

Cancer Patient Perspectives on the Opioid Treatment Agreement: Tool for Safety or Symbol of Distrust?

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Abstract

Context: As cancer survival rates improve, a growing number of patients experience persistent cancer- and non-cancer-related pain and require opioids; however, opioid treatment agreements (OTAs), which are standard in chronic non-cancer pain management, are not routinely used in cancer pain care.

Objectives: Our aim in this study was to evaluate adult cancer patients' comprehension of OTAs, their perceived purpose, and their acceptability in an outpatient cancer pain-management setting.

Methods: Adult patients with cancer related chronic pain at a tertiary cancer center completed this survey between January 2023 and December 2024. Eighty-nine adult cancer patients with chronic pain completed the survey, with a response rate of 98.9%.

Results: After reviewing an opioid agreement, most patients reported the agreement was clear and relevant to opioid treatment: 94% found it easy to understand, 96% felt consequences were clear, and 97% agreed it clarified pain management. Agreement with safety-related items was moderately high, including safe use of opioids (83%) and random drug screens being protective (81%). Notably, 28% still had outstanding questions or concerns.

Conclusion: Our survey patients expressed strong agreement with the opioid agreement, particularly regarding the clarity and relevance of safety-related components such as safe opioid use and the role of random drug screens. While approximately $\frac{3}{4}$ (78%) felt the agreement primarily protected the patient more, over $\frac{1}{4}$ (27%) believed it protected the physician more. Additionally, 28% of patients reported remaining questions or concerns, highlighting the need for improved communication and patient education in opioid prescribing for cancer pain.

Introduction

Cancer pain is highly prevalent and can have a debilitating impact on quality of life. A recent systematic review showed a pooled prevalence of cancer pain was 44.5%, with the lowest rates observed after curative treatment (35.8%) and the highest rates in advanced, metastatic, and terminal cancer populations (54.6%)(1). Advances in early detection and cancer treatment have led to a growing population of cancer survivors whose pain increasingly mirrors that of other chronic pain conditions in terms of duration and functional impact(2). Consequently, there is a need for long-term pain management strategies tailored to cancer patients and survivors.

Opioid analgesics remain important in alleviating moderate to severe cancer pain, with international and national guidelines consistently endorsing their use for managing cancer pain when non-opioid therapies are inadequate(3–5). In light of the opioid epidemic, physicians have been more cautious about prescribing opioid medications, even within the cancer population(6, 7). Thus, clinicians are challenged with providing effective pain control while mitigating opioid-associated risks like addiction and tolerance with long-term opioid use.

In patients with chronic, non-cancer-related pain, opioid treatment agreements (OTAs) are commonly used as risk-mitigation tools. These agreements outline expectations for appropriate opioid use, the risks and benefits of treatment, and consequences of non-adherence. OTAs are widely implemented in chronic pain and primary care practices to uphold comprehensive opioid stewardship requirements, and in recent years, the Centers for Disease Control and Prevention has advised the personalization of these strategies in alignment with the principles of shared decision-making(7–10).

However, there is no such clear role for OTAs in patients with cancer. Although some cancer centers have adopted OTAs, their use is inconsistent and is largely guided by frameworks established for the management of pain in patients without cancer. In addition, although studies in palliative medicine and oncology clinics have shown the potential for OTAs to reduce opioid misuse, strong empirical evidence supporting the use of OTAs for patients with cancer is lacking(11).

Previous studies exploring the perception of OTAs in patients without cancer have shown that some patients view OTAs as neutral and clarifying in regard to the appropriate use of opioids, whereas others have expressed fears associated with opioid use and concerns over stigmatization(11, 12). OTAs raise ethical concerns regarding trust and patient autonomy, particularly among patients with cancer, for whom therapeutic relationships are more complex. In one national survey, respondents generally regarded OTAs as burdensome and only marginally effective in preventing opioid misuse, though they continued to recognize their overall value. These agreements are frequently written at reading levels exceeding recommended standards and tend to emphasize punitive consequences rather than patient education(13).

Because data regarding cancer patients' comprehension of OTAs, their perceptions regarding the benefits of opioid use, and their concerns about opioid use remain limited, the present study sought to evaluate adult cancer patients' understanding of OTAs, their perceived purpose, and their acceptability in an outpatient cancer-pain-management setting. This critical information will aid in shaping the management of chronic cancer pain, a condition increasingly prevalent as cancer treatments prolong survival.

Methods

Participants

This Institutional Review Board–exempt study at a tertiary cancer center (Protocol #20220101) enrolled adult cancer patients with chronic pain who were treated from January 2023 through December 2024.

The study included English-speaking adults with chronic, cancer-related pain who presented to the outpatient pain-management clinic at MD Anderson Cancer Center, Houston for a new-patient visit and who were prescribed/continued on opioid therapy. Patients were provided informed consent.

Opioid Survey Agreement

The opioid treatment agreement survey used in this study was two pages long and designed to be easily comprehensible by individuals with reading level under 8th grade level (see Appendix A). The wording was intended to be collaborative and focused on patient safety rather than punitive. Key elements of the agreement included encouragement for patients to communicate openly with providers; explicit mention of drug screening through urinalysis, including the possibility of random testing to monitor appropriate opioid use; refill policies; and termination clauses.

The survey questions were developed by DK, based on the VA/ COC clinical practice guidelines(14). LW conducted the cognitive debriefing process, with some details in the revised IRB. Cognitive debriefing is a standard qualitative approach that involves patients completing the questionnaire and then answering questions on their understanding of each question item. It is completed with a trained interviewer and helps refine question wording and identify redundant questions. The first 10 respondents participated in cognitive debriefing interviews, which informed minor revisions to the final version of the questionnaire.

Survey Administration

Patients completed a 20-question written survey with structured questions assessing their understanding of the OTA, its perceived risk reduction, and its perceived purpose. One open-ended item asked how they would explain the agreement to others. Surveys were completed in person, by email, virtually over HIPAA secure virtual software, or by phone within four weeks of the initial clinic visit and took approximately 15–20 minutes to complete.

Statistical Analyses

Descriptive statistics summarized quantitative data using frequency counts and percentages for categorical variables and either means with standard deviations or medians with ranges for continuous variables. Qualitative responses were reviewed for common themes to supplement the interpretation of the structured responses. The first 10 patients participated in cognitive debriefing interviews, which informed minor revisions to the final version of the questionnaire(15).

Results

[Insert Table 1 here]

A total of 89 patients with cancer completed the survey. Their median age was 59 years (range, 26–81 years), and 56% were women (n = 50). Most patients identified as White (84%). Twelve percent of the patients identified as Hispanic/Latino (Table 1).

Twenty-one percent of patients reported comorbid mood disorders, consisting of anxiety (16%), depression (10%), and other mood disorders (2%). Screening for the risk of non-medical opioid use showed a low frequency of elevated risk (Cut down, Annoyed by criticism, Guilt, and Eye-opener Adapted to Include Drugs score, 3%; Screener and Opioid Assessment for Patients with Pain-14 score, 9%). The mean score on the total distress Edmonton Symptom Assessment System questionnaire was moderately high (mean = 30.2, standard deviation [SD] = 14.9).

Participants reported significant pain in the week prior to survey completion, with a mean worst-pain score of 8.4/10 (SD, 2.0), a mean least-pain score of 2.7/10 (SD, 2.2), and a mean current-pain score of 4.8/10 (SD, 2.7).

[Insert Table 2 here]

Comprehension and Clarity of the OTA

Patients generally reported high levels of understanding and clarity regarding the OTA (Table 2). Most patients indicated that they felt informed about signing the agreement (89%) and that the agreement was easy to understand (94%). Additionally, most reported that they had sufficient time to read the agreement (87%) and had received adequate explanations of it (84%). Ninety-six percent of patients agreed that the consequences of violating the agreement (bad-faith consequences) were clearly explained.

Patients also endorsed the agreement’s role in clarifying pain-management goals (89%) and improving understanding of their pain-management plan (97%). Over four-fifths of patients reported that the agreement helped them make more informed decisions (82%) and was relevant to their individual situation (91%).

Perceived Safety and Risk Reduction

Most patients perceived the OTA as contributing to safer opioid use. Eighty-three percent agreed that the agreement improved safe use of controlled medications, and 78% agreed that it decreased the likelihood of opioid misuse. Similarly, 81% agreed that random urine drug screening helped protect against misuse (Table 2).

Perceived Purpose of the OTA

Responses to the perceived purpose of the OTA are displayed in Figs. 1 and 2. Most patients agreed that the OTA protects the patient (Fig. 1). Specifically, 69 patients (78%) either completely or partially agreed that the agreement protects them, while 11 patients (12%) selected a neutral response. A smaller proportion, 9 patients (10%), partially or completely disagreed with the statement.

In contrast, responses were more evenly distributed when patients were asked whether the agreement protects the physician more than it protects the patient (Fig. 2). Twenty-four patients (27%) either completely or partially agreed with this statement, 32 patients (36%) neither agreed nor disagreed, and 33 patients (37%) partially or completely disagreed.

Discussion

In the present study, we surveyed cancer patients with chronic pain to gain insight into their perceptions of OTAs. In general, the patients in this study found the OTAs easily comprehensible, clear, and relevant and believed that they enhanced the informed consent process. Moreover, most patients viewed the OTAs as useful as a means of limiting opioid-related risks and protecting their safety. Our findings provide needed data on how OTAs are generally accepted by cancer patients with chronic pain and advance future development of comprehensive opioid risk-mitigation strategies for a rapidly growing population, as existing strategies have largely focused on patients with non-cancer pain.

Cancer patients' notions of the OTAs were largely positive with acknowledgement of OTA benefits, but their opinions regarding the perceived purpose of the forms were more varied. Most patients believed that OTAs protect patients; however, a small proportion of patients viewed OTAs as protecting physicians more than patients. This mixed result reflects the diverse impressions of OTAs among patients without cancer. Some believe that OTAs provide clarity and reassurance, whereas some may fear that OTAs may propagate stigma and mistrust(16).

There are several hypotheses as to why some patients may have negative perceptions of OTAs. Patients may interpret OTAs as legal safeguards for physicians, given pervasive news media on opioids, as OTAs formalize expectations regarding opioid usage and require compliance from the patient. OTAs may also unintentionally strengthen a sense of power imbalance, as providers have control over access to and continuation of opioids, and nonadherence to OTAs leads to termination of the medications. This feeling may be particularly heightened given the non-negotiable nature of the agreement and pre-formed rules. In addition, the uncertainty may extend beyond opioid-specific encounters. For example, many patients may have had prior medical decisions be dependent on insurance authorizations or protocolized management (e.g., needing to complete physical therapy before a procedure), and thus cynical of the additional financial costs and "hoop-jumping" that OTAs and its requirements may potentially represent (e.g., urine drug screens, frequent visits). Moreover, patients may have experienced medical surveillance with punitive framing and thus become sensitized to the discussion of drug screening via urinalysis in the study agreement form. Other patients may have had previous care discontinued, raising concerns regarding the potential termination of treatment as outlined in the study agreement. These remain speculations until additional qualitative studies can help us better understand patient uncertainty.

Regardless of the underlying cause of patients' uncertainty regarding OTAs, the heterogeneity in perceptions suggests that OTAs may be an informative addendum or a source of apprehension, depending on how the agreement is framed and interpreted. For further context, most of our patients in

the study were not at high risk for substance-use disorders. This characteristic suggests that patients' ambivalence regarding the intent of the OTA did not necessarily stem from resistance to compliance with safe opioid protocols but rather from the relational and symbolic connotations of the OTA.

Clinically, these findings underscore the importance of patient- and communication-centric presentations of OTAs for cancer patients with chronic pain. They suggest the need for intentional conversations addressing patient concerns and questions and for OTA wording that highlights shared objectives rather than punitive restrictions. A previous study has shown that patients with opioid prescriptions that have an accurate understanding of the benefits of opioid usage and a shared decision-making process have improved outcomes and reduced opioid misuse(17).

As aforementioned, the existing literature has shown that patient perception may be so mixed or conflicted, reflecting a tension between their intended role as safety tools and their potential symbolic association with mistrust or punishment. However, participants in this study overwhelmingly agree on OTAs with some important caveats. However, the mixed perception of the OTA's purpose (Fig. 2) indicates that it may also be beneficial to revisit OTAs to ensure that patients and providers agree regarding the treatment plan and to promote fairness and trust as symptom management evolves. Future qualitative interviews with patients expressing uncertainty may reveal opportunities for providers to improve communication strategies. Providers may need to explain that OTAs are tools supporting safety and open communication rather than legal or disciplinary documents. Likely additional clarification is needed for certain high-stakes items such as the drug screenings and termination clauses that better support patient safety. There is also likely benefit in framing OTAs as a means of increasing collaboration between providers and patients, with structured opportunities for patients to ask questions or express concerns. Lastly, it would likely be beneficial to screen for patients' prior negative health care experiences, if any, so that potential concerns can be directly addressed during OTA discussion.

This study has several limitations. First, it was conducted at a single tertiary cancer center, thus limiting the generalizability of the findings. Moreover, the cohort was relatively homogeneous with an English-speaking and predominantly White population; there may be differences in perceptions in other populations. Also, the cross-sectional nature of the study did not allow for an analysis of perception changes over the illness trajectory and with prolonged exposure to OTAs. Additionally, we cannot infer causality regarding patients' perceptions of OTAs, as this was not a randomized, controlled trial. Finally, the overwhelmingly positive responses raise the possibility of bias. Surveys were completed shortly after new-patient visits to a tertiary pain clinic, potentially introducing gratitude or acquiescence biases. Patients may have felt reluctant to express negative views due to perceived negative implications for care. However, to mitigate this bias, physicians were not involved in the survey itself and the study was conducted separately and research coordinators contacted patients and physicians were not aware of results.

Despite these limitations, our study provides important contributions regarding how OTAs are perceived by patients with chronic cancer pain, as few studies have examined cancer patient perspectives on

OTAs. With a growing number of cancer survivors and the subsequent longer-term use of opioid therapies to treat chronic cancer pain in this population, an accurate awareness of patient attitudes towards opioid stewardship tools such as OTAs becomes increasingly critical. Our study found that patients are largely receptive to and appreciative of the intent of OTAs. Still, minor adjustments to better convey and uphold principles such as patient autonomy and trust may alleviate any unease associated with their usage. Future studies should explore subgroup differences in OTA perceptions, as well as communication strategies to optimize patients' experiences with OTAs, leveraging qualitative and mixed methods approaches to support the development of patient-centered, best-practice opioid management interventions.

While most patients viewed OTAs as clear and supportive of safe opioid use, varied perspectives on its purpose underscores the need for improved implementation. To this end, OTAs should be written in simple language and be framed as a collaborative tool between the provider and patient. Additionally, patients should be educated on safe opioid use and monitoring practices with ample opportunities to revisit the document to ensure transparency and comprehension. Such focus on patient-centered approach upholds opioid stewardship and effective pain management in oncologic care.

Declarations

Author Contributions

Sriram Yennu: conceptualization, protocol creation, editing

Serena Jiyeon Kim: writing – original draft preparation, editing

Eduardo Bruera concept, protocol creation, editing

Lori Williams: cognitive testing tool, editing

Saba Javed: data collection, editing

Alice Ye: data collection, statistical analyses, editing

Lei Feng: data collection, statistical analyses

Dhanalakshmi Koyyalagunta: conceptualization, protocol write up, oversee data collection, editing

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Conflicts of Interest

The authors have no conflicts of interest to disclose.

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Data Availability: The data that support the findings of this study are available on request from the corresponding author.

Ethical Approval: This study was IRB approved and conducted in accordance with the ethical principles of the Declaration of Helsinki and was approved by the Institutional Review Board of The University of Texas MD Anderson Cancer Center.

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Tables

Tables 1 and 2 are available in the supplementary files section

Figures

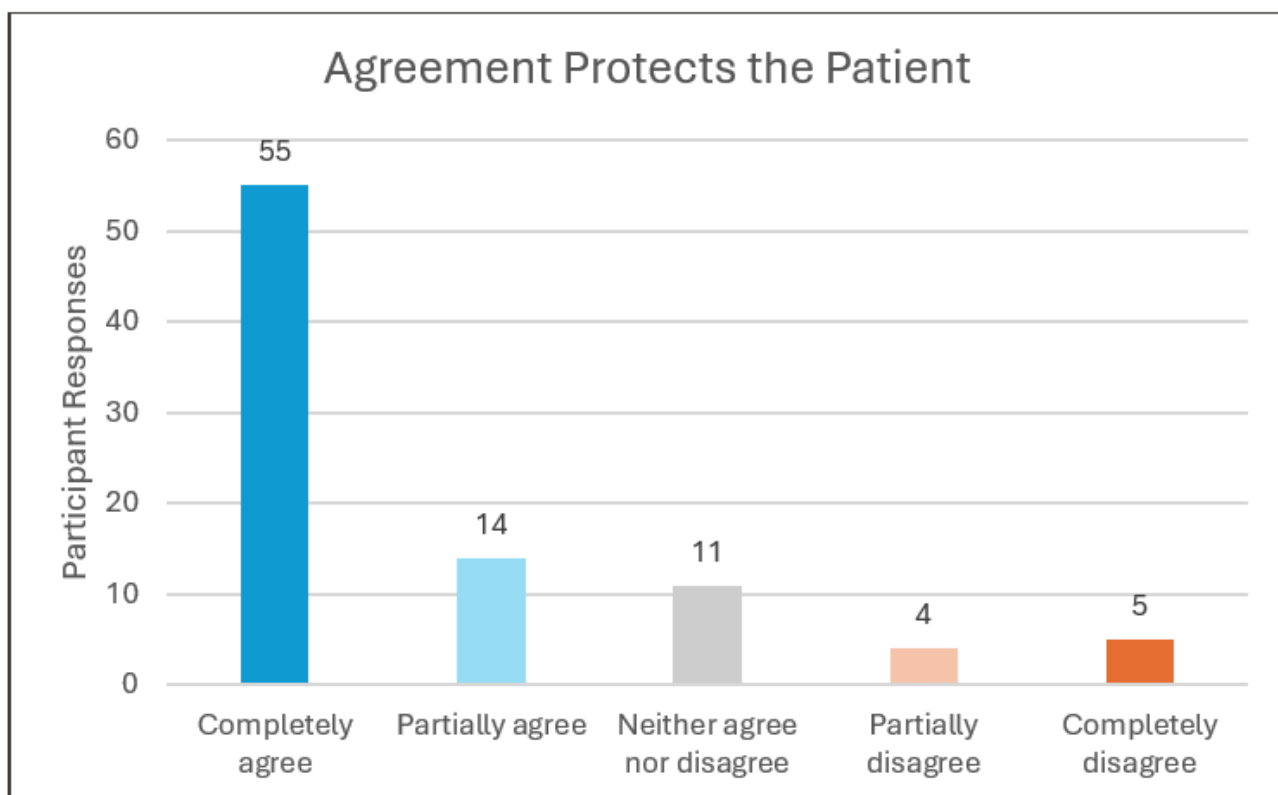


Figure 1

Likert-Scale responses to the statement *“The pain agreement protects me.”*

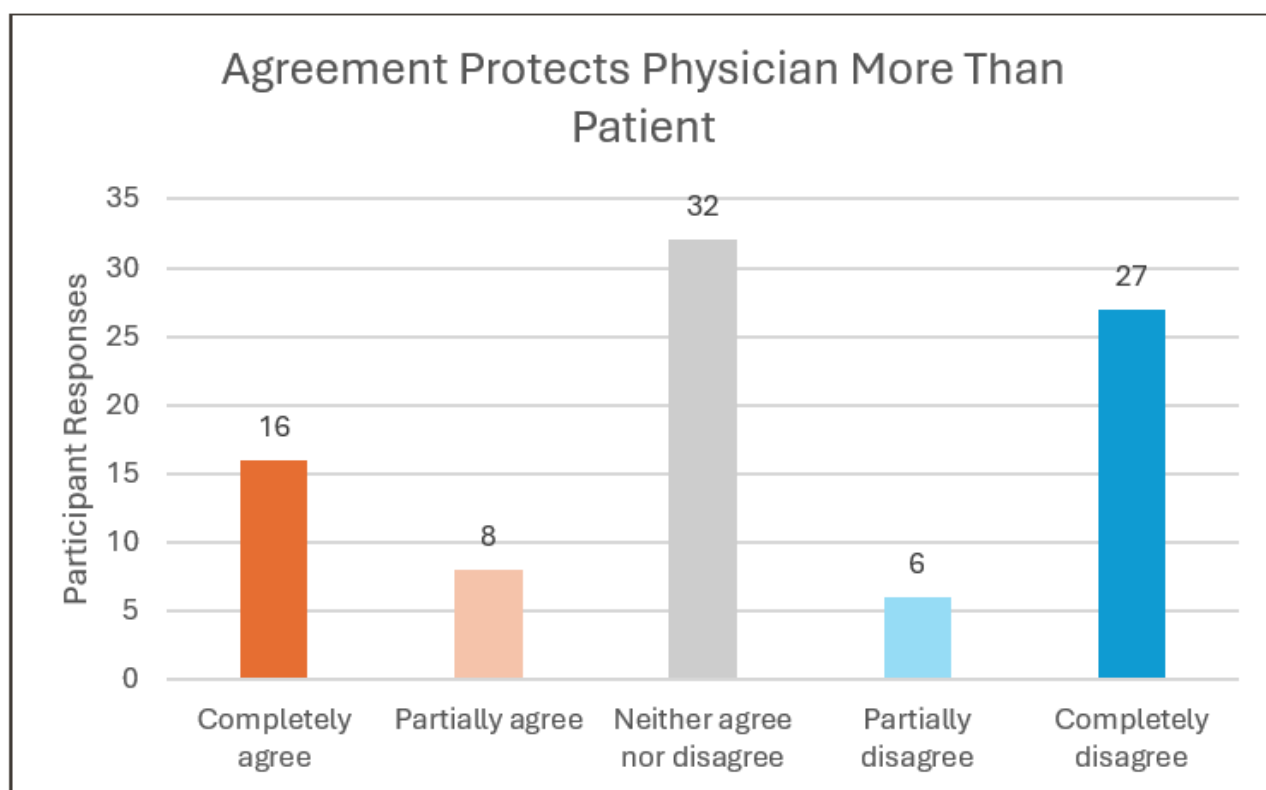


Figure 2

Likert-Scale responses to the statement *“The pain agreement protects the physician more than it protects me.”*

Supplementary Files

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