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Original Article

Cancer Patients' Perceived Difficulties Filling Opioid Prescriptions After Receiving Outpatient Supportive Care



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Abstract

Context. Limited access to opioids for patients with cancer has been reported as a potential unintended consequence of recent regulations restricting opioid use and prescribing practices. To our knowledge, there are a limited number of peer-reviewed studies that evaluate the perceived difficulties of the patients with cancer when filling their opioid prescription. To understand these difficulties, we surveyed patients receiving opioids in our outpatient supportive care center (SCC).

Objectives. The primary objective of this study was to evaluate cancer patients' perceptions of overall difficulties when filling their opioid prescription. Secondary objectives included determining associations between patient characteristics and difficulty and comparing difficulty between filling opioid and nonopioid prescriptions.

Methods. Patients with cancer receiving opioids that had been seen two times or more at our SCC were asked to complete a survey. The information collected included patient demographics, clinical characteristics, and patients' experiences filling their opioid prescription.

Results. The patients' median age was 60 years; 54% were female and 69% were white. Forty-four patients (32%) reported that they have experienced difficulty filling their opioid prescription. More than 25% of those 44 patients perceived difficulty from interactions with the pharmacy and/or pharmacist. Forty-six patients (33%) reported more difficulty filling their opioid prescriptions than filling their nonopioid prescriptions.

Conclusion. This study provides evidence that patients with cancer visiting our SCC perceived difficulties obtaining their opioid prescriptions. The results suggest that negative interactions with the pharmacy and/or pharmacist contribute to their perceived difficulty. Additional research is needed to further characterize the contributors of the difficulties patients with cancer face in filling their opioid prescriptions. *J Pain Symptom Manage* 2020;60:915–922. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Analgesics, opioid, prescriptions, cancer pain, opioid epidemic, palliative care, pain management

Key Message

Limited access to opioids for patients with cancer has been reported as a potential unintended consequence of recent regulations restricting opioid use and prescribing practices. After receiving outpatient supportive care, approximately one-third of cancer patients with an opioid prescription perceived having difficulties when filling their opioid prescription.

Introduction

Pain is one of the most frequent and burdensome symptoms among patients with cancer, with prevalence rates of 66% in patients with metastatic disease, 55% in patients during treatment, and 39% in patients after curative treatment.¹ Although opioid therapy remains the first line of defense for effective management of cancer-related pain,² the abuse and misuse of opioids

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continues to be a growing epidemic in the U.S.³ Subsequently, the Centers for Disease Control and Prevention, released guidelines for physicians to safely prescribe opioids to patients.⁴ Although these guidelines exclude patients undergoing active cancer treatment or palliative care, recent reports show that an unintended consequence of the systemic and regulatory changes has been limited access to opioids for patients with cancer.^{5–8} In a survey conducted by Public Opinion Strategies on behalf of the American Cancer Society Cancer Action Network and the Patient Quality of Life Coalition, cancer patients, survivors, and others with serious illnesses reported having experienced increased difficulties receiving their opioid prescription from 2016 to 2018.⁹ This limited access to opioids adversely impacts the management of cancer-related pain, as at least one-third of patients with cancer reported that they did not receive adequate medication for the intensity of their pain.^{10–12} The undertreatment of cancer pain is associated with other psychosocial and physical symptoms that negatively affect clinical outcomes and the patient's quality of life.^{9,13}

Barriers that prevent adequate pain management for patients with cancer have been previously described, including regulatory requirements, racial and socioeconomic disparities, societal attitudes toward pain management (i.e., opioid stigma),¹⁴ and parenteral opioid shortages.^{15–17} The availability of opioids has been further impacted by the reduction in opioid prescription patterns among oncologists. One study reported a significant decreasing annual trend of opioid use in patients with advanced cancer who received inpatient palliative care (morphine equivalent daily dose of 150 mg/day in 2008 to 83 mg/day in 2014).¹⁸ Another study showed that the amount of opioids prescribed to patients with cancer before referral to an outpatient palliative care clinic decreased to 40 mg/day in 2015 from 78 mg/day in 2010.¹⁹ Moreover, anecdotal patient reports to our clinic describing difficulties in filling opioid prescriptions make us suspicious that this may be a widespread problem.

Although the impact of the opioid epidemic and the recent regulatory changes on cancer patients' access to their opioid medications has been described,^{15,16,18,19} there are a limited number of peer-reviewed studies that have evaluated cancer patients' perceived difficulties when filling their opioid prescriptions. Based on the previous limited literature, we hypothesized that after receiving outpatient supportive care, cancer patients perceive difficulties when filling their opioid prescription. Therefore, this pilot study was conducted to determine cancer patients' perceived difficulties when filling their opioid prescription after receiving outpatient supportive care. To understand these difficulties, we conducted

a patient survey with questions about the patient's experiences in filling their opioid prescriptions. The patients also answered questions about their experiences filling prescriptions for their other regular (nonopioid) medications. Knowledge and understanding of these perceived difficulties will shed light on the contributors of these issues and allow for implementation of strategies to overcome the difficulties to ensure that patients with cancer are not negatively impacted when obtaining their legitimate opioid prescriptions.

Methods

This survey study was approved by the Institutional Review Board at The University of Texas MD Anderson Cancer Center. Patients were eligible to participate if they were at least of 18 years, had a cancer diagnosis, were receiving opioids prescribed by the MD Anderson supportive care center (SCC), had visited the SCC two previous times for the purpose of opioid pain management, and were able to understand, read, write, and speak English. The survey consisted of 24 questions relating to patients' perceptions of the problems that they encountered when filling their prescriptions for opioids. To our knowledge, there are no validated measurements to use for evaluation of patients' difficulties filling opioid prescriptions. The survey was developed based on a previous study conducted by Public Opinion Strategies on behalf of the American Cancer Society Cancer Action Network and the Patient Quality of Life Coalition,⁹ and questions used in the survey were refined by input from experts in the field at MD Anderson SCC. The survey was assessed for readability and was pilot-tested on volunteers to ensure that it took less than 10 minutes to complete. Five minutes was the average time to complete the survey. Before administration of the survey, patients' demographic and clinical information were collected, including scores on the Cut-down, Annoyed, Guilty, and Eye-opener questionnaire, opioid prescription history, and cancer diagnosis.

Our primary objective was to evaluate cancer patients' perceptions of overall difficulties when filling their opioid prescription. Overall difficulty was determined by a yes and/or no question on the survey. Our secondary objectives were to determine if associations existed between patient characteristics and patient difficulty filling opioid prescriptions, and to evaluate the patients' perceived difficulties when filling opioid vs. nonopioid prescriptions.

Statistical Analysis

Summary statistics were used to describe the demographic and clinical characteristics of the study population. The association between patients' perception

about difficulty filling opioids and their characteristics was evaluated by Wilcoxon rank sum test and Chi-squared (Fisher's exact) test for continuous and categorical variables, respectively. Estimates of odds ratio along with 95% CI were calculated by fitting univariate logistic models.

Results

A total of 962 patients with advanced cancer presenting to the MD Anderson SCC were screened between April and September 2019. Of the 238 patients who were eligible, 156 patients were approached and 140 patients completed the survey (Fig. 1). The reasons for not approaching 82 of the 238 eligible patients are listed in Fig. 1. One patient who completed the survey only received prescriptions

via mail order, so that patient's responses were removed from the analysis. Table 1 lists the demographic and clinical characteristics of 139 patients who completed the survey. The median age (interquartile range) was 60 (20, 90) years, and 55% of the patients were female.

Table 2 reports the perceived experiences of patients when filling their opioid prescription. Overall, 44 patients (32%) reported that they have experienced difficulty filling their opioid prescription. Of those 44 patients, 12 (27%) said that the pharmacist(s) remembers them each time, which is significantly lower than the 55% of patients (53 of 96) who have not experienced difficulty and also said that the pharmacist remembers them ($P < 0.005$). Table 3 reports the attitudes and beliefs of patients according to difficulty filling their opioid prescription. Those

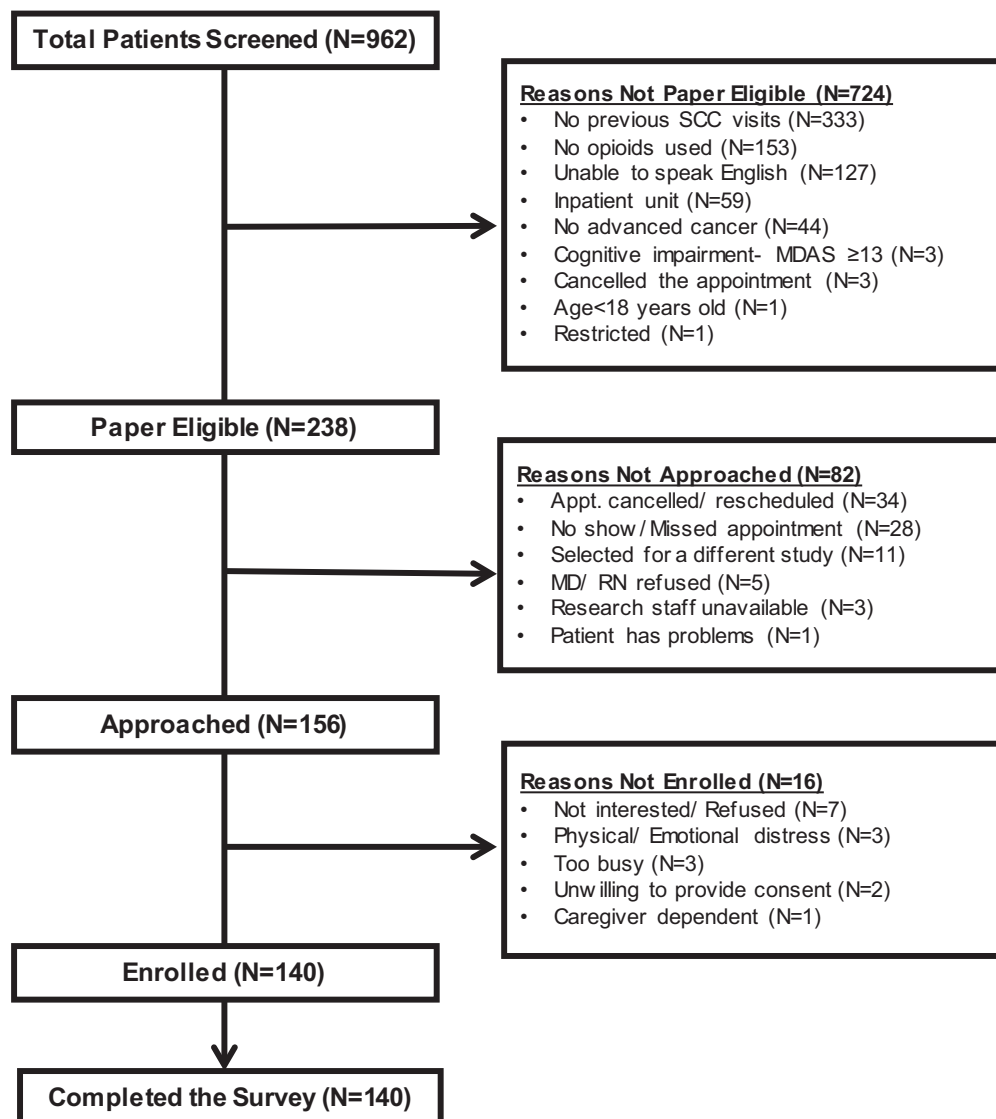


Fig. 1. Consolidated Standards of Reporting Trials diagram of patients' flow throughout the study. SCC = supportive care center; MDAS = Memorial Delirium Assessment Scale; MD = medical doctor; RN = registered nurse.

Table 1
Patient Characteristics

Variable	Total, <i>n</i> (%)	Overall, Has the Patient Had Difficulties When Filling Their Opioid Prescription? <i>n</i> (%) ^a	
		Yes	No
All patients	139 (100)	44 (32)	95 (68)
Median age (range)	60 (20, 90)	59 (20, 81)	62 (30, 90)
Female sex	76 (55)	25 (57)	51 (54)
Race/ethnicity			
White	96 (69)	33 (75)	63 (66)
African American	28 (20)	7 (16)	21 (22)
Hispanic	13 (10)	2 (4.5)	11 (12)
Asian/Pacific Islander	2 (1)	2 (4.5)	0
Marital status			
Married/significant other	92 (66)	25 (57)	67 (71)
Single	18 (13)	8 (18)	10 (11)
Divorced	16 (12)	7 (16)	9 (9)
Widowed/separated	13 (9)	4 (9)	9 (9)
Highest level of education completed			
Less than high school/tech school	12 (9)	4 (9)	8 (8)
High school/tech school	30 (22)	6 (14)	24 (25)
Incomplete college or junior college	38 (27)	12 (27)	26 (27)
Complete college	39 (28)	16 (36)	23 (24)
Incomplete masters/doctoral degree	3 (2)	0	3 (3)
Complete masters/doctoral degree	17 (12)	6 (14)	11 (12)
Annual household income			
<\$40,000	38 (28)	13 (30)	25 (27)
\$40,000–\$80,000	33 (24)	11 (24)	22 (23)
>\$80,000	36 (26)	13 (30)	23 (24)
Prefer not to say	31 (22)	7 (16)	25 (26)
Cancer diagnosis			
Breast	21 (15)	9 (21)	12 (13)
Gastrointestinal	23 (17)	8 (18)	15 (16)
Head and neck	18 (13)	6 (14)	12 (13)
Genitourinary	20 (14)	5 (11)	15 (16)
Gynecologic	13 (9)	5 (11)	8 (8)
Thoracic	23 (17)	5 (11)	18 (19)
Sarcoma	9 (7)	3 (7)	6 (6)
Other ^b	12 (8)	3 (7)	9 (9)
Current cancer stage			
Locally advanced	38 (27)	10 (23)	28 (30)
Metastatic	101 (73)	34 (77)	67 (70)
CAGE-AID positive	22 (16)	8 (18)	14 (15)
First given opioids (months)			
Less than three	11 (8)	5 (11)	6 (6)
Three to six	22 (16)	5 (11)	17 (18)
Six to 12	42 (30)	12 (27)	30 (32)
>12	64 (46)	22 (50)	42 (44)
Median MEDD (IQR)	120 (80, 185)	151 (82, 242)	120 (80, 180)

CAGE-AID = Cut Down, Annoyed, Guilty, Eye-opener Adapted to Include Drugs questionnaire; MEDD = morphine equivalent daily dose; IQR = interquartile range.

^aNumber and percentage of individuals reported are those who answered always/very often/sometimes to the stated variable.

^bOther diagnoses include skin, lymphoma, myeloma, and leukemia.

who reported difficulty filling their opioid prescription were more likely to feel emotional distress when going to the pharmacy (12 of 44 [27%] vs. 3 of 95 [3%]; $P < 0.001$), that the difficulty was caused by the pharmacy and/or pharmacist (12 of 44 [27%] vs. 1 of 95 [1%]; $P < 0.001$), and that the pharmacist makes them feel ashamed (6 of 44 [14%] vs. 0 of 95 [0%]; $P < 0.001$).

Difficulty filling opioid prescriptions as compared with nonopioid prescriptions was reported more frequently among the 44 patients who perceived overall difficulty filling their opioid prescription (30 of 44 [68%] vs. 16 of 95 [17%]; $P < 0.001$). We asked patients to report the most common reason they had difficulty filling their opioid prescription vs. their nonopioid prescription. Consistent with patients with

Table 2
Perceived Difficulties Experienced by Patients When Filling Opioid Prescriptions

Variable	Total, <i>n</i> (%) ^a	Overall, Has the Patient Had Difficulties When Filling Their Opioid Prescription? <i>n</i> (%) ^a		<i>P</i>
		Yes	No	
All patients	139 (100)	44 (32)	95 (68)	
Do you regularly receive your opioid prescription from the same pharmacist(s)? ^b	115 (83)	33 (75)	82 (85)	0.072
Does the pharmacist seem to remember you each time you visit the pharmacy? ^b	65 (48)	12 (27)	53 (55)	0.005
How often have you been unable to get your opioid prescription?	5 (4)	4 (9)	1 (1)	0.035
How often have you been unable to get your opioid prescription because the pharmacy did not have the particular drug in stock?	7 (5)	4 (9)	3 (3)	0.207
How often have you been unable to get your opioid prescription because your insurance would not cover it?	2 (1)	2 (5)	0 (0)	0.098
How often has a pharmacist asked you about why you needed your opioid prescription?	4 (3)	3 (7)	1 (1)	0.094
How often has your insurance company limited you to only one pharmacy to go to for filling your opioid prescription?	3 (2)	0 (0)	3 (3)	0.551
How often has your insurance company reduced the number of times you can refill your opioid prescription?	3 (2)	3 (7)	0 (0)	0.031
How often has your insurance company reduced the number of pills in your opioid prescription?	3 (2)	3 (7)	0 (0)	0.032
How often has the pharmacist given you only part of your opioid prescription (e.g., for seven days instead of the 30 days for which the prescription was written)?	3 (2)	3 (7)	0 (0)	0.030
How often have you paid a high copay (more than \$50) for your opioid prescription?	10 (7)	4 (9)	6 (63)	0.726

^aNumber and percentage of individuals reported are those who answered always/very often/sometimes to the stated variable.

^bNumber and percentage of individuals reported are those who answered yes to the stated variable.

difficulty indicating the pharmacist as the reason for their difficulty, 17 of 44 patients (39%) also identified the pharmacy and/or pharmacist as the most common reason. The other most common reasons for difficulty filling their opioid vs. nonopioid prescriptions included financial distress (11 patients; 25%) and emotional distress (7 patients; 16%) when picking up their opioid prescription. The mean morphine equivalent daily dose was statistically significantly greater in patients who reported more difficulty filling their opioid prescription than their nonopioid prescription (217 mg/day vs. 137 mg/day; $P < 0.001$). There was no association between reported difficulty and the patients' demographic characteristics.

Discussion

The results of this pilot study show that patients with cancer who are on opioid therapy to manage their pain have perceived having difficulties when filling their opioid prescriptions. Importantly, patients who reported difficulties were able to identify barriers related to psychological difficulties and the pharmacist's attitude toward them. The findings also show that patients perceived that it was more difficult to fill opioid prescriptions compared with nonopioid prescriptions. Overall, these results provide preliminary data on cancer patients' perceptions of the

difficulties encountered when trying to get their opioid prescription after visiting an outpatient SCC.

Our results are similar to another study conducted in adult cancer outpatients at a supportive care clinic that reports opioid stigma was endorsed by 59 of 97 (61%) patients who were prescribed opioids.²⁰ When queried about specific aspects of opioid stigma that they experienced, 21 of 97 (22%) patients identified trouble filling prescriptions and 14 of 97 (14%) patients reported difficulty getting prescriptions.²⁰ Our findings further suggest that the reason for difficulty in obtaining opioid prescriptions stems from emotional distress, most likely experienced from the interaction of the patient with the pharmacist when picking up their medication. Unlike other studies that report socioeconomic²¹ and racial^{22–24} disparities as a barrier to opioid access in general patient populations, this study did not show an association between patients' racial demographics and difficulty obtaining opioids. One reason for this could be that most patients who completed the survey were white (69%). However, a large percentage of the patients who reported difficulty were white (75%), suggesting that limited opioid access may affect people across various racial groups. More research is needed to fully characterize the patient demographics associated with difficulty getting opioid prescriptions in the adult cancer population.

Table 3
Attitudes and Beliefs of Patients Who Report Difficulty Filling Their Opioid Prescription

Variable	Total, n (%) ^a	Overall, Has Patient Had Difficulties When Filling Their Opioid Prescription? n (%) ^a		P
		Yes	No	
All patients	139 (100)	44 (32)	95 (68)	
I feel financial distress when filling my opioid prescription	18 (13)	6 (14)	12 (13)	1.00
I feel that the pharmacy/pharmacist makes the process of filling my opioid prescription difficult	13 (9)	12 (27)	1 (1)	<0.001
I feel emotional distress when I go to the pharmacy to fill my opioid prescription	15 (11)	12 (27)	3 (3)	<0.001
The pharmacist makes me feel ashamed for having an opioid prescription	6 (4)	6 (14)	0 (0)	<0.001
I feel more comfortable filling my opioid prescription at a pharmacy in a different neighborhood than where I live	11 (8)	5 (11)	6 (6)	0.324
Overall, it is more difficult to fill my opioid prescription than to fill my other nonopioid prescription medicine(s)	46 (33)	30 (68)	16 (17)	<0.001
I feel more financial distress when filling my opioid prescription than when filling my other nonopioid prescription medicine(s)	19 (14)	11 (25)	8 (8)	0.015
I feel that the pharmacy/pharmacist makes the process more complicated when I fill my opioid prescription than when I fill my other nonopioid prescription medicine(s)	20 (14)	17 (39)	3 (3)	<0.001
I feel more emotional distress at the pharmacy when I pick up my opioid prescription than when I pick up my other nonopioid prescription medicine(s)	9 (7)	7 (16)	2 (2)	0.005
The pharmacist treats me differently when I pick up my opioid prescription than when I pick up my other nonopioid prescription medicine(s)	7 (5)	5 (11)	2 (2)	0.033

^aNumber and percentage of individuals reported are those who strongly agree/agree with the stated variable.

We were surprised to find that patients did not perceive having logistical difficulty, such as restrictions from the insurance company, when filling their opioid prescription. Although these challenges have been reported previously by others, it is possible that by the time this study was carried out, the opioid access difficulties originating from prior authorizations of insurance companies had been mostly resolved. Another possible explanation is that many patients might not understand that the barrier might stem from insurance issues and therefore ascribe their difficulty to the pharmacy and/or pharmacist. Nonetheless, it is possible that the current coronavirus disease 2019 (COVID-19) pandemic may cause new logistical difficulties, as the medical product chains are impacted by shortages in medications and patients across diagnoses are facing increasing difficulties seeking medical care;²⁵ this makes it even more crucial that patients with cancer have access to their opioid prescriptions.

Some limitations of this study include its small sample size and the lack of a validated tool to assess patients' perceptions of the difficulties encountered when filling their opioid prescription. Although patients' demographic and clinical information was obtained, the geographic location of the pharmacy where the patient had difficulties was not collected because of concerns over patient privacy and zip code as potentially identifying information; thus, we

were unable to assess if certain geographic regions were associated with difficulty filling opioid prescriptions. Because reports suggest that geographic factors could play a role in opioid access for patients,²⁶ future studies overcoming privacy concerns around patient geography could prove extremely insightful. Another limitation is that the results might not be generalizable to patients receiving cancer care at other institutions and hospitals because this study was carried out at a single institution: a comprehensive cancer center with its own outpatient pharmacy. Moreover, the patients in this study were seen twice by our supportive care clinicians, who take extra care to ensure that patients have access to opioids for their pain by prescribing opioids that are less expensive. This scenario could be different in other clinics where financial concerns are not considered or in clinics that are not as experienced with strategies to overcome access barriers as in the SCC, suggesting that patients' financial distress could be underrepresented. Finally, our results may not be generalizable to the overall U.S. cancer patient population, as the opioid epidemic has been characterized as less severe in Texas compared with other regions of the country.²⁷

Despite the limitations of the study, these findings suggest that negative interactions with pharmacists contribute to cancer patients' perceived difficulties when obtaining their legitimate opioid medications.

These interactions that inflict shame and emotional distress on the patient with cancer can lead to negative outcomes via avoidance of pharmacies and health care providers, poor adherence to pain medication, and undertreatment of pain.²⁰ These findings further suggest opportunities to educate pharmacists on the experience of patients and their potential distress when filling their legitimate opioid prescriptions, along with educational opportunities to provide to patients in terms of their safe use of opioids and their rights when filling prescriptions. A study in our SCC showed that education focused on opioid safety for patients with advanced cancer led to improved patient-reported safe opioid storage, usage, and disposal.²⁸ Providing this type of opioid management education for patients at the time of prescribing (by the physician) and at the time of dispensing (by the pharmacist) could reduce the patient's emotional distress by alleviating their concerns about using opioids as well as decreasing potential complications around filling the prescription from the pharmacist. Evaluating the use of educational material for patients and pharmacists when receiving and filling an opioid prescription would therefore be a rich avenue of future research.

The tantalizing results of this study suggest that additional research could uncover other contributors of perceived difficulty to accessing opioids in the context of the cancer patient population. To accomplish this effort, studies should be carried out to investigate the types of pharmacies where these difficulties are taking place (i.e., community pharmacies vs. hospital pharmacies). Importantly, additional studies are needed to determine the sociodemographic and clinical characteristics of patients who perceive difficulties when filling their opioid prescriptions.

Conclusions

Evidence from this study shows that patients with cancer perceived difficulties when filling their opioid prescriptions, and the results suggest that negative interactions with the pharmacy and/or pharmacist contribute to their perceived difficulty. To ensure that patients with cancer can access their legitimate opioid prescriptions without negative impacts, including shame and emotional distress, further research efforts are needed to fully characterize these difficulties and to implement strategies that address their origins.

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