

Narratives about self-care by people at the end of their lives*

DOI: <http://doi.org/10.15446/av.enferm.v40n1.90912>

- 1 Patrícia Tuerlinckx Noguez
- 2 Rosani Manfrin Muniz
- 3 Juliana Graciela Vestena Zillmer

Abstract

Introduction: Cancer mobilizes people and families who search for healing practices that provide relief from physical, emotional, social, and spiritual distress.

Objective: To analyze the self-care of cancer ill people at the end of their lives; patients staying under Palliative Care in a home care service.

Materials and method: A qualitative study in Interpretative Anthropology and Medical Anthropology carried out in a home care service of a teaching hospital. From September 2015 to January 2016, eleven individuals at the end of their lives took part in the study. Unstructured observation and narrative interviews were the methods used to collect data, in addition to the narrative analysis from Fritz Schütze.

Results: The self-care modalities were biomedical, popular, traditional, simultaneous, overlapping, and juxtaposed. None of the participants noticed any defined scheme or practice. Some people assumed adaptation and experimentation depending on the practice's success to alleviate suffering.

Conclusions: The patients resorted to various forms of self-care during the disease, based on sociocultural aspects and sought different practices to meet their needs.

Descriptors: Neoplasms; Palliative Care; Complementary Therapies; Anthropology; Culture (Font: DECS, BIREME).

* This article derives from the PhD thesis "Experience of illness and self-care practices of people with cancer in Palliative Care" from the Nursing School of the Federal University of Pelotas.

1 Universidade Federal de Pelotas (Pelotas, Rio Grande do Sul, Brazil).

ORCID: <https://orcid.org/0000-0002-9987-6605>

E-mail: patriciatuer@hotmail.com

Contributions: Conception, planning, collection and data analysis and interpretation; critical review of the content; and approval of the final version of the manuscript.

2 Universidade Federal de Pelotas (Pelotas, Rio Grande do Sul, Brazil).

ORCID: <https://orcid.org/0000-0002-5642-7842>

E-mail: romaniz@terra.com.br

Contributions: Conception, planning and data analysis and interpretation; critical review of the content; and approval of the final version of the manuscript.

3 Universidade Federal de Pelotas (Pelotas, Rio Grande do Sul, Brazil).

ORCID: <https://orcid.org/0000-0002-6639-8918>

E-mail: juzillmer@gmail.com

Contributions: Conception, planning and data analysis and interpretation; critical revision of the content; and approval of the final version of the manuscript.

How to cite: Noguez PT; Muniz RM; Zillmer JGV. Narrative about self-care by people at the end of their lives. Av Enferm. 2022;40(1):63-76.
DOI: <http://doi.org/10.15446/av.enferm.v40n1.90912>

Received: 15/10/2020

Accepted: 23/12/2021

Published: 11/01/2022



ISSN (impreso): 0121-4500
ISSN (en línea): 2346-0261

Narrativas de personas al final de la vida sobre el autocuidado

Resumen

Introducción: el cáncer moviliza a personas y familias en la búsqueda de prácticas que alivien el sufrimiento físico, emocional, social y espiritual.

Objetivo: analizar el uso de formas de autocuidado en personas que padecen cáncer al final de la vida y se encuentran en Cuidados Paliativos en un servicio de atención domiciliaria.

Materiales y métodos: estudio cualitativo, en el campo de la Antropología Interpretativa y la Antropología Médica, realizado en un servicio de atención domiciliaria de un hospital escuela. Los participantes del estudio fueron 11 personas al final de su vida, con trabajo de campo realizado desde septiembre de 2015 hasta enero de 2016. Se utilizó observación no estructurada y entrevista narrativa para la recopilación de datos, además del análisis narrativo de Fritz Schütze.

Resultados: las modalidades de autocuidado fueron la atención biomédica, popular y tradicional, concomitante, superpuesta o yuxtapuesta. No hubo esquemas ni prácticas definidas, las personas fueron experimentando e implementando adaptaciones, conforme la práctica les aliviaba o no el sufrimiento.

Conclusiones: los pacientes recurrieron a diversas formas de autocuidado durante la enfermedad, se basaron en aspectos socioculturales y buscaron diferentes prácticas para atender sus necesidades.

Descriptores: Neoplasias; Cuidados paliativos; Terapias complementarias; Antropología; Cultura (source: DeCS, BIREME).

Narrativas de pessoas em final de vida sobre autoatenção

Resumo

Introdução: o adoecimento por câncer mobiliza pessoas e famílias na busca por práticas que proporcionem alívio ao sofrimento físico, emocional, social e espiritual.

Objetivo: analisar o uso das formas de autoatenção das pessoas que padecem por câncer em final de vida e estão em cuidados paliativos em serviço de atenção domiciliar.

Materiais e métodos: pesquisa qualitativa, no campo antropologia interpretativa e antropologia médica, realizada em serviço de atenção domiciliar de um hospital de ensino. Participaram do estudo 11 pessoas em final de vida, sendo o trabalho de campo realizado no período de setembro de 2015 a janeiro de 2016. Utilizou-se da observação não estruturada e da entrevista narrativa para a coleta de dados e a análise narrativa de Fritz Schütze.

Resultados: as formas de autoatenção foram biomédicas, atenção popular e tradicional, concomitante, sobreposta ou justaposta. Não havia esquema nem práticas

definidas, as pessoas foram experimentando e realizando adaptações conforme o retorno da prática, a fim de aliviar o sofrimento.

Conclusões: os pacientes recorreram a diversas formas de autoatenção durante o adoecimento, com base em aspectos socioculturais e buscaram diferentes práticas para atender suas necessidades.

Descritores: Neoplasias; Cuidados paliativos; Terapias Complementares; Antropologia; Cultura (fonte: DeCS, BIREME).

Introduction

Self-care of people with cancer at the end of their lives in Palliative Care is the central topic of this study. With the disease's natural progression, people can enter the final phase of life, which starts with confirming the impossibility of finding a cure and ends with death (1). At this stage, Palliative Care is a therapeutic approach that provides comfort, prevents, and alleviates physical, psychosocial, and spiritual distress to the patient and family members, improving the quality of life (2).

Cancer disease needs to be understood not only in biomedical terms (3) but also broadening the knowledge through culture on the disease etiology and the need for culturally appropriate treatments (4). Any disease implies care and prevention modalities, which can be met employing the actions taken by the subjects and social groups when ill (5, 6). There are different care modalities in which several diagnostic techniques and indicators are used, as many treatments and criteria for a cure.

Menéndez describes self-care modalities as the “representations and practices that the population uses both individually and socially to diagnose, explain, assist, control, alleviate, support, cure, solve or prevent the processes affecting their health in real or imaginary terms without the central, direct and intentional intervention of professional healers, although they can be the frameworks of this activity” (6, p. 48, free translation). This concept expands the perspective to the self-care actions of people and groups based on the meaning attributed to the disease experience (5, 6).

Menéndez classifies them as “biomedical knowledge and care modalities; popular and traditional knowledge and care modalities made possible by specialized workers such as masseurs, healers, sorcerers, midwives, spiritualists, shamans, etc.; alternative, parallel or new-age knowledge, and care modalities including bioenergetic healers, new community-type curative religions; knowledge and care modalities from other academic medical traditions: acupuncture, Ayurvedic medicine, Mandarin medicine, etc., and knowledge and self-care modalities of two basic types: centered on primary natural groups –especially on the households, and those organized in terms of self-help groups referring to specific ailments” (6, p. 24, free translation).

Self-care connects with any strategy adopted by the person from the moment they become ill since it is the first interaction activity that the micro-group –the patient and people perform with some family member in a social context (5). Such being the case, by facing the illness through self-care modalities, people and their groups validate diverse knowledge and powers (5, 6).

The literature revealed incipient studies on self-care modalities in people at the end of life who experience a disease with a cure impossibility. In the international literature, studies discuss using self-care practices as alternative and complementary therapies in cancer treatments (4, 7, 8) and other chronic diseases (9, 10).

In Brazil, different studies have sought to identify integrative and spiritual practices in cancer patients (11-14) and to analyze the meanings attributed by people to the use of plants in self-care practices in distress situations (15). Usage of other care modalities and the biomedical ones can bring benefits such as symptom relief and body balance reestablishment (4, 11-16).

Hence, the proposal is to analyze the experience of illness in self-care modalities of people with cancer at the end of life, believing that their practices are interpreted based on culture through symbolism in the actions and choices towards addressing their finitude. Thus, the theoretical question was: Which self-care modalities choose people with cancer at the end of their lives in Palliative Care? Therefore, the objective was to analyze the self-care modalities of people with cancer.

Materials and methods

This document is based on a qualitative study in Interpretative Anthropology by Clifford Geertz (17) and Medical Anthropology by Eduardo Luis Menéndez (5, 6). It was conducted in a home care service of a teaching hospital from southern Brazil, a local reference in Palliative Care. The fieldwork took place from September 2015 to January 2016, by the first author, an experienced nurse, and a researcher.

Intentional sampling helped select the participants under the following inclusion criteria: people with cancer in Palliative Care; aware of the disease and health condition; over 18 years old, and able to listen and speak without difficulty. A total of 12 patients who met the requirements were identified; however, one participant stayed excluded as the staff informed of senile dementia, thus totaling 11 participants. Saturation criterion determined sample size and data conclusion: as the information gathered repeated, the researcher left the field.

The data collection techniques included unstructured observation and narrative interviews. Guides for both were prepared, considering the study objective. The observation phase took place in the patients' homes, aiming to describe the scenario with field notes that provided information to complement the analysis of the narratives, documenting the fieldwork.

The question "Can you talk about your life since cancer started?" introduced the interviews individually and sometimes defined with the participants. The narratives lasted between 60 and 130 minutes, fully recorded and transcribed by a duly equipped transcriber, and later reviewed by the first author. In addition to the participant, a family member was present in all the interviews. Some of them commented throughout the interview, while others were only companions. The data resulting from the narratives and the observation records totaled 210 pages.

Analysis of the narratives was based on Fritz Schütze (18) and the representative scheme adapted by Meincke (19). Ethnograph V6 was used for data organization and management. However, for the narratives, a chart was created in a Word document, as it enabled visualization of the whole process, considering the six steps proposed in the narrative analysis.

First step

It corresponds to the formal analysis of the text, after the transcription. The different text types, plot, and the principal elements that marked the completion and initiation of a new event in the narrative were identified. In addition, the text was "cleaned", removing the non-narrative elements. In this

stage, it is crucial to identify the narrative passages to have a first impression on the declarations as a whole, identifying the main action movements for a change or the inaction in the life story (18-20).

Second step

It is a structural description of the content. Each narrative segment was analyzed in detail to ask questions, ascertain their function for the entire narrative, and identify those relevant or connected only with parts of the excerpts. For this, it was necessary to divide the text into indexed (who did what, when, where, and why) and non-indexed proposals, classified into a descriptive dimension (values, judgments, and life wisdom) and an argumentative dimension (reflections and conflicts). This stage's purpose is to identify different procedural structures in the course of life, such as culminating situations, the intertwining of events experienced, drastic points of transformation, or progressive change (18-20).

Third step

It corresponds to the analytical abstraction process. The researcher (the first author) took distance from the details observed in the analyzed segments and began to examine the abstract structural expressions of each life period, placing them in a systematic relationship with one another. In this step, the indexed proposals analyzed the ordered sequence of events for each person with cancer at the end of life, defining this result by Schütze (18) as "path". Thus, as the narrated material was divided into indexed and non-indexed proposals, the highlighted narrative segments were coded (18-20).

Fourth step

It is described as knowledge analysis. The non-indexed proposals, descriptive and argumentative dimensions were analyzed describing the explanatory theories elaborated by people about their life stories and identity. These theories emerged both in the initial passages of the narration and in the end phase of the narrative (18-20).

Fifth step

It was necessary to detach the individual narrative and to develop a comparison between the stories, including both indexed and non-indexed proposals to construct the object of the comparative analysis, established between a minimum and maximum data range (18). The minimal comparison sought to assess situations parallel to those in the first narrative analysis. Subsequently, the maximal comparison was made selecting narratives with contrasting differences about the first analyzed narrative, although still presenting elements for that comparison (18-20).

Sixth step

It corresponds to the identification of collective paths. In this phase, using a detailed analysis of the narratives and the case comparison, individual paths were contextualized, and the similarities were established. From the reconstruction of these people's life courses, these collective paths were presented as narrative synthesis, built with fragments taken from the participants' narratives revealing the experience of becoming ill from cancer and being in Palliative Care (18-20).

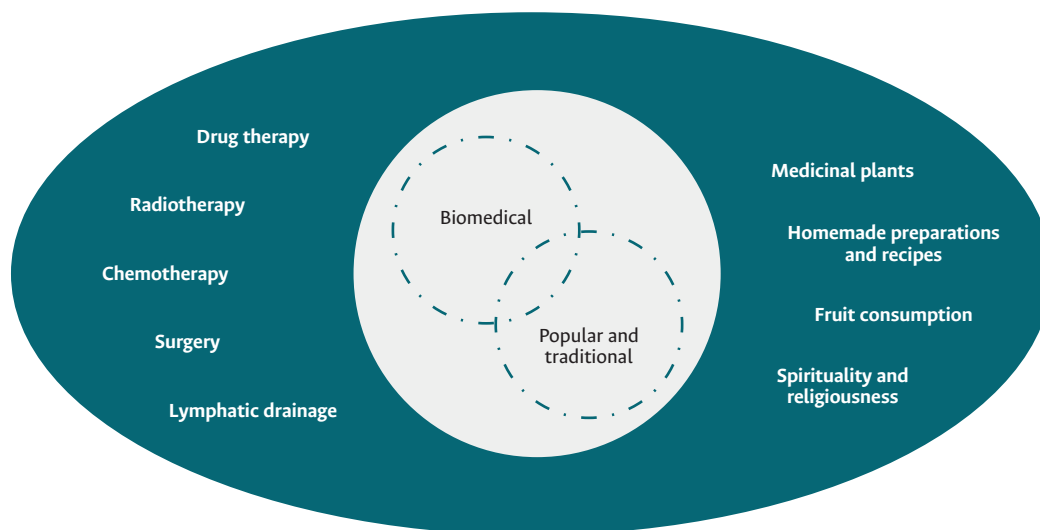
Data quality was ensured through the researcher’s constant reflexivity process. The study was approved by the Research Ethics Committee of the Nursing School at the Universidade Federal de Pelotas, numbered 1 190 419. The participants signed the Free and Informed Consent Form, and pseudonyms were used to grant anonymity, identified as “E”, corresponding to the interview (*Entrevista* in Portuguese), followed by a number to differentiate the participants according to the order in which the talks were conducted.

Results

Eleven patients with cancer participated while staying in Palliative Care: eight men and three women, aged from 51 to 79 years old. Regarding the diagnoses, there were two males with lung cancer, two males with rectal cancer, two females with breast cancer, and one male with colon, stomach, prostate central nervous system, and kidney tumors. Concerning religion and spirituality, four stated being Evangelicals, three believed in God, two were Catholics, one affirmed being a Gideon, and one, Spiritist. As for the main caregivers, there were five wives and four daughters, one patient was cared for by his daughters and wife, and another, by his nephew and daughter.

In the narratives, the participants used biomedical care and popular or traditional care modalities as supplements for biomedical cancer treatment, as described in Figure 1. The following categories were elaborated from the data analysis: *Biomedical care modalities and popular and traditional care modalities*.

Figure 1. Synthesis of the self-care modalities resorted to by the people with cancer at the end of their lives



Source: authors.

Biomedical care modalities

The following biomedical care modalities were identified: drug therapy, surgery, chemotherapy, radiotherapy, and lymphatic drainage. Such ones were initiated at confirmation of the cancer diagnosis, being prescribed by a physician specialized in oncology.

“A good medication is a strong medication”: radiotherapy and chemotherapy

The narratives about radiotherapy and chemotherapy were described as care modalities necessary to cure cancer. Chemotherapy was underlined in the narratives for its purpose and effects on the body since, for a “*bad disease*”, treatment needs to be aggressive to have “*results*”. The effects corresponded to a set of signs and symptoms, such as nausea, vomiting, heartburn, diarrhea, allergies, skin lesions, pain, and reduction in body immunity. For them (patients), chemotherapy is not only “*strong to fight against cancer*”; it is also “*strong for the body as a whole*”, as they experience the body’s transformation throughout the therapy.

In the first chemotherapy [...] I had an allergy like this, monstrous! I was in a lot, a lot of pain. I swelled all over, I skinned all over, I skinned down to the soles of my feet. I'm like a snake, I lost all my skin. I was going to have (a biopsy) in my liver too, but then it (the tumor) came back. I think that chemo that skinned my whole body was so strong that, thank God, it solved it (E1).

It was the radiotherapy that burned me inside; I used to put some things that looked like charcoal and that pain inside, just pain and pain. Those two, three days after the chemo, what I have seems to be heartburn up to the throat, coming and going, even vomiting (E6).

In the biomedical care modalities, especially chemotherapy, the participants found some barriers by undergoing the procedure and maintaining continuity, negatively influencing the “*battle against cancer*”. These barriers were related to lack of the medication in the oncology service and reduction in the immune system.

Then I've actually made only two chemos so far. Immunity is very low and that's not the worst thing [...]. I'm a little anxious about the delay in the chemo, so this took me by surprise. [...] It's going slow, but it's going (E1).

The surgery I underwent last year never healed; the wound remained always open. A really small ball appeared there. I talked to the doctor and she said “No, that's normal”. And it started to grow and grow from there. [...] It was the tumor coming out. [...] Then I was doing chemo, but it wasn't showing much result, so she asked for another one. We spent seven months waiting, then it came last month. [...] It's not easy! (E10).

When going through these care modalities, anxiety, fear, and uncertainties surrounded people with cancer as they experience moments of “*highs*” and “*lows*” and the presence of “*complications*”. Visible body changes showed that cancer was advancing, and the wait for chemotherapy made the situation even more distressing.

“It's a lot of medications”: polypharmacy

Another biomedical care modality identified in the narratives is the use of the drug therapy prescribed by the medical professional to be “complied with”, representing polypharmacy. Most of the medications were administered through the oral route and aimed at combating or relieving the effects of chemotherapy and radiotherapy, as well as those of cancer. Symptoms included pain, nausea, vomiting, diarrhea, dyspnea, heartburn, and anemia, among others. They had the support from family members to undertake such a modality.

It's a lot of medications, it's the antibody, it's for pain, for anemia, it's the antibiotic. And all together, they harm the stomach. [...] my wife helps me not to forget (E10).

I take my medications, with so many that I have, that I wait upon my girl to wake up to help me, because I forget (E11).

The narratives showed that to manage this biomedical care modality, the participants decided and chose not to follow the physician's prescription regarding the use of certain medications. Such a decision was made based on the signs and symptoms presented after their use: they observed and tested the medicaments, understanding that they could cause some undesirable effect.

He (physician) ordered me to take a medication and I said, “Ah, doctor, you're insisting, I'm not getting operated on.” “Then you take this medication here for 10 days; if you feel anything, at any time of the day or night, you call me.” I didn't take the medication because it was going to make me feel bad, I was going to end up going down (hospitalization), it was going to mess with me, at the time I told him, “why messing with a dormant giant” (E7).

The day I do the chemo I get really agitated, so agitated, believe me! Such a sad thing. After I found out that Plasil is what makes a person like that, then I stopped taking it (E4).

I take diazepam to sleep, but in the Z service, I was being practically doped, imagine: morphine and diazepam! Then I told my wife not to let me take them. They came and she didn't give me, she even filled the diazepam bag. [...] It was then that I started to get better because, if not, they'd even put a tube in me. Imagine: diazepam three times a day! (E10).

The biomedical care modalities mobilized the person with cancer towards better self-care and self-perspective. To know oneself as a person, participating in decisions about the care, identifying the body signs and symptoms experienced from the illness, beginning chemotherapy, radiotherapy, and using medications become familiar. Faced with polypharmacy, both in the type of medication and the frequency and daily amount, they acquired knowledge about themselves and the biomedical care modalities, which enabled self-management of the treatment. Consequently, a decision was made regarding what they considered adequate for them, according to the moment, the situation experienced, and how much it would influence on loss of autonomy in the disease.

Another biomedical care modality was the lymphatic drainage indicated by the medical professional. However, there were out-of-pocket expenses and, over time, the participants assessed that the drainage was not showing results, as they did not notice any relief or decrease in the signs and symptoms, as reported by E11.

There, it (the arm) really swells. [...] you do the drainage at that time, and tomorrow it's already swollen again. It's money, and more money, I gave up.

Popular and traditional care modalities

Practices with medicinal plants, fruit consumption, homemade preparations and recipes, spirituality, and religiousness were evidenced in the narratives. The most used medicinal plants were chamomile (*Matricaria recutita* L.), artemisia (*Artemisia absinthium* [Mill]. DC.), and physalis (*Physalis peruviana*) with infusion as main preparation, and others such as juice and *in natura* consumption. As for fruits, they used lemon (*Citrus spp.*) and soursop (*Annona muricata* L.); and, as homemade recipes, preparations made with aloe (*Aloe saponaria* Haw), honey, distilled spirits, and sodium bicarbonate. Such care modalities were used to cure cancer, of “killing the malignant cells”, slowing the progression of the disease, balancing the body, recovering immunity, and alleviating signs and symptoms, such as nausea, vomiting, pain, and indigestion; in addition to making it possible to reduce anxiety. As for the frequency, amount, and daily organization, they used them concomitantly, articulated, and/or overlapped with biomedical practices.

I use “physalis!” It's a plant that kills cancer cells, it has a shell on the outside, we make tea for the kidneys and liver. And the small fruit is for the lungs and for the white blood cells (E2).

And for stomachache, I've drunk some tea that my mother gives me, artemisia. I also drink chamomile tea (E10).

The soursop juice, they say, is very good; they say it kills the cancer cells, that it is very good, and I'm also using the leaf to make tea. I drink the juice three times a day (E8).

I knew I had cancer, but I didn't know where it was, so we made aloe syrup with honey and a distilled spirit, mixed it well in a blender, removed only the tips (aloe leaf), and took a spoon at lunch and another at dinner and that's how I spent the last ten years (E7).

In the narratives, the indication and recommendation occurred from the contact and sharing of their experiences with their peers, contact with family members, neighbors, and friends, in addition to consulting books and media. The situations that gained prominence, which determined and motivated, even more, to continue using such care modalities, were the following: improvement of the health condition, reduction and/or relief of signs, and symptoms, and delay in the progression of the disease. However, they constantly tested and assessed the usage of some practices from their body responses. Thus, the body was transformed into a mediator of the experience, being decisive or not with the care modality and transforming the person with cancer into an expert by experience.

Other popular and traditional care modalities were related to spirituality and religiousness. The participants reported practices from the Catholic, Umbanda, Spiritist, and Evangelical religions: prayers, cults, and spiritual surgery. They were performed individually or collectively; alone or in the company of family members, friends, and neighbors; and at their homes or in churches and temples. In some narratives, signs and symptoms of illness prevented them from going to churches and temples, although they did not preclude them from home practices. They developed their practices based on symbols not only from their religion but also taken from others, such as

the participant who was a Catholic welcoming the Evangelical pastor to receive prayers and had spiritual surgery; or the one that was an Evangelical participating in Umbanda practices. It unveils the multiplicity of “*spiritual sides*” to cope with the disease.

It is God that knows, it's no use. I attend X's religious services. It's Evangelical. It's really good! Then we go to church for faith, truly from the heart. I was once a Catholic, I was an Umbanda practitioner, I went there [...] to the (universal) pastor. I think to myself: “Help me Lord in such difficulty, give me the strength to get through it” (E5).

I love it, like this side (of religiousness) very much. I was really really bad those days, and I focused and talked to the Lord, and he answered me, thank you, God! And I cheered up, I calmed down, that pain calmed down, that vomiting calmed down, then I started to eat, then I slept peacefully for the rest of the night (E4).

I came back home (from church) super-happy, I slept all night. It didn't seem like there was anything like that; it took a weight off me (E10).

Spiritual surgery was one of the care modalities resorted by the participants, sustained by the beliefs and recommended by people from their social circle. After this practice, they evaluated it and the decision to follow the prescriptions or not was determined by not feeling physical “*improvements*”. A person from the community with a religious connection gave the blessing. The purpose of such practice was to keep faith in the face of the disease.

I had astral surgery once, but it wasn't done well. There's a lady [...] 'he's a very good neighbor, 'he's alive because of her faith. [...] she goes to church, takes my clothes, and blesses everything with oil [...] (E11).

The presence of faith and belief in something and/or someone had the purpose of “*relieving*” physical, emotional and spiritual sensations; in addition to being a way of approaching a “*higher being*” in the search for answers that would make it possible to understand and/or explain the disease. They developed these care modalities to attain the cure, relieve some sign or symptom, rescue the body-mind balance and for spiritual comfort, as well as a (new) meaning to life.

Discussion

Getting sick from cancer and being at the end of life led people to attribute a (new) meaning to this experience and mobilize in the search for practices in their life contexts, beliefs, and values, arising from social interaction with family members, friends, and community. These practices constitute them as a group and provide existential well-being, in addition to those from the biomedical model.

The self-care modalities for the person with cancer work both in a broad and restricted sense. The narratives revealed the efforts made by the family members to care for the person with cancer by using medicinal plants, blessings, religion, and/or spirituality. In the strict sense, the objective is to face distress (5); therefore, the practices applied occurred intentionally, for example, such as the use of drugs complemented with medicinal plants, homemade recipes, fruits, and blessings. Such being the case, the family, friends, and community were mobilized to welcome, support, and assist in the care provided to the person with cancer.

Studies evidence that there is family mobilization regarding a potentiating unit to care and develop practices that involve nutrition, medicinal plants, and faith. The family has beliefs and values that permeate their life, constituting both its individual and collective identity and, through the reproduction of knowledge among family members, they build their unique ways of caring in situations of illness (14, 15, 21).

The participants relied on the home groups to provide self-care, with the family members in charge of it. In those groups, women (daughters, wives, friends) promoted self-care practices. It was also evidenced that the caregiver role also fell on the women who participated in countless self-care activities. Therefore, the family network presented itself as a powerful source for the people at the end of their lives. A study with rural families who experienced caring for a family member with cancer pointed out that these practices are built from interactions among family members, sharing knowledge across generations and together with others developed in the community (21). Studies show that this knowledge comes from the family, especially from parents and grandparents, and is shared in the family's daily life; other sources of learning correspond to friends and neighbors, especially aged people (14, 15).

The use of popular and traditional self-care, such as self-medication, medicinal plants, and healing, was intensified according to the progression of the ailment and the effects produced by biomedical modalities. The participants not only described physical effects but also psychological such as anxiety, anguish, fear, and irritability. Similar findings were described in studies indicating that people in Palliative Care already used medicinal plants before contracting cancer to alleviate psychological and physical symptoms, but they intensified the use after diagnosis in search of therapeutic action to mitigate the symptoms of the disease, and also seeking the cure (14, 22, 23).

The use of medicinal plants as a self-care resource in patients with cancer is a growing practice (11, 14, 23) used as complements to biomedical treatments. Their purpose is to treat symptoms, cure and/or reduce the number of malignant cells to attain well-being, autonomy, and decision-making capacity regarding the care plan. In addition, they present themselves as a way to get closer to the health professionals, mainly nurses, establishing bonds (11, 14).

Another popular or traditional care modality that stood out in the narratives was the religious and spiritual practices. The fact of having a higher force helped them to accept life resulting from the disease. After confirming the cancer diagnosis, the people approached religiousness and spirituality, which led them to transcend in the face of finitude. Regardless of the religion, believing in something and/or someone promoted comfort and alleviated distress; besides led them to resort to multiple practices in different beliefs.

The number of studies pointing to spirituality and religiousness as important resources for cancer in life's final phase increases (24, 25). Both are intended to alleviate suffering even when death is imminent, to assist in understanding death as something natural, like turning the page or sleeping, valuing life considering the remaining time (24), and as a possibility of cure (11, 13). However, the cure is perceived as a slow and progressive process that can take place both in the physical and in the emotional and spiritual dimensions (13). They are modalities that promote an "existential encounter" between people at the end of their lives and health professionals in search of the provision of comprehensive care (24).

Cancer patients are likely to use complementary therapies to alleviate the cancer symptoms, the effects of chemotherapy and radiotherapy, and treat and manage psychological symptoms (anxiety and depression associated with cancer treatment). Such therapies are perceived as natural and safer than traditional treatments (4). A review study on the use of complementary and alternative therapies in cancer patients identified *reiki*, meditation, reflexology, and massage as beneficial in the short term in improving symptoms such as pain, anxiety, dyspnea, cough, fatigue, insomnia, nausea, and vomiting (23).

For Menéndez, the “existence of an incurable disease, as well as the search for solutions to existential sorrows, lead to a search and frequent creation of attributing new meanings to care modalities” (5, p. 188, free translation). Thus, when the treatments fail to control signs and symptoms or even produce undesirable effects, the patients, the families, and the caregivers can choose other approaches.

The use of therapies aimed at minimizing the undesirable effects of the disease and the treatment increases (4, 14, 26, 27). The decision not to inform the professionals about the use of non-conventional therapies is frequent among cancer patients and an identified situation in a study (14). In distress, when such care modalities are used, people still experience disrespect and discredit from the physician, resulting in a gap in the articulation between popular knowledge and scientific knowledge (14, 15).

Given the above, obstacles that hinder expanding these therapies in Brazil remain. This is justified in a study that points out that these obstacles can be due to insufficient professional training and deficient management of the health system, in addition to the legitimized tradition in using allopathic medicine and prioritizing biomedical practices (28, 29). The professionals can understand the primary role of the use of therapies in cancer patients, but they may underestimate the importance and need to establish policies (4).

As proposals for future research studies, it is recommended to explore self-care modalities from the perspective of gender and corporeality; and studies that investigate how to integrate different self-care modalities in health services, including oncology. In addition to studies that analyze the therapeutic itineraries of people at the end of their lives to understand the care models used in cancer.

The following can be mentioned as study limitations: the sample size and the conduction in just one home care service. However, it was possible to understand the phenomenon under study.

Conclusions

Narratives about suffering due to cancer made it possible to access the care modalities from biomedicine and the interaction in the family, group of friends, and the community. Based on the experience of the disease, spirituality and religiousness in the care of people at the end of their lives mainly stands out in the existential sense.

In a therapeutic aspect, the participants seek to understand and follow the therapy prescribed by the physician, the use of drugs and therapies with different modalities, frequencies, and amounts. They are shared with people from the same social circle, who also exert an influence on the choice about continuing their use or not. Throughout the treatment, it is noticed that other care modalities emerge, which are linked to the particularities of a disease like cancer, as well as to the final phase of life.

Regarding the implications for the practice, it is recommended to include the different self-care modalities as a possibility to attend people at the end of their lives. For the nursing practice, nurses must consider care needs to be guided from the perspective of those who experience the disease,

as a result of the significant changes that occur in their lives. Consequently, the professional can consider caring a collective construction that includes these people and their families in spaces where these experiences and practices are shared. Thus, each person will be able to develop more autonomy to express their wishes and decide on what is best for them. It is also necessary to implement actions to train nurses in the oncology services given that people in the final phase of life resort to different practices to meet their physical, social, emotional, and spiritual needs.

Financial support

The study did not receive any financial support.

Conflict of interest

The authors declare that there is no conflict of interest.

References

- (1) Hui D; Nooruddin Z; Didwaniya N; Dev R; De La Cruz M; Kim SH et al. Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review. *J Pain Symptom Manage.* 2014;47(1):77-89. <https://doi.org/10.1016/j.jpainsymman.2013.02.021>
- (2) International Association for Hospice and Palliative Care. Global consensus based palliative care definition. Houston: IAHPC; 2018. <https://bit.ly/31Yzzou>
- (3) Loza Taylor T; Ramírez Velázquez J. El cuerpo silenciado: reflexiones en torno a la experiencia de personas con cáncer terminal y sus metáforas. *Corpo-Grafiás Estudios Críticos de y desde los Cuerpos.* 2020;7(7):131-144. <https://doi.org/10.14483/25909398.16051>
- (4) Alqahtania MMJ; Holmes T; Al-Rammah TYM; Alqahtani KMM; Tamimi NA; Alhrbi FH et al. Are we meeting cancer patient needs? Complementary and alternative medicine use among Saudi cancer patients: a qualitative study of patients and healthcare professionals' views. *Eur J Integr Med.* 2018;24:54-60. <https://doi.org/10.1016/j.eujim.2018.11.002>
- (5) Menéndez EL. Modelos de atención de los padecimientos: de exclusiones teóricas y articulaciones prácticas. *Ciênc Saúde Coletiva.* 2003;8(1):185-207. <https://doi.org/10.1590/S1413-81232003000100014>
- (6) Menéndez EL. Sujeitos, saberes e estruturas: uma introdução ao enfoque relacional no estudo da saúde coletiva. São Paulo: Aderaldo & Rothschild; 2009.
- (7) River J; McKenzie H; Levy D; Pavlakis N; Back M; Oh B. Convergent priorities and tensions: a qualitative study of the integration of complementary and alternative therapies with conventional cancer treatment. *Support Care Cancer.* 2018;26:1791-1797. <https://doi.org/10.1007/s00520-017-4021-0>
- (8) Buckner CA; Lafrenie RM; Dénommée JA; Caswell JM; Want DA. Complementary and alternative medicine use in patients before and after a cancer diagnosis. *Curr Oncol.* 2018;25(4):275-281. <https://doi.org/10.3747/co.25.3884>
- (9) Alves APB; Pellegrini MA. Convivendo com a infecção pelo vírus da imunodeficiência humana em Boa Vista (RR): um estudo sobre autoatenção e itinerários terapêuticos. *Rev Eletrônica Acervo Saúde.* 2019;11(13):e941. <https://doi.org/10.25248/reas.e941.2019>
- (10) Osorio-Parraguez P; Navarrete LI; Briones BS. Perspectivas socioculturales de la autoatención y provisión de cuidados hacia personas nonagenarias y centenarias en zonas rurales en Chile. *Antípoda.* 2018;31:45-63. <https://doi.org/10.7440/antipoda31.2018.03>
- (11) Lima JF; Ceolin S; Pinto BK; Zillmer JGV; Muniz RM; Schwartz E. Uso de terapias integrativas e complementares por pacientes em quimioterapia. *Av Enferm.* 2015;33(3):372-380. <http://doi.org/10.15446/av.enferm.v33n3.53363>
- (12) Mendes AS; Arantes TC; Martins VE; Nicolussi AC. Práticas integrativas, espirituais e qualidade de vida do paciente com câncer durante o tratamento. *Rev Eletr Enferm.* 2020;22:57987. <https://doi.org/10.5216/ree.v22.57987>
- (13) Aureliano WA. Terapias espirituais e complementares no tratamento do câncer: a experiência de pacientes oncológicos em Florianópolis (SC). *Cad Saúde Colet.* 2013;21(1):18-24. <https://doi.org/10.1590/S1414-462X2013000100004>
- (14) Bonow CT; Ceolin T; Lopes CV; Zillmer JGV; Vargas NRC; Heck RM. Medicinal plants used in self-care by people with cancer in palliative care. *Texto Contexto Enferm.* 2020;29: e20190329. <https://doi.org/10.1590/1980-265X-TCE-2019-0329>
- (15) Badke MR; Barbieri RL; Ribeiro MV; Ceolin T; Martínez-Hernández Á; Alvim NAT. Meanings of the use of medicinal plants in self-care practices. *Rev Esc Enferm usp.* 2019;53:e03526. <http://doi.org/10.1590/S1980-220X2018047903526>
- (16) Cavers D; Habets L; Cunningham-Burley S; Watson E; Banks E; Campbell C. Living with and beyond cancer with comorbid illness: a qualitative systematic review and evidence synthesis. *J Cancer Surviv.* 2019;13:148-159. <https://doi.org/10.1007/s11764-019-0734-z>
- (17) Geertz C. *A interpretação das culturas.* 1 ed. Rio de Janeiro: Guanabara Koogan; 2008.
- (18) Schütze F. *Die technik des narrativen interviews in interaktionsfeldstudien: dargestellt an einem projekt zur erforschung von kommunalen machstrukturen.* Bielefeld: Universität Bielefeld; 1977.

- (19) Meincke SMK. A construção da paternidade da família do pai adolescente: contribuição para o cuidado de enfermagem. Florianópolis (Br): Universidade Federal de Santa Catarina; 2007.
<https://repositorio.ufsc.br/xmlui/handle/123456789/90500>
- (20) Weller W. Tradições hermenêuticas e interacionistas na pesquisa qualitativa: a análise de narrativas segundo Fritz Schütze. 32ª Reunião Anual da Anped; 04-07 de out 2009; Caxambu (MG): Anped; 2009.
<http://32reuniao.anped.org.br/arquivos/trabalhos/GT14-5656--Int.pdf>
- (21) Zillmer JGV; Schwartz E; Muniz RM. O olhar da enfermagem sobre as práticas de cuidado de famílias rurais à pessoa com câncer. *Rev Esc Enferm usp*. 2012;46(6):1371-1378.
<https://doi.org/10.1590/S0080-62342012000600013>
- (22) Minuto JC; Ceolin T; Mercali LMF; Bonow CT; Lopes CV; Azevedo NA. Práticas de cuidado realizadas por pessoas que convivem com o câncer. *J Health NPEPS*. 2021;6(2):185-201. <http://doi.org/10.30681/252610105387>
- (23) Zeng YS; Wang C; Ward KE; Hume AL. Complementary and alternative medicine in hospice and palliative care: a systematic review. *J Pain Symptom Manage*. 2018;56(5):781-794.
<https://doi.org/10.1016/j.jpainsymman.2018.07.016>
- (24) Arrieira ICO; Thofehrn MB; Milbrath VM; Schwonke CRGB; Cardoso DH; Fripp JC. O sentido da espiritualidade na transitoriedade da vida. *Esc Anna Nery*. 2017;21(1):e20170012.
<https://doi.org/10.5935/1414-8145.20170012>
- (25) Benites AC; Neme CMB; Santos MA. Significados da espiritualidade para pacientes com câncer em cuidados paliativos. *Estud Psicol*. 2017;34(2):269-279. <https://doi.org/10.1590/1982-02752017000200008>
- (26) Jones E; Nissen L; McCarthy A; Steadman K; Windsor C. Exploring the use of complementary and alternative medicine in cancer patients. *Integr Cancer Ther*. 2019;18:1-9. <https://doi.org/10.1177/1534735419854134>
- (27) Lopes-Júnior LC; Rosa GS; Pessanha RN; Schuab SIPC; Nunes KZ; Amorim MHC. Eficácia das terapias complementares no manejo da dor oncológica em cuidados paliativos: revisão sistemática. *Rev Latino-Am Enfermagem*. 2020;28:e3377. <https://doi.org/10.1590/1518-8345.4213.3377>
- (28) Reis BO; Esteves LR; Greco RM. Avanços e desafios para a implementação das práticas integrativas e complementares no Brasil. *Rev APS*. 2018;21(3):355-364.
<https://doi.org/10.34019/1809-8363.2018.v21.16383>
- (29) Barros LCN; Oliveira ESF; Hallais JAS; Teixeira RAG; Barros NF. Práticas integrativas e complementares na atenção primária à saúde: percepções dos gestores dos serviços. *Esc Anna Nery*. 2020;24(2):e20190081.
<https://doi.org/10.1590/2177-9465-ean-2019-0081>