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Quality of Life and Barriers to Symptom Management in Colon Cancer

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Abstract

Purpose of the Research—Pain and fatigue are recognized as critical symptoms that impact QOL for patients with colon cancer. Barriers to optimum pain and fatigue relief include patient-related beliefs and attitudes about the treatment of cancer-related symptoms. The overall objective of this paper was to describe quality of life (QOL) and barriers to pain and fatigue management in patients with colon cancer.

Methods and Sample—This longitudinal, descriptive study included was conducted in the ambulatory clinic of one NCI-designated comprehensive cancer center. A cohort of 56 patients with colon cancer and a pain and/or fatigue of 4 (moderate to severe) was recruited. Subjects

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Conflict of Interest Statement

None declared.

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completed questionnaires to assess subjective ratings of overall QOL, fatigue, barriers to pain and fatigue, and pain and fatigue knowledge.

Key Results—The majority of subjects (58%) reported having moderate to severe (4–6) fatigue at the time of accrual. Overall QOL score was moderate ($M=5.20$, $SD=1.43$), and the social well-being subscale had the lowest score ($M=4.57$, $SD=1.82$). Patient barriers to pain and fatigue existed in attitudes and beliefs regarding addiction, tolerance, and that fatigue is an inevitable part of cancer and its treatments. Patient knowledge of pain and fatigue was high (77%–88% correct), but lack of knowledge persisted in areas such as addiction to pain medications and utilizing physical activity to manage fatigue.

Conclusions—Several patient-related attitudes and beliefs may hinder optimum relief of symptoms such as pain and fatigue. Social well-being may be a major determinant of overall QOL for patients with colon cancer.

Keywords

QOL; pain; fatigue; symptoms; colon cancer

Introduction

Colon cancer is the third leading cause of all cancer diagnoses in both men and women in the United States (Jemal, et al., 2009). The current treatment regimens for colon cancer are extensive, and may include surgery and/or chemotherapy. Disease and treatment-related toxicities, such as pain and fatigue, are common in patients with colon cancer and may result in reduced overall quality of life (QOL) (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2006; Burton, Fanciullo, Beasley, & Fisch, 2007). However, efforts to provide optimal symptom management are hampered by barriers related to patient attitudes and beliefs. Patients are reluctant to report their pain for reasons including fear of side effects, fatalism about the possibility of achieving pain control, fear of distracting physicians from treating the cancer, and belief that pain is indicative of progressive disease (AHCPR, 1994; Cleeland, 1984; Duggleby, 2000; Duignan & Dunn, 2009; Edrington, et al., 2009; Green, Montague, & Hart-Johnson, 2009; Jacobsen, Moldrup, Christrup, & Sjogren, 2008; Oliver, et al., 2008; Shi, Wang, Mendoza, Pandya, & Cleeland, 2009; Sun, et al., 2007; Ward, et al., 1993). Patient-related barriers to fatigue include reluctance to report fatigue, and beliefs that fatigue is inevitable, unimportant, and untreatable (Ancoli-Israel, Moore, & Jones, 2001; de Jong, Courtens, Abu-Saad, & Schouten, 2002; Nail, 2002; NIH, 2002; Payne, 2002; Stone, et al., 2000). Although patient-related barriers to pain and fatigue have been identified extensively in the current literature, few studies have examined the role of patient-related barriers and QOL in patients with colon cancer (Al-Atiyyat, 2008; Bender, et al., 2008; Carr, 2007; Cohen, et al., 2008; Deandrea, Montanari, Moja, & Apolone, 2008; Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007; Iop, Manfredi, & Bonura, 2004; Jacobsen, et al., 2008; Nail, 2002; Prue, Rankin, Allen, Gracey, & Cramp, 2006; Siefert, 2010; Vallerand, Saunders, & Anthony, 2007; Vogelzang, et al., 1997). In the present study, we sought to describe overall QOL, patient-related barriers to pain and fatigue, and patient knowledge related to pain and fatigue in patients with colon cancer in ambulatory oncology settings.

Materials and Methods

Study participants were recruited from the Medical Oncology Adult Ambulatory Care Clinic at an NCI-designated comprehensive cancer center. Institutional Review Board approval was obtained prior to patient accrual. Patients with colon cancer were recruited and enrolled in the study if they met the following eligibility criteria: 1) time since diagnosis of at least

one month; 2) an expected prognosis of six months or greater; and 3) subjective pain and/or fatigue rating of 4 (moderate to severe pain) on a numeric scale of 0–10 (0=none; 10=worst imaginable). Research nurses approached all individuals meeting eligibility criteria during a regularly scheduled clinic visit. Written informed consent was obtained from all participants prior to participation in this study. Participants provided demographic and disease data along with other outcome measures to assess overall QOL, fatigue, barriers to pain and fatigue, and pain and fatigue knowledge.

Instruments

Subject characteristics were obtained using the Demographic and Treatment Data Tool, which was designed to capture key demographic, disease and treatment variables.

Overall QOL was assessed by the City of Hope-QOL-Patient Tool. This validated measure is a 45-item multidimensional tool encompassing four domains of physical, psychological, social, and spiritual well-being. Internal consistency reliability is .77–.89 for the four subscales and .93 overall. Measures of validity of the generic patient version include content validity with the FACT instrument ($r = .78$), and factor analysis. The instrument has demonstrated construct validity by discriminating between known groups. The 45 QOL items were factor analyzed using principal axis factoring with a varimax rotation. A four factor solution was identified, confirming the multidimensional QOL model. (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995)

The Piper Fatigue Scale (PFS) is a 22-item, self-report scale that measures four dimensions of subjective fatigue (behavioral/severity [6-items], sensory [5-items], cognitive/mood [6-items], and affective meaning [5-items]) confirmed by principal axes factor analysis. (Piper, et al., 1998) Internal consistency (Cronbach's alpha) reliabilities are strong (0.83–0.97) for the PFS and its subscales across various cultural, languages, and diagnostic groups and were 0.89–0.97 in this sample. Each item is measured on a 0–10 numeric rating scale, and higher scores indicate more fatigue. Five additional items, not included in the scale's scoring, assess perceived causes, relief measures, additional fatigue descriptors, presence of other symptoms, and duration of fatigue. (Piper, et al., 1998)

To assess patient-related barriers to pain, the Barriers Questionnaire (BQ II) was used. (Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002) Significant ($t = -2.16$, $p < 0.05$) construct validity and a factor analysis revealed four factors: (1) physiologic effects, (2) fatalism, (3) communication and (4) harmful effects. The BQ-II total has an internal consistency reliability coefficient alpha of 0.89 ($n = 134$), and a range of 0.75–0.85 for the subscales.

To assess patient-related barriers to fatigue, the Fatigue Barriers Scale (FBS) was used. It was developed based on an extensive literature review and clinical experience. In this study, the reliability estimates for the subscales were: Beliefs/Attitudes ($r = .30$), Good Patient ($r = .65$), and Fatalism ($r = .54$). For the total scale ($r = .73$) the reliability coefficient indicated good reliability for a new scale. To assess patient knowledge of pain and fatigue, the following tools were used. The Patient Pain Knowledge Tool and the Patient Fatigue Knowledge Tool was developed by the investigators and based on the NCCN Pain and Fatigue Guidelines, and were in a true or false format. (National Comprehensive Cancer Network, 2009) Cronbach's alpha in this sample was 0.67.

Statistical Analysis

Analyses included tabulation of standard summary statistics of demographic and disease/treatment characteristics. In addition to demographic and clinical characteristics, descriptive statistics were computed for QOL items, subscale scores and total score. Descriptive

statistics (subscale and total scores) were also computed for fatigue assessment using the Piper Fatigue Scale (PFS), patient-related barriers to pain (BQII), patient-related barriers to fatigue (FBS), and pain and fatigue knowledge test scores. Pearson's correlations were determined between fatigue prevalence and fatigue barriers and knowledge.

Subjects with missing scale or subscale scores were compared with subjects having non-missing scores to determine any bias underlying the missing data. For data that are missing completely at random (MCAR) or missing at random (MAR), the EM (estimation-maximization) method of imputation was used to replace missing values.

Results

Complete demographic and disease data is provided in Table 1. A total of 56 patients with colon cancer were accrued. The mean age of these subjects was 58 and 57% were male. The cohort included 65.5% Caucasian, 5.5% African American, 20% Hispanic and 7.3% Asian. The majority of subjects (67.9%) had a college or graduate degree. The majority of subjects (92.7%) had Stage III or IV disease at the time of accrual, and 94.6% were undergoing active treatment. Karnofsky Performance Status (KPS) score ranged from 100-60. Forty-five percent of subjects reported a baseline KPS of 90. In terms of pain and fatigue assessment, the majority of subjects (58.9%) reported having fatigue only, while 35.7% of subjects reported having both pain and fatigue. Almost equal percentages of the sample were recently diagnosed (48.2%) versus recurrent (46.4%). There were no significant differences in pain or fatigue frequency, KPS, or number of comorbidities by disease status (recently diagnosed vs. recurrent).

Overall QOL and Fatigue

Table 2 provides individual items, subscale scores, and total score for QOL. Overall QOL score was moderate. All domains, including physical, psychological, social, and spiritual well-being, had moderately low scores. The social well-being subscale had the lowest QOL score, followed by psychological well-being, spiritual well-being, and physical well-being. Several individual items within each of the QOL domains were troublesome for patients. For physical well-being, patients reported low scores for symptoms such as fatigue. Patients reported distress during their initial diagnosis and through their cancer treatments. Patients were also fearful of recurrence of their cancer. For social well-being, patients reported significant family distress, sexuality issues, and interference with their daily activities at home. Finally, low scores were reported for uncertainty in the spiritual well-being domain.

Table 3 provides subscale and total score for overall fatigue assessment using the Piper Fatigue Scale (PFS). Overall, the cognitive mood subscale had the lowest score, followed by affective/meaning, behavioral/severity, and sensory. Overall fatigue score was moderate. All correlations between fatigue prevalence and fatigue barriers and knowledge scores were small and not significant. However, positive association was found between affective meaning of fatigue and fatigue prevalence ($r=26$), where a higher prevalence of fatigue is associated with more affective meaning.

Patient-Related Barriers to Pain and Fatigue

The Barriers Pain Questionnaire (BQ II) captured patient-related barriers regarding pain management. The lowest scores were found in the subscales of harmful effects and physiological effects of pain medications (see Table 4). Overall, there was a strong belief that pain medicines are addictive, and that cancer patients are at high risk of developing addiction. Subjects also believed that their body becomes tolerant to the effects of pain medicine and the medications would not provide pain relief in the future. Additionally, there

was a fear that pain medicine will mask health changes. In terms of patient-related barriers to fatigue, patients believed that fatigue was an inevitable part of cancer and its treatments.

Patient Knowledge of Pain and Fatigue

Table 5 provides scores for patient knowledge of pain and fatigue. The overall score for the Patient Pain Knowledge Tool was 77% correct, which was fairly high. Subjects had the most knowledge in items such as the use of a pain scale, and methods used to prevent opioids-induced constipation. However, important knowledge deficits existed in the cause of pain and addiction with opioids. Similarly, overall patient knowledge of fatigue was high, with 88% of overall score being correct. Patients reported correctly that fatigue can be reduced by balancing rest and activities, but the worst scores were related to exercise items, such as the belief that exercise requires more energy and leads to more effort to do activities.

Discussion

In this study, we identified a colon cancer population with mainly advanced disease, which is typical for a tertiary cancer center. Baseline overall QOL, as expected, was moderate. Predictably, subjects had many QOL concerns. Physically, our sample reported problems fatigue, a symptom described in the literature as distressing for cancer patients (Al-Atiyyat, 2008; Bender, Hohenadel, Wong, et al., 2008). This result was expected given that virtually all patients enrolled in the study reported experiencing fatigue. Severe problems in this sample in the social and psychological domains of QOL underscore the need to explore further the emotional impact of colon cancer for patients. Subjects in this study also reported severe family distress. This is consistent with previous studies conducted by this team related to understanding the family perspective of cancer symptom management (Carr, 2007; Cohen, Botti, Hanna, Leach, Boyd, & Robbins, 2008; Deandrea, Montanari, Moja, & Apolone, 2008; Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007; Iop, Manfredi, & Bonura, 2004; Prue, Rankin, Allen, Gracey, & Cramp, 2006).

The patient-related barriers to pain and fatigue management obtained from this study confirm data reported in the literature as well as underscores the importance of addressing these barriers (Siefert, 2010; Vallerand, Saunders, & Anthony, 2007). For pain, numerous studies have documented the very significant patient barrier of fears of addiction (Burton et al., 2007; Jacobsen et al., 2008; Vogelzang, Breitbart, Cella, et al., 1997). Overall, subjects in this study scored fairly high on pain knowledge, but knowledge deficits again continue to exist in areas related to addiction. Model programs have emphasized patient teaching interventions including the use of pain assessment tools, strategies to dispel misconceptions, and patient coaching regarding the reporting and documenting of their symptoms (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Piper, Dibble, Dodd, Weiss, Slaughter, & Paul, 1998; Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002). The findings from our study support this hypothesis.

In terms of barriers to fatigue, colon cancer patients were unaware of the importance of exercise in managing cancer-related fatigue. We found that our patients believed that exercise does not increase energy but requires more energy. This belief is not supported by the current evidence that physical activity, including exercise, is an effective strategy for managing fatigue (Barsevick, Newhall, & Brown, 2008; de Nijs, Ros, & Grijpdonck, 2008; Dimeo, Thomas, Raabe-Menssen, Propper, & Mathias, 2004; Iop, et al., 2004; Jacobsen, Sjogren, Moldrup, & Christrup, 2007). Future studies need to address this important misconception.

The data presented must be interpreted in light of the strengths and limitations of the study. We were able to recruit 36% ethnic minorities for study participation. Although our sample

consisted of patients with diverse backgrounds, our recruitment strategy was to enroll patients who had symptomatic pain and fatigue that is moderate to severe. Therefore, our findings may not be generalizable for patients who are less symptomatic. This study was implemented at one national comprehensive cancer center outpatient setting located in Southern California where patients commonly are referred for treatment and second opinions, usually late in the course of their treatment and disease process. As a consequence, the findings may not be generalizable to other geographic areas or inpatient settings, or patients with other types of malignancies.

In conclusion, findings from this study suggest that patients with colon cancer experience QOL concerns, particularly in the areas of social and psychological well-being. The study also identified several patient-related barriers to pain and fatigue management that continues to hinder efforts to provide optimal symptom relief for patients with colon cancer. Further research is needed to identify determinants of QOL in colon cancer that will aid in the development of clinical interventions to maintain QOL and reduce barriers to cancer-related symptom management.

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References

- Agency for Health Care Policy & Research. Clinical Practice Guideline for Cancer Pain Management. Rockville: US Department of Health and Human Services; 1994.
- Al-Atiyyat N. Patient-related barriers to effective cancer pain management. *Journal of Hospice and Palliative Nursing*. 2008; 10:198–204.
- Ancoli-Israel S, Moore PJ, Jones V. The relationship between fatigue and sleep in cancer patients: a review. *European Journal of Cancer Care*. 2001; 10:245–255. [PubMed: 11806675]
- Arndt V, Merx H, Stegmaier C, Ziegler H, Brenner H. Restrictions in quality of life in colorectal cancer patients over three years after diagnosis: a population based study. *European Journal of Cancer*. 2006; 42:1848–1857. [PubMed: 16829069]
- Barsevick AM, Newhall T, Brown S. Management of cancer-related fatigue. *Clinical Journal of Oncology Nursing*. 2008; 12(5 Suppl):21–25. [PubMed: 18842521]
- Bender JL, Hohenadel J, Wong J, Katz J, Ferris LE, Shobbrook C, et al. What patients with cancer want to know about pain: a qualitative study. *Journal of Pain and Symptom Management*. 2008; 35(2):177–187. [PubMed: 18158232]
- Burton AW, Fanciullo GJ, Beasley RD, Fisch MJ. Chronic pain in the cancer survivor: a new frontier. *Pain Medicine*. 2007; 8(2):189–198. [PubMed: 17305690]
- Carr E. Barriers to effective pain management. *The Journal of Perioperative Practice*. 2007; 17(5):200–208.
- Cleeland CS. The impact of pain on the patient with cancer. *Cancer*. 1984; 54(11 Suppl):2635–2641. [PubMed: 6498754]
- Cohen E, Botti M, Hanna B, Leach S, Boyd S, Robbins J. Pain Beliefs and Pain Management of Oncology Patients. *Cancer Nursing*. 2008; 31(2):E1–E8. [PubMed: 18490876]
- de Jong N, Courtens AM, Abu-Saad HH, Schouten HC. Fatigue in patients with breast cancer receiving adjuvant chemotherapy: a review of the literature. *Cancer Nursing*. 2002; 25(4):283–297. [PubMed: 12181497]
- de Nijs EJ, Ros W, Grijpdonck MH. Nursing intervention for fatigue during the treatment for cancer. *Cancer Nursing*. 2008; 31(3):191–206. [PubMed: 18453875]

- Deandrea S, Montanari M, Moja L, Apolone G. Prevalence of undertreatment in cancer pain. A review of published literature. *Annals of Oncology*. 2008; 19(12):1985–1991. [PubMed: 18632721]
- Dimeo FC, Thomas F, Raabe-Menssen C, Propper F, Mathias M. Effect of aerobic exercise and relaxation training on fatigue and physical performance of cancer patients after surgery. A randomised controlled trial. *Supportive Care in Cancer*. 2004; 12(11):774–779. [PubMed: 15338385]
- Duggleby W. Enduring suffering: a grounded theory analysis of the pain experience of elderly hospice patients with cancer. *Oncology Nursing Forum*. 2000; 27(5):825–831. [PubMed: 10868393]
- Duignan M, Dunn V. Perceived barriers to pain management. *Emergency Nurse*. 2009; 16(9):31–35. [PubMed: 19263820]
- Edrington J, Sun A, Wong C, Dodd M, Padilla G, Paul S, et al. Barriers to pain management in a community sample of Chinese American patients with cancer. *Journal of Pain and Symptom Management*. 2009; 37(4):665–675. [PubMed: 19004613]
- Ferrell BR, Dow KH, Leigh S, Ly J, Gulasekaram P. Quality of life in long-term cancer survivors. *Oncology Nursing Forum*. 1995; 22(6):915–922. [PubMed: 7567610]
- Green CR, Montague L, Hart-Johnson TA. Consistent and breakthrough pain in diverse advanced cancer patients: a longitudinal examination. *Journal of Pain and Symptom Management*. 2009; 37(5):831–847. [PubMed: 19054648]
- Gunnarsdottir S, Donovan HS, Serlin RC, Voge C, Ward S. Patient-related barriers to pain management: the barriers questionnaire II (BQ-II). *Pain*. 2002; 99(3):385–396. [PubMed: 12406513]
- Hofman M, Ryan JL, Figueroa-Moseley CD, Jean-Pierre P, Morrow GR. Cancer-related fatigue: the scale of the problem. *Oncologist*. 2007; 12(Suppl 1):4–10. [PubMed: 17573451]
- Iop A, Manfredi AM, Bonura S. Fatigue in cancer patients receiving chemotherapy: an analysis of published studies. *Annals of Oncology*. 2004; 15(5):712–720. [PubMed: 15111337]
- Jacobsen R, Moldrup C, Christrup L, Sjogren P. Patient-related barriers to cancer pain management: a systematic exploratory review. *Scandinavian Journal of Caring Science*. 2008; 23(1):190–208.
- Jacobsen R, Sjogren P, Moldrup C, Christrup L. Physician-related barriers to cancer pain management with opioid analgesics: a systematic review. *Journal of Opioid Management*. 2007; 3(4):207–214.
- Jemal A, Siegel R, Ward E, Hao Y, Xu J, Thun MJ. Cancer Statistics, 2010. *CA A Cancer Journal for Clinicians*. 2010; 59(4):225–249. [PubMed: 19474385]
- Nail LM. Fatigue in patients with cancer. *Oncology Nursing Forum*. 2002; 29(3):537. [PubMed: 11979285]
- National Comprehensive Cancer Network. [Accessed May 18, 2011] NCCN Clinical Practice Guidelines in Oncology: Adult Cancer Pain. 2010. www.nccn.org
- National Institutes of Health. [Accessed May 11, 2011] Symptom management in cancer: pain, depression, and fatigue. 2008. Retrieved http://consensus.nih.gov/ta/022/022_statement.htm
- Oliver DP, Wittenberg-Lyles E, Demiris G, Washington K, Porock D, Day M. Barriers to pain management: caregiver perceptions and pain talk by hospice interdisciplinary teams. *Journal of Pain and Symptom Management*. 2008; 36(4):374–382. [PubMed: 18495415]
- Payne JK. The trajectory of fatigue in adult patients with breast and ovarian cancer receiving chemotherapy. *Oncology Nursing Forum*. 2002; 29(9):1334–1340. [PubMed: 12370703]
- Piper BF, Dibble SL, Dodd MJ, Weiss MC, Slaughter RE, Paul SM. The revised Piper Fatigue Scale: psychometric evaluation in women with breast cancer. *Oncology Nursing Forum*. 1998; 25(4):677–684. [PubMed: 9599351]
- Prue G, Rankin J, Allen J, Gracey J, Cramp F. Cancer-related fatigue: A critical appraisal. *European Journal of Cancer*. 2006; 42(7):846–863. [PubMed: 16460928]
- Shi Q, Wang XS, Mendoza TR, Pandya KJ, Cleeland CS. Assessing persistent cancer pain: a comparison of current pain ratings and pain recalled from the past week. *Journal of Pain and Symptom Management*. 2009; 37(2):168–174. [PubMed: 18676116]
- Siefert M. Fatigue, Pain, and Functional Status During Outpatient Chemotherapy. *Oncology Nursing Forum*. 2010; 37(2):E114–E123. [PubMed: 20189910]

- Stone P, Richardson A, Ream E, Smith AG, Kerr DJ, Kearney N. Cancer-related fatigue: inevitable, unimportant and untreatable? Results of a multi-centre patient survey. *Cancer Fatigue Forum. Annals of Oncology*. 2000; 11(8):971–975. [PubMed: 11038033]
- Sun VC, Borneman T, Ferrell B, Piper B, Koczywas M, Choi K. Overcoming barriers to cancer pain management: an institutional change model. *Journal of Pain and Symptom Management*. 2007; 34(4):359–369. [PubMed: 17616336]
- Vallerand AH, Saunders MM, Anthony M. Perceptions of control over pain by patients with cancer and their caregivers. *Pain Management Nursing*. 2007; 8(2):55–63. [PubMed: 17544124]
- Vogelzang NJ, Breitbart W, Cella D, Curt GA, Groopman JE, Horning SJ, et al. Patient, caregiver, and oncologist perceptions of cancer-related fatigue: results of a tripart assessment survey. *The Fatigue Coalition. Seminars in Hematology*. 1997; 34(3 Suppl 2):4–12. [PubMed: 9253778]
- Ward SE, Goldberg N, Miller-McCauley V, Mueller C, Nolan A, Pawlik-Plank D, et al. Patient-related barriers to management of cancer pain. *Pain*. 1993; 52(3):319–324. [PubMed: 7681557]

Table 1

Demographics and Treatment Data (n=56)

Age	Mean = 58.3	SD = 11.1
Gender	N	(%)
•Male	32	57.1
•Female	24	42.9
Race/Ethnicity		
•Caucasian	36	65.5
•African American	3	5.5
•Hispanic/Latino	11	20
•Asian	4	7.3
•Other	2	3.6
Education		
•Graduate	8	14.3
•College	30	53.6
•High School or Less	18	32.2
Marital Status		
•Married	38	67.9
•Other	18	32.1
Stage	N	(%)
I-II	4	7.3
III	16	29.1
IV	35	63.6
Disease Status		
Recently Diagnosed and undergoing rx	27	48.2
Recurrence and undergoing rx	26	46.4
Completed rx, NED	1	1.8
Other	2	3.6
Symptom Clusters		
Pain Only	3	5.4
Fatigue Only	33	58.9
Pain & Fatigue	20	35.7

KPS range =100-60 at baseline

Table 2

Quality of Life Scale: Individual Items and Subscale Scores (n=56)

TnQTable 1 To what degree has illness interfered with your activities at home?	2.82(2.44)
How much isolation do you feel?	5.63(2.90)
How much financial burden have you incurred as a result of illness?	4.30(3.45)
Social Subscale	4.57(1.82)
<hr/>	
<i>Spiritual Well Being</i>	
How important are religious activities such as praying, going to church?	6.27(4.03)
How important are spiritual activities such as meditation?	5.71(4.07)
How much has your spiritual life changed as a result of cancer diagnosis?	5.93(3.66)
How much uncertainty do you feel about your future?	3.30(3.21)
To what extent has illness made positive changes in your life?	4.75(3.49)
Do you sense a purpose/mission in life or a reason for being alive?	6.89(3.31)
How hopeful do you feel?	7.46(2.44)
Spiritual Subscale	5.76(2.44)
<hr/>	
OVERALL QOL SCALE SCORE	5.20(1.43)

(Range= 0–10; 0= poor QOL, 10=best QOL)

Table 3

Piper Fatigue Scale Total and Subscale Scores (N=56)

Scale/Subscale	Mean	SD
Sensory	6.37	2.13
Affective Meaning	5.66	2.31
Cognitive Mood	4.84	1.98
Behavioral Severity	5.73	2.50
PFS Total	5.61	1.96

*
0–10 scale; 0=worst, 10=best

Table 4

Patient-Related Barriers to Pain (BQII) (1–5 scale; 1=low barriers, 5=high barriers)

Variable	X (SD)
Subscale	
Physiological Effects	1.95 (.88)
Fatalism	1.40 (1.1)
Communication	1.03 (1.1)
Harmful Effects Overall	2.25 (1.1)
Items with High Barriers to Pain (>2, range 0–5)	
There is a danger of becoming addicted to pain medicine	3.2 (1.9)
Drowsiness from pain medicine is different to treat	2.7 (1.6)
When you use pain medicine your body becomes used to its effect and pretty soon it won't work anymore	2.7 (1.8)
Using pain medicine blocks your ability to know if you have any new pain	2.2 (1.5)
Pain medicine can keep you from knowing what's going on in your body	2.2 (1.6)

Table 5**Patient Knowledge of Pain and Fatigue**

Overall Score = 77% correct Items with low scores (<60% correct) <ul style="list-style-type: none">• Cancer is most common cause of pain• Taking opioids leads to addiction Items with high scores (>90% correct) <ul style="list-style-type: none">• Pain scale is used to describe how much pain you are feeling• Fluids, exercise, fiber, and laxatives can prevent constipation as a side effect of pain medications
Patient Knowledge of Fatigue
Overall Score = 88% correct Items with low scores (<60% correct) <ul style="list-style-type: none">• Exercise requires more energy and leads to more effort to do activities Items with high scores (>90% correct) <ul style="list-style-type: none">• Fatigue can be reduced by balancing rest and activities