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Exploring the concept of Total Pain in contemporary oncology palliative care: a qualitative study on patients' resources

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Abstract

Background According to the concept of Total Pain proposed by Cicely Saunders (1967), the treatment of pain for patients in need of palliative care requires considering its multidimensional nature, encompassing physical, social, psychological, and spiritual aspects. The aim of this study was to update the concept of Total Pain and explore the resources used by patients with cancer.

Methods Fourteen semi-structured interviews were conducted in one oncology center and one oncology rehabilitation center (median age = 70.5, range [55–77]; 8 women). The interview guide explored various dimensions of suffering, including physical (e.g., pain), social (e.g., isolation), psychological (e.g., emotional state), and spiritual (e.g., the role of spirituality in illness experience), as well as connections to nature, and patients' internal and external resources related to each sphere of suffering. Interpretative Phenomenological Approach (IPA) was employed to analyze the interviews.

Results The findings highlight several important aspects of suffering: the unpredictability of pain (physical sphere), loss of social roles (social sphere), negative affects (psychological sphere), evocation of the end of life (spiritual sphere), and loss of contact with nature. Besides in terms of resources, the study identifies several key coping mechanisms, such as mind-body practices for relieving physical and psychological pain, distraction engaging with the environment, nature as a source of positive emotions, and the search for meaning.

Conclusions Despite experiencing total pain, some patients utilize internal and external protective resources in the face of life-threatening illness. These findings underscore the importance of viewing Total Pain under its multidimensional aspect and as a dynamic process involving the individual's connection with their community and environment.

Trial registration This study received approval from the Ethical Committee of CPP SUD EST 1 (National number: 2019-A02263-54).

Keywords Total Pain, Palliative care, Coping, Qualitative research

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Introduction

According to the definition provided by the World Health Organization [1], palliative care is an approach aimed at enhancing the quality of life for patients, both adults and children, as well as their families, who are suffering from chronic and life-threatening illnesses. Palliative care encompasses comprehensive active support, including the assessment and treatment of pain and other distressing symptoms, whether they are physical, psychosocial, or spiritual in nature. This approach is available to patients, their families, and healthcare providers from the early stages of the palliative phase through to the patient's death and during the bereavement period.

Cicely Saunders [2], a pioneer in Palliative Care, listening to dying patients' description of their experience, introduced the concept of Total Pain, which has gained international recognition [3]. The Total Pain perspective acknowledges pain as a multifaceted subjective experience, a whole overwhelming experience, not only physical but also social, psychological, and spiritual dimensions, with interactions occurring between these dimensions. The emergence of this approach in the 1960s occurred against the backdrop of the post-World War II era, in response to the rise of individualism and materialism in society, as well as a medical paradigm focused on medical scientific advances and turned away from incurable disease [4]. Among the contemporary studies on Total Pain, Rome et al. [5] underscore Total Pain concept as central in the guidelines of The National Cancer Comprehensive Network, emphasizing the necessity of a multidisciplinary team to assess the diverse dimensions of Total Pain and assist patients in confronting these challenges.

Background

The concept of Total Pain reflects a quest for meaningful care, and contemporary authors are debating the need to reconsider this concept in the light of current issues [4]: for example advances in cancer prognosis, the rise of cancer survivors [6], the integration of early palliative care [7], advancements in pain management [8], or evolving patient needs and perceptions regarding physical and mental health [9, 10]. More recently, Brant [11] conducted a review highlighting the holistic nature of Total Pain, examining its four dimensions with cultural and contemporary considerations. These include, for instance, fear of opioid addiction, concerns about side effects opioids that can impact pain expression and patients' expectations; as well as the occurrence of anxiety and depression which can be addressed through cognitive behavioral approaches. In this paper, the author emphasizes the need for patients, medical staff, and families to be educated, trained to management and assessing of Total Pain, considering cultural aspects of Total Pain [12]. In line with this approach, Mehta and Chan [13] stress that optimal pain relief cannot be achieved unless all dimensions of "Total Pain" are addressed, they identified Total Pain as a central factor in pain assessment and management among palliative care patients.

Medical recommendations in oncologic supportive care [14] increasingly advocate for patient empowerment, emphasizing the importance of identifying patients' needs and expectations, but also their attitudes and reactions when facing end-of-life challenges [15].

But some authors like Krawczyk et al. [4] or Gomes-Ferraz et al. [16] note that this concept has not been sufficiently addressed in recent research. Despite its theoretical significance, the application of Total Pain in real-world palliative care settings remains underdeveloped.

These authors argue that this concept is confronted with the challenges of today's society, including clinician distress, the increased need for sedation or hastened death, alongside a contemporary healthcare system that is much more focused on the technical care and medications for pain management than on "the true meeting" between patients and healthcare professionals, as mentioned by Krawczyk et al. [4]. Gomes Ferraz et al. [16] observed that Total pain concept is not sufficiently integrated in clinical practice, despite the existence of multidisciplinary teams that should coordinate holistic care. This literature review also highlights the lack of that narrative-driven research - research that explores the patients' lived experiences. Understanding the multidimensional aspects of Total Pain directly from the patients' own words is essential for gaining insights into how it manifests in their lives, but such research remains scarce.

Krawczyk et al. [4] and Mehta and Chan [13] emphasize the interconnection between the four dimensions of Total Pain, too often treated as distinct elements by health professionals. Mehta proposes a diagram illustrating this interconnection.

In addition, conceptual reviews are focused on the management and assessment of Total Pain without considering what resources (i.e. coping strategies, resilience factors) that help patients face the global suffering associated with cancer and palliative care phase. New approaches to diseases, especially cancer, acknowledge the role of resources, coping and process of resiliency as protective to deal with aspects of suffering.

Coping refers to the cognitive, emotional and behavioral responses that individuals use and develop to face adversity and stressful situations [17]. Coping strategies employed during advanced cancer appear to be related to different aspects of disease management [18]. In the case of patients in palliative care, spiritual coping considerations are gaining recognition for their role in mitigating Total Pain [19–21], alongside other psychological factors such as positive emotions and connection to nature

[22–24], which are recognized as beneficial coping strategies and resilience factors. As cited by European Association for Palliative Care, spirituality is the dynamic dimension of human life that relates to the way individuals (both personally and within communities) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.").

The connection to nature can be mentioned. To our knowledge, no study has focused specifically on the role of natural environment in palliative care setting. This topic is indirectly addressed within the spiritual component of Total Pain, despite its significant role in the resilience process and in maintaining well-being [24].

In the context of palliative care, spirituality can be considered a protective coping and resilience factor [25–27].

The definition of resilience by Windle [28] seems particularly appropriate in the palliative care setting. According to Windle, resilience is the process of negotiating and adapting effectively to major sources of stress or trauma. The individual's resources and environment foster this capacity to adapt and recover from adversity. The experience of resilience varies throughout an individual's life.

Resilience has been recently studied in the context of palliative care, following the emergence of an integrative and global approach to mental health and illness proposed by the World Health Organization (2005, p. 2). Mental health is defined as "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community". This approach, conceptualized by Westerhof & Keyes [29] for example, considers health and illness as two distinct continua, where health is not only the absence of disease but also the presence of "positive" factors that promote well-being and resiliency [29]. Through the lived experience of patients dealing with life threatening disease, examining factors that promote and protect mental and physical health despite the coexistence of distress, pain and other challenges is a relatively new area of study [30]. In the case of life-threatening illness such as cancer, several coping strategies promote resiliency and alleviate suffering such as control, acceptance, optimism, spirituality, the search for meaning [31] or even gratitude [32]. Focusing on these latent resources is a promising avenue to addressing patients' needs, offering a complementary approach without denying the Total Pain symptomatology.

Among these resources, the connection to nature can be mentioned. To our knowledge, there is no study focusing on the role of natural environment in palliative care setting. This topic is indirectly studied and encompassed in the spiritual component of total pain despite its role in the resilience process and in maintaining well-being [24].

Purpose

We acknowledge that qualitative research exploring all dimensions of pain within a single interview, with an emphasis on personal resources, is scarce. Therefore, to address this gap, as noted in the work of Gomez-Ferras et al.'s work [16] for example, we conducted a study highlights its originality through three points: (1) transdisciplinarity with pain medicine and psychological sciences approaches, (2) a clinical illustration of the Total Pain concept through lived experiences and patient narratives using a new questionnaire to assess the multidimensional aspects of Total Pain, (3) an exploration of psychological/physical/social/spiritual resources (e.g. positive experiences, emotions, values, etc.…) to offer a comprehensive global approach of mental health/illness in palliative care [30].

Through these three key points, we sought to explore the following research question: how do people with advanced cancer cope with this phase of their illness and their lives?

Drawing from previous works such as Daneault [33] and Wilson et al. [34], we formulated open-ended questions that provided informative insights into the physical, social, psychological, and spiritual aspects of pain, including the relationship with nature as a specific sub dimension of spiritual pain [35]. Connection to nature is an aspect of both social and spiritual suffering, in line with the EAPC definition of spirituality. We noticed that this subdimension of Total Pain is seldom explored in detail in palliative care setting, and we hypothesize that it needs to be further examined. [36–37]. By considering the multifaceted impact of nature on patients' experiences, we aim to deepen our understanding of how nature-related resources can contribute to alleviating Total Pain in palliative care settings.

Furthermore, since patient's resources are rarely explored in recent literature and patient education is an emerging area of care, we adopted an integrative approach to the concept of Total Pain, focusing on two intertwined aspects: understanding the characteristics of Total Pain experienced by patients with cancer and identifying the psychological, social, spiritual, and physical resources they utilize to mitigate its different dimensions. To illustrate this, we applied Mehta and Chan's conceptual framework [13], emphasizing the interconnectedness of all dimensions of pain, specifically in patients in palliative phase of cancer. We also applied this conceptual framework inspired from Saunders'model, to explore the resources developed by patients to alleviate suffering related to the four dimensions of Total Pain.

Method

Study design

In order to delve into the lived experience of Total Pain among patients and their resources, we employed a qualitative research design and adopted the Interpretative Phenomenological Approach (IPA) [38] as a research method. Interpretative Phenomenological Approach is particularly relevant for exploring subjective experiences and deriving meaning from narratives without formulating personal expectations or research hypotheses as investigators. This approach ensures that the investigator is personally involved in the research process at each step of the study supporting the patient's narration, and staying as close as possible to the lived experience of the participant during the analysis process. In line with this widely used qualitative method in health psychology setting [39], semi-structured interviews were chosen as the primary method to facilitate open expression from participants, regarding their feelings, thoughts, bodily sensations, perceptions, representations and resources across various topics related to the four spheres of Total Pain.

Table 1 Interview guide

Physical sphere
Could you describe how is your physical pain?
What pain impacts your inner life (thoughts, emotions, sensations)?
What do you do to alleviate or relieve this pain?
What should be done to alleviate pain?
Social sphere/Connexion to nature
How isolated have you felt in the last few days? Can you describe this experience and tell me what might be causing this feeling of isolation?
What would you like to do or have done to alleviate this feeling of isolation?
How important is the connection to nature (mountains, forests, or perhaps lakes, ocean, etc.) to you?
How would you describe your connection to nature (the mountains, the forests, or perhaps the lakes, the ocean, etc.)?
Would you like to strengthen this connection ? If yes, could you give me some examples, how?
Psychological sphere
Can you describe your emotional state over the last few days?
What negative emotions are you feeling the most these days?
Do you know when these emotions are most apparent?
What are you doing to alleviate them?
What positive emotions can you feel in the last few days?
Under what circumstances do you feel them?
What are you doing to cultivate/increase them?
What do you accept most about your experience with illness?
If you had the opportunity, what would you currently do to remove the thoughts and emotions that cause you pain?
What are the most important things to you right now? or what matters most to you right now?
Spiritual sphere
If it is important, what does spirituality mean to you?
Can you tell me how spirituality takes place in your daily life? What do you do for that?
What helps you the most to face difficult days? What gives you the most hope or meaning in your life?
How does spirituality change the relationship you have with others? With yourself? With nature?

Based on the concept of Total Pain proposed by Cicely Saunders, we developed an interview guide for this study, composed of four sections (Table 1): physical, social, psychological, and spiritual pain, including the connection to nature.

The interview guide (Table 1) was developed collaboratively by the three researchers, drawing on a theoretical background from literature on palliative care and psychological processes affecting the mental and physical health of cancer patients [13–40]. The guide included open-ended questions covering each aspect of Total Pain and the resources mobilized by patients., as outlined in Table 1. The primary open-ended question guiding the interview was: how do you live this phase of illness in your life? This question was followed by several open-ended sub-questions addressing each aspect of Total Pain and the resources used by patients.

In line with the IPA guideline, we tested the interview guide with three patients, to ensure comprehension and feasibility, making refinements as needed.

Participants volunteered to take part in individual face-to-face interviews, which were conducted in their hospital rooms without no one else present, besides the participant and researcher.

All interviews were audio-recorded and subsequently transcribed manually. Field notes were also taken during the interview when relevant, for example, to ask patients to elaborate on specific points.

The data analysis process was guided by Interpretative Phenomenological Approach [38]. Throughout this study, efforts were made to adhere to the COREQ guidelines [41], ensuring transparency and rigor in the study design and reporting.

Key sub-themes emerged from the data analysis, capturing the essence of participants' experiences of Total Pain and the strategies they employed to alleviate their suffering. These sub-themes were synthesized into a coherent model, providing insights into the multifaceted nature of Total Pain and the diverse resources individuals draw upon to cope with it.

Setting

This study received approval from the Personal Data Protection Committee of CPP SUD EST 1 (National number: 2019-A02263-54), ensuring that the research adhered to ethical principles and guidelines. The interviews took place at the Medical Center of Ceyrat, a rehabilitation center specializing in Oncology, and at the Cancer Center Jean Perrin, both located in France. Participants were recruited and interviewed between June and November 2020, following the established ethical protocols, and obtaining informed consent from all participants prior to their involvement in the study.

Sample selection and recruitment

All staff at the two investigation centers were briefed about the study and provided with information regarding the eligibility criteria. Eligible patients who volunteered to participate were enrolled in the study following written informed consent and confirmation of inclusion and exclusion criteria. The study included male or female patients with cancer in need of palliative care, aged 18 years or older, affiliated with a social security scheme (i.e. health insurance cover), and who provided written informed consent.

Exclusion criteria comprised patient refusal, Karnofsky and Performance Palliative Scale scores lower than 20% (indicative of terminal stage of disease with rapid progression), moderate or severe cognitive impairment, confusion, bipolar disorder, schizophrenia, attention (vigilance) disorders, acute phase depression, suicidal risk, and patients under protective measures (guardianship, curatorship, or safeguard of justice).

Upon agreeing to participate, patients were approached by one of the interviewers to schedule an appointment, review the information sheet, and provide informed consent. Investigators were mindful of diversifying the sample in terms of gender and cancer types. However, the stage of the disease and patient frailty limited the choice of participants. Among the eighteen of the patients approached, three declined participation, while fifteen agreed. One participant did not complete the interview due to fatigue, and therefore, we decided to exclude this participant from the data collection and analysis process.

In line with the recommendations of Phenomenological Interpretative Phenomenological Analysis, the principle of data saturation was not applied [38]. According to this approach, we had decided in advance to recruit between ten and twenty participants. Given the inclusion/exclusion criteria and the number of people interested in participating, a sample of fourteen participants was considered sufficient to capture enough information from the data while respecting the principle of homogeneity. A larger sample size would have increased the heterogeneity of participants' characteristics, potentially compromising the consistency of the narratives.

Data collection

The semi-structured interviews were conducted by a Ph.D. female student in health psychology, who is also a psychologist, and a female doctor specialized in pain management and palliative care. The research background and clinical experience of both investigators in palliative care helped them be aware of the specific features of this population, create a trusting atmosphere during the interviews, and enrich the data analysis process through their conceptual and applied views. The Ph.D. student conducted ten interviews, while the doctor conducted four. Only four of the recruited participants were known by the doctor prior to the interviews.

Before or at the beginning of each interview, investigators introduced themselves and explained the study's aim to the participants. At the end of each interview, the investigator ensure a debriefing with participants to ensure they were not left in a state of distress following the interview. Additionally, we offered to share the study outcomes if they agreed. However, we did not propose that participants be involved in the data analysis process (i.e. correction or comments) dut to their fluctuating health condition.

The average duration of the interviews was 1.23 h, with a minimum duration of 49.59 min and a maximum duration of 2.03 h. All interactions between patients and interviewers took place in a single face-to-face session. The interviews were audio-recorded and subsequently transcribed for analysis and coding.

Data management and analysis

The transcription process began with the manual transcription of interviews by the Ph.D. student, followed by a review to improve the quality of each transcript. Both interviewers then meticulously read through the transcribed data multiple times to extract all meaningful verbatims in line with the main themes covered in the interview guide. According to IPA, the analysis process was entirely inductive, and the investigators carefully discussed, debriefed, and refined the extracted subthemes multiple times to reduce discrepancies in the interpretation of the narratives. However, if subthemes emerged that were not directly related to the interview guide, they were still included in the analysis, in accordance with the guidelines of Interpretative Phenomenological Analysis (IPA).

For each interview, numerous subthemes were identified and extracted from the main themes explored through the interview guide (i.e.physical, social, psychological and spiritual pain/resources), requiring several sessions of discussion and analysis to resolve discrepancies and reach a consensus among the researchers regarding the primary subthemes shared across multiple participants. A substantial number of meaningful subthemes were identified, ultimately resulting in the development of concise and coherent models (see Figs. 1 and 2).

The selection of relevant sentences was crucial for accurately depicting each subtheme, ensuring that the essence of participants' experiences was effectively captured in the analysis.

The following results are presented in a thematic analysis format. On one hand, this approach covers the richness and variety of elements extracted throughout all interviews. On the other hand, it offers a congruent

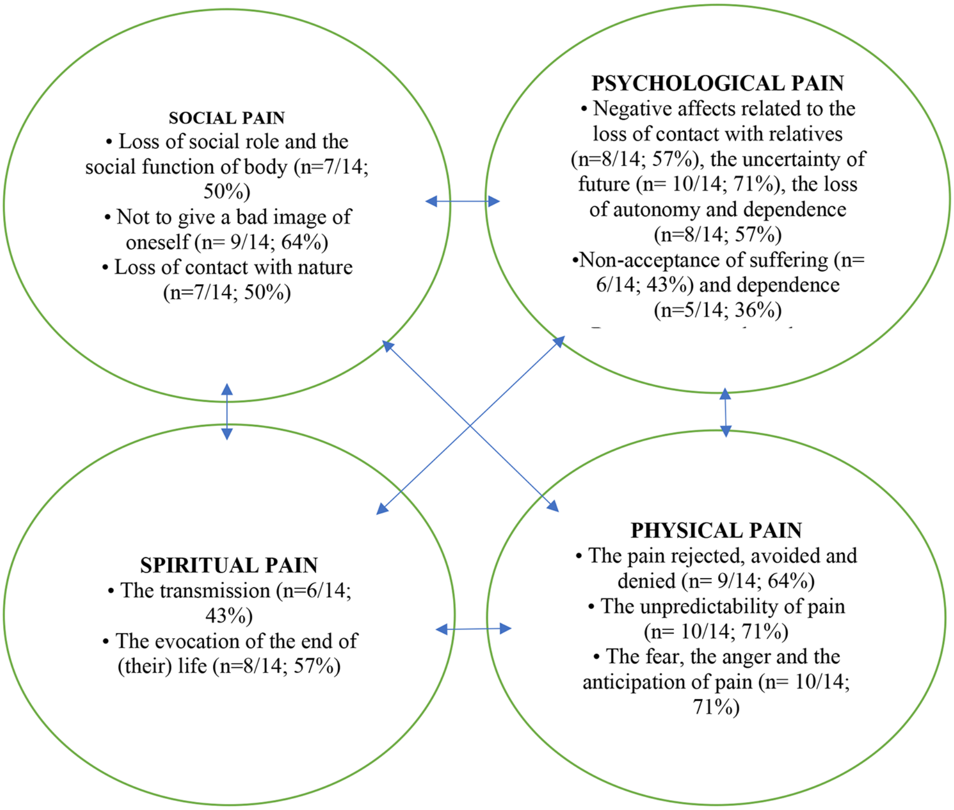

Fig. 1 The Total Pain experience inspired by the interactive model of Mehta & Chan (2008)

model aligned with Mehta and Chan's framework [13]. However, IPA (which can be considered a specific form of thematic analysis) was the preferred method guiding this study due to its particularities. Firstly, IPA focuses on the subjective lived experience which is not always the case with thematic analysis. Secondly, during the analysis process, we considered each case separately. In a second phase of the analysis, we performed a cross-case analysis to present the lived experiences coherently and propose a synthetic model.

Results

Characteristics of participants

Among the fourteen participants interviewed in this study, eight were women. The median age was 70.5 (range from 55 to 77). Nine out of the fourteen patients had a high socio-professional status. The minimum duration of hospitalization was two days, and the maximum was 105 days (with a median of 19 days). Only one participant was hospitalized as planned; the others were admitted due to a deterioration in their health. Two participants were recruited from the Oncology Centre, while twelve were recruited from the Rehabilitation Centre.

The average scores on the Karnofsky Performance Scale and Palliative Scale were at 50%: on average, participants were unable to work, required significant assistance and frequent medical care, and were bedridden for more than 50% of the day.

All participants died within 6 months following the study.

Among the patients, four were diagnosed with gynecologic cancer, two with bronchial adenocarcinoma, four with urologic cancer, four with gastrointestinal cancer, and one with brain cancer. All diseases were at stage III or IV. All participants were undergoing chemotherapy, and eleven of them were also undergoing radiotherapy. These characteristics are summarized in Table 2.

Qualitative results

The lived experience of total pain (See Fig. 1)

Physical pain

The rejection of pain Pain was rejected, avoided, and denied by a significant portion of the participants. Patients expressed a strong desire for physical pain to disappear and sought ways to divert their attention from it through distraction, sometimes resulting in the denial of physical pain.

(8) "Physical pain I would say is something that doesn't affect me", "I would tell her no, I'm not in pain, but I'm sure I was in pain", "Maybe it was completely stupid".

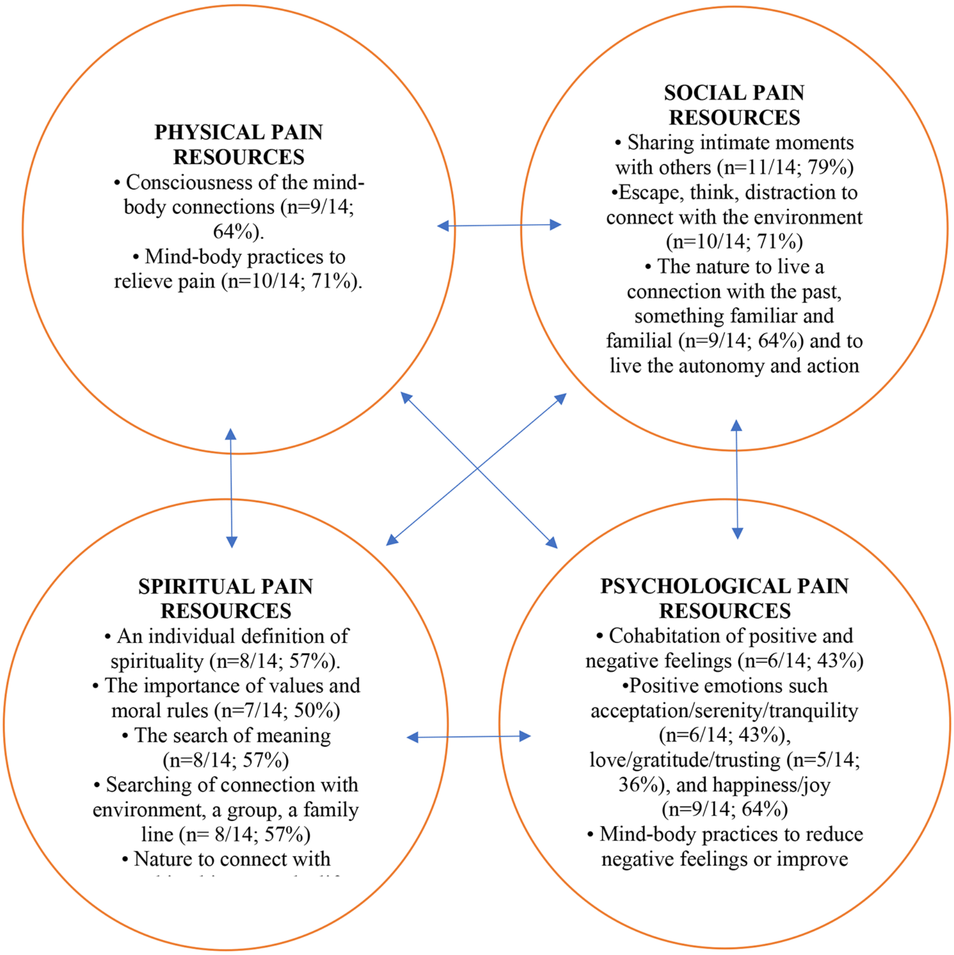

Fig. 2 Multidimensional resources of patients

Table 2 Characteristics of study participants ($N = 14$)[1]

Age (Median and range)	**70.5 [55–77]**
Sex (M/F ratio)	6/8
Socioprofessional category (N)	9
Senior level Salaried job	3
Mid-level Salaried job	2
Salaried job	
Karnofsky (%)	50
Type of cancer (N)	4
Gynecological cancer	1
Adenocarcinoma bronchial	4
Urologic cancer	4
Gastro-intestinal cancer	1
Brain cancer	
Duration of hospitalisation (Median days)	19
Specific oncologic treatments (N)	5
First line of chemotherapy	5
Second line	4
More than Three lines	

[1] The characteristics of all interviewed patients were described, but only 14 of them were included in the analysis due to one being unusable

(6) "I put it aside in a place, I forget, I think about other things, I push it away", "I know it's there but I try to put it on the periphery".

The unpredictability of pain When patients are describing cancer pain, the main characteristic they focus on is the rhythm of the pain: the fact that it is sudden, unpredictable, spontaneous, with no way of avoiding it, and it often takes the patient by surprise, intensifying feelings of fear and anticipation.

(5) "It's at times. You see, this is now, but if it is, all day it will be impeccable.", "Afraid that every hour...".

(3) "It's annoying because it's a background pain and at times there's a sudden acceleration that you can't control, which disappears in 15 seconds, but it bothers a lot."

(14) "It reminds you constantly, without too many pauses", "The intrusion of the pain puts a needle in the bubble".

The fear, anger, and anxious anticipation of pain Pain is mainly linked to fear, anger, and the end of life. There is a sense of insecurity (fear: what will happen?) and the perceived unfairness of pain, engendering anger due to changes in relationships, autonomy, and well-being.

(2) "I have no pain, but I am waiting for it, I wonder how it will appear", "Not afraid to die but afraid to suffer".

(9) "it annoys me""i'm angry being surrendered, being blocked, not daring to force anymore"

(14) "The main question I have is whether I should continue to live like this for the rest of my life. Clearly, I don't want to, I want to return to a previous serenity", "I dread the fact that it will always be like this".

Pain and the question of acceptance Cancer pain questions patients about their ability to accept it, as it is permanent, unpredictable, and sometimes intense. What patients expressed reveals that the attitude of acceptance is valued and sought after by some, while for others it feels antithetical. For some, the question becomes: how can they accept a 'no choice' situation?

(5) "we can no longer accept it, we no longer accept"?

(12) "I accept it (pain),yes absolutely. Well, listen to it like that... I have to deal with it".

"It's not even fear, I have no choice anyway".

(14) "it seems almost easier to get used to this background noise than to try and neutralize it (the pain)".

Social/natural environment pain

Loss of social roles Half of the participants reported a loss of social roles and the social function of the body. The repercussions of the disease, particularly its physical effects, hindered patients from living their social lives as they desired. For many patients, social suffering stemmed from the loss of their physical abilities to move, walk, work, and maintain their place among their peers and family members.

(3) "they don't give a damn about me. They're happy, i'm waiting."

(11) "I am no longer in my active professional life, I don't see the people I used to see, so since this illness we are a bit cut off from the world".

(12) "Of course, before I used to walk a lot, I used to do a lot of sports. I can no longer move", "I tell myself that I will depend on others anyway and what will I do afterwards once I get out of here?

Concern about not presenting a negative image of oneself was noted among a significant proportion of participants Some patients experienced distress at the thought of seeing their relatives because they were unwilling to appear in their current condition. This reluctance hindered their ability to fully enjoy moments spent with their loved ones.

(7) (Seeing people requires me to "forget myself as I am now in order to remain more or less as they knew me before", "Seeing people in bed, ugly, it doesn't smell good, it's not pleasant" "When I'm alone, even if I cry, it's like that, whereas when you have witnesses...".

(11) "I prefer to isolate myself, I don't feel like spreading myself with explanations. I'm not going to bother people with my stories".

(13) "I don't want to give them an image of me as tired and unwell".

Loss of contact with nature was reported by half of the participants The connection with nature is often associated with movement, activity, and overall well-being. Some patients expressed memories of their relationship with nature, such as interactions with animals, childhood experiences in gardens, or memorable travels. These recollections evoked both painful emotions and pleasant moments for the patients.

(13) "I'm not too connected anymore. I can't do anything" (recalls the walking club she used to belong to); "I don't have that desire anymore it's over (strengthening the connection with nature), there are things I can't do anymore".

(3) "not going to the seaside is a lack"

(8) "I can't see myself going for a walk, I can't, I can hardly walk. It's physically that I miss it."

Psychological pain

Negative emotions related to the loss of contact with relatives, uncertainty about the future, and loss of autonomy and dependence were prevalent among participants The primary negative emotions expressed by patients included annoyance, fear, and hopelessness.

(9) "Dependence, dependence. That's what bothers me the most, it's always latent", "The pain is there, since it's there, you have to deal with it... But it's the consequence of the immobility that it engenders that is annoying".

(3) "the disappointment of not spending time with my family".

(13) "I have no emotional state at all. I am jaded by everything"; "When my children come, I feel they are suffering. I'm not going to add insult to injury"; "I don't feel brave enough to do anything. I have completely given up. ".

Non-acceptance of suffering and dependence were notable themes throughout the interviews, closely linked with the rejection and refusal of pain Participants consistently expressed their reluctance to accept suffering and their discomfort with dependence on others.

(5)" That's the worst part. Pain is really the worst thing because you can't accept it. We don't accept it anymore. In any case, I don't accept it anymore."

(2) "All thoughts cause pain from the moment they relate to my state, to what I have become… make everything that relates to my state disappear, everything that is negative, everything that makes me suffer. To clean up".

(12) "All my life I've tried to help others, so you reverse the machine. It's not easy to accept."

Regrets about not meeting personal expectations or failing to achieve desired outcomes were expressed by half of the participants These regrets surfaced when patients reflected on their wishes to have approached certain aspects of their lives differently.

(9) "Well, I'm ashamed that I couldn't get over that pain…"; "All my life I've felt like a loser. I've never been self-satisfied. I've always thought that we can improve.

(5) "I didn't do well", "I regret not really expressing myself as I should have"

(3) "That's the way it is, but if I had to do it again, I would do it differently".

Spiritual pain

Transmission emerged as an unexpected but significant theme during the interviews Patients spontaneously expressed the importance of what they would leave behind and what their loved ones would remember about them. They shared their beliefs and concerns about what would happen to their family after their death, particularly regarding their legacy and the memories they would leave behind.

(15) "But if you want this notion of family, of continuity, of things that pass from one to the other, serenely, it was important. And I am in the middle, with something violent and that, for me, is terrible."

(6) "I tell myself that it's not over when I die and that I will continue to be there for my grandchildren in their minds."

(12) "We are here to transmit to them (children in general), not only knowledge… values, behaviors".

The contemplation of their own death arose spontaneously in a similar manner to the discussion of transmission Although not prompted, several patients shared their thoughts and feelings about the end of life. This topic evoked a range of emotions, including anxiety and fear, but also moments of serenity and acceptance. We interpreted this as a source of spiritual and existential suffering, albeit one that fluctuated and was not universally experienced by all patients.

(5) "What do I accept the most? That I am at the end. Not far from death but not suffering. I have suffered too much in my life", "I am coming to the last phase. I'm trying to get through it as best I can. "I can be very anxious (about death) but I have been through this stage".

(12) "If I could go like this it would be the greatest gift of my life. I think it's beautiful to be able to leave gently, with beautiful thoughts."

(8) "As death approaches, I feel a little bit outside (of my body). I am not totally inside", "Negative thinking is death", "I don't know how I will react the day it happens". "Not to continue I prepared myself for it, I accepted it".

The resources mobilized by patients facing total pain (see Fig. 2)

Physical pain resources

Consciousness of the mind-body connections was observed among several patients They recognized the correlation between their bodily sensations and emotional state, allowing them to make adjustments to their physical or psychological condition. This awareness enabled them to maintain control over their health and, in some cases, experience improvement. This connection is particularly evident concerning pain management.

(1) "the more we are tense, the more we think about it"

(14) "Before I was not in pain, so it did not affect my integrity in which I feel good, in my happiness, in my relationship with people", "Physical pain ends up affecting my emotional state".

(9) "I am in my brain. The body is my utility. The brain commands the body".

Mind-body practices to alleviate physical pain were reported by the majority of patients Techniques such as breathing exercises, walking, massage, meditation, and imagery (visualization) were spontaneously utilized by some patients to diminish their pain sensations. These techniques were adopted alongside medication as personal strategies to alleviate unpleasant bodily sensations. While some patients employed maladaptive strategies such as avoidance, most used effective and adaptive techniques to self-regulate their physical pain.

(13) "There's a little bit of medication. Sometimes I walk around the bed to activate everything so that I can… and then I breathe. I try to breathe in well, three or four times, to release some of the stress from the pain."

(1) "I do my sessions, my little breathing sessions. I take the opportunity to relax."

(5) "I massage myself. I try to press. After a while, it feels good. It's been coming for a long time. I've done martial arts and I've done a lot of courses on relaxation and all that. Relaxing, resting, emptying yourself, trying to take off, not being there anymore.

Social pain resources

Sharing intimate moments with others, including family members and care staff, emerged as a significant aspect of improving well-being Social support, characterized by humor, tenderness, and intimacy, was identified to enhance overall well-being. Conversations on various topics beyond medical and technical matters were found to be particularly beneficial. The involvement of care staff in fostering these interactions allowed patients to maintain meaningful connections beyond mere medical conversations.

(5) "It's nice when you have people you like standing next to you, soothing you, when you talk, that have a good time together."; "Chatting, exchanging, as they say remaking the world."

(7) "lots of little positive, funny moments with the grandkids on the phone."

(12) "I feel understood and not judged because when they clean you, I can tell you, the first time I was ashamed. You get to know people quickly, chat with them, and recognize their faces. You feel safe. I thank them every time they come to clean the room, for example. I admire their kindness (talks about the nursing staff)."

Escape, contemplation, and distraction to engage with the environment were commonly employed by patients Many patients employed methods other than physical movement to stay connected with the world and their surroundings. Some sought solace in their imagination, while others found refuge in documentaries, pictures, or simply by gazing out the window. These practices allowed patients to momentarily escape the confines of their hospital room and connect with the broader world.

(1) Beautiful pictures, beautiful images, happy change of scenery compared to... when I look at this wall. From time to time there are very beautiful pictures. I love wildlife documentaries, things like that that relate to space.", "Thinking about a thread, about the future, about things that don't even exist anymore."

(11) "Getting in touch with the world and knowing what's going on with the news."; "It's nice to have some pictures and some legends, to know what each other is doing."

Living in connection with nature to evoke the past, something familiar and Familial, and experiencing a connection with autonomy and action emerged as significant themes Nature serves as a way for patients to reconnect with themselves through memories of childhood and intimate moments, with others through reminiscences of travel and shared experiences, and with the environment through the desire to engage in activities such as walking and exploration. Despite being removed from direct contact with nature due to hospitalization, patients could transform their connection to nature into a positive experience. This involved drawing upon memories of the past, savoring the present moment through observation, and nurturing hope and wishes for the future within the context of the natural world.

(1) "reconnecting to your environment, your home," "walking. Get some fresh air. To feel active."

(3) "What is important is the connection with the sea, to the sea. I had a second home by the sea. I have always loved the sea", "I can walk on the beach, the beach I do it with the grandchildren".

(11) "She was always essential. It doesn't matter where I've been.", "Activities that are really in touch with the land.", "I'm lucky enough to be able to go out and walk, to walk around what's around me."

Psychological pain resources

The coexistence of positive and negative emotions, primarily related to relationships or memories, was notable This observation highlights that, despite facing illness and challenging physical or psychological conditions, some patients experience and express two seemingly contradictory emotions simultaneously - emotions that might intuitively be perceived as opposites.

(9) "it makes me sad and happy at the same time."

(2) "it soothes me as it Can, on the contrary, panic me."

(1) "Fear, it can actually be in relation to the disease, even if you say to yourself, you absolutely want to go well and get better... you have to have confidence, you have to trust. You have to trust yourself, you have to trust yourself."

Positive emotions such as acceptance, Serenity, and tranquility, love, gratitude, trust, as well as happiness and joy, were frequently reported by patients These positive emotions were often associated with relationships with their relatives, engaging in movement and action, and experiencing simple events, anecdotes, and memories. Despite enduring painful moments and experiencing negative feelings, patients expressed a wealth of pleasant emotions that contributed to improving their well-being in the face of illness. These positive emotions not only provided relief but also represented what patients hoped to experience amid their challenging circumstances.

(14) "I come back to the same serenity, joy, confidence. That's really it. That's where I find myself again".

(6) "I felt love from my children, from my husband"

(7) "I accept the diagnosis, the treatment, the dependence that it creates with respect to everything."

Mind-body practices to alleviate negative feelings or enhance positive emotions were commonly employed by patients Similar to managing physical pain, psychological distress motivated patients to seek ways to alleviate negative emotions. Patients utilized various mind-body techniques or artistic practices to achieve this goal. For instance, some practiced focusing attention to reduce negative feelings, while others engaged in drawing to enhance positive emotions. Patients described how these practices were accessible and effective despite their physical or emotional condition, highlighting their importance in coping with their circumstances.

(1) "I ask to go out and get some fresh air to walk a little bit, quietly," "When I can rest, then I do the little exercises and keep busy. Keep myself busy, take care of myself."

(11) "At night before I go to sleep, all I can think about is my breathing."

(15) "I can lie on the bed like this without TV, without anything, and go. I leave well, I'm happy, I'm fine," "Drawing brings me a lot…it has always brought me peace."

Nature as a source of positive emotions Nature serves a pathway for savoring and experiencing positive emotions. Just as nature facilitates patients in connecting with their surroundings, they derive enjoyment from immersing themselves in nature, savoring its beauty, and observing natural phenomena such as animals, trees, flowers, mountains, stars, sunsets, and more. This allows them to notice and appreciate things often overlooked in daily life, leading to a subsequent influx of positive emotions.

(1) "Pleasure that passes through the eyes". "A flower that grows". "Sometimes I stay like this and listen to the birds. It's beautiful, I love it."

(9) "I like to be in the garden because it is where there is air". "I am connected to the pavement while enjoying a beautiful landscape, a beautiful flower."

(15) "In the mornings, I like to look at the mountain a little bit, so those are things I enjoy. They're simple…it doesn't have to be grand to appreciate things."

Spiritual pain resources

An individual's Understanding of spirituality Patients distinguish between spirituality and religion, providing their own interpretation of what spirituality means to them and the extent to which they embrace these beliefs, often expressing a secular spirituality. For some, spirituality conveys a sense of interdependence or connection with a higher power, while for others, it relates to the pursuit of well-being or experiencing the beauty found in nature. Regardless of their definition, spirituality aids them in comprehending their experiences more deeply.

(1) "I would say, it's well-being."... we become aware of what surrounds us. To be cut a little bit effectively from the world. It's… we pass into something else.", "It's not materialized, it's not visual. It's really something that everyone experiences. It's individual."

(11) "I believe that living decently would be living in spirituality and trying to understand life.", "To experience the field of possibilities."

(14) "If spirituality is a kind of religious belief, I am completely atheist." "I'm pretty sensitive to Indian beliefs, animism type." "Spirituality is tasting the esthetic of things"; "Spirituality is walking in beauty."

The significance of values and moral principles Regardless of religious affiliation, many patients view values and morality as essential for imparting to their children or maintaining meaningful connections with others and the world in alignment with their own beliefs and principles.

(3) "It (spirituality) makes sense so far as it gives a moral, a sense of life, great principles.

(5) "(Martial arts) It's like religion anyway… it's respect for others, it's respect for oneself. It's also about doing good, avoiding evil," "It puts us at the right value." "You have to respect humans".

(9) "For me it's a set of values (kindness, love, tolerance) to live together. I try to instill these values in my children. ».

The quest for meaning in life's phenomena and self-discovery The pursuit of meaning permeates the entirety of the interviews, particularly concerning relationships, connections to nature, and something greater than oneself. Patients grapple with existential questions regarding what the experience of illness teaches them about themselves and others, as well as pondering life's phenomena beyond considerations of illness.

(6) "I say to myself, "You can't help it. Something will happen that will decide, something I can't control." "(Spirituality) it doesn't answer the questions, but it allows you to ask the questions."

(9) "maybe it's reassuring to think that there is a force."

(11) "Everyone is as they are at the stage they are at. He accompanies us, we accompany them", "There is something that happens… in the look, in the smile", "Need to understand, to continue to search", "I say to myself when we know what we are going to live, it is that we are capable of living it".

(15) "You have to tell yourself that there are beautiful things in life and that you shouldn't miss them and that helps with the disease."

Seeking connections with the environment, community, or Familial lineage Patients articulate their sense of connection with entities larger than themselves, such as God, community (the Others), or the Universe. Despite the challenges posed by illness, which often lead individuals to become more self-centered due to pain, psychological distress, or isolation, patients express a willingness to remain open and connected to something beyond their immediate experiences.

(5) "I think I'm in a line of people, I'm not just a number placed like that in the universe." "I am part of something, part of the people of God".

(1) "Idea of some universal spirit, something greater than ourselves that has no relation to individuality."

(10) "I think we all have the desire to belong to something. It's reassuring. It's nice to have heroes."

Nature as a pathway to connect with something greater Nature serves as a conduit for patients to establish a connection with forces beyond themselves, such as the cycle of life.

(5) "Well, I feel like that's where we come from. It's what gives us life… not more for me because well, it's life. It's infinite actually", "A facet of our species or our lives. The two are held together or it wouldn't exist."

(11) "There is life. Life from the smallest to the largest. How these birds fly in formation, how this tree grows. We don't know anything about it."

(12) "We are part of nature." "We are living only by others. We all need love, sweetness."

Life review Despite inquiries focused on the present experience of illness, many patients reflect on various aspects of their lives beyond the confines of the disease. Memories feature prominently in their narratives during interviews, evoking both positive emotions such as gratitude and joy, as well as negative feelings like regret and sadness. While their current experiences in the room are significant, they also delve into their concerns, dreams, and aspirations for the future. The interviews unfold within a framework of space and temporality, encompassing a before, during, and after.

(8) "I find that it felt good, I find that this exchange allowed me to maybe remember things that I had buried deep inside, but it felt good."

How are the dimensions of total pain and resources interconnected in the lived experience of patients?

As articulated by Cicely Saunders through the concept of Total Pain, at the end of life, suffering encompasses not only physical discomfort but also psychological, social, and spiritual anguish, with interconnectedness among these dimensions. Patient interviews support this concept, revealing that although the interviews aimed to explore each dimension independently, the artificiality of such separation becomes apparent.

For instance, patients frequently spontaneously intertwine physical and social distress, as noted by Brant [11]. Physical pain often leads to reduced physical activity, which, in turn, results in social isolation. Patients expressed such sentiments, stating, "the pain is there, you have to deal with it, but it's the immobility it engenders that's irritating. I feel a bit isolated because I can't do anything anymore" (9) or "pain makes me unfit to have nice relations with my wife" (14).

Moreover, the link between physical and psychological pain is evident. Emotions triggered by pain can overwhelm the individual and alter their overall mood. For example, one patient stated, "the pain has diminished, giving me a little more comfort and a feeling that I've regained some sort of balance. It gave me confidence" (10).

The loss of contact with relatives also generates social pain and negative affects, such as "the disappointment of not spending time with my family" (3). Additionally, feelings of uselessness due to immobility can contribute to a negative mood and a loss of meaning in life. Social pain is further linked to spiritual pain, as loneliness can affect the feeling of belonging. For instance, one woman expressed a desire to isolate herself at times and felt obligated to make an effort in the presence of loved ones, perceiving their presence as that of "witnesses". This woman finds solace in Catholicism, which allows her to feel connected to a lineage of people [23].

The qualitative analysis of the interviews reveals several common themes across all dimensions, such as uncertainty. Patients grapple with unpredictable pain, disease prognosis, suffering, and death. The search for meaning in physical pain mirrors the existential quest for meaning in life. For instance, patients expressed thoughts like, "these are pains that make you wonder: whether I should go on living like this for the rest of my life" (14) or "the situation is horribly sad and I can't find any justification for it. I have no explanation, I've given up saying why" (7). This existential questioning about meaning coexists with the acceptance or rejection of their circumstances. Most patients mentioned accepting death but not the suffering that accompanies it.

The narratives of patients revealed also the coexistence between positive experiences in a specific dimension such spirituality for example, and unpleasantness/suffering and challenging moments concerning experience of pain.

For patient n°5, non acceptance of pain ("we can no longer accept it, we no longer accept"), non acceptance of suffering (" That's the worst part. Pain is really the worst thing because you can't accept it. We don't accept it anymore. In any case, I don't accept it anymore."), regrets ("I didn't do well", "I regret not really expressing myself as I should have") coexist with values-intimate moment with others ("It's nice when you have people you like standing next to you, soothing you, that we can talk, that we can have a nice time."; "Chatting, exchanging, as they say remaking the world."), mind-body practices ("I massage myself. I try to press. After a while, it feels good. It's been coming for a long time. I've done martial arts and I've done a lot of courses on relaxation and all that stuff.

Relaxing, resting, emptying yourself, trying to take off, not being there anymore") and acceptance of the end of life ("What do I accept the most? That I am at the end. Not far from death but not suffering. I have suffered too much in my life", "I am coming to the last phase. I'm trying to get through it as best I can. "I can be very anxious (about death) but I have been through this stage").

For patient n° 9, the search for meaning ("Maybe it's reassuring to think that there is a force."), values/principles ("For me it's a set of values (kindness, love, tolerance) to live together. I try to instill these values in my children. »), nature connection ("I like to be in the garden because it is where there is air". "I am connected to the pavement while enjoying a beautiful landscape, a beautiful flower.") coexist with fear/anger of pain ("It annoys me" "I'm angry being surrendered, being blocked, not daring to force anymore"; "Dependence, dependence. That's what bothers me the most, it's always latent", "The pain is there, since it's there, you have to deal with it... But it's the consequence of the immobility that it engenders that is annoying".), negative emotions ("Well, I'm ashamed that I couldn't get over that pain..."); regrets ("All my life I've felt like a loser. I've never been self-satisfied. I've always thought that we can improve.").

For patient n°12, the loss of social role and social function of the body ("All my life I've tried to help others, so you reverse the machine. It's not easy to accept."), coexist with end-of-life questions ("If I could go like this it would be the greatest gift of my life. I think it's beautiful to be able to leave gently, with beautiful thoughts."), with intimate moments with others ("I feel understood and not judged because when they clean you, I can tell you the first time I was ashamed. You can get to know people quickly, chat with them, and recognize their faces. You feel safe. I thank them every time they come to clean the room for example. I admire their kindness (talks about the nursing staff)."), nature connection ("We are part of nature." "We are living only by others. We all need love, sweetness.").

For patient n° 11, the loss of social role and social function of the body ("I am no longer in my active professional life, I don't see the people I used to see, so since this illness we are a bit cut off from the world".), don't give a bad image of oneself ("I prefer to isolate myself, I don't feel like spreading myself with explanations. I'm not going to bother people with my stories") coexist with search for meaning ("There is life. Life from the smallest to the largest. How these birds fly in formation, how this tree grows. We don't know anything about it."), mind-body practices ("At night before I go to sleep, all I can think about is my breathing."), connection with nature ("She was always essential. It doesn't matter where I've been.", "Activities that are really in touch with the land.", "I'm lucky enough to be able to go out and walk, to walk around what's around me.").

For patient n°7, don't give a bad image of oneself ((Seeing people requires me to) "forget myself as I am now in order to remain more or less in what they know of what I was before", "Seeing people in bed, ugly, it doesn't smell good, it's not pleasant" "When I'm alone, even if I cry, it's like that, whereas when you have witnesses...".) coexists with positive emotions and intimate moments with others ("Lots of little positive, funny moments with the grandkids on the phone.").

And for patient n°14, the fear/anger of pain ("It reminds you constantly, without too many pauses", "The intrusion of the pain puts a needle in the bubble") coexists with positive emotion ("I come back to the same serenity, joy, confidence. That's really it. That's where I find myself again").

Discussion

Specific considerations regarding physical pain

Physical pain is defined by the International Association for the Study of Pain (IASP) as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." This definition highlights that physical pain is not just a sensory perception but also an emotional experience, emphasizing its broader nature and its frequent co-occurrence with psychological pain [44].

Cancer pain exhibits physiological characteristics: it manifests as both acute and chronic pain, often eliciting emotions such as depression, anxiety, fear, catastrophizing, uncertainty, and more generally, psychological distress, as evidenced by the interviews. According to Moorey and Greer [45], psychological distress contributes to maintaining pain through a vicious cycle, directing attention to physical sensations and leading to rumination, anxiety, muscle tension, and an increase in pain perception.

The rhythm of cancer pain, as described by the patients is particularly uncertain like noticed by Mehta and Chan [13], Gomes Ferraz et al. [16] or by Jespersen et al. [46] in their qualitative study about symptoms of total pain experienced by older people with advanced gastrointestinal cancer receiving palliative chemotherapy. The pain is linked to the disease state, treatments that may provoke painful side effects, and the type of pain experienced [16]. Referring to the model of breakthrough pain [47], patients experience unpredictable episodes of acute pain with intensity that could be paroxysmal in onset within a few minutes. These characteristics explain the reaction of fear and the feeling of being constantly on alert, as described by the interviewed patients.

Spiritual pain: an underexplored dimension of Total Pain

Regarding spiritual considerations, which may or may not include religious beliefs, research indicates that the pursuit of meaning, letting go, embracing the present moment, and fostering connections with oneself, others, nature, and a higher power (e.g., God), all play significant roles in pain management and the overall quality of life for patients [48]. However, a challenge remains in understanding what spirituality means for both patients and healthcare providers, as well as how to communicate effectively on this topic [40].

Edwards et al. [40] found that each patient has a unique definition of spirituality, distinct from those outlined in interview guides. Patients often differentiate between religion and spirituality which is expressed through various aspects of their lives, such as their relationship with nature, others, and God. Despite its personal nature, spirituality holds great importance for many patients. Spiritual suffering can be alleviated through compassionate and therapeutic communication between patients and healthcare professionals, leading to enhanced social, psychological, physical, and spiritual comfort [37].

In this qualitative study, our primary aim was to enrich the concept of Total Pain by incorporating the lived experiences of patients in palliative care across four dimensions. Interestingly, elements related to environmental pain (included in the social dimension of Total Pain in the interview guide) emerged as significant sources of suffering for patients. To address this, we propose the loss of connection with nature as an independent aspect of social or spiritual suffering, interconnected with the physical and psychological aspects of Total Pain. This is not simply a sub-dimension of the spiritual aspect of Total Pain. Recognized as a factor promoting well-being [24], the connection with nature and the environment emerged as spiritual and social resources that help patients navigate the challenges posed by their illness and hospitalization.

Interconnectedness between the four dimensions of Total Pain

It is important to note that while investigators categorized the different narratives to propose a coherent model, they observed during the process of data analysis process that subthemes could belong to multiple categories or themes (e.g., mind-body practices, connection with nature). These subthemes were so intertwined that classification was challenging. It reflects the interconnectedness between all dimensions of Total Pain and the impact of resources on different aspects of the lived experience. Therefore, addressing all dimensions in care for delivering the best possible palliative care.

From Total Pain to resources

Interviewers observed that, despite adversity, some people mobilize resources, and certain relational contexts (such as the interview setting) enabled them to express and become aware of these resources.

Despite facing Total Pain, some patients utilize psychological resources to better navigate adversity. Several studies indicate that meeting spiritual needs helps patients reduce psychological and physical distress while enhancing their quality of life [40]. Psychospiritual interventions, such as dignity therapy, are now being proposed to support patients through their end-of-life journey, though further research is needed to fully understand their effects [49].

This approach aligns closely with narrative medicine, a method that collects patients' stories and places them at the center of the care process to foster better understanding and support [50]. Moreover, patients often share very intimate aspects of their lives, such as memories and feelings, with strangers. Recognizing this dynamic is crucial for promoting the caregiver-patient relationship in palliative care.

When considering patients' resources, important questions arise: How can patients cultivate these resources and access them when they are unwell? How can caregivers promote these resources among patients? Furthermore, caregivers can engage in discussions about spirituality and how patients embody it to cope with their illness and find meaning amidst their struggles [30, 51].

The qualitative findings reveal a holistic approach to coping with Total Pain among patients in palliative care. They emphasize the interconnectedness of physical, social, psychological, and spiritual resources that patients use to navigate their experiences. From mindfulness practices to intimate connections with loved ones, patients draw upon diverse strategies to enhance their well-being amidst illness. These findings underscore the importance of a multidimensional understanding of patient care, highlighting the need for comprehensive support that addresses the entirety of patients' experiences in palliative settings.

Alternating pleasant and unpleasant experiences

Narratives vividly illustrate the coexistence between suffering and well-being in patients' experiences (e.g., pain versus enjoying the present moment). We also identified the broadening effect of pleasant experiences, such as focusing on environment and nature, which serve as protective resources and ways to live in the present. These resources promote mental health and are aligned with the Complete State Health Model of Westerhof and Keyes [29]. This model underscores the relevance of eliciting helpful, pleasant personal/ interpersonal experiences, which play a vital role in supportive care.

Several subthemes identified in our study are similar to those found in Rodriguez-Prat et al.'s study [42]. They explored control in patients with advanced cancer using an interpretative phenomenological analysis. Their findings highlighted the importance of empowerment, autonomy and perceived control in medical decisions, the environment, and general care, particularly in palliative care settings. They interpret control as a coping mechanism, both at a personal level (living at the present moment, adapting to disease stages, and accepting circumstances) and at an interpersonal level (through family, avoiding making others suffer, and not being a burden). Control is considered a multidimensional construct (physical, social, psychological, and spiritual), as we also identified. They emphasize that encouraging discussions about end-of-life concerns can provide patients a sense of control over their disease course [43]. In this sense, our interviews facilitated such discussions in an indirect manner, as patients spontaneously evoked end-of-life considerations.

As emphasized by Brant [11], educating healthcare workers about the concept of Total Pain is essential. This knowledge helps healthcare providers understand the complexity of end-of-life pain experiences, enabling them to move beyond a purely physical perspective. It's crucial for healthcare professionals to comprehend what the patient is truly experiencing.

Each dimension of multidimensional pain should be evaluated by a multidisciplinary team. This approach can uncover specific therapeutic needs, often requiring a combination of pharmacological and non-pharmacological treatments. However, achieving this comprehensive approach is challenging in today's increasingly specialized medical landscape, which sometimes leads to fragmented care [16].

Study limitations

There are three methodological limitations that should be acknowledged. First, the length of the interview guide: patients often experienced high levels of fatigue, which may have affected their cognitive and emotional availability to answer questions as the interview progressed. Secondly, the relationship between the interviewer and the patients: four patients were treated by the interviewer, who was a doctor, while the others did not have priori relationships with the interviewers. This difference in familiarity and trust with the interviewer may have influenced patients' willingness to confide and express intimate matters.

Third, the location of the oncology center and the oncology rehabilitation center may have influenced the connection to nature: these centers are located in a medium size town, with the oncology rehabilitation center situated in an area surrounded by nature. Most patients live in rural areas, so the sample may not be fully representative of the general population.

Additionally, the concept of Total Pain is influenced by the cultural context -in this case, French culture and the recent context of the Covid 19 pandemic. These factors may introduce biases that limit the generalizability of the results.

Lastly, due to the patients' specific medical conditions, there was no opportunity for participant feedback to confirm whether the data aligned with the researchers' interpretations. Furthermore, translating verbatim from French to English resulted in a loss of meaning for certain words or expressions that more accurately reflected the lived experiences of patients.

Conclusion

Through the lens of each individual's unique experiences-such as their personal definition of spirituality- and the shared experiences among patients, nurses, and caregivers, the challenge of addressing Total Pain becomes evident. Often, aspects of Total Pain are overlooked by medical professionals due to various constraints. Moreover, the concept of "Total Pain" typically receives limited direct focus in studies and lacks a robust evidence-based approach.

Addressing total pain necessitates clinicians to actively engage in exploring, understanding, and transforming their patients' experiences, thus recognizing the interconnectedness between individual experiences of pain, distress, and suffering. This study holds educational value, particularly for caregivers who play a crucial role in helping patients construct their worldview and relationships with others. Furthermore, the richness of positive experiences and resources expressed by several patients- despite the adversity they face- offers valuable insights for medical staff. These findings provide promising avenues for alleviating Total Pain and fostering resiliency in patients.

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Author contributions

Maya CORMAN, Michaël DAMBRUN and Katell MÉNARD have made the conception of the work. Angeline GINZAC was in charge of the administrative side of the project (declaration to the personal data protection committee, declaration to the authorities, compliance with recommendations). Maya CORMAN and Katell MÉNARD realized the interviews, collected the data. They did the analysis with Michaël DAMBRUN. All the authors have approved the submitted version.

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Data availability

The author confirms that all data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate

This study received approval from the Personal data Protection Committee of CPP SUD EST 1 (National number: 2019-A02263-54) which examined the study protocol, the consent form signed by the patient to take part in the study and compliance with European legislation so as to guarantee patient's rights protection. All participants in the study signed a consent form to participate in the interview.

Consent for publication

Not applicable. All patient's data respected anonymity.

Competing interests

The authors declare no competing interests.

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References

1. World Health Organization. National cancer control programs: policies and managerial guidelines. World Health Organization; 2002.
2. Saunders CM. The care of the terminal stages of cancer. Ann R Coll Surg Engl. 1967;41:162–9.
3. Wood J Cicely Saunders "Total pain" and emotional evidence at the end of life. Med Humanit. 2022;48(4):411–20.
4. Krawczyk M, Wood J, Clark D. Total pain: Origins, current practice, and future directions. Norwegian J Palliat Care. 2018; 2018:2.
5. Rome RB, Luminais HH, Bourgeois DA, Blais CM. The role of palliative care at the end of life. Ochsner J. 2011;11(4):348–52.
6. Shapiro CL. Cancer survivorship. N Engl J Med. 2018;379(25):2438–50.
7. Bauman JR, Temel JS. The integration of early palliative care with oncology care: the time has come for a new tradition. J Natl Compr Canc Netw. 2014;12(12):1763–71.
8. Wood H, Dickman A, Star A, Boland JW. Updates in palliative care–overview and recent advancements in the Pharmacological management of cancer pain. Clin Med. 2018;18(1):17–22.
9. Kamal AH, Bull J, Kavalieratos D, Taylor DH Jr, Downey W, Abernethy AP. Palliative care needs of patients with cancer living in the community. J Oncol Pract. 2011;7(6):382–8.
10. Evans Webb M, Murray E, Younger ZW, Goodfellow H, Ross J. The supportive care needs of cancer patients: a systematic review. J Cancer Educ. 2021;36(5):899–908
11. Brant JM. Holistic total pain management in palliative care: cultural and global considerations. Palliat Med Hosp Care. 2017;1:32–8.
12. Monette EM. Cultural considerations in palliative care provision: a scoping review of Canadian literature. Palliat Med Rep. 2021;2(1):146–56.
13. Mehta A, Cohen SR, Chan LS. Palliative care: a need for a family systems approach. Palliat Support Care. 2009;7(2):235–43.
14. Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, Smith TJ. Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. J Clin Oncol. 2017;35(1):96–112.
15. Wakefield D, Bayly J, Selman LE, Firth AM, Higginson IJ, Murtagh FE. Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: a systematic review using critical interpretive synthesis. Palliat Med. 2018;32(8):1288–304.
16. Gomes-Ferraz CA, Rezende G, Fagundes AA, De Carlo MMRDP. Assessment of total pain in people in oncologic palliative care: integrative literature review. Palliat Care Soc Pract. 2022;16:1–12.
17. Lazarus RS, Folkman S. Stress, appraisal, and coping. Springer publishing company.1984.
18. Greer JA, Applebaum AJ, Jacobsen JC, Temel JS, Jackson VA. Understanding and addressing the role of coping in palliative care for patients with advanced cancer. J Clin Oncol. 2020;38(9):915–25.
19. Gryschek G, Machado DDA, Otuyama LJ, Goodwin C, Lima M. C. P. Spiritual coping and psychological symptoms as the end approaches: a closer look on ambulatory palliative care patients. Psychol Health Med. 2020;25(4):426–33.
20. Balboni TA, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI,… Steinhauser KE. State of the science of spirituality and palliative care research part II: screening,assessment, and interventions. J Pain Symptom Management. 2017; 54(3): 441–453.
21. Karlsson M, Friberg F, Wallengren C, Öhlén J. Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. BMC Palliat Care. 2014;13(1):1–9.
22. Fredrickson BL. The role of positive emotions in positive psychology: the broaden-and-build theory of positive emotions. Am Psychol. 2001;56(3):218.
23. Garland EL, Thielking P, Thomas EA, Coombs M, White S, Lombardi J, Beck A. Linking dispositional mindfulness and positive psychological processes in cancer survivorship: a multivariate path analytic test of the mindfulness-to-meaning theory. Psycho Oncol. 2017;26(5):686–92.
24. Pritchard A, Richardson M, Sheffield D, McEwan K. The relationship between nature connectedness and Eudaimonic well-being: A meta-analysis. J Happiness Stud. 2020;21(3):1145–67.
25. Lau J, Khoo AMG, Ho AHY, Tan KK. Psychological resilience among palliative patients with advanced cancer: A systematic review of definitions and associated factors. Psycho-oncology. 2021;30(7):1029–40.
26. MacArtney JI, Broom A, Kirby E, Good P, Wootton J, Yates PM, Adams J. On resilience and acceptance in the transition to palliative care at the end of life. Health. 2015;19(3):263–79.
27. Somasundaram RO, Devamani K. A. A comparative study on resilience, perceived social support and hopelessness among cancer patients treated with curative and palliative care. Indian J Palliat Care. 2016;22(2):135.
28. Windle G. What is resilience? A review and concept analysis. Reviews Clin Gerontol. 2011;21(2):152–69.
29. Westerhof GJ, Keyes CL. Mental illness and mental health: the two continua model across the lifespan. J Adult Dev. 2010;17:110–9.
30. Bernard M, Arantzamendi M. Positive psychology and palliative care: A call for an integrative approach. Palliat Support Care. 2024;22(5):871–3.
31. Stewart KA. The spiritual framework of coping through the voices of cancer survivor narratives. OMEGA-Journal Death Dying. 2011;63(1):45–77.
32. Althaus B, Borasio GD, Bernard M. Gratitude at the end of life: a promising lead for palliative care. J Palliat Med. 2018;21(11):1566–72.
33. Daneault S, Azri M, Ummel D, Vinit F, Côté A, Leclerc-Loiselle J,… Gendron S. Non-somatic suffering in palliative care: A qualitative study on patients' perspectives. J Palliat Care. 2022; 37(4): 518–525.
34. Wilson KG, Chochinov HM, McPherson CJ, LeMay K, Allard P, Chary S,… Fainsinger RL.Suffering with advanced cancer. J Clin Oncol. 2007; 25(13): 1691–1697.
35. Navarro O, Olivos Jara P, Tapias-Fonllem C. (2021). Environnement et spiritualité: réflexions autour de la connexion à la nature et le bien-être. Roussiau N, éditeurs. Psychologie et spiritualité: Fondements, concepts et applications. Paris: Dunod. 2021. pp. 171–184.
36. Chao CSC, Chen CH, Yen M. The essence of spirituality of terminally ill patients. J Nurs Res. 2002;10(4):237–45.
37. Rego F, Rego G, Nunes R. The psychological and spiritual dimensions of palliative care: a descriptive systematic review. Neuropsychiatry. 2018;8(2):484–94.
38. Antoine P, Smith JA. Saisir l'expérience: présentation de L'analyse phénoménologique interprétative comme méthodologie qualitative En psychologie. Psychol Française. 2017;62(4):373–85.
39. Santiago-Delfosse M, Chamberlain K. Évolution des idées En psychologie de La Santé Dans Le Monde anglo-saxon. De La psychologie de La Santé (health psychology) à La psychologie critique de La Santé (critical health psychology). Psychologie Française. 2008;53(2):195–210.
40. Edwards A, Pang N, Shiu V, Chan C. The Understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliat Med. 2010;24(8):753–70.
41. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
42. Rodríguez-Prat A, Pergolizzi D, Crespo I, Balaguer A, Porta-Sales J, Monforte-Royo C. Control in patients with advanced cancer: an interpretative phenomenological study. BMC Palliat Care. 2022;21(1):97.
43. Volker DL. Patient control and end-of-life care part II: the patient perspective. Number 5/2004, 31(5): 954–60.

44. Laird BJ, Boyd AC, Colvin LA, Fallon MT. Are cancer pain and depression interdependent? A systematic review. J Psychol Soc Behav Dimens Cancer. 2009;18(5):459–64.
45. Moorey S, Greer S. Cognitive behaviour therapy for people with cancer. Oxford University Press; 2002. pp. 3–24.
46. Jespersen E, Minet LR, Nissen N. Symptoms of total pain experienced by older people with advanced Gastrointestinal cancer receiving palliative chemotherapy. Eur J Cancer Care. 2022; 31(6), e13674.
47. Portenoy RK, Hagen NA. Breakthrough pain: definition, prevalence and characteristics. Pain. 1990;41(3):273–81.
48. Lin HR, Bauer-Wu SM. Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. J Adv Nurs. 2003;44(1):69–80.
49. Zheng R, Guo Q, Chen Z, Zeng Y. Dignity therapy, psycho-spiritual well-being and quality of life in the terminally ill: systematic review and meta-analysis. BMJ Support Palliat Care. 2021;13:263–73.
50. Charon R. Narrative medicine. Oxford University Press; 2006.
51. Ebenau A, Groot M, Visser A, van Laarhoven HW, Van Leeuwen R, Garssen B. Spiritual care by nurses in curative oncology: a mixed-method study on patients' perspectives and experiences. Scand J Caring Sci. 2020;34(1):96–107.

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