

## Original Article

**Cite this article:** Trevizan FB, Paiva CE, de Almeida LF, Zimmermann C, Bruera E, Paiva BSR (2024) Exploring patient awareness of palliative care - optimal timing and preferred approaches. *Palliative and Supportive Care*, 1–11. <https://doi.org/10.1017/S1478951524001081>

Received: 16 February 2024

Revised: 10 May 2024

Accepted: 27 May 2024

**Keywords:**



Palliative care; cancer patients; awareness; optimal timing; communication strategies



**Corresponding author:**

Bianca Sakamoto Ribeiro Paiva;  
Email: [bsrpaiva@gmail.com](mailto:bsrpaiva@gmail.com)

# Exploring patient awareness of palliative care - optimal timing and preferred approaches

Fulvio Bergamo Trevizan, <sup>1</sup> , Carlos Eduardo Paiva, <sup>1</sup> ,

Laura Fiacadori de Almeida, <sup>1</sup> , Camila Zimmermann, <sup>2</sup> ,

Eduardo Bruera, <sup>3</sup> , and Bianca Sakamoto Ribeiro Paiva, <sup>1</sup> 

<sup>1</sup>Institute of Education and Research, GPQual - Research Group on Palliative Care and Quality of Life - Barretos Cancer Hospital, Barretos, SP Brazil; <sup>2</sup>Department of Supportive Care (C.Z.), Princess Margaret Cancer Centre, University Health Network, Toronto, ON, Canada and <sup>3</sup>Department of Palliative Care, Rehabilitation and Integrative Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX USA

**Abstract**

**Objectives.** To explore patients' awareness levels of palliative care (PC) and how this awareness shapes their preferences regarding the timing and approach for discussing it.

**Methods.** The study, conducted at a prominent institution specializing in oncology care, enrolled women aged 18–75 years who had been diagnosed with breast cancer. Patients completed guiding questions: Do you know what PC is?, When is the most appropriate time and the most appropriate way to discuss PC?. The interviews were conducted exclusively via video call and were recorded, transcribed, and then deleted.

**Results.** The study involved 61 participants, averaging 49 years old. Almost half (47.5%) had completed high school. Qualitative data analysis revealed 9 thematic categories. Regarding the first question, 2 divergent categories emerged: care for life and threatening treatment. For the second question, opinions diverged into 4 categories: At an early stage, mid-course of the disease, as late as possible, and no time at all. For the third question, 3 categories emerged: communication and support, care setting and environment, and improving the PC experience.

**Significance of Results.** This study reveals diverse perspectives on patients' awareness and preferences for discussing PC, challenging the misconception that it's only for end-of-life (EOL) situations. Comprehending PC influences when and how patients discuss it. If tied solely to EOL scenarios, discussions may be delayed. Conversely, understanding its role in enhancing advance support encourages earlier conversations. Limited awareness might delay talks, while informed patients actively contribute to shared decision-making. Some patients preferred early involvement, others find mid-treatment discussions stress-relieving. Community support, quiet environments, and accessible resources, underscoring the importance of a calm, empathetic approach, emphasizing the importance of understanding its role in advance support and providing valuable implications for enhancing patient care practices, theories, and policies.

**Introduction**

Currently, the scientific literature explores palliative care (PC) protocols and strategies, with established ones to be tested or validated. Structured interventions aimed at improving communication and support for end-of-life (EOL) care preferences in metastatic breast cancer patients encompass symptom management, coping strategies, and treatment decision-making. Findings demonstrate enhanced documentation of EOL care discussions in electronic health records and positive patient-reported outcomes in quality of life, anxiety, depression, and hospice utilization. Additionally, the studies offer a comprehensive review of psychological interventions for cancer patients, classifying them into cognitive-behavioral, mindfulness, and relaxation techniques (Greer et al. 2022; Semenenko et al. 2023).

Notably, approaching cancer patients for discussions and interventions often faces high rates of refusal, denial, fear, and sadness (Gontijo et al. 2023; Trevizan et al. 2023). This raises critical questions: Are cancer patients prepared for PC discussions? Do they grasp its nature? Furthermore, when is the appropriate time, and what would be their preferred mode of discussion? This brings up a broader concern about whether clinical efforts are genuinely attuned to the voices of these patients and aligned with their preferences.

© The Author(s), 2024. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

PC stands as a multifaceted approach to care that transcends the mere management of symptoms associated with serious illnesses (Back 2020; Radbrunch *et al.* 2020). Beyond symptom control, it encompasses discussions on quality of life, patient values, and the alleviation of physical, emotional, and spiritual distress. Importantly, these discussions extend beyond EOL scenarios, weaving through the entire trajectory of a life-threatening illness (Radbruch *et al.* 2020; Strang 2022). A delicate balance is struck in PC conversations, requiring acknowledgment of the challenging diagnosis's reality while fostering hope through support and comfort. This dynamic process necessitates a nuanced understanding of patient needs, cultural sensitivities, and effective communication strategies (Back 2020; Kuosmanen *et al.* 2021; Saretta *et al.* 2022). In cancer care, early PC is pivotal, and research confirms that its initiation at diagnosis improves symptom control and enhances patient and caregiver outcomes (Gofton *et al.* 2022; Temel *et al.* 2022).

Despite evident benefits, PC faces taboos and stigmas that may originate from patients, family caregivers, and/or health professional (Santos Neto *et al.* 2014). Denial and resistance to PC discussions may stem from misconceptions, equating it solely with EOL care (Saretta *et al.* 2022). These taboos arise from a lack of knowledge about its scope, often coupled with the misconceived notion that it implies relinquishing curative treatment (Bandieri *et al.* 2023). Preserving patient autonomy and enhancing acceptance hinge on healthcare professionals' ability to discern when and how to broach PC discussions. A fundamental aspect involves understanding the patient's perspective and actively listening to their concerns. Dismissing misconceptions, disseminating precise information, and selecting opportune moments for dialogue play a crucial role in diminishing resistance, alleviating stigmas, and, consequently, enhancing patient acceptance of early referral to PC (Bandieri *et al.* 2023).

In this context, hearing what the patient has to say is fundamental. Giving them space to acknowledge and validate their wishes, emotions, fears, and preferences promotes trust and facilitates more meaningful conversations. This approach not only contributes to improving patient outcomes but also initiates a paradigm shift in the perception and acceptance of PC (Greer *et al.* 2022). Thus, the study aimed to explore patients' awareness levels of PC and how this awareness shapes their preferences regarding the timing and approach for discussing it.

## Methods

### Study design

This is a qualitative descriptive study, which constitutes the second phase of an investigation. The first phase, involving quantitative data, has already been published (Trevizan *et al.* 2023). The qualitative aspect of this study entails a content analysis based on responses to 3 guiding questions.

### Participants

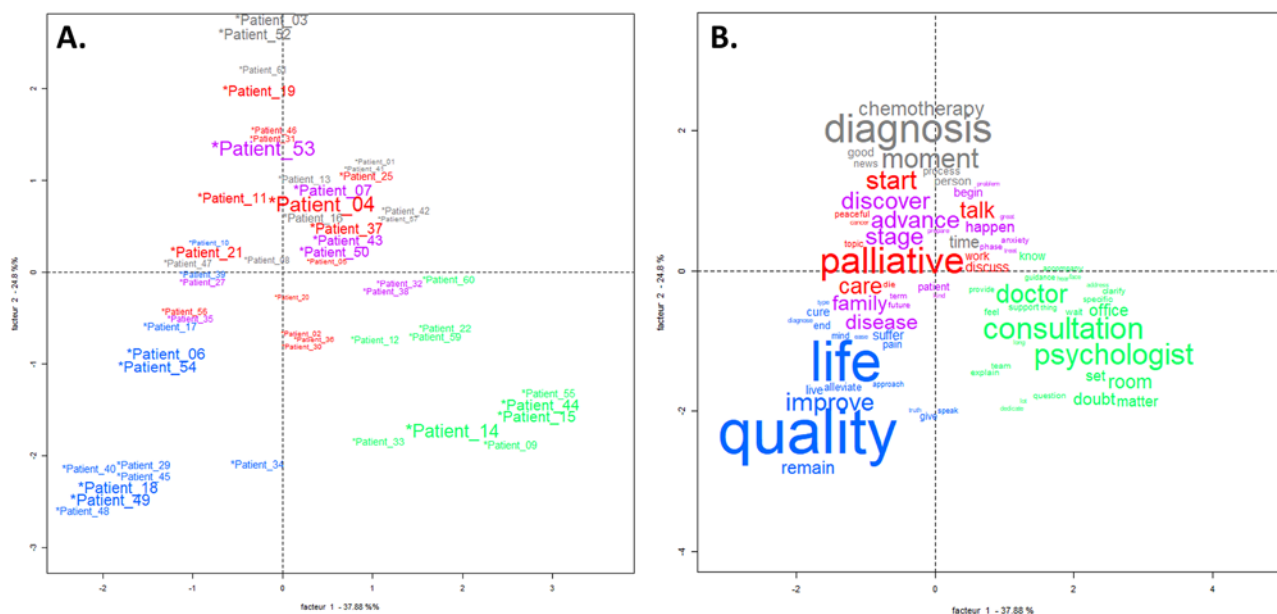
All patients were recruited from the Women's Outpatient Clinic and the Chemotherapy Infusion Center of a Brazilian hospital, which stands as one of the largest cancer treatment centers in Latin America, and adhered to all predetermined eligibility criteria. The study included females diagnosed with breast cancer, aged between 18 and 75 years, who were aware of their cancer diagnosis and undergoing treatment, with an Eastern Cooperative Oncologic

**Table 1.** Sociodemographic and clinical characteristics of the patients ( $N = 61$ )

Patients characteristics	Mean	SD
Age (years)	49.52	(8.67)
Time from diagnosis (months)	35.14	(41.81)
	<b>N</b>	<b>(%)</b>
<b>Marital status</b>		
Living as married	48	(78.7)
Does not live as married	13	(21.3)
<b>Religion</b>		
Catholic	37	(60.7)
Evangelic	13	(21.3)
Spiritist Kardecist	7	(11.5)
Other/without	4	(6.6)
<b>Educational level</b>		
Up to elementary school inc.	8	(13.1)
Elementary school comp. or inc.	3	(4.9)
High school complete	29	(47.5)
Higher education	21	(34.4)
<b>School-based time (years)</b>		
0–6	5	(8.2)
7–9	7	(11.5)
10–12	26	(42.6)
≥13	23	(37.7)
<b>ECOG-PS</b>		
0	23	(37.7)
1	30	(49.2)
2	8	(13.1)
<b>Metastasis</b>		
No	32	(52.5)
Yes	29	(47.5)
<b>Cancer staging (TNM)</b>		
Stage I	2	(3.3)
Stage II	13	(21.3)
Stage III	18	(29.3)
Stage IV	28	(45.9)
<b>Treatment</b>		
Adjuvant	15	(24.6)
Neoadjuvant	10	(16.4)
Systemic palliative	36	(59.0)

**Notes:** SD: standard deviation; *N*: number of participants; (%): percentage; ECOG-PS: Eastern Cooperative Oncology Group Performance Status.

Group Performance Status (ECOG-PS) of  $\leq 2$ . Exclusion criteria applied to individuals encountering challenges in establishing online video call connections or exhibiting significant deficits in auditory, visual, or verbal language skills. Participants were briefed on the purpose of the study and understood it. Ethical approval



**Figure 1.** Analysis of classification, occurrence and relationships of terms present in patients' discourses and the interrelationship of terms. The proximity of lines indicates similarities, suggesting shared terms within the same speech, while greater distance signifies dispersed and isolated terms within speeches. Note: Software: Iramuteq. (A.) Representation of the relationships between discourses per patient; (B.) Representation of the relationships between terms and their respective occurrences.

had been granted, and participants reviewed the study information documentation before providing their written informed consent to be involved.

### Data collection and analysis

Approximately seven to 14 days before the interviews, patients received an educational leaflet developed by the researchers. The material included technical and illustrated information about PC, covering topics such as "What is PC?," "Who is PC for?," and "Why is PC important?" The goal of this instructional material was to convey essential knowledge and reduce potential response bias associated with questions about "how" and "when." Furthermore, for patients who agreed to participate, semi-structured interviews were conducted by the primary author (FBT), a male clinical psychologist, master in health psychology, with extensive experience. After completing a sociodemographic and clinical questionnaire, participants engaged in three guiding inquiries: (1) *Are you familiar with the concepts of PC? What is PC all about?;* (2) *When do you think is the optimal timing for discussions regarding PC?;* and (3) *What approaches do you find most suitable for addressing PC?.*

These interviews were exclusively conducted via video conferencing and carefully recorded. LFDa transcribed the interviews in full, and the transcripts were independently verified by FBT and BSRP, representing a multistep approach to ensure accuracy. FBT and LFDa independently performed a floating reading to separate the main speeches and eliminate excessive information. Following that, under the oversight of another researcher (BSRP), a peer review process was conducted until a consensus was established.

Qualitative data analysis was conducted using Bardin's discourse analysis method, a qualitative research approach designed to systematically analyze language use in social contexts. The 3 main steps of the method included pre-analysis, where the researcher familiarized themselves with the data; analysis, involving breaking down the data into smaller units and identifying

themes; and interpretation, drawing conclusions about the meaning of the data (Bardin 2016).

The analysis involved gathering, organizing, and preparing fully transcribed speeches to identify patterns, themes, categories, and meanings. Analysis units were selected, and a coding system was created to represent themes or concepts. Codes, concise phrases encapsulating pertinent content elements, were then grouped into clusters. An analysis of similarities and relationships among clusters followed. After the formation of clusters, the coding process began, and the complete speeches were revisited, leading to the emergence of thematic categories and subcategories. During this step, the clusters were carefully examined, and when extracts matching the categories were encountered, the respective codes were assigned. As the codes were categorized and organized into broader groups, it became possible to discern trends and patterns.

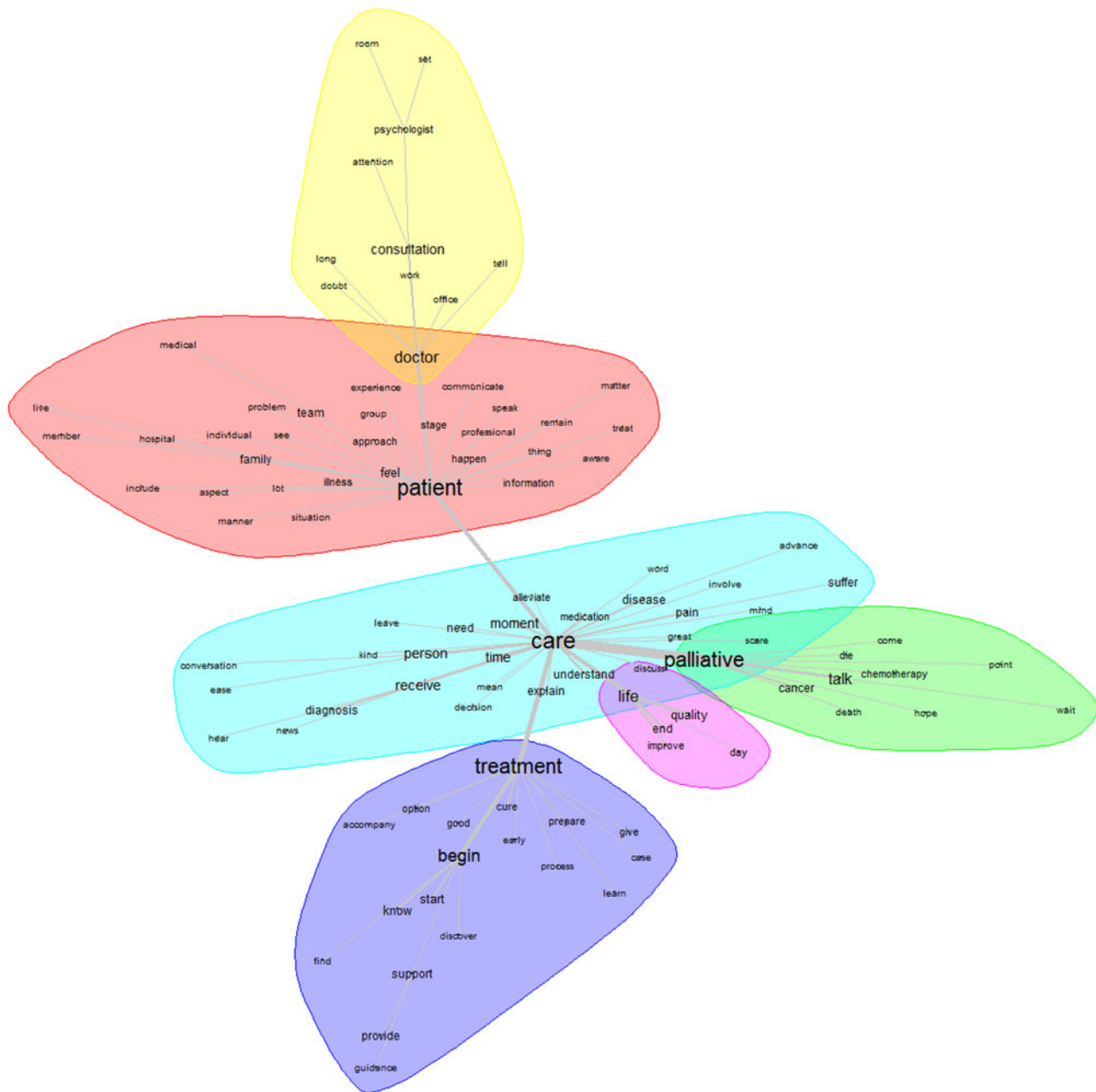
The qualitative data was analyzed using *Iramuteq 0.7 software*. The qualitative method followed the *Consolidated Criteria for Qualitative Research Reports* (Tong et al. 2007). All study processes were approved by the Ethics and Research Committee of the Barretos Cancer Hospital, under registration number 4.987.629.

### Results

In this study, 61 patients were included. Table 1 shows the sociodemographic and clinical characteristics of the patients.

The interviews conducted for the study totaled a duration of 8 hours and 38 minutes, with an average duration of approximately 9 minutes per interview. Figure 1 visually presents the discourse frequency graph, illustrating the grouping and similarity of patients' speeches. These graphs also demonstrate the clustering of patients based on similarities in their discourse.

Figure 2 presents a network representation of term similarities. Clusters of nodes depict groups of related terms, offering insights into dominant themes and their interconnections.



**Figure 2.** Analysis of similarities and relationships between patients' narrative variables. The size of nodes corresponds to term frequency, and the line thickness indicates the strength of associations.

Note: Software: Iramuteq.

Figure 3 provides a comprehensive overview of patients' responses systematically categorized based on 3 key questions, resulting in the identification of 9 main categories and a total of 28 subcategories.

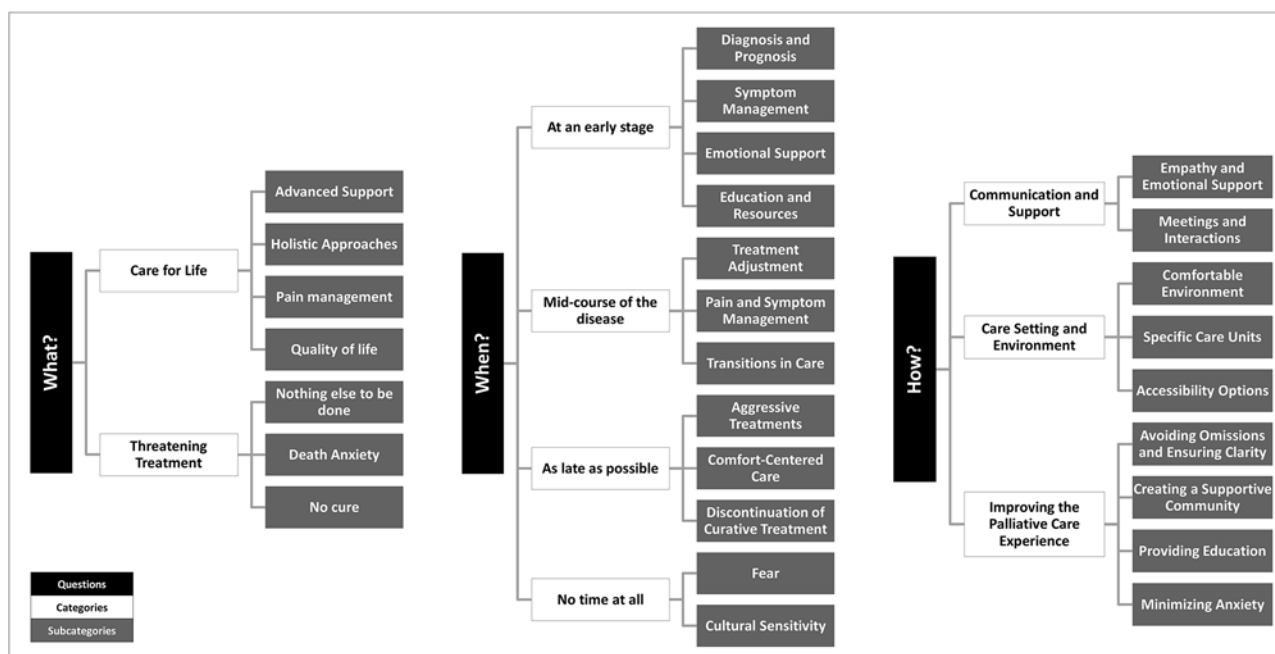
When examining patients' perspectives on PC, the answers obtained in the first question were categorized into themes, resulting in 2 main categories and 7 subcategories, as depicted in Table 2.

Table 4 offers insights into patients' preferred approaches for addressing PC. With 3 categories and 9 subcategories, these diverse perspectives underscore the need for patient-centered and adaptable approaches, considering elements such as emotional

support, comfortable environments, accessibility options, clear communication, and education to enhance the PC experience.

Table 3 presents patients' views on the optimal timing for PC discussions, with responses categorized into 3 primary categories comprising 12 distinct subcategories. This elucidates the nuanced considerations surrounding when to initiate PC discussions, emphasizing the importance of individualized approaches considering emotional states, treatment progress, and cultural factors.

Word clouds, generated from analyzed data, encapsulate patients' insights into the definition, timing, and approach of PC (Fig. 4). Patients perceived PC as providing emotional support,



**Figure 3.** Graphic description of the questions, categories, and subcategories based on the participants' statements.

pain relief, symptom management, and EOL planning, though some mistakenly believed it was only for those with no cure. Patients expressed a preference for early PC discussions, ideally at diagnosis or treatment initiation. Additionally, they emphasized the importance of clear, empathetic communication and often preferred clinic settings with prepared medical and psychological teams.

## Discussion

This study explored patients' awareness of PC, examining optimal timing and preferred approaches. Awareness of PC influenced how and when patients found it appropriate to discuss. Patients' perception of PC shaped their preferences in timing and approach. While associating PC with EOL may have hindered discussions, a clear awareness of PC may have stimulated earlier consideration, addressing patient goals and preferences while active participation was feasible. However, misconceptions created reluctance in some patients; nonetheless, informed individuals actively sought conversations, expressing preferences for information delivery. Shifting perception from PC as a transition from curative to supportive care fostered willingness for holistic discussions (Trevizan et al. 2023).

In this dataset, the educational background of patients was relevant, with 47.5% having completed high school, impacting their ability to interpret and comprehend health information (Chen et al. 2022). Education shapes awareness of diagnosis and prognosis, influencing health literacy and patient engagement in PC discussions (Kuosmanen et al. 2021).

When defining PC, patients viewed it as lifelong care and holistic support throughout serious illnesses (Back 2020; Wantonoro, 2022). They valued PC's advanced support, which integrates psychological and physical aspects, reflecting holistic well-being (Rego and Nunes 2019). For some patients, PC was seen as beyond conventional medical approaches (Rego and Nunes 2019; Semenenko et al. 2023; Wake 2022). For patients facing incurable

conditions, PC was essential for attentive monitoring and to prevent unnecessary suffering (Andriastuti et al. 2022; Chung et al. 2022).

Contrarily, some patients held fears and stigmas about PC (Semenenko et al. 2023). Data revealed emotional challenges associated with limited treatment options and EOL considerations. Patients linked PC with advanced disease stages, expressing sadness and viewing it as a difficult transition (Emanuel et al. 2023). This balance addressed the limitations of medical interventions and existential concerns during life-threatening stages (Bennardi et al. 2020). Anxiety and vulnerability arose from the perception that PC was only for those actively dying (Greer et al. 2022; Ivey and Johnston 2022).

"Nothing more to be done," "No cure," and "Death anxiety" were closely linked subcategories (Emanuel et al. 2023; Martí-García et al. 2023; Pătru et al. 2014). Patients felt sadness, viewing PC as a sign that conventional treatments were exhausted. PC was seen as daunting, marking a challenging disease transition when conventional resources were depleted (Greer et al. 2022). Patients struggled to connect PC with alleviating death-related anxieties, intensifying anxieties due to the perceived proximity to death (Beng et al. 2022; Emanuel et al. 2023).

While some patients associated PC with EOL, others emphasized early PC discussions (Gofton et al. 2022; Kuosmanen et al. 2021; Temel et al. 2022). Timing perspectives were influenced by emotional state and treatment progression (Murray et al. 2005; Pedrini Cruz 2022). Some suggested early discussions aligning with chemotherapy initiation, balancing information needs with potential distress (Gofton et al. 2022), while others found presenting this information during diagnosis disruptive (Gofton et al. 2022; Kida et al. 2021).

*I believe that when doctors begin chemotherapy treatment, because if you receive this information earlier, when you are still in the process of exams, you become very afraid. Oncology patients often focus a lot on chemotherapy. (P.006)*

**Table 2.** Are you familiar with the concepts of PC? What PC is all about?

Category 1. Care for life	
Subcategories	Corresponding discourses
<b>Advanced support</b>	PC is all guidance on treatment and how the course that you will go through will be, from the moment you found out about the diagnosis until the cure [pause] or not. (P.008)
	They accompany patients from the start of treatment until the end. [...] It would be a support in all phases, from the discovery of the disease. (P.012)
<b>Holistic approaches</b>	Everything you need outside of medicine [...], like psychology. (P.003)
	It's something that may help more in the psychological aspect of the patient: sadness, anxiety, expectations [...] in the relationship with family members in a situation of illness. (P.053)
	It's care we receive when the disease is in an advanced stage and we need comfort, psychological assistance, and treatment to alleviate pain or any other problem. (P.057)
<b>Pain management</b>	These are the care offered to patients so that they can feel better in relation to pain [...]. For me, it is the treatments that help the patient have a more peaceful life in relation to the disease. (P.018)
	Would be the medications used, for example, to ease pain, suffering, and prolong the person's quality of life. (P.008)
	It alleviates symptoms that you feel such as nausea, pain and other side effects. (P.002)
<b>Quality of life</b>	If there is no cure, at least improve the quality of life. (P.008)
	PC is a way to approach treatment in a less stressful manner. It doesn't mean that you're dying, but rather that you'll have a better quality of life. (P.034)
	Palliative treatment is intended so that I can have a dignified treatment, without pain or suffering, receiving the right medications. [...] PC aims to provide a good quality of life. (P.056)
Category 2. Threatening treatment	
Subcategories	Corresponding discourses
<b>Nothing else to be done</b>	PC is a more specialized care when there are no more resources, there is nothing left to do. Although the doctor may try different types of treatment, it's the stage when there's no way out. (P.031)
	PC would be when there's nothing more to do. Then some medicine or some treatment would be given to the patient ... [pause] so that he may have a peaceful departure. (P.010)
	PC is when there is nothing more to do. It's necessary to keep caring until the moment comes to depart. (P.025)
<b>Death anxiety</b>	From what I understand, PC is the beginning of an end. (P.037)
	[Long Pause] Usually, when palliative treatment is mentioned, people think: "I'm going to die ...," there is no other option. (P.021)
	It relieves anxiety and sadness. Palliative treatment reminds us of death and that it's coming closer. (P.050)
<b>No cure</b>	It is when a patient has already sought all possible treatments for their illness, but has reached a point where there is no cure, so they remain under care to prolong their life. (P.017)
	PC is intended for patients without hope of a cure. (P.049)
	It is a treatment that has no cure. The doctor told me that it's a palliative treatment, that there's no cure anymore. (P.09)

**Notes:** P.: patient's id; "..." indicates incomplete sentence on the part of the participant; [...] indicates part of the interview omitted by the authors for conciseness.

Patients may delay PC discussions until the disease significantly advances, influenced by fear of death, cultural taboos, and aggressive treatments (Abel and Kellehear 2022; Santos Neto *et al.* 2014). During this period, they may be more open to discussing symptom management and EOL considerations (Mathews *et al.* 2021), but early discussions may evoke emotional implications and worries (Rhondali *et al.* 2013).

Some patients found it challenging to identify the right time for PC discussions due to time constraints or cultural inappropriateness (Emanuel *et al.* 2023). These individuals feared such discussions because of their negative connotations related to worsening health, ineffective treatments, and impending death (Bandieri *et al.* 2023; Ivey and Johnston 2022; Rhondali *et al.* 2013; Dalal *et al.* 2011). Balancing the optimal timing for PC with patients'

preferences, cultural sensitivities, and individual readiness proved challenging.

When it comes to strategies for engaging in PC conversations, patients stressed the importance of personalized, multidisciplinary approaches, emphasizing clear, gentle, and direct communication from doctors (Chen *et al.* 2022; Rothschild *et al.* 2022).

*There shouldn't be too much beating around the bush; it's important to be straightforward, yet gentle and direct. You will find a way to ensure we don't suffer. (P.010)*

Patients favored calm settings, such as clinic rooms with psychologists, for PC discussions (Kuusmanen *et al.* 2021). This setting was seen as conducive to addressing difficult topics (Greer *et al.* 2022).

**Table 3.** When would you consider the optimal timing for discussions regarding PC?

<b>Category 3. At an early stage</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Diagnosis and prognosis</b>	Right from the beginning, [...] I think they should talk to us, and tell us how the patient's condition is. (P.014)
	In the beginning, as a prevention measure even. Because the patient will have a more open mind to receive all the information, to better understand their illness, diagnosis. (P.030)
	From the moment you enter the doctor's office and receive the diagnosis. Everything at the first time. (P.054)
<b>Symptom management</b>	From the beginning, since the first day. Received the diagnosis, has a cancer, could already be advised: "[...] there is treatment, it's strong, aggressive, but there are also palliative treatments that will alleviate it in one way or another." (P.034)
	The best time is at the beginning when the patient finds out they have cancer. You can start talking about it and do a more detailed investigation of the body. (P.005)
	As soon as we receive the diagnosis, it would be good to talk about PC because there is so much information that comes at once ... We don't think that there is a treatment. (P.013)
<b>Emotional support</b>	[...] From the beginning ... [...] We needed this support, to talk and accompany through this phase. We feel "lost." (P.012)
	I think the best time is from the moment you receive the news that you are sick. It is very important for our emotional well-being to have the opportunity to talk and explain to us what PC is. (P.016)
	From the moment the biopsy is done and cancer is diagnosed. I think PC would come in there, at least in terms of psychological support, because it can be emotionally devastating. (P.048)
<b>Education and resources</b>	When we start chemotherapy for the first time, it would be great if you explain everything to us. Hearing about PC during my first time receiving chemotherapy was interesting. (P.001)
	I could have been guided at the beginning and made other decisions in my life. When the time comes, they won't feel as shocked. They won't be afraid to die. (P.004)
	From the beginning, I always fought ..., but if I had known, if I had had this information and understanding of PC, if I had these orientations, it would have been less difficult, less painful. (P.011)
<b>Category 4. Mid-course of the disease</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Treatment adjustment</b>	I don't think there is a specific time. Any moment, as long as you have started treatment, all the time is valid. (P.026)
	I'm not saying the very first moment because many people get very desperate when they understand they're sick. As soon as possible, as soon as the news is given and treatment begins. (P.057)
<b>Pain and symptom management</b>	When someone arrives, it is not the right time to talk about PC. It will scare them and they are already scared. And after they receive some attention, then I think it's the right time. There is no perfect timing, it depends on the person, on their emotional state at that moment. (P.019)
<b>Transitions in care</b>	The moment when the doctor thinks they need to start PC. When there is no more options left, and medication needs to be taken. That's the moment. (P.036)
	At the moment when you switch to that treatment. We have doubts, not knowing how long we will be treated or how it will be treated. (P.044)
	I think it should be at the time of making a decision. For example, I need to talk to my doctor about my chemotherapy. (P.045)
<b>Category 5. As late as possible</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Aggressive treatments</b>	When the patient was hospitalized, full of tubes and needles. [...] At this moment, the patient would say: "give me medicine so that I don't feel pain." Nobody wants to feel pain, nobody wants to suffer, but there are times when you have to suffer. You can't make an omelet without breaking eggs, sometimes you will have to suffer. But, this is the moment to talk about it. (P.010)
<b>Comfort-centered care</b>	When she is already declining, start preparing her. The medical team comes to talk, ease her mind. Give her more encouragement so that she can live her last days peacefully. (P.029)
<b>Discontinuation of curative treatment</b>	The moment when chemotherapy is not helping. I think it's the best time for the doctor to talk to the patient. (P.042)
	I think it's when [the patient] is in a situation where there's nothing left to do, or their emotional state is very shaken. When they can't handle it anymore. (P.059)
<b>Category 6. No time at all</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Fear</b>	[...] There are patients who may not want to listen and become scared. They may think that something is not working well because "palliative" sounds scary. (P.002)

(Continued)

**Table 3.** (Continued.)

	In the beginning, we feel lost, without expectations of successful treatment, afraid of everything, scared of tests. When they talk about palliative treatment, we think of a death sentence. (P.013)
	There are patients who you can open up to and talk to, there are some who you'll talk to, but they still have hope and panic sets in. So sometimes it's better not to say anything. (P.049)
<b>Cultural sensitivity</b>	I can't say a specific moment, because when they come to talk about it, it feels like we're already leaving. It's very difficult. I am in terrible doubt because I, personally, wouldn't want to know that we are dying. I'd prefer to keep fighting and fighting. (P.038)

**Notes:** P.: patient's id; "..." indicates incomplete sentence on the part of the participant; [...] indicates part of the interview omitted by the authors for conciseness.

**Table 4.** What approaches do you find most suitable for addressing PC?

<b>Category 7. Communication and support</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Empathy and emotional support</b>	Start like this: "Hi, how are you? How was your day? Did you have a good trip? Were you treated well? Have you had breakfast? Are you hungry?" By approaching in this way, the person feels good. (P.019)
	They would say: "[...] you have been diagnosed with cancer [...], but don't worry, you will undergo chemotherapy, and we also have PC available for improving your quality of life, regardless of the progression or outcome of your disease. We will take care of your pain and emotional well-being." (P.039)
	The doctor having a bit of patience and speaking right there, during the consultation, in a gentle and subtle way, using delicate language. (P.059)
<b>Meetings and interactions</b>	It was great to learn that it's actually a support system, a preparation to assist us. One suggestion would be to have some group meetings, inviting patients to participate for a group conversation. (P.012)
	[...] It could be like this from the beginning of the treatment, with the patient and their accompanying family member together. (P.007)
	With a multidisciplinary team that knows the patient and includes their attending physician. It's important to approach the topic gradually. There is no one-size-fits-all approach. (P.049)
<b>Category 8. Care setting and environment</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Comfortable environment</b>	The place was calm and quiet. [...] It could be at a medical office, with doctors. (P.001)
	If it's anticipated and I know there's no hope, I would prefer it to be in a clinic. (P.029)
	Provide a room for the patient to talk. [...] It would be better to have an individual setting [...] to feel more comfortable. (P.043)
<b>Specific care units</b>	When they approach to talk about cancer, they could schedule a consultation with the PC Unit, providing referrals and explanations so that we can orient ourselves. (P.004)
	I think at the doctor's office or maybe being directed to another more specific department. Perhaps a team that is better prepared, so that it doesn't take so long in the doctor's room. (P.005)
	In PC unit, we receive better guidance. They provide the opportunity to learn more about the treatment and offer better guidance, both to the patient and their family members. (P.027)
<b>Accessibility options</b>	I would like the PC team to provide more frequent follow-ups between appointments. The quicker the meetings, the more secure patients feel, and the more questions they can have clarified. (P.022)
	I think having pamphlets available during the mobile clinics or when filling out forms for examinations would be helpful. It would allow individuals to take informational materials home with them. (P.028)
	It could take place in the waiting room, with lectures, activities, and sharing of experiences. (P.033)
<b>Category 9. Improving the PC experience</b>	
<b>Subcategories</b>	<b>Corresponding discourses</b>
<b>Avoiding omissions and ensuring clarity</b>	I believe it's important to have that transparency. I would prefer if they spoke directly to me, even if I'm alone. (P.013)
	It would involve the family, with transparency and honesty. This way, both the patient and the family would be aware of the situation and how things are progressing. (P.022)
	Nothing should be hidden, everything needs to be disclosed straightforwardly. The person should have [pause] everything in its proper time to avoid suffering later. (P.061)

(Continued)



Table 4. (Continued.)

<b>Creating a supportive community</b>	Sharing experiences among patients and their families. This could include live discussions with professionals participating, creating a sense of community. So that you know you are not alone. (P.008)
	A medical team would be ideal. So that everyone together, patient and doctors, can make decisions. (P.045)
<b>Providing education</b>	Speak directly to the patient, explaining first that there is a way to alleviate suffering and extend the number of days with treatment. They tend to receive it more calmly. (P.006)
	With the knowledge, the family member become more aware of what's happening, and what might come next. (P.007)
	I think the first thing is to remove the word "palliative" from the equation. Many people associate PC with end-of-life situations. So, the first step would be to explain what PC actually means. (P.016)
<b>Minimizing anxiety</b>	It can be quite overwhelming for us. The doctors need to be mindful of how they communicate because sometimes, the way they speak can give the impression that we are dying. (P.014)
	It depends on the person ... not everyone will want to discuss this topic, especially for those who have anxiety. (P.025)
	There isn't a one-size-fits-all approach, but it's necessary to know, especially if you're going through a painful process. The patient may experience a lot of suffering, crying, and despair. (P.038)

Notes: P: patient's id; "..." indicates incomplete sentence on the part of the participant; [...] indicates part of the interview omitted by the authors for conciseness.

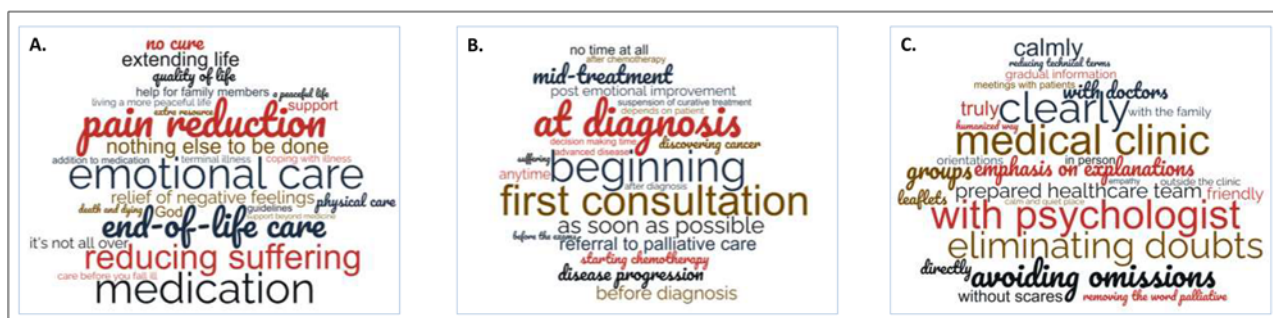


Figure 4. Representation by word cloud of the most frequent occurrences of answers to the questions. Notes: A.: Are you familiar with the concepts of PC? What PC is all about?; B.: When would you consider the optimal timing for discussions regarding PC?; and C.: What approaches do you find most suitable for addressing PC?.

Dedicated resources were crucial to simplify and facilitate PC in hospitals (Robson and Craswell 2022). Patients desired more interactive conversations and multidisciplinary teams for individualized care (Gofton et al. 2022; Rothschild et al. 2022).

In addition, patients desired PC discussions in specialized units, staffed by PC-trained teams (Ferner et al. 2020). They believed these teams offered clearer guidance and explained unique PC aspects more effectively (Grabda and Lim 2021). Adapting environments to meet patients' needs ensured a compassionate experience (Robson and Craswell 2022). To enhance accessibility, patients suggested more follow-ups, material distribution, and the integration of PC discussions into waiting rooms (Robson and Craswell 2022). Visual elements conveyed empathy and understanding, serving as educational tools (Robson and Craswell 2022).

Transparent communication is crucial, even in challenging situations (Chen et al. 2022). Patients advocated for post-treatment groups to share coping strategies (Bandieri et al. 2023; Kuosmanen et al. 2021). Diverse workforces may address varied needs, but cultural sensitivity training is crucial to avoid perpetuating cultural assumptions about healthcare (Cain et al. 2018). Adapting PC strategies to diverse preferences and cultural contexts improves the experience (Cain et al. 2018). Collaboration with communities may help healthcare facilities create culturally informed approaches, harmonizing cultural perceptions with practicalities to improve the PC experience (Cain et al. 2018).

In conclusion, awareness is pivotal for determining the timing and nature of PC discussions, empowering patients and fostering a collaborative care approach. It is perceived holistically, offering support throughout the entire illness process. Despite some patients associating PC only with EOL care, early discussions are deemed appropriate. As treatment progresses, PC discussions alleviate the patient's burden amid information demands at diagnosis. Serene environments, like PC clinics, are preferred, while proposed accessibility options, such as frequent follow-ups and educational materials, aim to enhance comprehension, avoid omissions, ensure clarity, and foster a support network, providing holistic health education.

This study has limitations, including the sample being limited to female breast cancer patients, potentially restricting data generalization. The study's focus solely on female breast cancer patients is justified by the well-documented vulnerability of women to oncological diseases, especially breast cancer, and the unique psychosocial challenges they face. However, focusing on a homogeneous cohort of breast cancer patients enabled a more standardized, rigorous, and targeted analysis of the results and their implications for clinical practice. The use of video conferencing may limit the observation of body language and non-verbal cues; however, the researchers made a careful effort to assess all content, identifying changes in the tone of voice associated with emotional shifts, among other factors. Future studies should explore PC discussions

in different cultural contexts and conduct longitudinal studies to assess evolving patient preferences at various disease stages.

**Acknowledgments.** We extend our sincere thanks to the Barretos Cancer Hospital, specifically the dedicated team of doctors, nurses, and nursing technicians at the Chemotherapy Infusion Center. We are also grateful to the participating patients and their family members, especially for providing them with the necessary support during the videoconferences. Lastly, we express special appreciation to the members of the GPQual for their unwavering and invaluable assistance.

**Competing interests.** Nothing to disclose.

**Funding.** This work was supported by the National Council for Scientific and Technological Development (CNPq) [grant number 313601/2021-6] and São Paulo Research Foundation (FAPESP) [grant number 2022/03842-1].

## References

- Abel J and Kellehear A (2022) Public health palliative care: Reframing death, dying, loss and caregiving. *Palliative Medicine* **36**(5), 768–769. doi:10.1177/02692163221096606
- Andriastuti M, Halim PG, Tunjungsari E, *et al.* (2022) Home-based palliative intervention to improve quality of life in children with cancer: A randomized controlled trial. *Asian Pacific Journal of Cancer Prevention* **23**(9), 3029–3034. doi:10.31557/APJCP.2022.23.9.3029
- Back AL (2020) Patient-clinician communication issues in palliative care for patients with advanced cancer. *Journal of Clinical Oncology* **38**(9), 866–876. doi:10.1200/JCO.19.00128
- Bandieri E, Borelli E, Gilioli F, *et al.* (2023) Stigma of palliative care among patients with advanced cancer and their caregivers on early palliative care. *Cancers (Basel)* **15**(14), 3656. doi:10.3390/cancers15143656
- Bardin L (2016) Análise de conteúdo/Laurence Bardin; tradução Luís Antero Reto., Augusto Pinheiro. São Paulo: Edições 70, 279.
- Beng TS, Xin CA, Ying YK, *et al.* (2022) Hope in palliative care: A thematic analysis. *Journal of Palliative Care* **37**(2), 177–182. doi:10.1177/0825859720948976
- Bennardi M, Diviani N, Gamondi C, *et al.* (2020) Palliative care utilization in oncology and hemato-oncology: A systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families. *BMC Palliative Care* **19**(1), 47. doi:10.1186/s12904-020-00556-7
- Cain CL, Surbone A, Elk R, *et al.* (2018) Culture and palliative care: Preferences, communication, meaning, and mutual decision making. *Journal of Pain Symptom Management* **55**(5), 1408–1419. doi:10.1016/j.jpainsymman.2018.01.007
- Chen JJ, Roldan CS, Nichipor NA, *et al.* (2022) Prognostic understanding and goals of palliative radiotherapy: A qualitative study. *Journal of Pain Symptom Management* **64**(6), 567–576. doi:10.1016/j.jpainsymman.2022.08.011
- Chung V, Sun V, Ruel N, *et al.* (2022) Improving palliative care and quality of life in pancreatic cancer patients. *Journal of Palliative Medicine* **25**(5), 720–727. doi:10.1089/jpm.2021.0187
- Dalal S, Palla S, Hui D, *et al.* (2011) Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *Oncologist* **16**(1), 105–111. doi:10.1634/theoncologist.2010-0161
- Emanuel LL, Solomon S, Chochinov HM, *et al.* (2023) Death anxiety and correlates in cancer patients receiving palliative care. *Journal of Palliative Medicine* **26**(2), 235–243. doi:10.1089/jpm.2022.0052
- Ferner M, Nauck F and Laufenberg-Feldmann R (2020) Palliativmedizin meets Intensivmedizin [Palliative care in intensive care units]. *Anästhesiol Intensivmed Notfallmed Schmerzther* **55**(1), 41–53. doi:10.1055/a-0862-4790
- Goffon C, Agar M and George J (2022) Early implementation of palliative and supportive care in hepatocellular carcinoma. *Seminars in Liver Disease* **42**(4), 514–530. doi:10.1055/a-1946-5592
- Gontijo Garcia GS, Meira KC, de Souza AH, *et al.* (2023) Anxiety and depression disorders in oncological patients under palliative care at a hospital service: A cross-sectional study. *BMC Palliative Care* **22**(1), 116. doi:10.1186/s12904-023-01233-1
- Grabda M and Lim FA (2021) Palliative care consult among older adult patients in intensive care units: An integrative review. *Critical Care Nursing Quarterly* **44**(2), 248–22. doi:10.1097/CNQ.0000000000000358
- Greer JA, Moy B, El-Jawahri A, *et al.* (2022) Randomized trial of a palliative care intervention to improve end-of-life care discussions in patients with metastatic breast cancer. *Journal of the National Comprehensive Cancer Network: JNCCN* **20**(2), 136–143. doi:10.6004/jnccn.2021.7040
- Ivey GD and Johnston FM (2022) Barriers to equitable palliative care utilization among patients with cancer. *Surgical Oncology Clinics of North America* **31**(1), 9–20. doi:10.1016/j.soc.2021.07.003
- Kida K, Olver I, Yennu S, *et al.* (2021) Optimal supportive care for patients with metastatic breast cancer according to their disease progression phase. *JCO Oncology Practice* **17**(4), 177–183. doi:10.1200/OP.20.00622
- Kuosmanen L, Hupli M, Ahiluoto S, *et al.* (2021) Patient participation in shared decision-making in palliative care - an integrative review. *Journal of Clinical Nursing* **30**(23-24), 3415–3428. doi:10.1111/jocn.15866
- Martí-García C, Fernández-Férez A, Fernández-Sola C, *et al.* (2023) Patients' experiences and perceptions of dignity in end-of-life care in emergency departments: A qualitative study. *Journal of Advanced Nursing* **79**(1), 269–280. doi:10.1111/jan.15432
- Mathews JJ, Hausner D, Avery J, *et al.* (2021) Impact of medical assistance in dying on palliative care: A qualitative study. *Palliative Medicine* **35**(2), 447–454. doi:10.1177/0269216320968517
- Murray SA, Kendall M, Boyd K, *et al.* (2005) Illness trajectories and palliative care. *BMJ* **330**(7498), 1007–1011. doi:10.1136/bmj.330.7498.1007
- Pătru E, Călina DC, Pătru CL, *et al.* (2014) The physician's attitude towards the end of the existence. *Current Health Sciences Journal* **40**(2), 134–138. doi:10.12865/CHSJ.40.02.10
- Pedriani Cruz R (2022) Death with dignity: Are we providing adequate palliative care to cancer patients? *European Journal of Cancer Care* **31**(6), e13512. doi:10.1111/ecc.13512
- Radbruch L, De Lima L, Knaut F, *et al.* (2020) Redefining palliative care-A new consensus-based definition. *Journal of Pain Symptom Management* **60**(4), 754–764. doi:10.1016/j.jpainsymman.2020.04.027
- Rego F and Nunes R (2019) The interface between psychology and spirituality in palliative care. *Journal of Health Psychology* **24**(3), 279–287. doi:10.1177/1359105316664138
- Rhondali W, Burt S, Wittenberg-Lyles E, *et al.* (2013) Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study. *Palliat Support Care* **11**(5), 397–404. doi:10.1017/S1478951512000685
- Robson S and Craswell A (2022) Experiences of emergency department nurses using palliative care resources and associated tools in the provision of quality care of a dying patient. *International Journal of Palliative Nursing* **28**(10), 464–472. doi:10.12968/ijpn.2022.28.10.464
- Rothschild CB, Chaiyachati BH, Finck KR, *et al.* (2022) A Venn diagram of vulnerability: The convergence of pediatric palliative care and child maltreatment a narrative review, and a focus on communication. *Child Abuse and Neglect* **128**, 105605. doi:10.1016/j.chiabu.2022.105605
- Santos Neto MFD, Paiva CE, de Lima C, *et al.* (2014) Oncology palliative care: Access barriers: Bibliometric study. *BMJ Support Palliat Care* **14**, e250–e259. doi:10.1136/bmjspcare-2021-003387
- Saretta M, Doñate-Martínez A and Alhambra-Borrás T (2022) Barriers and facilitators for an effective palliative care communication with older people: A systematic review. *Patient Education and Counseling* **105**(8), 2671–2682. doi:10.1016/j.pec.2022.04.003
- Semenenko E, Banerjee S, Olver I, *et al.* (2023) Review of psychological interventions in patients with cancer. *Support Care Cancer* **31**(4), 210. doi:10.1007/s00520-023-07675-w
- Strang P (2022) Palliative oncology and palliative care. *Molecular Oncology* **16**(19), 3399–3409. doi:10.1002/1878-0261.13278

- Temel JS, Petrillo LA and Greer JA** (2022) Patient-centered palliative care for patients with advanced lung cancer. *Journal of Clinical Oncology* **40**(6), 626–634. doi:10.1200/JCO.21.01710
- Tong A, Sainsbury P and Craig J** (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* **19**(6), 349–357. doi:10.1093/intqhc/mzm042
- Trevizan FB, Paiva CE, de Almeida LF, et al.** (2023) When and how to discuss about palliative care and advance care planning with cancer patients: A mixed-methods study. *Palliat Support Care* **27**, 1–9. doi:10.1017/S1478951523001517
- Wake AD** (2022) Knowledge and associated factors towards palliative care among nurses in Ethiopia: A systematic review and meta-analysis. *Sage Open Medicine* **10**, 20503121221092338. doi:10.1177/20503121221092338
- Wantonoro W, Suryaningsih EK, Anita DC, et al.** (2022) Palliative care: A concept analysis review. *SAGE Open Nursing* **8**, 23779608221117379. doi:10.1177/23779608221117379