

This is a postprint version of the article published as:

Valeberg, B. T., Miaskowski, C., Paul, S. M., & Rustøen, T. (2015). Comparison of Oncology Patients' and Their Family Caregivers' Attitudes and Concerns Toward Pain and Pain Management. *Cancer nursing*. doi: <http://dx.doi.org/10.1097/NCC.0000000000000319>

Comparison of Oncology Patients' and Their Family Caregivers' Attitudes and Concerns Toward Pain and Pain Management

Introduction

The role of family caregivers (FCs) is changing as most cancer patients get treatment in outpatient clinics. Unrelieved pain in cancer patients remains a significant clinical problem.^{1,2} Compared to hospitalized patients, oncology outpatients and their FCs face greater challenges when making daily decisions about pain management. Most FCs are actively engaged in assisting with pain management and experience significant needs and concerns related to this role.^{3,4} Prior research indicates that decreases in FCs' quality of life parallel decrements in patients' physical and psychological well-being.^{5,6}

Both patients and their FCs may be reluctant to report pain and to use adequate amounts of analgesics. This reluctance may be based on erroneous beliefs or misconceptions about pain and its management which act as barriers to effective pain management.⁷⁻¹¹ A systematic review of barriers to effective cancer pain management found that patients were most concerned about addiction, side-effects of analgesics, and interpreted increased pain to be progression of their disease.¹² While concern about addiction was the most common barrier in subsequent studies,^{8,13} the specific reported barriers varied across studies. For example, in one study,¹³ patients had the fewest misconceptions about the side-effects of analgesics. Other patients had concerns about the development of tolerance to

analgesics.⁸ These differences may be related to the evaluation of patients at different stages of their disease trajectory as well as cultural differences.¹⁴

FCs of oncology patients also report barriers to pain management. In one study,⁹ between 46% and 94% of FCs reported at least some agreement with a number of barriers listed on the Barrier Questionnaire (BQ) and up to 15% reported strong agreement. In another study,¹⁰ 87% of the FCs of patients receiving home hospice care had concerns about the pharmacologic management of pain. Similar to patients, fear of addiction was the most common barrier reported by FCs.⁴

The developmental-contextual model of dyads coping with illness proposes that dyads should work together as a unit to appraise, cope, and adjust to the illness experience. The dyadic reaction to an illness, like cancer, has an impact on the adjustments of both patients and their FCs. Spouses may react to the patients' illness in similar or different ways than the patients which can affect the ways that dyads cope.¹⁵ Therefore, congruence between patients' and FCs' beliefs and attitudes towards pain management may influence their communications about coping with and management of the patients' pain.

Only two studies evaluated the congruence between patient and FC dyads' concerns and attitudes towards pain and pain management.^{16, 17} In one study,¹⁷ barriers to pain management were evaluated in a sample of 35 palliative cancer patients and their FCs before admission to hospice. Only a weak correlation was found between patients' and their FCs' ratings regarding fatalistic notions about treatment of cancer pain. In addition, no differences were found between patients' and FCs' scores on the BQ, except that patients reported higher scores on the subscale concerning the desire "to be a good patient". This finding suggests that either the patients or their FCs had a higher level of concern about reporting pain or the use of analgesics. The sample size

for this study was very small and it is not clear whether findings from palliative patients and their FCs can be generalized to oncology outpatients and their FCs.

In contrast to the study by Ward et al,¹⁷ in a study of 159 oncology outpatients and their FCs,¹⁶ statistically significant correlations were found between dyads on all of the subscales and the total BQ score. The highest correlations were found for the “Addiction” ($r = .48$) and “Side-effects” ($r = .48$) subscale scores. In addition, patients scored significantly higher on the subscales “Distracting the medical doctor”, “Tolerance”, “Religious beliefs”, “Medication should be taken as needed (PRN)”, and total BQ scores.

Given the paucity of research on the congruence between patients’ and FCs’ perceptions of barriers to effective cancer pain management and the notion that a lack of congruence in dyadic concerns may result in poorer pain control, the purposes of this study, in a sample of oncology outpatients and their FCs were to examine the strength of the associations between patients’ and FCs’ responses to the BQ-II questionnaire and to evaluate which member of the dyad had higher subscale and total BQ scores. We hypothesized that patients and FC’s responses would be highly correlated and that no differences would be found in the subscale and total BQ scores between patients and FCs.

Methods

Sample and data collection

This descriptive, cross-sectional study is part of a larger epidemiologic study of cancer pain management¹⁸⁻²⁰ that evaluated the occurrence and characteristics of pain and analgesics use in a large oncology outpatient clinic in Norway. Patients ($n=217$) were recruited from outpatient oncology clinics (i.e., general, gynecology, lung, pain, chemotherapy (CTX), and radiotherapy (RT)) in a large, tertiary referral cancer hospital in Norway. Most of the patients at this facility had solid tumors and required RT and/or complex CTX regimens for treatment of primary or

metastatic disease. Some of the patients were seen for regular follow-up visits. Patients were included if they were >18 years of age; had a diagnosis of cancer; self-reported pain of any intensity and/or use of analgesics; and were able to read, write, and understand Norwegian.

Patients who consented to participate were asked if the researcher could contact their FC to obtain their consent to participate in the study. A total of 97 patients gave their permission to contact their FC. The FC were given written information about the study and provided written informed consent. A total of 71 FCs consented and completed the study questionnaires, a response rate of 73%. Only patients with a FC who consented to participate were included in the study. This study was approved by the Regional Ethics Committee, the Norwegian Radium Hospital's protocol review system and the data inspectorate.

Instruments

Demographic and disease specific characteristics

Demographic data for both the patients and the FCs included gender, age, marital status, educational level, employment status, and the relationship between the patient and the FC. To obtain data on cancer diagnosis and the presence of metastasis, a physician or a research assistant reviewed the patients' medical records. Patients' functional status was measured by self-report using the Karnofsky Performance Status (KPS) scale.²¹⁻²³ The KPS score in this study ranged from 40 (disabled, need special help and care) to 100 (adequate health status with no complaints and no evidence of disease). The KPS is a valid and reliable self-report measure of the functional status of patients with cancer.

Barriers questionnaire (BQ-II)

The 27- item BQ-II is the revised version of the BQ that measures beliefs about cancer pain and the use of analgesics that can act as barriers to pain management.⁷ Participants rated the

extent to which they agreed with each statement on a Likert scale that ranged from 0 (do not agree) to 5 (agree very much) with higher scores indicating stronger barriers. In order to compare the results to prior studies^{15,16} the subscales “Addiction”, “Tolerance”, “Fatalism”, “Side-effects”, “Desire to be good” (e.g., good patients do not complain about pain), and “Distracting the medical doctor” are the same as the original BQ. The more recent subscales of the BQ-II are “Monitoring (e.g., analgesics may block or mask one’s ability to monitor symptoms) and “Immune function”.⁷ The subscale and total scores can range from 0 to 5. In this study, the total score for the Norwegian version of the BQ-II had a Cronbach’s alpha of 0.89.⁸

Pain characteristics

The Brief Pain Inventory (BPI)²⁴ was used to evaluate pain intensity, pain interference, and pain relief in the last 24 hours. Pain intensity scores were rated using a 0 (no pain) to 10 (worst pain imaginable) numeric rating scale (NRS). Pain relief was rated on a 0% (no relief) to 100% (completely relief) NRS. Pain interference with seven functions was measured using 0 (does not interfere) to 10 (completely interference) NRSs. The Norwegian version of the BPI has satisfactory psychometric properties.²⁵ Categories of pain severity were determined from the worst pain intensity scores (i.e., 1 to 4 is mild pain, 5 to 6 is moderate pain, and 7 to 10 is severe pain).²⁶

Statistical analyses

All analyses were done using the Statistical Package for the Social Sciences (SPSS Inc., Chicago, Illinois) version 20. Descriptive statistics were used to present demographic and clinical characteristics of the patients and demographic characteristics of the FCs, as well as the scores from the individual BQ-II items. To identify differences between patients’ and FCs’ ratings, paired t-tests were done on the subscales and the total BQ-II scores and matched paired Wilcoxin tests were done on the individual ordinal BQ-II items. In addition, correlations were done to

explore the strength of the associations between patients' and the FCs' ratings for the subscale and total BQ-II scores. A p -value of < 0.05 was considered statistically significant.

Results

Characteristics of the sample

Patients' demographics and clinical characteristics are shown in Table 1. The majority of the patients were female and married with a mean age of 56.0 years ($SD = 12.0$), and a range from 24 to 86 years. The majority were not employed and had a secondary school or university education. The majority had breast cancer and half of the sample had metastatic disease. The mean KPS score was 74.7 ($SD = 11.5$), with a range from 40 to 90.

The majority of the FCs were male and worked either full or part-time and their mean age was 55.1 ($SD = 11.0$), with a range from 23 to 78 years. Ninety percent were married to the patient (Table 1). Fifty-seven percent of the patients were characterized as having moderate or severe pain. Total pain interference with function was 4.2 ($SD = 2.3$), with a range from 0 to 9. The patients had a mean pain relief score of 59.7% ($SD = 29.9$) (Table 2).

Differences in patients' and FCs' ratings of the BQ-II items, subscales, and total scores

Except for the "Fatalism" subscale of the BQ-II, no differences in mean scores were found between patients and FCs on any of the subscales or total scores (Table 3). However, although not large in magnitude, the correlation between patients' and their FCs' scores were statistically significant for the "Tolerance", "Immune system", "Side effects", "Distract the MD" subscales as well as the total BQ-II scores (Table 3). In addition, compared to FCs, patients reported higher scores on one "Addition" item, two "Monitoring" items, and two "Desire to be good" items. FCs reported higher scores than the patients on one "Fatalism" item and one "Side-effect" item (Table 4).

Discussion

This study is one of the first to evaluate congruence between cancer patients' and their FCs' ratings of barriers to pain management. Except for fatalism, patients and FCs did not differ in average magnitude. Although none of the correlations are very strong, the dyads were significantly correlated in their ratings for four out of seven subscales (i.e., "Tolerance", "Immune system", "Distract the MD", "Side-effects"), as well as the total BQ-II scores. These findings are in sharp contrast to a previous study that found that dyads were only congruent on the fatalism subscale of the BQ.¹⁷ However, they are consistent with a more recent study that found congruence in five out of 9 subscales (i.e., "Fatalism", "Addiction", "Desire to be good", and "Side-effects", "Disease progression").¹⁶ These inconsistent findings may be partially explained by the fact that the study by Ward et al¹⁷ was published over 18 years ago. In the past two decades, oncology clinicians have focused on improving pain management²⁷ and involving FCs in pain management.^{4,28,29} Another reason for the inconsistent findings can be variations in gender distribution among the studies. In our study, 80% of the patients were female, whereas the 2 previous studies both had a distribution of 59% female patients.^{16,17} Education of both patients and FCs about concerns and negative attitudes towards pain management in both members of the dyads.^{30,31} may lead to more congruence between patients' and their FCs' concerns and attitudes towards pain and pain management.

For three of the subscales (i.e., "Desire to be good", "Monitor", "Addiction"), no differences in mean scores or significant correlations were found. This finding suggests that in a given dyad it is equally possible for the patient or the FC to have greater concerns. To explain this finding further, we evaluated for dyadic differences in scores for the single items on each of these subscales (Table 4). For the "Desire to be good" subscale, patients had higher barrier scores

for two of the items that concerned talking about pain. One explanation may be that patients do not want to distress their FCs further by talking about their pain. This hypothesis is supported by the fact that less than half of the patients gave consent to enroll their FC in the study. Many patients explained that they did not want to increase the strain their FCs were experiencing. In addition, a previous study found that because patients do not want to upset their loved ones, they avoid talking about their feelings and concerns.³²

For the “Monitor” subscale, patients scored higher than their FCs on one item that addressed pain medications’ ability to block new pain and another that addressed the ability of pain medicines to mask changes in their health. One explanation could be that the patients wanted to be able to monitor changes in the status of their cancer. Previous research found that oncology patients often associate pain with cancer progression.^{33 34} Therefore, they may be unwilling to take a sufficient amount of pain medication to be able to identify changes in their medical condition. This hypothesis is supported by the fact that patients in this study reported only about 60% pain relief and that for 57% of the patients their pain was in the moderate to severe range.

For the “Addiction” subscale, patients scored higher than their FCs on the item that stated that pain medicine is very addictive. However, prior studies found that both patients and their FCs are most concerned about addiction.^{9, 12, 13, 35} Myths and fears about opioid use remain widespread across cultures and across care settings.⁴ Antidrug campaigns that attempt to combat trafficking and demand for illicit drugs as well as abuse of prescription opioids may contribute to the perception that analgesics are dangerous even when they are used for the management of cancer pain.

Consistent with previous studies,^{7, 16, 17, 34, 36-41} both patients and FCs in Norway have barriers to pain management that may contribute to inadequate pain management. An examination of differences in patients’ and FCs’ BQ scores, between the Norwegian sample and

other samples found some differences. For example, medium to large differences in total BQ scores were found between the Norwegian FCs and FCs in 2 studies from Taiwan in which Taiwanese cancer patients reported higher barriers scores (effect sizes -0.42^{16} and -0.57^{11}) and FCs from the United States reported lower barrier scores (effect size 0.29^{17}).⁴² In terms of patients' total BQ scores, Norwegian patients' scores were a bit lower compared to both Danish patients (effect size -0.25)⁴¹ and those of Asian patients from 3 different studies (effect sizes -0.63^{16} , -1.12^{38} and -0.63^{40}). When the Norwegian patients' scores were compared to patients in the United States, the results are inconsistent. Some studies from the United States reported lower BQ scores than the Norwegian sample (effect sizes 0.75^{7} , 0.25^{17} , and 0.25^{36}), while another found a slightly higher BQ score in the United States (effect size -0.25^{34}).

Meekers and colleagues⁴ concluded in their review about the FCs' role in cancer pain management that FCs need education about pain management, training in problem-solving skills, and recognition from clinicians about their role in pain management. When clinicians better understand and respond to the needs of FCs, they can enhance the quality of life and care outcomes for both patients and their FCs.⁴ Oncology nurses need to be aware that patients and FCs may benefit from being coached together about barriers as both patients and their FCs are involved in pain management. In a study by Rustøen et al.,²⁹ they used a short knowledge and attitude survey (i.e., the Pain Experience Scale (PES)⁴³), as part of a psychoeducational intervention. The PES provided an effective foundation for patients' and FCs' education about cancer pain management. Nurses can use this individualized approach to educate patients and FCs about pain management. The use of the PES to focus educational content may save staff time and improve patient outcomes. Because a cancer patients' pain experience may disrupt family communication,^{32,44} it is important to talk to both patients and their FCs together.

Several study limitations need to be acknowledged. The study was cross-sectional and did not allow for an evaluation of changes over time in patients' and FCs' congruence in attitudes and concerns about pain management. In addition, because only a single site was used for recruitment, these findings may not generalize across other settings. Finally, because only one third of the patients gave permission to ask their FC to participate in this study, the findings may not generalize to all FCs on oncology patients with pain. It may be that the FCs with the highest barriers were not included in the present study. A similar study with a larger sample may detect additional differences between patients and their FCs.

Additional research is needed to examine whether increased congruence in patients' and FCs' barriers to pain management can enhance the dyadic adjustment as proposed by the developmental-contextual model.¹⁵

References

1. van den Beuken-van Everdingen MHJ, de Rijke JM, Kessels AG, Schouten HC, van Kleef M, Patijn J. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol.* 2007;18(9):1437-1449.
2. Cherny NI. *Wall and Melzack's Textbook of Pain*. Fifth ed: Elsevier Churchill Livingstone 2006.
3. Ferrell B, Hanson J, Grant M. An overview and evaluation of the oncology family caregiver project: improving quality of life and quality of care for oncology family caregivers. *Psycho-Oncology.* 2013;22(7):1645-1652.
4. Meeker MA, Finnell D, Othman AK. Family Caregivers and Cancer Pain Management: A Review. *J Fam Nurs.* 2011;17(1):29-60.
5. Wadhwa D, Burman D, Swami N, Rodin G, Lo C, Zimmermann C. Quality of life and mental health in caregivers of outpatients with advanced cancer. *Psycho-Oncology.* 2013;22(2):403-410.
6. Valeberg BT, Grov EK. Symptoms in the cancer patient – Of importance for their caregivers' quality of life and mental health? *Eur J Oncol Nurs.* 2012(0).
7. 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.
8. Valeberg BT, Hanestad BR, Klepstad P, Miaskowski C, Moum T, Rustoen T. Cancer patients' barriers to pain management and psychometric properties of the Norwegian version of the Barriers Questionnaire II. *Scand J Caring Sci.* 2009;23(3):518-528.
9. Vallerand AH, Collins-Bohler D, Templin T, Hasenau SM. Knowledge of and barriers to pain management in caregivers of cancer patients receiving homecare. *Cancer Nurs.* 2007;30(1):31-37.
10. 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. *J Pain Symptom Manage.* 2008;36(4):374-382.
11. Lin CC, Wang P, Lai YL, Lin CL, Tsai SL, Chen TT. Identifying attitudinal barriers to family management of cancer pain in palliative care in Taiwan. *Palliat Med.* 2000;14(6):463-470.
12. Oldenmenger WH, Sillevs Smitt PAE, van Dooren S, Stoter G, van der Rijt CCD. A systematic review on barriers hindering adequate cancer pain management and interventions to reduce them: A critical appraisal. *Eur J Cancer.* 2009;45(8):1370-1380.
13. Bağçivan G, Tosun N, Kömürçü Ş, Akbayrak N, Özet A. Analysis of Patient-Related Barriers in Cancer Pain Management in Turkish Patients. *J Pain Symptom Manage.* 2009;38(5):727-737.
14. Chen CH, Tang ST, Chen CH. Meta-analysis of cultural differences in Western and Asian patient-perceived barriers to managing cancer pain. *Palliat Med.* 2012;26(3):206-221.
15. Berg CA, Upchurch R. A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol Bull.* 2007;133(6):920-954.
16. Lin C-C. Barriers to the analgesic management of cancer pain: a comparison of attitudes of Taiwanese patients and their family caregivers. *Pain.* 2000;88(1):7-14.
17. Ward SE, Berry PE, Misiewicz H. Concerns about analgesics among patients and family caregivers in a hospice setting. *Res Nurs Health.* 1996;19(3):205-211.

18. Valeberg BT, Miaskowski C, Hanestad BR, Bjordal K, Moum T, Rustoen T. Prevalence rates for and predictors of self-reported adherence of oncology outpatients with analgesic medications. *Clin J Pain*. 2008;24(7):627-636.
19. Valeberg BT, Miaskowski C, Hanestad BR, Bjordal K, Paul S, Rustøen T. Demographic, Clinical, and Pain Characteristics Are Associated With Average Pain Severity Groups in a Sample of Oncology Outpatients. *J Pain*. 2008;9(10):873-882.
20. Valeberg BT, Rustoen T, Bjordal K, Hanestad BR, Paul S, Miaskowski C. Self-reported prevalence, etiology, and characteristics of pain in oncology outpatients. *Eur J Pain*. 2008;12 (5):582-590.
21. Schag CC, Heinrich RL, Gannz PA. Karnofsky Performance Status revisited: Reliability, validity, and guidelines. *J Clin Oncol*. 1984;2:187-193.
22. Karnofsky D, Burchenal J. *The clinical evaluation of chemotherapeutic agents in cancer* New York: Columbia University Press; 1949.
23. Conill C, Verger E, Salamero M: Performance status assessment in cancer patients. *Cancer*. 1990;65:1864-1866.
24. Daut RL, Cleeland CS, Flanery RC. Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other diseases. *Pain*. 1983;17(2):197-210.
25. Klepstad P, Loge JH, Borchgrevink PC, Mendoza TR, Cleeland CS, Kaasa S. The Norwegian Brief Pain Inventory Questionnaire: Translation and validation in cancer pain patients. *J Pain Symptom Manage*. 2002;24(5):517-525.
26. Serlin RC, Mendoza TR, Nakamura Y, Edwards KR, Cleeland CS. When is cancer pain mild, moderate or severe? Grading pain severity by its interference with function. *Pain*. 1995;61(2):277-284.
27. Bennett Michael I, Bagnall Anne-Marie, Jose CS. How effective are patient-based educational interventions in the management of cancer pain? Systematic review and meta-analysis. *Pain*. 2009;143(3):192-199.
28. Miaskowski C, Dodd M, West C, et al. Randomized clinical trial of the effectiveness of a self-care intervention to improve cancer pain management. *J Clin Oncol*. 2004;1(22):13-20.
29. Rustøen T, Valeberg BT, Kolstad E, Wist E, Paul S, Miaskowski C. A Randomized Clinical Trial of the Efficacy of a Self-care Intervention to Improve Cancer Pain Management. *Cancer Nurs*. 2014;37(1):34-43.
30. Rustøen T, Valeberg BT, Kolstad E, Wist E, Paul S, Miaskowski C. The Pro-Self© Pain Control Program Improves Patients' Knowledge of Cancer Pain Management. *J Pain Symptom Manage*. 2012;44(3):321-330.
31. Valeberg BT, Kolstad E, Smastuen MC, Miaskowski C, Rustoen T. The PRO-SELF Pain Control Program Improves Family Caregivers' Knowledge of Cancer Pain Management. *Cancer Nurs*. 2012.
32. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate? *Health Commun*. 2003;15(4):415-429.
33. Ferrell BF, Johnston Taylor E, Sattler GR, al e. Searching for the meaning of pain: Cancer patients', caregivers' and nurses' perspectives. *Cancer Practice*. 1993;1:185-194.
34. Dawson R, Sellers DE, Spross JA, Jablonski ES, Hoyer DR, Solomon MZ. Do patients' beliefs act as barriers to effective pain management behaviors and outcomes in patients with cancer-related or noncancer-related pain? *Oncol Nurs Forum*. 2005;32(2):363-374.

35. Naveh P, Leshem R, Dror YF, Musgrave CF. Pain Severity, Satisfaction With Pain Management, and Patient-Related Barriers to Pain Management in Patients With Cancer in Israel. *Oncol Nurs Forum*. 2011;38(4):E305-313.
36. Ward S, Hernandez L. Patient - related barriers to management of cancer pain in Puerto Rico. *Pain*. 1994;58:233-238.
37. Wills BSH, Wotton YSY. Concerns and misconceptions about pain among Hong Kong Chinese patients with cancer. *Cancer Nurs*. 1999;22(6):408-413.
38. Chung T, French P, Chan S. Patient-related barriers to cancer pain management in a palliative care setting in Hong Kong. *Cancer Nurs*. 1999;22(3):196-203.
39. Lin C-C. Congruity of Cancer Pain Perceptions Between Taiwanese Patients and Family Caregivers: Relationship to Patients' Concerns About Reporting Pain and Using Analgesics. *J Pain Symptom Manage*. 2001;21(1):18-26.
40. Edrington J, Sun A, Wong C, et al. Barriers to Pain Management in a Community Sample of Chinese American Patients with Cancer. *J Pain Symptom Manage*. 2009;37(4):665-675.
41. Jacobsen R, Møldrup C, Christrup L, Sjøgren P, Hansen OB. The Danish Barriers Questionnaire-II: Preliminary Validation in Cancer Pain Patients. *Pain Practice*. 2009;9(4):266-274.
42. Cohen J. *Statistical power analysis for the behavioral sciences*; 1988.
43. Ferrell BR, Rhiner M, Rivera LM. Development and evaluation of the family pain questionnaire. *Psychosoc Oncol*. 1993;10(4):21-35.
44. Glajchen M, Fitzmartin RD, Blum D, Swanton R. Psychosocial barriers to cancer pain relief. *Cancer Pract*. 1995;3(2):76-82.

Table 1. Demographic Characteristics of the Patients (n=71) and their Family Caregivers (n=71) and Clinical Characteristics of the Patients

Characteristics	Patients		Family Caregivers	
	Mean (SD)		Mean (SD)	
Age (years)	56.0 (12.0)		55.1 (11.0)	
Karnofsky Performance Status score	74.7 (11.5)			
	N	%	N	%
Gender				
Male	14	20	53	75
Female	55	80	18	25
Education				
Primary school	8	12	10	14
Secondary school	30	44	28	41
College/University	30	44	31	45
Work				
Full/part time	11	16	46	65
Sick leave	24	35	4	6
Disability/rehabilitation	23	33	10	14
Retired	11	16	10	14
Unemployed	0	0	1	1

Marital status				
Married	68	96	64	90
Single	1	1		
Widowed	2	3		
Unknown			7	10
Cancer diagnosis				
Breast	23	35		
Prostate	5	7		
Colon	7	10		
Gynecologic	8	11		
Head and neck	8	11		
Other	18	26		
Metastasis				
Yes	35	50		
No	35	50		

Abbreviation: SD, standard deviation

Table 2. Pain Characteristics of the Patients (n=71)^a

Pain Characteristics			
Pain intensity (0 to 10)			
Pain now		3.5	(2.7)
Least pain		2.3	(2.0)
Average pain		4.3	(2.0)
Worst pain		4.9	(2.3)
Pain interference (0 to 10)			
Daily activity		4.8	(2.9)
Mood		4.0	(2.8)
Walking ability		3.9	(3.3)
Normal work		5.3	(3.1)
Relations with other people		3.5	(2.9)
Sleep		4.1	(3.1)
Enjoyment of life		3.9	(2.9)
Total interference		4.2	(2.3)
Pain relief (0% to 100%)		59.7	(29.9)
		N	%
Pain severity			
Mild (1-4)		29	43
Moderate (5-6)		22	32

Severe (7-10)	17	25
---------------	----	----

^a Values given are mean (SD)

Abbreviation: SD, standard deviation

Table 3. Differences in Patients' and Family Caregivers' Subscale and Total BQ-II scores

Subscales for BQ-II	Patients	Family Caregivers	Paired T-test	Correlation
	Mean (SD)	Mean (SD)	t	r
Addiction	3.4 (1.2)	3.1 (1.1)	1.86	.19
Monitor	3.1 (1.3)	2.7 (1.1)	1.81	.15
Tolerance	2.5 (1.2)	2.3 (1.1)	.70	.28 ^a
Immune system	2.2 (1.4)	1.9 (1.2)	1.12	.31 ^a
Side effects	1.6 (1.1)	1.5 (1.1)	.26	.35 ^a
Be good	1.1 (1.1)	1.4 (1.1)	-1.85	.15
Distract the MD	1.1 (1.1)	1.2 (1.2)	-.43	.24 ^a
Fatalism	0.9 (0.7)	1.2 (0.8)	-2.05 ^a	.23
Total BQ II score	2.1 (0.8)	2.0 (0.7)	.93	.41 ^b

^a p = .05^b p = .01

Abbreviations: BQ - II, Barriers Questionnaire - II ; MD, medical doctor ; SD, standard deviation.

Table 4. Differences in Patients' and Family Caregivers' Ratings of the Single Items on the Barriers Questionnaire -II (n=71) ^a

Individual Items in the Subscales of the Barriers Questionnaire - II	Patients	Family caregivers	p-value
Addiction			
There is a danger of becoming addicted to pain medicine	3.8 (1.4)	3.5 (1.4)	.09
Many people with cancer get addicted to pain medicine	3.3 (1.5)	3.1 (1.4)	.25
Pain medicine is very addictive	3.1 (1.4)	2.7 (1.4)	.05
Monitor			
Using pain medicine blocks your ability to know if you have any new pain	3.3 (1.4)	2.9 (1.3)	.05
Pain medicine can mask changes in your health	3.2 (1.7)	2.7 (1.4)	.04
Pain medicine can keep you from knowing what's going on in your body	2.8 (1.7)	2.7 (1.4)	.76
Tolerance			
When you use pain medicine your body becomes used to its effects and pretty soon it won't work any more	3.2 (1.5)	2.8 (1.2)	.10
If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse	2.3 (1.7)	2.3 (1.4)	.72
If you use pain medicine now, it won't work as well if you need it later	2.0 (1.6)	2.0 (1.4)	.71
Immune system			
Pain medicine weakens the immune system	2.3 (1.6)	2.3 (1.4)	.94
Using pain medicine can harm your immune system	2.2 (1.5)	1.9 (1.4)	.36
Pain medicine can hurt your immune system	2.1 (1.5)	1.7 (1.3)	.07

Be good			
If I talk about pain, people will think I'm a complainer	2.2 (1.7)	1.6 (1.5)	.04
It is important to be strong by not talking about pain	1.6 (1.8)	1.0 (1.4)	.02
Doctors might find it annoying to be told about pain	1.2 (1.4)	1.5 (1.5)	.19
Side-effects			
Drowsiness from pain medicine is difficult to control	3.1 (1.6)	3.3 (1.1)	.65
Confusion from pain medicine cannot be controlled	2.6 (1.5)	2.4 (1.2)	.45
It is easier to put up with pain than with the side effects that come from pain medicine	2.1 (1.6)	2.2 (1.4)	.71
Pain medicine makes you say or do embarrassing things	1.1 (1.4)	1.8 (1.5)	<.01
Nausea from pain medicine cannot be relieved	1.8 (1.4)	1.6 (1.2)	.45
Constipation from pain medicine cannot be relieved	1.4 (1.4)	1.4 (1.2)	.78
Fatalism			
Pain medicine can not effectively control cancer pain ^b	1.1 (1.0)	1.6 (1.0)	.01
Cancer pain can not be relieved ^b	0.9 (1.0)	1.1 (1.0)	.29
Medicine can not relieve cancer pain ^b	0.8 (0.8)	0.8 (0.9)	1.0
Distracting the medical doctor			
It is important for the doctor to focus on curing illness, and not waste time controlling pain	1.7 (1.9)	1.5 (1.8)	.37
If doctors have to deal with pain they won't concentrate on curing the disease	0.9 (1.3)	1.0 (1.3)	.79
Reports of pain could distract a doctor from curing the cancer	0.7 (1.1)	1.0 (1.3)	.11