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Cancer Pain and Quality of Life

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Cancer pain is an unrelenting symptom with the potential to alter the quality of life of patients. To adequately manage pain, nurses caring for cancer patients need to fully understand each patient's pain experience. The purpose of this study was to identify the intensity, distress, frequency, or constancy of pain in patients treated for cancer or cancer symptoms and to better understand patient barriers to pain management. This cross-sectional study included patients (N = 105) treated for cancer or cancer symptoms at 2 outpatient medical centers. Assessments included the Pain Barriers Scale, the Cancer Symptom Scale, and the Multidimensional QOL Scale–Cancer. Descriptive statistics and Spearman correlations were used to analyze the data. Sixty-nine percent of patients reported present pain of moderate to severe intensity that caused distress, was frequent/constant, or interfered with their lives. Patients with the greatest pain distress reported the greatest intensity of pain ($r = 0.77$) and the greatest interference ($r = 0.78$) with daily lives. Cancer pain was associated with significant distress and interference with life activities and occurred frequently or constantly for many study patients.

KEY WORDS

cancer, pain barriers, pain, quality of life

Approximately 48% of Medicare recipients receive hospice care annually, and the most common diagnosis among these patients is cancer.[1] In addition, more than 1.7 million individuals in the United States will be diagnosed with cancer this year, and a large number of these will experience pain, making it a priority for palliative care services.[2] Moreover, cancer pain is recognized as a serious global concern affecting billions of people worldwide.[3] Pain is seen in 64% of patients with advanced or terminal disease, 59% of patients on cancer treatment, and 33% of patients who had been cured of cancer.[4] Despite the availability of effective pharmacological agents and evidence-based pain management guidelines, cancer pain continues to be a challenging symptom associated with multiple barriers that hinder its control.[5-10] Barriers to adequate pain control originate from attitudes toward pain management, system and regulatory sources, clinician and patient sources, and racial and socioeconomic disparities in the assessment and management of pain.[7-10] Because inadequate cancer pain control is a problem that has prevailed over the years, research that explores barriers to pain management and strategies to enhance pain control are essential to decrease the burden associated with inadequate pain management and the resulting decrease in quality of life (QOL).

According to Paice and Ferrell,[11(p157)] cancer pain is a "critical symptom" with the potential to impact "all dimensions of QOL" across the disease trajectory. Cancer pain is associated with psychological distress that is manifested as mood disturbances, depression, emotional distress, fear, anxiety, irritability, difficulty concentrating, and worry.[12,13] These manifestations are observed independently or concomitantly, such as the co-occurrence of anxiety and depression, further challenging cancer patients.[14] Cancer pain interferes with multiple aspects of QOL of patients, including activities of daily living, social function, and sleep quality.[15-22] Moreover, cancer patients may experience cognitive changes as a result of pharmacotherapeutic agents used to manage cancer pain.[23]

As patients increasingly are expected to manage pain themselves in the home, 1 factor contributing to inadequately managed pain is believed to be patient fears about analgesics and concerns about whether pain can really be managed. These barriers have been studied in cancer patients and found to be related to other issues, including age and knowledge about pain.[15,24,25] To fully understand pain from the patient's perspective, it may be necessary to more fully understand their perceptions about barriers facing them as they try to manage cancer pain day to day.

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To adequately manage pain, nurses caring for patients with cancer need to fully understand each patient's pain experience. Cancer pain may be experienced at any phase in the cancer spectrum, from diagnosis to the end of life, giving nurses the opportunity to improve the quality of care that patients receive across settings. Despite the progress achieved in the management of pain, better understanding of factors with the potential to influence pain management is critical to enhance palliation of pain in persons with cancer. The purpose of this study was to better understand patient barriers to pain management and identify the intensity, distress, frequency, or constancy of pain and how the pain interferes with daily activities. In addition, we looked at relationships among pain characteristics, QOL, and perceived barriers to pain management. The following research questions guided the study:

1. What barriers to pain management are most commonly reported by study participants?
2. What are the intensity, distress, frequency, and interference reported by participants in the study?
3. Is there a relationship between characteristics reported by patients and their perceived barriers to pain management?

Conceptual Framework

This study is based on the Theory of Unpleasant Symptoms,[26,27] which proposes 3 major components: the symptom experienced by the individual, the influencing factors that give rise to or affect the nature of the symptom experience, and the consequences of the symptom experience. The model (Figure)[26] asserts that symptoms can occur alone or along with other symptoms. This study focuses only on the problem of pain, although it is very likely that other problems may be occurring simultaneously. Several dimensions of the symptom experience are included in the model: intensity, distress, quality, and timing or duration. Intensity refers to the severity of the symptom. Distress is defined as the amount of physical or mental upset, anguish, or suffering that the patient experiences as a result of the symptom.[27] Timing includes the frequency and duration with which a symptom occurs. Finally, quality encompasses the way that the symptom is manifested and how the patient experiences the symptom. In this study, intensity, distress, quality, and timing or duration will be assessed with the Cancer Symptom Scale (CSS)[28] in patients who report present pain.

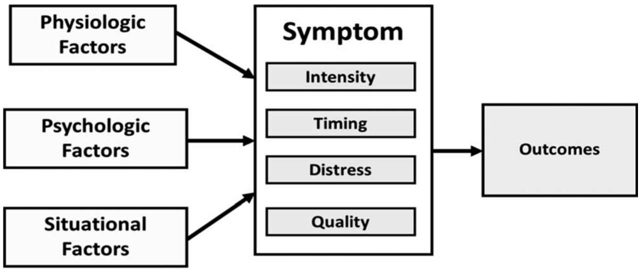

FIGURE. Theory of unpleasant symptoms.[19]

In this theory, physiologic, psychologic, and situational factors are hypothesized to influence symptoms. In this study, the physiologic factors represented in the model are factors associated with having a cancer diagnosis and undergoing treatment. The psychologic factors include mental state or mood and affective reaction to illness with the potential to interfere with patient self-care or adherence to treatment. Patients will be seen in an outpatient setting (situational factor), and most self-care for their pain management needs will be self-administered at home. Previous research has demonstrated that pain has been positively correlated with overall QOL.[29] Consequences or outcomes in this study will include QOL, including functional, cognitive, physical, and psychological well-being elements.

METHODS

Sample

This secondary data analysis study used data from a larger validity study of the CSS.[28] Two hundred forty patients were sought for this validation study. The sample for the original symptom study consisted of 234 patients with any cancer diagnosis who were being treated for cancer or cancer symptoms at 2 local cancer centers. Patients could be in the centers for scheduled appointments or for infusions in the centers' infusion centers. Patients who were alert and oriented adults (≥18 years old), able to read and understand English, and able to consent to the study were included. Patients who were within 3 weeks after surgery were excluded to avoid confusing cancer symptoms and symptoms due to anesthesia (like nausea or drowsiness) or surgery (such as pain). This secondary analysis included only patients who reported current pain (N = 105).

Instruments

Data pertinent to this study were collected with the CSS,[28] the Pain Barriers Questionnaire,[29] and the Multidimensional QOL Scale Cancer (MQOL-C).[30] In addition, demographic data were collected to facilitate description of the sample.

The CSS[28] assesses the presence, intensity, distress, frequency, and interference of a list of 35 symptoms, including pain intensity and frequency, on a scale of 1 to 10 (1 = least and 10 = most) and distress and interference on a scale of 0 to 10 (0 = least and 10 = most). Like similar scales in the literature,[31-36] this scale allows the patient to identify whether a symptom has occurred in the past week, and only if the response is *yes* does the patient respond about intensity, distress, frequency, and interference of that symptom. Adding dimensions other than intensity to an assessment allows the nurse to better understand the impact of a given symptom to prioritize the symptoms causing patients the most distress or interference at the greatest frequency. Construct validity was demonstrated by correlation of CSS subscales with a QOL measure, the

MQOL-C, at the hypothesized levels ($r = -0.34$ to -0.56; $P = .000$). Test-retest reliability ($r = 0.74$-0.81) and internal consistency ($\alpha = .73$-$.74$) were excellent. Only pain items (intensity, distress, frequency, and interference) were used in this analysis.[28]

The Pain Barriers Questionnaire[29] is a summated rating scale that contains 17 items using a 6-point (0–5) scale with responses ranging from "strongly disagree" to "strongly agree." Higher scores indicate that patients perceive greater barriers to pain management. This scale has been used successfully by other investigators[29-31] and was evaluated using factor analysis, which confirmed 2 subscales, communication about pain and use of analgesics. Internal consistency reliability using Cronbach α was reported ($r = 0.78$-0.79).[33]

The MQOL-C[30] was used to assess the patients' QOL. The MQOL-C has 33 items that measure 4 dimensions of QOL: physical and psychological well-being, social concerns, and symptoms. Items are scaled 0 to 10, with total scale scores that may range from 0 (lowest QOL) to 330 (highest quality). Validity was supported by correlation with measures of depression, social functioning, and physical functioning. Cronbach α has been reported (0.89-0.91).[36-38]

Demographic data were collected to describe the sample. Patient age, sex, race/ethnicity, marital status, and cancer diagnosis were included.

Procedures

The project was submitted to the bioethics committees for the medical centers where data were collected. After approval was given by these institutions, the project was submitted to and received approval from the institutional review board at the university.

For the original study, patients were accrued from the outpatient clinics at the medical centers. Patients often were approached in the infusion centers in both settings where patients are in private bays undergoing treatment. The study was explained to interested patients, questions were answered, and consent was obtained. The study questionnaires were administered to patients by the research assistants (nursing graduate students) trained by the study principal investigator.

For the current secondary analysis, pain barriers and QOL scores, along with demographic data, for the 105 patients who reported pain in the last week were extracted. For the 105 patients reporting present pain, intensity, distress, frequency and interference were analyzed. Patients' pain scores were reported to the nursing staff.

Data Analysis

Descriptive statistics were used to analyze demographic data. Measures of central tendency (means) and dispersion (standard deviations) were obtained to describe scores on QOL and pain barriers. Frequencies and percentages were used to describe the intensity, distress, frequency, and interference of pain in study participants. To evaluate the relationships between pain, QOL, and demographic variables, Spearman correlations were used. Tables based on participants' responses are used to present the data. The SPSS 24.0 program was used to analyze the data.

RESULTS

Sample

Patients with cancer who were reporting current pain made up the sample for this study (N = 105). The sample consisted of slightly more women, and patients were mostly white and married (Table 1). The most common cancer diagnoses were leukemia, genitourinary cancers, lymphoma, breast, colon, and lung cancers; 36 patients reported a variety of other solid tumors. Patients had a mean age of 57.9 years (SD = 11.8) and a mean educational level of 14.1 years (SD = 2.6). Age and educational ranges included 25-86 years and 9-22 years respectively.

Present Pain

Patients in the study who reported having current pain (N = 105) were asked about the pain's intensity, the distress it was causing, how constant or frequent it was, and how much it interfered with their life activities. About intensity, 69% reported having moderate to severe pain (at a level of 5 or higher on a 0-10 scale). Approximately 64% reported pain distress at a moderate to severe level. When asked about frequency or constancy of pain, 68% of patients reported it to be at a level of 5 or higher. Sixty-one percent of the participants (N = 60) indicated pain caused moderate to severe interference with life activities (Table 2).

Cancer Pain Barriers

Pain Barriers Scale scores could range between 0 and 85; the mean for this sample was 27.3 (Table 3). Item analysis for the Barriers Scale showed which items patients identified with most strongly. Frequencies from participants who reported their agreement as "agree" and "strongly agree" for single items of the questionnaire were combined to identify pain barriers reported. The questions receiving the most positive responses included the importance of the oncologist focusing on the cancer rather than pain (50.51%) and concern that people get addicted to the medications (28.42%) (Table 4).

The MQOL-C scores could range from 0 to 330. The mean was 202.60 (Table 3). All patients (N = 105) identified pain as an issue on the QOL scale.

Relationships Among Variables

Significant positive relationships were found among all the pain variables on the CSS (Table 5), with the strongest relationships being between pain distress and pain

TABLE 1 Frequency and Percentage of Patients by Demographic Variables (N = 105)

Variable	n	%
Sex		
Women	61	58.1
Men	44	41.9
Marital status		
Married	67	63.8
Single	38	36.2
Ethnicity		
White	85	81.0
Black	8	7.6
Hispanic	9	8.6
Asian/Pacific Islander	1	1.0
Mixed	2	1.9
Cancer diagnosis		
Breast	13	12.4
Leukemia	12	11.4
Genitourinary	10	9.52
Lymphoma	11	10.5
Lung	9	8.6
Ovarian	8	7.6
Pancreas	6	5.7
Multiple myeloma	6	5.7
Colon	5	4.8
Other solid tumors	25	23.8

interference ($r = 0.78$), pain distress and pain intensity ($r = 0.77$), and pain interference and pain intensity ($r = 0.75$). Quality of life was significantly, negatively correlated with pain intensity, distress, and interference.

DISCUSSION

Most patients (69%) who reported present pain were experiencing moderate to severe pain that caused distress, was frequent or constant, or interfered with their lives.[29] Pain distress also was reported to be between 5 and 10 for most patients (64%). This level of distress needs and deserves attention. Most patients (68%) reported that their pain occurred frequently or was constant. Interference with daily activities scores tended to be somewhat lower; however, more than half (61%) reported that pain caused noticeable interference with their lives. Regardless, it is important to note that pain continues to be a problem in the cancer outpatient setting despite our greatly improved medications and routes of administration. Thus, a continued focus on preparing patients to do their own pain management at home is critical in all settings.

TABLE 2 Frequency and Percentage of Patients Reporting Present Pain Intensity, Distress, Frequency, and Interference as 5 or higher on a 0 to 10 Scale (N = 105)

Variable	n	%
Pain intensity[a]	72	69.2
Pain distress[b]	65	64.4
Pain frequency/constancy[c]	67	68.4
Pain interference with life[d]	60	61.0

[a] *Missing value = 1*
[b] *Missing value = 4.*
[c] *Missing value = 7.*
[d] *Missing value = 6.*

It is to be expected that the pain variables would show intercorrelations, and they did. The strongest correlations revealed that patients with the greatest pain distress experienced the greatest intensity of pain and interference with daily lives. Pain interference was also strongly related ($r = 0.75$; $P = .000$) with pain intensity; again, it is not an unexpected finding that patients with the worst pain intensity would report the greatest interference with their daily lives. Thus, these findings support the relatedness of the pain variables, but the fact that the correlations were not perfect also demonstrates that these items are measuring different aspects of the pain experience.

The mean Pain Barriers Scale scores for this sample was low at about 32% of the maximum possible score (mean, 27.3). This means that although this group did

TABLE 3 Means and Standard Deviations for Scores on Quality of Life and Pain Barriers (N = 105)

Variable	Possible Range	Mean	SD
Pain barriers[a]	0-85	27.3	8.60
QOL	0-330	202.60	41.53

[a] *Missing values = 5.*

TABLE 4 Frequency and Percentage of Patients who Agreed or Strongly Agreed With a Pain Barrier Statement (N = 105)

Pain Barriers Item	n	%
It is more important for the doctor to focus on curing the cancer	49	50.51
People get addicted easily	27	28.42
It does not do any good to talk about pain	21	21.65
It is easier to put up with pain rather than side effects of meds	19	20.0
Pain meds cause constipation	16	16.49
Meds cause unacceptable drowsiness	15	15.31
Pain meds can cause confusion	13	13.54
Analgesics cannot control the pain	10	10.41
Nausea from the meds is worse than the pain	10	10.87
The doctor is annoyed to be told about the pain	10	10.31
Meds cannot relieve cancer pain	56	6.38
Complaints of pain distract the doctor from curing the cancer	6	6.19
Pain meds should be saved for the end	5	5.10
Good patients avoid talking about pain	6	6.19
Pain meds make you do or say embarrassing things	5	5.21

see some barriers to the management of their pain, they did not see really overwhelming barriers. However, like earlier studies, this study found that most patients identified at least a few barriers.[30,33]

About a third of the patients agreed with the statement that it is more important for the physician to focus on treating the cancer rather than the pain. This may lead to patients failing to report pain to the physician to avoid

TABLE 5 Spearman Correlations Among Pain Variables, QOL, and Pain Barrier Scores (N = 105)

Variable		Pain Intensity	Pain Distress	Pain Frequency	Pain Interference	QOL
Pain intensity	*r*		**0.77**	**0.48**	**0.75**	**−0.29**
	P	–	**.000**	**.000**	**.000**	**.004**
Pain distress	*r*	**0.77**		**0.44**	**0.78**	**−0.30**
	P	**.000**	–	**.000**	**.000**	**.002**
Pain frequency	*r*	**0.48**	**0.44**		**0.51**	−0.17
	P	**.000**	**.000**	–	**.000**	.086
Pain interference	*r*	**0.75**	**0.78**	**0.51**		**−0.38**
	P	**.000**	**.000**	**.000**	–	**.000**
QOL	*r*	**−0.29**	**−0.30**	−0.17	**−0.38**	1.00
	P	**.004**	**.002**	.086	**.000**	

Values in bold are statistically significant.
Abbreviation: QOL, quality of life.

distracting the oncologist, with the result that pain is not adequately managed. Nurses should help patients to understand the importance of communicating all problems to the physician, including pain, and should assess the pain themselves so that they can be more effective patient advocates.

For the most part, the patients in this sample seemed to disagree with most of the barriers statements in the questionnaire. There may be multiple explanations for the unexpected result. First, it is possible that the focus on pain management in health care facilities (the fifth vital sign) has actually had a positive effect on patients' perceptions of barriers. Second, it may be that the barriers in the scale were not the ones that patients perceived as the reasons they do not want to take pain medications or believe their pain should be adequately managed. Not included in the Barriers questionnaire is access to the prescribed medication. It is possible that patients see getting to the pharmacy to pick up the prescription or having to pay for it to be barriers. However, as this was not asked in this questionnaire, further study is needed to determine whether there might be other barriers than the ones assessed.

Quality of life scores were fairly high at about 67% of the maximum score possible in the 105 patients who were experiencing current pain. These relatively high QOL scores were most likely a reflection of the fact that all the patients in the study were outpatients who were returning for outpatient appointments at the cancer clinic where they received care. As such, they were well enough to be residing at home. Had they been inpatients who were acutely ill, the QOL scores most likely would have been lower. However, even in cancer patients near the end of life, QOL scores can be high.[39,40] It is noteworthy that patients perceived fairly good QOL while having symptoms. This result might have occurred because QOL is a multidimensional concept, and having pain or other symptoms does not necessarily mean that all aspects of QOL are bad. It also should be noted that these patients reported having current pain at the time of the data collection.

The significant negative correlations between QOL and all of the pain variables also could be anticipated. The correlations were negative, indicating that as the pain scores worsened (got higher), the QOL scores also got worse (lower). It is to be expected that all aspects of pain are likely to have an impact on some aspects of QOL. However, it should be noted that because QOL is a multidimensional concept, many aspects of the patients' lives could be maintained at a high level even in the face of real pain.

The Theory of Unpleasant Symptoms was used as a framework to provide direction to this study. This theory can be applied to understand how unpleasant symptoms such as pain may be influenced by factors with the potential to affect the pain experience, and the consequences of the symptom experience.[26,27] The findings of this study support the association of an unpleasant symptom, cancer pain, with significant distress and interference with life activities, occurring frequently or constantly for many of the patients who participated in the study while experiencing pain. Consistent with the theory, the pain affected overall QOL of these patients.

Study Limitations

The sex and ethnic make-up of the sample is consistent with the centers in which the study was conducted, but it may not be reflective of all the communities in the United States, and thus, results may not be widely generalizable. Although the most commonly occurring cancers in the United States (breast. prostate, lung, colon) were found in the study, less commonly occurring cancers in the United States were identified (leukemias and lymphomas).[2] Inclusion criteria for the study were that the patients had to have a cancer diagnosis and pain or other symptoms. The data collectors, who were experienced oncology nurses, fairly quickly surmised that patients with hematologic malignancies were very likely to have symptoms, so they visited the hematology oncology clinic every day that data were collected. Thus, although the distribution of cancers in this sample is not consistent with cancer diagnoses in this country, it probably is somewhat more reflective of cancer patients with significant symptoms.

Implications for Nursing and Future Research

Given the trajectory of cancer as a chronic and possibly life-limiting disease, it is not uncommon for nurses to encounter patients experiencing pain across the disease trajectory, from a new cancer diagnosis to patients undergoing end-of-life care. As a result, it is essential to consider pain management needs and factors with the potential to influence pain for cancer patients cared for in any health care setting, including home-based settings. Pain management should continue to be a focus for in-service and more formal education programs directed at nursing staff with the potential to care for cancer patients. In addition, colleges of nursing need to ensure that new graduates leave their programs with sufficient knowledge to help patients acknowledge and manage perceived barriers to pain management.

Further research is needed to determine if cancer patients experience other barriers to pain management not captured by instruments used in this study. Other methods of inquiry, including qualitative methods, may be of assistance to explore the patients' perceptions and obtain in-depth understanding about barriers to pain management.

CONCLUSIONS

This study found that patients with a variety of cancers experienced significant pain intensity, distress, and interference with life activities and that pain occurred frequently or constantly for many of them. QOL was significantly negatively correlated with pain intensity, distress, and interference. Patients experienced fairly good QOL despite their symptoms. Future research should continue to explore these important issues so that nurses in all settings can better support patients as they attempt to manage their cancer pain.

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