospice nurses used when working with patients they considered to be suffering. Grounded theory methodology guided the study design with 22 hospice nurses participating in semistructured interviews. Participants responded to their patients' suffering within a 4-phase process of the nurse-patient relationship: observation, issue assessment, labeling the suffering, and intervention. In addition to signs of physical suffering, the participants identified other aspects of patient suffering: role losses, fear of the impending death, aloneness, and feelings of guilt or regret. While participants recognized the importance of self-care, they had difficulty naming strategies used to cope with patient suffering. Study findings can be used to develop effective interventions to alleviate patient suffering and mitigate its consequences on nurses. By understanding strategies that nurses use for coping with patient suffering, administrators could institute educational programs, build supportive environments, and develop policies to support their staff.

KEY WORDS

end of life, grounded theory, hospice, nurses, suffering

Kahn and Steeves[1] defined suffering as an individual's experience of threat to self and is the meaning given to events such as pain or loss. Suffering—one of the most debilitating conditions faced at end of life (EOL)—is often clinically neglected, resulting in uncontrolled pain, depression, and a paralyzing inability to move beyond the symptom experience.[2] Physical symptoms may act as a springboard into the experiential aspects of suffering, which in turn increases physical distress.[3] Rarely are patient symptoms linked to patient suffering.[4] Unfortunately, focusing solely on physical symptoms often results in poor quality of life (QOL), increased costs (eg, financial, emotional), and further patient suffering.[5]

Through their care, nurses help patients to recover and maintain composure in the face of illness while coping with the vulnerability and uncertainty of life.[6] Psychiatric approaches (eg, meaning-centered therapy, cognitive-behavioral intervention) aside, there are no frameworks to guide care provided to suffering patients.[2] Studies have found that suffering is a misunderstood condition for which there is no consensus regarding appropriate treatment.[2,7,8] In addition, some nurses engage in unhelpful behavior such as minimizing the patient's expressions of distress or simply avoiding the patient in order to distance themselves from their patient's suffering.[2,9] Contributing factors may include an insufficient evidence base to care for suffering patients at EOL and a lack of personal coping strategies.

An understanding of the nurse's experience of patient suffering and accompanying responses (eg, thoughts, actions) toward this suffering is important because such understanding can inform strategies to improve patient outcomes at the EOL. The aims of this study were to uncover (1) what hospice nurses characterize as patient suffering, (2) the process they use to respond to their patients' suffering, and (3) what they do to personally care for themselves or cope with their patients' suffering.

BACKGROUND

Studies concerning patient suffering at EOL highlight several themes: physical symptom experience, psychological distress, emotional isolation, and identity changes.[2,10-15] In these studies, the sufferers focused attention on their physical symptoms, often putting life tasks on hold and attributing negative meanings to their symptoms that, in turn, increased their psychological distress. Unrestrained concern about their symptoms and life circumstances consumed emotional energy, decreasing their ability to cope, which increased their sense of uncertainty and situational vulnerability. As the psychological distress increased in the presence of declining functional ability, it became linked to a sense of impending death, and the sufferer experienced a

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devastating sense of isolation. Frequently, the sufferers perceived themselves as losing their self-identity. Through the lens of ''being a burden,'' they described changed roles and relationships. Ideally, if nurses could identify these themes in clinical situations, they could thoughtfully respond to them.

Although the relief of suffering is a core skill in caring for dying patients,[6-8,16] only a few studies have addressed how nurses identify and respond to patient suffering.[2,16-21] Interestingly, these studies revealed that participants did identify suffering at times, but when they did, they did not know what to do to alleviate it. Findings also revealed that the participants were affected by their patients' suffering and had difficulty coping with it. Of note, these studies indicate that working with suffering patients negatively impacted the nurse. Feelings of distress, sadness, failure, and being overwhelmed were commonalities. Some participants indicated that they needed emotional support and someone to talk to in order to process what they were experiencing. They reported difficulty maintaining boundaries between caring for their suffering patients and their personal lives. Participants shared various personal coping strategies: taking time off from work, exercise, hobbies, participation in religious activities, and talking with other people; some left working in the field of EOL care. Importantly, being able to successfully deal with their patients' suffering was a motivator for them to continue to work in EOL settings.

While some of these studies seemed to indicate that nurses lack clarity concerning what suffering is, others indicated that nurses do know what suffering is and can clinically identify it. This inconsistency may be explained by the nursing discipline's overall lack of theoretical development within the area of suffering or clinician uncertainty regarding how to translate research findings into practical applications.

A recent systematic review of suffering at EOL identified 2 areas where nurses could potentially intervene to ameliorate suffering.[3] First, suffering individuals perceived themselves as losing their personal identity when others (including nurses) related to the sufferers as inanimate objects. This objectification increased a sense of devastating aloneness, making it difficult for the sufferer to ask for help. Second, there was evidence that suffering played a role in the symptom experience. Specifically, the emotional component of suffering increased perceived physical distress. As sufferers spent more time attributing meaning (eg, ''I am dying'') to their physical experiences (eg, increased pain), their coping abilities decreased. Unfortunately, suffering is often neglected, resulting in uncontrolled symptoms that exacerbate and are exacerbated by the suffering, resulting in poor QOL.[2,17,22] Because nurses lack clear direction for how to effectively alleviate suffering, they can unknowingly intensify and prolong the suffering experience.

METHODS

Symbolic interactionism provided the philosophical perspective, and grounded theory (GT) methodology as described by Charmaz[23] guided the study design and data analysis. Symbolic interactionism provides a framework that links what nurses identify as patient suffering with how they think about this suffering and consequently address it. Using a constructionist lens, GT is constructed through the researcher's interactions with people and their perspectives, which acknowledges the resulting GT as an interpretive portrayal of a process and not a literal schematic. This is different from a positivist approach that identifies a single, basic social process or ''core variable.''[23] A constructionist lens is better suited for comprehending how nurses' subjective experiences related to the meanings of their patients' sufferings translate into patterns and relationships used in responding to suffering.

Participants

Participant selection was based on theoretical sampling.[23] This means that participants were initially selected because they met specific inclusion criteria: registered or vocational nurse, currently employed in a hospice setting for at least 3 months, and spoke English. The data from these participants served to identify and define categories of information. Based on these categories, further sampling was theoretically determined in order to develop and refine categories until they became saturated, meaning that no new data emerged from subsequent participant interviews.[23] The final sample included 22 hospice nurses from 5 different hospices in a large metropolitan area in the southwestern United States. The nurses' ages ranged from 37 to 70 years; 18 nurses were female, and 4 were male; 18 nurses were registered nurses, and 4 were licensed vocational nurses. Years of nursing experience ranged from 2 to 45 years.

Data Analysis

After institutional review board approval was received and informed consent obtained from participants, audiotaped, semistructured interviews were conducted using open-ended questions and a demographic data sheet. Field notes and memos supplemented participant-generated data. Based on the ongoing analysis, the interview guide evolved. Interviews were transcribed using a word processor, and transcription accuracy was verified. Constant comparison was used to generate the theory.[23] Trustworthiness was promoted by adhering to the methodology's design, reviewing raw data and analytic components between the researchers, and also member checking with participants as needed.

RESULTS

Study findings revealed that the participants identified and responded to their patients' suffering within the context of a carefully cultivated nurse-patient relationship designed to build trust. Cultivating this trusting relationship enabled the participants to focus on accomplishing their goals of optimizing the patient's QOL and orchestrating a peaceful death. Over the course of time, through this relational context, the participants responded to their patients' suffering using a sequential process of observation, issue assessment, labeling the suffering, and intervention.

Characterization of Patient Suffering

Aim 1 focused on what hospice nurses characterized as patient suffering. Participants described aspects of their patients' suffering in terms of pain, emotional suffering, a family affair, loss of identity, and frequently with the phrase "suffering is suffering." Participants began patient encounters with the goal of improving a patient's QOL and would seek signs that either supported or disproved the idea of patient comfort. Usually, a component of physical suffering (eg, pain or anxiety) was observed first. However, this physical symptom experience was not considered suffering until the usual measures of education and medication titration had been tried and failed. After these initial measures failed, the participants began searching for other factors that might be influencing the situation. Within this context, patient suffering was then identified as "suffering," and interventions were aimed at relieving that suffering.

Pain

Every participant cited pain as their first description of suffering. Using the word "pain" as their starting point, they then qualified it by describing an unrelenting physical experience. For instance, when participant 1 began considering what suffering was, she immediately shared, "I have a patient right now who is suffering because she fell, and she can't get relief from her pain, and to me that's suffering. Either they can't do what they used to do, what they always do, or they're in pain and they don't see life without pain." Many participants recited textbook-type definitions of pain. While many of the nurses provided multiple examples of physical and emotional pain, examples of spiritual pain were much harder for them to recall. The exception to this was descriptions of terminal restlessness, often attributing it to a spiritual suffering due to "unfinished business."

When pain relief was not easily achieved or if there was a sense of "unease" or "discomfort" about the patient, then the participants investigated this much more thoroughly. During these times, the participants linked the pain to additional physical manifestations and verbal disclosures by the patient. For instance, participants described declining physical function, anxiety, looking depressed or "down," overarching fatigue, and hearing patients verbalize fears, regrets, aloneness, and a general hopelessness about the present situation. Participant 20 shared:

> I had a little lady who told me she wasn't having any pain. I watched her, and she did this (makes a hand gesture) constantly, the whole time I was there. Finally, I took her hands and said, "I want you to tell me why you're doing that." And she said, "Oh honey, there's just so many things going on. And I just don't know what to do about them." And her whole face scrunched up; you could see the stress. That's suffering.

Emotional Suffering

Suffering not predicated on a physical symptom included emotional and relational components. Examples included role losses, impending death, aloneness, feelings of guilt and regret, insomnia, worry, expressions of grief, need for frequent reassurance, inability to tolerate any change, and "acting out" behaviors inconsistent with the patient's usual personality. Oftentimes, participants identified aspects of spiritual suffering, such as meanings associated with losses or changes in roles, when they discussed emotional suffering.

Family Affair

Interestingly, the participants also identified suffering as a family affair. For them, suffering not only occurred within an individual but also encompassed the entire family unit, with each family member experiencing his/her own personal suffering and a communal suffering. Participants began talking about "family suffering" when they discussed "family dysfunction" and "caregiver breakdown." They often observed chaotic homes, noticed tension between family members, saw open secrets not being acknowledged between family members, and listened to family members who did not ask each other important questions or answer important questions when they were asked. Frequently, patients and/or family members wanted private opportunities to share regrets, feelings of guilt, anger, and just general fear of what was happening. Participant 15 shared, "The family is just sorrowful. I think the suffering is individualized and family-wide. When they're dying, you get a lot of 'I wishes.' And when the person is in that mode of feeling guilt, per se, the whole family is feeling it. They have this unspoken... not peaceful, with them."

Identity

Loss of self-identity was an especially poignant aspect of suffering. Participant 20 succinctly summarized it with these words: "And when someone has been given a terminal diagnosis, there's the pain of a loss that's impending. And it's the greatest loss any of us will ever suffer because it's the loss of ourselves." While considering a suffering situation over time, participant 17 stated, "[Suffering] affects everything about them. And some people lose their self-identity with that. They lose the dignity they had before that; they lose who they were. They forget who they were, what they did in life. All they think about is that they're dying."

Suffering Is Suffering

When queried about the role of age, gender, race, and culture within suffering, the participants reported that ‘‘suffering was suffering,’’ and these attributes did not matter. When probed, they often admitted that ‘‘stoic’’ patients were the most difficult to assess. It seemed that stoicism prevented the individual from disclosing what was going on and, if something was occurring, the extent of the issue. Almost always, the participants expressed some uncertainty regarding stoic individuals and their suffering. Sometimes, age would make a difference in what issues the participants expected individuals to verbalize.

Pediatric hospice patients and their families were especially concerning to the participants. Participant 15 observed that children were more spiritually connected with themselves, were not afraid, and seemed to sense that they were dying. While the dying itself was not scary, the worry they had for their parents and family could be overwhelming: ‘‘They’re [the kids] are okay with right now. The worry is for their mom and dad. [A] 7-year-old boy said to me, ‘I’m ready to die but mommy isn’t ready for me to go yet. Will you tell her?’ And I was like, ‘Oh God, how am I going to tell her?’ And he goes, ‘Please.’ He had tears in his eyes. ‘Please, please, please tell her.’’’ She then shared this conversation with the child’s mother who subsequently told her son that he could go. The child then slipped into unconsciousness and died 8 hours later.

The Process Hospice Nurses Use to Respond to Suffering Patients

Aim 2 focused on the process that hospice nurses used to respond to their patients’ suffering. In order to respond to patient suffering, the participants tried to understand what QOL meant to the patient and to address concerns a patient and family might have. Through the cultivation of the nurse-patient relationship, the participants gained insight into the psychosocial and existential aspects of the patient’s and family’s psyches. Within this relational context, the participants used a 4-phase process to respond to their patient’s suffering.

Observation

As part of observing the expected signs and symptoms that accompany various disease processes, the participants specifically searched for indicators of physical decline, medication adverse effects, emotional vulnerability, and indicators of how well the patient was being cared for when the nurse was not at the patient’s residence. Even though the conversation was about a patient—what the patient was experiencing or doing—the participants relied on their established relationships in order to intervene and influence decision making by the patient, family, and health care team. Every interaction the participant had with a patient/family was geared toward increasing the trust the patient/family had in the nurse.

Participants used an accepting attitude and gentle probes to explore potentially volatile emotions and issues that the patient and family may be hesitant to bring up. The purpose of these discussions was to provide the nurse with information regarding how the family unit currently worked, the potential effects of the patient’s eventual death, and an understanding of what was currently most important to them. With this information, participants were able to offer emotional support, anticipate occurrence of potential issues, and provide relevant information (teaching) to the patient/family. Participant 14 shared, ‘‘It’s giving the family feedback, giving them things they can look at so they can analyze the situation. When they’re in crisis of losing their loved one, they can’t think of everything. So, it’s our job, based on our experiences, to bring these things to light so that they can think about it and choose. And then we can try as the patient declines to rearrange things if needed.’’

Issue Assessment

An issue was any concern or problem that interfered with the patient’s QOL. The nature and character of issues changed over the course of time and over the course of the relationship. In general, issues in a ‘‘new’’ relationship tended to be more physically focused. As the relationship matured, and the patient’s/family’s trust with the nurse increased, more emotionally charged issues were brought up (eg, relational discord, existential angst).

As participants became aware of an issue, they did a more focused assessment trying to understand the underlying problem(s). At first, the usual strategies were tried: assessing signs/symptoms, giving medications, educating the patient and family, listening to patient and family talk out their concerns, and providing options for what could be done. When these strategies did not work, the participants engaged in a more in-depth analysis of the situation, beginning with a reconsideration of the patient’s situation with respect to how his/her QOL was affected by the broader context of his/her current surroundings. This included examining how patient circumstances (eg, changes in clinical condition, functional ability, personal resources, coping ability), disease progression, expected survival horizon, patient-family dynamics (ie, cohesiveness, enmeshment, disconnection, fighting), secrets (either acknowledged by patient or by family member), and care setting might be affecting the patient and family members. As participants thought about the situation and tried to imagine what it would be like to be in the patient’s situation, they had a basis for many of the empathic verbal responses and creative options that could then be suggested to the patient/family. Participant 18 reflected, ‘‘You have to risk yourself too. You have to let them in for them to let you in. And you have to meet them where they are. And almost like you are transporting part of yourself into them to be able to understand them and understand where they are at. But then, you also have to be able to be detached to advise them, to recommend to them, and to help them through it."

While participants initially discussed the issue with the patient/family, they also conferred with and brought in other disciplines to gain insights, consider other perspectives, and develop strategies to ease distress. Equipped with the various insights and perspectives, the participants were now in a position to discuss goals with the patient and family in order to come to some agreement over what was acceptable and achievable from the patient's/family's perspective. As they continued to consider what might happen in the patient's future, they continued to gently probe at issues that might eventually cause/heighten patient-family discord or prevent the patient from receiving adequate support (eg, medications, emotional support, life closure activities) to see how strongly current beliefs were held to, what potential options might be, and where movement was likely to occur. Participant 21 remembered an 8-year-old hospice patient and her family:

> Well, I came to know mom pretty well. I used to tell her, "Mom, you know, the best thing you can do is show her that you love her and be there for her." When she would push her other children away, I would talk to her about they are going to need some love and support when the patient passes. It was a very sensitive time for the family. I had to really stress that they needed to express their emotions. Just talking to them, talking to them and finding the right time. I really had to make sure it was the right time, because mom was so sensitive to these topics.

When the nurses were confident of the patient/family goal(s) and reasonable interventional strategies were clear, then they conferred with the patient/family to seek endorsement of the plan.

Labeling the Suffering as "Suffering"

As identified in aim 1, participants' characterizations of their patient's suffering included pain, emotional suffering, a family affair, loss of identity, and a general recognition that "suffering was suffering." Participants identified their patient's suffering by trusting that the relationship with the patient (or family member) was sound enough that the affected individual would self-disclose what was occurring (eg, pain, fear of impending death, relational discord, inability to cope with a situation). Participants monitored and evaluated the relationship's strength by its degree of trust; specifically, the degree to which the patient and family "believed in" the nurse, confided what was happening within the patient/family context, and used the nurse as a resource that was listened to and suggested options that were acted upon. As the participants observed the patient/family behavior, they made judgments regarding the relationship's strength and the degree of distress caused by the issue. If additional intervention options still did not resolve an issue, the nurses would then label the suffering as "suffering." Participant 3 shared about a 41-year-old gentleman with metastatic colon cancer: "I could see the physical signs when I walk in, I… I observe suffering with my eyes and with my heart. I can see he wasn't sleeping, so I talked with him a bit. He's worried. He's leaving a young family. I sense it. You can hear it in the tone of their voice and you can see it… and they make little comments."

Intervention

The participants intervened by alleviating physical distress and emotionally supporting the patient and family. They regarded their work as occurring within the context of a difficult, frightening, and potentially meaningful time period for the patient/family. Educating and emotionally supporting the patient and family were the cornerstone interventions. As participants advocated for their patients, they also engaged in some unique interventional strategies, the first of which was "accepting." This was simply giving permission for people to feel the way they did and not need or want to change. Participant 6, reflecting on some of the difficulties patients and families have communicating with each other commented, "They get so wrapped up in that [their minds] that they can't open up… Your job becomes giving them permission… [helping them find options] to give permission to say 'yes' or 'no.' We're going to support you." This helped the participants to maintain the integrity of the trusting relationship with the patient and accompanying family members.

The second intervention strategy was "touching." As part of assessing and responding to patient suffering, the participants described the importance of touching the patients, usually by holding their hand, touching their forearm, or hugging them. Initially, the touches were used to probe how accepting the patient was of the nurse and to gauge the patient's need for physical control of their body space. Some of the participants observed that their patients' social world was decreasing and with it, the ability to connect with other people. If the patient's physical experience included pain or other distressing symptoms, family members would also decrease their time around the patient and almost become fearful of hugging or otherwise touching the patient. These participants recounted that oftentimes they would physically hug or otherwise touch the patient in order to give permission to the family that touching the patient was acceptable; dying was not a communicable disease.

The third intriguing aspect of the participants' intervention strategies focused on how they evaluated the patient's/family's situation by "sensing energy." During their interactions, many of the participants had a sense that they felt energy in the room, surrounding the patient. Various participants interpreted the energy differently. Some referred to it as a tension, "unease," or a person's spirit. Each of the participants who discussed sensing energy from the patient indicated that interpretation of this energy provided direction for the next step in the patient's care. When the energy was interpreted as peaceful or calm, the participants used this as an indicator that the patient was at ease, and the death would be peaceful. Conversely, the nurses also sensed energy that indicated the patient's death would be difficult. Participant 9 shared:

> You're always assessing what's working and what's not working. There are phenomena that no one else can witness. We had this 1 young man in his 20s. He was scared. He was moving against the bed, away from whatever was coming toward him. There was so much negative energy that they [the nurses assigned to him that day] couldn't enter the room. The nurses felt stopped at the doorway and after he died… they felt so sad inside that room.

Finally, "hoping" enabled the participants to maintain a personal sense of optimism that they were able to share with the family. This optimism focused on being present centered, focused on maintaining or improving QOL today, even though the patient was declining. By being able to maintain a time orientation focused on an expanded present, the nurse and the patient/family were able to continue to express hope for the "now" and realize these hopes in the immediate future, which could be a source of comfort. Participant 3 reflected, "I accept them (the patient and family). It's about them. We come in to support. They're still in control; that's where the hope is and their will, because they have the control. As I say, you can be very direct with a gentle attitude. Pick your words carefully; they (the patient) will guide you."

Hospice Nurses' Coping Strategies

Aim 3 focused on the description of personal coping strategies used by hospice nurses when working with patients they perceived as suffering. Many of the study participants had a difficult time discussing how they personally felt while working with suffering individuals. The invitation to discuss their personal reactions to working with patient/family suffering was often initially met with a silence. At first, the participants struggled, stating they did not understand, or they were dismissive of these questions, stating it was just part of their job. However, subsequent probing revealed 4 themes that characterized their coping.

Rewards

The participants found certain aspects of working with hospice patients rewarding. First, there was a sense of being honored or privileged to be the 1 individual in the patient's/family's life who could make the patient's life better. During these times, the participants spoke of how grateful they were for the opportunity to work with the patient/family, of confidence in their skill set, and of how victorious they felt when there was issue resolution. Another important reward for these participants was the sense of sharing a strong personal connection with the patient/family. This personal connection energized the participant and often provided enough motivation to overcome any negative experiences the participant was going through with that patient. Participant 3 offered:

> Sometimes the patient will do something, and it's like my heart opens up. It's like a feeling of warmth or something. I had 1 patient; he was a real bear. I couldn't find anything good about him. Anyway, I was pushing a drug in his central line. He touched my cheek, and I thought he was going to hit me. But no, all he did was touch my cheek and look at me. And I thought "Wow." He was not a nice patient, but from then on, we got along.

Costs of Caregiving

Even though the participants initially had difficulty identifying personal coping responses, some discussed how emotionally draining the job could be. Within the context of stressors about their jobs, they discussed needing time to process through some of their emotional reactions to their patients' situations, including feelings of sadness, anger, helplessness, and frustration after patient encounters. Sometimes, these feelings would become more pervasive, crowding into other patient encounters or being recognized as interfering with the participant's personal life. There were even times these feelings become more global, and the participants shared that there was just a sense of mourning about them or that they were "broken" by the job. During these times, they related they could not "hold it together" anymore, needing time to cry, and were emotionally shut down, unable and unwilling to emotionally engage with their patients or families. Participant 8 shared, "Periodically during the year each year, it'll come to my mind when I meet a new patient, and I really like them that they're not going to be there in a year. And during these times, I'll just cry for the situation I'm in. I hate to see another person die; I drag around for a few days."

Coping Strategies

The most common answer participants gave to questions related to what they did for their own self-care was "nothing." Even though they endorsed the idea that self-care was important, they often had difficulty identifying any actions they took to care for themselves. While they initially focused only on physical activities, ideas regarding their mental, emotional, and spiritual lives became apparent. For instance, participants related the importance of knowing themselves, being comfortable with who they are, being emotionally mature because they would frequently be confronted by death and other people's poor reactions, and being comfortable with their spiritual beliefs, especially as it related to an afterlife. Within these spheres, they discussed stresses related to patient/family situations that caused some people to say hurtful things to the nurse. While it was unfair and sometimes emotionally wounding, these attacks were not considered personal. For instance, participant 7 stated, "They may be hiding their feelings, but they're angry because of the situation that they're in. And sometimes, they tend to lash out at you. But, we can't take it to heart. It's just because of the situation that they're in."

A frequently shared coping strategy was talking with a spouse, coworker, or friend to work through the weight of heavy emotions and difficult patient encounters. Many times, they did this to let someone else know what they were going through, and so they might gain ideas about how to handle a situation. In addition to sharing how these challenging interactions currently affected them, they also needed reminders that the situation was temporary.

Boundaries

Many of the nurses discussed the importance of boundaries in maintaining a professional relationship that was still intensely personal. The nurses discussed how boundaries facilitated their ability to turn off their phones and to "not be on" as a nurse when they were in their personal space. Participant 13 shared, "I think we can be highly involved and still have a healthy boundary. Mostly, they are looking for you to care about them, and they want informed guidance. I do set boundaries. I can tell them, 'This is where you can be a little familiar, but this is where the line is drawn.'" The participants identified another important aspect of boundaries: that of not bringing their own issues into the nurse-patient interactions. They had to be able to separate what was going on in their own lives and the lives of other patients from the current patient's situation. Participant 18 reflected, "The nurses cannot handle it if it's crazy on both fronts. If it's crazy at work and at home, the nurses usually bite the dust because they can't be there for their patients. They can't handle that. They have to have someone in their life that they can share with, that's empathetic to them."

In summary, participants identified and responded to their patients' suffering within the context of the nurse-patient relationship. Through the lens of relationship, the participants identified and empathized with multiple aspects of suffering: unpleasant symptom experiences (eg, pain, dyspnea), role losses, fears related to impending death, aloneness, and feelings of guilt or regret. The participants recognized that suffering could cause a loss of self-identity and could be a family affair. In order to respond to their patients' suffering, the participants used a 4-phase process: observation, issue assessment, suffering, and intervention. Even though the participants endorsed the idea that self-care was important, many had difficulty naming personal-care strategies they used while responding and coping with their patients' suffering.

DISCUSSION

Even without a clear evidence base to guide practice focused on the identification and alleviation of patient suffering at EOL, nurses have developed anecdotal strategies to work with patients they regard as suffering.[7,16-18,20,21] In this study, the participants identified their main goals as optimizing their patients' QOL and orchestrating a peaceful death for the patient. Bounded by the context of the nurse-patient relationship, the participants observed, assessed issues, identified suffering, and intervened to relieve their patients' suffering. For these participants, fidelity to their patients included relationally caring and educating family members in an effort to bring comfort and calmness to difficult situations.

One of the differences between this study and prior studies is the nurse's starting place for identifying and responding to suffering. Prior studies often begin with an acknowledgement that the patient is suffering, and the nurse actively seeks out the signs of this suffering. For example, Martins and Basto[17] studied the process nurses in a Portuguese oncology-palliative unit used to relieve suffering in their patients at EOL. They identified patient accompaniment as the basic process, including the nurse's perception of a patient suffering and activities to alleviate that suffering. Similarly, Rydahl-Hansen and Eriksen[18] found that nurses in a Danish palliative unit first attempted to explain and mitigate physical signs/symptoms, but only sought out indicators of "suffering" after the physical signs did not resolve late in the shift. Even though the current study specifically examined "identifying and responding" to suffering, the participants began with a focus on QOL. In essence, they might not identify suffering if it did not interfere with what they understood as QOL for a particular patient.

Prior studies included various strategies that hospice nurses use when working with suffering patients.[7,9,16,17,20] In essence, each aspect of suffering is seen as a separate issue instead of one component of the larger issue of "suffering." For example, pain is considered a physical issue until declining functional status and resultant role changes are factored in as part of the larger relational context of what the pain means and is doing to the patient. Findings from the current study suggest that the participants' strategies were deliberately chosen and thoughtfully used. Sound symptom management coupled with strong interpersonal skills became the gateway nurses used to establish rapport and build trusting relationships. Accordingly, Zolnierek[24] found a nurse's knowing the patient was a personal process that included the nurse's awareness, cognitions, perceptions, experiences, and reflections as the basis for determining how the nurse responds to a patient. A nurse's skill in knowing the patient affects the nurse's ability to provide safe care, develop positive relationships, and engage in expert practice.

This study and other studies indicate that nurses need various coping strategies in order to continue working with hospice patients over time. Prior studies indicate that working with suffering patients negatively impacts the nurse.[7,9,16,17,20,25] Feelings of distress, sadness, failure, and "being overwhelmed" are common experiences accompanied by a difficulty maintaining boundaries between caring for their suffering patients and engaging in their own personal lives.[7,9,20,25] The current study findings are congruent with the previously mentioned studies regarding nurses' coping strategies in the sense that there is the same awareness of being overwhelmed at times, and the same coping strategies were repeatedly identified. Nurses in the current study seemed to have the most difficulty with boundary work and consistently engaging in coping strategies when they were novice hospice nurses.

IMPLICATIONS

Nurses in this study repeatedly emphasized the importance of the nurse-patient relationship as the context for identifying and responding to their patients' suffering, indicating that consistency with the same nurse is important. The nurse needs flexibility to engage in patient interactions where there is time to enter into the small talk that leads to the larger, value-laden conversations that may affect subsequent care. These relational conversations rarely occur in the first couple of nurse-patient interactions, highlighting the need for nurse continuity. This is even more important when a patient is admitted to hospice with a short projected length of stay.

Nurses engaged in conversations around meanings when the patient brought up the subject or the nurse needed to prepare a family for the impending death. Expanding this to a routine practice of asking about meanings associated with symptom (or other life) experiences could provide direction to what the patient expects in regard to troubling areas and might provide additional insight, especially when medication response is unsatisfactory.

Providing the relational space and time to engage in value-laden, relational conversations require an arduous compassion from the nurses because it demands insight into each individual's situation. Nurses need guidance for how to cope with their varied thoughts and feelings. This sample of nurses knew their job required them to personally give of themselves, and they needed help replenishing themselves through self-care activities. Frequently, they admitted this with a sense of personal failure. Almost as an aside, some would discuss the importance of needing others to touch or hug them with no expectation that they also reciprocate at that time. Because of the nature of hospice work, with time as a precious resource compelling the nurses to help patients reconcile relationships, some of the nurses missed being able to share "small talk" with other people about normal things. Clinical supervision and emotional support through mentoring and practical guidance need to be further developed to help nurses cope with the complexity of feelings that arise when caring for dying people.

A novel finding in this study is the recognition of suffering as a family affair. While this may be unique to these particular participants, further research is needed to ascertain whether suffering could be understood from a family perspective, how an individual's suffering would fit into this type of schema, and what aspects of suffering are present. Recognizing that a family group may be suffering instead of individuals within a family may also open avenues for finding interventional strategies that are more congruent to the group need.

When some of the participants in this study discussed what they would do if they were unsure if a patient was suffering or not, they indicated that they ask that patient's nursing assistant. They explained that the assistants spent more time doing personal care and often spent this time engaging the patient in conversation. In this way, the assistants often found out more information about what was currently important to the patient and how tension in family relationships currently affected the patient. More research is needed in this area to ascertain how the assistants could work with the nurses in order to mitigate the patient's suffering.

Limitations of this study include issues related to the sample and to the types of patients that these nurses care for. The sample was hospice nurses from a large metropolitan area in the southwestern United States. The results may not be applicable to other demographic areas; however, these findings provide a springboard to the development of formal theory when research is conducted in other populations. These nurses chose to work with a dying population. Their skill set may be different (eg, pain management, communication with sensitive topics), and their contextual work environment may facilitate identifying suffering that otherwise would go unnoticed. In addition, the "typical" hospice patient may be different (eg, age, diagnoses, personal belief system related to death, caregiver availability) from patients not attended to by hospice services.

In summary, hospice nurses need a knowledge base to understand suffering, how to intervene to alleviate suffering, and how to cope with their own reactions to their patients' suffering. This study is significant because the evidence base for effectively identifying and intervening in hospice patients' suffering is sparse, and by purposefully addressing patient suffering, it is conceivable that a patient's QOL could be improved. By examining nurses' responses to suffering, information from this study could be used to develop interventions that hospice nurses could use to care for their suffering patients and potentially provide insights into how these nurses personally cope with their patients' suffering.

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