



Construction of new personal meanings by cancer patients: a qualitative analysis in an Italian patient population

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Abstract

Purpose The goal of this study is to investigate the meaning that cancer patients in active therapy and/or rehabilitation give to their illness and resources they rely on to build new experiences of meaning and a future perspective.

Methods The present study consisted in a summative content analysis of answers to open questions of the Purpose In Life (PIL) Questionnaire administered to 158 consecutive patients with non-advanced cancer (no metastases). The PIL is an attitude scale that indicates the degree of attainment of meaning and purpose in life and is divided into three sections: a first 20-item quantitative section, with statements rated on a 7-point verbal scale with two anchoring phrases (part A); a qualitative section with 13 open-end items and paragraph composition section addressing the future goals (part B) and past meaningful experience (part C). For the present study, we analyzed the answers to open questions, most interesting in a therapeutic contest related to the meanings associated with life, illness, and suffering to understand the experienced of the cancer patients.

Results The main recurring themes in PIL section B analyzed associated to the sense of life, disease, and death are as follows: meaning (positive/negative), personal dimension, religiousness; physical health, family, normal life; negative sense of death, the end, natural transition, religious belief, consolation, mystery, rejection; opportunity, negativity. Whereas main themes emerging from section C were associated to life goals of the interviewed patients: the desire of realization in the future perspective; the value of life; physical health and healing; guiding values; plus three more themes, distinguishable, but with a minor recurrence: legacy responsibility, religiousness, lack of purpose/resignation.

Conclusion The use of summative content analysis evidenced the recurrence of a strong sense of positivity, present in the majority of the interviews. In particular, this positivity is shown by the use of words associated frequently to self-consciousness and self-evaluation, desire of happiness, and desire of contributing to the good of significant others and of taking care of your own life in order to give a positive contribution.

Keywords Awareness · Meaning · Sense · Cancer · Spiritual well-being

Background

People facing an oncologic disease report suffering from psychological and existential distress, often as a reaction to an

experience that causes changes at different levels: personal, relational, spiritual, and professional [1–6].

In literature, this psychopathological condition, which is identified by nosological systems of psychiatric classification, is

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found in up to 25–30% of patients [1, 2]. The most common symptoms include stress-related and adjustment disorders, depressive spectrum disorders, sexual disorders, and other psychological conditions such as demoralization syndrome, health anxiety, and somatic symptom disorders [3–6]. However, they also include feelings of loneliness, problems in returning to work, marginalization, and stigmatization [3, 6, 7].

Distress in cancer patients has been defined as “a multifactorial, unpleasant, emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to effectively cope with cancer, its physical symptoms and its treatment and that extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis” [1].

Patients, however, may also experience positive aspects, as the illness often make individuals become more aware of issues and problems they had ignored or deny prior to their physical illness [8, 9].

W. Breitbart and colleagues investigated the issues of spirituality and religion in terminally ill cancer patients, studying their drive towards faith, spiritual beliefs, the search of meaning, and spiritual well-being [10–12]. They evaluated the relationship between spirituality and depression regardless of personal religious beliefs and practices, highlighting the role of spiritual well-being and the search of meaning, as agents of protection against depression, the loss of hope, and the desire to hasten death [10–12]. Spirituality is therefore what allows the person to experience the transcendent meaning of life, including faith, believing in a higher transcendent power, not necessarily identified with God and not necessarily through participation in religious rites [13–15].

The goal of the present study was to investigate the meaning that oncological patients in active therapy and/or rehabilitation—not in palliative care—assign to their illness and which resources they rely on to build new experiences of meaning and a future perspective.

Methods

Setting and scope

The present work was a summative analysis on data collected from a previous questionnaire validation project carried out in several centers across Italy in 2011 and involving approximately 300 cancer patients on oncological therapies with a curative intent at the first diagnosis or relapse. The overall validation process concerned a number of self-administered questionnaires specifically constructed to assess the existential dimensions of the patients’ experience (dignity, hope) and

how such dimensions correlate with patient symptoms, as assessed by the Italian version of ESAS [16–19].

The inclusion criteria of that study were as follows: age > 18 years; ability to read and speak Italian; on active oncological therapy; life expectancy > 6 months; Karnofsky performance status (KPS) \geq 70; no severe symptoms caused by anticancer treatments (nausea, vomiting, pain) which could cause discomfort during the compilation of the questionnaires; no signs of cognitive impairments; outpatients; written informed consent. In addition, the study had collected sociodemographic and clinical information such as age, gender, civil status, education, occupation, religiousness, primary cancer, and phase of disease.

Our analysis focused on the answers from the validation of one specific questionnaire, the Purpose In Life (PIL) Questionnaire, which is an attitude scale developed by Crumbaugh and Maholick [20], validated in Italian [21]. It indicates the degree to which meaning and purpose in life have been attained by the respondents. It consists of 20 statements, each rated on a 7-point verbal scale with two anchoring phrases (part A). PIL also includes a qualitative section that consists of 13 sentence completion items (part B) and a paragraph composition section addressing the future goals and past meaningful experience (part C).

For the purpose of our study, we limited the scope of analysis to sections B and C, which were most interesting in a therapeutic setting and thus analyzed the answers to the open questions related to the meanings associated with life, illness, and suffering to understand the experienced of the cancer patients. The patients were assisted in the Oncology-Supportive Care Unit, Fondazione IRCCS, Istituto Nazionale Tumori Milano and Center of Oncological Rehabilitation-LILT, CERION Florence.

The physician (C.I.R.) and/or psychologists (L.B.; A.M.) explained face to face the terms and objectives of the study, gathering questions and doubts and delivering the patient questionnaires that were self-compiled. The team dealt with issues concerning the quality of life of cancer patients not only from a clinical perspective but also from psychological and spiritual ones.

Summative analysis

All answers were analyzed using a summative content analysis by two independent female psychologist psychotherapists (L.B.; A.M.) who had participated in the big cross-sectional study [22–24]. The two researchers independently identified and quantified certain words or content into data sets with the purpose of understanding the contextual use of the words or content. The answers of the patients were read several times in order to identify content categories and develop emerging themes, as foreseen by this qualitative approach. During the analysis, the authors identified representative sentences for

each theme. Both inductive and deductive approaches were adopted. The two independent resulting works of the two researchers have been compared, and differences have been discussed to reach a shared list of themes and sub-themes. The researchers are agreed on all the themes that emerged, and they modified some words to describe the themes that emerged. A third researcher, a community doctor with experience in palliative care and in qualitative research (G.M.), ensured methodological rigor supervising the process. As a first step, creation of categories and themes was developed with a “paper and pencil” approach. After merging themes in the final shared list, researchers sorted and ordered data in charts by means of Microsoft Office Excel software in order data to provide quantitative data to support the assessments of qualitative aspects considered relevant from the authors’ perspective.

The authors intentionally decided to report all themes independently from quantifiable measures but in terms of whether it captured a relevant aspect in relation to the study. Researchers identified as many themes as possible so to accurately represent the content of the entire data set [23], and the findings were described through a rich thematic description of the entire data set, in order to explain the meaning of the most predominant or important themes. Approval was obtained from the ethics committees of all participating centers, with the number 68/2010 Istituto Nazionale dei Tumori.

Results

Of the overall 300 patients recruited for the multicenter validation project, the present analysis was restricted to a sample of 158 consecutive patients with non-advanced cancer excluding those from centers treating patient in palliative care. Table 1 shows sociodemographic and clinical characteristics of the sample.

Given the personal nature of the questions, 24 questionnaires were left incomplete, as patient did not feel comfortable in providing feedback (16 patients did not accepted to fill in all the questionnaires and 18 did not complete all the questionnaires after having given the informed consent because the compilation caused them distress; in particular, they were not available to complete the spiritual well-being questionnaires because these were considered very personal dimension that had not to be shared with others).

The patients had an average age of 58.8 (range 19–96); most were male (59.5%), married (72.8%), with a high-school education (45%), retired (43.6%), and church attenders (45%). Most patients had a Karnofsky performance status of 80–100 (95.6%), were in active treatment/rehabilitation (75.3%), and had a breast cancer (45%); 36.7% of the patients received psychological support.

Table 1 Demographic, clinical characteristics and setting of care of the sample

<i>N</i> = 158	%	<i>N</i>
Age		
Mean	58.8	
DS	12.8	
Range	19–86	
Gender		
Male	59.5	94
Female	40.5	64
Civil status		
With partner	72.8	115
Widowed	8.9	14
Separated/divorced	7.6	12
Single	10.7	17
Education		
University degree	19	30
High school	45	71
Middle school	28.5	45
Primary school	7.5	12
Occupation		
Retired	43.6	69
Employed	28.5	45
Self-employed	13.3	21
Housewife	7.6	2
Unemployed	3.2	5
Other	3.8	6
Religiousness		
Churchgoer	45	71
Believer non-churchgoer	42	66
Non-believer	13	21
Karnofsky performance status		
70	4.4	7
80–100	95.6	151
Phase of disease		
Diagnosis	1.3	2
In treatment/rehabilitation	75.3	121
Follow-up	22.2	35
Psychological support		
	36.7	58
Oncological diagnosis		
Breast	35	55
Lung	4.4	7
Colorectal/stomach	5.6	9
Ovarian/prostate	12	19
Hematologic	20.2	32
Head-neck	7.6	12
Other	23	14.4

As in the validated original Italian version of the PIL, patients were invited to reply to 13 open-end items and paragraph composition section addressing the future goals (part B) and past meaningful experience (part C). The themes emerging from the content analysis of the answers to questions of PIL, part B, are summarized in Table 2 and are described below for each question, through representative examples.

Part B of PIL

We will discuss the thematic analysis of the answers to four different questions of part B (Table 2).

Question: “To me all life is”

Theme (i): matter of meaning/global opinion

The first theme collects the majority of answers: patients give a brief judgment on life in general and its own meaning. Often, the meaning is positive (64 cases over 90) and less frequently negative (19 cases). Sometimes they reveal two opposite—but not mutually—exclusive interpretations, one positive and one negative, side-by-side:

[C160: “An obstacle course race, but one that we can win and we can overcome”].

The completely negative meaning, even if not frequent, is still present:

[C10: “A heavy weight”].

Theme (ii): personal dimension

Another theme, which emerged though not very frequently, was the topic of the personal dimension, as in family and professional role, and the related meaningful relationships: talking about life became a means for talking about what one wants to do and the role ones identify themselves in: [C80: (Life has been) “Work, children, family”].

Theme (iii): religiousness

Despite explicit religiousness was quite infrequent, this still was present as a marginal theme (three explicit recurrences): [C1; C107: “A gift from God”].

Question: “More than anything else I desire”

Three main themes occurred:

Theme (i): physical health

The word “recovering” occurred 29 times; sometimes, it is the only word used to answer the question; the word “health” was present 25 times. Even the topic of others’ health was present:

[C113: “Health for my family”].

Themes (ii): family affection

Table 2 Part B of the PIL Questionnaire

Question: “To me all life is”: themes and sub-themes								
Themes	Matter of meaning/global opinion					Personal dimension	Minor occurrence: religiosity	
Number of patients†	90	Sub-theme: positive meaning: 64	Sub-theme: negative meaning: 19	Sub-theme: positive and negative: 6	Sub-theme: relation with time: 6	24	3	
Question: “More than anything I want”: themes and sub-themes								
Themes	Physical health				Family affection		Normal life	
Number of patients†	95	Sub-theme: other’s health: 11			19		39	
Question: “Death is”: themes and sub-themes								
Themes	Negative meaning	The end	Natural transition		Religious belief	Consolation	Mystery	Rejection
Number of patients†	45	16	53	Sub-theme: unavoidable: 15	10	10	3	7
Question: “The illness and suffering can be”: themes								
Themes	Opportunity				Negativity			
Number of patients†	77				47			

† It is the number of patients that expressed the considered theme in their responses, on the total number of 158 patients that were asked to answer the questionnaire

Often represented as a topic, we could identify family affection as an independent theme:

[C 28: “Happiness for my family”].

Theme (iii): normal life

Close but independent, this theme was explicit in some cases [“Living my daily life”]; sometimes, it is just the desire of small things, seen as desirable and highly valuable, as the desire of a normal life that the patients hope to restore or maintain.

[C80: “Just traveling (with my camper)”].

Question: “Death is”

The emerging themes for this question were as follows: (1) negative meaning, (2) the end, (3) natural transition, (4) religious belief, (5) consolation, (6) mystery, (7) rejection.

Many of the people interviewed, however, described death with more positive hues, or they often presented the negative meaning along with other possible meanings, like the vision of death as a natural transition in their existence or as a normal part of life:

[C5: “Unavoidable for everyone”]. (The word “unavoidable” was found 23 times and it has been counted in the wider theme of “natural transition.”)

A minority of the interviewed sees death in a religious perspective, intended as the transition to another stage of existence.

Some of the participants described death with a positive sense, seen as peace and consolation:

[C119: “It will be at some stage as a relief”].

Question: “The illness and suffering can be”

The main themes were opportunity and negativity.

In the answers, we can find the theme, already found in many other parts of our analysis, of the duality of the attitudes towards the illness that is expressed both in a positive and negative perspective. Despite facing the same experience, we clearly observed how patients, in facing the same experience, a strong one in any case, as it is the suffering from the oncologic disease, can express different views in their interviews. The most recurring theme is that of illness as an “opportunity”: disease helped understanding oneself, their neighbors, and helping them according to their possibility. Seventy-seven people live the illness as the experience that set the conditions for positive changes, for the opportunity for growth and self-confrontation.

[C160: “A moment in which we have to stop and reflect on the true meaning of life”].

On the other side, it emerges the negative meaning of the illness: 47 patients experience illness as “tiresome,

debilitating, deleterious,” as they just simply express negative judgment towards their illness, without adding any other meaning.

Part C of PIL

Question: “Write a paragraph describing in detail your aims, ambitions, goals in life. How much progress are you making in achieving them?”

The analyses evidenced four main themes at high recurrence, plus three minor less frequent themes (Table 3).

1) Desire of self-realization and future perspective

We group under this theme the answers focused on the future, directed to the achievement of personal objectives already pursued in the past, but more clearly focused during the illness experience. The illness is often internalized as a phase of life, seen as a moment of renovation of oneself, through a change of self-identity that helps to clarify the objectives seen as more relevant and worthy of their future efforts.

[C132: “I hope I can manage my situation again and enjoy every moment of my life more peacefully. I don’t have great expectations, but I hope that my life will bring good things (..) for a woman of my age, even if I know that I will have to accept the ups and downs of life! I’m going to try as hard as I can!”].

Words associated to the beauty of life, re-evaluated through the experience of illness, occur in the interviews.

C166: [“One of my purposes, maybe the main one, is not to waste this vital energy, that I now feel inside of me, for pointless things. I want to appreciate what I have. I would like to help women that went under surgery for breast cancer. The purpose of my life is to know myself more and more, to get in contact with my perception (..)”].

Words are used to often express a sense of lightness: “weights” left behind, responsible for “making people sick.” A growing sense of lovability towards themselves and others is expressed, in sentences that express the will of “taking more care of yourself,” “let go of things,” and “being present with more love.”

2) The value of life

This theme was consequent to the previous one, because the change in perspective due to the illness experience seems to inspire a different perception of the value of life, often intended as an absolute value: desire of “harmony,” “life at its fullest,” “enjoying life.” Sometimes, these topics appeared to be linked to the flowing of time.

Table 3 Part C of the PIL questionnaire

Themes	Desire of self-realization	The value of life	Healing and physical	Main values	Transmission's responsibility	Religiosity	Lack of goal/resignation
Number of patients [†]	46	32	26	41	8	7	10

[†] It is the number of patients that expressed the considered theme in their responses, on the total number of 158 patients that were asked to answer the questionnaire

[C147: “Living your daily life at the fullest, let go of the past, death, find myself, living in the present, search for beauty and lightness, loving and saying it out loud”].

3) Healing and physical health

This theme is expressed in two different ways: rarely, as the only one aspect (9 times vs the 26 occurrences), or more often, in relation to other objectives and meanings. This theme was strongly linked to the previous ones: the patients expressed many times the desire of “Recovering in order to...”: to spend more time with their significant others or to achieve their own objectives.

[C9: “(...) Being as healthy as I can. As a consequence of this I know that I will be able to take care of my home, traveling to some places, even if not far, and see my daughters settle down in their lives, and helping them with my presence (...)”].

4) Main values

This theme groups together the expressions that identify main values that orient the patient's entire life of the patients: sometimes abstract, like hope, willpower, love, and friendship; sometimes more practical, like family, songs, and work. [C157: “The purpose of my life is having a safe job and a peaceful family”].

The analysis evidenced a second group of themes emerges, less recurring, but autonomous.

5) Transmission responsibility

The patients expressed the need of passing on the experience gained from the illness, perceived as another chance to life.

[C151: “Keeping working with passion, (...) transmitting the chance to say that life, even with all these slaps, is worth living”].

6) Religiosity

Explicit religious sentences were not frequent both in the entire data set and in the answers of part C. Nonetheless, when this theme was present, it appeared as a strong value.

[C91: “Enjoying all the things that God created”].

7) Lack of purpose/resignation

It had a rare recurrence (ten cases). In some patients, it was mixed with other aspects. In almost all the sentences, it was connected to the topic of the limited amount of time that is left.

[C24: “I am 86 years old, what do you still want from me? I achieved many goals. Now I take a break”].

Conclusions

The experience of many oncological patients suggests that illness, with all the suffering that it takes, might be a chance to change towards a greater affirmation of self-identity and of life itself [10, 13, 14, 25]. This result is also confirmed by our study. The most important values which the patients orient their life to emerge in the theme “main values”: some of them might be in the field of experiential values (as willpower, love for the family); other might be creative values as “work.” The specificity of these themes, indicated by the patients as motivations to deal with the diseases to participate in a positive change, in respect of themselves and the others too, might be stimulating for clinicians, moving them towards deepening both the collection of the clinical history and a successive clinical encounter with the patients.

Chochinov and colleagues have developed a dignity questionnaire for patients called the Patient Dignity Question (PDQ), which guides a conversation of about 10–20 min and aims to better understand the patient as a person: “What would you like your healthcare professionals to know about you or your loved one as a person, to provide the best possible care?” [26]. One recent scoping review on this topic showed that between 69 and 90% of clinicians said that through the PDQ, they learned something new about the patient, 63–64% said that it affected them emotionally, and 49 and 63% of them felt that it influenced the personal satisfaction they get from providing care to a patient [27]. The studies were conducted in palliative care, but Chochinov suggests that the PDQ can be used also in other clinical settings [26].

The attention of the clinicians is focused on deviances from the average as they were, automatically, risk factors [1–3, 6,

28]. The variability of values and conditions, instead, suggests which are most likely the important personal issues to be dealt with a particular patient and which are his/her main inner resources [29]. Our results suggest to focus on factors which can make easier coping with the disease. This is said by the patients themselves with their own words, if we take time to listen adequately to them. Desire of “harmony” and “fullness of life” are highly frequent in the patients’ answers, particularly related to the flowing of time. The strong desire of realization and pursuing of personal objectives, both from the personal past and newly found through the experience of illness, might be surprising, when often patients feel themselves relegated to the role of “sick person.”

One study, using ethnographically based interviews, showed how chronically ill older adults experience a new cancer diagnosis and the effects of this on their interpretations of personal health, aging, and the future [30]. One of the major findings was the role of cancer in disrupting individual biography. Our data suggest something different: that the illness is often internalized as a phase of life, seen as a moment of renovation of oneself, through a change of self-identity that helps to clarify the objectives seen as more relevant and worthy of their future efforts.

The desire of being there for their loved ones and learning how to show them more affection emerge. These issues have been much investigated in patients assisted in palliative care. For instance, Chochinov and colleagues developed a brief psychotherapy named Dignity Therapy [31]. The patients are invited to discuss issues that matter most about their life; sessions are transcribed and edited with a final version to create a generativity document for the patient to bequeath to a family member or friend, thus becoming part of a personal legacy. The patients of our study were on active treatment at the first diagnosis or relapse, but they too report the value of transmitting some kind of teaching from life, and of leaving something positive to others, suggesting that “legacy” is a purpose to be found also in a perspective of cure and healing.

Clinical implications

In our analysis, the illness has been mainly seen as an opportunity: 77 patients over 124 lived the illness as an occasion to grow and confront themselves.

Being aware of the themes and topics important to the patients can improve communication patterns and build on openness to the patient’s opportunity for positive change through the experience of disease.

Study limitations

The 36.7% of interviewed patients already received a psychological consultation, and this might have facilitated the research for meaning in the direction of a positive change.

Our patient samples had oncologic disease and were in active treatment and in out-of-hospital setting. It will be necessary to investigate in future studies, goals, and meanings attributed to the illness in other settings and in different samples.

Compliance with ethical standards

Approval was obtained from the ethics committees of all participating centers, with the number 68/2010 Istituto Nazionale dei Tumori.

Conflict of interest The authors declare that they have no conflict of interest.

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