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Cancer Patient Attitudes Towards Analgesic Utilization and Pain Intervention

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Abstract

Objectives—Although pain is commonly experienced among cancer patients, many receive inadequate pain management. Little data exist quantifying analgesic utilization among oncology patients. This study evaluates perceived causes of pain and investigates reasons oncology patients fail to receive optimal pain management.

Methods—An IRB-approved questionnaire assessing pain control and analgesic utilization was posted on OncoLink. Between 11/05-7/08, 1107 patients responded. Respondents were female (73%), Caucasian (74%), educated beyond high school (64%), and had surgery (69%), chemotherapy (64%), and radiation (47%). Most had breast (30%), gastrointestinal (12%), gynecologic (11%), and lung (8%) malignancies.

Results—Sixty-seven percent of respondents reported pain, with 48% reporting pain directly from their cancer and 47% reporting pain from their cancer treatment. Among patients in pain, 25% did not use analgesics. Analgesic utilization was significantly less in men (44% vs. 52%, $p=0.023$), minorities (42% vs. 53%, $p=0.001$), and patients with lower education levels (45% vs. 53%, $p=0.013$). Utilization varied by cancer diagnosis and was higher among patients who received chemotherapy (56% vs. 40%, $p<0.001$) and radiation (53% vs. 47%, $p=0.058$). Reasons for not taking analgesics included: healthcare provider not recommending medications (85%), fearing addiction/dependence (80%), and inability to pay (76%). Many patients reporting pain, not taking analgesics, pursued alternative therapies (94%).

Discussion—Most cancer patients perceive pain from their disease or treatment, regardless of therapy received. Many, however, did not use analgesics due to concerns of addiction, cost, or lack of healthcare provider endorsement. Providers should regularly discuss pain symptoms and management with cancer patients.

Keywords

Pain; Analgesic; Quality of Life; Internet; Cancer

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INTRODUCTION

Pain is commonly experienced among cancer patients and can cause significant patient anxiety, depression, and a sense of hopelessness.^{1–3} Patients can suffer from pain directly from their underlying disease or from therapies utilized to treat their malignancy. Cancer itself can cause pain by exerting mass effect, directly invading adjacent tissues, spreading to other organs, compressing nerves, or causing infections or chronic inflammatory changes. Standard cancer treatment modalities, including surgery, chemotherapy, and radiotherapy, can also contribute to patient pain and morbidity.

Malignant pain is typically very responsive to medical management. Adequate pain control from cancer-related pain has been reported in up to 90% of patients with individualized pain management strategies that optimize analgesic medications, doses, and dose intervals.^{4–5} Despite this, many patients receive inadequate medical management for their pain.^{6–15}

Although clinical guidelines recommending systematic pain assessment exist to optimize pain management among cancer patients, numerous studies have shown that oncology patients experience pain throughout their journey after a diagnosis of cancer and during their treatment course.^{6–7,9–16} Furthermore, pain remains a significant source of fear in those that receive a diagnosis of cancer and can have a detrimental direct and indirect impact on many quality of life measures.^{6,9–10,17} Inadequate pain control and barriers to optimal pain management have been recognized in numerous studies from both a patient and healthcare provider perspective.^{6–13,15,18}

Currently, there are limited data quantifying patient pain medication utilization in the oncology setting or reasons why cancer patients fail to receive optimal analgesic treatment. The authors have previously reported on the initial 106 patients who completed the Internet-based questionnaire and received radiation therapy as part of their cancer treatment to investigate the perceived causes of pain among that small subset of patients.¹¹ This markedly expanded Internet-based study assesses all cancer patients, regardless of therapy received.

MATERIALS AND METHODS

Between November 2005 and July 2008, an Internet-based questionnaire¹¹ assessing patient demographics and pain symptoms was posted on the OncoLink website (<http://www.oncolink.org>). OncoLink is the oldest and one of the largest general cancer information resources on the Internet and currently serves up to 3.9 million web pages per month to over 375,000 unique IP addresses. The questionnaire was rotated on the homepage and randomly featured in high profile locations on the website. There was no external advertising or directed email announcements.

Study participants voluntarily and anonymously completed an online survey that was internally developed, piloted, and modified based on interviews with physicians, nursing staff, and patients at the University of Pennsylvania. Study participants, however, were not a patient population of University of Pennsylvania. Study participants were all users of the OncoLink site that is available to anyone with Internet access. The current user base of OncoLink is 75% from the United States and 25% International. This prospective study was approved by the University of Pennsylvania Institutional Review Board.

The questionnaire included 22 queries assessing patient demographics, primary cancer diagnoses, treatment modalities received, enrollment on clinical trials, causes of pain, pain characteristics, medical management for pain, types and frequency of analgesics used, cost

of analgesic therapies, reasons for not taking pain medications, and other therapies used to treat pain. Analgesic usage included prescription and over-the-counter pain medications. Survey questions and responses were held on a physically and electronically secure server and downloaded for analysis.

Statistical analysis was performed using Excel for Windows (Microsoft Office Excel 2003). Chi-squared or Fisher's exact test for independence were used to compare proportions, and Student's t-Test was used for continuous measures. Statistical significance was defined as $p < 0.05$.

RESULTS

During the study period, 1107 patients with cancer responded to the questionnaire and were included in this analysis. The majority of respondents were female (73%) and identified themselves as Caucasian (74%) (Table 1). The highest level of formal education achieved among respondents included grade school (5%), high school (25%), some college (27%), four-year college degree (22%), and graduate school (16%). For subset analyses, data from the latter three groups of respondents were compiled together as participants pursuing education beyond high school (64%).

The most common cancer primary diagnoses among participants included breast (30%), gastrointestinal (12%), gynecologic (11%), lung (8%), and genitourinary (7%) malignancies (Fig. 1). Respondents received current or prior surgery (69%), chemotherapy (64%), and radiotherapy (47%). Eighteen percent of respondents were enrolled in a clinical oncology trial or experimental study.

In total, 67% of respondents reported pain during the course of their disease and cancer treatment. Nearly half (48%) of respondents perceived pain directly from their cancer, and a similar proportion (47%) perceived pain resulting from their cancer treatment. One-fifth (20%) of patients denied pain directly from their disease, while 32% were unsure if they experienced pain from their disease. Similarly, 24% indicated their cancer treatment did not cause pain, while 29% were unsure if their treatment caused pain. Twenty-three percent of participants reported pain both from their cancer and their cancer therapy. An additional 62% of respondents reported suffering from pain on a regular basis but were unsure of the primary cause.

Among respondents reporting pain, their pain was primarily chronic (43%) or intermittent (43%), while few reported acute (9%) or other (5%) pain symptoms. The primary sites of pain were back or spine (45%), chest (35%), abdomen (33%), or lower extremities (28%).

Although 67% (738/1107) of respondents reported pain, only 50% (553/1107) of all surveyed were taking or had taken medication specifically to help manage their pain. Of respondents reporting pain, 25% (185/738) did not take analgesics. Although the degree of pain relief was not quantified, 70% (389/553) of patients who took analgesics reported their pain medications were helping. However, study respondents in pain and taking analgesics were more likely to report pain directly from their cancer (56% vs. 40%, $p < 0.001$) and cancer treatment (52% vs. 42%, $p = 0.001$) than those in pain but not taking analgesics.

Respondents who reported consuming analgesics for pain management most often utilized over-the-counter oral pain medications (51%) and short-acting oral narcotics (45%). Patients less commonly utilized long-acting oral narcotics (16%), long-acting transdermal narcotics (14%), and non-narcotic prescription oral analgesics (16%) (Table 2). Among respondents taking short-acting analgesics at the time they completed the questionnaire, most reported utilizing these medications once or twice daily (41%), every four to six hours (25%), or

every two to four hours (20%). Only 4% of respondents utilized short-acting analgesics more frequently than every two hours, whereas 10% employed every six to eight hour dosing regimens.

Analgesic utilization was significantly lower in men than women (44% vs. 52%, $p=0.023$). Analgesic usage was significantly higher among Caucasians when compared to the aggregate of all other races (53% vs. 42%, $p=0.001$) and among patients with education beyond high school compared to those with a lower level (53% vs. 45%, $p=0.013$).

Patients who underwent chemotherapy were significantly more likely to consume analgesics (56% vs. 40% no chemotherapy, $p<0.001$). Patients who received radiation therapy trended towards higher rates of analgesic utilization (53% vs. 47% no radiation, $p=0.058$), whereas no difference in utilization rates was observed among patients who did or did not undergo surgery (50% vs. 51%, $p=0.683$). When assessing usage according to the most common primary cancer diagnoses reported, patients with lung cancer were more likely to take analgesics than those with breast cancer (62% vs. 47%, $p=0.011$), whereas patients with gastrointestinal (52%) and gynecologic (54%) malignancies had intermediate utilization rates.

Among patients reporting pain, but not taking analgesic medications, reasons most commonly cited for lack of analgesic usage included: failure of the healthcare provider to recommend medications (85%), fear of becoming addicted or dependent (80%), and an inability to pay for medications (76%). Participants experiencing pain but not taking analgesics pursued physical therapy (88%), massage (5%), and acupuncture (1%) as alternative measures for pain control.

DISCUSSION

This study demonstrates that a significant number of oncology patients experience pain symptoms that they attribute both to their underlying cancer and to standard cancer treatment modalities. Although most patients reported pain symptoms, an alarming percentage of those in pain did not take analgesics to alleviate their pain. Reasons given by study participants for not taking analgesics largely mirrored those of the general population and most commonly included lack of healthcare provider recommendation, fear of becoming addicted or dependent, and inability to pay for pain medications. This study also demonstrated that many cancer patients not utilizing analgesics will enlist complementary therapies to control pain. Additionally, insufficient pain control was documented in this study; among respondents taking analgesics, more than half still reported pain both from their cancer and their cancer treatment. Furthermore, since most respondents described their pain as chronic or intermittent and a substantial minority of respondents utilized short-acting analgesics every four or fewer hours, this study suggests that many oncology patients may benefit more from optimizing longer-acting pain medications than from acute or inconsistent analgesic usage.

Cancer patients who experience pain often deny or do not report having pain symptoms to their providers.^{6-9,16-17,19-21} Some patients have a stoicism or fatalism regarding their disease and believe an ideal patient does not complain about pain, that pain should be tolerated, or that it cannot be better controlled with analgesics.^{9,17,20} Others do not report symptoms out of fear that pain is a direct sign of disease progression^{17,22} or concern that their physicians might alter their therapeutic regimens and take focus away from treating their malignancies.²⁰ Some patients choose not to take analgesics until they believe their pain is severe or intolerable.^{8,13,15-16} Others decline analgesics due to concerns about not being able to monitor changes in their body while taking pain medications.^{17,20}

Furthermore, some patients forget or misunderstand how to take their analgesics as prescribed.^{9,21}

Healthcare providers also contribute to undermedication of oncology patients who experience pain. Inadequate pain assessments by providers and discrepancies between patients and physicians in judging patient pain severity predict for suboptimal pain management.^{7–8,10,12,17,19,21,23} Physicians are also more hesitant to prescribe analgesics if patients have a high performance status, are elderly, or have pain they believe primarily from a cause other than cancer.¹⁰ Providers also cite lack of time as a leading reason patients receive inadequate pain management.^{7,18–19} Self-reported lack of basic knowledge about cancer pain evaluation and management by providers may also contribute to inadequate pain management.^{12–13,16,18–19,24}

Furthermore, cancer patients and their providers report fear of side-effects as a cause for limited analgesic usage.^{6,9,13,17,19–26} Due to shared concerns of patient addiction, physicians often avoid prescribing narcotics and patients often hesitate to take such medications.^{9,11,16,19–27} Physicians and patients also share concerns about the development of drug tolerance that limit patient pain management.^{9,13,17,20–21,27}

In this study, patients reporting pain who completed education beyond high school were significantly more likely to utilize analgesics. This is in keeping with previously published studies demonstrating a higher prevalence of uncontrolled pain in cancer patients with lower education levels.^{28–29} One population-based study reported pain prevalence rates 1.7–2.0 times higher in oncology patients with lower education levels, compared to those completing pre-university, university, or higher vocational education.²⁸ It is possible that patients with lower education levels communicate their pain symptoms less effectively with their healthcare providers, have more difficulty paying for analgesics, or have greater concerns about the side effects or addictive properties of narcotics.

The authors have previously reported early results with patients specifically treated with radiotherapy.¹¹ However, the current study includes significantly more patients and those treated with all modalities of cancer therapy, including chemotherapy and surgery. This expanded dataset has allowed for more detailed analyses and conclusions applicable to the broader cancer community. Also, there are some differences from the previous report that was limited just to patients who received radiotherapy. In the prior study, we found lower analgesic usage among more highly educated patients. As the current study demonstrated low rates of analgesic utilization among patients with breast cancer, the difference between the current and prior reports is likely attributable to the high proportion of patients (49%) with breast cancer among the 106-patient subset, with breast cancer diagnosed in 57% of patients with higher education levels in that subset.

Analgesic usage in this study was also found to vary according to gender and treatment modality received. Higher overall utilization rates among women were seen despite low utilization among the many female respondents with breast cancer. In contrast, prior studies have not reported varying pain scores or frequency of analgesic usage by gender.^{28–29} Perhaps women in this study were more likely to volunteer information regarding their pain symptoms to their healthcare providers, thus allowing for more effective pain management regimens to be instituted. It is also possible that women with cancer-related pain had more knowledge than men about pain and pain management, as has been previously reported.³⁰ Higher analgesic utilization rates were also seen among patients who received chemotherapy and radiation. It is possible that these patients were assessed for pain at regular intervals during and immediately following their treatments and given analgesics as needed based on those frequent assessments.

Analgesic utilization was also found to vary by primary cancer diagnosis. To date, limited data have assessed the relationship between cancer pain prevalence, analgesic usage, and the type and stage of cancer diagnosis, and those studies have largely reported discrepant findings.^{10,28–29,31–34} Among the most commonly reported disease sites in this study, respondents with lung cancer had the highest rates of pain and analgesic utilization. Prior studies have also reported higher rates of pain among patients with lung cancer when compared with other cancer types.^{28–29,31} In contrast to certain malignancies that are curable with a single treatment modality, cancers that require multiple and concurrent treatment modalities may cause increased rates of pain. Furthermore, cancer diagnoses associated with shorter life expectancies or earlier propensities for metastasis may also result in higher rates of pain. Delays in cancer diagnosis for certain disease sites are also correlated with increased likelihood of patients experiencing pain at diagnosis.³⁵ As the study questionnaire did not assess stage of disease or time from symptomatic presentation to cancer diagnosis, future studies are needed to evaluate pain and analgesic utilization by cancer diagnosis, stage of disease, and time to diagnosis.

There are specific biases that need to be acknowledged with this and any Internet-based study. These biases include both individual and societal biases of Internet use. Individuals self selected themselves to participate in this questionnaire, which may influence the generalizability of the results.³⁶ Our survey allowed for self-administration by anyone with access to the Internet and who visited the OncoLink website. There were no email requests, advertisements or solicitation outside of those surfing the OncoLink website itself. However, among the thousands of visitors to the OncoLink website, only a minority completed this survey. This bias has been well described previously and is termed the "volunteer effect".³⁷ It is possible that individuals electing to complete a questionnaire entitled "Cancer Pain Survey" were specifically interested in the subject of pain since they were experiencing pain that was inadequately managed. The Internet itself selects a unique slice of society that does not represent all populations with cancer. Caucasian oncology patients are more likely to use the Internet to search for information about their cancer than are African-American and other non-Caucasian patients.^{38–39} This is in concordance with Internet usage of the United States as a whole, where 71% of non-Hispanic whites, 56% of Hispanics, and 51% of African Americans use the Internet on an average day.⁴⁰ There is also greater Internet utilization among those who achieve higher education levels, earn higher annual incomes, receive oncology care at academic hospital settings, are younger, and are less satisfied with the amount of treatment-related information they receive from healthcare providers.^{38–42}

Respondents in this study were more likely to be Caucasian and less likely to be African American or Hispanic/Latino(a), when compared to the demographic composition of the United States general public. Respondents were also more likely than the general public to pursue higher education and be of female gender.⁴³ Furthermore, more participants were diagnosed with breast cancer and fewer with prostate, lung, or colorectal malignancies than would be expected based on current cancer statistics data.⁴⁴ This survey was not presented in Spanish, which may have led to underrepresentation of the Hispanic population. These representation discrepancies may limit the generalizability of the current study.

This study did not assess the impact of participant age or socioeconomic status and could not account for evolving prescriber practices over the past several years. Age has been shown to significantly predict for pain control and analgesic utilization among oncology patients.^{30,45–46} Furthermore, analgesic utilization in this study was lower among minorities. In addition to differences in Internet utilization between races and the low number of minority patients completing the survey, it is possible that race is acting as a surrogate for socioeconomic status. As such, different rates of analgesic usage seen among varying races may be explained by differences in socioeconomic backgrounds or occupations. As patients

who solicit medical information on the Internet are more likely to have higher education levels and socioeconomic statuses,^{39,41–42} future research should attempt to minimize such potentially confounding variables as race, education, and socioeconomic status. Furthermore, since late 2005 when the study questionnaire was first posted on the OncoLink website, further attention in the medical community has been given to inadequate pain management among oncology patients, and greater awareness of opioid diversion and misuse has also developed. As such, the results reported in this study may be somewhat different than for a similar study beginning to enroll participants today.

Despite attempts by the NIH, World Health Organization, Institute of Medicine, American Society of Clinical Oncology, and Joint Commission on the Accreditation of Healthcare Organizations, the incidence of inadequate pain management among oncology patients remains high.^{47–48} To decrease patient morbidity and provide optimal pain management for their oncology patients, healthcare providers should strive to perform medication reconciliation and evaluate and document patient pain levels and analgesic responses during each patient encounter.

CONCLUSION

This study demonstrates that pain is a major cause of perceived morbidity among cancer patients. While the majority of patients in this study suffered from pain, most reported receiving inadequate pain management. Healthcare providers working with oncology patients should make pain management a priority and regularly have open discussions with their oncology patients regarding pain symptoms and pain management options to improve the quality of life for their oncology patients.

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Figure 1.
Distribution of Survey Respondents According to Primary Cancer Diagnosis

Table 1**Patient Characteristics (N=1107)**

Sex		
Female	805	(72.7%)
Male	302	(27.3%)
Race		
Caucasian	821	(74.2%)
African American	69	(6.2%)
Asian/Pacific Islander	47	(4.2%)
Hispanic/Latino/a	35	(3.2%)
Mixed Race	31	(2.8%)
Other	79	(7.1%)
Unspecified	25	(2.3%)
Highest Education Level ^a		
Grade School	60	(5.4%)
High School	272	(24.6%)
Some College	296	(26.7%)
College Degree	245	(22.1%)
Graduate School	172	(15.5%)
Unspecified	62	(5.6%)
Treatment Modality Received ^b		
Radiation Therapy	519	(46.9%)
Chemotherapy	703	(63.5%)
Surgery	761	(68.7%)
Clinical Trial		
Current/Prior Enrollment	197	(17.8%)

^aPercentages do not sum exactly to 100.0% due to rounding.

^bPercentages sum to greater than 100% since patients could report receiving multiple treatment modalities.

Table 2

Classes of Analgesic Medications and Specific Medications Utilized Among Oncology Study Participants Who Reported Consuming Analgesic Medications (N=553)

Analgesic Medication Drug Classes (Specific Medications)	Percentage ^a
Short-acting oral narcotics (morphine, oxycodone, hydromorphone)	44.8%
Short-acting transmucosal narcotics (fentanyl)	3.3%
Long-acting oral narcotics (morphine, oxycodone)	16.3%
Long-acting transdermal narcotics (fentanyl)	13.9%
Non-narcotic prescription oral analgesics (gabapentin, tramadol, butalbital)	16.5%
Over-the-counter oral analgesics (acetaminophen, aspirin, ibuprofen)	50.8%
Vitamins/herbal supplements for pain management (pills, powder, tea, etc)	19.2%
Other analgesics	17.7%
Oral analgesics, uncertain of the drug name or drug class	7.1%

^aPercentages sum to greater than 100% since patients could report utilizing multiple medication classes for pain management.