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The voices of breast cancer survivors with chronic pain: A qualitative thematic analysis of patients' challenges to pain management

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ABSTRACT

Objectives: Recognizing the limitations of the current pain therapies, the study aimed to explore the unique needs and obstacles related to pain management in Breast Cancer Survivors (BCs) with Chronic Pain (CP).

Methods: 4 focus groups were conducted involving 17 BCs with CP (Mage = 51, SD = 7.99) with varying pain intensities. Thematic analysis was applied to transcribed discussions.

Findings: Three key themes emerged: (1) Challenges to pain management, including "Doctor-patients communications barriers" and "Contextual and societal barriers"; (2) Self-management needs, encompassing "Psycho-social support," "Care-related needs," and "Shared decision-making"; (3) Treatment preferences and perceptions of pain management, with subthemes like "Treatment preferences," "Institution preference," and "Decision role perception."

Conclusions: This study emphasizes tailored support systems targeting patient hesitancy, countering pain normalization, and addressing healthcare providers' attitudes. It underscores the importance of integrating caregiver and peer support. Findings advocate refining healthcare provider education, adopting a comprehensive multidisciplinary approach, and strategically incorporating eHealth tools into such care.

KEYWORDS

Cancer pain; medical decision-making; patient perspectives; survivorship; treatment preferences; unmet needs

Introduction

Breast cancer survivors (BCs) commonly experience persistent pain following surgery, with prevalence ranging from 27% to 46%, depending on

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location and severity. This pain typically persists beyond the three-month mark, becoming chronic, and it tends to remain stable for up to two years without significantly improving prevalence or intensity.¹ Such pain has a profound impact on the quality of life (QoL) not only for patients but also for their families.²

Guideline-based treatments for cancer pain, while proven to effectively control it in 70–90% of cases,³ still leave many patients grappling with inadequate pain management. This ongoing struggle may be attributed to various difficulties in both pain communication and treatments. Regarding pain communication, pain presents a complex, biopsychological, and subjective experience, making it challenging to measure and, consequently, to treat effectively.⁴ Moreover, patients may be reluctant to report their pain, with the consequence that approximately one-third of patients do not receive pain medication.⁵ As regards pain treatment, despite the availability of various pain management strategies, including self-management interventions,⁶ cancer survivors continue to face difficulties in accessing appropriate care. A recent report⁷ found that a lack of skills, knowledge, and misconceptions about pain and its management hindered optimal pain control. Therefore, achieving significant relief remains a challenge for many patients.

In this context, the psychosocial literature is particularly interested in improving pain communication and overcoming the potential barriers due, for example, to the patient's hesitancy to report pain. According to this, different tools are necessary to assess it. Peretti-Watel⁷ utilized mixed methods to assess pain experiences in BC patients, revealing a notable incongruity between results from quantitative and qualitative methods. While patients verbally articulated a rich and intense pain experience, they downplayed their pain when using quantitative scales. This discrepancy may stem from the normalization of pain, influenced by misconceptions such as viewing pain as a necessary step for recovery or a perpetual condition.^{7,8} This normalization could impede accurate reporting in self-report questionnaires, emphasizing the value of qualitative methods in exploring psycho-oncological topics marked by sensitivity and requiring in-depth analysis.⁹

For this reason, qualitative research is fundamental when studying cancer pain. A recent meta-synthesis of qualitative studies¹⁰ has shown that cancer patients need to understand deeply the cause and significance of pain and share and discuss expectations with family members and healthcare providers to increase access to assistance and develop skills to avoid isolation.

As pain management in specific populations is a rising subject of interest in the literature, the focus on Chronic Pain (CP) in BCs still needs further investigation. Considering the reported evidence, the current study aims to explore the unique needs and obstacles related to pain management in this sample.

Materials and methods

Study design and recruitment

The present study employed focus groups consisting of BCs with CP. Due to the COVID-19 emergency and transportation constraints for some patients, focus groups were conducted online *via* Zoom video calls. We followed the guidelines for conducting focus groups given by Krueger and Casey,¹¹ considering the specificities of online settings.¹² Exclusion criteria encompassed patients with psychiatric or neurological diseases, other pre-existing medical conditions causing CP, and individuals with CP before surgery or other pain-related diseases. Additionally, those who refused to participate or sign the informed consent ($n=53$) were not recruited. The main reasons provided by the patients who refused to participate were the absence of pain and the inability to participate online. The final sample consisted of 17 BCs with CP from the European Institute of Oncology (IEO) afferent to the Breast Unit (see Table 1).

All patients were in the follow-up phase and participated in the discussion once. This study was performed in line with the principles of the

Table 1. Clinical characteristics of the sample ($N=17$).

	<i>N</i> (%) of patients
Diagnosis	
Infiltrating ductal carcinoma	7 (41.18)
Ductal carcinoma	7 (41.18)
Lobular carcinoma	3 (17.65)
Type of surgery	
Quadrantectomy	8 (47.06)
Traditional mastectomy	2 (11.76)
Nipple-sparing mastectomy	3 (17.65)
Both ^a	4 (23.53)
Cancer treatment	
ET	2 (11.76)
Combined	15 (88.24)
ET + Rt	8 (47.06)
Cht + Rt	3 (17.65)
Cht + ET	1 (5.88)
Cht + Rt + ET	3 (17.65)
Other cancer procedure	
SLNB	17 (100)
Breast reconstruction	7 (41.18)
Followed by a prosthetic replacement	5 (29.41)
Breast lipofilling	3 (17.65)
Port-A-Cath	1 (5.88)
Breast lift	1 (5.88)
Current situation of the disease	
Without recurrence	12 (70.59)
With recurrence	5 (29.41)
Psychological support	
Yes	5 (29.41)
No	12 (70.59)
Taking charge in pain therapy	
In palliative care and pain therapy	3 (17.65)
In acupuncture	2 (11.76)

^aQuadrantectomy and Nipple-sparing mastectomy; Cht=Chemotherapy; ET=Endocrine Therapy; Rt=Radiotherapy; SLNB=Sentinel lymph node biopsy.

Declaration of Helsinki. Approval was granted by the Ethics Committee of IEO in July 2021 (R1508/21- IEO1594).

Procedure

Before participating in the focus group, each participant signed the informed consent *via* digital and hand-written signatures. The enrolled participants were divided into 4 focus groups (4/5 patients per group). The focus groups lasted approximately 60–90 min. To avoid excessive fatigue, an intermediate break was made during the meeting. Two psychologist-researchers (CF, ST, FD) trained in conducting focus groups led the discussions.

After a brief introduction of the focus of the research, followed by self-presentations between participants concerning their experiences, a set of core questions were asked:¹³

1. Thinking about yourself and your daily life, what are your difficulties in managing pain or barriers that hinder good pain management?
2. What are your needs in relation to pain and its management?
3. Have you discussed your treatment preferences with your doctor, caregiver, or anyone important to you?
4. Which treatment would you prefer to follow to treat pain?

The focus groups were audio-recorded and transcribed verbatim by the first author, who removed all identifiable information. The number of focus groups was determined following the literature^{14,15} to identify relevant themes. The composition of each group was determined based on the homogeneity of the pain experience, considering the intensity measured during the recruitment phone call and participants' preferences. Field notes were made during the discussion.

Data analysis

A descriptive analysis was made considering the clinical data retrieved from the patient's electronic health records and data collected during phone calls for recruitment. The pain's intensity was measured during the call using the Numeric Rating Scale.¹⁶

During the focus group discussion, this information was integrated with the participants' data on self-reported pain features (type, semantics, and location of pain). Then, a body map was created with Python using the matplotlib library.

A reflexive thematic analysis (TA) was applied for data analysis, as Braun and Clarke^{17,18} outlined. We followed the steps of reflexive TA,¹⁷

from familiarizing ourselves with the data. The coding approach was collaborative and reflexive. The primary coder (CF) first read and re-read transcripts making notes of potential interest items to familiarize with the data (step 1). Initial codes were generated (step 2), and transcripts were coded and clustered manually in candidate themes by CF (step 3). Afterward, an iterative discussion with EF, MC, and DM was made to revise the themes generated (step 4), define and name the final themes (step 5), and finally write up the report (step 6). The COREQ checklist for reporting qualitative research was followed¹⁹ (see [Table 2](#)).

Results

The characteristics of the sample

The characteristics of the 17 BCs with CP ($M_{\text{age}} = 51$, $SD = 7.88$) are shown in [Table 1](#). The average time after the end of radiotherapy and/or chemotherapy was 7 years, ranging from less than 2 years to 16 years.

Most participants reported that they were undergoing quadrantectomy ($n=8$, 47%) and combined treatments ($n=15$, 88%), specifically radiotherapy with endocrine therapy for 5 years ($n=8$, 47%). All study participants did the sentinel lymph node biopsy (100%). 7 (41%) of 17 participants reported breast reconstruction surgery, followed by prosthetic replacement in 5 (29%). The most common diagnosis was ductal carcinoma ($n=14$, 82%). Moreover, more than half had no recurrence, and intervals between reviews were mostly between 6 months and 1 year. Concerning the psychological support from the psycho-oncology division of IEO, only 5 (29%) participants followed it. As for pain therapy, 2 (12%) were admitted in acupuncture treatment, while 3 (18%) were in palliative care and pain therapy (e.g. for thoracic and lumbar algia, bone pain, chronic sacroiliac, and neuropathic pain (burning sensation).

Regarding the pain disease condition, the sample's characteristics according to intensity, type of pain, and sensations felt are provided in [Table 3](#).

All participants reported still suffering from CP, from mild ($n=8$, 47%) – moderate ($n=5$, 29%) – to severe ($n=4$, 23%) intensity. Participants in this study reported experiencing pain primarily attributed to iatrogenic causes rather than the cancer itself. Moreover, the intensity was reported by participants differently depending on the pain threshold that decreased after cancer procedures (e.g. biopsy, needle aspiration).

Regarding the type of CP, more than half of the sample ($n=9$, 53%) described the mechanisms of pain and sensations felt with possible overlaps between the types. Specifically, 5 (29%) participants reported nociceptive pain, while 4 (23%) were neuropathic. The sensations were matched to the type of pain. Participants with neuropathic pain tended to report their pain regarding burning sensations ($n=3$, 18%) or sensitivity to touch and water

Table 2. The COREQ (COnsolidated criteria for REporting qualitative research) checklist.

Topic	Item no.	Guide questions/Description	Reported on page no.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p. 4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	NA
Occupation	3	What was their occupation at the time of the study?	p. 4
Sex	4	Was the researcher male or female?	NA
Experience and training	5	What experience or training did the researcher have?	p. 4
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	p. 4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	p. 4
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	NA
Domain 2: Study design			
Theoretical framework			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p. 4
Sample size	12	How many participants were in the study?	p. 4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p. 4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	p. 4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	p. 4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	p. 6
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p. 4–5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	p. 4
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p. 5
Field notes	20	Were field notes made during and/or after the interview or focus group?	p. 5
Duration	21	What was the duration of the inter views or focus group?	p. 4
Data saturation	22	Was data saturation discussed?	p. 5
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	NA
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	p. 5
Description of the coding tree	25	Did authors provide a description of the coding tree?	p. 7
Derivation of themes	26	Were themes identified in advance or derived from the data?	p. 5

(Continued)

Table 2. Continued.

Topic	Item no.	Guide questions/Description	Reported on page no.
Software	27	What software, if applicable, was used to manage the data?	p. 5
Participant checking	28	Did participants provide feedback on the findings?	NA
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	p. 9
Data and findings consistent	30	Was each quotation identified? e.g. participant number	p. 7–12
Clarity of major themes	31	Was there consistency between the data presented and the findings?	p. 7–12
Clarity of minor themes	32	Were major themes clearly presented in the findings?	p. 7–12
		Is there a description of diverse cases or discussion of minor themes?	

Table 3. Features of chronic pain in breast cancer survivors.

	N (%)	Quotes
Intensity	17 (100)	
Mild	8 (47.06)	“At a distance of 3 years to intervention, but with a mild intensity...” [id3]
Moderate-severe	5 (29.41)	“Post-radiation therapy pain variable moderate-severe intensity depending on periods...” [id5]
Severe	4 (23.53)	“...I feel severe pain in my armpit...” [id1]
Type of pain	9 (52.94)	
Nociceptive pain	5 (29.41)	“The breast was inflamed in a monstrous way, especially in the part under the glands.... So much so that I have a bigger right breast halo because there’s still some liquid underneath, you can really see it, it swells up...” [id1]
		“The pain...but actually in the area of my abdomen that then obviously the whole abdomen is not just like a small piece that I have the skin that pulls, I have this posture because they told me in short that it is due to the fact that the skin was anyway sewn, we say sewn” [id9]
Neuropathic pain	4 (23.53)	“The neurologist called them peripheral paresthesias...” [id6]
		“Now I cannot repeat the correct terms, but they ruined my nerve endings...” [id4]
Semantics of pain	8* (47.06)	
Pull/tension-like elastic bands	4 (23.53)	“I had terrible pains, like elastic bands stretching me from the inside” [id7]
		“a nuisance that you are a little atrophied... hardened like a tennis ball. Let’s say a little pull me...” [id17]
Twinge	2 (11.76)	“But the scar, I have to tell the truth that scar gives me... let’s say this is the only kind of twinge I feel” [id15]
		“I pulled up this ladder, and immediately after I felt the twinge of the breast toward the nipple, I felt a little annoyed...” [id1]
Burning sensation	3 (17.65)	“I feel a little peculiar in the face of serious damage of radiation therapy... you feel burning...” [id3]
		“It was like my arm was on fire and...” [id4]
Sensitivity to water/touch	2 (5.88)	“I also resented the feeling of water, [...] only to the touch, I still feel it is bad.” [id4]
		“If you touch my breast, it’s a mind-blowing pain...” [id5]

Notes. *Some patients experience multiple pain sensations, which can be matched together depending on the type of pain.

($n=2$, 6%). In contrast, pull/tension-like elastic bands ($n=4$, 23%) and twinges ($n=2$, 12%) were experienced by participants with nociceptive pain.

All participants received a medical recommendation in the presence of pain to take 1000 mg of paracetamol and one tablet in case of pain (maximum dosage three times a day, one tablet every 8 h).

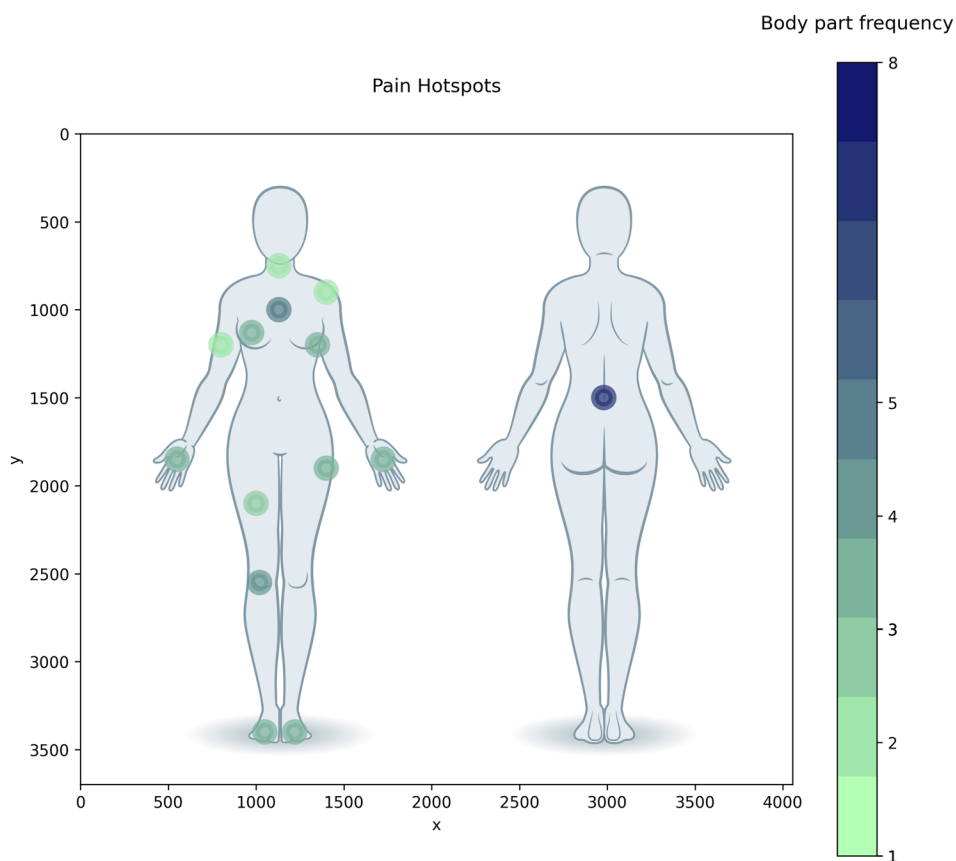


Figure 1. Breast cancer pain markings on the body map. *Notes.* The figure employs a gradation of colors (ranging from light green to dark blue) to visually represent the distribution of reported pain across different body parts. Lighter colors correspond to fewer patients reporting pain, while darker colors indicate a higher frequency of patients reporting pain. The x and y axes within the illustration denote the coordinates of the reported pain locations. It's crucial to clarify that the color shading in the figure is specifically associated with the number of patients reporting pain in each respective body part, rather than reflecting the intensity of the reported pain. Additionally, it is noteworthy that the body parts were documented irrespective of whether they occurred on the left or right side. Furthermore, it's important to mention that joints, bones, and muscle retraction were cited as additional sources of pain by some patients. Unfortunately, these specific details couldn't be visually represented on the map.

The body map

The frequency of reported pain in different parts of the body was analyzed. As depicted in [Figure 1](#), participants consistently identified the lumbar region as the most frequently reported area ($n=8$, 47%), followed by the arm ($n=5$, 29%) and chest ($n=5$, 29%). Other body parts adjacent to these regions, particularly those where surgical procedures had taken place (i.e. breast, armpit), were also frequently reported as sources of pain.

Many participants reported joints as a common source of pain ($n=10$, 59%). This was followed by bones ($n=3$, 18%) and muscle retraction ($n=1$, 6%).

The thematic analysis

The analysis yielded three major themes that showcase patients' viewpoints on pain and its management. Each theme is presented below. See Figure 2.

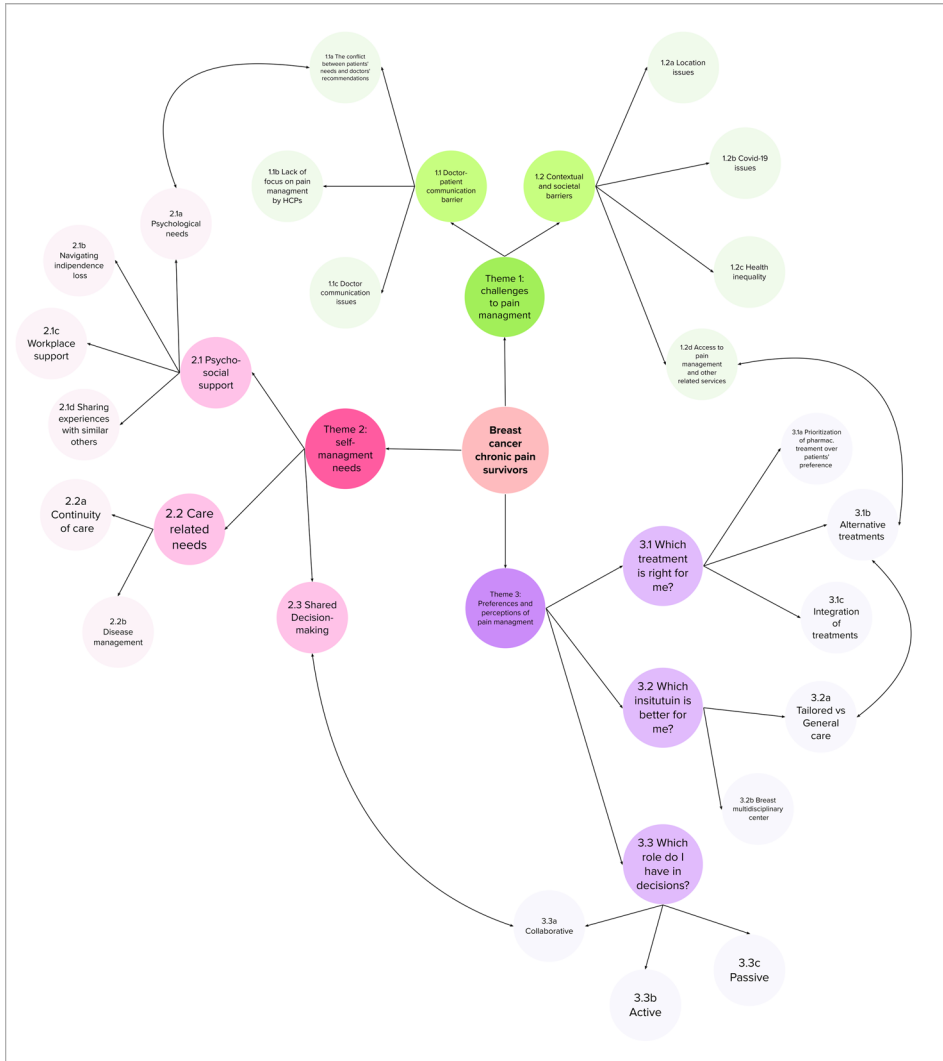


Figure 2. Map of themes derived from the qualitative thematic analysis. *Note.* HCPs=Healthcare providers; Pharmac. = Pharmacological. In the figure, the use of different colors (green, purple, violet) represents the three main themes that have emerged from the thematic analysis. Unidirectional arrows have been employed to connect each main theme with its corresponding subthemes. Additionally, bidirectional arrows have been utilized to indicate connections between subthemes belonging to different main themes. The color-coded and directional arrows help visualize the relationships and interconnections between the themes and sub-themes identified in the analysis. It's important to note that the first two levels represent the main themes and sub-themes, whereas the third level is the related topic.

Theme 1: Patients' challenges to pain management

Theme 1 explores patient challenges in pain management, with sub-themes of (1.1) “Doctor-patient communication barriers” and (1.2) “Contextual and societal barriers.”

In sub-theme 1.1, participants described conflicts between their needs and doctors' recommendations (1.1a), highlighting concerns about adhering to cancer treatment plans. Dissatisfaction arose from doctors downplaying pain intensity (1.1b), straining relationships and impeding pain management. Participants emphasized the need for clear information to avoid regrettable treatment decisions. A substantial factor contributing to the doctor-patient communication barrier is related to issues in doctor communication (1.1c). As participants shared their experiences, two specific concerns emerged. Firstly, they voiced frustration over physicians primarily viewing pain as a physical sensation, hindering their ability to convey psychological struggles linked to their pain. The separation of knowledge and specialization limits their expression of emotions. Secondly, participants perceived a lack of empathy from doctors as a significant barrier, expressing dissatisfaction with being treated as fictional patients or mere statistics rather than as human beings experiencing real suffering. Conversely, those who felt supported and understood by doctors expressed gratitude, which alleviated apprehension and increased their willingness to discuss openly worries, ultimately building trust with their doctors.

In sub-theme 1.2, contextual and societal barriers included location issues (1.2a), Covid-19 restrictions (1.2b), and health inequality (1.2c). These factors resulted in patient frustration, anxiety, fear, and a sense of abandonment due to the uncertainty and financial burden of seeking private medical consultations. Participants faced obstacles like increased transportation costs, healthcare service delays, and gym closures during the pandemic, affecting coping mechanisms.

Health inequality concerns (1.2c) involved challenges in pain management, medical malpractice fears, treatment disparities, and long waiting lists in public health services, all of which influenced the relationship with their doctors, as they reported.

Participants faced issues accessing pain management services (1.2d), including a lack of information, limited awareness, and the absence of practical tools. Proposed solutions included seeking informative resources (e.g. brochures, booklets, or educational videos). See [Table 4](#) for a summary.

Theme 2: Patients' self-management needs

Theme 2 focuses on patient needs in pain management, with sub-themes of (2.1) “Psycho-social support,” (2.2) “Care-related needs,” and (2.3) “Shared decision-making.” Participants perceived these needs as being met or unmet based on their experiences.

In the first subtheme, participants voiced psychological needs (2.1a), expressing discontent with doctors' lack of acknowledgment, understanding, trust, and reassurance. These unmet emotional needs led to frustration and anger. Hope was emphasized, along with the need for accessible information on available services, advocating for specialized psycho-oncology services. Participants also stressed the significance of psychological support for themselves and their caregivers, recognizing their active involvement in the cancer journey. While grappling with a chronic condition, participants expressed three essential support needs: navigating independence loss with their partner (2.1b), which evoked feelings of being a burden; seeking workplace support for work-health balance, emphasizing flexibility and accommodations (2.1c); and sharing experiences with those who have undergone similar situations (2.1d). They highlighted the comfort of opening up exclusively with individuals who shared similar experiences, fostering understanding, attentive listening, and a judgment-free environment. Actively seeking information about treatments from fellow patients, they emphasized the emotional expression and community-building aspects of such sharing. Recognizing the value of these connections, participants suggested the establishment of online social groups for open exchange among those facing similar circumstances.

The second subtheme focused on care-related needs (2.2), emphasizing continuity of care (2.2a) post-recovery, including home assistance and physical rehabilitation recommendations. The importance of physical activity was once again emphasized to cope with and manage pain, sometimes even conflicting with suggestions from one's romantic partner. Concerns about disease management (2.2b) led participants to suggest a mobile application for long-term monitoring and information aligned with their preferences. According to them, remembering numerous appointments often overwhelms them, and they need more tools to address this issue effectively. Consequently, this situation can worsen their condition, as they worry about their illness and remember various related tasks.

The third subtheme addressed the need for shared decision-making (2.3). Participants emphasized active participation and meaningful discussions with doctors, expressing frustration over time constraints during consultations. They advocated a more inclusive and collaborative approach (2.3a) to decision-making for better care quality. See [Table 4](#) for a summary.

Theme 3: Patients' preferences and perceptions of pain management

Theme 3 explores patient preferences and perceptions of pain management, with three sub-themes: (3.1) "Treatment preferences," (3.2) "Institution preference," and (3.3) "Decision role perception."

Table 4. Themes and subthemes of the thematic analysis.

Themes	Sub-themes	Main points	Quotes
(1) Challenges faced by patients in pain management	(1.1) Doctor-patient communication barriers	(1.1.a) The conflict between their personal needs and the recommendations provided by doctors	<p>“Unfortunately, I had to set aside my therapy because pain treatment can be helpful, but they load you up with medications, and I felt even worse. They said I had to endure and get used to them, but I remember perfectly well in what condition I was. Even when they used morphine patches to reduce the pain, it was as if I had just come out of total anesthesia. They even told me to take painkillers before coming because I still felt pain when touched... I didn't want to take more medications.” [id5]</p> <p>“[...] I didn't want to take other drugs.” [id5]</p>
		- Lack of consideration of patients' needs	<p>“I talked about my pain with the oncologist, but she minimized it... this didn't help me much, in the sense that my doubts and fears remained, and I don't know, this problem was treated a little bit like, a little bit hastily.” [id3]</p>
		(1.1.b) Lack of focus on pain management by HCPs	<p>“So, I started pain therapy just by chance. I had gone to this hospital one Saturday in late August. [...] It just so happened to be “the day of pain”; [...] it was by chance that I found out, no action was taken, no publicity. So, the patient has to look for everything they need and know what services are available, and you don't always know what you need. Yes, information is the most important thing. Many times, I got angry; I used to tell my psychologist that there is a lack, much information is missing.” [id8]</p>
		- Adherence (vs non-adherence)	
		- Normalization of pain condition	
		- Lack of adequate knowledge and information about pain and its treatment, available services, etc.	
	(1.1.c) The doctor's communication issues	- Lack of empathy (vs Presence of trust)	<p>“I am still fighting with neurologists and neurosurgeons because they found something else in my head, but they are not getting to the bottom of it... I'm going around, I'm going against doctors to get to the bottom of this thing because even psychologically, it affects you. But sometimes, I'm seen as a delusional sick person, which angers me. This thing gets on my nerves; I mean, holy crap, I have the pains. It's not like I'm making them up...” [id6]</p> <p>“In my experience, I would say that... when you find yourself on the patient's side, at the moment when you have to undergo treatments and therapies, it's difficult to establish an empathetic connection with the doctor...” [id16]</p> <p>“I had a fear of having to do chemo, and I immediately intervened with my psychologist even before the surgery; I asked for preparation support to get ready for the surgery. Before and after the surgery, each time I had a chance to go back to the psychologist, we had sessions to handle everything positively. [...] My plastic surgeon, Dr. [Name of the doctor], was there for me for two months. We talked every week. He's genuine every time I go for visits. [...] He always has an approach that makes me come out of there with a smile and feel good.” [id9]</p>

(Continued)

Table 4. Continued.

Themes	Sub-themes	Main points	Quotes
	<ul style="list-style-type: none"> - Compartmentalization of physician's expertise 		<p>"When I go to the oncologist, I tell him everything; if there is something that worries me a little bit, I try, however, to stay in his field because, as all others said, their expertise is limited to one field, the field of pathology." [id4]</p>
<p>(1.2) Contextual and societal barriers</p>	<p>(1.2a) Location issues</p> <ul style="list-style-type: none"> -Far away from home -Transport cost -Roadblocks <p>(1.2b) Covid-19 issues</p> <ul style="list-style-type: none"> -Gym closed -Lockdown: Sense of abandonment and healthcare slowdowns due to emergency <p>(1.2c) Health inequality</p> <ul style="list-style-type: none"> -Medical malpractice -Disparities -Long waiting list in health public services <p>(1.2d) Lack of access to pain management and related services</p> <ul style="list-style-type: none"> -Lack of knowledge/awareness about services offered/available -Lack of instruments to better management 		<p>"[...] I live in Sardinia. This represents a problem because I must always cross the sea to visit this hospital. [...] During chemotherapy and radiation therapy, I had to move for a month to Milan because then we were in full lockdown [COVID-19]. I started it [referring to therapy] in March 2020 and moved there, but not everybody can afford to do something like that, so I don't know." [id6]</p> <p>"You could not go in the gym because it was closed for a while [...]. After starting hormone therapy, I put on 2 kg. This bothers me very, very much." [id16]</p> <p>"Among other things, the second surgery, unfortunately, was the mastectomy with dorsal flap reconstruction, and it happened just near the beginning of the pandemic. So I found myself in Umbria, and I had to return to Milan for medication. It was disappointing because here in Perugia, they did not allow me to go anywhere. I really had a moment of crisis. [...] During this pandemic, it's really difficult to have meaningful conversations with the family doctor. Ah, this hospital is always there, but with the family doctor, I feel somewhat abandoned to myself. We hope this situation will improve." [id9]</p> <p>"I started a consultation here earlier [referring to the hospital in her country], and I must say that I didn't feel well at all with the doctor-patient approach. It made me quite alarmed, and things were already at their worst, to be honest. I preferred coming to your hospital because there's a noticeable difference in the way you handle things. Even though we might say that the same procedures are available, they don't always follow the protocol. But I wanted to address another issue as well, which is what I mentioned at the beginning. Unfortunately, there's a significant disparity in healthcare between the South and the North. That's been my experience, and it remains a significant problem." [id11]</p> <p>"I was fortunate to learn about this service, as [name of another patient] mentioned. I have a friend who works at this hospital as a psycho-oncologist. She came to visit me when I had surgery and said, 'Did you know about this service here?' If she hadn't been there, I probably wouldn't have known about it." [id7]</p>

(Continued)



Table 4. Continued.

Themes	Sub-themes	Main points	Quotes
(2) Patients' self-management needs	(2.1) Psycho-social support	- Patients' suggestions: brochures/ booklet, tv programme	"[...] In the hospitals, it would be nice to receive education and psychological support to deal with hair loss. It would be nice to have such information disseminated through TV or pamphlets... The information is needed not only about procedures being already done for us but also about all the other services in this hospital. This could be very helpful." [id8]
		(2.1a) Psychological needs	"If I complain, it's not because I want to be a victim or because I can't cope with the chronic pain in my knee... I know what I'm going through, and I do not complain because of being volatile... They indeed leave you the email and contacts, but you can't nag the Doctor, 'Sorry, but I'm in pain, I'm in pain here.'" [id5].
	(2.1b) Navigating independence loss	-Need of acknowledgment, understanding, trust, and reassurance by doctors	"When I consider that I should endure another three years of treatments... sometimes I even contemplate giving up. But whatever will be, will be... so I hope everything will turn out for the best. I will endure it, knowing it will take time, and I hope that ongoing research will yield valuable insights." [id6]
		-Need for hope	"I believe there have been times when I needed psychological support... I think psycho-oncology should be an integral part of the treatment plan. In any case, cancer patients experience significant impacts on their lives. It [referring to psychological support] should be given the same importance as checkups with a senologist, oncologist, or other specialists... But the reality is that it's not often discussed. Some individuals feel ashamed to admit they require this support. [...]. Caregivers also require psychological support... I've noticed changes in my husband." [id6]
(2.1c) Workplace support	-Shift from independence to dependence	"There are moments when I think I could tell my partner to live another life because I feel like a burden. I wanted to slap myself for having such thoughts. But I expressed them because, at some point, I felt like I was becoming a limitation for him. Yet, he always tells me, 'We're in this together; we'll face it together. It's not just your struggle; it's mine too. So, we move forward together.'" [id6]	
	-Perception to be a burden	"It must be said that, at least as far as I'm concerned, even the world of work doesn't accommodate you in any way. [...]. I say: let me work in a place where I can move more, I'm not asking for something extraordinary, I always want to work, but let me work in a way that allows me to feel well. However, it's truly absurd. But, well, now slowly, I leave work, I walk a lot, I try to keep moving so that the pains go away." [id14]	

(Continued)

Table 4. Continued.

Themes	Sub-themes	Main points	Quotes
(2.2) Shared decision-making	(2.1d) Sharing experiences with similar others	<ul style="list-style-type: none"> - Reduction of the reluctance to report their feelings and emotions -Sense of community -Emotional exposure -Patients' suggestion: online social group 	<p>"In the family, they all reacted badly, even friends; however, over time, I realized that it's one thing to talk to a person who has gone through a similar experience as you. [...] It's another thing to discuss with someone with no such experience, even if they are family members. Because nobody besides you [referring to other patients in the focus group] can understand what I'm going through, what we're going through." [id4]</p> <p>"I think it would be beneficial to have forums specifically for patients of this hospital categorized by diseases. We could have sections for breast problems, uterine problems, and other areas. It would be beneficial not just for psychological support but also to alert each other if there are any alarming signs. For example, if someone says, 'I had the same experience, and it turned out to be serious,' it could prompt others to seek medical attention. Having such a forum would be truly valuable." [id1]</p>
		<p>(2.2) Care-related needs</p> <p>(2.2a) The continuity of care</p> <ul style="list-style-type: none"> - Home assistance: ongoing support after recovery - Physical rehabilitation from home <p>(2.2b) Concerns about disease management</p> <ul style="list-style-type: none"> - Healthcare agenda - Patient-centered management - Patients' suggestion: App 	<p>"When I keep moving, walking, even just around the house, my husband tells me to take a break. Paradoxically, it's worse because if I truly stop, it's the end. That's why the only solution is to stay active, even on Sundays." [id14].</p>
(2.3) Shared decision-making	(2.3a) Collaborative-active approach	<ul style="list-style-type: none"> -Need for active involvement in decisions 	<p>"[...] some apps that would ask me to make notes in the form of a diary in which I would also speak about psychological aspects rather than physical, the pain, etc., [...]. This could also indicate some alarming changes happening in you. Knowing there is communication, even if indirect or technological, would make us feel better. The perception that someone has taken us by the hand carries on, even if they are not there. [...] An app where I could report perceptions or experiences related to various states of my being." [id4]</p> <p>"I made a pain diary. I had just pages and pages with dates, hours, and activities. I did it because when you go to the doctor, you cannot tell them: 'I have pain'; I had the pain of getting in the car to go up the stairs. I mean, I was prevented from doing several daily activities. So, I believe an app where you can write about all of this could be helpful." [id17]</p>
		<ul style="list-style-type: none"> -Need for active involvement in decisions 	<p>"They don't tell you what will be waiting for you in the short term, in a month, in the long term, 24 months. [...] They speak of the present, but sometimes it's not enough. If I had known, if I had been made aware, of the trouble I was heading to, I would have made different choices." [id4]</p>

(Continued)



Table 4. Continued.

Themes	Sub-themes	Main points	Quotes
(3) Patients' preferences and perceptions of pain management	(3.1) Treatment preferences	(3.1a) Prioritizing of pharmacological treatments over patients' preferences	"I cannot go on anymore with all the drugs." [Id13]
			"[...] the only side effect that deteriorates the bones." [Id14]
			"[...] and then with the help of the physiotherapist I did a lot of pain therapy... I had physical therapy at home [...]. I remember I used to tell the physical therapist: 'Take my arm; because, as [name of another patient] said, I had a piece of cement instead of an arm. I used to say: 'Take my arm and move it because if I have to do it myself, I stop right away due to pain: So, you would say in these services: 'Okay, it's the first time for me, I'm hurting; whom can I lean on, what do I need?' and the answer would be: 'Here's this; here's what we offer.'" [Id5]
			"My life companion for ten years now is physical activity. It's not so much, but I always walk and avoid taking the elevator...if I go somewhere within walking distance, I walk. It's my life partner: physical activity. [...] I do it along with other drugs. So, I took it as a medicine." [Id13]
			"I preferred to come to this hospital since there is a significant difference in treatment between hospitals. Even though they say you can do the same things at their place [referring to the general hospital], they sometimes need to follow the protocol. They follow the existing general protocol, whereas, at this hospital, it can be tailored. So, it is more specific." [Id11]
(3.2) Institution preferences	(3.2a) Tailored vs General care	(3.2b) Breast multidisciplinary center	"I would have really preferred it because when I joined doctors at this hospital for various health issues, they were more attuned to our needs and our medical conditions rather than a generic psychologist, using this term - mine is excellent, okay - but I find that even the physiotherapist, in simple terms, was much more in tune, forgave the expression, than the physiotherapist I've been seeing for twenty years when they treated me... no, I mean, I would have preferred it, maybe, well, there's distance, but there's technology that helps us, as in this case, right." [Id4]
			-Concerns and Unsatisfaction with drugs prescribed
			-Worries about side effects
			-Immediate relief, but then?
			(3.1b) Alternative treatments
- Attempts due to drug failure			
- Discovered by chance			
(3.1c) Integration of treatments	(3.2a) Tailored vs General care	(3.2b) Breast multidisciplinary center	"I preferred to come to this hospital since there is a significant difference in treatment between hospitals. Even though they say you can do the same things at their place [referring to the general hospital], they sometimes need to follow the protocol. They follow the existing general protocol, whereas, at this hospital, it can be tailored. So, it is more specific." [Id11]
			-Attempts with a combination of treatments
			It's not for everyone: you must discuss it with your physician
			-Better take charge
			-Being seen as a person instead of a disease
(3.2) Institution preferences	(3.2a) Tailored vs General care	(3.2b) Breast multidisciplinary center	"I would have really preferred it because when I joined doctors at this hospital for various health issues, they were more attuned to our needs and our medical conditions rather than a generic psychologist, using this term - mine is excellent, okay - but I find that even the physiotherapist, in simple terms, was much more in tune, forgave the expression, than the physiotherapist I've been seeing for twenty years when they treated me... no, I mean, I would have preferred it, maybe, well, there's distance, but there's technology that helps us, as in this case, right." [Id4]
			- Attempts due to drug failure
			- Discovered by chance
			(3.1b) Alternative treatments
			- Attempts due to drug failure
- Discovered by chance			

(Continued)

Table 4. Continued.

Themes	Sub-themes	Main points	Quotes
(3.3) Decision role perception	(3.3a) Active	- Regretting the attitude for being a devil advocate	“When it came to the reconstruction surgery, I’ve always been antagonistic... But, it was for me... I damaged myself by not trusting them. Accepting this kind of procedure... seemed to me too invasive. So, I went mad about deciding and in the end, I said: ‘Listen, I’m going to leave my back the way it is.’ [...] however, now... maybe I’ll have another visit with a plastic surgeon, let’s see.” [id16]
	(3.3b) Passive	- Complete acceptance and resignation to the medical decision - Passive narratives	“I was under the impression that I only had to do the radiotherapy. But instead, after the multidisciplinary meeting, they decided to have me do chemo as well... The pains have decreased a little bit; however, I realized that my oncologist did not want to change the therapy and preferred to go on with Letrozole, so I put my mind at rest; I continued to take Letrozole, which is what I’m taking now.” [id7]
	(3.3c) Collaborative	- Mutual involvement and a sense of gratitude	“[...] so, I fought for that not to happen, but I did well to listen to them in the end. Otherwise, I would be very prone to recurrence. [...] Having agreed to the mastectomy, I didn’t think the nipple would go away either - you see, in my head, I did not expect it... But they have informed me about this, so I put it off, but then I was convinced; [...] I am thankful it went well. As for how they approached my pain, it was explained to me that it was due to the surgery. So, it was nobody’s fault.” [id10]

Note. HCPs = Healthcare providers.

In the first sub-theme, participants debated prioritizing pharmacological treatments over personal preferences (3.1a). Concerns included side effects and dissatisfaction despite temporary relief. Integrative treatments (3.1b) were considered when pharmacological options failed, but limited awareness and delayed introduction added complexity to pain treatment. However, it should be noted that not all patients are offered these options (as reported by patients: acupuncture, psychological support, holistic practices such as reiki, yoga, and pilates), except for physical activities (walking and swimming) and massage, which are specifically mentioned in the medical report. The availability of integrative treatments varies based on individual circumstances and the effectiveness of painkillers. Some participants favored the integration of treatments (3.1c) as an ideal approach, viewing pharmacological treatments as one component of their overall care.

The second sub-theme, institution preference (3.2), highlighted the desire for personalized interventions (3.2a). Participants valued individualized care and preferred breast unit multidisciplinary centers (3.2b) for comprehensive, specialized care. They value the expertise and collaboration of specialists to provide holistic and coordinated care throughout their treatment journey.

The third sub-theme, decision role perception (3.3), revealed three roles: collaborative (3.3a), active (3.3b), and passive (3.3c). Participants preferred shared decision-making (3.3a) and expressed gratitude for understanding despite time constraints. Some acted actively, questioning options and seeking information (3.3b), but they regretted this attitude afterward. The passive role (3.3c) involved acceptance and resignation to medical decisions. See [Table 4](#) for a summary.

Discussion

This work delves into three significant themes: the challenges, self-management needs, and treatment preferences and perceptions among BCs with CP. Subthemes encapsulate participants' perspectives on the three overarching themes. Viewing these themes and subthemes not in isolation but as interconnected elements forming a continuum is crucial, as it reveals how needs and preferences arise in response to obstacles in BC pain management.

Using focus groups, we could go in-depth about patients' personal needs and emotions, which are sometimes difficult to assess with other quantitative methods, such as questionnaires.²⁰ Specifically, patients often are reluctant to report their pain, underestimating it and calling it "a normal nuisance." As found by Peretti-Watel⁷ patients tend to be more prone to open up about their experiences in regards to pain verbally compared to self-reported measures. This was also evident in our study. Although few

participants reported high pain intensity when asked through a questionnaire, most participants spoke extensively about their pain experiences during the focus groups. Additionally, in the recruitment phase, several participants refused to participate in the study due to the reported absence of pain, even if they went on to discuss their pain with the recruiting researcher. This may be the indication of normalizing pain and denial of the painful experience.

The resistance to addressing experienced pain may be attributed to two potential factors: patient misconceptions and doctor attitudes. Patients, as highlighted by their experiences and consistent with existing literature, often perceive pain as an unavoidable aspect of the recovery process or a chronic condition that must be endured.^{7,8} On the other hand, doctors tend to normalize pain, considering it a secondary symptom that will naturally diminish over time.²¹ This last aspect is part of the doctor-patient communication barrier, specifically related to doctors' approach to pain and its management. As it has also been emphasized in the literature, there is still a need to solve the knowledge deficiencies in cancer pain management among healthcare providers.^{5,22,23} Insufficient education emerges as one of the predominant obstacles to effective pain management, affecting healthcare providers and patients. For example, in another qualitative study,²⁴ it has been shown that BC patients did not expect that their pain would persist after surgery, complaining about the fact that appropriate information about pain or risk of persistent pain after surgery wasn't given at the time of recovery and follow-ups.

Moreover, as our participants emphasized, patients must also be informed about available pain management services, tools, and treatment options (i.e. pharmacological and nonpharmacological treatments). This need aligns with the literature,^{26,27} which underlines the importance of multidisciplinary and biopsychosocial approaches in cancer pain, in which patients' preferences will be heard, and their cultural background and belief systems will be considered. It is important to move beyond the predominant belief that cancer pain is primarily driven by physical and biological factors and explore the psychosocial components contributing to pain. Focusing on its underlying mechanisms in their bodies and minds and its unique impact on individuals may address the needs that the participants expressed in this study. By adopting the biopsychosocial approach, cancer pain is no longer reduced to tissue damage but is considered a holistic experience involving different areas of QoL.

Patients often experience uncertainty concerning numerous pain management challenges, as our study shows. This includes concerns about the pain and future worries.²⁵ The uncertainty takes shape as a series of "what-if" scenarios entwined with cancer, accompanied by the anguish and apprehension it brings. For example, they consider whether cancer will

spread, diminish, or reappear. Additionally, they grapple with uncertainty surrounding the myriad of cancer treatments, procedures, and the duration and origin of the pain they endure. According to a recent systematic review,²⁶ interventions to manage uncertainty encompass various components, with information support playing a pivotal role in uncertainty management. In this regard, eHealth tools present a potential avenue for implementing such interventions,²⁷⁻³⁰ as proposed by participants during the discussion. These eHealth tools can facilitate the transition from hospital to home care, fostering a smooth and uninterrupted continuum of care. Doing so helps bridge the gaps between these two healthcare settings, ultimately reducing disparities in healthcare services and providing access to all patients, regardless of contextual and societal barriers. However, as participants highlighted during the discussion, this tool should not replace the relationship with the doctor, which is key for effective satisfaction with care management.

The findings of this study indicate that when patients perceive support and empathy from their doctors, it breaks down barriers in the doctor-patient relationship, establishing a safe environment where they feel comfortable expressing their emotions and feelings. Particularly in this context, participants expressed gratitude toward their doctors for providing comprehensive support, alleviating their concerns, and encouraging them to discuss their worries about pain openly. Consequently, this strengthened their trust in their doctors. This result aligns with a recent meta-analysis³¹ that demonstrated positive outcomes for cancer patients, including reduced psychological distress and higher patient satisfaction with care. These improvements were observed concerning patient-reported physician empathy.

The need for support extends beyond healthcare providers and encompasses primary caregivers. Our study reveals that even though patients' sense of independence is disrupted when they confront a chronic condition, patients recognize that they are not traversing this journey alone. Instead, they acknowledge the indispensability of others, which we previously referred to as the co-dependence effect in our work.² According to the Systemic Transactional Model,³⁵ interdependence and mutuality come into play when two partners navigate a chronic illness. While it may mean that the stress experienced by one partner invariably impacts the other, it also signifies that one partner's resources augment the other's resources, fostering the creation of new synergies to cope with the illness.

An additional source of support emerges from individuals who have undergone similar experiences. Participants view group discussions as valuable for expressing emotions, emphasizing that only those who have lived through comparable circumstances truly understand their journey. This connection, termed emotional exposure, allows patients to authentically share emotions, thoughts, and experiences. The shared experiences

foster a sense of belonging and offer reassurance and support during times of hardship, as demonstrated in other studies.^{25,32–34} Our participants suggested a social media group as a potential solution—a space for connecting with peers, fostering mutual understanding and empathy, and exchanging knowledge and support. Specifically, it has also been demonstrated that these online social groups may serve as a tool for empowered patients to manage their chronic diseases.³⁵

In summary, this work emphasizes the importance of addressing patients' needs and preferences in pain management and engaging them in the decision-making process. By a recent meta-synthesis of qualitative studies,¹⁰ it has been emphasized that healthcare providers should focus on supporting the patients by considering their needs and preferences rather than trying to manage them. A primary concern in medical practice should be providing patients with information, enabling them to participate actively in their medical decisions. This approach aligns with shared decision-making, representing patient-centered medicine's essence.³⁶ Shared decision-making involves patients and doctors considering the best available evidence when faced with decision-making tasks while supporting patients in exploring options to achieve informed preferences. Considering patients' preferences may prevent the future regret they may experience regarding these decisions.³⁷ In the current study, participants express the need for collaborative decision-making with their doctors, where they can actively participate and be involved. This need is crucial to ensure patients' concerns are addressed and their voices are heard.

This study raises important clinical implications that demand consideration. First, we advocate the importance of a multidisciplinary team comprising social workers, psychologists, and other healthcare providers to treat patients with chronic illnesses. For instance, Melanie McDonald and Hardeep Gill of Pain BC³⁸ have provided free materials specifically designed for British Columbian BC patients dealing with chronic pain. These resources cover a wide range of support services, such as setting up a specific pain support line, offering activities for at-home use, educating people on the subjective nature of pain experiences, and organizing support groups and coaching sessions to help healthcare providers. By their professional ethos, social workers are compelled to prioritize pain management proactively, advocate for considering patients' holistic needs, and foster collaboration within relationship models to guarantee their empowerment.³⁹ Since sustaining continuity of care after five years of survival is one of the most difficult challenges after hospital discharge, it is critical to provide cutting-edge facilities that are easily incorporated into daily life. Profiling patients' based on their preferences in relation to treatments and their clinical features can empower patients, increase their knowledge of available

treatments, and promote collaborative decision-making about their care. In this process, the role of a psychologist is essential. As recently shown,⁴⁰ this vision can be realized by developing a novel digital health ecosystem interconnected with mobile apps to guarantee the transaction and continuity of care from hospital to home, breaking down barriers to pain management and respecting the unique needs of patients and their caregivers.

Limitations

This work has several limitations that warrant consideration. Firstly, detailed socio-demographic information, such as education level, marital status, and employment, was not collected. The study participants were also exclusively Italian and shared the same cultural background. As such, caution should be exercised when generalizing the findings to diverse cultural contexts. Moreover, it is important to acknowledge that descriptors and reports concerning pain characteristics were self-reported and not based on clinical examination. The multifaceted nature of cancer care, encompassing a variety of medical interventions, poses challenges in specifying the exact source of pain for each participant. However, our focus on characterizing the iatrogenic nature of reported pain aligns with our aim to contribute valuable insights into the unique pain experiences of individuals undergoing cancer care. This recognition underscores the need for targeted pain management strategies in the post-treatment phase. Furthermore, data on pain type, experienced sensations, specific body parts mentioned, and administered medications were solely derived from patient narratives. It is acknowledged that these narratives may be incomplete for certain individuals, adding a layer of complexity to the interpretation of pain experiences within the study cohort.

While these limitations temper the generalizability and completeness of our findings, they provide a foundation for future research to delve deeper into the nuanced aspects of pain experiences in diverse populations undergoing cancer care.

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Author contributions

CF, MM, and GP contributed to the study's conception and design. CF performed material preparation, data collection, and analysis. FD supervised focus group discussions. Generated codes and themes were discussed among CF, MC, DM, and EF. MC contributed to the

analysis part, revised by DM. CF performed the first manuscript draft, including figures and tables. GP supervised all the work. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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