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Experience and knowledge of pain management in patients receiving outpatient cancer treatment: What do older adults really know about their cancer pain?

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Abstract

Objective—An individual's ability to effectively manage their cancer pain is influenced by knowledge and perceptions regarding the pain experience. While significance of the physician's knowledge of cancer pain management has been reported, much less is known how a patient's knowledge may influence their ability to optimally manage their pain. The purpose of this study is to determine the influence identified health and social factors have on the knowledge and experience of cancer pain among older adults.

Design—A prospective cross-sectional study of older Black and White patients presenting for outpatient cancer treatment.

Methods—Participants were surveyed on questions assessing pain severity, knowledge and experience of pain, self-efficacy for pain treatment, satisfaction with pain treatment, and additional social, health, and demographic characteristics. A series of hierarchical regression models were specified to examine predictors of cancer pain knowledge and experience.

Results—Education, race, and trust were significant predictors of pain knowledge, whereas self-efficacy for pain, pain interference, and pain severity were indicators of the experience of cancer pain.

Conclusions—Knowledge and experience of (cancer) pain are contingent upon a myriad of social and clinical factors that are not exclusive, but rather coexisting determinants of health. Understanding older adults' knowledge of pain may begin to diminish the disparities in the diagnosis and treatment of pain among this growing diverse population of older adults. It may similarly allow for programs to be tailored to fit the specific needs of the patient in the treatment and management of their cancer pain.

Keywords

older adults; pain knowledge and experience; pain severity; trust; self-efficacy; cancer pain

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INTRODUCTION

An estimated 30–85% of early to advanced stage cancer patients report chronic pain.^{1–3} This variability suggests longer survival with the disease and the increase in the number of older adults, whom are reported to have a higher incidence of cancer diagnoses.^{4,5} The increased prevalence of symptomatic outcomes (pain) implies the difficulties in treatment and diagnosis, where cancer patients' pain is often misdiagnosed and undertreated.⁶

Empirical evidence shows a myriad of barriers that may lead to the unequal burden of cancer pain, which may occur at any level along the continuum of screening, primary, secondary, and tertiary preventions.⁷ Whether at the institutional, provider, or patient level, there is an ongoing need to understand the (in)direct impact these factors have in the day-to-day lived experiences of this patient population, but more importantly why they present as barriers in achieving optimal pain management.

One area gaining considerable attention is the patient's knowledge and experience with cancer pain. While the knowledge of the physician in cancer pain management is reported, less attention has focused on the patient's knowledge of pain resources and their experience with pain.⁸ Even with available treatment options, it is estimated that 40% of all cancer patients lack the resources to effectively manage their pain.⁹ This lack of information may influence the patient's reluctance to report pain for fear of distracting the physician from treating the underlying medical condition,¹⁰ fear of addiction, and believing that pain is an inevitable consequence of cancer;¹¹ all of which may present as major barriers to proper pain management.¹²

Efforts have been made to dispel these misconceptions, while examining resources to cancer pain management.^{13,14} Low levels of health and pain literacy, along with various social and clinical variables are demonstrated to augment the negative perceptions and attitudes related to pain treatment.^{15–17} Data have outlined best practices where the benefits of education-based interventions, for example are shown as a mechanism by which to obtain accurate information to achieving manageable pain control,^{9,15,18–20} changing the patient's negative attitudes related to adherence and misconceptions regarding analgesic medications,⁹ and recognizing the importance of having an efficacious doctor-patient relationship to successful pain control.¹

While proven beneficial in understanding the impact patient-related barriers have on pain management, few studies have examined the specific patient characteristics (social, clinical) that may influence knowledge and experiences with cancer pain. The potential benefits of knowing which patients are more (or less) likely to be knowledgeable of their cancer pain may facilitate existing programs from the "one size fits all" assessment to a more patient-centered approach. This methodology may prove beneficial in the implementation of (intervention) programs, thereby addressing the specific needs of the patient, while improving their quality of life.^{14,15}

There is a compendium of research addressing barriers to the proper diagnosis and treatment of cancer pain across diverse race, socioeconomic, sex, age, and cancer types.^{21–24} While the impact of pain among younger cancer patients has received overwhelming attention, evidence assessing knowledge and experience of cancer pain among older adults is less apparent. To contribute to our understanding of cancer pain in older adults, this prospective cross-sectional study aimed to determine the significance identified demographic (age, race, sex, income, and education), health (pain interference, self-efficacy, comorbidities, pain severity), and social (patient satisfaction, trust, communication) characteristics have in the knowledge and experience of cancer pain and pain management among older Black and White patients receiving outpatient cancer treatment from a National Cancer Institute-

Designated Comprehensive Cancer Center (NCI). Determining the influence social factors, beyond that of clinical and health variables, and measures of self-efficacy for pain management are strengths of this study.

METHODS

Participants

Data were analyzed from a multi-year project designed to examine social, cultural, and psychological constructs of pain in older Black and White adults. Analyses were conducted on patients who self-identified as Black/African American or White/Caucasian, 55 years of age, rated their cancer- pain severity 4 (as rated by the Brief Pain Inventory), and able to provide consent.

Recruitment efforts and interviews were conducted among patients receiving treatment at the Psychosocial & Palliative Care, Clinical Research, and/or Infusion clinics at the cancer center. All patients were approached (and recruited) by a research assistant during the patient's medical visit (waiting area or receiving chemotherapy) to determine their interest and eligibility for study participation. All interviews consisted of participants completing a series of questions assessing health, social, and demographic characteristics. Each interview lasted approximately 45 minutes and was conducted in a private area in the clinic. All participants provided verbal and written informed consent and were compensated for their participation. Moffitt Cancer Center's Protocol Review Monitoring Committee and the University of South Florida's Institutional Review Board (IRB) approved the study.

Measures

Knowledge and experience with cancer pain—The Patient Pain Questionnaire (PPQ) is a validated 16-item (ordinal) scale measuring the knowledge and experience in managing cancer pain. The knowledge subscale includes nine items assessing how knowledgeable a patient is in taking pain medications and managing their pain. The experience subscale consists of seven items measuring pain relief, distress, and control of pain. Response choices were rated on an 11-point numeric scale, with high scores endorsing less knowledge of cancer pain on the knowledge subscale, and more experience with pain on the experience subscale. While it is suggested that each subscale be assessed as total summed scores, it is also recommended to analyze the individual questions of each subscale, as they similarly have important implications to assessment.^{25,26}

Pain severity—The Brief Pain Inventory (BPI) is a 32-item quantitative measure used to assess clinical pain. For purposes of this study, the mean (total) pain severity score (composite of four single pain items: current, average, worst, least) was included in subsequent analyses. Response choices were rated on an 11-point numeric summated rating scale (0 – 10), with high scores indicating greater pain severity.²⁷

Satisfaction with pain treatment—The American Pain Society's Patient Outcome Questionnaire (APS-POQ) is a 16-item measure used to quantify each patient's satisfaction with pain treatment. The APS-POQ has a total of four subscales: pain intensity, pain interference, satisfaction with pain management, and beliefs about pain and pain management. For purposes of this study, only the satisfaction with pain management subscale was examined. Questions were measured on a six-point numeric Likert-scale, with higher scores endorsing greater satisfaction with pain treatment (very dissatisfied=0 to very satisfied=5).²⁸

Self-Efficacy for pain management—Self-efficacy to cope with chronic pain was measured with the Chronic Pain Self-Efficacy Scale (CPSS). This measure consists of two subscales: pain self-efficacy (PSE) and self-efficacy for coping with other symptoms (CSE). Only the PSE subscale was assessed, with each question scored on an 11-point numeric scale (10–100; increments of 10, high scores denote greater self-efficacy).²⁹

Trust—The seven-item trust summary scale, of the Primary Care Assessment Survey (PCAS), assessed each patient's level of trust with their primary medical oncologist. Each statement was scored on a five-point Likert scale, with lower summary scores suggesting less trust toward the provider.³⁰

Communication—A summed score was determined using the five-item communication subscale of the PCAS. Each item was assessed on a six-point scale with response choices ranging from very poor (0) to excellent (5). Higher summed scores suggest a more positive relationship between the patient and provider.³⁰

Health Indicators—A checklist of physical comorbidities assessed the presence of common medical illnesses. Type of cancer was assessed with a single-item question asking participants their cancer diagnosis. Pain interference (subscale of the BPI) assessed how much pain interferes with daily activities. Response items were measured on an 11-point Likert scale, with higher scores denoting more interference with daily activities.²⁷

Demographic characteristics—Five demographic variables were included in the analyses: age, race, sex, income, and education. Age was scored in a continuous format. Education was assessed as the total number of years of formal schooling. Monthly income was coded as a categorical variable. Race was examined via nominal categories, with those who identified as Black/African American or White/Caucasian being included in subsequent analyses.

Statistical Analyses

Descriptive analyses were calculated to provide measure performance and a profile of the sample's demographic (age, race, sex, education, income), health (comorbidities, pain interference, satisfaction with pain treatment, pain severity), and social (self-efficacy, communication, trust) characteristics. Using a pairwise deletion procedure, a series of Pearson Product-Moment correlation coefficients were examined to assess the strength of the bivariate associations between knowledge and experience of pain and each indicator variable.²⁷

To estimate missing data on the PPQ (only 2% of the total sample, with none missing the entire scale), multiple imputations were used via multiple regression models, in which each participant's completed items were used to estimate missing data. Five datasets with imputed values were created with results being the averages of the datasets.

An exploratory factor analysis was also conducted on all items of the PPQ. Although the PPQ was designed with two subscales, analyses were conducted to validate the use of this measure among this sample of cancer patients. Items that loaded on the knowledge factor were summed into one composite, with items loading on the experience factor summed into another (composites were analyzed as separate outcome variables). Composite scores from the factor loadings were included in a series of hierarchical multiple regression models to determine the amount of unique variance in knowledge and experience with cancer pain accounted for by specific social variables, while controlling for the demographic and health indicators. The regression procedure entered the predictor variables into three models. The

demographic variables (sex, income, age, education, race) were entered first (Model I), followed by self-efficacy, physical functioning, pain severity, and comorbidities (health variables; Model II). The social indicators (patient satisfaction, trust, communication) were entered as the final set of predictor variables (Model III). Standardized beta coefficients were reported to describe the relative importance of the predictor variables within the regression model. All statistical analyses were conducted using SPSS version 21.0.

RESULTS

Sample Characteristics

The sample included older Black and White patients, with a mean age of 65.4 ± 7.72 years. More than half of the sample was female and self-identified as non-Hispanic White/Caucasian. Breast (17%), hematologic (13%), and lung (11%) were the most common cancer diagnoses. Medication(s) taken for pain was recorded, with more than half of the sample taking oxycodone/oxycotin (61%), followed by morphine (15%), and hydrocodone (9%) and fentanyl (9%). Participants reported living with an average of two (2.68 ± 2.21) chronic medical conditions (in addition to cancer). Other demographic, health, and social characteristics are provided in Table 1.

Correlations were calculated to determine the association between knowledge and experience with cancer pain and measures of pain severity, self-efficacy, comorbidities, trust, and additional social, health and demographic characteristics. Table 2 shows that lack of trust was negatively associated with cancer pain knowledge. None of the remaining social and health indicators were significantly related to knowledge of cancer pain. Analyses further showed that pain interference, greater pain severity, and reporting more chronic illnesses were moderately associated with the experience of cancer pain. Similarly, lower rates of self-efficacy and health communication were associated with a negative experience with pain. None of the demographic characteristics were significantly associated with either outcome variable (knowledge or experience).

Exploratory Factor Analysis

To validate the use of the PPQ among this sample of cancer patients, a principal components analysis was calculated to extract two factors from the PPQ items. This solution explained 29.5% of the variance. An oblique rotation (direct oblimin, $\delta = 0$) was used, with factors correlated at $r = 0.14$. With few cross-loadings, all of the knowledge items significantly loaded on one scale, with the experience items significantly loading onto the other ($\alpha = 0.60$ and 0.58 , respectively). Two knowledge items (“Cancer pain can be effectively relieved” and “Treatments other than medications can be effective for relieving pain”) and one experience item (“How much pain relief are you currently receiving?”) had loadings of less than 0.25 on their primary factors. When these items were deleted ($\alpha = 0.71$ for knowledge and $\alpha = 0.68$ for experience) 35.3% of the variance was explained. Given these findings, two composites were created for both the knowledge and experience items. One composite contained a sum of all the items from the original subscale, while the other excluded the items with the poor fit. Analyses were run separately for the two sets of composite scores to examine whether there were any discrepancies in the results. None were observed therefore, subsequent analyses included the composite scores of the nine and seven items from the original knowledge and experience with pain subscales, respectively.

Multivariate analyses

Knowledge—The first step in model development involved entering the demographic (age, sex, race, income, education) variables, in which none were significant. The health (pain interference, self-efficacy, comorbidities, pain severity) variables were entered next

(Model II), followed by the social indicators (patient satisfaction, trust, communication) (Model III). The full regression model was significant ($F[5,106] = 5.21, p < 0.001$) and accounted for 25% of the total variation in knowledge of pain. When the three models were included in the final analysis, education ($\beta = -3.44, p < .05$), race ($\beta = 13.17, p < .05$), and trust ($\beta = -2.87, p < .05$) were significant indicators of pain knowledge, with patients with more formal education, greater trust, and self-identifying as White were more knowledgeable of resources in how to better manage their cancer pain. None of the health variables were significant in the full regression model (Table 3).

Experience—Three models were entered to determine the amount of unique variance in the experience of cancer pain accounted for by specific social variables, while controlling for the demographic and health indicators. Table 4 shows that the full regression model was significant ($F[12,99] = 8.33, p < 0.001$) and produced significant indicators of experience with pain. Self-efficacy for pain management ($\beta = -1.83, p < .05$), pain interference ($\beta = 2.31, p < .05$), and pain severity ($\beta = 3.91, p < .05$) were significant indicators of the experience of cancer pain. When all the variables in the respective models were taken into account, patients with higher reported self-efficacy had a more positive experience with cancer pain, while those reporting greater pain severity and interference with daily activities had more negative experiences with their cancer pain. None of the demographic or social variables accounted for significant variance in the experience of pain.

Preliminary exploratory analyses by race group

Although race differences in the knowledge and experience of cancer pain is not the primary focus of this investigation, but of interest, descriptive preliminary data were analyzed. To yield higher levels of power and to account for the non-normal distribution of some of the variables, a Mann-Whitney U test was employed to test the null hypotheses of no difference between older Blacks and Whites on mean scores of knowledge and experience with cancer pain. Categorical data were analyzed using the chi-square test statistic. Preliminary analyses showed a significant difference between older Blacks and Whites in the knowledge of cancer pain (41.7 ± 15.8 vs. $31.5 \pm 12.3, p < .01$). However, no difference was found in the experience of pain. When analyzing the individual items from each subscale, older Whites were more likely to believe that if pain is worse, than the cancer must be getting worse (36% vs. 27%, $p = .05$). None of the remaining individual items showed significant differences between the two race groups.

To further investigate racial differences in the knowledge of pain, a multi-group structural equation model (SEM) of the final regression model was constructed, with model parameters compared between Blacks and Whites. Race did not appear to moderate the effect of the other predictors on pain knowledge. Because the pain experience in the final model was not significant for the total sample, a separate structural equation model was not calculated.

Additional preliminary analyses showed no significant mean group differences on the remaining study covariates (trust, communication, self-efficacy, pain severity, pain interference, and satisfaction with pain treatment).

Findings from these exploratory (and preliminary) analyses suggest that important factors concerning the knowledge and experiences in managing cancer pain may vary by race. This, of course, suggests further research among this population of older adults.

DISCUSSION

Findings from this study build on an expanding body of evidence indicating the importance of psychosocial factors in the knowledge and experience of cancer pain.^{24,31–33} This study adds to the literature by identifying the facilitators and barriers to the knowledge of cancer pain and pain management in a sample of older adults receiving outpatient treatment for various cancer diagnoses. Lack of knowledge, knowledge gaps, misconceptions about pain self-management, and difficulties putting pain management strategies into practice hinder the efficacy of pharmacologic and non-pharmacologic interventions in cancer patients.^{1,11,34,35} In the current study, low education, being Black, and physician mistrust were significant predictors in serving as barriers to the knowledge of pain management.

The literature cites lower education, along with a number of psychosocial factors as barriers to receiving and understanding information regarding cancer treatment and pain management.^{36–39} A recent study found that when given educational materials about cancer treatments, lower educated individuals were more likely to scan the information instead of reading for comprehension compared to higher educated patients.⁴⁰ Additional findings suggest that individuals with higher education actively seek information regarding their cancer treatment and discuss that information with their physicians.^{41,42} By providing, reviewing, and discussing educational materials about cancer pain with their patients, physicians can individualize pain management regimens, and possibly increase the patient's perception of control, hence improving self-efficacy of health and pain management. This process is all the more important among minority patients who may perceive a lack of control within the healthcare setting.⁴³

Results from the current investigation are consistent with previous literature suggesting that being Black is significantly associated with higher information needs throughout the course of cancer treatment.⁴² Other studies have found similar results suggesting a continued need for patient awareness of pain control regimens.^{43,44} The observed informational needs and misconceptions may be due to the difference in information sources of pain information, physician mistrust, and specific needs between White and Black patients. Compared to Whites, Blacks are more likely to trust health information acquired from the media, religious organizations, and government health agencies.⁴⁵ Another plausible explanation for the observed outcome is the possible difference in type of information offered to White and Black patients. Other recent data showed that physician communication about pain management was less patient-centered among Blacks, which may impede a patient's knowledge about their cancer pain. Minority patient factors, including general medical mistrust, concerns about opioid addiction, and the value of stoicism may further exacerbate the difference between race groups.^{2,47,48} Increasing a patient's knowledge regarding pain and decreasing barriers to knowledge of pain control may be effective in increasing one's perception of control over pain, thus possibly decreasing disparities.

Data from this study further showed trust as a significant indicator of pain knowledge. Perceived trust in the physician has been associated with a patient's willingness to accept and adhere to the physician's advice for treatment including taking opioids for cancer pain.^{49,50} As evidenced, trust in one's physician is crucial for productive communication, where patient receptiveness of supplied pain information may facilitate positive outcomes such as increased knowledge of pain and improved pain control. Conversely, distrust of physicians' motives and health information may impact negatively on the therapeutic alliance, causing cancer patients to withhold reporting of pain and refusal of recommendations for further treatments.^{1,51} More research is needed to increase the understanding of what trust in physicians encompasses to cancer patients, how physicians

can contribute to such trust, and ways to reduce barriers (physician mistrust) among racially diverse cancer patient populations.⁵²

Pain is a complex and multidimensional symptom that is affected by psychological and social variables as well as the disease itself. Using a biopsychosocial approach offers the best understanding of the biological, psychological, and social issues involved in the cancer pain experience.⁵³ Despite improvements in cancer pain management, more efforts are needed to effectively manage pain. An area of improvement is a more in-depth and tailored assessment to attain a comprehensive understanding of the patient's pain experience. This holistic understanding requires productive patient-physician communication to provide patient-centered care and address any misconceptions, fears, and uncertainty. As evidenced in this study and previous research, educating the patient about pain management and examining and correcting misconceptions may decrease the patient barriers to pain control, thereby leading to improved perceptions of control over pain. Lastly, a better understanding of patient, health professional, and the health care system level barriers is needed to inform implementation strategies aimed at ensuring evidence-based assessment and management that will improve outcomes.⁵⁴

Although this study demonstrated important and significant results focusing on patient pain knowledge and pain experience among older Black and White cancer patients, there were some limitations that must be acknowledged. First, this was a cross-sectional study, therefore changes over time or established causal relationships in reported pain severity, patient satisfaction, trust, and communication could not be determined. Another limitation was the lack of racial diversity within the sample. The majority of the sample was White and well-educated, therefore our ability to generalize these findings to other cancer populations is limited. Future efforts should focus on diversifying the sample. Additionally, the data were collected via self-reports which may result in potential reporting bias such as social desirability. Reactions to social desirability may have yielded responses that were favorable to that of the patient. Finally, our inclusion criteria was not limited to a specific cancer diagnosis, prognosis, or treatment regimen (e.g., pharmacological, radiation, chemotherapy), therefore we cannot definitively compare our findings to other studies examining specific cancer diagnoses. Despite these limitations, our findings make a significant contribution to the literature as it explores trends (and heterogeneity) of an older adult patient population from an NCI-designated comprehensive cancer center.

CONCLUSION

Cancer-related pain remains a significant concern in ambulatory oncology. A need exists for culturally competent pain education that addresses misunderstandings and concerns in managing cancer pain. Beliefs about cancer pain may be modified by educational interventions that address communication barriers, misconceptions, and knowledge gaps, but also implement strategies for changing patient behavior. Further education on pain management is needed for clinicians, nurses, and pharmacists; thus dispelling the notion that pain is not a priority in patient care. In addition, providers should be aware of the psychosocial factors that may influence patient pain management. Utilizing a multidimensional approach to cancer pain management is important to achieve optimal quality of life for all cancer patients regardless of age, race, sex, or economic status.

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Table 1

Demographic, health, and social characteristics (N=150)

Variable	M±SD	%	Scale
Age	65.4±7.72		
Years of Education	14.0±2.41		
Monthly Income (\$1,000)		73%	
Sex (Female)		57%	
Race (Whites)		82%	
Receiving chemotherapy		50%	
Receiving Palliative care		39%	
Pain Knowledge (PPQ) ^a	33.36±13.55		0–90
Pain Experience (PPQ)	29.93±8.87		0–70
Satisfaction with pain treatment	4.37±0.74		0–5
Pain Severity	4.01±1.91		0–10
Pain Interference ^a	4.75±2.46		0–10
Self-efficacy	55.7±18.83		0–100
Trust	12.8±2.69		0–28
Communication	21.9±4.12		0–25

^aHigh scores indicate less knowledge^bHigh scores indicate greater pain interference

Table 2

Associations between knowledge and experience with cancer pain, and health and social characteristics

Variable	r
Pain knowledge	
Trust	-.21*
Pain experience	
Pain interference	.56**
Pain severity	.65**
Chronic conditions	.25**
Self-efficacy	-.43**
Communication	-.19*

*
p < 0.05;**
p < 0.01;***
p < 0.001;

Table 3

Social and health predictors of knowledge in managing cancer pain

	B (SE)	p	R²	ΔR²
Model I. Demographics			0.20	0.20
Model II. Demographics and Health			0.20	<0.01
Model III. Demographics, Health, Social			0.25	0.05
Age	0.80 (1.35)	0.55		
Income	6.36 (3.45)	0.07		
Education	-3.44 (1.69)	0.04*		
Sex	-3.93 (2.78)	0.16		
Race	13.17 (3.50)	<0.01*		
Self-efficacy	-0.41 (1.41)	0.77		
Pain interference	0.56 (1.69)	0.74		
Pain severity	-0.16 (1.76)	0.93		
Co-morbidities	-0.09 (1.39)	0.95		
Satisfaction with pain treatment	-0.48 (1.42)	0.74		
Trust	-2.87 (1.20)	0.02*		
Communication	-0.86 (1.37)	0.53		

Note. The reference category for income was < \$1,000 a month, the reference category for sex was males, and the reference category for race was Whites.

* Significant at $p < 0.05$.

Table 4

Social and health predictors of experience with managing cancer pain

	B (SE)	p	R²	ΔR²
Model I. Demographics			0.03	0.03
Model II. Demographics and Health			0.49	0.46
Model III. Demographics, Health, Social			0.50	0.01
Age	-0.55 (0.73)	0.45		
Income	-1.82 (1.87)	0.33		
Education	1.32 (0.92)	0.15		
Sex	0.90 (1.53)	0.56		
Race	-2.20 (1.90)	0.25		
Self-efficacy	-1.83 (0.77)	0.02*		
Pain interference	2.31 (0.92)	0.01*		
Pain severity	3.91 (0.96)	<0.01*		
Co-morbidities	1.04 (0.76)	0.17		
Satisfaction with pain treatment	-0.54 (0.78)	0.49		
Trust	0.10 (0.65)	0.87		
Communication	-0.67 (1.37)	0.51		

Note. The reference category for income was < \$1,000 a month, the reference category for sex was males, and the reference category for race was Whites.

* Significant at $p < 0.05$.