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Palliative Care's Role Managing Cancer Pain During the Opioid Crisis: A Qualitative Study of Patients, Caregivers, and Clinicians

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Abstract

Context.—Patients with cancer face symptoms because of disease and treatment, and pain is common and complex. The opioid crisis may complicate patients' and clinicians' experiences of managing pain in cancer care.

Objectives.—In our study of perceptions and experiences with palliative care (PC) at an outpatient cancer center, we examined communication around symptom management throughout cancer care, and pain and its management emerged as particularly salient. The objective of this article is to describe, from the perspectives of patients, caregivers, and oncology health care professionals, the role of PC in navigating the complicated dynamics of pain management amidst the opioid crisis.

Methods.—A qualitative descriptive study with grounded theory components was designed to investigate experiences with and perceptions of specialist PC and symptom management, including pain. Interviews were audiorecorded and transcribed, and focused coding identified themes related to pain and pain management from all three perspectives.

Results.—About 44 patients, caregivers, and non-PC health care professionals completed interviews. Patients with cancer and their caregivers had many concerns about pain management and were specifically concerned about opioid use and stigma. For patients, PC improved pain management and helped to destigmatize appropriate pain management. Oncology clinicians reported that partnering with PC facilitated complex pain management and also provided moral support around difficult opioid recommendations for patients.

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Conclusion.—PC offers the potential to uniquely support both patients and other oncology professionals in optimally navigating the complexity around pain management for cancer care in the midst of the opioid crisis.

Keywords

Opioid crisis; palliative care; cancer pain; pain management; qualitative research

Introduction

Despite its prevalence in all stages of cancer, pain remains undertreated.[1–7] Management of pain can be difficult because it is dynamic, complex, and multidimensional. Cancer pain affects symptoms such as fatigue, insomnia, and inactivity,[1–5,8–13] affects mood, emotional stability, and psychological well-being, and impacts caregivers and social relationships.[1–5,8–14] Despite the goal of tailoring pain management to each patient,[5,9,12] patients report that their pain is often not taken seriously.[2,3,5,11,12] Barriers to optimal pain management include lack of access to pain specialists, patient and family concerns about pain medications and side effects, and health care professionals' lack of knowledge or reluctance to prescribe opioids.[3–5,10,15,16]

Pain management for patients with cancer has been further complicated by the opioid crisis, with mounting uncertainty about how to provide appropriate management of pain while also balancing risks for opioid misuse in a population that is surviving longer.[15,17–19] Patients with cancer are typically excluded from opioid risk analyses, limiting data that could inform best opioid practices for this population.[20,21] Although cancer-related pain remains exempt from many restrictions, the full effect of this crisis on the experiences of patients with cancer is unknown.[19,22–24] A recent study considering the role of opioid stigma on patients with cancer found that many patients had concerns about addiction, and some reported stigma-related behaviors, such as taking less opioid medication than needed.[25] Another study found that patients reported similar behaviors to minimize opioid use, even some that were potentially unsafe.[24]

The specialty of palliative care (PC) is expanding its role in symptom management and increasingly comanaging patients even during active treatment.[26–30] This specialty has the potential to help address the long-standing challenge of pain management in cancer that has been further complicated by the opioid crisis. Through in-depth interviews with patients, caregivers, and cancer health care professionals, we assessed perceptions of and experiences with the role of PC in managing pain in individuals with cancer.

Methods

Study Design

This is a qualitative descriptive study with grounded theory components.[31,32] The overarching goal of the project was to understand patients', caregivers', and cancer health care professionals' experiences with PC and symptom management. When asked about pain and symptom management in general, use of opioids and the crisis of opioids were spontaneously mentioned by many participants. After bringing up these themes, participants were further prompted to elaborate on the subject by the interviewer, congruent with inductive interview methodology standards.[33] Although this study was not designed specifically around pain management or opioids, during data analysis, we noted the persistence of these themes in multiple interviews, calling attention to the role of PC in managing pain in the midst of the opioid crisis. Therefore, this article reports specifically on the findings about pain, opioids, and pain management.

Recruitment and Population

Recruitment was conducted at one outpatient cancer center that offers care to patients with a variety of solid organ tumors and hematologic malignancies and those needing blood and marrow transplants for other blood disorders. PC services consist of visits with PC physician-nurse team. Patients are typically referred to PC by their oncology team, and their colocation allows for coordination of specialty PC appointments with other cancer care appointments. Eligible patients included patients receiving care at the clinic, with varying stages of disease. The vast majority of patients participating in our study were undergoing active treatment; a few were no long receiving curative treatment or were managing ongoing symptoms while in remission. Eligible caregivers included family or friends who accompanied patients to their appointments; caregiver relationships with patients included spouse, child, sibling, and friend. In our study, only a few were paired dyads; most participants did not have a connected caregiver or patient partner in the study.

Patients and caregivers were purposefully recruited with varying levels of exposure to PC for maximum variability of attitudes and experiences with PC. Our targeted sample size was guided by prior qualitative work indicating that code saturation (in which no new themes are emerging) usually occurs around nine to 10 interviews.[34] Most patients and/or caregivers were recruited at either an initial appointment or a subsequent appointment with PC. We purposively recruited a minority of disconfirming cases,[35] which included two caregivers after death of the patient, both of which had seen PC, and one patient and one caregiver who had never seen PC. Researchers partnered with PC nurses to identify patients and/or caregivers willing to participate. In most cases, a PC nurse approached potential participants during visits with PC and explained the study objectives. If individuals demonstrated interest in participating, a study member contacted them to further explain the study and obtain informed consent.

Eligible health care professionals included non-PC professionals. We used a maximum variation purposive sampling strategy to recruit a wide range of professionals capturing perspectives of clinicians who have the ability to refer patients to PC, while also capturing the perspectives of other cancer care professionals (e.g., nurses, pharmacists), whose vantage points and proximity to patients are different. Specific roles are not included to maintain confidentiality. To recruit health care professionals, flyers were displayed in common areas throughout the cancer center with information about the study and contact information of the research team. Professional contacts also sent electronic mails to non-PC professionals to facilitate recruitment. Interviews were scheduled at a time and location convenient for participants.

Data Collection

Semistructured and audiotaped interviews were conducted with participants from June to December 2018 and ranged from 9 to 71 minutes. Two interview guides (one for patients and/or caregivers and one for health care professionals) were developed to elicit participants' experiences with and perceptions of PC (see Appendix for full guide). All interviews were conducted in person, with the exception of one phone interview, requested by the participant. Written informed consent was obtained from all participants before the interview. Patients and/or caregivers who participated in the interview were offered a $30 gift card. This study was approved by the university's institutional review board.

Data Analysis

Interview transcripts were deidentified and verified against the recordings to ensure accuracy. Data analysis followed the principles of qualitative descriptive grounded theory[31,32] and followed a series of steps to ensure rigor.[36] Initially, three investigators, whose backgrounds in sociology, psychology, and clinical nursing facilitated a multidisciplinary approach, independently coded a subset of six transcripts. During this initial open coding, the research team created an audit trail by documenting preliminary codes and engaging in reflexive discussion around how perspectives impacted interpretations.[36,37] The team had a series of meetings to review the concepts and resolve questions, arriving by consensus on two codebooks—one for patient and/or caregivers and one for health care professionals. Each transcript was assigned a primary coder and reviewed by a second coder. All questions about codes were resolved through discussion. The coding process was managed using NVivo 11 qualitative software (QSR International Pty Ltd Victoria, Australia).[38] For this article, focused coding[31] was conducted on data in the pain management codes to identify the themes presented later. Focused coding is a type of coding in grounded theory that is directed and focused on categorizing data based on thematic content.[31] This coding led to the themes presented here. Throughout the article, participant quotes are presented with a randomly assigned two-digit identifier.

Results

A total of 18 patients, 13 caregivers, and 13 health care professionals completed interviews. During interviews, patients, caregivers, and clinicians were asked to talk about management of pain and other symptoms they found challenging. Pain management was specifically discussed in 14 of 18 (77.7%) patient interviews, nine of 13 (69.2%) caregiver interviews, and 10 of 13 (77%) clinician interviews. Responses about opioids specifically occurred in eight of 18 (44.4%) patient interviews, seven of 13 (53.8%) caregiver interviews, and seven of 13 (53.8%) clinician interviews.

Later, we first present themes from the patient and caregiver data: stigmatizing experiences around opioids, PC messages about opioids, and pain management with PC. This is followed by the two themes identified in the clinician data: support for complex pain management and potential over-reliance on PC.

Role of PC: Patient and Caregiver Perspectives

Stigmatizing Experiences Around Opioids.—Patients and caregivers had many concerns about pain management, including pain medication types and dosing, uncontrolled pain, and how pain management would impact their relationships with their doctors. Patients also shared experiences of stigma around opioid use. One patient described a stigmatizing conversation with his pain management doctor about adjusting medications:

> He asked me how much [tramadol] I had left […]. He wrote the script for ten days past where I was going to run out of pain meds and told me to stretch it. And that was after he found out I had cancer again. So, I'm like all right, you're going to tell me after I start cancer treatments and stuff to stretch it?
>
> —(66, Patient)

This patient was upset that given his diagnosis and pain; his doctor was asking him to stretch the prescription. Interestingly, his assessment was that this frustration was related to the broader crisis:

> I guess they get so used to seeing pill chasers over there they treat everybody the same way, whether you're a cancer patient or not.
>
> —(66, Patient)

A different patient shared that although she had not experienced stigma in interactions herself, she was still concerned about how the crisis might impact her ability to access the pain medications needed for pain management:

> A lot of people out there, you know, this whole abusing the drugs. That makes me mad because cancer patients like us and people who actually need them […]. It's just what I hear on the news, or when I hear people around me talking about it.
>
> —(19, Patient)

Other patients reported their own initial resistance to taking opioids because of fears and perceptions about the wider crisis. One patient was asked where she had gotten messages about opioids being bad:

> From the media and even from doctors […] Before I was diagnosed I had such bad headaches that I went to the ER, and I feel like the ER was kind of like "we don't give opiates, just to let you know." And I'm like "I do not want an opiate, I just want the headache to go away,"[…]. And just even from doctors and stuff like that, where "you can have this while you're here, but you can't have it when you go home," so it just makes you think like, you know, I don't want to.
>
> —(25, Patient)

This patient describes exposure to the opioid stigma before her cancer diagnosis, an experience that, she later explained, shaped how she approached opioid use during her subsequent cancer treatment.

PC Messages About Opioids.—Respondents also reported that after referral, their PC team directly referenced the opioid crisis during conversations about pain management. For example, one caregiver said that her PC doctor said not to listen to what other people say or what's on the news about opioids—(75). In addition to descriptions of stigma, both patients and caregivers explained how PC impacted both their perceptions of opioids and the surrounding stigma:

> It surprised us how much they actually cared about my sister and how much pain she was in. It was the first time someone actually said "Oh, so you could use some Oxycontin or Oxycodone. We can get your pain under control." Because everyone else, like her primary care physician, is like well, "I'm not giving you that. I'm not going to give you any opioids." The big opioid scandal right now.
>
> —(75, Caregiver)

> People kind of think that you're kind of chasing certain things if you kind of say you're in pain. There's a lot of people who think that you're using that as an excuse or using that as a crutch […] But here, with the palliative care team, I'll say that they didn't have any hesitation to go ahead and put things in order or put things in place.
>
> —(93, Patient)

For Patient 25, who previously described the messages about opioids she received in the emergency room before diagnosis, PC reframed her understanding of opioids:

> It's been kind of beaten into my head that opioid drugs are bad, […] And I think it was surprising to me that [palliative care] said that they use them and that they're part of what they use to make things better […] They kind of had to convince me to do that, and that it's okay, and that it doesn't mean you're addicted, and that people are on really high doses and still okay, and that kind of stuff.
>
> —(25, Patient)

According to this patient, the approach of PC to opioids was surprising in how different it was from other medical professionals. This patient, whose pain was not well controlled before seeing PC, appreciated that her PC team could frame opioid use in a way that helped her move past misconceptions.

Pain Management With PC.—Both patients and caregivers reported on their experience with PC managing pain and the ways in which their management approach helped navigate concerns about opioid use. For example, one patient shared:

> And I don't think that they're loose with [opioids] at all. They started me off on super, super tiny doses, and they asked about my background and all that kind of stuff, too, just to make sure that I wasn't a type of person that had an addictive personality or something like that.
>
> —(25, Patient)

For another patient, fear of abusing medicine drove his previous unwillingness to communicate about his pain, and conversations with his PC team helped him communicate honestly:

> Yeah, when I was in the hospital […] they were like “do you need any pain medicine?” And I was like “No.” And it was my first major surgery […] I did not want to abuse any medicine […] But at the same time, I’ve realized […] that’s why they’re here, to keep you comfortable and make sure you’re okay. Now if I’m in any kind of pain I make sure I say I’m in pain.
>
> —(38, Patient)

Patients and caregivers reported how detailed conversations during PC visits about pain management helped them feel confident that they and their loved ones were using the safest and most effective strategies, including when they were tapering off pain medication:

> [Patient’s] biggest concern now is now that the cancer is … she’s cancer-free, is coming off the medications, and her biggest—our biggest concern is her withdrawals and just getting her off. And they’ve been real consistent with giving us a schedule, and why they’re doing it this way.
>
> —(96, Caregiver)

> Like today we were talking about potentially reducing my pain medication because my treatments are starting to work my numbers are looking better. I’m in less pain. I’m not using the extra pills that I’ve been given for breakthrough pain and stuff like that […] they’re very good about, well, “how often are you taking this? You skipped a pill—how do you feel?”
>
> —(59, Patient)

Two other caregivers articulated the impact of the responsiveness of PC to patients’ concerns about pain:

> And I felt good about [palliative care] because as [patient] was describing the pain that she went through, and how often and constant it was, they actually did something to help that.
>
> —(54, Caregiver)

> [My mom] was actually taking more meds where she was really loopy and couldn’t stand up straight and [PC] helped fix her medications, and made sure she got the right thing so she was standing up and knew where she was going. Yeah, [PC has] helped a lot.
>
> —(85, Caregiver)

Although almost all patients and caregivers reported a positive experience with PC regarding pain management, one bereaved caregiver did express initial frustration with PC over limited pain medications for her mother:

> I kept stomping my feet and saying I don’t understand. She has cancer. She’s not being treated. She needs pain medicine. I don’t understand why we’re having to fight about it … So I felt like they missed the boat.
>
> —(65, Caregiver)

After a very long and emotional conversation with a nurse, this caregiver felt she was able to better work with the PC team to adequately control her mother's pain.

Role of PC: Clinician Perspectives

Support for Complex Pain Management.—Clinicians were asked about the circumstances under which they would refer a patient to PC. Uncontrolled pain and pain management were a clear trigger for referral:

> The other thing is like to help with pain management. I've sometimes, you know, acutely, I'm like I don't know what to do. They're on a long-acting pain med, they're on breakthrough, and they're still having pain; any ideas or suggestions? Because this is getting above me when we're on three, four pain meds […] I still need some help.
>
> —(53)

A number of clinicians shared they did not feel like they had adequate training and experience to manage complex pain, but they saw PC as having specific expertise to manage pain:

> I don't have really good experience switching pain medications to different narcotics and then handling the toxicity of that and the overall picture. With running the therapeutic plan […], I prefer another set of eyes on the pain issues. […] And I feel a palliative care person might be better suited managing high doses and switching to optimize the pain regimen better than the oncologists or any other physician.
>
> —(13)

Some clinicians identified opioids in particular as a salient factor in how they thought about referring patients to PC:

> [Palliative care has] probably seen a lot more patients with different types of pain and may have different modalities that are maybe more outside the box, or that I'm not thinking of to help address that patient's pain or coping strategies. [Patients are] not eager to be on opioids or that much opioid, so their quality of life is very important, and a lot of times in these metastatic patients who are otherwise pretty functional, that includes not being sleepy and tired from pain medication, so they're looking for other strategies.
>
> —(12)

> And as patients come to us on varying degrees of narcotics or whatnot, they're able to also assist us in assessing the status of their current regimen and whether there needs to be any adjustments or keeping them on schedule or whatnot as they go through.
>
> —(123)

Similar to patients, clinicians recognized that in addition to expertise, PC also contributed a thorough and holistic approach to pain management:

> There’s not enough time to go over just the pain alone when we see them. But when we refer them to palliative care for pain, they’re able to go over the pain symptoms and also the side effects from the pain medications like nausea and constipation. And I feel like we get better control on the whole pain medication regimen and also the side effect regimen better rather than we trying to do it in the same visit in addition to the chemo, and so we’re talking to them about chemo, side effects from chemo, prophylactic antibiotics, and then add pain regimen on top of that with the long schedule, it just gets a little harder to focus on just pain alone.
>
> —(95)

A number of clinicians, like patients and caregivers, appreciated the way that PC could approach pain management in a tailored and intentional manner that improved patient outcomes:

> I think [PC is] really well trained and focused when it comes to those pain and symptoms, that they know some tweaks that can be beneficial. And a month later [patient] is calling me saying “[clinician], I had no idea how much pain I was in for the past two years, and I had no idea how bad I felt.” Just being able to leave her home is mentally freeing for her.
>
> —(107)

Potential Overreliance on PC.—Clinicians also conveyed a degree of unease about their requests to PC for support. One respondent shared a practice of referring to PC, with some uneasiness:

> We don’t really have a great pain service here, so I think sometimes we actually probably abuse the palliative care system and over-refer for pain because we don’t have good pain management.
>
> —(62)

Another clinician mentioned another reason they refer to PC for pain management—as a form of backup.

> When we suspect there’s inappropriate pain med use we will bring [palliative care …] When you have a patient who comes in who can only take Dilaudid,[…] I’m going to have a little backup. That way I’m not the only bad guy saying “No, I’m not giving you IV Dilaudid every two hours.” So that’s a little bit selfish on our part that we bring them in to help be the bad guy in limiting pain meds.
>
> —(80)

This clinician acknowledges that part of what makes pain difficult to manage is possible inappropriate pain medication use. In this case, PC may be consulted to provide support to limit access to pain medications.

Discussion

Managing pain in individuals with cancer is difficult and further complicated by the opioid crisis. The objective of this study was to describe, from the perspectives of patients, caregivers, and oncology health care professionals, the role of PC in navigating the complicated dynamics of pain management amidst the opioid crisis. Our findings show that PC was used as a resource for both patients and clinicians to facilitate appropriate pain management. Patients and caregivers reported receiving messages from PC that destigmatized opioid use to control pain, often neutralizing previous negative messages patients and caregivers had received about opioids from other sources. Respondents also reported helpful and thorough communication with PC about medication options and adjustment for pain management, including opioids.

Although researchers agree about the need to consider both individual and societal risks and benefits of opioid use,[39] navigating how to balance risks and benefits for patients with cancer is particularly difficult given the symptom burden and lack of evidence about long-term opioid therapy in this population.[40,41] Patients with cancer experience multiple concerns regarding pain management and opioid use.[24,42,43] Our article shows that patients and caregivers believed that PC addressed many of these concerns, such as concerns about side effects and fear of addiction, while also providing appropriate and tailored management of patients' use of opioids.

Other studies show that certain concerns, like worry and fear of addiction, are becoming increasingly important to patients as they manage pain alongside cancer and treatment.[24,43] Our findings add evidence of this shift, showing that the current opioid crisis is further complicating these experiences of managing pain with cancer because they must wrestle with not only pain and medication side effects but also increasing messages that opioids are always bad and addictive, consistent with other research showing the influence and role opioid stigma for this population.[25] Conversations with the PC team helped to reframe these messages and encourage appropriate opioid use for some patients with uncontrolled pain. This function is important given that patients with cancer are affected by restrictions created to address the broader opioid crisis, and exemptions are being implemented in inconsistent and sometimes ineffective ways.[15,21,22]

PC is also providing support for clinicians caring for patients with cancer. Clinicians reported that PC offers pain management expertise and time to develop tailored plans and could also offer backup support when it was appropriate but difficult to restrict opioids for a patient. Although clinicians in our study benefitted from partnering with PC, some conveyed unease about their own motivations for expecting PC to fulfill this role. This finding is consistent with results from a recent study that showed PC clinicians believe referrals to PC are sometimes motivated by a wariness about managing opioids in the current crisis.[44] Of note, research from the perspective of PC clinicians on this topic report that PC clinicians find opioid management in this population to be challenging and often do not feel equipped or adequately trained to manage opioid misuse or addiction.[41,44] Although PC clinicians have reported confidence managing common misuse behaviors,[41] there are ongoing training needs and a continued dearth of evidence about safe opioid prescribing for this population.[45] Although our study provides evidence that, from the perspectives of patients, caregivers, and other clinicians, PC is playing a helpful role, it may be that PC clinicians themselves do not feel trained or equipped to fill this role. Our findings suggest that patients, caregivers, and oncologists are looking to PC to help with opioid management and related issues. As others have written, whether it should fall in the scope of PC is a separate issue from the fact that they are routinely confronted by these issues.[44]

Our study has limitations. The study took place at one outpatient cancer center, and it is possible that the role and relationships with PC may not be transferable to other settings. The variation in types of professionals interviewed, while maximizing distinct perspectives, prevents drawing any conclusions based on specific roles. Our study did not collect prescription history or demographic information of participants, out of concern for identifiability given the small sample, which limits our ability to speak to established and serious disparities related to opioids and pain management between black and white patients.[46–48]

Because our study was not focused exclusively on pain and opioid use, this may have limited the comprehensiveness of identified themes. However, one of the strengths of our article is its ability to demonstrate how salient navigating pain and the opioid crisis is for patients—so salient that most brought up the topic without direct interview questions prompting them to do so. Another strength of our study is the ability to capture the perspectives of different stakeholders about the topic of pain management for patients with cancer.

Given the current uncertainties of how to provide appropriate pain management for patients suffering from pain and accompanying lack of guidelines and research on opioids and cancer populations,[20,21,40] it is imperative that we continue to better understand patient experiences, problems, and potential responses that can preserve optimal pain management for patients with cancer. Further research is needed to assess how the opioid crisis is impacting the management of pain for patients with cancer, including prescribing patterns, barriers to care, dynamics between specialists, and patient and/or caregiver concerns. Future research should study what factors impact patients' experience of stigma and how PC can intentionally address and respond to stigma around pain management and opioids in particular. A better understanding of the experiences and perspectives of patients with cancer who misuse opioids is also needed. Furthermore, research on patient and clinician partnerships to understand the degree of alignment about perceptions of the risks of opioid use and/or misuse and pain management satisfaction is warranted. Our findings suggest that the referral and involvement of PC in the context of pain in patients with cancer may result in improved pain outcomes and clinician support. Our research highlights that PC is an emerging and needed resource for patients, families, and clinicians to navigate the complexity around pain management in the midst of the opioid crisis.

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Appendix

PC in Oncology: Patient Utilization and Awareness Provider Interview Guide

Thank you for being willing to take time to meet with me and participate in this study.

We are interested in learning about your perspective on PC and your views and practices around symptom communication with cancer patients. This interview is entirely voluntary, and you are welcome to stop it at any point. You do not have to answer any question you do not wish to answer.

With your permission, I will record and transcribe our conversation, but what you share will only be used in an aggregate or deidentified form (your name will be removed). The interview will last 30–45 minutes.

Do you have any questions before I begin?

Training and Background

- To begin, can you tell me the title of your position and give a brief overview of your responsibilities?
- Can you describe what a typical day at work is like?
    - Probe as needed to gain a full understanding of their interactions with patients and their scope of responsibility.

Experiences and Perceptions of PC

- Can you tell me the first time you heard about PC?
    - Probe: who told you about it? What was the context?
- Did you learn about PC in medical school or in your clinical training?
    - If yes, what kind of experiences did you have?
- What is your understanding of the differences between hospice care and PC?
- Have you or a family member had personal experience with hospice or PC?
    - If yes, can you tell me more about that?

      (For respondents who can refer [oncologists]):
    - Have you referred any of your patients to PC?
        - ♦ If so, under what circumstances?
        - ♦ What has their experience been?
    - What percentage of your patients see PC?

    - Have any of your patients followed with PC while they were still receiving disease-directed therapies?
- (If respondent cannot refer patients):
    - Can you explain to me when a patient with cancer might be referred to PC?
    - How do patients and families react when they are referred to PC?
    - In your opinion, what are the benefits that PC can offer patients?
- If you had to explain to a patient and/or caregiver what PC is, how would you describe it?
- Do you think there are patients with cancer who could benefit from PC but do not receive it?
    - If yes, what do you see as the barriers to accessing PC for those patients?
- Any other final comments or impressions of PC that you think are important for me to know?

Symptom Management + Communication

I would also like to ask you questions about symptom management and communication.

- How do you communicate with your patients about symptoms?
    - Probe: Can you provide a specific example?
- Do you feel satisfied with communication around symptoms with your patients?
    - Probe: What are the barriers to improved communication?
- What symptoms are typically most problematic for your patients?
- Which symptoms are most challenging to manage for your patients?
- (For providers who have referred to PC):
    - Do you discuss symptom management of your patients with PC physicians after you have referred them?
    - In your experience, are there any differences between how you approach symptom management and how PC approaches it?
- What changes and/or improvements would make symptom communication and management more effective?

PC in Oncology: Patient Utilization and Awareness Patient and/or Caregiver Interview Guide

Thank you for being willing to take time to meet with me and participate in this study.

We are interested in learning about your perspective on PC and your perspectives and experiences surrounding management of uncomfortable symptoms, including pain, nausea, anxiety, and shortness of breath. This interview is entirely voluntary, and you are welcome to stop it at any point. You do not have to answer any question you do not wish to answer.

With your permission, I will record and transcribe our conversation, but what you share will only be used in an aggregate or deidentified form (your name will be removed). The interview will last 30–45 minutes. Is it ok to begin?

Do you have any questions before I begin?

Experiences and Perceptions of PC

- To begin, can you tell me the first time you heard of PC?
  - Probe: Who told you about it? What was the context?
- Have you had any direct experiences with PC?
  - Probe: If yes, describe experiences. Who/what/when.
- Has anyone in your family had any experience with hospice or PC?
  - Probe: If yes, describe experiences. Who/what/when.
  - Has your own impression or experience been similar to or different from those of people you know?
- If you had to explain to another patient and/or caregiver what PC is, how would you describe it?
- From your perspective, is there a difference between PC and hospice?
- (For those who have had PC clinic visits):
  - Can you remember your first clinic visit with your PC physician?
  - How was it similar or different from what you expected?
  - Did anything surprise you about your visits with your PC doctor?
  - What is your favorite and/or least favorite part of the clinic visits?
  - Has your perspective on PC changed at all since you have been seeing PC providers?
  - Are you currently undergoing treatments for cancer? What is your understanding of how PC physicians work with your cancer doctors?
- What would you tell other patients about seeing the PC team?
- Any other final comments or impressions of PC that you think are important for me to know?

Symptom Management + Communication

I would also like to ask you questions about symptom management and communication.

- Have you had pain or other uncomfortable symptoms because of your diagnosis?
- Who on your team helps you most with pain and other symptoms?
- Have you had to seek help from people outside your medical team for symptoms, including friends, family, therapists, or alternative health providers?
- How do you communicate with your health care team about any symptoms you may have?
    - Probe: Can you provide a specific example?
- Do you feel satisfied with communication around your symptoms?
- How do you decide what to communicate about symptoms and when to communicate it?
    - Probe for specific examples.
- Are you satisfied with your symptom management?
- (For patients who have seen PC)
    - Who do you discuss symptoms with?
    - How would you compare symptom communication and management with your oncologist to symptom communication and management with your PC provider?
- Have you ever completed the Edmonton Symptom Assessment System (ESAS)? (Show a blank ESAS)
    - What did you think about the tool?
    - Did you feel like it adequately captured your symptoms?
    - Did it help you talk about your symptoms with your physician?
    - How could the ESAS be improved?
- What one change would make symptom communication and management more effective?

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Key Message

This article describes a qualitative study examining experiences with outpatient palliative care for patients with cancer. The results show that the opioid crisis has complicated pain management for this population. Palliative care emerged as a resource to help both clinicians and patients navigate pain management during the opioid crisis.