

Cancer Pain: Knowledge and Experiences from the Perspective of the Patient and their Family Caregivers

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Abstract

Aim: The aim of this study which is descriptive and comparative design was to examine knowledge and experiences regarding cancer pain in a Turkish population from the perspective of the patient and their family caregivers.

Methods: Thirty-one cancer patients and 31 family caregivers completed the pain questionnaire in a sample who had been hospitalized in oncology and bone marrow transplantation center of a large Turkish university hospital. Descriptive statistics were used to analyse demographic variables within the sample whilst Pearson's correlation coefficients and paired-sample t-tests were used to compare patient and family caregiver scores on the pain questionnaire.

Results: Of the participating patients with cancer pain and their family caregivers, the majority were women (patient: 67.7% , family caregivers: 64.5%), 51.6% of the patients were aged 51 and over, and 45.2% of the family caregivers were in the 31-50 age group. In the evaluation of the study findings were found as 6.28 (SD=0.79) mean score of the patients' total pain knowledge and as 6.30 (SD=0.76) mean score of the family caregivers' total pain knowledge.

Conclusion: The study results showed that the total pain knowledge of cancer patients and their family caregivers is inadequate level. Also, there are no differences between the knowledge and experiences of patients and family caregivers. Nurses should play a vital role in the assessment of cancer pain and argue for greater support and better education for patients and their family caregivers in relation to all aspects of cancer pain.

Keywords: cancer patient, experience, family caregivers, knowledge, nursing, pain

1. INTRODUCTION

Cancer, one of the chronic diseases, is a major health problem in terms of morbidity and mortality in almost every country. At the turn of the century, cancer was seventh-eighth in the list of most deadly diseases. Today, it is second on the list after cardiovascular diseases (1,2,3).

Every year cancer shows an increase of 2 % and kills, on average, 5 million people (2). Patients, their families and society are negatively affected physically, psychologically, socially and economically. Members of health teams providing care and treatment are also negatively affected (1,4,5).

Cancer patients experience intense symptoms such as pain, dyspnoea, fatigue, anorexia, cachexia, changes in taste and alopecia as a

result of the natural course of the illness itself, or also as side effects of treatment such as chemotherapy and radiotherapy (4,5,6,7). Of these symptoms, which cause trouble for patients and their families, pain is one of the most widely seen in palliative care. It is estimated that 30-70% of cancer patients with metastatic disease and 60-95% of patients in the terminal stage suffer pain (8,9,10). Cancer pain is a complex concept which is affected by both medical and psychosocial variables and by many contributing factors such as size of the tumour, treatment/procedure, infection and vascular problems (11,12).

Cancer-related pain can be the cause of unwelcome circumstances in the patient's functions such as reduced capacity to sleep and

concentrate and an increased level of fatigue and anxiety resulting in a decline in quality of life (13,14,15). Alongside this, cancer pain has undesirable effects on the families of patients. Families feel inadequate in pain relieving processes, experience fear and worry regarding dependence, and feel helpless with regard to the management of pain. Family members also encounter stress in the later stages of the disease related to the burden of providing care, demands of pain management and inability to relieve the pain (16,17).

Such an issue as cancer pain, that brings about such negative and unwelcome consequences for patients and their families, naturally requires considerable knowledge. Studies made on the subject have shown the importance of patients' and families' knowledge and experience in the management of cancer pain and they have shown that families, in particular, confront difficulties in this regard (16). In the literature on the topic, the results of studies performed have indicated that there are differences between the knowledge and experience (of cancer pain) of patients and those of their families (18). The fact that families of patients have been found to play an important role in the management of cancer pain must not be ignored. Families should be supported in their task of pain management by a multidisciplinary team, involving nurses as well, and the pain management must be effectively carried out so that their stress can be reduced (16). Of great importance is minimizing the differences between the knowledge and experiences of patients and that of families, and also improving communication regarding cancer pain (18,19). In the light of all this information, the planned objective of this study is to examine knowledge and experiences regarding cancer pain from the perspective of the patient and the patients' family caregivers.

2. METHODS

2.1. Sample, Setting and Ethical Consideration

The comparative and descriptive design were used to perform the study. This study was carried out in the oncology and bone marrow transplantation center at a large university hospital in Izmir, Turkey. A total of 62 participants (31 patient with cancer pain and 31 their family caregivers) participated in this study.

The study was approved by the ethics committees of the university faculty of nursing.

Permission to conduct this study written consent was obtained from the oncology and bone marrow transplantation center review board. Also, permission to use the scale in this study was obtained from the developer before starting this study. Patients and their family caregivers were invited to participate in the study and were informed before written consent was obtained. All were given information about opportunities to withdraw from the study and told that there would be no disadvantages if they chose to withdraw from the study.

2.2. Study Instruments

The data were collected by using four forms: patient identification form, the patient pain questionnaire, the family identification form and the family pain questionnaire.

Patient Identification Form: The form was developed by the authors to obtain data related to patients' socio-demographic (age, gender, marital status, education, occupation, economic circumstances etc) and illness-related variables (diagnosis of the disease, chronic illnesses apart from cancer, length of disease, type of treatment, etc) as well as on cancer pain (description of the pain, factors which increase or decrease the pain, methods used to control the pain, required information relating to pain treatment).

The Patient Pain Questionnaire (PPQ): This form was developed by Ferrell and contains the headings "knowledge on cancer pain" and "experience with cancer pain". Under the "knowledge" heading there are 9 questions and under the "experience" heading there are 7 questions. All items in the scale are scored on between 0 point and 10 point basis (20).

The validity and reliability of the tool for the Turkish population was conducted by Yildirim (2006a) Cronbach' alpha was 0.66 for the total scale. For second implication the internal consistency reliability Cronbach's alpha was 0.65 for the total scale. The test-retest interval correlation coefficient for total scale was 0.96 (29).

Cronbach alpha coefficient for the PPQ was 0.74, and reliability coefficient was 0.65 (20).

Family Identification Form: The form was developed by the authors to obtain data related to patients' family caregivers' socio-demographic variables (such as age, gender, marital status and education). Besides descriptive information, the questions also address necessary information about the method

used to dispel the patient’s pain and pain management.

The Family Pain Questionnaire (FPQ): This questionnaire was developed by Ferrell to determine the knowledge and experiences of families of patients suffering from cancer pain. It consists of 16 questions under the headings “knowledge” and “experience”. The questionnaire is scored in the same way as the Patient Pain Questionnaire (21).

The validity and reliability of the FPQ for the Turkish population was conducted by the authors with 58 patients’ family caregivers who were not included in the main sample. Cronbach alpha coefficient for the FPQ was 0.60.

Ferrell et al. found the tools’ Cronbach alpha coefficient for the FPQ was 0.60, and reliability coefficient was 0.80 (21).

2.3. Data Collection

Patients and their family caregivers attending the inpatient unit were informed about the aims and objectives of the study and if they expressed an interest in participating, the researcher provided either verbal or written information about the study as requested. A convenience sample of patients and their family caregivers were obtained from all participants who were receiving treatment in the inpatient unit. The inclusion criteria for patients were a) inpatient treatment, b) experiencing pain at least once in last one month, c) age 18 years or more, d) no auditory or visual impairment, and e) able to speak, read, write Turkish language, f) willingness to participate in the study. The criteria for participation of primary family caregivers included the following: a) identified by the patient as being the person who provided

the most physical and/or emotional support during their illness, b) able to speak, read, write Turkish language, c) was willing to participate to study.

2.4. Statistical Analysis

Data analysis was performed using SPSS software (version 11.0 of the SPSS). Descriptive statistics, means, frequencies, and percentages were used to show the distribution of socio-demographic of patients and their family caregivers, illness-related characteristics, and questionnaire scores. In comparing the mean score of patients and their caregivers was used independent *t*- test.

Furthermore, the relationship between patient and family caregivers scores was examined using Pearson’s correlations. For all statistical analyses the significant levels were set as *p*< 0.05.

3. RESULTS

The sociodemographic variables for the 31 patients and their family caregivers in the study are summarized in Table 1. The mean age of patients was 53.35 years (SD=10.89) and 67.7% of the participants were female. Most patients (77.4%) were married. Less than half the patients had completed their primary school education (51.6%) and all patients (100%) were unemployed. Patients taking part in the study had predominantly been diagnosed with breast cancer (48.4%) and were receiving chemotherapy treatment (93.5%).

The mean age of their family caregivers age was 40.13±14.31, 64.5% of the participants were female, and 54.8% were married, 35.5% had completed university education (Table 1).

Table1. Socio-Demographic Variables

Variables	Patient n (%)	Family Caregivers n (%)
Age (Mean±SD)	(X=53.35±10.89)	(X=40.13±14.31)
30 years and below	-	11 (35.5)
31-50 years	15 (48.4)	14 (45.2)
51 years and above	16 (51.6)	6 (19.3)
Gender		
Female	21 (67.7)	20 (64.5)
Male	10 (32.3)	11 (35.5)
Marital status		
Single	-	12 (38.7)
Married	24 (77.4)	17 (54.8)
Divorced/widowed	7 (22.6)	2 (6.5)
Education status		
Able to read and write	1 (3.2)	1 (3.2)
Primary school	16 (51.6)	9 (29.0)

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Secondary school	7 (22.6)	10 (32.3)
University	7 (22.6)	11 (35.5)
Work status		
Unemployed	31 (100.0)	22 (71.0)
Employed	-	9 (29.0)

In this study all of the patients said that not experiencing pain during the data collection. But ten patients who were found to have experienced pain were asked what they used to cope with it. Thirty percent stated that they

Table2. *Methods for Coping with Pain*

Methods (n=10)	Patient	
	n	%
Medication	3	30.0
Herbal product	2	20.0
Massage	3	30.0
Massage + Herbal product	2	20.0

Mean Scores of Each Items

Comparison of pain knowledge, experience scores for each items, both patients and their family caregivers are showed in Table 3. As seen that there were not significant differences in all items ($p > 0.05$). Similar results were

Table3. *Comparison of patients' and family caregivers' scores for each items on questionnaire*

	Patient (P)	Family Caregiver (FC)	t/p
Pain Knowledge (Sub-Dimension)	Mean (SD) 6.85±1.20	Mean (SD) 6.75±1.12	t:0.39 p:0.69
4. Cancer pain can be effectively relieved.	1.03±1.49 (0=agree, 10=disagree)	2.03±2.84 (0=agree, 10=disagree)	t: -1.76 p: 0.08
5. Pain medicines should be given only when pain is severe.	8.13±2.76 (0=disagree, 10=agree)	7.81±3.15 (0=disagree, 10=agree)	t: 0.59 p: 0.55
6. Most cancer patients on pain medicines will become addicted to the medicines over time.	8.52±1.84 (0=disagree, 10=agree)	8.16±2.72 (0=disagree, 10=agree)	t: 0.76 p: 0.45
7. It is important to give lowest amount of medicine possible to save larger doses for latter when the pain is worse.	8.68±1.75 (0=disagree, 10=agree)	8.19±2.21 (0=disagree, 10=agree)	t: 1.22 p: 0.23
8. It is better to give pain medications around the clock (on a Schedule) rather than only when needed.	6.39±3.74 (0=agree, 10=disagree)	5.71±3.73 (0=agree, 10=disagree)	t: 1.00 p: 0.32
9. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.	4.65±3.44 (0=agree, 10=disagree)	4.81±3.97 (0=agree, 10=disagree)	t: -0.21 p: 0.83
10. Pain medicines can be dangerous and can often interfere with breathing.	7.55 ± 3.11 (0=disagree, 10=agree)	7.55±3.18 (0=disagree, 10=agree)	t: 0.00 p: 1.00
11. Patients are often given to much pain medicine.	8.65±1.79 (0=disagree, 10=agree)	8.61±1.92 (0=disagree, 10=agree)	t: 0.07 p: 0.93
12. If pain is worse, the cancer must be getting worse.	8.10±3.07 (0=disagree, 10=agree)	7.94±3.21 (0=disagree, 10=agree)	t: 0.23 p: 0.81
Pain Experience (Sub-Dimension)	5.56±0.97	5.71±0.76	t: -0.91 p: 0.36
1. Over the past week, how much	5.10±2.21	4.94±1.87	t: 0.38

taken their medications. In addition to taking medications, other measures used included using herbal product and making massage (Table 2).

found for each subscales (knowledge, experience) and total questionnaire (Patient= knowledge scores (KS): 6.85 (SD= 1.20) / experience scores (ES): 5.56 (SD= 0.97) / Family caregivers= KS: 6.75 (SD=1.12), ES: 5.71(SD= 0.76) ($p > 0.05$).

pain have you had? (P)/Over the past week, how much pain do you feel your family member has had? (FC)	(0=no pain, 10=a great deal)	(0=no pain, 10=a great deal)	p: 0.70
2. How much pain are you having now? (P)/How much pain is your family member having now? (FC)	4.61±2.29 (0=no pain, 10=a great deal)	5.16±1.86 (0=no pain, 10=a great deal)	t: -1.56 p: 0.12
3. How much pain relief are you currently receiving? (P)/How much pain relief is your family member currently receiving? (FC)	1.39±1.47 (0=a great deal, 10= no relief)	1.48±1.63 (0=a great deal, 10=no relief)	t: -0.28 p: 0.77
4. How distressing is the pain to you? (P)/How distressing do you think the pain is to your family member? (FC)	9.23±2.09 (0=not at all,10=extremely)	9.23±1.70 (0=not at all, 10=a great deal)	t: 0.00 p: 1.00
5. How distressing is your pain to your family members? (P)/How distressing is your family members' pain to you? (FC)	9.39±1.58 (0=not at all, 10=extremely)	9.58±1.08 (0=not at all, 10=a great deal)	t: -0.70 p: 0.48
6. To what extent do you feel you are able to control your pain? (P)/To what extent do you feel you are able to control the patient's pain? (FC)	2.06±2.06 (0=extremely, 10=not at all)	2.45±2.01 (0=a great deal, 10=not at all)	t: -0.77 p: 0.44
7. What do you expect will happen with your pain in the future? (P)/What do you expect will happen with your family member's pain in the future? (FC)	7,16±2.45 (0=pain will get better; 10=pain will get worse)	7.16±2.79 (0=will get better; 10=will get worse)	t: 0.00 p: 1.00
Total questionnaire	6.28±0.79	6.30±0.76	t: -0.09 p: 0.92

4. CORRELATION

There was a poor level positive correlation ($r:0.49$, $p< 0.01$) between patients' and family caregivers' scores for fifth items on pain knowledge questionnaire. Also, patients' score for second items on pain knowledge questionnaire was significantly correlated with family caregivers' score ($r: 0.57$; $p< 0.01$) (not shown in a table).

5. DISCUSSION

Despite significant progress in pain management, cancer pain still cannot be successfully managed in all patients. Insufficient management of cancer pain can lead to undesirable conditions such as impairment of functions, growing tiredness and reduced quality of life. Controlling cancer pain is a complicated process that involves the patient, the family and the healthcare service providers (14). The cancer pain knowledge and experiences of patients and their family caregivers are very important factors in this process.

In this study, where knowledge and experience in cancer pain from the point of view of patients and family caregivers was examined, a majority of cancer patients with pain suggested that changing position or taking analgesics would

relieve the pain, and that moving or eating would increase it. This result is considered to be an important indicator for nurses, who are in a critical position in pain management, in their provision of appropriate pain care services. Nurses can help to relieve the patient's pain, and thus the need for analgesics, by very easy non-pharmacological interventions such as changes of position. Contrary to this opinion of ours, Chung, Wong, & Yang, (2000) stated that nurses believe analgesics are the most effective method of easing the patient's pain. However, it is purported in the literature that pharmacological intervention alone will not be sufficient to ensure pain control, and that the pain can be much more effectively managed with a combination of pharmacological and non-pharmacological approaches (23).

Cancer pain considerably restricts patients' daily living activities (15,17,24). Therefore, it is a natural consequence that patients state that activities such as moving, eating and drinking increase the pain that patients experience.

It was determined that patients and their family caregivers aiming to relieve or eliminate pain, use, along with various study results and literature knowledge, also massages, herbal products and massage plus herbal products. In

Yıldırım's study (2006a) was found that in order to ease the pain, besides taking drugs, patients massage the aching part of the body, or completely or partially immobilize the entire body, or just certain parts, and position some particular body parts. Işıkhan et al. (2005) found that herbal products and massages are options often used by cancer patients to relieve pain. It is said that massages enable relaxation for cancer patients by decreasing the perception of the severity of the pain and anxiety (14). Family caregivers also use various methods to relieve their patient's pain, such as positioning, massages, creams and ointments, hot or cold poultices, and allowing their presence to be felt by touching, chatting with and distracting the patient (26).

When the cancer pain "knowledge" sections were analysed, it was found that patients' knowledge and their family caregivers' knowledge (in response to the question of whether cancer pain can be effectively relieved or not) were positive and similar to each other. However, as a matter of fact, common cancer pain often cannot be treated effectively due to its complexity and there are many barriers to be confronted in the course of treatment (27,28, 29). These barriers can be healthcare service providers, the healthcare system itself and they can be related to the patient (29).

Patients and family caregivers believed that it was only necessary to take analgesics in cases of severe pain. The validity of this belief, held by both the patients and family caregivers, is supported by the information contained in the literature. According to the guidelines of the World Health Organization, in the management of cancer pain the pharmacological treatment should be conducted in the form of a three step analgesia. Opioids are to be used in moderate and severe cases of cancer pain (14, 27, 30).

As with the patients who took part in the study, the family caregivers experience anxiety over the possibility of becoming dependent on analgesics. This result shows parallels with the results of the relevant study conducted (19,26,31,32,33). It is also seen that patients and family caregivers may be reluctant to go along with treatment due to the side effects associated with the use of opioids (addiction in particular), concerns about the development of medicine tolerances, and the damaging belief that cancer pain is a consequence of the natural course of the illness (12).

The results obtained from the present study reveal that patients' knowledge and their family caregivers' knowledge of when to take analgesics is at an inadequate level. The lack of knowledge in this regard is considered to constitute an obstacle to effective pain management.

It was established that patients' and family caregivers' knowledge on non-pharmacological treatment is medium level. In the literature it is stated that non-pharmacological interventions in the management of pain (such as musical therapy, bio-feedback, relaxation therapy, fantasising, acupuncture in recent years) is at least as effective as pharmacological interventions, that it reduces pain behaviour and the pain level that is focused on, that it decreases the dosage of analgesic drugs and thus the side effects of drug therapy (34,35,36).

Patients and family caregivers included in the study described the severity of pain in the past week as medium level. This result is similar to the study results of Aranda, Yates, Edwards, Nash, Skerman, & McCarthy (2004). In your study was found that family members described their patient's mean pain severity experienced as 5.5 and that they think that pain is a significant problem for their patients.

It is seen that the severity of pain was described by patients and family caregivers in the completion of the questionnaires as medium level. In a study conducted by Rustoen, Fossa, Skarstein, & Moum, (2003) on 1392 patients, the medium pain level on a scale of 0 to 100 was found to be 27.6.

It is thought that pain will negatively affect both the patient's and the family caregivers' quality of life, since a large majority of patients and their family caregivers describe it as 'very discomforting'.

According to the mean scores obtained, the total pain knowledge level of patients and family caregivers included in the research is inadequate. It has been stated in the literature that insufficient pain knowledge is one of the most important obstacles to achieving a successful management of pain (14). When the knowledge level of patients and family caregivers is analysed, it emerges that in some of the knowledge areas patients and caregivers are insufficiently aware that it is much more appropriate to take analgesics not only when needed, but according to a certain time schedule (patient: 6.39 ± 3.74 , family caregiver:

5.71±3.73). It also emerges that patients and caregivers have a medium level of knowledge (patient: 4.65±3.44, family caregiver: 4.81±3.97) regarding the efficacy of nonpharmacological treatment in relieving the pain. Contrary to our research results, it was ascertained in the other studies that patients' knowledge in the area of 'nonpharmacological treatment' is of a high level (37,38,39).

In the literature it is stated that there are differences between the cancer pain knowledge and experiences of patients and those of family caregivers (17). However, our study produced an opposing view; namely, that there are no significant statistical differences between the pain knowledge and experiences of patients and their family caregivers. We can therefore state that cancer pain causes similar effects on the knowledge and experiences of patients and their family caregivers.

In the study's patient group it was determined that the pain knowledge was not affected by independent variables such as gender and educational background, just as in Yıldırım's study (2006a) results. Wit, Van Dam, Vielvoye-Kerkmeer, Mattern, & Abu-Saad (1999) found that age and educational background do affect the pain knowledge, but gender does not.

The results of this study may not generalize the following limitations. Firstly, the number of sample was small. Secondly, in this study a comparative design was used. A longitudinal study would provide a more comprehensive understanding of cancer patients' and their family caregivers' pain knowledge and experiences. Finally, the findings of this study could be culturally specific and the study would need to be replicated in different cultural settings. In the future study, this limitations should be take into consideration.

6. CONCLUSION

This study's findings show that the total pain knowledge of cancer patients and their family caregivers is inadequate level, that there are no differences between the knowledge and experiences of patients and family caregivers and that independent variables (gender and education level) do not affect the pain knowledge. Therefore, it is recommended that the pain knowledge of patients experiencing cancer pain and family caregivers should be regularly monitored, briefings on pain should be organized, communication with healthcare

personnel should be improved in order to enhance pain knowledge and health care professionals should trained be accordingly, nurses should play an active role in pain training programs and guide patients, family caregivers and other healthcare professionals, and that similar studies should be conducted on larger samples.

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