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Cancer Pain Social Processes and Pain Management in Home Hospice Care

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ABSTRACT

Background: The high incidence of pain associated with end-stage cancers indicates the need for a new approach to understanding how and why patients, caregivers, and clinicians make pain management choices.
Aims: To provide pilot data and preliminary categories for developing a middle-range nursing theory and framework through which to scrutinize and identify problematic processes involved in management of poorly controlled pain for home hospice patients, caregivers, and nurses, the "caring triad."
Design: A qualitative pilot study using constructivist grounded theory methodology to answer the question, "In the context of hospice, what are the social processes occurring for and between each member of the hospice caring triad and how can these processes be categorized?"
Settings: Home hospice care.
Participants/Subjects: Hospice patients experiencing cancer pain, family caregivers, hospice nurses.
Methods: From a sample of triads including hospice patients, caregivers and nurses, data were collected at observational visits, individual interviews, and a focus group over the course of each triad's study involvement. We used recursive coding processes to interpret data.
Results: Three preliminary categories of social processes were identified: *Pain Meaning, Working Toward Comfort,* and *Bridging Pain*; and six subcategories: *perceiving pain and discomfort, knowing what to do, planning activities, negotiating a pain plan, talking about pain,* and *being together in pain*.
Conclusions: As illustrated in the caring triad cases presented, this study moved the management approach of pain from a dichotomous realm of nurse-patient, to the more naturalistic realm for home hospice of nurse-patient-caregiver. In analyzing social processes within and across triad members, we identified categories of impact to target assessment, intervention, and education to improve pain outcomes.

Key Practice Point

- Of importance for nurses is knowing whether CT members share perceptions of controlled pain or pain meaning and facilitating CT member communication about cancer pain social processes to advance shared goals for pain control.

The high incidence of pain associated with end-stage cancers indicates the need for a new approach to understanding how and why patients, caregivers, and clinicians make pain management choices (Coyne, Mulvenon, & Paice, 2018; van den Beuken–van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). Rates of

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moderate to severe pain for end-stage cancer patients have not decreased (van den Beuken–van Everdingen et al., 2016), despite a plethora of educational resources: textbook content (Fink & Gates, 2015) and specialty courses (American Association of Colleges of Nursing, 2018), freely available resources for pain assessment (City of Hope Pain & Palliative Care Resource Center, 2018), and guidelines for best practice pain management (Paice et al., 2016).

There is a lack of recent research outlining what hospice nurses are in fact doing when managing pain in the home setting. Herr et al. (2010) developed and tested the Cancer Pain Practices Index to assess how hospice agencies applied clinical practice guidelines for the management of cancer pain in older hospice patients and reported that few of the 11 best practices were experienced by a majority of patients treated by 16 hospices. More recently there has been an interest in the caregiver role in home hospice cancer pain management, with studies reporting communication with hospice providers as a concern identified by caregivers (Han et al., 2018). Studies of collaborative processes involving patients, nurses, and family caregivers demonstrate the inherent social nature of managing pain for hospice cancer patients. For instance, Kelley et al. (2013) identified communication with nurses and other family members as pivotal to how caregivers managed pain.

The inherent social and collaborative endeavor of managing pain at the end of life is further complicated by pain meaning (Barkwell, 1991; Ferrell, Taylor, Sattler, Fowler, & Cheyney, 1993). When patients, caregivers, and clinicians interpret cancer pain meaning separately, they may choose different pain management approaches, adding to the overall complexity of the work at hand (McPherson, Hadjistavropoulos, Devereaux, & Lobchuk, 2014; Mehta, Chan, & Cohen, 2014). Patients and family caregivers may not reveal underlying physical, psychosocial, and spiritual concerns to clinicians (Ehrlich & Walker, 2016). Thoughts, behaviors, and communications that can be open or hidden exemplify underlying social processes that affect how individuals approach pain management. Important concerns related to end-stage cancer pain may be overlooked when social processes are absent from nursing assessment and intervention. For example, do patients and family caregivers talk about perceived discomfort or work together in using interventions to achieve comfort? Yet little is known about the intersection between cancer pain social processes and pain in hospice care (Ehrlich & Walker, 2016). Understanding hospice cancer pain social processes—which is to say, outlining how end-stage cancer patients, their family caregivers, and hospice care nurses may differentially assess, interpret, and act on patients' pain experiences—will fill a gap in this area of pain management.

Purpose

The purpose of this study was to provide pilot data and preliminary categories for developing a middle-range nursing theory and framework through which to scrutinize and identify problematic processes involved in management of poorly controlled pain for home hospice patients, caregivers, and nurses—the "caring triad." We examined underlying social processes, and the three-person group of hospice patient, family caregiver (FCG), and nurse as a caring triad (CT), guided by the question, "In the context of hospice, what are the social processes occurring for and between each member of the hospice caring triad and how can these processes be categorized?" Because older persons comprise the largest percentage of hospice recipients (85.5% of hospice care was paid for by Medicare in 2014) (National Hospice and Palliative Care Organization [NHPCO], 2015), the majority of whom received care for cancer (27.2% in 2016) (NHPCO, 2018), we identified a need for understanding how cancer pain social processes affect the largest hospice user group.

Literature Review

The National Institute of Mental Health (NIMH) (2012) has defined social processes as reflective and interactive behaviors like thought processes, assigning of meaning, and conscious or unconscious actions. Many such social processes occur during hospice CT cancer pain management. NIMH identified four social processes types: affiliation and attachment, social communication, perception and understanding of self, and perception and understanding of others. These social processes and the literature review have been presented at length in a related article (Ehrlich & Walker, 2016) and are discussed briefly here.

In the literature review, we identified a gap in knowledge of how cancer pain social processes contribute to overall pain management and control, making clear a need to identify social processes components to advance understanding of poor pain control in the hospice cancer context. Although hospice nurses are expected to have robust knowledge of effective opioid and non-opioid pharmacological solutions for cancer pain (Coyle, Layman-Goldstein, & Hunter-Johnson, 2015; Murray, 2016; Paice, 2010), known barriers to effective opioid use include inappropriate prescribing (Flemming, 2010), not applying clinical cancer pain best practices (Herr et al., 2010), and clinician fears (Barnett, Mulvenon, Dalrymple, & Conno, 2010; Howes, 2015). Zerwekh et al. (2002) found that even experienced hospice nurses feared (a) being accused of killing patients, (b) becoming too emotionally close to patients to accurately assess pain, and (c) standing up to physicians to advocate for medication needs. Such barriers to effective pain control are examples of social processes. However, few studies have described social processes for hospice cancer pain, and these were not recent studies, with only a very small number having applied a triadic approach (Ehrlich & Walker, 2016). Of those, two studies involving the CT reported on cancer pain meaning (Barkwell, 1991; Ferrell & Dean, 1995), and a third described discreet types of communication used in hospice nurse pain management visits (Ellington, Reblin, Clayton, Berry, & Mooney, 2012). We also found an absence of frameworks or theories within which to place hospice cancer pain social processes; therefore, this pilot study identified categories to be used in framing the early phase of middle-range theory development (Ehrlich & Walker, 2016). Our research study advances understanding of hospice CT social processes used in managing pain at home.

Methods

To develop theoretical categories of social processes, the study followed Charmaz's (2014) constructivist grounded theory (CGT) methods. An ontology underlying grounded theory is symbolic interactionism, or the premise that people express subjective meanings using language and communication as processes in which they construct their realities. CGT is a robust approach for studying participants in natural settings, through prolonged engagement and multiple data-gathering activities by which researchers can produce descriptive and explanatory data and propose theoretical categories and relationships for complex phenomena. Constant comparative data analysis includes coding, memoing, purposive and theoretical sampling, and triangulation concurrent with data collection. Comparing data from different participants and in different forms (e.g., passive observational notes and interactive in-depth interviews) were two elements of our strategy of triangulation and trustworthiness. Others included writing reflexive memos and discussing these among research team members. When using CGT, researchers acknowledge personal experiences, values, and beliefs they hold (Charmaz, 2014). Taking these into account, concepts, categories, and knowledge about categorical relationships are constructed from the raw data.

Early gerund coding, theoretical sampling, and free writing help to home in on factual and value-laden data, which are critical elements of social processes. The first author, a doctoral candidate, conducted all recruitment, consent, and data collection activities.

Setting, Eligibility, and Procedure

Setting

To generate data authentic to home hospice cancer pain management, the study was conducted in homes of patients, or homes or offices of FCGs or nurses. Additionally, because of the likelihood that patients would be unable to easily participate, all patient interviews were conducted in their homes. Similarly, FCG study activities occurred in their chosen locations, an office or home setting. To increase the likelihood that nurses would participate, they were interviewed at their office or other locations of their choosing.

Eligibility

Patients 60 years of age and older, with a primary hospice diagnosis of cancer and current related pain that had been reported to participating nurses, and who could converse in English, were eligible. FCGs 18 years of age or older, identified by patients as their FCG, able to converse in English, and who were involved in in-person care at least 2 days per week were eligible. To minimize chances of data resulting from inadequate knowledge and experience, hospice nurses who had worked at least two shifts per week for the previous 12 months were eligible.

Procedure

Because of the pilot nature of this study, the planned sample was five or more triads to gather a body of data representative of differing triad member experiences. Experts in the lived experiences of hospice cancer pain—members of CTs—were intentionally recruited. The medium-sized rural hospice agency, where the first author was employed, collaborated in recruitment. Convenience sampling was used to facilitate participation in this population identified to have short average hospice stays (mean = 46 days; median = 19 days) (NHPCO, 2018).

Participant recruitment began after approval from the Institutional Review Board at University of Massachusetts Amherst (protocol number 2015-2555). Nurses at the hospice agency who had attended an information session and provided written consent used a script to recruit eligible patients during home visits. Patients provided contact information to be shared with the first author and met with the first author in their homes for written consent. FCGs were invited to participate by eligible patients. Written consent was provided before study participation. Complete recruitment and retention methods were described in a previous article (Ehrlich & Walker, 2018).

Data Collection

We used two primary data collection activities conducted by the first author—CT observational visits and in-depth individual CT member interviews. Each CT was observed during routine pain management by nurses at the beginning of study participation to capture natural physical settings, behaviors, types of language, and emotions occurring as pain management social processes, with two of the triads having a second observational visit (Kawulich, 2005). The third triad did not have a second observational visit because of rapid disease progression. Based on passive observation of the triads, written notes, audio memos, and drawings were made during and immediately after each visit to record this data. At the first interview, each triad member was asked demographic questions for summary reporting of the sample characteristics. The interviews were semi-structured and lasted from approximately 60-90 minutes, according to participant engagement in the conversation.

Because the focus of the study was social processes associated with managing pain, we used the sensitizing concept of pain perception as a starting point for understanding the pain management context (Charmaz, 2014). In the first interview, patients were prompted, “Please rate your pain severity on a scale of 0-10, where zero is no pain and 10 is the worst imaginable,” and “Do you consider your pain to be controlled?” FCGs and nurses were asked to report the approximate date that they considered pain to have been well controlled for the first time. The rationale for asking about pain severity and perception of control was to establish a baseline of two factors: (a) ability of the participant to self-report pain severity and controlled pain, and (b) to compare perceived severity and controlled pain across CT members. All CT members were asked to describe a time or day or when pain was well controlled to gauge how pain control was perceived. Open-ended questions were used during individual interviews to elicit discussion of cancer pain experiences, general ideas and beliefs about pain, and pain management activities. Given the short length of hospice cancer care (NHPCO, 2018) and overall illness intensity, we determined that three interviews would limit the burden of participation while allowing for theoretical sampling of data and triangulation within and across triads.

Secondary data collection activities included a video-recorded nurse focus group and a survey for nurses asking open-ended questions about emerging study categories and subcategories. The focus group was attended by two of three triad nurses and another enrolled nurse who did not have a triad. Focus group questions elicited nurse experiences with pain meaning and how to address pain meaning in provision of care. A second planned focus group was not held because nurses were unable to attend. Instead, a paper survey asking the open-ended questions planned for the focus group was completed by nurses. Survey content explored nurse experiences and thoughts about using goals for individualized pain management.

Data Analysis: Initial and Focused Coding

The first author transcribed nine audio-recorded interviews using NVivo 11 Pro for Students software (QSR International Pty Ltd, 2014), with remaining interviews transcribed by a professional service. We used Charmaz's (2014) coding method which begins with line-by-line description of actions and experiences in transcribed data, using gerunds to capture actions and behaviors rather than topics. Line-by-line coding resulted in identification of many codes. We used theoretical sampling to follow up on coded content mentioned multiple times by participants, phrases participants said with emphasis, and behaviors noted. Focused coding included revisiting initial codes with the same or other participants in subsequent interviews and re-examining notes and transcripts to look for categorical or incidental patterns. In this manner, using constant comparison, theoretical data sampling, concept mapping, and writing of memos, initial codes could be clustered in focused codes, and theoretical coding used to examine relationships. The research team maintained an audit trail composed of digitally stored records to demonstrate transparency and trustworthiness.

Results

Sample and Data Collection

Although all five full-time hospice agency nurses met eligibility criteria and consented in writing, two were unable to participate in providing CT data because they had no eligible CT. When approached by their nurses, 12 patients requested information about the study. Of 11 who had FCGs, 2 declined for personal reasons and 6

experienced disease progression that prevented participation. All participants identified as non-Hispanic, white, and female. Patients ranged in age from 71-79 years of age, caregivers from 43-56 years of age, and nurses from 38-62 years of age. Nurses had 5-20 years of hospice experience and specialty certification. Caregivers were daughters who lived outside of patients' homes and, despite working full-time, visited their mothers' homes more than two times a week, spoke daily on the phone, and attended the observational visits for the study. Because of resource constraints, accrual of the planned five triads was not possible and data from three triads were analyzed. The analysis was based on 44 total data points, including notes from 7 observational visits, 24 interview recordings and transcripts (8 from patients, 7 from FCGs, and 9 from nurses), focus group content, 3 survey responses, and 6 researcher memos.

Cancer Pain Social Processes

As shown in Figure 1, we constructed three main categories of hospice cancer pain social processes that occurred in the CT context: *Pain Meaning (Meaning), Working Toward Comfort (Working), and Bridging Pain (Bridging).* Each of these categories included the individual processes that patients, FCGs, and nurses brought to the shared experiences of managing pain. We framed the data interpretation as "managing pain" because our analysis was intended to supplement nursing clinical practice or research, in contrast to framing an analysis speaking from the human cancer pain experience, which is much more complex and includes aspects of life not addressed by nursing care. The individual experiences of triad members—thoughts, feelings, interpretations, behaviors—included complex, often subtle or unspoken reciprocally interactive social processes that we applied within and across triad members. Our analysis is presented here as two CT cases, each illustrating variations in how social processes were involved in managing pain. A third CT, in which the social processes were congruent across members, and therefore indicative of desired hospice nursing outcomes for cancer pain, is archived in an online supplement that includes examples from the three triads, viewable at: [http://dx.doi.org/10.17632/tk6dgv373n.2].

The underlying role of *Meaning* was the most complicated influence in making sense of how CTs approached all pain social processes. *Meaning* varied by CT, and within each CT. Although we interpreted the meanings that participants spoke of in general terms as influencing their cancer pain, these meanings were informed by talk of family histories, experiences of physical and emotional pain, and experiences of illness. Each patient spoke at length of the loss of parents, spouses, and siblings to chronic illnesses, including acquired immunodeficiency syndrome, chronic obstructive pulmonary disease, heart failure, and cancer, and each had been actively involved in end-of-life care for these significant others. Thus family and past illness experiences played significant roles in topics discussed in individual interviews. The primary topic of discussion at the nurse focus group was pain meaning. Nurses agreed that fear often defined cancer pain meaning for patients and FCGs. They also said that nurses had the capacity to change the meaning of pain by developing trusting relationships with patients and FCGs so that pain interventions would be acceptable and would increase comfort over time.

The second category, *Working*, was inclusive of three subcategories—*perceiving pain and discomfort*, *knowing what to do*, and *planning activities*. The choice of *Working Toward Comfort* replaced our initial code of *Controlling Pain* because it became clear over the course of analysis that the early category name was reflective of only the clinician point of view; thus, it excluded how others spoke of the daily workings of living with pain and trying to achieve comfort. *Perceiving pain and discomfort* was inclusive of opinions and observations about whether pain or discomfort were present. Some participants used the term *discomfort* or *uncomfortable,* whereas others used the term *pain* when referring to the same patient's experience, so both were included in the category label. *Knowing what to do* included talk or observations of knowledge and behaviors used to achieve comfort, such as taking medications or

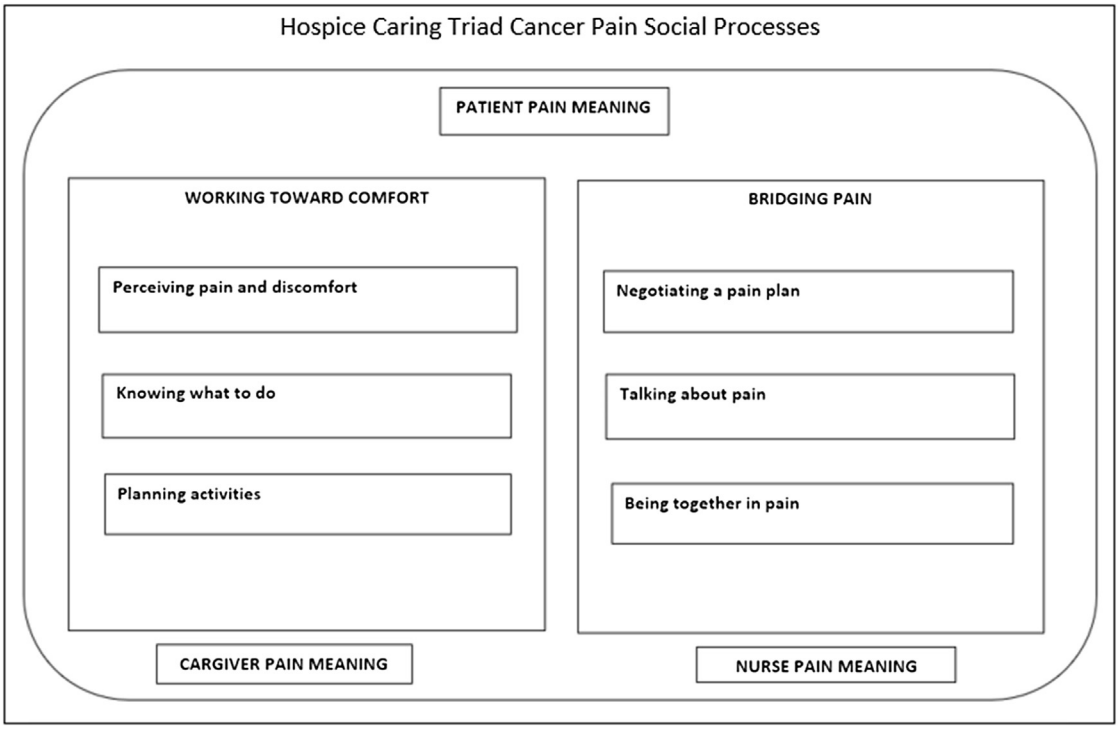

Figure 1. Three main categories of hospice cancer pain social process were *Pain Meaning*, *Working Toward Comfort*, and *Bridging Pain*. *Pain Meaning* underpinned the other categories and subcategories for each member of caring triads. Subcategories were nested within each category. All categories and subcategories occurred for each caring triad member.

using massage. *Planning activities* included talk of the activities that patients deemed important to daily living.

The third category, *Bridging*, was composed of the three subcategories *negotiating a pain plan*, *talking about pain*, and *being together in pain*. These categories were evident in CT behaviors and were relational in nature. For instance, *negotiating a pain plan* addressed how CT members reached agreement on what to do for achieving comfort. *Talking about pain* included instances of when CT members spoke of pain to one another, or not. *Being together in pain* described the emotional and physical distancing between CT members that was inextricably tied to other pain social processes. Distancing was observed at visits and recorded in interviews.

Triad Case Comparisons

To present examples of how the hospice cancer pain social processes occurred and varied by group, we organized data into three triadic cases, which were abbreviated for the sake of demonstration; however, the full cases are available in an online supplement (http://dx.doi.org/10.17632/tk6dgv373n.2). Some triads embodied change in processes over time, from the beginning to the end of study participation, which varied from 3 weeks to 6 months. The first triad exemplified the most extreme physical-emotional distance and the greatest emotional distress, despite having the longest hospice experience and therefore greater potential for nursing or hospice team intervention. In this triad, talking about pain perception and negotiating the plan for improving comfort occurred only between the nurse and patient as observed, with the FCG speaking to the researcher in interviews, but not to the other triad members, about these processes. Communication between the patient and FCG was largely nonverbal or indirect when talking within the CT. The second triad exemplified a balance of physical-emotional distance and increased closeness over the 5 weeks of study participation, as open communication about pain increased. Negotiating a pain plan shifted from the patient controlling everything to a collaborative plan that included suggestions from the FCG and nurse to help the patient achieve her planned activities. The third triad exemplified emotional and physical closeness, speaking of one another's feelings comfortably and accurately, talking about pain and how it interfered, easily negotiating a plan, and using physical touch for comfort over the 3 weeks of participation.

Triad One

Meaning varied across CT members. For the patient, pain posed a dilemma that precluded simply following instructions provided by the nurse for reducing pain: “Not knowing what this cancer does… and not knowing whether it's creating a tumor inside of something, or outside of something. I'm not sure anybody else knows either what progression or where this thing is.” Fear on the patient's part of letting down her family who had also lost her spouse in the previous few years manifested in this dilemma. The FCG sensed this unspoken fear in interactions, which had shifted from humorous to emotionally charged: “She's just like, crotchety, or I don't know… mean, mean! I think that's eating me away, cause it's not who my mom was, you know? I want, the mom that I had.” She often returned to this theme of losing her mother during interviews but did not speak of it with the patient or nurse. The nurse perceived *Meaning* for the patient as an unpredictable and therefore frightening loss of control.

When it came to *Working*, CT members engaged with one another in different ways. *Perceiving pain* included the interpretation of discomfort from pain. The nurse would ask the patient to report her pain severity, describe pain location and qualities, or visualize and palpate painful areas: “She minimizes any distress that she's having, and I think part of that is because where it's going is a bit overwhelming to her—the uncertainty of how this story will unfold is terrifying to her, I think.” The patient said of her pain: “It's up through the neck, and of course the stiff neck is irritating as all heck.” The FCG considered the pain to be poorly controlled: “I can see it when she's like wincing in pain or for her it's personality change and she just gets… mean.” CT members were versed in *knowing what to do* to improve comfort yet made different choices. The nurse tried to convince the patient to use a greater dose of medication, the patient chose to use minimal medications mostly at night, supplementing those with massage and heat during the day, and the FCG tried to convince her mother to follow the nurse's advice. *Planning activities* was an area where CT members agreed on what the patient wanted to achieve functionally, including crafting and taking care of her grandchildren every morning before school. The nurse said:

> When I met her, she still felt pretty hopeless about her quality of life and so, to me, her story is a really beautiful unfolding of incredible quality elements that include regaining her interest in participating in activities that she loved. And so—once the pain were [sic] managed, she then went back to watercolor painting; has gone on many trips.

Although pain perceptions were described differently across triad members and each applied knowledge of how to achieve comfort in different ways, they worked together to help the patient do the things she valued—take care of grandchildren, handcrafts, painting, and travel.

When it came to *Bridging*, the relational processes used by this CT were indicative of discord. For example, when talking about pain, the patient and FCG rarely spoke openly about pain. Privately, the daughter said: “I don't probe like ‘How is your neck today? How is your hip today?’ I just see her and like, ‘You're not standing well today’ and just like, ‘Okay, but if the nurse asks you, you would have a different answer!’” And the nurse said: “I think [she] minimizes it because she doesn't want to worry them because she already feels like she's a burden to [FCG], that [FGC's] already got too much on her plate.” The patient said: “Her life has been pretty full so you know as long as I don't say much she's not real aware of how I'm feeling anyway.” The nurse, when *negotiating a plan,* stated that she had suggested increasing the pain medication and when the patient did not engage in discussion, the nurse felt as though she was “blabbering.” Privately, the patient said: “The minute I mention any pain at all it’s like, ‘Do you want to go up on the medication?’ I'm like, ‘No, no!’ I mean it took weeks of them suggesting the 48 hours before I finally said ‘yes.’” Her daughter said: “I get more frustrated because she doesn't want to listen. If she would just accept the pain medication, then I think she would be happier.” For this triad, *being together in pain* was typified by a nurse statement: “There's quite a tension between her and her daughter which I was not aware of. She's never really shared about that, with me, and I've been her nurse for months and months.” Although the patient and FCG lived next door to one another, their usual mode of communication was a daily phone call or brief exchange during which time the daughter changed a fentanyl patch. In an interview the FCG said she was angry and felt unappreciated. These feelings were exemplified by her minimal contact with her mother, mostly via daily phone calls and no observed touching or sitting close to one another.

Triad Two

Meaning for the second triad again varied by members. The patient used a phrase she had learned from her mother as a little girl when framing her situation: “Big girls don't cry.” Both she and her FCG had spoken of this in interviews. For the patient, having

followed this mantra over her life, once on hospice she began to regret that this stoicism and controlled communication had resulted in a fragmented family, which was distressing to her. Her daughter viewed the underlying meaning of pain as a loss of control over everything instead of loss of family. The nurse's perspective was one of multidimensional suffering attached to the physical pain.

Working included changes in categorical dimensions over time. For instance, early in participation, in the *perceiving pain* category the nurse said she accepted what the patient reported when asking if she was uncomfortable, and the patient said: "My leg was bothering me some, but I didn't have to take an extra pill." The FCG said her mother was toughing it out. By the end of their participation, the daughter said she and her mother agreed that pain was well controlled with medications. When it came to *knowing what to do*, the nurse provided education to the patient and FCG about using the pain medications, and they reported using them as prescribed. When it came to *planning activities*, the patient told the nurse and FCG what she was doing or was planning to do, which included driving herself to go shopping and taking care of her household. As she became more debilitated, *planning activities* changed to accepting assistance from her FCG: "And I went downstairs yesterday. They were going to hold my arm. I had so much ice cream and stuff down in that freezer. I brought [it] up for [them]. [That] made me feel happy." Talking of her daily life activities and family were important topics for her.

The category of *Bridging* was complicated for this CT. Whereas in Triad One, these processes represented discord across time, in Triad Two, change occurred from the beginning to the end of study participation. When *negotiating a pain plan*, the patient insisted on control:

> I discussed the morphine with [FCG]. I said I'm going to stay with what I got for now. I've never had morphine. I don't know how it'll affect me. But I'd know when the pain was bad enough I'd have to switch over to it.

And the FCG said: "But she also wants to be coherent and with the [oxycodone] you know some people, they—their mind isn't as sharp. And then she wouldn't be in control." The nurse had provided education to the patient about both medications and the patient continued to choose oxycodone until 2 days before she died, at which time she was willing to accept morphine from her daughter after the nurse administered the first few doses. The patient had been familiar with morphine used at the very end of life with both her husband and her mother. When it came to *talking about pain*, initially the patient had been reluctant to talk about it according to the FCG: "I think that she thinks, I'm just guessing here, that if people think she's in pain they're gonna wanna take care of her. And she doesn't want that." Whereas the nurse initially had been unaware of their lack of *talking about pain*. As with other social processes in this CT, all members spoke more openly about pain over time, especially in the last weeks. A week before her mother died, the FCG said: "I ask her if she's having pain and remind [sic] that it's okay to take more [medicine]." The remaining social process category in *Bridging* was *being together in pain*. For this CT, the patient controlled the physical-emotional distance, and this was confirmed by the nurse and FCG. Initially, the patient wanted to keep the FCG at an arm's length, which was consistent with behavior before her advanced cancer diagnosis. She admitted that by the time she was approaching the end of her life, that had changed: "Well I was always the mother, she's the daughter. Then, when I became ill, I saw a side of her I never knew, never thought about. Her care, and her attitude. She doesn't seem to mind at all."

Discussion

This study about CT cancer pain management in a home hospice setting resulted in generating new related categories that outlined social processes thoughts, feelings, and behaviors influenced by variations in personal underlying pain meanings. Our results confirmed some previous findings about the varying meanings of pain for hospice patients with cancer, their caregivers, and nurses (Ferrell et al., 1993; Ferrell & Dean, 1995; Flemming, 2010). Nurses in our study talked about the perspective that fear often influences pain meaning. A unique finding in our study was that nurses told stories about helping patients transform the meaning of pain from a fear-based standard at the beginning of care to one of facilitating meaningful activities by the time of death. However, this was a caring behavior specific to the group of nurses attending the focus group. Additional qualitative research can outline how CTs transform pain meanings. The development and testing of assessments for and interventions that incorporate pain meaning into the care plan would fill a void in this area of pain management practice.

Members of hospice CTs here spoke of concerns also voiced by previous study participants, like patient and caregiver concerns of addiction when using opioids (Flemming, 2010) and caregivers believing that the person with pain was underrating pain severity (Oliver et al., 2013). Despite the professional nursing obligation to provide patient education about medication side effects such as dependence and fear of addiction, a lack of standardized pain education for nurses can result in knowledge deficits that affect practice (American Nurses Association, 2018). Additionally, research describing how nurses provide pain medication education and address conflicting pain perceptions is lacking.

Nursing process—related findings from this study pointed to a gap in communication about activity goals when negotiating care plans. This was evidenced by the overall discussion of meaningful activities by each CT member, but a lack of goals-planning discussions was consistent with previous research findings. In Herr et al.'s (2010) retrospective cross-sectional study of 16 hospices and 399 patients, only 22.7% of patients had been asked to set a severity-related goal during routine pain management. Hospice nursing practice guidelines (Fine et al., 2010) and educational texts outline how to assess cancer pain intensity, type and location of pain, patterns of pain, and severity-related goals (Fink & Gates, 2015). There are non—hospice-specific pain interference assessments available (e.g., Brief Pain Inventory) (Cleeland, 2009), yet, to our knowledge, no assessment tools for directly assessing patient functional pain (activity) goals.

A noted gap in nursing practice guidelines for cancer pain management is the lack of evidence about assessing and setting functional pain goals. This omission is problematic because it leaves home hospice nurses to ad-lib the process of assessing what patients want and expect from pain management interventions. Such informal processes may not be documented for follow-up by other clinicians and therefore do not reflect best practice. One expert opinion in a palliative care practitioner blog (UW Health, n.d.) stated that clinicians should ask patients to state what they would do when the pain was controlled and should address physical or emotional outcomes related to pain. In the blog, the expert opinion suggested using severity-related and functional goals together to direct pain control behaviors in ways that are meaningful for patients and caregivers. Yet use of direct or open-ended questions in pain management goal-setting remains to be tested in research studies.

Despite the fact that there are no assessments or interventions for triad communication, congruence of perceptions of comfort, and planning of meaningful activity as it relates to functional goals, we identified one model that addresses the need to develop such

clinical tools. Rosa's (2017) theory-based transcultural pain management (TPM) model adapted transcultural domains to nursing pain practice. In the TPM are outlined domains that can inform practice for nurses in any setting and with any population. By applying the domains, nurses could improve their capacity for understanding and responding in authentic caring practices to the complexity and uniqueness of a person's pain. The TPM model (Rosa, 2017) represented an important new approach to patient-centered pain management that could guide nurses in the hospice cancer pain setting in talking about underlying pain meanings, perceptions of comfort, and meaningful activities. However, the theoretical domains remain to be empirically tested, and assessment techniques and interventions that can be applied in the clinical setting need to be developed.

Strengths and Limitations

A strength of using Charmaz's (2014) grounded theory methods in this study was giving voice to what CTs believed influenced their cancer pain management behaviors. Limitations of this study included narrow dimensional descriptions of the categories identified because of the homogenous study sample and small sample size, lacking demographic variations. Also, it is possible that with a larger sample, changes in pain social processes that could occur over time could be captured, which this study was not able to do. The transferability of our findings could also be limited by not exploring relationships between cancer type and social processes.

Clinical Implications

The results of this study are preliminary and do not carry the weight of evidence to change clinical practice. However, nurses should know whether CT members share perceptions of controlled pain or pain meaning. Facilitating CT member communication so that shared goals for pain control can be documented and included in the care plan is consistent with the nursing process.

Future Research

These hospice cancer pain social processes categories and subcategories set the groundwork for future development of a middle-range theory. Additional social processes categories remain to be identified and explored in future studies if a theoretical framework is to be developed. Next steps will include conducting the constructivist grounded theory study described here with a larger, more diverse sample of hospice caring triads.

Conclusions

This research study has identified and labeled new phenomena for hospice cancer pain management in social processes categories to generate new knowledge through which to understand how CT members interact in the face of pain. As illustrated in the caring triad cases presented, this study approaches pain in the context of a group that is often the norm for pain management in home hospice care: the nurse-patient-caregiver. Importantly, these social processes are based on each member of the CT to better understand how pain is managed when poorly controlled pain is present. The social processes categories can be researched and expanded in the context of more diverse caring triad samples to generate a theory of hospice cancer pain social processes to target for development and testing of assessment tools and interventions to improve poorly controlled pain.

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