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Pain Reports by Older Hospice Cancer Patients and Family Caregivers: The Role of Cognitive Functioning

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Abstract

Purpose—Prior research in nursing homes has shown that cognitive impairment may reduce self-reported pain, but this relation has not been systematically explored among hospice patients. The assessment and treatment of pain is a primary goal of hospice care, and both disease processes and the use of opioid analgesics may lead to cognitive impairment among hospice patients. However, little is known about how cognitive functioning may impact the self-report of pain or the report of care recipient pain by family caregivers.

Design and Methods—We explored the associations between pain, cognitive functioning, and gender among cancer patients and their family caregivers (*N* = 176 dyads) during in-home hospice care. This was a cross-sectional, correlational study.

Results—Contrary to expectation, care recipients with cognitive impairment reported more intense pain than care recipients with intact cognitive functioning. However, cognitive impairment among care recipients had no impact on the pain report of family caregivers. Care recipient cognitive impairment was related to greater discrepancy in the pain reports of caregivers and care recipients. No gender differences in pain intensity report were found.

Implications—Measurement issues and implications for assessing self-reported pain among hospice cancer patients with impaired cognitive functioning and the report of care recipient pain by family caregivers are discussed. Specifically, hospice staff must educate family caregivers regarding the potential impact of care recipient cognitive impairment on pain reports in order to facilitate accurate pain assessment and management.

Keywords

Pain; Hospice; Cognitive impairment; Cancer

The need to alleviate pain while caring for individuals at the end of life has become a national health concern. From 1992 to 1998, the number of Medicare beneficiaries enrolling in hospice care more than doubled to nearly 360,000 (U.S. General Accounting Office, 2000). The percentage of dying patients receiving hospice care may be close to 40% when the number of

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deaths nationally is adjusted to reflect only individuals appropriate for hospice (Mahoney, 1998).

Notably, more than 50% of terminal cancer patients have physical suffering that requires sedation in the last days of life (Fainsinger, Miller, Bruera, Hanson, & Maceachern, 1991). However, Kaiser and Brock (1992) found that approximately 20% of elderly decedents with cancer as the cause of death were in moderate to severe pain 6 hours before they died. The treatment of pain is a primary goal of hospice care, and a majority (75%–94%) of hospice patients experience pain (Bonneh & Shvartzman, 1997; McCarthy, Addington-Hall, & Altmann, 1997). Being pain-free and having adequate symptom control are integral components of hospice patients' definition of "a good death" (Payne, Hillier, Langley-Evans, & Roberts, 1996). Even high-quality hospice care, however, fails to eliminate pain in up to 75% of cases (McMillan & Tittle, 1995; Zeppetella, O'Doherty, & Collins, 2000). In a study of hospice patients with cancer, pain relief was not optimal, with 42% of patients reporting only one half or less of their pain relieved (McMillan, 1996).

Pain may be expressed as: (a) *neuropathic pain*— pain experienced as numbness or tingling in the nervous system, (b) *somatic pain*—pain experienced in the musculoskeletal system, and (c) *visceral pain*—pain experienced in the bones of the pelvis, ribs, or sternum. Zeppetella and colleagues (Zeppetella et al., 2000) found that, among cancer patients admitted to hospice, breakthrough pain was classified as: somatic, 46%; visceral, 30%; neuropathic, 8%; and mixed etiology, 16%. The terminal disease process and some end-of-life medical treatments may intensify affective and physical components of the pain experience, leading to acute exacerbations of pain. Episodic pain, or pain that varies with time, is common among hospice patients with cancer (Swanwick, Haworth, & Lennard, 2001).

Because pain is a subjective experience, including affective and sensory components, the Acute Pain Management Guideline Panel (1992, 1994) has stated that the single most reliable indicator of acute and postsurgical pain is a person's self-report. The presence of cognitive and sensory deficits, however, may hamper an individual's ability to communicate painful experiences (Farrell, Katz, & Helm, 1996; Horgas & Baltes, 1994; Jancar & Speller, 1994). For example, cognitively impaired nursing home residents are less likely to be identified by health care professionals as suffering from pain (Sengstaken & King, 1993). They are also less likely than their cognitively intact peers to report pain or to receive analgesic medication even when diagnosed with conditions known to be painful, including cancer (Bernabei et al., 1998; Farrell et al., 1996; Horgas & Tsai, 1998; Kaasalainen et al., 1998; Parmelee, Smith, & Katz, 1993; Won et al., 1999). Weiner and colleagues (Weiner, Peterson, Logue, & Keefe, 1998) found that cognitive impairment was related to lower test-retest agreement and greater 4-week variability in intensity of self-reported pain using a 10-point visual analogue scale and a pain thermometer. The authors found that nursing home residents with higher Mini-Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975) scores reported greater pain intensity, and that residents with MMSE scores of 22–26 were more likely to show test-retest disagreement than residents with MMSE less than 22 or MMSE greater than 26. High scores on the MMSE indicate better cognitive functioning.

Although only 5% of hospice patients have a primary diagnosis of dementia (National Hospice and Palliative Care Organization, 2001), terminally ill individuals are at risk for various types of cognitive impairment. These include not only dementia, but also confusion associated with opioid dosage escalation (Mercadante, Dardanoni, Salvaggio, Armata, & Agnello, 1997), delirium (Lawlor, Fainsinger, & Bruera, 2000), and brain metastases. Martin (1990) found that confusion was common during hospice care, but that neuropsychiatric problems went unrecognized and untreated, and frequently resulted in disturbing, violent, and disruptive patient behavior. Radbruch and colleagues (2000) found that, among older palliative care inpatients, 35% were cognitively impaired using a cut-point of 20 on the MMSE.

Reliance on the self-report of pain as the sole indicator of a hospice patient's pain experience may be further complicated by gender differences in the response to pain and its treatment. There even may be gender differences in the type of pain experienced. Among cancer patients, Mercadante and colleagues (Mercadante, Casuccio, Pumo, & Fulfaro, 2000) found that, in the last 4 weeks of life, visceral pain was more frequently reported among women, whereas men more frequently reported somatic pain. Neuropathic pain was equally reported across gender. Mercadante and colleagues (Mercadante et al., 1997) found that female gender reduced opioid escalation during the 6 weeks before death. Yeager and colleagues (Yeager, Miaskowski, Dibble, & Wallhagan,1997) reported that women who were oncology outpatients had more knowledge about pain and pain management. In noncancer research, women typically report higher levels of pain and physical disability, exhibit more pain behaviors, and are more likely to catastrophize in response to the pain experience (Dixon, 2001; Keefe et al., 2000; Stroud, Thorn, Jensen, & Boothby, 2000; Thorn, Rich, & Boothby, 1999). Coward and Wilkie (2000), however, found no clear gender differences in pain report among cancer patients with bone metastases. Likewise, Petzke, Radbruch, Zech, Loick, and Grond (1999) found that gender, age, tumor site, stage of cancer, and therapy were not related to the presence of transitory pain.

Given that cognitive functioning and gender differences may affect a person's self-report of pain, caregivers are commonly used as proxies for obtaining pain reports in clinical settings (Fisher et al., 2002; Krulewitch et al., 2000; Parmelee, 1994, 1996; Weiner, Peterson, & Keefe, 1999). Hospice staff routinely rely on the report of family caregivers regarding care recipients' symptoms, including pain intensity (Weitzner, Moody, & McMillan, 1997). Yet family caregiver reports of care recipient pain correspond poorly to the patients' self-reported pain experience (Brescia, Portenoy, Ryan, Krasnoff, & Gray, 1992; Gaston-Johansson, Franco, & Zimmerman, 1992). Elliott and colleagues (Elliott, Elliott, Murray, Braun, & Johnson, 1996) found that family caregivers consistently reported greater hospice patient pain and disability than did the patients themselves. Interestingly, cognitive status of the care recipient was associated with caregiver report, but not self-report, of pain in this study. Prior research suggests that the quality of communication among terminally ill individuals, their caregivers, and hospice staff influences patient and caregiver outcomes (Beach, 1995; Hull, 1991). Thus, it is of vital importance to examine the potential impact of care recipients' cognitive impairment and gender on the relation between self-reported and caregiver-reported pain during hospice care.

This study examined the relation of hospice cancer patient self-reported pain, family caregiver report of care recipient pain, discrepancies between care recipient and caregiver pain report, and care recipient cognitive functioning and gender. Our specific hypotheses were as follows. First, we hypothesized that more cognitive errors made by care recipients on a cognitive screening instrument would be associated with lower self-reported pain, but not with care recipient pain as reported by caregivers. Second, we proposed that care recipient cognitive impairment would moderate the relation between self-reported pain and caregiver-reported pain (Farrell et al., 1996; Parmelee et al., 1993; Weiner et al., 1998). We proposed that care recipients with intact cognitive functioning would show higher concordance between their report of pain and their caregivers' report of their pain. Care recipients with evidence of impaired cognitive functioning, however, were predicted to show a lower degree of association between their self-report of pain and the pain report of their family caregivers (Brescia et al., 1992; Gaston-Johansson et al., 1992; Weiner et al., 1998). Furthermore, we predicted that care recipients would consistently report less intense pain than would their caregivers (Elliott et al., 1996). Our third and final hypothesis was that female care recipients would report more intense pain than male care recipients (Dixon, 2001; Keefe et al., 2000; Thorn et al., 1999; Yeager et al., 1997).

Methods

Settings

The sample for this study was drawn from the second largest hospice in the United States, a community-based, nonprofit agency serving a four-county area in the state of Florida with an average daily census of 1,000 patients. The average length of stay is 83 days, whereas the median length of stay 25 days. This hospice subscribes to the mission and goals of the National Hospice and Palliative Care Organization, providing community-based care with a ratio of one registered nurse for every 11 patients. Sixty-two percent of patients are admitted with a primary cancer diagnosis.

In 1998, Florida was 1 of the 5 states reporting the highest use of hospice services (29%; U.S. General Accounting Office, 2000). In comparison with national averages, participants in this hospice program have slightly longer lengths of stay (national average = 59 days in 1998; median length of stay 19 days) and a slightly higher tendency to be admitted with a primary cancer diagnosis (national average = 57.4%; U.S. General Accounting Office, 2000).

Participants

Care Recipients—Participants (*N* = 226) were approached for enrollment in a clinical trial designed to improve the quality of life of cancer patients and their family caregivers receiving hospice care in the home. This trial focuses on symptom management in each of three areas: (a) pain, (b) dyspnea, and (c) constipation. These symptoms are common among terminal cancer patients; care recipients were required to exhibit 2 of the 3 symptoms to be included.

Care recipients were entered into the clinical trial based on the following additional criteria: (a) presence of a diagnosis of terminal cancer, (b) age at least 18 years, (c) presence of a family caregiver, (d) evidence of ability to respond to brief mental status screening on the Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1975) with a minimum score of six correct responses, (e) ability to give informed consent, (f) at least a sixth-grade education, (g) English-speaking, and (h) Karnofsky Performance Status (KPS; Karnofsky & Burcheral, 1949) score greater than 40 as rated by a home health aide. It is important to note that 23 care recipients were excluded from participation in the clinical trial because of cognitive impairment, defined as a score of 5 or lower on the SPMSQ. A further criterion for inclusion in this study was the presence of pain in the care recipient (*N* = 191), reported either by the care recipient or the family caregiver at the time of the initial assessment. Finally, 15 (7.9%) persons were lost because of missing or incomplete data. Comparisons between those with or without complete data revealed no significant differences in terms of caregiver age, gender, race, or years of education. Among the care recipient characteristics, no differences were present for age, gender, or years of education. However, care recipients who were eliminated because of missing data had significantly poorer SPMSQ scores in relation to those with complete data (7.66 vs. 9.02, respectively; $F(l,189) = 25.10$, $p < .001$). In addition, there were proportionally more White patients among the individuals with complete data, compared with those with missing information (84.6%, 58.3%, respectively; $\chi^2(1) = 5.51$, $p<.05$).

One hundred and seventy-six care recipients met all eligibility criteria and received preintervention assessment. The most frequent cancer diagnoses included lung (33.0%), colon (15.3%), prostate (8.5%), pancreatic (6.3%), and breast (4.5%). The average length of time since diagnosis was 30.30 months (*SD* = 54.99 months, Range 0–360). The average age of care recipients was 70.69 years (*SD* = 11.34, Range 37.79–95.62). Their average level of education was 12.01 years (*SD* = 3.27, Range 1–25), and 42.6% were female, 84.7% were White, 7.4% African American, and 6.8% Hispanic (in 1998, 89% of hospice enrollees were White; U.S. General Accounting Office, 2000). Their average score on the SPMSQ was 8.93 correct responses (*SD* = 0.96, Range 6–10). Sixty-eight individuals (38.6%) scored between 6 and 8 correct responses on the SPMSQ, indicating impaired cognitive functioning (Erkinjuntti, Sulkava, Wikström, & Autio, 1987). Care recipients scoring 9 or greater correct responses on the SPMSQ were considered to have no indication of cognitive impairment. The average KPS score of care recipients was 55.34 (*SD* = 8.55, Range 40–100), and their average activities of daily living index (ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) was 4.01 (*SD* = 3.41, Range 0–12).

Caregivers—For entry into the study, referred caregivers were required: (a) to not be in active treatment for cancer themselves, (b) to evidence the ability to respond to brief mental status screening on the SPMSQ (Pfeiffer, 1975), with a minimum score of 8 correct responses, (c) to be able to give informed consent, (d) to have at least a sixth-grade education, and (e) to be English-speaking. A higher threshold on the SPMSQ was required for inclusion of caregivers in comparison with care recipients due to the need for caregivers to complete a complex intervention regimen.

One hundred and seventy-six primary caregivers met all eligibility criteria and received preintervention assessment. None of these caregivers had to be excluded based on cognitive impairment, defined as a score of 7 or less on the SPMSQ. Their average age was 63.23 years (*SD* = 14.06, Range 23.98–91.90). Their average level of education was 12.59 years (*SD* = 2.71, Range 4–22), 73.9% were female, 85.8% were White, 6.8% were African American, and 6.3% were Hispanic. Their average score on the SPMSQ was 9.64 correct responses (*SD* = 0.59, Range 8–10). Sixty-six percent of family caregivers were spouses of the care recipient, 17% were adult children, 17.1% were other relatives.

Design and Procedures

All data used in this study were collected as part of the preintervention phase of the larger study (McMillan, 1995; PI, R01CA77307). A registered nurse and a home health aide with hospice experience were employed by the project to collect assessment information with the care recipient/caregiver dyad in the home. Initial assessment interviews were conducted no more than 48 hr after admission to hospice. A bulleted descriptive overview was given to the caregiver and care recipient, and the project was fully explained prior to obtaining informed consent. The RN then interviewed the caregiver while the home health aide interviewed the care recipient.

Screening and Demographic Measures

SPMSQ (Pfeiffer, 1975)—This simple 10-item test of remote memory, knowledge of current events, and mathematical ability screens for gross cognitive impairment. For purposes of this study, the instrument was scored for the number of correct responses. Erkinjuntti, Sulkava, Wikström, & Autio (1987) found that, using a cutoff of eight correct responses and two errors, the sensitivity was 100% and specificity was 89.1% for dementia and 73.2% and 89.1%, respectively, for delirium.

The SPMSQ was originally standardized and validated using adjustments for race and education with community-residing older adults, individuals referred to a multipurpose clinic, and persons residing in congregate living facilities (Pfeiffer, 1975). However, more recent data suggest that it is not necessary to adjust for education in scoring (Erkinjuntti et al., 1987). Additionally, adjusting scores on other cognitive screening instruments based on race or level of education is controversial and is likely to reduce rather than improve sensitivity and specificity (Ford, Haley, Thrower, West, & Harrell, 1996; Kraemer, Moritz, & Yesavage, 1998). Thus, we do not make scoring adjustments based on education or race in the current study.

KPS (Karnofsky & Burcheral, 1949)—The KPS is a measure of functional status that is widely used in cancer research and oncology settings to assess patient functioning. The KPS is scored on a scale from 0 (dead) to 100 (normal functioning). The KPS has been shown to have moderately high interrater reliability (r = .66–.69; Yates, Chalmer, & McKegney, 1980). In the current study, the home health aide who interviewed care recipients assigned the KPS score.

ADL Index (Katz et al., 1963)—This index assesses six activities involving independence in self-care, including bathing, dressing, toileting, transfer, continence, and feeding. The measure has high interrater reliability, as evidenced by agreement of over 95% between professional raters (Lowenstein & Mogosky, 1999). There is also good evidence for criterion-related and construct validity as indicated by associations with mobility impairment and house confinement following hospital discharge, and significant associations with measures of cognitive and functional abilities (Lowenstein & Mogosky, 1999).

Care Recipient Demographics—Standard demographic data were gathered: age, gender, education level, cancer diagnosis, and length of time since diagnosis.

Caregiver Demographics—Standard demographic data were gathered: age, race, gender, and education.

Outcome Measures

An 11-point numeric rating scale (NRS) was used to assess care recipient pain intensity as reported by the care recipient and the family caregiver at the time of the initial assessment. Participants were asked to respond verbally with a number between 0 (no pain) and 10 (worst pain) to rate pain intensity at that moment (McGuire, 1984; Stewart, 1977). Investigators have found that patients prefer to use the 0–10 NRS rather than other pain rating scales because the scaling is understandable (Kremer, Atkinson, & Ignelzi, 1981). The NRS correlates well with other measures of pain intensity (r = .59–.86; Kremer et al., 1981) and was found to be a more sensitive predictor than other measures in comparison with a behavioral rating scale for pain (Jensen, Karoly, & Braver, 1986). Discrepancies in pain report were calculated by subtracting the caregiver’s report of patient pain from the patient’s own self-report of pain. Thus, high positive scores indicate more intense pain reported by the patient, high negative scores indicate more intense pain reported by the caregiver, and scores near zero indicate small discrepancy in the report of pain by patients and caregivers.

Results

Descriptive Statistics

The sample size for all of the analyses was 176, as listwise deletion was used on the data. We did not utilize any missing data imputation procedures in the current dataset. The pain scores were assessed for distributional properties, and no severe problems with variate normality were detected (skewness = .6; kurtosis = −.55).

The associations among the study variables are reported in Table 1. More intense self-reports of pain among care recipients were associated with more intense reports of care recipient pain by the family caregiver. Care recipient self-reported pain was also significantly associated with lower SPMSQ score and lower education. Contrary to expectation, better cognitive functioning was associated with self-reports of less intense pain. As shown in Table 1, the number of years of education of the family caregiver was associated with a number of study variables, including caregiver report of less intense care recipient pain.

Cognitive Functioning and Self-Report of Pain

Our first hypothesis was that care recipients with impaired cognitive functioning would report less intense pain than would care recipients without evidence of cognitive impairment as measured by the SPMSQ. In contrast, we found that the care recipients answering fewer than nine items correctly reported significantly more intense pain in the moment ($M = 3.62$, $SD = 3.18$) than did their peers with higher SPMSQ scores ($M = 2.73$, $SD = 2.52$), $F(1,174) = 4.21$, $p = .042$. Caregivers of care recipients with impaired cognitive functioning, however, did not differ in their report of care recipient pain ($M = 4.78$, $SD = 2.56$) in comparison with caregivers of care recipients without cognitive impairment ($M = 4.41$, SD = 2.21).

Cognitive Functioning and Discrepancy in Pain Report

Second, we hypothesized that care recipient cognitive impairment would moderate the relation between care recipient self-report of pain and caregiver report of care recipient pain. In comparison with caregivers ($M = 4.55$, $SD = 2.35$), care recipients reported experiencing significantly less pain ($M = 3.07$, $SD = 2.82$; $F(1,175) = 39.36$, $p < .001$). Furthermore, 29.5% of care recipients reported no pain when caregivers reported they had pain; only 3.4% of caregivers reported the care recipient had no pain when he or she reported pain. This discrepancy represents an absolute difference in pain report between care recipients and caregivers, not a difference in magnitude. Greater discrepancy between care recipient and caregiver reports of care recipient pain was significantly associated with lower SPMSQ scores among care recipients (see Table 1).

Regression analyses showed that cognitive impairment had a direct effect on self-report of pain when controlling for the effects of care recipient education, $t(175) = -2.68$, $p = .008$, standardized beta = −.20, but the model only accounted for 8.4% of the variance, $F(2,173) = 7.44$, $p = .001$. However, the quadratic term for the SPMSQ did not account for significant unique variance in self-reported pain after controlling for care recipient education and the linear SPMSQ term. The quadratic SPMSQ term should be significant if the relation between self-reported pain and cognition becomes stronger as cognitive impairment increases. In contrast, the better the care recipient’s cognitive functioning, the less intense was the care recipient’s self-report of pain.

Self-Report of Pain and Gender

Our third hypothesis was that women with cancer and receiving hospice care would report more intense pain than would men with cancer and receiving hospice care. Examination of the bivariate correlations in Table 1, however, reveals no significant correlations between gender of the care recipient and their self-report of pain.

Discussion

This study extends prior research by examining self-reported pain, caregiver-reported care recipient pain, and the impact of cognitive functioning among care recipients on pain reports of cancer patients and their family caregivers during hospice care in the home. The treatment of pain is a primary goal of hospice care, but enactment of this goal can be complicated by communication breakdown between care recipients, caregivers, and hospice staff. Communication impairments are more likely to occur in the context of care recipient cognitive impairment, even when this impairment is mild. Cancer patients in hospice may suffer from cognitive impairments resulting from brain metastases, opioid intoxication, severe depression, delirium, and dementia. Thus, to promote the treatment goal of effective pain management, the relation between pain self-report, caregiver pain report, and cognitive functioning among hospice care recipients must be better understood.

Our first goal in this study was to examine the relation between care recipient self-report of pain and cognitive functioning. Contrary to research investigating pain self-report among cognitively impaired nursing home residents, we found the care recipients with cognitive impairment in this sample reported more intense pain than their cognitively intact counterparts. Interestingly, Frisoni and colleagues (Frisoni, Fedi, Geroldi, & Trabucchi, 1999) found that symptom report among community-dwelling individuals older than age 75 increased with cognitive impairment. Several possible explanations for this finding exist. First, as disease severity increases, it is possible that cancer patients experience both greater pain and greater cognitive impairment. Second, the cognitive impairment experienced by the cancer patients in this sample could have been relatively mild and may have functioned to release patients' inhibitions about reporting pain experienced in the moment. In contrast, nursing home residents with dementia may have communication deficits, making them less likely to report experiencing pain in the moment. Third, the etiology of cognitive impairment may influence the verbal and behavioral expression of pain. This idea would be interesting to explore in future hospice research, with care recipients suffering from diverse illnesses, including cancer, Alzheimer's disease, vascular dementia, AIDS dementia, and delirium.

As hypothesized, cognitive functioning among care recipients did not impact the pain report of their caregivers. In other words, caregivers of patients with cognitive impairment reported the same amount of care recipient pain as did caregivers of patients without cognitive impairment. It could be that family caregivers rely more heavily on nonverbal behavioral cues to their care recipient's experience of pain. Family caregivers' observation of nonverbal pain behaviors exhibited by their patient may thus provide more accurate, albeit discrepant, pain reports. In a recent study of pain reports by cognitively impaired adults in the community and their caregivers, Krulewitch and colleagues (Krulewitch et al., 2000) found that the Hospice Approach Discomfort Scale, a tool based on observed pain behaviors, did not correlate well with other measures. Future studies need to further explore the associations between the pain reports of hospice care recipients, their family caregivers, and behavioral indicators of care recipient pain.

Our second goal in this study was to examine the impact of cognitive functioning among care recipients on the relation between care recipient self-report of pain and the family caregiver's report of care recipient pain. Care recipient and family caregiver pain reports were only modestly associated (7.8% shared variance), indicating a high degree of variability in the assessment of care recipient pain. We found that only 3.4% of caregivers reported their care recipient had no pain when the care recipient reported pain, but that more than 29% of care recipients reported no pain when their caregivers reported them to be in pain. Consistent with other studies (Elliott et al., 1996), we found that cognitive impairment among care recipients was associated with greater discrepancy between the pain reports of care recipients and their family caregivers (i.e., higher pain reports by family caregivers relative to the patient's own self-report of pain).

This finding supports the notion that pain assessment and management during hospice care may be hampered by cognitive impairments in hospice patients. Such discrepancies in pain report may decrease the confidence hospice staff place in a care recipient's self-report, but at this time it is unclear at which level of cognitive impairment the validity of self-report becomes questionable. As in other clinical settings (Fisher et al., 2002; Krulewitch et al., 2000; Weiner et al., 1999), we recommend consideration of proxy pain report by caregivers in conjunction with hospice care recipients' self-report of pain. Such comprehensive assessment will aid in the development of pain treatment programs during hospice care.

Our third goal was to examine gender differences in the pain report of cancer patients receiving hospice care. Previous research has shown that women and men may experience the affective and sensory components of pain differently (Dixon, 2001; Keefe et al., 2000; Mercadante et al., 1997; Thorn et al., 1999). Physiological differences may be partially due to the differential etiology of cancer among men and women. However, women are typically more knowledgeable about pain and symptom management and more emotionally reactive to pain. We found no evidence of gender differences in the report of current pain intensity in this sample.

Several limitations of this study are acknowledged. First, these data were collected as part of a larger intervention study designed to improve symptom management for care recipients and decrease distress among family caregivers of cancer patients receiving hospice care in the home. Thus, exploration of the relation between care recipient cognitive impairment and self-report of pain in relation to family caregiver report of care recipient pain was never intended to be a primary outcome of this study. Indeed, care recipients were excluded on the basis of moderate cognitive impairment (Pfeiffer, 1975).

It is also possible that pain may have been a more salient issue to our participants in comparison with other hospice patients, given that our participants had consented to an intervention focused on symptom management, including pain. Thus, our participants may have reported more intense pain than would the hospice patient population in general. However, pain management was only 1 of 3 target symptoms (i.e., dyspnea, constipation) of this clinical intervention trial, and 75%–94% of all hospice patients experience pain (Bonneh & Shvartzman, 1997; McCarthy et al., 1997). Thus, it is our contention that most hospice patients find pain a very salient issue, with the absence of pain being central to conceptualizations of a good death (Payne et al., 1996).

In summary, these findings replicate and extend prior research by illuminating the associations between cognitive impairment and pain report during in-home hospice care. Future longitudinal research is needed to examine the impact of care recipient cognitive impairment on self-reported pain and caregiver-reported care recipient pain over time. Such investigations will inform the development of educational interventions in pain management for use by hospice staff with family caregivers.

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Table 1

Pearson Product-Moment Correlations

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Care recipient pain															
2. Caregiver pain	.28***														
3. Pain discrepancy	.69***	−.51***													
4. CR age	−.11	−.27***	.10												
5. CR race	.05	−.04	.08	.04											
6. CR gender	−.08	.06	−.12	−.08	−.10										
7. CR education	−.21**	−.13*	−.10	−.15*	−.05	.03									
8. CR Karnofsky	−.06	.12	−.04	−.01	.03	−.07	−.13								
9. CR ADL	−.04	−.15*	.08	.05	−.01	.09	.15*	−.78***							
10. CR SPMSQ	−.25**	−.07	−.17*	.01	−.12	−.06	.18**	.07	−.09						
11. CG age	−.06	−.14	.06	.29***	−.06	−.08	.02	.07	−.02	−.08					
12. CG race	.01	−.08	.07	−.02	.71***	−.13	−.03	.03	−.02	−.18*	−.07				
13. CG gender	−.02	−.02	.00	.04	.09	−.59***	−.05	.01	−.06	.10	−.14	.12*			
14. CG education	−.03	−.20**	.13	.04	−.11	.07	.22**	−.14	.12	−.13	−.19*	.04	−.05		
15. CG SPMSQ	−.03	−.05	.07	.18*	.00	.08	.08	−.02	.07	−.11	−.04	.00	−.13	.14	

Note: CR = care recipient; CG = caregiver; ADL = activities of daily living; SPMSQ = Short Portable Mental Status Questionnaire.

* $p<.05$;

** $p< .01$;

*** $p < .001$.