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Original Research Article

The Relationships among Pain, Nonpain Symptoms, and Quality of Life Measures in Older Adults with Cancer Receiving Hospice Care

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Abstract

Objective. Gathering firsthand or reported information about patients in the final stages of terminal cancer is difficult due to patient frailty, cognitive impairment, excessive fatigue, and severity of illness, as well as gatekeeping by hospice providers and caregivers, and highly variable documentation practices. We sought to further understand and elucidate end-of-life experiences in older cancer patients through the application of validated tools employed in the hospice setting. This article summarizes data collected about pain, non-pain symptoms, and other aspects of quality of life (QOL) as reported by older hospice patients or by their caregivers during the 2 weeks of hospice care.

Design. Data was collected from an ongoing Institutional Human Subjects Review Board-approved research project with 94 older adults with cancer or their caregivers receiving service in a home setting from 14 Midwestern hospices. Participants completed one or two telephone interviews. Instruments used to gather information include the Brief Pain Inventory and the Brief Hospice Inventory.

Results. Data analysis showed mean "worst pain" ratings significantly decreased from Interview 1 to Interview 2, and pain reports were significantly correlated with fatigue, anxiety, appetite, comfort, symptom control, and overall QOL.

Conclusions. Our findings reinforce previously held views that older patients with cancer experience pain and non-pain symptoms. And both pain and non-pain symptoms can impact and confound the treatment of other symptoms and interfere with the patient's overall QOL. The results of this study support the assertion that hospice care can have a positive impact on pain severity and related suffering, as well as patient QOL as death approaches.

Key Words. Older Adult; Cancer Pain; Pain Assessment; Pain Management; Quality of Life; Hospice

Introduction

Background

In 2010, approximately 1.5 million Americans will be diagnosed with cancer—a complex set of often progressive and fatal diseases that increases with age and commonly results in pain, multiple other distressing symptoms, such as fatigue, weight loss, bleeding, etc, and deterioration in quality of life (QOL) [1]. Pain continues to be one of the most common symptoms associated with cancer, with up to 90% of patients experiencing pain during the course of their illness and 50–80% having poorly managed pain [2,3]. Additionally, 25–40% of cancer patients ages 65 and older will experience daily pain [4]. Fine and Busch [5] reported that breakthrough pain increases as cancer

progresses, and Zepetella et al. [6] corroborated this finding, reporting that 89% of cancer patients in a hospice setting experience breakthrough pain.

Cancer pain is multidimensional and multifaceted [7] and is directly associated with QOL. As defined by The World Health Organization (WHO), QOL represents individuals' perception of their "position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns" [8]. The WHO identifies six domains of quality of care including: physical, psychological, level of independence, social relationships, environment and spiritual [8]. For cancer patients, pain and symptom control is one of the best predictors of overall QOL scores as the effects of unrelieved pain and poorly managed symptoms have been shown to interfere with activities of daily living (ADLs), mood, mobility, and independence. When these factors are not attended to, QOL can be diminished [9,10]. Moreover, increased pain severity often mirrors increases in the occurrence of non-pain symptoms and greater pain interference [11].

Hospice programs strive to improve the QOL of dying patients through decreasing the distress caused by pain and non-pain symptoms [11–13]. Nearly 40% of hospice patients have a cancer diagnosis [14]. To address the needs of cancer patients at the end of life (EOL) and address issues related to pain, symptom control, and QOL, hospice care has increasingly become an essential part of the health care system [14,15]. Hospice teams aim to have pain adequately managed within the first 48 hours of admission, yet, as one approaches death, the ability to manage pain is often complicated by rapidly progressive disease, multiple comorbidities, and psychological and spiritual distress. The relatively short mean length of stay (approximately 7–10 days for patients with cancer) in the hospice setting causes additional challenges in managing symptoms. In 2007, the median length of stay for all hospice patients was 20.0 days, which increased to 21.3 days in 2009 [14]. Although prevalence data regarding cancer pain in older adults is available, information about pain and its impact on QOL in the hospice setting for this population is limited.

Obtaining information on pain and its association with non-pain symptoms in older adults with cancer in hospice is challenging. Some patients admitted to hospice are unable to offer self-reports of pain and QOL due to worsening disease processes, dementia, confusion, or other related reasons [6,16,17]. Consequently, the need for caregiver proxy reports and assistance with managing pain can increase as death approaches. Letizia et al. [16] found that 80% of their study participants were receiving caregiver support with pain management practices or pain reporting. While caregiver report is essential when the patient is unable to provide this information, caregivers have been found to overreport the pain and non-pain symptoms of patients. Allen and colleagues [18] found that 29% of caregivers reported that their loved ones were experiencing pain when the patient self-reported experiencing no pain. Although difficult to retrieve, efforts to obtain self-report even in patients with deteriorating conditions is a priority [19] and many are able to clearly describe pain and differentiate pain at different sites at the EOL [5,20]. Finally, highly variable documentation practices and the noted barriers to patient recruitment at the EOL add to the difficulty of retrieving data that are based on patient self-reports of pain and non-pain symptoms in the hospice setting [21,22]; and these challenges impact the methods used to gather direct information from older adults at the EOL.

While a closely related study has been conducted to explore patient experiences in inpatient hospice programs [23], few studies specifically focus on community-based hospice care [9,11,17,24]. For the purposes of this study, community-based hospice was defined as a setting where patients received hospice care in an environment that allowed the patient or their family caregiver to oversee the implementation of the pain treatment plan (e.g., personal home or assisted living facility). Furthermore, of the available studies that have examined the experiences of pain and QOL in community-based hospice settings, these studies have not specifically focused on older adults and include a wide range of ages. Steele et al. [17] conducted a similar study; however, while the mean age of their participants was 67.28 years, their study was not specifically focused on the experiences of older adults. Subjects' ages ranged from 30–89 years. Similarly, Lasheen et al. [24], Rustoen et al. [9], and McMillan and Small [11] studied subjects with ages ranging from 42–87, 28–88, and 37–95 years, respectively. Because of multiple factors in older adults that impact the experience of pain and associated symptoms (e.g., comorbities, polypharmacy, and cognitive and sensory impairment) findings in studies from younger or mixed populations cannot be generalized. Consequently, capturing the experiences of pain and QOL in older populations within community-based hospice settings remains a gap within the literature.

Based on the state of the existing literature, the purpose of this study was to examine the pain experiences and QOL of older patients newly admitted to community-based hospices in the Midwest. Interviews specifically examined these patients' pain experiences and respective QOL. The study examined the following research questions during the first 2 weeks of hospice care: 1) What is the experience of pain, pain severity, and pain interference for older adults with cancer in hospice as reported by the patient or by caregivers? 2) What is the experience of non-pain symptoms, overall QOL, and symptom control for older adults receiving hospice care? 3) Is there a change in pain, pain severity, pain interference, non-pain symptoms, QOL, and symptom control as reported by the older adult with cancer or her/his caregiver within 72 hours of admission and 2 weeks thereafter? 4) What is the relationship between pain and non-pain symptoms, overall QOL, and symptom control in older adults with cancer receiving care in the hospice setting? 5) Does a predictive relationship exist between pain severity, non-pain symptoms, overall

QOL, and symptom control following admission to a hospice?

Methods

A descriptive, correlational design was used to answer questions regarding the experience of pain, pain interference related to non-pain symptoms and impact on QOL in older adults with cancer receiving hospice care at home. Human subjects' approval was obtained from the Institutional Human Subjects Review Board (IRB) at The University of Iowa which served as the IRB of record for hospices without an internal IRB. Approval was obtained from the corresponding human subjects review boards at participating hospices with an internal IRB.

In the consent process, capacity for decision-making was determined through a series of structured questions that documented understanding of the study risks and benefits. If decision-making capacity was acceptable the patient was judged able to reliably complete the study instruments. If not, permission for the primary caregiver to complete the instruments as a proxy for the patient was obtained from the patient's legal guardian. All participants or their legal guardians provided verbal informed consent and completion of the study interviews was verification of their implied consent.

Sample

Patients or their caregivers (N = 94) in this study were part of a larger study [25–27] testing a multifaceted intervention to promote use of evidence-based practices (EBP) for pain management. Patients meeting the following criteria for inclusion in the study were invited to participate in the telephone interviews: 1) 55 years of age or older; 2) diagnosis of cancer; 3) newly admitted to a participating hospice; 4) receiving community-based hospice services in one of fourteen hospices in the Midwest. Four hundred thirty-five patients were identified by the participating hospices as meeting the established inclusion criteria. Ninety-four patients (22% of eligible patients) admitted during the study period in fourteen community-based hospices in the Midwest participated or had their caregivers serve as their proxy.

A total of 341 patients refused participation in the study. Reasons for refusing to participate included: lack of interest in participation (n = 76); health conditions too severe (n = 70); caregiver unwilling to assist patients with reporting (n = 45); patient was actively dying or died before recruitment call (n = 42); patient too fatigued to participate (n = 23); patient in the midst of a crisis situation (n = 16); patient confused (n = 12); patient lacked adequate time for participation (n = 11); patient unable to speak English (n = 2); hearing difficulties (n = 1); admitted to long term care facility (n = 1); or, patient did not answer repeated attempts to contact via telephone (n = 42).

Data Collection

Participating patients or their caregivers (if patients were unable to self report) were asked to complete two instruments via telephone interview within 72 hours of hospice admission (T^1) and again 7–10 days after the initial interview (T^2). Whenever possible, patients completed the interviews independently. If unable to self-report for any reason, then their primary caregiver served as a proxy reporter. We did not obtain caregiver reports and patient reports for each patient, rather a report was provided by either the patient or their proxy caregiver. Forty of the 94 patients participating completed the study instruments independently (43%). Forty-nine patients had primary caregivers serve as their proxy reporters (52%) and in five cases, the responses were a combination of patient and caregiver report (5%), with the patient completing the instruments at T^1 and the caregiver completing the instruments at T^2. A total of 94 patients or their proxy reporters completed the T^1 interview (within 72 hours of hospice admission). Of the participating patients or proxy reporters, 71 (76%) completed the study instruments again at T^2, 7–10 days after the initial interview. For those patients unable to complete the study, the most common reasons were death or admission to an institution, such as a long-term care facility or acute care facility. The average amount of time to complete the study instruments was approximately 15 minutes per patient (range10–40 minutes).

Patients and/or their caregivers received copies of all study instruments in a sealed envelope from hospice staff prior to the interview. Respondents were asked to follow along as the trained Research Assistant (RA) asked each question on the instruments and documented the response on a duplicate copy in the project office. Individual responses were entered by the RA into an Access database specifically developed for the study. A second RA entered a random sample of 10% of the instruments establishing inter-rater reliability of data entry at 94%.

Measures

Participating patients or their caregivers were asked to complete the Brief Pain Inventory (BPI) and the Brief Hospice Inventory (BHI) at two time periods during the first 2 weeks of the patient's hospice experience.

BPI

The BPI is a valid and reliable multidimensional pain instrument assessing pain history, intensity, location, and quality with excellent reliability across a large number of different cancer pain samples [28–31] and is relatively free of cultural and linguistic bias [32]. It also elicits information regarding pain treatment effectiveness and pain-related interference with daily activities, such as sleep, mood, and mobility among others. Pain intensity was evaluated using "worst pain" and "average pain" during the last 24 hours, and the pain interference subscale was used. Internal consistency of the 7-item pain interference subscale is acceptable, ranging from 0.86 to 0.92 [31,33,34].

Although developed for use with cancer patients, the BPI has been validated and is recommended for palliative care and geriatrics patients [30,35].

The BPI uses a numeric rating scale (NRS) approach that has been demonstrated reliable and valid for use with older adults, including those with mild to moderate cognitive impairment [31,36]. In this study, the Cronbach's alpha for the BPI was 0.89 completed by patient, and 0.90 by caregiver. For purposes of this study, the patient's pain experience is defined by the responses given to the following seven BPI items: 1) "average pain" in the last 24 hours; 2) "least pain" in the last 24 hours; 3) "worst pain" in the last 24 hours; 4) "pain now"; 5) percent of pain relief in the last 24 hours; 6) level of pain control in the last 24 hours; and 7) pain interferences with activities and mood.

BHI

The BHI is a valid and reliable multidimensional instrument developed to assess outcomes among hospice patients that is simple and minimizes subject burden [37]. The BHI assesses a patient's pain and non-pain symptoms, satisfaction with care, and QOL using a 0–10 rating scale demonstrated as effective for obtaining self-report in frail hospice patients and older adults [36,38]. In a study of 145 hospice patients [37], with 80% being 70 years or older, two subscales were identified in the BHI: symptom subscale and QOL subscale. Internal consistency of the BHI patient survey symptom subscale was 0.88 and QOL subscale 0.94. Test–retest reliabilities between Weeks 1 and 2 ranged from 0.58 to 0.63, with lower reliabilities expected due to changing health status of hospice patients. Correlations between patient and caregiver reports were significant ranging from 0.71 to 0.83. The BHI includes pain, non-pain symptom assessment (including depression, anxiety, tiredness, loss of appetite, nausea, shortness of breath, and distress due to functional changes), QOL, and symptom control.

For purposes of this study, adaptations were made to the BHI. Four of the original 17 BHI items were deleted because they did not relate to pain or the impact of pain on QOL. In the event a patient was unable to complete the BHI, similar procedures as discussed above under the BPI were used. In this study, the Cronbach's alpha for the BHI was 0.80 for patient and 0.78 for caregiver. QOL is defined by the responses given to the following three BHI items: 1) degree of comfort over the past 24 hours; 2) overall QOL; and 3) level of non-pain symptom control.

Data Analysis

The statistical results in this article were obtained using SAS 9.1 (SAS Institute, Inc., Cary, NC). Demographical differences between patient and caregiver groups at T^1 and T^2 were investigated using independent *t*-tests. To assess for differences in patient and caregiver reports, responses on the BPI and BHI were grouped accordingly and Student's *t*-tests for two independent samples were used. There were no statistically significant differences between the two groups on BPI items; thus, patient and caregiver reports were combined and will be reported as a single mean. However, differences did exist on BHI items as reported by the patient vs the caregiver; therefore, data for the BHI were analyzed separately and will be reported as two independent means.

Some patients did not complete the follow-up interview at 7–10 days (n = 23), while other patients were able to complete the first interview independently, but had the caregiver complete the second interview for them (n = 5). In order to make full use of the collected data, all records were included in the statistical analysis. However, data from only those patients who have a completed interview at both time periods were included in the analysis of changes from T^1 to T^2 (n = 71).

To assess experiences of pain, pain severity, pain interferences, non-pain symptoms, QOL, and symptom control, samples means were calculated for T^1 and T^2. Pearson product–moment correlations were used to measure relationships between pain severity ("average pain," "worst pain," and "pain now") and non-pain symptoms, QOL, and symptom control. Poisson generalized linear model (GLM) with generalized estimating equations (GEE) approach was used to further explore the relationship between pain severity and non-pain symptoms, QOL, and symptom control.

Results

In the overall sample gender distribution was nearly equal with 52.1% male and 47.9% female. The age criteria for inclusion was reduced from 65 years to 55 years in order to improve recruitment and increase the sample, resulting in 14.9% of participants between the ages of 55–64, 27.7% between the ages of 65–74, 38.3% between the ages of 75–84, and 19.1% for those greater than 85 years of age. The sample was predominantly Caucasian at 83%. See Table 1 for specific demographic data for the patient sample (n = 71) which had interviews completed at both time periods (T^1 and T^2) by either the patient or their caregiver.

Pain Severity Reports

Complete respondent reporting for T^1 and T^2 on "worst pain," "least pain," "pain right now," and "average pain" is listed in Table 2. A statistically significant change in the mean "worst pain," of 4.55 at T^1 to 3.76 at T^2 was noted. At T^1, 22 respondents (31%) rated the highest level of pain in the last 24 hours as severe, 15 (21.1%) rated the highest level of pain as moderate, 19 (26.8%) rated the "worst pain" as mild, and the remaining 15 (21.1%) had no complaints of pain. At T^2, 19 respondents (26.8%) rated the highest level of pain in the last 24 hours as severe, 15 (21.1%) rated the highest level of pain as moderate, 14 (19.7%) rated the "worst pain" as mild, and the remaining 23 (32.4%) had no complaints of pain. In the past 24 hours, patients at T^1 reported spending an average of 4.82 hours in mild pain, 2.98 hours in moderate pain, and 1.71 hours in severe pain. By T^2, hours spent in moderate to

Table 1 Demographic characteristics of patients who completed interviews at both T^1 and T^2 as reported by patients or caregivers

	Patient report n (%)		Caregiver report n (%)	
Participating patients	T^1	T^2	T^1	T^2
Number of patients				
Total = 71	38	35	33	36
Gender				
Males	20 (52.6)	19 (54.5)	18 (54.5)	19 (52.8)
Females	18 (47.4)	16 (45.7)	15 (45.5)	17 (47.2)
Age				
<65	7 (18.4)	6 (17.1)	3 (9.1)	4 (11.1)
65–74	10 (26.3)	10 (28.6)	10 (30.3)	10 (27.8)
75–84	13 (34.2)	12 (34.3)	12 (36.4)	13 (36.1)
>85	8 (21.1)	7 (20.0)	8 (24.2)	9 (25.0)
Race				
Black	2 (8.2)	2 (5.7)	2 (6.1)	2 (5.5)
White	32 (77.5)	30 (85.7)	31 (93.9)	33 (91.7)
Other	4 (14.3)	3 (8.6)	0 (0)	1 (2.8)

$P \leq 0.05$, no statistically significant differences between patient or caregiver groups at Interviews 1 and 2.

severe pain decreased to 2.53 in moderate pain, and 0.99 hours in severe pain, while hours in mild pain increased to 5.21 hours. No statistically significant changes were noted.

Pain Interference

No statistically significant findings were noted on the BPI in the means for pain interference with the following: general activity, ADLs, enjoyment of life, mood, walking ability, relations with others, and sleep (Table 3).

Table 2 Patient and caregiver ratings of pain severity and experience as measured on the Brief Pain Inventory

0–10 scale	Interview 1 $\bar{X}$ (SD)	Interview 2 $\bar{X}$ (SD)
"Worst pain"	4.55 (3.29)	3.76 (3.17)*
"Average pain"	2.64 (2.16)	2.51 (2.37)
"Least pain"	1.07 (1.6)	1.03 (1.72)
"Pain right now"	1.59 (2.29)	1.62 (2.24)
Number of hours spent in mild pain	4.82 (6.06)	5.21 (7.1)
Number of hours spent in moderate pain	2.98 (5.00)	2.53 (4.92)
Number of hours spent in severe pain	1.71 (3.99)	0.99 (3.29)

* $P \leq 0.05$.
SD = standard deviation.

Mean "average pain" scores on the BHI were 2.32 at T^1 and 2.45 at T^2 for patients able to self-report and 3.2 at T^1 and 2.43 at T^2 for patient pain reported by a caregiver. These means are similar to the mean "average pain" rating that was noted on the BPI (2.64 at T^1 and 2.51 at T^2). No significant differences were found between the mean "average pain" measured on BPI and the mean "average pain" measured on BHI, supporting the reliability of patient and caregiver reporting of pain severity on these two instruments.

BHI

When examining other non-pain symptoms from the BHI, decreases were noted in tiredness, nausea, and depression between T^1 and T^2. Patient reports on the non-pain

Table 3 Pain interference as reported at Interviews 1 (T^1) and 2 (T^2) on the Brief Pain Inventory

n = 71	Interview 1	Interview 2
General activity	3.06 (3.76)	3.02 (3.87)
Activities of daily living	2.59 (3.10)	2.25 (3.15)
Enjoyment of life	3.71 (3.83)	3.08 (3.70)
Mood	2.33 (2.95)	1.86 (2.52)
Walking ability	2.54 (3.27)	2.59 (3.48)
Relations w/others	1.24 (2.25)	1.63 (2.52)
Sleep	2.17 (3.10)	2.05 (3.17)

$P \leq 0.05$.
No significant finding noted.

Table 4 Pain, other non-pain symptoms, and Overall QOL indicators as reported at Interview 1(T^1) and Interview 2 (T^2) on Brief Hospice Inventory

	Patient		Caregiver Report	
	T^1	T^2	T^1	T^2
Mean "average pain"	2.32 (2.56)	2.45 (2.34)	3.20 (2.64)	2.43 (2.74)
Tired	5.54 (2.98)	5.26 (2.64)	7.58 (2.23)	7.26 (2.75)
Nausea	1.59 (2.69)	1.47 (2.80)	1.65 (2.65)	1.22 (2.37)*
Depression	1.63 (2.58)	1.59 (2.68)	4.00 (3.52)	3.43 (2.81)*
Anxiety	1.20 (1.85)	1.91 (2.79)	3.91 (3.50)	3.88 (3.13)
Appetite	5.04 (3.22)	4.67 (3.36)	6.47 (3.06)	6.11 (3.24)
SOB	3.26 (3.27)	3.41 (3.45)	4.54 (4.08)	3.57 (3.48)
Gift or burden	2.79 (3.29)	2.67 (3.25)	4.81 (3.22)	4.52 (3.73)
Independence	2.45 (3.05)	2.71 (2.99)	5.05 (3.58)	4.79 (3.84)
Degree of comfort	2.80 (2.55)	3.15 (2.34)	4.17 (2.15)	4.11 (2.75)
Symptom control	3.60 (2.83)	3.56 (2.79)	4.67 (3.01)	3.94 (2.88)
Overall QOL	4.02 (3.14)	4.26 (2.84)	6.44 (2.53)	6.44 (2.93)

* $P \leq 0.05$.
QOL = quality of life; SOB = shortness of breath.

symptoms tiredness, nausea, and depression were 5.54, 1.59, and 1.63, respectively, for T^1, decreasing to 5.26, 1.47, and 1.59 for T^2. The changes between interviews at T^1 and T^2 for these non-pain symptoms (tiredness, nausea, and depression) for patients able to self-report were not found to be statistically significant. The mean overall QOL reported by the patient increased from T^1 (4.02) to T^2 (4.26) and patient reports of symptom control decreased from 3.60 to 3.56 between time points; neither was significant (Table 4).

A statistically significant decrease was noted in caregiver reports of the non-pain symptom nausea between T^1 (1.65) and T^2 (1.22) and depression ratings also significantly decreased with caregiver ratings of 4 at T^1 to 3.43 at T^2. Patient and caregiver reporting for other non-pain symptoms, QOL, and symptom control were not significant and are listed in Table 4.

The relationship between pain severity, non-pain symptoms (tiredness, anxiety, appetite, and degree of comfort), QOL, and symptom control can be seen in Table 5. When reported by the patient during T^1, pain was significantly correlated with anxiety (r = 0.31), appetite (r = 0.30), degree of comfort (r = 0.73), symptom control (r = 0.45), and QOL (r = 0.32). At T^2 pain was significantly correlated with appetite (r = 0.41), degree of comfort (r = 0.73), and symptom control (r = 0.54). Caregiver reports at T^1 showed no statistically significant correlations between pain, non-pain symptoms, and QOL; however, caregiver

Table 5 Pearson product moment correlation between pain severity and non-pain symptoms, QOL, and symptom control as measured by the Brief Hospice Inventory

	Patient		Caregiver report	
Pain severity	T^1 (n = 40–44)	T^2 (n = 28–29)	T^1 (n = 33–40)	T^2 (n = 29–35)
Tired	0.29	0.10	0.17	0.38*
Anxiety	0.31*	–0.04	0.08	–0.03
Appetite	0.30*	0.41*	–0.07	0.40*
Degree of comfort	0.73***	0.73***	0.15	0.37*
Symptom control	0.45**	0.54**	0.29	0.29
QOL	0.32*	0.16	–0.19	0.31

* $P \leq 0.05$; ** $P \leq 0.01$; *** $P \leq 0.001$.
QOL = quality of life.

reports at T^2 showed pain was significantly correlated with tiredness (r = 0.38), appetite (r = 0.40), and degree of comfort (r = 0.37).

Poisson GLM with GEE Approach (BPI and BHI)

Table 6 shows the results from Poisson GLM with GEE approach for the BPI indicators of "worst pain" and "pain right now" based on each of the non-pain symptom indicators listed on the BHI, respectively, where the exponential values are indicative of an increase in the percent of pain as the related symptom increases by 1. For example, "worst pain" was significantly impacted by tiredness (when tiredness increased by 1, "worst pain" increased by 5%). "Worst pain" was also impacted in a similar manner by the following non-pain symptoms with increases in "worst pain" of 9% from depression, 10% from degree of comfort, and 7% from symptom control. "Pain right now" was also significantly impacted by the following non-pain symptoms with increases in "pain right now" of 4% from tiredness, 11% from nausea, 10% from depression, 6% from appetite, 11% from degree of comfort, and 9% from symptom control. Exact estimates and *P*-values can be found in Table 6. Non-pain symptoms that are not significantly associated with "worst pain" and "pain right now" do not appear in the table. Additionally, the BPI indicator "average pain" was not significantly impacted by any of the BHI non-pain symptoms and thus was not included.

Discussion

Patient and caregiver responses in this study provided valuable insight into older adults' EOL experiences of pain, pain severity, non-pain symptoms, QOL, and symptom control. This is a noted gap within the literature. Our study supports that pain, is positively associated with non-pain symptoms, QOL, and symptom control during the EOL process in older adults with cancer pain. Studies in mixed adult populations noted significant relationships between pain and QOL [11] with two specifically examining pain severity and QOL [9,23].

Our study of older adult hospice patients affirmed these relationships and contributed findings on additional QOL factors. The impact of pain severity on the BPI was examined in relation to the patient/caregiver reports of non-pain symptoms, QOL, and symptom control. The BPI pain severity ratings of "worst pain" and "pain right now" were significantly associated with the following QOL indicators: tiredness, depression, degree of comfort, and symptom control. Additionally, "pain right now" was significantly associated with nausea and appetite. These associations are all important to note as control of pain is one of the primary goals of hospice.

Although this study provides insight into the personal experiences of pain, non-pain symptoms, and overall QOL from interviews with patients or their caregivers, decreases in the reported means for all the questions on the BPI and BHI from T^1 to T^2 were rarely found to be statistically significant. "Worst pain" was the only factor shown to decrease significantly from T^1 to T^2. It is possible that higher scores at T^1 might result in greater potential for intervention and thus increased improvement by T^2. Nonetheless, these data provide a snap shot of the experience of pain in the first 2 weeks of hospice admission for older adults with a cancer diagnoses and its impact on QOL, and as such are valuable additions to current research in this area. Findings from the BHI analyses affirm the associations between pain and non-pain symptoms (such as anxiety, appetite, degree of comfort, etc.) as well as, QOL, or symptom control, in the older adult with cancer pain. Hospice providers should assess for non-pain symptoms,

Table 6 Results of Poisson generalized linear model with GEE approach for "worst pain" in the past 24 hours on the BPI and "Pain Right Now" on the BPI based on each of the 10 Non-Pain symptoms and QOL indicators* in BHI, respectively

	Independent variables	Estimate	Exp (est.)	*P*-value
"Worst pain" on BPI	Tired	0.05	1.05	0.00
	Depression	0.09	1.09	0.05
	Degree of comfort	0.10	1.10	<0.00
	Symptom control	0.07	1.07	0.00
"Pain right now" on BPI	Tired	0.04	1.04	<0.00
	Nausea	0.11	1.12	0.01
	Depression	0.10	1.10	0.01
	Appetite	0.06	1.06	0.00
	Degree of comfort	0.11	1.11	<0.00
	Symptom control	0.09	1.10	<0.00

$P \leq 0.05$.

* Only those BHI non-pain symptoms and quality of life indicators that significantly impacted BPI "worst pain" or "pain right now" are included in this table.

BHI = Brief Hospice Inventory; BPI = Brief Pain Inventory.

QOL, and symptom control as part of their ongoing reassessments, as these may impact pain severity. Interventions tailored to individual patient needs are recommended to address all symptoms that interfere with attainable goals. The statistically significant drop in "worst pain" reports between the two data collection points in our study support the belief that hospice care can decrease pain severity; although this study is descriptive, not causal, and other factors may have impacted this change outside the hospice experience.

Our overall mean "average pain" reporting was found to be between 2.32 and 3.2, which is consistent with other research on newly admitted cancer patients in hospice programs [11]. In a sample of 75 cancer patients, that ranged in age from 35 to 84, Bostrom et al. [39] found that 22 subjects receiving palliative care rated their "worst pain" at 4.4 (standard deviation [SD] 4.0), comparable with the 4.55 (SD 3.29) found in our study at admission to hospice. Rustoen et al. [9] also found "pain right now" reports of 3.8 (SD 2.1), higher than the 1.59 (SD 2.29) found in our study at admission to hospice. Based on the reasons given for refusal to participate, one might suspect that the patients who joined the study were experiencing less pain than those who were too ill to participate. Study findings support that the "worst pain" participants were experiencing at both 72 hours and 1 week in hospice was moderate pain. However, based on the reported number of hours spent in various levels of pain, patients were reporting an average of 1–2 hours in severe pain daily. The reasons for the discrepancy between reported pain severity and reported hours spent in various levels of pain is unknown, but it is important to consider that similar research studies have noted differences in older adults' abilities to report pain that requires memory of past events. Furthermore, while the patient and caregiver ratings on the mean "worst pain" rating for the last 24 hours suggest this to be moderate pain, our findings were consistent with a similar research study as indicated above.

Our study confirmed the findings of other studies with mixed populations, that pain is an issue for many older patients with cancer who are admitted to hospice for care [24]. Though not significant, the number of hours subjects in our study spent in mild pain increased from T^1 to T^2, while there was a simultaneous decrease in severe and moderate pain reports. One probable explanation would be that patients who experienced severe and moderate levels of pain may have had their pain properly managed to the level of mild pain suggesting that hospice care had a positive impact on pain management, although there could be other contributing factors to this change. While the overall number of patients experiencing severe pain was low following admission to hospice, it is a concern when even 26.8% of patients are reporting severe pain experiences. Although statistically significant changes in pain severity were noted, we also acknowledge that the level of change is small and this may not be clinically significant to the patient. And, because this study did not analyze the treatment of these patients' pain, we are not able to judge the appropriateness of the pain care plan, nor patient/caregiver adherence to that plan.

Although some data suggests that family caregivers can provide valid reports of pain intensity at the EOL, more reports of overestimation of pain intensity by family caregivers suggest caution with this estimation. In our study, caregiver reports of pain showed higher means than patient reports of pain on the BHI. While we can only speculate, subjects who require proxy reporting are probably more frail, ill, or impaired and likely to be experiencing worse symptoms than those able to self-report. Thus, there is a possibility that higher reports provided by caregivers are actually related to the patient's condition and worsening of symptoms.

Limitations

The results of this descriptive study provide information about pain, non-pain symptoms, and QOL specific to a sample of older adults with cancer pain receiving care in the home setting and thus are not generalizable to other settings, such as inpatient hospice or hospice services provided to older adults in nursing homes. While a prospective sample of 94 patients is larger than that reported in previous studies, we experienced similar issues with recruitment of subjects [22]. Of the 435 eligible patients, 22% agreed to participate, and of that group only, 16% were able to complete both telephone interviews. Additionally, half of the interviews were completed by proxy reporters and in 5% of the cases, the initial and follow-up data came from different sources (patient and caregiver). In addition, it is possible that the group of patients who agreed to participate were less impaired by their illness and/or were not as close to EOL then than those who opted out, so the sample may not be representative of all older adults with cancer receiving hospice care in a home setting. This is a possible source of bias that can be determined in future studies through the inclusion of performance status measures. Additionally, the study provides descriptive data from the subjects as reported by the patient or by their caregiver, and due to differences between the two reporting groups, the study does not allow for generalizations across the total sample. Finally, the results from this study do not include an analysis of clinical interventions provided by the hospices nor patient/caregiver adherence to the pain treatment plan, and thus does not allow for interpretation of the clinical significance of the findings.

Implications for Research and Practice

Our findings contribute to evidence in mixed adult samples that pain is impacted by non-pain symptoms and related to QOL. Our study provides information on self-reported pain and pain-related symptoms in older adults, a group for which focused evaluation has been limited. Consistent with the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care

[40], we suggest that hospice providers use evidence-based practices to promote optimal management of pain and QOL-related symptoms in older adults with cancer pain. Future research should examine aspects of pain management in community-based hospices that contribute to decreased pain and pain interference, non-pain symptoms, and improved QOL in older adults with cancer admitted to hospices. In particular, patients with moderate to severe pain need careful attention to the development of effective pain treatment plans that include monitoring treatment adherence and expected outcomes.

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