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PATIENT AND CAREGIVER PERCEPTIONS
OF CANCER PAIN CONTROL
(PERCEPTIONS OF CANCER PAIN CONTROL)

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Abstract

PURPOSE: This study measured the perceptions of Utah cancer patients and caregivers concerning knowledge about and adequacy of pharmacologic cancer pain control.

METHODS: A descriptive survey was used. Questionnaires were sent to cancer patients and caregivers surveying their knowledge about and perceptions of the adequacy of pharmacologic cancer pain control.

RESULTS: The study had a 52% response rate (259 of 500). Eighty five percent (219 of 259) of the respondents stated they had no cancer pain.

CLINICAL IMPLICATIONS: Cancer literature indicated that much cancer pain is not effectively controlled. The majority of the respondents of this study reported no pain. Since this result is different than that reported by the literature, it may indicate an inability of the study to obtain data from those patients having cancer pain. The study should be repeated with a focused population of advanced stage cancer patients with types of cancer typically producing high levels of cancer pain.

KEY WORDS: cancer, pain management, pain control, patient, patient perception, caregiver.

INTRODUCTION

In 1994, the Commission on Cancer Pain for the Agency for Health Care Policy and Research (AHCPR) under the U.S. Department of Health and Human Services, provided an update

on the problem of cancer pain. The panel noted the following:

1. Eight million people in the United States have a diagnosis of cancer.
2. One million people are newly diagnosed annually.
3. The degree of cancer pain varies with type and stage of disease, but 75% of patients have pain in the final stages.
4. Therapies are available to provide relief to over 90% of patients suffering from cancer, using relatively simple pain management techniques.
5. However, cancer pain control continues to be a major problem in caring for cancer patients.

Since it is patients and families who suffer, it seemed appropriate to use their perceptions about their pain control as the basis for measuring the success of current cancer pain control in the State of Utah.

This study investigated the perceptions of Utah cancer patients and their families concerning knowledge about and effectiveness of pharmacologic cancer pain control. No such study has been performed with Utah cancer patients, though similar research projects have been pursued nationwide.

LITERATURE REVIEW

The report from AHCPR noted that unrelieved pain causes unnecessary suffering and destroys quality of life. Patients with pain often decrease activity, lose appetite and sleep less, all of which cause weakness. Patients in pain may lose hope and reject active therapy because pain is severe and depression is present. Uncontrolled pain may prevent patients from working, enjoying recreation, or taking pleasure in their usual role in the family and society. According to the AHCPR Guidelines, pain control merits a high priority since it allows cancer patients to lead a

more productive life, regardless of the stage of their disease. If the cancer pain control is so important and over 90% of patients experiencing pain can achieve control using relatively simple pharmacologic means, why is it that cancer pain is continually under treated? There are many barriers to effective pain management. The AHCPR Guideline describes these barriers in three major categories of problems related to: 1) health care professionals, 2) patients, and 3) health care management. The guideline discussed each of these barriers as follows.

Problems related to health care professionals

Problems related to health care professionals include the following:

1. Little training in pain management.
2. Inadequate ability to assess pain.
3. Concerns about regulations around controlled substances.
4. Unfounded fears of patient addiction.
5. Concerns about side effects of potent analgesics.

All of these concerns could be potentially addressed by proper education.

Problems related to patients

Patients also present barriers. These barriers include:

1. Reluctance to report pain because of fear about distracting physicians from treating their underlying disease.
2. Fear that increased pain means the disease is progressing.
3. Belief that "good" patients don't complain about pain.
4. Reluctance to take pain medications.
5. Unfounded fears of addiction or being thought of as an addict.
6. Concern about unmanaged side effects such as being too sleepy to be functional.

7. Fear about becoming tolerant to pain medications.

8. Fearing that drugs will lose their potency over time. Patient fears can also be addressed by appropriate education.

Problems related to health care management

Barriers exist in the health care system. These are:

1. Low priority given to cancer pain treatment.

2. Inadequate reimbursement and restrictive regulation of controlled substances which inhibit the appropriate use of potent analgesics.

3. No access to treatment.

In a two part study, Ferrell, Rhiner, Cohen, and Grant, described the impact of cancer pain on family caregivers and on their management of cancer pain at home. The study concluded that cancer pain had an impact on caregivers and the family because it was perceived as a symptom of progressive disease and death. Ferrell, Rhiner, Shapiro, and Strause studied the impact of cancer pain management on the family of the pediatric cancer patient. The study concluded that family caregivers made great sacrifices to care for their children, but had a feeling of great helplessness in this care. It also determined that family caregivers would benefit by more education about correct principles of cancer pain management. Ferrell, Grant, Chan, Ahn, and Ferrell studied the impact of cancer pain education in the elderly patient. Again, the study showed a need for information about correct principles of cancer pain control improved pain control in the elderly patient.

Dar, Beach, Barden, and Cleeland, in a quantitative study done with a combination of questionnaires and interviews, noted that patients consistently underestimated the amount of distress their pain produced in their family members. Family members also underestimated how much pain the patient was experiencing.

Yeager, Miaskowski, Dibble, and Wallhagen, in a descriptive correlation study, found two differences in perceptions between cancer patients and their family members. The first was disagreement about using low doses of pain medication early in the course of the disease in order to have access to higher doses as the disease progressed. The second was disagreement in the benefit of using pain medication around the clock as opposed to prn. These disagreements demonstrated the lack of education and understanding of patients and families concerning the most effective means of administering pain medication.

Higginson and Hearn, in a multi center evaluation of cancer pain control by palliative care teams, noted that patients with advanced cancer in the community experienced a 70% rate of cancer pain and similar patients in the hospital experienced a 60-79% rate of cancer pain. The study found the factors which influence cancer pain include site of the tumor, the type of pathophysiology of the pain(nociceptive vs neuropathic), and pain etiology (tumor vs nonmalignant). Higgins and Hearn noted that the degree of pain and its effect on ability to function needed to be taken into effect when assessing cancer pain.

Trowbridge et.al., documented a cancer pain rate of 62% among patients seeing an oncologist. The purpose of the study was to document the effect of cancer pain assessment on the prescriptive practice of the oncologists involved.

Another factor that may play a part in the control of cancer pain in Utah is the use of alternative or nontraditional methods of pain control. In an unpublished study done by Mooney, it was demonstrated that Utah had the highest rate of use of alternative methods of treating cancer ever measured, 18.3%. This was corroborated by Lerner and Kennedy in a national telephone survey which showed that 14.7% of cancer patients in the Mountain States region of the United States used alternative methods in treating cancer.

Research Question

This study focused on measuring the perceptions of Utah cancer patients and caregivers in Utah concerning knowledge about and perceptions of cancer pain control. Though national studies dealing with cancer pain control are cited in the literature review, no studies had been carried out in the Utah population. Therefore, it was unknown whether or not the perception among patients in Utah were consistent with populations studied in other areas of the nation.

Specific aims were as follows:

1. Measure perceptions of Utah cancer patients and their caregivers concerning knowledge of appropriate cancer pain control, as assessed by the Patient Pain Questionnaire and the Family Pain questionnaire, validated research tools developed at City of Hope National Cancer Center.
2. Measure perceptions of Utah cancer patients and their caregivers concerning the adequacy of current cancer pain treatment, as assessed by the tools mentioned above.

METHODOLOGY

Design

This descriptive survey was designed to measure the perceptions of Utah cancer patients and caregivers concerning knowledge about and adequacy of pharmacologic cancer pain control. Questionnaires were sent to cancer patients and their caregivers throughout the State of Utah.

Sample

A stratified random sample of adult patients with breast, colon, lung and prostate cancer was acquired from the Utah Tumor Registry. These cancers were recruited because they are known to frequently involve pain as a symptom during the course of the disease. A random sample of other cancers were chosen to bring the total number of potential participants to 500. Table 1

summarizes the types of cancer included in the study.

Table 1. Types of Cancer

Breast	- 100
GI	- 102
Lung	- 96
Prostate	- 100
Parotid gland	- 2
Larynx	- 2
Bone, limbs	- 1
Blood sys	- 8
Skin	- 15
Peritoneum	- 1
Connective	- 1
Vulva	- 2
Uterine	- 25
Ovary	- 8
Penis	- 1
Testis	- 4
Kidney	- 3
Ureter	- 1
Bladder	- 6
Eye	- 1
Brain	- 4
Thyroid	- 5
Lymph node	- 6
Unknown	- 1

Inclusion criteria for the study were as follows:

1. Any cancer patient/caregiver over the age of 18.
2. English speaking.
3. Receiving active treatment or palliative "comfort care".
4. Receiving treatment as inpatients or outpatients.
5. Diagnosis had to have been made in the last five years. On the advice of the Utah Tumor Registry, five years was chosen because it provided both patients who had been recently

diagnosed, and patients who had dealt with their disease, its treatment and effects for a period of time.

6. Caregivers were designated by the patient.

Procedures

A letter explaining the project and the research tools was sent to study patients. A stamped, return addressed envelope was included. A reminder post card was mailed to those who had not returned their information in two weeks. Responses were returned to the Utah Tumor Registry. Consent to participate in the study by the patient and caregiver was indicated by the return of a response.

The Patient Pain Questionnaire (P.P.Q.) was to be answered by the patient. The Family Pain Questionnaire (F.P.Q.) was to be answered by a caregiver. Demographic data were also obtained. After questionnaires were returned, all identifying information was deleted. Patient and caregiver questionnaires were given matching anonymous numbers by which they were identified during data analysis.

Tool

Two 16 item Likert Scale questionnaires developed by City of Hope Cancer Center, were used to collect data from the patients and their families. These were the Patient Pain Questionnaire (P.P.Q.) and the Family Pain Questionnaire (F.P.Q.). These tools were chosen because of their previous wide applicability and their ease of understanding and simplicity in administration. Validity and reliability had been established by Dr. Betty Ferrell and her colleagues in previous studies. Ferrell reported the tools "had been tested with established reliability (test, retest, internal consistency) and validity (content, construct, concurrent). A series of psychometric analysis were performed on the instrument including content validity (CVI=.90), construct validity (ANOVA,

P. less than .05), concurrent validity ($r=60$, p. less than .05), factor analysis and test-retest reliability ($r=.80$) established with a retest of caregivers ($N=67$).".9-16

Data Analysis

Frequencies were to be calculated on responses to pain questionnaires and demographic characteristics. However, secondary to the low number of usable responses (see results) no data analysis was performed.

RESULTS

Packets consisting of demographic questionnaires and accompanying pain questionnaires were mailed to 500 cancer patients and their care givers. The results of returns are summarized in Table 2.

Table 2. Results of Questionnaire Returns

Questionnaires returned -----	259
Questionnaires returned with NO PAIN response -----	219 (85 %)
Unusable returns -----	18 (7 %)
Patients stating they did not want to participate --	3 (1 %)
Deceased patients -----	4 (2 %)
<u>Usable returns -----</u>	<u>15 (5 %)</u>

Table 3 summarizes the stages of patients not responding.

Table 3. Stages of Cancer in Patients not Returning Survey (241) Unknown - 13 (8%)

In situ - 19 (12%)

Local - 69 (42%)

Regional - 50 (31%)

Distant - 12 (7%)

The 219 responses

returned with a "no pain" statement were evaluated according to stage of disease at diagnosis.

These results are summarized in table 4.

Table 4. Stage of cancer in patients with "no pain". (219) Unknown - 16 (7%)

Insitu - 18 (8%)

Local - 108 (49%)

Regional - 66 (30%)

Distant - 11 (5%)

Because of the small

number of usable returns (15), no statistical test could be effectively applied to the data. A manual tabulation of the demographic and pain questionnaire data data showed no pattern in responses. Table 5 summarizes the stages of these patients.

Table 5. Stages of cancer in patients returning usable returns.(15)

Unknown - 0 (0%)

Insitu - 0 (0%)

Local - 6 (40%)

Regional - 6 (40%)

Distant - 3 (20%)

Table 6 shows the stages of

cancer in the patients returning unusable data.

Table 6. Stages of cancer in patients returning unusable data.(18) Unknown - 2 (11%)

Insitu - 0 (0%)

Local - 11 (61%)

Regional - 3 (17%)

Distant - 2 (11%)

DISCUSSION

The results of the study made it impossible to evaluate the Utah cancer patients' perceptions concerning their knowledge about or the adequacy of cancer pain control. There may be several reasons for this result.

First, the research was undertaken with a literature review and clinical experience indicating that the majority of cancer patients experienced some degree of pain. In this study, 85% of responding patients indicated that they had no pain, regardless of the stage of disease. Though it would be wonderful to think that

Utah cancer patients suffered less than the national figures suggest, there may be other reasons.

- The majority of patients who responded "no pain" had local disease (see table 4). This sample may not have addressed patients with disease sufficiently advanced to produce pain.
- The majority of patients who did not respond (table 3) and who did not return usable data (table 6) also had local disease. This sample, also, may not have addressed patients who had pain from advanced disease, even if the responses had provided usable data.
- The patients who did not respond may have had disease that advanced since the time of their diagnosis to metastatic disease. These patients may have been unable to respond because of illness or death. If this were the situation, these patients may have experienced pain, but been unable to report their perceptions.

2. The "questionnaire only" format, as opposed to questionnaire and interview format, may have contributed to the small amount of evaluable data. Did the respondents understand the introduction letter and questionnaire? Would the results have been different if an interview format had been added? The "questionnaire only" format was used because of the logistical difficulty of attempting to interview 500 subjects and their caregivers

RECOMMENDATIONS

The study should be repeated with the following modifications.

1. The study should be carried out with a more focused cancer population consisting of cancer patients with regional and distant metastasis. Patients with insitu or localized disease might not have pain. Therefore, a better measure of perceptions concerning knowledge about and adequacy of pharmacologic cancer pain relief might be obtained by studying patients who have advanced disease.

2. Consideration should be given to recruiting participants who have been diagnosed in the last 6 months to 1 year in order to ensure that participants will be live patients with advanced disease.

3. An interview format should be used. Skilled interviewers could assist patients and their caregivers to understand the question, but not lead them to specific answers.

4. The sample size should be small enough to allow reasonable use of the interview method, but large enough to collect statistically evaluable information.

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