Research Article

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The family caregiver's experience of oncology patients

Abstract

The aim of the study was to understand the experiences of family caregivers of patients diagnosed with cancer. The information was collected through semi-structured interviews with topics related to experiences during the accompaniment of the family member with cancer. The results allowed the construction of five categories that integrate the experiences of family caregivers of cancer patients: emotions, communication, biographical break, care for the patient and transformation. It is concluded that the caregivers' experiences show a variety of experiences ranging from suffering to significant learning. One of the major contributions of this study are the proposals to accompany the caregiver of cancer patients in two dimensions: the health/organizational dimension and the social family dimension.

Keywords: construction of meanings, family, cancer, caregivers, grounded theory

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Introduction

By 2025, approximately 83,562 new cancer cases and 33,280 cancer deaths are estimated in Venezuela, representing an increase of 14.64% in incidence and 28.8% in mortality compared to previous data from 2016. Cancer continues to be the second leading cause of death in the country, with the most common types being lung, breast, prostate, colon and rectum.[1] Venezuelan family caregivers of cancer patients continue to face a high physical and emotional burden. A 2020 study of 200 caregivers in Caracas showed that the majority are women who dedicate between 13 and 24 hours per day to caregiving, and that active coping and good family functioning are protective factors for their health-related quality of life.[2] Psycho-oncology plays a fundamental role in mitigating the emotional exhaustion of caregivers, who frequently present symptoms such as anxiety, depression, insomnia and social isolation. Psycho-oncological intervention includes cognitive and supportive therapies, psycho education and bereavement support, improving the quality of life of both the patient and the caregiver.[3] Despite the recognized importance of psycho-oncology, access to specialized services remains limited in Venezuela, underscoring the need to expand psychosocial support programs for caregivers and oncology patients.[4] A recent study in Ecuador[5] confirms similar trends in the emotional and physical burden of family caregivers, which may be representative for the region.

Recent authors have corroborated and expanded Baider's approach[6] on the systemic impact of cancer on the family environment. The diagnosis of this disease does not affect only the patient,[7] but incites a collective process of emotional, cognitive and relational adaptation among family members. The presence of a cancer patient generates a process of reflection, reorganization and redefinition of roles and priorities among family members. The family becomes an integral part of the disease process: its members are affected in their daily lives, in their plans for the future, and in the meaning they give to themselves and to their emotional ties.[8,9] Primary family caregivers often experience high levels of stress, anxiety and depression, especially when faced with a significant caregiving burden. This burden can negatively affect their quality of life, interfering with their daily routines and overall well-being. In addition, perceived severity of illness and psychological inflexibility can mediate the quality of life of parents with cancer, affecting family outcomes as well.[10,11] Illness can represent a threat to family cohesion, but also an opportunity for post-traumatic growth, deepening of bonds and strengthening of the resilience of the family system.[12,13] Recent studies have shown that the quality of family relationships, open communication and mutual support act as protective factors that mitigate the impact of cancer and improve both the well-being of the patient and his or her family members.[14] Furthermore, it has been identified that joint coping with the disease involves a re-signification of the meaning of life, and that this process is mediated by the family's ability to adapt emotionally, to share fears and to construct a common narrative of the cancer experience.[15,16] In this sense, the disease becomes a collective experience that, although painful, can also generate processes of introspection, solidarity and transformation Despite the challenges, many families develop resilience, adapting to new circumstances and strengthening their bonds. Family resilience has been positively associated with patients' subjective well-being, mediated by perceived social support and psychological resilience.[17] Likewise, the ability of parents to use personal resources in the face of significant challenges enhances the resilience of the family system, suggesting the need for targeted interventions that provide support not only to the patient, but to the entire family system.[18] Open communication within the family is crucial in coping with cancer. Studies have highlighted the need to foster open communication in families with parental cancer, as this can influence family dynamics and adaptation to the disease process. In addition, cancer can affect intimacy and family life, and addressing these aspects is essential to maintain healthy relationships during treatment and recovery.[18,19] Family caregivers often experience anticipatory grief, especially when the patient is in advanced stages of the disease. This type of grief may be related to caregiver burden, family resilience, and coping strategies.[20]

To mitigate the negative effects of cancer on the family, various interventions have been proposed. Psycho educational education has been shown to be effective in improving the quality of life of caregivers and reducing their burden. Interventions focused on emotional regulation and psychological support can be beneficial for caregivers, helping them to manage anxiety and depression associated with caring for a loved one with cancer.[21] Several recent studies have pointed out that, although researchers in the social sciences continue to collect a wide range of accounts from their informants in order to understand their experiences, the necessary attention is not always paid to the narrative forms these discourses take. The relationship between the content of narratives, their narrative structures and the performative modes of enunciation remains a crucial analytical challenge in the qualitative field.[22] In addition, the role of narrative schemas - cultural and linguistic models that structure the way in which an experience is told - has been revalued as key tools for interpreting complex social phenomena. Thus, contemporary narrative analysis is situated at the intersection between language, identity, power and subjectivity, and becomes relevant not only as a methodological technique, but also as an epistemological framework for the production of situated knowledge.[23]

Method

The research is framed within the paradigm of constructivism that points to a relativistic epistemology, i.e., it assumes the existence of multiple realities because they depend on the mental constructions of the people who conceive them. From this epistemology, the only thing knowable are the meanings attributed by individuals, which are accessed, among other ways, through language.[24] A qualitative methodology was used with descriptive data with characteristics such as: induction, holistic perspective, sensitivity to the effect of the researchers on the subjects, consideration of the frame of reference of the researched who bring their own perspectives and consider the others valuable, and emphasize the credibility of their findings.[25]

Selection of the context and participants

The participants were fourteen family members accompanying patients hospitalized at the Luis Razetti Oncology Institute located in Caracas: 9 women and 5 men, with different relationships with the patient (6 daughters, 1 son, 2 mothers, 1 daughter-in-law, 1 sister, 2 husbands, 1 nephew), aged between 29 and 78 years. The participants attended the talks for the family members, and gave their consent to conduct the interviews, which made it possible to initiate a "theoretical sampling"[26] oriented to the exploration and deepening of the concepts emanating from the analysis of the first texts collected. The sampling process continued until it came as close as possible to theoretical saturation, that is, to "the point in the construction of the category at which no new properties, dimensions, or relationships emerge during the analysis" (p. 157).[2,6] The Doctoral Studies Committee of the Universidad Central de Venezuela (UCV), endorsed the methodology and procedure for the collection and validation of the information presented in this research as a degree work for obtaining a doctoral degree. In reference to the ethical aspects, we considered the anonymous nature and the use of informed consent to participate in the research and to be recorded during the interviews.[27–29]

Data collection techniques and instruments

The central technique used was the semi-structured interview[25] with a "script", which collected the central themes of the experiences of family caregivers of cancer patients:

i. Experiences in the presence or current accompaniment of people with cancer, previous experiences, needs, concerns, personal, family, community and cultural strengths that they find in their context.

ii. Relationship with the patient, between family members and health professionals during the illness.

iii. Restructuring of personal and family routine in the presence of the disease.

iv. Lessons learned from the experience of the disease.

v. Resilience factors. Factors to identify what is useful and effective in overcoming adversity.

Data analysis and processing method

Grounded Theory, which corresponds to the research strategy followed here, involves a process of information analysis with two basic operations: the formulation of questions to initiate the inquiry and direct the theoretical sampling, and the making of constant comparisons between phenomena and theory, in order for the researcher to formulate properties and dimensions of the categories.[26] To advance this last process of comparison, three basic analytical processes were proposed: a) Open Coding, through which"(...) concepts are identified and their properties and dimensions are discovered in the data";[26] b) Axial Coding, in which the data that were fragmented through open coding were regrouped. This grouping was carried out around a central category, hence the name Axial, and c) Selective Coding, in which the main categories were integrated to form the theory. Here the saturation of the categories was observed, excess data were eliminated and the theory was outlined. A theoretical proposal called "The experience of the family caregiver of oncology patients" was created, which contemplated five categories that synthesize the experience of the family caregivers of oncology patients (emotions, communication, biographical breakdown, adjustments and transformation).

Results

The analysis and categorization of the family caregivers' narratives allowed the construction of five major categories that integrate the experiences of family caregivers of cancer patients: emotions, communication, biographical break, care for the patient and transformation. The categories created are presented below, initially by characterizing them and then by describing the experiences encountered:

I. Emotions/feelings: Basic emotions such as fear (or joy) constitute those responses of the individual with a high intensity, short duration, accompanied by physiological responses and part of the genetic baggage. The basic emotions give way to other less intense, more lasting and with less physiological responses that become the so-called feelings that accompany us in a more lasting way that make us "suffer" or experience "well-being" or "happiness". When family members of cancer patients tell the stories of their relatives with cancer, basic emotions such as fear often surface from the beginning: fear of what is to come, fear of challenges, fear of suffering, fear of information and its impact, fear of loss. This fear is often accompanied by episodes of crying and anguish, as evidenced by physiological manifestations such as sweating, hand rubbing and impaired speech (low volume, lack of fluency, silences). The relatives' accounts include different aspects: the patients' own denial of their condition, which leads to reluctance to visit doctors or undergo examinations, then the relatives' refusal to share information about the disease with the patient or other relatives, as well as the refusal to explicitly express fear or pain in front of others. On the other hand, some family members report that, once they had experienced the initial emotional shock, they presented thoughts, feelings and active coping actions to accompany their relatives. Manifestations of family unity, contribution of all members, shared concern-occupation, as well as the recharge of a single member, lack of family unity and even abandonment or hindrance, were also evidenced in some of the interviews, highlighting the positive-negative polarity of the appreciation of human behavior in a situation (in this case the presence of a sick family member).

II. Communication: Exchange of information between the different actors (patients-families-doctors) in reference to aspects related to the disease (symptoms, emotions, diagnosis, needs, learning) and the appreciation (positive or negative) that is made of them. The communication of the relatives with the patient, physicians and other relatives is repeatedly pointed out by the latter, most of the times with the inclusion of a value judgment on its adequacy-inadequacy. Making a negative evaluation of the communication carried out, making a positive and grateful judgment of the information received, stating without judgment the information received, feeling excluded from the information about the family member, pointing out that other family members are not interested in knowing or having the information, are samples of the episodes narrated by them on the communication between the different actors and their evaluations. In reference to the communication of the diagnosis to the rest of the family members, we also see a continuum that goes from the importance and valuation to the exclusion of information to the patient or to some member of the family. The denial of information about the disease has already been studied and described in the literature and is known as the "conspiracy of silence".[30] This phenomenon occurs when family members or a group of family members hide information from the patient and even from other family members who are considered weaker. Some people require and demand information about the cancer disease. Other family members, as an alternative form of communication, with a high adaptive value, resort to humor to relate to the patient, as a way to face the difficulties and demands they present.

III. Biographical break: Changes and interactions required in the interpersonal relationships and routines of the family (patient and family) when the disease is diagnosed and the medical consultations and indicated treatments begin, secondary consequences of the treatments, variations in family, work and social routines. The onset of the disease is presented as the scapegoat, the trigger, the responsible and the cause of what happens in the relationships between family members. The presence of cancer in a family generates mobilization in each of the members and can exacerbate some characteristics, show situations that had been kept hidden or serve as a scapegoat to justify some difficulty present in the family climate. Interactions and their negative or positive connotations arise from the family member with the patient, the doctors and other family members taking the disease (cancer) as the center, making the appearance of the disease appear as the trigger, the responsible and the cause of what was already happening in the relationships between family members. The meaning of cancer disease in a family (its members) as a *biographical break* refers to the moment of onset of the disease in one of its members and the evolutionary phase of the disease. Various elements begin to emerge in the form of questions: what is the role within the family of the sick member, do the adjustments and demands of the cancer disease affect the family? What is the meaning of the cancer disease and the level of uncertainty about the patient's future health? It seems that all these concerns arise from previous experiences or recent information that each family has had with the same family member or other close cancer patients. It seems that among the related problems faced by the couple and the family in general are: the obligation to provide constant care to the patient, the interruption in their marital, family and social intimacy, trying to reduce the emotional anxiety of the patient, as well as the needs and expectations that conflict with each of the healthy members of the family. On the other hand, family members become an integral part of the trajectory of the disease, and the disease can be perceived as a potential danger of personal and family disintegration or as an opportunity for strengthening the family, recovery, adaptation and understanding of the needs and expectations of each family member.[6]

One of the most significant elements of this point appears in the family members' accounts, referring to the fact that the patient is taking medications or natural products (thistles, yogurts with weevils or other animals), parallel to the formal treatment they are receiving in the hospital. The taking of natural treatment for some is pointed out as something that can do them good, others make reference to friends who have been saved thanks to them and others point out that it is necessary to try everything "just in case". In reference to what it means for the family, and specifically for each of its members, the presence of a cancer patient in their midst can provoke very varied reactions. It seems that a certain type of cancer can inspire so much uncertainty, thinking that it can be contagious, that it causes some family members to flee. The relationship with cancer, the word that evokes it, the associated meanings, the lack of information about it, previous experiences or its relationship for some with death, make up for many relatives a particular way of referring and relating to this disease.

IV. Care of the sick person: Actions of the family caregiver aimed at caring for the sick person and their evaluation as stressful events or not because they consider that personal resources are sufficient to cope with them related to medical appointments, food, medication, emotional reactions and company in general where the individual must reframe or reorganize all his/her routines to care for the other sick person and him/herself. Generally, the task of caregiving requires a person who is always accompanying the patient; in many cases, only one person is in charge of these functions. The main caregiver of a chronically ill person is a person who is self-appointed, delegated by the family group or the result of a consensus, and becomes the one who shares most of the time with the patient and helps to meet his or her needs. It seems, on many occasions, that the relatives feel that they play a very important role in their lives in the care of their loved one, but at the same time there is a feeling of exhaustion and a feeling of "being alone and needing help". Also in some relatives the use of the first person singular "I" or "me" is very marked, which denotes in many cases, and is confirmed in the rest of the story, that they are the only caregivers of the sick person, generally with a very hard and lonely burden. Others are concerned that the patients do not show signs of distress, but rather hide it. In some accounts the family member is cared for by the nuclear family that takes charge. In these cases the women (generally daughters) take charge with the help of other family members, mainly children and grandchildren, who present it as a shared care. However, there are feelings of abandonment and lack of attention from the extended family. Other caregivers' testimonies show that some members of the family are gradually collaborating in the care of the patient. Some relatives think that the way in which other relatives collaborate is not the best, and this disagreement is manifest. Others, when talking about the people who have supported them during the family member's illness, do not refer to relatives, but to friends. Other relatives report an excellent team with the family members, where each one uses his or her strengths to take care of the patient. On the other hand, some family members (mainly men) feel excluded from the care, information and everything that the disease implies.

V. Transformation: Conscious manifestations by the family member of the changes that have occurred in his or her person, or in others, as a result of the demands of the illness of his or her loved one, which are evaluated as transformations, achievements or learning. All the constructs found and defined present a polarity in their manifestation in the persons interviewed, in our particular case, the relatives of cancer patients. In this way and as is usual in the literature on the clinical and health area in psychology, what first becomes evident, and even what people expect to be asked or wish to tell, is referred to the negative or difficult side of the situation they are going through, but in many circumstances the elements, supports or positive experiences presented in parallel (for some) and as a later balance (for others), which have flourished, are subsequently recognized, allowing the evaluation of positive aspects in the performance and development of the different actors. When we go deeper into the interviews with family members about the experiences lived in the care of the sick person, the changes that occurred in their person or in others as a result of the demands of the disease appear, which are later perceived as transformations, achievements or learning. Moving away from the disease and the moments of highest physical and psychological demands seems to allow taking stock of what has been learned about life, health, family, faith and small details. Some interviewees mention faith, the will to live and the examples of recovery of others, as lessons learned and the best treatments for recovery. All of the family members' accounts show the lessons learned from the experience of accompanying and caring for their sick family members. These include the development of personal strengths such as perseverance, the current management of information or skills about the disease and the care of the sick, valuing others, valuing life and health more, and recognizing changes in others. All the family members mentioned the importance of support networks and the family, but when referring to the lessons learned from the experience of accompanying a family member with cancer, the men are the ones who most explicitly stated that they learned that the family is the most important thing and that it is necessary to take care of oneself.

Discussion

The experience of the cancer disease by the family members, particularly the caregivers, who were the protagonists of this study, and by the patient himself, seem to be two sides of the same coin. The caregiver experiences the disease as if it were his or her own: feels the same, fears the same, wonders the same, suffers the same, learns the same, confirms in a deep and complex process that we are vulnerable, mortal. The reading and analysis of the narratives of the relatives have allowed us to approach the meanings that they have constructed in the accompaniment of the oncological patient.[30] Considering the authors' ideas on the construction of meaning in narratives,[31,32] we learned that family members relate their experience of their relative's cancer story as co-protagonists, and sometimes even as the main actor in the story, because they are the ones who first heard the news and/or have had to lead or undertake, with different levels of help from other family members, all the decisions and adjustments necessary for the care of the patient. In the narratives of the accompanying family members or caregivers of cancer patients, in spite of how varied they may be, which is considered a value for diversity, we note a generalized concern for the care and well-being of the patient, evidencing a biographical break due to the onset of the disease as an element of vulnerability. This confirms the findings of another study with Venezuelan caregivers who showed a high physical and emotional burden derived from the care of the family with cancer.[2] The study of the personal processes that accompany the family member during the history of accompaniment of his family with cancer resulted in the creation of five major processes (**emotions, communication, biographical break, care of the patient and transformation**), which appeared recurrently during all the interviews. These elements made it possible to create a large album of the family member and his most intimate experiences, which made it possible to diagnose his needs and at the same time his resources and learning.

The personal processes collected, with their varied manifestations, can help to validate, on the one hand, the care spaces for family members and, on the other, the design of new scenarios. In their experiences, many informants referred to the chronic fatigue they suffer as a result of the same. This phenomenon has been described by various international and Latin authors associated with public service professions such as doctors and teachers.[33,34] Some research reports that close relatives of cancer patients experience poor psychological well-being, diminish the quality of the relationship with the patient, suffer and reduce their physical health[4] One study analyzed the experiences of caregivers (mostly family caregivers) of patients in cancer settings, finding that both genders work hard to manage patients' emotions as well as the stage of their own emotions, aspects that are intimately connected.[36] As was found in our interviews, some caregivers expressed the need for help in particular tasks and manifested presenting personal effects of caregiver task fatigue. The cited authors also state that caregivers feel that they have and want to be strong and positive and try to maximize the meaning of life by leading it as normal. In performing this emotional labor, caregivers, especially spouses, often symbolically share the illness as a joint struggle. All studies highlight the importance of the couple in caregiving and the positive effects when the couple is involved and attends intervention programs, presenting positive effects in both members. The Venezuelan reality, where it seems that couples do not play this role of complementarity and the relational need is filled with the "children, being caregivers or allowing themselves to be cared for,[37,38] indicates that the support provided by the relatives that make up each family nucleus (older children, nieces, nephews, also sisters and parents) who care and offer their support, is more relevant and becomes a figure, in all the stories of the relatives, before the support of the couples. As we have pointed out on previous occasions, two accounts of men (husbands) corroborate this reality of not considering male caregiving as ideal, mainly on the part of women. The Venezuelan Anticancer Society[4] suggests the need to expand psychosocial support programs for caregivers and cancer patients.

Some stories focused on the request to others (physicians or health personnel in general) to provide them with this information in order to be able to care for their loved ones; other testimonies referred to the impulse that the news had generated in them to inform themselves and independently seek information about cancer in books, on the Internet, from other people who had suffered from it, in the services provided by the hospital or from some other source. The importance given by family members-informants to the support of other family members and professionals is confirmed by another study[39] which emphasizes the role played by social support (whether family, community, health centers or state policies) in the prevention, maintenance of health and cure of the disease. In this way, he suggests that concepts such as "social networks," "community support systems," "social support" or "environmental resources" are fundamental for care when a person has health problems.[40] Different authors stress the importance for the well-being of individuals of the resources derived from the different social relationships maintained, such as emotional and instrumental support, emphasizing the role communication and family cohesion.[14–16] Continuing the development of the personal processes experienced by the family member, we found the dimension referring to the personal process of suffering, which contemplated various stories that made mention of personal suffering and the avoidance of the suffering of the patient. In other researches that studied the effects of an intervention group among family members, positive effects were found for burnout syndrome, depression and anxiety.[41,42] Recent studies[18,43] confirm that it is possible to develop the capacity of parents to use personal resources for coping and resilience of all members, suggesting the need for targeted interventions that provide support not only to the patient, but to the entire family system.[21] The end of all the stories contemplated the learning that the family informants expressed as a result of their experience of accompanying their relative with cancer: perseverance, valuing life, faith, health care, the importance of caring for others and being good, the support of the family, the knowledge acquired and the significance of the spaces for learning and reflection with people who share the same reality. These same results have been confirmed in various studies pointing out the importance of support groups.[43,44] On the other hand, the testimonies collected in this category confirm what has been found in studies of caregivers of family members with cancer in Spanish samples, where they state that caregivers experience emotional problems when they do not understand why their family member got cancer, and at the same time they are in a search for meaning that allows them to experience positive elements and learning in caregiving, which can provide enriching meanings for their own existence.[45]

In relation to the information provided by the physician, there is an enormous variation between different countries, although there is a progressive tendency to increase the information, motivated in part by changes in the attitude of physicians, but above all by legal and technical aspects. The authors present a compilation of studies that show how the criteria for non-communication of the diagnosis have been changing in recent decades.[46] Studies on the desire for information about a cancer diagnosis indicate that the majority of the population stated that if they had a serious illness they would want their physician to tell them, while at the same time expressing the desire to withhold the information from a close relative if they were in such a situation.[47,48] This tendency, known as the "conspiracy of silence" appeared in the accounts of our family informants and in a multitude of studies, independently of socio-demographic and cultural factors. The construction of the grounded theory on the meanings constructed by the family members in the accompaniment of the oncological patient allowed relating the explanatory framework already created by different scholars in the area of the health-illness continuum, psycho-oncology and the characteristics of the Venezuelan family, with the narratives of the interviewees. This made it possible to consider narrative schemes as cultural and linguistic models that structure the way in which an experience is told in each society.[23] It was possible to corroborate theoretical findings such as the sequence of the mourning process through which chronic and cancer patients go through, initially described by Kubler Ross:[49] denial, anger, negotiation, depression and integration. Even recent studies emphasize the accompaniment of the anticipated mourning to the relatives when the patient is in advanced stages of the disease. The presence of the phenomenon called conspiracy of silence has also been confirmed.[30] On the other hand, we found some characteristics in our interviewees that corroborate aspects already studied of the Venezuelan family and the role of men and women, particularly in child rearing and caregiving, where women exercise their role as caregiving mothers.[37] We were able to go deeper into the role of men in caregiving, thanks to our male informants, mostly husbands, who were present but some said they felt "excluded" from information and caregiving and/or labeled as "attached to the sick" for wanting to be always close and informed. This point seems to explain the nonparticipation of some men in caregiving, on the part of women, because they are not considered prepared for it.

Everything presented in this study allowed characterizing the experiences of relatives of patients accompanying the oncology patient, presenting general aspects found by researchers in other countries and aspects that seem to be characteristic of the Latin American and Venezuelan family and culture. The synthesis of the aspects found in the construction of meanings of the relatives of cancer patients taken from the testimonies of the relatives allowed pointing out the presence of five concepts or constructs: emotions, communication, biographical break, care for the patient and transformation. These processes are present in all family members of oncology patients and present the positive-negative continuum, presenting themselves in different ways in each member. The theory of complexity and its principles support what was found in the accounts of our family-caregiver informants, who, experiencing the same processes and in contrast to simplification, presented a varied range of meanings (which evidences diversity as a value). The meanings of the experiences in the presence of a family member with cancer present their personal construction and their way of self-organization in the face of uncertainty, suffering and vulnerability.[32]

Conclusion

Understanding the meanings constructed by family members in accompanying the cancer patient through the different stages of their trajectories makes it possible to analyze the vulnerability and variability of the main family caregivers and other actors such as the patients and health personnel, while revealing the possibilities of constructing new meanings and practices. Vulnerability and variability in family and professional involvement are mutually implicated, and both processes can give rise to recommendations from two dimensions: the health/organizational and the family/social.

Recommendations in the health/organizational dimension

This dimension covers the health system, its organizers and its actors, presenting facilitating and hindering aspects of care for cancer patients and their families. Although this study was carried out in a single health center, which is the national reference institute for oncological diseases, we know that some of the realities encountered are particular to this center and others are common to all health care centers throughout the country. One of the first points that appeared in all the interviews as a very important element for the family members who become caregivers and attend the consultations with them is the relationship and exchange with the health professionals who take care of them. This point seems to require revision and resizing on the part of some of the protagonists. The exchange with the patient and all family members who can accompany and support in any way, exploring their knowledge, needs and resources, is fundamental for the care of the cancer patient. From the first moments of onset of symptoms of the disease, followed by visits and medical examinations and obtaining a diagnosis of cancer, the need for accompaniment and support with information about the disease and its treatment, knowledge of the emotions that arise, the importance of shared care, communication with the patient and among the different members, the management of the change of routines, the possibility of learning and the transformations resulting from the experience become enlightening elements to transit and accompany from the different roles of the family members together with the cancer patient. This exchange with the patient and his family can be strengthened in the consultations with the doctor, in the delivery and explanation of test results and in the accompaniment during the whole disease. The diagnosis is the starting point and model for the exchange of information between health personnel, patient and family members. The information to the family and the patient about the diagnosis of cancer should be led by the attending physicians and the entire hospital health team, in order to facilitate good management of the disease by the whole family from the beginning. Great differences were evidenced on this point, which requires study and training of health personnel, particularly physicians, in the form of workshops in the area or some type of training during their undergraduate or graduate studies as health professionals who must deal with vulnerability, illness and even death. However, a review of the existing literature on this topic reveals the complexity that this point brings to light.

The psychosocial connotation of this disease, to which health professionals are no strangers and which fundamentally affects the physician to a great extent, makes the communication of the diagnosis a real problem and this is reflected in the different positions that are reflected in the most updated world literature on the subject. Some authors[46,50,51] remind us of a point that should be considered in any training program for health professionals working with chronic and fatal diseases in reference to the psychosocial connotation of this disease, which marks great differences in the positions of physicians, patients and family members regarding the management of information and exchange with other actors about the disease. Seminars on the analysis of personality differences, cultural elements associated with the disease and acceptance of diversity from a comprehensive framework of complexity theory[32] seem to be mandatory. A second point within this dimension of recommendations in the health/organizational area. It is a complement to the first point and refers to the presence of support groups for cancer patients and/or their families. The presence in oncology hospitals of teams that systematically provide group and individual attention and guidance to all patients and their families is reported as a very useful aspect in coping with cancer. This need to know and get specialized support can be crystallized in initial informative psycho educational talks or in permanent support groups.

On the other hand, the presence of educational materials on the treatments, the patient's nutrition, the psychological processes experienced by the patient and caregivers and the different medical and logistical aspects of the patient's care are of great help to the family members. Similarly, the possibility of visits to the patients' homes by physicians, psycho-oncologists or groups of volunteers was considered a highly valuable alternative for the care of patients and their families. The possibility of telephone lines or web pages available for consultations in reference to doubts or needs directed to the patient and their relatives seem to be emerging alternatives that could cover primary care in a more massified and efficient way, referring only those situations that require more direct attention. Some of the aspects presented in this point were extracted from the interviews with family members and health personnel working at the Luis Razzeti Oncology Institute (IOLR), such as a permanent support group led by the center's Psycho-oncology service, which periodically offers talks for new patients and their families and a permanent program of talks, workshops and activities for the patients and their families as an aid that they report as very important and very useful for "dealing with the disease" and which the health professionals recognize as the central nucleus of their work at the center. The other aspect is home visits by health professionals to patients with mobility difficulties. These two services for patients and their families could be examples to be applied as institutional policies in other cancer institutes in the country. Other aspects presented in this section for the support of oncology patients and their families such as informative material, web pages and telephone hotlines have been taken from other institutions or initiatives at the national or international level for the care of oncology patients-families or those with other diagnoses and have been of great help as an individual tool or as a complement to the face-to-face care offered by talks, workshops or home visits.

As a third recommendation, it is suggested that health personnel should respect the use of alternative anesthesia by patients. We recall once again the approach of the authors[52] who remind us that the combination of conventional or allopathic treatments with non-conventional treatments (alternative/complementary, traditional, religious and self-medication) are phenomena that occur worldwide and present specific practices rooted in popular beliefs considered as traditional (as in the case of Latin America) or more globalized as the use of alternative/complementary treatments such as yoga or reiki (as in the case of Europe). The study of these customs, the flexibility in the incorporation by patients of healing practices brought from other cultures that aim to provide physical or psychological well-being, should be the object of study by health professionals as part of the psychosocial strategies that they should know for the care of patients who are, like them, bio psychosocial beings, complex and vulnerable with fears and apprehensions about the losses that cancer can present them with.

Recommendations in the family/social dimension

In this dimension, which includes the family system, its relationship networks and the entire cultural-social environment with its beliefs regarding health and disease, and cancer in particular, there are also facilitating and hindering aspects of the care of the cancer patient and his or her family members. The first element to be included in the recommendations of this dimension is the management by each family group of the care of the patient and the attention to his or her needs. Family support when one of the family members becomes ill, has a disability or grows old is very complex because it implies the readjustment of a system and is part of the broader concept of social support. These systems, family and social, are characterized by their multidimensionality, which is why they have been defined as the totality of resources provided by other people. According to pioneering scholars in this area,[53] among the dimensions studied in reference to the support provided by these systems are: a) Direction of the support: received or provided; b) Content of the support: emotional, instrumental, informative and evaluative; and c) Social network in which it is found: family, friends, neighbors, coworkers, community and others. We found in our study, and also with reference to other studies and national and international realities, that there are great differences in family groups in the way care is organized, ranging from groups where there is balanced participation of at least one subgroup of the family - where care is shared - to family groups where there is a single caregiver, generally a woman and/or daughter, overburdened with responsibilities and even in many cases with burnout syndrome. A characteristic aspect that appeared in this sample and that is part of the recommendations of this section is the incorporation of men into family caregiving, since we found testimonies of men (in this study in particular of husbands and nephews) who are part of the caregiving network or are the main caregivers of the sick, but also others who state that information or caregiving spaces in which they would like to participate are not shared with them. We also found testimonies, mainly from women who protest against the non-participation or negatively qualify the form of participation of the male members of the family; sons, brothers or other relatives of the sick person.

The presence of men in the family in caregiving seems to require a work directed to the whole family, and mainly to women, in order to involve men and not exclude those who wish to participate. Linked to the matricentric role of the Venezuelan family where women are the ones in charge of caregiving, because they believe they are better qualified, initially for the children and later transferred to any sick member, it seems to be the central belief to work on in order to achieve the incorporation of male members in a balanced and valued way in caregiving. It would even seem that the conspiracy of silence[30] studied in other latitudes as the silencing of information to the sick person about his illness because he is considered vulnerable, appears in our context in some opportunities towards men because they are considered more vulnerable. The presence and use of testimonies of men, who have harmoniously integrated into the care of sick relatives, including them in the support groups or psycho-educational talks present in the oncology centers, can be one of the strategies for changing this belief that can lead to new practices. In another way, the inclusion of the male figure in posters, informative brochures and different means of dissemination can be another element to consider. The second element to be included in the recommendations of this family/social dimension, which places great emphasis on the "social" element, is the design and use of mass media campaigns on cancer and its comprehensive care from all stakeholders. The discourse of the mass media (MMC) constructs realities about cancer patients, families and health professionals that will permeate the ideas circulating in the social and cultural environment. As can be seen in the discourse of the interviewees - and in part of the scientific discourse on the subject - the meanings associated with cancer, patients, their families and health professionals, in some cases, guide the selection of information and the construction of news and recreational programs transmitted by the mass media towards a yellow or negative view of the disease and its actors.

The treatment of this information in the CMMs often does not include the description of the context in which the reported event occurs, such as the demographic characteristics of the family groups, the socioeconomic situation of the same, specifications about the type of cancer and the experiences of the family members in the care of the same. Since the 1980s it was claimed that the real power of CMMs lay not so much in what they say, but in the things they do not say. Successful experiences, hospitals with entrepreneurial initiatives in patient and family care, resilient families who, despite pain and difficulties, cope with the presence of a cancer patient, health professionals who recognize their vulnerability and work as a team to provide their services, occupy very little space in the media, unlike dysfunctional families, inefficient hospitals and doctors on strike.[54] A realistic and balanced vision of how varied the cancer disease can be, the physical and psychological manifestations in the actors and the multiple possibilities of a healthy accompaniment to all the actors that exist or could be created, would allow an understanding of the vulnerability of people and the complexity of human behavior and an empowerment of possible initiatives of support or accompaniment from the social, institutional, family and even personal for the transit of all those people who are involved in the accompaniment of a family member with cancer.

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Conflicts of interest

The author declared that there are no conflicts of interest.

References

1. Caroní Mail. *Cancer.*2025.
2. Hernandez, Salas A, Altuve JJ. Coping, family functioning and health-related quality of life in Venezuelan caregivers of cancer patients. *Psicología y Salud.* 2020;30(2):161–172.
3. Raimon G. Masterclass: meaning-based psychotherapy for emotional disorders. 2023.
4. Anticancer Society of Venezuela. Forecasts of cancer mortality and incidence. Caracas: Sociedad Anticancerosa de Venezuela; 2023.
5. Guevara GVK, Cuello FGE, Alvarado CRE, et al. Family perceptions of caregivers of oncology patients. *Gaceta Médica Estudiantil*. 2024;5(3):e608.
6. Baider L. Cancer and family: theoretical and therapeutic aspects. *International journal of clinical and health psychology*. 2003;1(3):505–520.
7. Samblas J. Living with cancer. *Fighting to win. Realities versus taboos.* Madrid: The sphere of books; 2008.
8. Rolland J. *Families, illness and disability*. Barcelona: Gedisa; 2000.
9. Zhang Y, Zhang X, Li, et al. Family resilience and psychological well-being in families affected by cancer: A structural equation model. *Frontiers in Psychology.* 2023;14:1222792.
10. Wehrli S, Rohrbach M, Landolt MA. Quality of life of pediatric and adult individuals with Osteogenesis Imperfecta: a meta-analysis. *Orphanet J Rare Dis*. 2023;18(1):123.
11. Ehrler M, Wettach C, Beck I, et al. Mental health-related quality of life in mothers of children with surgically repaired congenital heart disease: a 13-year longitudinal study. *Qual Life Res*. 2023;32(10):2975–2986.
12. Dąbrowska A, Malicka I. Pediatric cancer as a factor of changes in the family. *Int J Environ Res Public Health*. 2022;19(9):5002.
13. Luo Y, Wei X, He X, et al. Psychological interventions for enhancing resilience in parents of children with cancer: a systematic review and meta-analysis. *Support Care Cancer*. 2021;29(11):7101–7110.
14. Secinti E, Tometich DB, Johns SA, et al. The relationship between acceptance of cancer and distress: a meta-analytic review. *Clin Psychol Rev.* 2019;71:27–38.
15. Lichtenthal WG, Breitbart W. The central role of meaning in adjustment to the loss of a child to cancer: implications for the development of meaning-centered grief therapy. *Curr Opin Support Palliat Care*. 2015; 9(1):46–51.
16. Casellas A, Casellas GA, Serra A, et al. Feasibility study of the psychosocial effects of an online mindfulness intervention in children and adolescents with achondroplasia and their parents. *Eur J Med Genet*. 2024;72:104984.
17. Carratalá A, Peña C. *Resilience in accompanying family members of oncology patients*. Unpublished thesis for the degree of Licenciado en Psicología. Universidad Metropolitana. Caracas. Venezuela. 2009.
18. Yang Y, He F, Li D, et al. Effect of family resilience on subjective well-being in patients with advanced cancer: the chain mediating role of perceived social support and psychological resilience. *Frontiers in Psychology.* 2024;14:1222792.
19. Wikman A, Orneus S, Melzi G, et al. Balancing intimacy, family life and cancer - a qualitative study on the impact of parental cancer on the couple relationship in couples with dependent children. *European Journal of Oncology Nursing*. 2025;75:102814.
20. Sun D, Zhang X, Li J, et al. Mediating effect of cognitive appraisal and coping on anticipatory grief in family caregivers of patients with cancer: a Bayesian structural equation model study. *BMC Nurs*. 2024;23(1):636.
21. Mirhosseini S, Imani PF, Moghadam RH, et al. Support based on psychoeducation intervention to address quality of life and care burden among caregivers of patients with cancer: a randomized controlled trial. *Frontiers in Psychology.* 2025;16:1430371.
22. Riessman CK. Narrative methods for the human sciences. California: SAGE Publications; 2002.
23. Bold C. *Using narrative in research* (2nd edition). California: SAGE; 2022.

24. Guba E. *The paradigm dialog*. California: SAGE; 1990.
25. Taylor S, Bogdan R. *Introduction to qualitative research methods*. Spain: Paidós; 1992.
26. Strauss A, Corbin J. *Bases of qualitative research: Techniques and procedures to develop grounded theory*. Colombia: Universidad de Antioquia; 2002.
27. Federation of psychologists of Venezuela. *Code of Professional Ethics*. 1981.
28. Sojo V. Ethics in psychological research with humans. Universidad Central de Venezuela (UCV)-Universidad Simón Bolívar; 2004.
29. American Psychology Association (A.P.A). Psychologist's Code of Ethics. 2010.
30. Gómez M. *Palliative medicine in Latin Culture*. Madrid: Arana; 2000.
31. Bruner J. *Acts of meaning*. Four lectures on mind and culture. Madrid: Alianza; 1991.
32. Morín E. *The seven knowledges necessary for the education of the future*. Barcelona: Piados; 2001.
33. Vandenberghe R, Huberman AM. *Understanding and preventing teacher burnout: a sourcebook of international research and practice.* Cambridge University Press: Cambridge, UK; 1999.
34. Maslach C. Job burnout: new directions in research and intervention. *Current Directions in Psychological Science*. 2003;12(5):189–192.
35. Martire L, Lustig A, Schulz R, et al. Is it beneficial to involve a family member? a meta-analysis of psychosocial interventions for chronic illnes. *Health Psychol*. 2004;2(6):599–611.
36. Thomas C, Morris S, Harman J. Companions through cancer: the care given by informal carers in cancer contexts. *Soc Sci Med*. 2002;54(4):529–544.
37. Moreno A. *And we went out to kill people*. Maracaibo: Editions of the Academic Vice Rectorate of the University of Zulia (LUZ); 2007.
38. Mora L. The meaning of family: a construction with the life stories of three generations. *Forum: Qualitative Social Research*. 2008;9(2):1–38.
39. Fernández R. Social networks, social support and health. *Periféria.*2005;3:1–16.
40. Landi G, Pakenh KI, Cattivelli R. et al. Parental cancer: mediating and moderating roles of psychological inflexibility in the links between illness severity and parental quality of life and family outcomes. *Current Psychology.* 2024;43:22978–22988.
41. Wellisch D, Hoffman A, Goldman S, et al. Depression and anxiety symptoms in women at high risk for breast cancer: pilot study of a group intervention. *Am J Psychiatry.* 1999;156(10):1644–1645.
42. Araneda G, Aparicio A, Escobar P. et al. Characteristics of the primary caregiver and their relationship with the perception of satisfaction of basic needs of the terminally ill patient. *Culture of Care.* 2006;19:79–86.
43. Perak K, McDonald FEJ, Conti J, et al. Family adjustment and resilience after a parental cancer diagnosis. *Support Care Cancer*. 2024;32(7):409.
44. Weaver A, Flanelly K. The role of religion/spirituality for cancer patients and their caregivers. *South Med J*. 2004;97(12):1210–1214.
45. Lopéz J, Rodriguez MI. The possibility of finding meaning in caring for a loved one with cancer. *Psycho-oncology*. 2007:4(1):111–120.
46. Astudillo W, Mendinueta C, How can we help children during the terminal phase? *Rev Med Univ Navarra*. 1995; 39(3):173–179.
47. Estape J, Estape T. Improving diagnostic information to the cancer patient. *Fund Cient Fund of the Spanish Cancer Association.* INFORMA. 1992; pp. 13–26.
48. Abreu MT, Martin A. Attitudes of medical students and teachers to the communication of the diagnosis to the patient with cancer. *Cuban Journal of Oncology*. 1992;8(2):118–122.
49. Kübler Ross E. *On death and dying. Relief of psychological suffering for those affected*. Barcelona: DEBOLSILLO; 2005.
50. Marinello Z. *The diagnosis of cancer*. Havana: Edit. Ciencias Médicas; 1990.
51. Vanchieri. Cultural gaps leave patients angry: doctor confused. *Natural Cancer Institut.* 1995;87:1576–1577.
52. Idagoya A, Luxardo N. Nonconventional therapies in cancer. *Medicina.* 2005;65(5):390–394.
53. Cohen S, Syme SL. *Social support and health*. New York: Academic Press; 1985.
54. Saperas E. The cognitive effects of mass communication. Barcelona: Editorial Ariel SA; 1989.