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Patient Satisfaction with Pain Level in Patients with Cancer

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Abstract

Interest in satisfaction as a pain-related outcome variable wavered when investigators found poor correlations with pain intensity when they measured satisfaction with pain management rather than satisfaction with pain level. Before abandoning the concept of satisfaction as an outcome, we explored the relationship between satisfaction with pain level and pain intensity among patients receiving ongoing outpatient cancer care at large community, university affiliated, Veteran's Administration, or small community medical centers in the Midwest or on the west coast of the United States. A comparative, secondary data analysis was conducted on a crosssectional sample of 806 cancer patients (57% male, mean age 56 ± 13 years, 77% Caucasian). We measured satisfaction with pain level as a single item (yes, no, not sure) and pain intensity as an average (API) of current, least and worst pain intensity (all 0–10 scales) in the last 24 hours. Of the 806 participants, 447 (56%) subjects were satisfied with their pain level, 291 (36%) were not satisfied, and 68 (8%) were not sure. Satisfaction was moderately correlated with API ($\rho = -0.43$, $P < .001$). Patients satisfied with their pain levels reported statistically lower mean API scores (2.26 ± 1.70) than those not satisfied (4.68 ± 2.07) or not sure (4.21 ± 2.21), $P < .001$. With pair wise post hoc comparisons, mean API scores of satisfied patients were significantly lower than those not satisfied or not sure. In contrast with other researchers who have not found associations between satisfaction with pain management and pain intensity, we demonstrate that when satisfaction is measured specifically, patients with higher pain intensity are not satisfied. We recommend that

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researchers use ‘satisfaction with pain level’ instead of ‘satisfaction with pain management’ as the pain satisfaction outcome.

Keywords

satisfaction; pain; intensity; management; cancer; outpatients

Introduction

The considerable interest in satisfaction related to pain as an outcome variable waned after investigators studied postoperative and cancer patients and found poor correlations between satisfaction and pain *intensity*. In these studies, patients commonly reported moderate to severe pain (4 on a 0–10 scale), but indicated they were satisfied with their pain *management* (Cohen, 1980; Dawson et al., 2002; Jamison, Taft, O'Hara, & Ferrante, 1993; Miaskowski, Nichols, Brody, & Synold, 1994). These findings are counter intuitive, and authors have speculated about explanations for the inconsistency. Not many authors, however, have considered the validity of the satisfaction item. Most investigators measured satisfaction with pain *management*, not *pain level*, but the former is a vague concept that could be interpreted many ways. A few investigators measured satisfaction with pain relief or satisfaction with pain level in small samples (Corizzo, Baker, & Henkelmann, 2000) and did not observe the inconsistency that investigators observed when measuring satisfaction with pain management. These findings are encouraging, but there is a need for a larger study to provide stronger evidence. The purpose of the study reported here was to examine the relationship between satisfaction and pain intensity when satisfaction with pain level was reported by outpatients with cancer.

Cancer is a common health problem frequently associated with pain and is an important illness condition for studying patient satisfaction. The incidence of patients with cancer is on the rise both nationally and worldwide with projected global numbers for 2030 at 21.4 million new cases and 13.2 million deaths per year (Boyle, 2008). Pain is a major symptom in 40–50% of newly diagnosed patients and as high as 80–90% (Wilson et al., 2009) of those in the advanced stages of the disease (Cleary & McNeil, 1988; Cleeland, 1993; Lesage & Portenoy, 1999). Patient satisfaction, including satisfaction with pain management, is an important measurement, so much so, that in 2008 the Centers for Medicare & Medicaid Services (CMS) implemented surveys that measured patient satisfaction experiences in hospitals and home health agencies. Not only is patient satisfaction an important measurement from a regulatory perspective, but from a financial perspective as well. Studies have shown that higher patient satisfaction is associated with decreased treatment costs and patient defections to other facilities or providers (Drain, 1999). Increased patient volumes and referrals (Office of Consumer Affairs, 2012) have also been associated with patient satisfaction. Since patient satisfaction is an important concept, and since pain occurs so often in patients with cancer, the contradiction related to satisfaction with moderate to severe pain warrants further investigation.

Literature Review

Much of the literature dealing with pain and patient satisfaction has focused upon satisfaction with pain *management*, not satisfaction with pain *level*. A large proportion of patients with cancer pain, e.g., 80% (Beauregard, Pomp, & Choiniere, 1998) to 99% (Panteli & Patistea, 2007), and postoperative pain, e.g., 75% have reported a high degree of satisfaction with pain management despite reporting moderate to severe pain intensity. Similar study results have been found in other countries, including the Netherlands, Sweden and China (Beauregard et al., 1998; de Wit, van Dam, Vielvoye-Kerkmeier, Mattern, & Abu-Saad, 1999; Hurwitz, Morgenstern, & Yu, 2005; Jensen, Mendoza, Hanna, Chen, & Cleeland, 2004). Possible explanations for this dissonance are varied.

To providers pain *management* may include the degree to which pain is controlled, but to patients pain *management* may include the efforts of the providers to help the patient obtain pain relief. Patients therefore may report being satisfied with their providers' efforts rather than being satisfied with the amount of pain they experienced (Boyle, 2008; Cleary & McNeil, 1988). Several studies have revealed that satisfaction with pain *management* includes satisfaction with (1) the doctor's attention to pain (Adams, 1998; Bostrom, Ramberg, Davis, & Fridlund, 1997; Dawson et al., 2002; Maroney, Litke, Fischberg, Moore, & Morrison, 2004; Ward & Gordon, 1996), (2) nurses attention to pain and other needs (Bostrom et al., 1997; Carlson, Youngblood, Dalton, Blau, & Lindley, 2003; Dawson et al., 2002; Panteli & Patistea, 2007; Ward & Gordon, 1996), (3) health professionals' rapid responsiveness --"always helped right away" (Adams, 1998; Carlson et al., 2003), (4) patient's pain knowledge (deWit, 1999), (5) fear of side effects (Maroney et al., 2004; Panteli & Patistea, 2007), and (6) the perception that "nothing else could be done" (Dawson et al., 2002; Maroney et al., 2004). Although such factors as fear of side effects and "nothing else could be done" are not necessarily positive attributes to satisfaction, it appears the patients' perceptions were that everything that could be done to decrease pain was done; hence they reported satisfaction with the efforts of healthcare workers rather than satisfaction with the actual intensity of the pain they experienced.

Findings from the one study in which satisfaction with pain level was specifically studied showed that patients experiencing higher pain intensity (>4 on a scale of 0–10) reported less satisfaction (Corizzo et al, 2000). They studied 114 patients with either cancer related pain or acute postoperative pain and found a weak to moderately strong negative correlation between satisfaction and pain intensity; higher pain intensity was associated with lower satisfaction with current pain level. Therefore, Corizzo et al (2000) provide some but insufficient evidence for the validity of the satisfaction with pain level measure. Although some authors have suggested abandoning the measure of satisfaction related to pain as an outcome (Svensson, Sjoström, & Haljamae, 2001), before doing so, it is important to measure satisfaction with pain level in a large enough sample to draw meaningful conclusions. The aim of this study was to determine the relationship between satisfaction with pain level and pain intensity among outpatients with cancer.

Methods

Design

A comparative analysis was conducted using pre-existing, de-identified databases from four studies. Primary data collection was approved by the institutional review board (IRB) at the University of Washington and ongoing data analysis and additional primary data collection were approved by the IRB at the University of Illinois Chicago. Participants consented to their information being used for future research.

Setting

Subjects received ongoing outpatient cancer care at large community, university-affiliated, Veterans Administration, or small community medical centers. The cancer care included treatment with radiation, chemotherapy, a combination of radiation and chemotherapy, or follow-up oncology care. All facilities were located on the west coast or in the Midwest of the United States.

Sample

A convenience sample was recruited between 1994 and 2007 in a series of four completed studies. Of the 806 patients with cancer who were receiving ongoing cancer care, were alert and oriented, could speak and read English, and were 18 years or older, 56.5% percent were male. Patients, who were legally blind, did not speak or read English, or who were unable to complete the study questionnaires were excluded from the original studies. The mean age of the sample was 56.7 ± 13 years (18 to 87). The racial/ethnic distribution was: 77% Caucasian, 14% African-American, 3% Asian, 3% Hispanic, 1% Native American, and 2% mixed. They were diagnosed with various types of cancer including head/neck, lung, breast, prostate, sarcoma, cervical, colorectal, and other as indicated in Table 1. Of the participants, 12.9% had stage 1 cancer, 13.02% stage 2, 18.32% stage 3, 53.83% stage 4, and 1.93% unknown cancer stage.

Procedure

Although this study is focused on secondary data analysis, during the original studies the clinic nurses or physicians referred potential subjects to the research assistants (RAs) who screened patients for suitability in the study and consented those who met the inclusion criteria. During the original early studies, participants completed a paper and pencil version of the measures at the beginning of the study. In later studies, participants completed an electronic version of the measures at the beginning of the study. The RA collected all personal demographic data at the first study visit. Clinical data were collected from the patient or from the patient's medical records.

Measures

Satisfaction with pain level was measured by an item that specifically asked participants "Are you satisfied with your pain level?" Response options were "yes," "no," or "not sure." Since patient satisfaction with pain intensity has not been well studied, the stability of the measure over time has not been established. Validity of the item was supported by focus

group findings that indicated patients wanted a “not sure” option in addition to “yes” and “no” (Huang, 2003) and by cognitive interviews with patients in another study (Jha et al., 2010).

The Pain Intensity Number Scale (PINS) was used to determine the current, least and worst pain intensity over the past 24 hours. Directions for the PINS asked subjects to call their pain a number from 0 to 10 with 0 being “no pain” and 10 being “pain as bad as it could possibly be.” A systematic literature review revealed that the use of a unidimensional pain rating scale like the PINS is recommended for the assessment of pain intensity (Hjermstad et al., 2011). When compared to other pain rating scales like the visual analog scale (VAS) and the Verbal Rating Scale (VRS), it was found that the PINS was preferred by patients leading to higher compliance, ease of use and by researchers for the improved responsiveness and applicability (Hjermstad et al., 2011). The PINS has revealed very strong associations with VAS scales (Kremer & Atkinson, 1981; Price, Bush, Long, & Harkins, 1994). The PINS was found to be a valid measure of pain intensity (Downie et al., 1978; Kremer & Atkinson, 1981) and has been supported as to criterion related validity (Daut, Cleeland, & Flanery, 1983) and concurrent validity (Ramage-Morin, 2008; Wilkie, Lovejoy, Dodd, & Tesler, 1990). Ware et al (2006) found test-re-test reliability was supported in a group of older minority adults with coefficients ranging from 0.77 to 0.89.

Analysis

We averaged the current, least and worst PINS scores to create an Average Pain Intensity (API) score that represented the typical intensity of the patient's pain over a 24-hour period. The API score could range from 0 to 10.

Data analysis included the calculation of the means, SD and frequency distributions. ANOVA was used to evaluate the difference between groups of subjects. A correlation was calculated to determine how strongly patient pain level satisfaction and pain intensity were related. All statistical analyses were performed with SPSS 16.0 statistical package.

Results

When data from all four studies were combined, there were 806 patients who completed the satisfaction questionnaire. Of these patients, 447 (56%) were satisfied with their pain level, 291 (37%) were not satisfied with their pain level, and 68 (8%) were not sure if they were satisfied with their pain level (Table 2).

There were statistically significant but weak correlation coefficients for satisfaction with pain level and current ($r_s = -.34$, $p < .01$), least ($r_s = -.24$, $p < .01$) and worst ($r_s = -.34$, $p < .01$) pain intensity. Also, there was a weak linear correlation between satisfaction with pain level and API ($r_s = -.36$, $p = .01$) (Table 4).

Mean current, least, worst and API scores were compared by satisfaction with pain level as shown in Table 3. There were statistically significant differences in the scores for current, least, worst and API scores by satisfaction with pain level options. Those participants who were satisfied reported a lower mean for all four pain intensity scores than those not satisfied

or not sure (Table 3). Post hoc comparisons of all the mean pain intensity scores showed that the differences were significant for subjects who reported 'yes' compared to those who reported 'no' and those who reported 'yes' compared to those who reported 'not sure' (Table 3). These differences, however, were not significant for subjects who reported 'no' compared to those who reported 'not sure' (Table 3). The mean pain intensity scores differed by 1.4 to 2.8 points for current, least, worst, and API for subjects reporting 'yes', 'no' and 'not sure' on the satisfaction with pain level item.

Discussion

This study of outpatients with cancer is the first to show that when satisfaction is measured with an item focused on pain level there are slightly more than half of the outpatients who are satisfied with their pain levels and the mean pain intensity scores differ significantly as would be expected. The differences between the mean API score of subjects reporting "no" and "yes" on the satisfaction with pain level item (4.68 versus 2.26, respectively) was significant. This finding supports our hypothesis that the more intense the pain is, the less satisfaction with pain level that the outpatient with cancer will report. In contrast with other researchers who have not found associations between satisfaction with pain management and pain intensity, we found that when the pain score and satisfaction is measured specifically related to the amount of pain the person has, outpatients with cancer and higher pain intensity are not satisfied but those with lower pain intensity are satisfied. This finding is intuitive, but has eluded other researchers in their studies of patients who had pain related to a variety of conditions, including those with cancer and recovering from surgery. Our findings from a large sample of outpatients indicate that satisfaction with pain level can be used as an outcome of pain treatment effectiveness. Also, our sample included outpatients with all four stages of the disease as well as different types of cancer increasing the heterogeneity and possibly the generalizability of our findings.

Outpatients satisfied with the mean values of their pain intensity for their current, least and worst pain (1.57, 1.09 and 4.10 respectively) versus those not satisfied for current, least and worst (4.28, 2.89 and 6.88) reported values that were on the lower end of the 0–10 PINS scale (1.57 – 4.10) than those not satisfied (4.28 – 6.88). Although few studies are available specifically measuring patient satisfaction and pain intensity, those that are, found similar results to our study (Corizzo et al., 2000; Daut & Cleeland, 1982).

While small differences in PINS scores may be statistically significant and important in the research process, the clinical significance may be trivial. Therefore, it is equally important to determine the size of the treatment effect that matters to patients in pain, or clinical significance. Studies have shown that a change in pain rating on a PINS-11 scale (scale of 0–10) of 1.5 to 2.4 (Bijur, Chang, Esses, & Gallagher, 2010; Farrar, Portenoy, Berlin, Kinman, & Strom, 2000; Gallagher, Liebman, & Bijur, 2001; Kendrick & Strout, 2005; Todd, Funk, Funk, & Bonacci, 1996) is clinically significant. Therefore, the differences in the mean pain intensity scores by satisfaction groups were all clinically important.

The worst and average pain intensity scores for outpatients in our study are similar to those of patients in other cancer pain studies. Daut and Cleeland (1982) in their study of 667

cancer patients found that cancer patients with metastasis reported a mean worst pain (0–10 scale) of 6.4 ($\pm$ 2.6) in breast cancer patients with metastasis and 6.6 ($\pm$ 2.7) in prostate cancer patients with metastasis. Corizzo et al (2000) explored cancer pain and acute postoperative pain in 114 inpatients and outpatients. They found that the worst pain experienced by patients in 24 hours was a mean of 6.85 ($\pm$ 3.17) for inpatients and 5.13 ($\pm$ 2.75) for their outpatients. Average pain in the inpatients was 4.88 ($\pm$ 2.72) and 4.04 ($\pm$ 2.22) in the outpatients. Just as we found a correlation between satisfaction and pain intensity so did Corizzo et al (2000); the more intense the pain the less satisfaction patients reported.

Considering Daut and Cleeland's study in 1982, Corizzo et al's in 2000 and our analysis of data collected over a period of 13 years, outpatients' reports of their pain intensity levels have not changed dramatically. Despite the fact that during these years an increased interest in pain intensity on the part of the medical arena and private sector has emerged, various regulatory bodies (The Joint Commission, Centers for Medicare Medicaid Services, etc) have placed a high priority on pain assessment, pain management technology has improved (e.g., epidural and intrathecal infusion pumps), there is a greater awareness of pain and its detrimental effects on healing, and new drug therapies are available, little progress has been made in the realm of controlling pain for the cancer outpatients who continue to report moderate to severe worst pain intensity.

There was only a weak negative correlation between satisfaction with pain level and pain intensity in this study possibly due to the fact the patient population for this analysis consisted entirely of cancer outpatients. Patients in chronic severe pain expect more dramatic decreases in the level of their pain before reporting satisfaction with pain intensity (Ward & Gordon, 1996). On the other hand, postoperative patients exhibit satisfaction with pain intensity even when the decrease in the level of their pain is not as pronounced perhaps because they expect to experience severe pain postoperatively. Authors of studies regarding patient satisfaction with intensity postulate that other factors may contribute to satisfaction with pain intensity including effectiveness of medication, finances, education for both the caregivers and the patients, communications and expectation versus actual pain intensity (Carlson, Youngblood, Dalton, Blau & Lindley, 2003; Corizzo & Henkelmann, 2000; deWit, et al., 1999). Future studies might separate these patient populations out to determine if patient's satisfaction with pain intensity varies with these factors.

Limitations

Secondary use of existing data, which can be very rich and provide much information, does not come without its own unique set of concerns. Data quality is always a concern as the investigator relies on the integrity of the initial researcher collecting the data. The data were cleaned and double checked before analysis as there were different codebooks for the four studies and some of the demographic information was coded differently. For example, in one study gender coding was reversed and men were coded as 01 instead of 00 and required recoding before the data were merged. In addition to issues related to the actual data, historical changes over time should be also considered when analyzing data. During the span of 13 years pain treatment has changed and could affect the responses of patients. Drug

therapy has improved, and if administered appropriately, could affect intensity and therefore satisfaction. In 1999 The Joint Commission mandated that healthcare workers include pain as the fifth vital sign forcing healthcare workers to focus their attention on this symptom. Finally, health care facilities are becoming more aware of the importance of patient satisfaction through the use of patient satisfaction surveys to promote brand loyalty, decrease defections and decrease patient waiting times.

Recommendations for Further Study

It has been demonstrated that when outpatients have the opportunity to rate their satisfaction with their pain intensity versus their pain management, more intense pain is related to less satisfaction. More research is necessary to not only specifically measure pain intensity as an outcome but to replicate findings in other samples. While many studies exist related to patient satisfaction with drug therapy, pain management, surgical treatments and pain management tools, few studies have been done explicitly addressing patient satisfaction with pain intensity and the validity of the satisfaction item. In addition, other mediating and moderating factors that impact pain intensity should be considered. Limited research is available regarding differences in satisfaction with pain level by demographic characteristics including gender, age, ethnicity and socioeconomic status. Even more limited, but nonetheless equally important are differences in satisfaction by other factors associated with cancer pain such as type of cancer, stage of the disease and type of pain.

In summary, this study provides compelling evidence to reduce the paradox that has plagued pain-related satisfaction studies. By measuring satisfaction with a single item focused specifically on satisfaction with pain level, we demonstrate that outpatients with cancer report that they are not satisfied when they report moderate to severe pain, report satisfaction when they also report mild to moderate pain, and report they are not sure if they are satisfied when they report moderate pain. The differences in mean pain intensity by satisfaction groups are statistically significant and clinically meaningful. Although the findings of this study are an advance for pain research, additional studies are warranted to better understand the factors that influence satisfaction with pain level.

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Table 1

Cancer Types

Diagnosis	Percent
Head/Neck	24.6
Lung	21.6
Breast	18
Prostate	14
Sarcoma	5.2
Cervical	2.4
Colorectal	2.3
Other (including, but not limited to cervical, lymphoma, myeloma)	11.9
Total	100

Table 2

Description of Response Option for Satisfaction with Pain Level

	N	Percent	Mean Pain Score	SD
Yes	447	55.5	2.26	1.70
No	291	36.1	4.68	2.07
Not Sure	68	8.4	4.21	2.21
TOTAL	806	100		

Table 3
Mean Intensity Variables by Satisfaction with Pain Level: Descriptions and Comparisons

Intensity Variable	Satisfied with Pain Level	Mean	SD	F	df	P	Post Hoc Comparisons
Present Pain Intensity	Yes	1.57	1.76	147.8	2	<.001	+ \$ #
	Not Sure	4.03	2.5				
Least Pain	No	4.28	2.65	84.91	2	<.001	+ \$ #
	Yes	1.09	1.52				
Worst Pain	Not Sure	3.09	2.45	86.15	2	<.001	+ \$
	No	2.89	2.45				
Average Pain Intensity	Yes	2.26	1.7	154.74	2	<.001	+ \$ #
	No	4.21	2.21				
	Not Sure	4.68	2.07				

KEY

+ Yes – No are significantly different

\$ Yes – Not Sure are significantly different

No – Not Sure are not significantly different