Personal positioning of oncology patients in palliative care: a mixed-method study

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Abstract

Background

The condition of advanced oncological disorders demands a complete health care, although attention has been predominant on physical aspects. To consider personal positioning entails other aspects when dealing with patients' diseases – such as their existential aspects – expanding forms of care. This study aims to comprehend the personal positioning of oncology patients receiving palliative care.

Methods

This is a cross-sectional, convergent parallel mixed-methods study. Seventy-one oncology patients in palliative care cooperated with this study, 14 of whom participated in a qualitative approach and 56 in a quantitative approach only. In the former approach, we conducted a phenomenological interview and, in the latter, we used tools to measure meaning of life (PIL-Test), quality of life (EORTC QLQ C-30), anxiety and depression (HADS), and to collect sociodemographic data. Data obtained through the interview were analyzed according to the principles of Classical Phenomenology, and the quantitative data were analyzed through generalized structural equation models.

Results

Our results showed that patients regained their focus on life, accentuating its possibilities and distancing themselves from the impact of their condition, such as imminent death, which was associated with giving up fighting depression. These signs were observed in 21% of the participants. This demands a tenacious fight that supports a positioning nurtured by sensitivity. Related to such position is the religious belief in life continuation, together with their awareness of the meaning of their own lives. Additionally, we found a direct association between purpose in life and an increase in the scores of functional scales ($p < 0.01$) and a decrease in scores of symptoms ($p < 0.01$), anxiety ($p = 0.02$) and depression ($p < 0.01$). The last elements to appear and structure the patients' experience were their intense will to live and the value of life.

Conclusions

Through the complementarity of a mixed-method approach, this study acknowledged the existential positioning of oncology patients in palliative care that may help in more comprehensive and real treatment plans, contributing for humanization in this area.

Background

Experiencing a life-threatening disease completely involves a patient and demands a comprehensive health care (1, 2). Although some efforts are focused on a more thorough care that entails existential aspects, most professionals – even those specialized in Palliative Care – are more dedicated to assessing and dealing with physical symptoms (3–5). Taking the existential aspect into account, we approach attitudes that are specifically human, such as the ability to take a stand. As the human being is ontologically free and outward oriented, they are affected, but not determined, by their condition and may go beyond it, toward meaning-making (6).

Exploring the meaning of life in the field of health points out to possibilities of having a healthier life (7, 8). Specifically in Palliative Care, an association was found between high scores of meaning of life and low levels of psychological distress, anxiety, and depression (9). Meaning of life was also associated with a higher quality of life, which is the greatest goal to be accomplished by oncology patients receiving Palliative Care (10, 11).

The concept of quality of life, as others in the field of health, is usually based solely on the disease, and measurement tools are fundamentally related to biostatistics, psychometry, and economy; analyses of non-measurable key issues, such as the individual's story, their context, and values, are absent (12). Qualitative studies with a phenomenological approach, or a similar one, have increased our comprehension on the life of advanced oncology patients, revealing some impactful experiences of this type of life-threatening disease, such as their uncertainties about disconnection from life and their attitude of holding on to it with hope (13). An everyday-life-oriented perspective centered in the present and guided by existence helps to deal with the disease, allowing patients to consider life's values and the possibility of its continuation (14). This belief in the continuation of life is rooted in the possibility of being cured, or in the disease control through treatments, or in religion, all of which give them some hope (15–18).

Researching the area of Oncology Palliative Care involves complex and challenging situations. Thus, exploring human positioning more precisely and thoroughly than biopsychosocial approaches, through the complementarity of mixed methods, is important although non-existent in literature (19–23). Additionally, in most phenomenological studies and similar ones, the definition of the object and the questions addressed to the patients varied and were not always explicit, concentrating on the disease or on its management, but never on the condition of experiencing illness, which is the focus of this study. Therefore, we aim to understand the patients' personal positioning, both qualitatively and quantitatively, using meaning of life as a variable related to personal positioning and associated with quality of life, anxiety, and depression.

Methods

Participants and Procedures

This is a cross-sectional study using convergent parallel mixed methods, according to Creswell and Clark (24). We applied the consolidated criteria for reporting qualitative research (COREQ) (25). A convenience sample was composed of 71 oncology patients in palliative care, 14 of whom participated in a qualitative approach and 56 in a quantitative approach only. The participants were outpatients attending the Clinical Oncology Services and Palliative Care Group from the General Hospital of Ribeirão Preto Medical School of University of São Paulo (GHRPMS-USP). The first author of this study is a psychologist in the group aforementioned, and hence her patients were not included in this research. Inclusion criteria for both quantitative and qualitative approaches were as follows: patients aged ≥ 18 ; both sexes; diagnosed with malignant neoplasm, confirmed by anatomopathological examination – for hepatocellular carcinoma, we considered the diagnosis specific for this neoplasm (information was collected in medical records); aware of their diagnosis in a palliative stage; having any location as a primary site; in stage IV, updated until the moment of recruitment; with Karnofsky Performance Scale (KPS) greater than or equal to 50; and being an outpatient attending the GHRPMS-USP's Clinical Oncology Services and/or Palliative Care Group. Non-inclusion criteria referred to oncology patients in curative care, patients with non-oncological disorders, and those who had been treated by the first author of this study. Exclusion criteria involved patients who had difficulties to understand the Informed Consent and the questions present in the research instruments. All Brazilian principles of research ethics and of Declaration of Helsinki were followed. This study was approved by the Research Ethics Committee of the institution where it was conducted (GHRPMS-USP Approval n. 10402/2017).

We began the procedures for data collection by screening the institution's electronic medical records, which showed a list of patients of the day, to verify the inclusion and non-inclusion criteria. Subsequently, patients were invited to participate in the research at the clinic's waiting room. Those who accepted to participate were taken to the Palliative Care room, where the research instruments were applied. We began collection through the qualitative analysis, and all 14 patients who participated read and signed the Informed Consent 1. To avoid patients' fatigue and to respect their availability, they returned on another day for the application of the quantitative approach instruments. A total of 57 patients participated in the quantitative data collection, after reading and signing the Informed Consent 2. When the data collection was completed, the last author of this study, an oncologist, confirmed that all patients were in the palliative care condition.

Instruments

Patients' physical performance was determined through a Brazilian version of the KPS scale, developed to assess physical abilities of oncology patients (26). The level of willingness to pursue a purpose in life was assessed by the Purpose in Life-Test (PIL-Test), originally created by Crumbaugh and Maholick (27) and adapted in Brazil by Aquino (28) and later by Nobre (29); the latter adaptation was used in this study. The adapted Brazilian test contains 14 items in Likert scale of 1 to 7 points, in which scores varied from 14 to 98 (29). Quality of life was assessed through European Organization for Research and Treatment for Cancer (EORTC QLQ C-30), version 3.0, certified in Brazil (30). The EORTC QLQ-C30 questionnaire contains 30 questions approaching five functional scales (physical, functional, emotional, social, and cognitive), one scale on general health condition/quality of life, three scales on symptoms (fatigue, pain, nausea/vomiting), and six items on additional symptoms (dyspnea, insomnia, decreased appetite, constipation, diarrhea, and financial difficulties). Symptoms of anxiety and depression were tracked by Hospital Anxiety and Depression Scale (HADS), created by Zigmond and Snaith (31) and certified in Brazil by Botega et al. (32) for outpatients with a score of 8 as a cut-off point, parameter used in this study.

The phenomenological interview encouraged the patients to narrate their life experiences, aiming at a mutual comprehension on the part of both the participant and the investigator (33). The interview was conducted by the first author of this study, supervised by the second and third authors, who are experts in this type of interview. It contained open-ended, in depth questions, as indicated by Revan (34), and began with a contextualization question: "How did your illness start?". After this question, we asked two guiding ones in a logical sequence and a graduation of complexity: "How is it like for you to go through this illness experience?" and "How are you dealing with the experience of getting sick?". The answers led to other questions asked gradually to bring the patient to the type of experience at stake (personal positioning on the condition of illness), which was explained more profoundly. The phenomenon of empathy, as explained by Edith Stein (35), leads to comprehension on the part of the interviewer, who operates suspensive listening. An empathic comprehension aims to accompany the experience reported, to clarify it, and to confirm it, when necessary, pursuing its meanings. Suspensive listening is free from theories, pre-judgments, categorical frameworks, and abstractions about the phenomenon, in a way that the interviewer's life experience completes the meanings of the questions (33). Each interview, lasting approximately 60 minutes, was recorded after the participants' permission and transcribed by the first author for analysis. Sociodemographic data and clinical information were collected from patient records. All data collection was performed in the participants' native language (Portuguese).

ação de questionários

Statistical and Qualitative Analysis

Analysis of the relations between meaning of life and EORTC QLQ-C30 domains was conducted through the multiple linear regression model, controlling for anxiety, depression, age, gender, income, marital status, religion, education, and oncology treatment (possible factors for confusion). A Generalized Structural Equation Modeling (GSEM) was used to analyze simultaneously the associations of meaning of life, quality of life (general scores: global, functional, and symptoms), and symptoms of anxiety and depression with possible factors for confusion, such as age, gender, income, marital status, religion, and oncological treatment (Figure 1). The use of GSEM helped to estimate relations between continuous and binary variables, the latter being estimated through a probit model (36, 37). The maximum likelihood estimation method was used, and analyses were performed with STATA software, version 14.0 (38). A significance level of 5% was adopted for all comparisons.

Qualitative data were analyzed by getting rid of preconceptions, judgements, theories, and previous beliefs about the meaning of the phenomenon, according to Barreira (39). The first step was the psychology's reductionism, that is, the researcher comprehended and described meaningful moments (life experiences in the first person, and not facts or rational information about them) related to the object under investigation of each patient separately. Subsequently, we carried out an intentional crossing, which compares this interview with others to verify their invariant meanings. Then, we proceeded to an intersubjective reductionism, which deepens this crossing through successive eidetic or imaginary variations, identifying the elements without which the phenomenon would not be recognized as such (39, 40). Using the convergent parallel mixed

method, our results were obtained separately and then compared with each other, observing and highlighting their differences and similarities in order to extract their essential elements and reach an interpretation of the phenomenon being studied (19, 24).

Results

Quantitative Results

The numbers related to the collection process were structured in a flowchart shown in Fig. 2.

Sociodemographic data show that 58% of the participants are female, 55% are ≤ 60 years of age, 65% have a partner, 55% have completed a maximum of eight years of formal education, 84% earn a maximum of four minimum wages, and 66% are Catholics. Regarding clinical issues, the majority have a KPS performance from 80 to 100 (76%) and almost all of them received oncological treatment (91%). In relation to mental and existential health, 21% show depression and 24% anxiety.

The GSEM shows direct and indirect effects between meaning of life, quality of life, symptoms of anxiety and depression, age, gender, marital status, religion, and treatment. These results are presented in Fig. 3.

Table 1 shows the direct effects between the variables of the GSEM and Table 2 shows relevant indirect effects found by this model.

Table 1
– Direct effects between variables in GSEM

Variable	Anxiety		Depression		Global health status		Functional scales		Symptom scales		Sentido de vida	
	EC (CI)	p	EC (CI)	p	EC (CI)	p	EC (CI)	p	EC (CI)	p		
<i>Meaning of life</i>	-0.05 (-0.09 to -0.01)	0.02	-0.08 (-0.14 to -0.02)	< 0.01	-0.06 (-0.41-0.30)	0.76	0.39 (0.12 to 0.66)	< 0.01	-0.74 (-1.05 to -0.42)	< 0.01		
<i>Marital status</i> with vs. without a partner	-0.54 (-1.52 to -0.43)	0.28	1.04 (-0.70 to 2.78)	0.24	0.53 (-7.62 to 8.68)	0.90	0.90 (-5.69 to 7.48)	0.79	1.62 (-7.05 to 10.30)	0.71	-5,87 (-12,09 to 0,34)	0,06
<i>Income</i> Up to 4mw vs. Above 4mw	1.50 (-0.44 to 3.45)	0.13	0.00 (-2.37 to 2.38)	0.99	2.25 (-8.68 to 13.19)	0.69	-3.61 (-12.41 to 5.18)	0.42	5.46 (-6.07 to 17.00)	0.35	-0,84 (-9,45 to 7,77)	0,85
<i>Religion</i> Catholic vs. other	-0.58 (-1.96 to 0.79)	0.41	-1.12 (-3.86 to 1.63)	0.43	11.03 (-1.35 to 23.41)	0.08	-10.05 (-19.78 to -0.32)	0.04	-16.14 (-28.41 to -3.87)	0.01	-2,66 (-11,62 to 6,31)	0,56
<i>Religion</i> Protestant vs. other	-0.52 (-2.07 to 1.04)	0.51	-0.85 (-3.69 to 1.99)	0.56	11.29 (-2.77 to 25.36)	0.12	-11.91 (-22.94 to -0.89)	0.03	-8.43 (-22.85 to 5.98)	0.25	-0,12 (-10,57 to 10,33)	0,98
<i>Age</i> < 60 vs. >60	1.36 (0.19 to 2.52)	0.02	0.11 (-1.28 to 1.50)	0.87							4,52 (-1,83 to 10,87)	0,16
<i>Treatment</i> Yes vs. No	0.32 (-1.80 to 2.43)	0.77	5.26 (Not estimated)	0.96	6.80 (-9.20 to 22.79)	0.41	22.79 (10.99 to 34.58)	< 0.01			-7,51 (-18,45 to 3,43)	0,18
<i>Gender</i> M vs. F	0.29 (-0.74 to 1.32)	0.58	0.76 (-0.67 to 2.20)	0.3	5.26 (-3.23 to 13.74)	0.23	6.74 (0.07 to 13.41)	0.04	-9.03 (-17.57 to -0.48)	0.04	2,13 (-4,24 to 8,50)	0,51
<i>Education</i> up to 8 years vs. Above 8 years											-3,73 (-10,24 to 2,78)	0,26

EC (CI) = Estimated coefficient (Confidence Intervals).

Variable	Anxiety		Depression		Global health status	Functional scales	Symptom scales	Sentido de vida
<i>Global health status</i>	-0.04 (-0.07 to -0.01)	< 0.01	0.03 (-0.01 to 0.07)	0.14				
<i>Functional scales</i>	0.00 (-0.03 to 0.03)	0.93	-0.10 (-0.15 to -0.02)	0.02	0.42 (0.13 to 0.71)	< 0.01		
<i>Symptom scales</i>	0.01 (-0.02 to 0.04)	0.48	-0.06 (-0.11 to 0.00)	0.06	0.02 (-0.26 to 0.29)	0.92	-0.59 (-0.77 to -0.41)	< 0.01
EC (CI) = Estimated coefficient (Confidence Intervals).								

Table 2
Relevant indirect effects found by GSEM

Outcome	Independent variable	Mediator variable	Estimated coefficient	p-value
Depression	Symptoms QoL	Functional QoL	0.06 (0.01 to 0.11)	0.03
	Ttm (Yes vs. No)	Functional QoL	-2.25 (-4.47 to -0.02)	0.04
Global QoL	Ttm (Yes vs. No)	Functional QoL	9.54 (1.33 to 17.74)	0.02
	Symptoms QoL	Functional QoL	-0.25 (-0.43 to -0.06)	< 0.01
	Meaning of life	Functional QoL	0.16 (0 to 0.32)	0.04
Functional	Gender (M vs. F)	Symptoms QoL	5.34 (0.04 to 10.63)	0.04
QoL	Religion (Catholic vs. other)	Symptoms QoL	9.54 (1.75 to 17.33)	0.02
QoL = quality of life. Ttm = treatment				

Considering the direct effects, meaning of life was related to an increase in the scores of functional scales ($p < 0.01$), to a decrease in scores of symptoms ($p < 0.01$), and to a decrease in the occurrence of anxiety ($p = 0.02$) and depression ($p < 0.01$) symptoms. In an indirect way, meaning of life was associated with an increase in scores of global health when there is a mediation of functional scales ($p = 0.04$). No sociodemographic (gender, age, education, income, marital status, and religion) or treatment variable were directly correlated with meaning of life, that is, general conditions of patients' life and treatment were not associated with high or low meaning-of-life scores. Gender was directly related to data from functional and symptoms scales, indicating that men scored higher in functional scales ($p = 0.04$) and lower in symptoms scales than women ($p = 0.04$). Additionally, gender was indirectly related to data from functional scales moderated by symptoms scales ($p = 0.04$), indicating that men had fewer symptoms and, consequently, scored higher in functional scales. Age had a direct relation to anxiety, that is, patients younger than 60 ($p = 0.02$) scored an average of 1.36 higher in the scale than the elderly. Religion had a direct and indirect association in functional scales and a direct association in the symptoms scale. Catholicism ($p = 0.04$) and Protestantism ($p = 0.03$) – compared with other religions (Buddhism, Candomblé, Spiritism, and

being Christian) – were correlated with decreased scores of functional scales. Only Catholicism was associated with an improvement in functional scales by mediation of the symptoms scale ($p = 0.02$), as Catholics had decreased symptoms and hence better scores in functional scales. Oncological palliative treatment had a direct effect on functional scales ($p < 0.01$), significantly increasing the scores (average of 22.79), and had indirect effects on the global health status ($p = 0.02$) and depression ($p = 0.04$) by mediation of functional scales for both. In other words, going through the treatment increased scores in functional scales (physical function, role performance, and social role) and consequently increased global health status and decreased scores of depression. Global health status had a direct effect on anxiety ($p < 0.01$), as it decreased occurrence of anxiety symptoms. Functional scales had a direct effect on global health state ($p < 0.01$), increasing its score, and also on the occurrence of depression symptoms ($p = 0.02$), decreasing its score. The symptoms scale had a direct effect on functional scales ($p < 0.01$), reducing its scores, and had an indirect effect on global health status ($p < 0.01$) and on depression symptoms ($p = 0.03$) by mediation of functional scales. This means that the symptoms scales reduced the scores of functional scales and hence decreased the score of global health status and increased the scores of depression symptoms.

Qualitative Results

Phenomenology-oriented qualitative results revealed the experience of illness in an everyday palliative oncological condition. It is understood as the comprehension of experience in its entirety, identifying interconnected life elements that structure it, which results in the motivation characteristic of an existential positioning; this could be named as fight for life. This description is in accordance with the phenomenological psychology model present in Edith Stein (41) and Edmund Husserl (42) and may be apprehended from the participant's report below:

(...) it's what I say, not to overthink, because I guess it interferes too much if we focus on that, if we keep that in mind all day long. Some days I don't even think that I have this stuff, you know? (...) So, we have to forget we have this problem and move on with our lives, work, and live. (patient 12)

We observed that patients avoid thinking about the incurable disease and focus on other aspects of their lives, making a deliberate effort to keep those thoughts away in their everyday lives, as they take into account the consequences of such positioning:

When I start feeling depressed, you know, then I feel agony, fatigue... so I try to forget it, because I think we shouldn't worry so much (...) about keeping negative stuff, problems of the disease, in mind, thinking too much about it, that it will get worse, that it will do this and that, because the worst thing is the so-called depression. I keep these thoughts away, you know? (patient 13)

Thematizing an incurable disease involves, in a near or distant future, a worse physical condition followed by death. The patients constantly made an effort to escape from this type of theme to deliberately avoid a negative psychological impact on themselves. Time issues appeared as a determining factor in this study, as the patients live their everyday lives and possibilities in the present, avoiding a psychological suffering due to anticipation of future difficulties inherent to this incurable condition. This does not mean that they did not thematize the illness and the finitude, but they avoided giving in to it constantly in their everyday lives. They presented a way of relating to life that is, more precisely, connected to real possibilities and not to restrictions and losses: *"Yes... I have to take care of my family! Why not? I have my salary, my stuff, I earn money, have to do things around the house to do, let's do it, I have to buy stuff for my girl (...)"* (patient 2). This is a deliberate personal positioning of fight generally against what diminishes life, in the new existential condition, and at the same time favors what may be a fulfillment.

This fight, inherent to the condition of living with the disease, highlighted life possibilities. The condition itself altered the way life was perceived, bringing up an affective and valued, sometimes aesthetic, sensitivity concerning the world and the others; when noted, this sensitivity nourishes a positioning that the patients sought to maintain and renew. From this point of view, we observe a motivation for living, and life being a force of attraction. These are personal findings appreciated under a new

condition, capable of boosting individuals' motivations for life: *"So, I found out that I was really loved. I knew they liked me, but you don't know the extent of the love that a person feels for you"* (patient 4).

This sensitivity appears to be a type of motivation lying between what life may offer here and now and what future may hold, with hopes for achievements and life continuation. We observed some acquiescence that permeates this positioning: every day they surrender to here and now, seeking not to know, but to live and do: *"So, well... I don't know how it ends. (...) Then I told myself: "Look, I'm going to put myself into God's hands" (...) So I only ask God to give me quality of life, and I have it"* (patient 1). The acquiescence to the present condition comes as inseparable from giving themselves the chance to believe in possibilities, and not impossibilities, of life continuation. In this structural element of a positioning on the meaning of life highlighted by the condition, there is an acquiescence, in different ways, to something that exceeds what may be comprehended, predicted, or known. We see a religious existential orientation according to which the individual and their own life are in the hands of a bigger entity that somehow could decide about their destiny in life and their death. The responses evidence that this life experience element intensifies the value of here and now – *I only ask God to give me quality of life, and I have it*. Trusting in a divine entity is correlated with taking care of oneself and with the uncertainties of the disease. Thus, God emerges as something that invigorates, sensitizes, and strengthens the individual in their link to the present, to life, and to the divine. Therefore, the belief in life continuation is brought up in a significant way, being a strong connection to religious faith, to aspects of safety and hope, which open up possibilities of achievements in the present and future: *"I think faith helps not to be more desperate, I mean, to have hopes, to have hope for the future, to live more (becomes emotional)"* (patient 10). The experience of life continuation and its value is also observable in the attentive and affectionate presence of the medical team and of their beloved ones, who, similarly to the patient, do not emphasize the condition and/or do believe in life continuation: *"Without help, from doctors, friends, family, we can't win (...) oh... I'll go far, if it's God's will"* (patient 9).

Belief in life continuation is strengthened in its relation with what is perceived, here and now, as meaning of life and fulfillment: *"(...) because I want to live more, you know? A little more, to see my children, my daughter is getting married next year, I have two grandchildren. So I want to live a little more (...)"* (patient 3). Therefore, faith in life continuation – faith in God – enjoyment of life, and motivation/reason to live are interconnected. Invariably, this experience appears to be intense when the patients are related with meaningful people: *"(...) they... so, I think this gave me more strength to say: "Why would I give up if I have my children who are giving me strength? They still need me"* (patient 1). The meaning and value of life come into play encouraging the patient to live his life.

Discussion

The patients of the qualitative analysis appeared to be focused on living in the present, prolonging it to what it may offer, which is a future, although uncertain and not long. Intensification and relative extension of the present is correlated with some distancing from the condition and the death threat, in which meaning and value of life are emphasized, followed by hope and life continuation. Coherently with these reports, our quantitative analysis showed that the meaning of life had a positive impact on quality of life and on the patients' mental health, indicating a positioning of hope and an assertive appreciation of life. Commonly, health professionals become perplexed when they see this positioning, as they are dealing with patients whose lives are threatened by an incurable oncological disorder (43). This scenario points out to the importance of better understanding the elements present in experiencing this type of illness and, based on this, extending reflections on, and practices of, Palliative Care in Oncology.

Being focused on living was a position similarly identified in other studies, which observed some connection with the present life through strategies of adaptation, emphasis on positive aspects of life, and activities that need to be accomplished by the patients themselves (13, 14, 44, 45). However, most of the studies do not clearly show how those elements are interconnected, aspect which is evidenced here due to the use of the phenomenological approach. Deliberately avoiding thoughts and speeches about the incurable disease was one of the elements of their personal positioning, an attitude that is based on strengthening connections with life and possibilities of fulfillment; frustration is then avoided when they do not focus on limitations and on imminent complications, followed by death. Likewise, Arantzamendi et al. (44) confirm that patients

deliberately control thoughts about the disease/death in order to enjoy the present moment, feeling that these thoughts are not useful. The authors observed a return of conflicts when negative thoughts are intrusive and persistent, leading to anxiety, fear, and anger, which hindered the process of disease acceptance. The patients of our study showed to be aware of the consequences, mentioning some concern about having mental disorders, such as depression. This symptom is the most prevalent amongst patients in Palliative Care, being present in 21% of our sample, similar to worldwide and Brazilian numbers. It may lead to intense and prolonged emotions due to recurrence and confrontation with finitude (46–49). Anxiety was associated with < 60-year-old patients, in accordance with O'Connor et al. (50); however, this data does not seem to be consistent in literature, as results are diverse (50, 51). Avoiding thoughts about the disease and death, supported by connections with possibilities of enjoying life, may help patients to acknowledge and manage their personal resources, such as their ability to escape from certain situations and to focus on possibilities of accomplishment (6, 45).

We observed that the positioning of avoiding daily thoughts about their incurable condition is based on their fights. Likewise, other studies reported such deliberate efforts, which demanded great energy, determination, and resistance (13, 17, 43, 45). The act of fighting shows the “defiant power of human spirit”, which means that an individual is not determined by their numerous and rigorous conditions and hence is able to regulate their actions (41 pp. 6). The fights of our patients present some modalities, and one of them is the accomplishment of tasks/responsibilities, which was similarly reported by Willig and Wirth (13). Differently, other studies found that activities appeared only as some guidance in life (14, 44) or as something incompatible with the illness condition, being used as an escape from reality (43). Our results suggest that the latter interpretation was inattentive and phenomenologically debatable, as the patients, attached to meaning of life, are aware of the threat to which they are subjected and throw themselves into activities that have a close correspondence with their past, present, and future daily lives. Similarly, studies point out that daily activities are a powerful and positive influence to fight the disease, allowing some normality, identity, and adaptation to changes (13, 45, 53). Likewise, our quantitative study showed that the more functional patients, due to oncological treatment, had their symptoms of depression reduced. Studies usually emphasize the contrary, that is, lower rates of depression associated with a better quality of life (54, 55). However, the association found in this study is also valid, because a more functional patient may pursue activities that satisfy them, resulting in pleasure/happiness as a collateral effect (6), which helps reduce depression. Future studies could investigate this relation between quality of life and depression.

Sensitivity to life, identified in this study, is understood as nurture of their fight, allowing patients to perceive more clearly their possibilities of actions, as well as their affections, the aesthetic aspect of the environment, and the meaning of life. We found similar reports in the literature on the experience of life moments intensified by a connection with the present (13, 14, 45). Our study adds that sensitivity to life is part of this process, enabling patients to live the present moment more intensely.

Another element of our patients' experience is the reason to live, even not knowing until when this is possible. Patients with advanced cancer may have deep insights concerning essential goals in life (56), suggesting the human ability to pursue and find meanings in life and in sorrow (6, 57). This search for meaning, according to Frankl, is a motivation characteristic of the human beings, who dynamically pursue their more important aspirations; when satisfied, their life becomes happier and healthier (8, 58, 59). Haug et al. (14) identified meaning as a central element in the experience of their elderly patients, helping them to handle decline and loss and protecting them from some age-related difficulties. Our quantitative results verified the relation between meaning of life, a better quality of life, and a decrease in anxiety and depression, corroborating the literature on this theme (9–11). Meaning of life is also associated with a decrease in physical symptoms, which had not been reported in the literature yet, and it is a relevant finding, as a rigorous control of physical symptoms is one of the principles of Palliative Care to achieve quality of life (1, 2). Studying HIV patients, Pontes (60) similarly found that meaning of life was correlated with improvement of their affections, which was consequently associated with better ratios of lymphocytes CD4+/CD8+. Theoretically, according to Logotherapy and Existential Analysis, this relation is explained by fulfillment of meaning, which leads to pleasure/happiness in psychophysical levels, being a concomitant and non-intentional phenomenon (6, 58, 59). However, further studies in this area are necessary to clarify and prove this relation. Another new and relevant result of our study is the finding that meaning of life or its loss are not associated with the patients' sociodemographic variables, which

was also observed by Dobríková et al. (10) with Slovenian patients. These results support Frankl's (6, 58) anthropology, who states that the will to meaning is ontological. Nevertheless, further studies in other cultures are necessary.

We found that meaning of life was pervaded by an intense will to life continuation, which revealed to be interconnected with religious beliefs when the patients attributed the possibilities of living to the divine, giving them hopes. The phenomenology of the religious experience defines it as a contact with a Force that is superior and supports the individual who contacts it (61). Similar results were found in Brazilian studies (62–64), as well as in other studies conducted in traditionally religious countries (17, 64). In contrast, studies conducted in countries whose population does not traditionally show religious beliefs, such as great part of Europe and North America, found that patients' belief in life continuation was based on performed or available medical treatments (13, 14, 44). Hope contributes for patients to be active and motivated, even in extreme contexts, being a central element in the process of resilience (14, 16, 56, 66). In our study, the belief in life continuation is supported by the attentive and affectionate presence of the medical team and of their beloved ones, who, together with the patients, do not thematize the illness and similarly believe in or empathically accept the patients' positioning. Affective relations, which show empathy and will to spend time with the patient, help to keep hopes alive (10, 14, 16, 67). It is of utmost importance that the health professionals be aligned with the patients, supporting their positioning and paying attention to their real needs (68). Our quantitative results revealed different associations, between religions, in one of the scales for quality of life; however, the higher number of Catholics ($n = 47$) and Protestants ($n = 14$) may have led to biased results. There are no similar findings, in the literature, on this difference and its effect on quality of life, which may be clarified only by further studies. Therefore, we emphasize the therapeutic aspect of hope that comes from faith, in Palliative Care, questioning the interpretations that assume it as a denial or a escape from reality and reject faith as a support for believing in life continuation or for changing the situation, as pointed out by Reis, Farias and Quintana (69).

By connecting the belief in life continuation with religious faith, the will to live appeared as another element that gives meaning to life. This will to live was also reported by Neirop-Van Ballen (18) as a primordial source of hope, corroborated by comprehending the connection between the elements. Will to live is not discussed very clearly by most authors but discretely appears when authors mentioned that patients held on to life and wished to live intensely (13, 14, 45). These life experiences are similar to Frankl's (6) vision, who states life and its unconditional meaning under any circumstances as a fact.

The number of patients in our quantitative study did not allow us to perform a randomized design, a limitation due to the exclusion of 51% of the invited patients who were not aware of the prognosis, as this was an inclusion criterion. Regarding their religious affiliations, our sample did not contain atheists or agnostics, which could have different results on the faith in life continuation or on the way of handling illness and death by Brazilian patients. Therefore, further research containing this population is necessary. Although our quantitative study identified a statistically significant direct and indirect association between the variables, it mostly did not reveal clinical relevance when we observed reliability levels and confidence intervals. This might have been due to the Purpose in Life-Test, because we observed some comprehension difficulties and discomfort on the part of the patients when answering it. We suggest that future studies consider changing the instrument to assess meaning of life and its relation with the same variables of this study.

Conclusions

The interconnection between qualitative and quantitative data points out to the recognition of human existential positioning toward living in Palliative Care under the condition of an oncological illness, aiming to improve quality of life in this phase. Unveiling how this positioning was supported and getting to know the correlations between quantitative variables allowed us to understand, more deeply and consistently, this phenomenon in the context of health care. Our results demand the inclusion of human existential dimension in care plans so that humanization and quality of life, prescribed by Palliative Care in Oncology, are thoroughly taken into consideration.

Abbreviations

COREQ: consolidated criteria for reporting qualitative research; EORTC QLQ C-30: European Organization for Research and Treatment for Cancer; HADS: Hospital Anxiety and Depression Scale; GHRPMS-USP: General Hospital of Ribeirão Preto Medical School of University of São Paulo; GSEM: Generalized Structural Equation Modeling; KPS: Karnofsky Performance Scale; PIL-Test: Purpose in Life-Test.

Declarations

Ethics approval and consent to participate

This study was approved by the Research Ethics Committee of General Hospital of Ribeirão Preto Medical School of University of São Paulo where the study was conducted (HCRP nº 10402/2017). All study participants provided written informed consent for study participation, data analysis, and publication. All principles of research ethics from the Declaration of Helsinki were followed.

Consent for publication

Not applicable

Availability of data and material

The quantitative datasets used and/or analyzed by the study are available from the corresponding author on reasonable request. The qualitative datasets generated and/or analyzed by the study are not publicly available due to the necessity to protect patient's identity but are available from the corresponding author on reasonable request.

Competing interests

The authors declare no competing interests.

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Authors' contributions

HLMS is principal investigator, responsible for study design, project management, recruitment, data collection, data analysis and dissemination. PHMV, CRAB, and FMP are responsible for data analysis. All authors helped in revising and making substantial contributions to the manuscript and approved the final manuscript.

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References

1. Carvalho, RT, Parsons, HF., organizers. Manual de Cuidados Paliativos ANCP. 2 ed. Porto Alegre: Sulina, 2012. <http://biblioteca.cofen.gov.br/wp-content/uploads/2017/05/Manual-de-cuidados-paliativos-ANCP.pdf>. Accessed 10 jul 2017.
2. World Health Organization. National cancer control programs: policies and managerial guidelines. 2nd ed. Geneva; 2002. <http://apps.who.int/iris/bitstream/10665/42494/1/9241545577.pdf>. Accessed 15 jul 2016.
3. Bates, AT. Addressing existential suffering. BCMJ, 2016;58:268–73.
4. Kamal, AH, Gradison, M, Maguire, JM, Taylor, D, Abernethy, AM. Quality Measures for Palliative Care in Patients With Cancer: A Systematic Review. J Oncol Pract. 2014 Jul;10(4):281–287.
5. Rodrigues P, Crokaert J, Gastmans, C. Palliative Sedation for Existential Suffering: A Systematic Review of Argument-Based Ethics Literature. J Pain Symptom Manage. 2018 Jun;55(6):1577–90.
6. Frankl, VE. Psicoterapia e sentido da vida. Castro, AM [translator]. 5 rd ed. São Paulo: Quadrante; 2010.
7. Lukas, E. Prevenção psicológica: a prevenção de crises e a proteção do mundo interior do ponto de vista da logoterapia. Reinhold, HH [translator]. Petrópolis: Editora Vozes; 1989a.
8. Silveira, D. R.; Gradim, F. J. Contribuições de Viktor Frankl ao movimento da saúde coletiva. Rev. abordagem gestalt. 2015;22(2):153–61.
9. Testoni I, Sansonetto G, Ronconi L, Rodelli M, Baracco G, Frassi L. Meaning of life, representation of death, and their association with psychological distress. Palliat Support Care. 2018 Oct;16(5):511–19.
10. Dobříková P, Pcolková D, Alturabi LK, West Jr., DJ. The effect of social support and meaning of life on the quality-of-life care for terminally ill patients. Am J Hosp Palliat Care. 2015 Nov; 32(7):767–71.
11. Yoon SJ, Suh SY, Kim SH, Park J, Kim YJ, Kang, B et al. Spiritual Well-being Among Palliative Care Patients With Different Religious Affiliations: a Multicenter Korean Study. J Pain Symptom Manage. 2018 Dec;56(6):893–901.
12. Minayo MCS, Hartz ZMA, Buss PM. *Qualidade de vida e saúde: um debate necessário*. Ciênc. saúde coletiva. 2000;5(1):p.7–18.
13. Willig, C, Wirth, L. A meta-synthesis of studies of patients' experience of living with terminal cancer. Health Psychol. 2018 Mar;37(3):228–37.
14. Haug SHK, Danbolt LJ, Kvigne K, Demarinis, V. How older people with incurable cancer experience daily living: A qualitative study from Norway. Palliat Support Care. 2015;13(4):1037–48.
15. Benites, AC, Neme, CMB, Santos, MA. Significados da espiritualidade para pacientes com câncer em cuidados paliativos. Estud. Psicol. (Campinas). 2017;34(2):269–279.
16. Robinson, CA. "Our best hope is a cure." Hope in the context of advance care planning. Palliat Support Care. 2012 Jun;10(2):75–82.
17. Nedjat-Haiem, FR. Lorenz, KA, Ell K, Hamilton A. **Experiences with advanced cancer among Latinas in a public health care system**. J Pain Symptom Manage. 2012 Jun;43(6):1013-24.
18. van Baalen, NC, Grypdonck M, van Hecke A, Verhaeghe S. **Hope dies last ... A qualitative study into the meaning of hope for people with cancer in the palliative phase**. Eur J Cancer Care (Engl). 2016 Jul;25(4):570 – 79.
19. Deslandes, SF. Abordagens quantitativa e qualitativa em saúde: o diálogo das diferenças. In: Minayo, MCS, Deslandes, SF. Caminhos do pensamento: epistemologia e método. Rio de Janeiro: Fiocruz; 2002. p.195–223.

20. Duarte, T. A possibilidade de investigação a 3: reflexões sobre triangulação (metodológica). CIES e-Working Paper. 2009;60.
21. Modell, S. Triangulation between case study and survey methods in management accounting research: An assessment of validity implications. *Management Accounting Research*. 2005;16(2):231–54.
22. Shah, SK, Corley, KG. Building better theory by bridging the quantitative-qualitative divide. *Journal of Management Studies*. 2006;46(8):1821–35.
23. Walshe, CE. Mixed method research in palliative care. In: Macleod, RD, Block, L, editors. *Textbook of palliative care*. Springer, 2018.
24. Creswell, JW, Clark, P. *Pesquisa de métodos mistos*. Lopes, MF [translator]. 2nd ed., Porto Alegre: Penso; 2013.
25. 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 J Int Soc Qual Health Care*. 2007;19:349–5
26. Coordenação Institucional de Reinaldo Ayer de Oliveira. São Paulo: Conselho Regional de Medicina do Estado de São Paulo, 2008. Accessed 12 fev 2017.
27. Crumbaugh, JH, Maholick, LT. The psychometric approach to Frankl's concept of noogenic neurosis. *J Cl Psychol*. 1964;20:200–07.
28. Aquino, TAA. *Atitudes e intenções de cometer suicídio: seus correlatos existenciais e normativos [Doctorate Thesis]*. João Pessoa: Departamento de Psicologia, Universidade Federal da Paraíba; 2009.
29. Nobre, MAR. *Purpose in Life Test (PIL-Test) evidências de validade e precisão. Monografia [Undergraduate Thesis]*. Fortaleza: Universidade Federal do Ceará; 2014.
30. Fayers PM, Aaronson NK, Bjordal K, Groenvold M, Curran D, Bottomley A. *The EORTC QLQ-C30 Scoring Manual*. 3rd ed. European Organization for Research and Treatment of Cancer. Brussels; 2001.
<https://www.eortc.org/app/uploads/sites/2/2018/02/SCmanual.pdf>. Accessed 01 jan 2016.
31. Zigmond, AS, Snaith, RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand*, 1983;67:361–370.
32. Botega, NJ, Pondé MP, Medeiros, PG, Lima MG. Validação da escala hospitalar de ansiedade e depressão (HAD) em pacientes epiléticos ambulatoriais. *J. bras. psiquiatr*. 1998;47(6):285–89.
33. Barreira, CRA, Ranieri, LP. Aplicação de contribuições de Edith Stein à sistematização de pesquisa fenomenológica em psicologia: a entrevista como fonte de acesso às vivências. In: Mahfoud, M, Massimi, M. *Edith Stein e a psicologia: teoria e pesquisa*. Belo Horizonte: Artesã; 2013. p. 449–66.
34. Revan, MT. A method of phenomenological interview. *Qualitative Health Research*. 2014;24(1):136–44.
35. Stein, E. *On the Problem of Empathy*. Stein, W [translator]. 3rd Revised ed. ICS Publications; 1989.
36. Canette, I. Fitting ordered probit models with endogenous covariates with Stata's gsem command. *The Stata Blog: Not Elsewhere Classified*. 2013. <http://blog.stata.com/2013/11/07/fitting-ordered-probit-models-with-endogenous-covariates-with-stata-gsem-command/>. Accessed 20 jun 2018.
37. Lindsey C, Pinzon E. Comment on: Multiple equation models: Estimation and marginal effects using gsem. 2016 Jun 07. In: *The Stata Blog: Not Elsewhere Classified*. [blog Internet]. <https://blog.stata.com/2016/06/07/multiple-equation-models-estimation-and-marginal-effects-using-gsem/> Accessed 20 jun 2018.
38. StataCorp. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP; 2015.
39. Barreira, CRA. Análise fenomenológica aplicada à Psicologia: recursos operacionais para a pesquisa empírica. In: Mahfoud, M, Savian Filho, J. *Diálogos com Edith Stein: filosofia, psicologia, educação*. São Paulo: Paulus; 2017. p. 317–68.
40. Giorgi A, Sousa D. *Método fenomenológico de investigação em psicologia*. Lisboa: Fim de século; 2010.
41. Mahfoud, M, editor. *Psicologia com alma: a fenomenologia de Edith Stein*. Belo Horizonte: Artesã; 2019.
42. Husserl, E. *Phenomenological Psychology: Lectures, Summer Semester, 1925*. John, S [translator]. The Hague: Martinus Nijhoff; 1977.

43. José SAP, Leite JL, do Carmo, SA, José SAP. A experiência de viver com câncer de mama localmente avançado: um estudo de enfermagem. *Paraninfo Digital Monográficos de Investigación em Salud*. 2014;3(20).
44. Arantzamendi, M, García-Rueda, N, Carvajal A, Robinson CA. People with advanced cancer: the processo of living well with awareness of dying. *Qual Health Res*. 2020 Jul;30(8):1143–55.
45. Warmenhoven F, Lucassen P, Vermandere M, Aertgeerts B, van Well C, Vissers K et al. 'Life is still worth living': a pilot exploration of self-reported resources of palliative care patients. *BMC Fam Pract*. 2016 May 10;17:52.
46. Fanelli MF, Oliveira, MLFN. Cuidados com paciente oncológico. In: Fukumitsu, KO, editor. *Vida, morte e luto: atualidades brasileiras*. São Paulo: Summus, 2018.
47. Ferreira AS. Prevalência de Ansiedade e Depressão em Pacientes Oncológicos e Identificação de Variáveis Predisponentes. *Rev. bras. cancerol*. 2016; 62(4):321–28.
48. Mitchell AJ. et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol*. 2011;12:160–74.
49. Rayner L, Higginson IJ, Price A, Hotopf M. *The Management of Depression in Palliative Care: European Clinical Guidelines*. London: Department of Palliative Care, Policy & Rehabilitation (European Palliative Care Research Collaborative (www.epcrc.org); 2010.
50. O'Connor M, White K, Kristjanson LJ, Wilkes KCL. The prevalence of anxiety and depression in palliative care patients with cancer in Western Australia and New South Wales. *Med J Aust*. 2010 Sep 6;193(S5):S44-7.
51. Neel C, Lo C, Rydall A, Hales S, Rodin G. Determinants of death anxiety in patients with advanced câncer. *BMJ Support Palliat Care*. 2015;5:373–80.
52. Rios MCV, Pedraza RS. Trastornos de ansiedad y depresión en relación con la calidad de vida de pacientes con cáncer de mama en estadio localmente avanzado o disseminado. *Rev.colomb.psiquiater*. 2018;47(4).
53. Liberato, RP, Carvalho, VA. Terapias integradas à oncologia. In: Carvalho, VA, Macieira, RC, Liberato, RP. *Temas em psico-oncologia*. São Paulo: Summus editorial, 2008. p. 351–57.
54. Grotmol KS, Lie HC, Hjerstad MJ, Aass N, Currow D, Kaasa S, et al. European Palliative Care Research Collaborative (EPCRC). Depression-A Major Contributor to Poor Quality of Life in Patients With Advanced Cancer. *J Pain Symptom Manage*. 2017 Dec;54(6):889–87.
55. De Mol M, Visser S, Aerts J, Lodder P, van Walree N, Belderbos H, den Oudsten B. The association of depressive symptoms, personality traits, and sociodemographic factors with health-related quality of life and quality of life in patients with advanced-stage lung câncer: na observational multi-center cohort study. *BMC Cancer*. 2020; 20:431.
56. Bentur N, Stark DY, Resnizky S, Symon Z. Coping strategies for existencial and spiritual suffering in Israeli patients with advanced cancer. *Isr J Health Policy Res*. 2014;3:21.
57. Frankl VE. *Fundamentos antropológicos da psicoterapia*. Bittencourt R [translator]. Rio de Janeiro, RJ: Zahar, 1978.
58. Frankl VE. *A vontade de sentido*. Pereira IS [translator]. São Paulo, SP: Paulus, 2011.
59. Lukas E. *Logoterapia: a força desafiadora do espírito*. Porto JS [translator]. São Paulo: Edições Loyola, 1989.
60. Pontes A. *Evidências Empíricas de um Modelo Teórico para explicar a Noopsicossomática em Pessoas vivendo com HIV/AIDS*. [master thesis]. João Pessoa: Universidade Federal da Paraíba; 2012.
61. Ales Bello A. *O sentido do sagrado*. Gonçalves PSL, Daldoce Júnior D. São Paulo: Paulus, 2018.
62. Arrieira ICO, Thoferhn MB, Schaefer OM, Fonseca AD, Kantorski LP, Cardoso DH. O sentido do cuidado espiritual na integralidade da atenção em cuidados paliativos. *Rev. Gaucha Enferm*. 2017;38(3).
63. Meneguim S, Matos, TDS, Ferreira, MFSM. A percepção de pacientes em cuidados paliativos sobre qualidade de vida. *Rev bras Enferm*. 2018; 71(4):2114–20.
64. Vasconcelos SXP, Alencar LCA, Biseli ACT, Aquino, TAA, Caldas, MT. Religiosidade para pacientes sob cuidados paliativos. In: Aquino, TAA, Caldas, MT, Pontes, AM, editors. *Espiritualidade e saúde: teoria e pesquisa*. Curitiba: CDV, 2016. p.153 – 66.

65. Doumit MAA, Huijjer, HA, Kelley JH. The lived experience of Lebanese oncology patients receiving palliative care. *Eur J Oncol Nurs.* 2009;11(4):309–19.
66. Davis, MP, Lagman R, Parala A, Patel C, Sanford T, Fielding F, et al. Hope, symptoms, and palliative care: Do symptoms influence hope? *Am J Hosp Palliat Care.* 2017;34(3):223–32.
67. Kodish EP, Post SG. *J Clin Oncol.* 1995 Jul;13(7):1817–22.
68. Kohler LB, Cerchiaro ACB, Levites MR. Cuidados paliativos ambulatoriais e qualidade de vida em pacientes oncológicos. *Diagn Tratamento.* 2016;21(3):101–05.
69. Reis, CGC, Farias, CP, Quintana, AM. O vazio de sentido: suporte da religiosidade para pacientes com câncer avançado. *Psicologia: Ciência e Profissão.* 2017;37(1): 106–18.

Figures

Figure 1

Structure of the GSEM tested *Global QoL means global health-status scale, Functional QoL means functional scales, and Symptom QoL means symptoms scales. All scales are part of the EORTC-QLQ-C30.

1

Figure 2

Chart representing flow of data collection. PC= Palliative Care.

Figure 3

Result of the GSEM. *Continuous lines=direct effect. Dotted lines=indirect effect. **Global QoL represents the global health-status scale, Functional QoL represents the functional scales, and Symptom QoL represents the symptoms scales. All scales are part of the EORTC-QLQ-C30.