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Cancer and Opioids: Patient Experiences with Stigma (COPES) – a Pilot Study

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Abstract

Context: Cancer-related pain is a common symptom that is often treated with opioids. However, legislation aimed at containing the opioid crisis, coupled with public fears about opioid risks, may contribute to opioid stigma in cancer patients. To our knowledge, no prior research has examined opioid stigma and stigma-related behavior in this population.

Objective: To describe opioid use, including reasons for use and over- and under-use behavior; characterize opioid stigma; and identify potentially maladaptive associated behaviors.

Methods: Participants were 125 adults undergoing active cancer treatment being seen at the Moffitt Supportive Care Medicine Clinic. Patients completed a brief, anonymous questionnaire evaluating opioid use, opioid stigma, and stigma-related behaviors.

Results: Patients were primarily women (65%) aged 45–64 years (49%), most commonly diagnosed with breast (23%) and hematologic (15%) cancer. Among patients who reported opioid use (n=109), the most common reason for use was pain relief (94%), followed by improved sleep (25%). A subset of patients reported using less (13%) or more (8%) opioid medication than advised. Opioid stigma was endorsed by 59/97 patients prescribed opioids (61%), including fear of addiction (36%), difficulty filling prescriptions (22%), and awkwardness communicating with providers (15%). Stigma-related behaviors were endorsed by 28 (29%) of respondents prescribed opioids, with “taking less opioid medication than needed” as the most commonly endorsed behavior (20%).

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Conclusion: To our knowledge, this study provides the first evidence of opioid stigma and its consequences in cancer patients and offers potential targets for interventions aimed at reducing stigma and encouraging safe, effective opioid use.

Keywords

opioids; opioid stigma; cancer pain; pain management

Introduction

Pain is a common symptom which often goes unrelieved in cancer patients, with prevalence rates of up to 55% during active treatment for cancer.[1] Under-treatment of cancer pain is a significant problem[2] associated with worse quality of life, increased depression and anxiety, social withdrawal, and insomnia.[3–6] Opioids are a mainstay in the management of cancer pain.[7] However, the emergence of the opioid crisis, or the unprecedented increase in opioid abuse in the United States, has sparked regulations restricting opioid prescribing and dispensing, in addition to public fears about risks associated with opioids.[8] Though cancer-related pain is often explicitly excluded from such regulations,[9] cancer patients may nonetheless internalize stigma associated with opioid use.

Stigma, or the process by which characteristics are labelled as socially undesirable and contribute to negative stereotypes,[10] may have a negative impact on pain management in cancer patients. Opioid stigma may manifest as internalized fears about one's own opioid use,, experienced or anticipated judgments from others, and/or barriers to obtaining prescribed opioids. As a result, stigmatized individuals may experience guilt, shame, embarrassment, and discrimination from others, and may engage in potentially maladaptive behaviors as a consequence. Conceptually, these behaviors may include avoidance of healthcare providers or poor adherence to opioid recommendations, among others. However, to our knowledge, no peer-reviewed studies have evaluated opioid stigma or associated behaviors in cancer patients.

Thus, the current pilot study was conducted to provide preliminary data supporting opioid stigma as a commonly endorsed problem in cancer patients. The study addressed the following three aims: to 1) describe self-reported opioid use in cancer patients; 2) characterize opioid stigma, and 3) identify behaviors associated with opioid stigma.

Methods

Patients & Procedures

Participants were adult outpatients in the Moffitt Supportive Care Medicine Clinic, which manages cancer-related pain during treatment. Questionnaires were administered to every patient who presented to the clinic from 07/2018–09/2018 as part of their routine care. Front desk staff provided the survey to the patients as part of a questionnaire packet with the following instructions: "There's an extra questionnaire in the packet for you that's part of a research study that we're doing. It's completely anonymous and your answers will not be part of your medical care here, so when you are finished, please put it in the green box. If

you've already done it once, no need to do it again." Minimal demographic information was collected in order to maintain privacy and obtain a broad sample of patient responses. A return box was provided in a separate area of the clinic, from which questionnaires were collected each day.

Measures

To our knowledge, there are no validated assessment measures for opioid stigma. Thus, an initial item bank was generated by study investigators and refined based on input from clinicians with expertise in cancer pain management. The final questionnaire consisted of 7 items. All patients completed basic demographic information, then indicated the last time that they had used opioids and for what reason. Finally, all patients indicated whether they had taken more or less of their opioid medication than prescribed over the past two weeks.

Patients currently prescribed opioid medication were asked to indicate whether or not they had experienced 10 potential aspects of opioid stigma, including anticipated and enacted judgment from friends/family and providers/pharmacists, difficulty obtaining prescription opioids, communication difficulties, and fears of addiction. Patients also endorsed up to 7 potentially maladaptive behaviors related to opioid stigma, including under-utilization or avoidance of prescribed opioids, hoarding, evasion of discussions with others about opioid pain management, and avoidance of social engagements in which others might notice prescription opioid use. Items were considered on a yes/no basis (e.g., whether the patient had ever experienced that aspect of stigma or engaged in an associated behavior).

Data Analysis

Descriptive analyses were conducted in SAS 9.4 (Cary, NC) to characterize sociodemographic and clinical characteristics, opioid use, opioid stigma, and associated behaviors.

Results

The total sample was comprised of 125 patients, who were primarily female (61%) and between 45–64 years old (48%). Complete demographic and cancer site information is shown in Table 1.

Of the total sample, 16 participants reported only demographic information, while 109 participants responded to any question characterizing opioid use; only these participants were included for subsequent analyses. Pain relief (102/109, 94%) was the most common reason for opioid use, followed by better sleep (27/109, 25%), relaxation (12/109, 11%), increased energy (8/109, 7%), and improved mood (7/109, 6%). A subset of these patients reported using less (14/109, 13%) or more (9/109, 8%) opioid medication than prescribed.

In the 97 patients currently prescribed opioids, 59 (61%) patients endorsed at least one possible aspect of opioid stigma (Table 2). On average, patients endorsed 1–2 instances of opioid stigma each (M(SD) = 1.4(1.9), range 0–10). Patients most commonly reported fear of becoming addicted (35/97, 36%), trouble filling prescriptions (21/97, 22%), feeling

awkward discussing pain with providers (15/97, 15%), and worrying about appearing drug-seeking (15/97, 15%).

Behaviors related to with opioid stigma were endorsed by 28 (29%) respondents (Table 3), with an average of <1 behavior endorsed per patient (M(SD) = 0.5 (0.8), range 0–3). “Taking less opioid medication than needed” was the most commonly endorsed behavior (19/97, 20%), followed by saving up medication (6/97, 6%), and avoiding discussing pain with providers or family/friends (both 5/97, 5%).

Discussion

This pilot study examined opioid use, opioid stigma, and associated behaviors endorsed by a heterogeneous group of cancer patients receiving outpatient supportive care. Results indicated that opioid medications are commonly used in this group, primarily for pain relief. Opioid stigma was endorsed by a majority of patients currently prescribed opioids, most commonly pertaining to fears of addiction, barriers to obtaining medications, and communication difficulties with providers. Further, over a quarter of patients endorsed potentially maladaptive behaviors associated with their opioid stigma, most commonly underutilizing opioid medications. Taken together, these results provide preliminary evidence that opioid stigma is a commonly endorsed problem in cancer patients, and is worthy of continued investigation.

Limitations of this pilot study include a small sample and a lack of validated assessment tools with which to assess opioid stigma. The questionnaire was also anonymous, which likely allowed participants to be forthcoming about their experiences, but limited the ability to comprehensively characterize this sample. Finally, due to the anonymous nature of this study, we were unable to assess the response rate and representativeness of this sample.

Despite limitations, our findings suggest that in oncology care there may be negative consequences of public health campaigns aimed at restricting opioid use. This topic would benefit from thorough further research in a large, well-characterized sample of cancer patients. A validated measure is needed in order to assess opioid stigma in cancer patients. Thus, further work will be completed in this area in order to develop a comprehensive, psychometrically validated assessment tool. Such a measure will allow standardized assessment of opioid stigma in subsequent studies. Evaluation of detailed sociodemographic and clinical characteristics may provide important context for patient experiences with opioid stigma that were not available in the current study. Finally, future research should examine contributors and consequences of opioid stigma. For example, if patients fear stigma from healthcare providers, they may subsequently avoid discussing their opioid pain management with physicians to avoid awkward conversations or appearing drug-seeking. This is likely to result in negative outcomes, such as perpetuation of common misconceptions and lack of knowledge about opioid management, worse opioid adherence, and medical mistrust. Further, patients underutilizing prescription opioid medications due to stigma, lack of education, and unsubstantiated fears may contribute to the under-treatment of pain in this group. Future evaluation of the contributors to and consequences of opioid stigma may culminate in 1) development of psychoeducational and/or cognitive-behavioral

interventions to manage opioid stigma and 2) public health policy changes to mitigate the impact of opioid crisis legislation on cancer patients.

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Table 1:

Patient characteristics (N=125)

Variable	N (%)
Age range:	
18–29	6 (5%)
30–44	16 (13%)
45–64	60 (48%)
65+	40 (32%)
No response	3 (2%)
Gender:	
Male	41(33%)
Female	76 (61%)
No response	8 (6%)
Primary Cancer Diagnosis:	
Breast	27 (22%)
Hematologic	19 (15%)
Lung	16 (13%)
Other	16 (13%)
Genitourinary	13 (10%)
Gynecologic	13 (10%)
Gastrointestinal	7 (6%)
Head & Neck	7 (6%)
Melanoma	4 (3%)
No response	3 (2%)

Percentages rounded to nearest whole number.

Table 2:

Opioid stigma in patients currently prescribed opioids (N=97)

Variable	N (%)
Concern, Any Level:	
Yes	59 (61%)
No	38 (39%)
Specific Concerns Endorsed	Total
Worry about addiction	35 (36%)
Difficulty filling prescriptions	21 (22%)
Awkward discussing with providers	15 (15%)
Worry about appearing drug-seeking	15 (15%)
Difficulty getting prescription	14 (14%)
Worry about judgment from providers	10 (10%)
Problems with insurance	10 (10%)
Feeling judged by providers	9 (9%)
Worry about judgment from family/friends	6 (6%)
Experience of judgment from family/friends	3 (3%)

Percentages rounded to nearest whole number.

Table 3:

Opioid stigma-related behaviors in patients currently prescribed opioids (N=97)

Variable	N (%)
Stigma-Related Behavior, Any:	
Yes	28 (29%)
No	64 (66%)
Specific Behaviors (% of total respondents)	
Using less opioid medication than needed	19 (20%)
Hoarding/saving up medication	6 (6%)
Avoiding discussing pain with providers	5 (5%)
Avoiding discussing pain with family/friends	5 (5%)
Avoided taking opioids altogether	4 (4%)
Did not fill opioid prescription	3 (3%)
Avoided social events where others may notice pain medication usage	3 (3%)

Percentages rounded to nearest whole number.