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Barriers to Pain Management: Caregiver Perceptions and Pain Talk by Hospice Interdisciplinary Teams

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Abstract

As patients are cared for in their home by family caregivers, several challenges arise in effective pain and symptom management. Despite hospice's reputation as the gold standard for terminal care, there is still a need to improve pain management practices including challenges that caregivers face, related to pain assessment, reluctance and fear of administering medication, noncompliance with pain medicine regimens, and hesitance to report pain. The hospice philosophy of care promotes service for both patients and their family by an interdisciplinary team, and total pain management is a goal of this care. The aim of this control phase of a larger National Cancer Institute-funded mixed methods study was to understand the current practice of hospice assessment and collaboration on informal caregiver issues related to pain management. This study of 30 hospice caregiver/patient dyads from one rural hospice found that 87% of caregivers indicated concern with at least one question on the Caregiver Pain Medicine Questionnaire (CPMQ). Interdisciplinary team discussions for 23 of the dyads were recorded over nine months for a total of 86 sessions. Although caregiver concerns were identified with the CPMQ by the research team, there was only one discussion of caregiver pain related concerns during the hospice team meeting. This despite the finding that 38% of the time involved in a patient discussion is spent on pain related talk. These findings indicate an opportunity for improvement by hospice teams through focusing on caregiver assessment and intervention.

Keywords

Caregiver Pain Medicine Questionnaire (CPMQ); hospice; pain management; interdisciplinary teams

Introduction

Hospice care is provided to over one million Americans each year [1]. Essential to successful hospice care, yet lost in these statistics, are the family members and friends who serve as informal caregivers. The physical and mental health of these individuals directly impacts the

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ability of patients to die comfortably [2,3]. The home of a dying cancer patient becomes like a hospital unit where informal caregivers are expected to manage all aspects of patient care without formal education; this responsibility is often leaving them anxious, exhausted, and burdened [4]. Hospice standards of care hold that the patient and family are a unit of care as issues affecting caregivers also impact patients [5].

Good pain and symptom management require the intervention of all disciplines in a holistic approach [6]. Unrelieved pain affects the patient's physical, psychological, social, and spiritual well-being [7]. This recognition of total pain has been with hospice since its beginning, deriving from the initial experiences of founder Dame Cicely Saunders [8]. While numerous advances have been made in the art and science of pain management, many challenges remain. Studies have found that hospice staff members lack sufficient information to rate symptoms, especially related to psychosocial concerns. There has been documentation of a significant burden of unrelieved symptoms among hospice patients [9]. Pain is reported as a very common symptom, with 76–90% of the hospice patients having pain documented [9,10]. Interventions have been found to be largely pharmacologic. The effectiveness of the interventions is difficult to determine based on a lack of documentation and the necessity to rely on caregivers assessment skills, whose proxy has been brought into question [11].

One of the greatest barriers to effective palliative care is poor communication between patients, their caregivers, and health care providers [12–14]. A principal reason for initiation of hospice care is the need for expert pain and symptom management. As patients are cared for in their home by family caregivers, several challenges arise in effective pain and symptom management. Problems include pain assessment [15], reluctance to administer medication [16], fear of pain medications [17], noncompliance with pain medicine regimens [18], hesitance to report pain [19], negative past experiences [20],caregiver strain impacting pain management [21], and the need for caregiver education and patient care information [22].

While hospice patients receive the gold standard of palliative care [23], improvements are still needed, specifically in pain and symptom management and emotional support for families [9,10,24]. Studies have shown that even in the care-oriented culture of hospice, pain is still a frequent problem [9,10,25]. A recent study found that 35% of hospice patients and 20% of their families reported receiving inadequate emotional support. Additionally, the same study reported that over one-third of hospice families had concerns about the amount of information they received regarding what to expect when the patient was dying [24]. These findings illustrate problems even in the most established palliative care model.

This study seeks to identify the perceptions of hospice caregivers related to the administration of pain medication and the current practices of hospice interdisciplinary teams in addressing caregiver concerns through their talk regarding pain. Pain talk is defined in this study as any utterance that pertained to the patient's pain (including caregiver concerns related to patient pain) from a holistic perspective (physical, spiritual, psychological, and social). The project was focused on three research questions 1) What are the perceptions of hospice caregivers related to the administration of pain medication?, 2) How do those perceptions change during the course of a hospice stay?, and 3) In what ways are caregiver concerns related to the administration of pain medication reflected in the pain talk in hospice interdisciplinary meetings?

Methods

This paper represents preliminary findings from a current larger two phase quasi-experimental mixed method project funded by the National Cancer Institute (R21 CA120179). This project explores the results of the control phase, analyzing the quantitative data reflecting the perceptions of pain management by hospice caregivers and qualitative observation and recording of corresponding hospice interdisciplinary team meetings for the consenting patients. The study was approved by the University of Missouri Institutional Review Board as well as the Institutional Review Board of the hospice agency.

Setting

Data were collected from consenting hospice caregivers in one rural hospice program in the Midwest. The program is hospital-based, Joint Commission on the Accreditation of Health Care Organizations-accredited, Medicare certified, state licensed and not for profit. The average length of stay for the program is 63 days, with an average daily census of 89 [26]. No individual or aggregated results were shared with the hospice team. Our goal was to observe normal care and thus the team did not have access to our assessments, they relied solely on usual patient and caregiver assessments.

The project uses a mixed method approach with qualitative and quantitative methods in parallel and equal status [27]. Data were mixed during analysis, as the concepts evident in the standardized instrument were used to develop a coding frame for the qualitative analysis of pain talk utterances. Qualitative data were used to follow up on identified issues found in the quantitative measure.

Participants

Participants were caregivers of home hospice patients. Both patients and caregivers consented to the study although the focus of the project was on caregiving. All caregivers and patients had to be enrolled in the hospice, without cognitive impairment, consent to the study, and over 18 years of age. Participants were enrolled between October 1, 2006 and April 18, 2007. Hospice staff were also considered as participants in this study as their behavior and communication during team meetings were analyzed. The staff represented individuals from numerous disciplines with a range of hospice experience. Each staff member signed an informed consent and agreed to being videotaped. They were fully aware of the specific aims of the project.

Measures

The instrument used in this study was the Caregiver Pain Medicine Questionnaire (CPMQ) [19]. Letizia et al. developed the CPMQ by first modifying an existing instrument that measured concerns regarding pharmacological pain management that were expressed by ambulatory cancer patients [15]. When adapting the scale for use with hospice caregivers, they made certain that three concepts were adequately addressed: concerns about reporting pain, concerns about administering analgesics, and difficulties administering pain medications [19].

Research assistants on the staff contacted caregivers via telephone every 30 days to review the questions on the Caregiver Pain Medicine Questionnaire. The CPMQ is a 22-item self report instrument. Each of 22 items is scored on a 5-point Likert scale of agreement. A low number indicates a high level of agreement and greater concern about the issue. The validity of the instrument was tested using the Content Validity Index (CVI) and found to have a CVI of 0.89 [28]. The original study reports reliability tests found that the total instrument alpha coefficient was 0.89. Factor alpha scores were reported as 0.74 for items measuring concerns about reporting pain, 0.89 for items measuring concern about administering medications, and 0.89 for items measuring difficulties administering medications.

The CPMQ items focused on concerns about reporting pain essentially measure the degree to which respondents agree with two core beliefs. The first, *fatalism*, is the belief that pain is inevitable and cannot be adequately controlled by existing medications or technologies. The second, *stoicism*, refers to the belief that individuals should be strong and tolerate discomfort without complaint. Items that measure caregiver concerns regarding medication administration record the degree to which respondents agree with statements indicating fears of pain medication addiction, side effects, and tolerance. Respondents who express agreement with these items reply positively to statements such as "*It is dangerous if hospice patients become addicted to pain medicine*." Items that described caregiver difficulties administering pain medications are not divided into specific subcategories. When testing the instrument, Letizia et al. recorded the degree to which respondents experienced difficulty deciding and/or remembering which specific medications and dosages were appropriate for pain management and at which times they were most likely to be effective. Respondents were also asked to share the degree to which they worried that they were doing "something wrong" when administering analgesics [19].

Interdisciplinary Team (IDT) Observations

The qualitative component of this project utilized videotaped hospice interdisciplinary team meeting discussions for each of the consenting patient/caregiver dyads. The interdisciplinary meeting discussions pertaining to consenting hospice patients were videotaped over nine months and transcribed verbatim. Field notes were collected for each meeting and included a seating chart designating the discipline of each person present, allowing identification in the transcription process. Although the CPMQ data were collected for 30 hospice dyads, descriptive data of hospice interdisciplinary teams were limited to 23 hospice dyads due to death or nursing home transfer prior to the agency's discussion of the case at an IDT meeting. A total of 86 meetings were videotaped, transcribed, and analyzed for this study.

Data Analysis

Selected demographic variables and question responses to the CPMQ were entered into SPSS and subscales and total scores were computed using the prescribed method obtained from the instrument's author [19]. Open ended responses were not a part of this analysis. Given the small sample size, statistical analysis was restricted to descriptive and nonparametric measures only.

Analyses of IDT meetings focused on pain talk, defined in this study as any utterance that pertained to the patient's pain (including the caregiver concerns related to the patients pain) from an interdisciplinary holistic perspective (physical, spiritual, psychological, and social). A pre-established coding frame was developed based on the CPMQ data and the research team experience initial review of the tapes. Data collected included the speaker's professional discipline (physician, nurse, social worker, etc.), the speaker's mention of the role of the caregiver, specific topics relative to pain, and the time spent discussing pain. Transcripts of the interdisciplinary team meetings were coded independently by two coders. Both coders attended a 45-minute coding session, which included a review of the four dimensions of pain and the CPMQ instrument. Each transcript clearly indicated the speaker's discipline (i.e., medical director, nurse, etc.) and it was agreed that a natural talking turn that included the word pain would be defined as pain talk. Coders independently timed and calculated pain talk time and the total time of the discussion. Additional nominal categories included the presence of pain topics and coders indicated the presence of such topic within the manuscript.

Results

Demographic variables are summarized in Table 1 for both patients and caregivers. Table 2 reports on the mean subscale scores at baseline and monthly intervals. Patients and caregivers were in the study for an average of 41 days and in hospice care an average of 56 days. The mean age of patients was 77 while the mean age of caregivers was 60. The majority of patients (60%) had a cancer diagnosis.

An overwhelming majority of caregivers were women (87%), however, patients were more evenly split as 48% were male and 52% were female. Caregivers were more educated than the patients as 37% of patients had less than a high school education and only 10% of the caregivers did not at least have a high school education. Slightly more than one third (39%) of caregivers were adult children, one third (32%) were spouse or partner of the patient, and the final near third (29%) were otherwise related.

CPMQ Results

The lower the score on the CPMQ the more agreement the respondent shows with the statement and thus the more agreement there is with a potential barrier to pain management. Scoring of the instrument showed a normal distribution of responses. As demonstrated in Table 2, the overall mean response to the CPMQ was 3.22 indicating mild overall disagreement. The average subscale scores did not exemplify any strong reaction in any of the categories. The variance of subscale means ranged from 3.08 (addiction) to 3.32 (fatalism). This surprising lack of variance impairs the drawing of specific conclusions related to those scores.

The most significant finding was not in the mean scores, but rather in the analysis of individual questions. The overwhelming majority (87%) of caregivers indicated strong agreement or agreement with at least one statement on the questionnaire. Only four individuals did not agree with a single statement. In fact, respondents agreed or strongly agreed with an average of four statements on the CPMQ with a range of 0–11 responses indicating agreement.

The lowest mean response upon admission was 2.77 demonstrating agreement with the statement, "*I am afraid of doing something wrong when I give the pain medication*." The highest mean response upon admission showing the greatest disagreement was with the statement, "*It is easier to put up with pain than the side effects that come from pain medicine*." As Table 2 illustrates, analysis of the baseline response and the response thirty days later, show the mean total CPMQ scores decreasing from 3.22 to 2.89. A paired sample t test indicated the change was significant ($P<0.001$). A paired sample t test comparing the mean admission CPQM of 3.22 with the final mean measure for the caregivers ninety days later ($n=8$), shows significance is still present as it moves from 3.18 to 3.08 ($P< 0.001$). Although the sample is very limited, the trend indicating increased agreement during the hospice care seems to continue with the changed scores demonstrating increased agreement with the statements and thus increased barriers to pain management.

Analysis of Team Meetings

Observations were recorded for 86 IDT meetings, representing 23 hospice dyads. Eight of the dyads represented in the CPQM results ($n=31$) were not represented in the qualitative analysis of team discussions because they either were not scheduled for discussion prior to analysis, or died before their case could be discussed at a meeting. The number of meetings for an individual subject ranged from 1–10. The average number of observations was 3.73, with 59% of the observations representing three discussions of a particular patient. Qualitative analysis focused on the third research question related to the team practice of discussing pain, with specific attention on how the team addresses caregiver concerns related to the administration of pain medication. Patient cases were discussed for an average of 3 minutes 44 seconds, with a mean of 1 minute 27 seconds devoted to pain talk. In other words, nearly 38% of the discussion related to pain issues.

In total, 230 pain talk utterances were coded and involved patient complaint of pain 20% of the time. The amount of time devoted to specific pain types varied, with nurses averaging 59 seconds on physical pain, 58 seconds on psychological pain, 101 seconds on spiritual pain, and no time devoted to social pain. Table 3 portrays the number of pain talk utterances for each pain type by speaker. Moreover, nurses (65.2%) were usually the ones speaking about pain, with the medical director a distant second (11.7%). Overall, physical elements of pain dominated pain talk (76.1%), with little discussion on the psychological aspects of pain (20.9%) and spiritual pain (1.3%) and no discussion of the social elements of pain.

Two examples of nurses discussing psychological and spiritual pain are below. These examples were not followed by any discussion from the Chaplain or Social Worker nor did they result in any discussion of a specific intervention strategy to address the concerns. Psychological distress is noted in the following nursing report:

Nurse:: The young son fell. He was doing something in the yard on a ladder and fell, and when he fell he knocked his head and he knocked himself out. He was in intensive care.

Bereavement Coordinator:: And they already lost one son

Nurse:: Yeah, yeah, yeah. And so they just took him out of intensive care yesterday. … he's (patient) just like, you know, "Nothing can happen to my son. If God needs to take somebody, he's gonna take me and leave my son."

An example of a discussion on spiritual issues:

Nurse:: ….Um, very depressed, she was tearful. I think she's got some spiritual things she's not resolved because she talks about her dead sister, thinking that she's seeing her, but she feels she needs to talk to her, things she's got some things to tell her. But she didn't share what those things were. But she's talked several times about, she didn't understand why she was still here…

The majority of the pain talk did not include a discussion of the caregiver (75.7%), and in instances when the caregiver was mentioned, it was primarily a positive reference (16.5%). Primary topics of discussion relative to pain included patient appetite (24.7%), activity (24.7%), anxiety (22.0%), and overall pain (20.7%). IDT members also shared information about problems with patients not administering pain medication (20.4%); however, there was only one discussion about a problem with a caregiver not administering pain medication.

Discussion

Although observations were extensive over a significant period of time, this study is limited by size of the sample. It represents only one hospice program. Additionally, it is a sample which is from a rural area and there is no ethnic or racial diversity as 100% of the sample was non-Hispanic Caucasian. For these reasons no generalizations should be made to hospice teams in general, rather the findings only lend direction in opportunity for further study.

The first research question referred to the perceptions of hospice caregivers related to the administration of pain medication. Although there was no significant change in the caregiver perceptions over time as measured by the instrument score or subscales, the overwhelming majority of caregivers expressed agreement with at least one statement that indicates some reservations or misinformation regarding pain management or medication administration. Team discussions were assessed relating to regarding caregiver concerns with pain of any type. Analysis showed that 20% of the patients were experiencing various pain issues. However, when the data were mixed, these findings indicate that while caregivers are having concerns related to pain management and these concerns are either not identified by the team or not discussed in team meetings, even though more than a third of the discussion time was related to pain issues and 20% of the patients were experiencing pain concerns.

The second research question explored how perceptions change during the course of a hospice stay. A significant change in perception was identified, and this change indicates that caregivers may have more problems with pain management as the patient care moves closer to death and the care demands increase. This increasing caregiver concern is in spite of an expanding length of time in hospice and an increased presence by the hospice staff. Despite the increasing concern over time related to pain issues, the pain talk of the hospice team related to caregiver concerns was absent.

The final research question revealed that nurses are the primary team members who report and discuss pain in hospice IDT meetings. This finding is not surprising given that nurses dominate information sharing in IDT meetings [29,30]. The nurse's background in physical medical care, in addition to the role of case manager, sustains a large speaking role in the IDT meeting. Likewise, the physical elements of pain dominated the nursing contribution and pain talk in general. The prominent focus on physical pain, relative to other dimensions of pain (psychological, spiritual, and social) are questionable given the goals of hospice and the management of total pain, illustrating potential barriers to adequate management of all domains of pain.

Although discussion of physical pain dominated patient reports, nurses also commented on psychological and spiritual pain. While these contributions are important, some would expect these issues to be the central focus of disciplines such as social work or chaplains, whose training is on these dimensions. Pain talk contributions by other hospice IDT members are perhaps limited by the nurse's primary role as reporter. As a result, varying dimensions of pain appear to be not adequately addressed by experts in the field as represented on the hospice IDT team. Perhaps due in part to these dynamics, this study found no mention of social aspects of pain in the hospice IDT meeting.

With specific regards to information sharing about the role of the caregiver during pain talk, the normative practice did not include a discussion of the caregiver in administering pain medication, despite team members being aware that this research was focusing on caregiver pain concern. Rather, talk about the role of the caregiver was shared only in certain instances, typically to report good care provided by the caregiver. In rare instances caregiver information was shared to document inconsistent care or evidence for inadequate pain regimen (e.g. caregiver's possible substance abuse). Data from this study found that 67% of pain talk reported by nurses did not mention the caregiver. Although limited, pain talk contributions by other team members also indicate a lack of attention to the role of the caregiver.

Implications

The results of responses from the CPMQ are consistent with findings from other studies which have found similar results. Other researchers have found similar results with between 46 percent and 94 percent of caregivers reporting as least some agreement with various concerns to reporting pain and using analgesics [19,31]. The unique aspect of this study is the follow-up observations of the hospice team during active case discussion and the care planning process. These findings indicate opportunity for hospice teams to systematically assess the perceptions of caregivers toward pain management as a part of their discussion and care plan. The findings revealed by mixing of the qualitative and quantitative data indicate that not only do caregivers continue to have issues related to pain management, but hospice teams do not seem to routinely address these concerns. Given the hospice philosophy regarding total pain, and the attention of the patient/family unit of care, the data demonstrate that hospice teams are not discussing the perceptions or concerns of caregivers related to pain management and suggest they may benefit from such discussions.

Likewise, it is clear not only from the results of this study but also others [19,31] that caregivers need specific education related to pain management issues. Since hospices rely on family caregivers to provide ongoing care, and consider the patient and family a unit of care, they have the responsibility in educating and supporting them. Hospices are in a perfect position to routinely educate caregivers on the influence of psychological, social, and spiritual factors on pain and the myths of pain management in an effort to ease caregiver anxiety and fear, promote adherence to medication regimens. Further research of a targeted caregiver educational intervention should be assessed for its potential impact on patient reports of pain.

These findings also indicate that nurses may be assuming some of the responsibility for psychosocial and spiritual care which could be more appropriately addressed by social workers and chaplains. The findings imply that hospice care might be enhanced with a systematic assessment of caregiver concerns related to patient pain and provide the team, as a whole, with valuable information by sharing these assessments and developing plans of care to address those issues. If hospice teams must rely on nurses to conduct and report all assessments and provide the interventions for all team members, then the communication of total pain concepts and input by all disciplines at team meetings needs to be more explicit. Pain talk in hospice teams should reflect the total needs of the patient and caregiver as well as the interdisciplinary work of all of the members.

Further research is needed before generalizations can be made outside this particular hospice team. The second phase of this work will bring the patient and family caregiver into the IDT meeting by videophone technology. The impact of the direct contact with the team may change the content of pain talk and this aspect will be of particular interest in our research. These preliminary findings however, offer direction for the future study of barriers to adequate pain management and the testing of interventions to overcome these concerns and improve hospice care.

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Table 1

Summary Demographic Variables Patients and Caregivers

Variable	**Caregiver**	**Patient**
Diagnosis	Not applicable	
Cancer		60% (18)
No cancer		40% (12)
Discharge reason	Not applicable	
Death		46.7% (14)
Withdrew		6.7% (2)
Entered nursing home		10% (3)
Still active		36.7% (11)
Mean hospice length of stay	Not applicable	56 days
Mean length of stay in study		41 days
Mean Age	60 years	77 years
Sex		
Male	13% (4)	15 48%
Female	87% (27)	16 52%
Marital status		
Never married	3% (1)	7% (2)
Widowed	3% (1)	48% (15)
Divorced	19% (6)	6 % (2)
Married	71% (22)	39% (3)
Race- white	100%	100%
Education		
Less than high school	10% (3)	37% (11)
High school	19% (6)	24% (7)
Some college	45% (14)	21% (6)
Undergrad	10% (3)	10% (3)
Graduate	10% (3)	6.0% (2)
Unknown		3% (1)
Employment status		Not applicable
None outside of home	71% (22)	
Full time	13% (4)	
Part time	6% (2)	
Volunteer	6% (3)	
Relationship to patient		Not applicable
Spouse/partner	32% (10)	
Adult child	39% (12)	
Other	29% (9)	
Other caregiving responsibility		Not applicable
No one else	55% (17)	
Yes, I care for someone else	42% (13)	

Table 2

CPQM Mean Total and Summary Subscale Score

CPQM	**Admission** **_n_=31**	**Time #2** **_n_=19**	**Time #3** **_n_=8**	**Time #4** **_n_=5**
Total	3.22	2.89	3.09	3.19
Reporting	3.3	3.24	3.31	3.35
Fatalism	3.32	3.32	3.19	3.20
Stoicism	3.28	3.21	3.44	3.55
Administration concerns	3.18	2.87	3.05	3.14
Addiction	3.08	2.93	3.0	3.07
Tolerance	3.22	2.92	3.19	3.2
Side effects	3.22	2.74	2.96	3.4
Administration difficulties	3.10	2.98	2.91	3.19

Table 3

Pain Type Addressed in Pain Talk by Speaker[a]

	Physical *n*	Psychological *n*	Spiritual *n*	Social *n*	Total *n*
Medical Director	20	7	0	0	27
Nurse	119	28	3	0	150
Social Worker	14	5	0	0	19
Chaplain	11	2	0	0	13
Other	11	6	0	0	17
Total	175	48	3	0	230

n indicates number of utterances by speaker.

[a] Four observations did not include a discussion of patient pain.