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Clinical Pain Research

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Cancer-related pain experienced in daily life is difficult to communicate and to manage – for patients and for professionals[#]

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Abstract

Objectives – The aim of this study was to gain qualitative insight into cancer patients' experiences, explanations, and management strategies regarding their cancer-related pain (CP).

Methods – Seventeen patients with CP were interviewed using a semi-structured interview approach. Braun and Clarke's thematic analysis method was used to analyze the transcribed interviews. The patients all participated in cancer rehabilitation courses arranged by the research clinic at The Danish Knowledge Centre for Rehabilitation and Palliative Care.

Results – Three themes were identified: (1) *Explaining CP:* Patients found it difficult to explain how they experienced their pain. They lacked words, and they frequently used invasive metaphors such as "*Pain feels like a heart attack*" (2). *Strategies and barriers to the management of CP*: Initiatives provided by healthcare professionals (HCPs) were perceived as insufficient, and the patients missed guidance in both pharmacological and non-pharmacological approaches to pain management. Several saw medicine as unnatural for their body, and they focused on side effects and the medicine affecting their quality of life. (3) *Responsibility for managing CP:* A lack of responsiveness from the HCPs and taking on responsibility for pain management were experienced by several of the patients. The patients expressed uncertainty about whom to contact for help with the management of their CP.

Conclusion – The patients' difficulties in explaining, understanding and communicating their pain and pain management contributed to insufficient pain management. They were also uncertain about who had the responsibility to help them to achieve pain relief. These results share the evidence drawn from studies on patients with chronic non-cancer pain. This qualitative study highlights the need for having more focus on a common language and shared understanding between patients and HCPs. It also underpins the importance of HCPs to assume their responsibility to help patients manage their pain conditions.

1 Introduction

Cancer-related pain (CP), defined as pain caused by the cancer or the cancer treatment [1], may cause both physical and emotional disabling and lead to interference with daily activities, suffering, and reduced quality of life [2]. Pain often coexists with other problems, which may act synergistically on perceived health [3,4] and make the patient vulnerable [1,5–8].

Despite advances in treatment modalities [1] and recommendations to relieve CP [9–12], pain continues to be prevalent among people living with or after cancer. During cancer treatment, after curative treatment, and for patients

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[#] The study data have not previously been presented at scientific meetings.

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with incurable cancer, the pain prevalence is 50, 36, and 55%, respectively [9,13], and in survivors of solid cancer, the prevalence is 47% [14]. Therefore, more efforts are needed to find explanations for and take action against insufficient treatment of CP. Healthcare professionals (HCPs), patients, caregivers, and the public have been shown to share similar attitudinal barriers to the effective management of CP with opioids [15]. Other barriers to sufficient pain management were reported in two other reviews. One review demonstrated inadequate knowledge and poor attitudes among HCPs regarding CP [16]. Both the severity of the patients' pain and their need for analgesia were questioned by HCPs, and consequently, the patients were left in pain [16]. The other review demonstrated poor knowledge of CP management among nurses [17], strengthening the importance of clinical recommendations and education [17]. Quantitative studies are supported by qualitative studies, which have demonstrated unsupportive healthcare systems, poor communication between patients and HCPs, and a lack of pain assessment by HCPs, leading to insufficient pain management [18,19].

Another angle to the high prevalence of insufficient CP management is the patients' perspectives on their pain conditions, pain treatment, and capabilities to communicate their pain problems. We hypothesize this angle to be equally important in the search for explanations for insufficient pain management. Patients' perspectives and difficulties with expressing their pain problems must not be overlooked or disregarded. Qualitative research on patients' perspectives and beliefs in relation to CP and pain management is sparse. As nicely expressed in a paper on chronic non-cancer pain (CNCP) [20], "Despite the increasing number of qualitative studies on pain, the lived experience of pain remains a blind spot in the field." Pain was reported as one of the nine main categories of problems cancer patients deal with [4]. The paper indicated a need for improved communication between patients and HCPs and help to the patients to deal with their symptoms [4]. A review on cancer survivors' experience with persistent pain [21] only identified four studies, all dealing with breast cancer survivors. They reported that their pain problems were unexpected, and they did not feel supported [21]. In a study on patients with advanced cancer and their caregivers [22], the main drivers of help-seeking and action by patients to manage their pain were the sensory experience of pain and the meaning attached to it, not beliefs about analgesia. In contrast, a study from the USA on cancer survivors' perspectives on their use of opioids to manage CP [23] showed that opioids were regarded as illicit drugs, and opioid use was perceived as negative based on the media narrative of the opioid epidemic, the surroundings' perceptions of opioids, and fear of opioid addiction. These perspectives resulted in unrelieved cancer pain and poor quality of life [23]. In a recent study on cancer survivors' experience with the management of chronic pain after curative-intent treatment [24], the patients described that their pain often went unrecognized by their providers, they experienced limitations in pain assessment and a tendency to minimize or invalidate their pain experience [24].

The present evidence calls for more research into patients' perspectives and capabilities to communicate their CP problems. Another incentive for us to perform a qualitative study on CP has been our clinical experience with patients participating in our rehabilitation courses in REHPA, Knowledge Center for Rehabilitation and Palliative Care. Among 800 participants in our courses during 2018–2020, 62% reported living with moderate to severe pain in their daily lives (unpublished data).

This study aims to gain qualitative insight from patients living with CP. How patients experience and explain their CP and its' management, and their expectations of the healthcare system.

2 Methods

2.1 Research design

The study is an explorative qualitative study using semi-structured interviews inspired by Kvale's approach [25]. Data were analyzed using a thematic text condensation by Braun and Clarke [26]. To structure the article, we used the Standards for Reporting Qualitative Research [27].

2.2 Participants

Patients were recruited among participants attending cancer rehabilitation courses provided by The Research Clinic at REHPA, the Knowledge Center for Rehabilitation and Palliative Care. The participants in these courses are patients living with or after a cancer diagnosis. Inclusion criteria were living with pain, considered by the patient to be related to cancer or its treatment, a mean pain intensity (PI) higher than three on the 11-point Numeric Rating Scale (NRS) [28] over the last 2 days, or pain significantly interfering with daily activities.

The patients' characteristics are presented in Table 1.

Table 1: Characteristics of patients

Variable	*n* = 17
Sex	
Female	16
Male	1
Age (years)	
Mean (range)	41.5 (23–74)
Pain rated on NRS scale*	
4–6 Moderate pain	10
7–10 Severe pain	6
Cancer types	
Breast cancer	12
Other types**	5
Relation	
Living alone	4
Living with spouse and/or children	13
Educational level	
Basic (less than 10 years)	4
Youth (high school)	3
Medium (profession)	6
Higher (university)	4
Employment status	
Fully or partial	6
Retired	3
Sick leave	4
Other	4

*One patient rated PI as NRS = 1; however, she reported that pain affected her daily life.
** Prostate, colon, and hematological cancer.

2.3 Interview guide

A guide for conducting semi-structured interviews was developed, drawing inspiration from the methodology of Kvale and Brinkman [25]. The semi-structured interview permits researchers to integrate a predetermined set of open questions while also providing the flexibility to further explore respondents' responses [25].

The content of the questions was inspired by the literature, LJ's clinical experience with cancer patients and CP, and TI's and MR's experience with qualitative methods.

The interview guide is shown in Table 2.

2.4 Data collection

A convenience sample of 17 patients was recruited for interviews. Six patients reported to live with severe pain (PI > 6). One patient reported a PI of 1 but reported pain to affect her daily life. The mean age was 42 years, and the majority of the patients were women treated for breast cancer. The patients' characteristics are presented in Table 1.

2.5 Data analysis

Interviews were recorded and transcribed verbatim in Microsoft Word. Data were analyzed using a thematic text condensation with six steps by the approach described by Braun and Clarke [26]. In the first step, data were read several times to get a sense of the dataset. Second, initial codes were carried out. In the third step, all codes were organized into meaningful groups/themes. Fourth, the search for themes continued, and the preliminary results were presented to and validated by clinicians at the research clinic at REHPA and by the REHPA's user panel, which discussed the results in a workshop. Fifth, the three themes were defined, and finally, the report was produced; Table 3 shows an overview of the process of data analysis.

3 Results

The interviews were carried out between April 2022 and December 2022 by the third author (CV) and fourth author (CVP). Interviews lasted from 40 to 90 min. Nine patients were interviewed face-to-face in their own homes and two online, and six were interviewed at REHPA locations.

The following three themes were identified:

Theme 1: Explaining CP.

Theme 2: Strategies and barriers to the management of CP.

Theme 3: Responsibility for managing CP.

3.1 Theme 1: Explaining CP

The patients expressed a lack of words and knowledge to describe and understand their CP. A woman said that she found it difficult to describe her CP for herself, her family, and the HCPs because she missed words: "I miss words to describe the pain" (P2). Another woman expressed that she lacked the knowledge to understand her CP: "There must be a reason why the pain is there, I feel, there must be an explanation?" (P12). In contrast, three patients stated they had sufficient knowledge to understand the CP, which led to a minor focus on their CP.

The theme further revealed that patients felt a lack of knowledge regarding CP among HCPs. A woman said: "The oncologist acknowledges the pain, but he has never experienced anything like this before" (P10). Another woman also described: "I don't think the physicians can help anymore, they are just confused" (P7). When patients experienced

Table 2: Interview guide

Themes	**Questions**	**Supplementary**
Experiences with pain	"How do you perceive that pain impacts your daily life?"	Everyday functions? Relationship with family and friends? Word and leisure? Daily routines? Existentially?
	"How do you perceive your pain to impact the people you interact with in your daily life, such as your family, friends, and colleagues?"	
	"How do you think about, or describe your pain to yourself?"	
	"How do you communicate or explain your pain to other people you encounter or spend time with, such as family, friends, and colleagues? Professionals?"	Follow-up questions: Can you provide an example? Feel free to elaborate. Please tell me…
	"What considerations or concerns do you have regarding your pain?"	
Pain management	"What do you do to alleviate or endure your pain?"	For example: Do you take medication to relieve your pain?
	"Who do you talk to when you have pain that you can't relieve?"	For example: family, friends, and colleagues? Professionals?
	"What do you do when you have pain that needs relief?"	Do you use methods other than medication, such as alternative treatments, mindfulness, etc.?
	"How effective do you find the methods you use for pain relief?"	
	"What difficulties do you encounter when using methods to alleviate pain?"	
	"How can the people you're with help you with your pain?"	
	"Which professionals are currently responsible for helping you with your pain?"	(For example: hospital doctors? General practitioner? Palliative care team? Rehabilitation services? Physiotherapist? Psychologist? Nurse? Others? None?)
	"Who is responsible for following up on your pain situation in practical terms?"	
	"Do you experience any challenges associated with this?"	
	"Who do you think should have the responsibility?"	
	"Do you feel that the help you receive can alleviate your pain?" Yes – how? No – why not?	Folow-up questions: Can you provide an example? Feel free to elaborate. Please tell me…
	"Do you lack knowledge to understand and explain your pain to yourself and your surroundings?" Yes – what kind? No – why not?	
Closing	Finally, is there anything we haven't discussed that could be important to include?	

Table 3: Data analysis

Phase 2: Generating initial codes across the dataset	**Phase 3: Searching for potential/meaningful themes**	**Phase 4: Reviewing themes**	**Phase 5: Defining and naming themes**
Explaining pain	*Explaining pain*: Metephoric descriptions Language, words, knowledge	This was carried out by presenting data for relevant clinicians in REHPA and REHPAs user panel	Explaining CP
Pain management	*Pain management*: 1. Failed pain management; 2. Medical pain management; 3. Non-pharmacological management/Alternative experiments; 4. Economic challenge		Strategies and barriers to the management of CP
Knowledge			Responsibility for managing CP
Pain and responsibility	*Pain and responsibility:* 5. Unknown responsible		

that HCPs did not have sufficient knowledge, it led to poor management of their pain.

Patients described their experience of CP to themselves and their surroundings, including their families and HCPs, by using metaphors. A patient told: “It is like walking on shards of glass, a fire in my body that’s just burning, burning, and burning” (P2). This citation revealed that CP is described in detail and relatable.

Patients also adapted their pain descriptions according to the recipient for their explanations. A woman said that she described pain more honestly to HCPs than to her friends or family because she did not want to hurt the family, she said: “[…] there are feelings involved with friends and family. With HCPs I don’t have to think about their reactions” (P17). When describing the pain for the family, patients used other terms, and the descriptions were less detailed, for example: “My leg hurts today. You have to be careful. Maybe we could draw instead of jumping about?” (P10), a woman said when trying to tell her grandchildren that she was not able to play because of CP.

3.2 Theme 2: Strategies and barriers to the management of CP

Theme 2 describes that patients used both pharmacological and non-pharmacological strategies to relieve their pain. Patients told about their use of pharmacological treatment, such as paracetamol, and many patients had tried other types of prescribed medication such as morphine and prednisolone. However, patients also told how they did not want to take the prescribed medication because of side effects. A woman said: “The medicine just has a lot of side effects” (P14). Other patients talked about the medicine being bad for their bodies, as a woman described: “Taking medicine is not natural for the body. I feel like I try artificially removing something (the CP) that is there for a reason” (P5). Some patients even described how they felt sedated by the pain medicine, a woman said: “I remember the first time taking prednisolone, in huge amounts. I felt awful. I was like a zombie” (P2). In that way, patients told that pain medicine affected their quality of life, and then they were not able to follow the progress of their pain.

Patients also perceived that physicians were only able to help with pain management by prescribing pain medicine and that prescribing medicine “[…] would remain a temporary solution” (P17). Many patients described the use of several non-pharmacological strategies to relieve their CP. Most patients had consulted countless treatments, among others, massage, acupuncture, and yoga. They lacked treatment guidance, especially in access to non-pharmacological pain management strategies. Therefore, patients had to deal with many non-pharmacological treatment suggestions, which the patients felt, were difficult to navigate in. A woman said: “I didn’t have much energy to navigate in all these opportunities. This is too big for you to handle, and you don’t get any help” (P3). This citation reveals that this responsibility was too big for the patients.

Finally, patients experienced an economic barrier to non-pharmacological pain management, a woman described: “There are some economic challenges in pain management when talking about non-pharmacological approaches. For example, it is very expensive to attend retreats, and I think that massage is way too expensive, even though I know it may help” (P2). For some patients, this meant that they felt excluded from access to treatment that could potentially relieve their pain.

3.3 Theme 3: Responsibility for managing CP

Theme 3 describes that patients were not sure whom they could contact in case of the need for pain management of their CP. A total of 11 of the 17 patients described feeling uncertain about who had the responsibility for managing their CP. When asked to identify who was responsible for their pain management, they provided different suggestions: “The general practitioner” (P8), “[…] contact nurse at the hospital” (P1), “[…] own responsibility” (P11), “No one is responsible” (P4), “[…] late effect clinic” (P5), “All healthcare professionals can be the responsible” (P2), “[…] oncologic department/generic department/the department of surgery” (P12), “[…] oncologic department” (P9). Only five patients expressed that they were fully aware of whom to contact if they needed help with their CP management. One patient said: “My general practitioner is responsible; he keeps an eye on everything and knows me very well” (P6). One among those five mentioned the specialized palliative care team as responsible for CP management.

The majority of patients felt let down by the healthcare system when it came to receiving help with their CP management. A woman expressed: “The oncologist is not even listening” (P15). The patients felt let down because no one in the healthcare system took this responsibility. The patients further said they were unable to manage their CP by themselves: “I need help, but I don’t know where to begin” (P13). Patients expressed a need for someone to take responsibility for the pain management.

4 Discussion and conclusion

This study adds to the sparse, qualitative knowledge of cancer patients' lived experience with pain. How they understand, experience, and explain CP and its management. Communication between patients and their surroundings regarding their pain is of fundamental importance for relevant treatment. Capability to express pain problems for oneself, to the surroundings, families, friends, and colleagues, and HCP is one of three important premises for providing appropriate treatment strategies to relieve patients' pain. The second premise is the recipients' abilities to respond properly to this communication, and the third premise is the healthcare systems' capability to build a structure, which can respond to the patients' needs.

In the first theme in this study, the patients described a lack of words and knowledge when they should describe their CP. Patients' lack of words has previously been recognized by HCP, who reported that patients replied: "What do you mean by describing the pain, it's just there" when they were asked to describe their CP [29]. When explaining their CP experiences, the patients in our study used metaphors, and they adapted their pain descriptions according to the recipient. Metaphors are often used to describe pain. In a qualitative study on how language was used to describe pain experienced by patients with CNCP, the patients consistently used metaphors across different themes as part of their desire to communicate to others and make the invisible pain visible [30]. An interview study of older adults with CNCP gave insight in the way pain was described by the patients to inform HCPs' approaches to assess the pain. The patients tended to personalize the meaning of pain using stories, similes, and metaphors, and they contextualized pain in relation to its impact on everyday activities [31]. Metaphors shape us and help us to tell our stories, and they can either open up or close opportunities in our lives [32,33]. The use of negative and invasive metaphors to describe pain can hinder CP management [33]. If HCPs can help patients to transform or reframe negative metaphors into more positive ones, this has been suggested to have a significant impact on how patients manage CP [33]. Other research groups have supported the view that awareness among HCPs to use metaphors can lead to communication that is more effective and with great therapeutic effects for patients [34,35]. Interestingly, all patients in our study who faced challenges in explaining their pain used invasive metaphors to describe their pain. The variation and unpredictability of pain frequently made it hard and sometimes meaningless for the patients to rate their pain numerically [31]. A similar finding was reported in a study intended to develop a patient self-management resource to support care for CP and to overcome barriers at the levels of the patient, provider, and health system [36]. In that study, several patients struggled with using numerical rating scales for pain severity, and they preferred goal-setting tools for informing anticipatory analgesia [36]. To improve communication about pain, it may be helpful to have less focus on NRS and increased willingness among HCPs to listen to the patients' ways to measure their pain in relation to their activities of importance. We found that patients lacked knowledge regarding CP, but we also found that the patients felt the HCPs lacked knowledge of CP. The patients experienced this as a further barrier to CP management. Inadequate knowledge among HCPs has been reported as a barrier to sufficient CP management in other studies [16,37,38]

In the second theme, on strategies and barriers to pain management, some patients reported barriers in their use of pharmacological pain management, because of side effects and the medicine affecting their quality of life, and medicine being seen as bad or unnatural for the body. This perception of medicine is also reported in previous studies [39,40], where patients with cancer expressed concerns about using the medication, such as fear of unmanageable side effects, fear of harming the immune system, and fear of potential changes in the body [39,40]. The same concerns were found in an integrative review of barriers and facilitators for self-management among patients with CP. Concerns which hindered effective pain treatment [41]. Several of the patients in our study used non-pharmacological strategies to manage their pain. The patients missed guidance in both pharmacological and non-pharmacological approaches to pain management. This lack of guidance was experienced as a major barrier to achieving sufficient CP management. In line with our results, the need for more guidance from HCPs in non-pharmacological pain management strategies has been described among patients with advanced gastrointestinal cancer [42]. An integrative review has found that patients did not receive enough information from HCPs about CP and CP management, and they had to find all the information by themselves [39]. A survey on the nurses' knowledge of pain management showed that 76% of the nurses thought that the best way to relieve a patient's pain was using medicine [43], and the nurses missed formal training in pain management [43]. As more non-pharmacological treatments, such as physical activity [44,45], mindful-based cognitive therapy, acceptance and commitment therapy, and music therapy [11], have shown effects in the management of CP, it may be beneficial to include non-pharmacological treatment strategies alone or in combination with pharmacological treatments as standard.

Interestingly, some of the patients related the use of medicine to express how they understood the meaning of their pain. “The pain is there for a reason” as one of the patients said, and some stated that medical pain relief hindered them from following the progress of the pain. The meaning of pain was discussed in a longitudinal qualitative study, where pain was embodied with uncertainty and conflicting emotions. Particularly, the fear that pain represented disease progression could delay patients’ communication with HCPs and hinder effective relief [22].

Finally, theme 2 revealed that economy was a barrier for accessing non-pharmacological treatments. Economy was described as a top-ranked barrier in a qualitative study investigating barriers to non-pharmacological treatments in chronic pain [46].

Theme 3 is related to the responsibility for managing CP. In our study, several of the patients felt let down by the HCPs, from whom they experienced a lack of responsiveness in taking on this responsibility. The patients expressed uncertainty about whom to contact for help with the management of their CP. Most of the patients mentioned a range of HCPs, whom they saw as responsible for taking care of and guiding them in the management of their pain. This is supported by an interview study of cancer survivors [24], where the patients in general did not identify one or more providers as their primary pain provider. This lack of clarity regarding who is responsible for the patient’s pain treatment is in opposition to the recommendations from both the World Health Organization and the Danish Board of Health. These recommendations state that patients should have a designated healthcare person responsible for their pain treatment [47]. Other studies regarding this uncertainty support the patients’ experiences in our study. A study has shown that oncologist did not see their role as a key person in managing CP. They explained that they had fewer interactions with the patients compared to other healthcare providers, which limited their involvement in managing patients’ CP [29]. Nurses did not see themselves as an independent caregiver of CP, and they pointed to the physicians as responsible for the management of CP [38]. However, this is opposed by another study, which found that nurses played an important and active role in CP management in assessing and specifying the cause of pain, planning treatment, and evaluating outcomes [48]. These differing views on responsibility highlight the importance of clarifying the roles and responsibilities of CP management among healthcare providers in order to accommodate the recommendations from the health authorities for the benefit of the patients.

This study has several limitations. Patients were only recruited from one setting, which may have skewed the results and missed out on other nuances to the findings. Women treated for breast cancer were overrepresented, which seems to be a general experience in the sparse qualitative studies in CP. This may have influenced some of the perspectives. Regarding strengths, the first author presented the results to HCPs at the research clinic of REHPA and to REHPA’s user panel, which validated the findings. The user panel consists of both patients and relatives. The user panel expressed a strong connection to the findings and eagerly discussed their own experiences related to the results. The findings were discussed with the co-authors, who conducted the interviews. They confirmed that the resulting themes captured what they experienced during the interviews.

In conclusion, this study has demonstrated patients’ difficulties in explaining, understanding, and communicating their pain. It has revealed an unawareness of who is responsible for the patients’ pain treatment, and where they can get guidance in both pharmacological and non-pharmacological treatment opportunities. These factors contribute to the understanding of why many cancer patients still experience insufficient pain management. Although no direct comparison was made, patients’ experiences in this study do not seem to deviate much from the qualitative evidence of CNCP patients’ experiences. The study highlights the need to focus more on a common language and a shared understanding of CP and its management between patients and HCPs. Finally, it points to HCPs’ roles and their obligations to assume the responsibility to help patients manage their CP.

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Research ethics: The study was conducted in accordance with the Declaration of Helsinki [49], and registered at Region South Denmark’s internal registry of research projects and complies with GDPR legislation (Journal no.: 22/1381). All data were stored safely in SharePoint. The study did not require approval by the Regional Committees on Health Research Ethics for Southern Denmark (Journal no.: 20222000-21).

Informed consent: Oral and written informed consent was obtained, and participants could, at all times, withdraw from the study.

Author contributions: All authors contributed to the interpretation of data, discussed the study objective and the results, and revised the manuscript's intellectual content. T.I. drafted and revised the manuscript. C.V. C.V.P., M.R., and L.J. contributed by analyzing and interpreting the data. M.R. and L.J. contributed by substantially revising the manuscript's intellectual content. All authors have read, commented, and approved the final version of the manuscript.

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