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“It Is So Easy For Them to Dismiss”: A Phenomenological Study of Cancer Survivors With Chronic Cancer-Related Pain

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Abstract

Background: For many cancer survivors post-cure, chronic pain is a devastating complication of cancer treatment. The prevalence of chronic pain among cancer survivors is double that of the general population. However, little is known about the pain experience of cancer survivors who may have a different perspective than people with advanced cancer or people with noncancer pain.

Objective: To understand the lived experience of chronic cancer-related pain in cancer survivors.

Methods: We used a qualitative design with a descriptive phenomenological method to conduct in-depth interviews of 13 cancer survivors residing in the United States who completed curative cancer therapy, were at least three months from treatment, and experienced pain attributable to cancer. Data collection was focused on the lived experience and management of chronic cancer-related pain and a deep understanding of how the experience of chronic cancer-related pain shapes pain management choices.

Results: The participants had a variety of primary cancer types and cancer pain syndromes. Three essential themes epitomized the experience of living with chronic cancer-related pain: invisible suffering at the cost of survival, an opioid paradox, and a lack of answers on what to expect and what might help.

Conclusion and Implications: The results highlight an opportunity for pain self-management, education, and psychosocial interventions to optimize pain in cancer. Participants' experiences identify several opportunities to improve chronic cancer-related pain. Future efforts should prioritize access to multimodal pain treatments, high-quality communication, and expand clinicians' knowledge and skills to manage chronic pain.

Keywords: cancer; cancer survivor; chronic pain; opioids

Introduction

CANCER-RELATED PAIN, often caused by cancer treatment, including surgery, radiation, chemotherapy, or other therapies, poses a challenge for many cancer survivors.¹ The International Association for the Study of Pain empha-

sizes that chronic cancer-related pain be distinguished from other forms of chronic pain (i.e., noncancer pain) and defines chronic cancer-related pain as pain that persists for greater than or equal to three months.² The prevalence of chronic pain among cancer survivors is nearly double that of the general U.S. population, with an estimated 5.39 million of

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cancer survivors experiencing chronic pain.^{3,4} Chronic cancer-related pain reduces quality of life and interferes with care, including adherence and engagement in surveillance care.^{5,6}

Examining chronic pain in cancer survivors can be challenging because there are several definitions of a cancer survivor. We define cancer survivors as people who have completed primary cancer treatment (except for maintenance therapy) and have no active disease.⁷ Examining chronic cancer-related pain in cancer survivors, using a narrow definition and focusing on pain attributed to cancer treatment, is especially relevant now that many cancers' detection, treatment, and survival have dramatically improved.⁸

Clinicians and cancer survivors may not anticipate when cancer-related pain will persist and struggle with devising management strategies.⁵ Historically, cancer survivors are referred to being "lost in translation" because there is a lack of coordinated care of medical, functional, and psychological consequences of cancer care.⁹ Consequently, the treatment of pain may follow the same approach as it did during cancer treatment,¹⁰ although it is unclear whether this approach is appropriate for cancer survivors with longer prognoses, particularly concerning opioid therapy.¹⁰ Yet, cancer survivors several months or years after curative treatment use opioids at a significantly higher rate than the general population.¹¹⁻¹³

TABLE 1. HUSSERLIAN DESCRIPTIVE PHENOMENOLOGICAL METHODOLOGICAL CONSIDERATIONS AND STUDY ASSUMPTIONS

<i>Key aspects of Husserlian descriptive phenomenology</i>		<i>Methodological considerations, philosophical underpinnings, and assumption of the study</i>
Goal	<ul style="list-style-type: none"> The goal is to understand the lived experience as it is lived by the individuals through intensive dialog 	Little is known about the experience of chronic cancer-related pain in the present context of prolonged survival. The method was selected to bring forward the experience of cancer survivors with chronic cancer-related pain in a way that was free of assumptions.
Core assumption	<ul style="list-style-type: none"> "Natural knowledge begins with the experience (Ergahrung) and remains within the experience" "Every experience... has intentionality" 	<p>Cancer survivors' experiences of chronic cancer-related pain emerge from the experiences in which they interact with the condition of persistent pain from cancer diagnosis or treatment.</p> <p>Cancer survivors can purposefully reflect on their experience of having chronic cancer-related pain and any related impact this has on their daily lives.</p>
Overarching research questions	<ul style="list-style-type: none"> Focus on what and how of living with an experience and managing it in everyday life Probes are used throughout the interview such as "please tell me more" or "what else do you do" 	<p>The three overarching research questions were (1) What is the lived experience of chronic cancer-related pain in cancer survivors? (2) How do cancer survivors manage chronic cancer-related pain in their daily lives? (3) How does the experience of chronic cancer-related pain shape pain management choices?</p> <p>The full semistructured interview guide can be found in Table 2.</p>
Essential aspects of the method for gathering and analyzing data	<ul style="list-style-type: none"> Purposeful sampling: inclusion of people who are living with the experience. Bracketing: the researchers set aside conventional knowledge before and during data collection and analysis. Data saturation: ideas that surface from interviews are repeated by several participants and no new ideas or concepts emerge in subsequent interviews. 	<p>Participants without pain or noncancer were excluded. We intentionally selected people with varying pain intensity to capture diverse experiences and the universality of living with chronic cancer-related pain</p> <p>The first author (K.F.J.) journaled throughout the study period and had weekly meetings with the phenomenological expert (M.R.F.) to confirm key ideas about chronic cancer-related pain were set aside so that the essential structure of the participant's experience was captured.</p> <p>Data saturation was determined by three researchers (K.F.J., L.W.M., and M.R.F.) at 11 participants; 2 additional participants were interviewed to ensure no new information or themes emerged.</p>

Adapted from Beech,²⁶ Fu et al.,³⁵ Porter,²⁵ Husserl,²⁴ and Shorey and Ng.²⁷

The higher rates of opioid prescribing in cancer survivors likely reflect that cancer-related pain is treated differently than noncancer pain. For better or worse, cancer-related pain is exempt from guidelines that often favor an opioid-sparing approach.^{14–16} As a result, cancer survivors are in limbo between chronic noncancer pain and cancer-related pain treatment paradigms.¹⁷

Indeed, little is known about the pain experience in cancer survivors who may have a different perspective than people with advanced cancer or people with noncancer pain. The few available qualitative studies do not reflect the current reality of prolonged survival with newer agents. For example, immunotherapy has revolutionized the treatment of several cancers but can be associated with painful sequelae, such as rheumatologic toxicities.^{18,19} Nor does existing literature reveal the cancer survivors' perspective on the current tension of prioritizing opioid-sparing approaches.^{20,21} Also, existing studies often focus on a single pain syndrome, such as postmastectomy pain or chemotherapy-induced peripheral neuropathy,²² which fails to capture the collective burden of co-occurring pain syndromes.²³ To address this evidence gap, the purpose of this study was to gain a deeper understanding of the daily lived experience of cancer survivors with chronic cancer-related pain, independent of cancer type.

Methods

Study design

We used Husserl's descriptive phenomenology qualitative method, described in Table 1, for bracketing, gathering, and analyzing data.^{24–27}

Sampling and participants

The qualitative study was part of a more extensive multi-method study of 41 cancer survivors with chronic cancer-related pain. During enrollment in the larger study, we noted the participants' willingness to engage in an interview and the ability to communicate experiences in an articulate and reflective manner, consistent with purposeful sampling technique.²⁵ To understand the breadth of experiences of chronic cancer-related pain and the shared experiences that may emerge despite heterogeneity, we used maximum variation sampling, selecting participants' cancer-related pain syndromes with varying pain intensity, pain diagnoses, and perceptions of pain control.²⁸ Interviews continued until data saturation was achieved, which in phenomenological studies can range from a minimum sample size of 6–15.^{29,30}

Potential participants were identified from an adult survivorship program in the Northeast United States. Recruitment letters were sent to participants following an electronic medical review using eligibility criteria. Patients were eligible if they were (1) adult solid tumor cancer survivor ≥ 18 years of age, (2) free of active disease, (3) experiencing self-reported chronic cancer-related pain that is a result of cancer diagnosis and treatment, (4) greater than or equal to three months from last active cancer treatment (chemotherapy, radiation, or surgery), (5) able to provide informed consent and read and comprehend fifth grade English, and (6) participate in an online interview using Zoom. Participants with chronic pain before cancer diagnosis or pain unrelated to cancer were excluded. Potential subjects were provided a telephone number

to call if they were not interested in participating in the study. For those who did not opt-out, the first author (K.F.J.) contacted potential participants to assess interest in participation and confirm eligibility. Additionally, the study was advertised on patient-facing platforms or referred directly by clinicians.

Study procedure and data collection

The research team developed and pilot tested a semi-structured interview guide provided in Table 2. The interviews were conducted by the first author (K.F.J.) with

TABLE 2. SEMISTRUCTURED INTERVIEW GUIDE

-
1. Please tell me what it was like for you when you were diagnosed with cancer.
Probes:
 - a. When and how were you diagnosed with cancer?
 2. Please describe your experience of having pain related to cancer and cancer treatment or as we call chronic cancer-related pain.
Probes:
 - a. When did you start to experience pain related to cancer or cancer treatment?
 - b. How has your experience of pain changed over time since you completed your cancer treatment?
 3. Before your cancer treatment, did anybody tell you about the possibility of having chronic cancer-related pain?
 4. What has it been like for you to experience chronic cancer-related pain?
Probes:
 - a. What is hard for you in your everyday due to your chronic cancer-related pain and cancer experience?
 5. Tell me how your life has changed since you have had chronic cancer-related pain?
 - a. How have things changed with regard to your typical day?
 - b. How have things changed for you with regard to your family and friends?
 - c. How have things changed with regard to your work outside the home (if this applies)?
 - d. How have things changed with regard to your favorite leisure activities?
 - e. How have things changed with regard to your social activities?
 6. As a person who has chronic cancer-related pain, please tell me what do you do to manage your chronic cancer-related pain?
Probes for the questions:
 - a. What types of things do you do to manage your pain? Medications, coping strategies, and nonpharmacologic treatments.
 - b. How much do these things help you manage your pain?
 - c. I am interested in knowing how you select your pain management choices.
 - d. What motivates you to manage your pain?
 7. How much do you think about your pain?
 - a. Please tell me about your thoughts when you experience pain or what you think causes the pain.
 - b. How do you deal with these feelings?
 - c. Please describe for me any changes that you have to make for your plans for the future because of your experience of chronic cancer pain.
 8. What advice would you give to other cancer survivors who experience chronic cancer pain?
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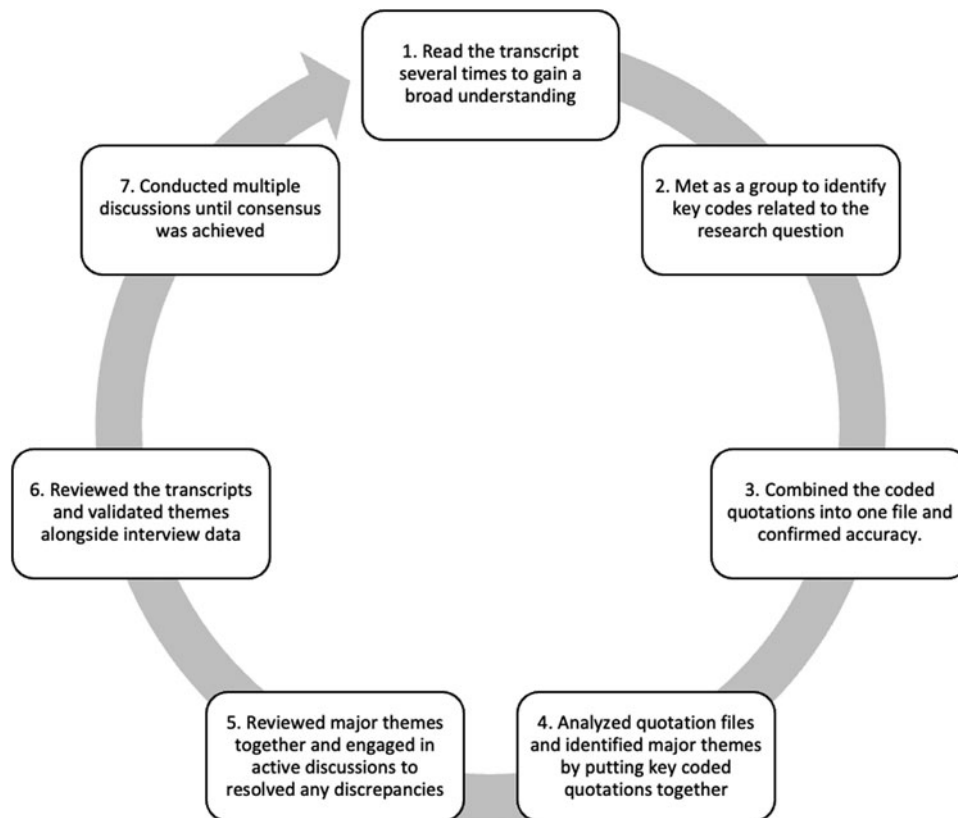


FIG. 1. Seven-step method for data analysis.

supervision from a descriptive phenomenology expert (M.R.F.). The interviews were conducted from November 2021 to March 2022 and lasted ~60 minutes. The interviews were recorded and professionally transcribed; participants received a \$60 gift card. The Institutional Review Board approved the study and procedures.

Before the interview, participants completed an informed consent using the browser-based research electronic data capture (REDCap) platform. Following consent, a REDCap secure link was sent to each participant to collect demographic information. Participants self-reported primary cancer type, cancer treatment, length of time since treatment, and details about pain diagnosis and nonpharmacologic and pharmacologic management strategies.

To better describe our sample, the Brief Pain Inventory (BPI) was collected. The BPI is an 11-item self-administered questionnaire on a 0 (no pain) to 10 (worst pain imaginable) measuring the degree pain interferes with general activity, mood, walking ability, normal work, mood, relations with other people, sleep, and enjoyment of life.³¹ Additionally, each participant completed the Collaborative Health Outcomes Information Registry (CHOIR) body map, an electronic visual representation asking participants to select areas of pain.³²

Data analysis

We used a modified iterative seven-step descriptive data analysis method to examine data, compare codes, challenge interpretations, and inductively develop themes (outlined

in Fig. 1).^{33–36} Credibility, transferability, dependability, and confirmability were the criteria for assessing trustworthiness.³⁷ The use of reflective journals, field notes, and verbatim transcriptions confirmed credibility, which was further ensured by listening to the recording of each interview while checking against the transcripts to guarantee accuracy. Detailed descriptions from participants supported transferability. The emergence of similar data from different participants in this study demonstrated strong evidence of dependability. Interrater reliability established during data analysis provided evidence for confirmability of the study. The researchers discussed the analysis and reached a consensus regarding the results.

Results

Thirteen cancer survivors were enrolled and participated in qualitative interviews. Table 3 outlines participant demographics. Participants had a mean age of 58.8 (standard deviation = 7.1) years and a variety of primary cancer types and treatments, including breast ($n=6$), head and neck ($n=5$), sarcoma ($n=1$), and lung ($n=2$); one participant had both lung and breast cancer. The time since treatment ranged from 6 months to >10 years, with 53.8% being >3 years' post-treatment.

Table 4 summarizes individual participants' clinical characteristics, including prior cancer treatments, pain diagnosis, pain scores, and a body map depicting pain locations. Participants had a variety of co-occurring cancer pain diagnoses (chemotherapy-induced peripheral neuropathy $n=5$,

TABLE 3. PARTICIPANT DEMOGRAPHICS (N=13)

Age (mean, SD)	58.8 ± 7.1
Gender self-report, n (%)	
Man	2 (15.4)
Women	11 (84.6)
Education, n (%)	
HS or partial college or associates degree	4 (30.7)
Bachelor's degree	4 (30.7)
Graduate degree	5 (38.5)
Financial status, n (%)	
Comfortable	5 (38.5)
Have enough to make ends meet	7 (53.8)
Do not have enough	1 (7.7)
Partnered status, n (%)	
Single	1 (7.7)
Married	8 (61.2)
Divorced	4 (30)
Employment, n (%)	
Employed	6 (46.1)
Unemployed	1 (7.7)
Retired	2 (15.4)
Sick leave	3 (23.1)
Volunteer	1 (7.7)
Cancer type, n (%)	
Breast ^a	6 (46.1)
Head and neck	5 (38.5)
Lung ^a	2 (15.4)
Sarcoma	1 (7.7)
Time since treatment, n (%)	
3 Months to 1 year	3 (23.1)
Between 1 and 3 years	3 (23.1)
Between 3 and 6 years	2 (15.4)
Between 7 and 10 years	4 (30.7)
More than 11 years	1 (7.7)
Pain interference (mean, SD)	4.3 ± 1.6
Pain severity (mean, SD)	4.4 ± 1.6
No. of sites of pain (mean, SD)	11.5 ± 6.3 (3–24)

^aOne participant had a history of breast and lung cancer. SD, standard deviation.

postsurgical pain $n=7$, pain related to radiation treatment $n=6$, bone pain $n=2$, lymphedema $n=4$, and other cancer-related pain diagnoses $n=6$). All participants had >3 locations of pain.

Several themes, noted in Table 5, emerged to describe cancer survivors' perceptions of living with and managing chronic cancer-related pain. The three essential themes epitomized the experience of living with chronic cancer-related pain: invisible suffering at the cost of survival, an opioid paradox, and a lack of answers on what to expect and what might help.

Invisible suffering as the cost of survival

Participants described chronic cancer-related pain as an unanticipated tradeoff for being alive; it is a "very complicated thing to be grateful and also to acknowledge that you have this pain and it's frustrating, and it is a result of saving

your life" (Participant 6). For some, survival was a second chance at living; citing gratitude helps buffer the hardships of adjusting to chronic cancer-related pain.

Participants expected that they should maintain an optimistic attitude in survivorship. When they did not, many were critical of themselves and frustrated by the toll of chronic cancer-related pain. "I'm grateful... I'm blessed that I was able to fight it, and I should be happy... should be dancing on air, but it's just not like that, and pain is one of the things added to the mix" (Participant 4).

Participants reported that chronic cancer-related pain differed from pain in active treatment because it brought a new type of suffering that was invisible to others. Living with chronic cancer-related pain impacted how participants saw themselves, "sometimes you feel a little lesser than everybody else...cause they're not walking around in pain and I am...No one, no one really understands ... they don't understand how bad it is and that hurts" (Participant 3).

Participants described an assumption on the part of clinicians, family, and friends that they should be back to their precancer selves but living with pain after cancer prevents them from ever fully returning to the way things were before. "The interesting thing about living with chronic pain, especially pain that you have gotten after cancer is that people think, well you're okay now ... I think when you have pain after cancer, it's like the body says, we pulled you through, but don't forget it" (Participant 8).

Several participants described less clinical attention once there was no identifiable source of pain or when there were no answers. "It's so easy for them to dismiss something that's consuming of your life" (Participant 1).

An opioid paradox

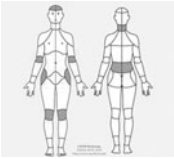
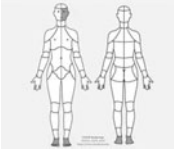
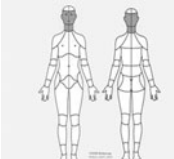
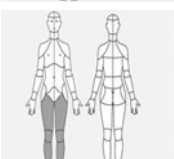

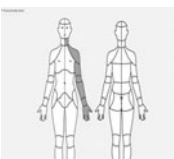
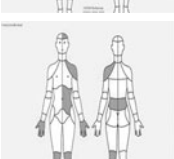
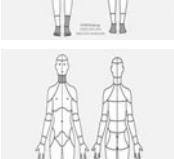
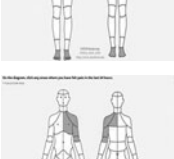
Six of the 13 participants remained on opioids for their chronic cancer-related pain. The paradox of opioids created a strain on relationships with clinicians, whether a participant was taking opioids or not.

For cancer survivors on opioids, they perceived the clinician's urgency to stop opioids after cessation of cancer treatment because of concerns of long-term risks. This priority was often a mismatch with the goals and values of cancer survivors who prioritized optimizing pain in the moment and viewed opioid therapy as an important aspect of cancer-related pain treatment.

Opioids, for many, were a roadblock to meaningful person-centered communication. "I think the biggest concern of the doctors is my opioids. And I understand that but I'm tired of being a guinea pig...I feel like I found something that works for me. So why change it? ...if it's not broken, don't fix it. I have something to help me manage it now" (Participant 4). For others, remaining on opioids triggered stigma among interdisciplinary team members and shame within themselves.

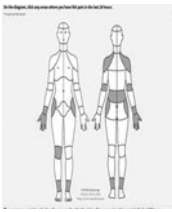
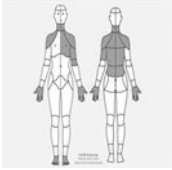

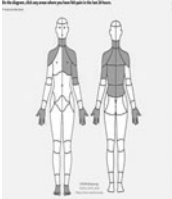
Seven participants favored avoiding opioids, which generated a clinician's assumption that this meant their pain was minimal and did not warrant treatment. Cancer survivors felt dismissed by clinicians who treated opioids and pharmacologic treatments as a proxy for pain severity, "they assume because you're not taking anything that it must not be so bad... But I'm not taking anything because I don't want to live on medication, and it is bad" (Participant 1).

TABLE 4. INDIVIDUAL PARTICIPANT CHARACTERISTICS

<i>Participant no.</i>	<i>Age</i>	<i>Gender</i>	<i>Disease site</i>	<i>Treatment</i>	<i>Time since treatment</i>	<i>Pain at its worse in the past 24 hours</i>	<i>Pain diagnosis</i>	<i>Body map</i>
1	52	F	Breast	Surgery Radiation Hormone treatment	1 Year	6	Generalized bone pain from cancer treatment Postsurgical pain	
2	63	M	Head and neck	Surgery Radiation Chemotherapy	1–3 Years	3	CIPN Postsurgical Generalized bone pain from cancer treatment Pain-related to radiation	
3	58	M	Head and neck	Surgery Radiation Chemotherapy	3–6 Years	6	Postsurgical Pain-related to radiation	
4	60	F	Lung	Chemotherapy Immunotherapy	1 Year	7	Bone pain from cancer treatment	
5	73	F	Head and neck	Surgery Immunotherapy	1 Year	4	Postsurgical Generalized bone pain from cancer treatment Lymphedema	
6	61	F	Sarcoma	Surgery Radiation	>11 Years	7	Postsurgical Lymphedema	
7	69	F	Breast	Surgery Chemotherapy	7–10 Years	8	CIPN Postsurgical Lymphedema	
8	48	F	Head and neck	Radiation Chemotherapy Immunotherapy	1–3 Years	4	CIPN Pain-related to radiation	
9	63	F	Breast	Surgery Hormonal treatment	7–10 Years	5	Postsurgical Generalized pain	

(continued)

TABLE 4. (CONTINUED)

Participant no.	Age	Gender	Disease site	Treatment	Time since treatment	Pain at its worse in the past 24 hours	Pain diagnosis	Body map
10	51	F	Breast and lung	Surgery Radiation Hormonal treatment	3–6 Years	7	Bone pain from cancer treatments DeQuervain tenosynovitis	
11	55	F	Breast	Surgery Radiation Chemotherapy	7–10 Years	7	Surgery Radiation Chemotherapy	
12	58	F	Head and neck	Surgery Radiation Chemotherapy	7–10 Years	6	CIPN Postsurgical Pain related to radiation	
13	55	F	Breast and lung	Surgery Radiation Chemotherapy	7–10 Years	10	CIPN Postsurgery Pain related to radiation Lymphedema	

CIPN, chemotherapy induced peripheral neuropathy.

A lack of answers on what to expect and what might help

Despite having diverse pain experiences, participants believed clinicians “don’t have answers. It’s all very vague... * We’re busy researching what keeps people alive. We don’t give this enough attention...and maybe it’s not a matter of life and death, but if I had the information, it would help me figure out what I need to do and how to cope with it” (Participant 1). Participants also described it would have been helpful to know chronic cancer pain could last the rest of their lives so they could develop a self-management plan sooner. “They told me

it would be painful for a little while...And when I was into this several years in, I told my oncologist that the pain’s still going. She says you might have it permanently. And I said, why didn’t you tell me that in the beginning?” (Participant 9).

Participants described that oncology-based clinicians were ill prepared to manage chronic cancer-related pain and frequently sent participants to other specialists hoping for a solution. “I was almost like racing to see what they could do to make this stop...like everybody keeps wanting to send me different places ...it’s really hard to go to all the appointments to begin with and then to go and feel like you have some hope and then the rug is pulled out. That has happened a

TABLE 5. ESSENTIAL THEMES AND SUBTHEMES ON THE CANCER SURVIVOR’S EXPERIENCE OF LIVING WITH CHRONIC CANCER-RELATED PAIN

Essential themes	Subthemes
Invisible suffering at the cost of survival	The role of gratitude and optimism Suffering differs from active cancer Assumption cancer survivors were back to their precancer selves Less clinical attention when there was no identifiable source of pain
An opioid paradox	Perceived clinician urgency to stop opioids Opioids were a roadblock to meaningful communication Opioids were often treated as a proxy for pain severity
A lack of answers on what to expect and what might help	Clinicians do not have answers or pain management strategies to offer A need to self-navigate pain management with cost, insurance, and availability challenges

couple of times” (Participant 7). In light of the lack of clinician support, participants reported that managing pain required troubleshooting and a willingness to try many approaches, some evidence-based and some not. Many participants reported being surprised there were effective treatments such as physical therapy, but cost, insurance, availability, and pilot program duration were common issues. “I would take acupuncture in a heartbeat, over opioid pain meds, over anything. But it’s so expensive. And your insurance company won’t pay for it” (Participant 10).

Discussion

The study findings provide insights into the lived experience of chronic cancer-related pain in cancer survivors. The results suggest an opportunity to support patients’ pain self-management of their pain, education to both clinicians and patients, and psychosocial interventions to optimize pain. The study also highlights several areas where cancer care falls short in managing chronic cancer-related pain. Participants described communication challenges with clinicians, particularly surrounding opioids and feeling dismissed and unprepared to move forward due to lack of information and options.

Participants voiced wanting clinician acknowledgment and advisement concerning chronic cancer-related pain management, at different times desiring problem-focused strategies (i.e., referral to physical therapy) and other times emotionally focused strategies (i.e., recognizing pain and avoiding assumptions). Failure to offer emotional support or management approaches compounded suffering. This finding is observed in people with noncancer pain who describe chronic pain as a “hidden” condition.³⁸ When pain was dismissed, participants often put their life on hold because they did not know how long pain would last and if it would improve. For some participants, focusing too much on getting concrete answers appeared to stall the development of treatment plan that could improve function and provide relief earlier in survivorship.

Nonetheless, a challenge to improving chronic pain care in cancer survivors is that most physicians, nurse practitioners, and mental health clinicians report having little education or training about chronic pain and express low confidence in treating chronic pain.^{39–41} The findings underscore an urgent need to implement chronic pain management strategies for cancer survivors and improve coordinated care.⁴²

The transition from acute to chronic cancer-related pain was difficult for participants and many participants relied on effective strategies used during treatment, like opioids.⁴³ When opioids were not used as treatment strategies, participants noted that clinicians did not have more to offer. The current emphasis on opioids in cancer care appears to have negative consequences, including impaired communication on the risks and benefits and collaboratively working to craft an individual treatment plan. For people who did not use opioids, clinicians rarely suggested alternative chronic pain treatment modalities, and when they did, access was limited. Although cancer centers are often comprehensive, our findings mimic others that chronic pain care, especially psychosocial-based treatments, are not well integrated into cancer pain treatment.⁴⁴ Our findings suggest a greater need to improve access to nonopioid treatments and psychosocial

interventions for people with cancer-related pain along the full cancer trajectory.

Many of our participants viewed chronic cancer-related pain as a tradeoff to being alive, leveraging gratitude to cope with chronic cancer-related pain. Related work in women with breast cancer demonstrates that a gratitude practice can improve daily psychological functioning, perceived support, and adaptive coping strategies.⁴⁵ Whereas some participants had a different reaction, for example, a sense they “should be grateful,” creating cognitive dissonance, and highlighting a need to match psychosocial pain treatments to the individual. For example, gratitude may be less effective for cancer survivors with negative thought patterns such as feeling victimized by cancer and acceptance and commitment therapy (ACT) may be preferred.⁴⁶ ACT aims to mindfully observe thoughts while engaging in meaningful goals despite the pain to diffuse the impact of negative thought patterns.⁴³ ACT has the potential to improve pain-related distress, but its use in cancer survivors has been limited to stress, anxiety, fatigue, and depression.^{46,47} Expanding access and the precision of psychosocial-based interventions for cancer survivors has the potential to improve pain perhaps decreasing the use of opioids.³⁹

Limitations

The goal of qualitative research is not generalizability but a deep understanding of a phenomenon.^{29,30} Consistent with the objective of the descriptive phenomenological approach, we captured a deeper understanding of the lived experience of chronic cancer-related pain in cancer survivors. However, most participants in the study were White, middle class, and female breast cancer survivors. Further examination with a more diverse sample would help ascertain whether there are divergent or consistent findings. The findings of this study were also based on a single cancer center with selection bias of people who wished to further discuss their experience. Cancer survivors receiving care at different cancer centers and people with active disease may have a different perception and management of chronic cancer-related pain influenced by the availability of pain treatments or organizational culture.

Conclusions

Our study provides insight on perceptions and management strategies used by cancer survivors with chronic cancer-related pain. The findings describe how a lack of recognition of pain, opioid stigma, and insufficient knowledge of chronic pain treatments compromise therapeutic relationships with cancer survivors and their clinicians. Research, policy, and clinical practice should prioritize access to multimodal pain treatments, improve high-quality communication, and expand clinician’s knowledge and skills to manage chronic pain. Increasing pain education to survivors with chronic cancer-related pain can potentially improve the development of an individualized pain self-management treatment plan.

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Authors' Contributions

K.F.J., L.W.M., and M.R.F. had full access to the data in the study and take full responsibility for the integrity of the data and the accuracy of the data analysis. Concept and design: K.F.J., L.W.M., J.M., and H.W.B. Analysis and interpretation of the data: K.F.J., L.W.M., M.M., J.M., and H.W.B. Drafting of the article: K.F.J. Critical revision of the article for important intellectual content: all authors. Supervision: M.R.F., L.W.M., J.M., H.W.B., and R.B.

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