



The experience of family caregivers of people with cancer. Phenomenological study

La experiencia de los cuidadores familiares de personas con cáncer. Estudio fenomenológico

A experiência dos cuidadores familiares de pessoas com câncer. Estudo fenomenológico

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Abstract


Objective: Understand the experience of family caregivers of people with oncologic diseases.

Materials and methods: Study with a qualitative approach, based on the interpretative phenomenology analysis. It was developed in Medellín, Colombia, between July of 2018 and June of 2019. The recollection of information was made through semi-structured interviews on ten family caregivers of people with oncologic diseases. The total of the participants was determined by the theoretical saturation of the emerging subjects. **Results:** The experience lived by the family caregiver of a person with cancer, is manifested through three emerging subjects: facing a new way, where there are new situations derived from the disease that impose workloads and demand an over exertion of the caregiver. Organizing to care, which refers to the ways they organize themselves through the establishment of roles, routines and support networks, to cope with the care of loved one. Life transformations, which refers to the way that life changes from the experience of care. **Conclusions:** The experience of family caregivers of people with cancer is interpreted as a life dedicated to their sick relative, where the new path they face, the organization of their life for caring and the transformations experiences, revolve around the disease and the care demanded by a person with cancer.

Keywords: Caregivers; emotions; psychological adaptation; cost of the disease.

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Resumen

Objetivo: Comprender la experiencia vivida de los cuidadores familiares de personas que padecen enfermedades oncológicas. **Materiales y métodos:** Estudio de enfoque cualitativo, basado en la fenomenología interpretativa. Se desarrolló en Medellín, Colombia, entre julio de 2018 y junio de 2019. La recolección de la información se realizó a través de entrevistas semiestructuradas realizadas a diez cuidadores familiares de personas con enfermedades oncológicas. El total de los participantes estuvo determinado por la saturación teórica de los temas emergentes. **Resultados:** La experiencia que vive el cuidador familiar de una persona que padece cáncer, se manifiesta a través de tres temas emergentes: enfrentarse a un nuevo camino, en el que hay situaciones derivadas de la enfermedad que imponen unas cargas y demandan un sobre-esfuerzo al cuidador. Organizarse para cuidar, el cual se refiere a la manera como se organizan a través del establecimiento de roles, rutinas y redes de apoyo, para hacer frente al cuidado del ser querido. Transformaciones para la vida, que se refieren a la manera como la vida cambia a partir de la experiencia de cuidado. **Conclusiones:** La experiencia que



viven los cuidadores familiares de personas con cáncer se interpreta como una vida de entrega hacia su pariente enfermo, en la que el nuevo camino al que se enfrentan, la organización de su vida para cuidarlo y las transformaciones que experimentan, giran en torno a la enfermedad y al cuidado que demanda la persona con cáncer.

Palabras clave: Cuidadores; emociones; adaptación psicológica; costo de enfermedad.

Resumo

Objetivo: compreender a experiência vivida dos cuidadores familiares de pessoas que padecem doenças oncológicas. **Materiais e métodos:** estudo qualitativo baseado na fenomenologia interpretativa. Desenvolveu-se em Medellín, Colômbia, entre julho de 2018 e junho de 2019. A informação foi coletada através de entrevistas semiestruturadas realizadas a dez cuidadores familiares de pessoas com doenças oncológicas. O total dos participantes esteve determinado pela saturação teórica dos temas emergentes. **Resultados:** a experiência que vive o cuidador familiar da pessoa com câncer, manifesta-se através de três temas: enfrentar-se ao novo caminho, em que há situações derivadas da doença que impõem cargas e demandam maior esforço do cuidador. Organizar-se para cuidar, refere-se à maneira como organiza os seus papéis, rotinas e redes de apoio, para fazer frente ao cuidado requerido. Transformações para a vida, maneira como a vida muda a partir da experiência do cuidado. **Conclusões:** a experiência vivida pelos cuidadores familiares de pessoas com câncer interpreta-se como uma vida de doação ao seu parente doente, na que o novo caminho percorrido, a organização da sua vida para cuidar-lhe e as transformações que experimentam ao redor da doença e ao cuidado que demanda a pessoa com câncer.

Palavras-chave: Cuidadores; adaptação psicológica; emoções; efeitos psicossociais da doença

Introduction

Cancer is a chronic disease that, according to Wang et al. (1) generates physical deterioration and mental, social, economic and spiritual alterations, which can lead a person with cancer to lose the ability to care for themselves and require the support of other individuals, who are called caregivers.

The person with cancer can show a deterioration of their health conditions, both for the disease itself as well as for the treatment it implies, to the point of preventing them from autonomously doing basic activities of daily life. Therefore these people develop partial or total dependence on their caregiver, which tends to be a relative (2). This way, the family caregiver, besides keeping on with their own life, assumes the care of another person, up to the point of prioritizing the needs of them over their own (3).

Flores et al. (4) consider that the caregiver is the person that assists or cares for another person that shows disability, alteration or inability for the normal devel-

opment of their vital activities or social relationships. Among the types of caregivers, the family caregiver is defined as a person that is related or close and assumes the responsibility of caring a loved one (5).

The family caregiver also tends to be the emotional and economic support of the patient. Emotionally, accompanying the patient in the process of coping and helping the person with cancer to adapt to the changes derived from the disease process (5, 6). Economically, assuming the expenses from the treatment and care of the patient. The latter, makes the family caregiver undertake new ways of economic income through additional or informal jobs (7).

Adashek y Sibbiah (8) state that family caregivers change their personal, work, family and social dynamics, since the care of a sick person imposes new challenges that contrasts and prevents them from continuing with their daily activities. Thomas-Hebdon et al. (2) and Chaparro et al. (9) expose that the new dynamics faced by the family caregivers, that although, are oriented to improve the well-being of the patient, tend to produce physical, mental and social alterations, that

could lead them to lose the role in their usual context, social interactions, difficulties at work and a feeling of discomfort regarding life.

Sarabia et al. (10) establish that caregivers perceive a lack of social support and support from the health systems. In this sense, they expect to receive information and accompaniment regarding the development of caring skills and the acquisition of knowledge about the disease of the person they care for. Moreover, they wish to count with an emotional support that contributes to coping with the experience of being a caregiver. On the other hand, the association between cancer and death, its abrupt and untimely onset, the high cost it generates and the emotional impact that it usually has on the patient and family, could lead the experience of caring for a person with cancer to have a different reality and meaning than when caring for people with other chronic diseases (2, 3, 6-9, 11).

Xiaoyum y Fenglan (12) express that it is important to know the experiences lived by the caregivers in situations of chronic disease, this way, having a basis and an approximation to the reality perceived by these people. Similarly, Wyatt et al. (13) propose to obtain a better understanding of the experience of the family caregiver of the person with cancer. From this, the objective of the present study is to understand the experience of family caregivers of people with cancer

Materiales y métodos

The present study was developed under a qualitative research approach and from the interpretative phenomenological analysis.

The inclusion criteria that guided the selection of participants were the following: people that, by being related or affiliated, were recognized by the cancer patients as their relative and, at the same time, were accepted by them as caregivers; for the patient to be over 18 years old and have cancer, without considering the type of cancer or the stage of treatment.

The search for participants was made through convenience sampling and snowball sampling. The selection was guided by a theorist and the total of participants was determined by the saturation of emerging subjects.

Also, counting with the participation of ten family caregivers, which were contacted in two ways: a) by colleagues, friends and relatives locating seven participants; b) through a foundation for the assistance of patients with cancer, where three family caregivers were identified and contacted. All the invited participants accepted to collaborate on the research.

The study was made in the city of Medellin, Colombia. The period for the recollection of the information was between July of 2018 and June of 2019. For the technique of recollection of data, a semi-structured interview was used. The interviews had an approximate duration between 45 to 90 minutes and was made by the main researcher. Likewise, informed consent was previously requested to the interviewee. The places of the interviews were agreed with the participants, favoring the place where they felt comfortable. In most of the cases, the interviews were made at the house of the interviewee and in other cases, the participants did it in the health institutions where they were caring for their loved one. In the latter, the interview was made in a different place from the room of the patient with the purpose of maintaining privacy.

The interviews were structured around a guide of five questions to elicit information about: what a day was like taking care of their relative, the relationship with their family and the patient, learnings obtained during the care process and the changes experienced since they began caring of their ill relative.

The interviews were recorded on an audio device, also having fieldnotes to register the attitudes, emotional responses or aspects that arose. It is important to note that this data made possible to formulate further questions that allowed to deepen and broaden the understanding of the experience of the caregiver. Subsequently these were transcribed in a word processor and pseudonyms were assigned for each participant to guarantee the confidentiality of the information.

The data analysis was developed through Microsoft Excel and was guided by the Interpretative Phenomenological Analysis- IPA. The IPA was described by Smith (14) as a process that is double hermeneutic, since it allows the participants to give sense to their world and for the researcher facilitates its codification and interpretation. The process of analysis was developed in three phases, which are described in Table 1

Table 1. Phases of the process of analysis

Phases	Description
1	Pre-coding of each interview, line-by-line from the transcriptions. Annotation of reflections or codes, on side notes. Read two or three times each interview. Adjusting the notes and codes in each re-reading.
2	Identification of Units of Analysis (interview fragments) and assignment of a code. In some cases, keeping the codes from the last step and in other cases doing a re-codification
3	Identification of conceptual similarities between the codes. Grouping into broader conceptual terms, called subthemes. The subthemes were grouped in themes. The hierarchic conceptual structuration through themes and subthemes allowed to represent the experiences of family caregivers of people with cancer and orientated the writing and description of the findings that emerged from the analysis.

Source: Application of the strategy Interpretative Phenomenological Analysis - IPA

The analysis of the data was oriented by theoretical sampling, where periods for the gathering of information were programmed followed by periods of analysis. To support the process of analysis, theoretical and analytical diagrams and memos were used.

To give scientific rigor to the research the criteria of credibility, auditability and transferability were consid-

ered, as described in Table 2.

The study was presented to the Ethics Committee of Health Research of Universidad Pontificia Bolivariana in the city of Medellin, Colombia, which gave the guarantee for its execution through the Act No. 10, June 25th of 2018.

Table 2. Criteria for the scientific rigor of the study

Criterion	Description
Credibilidad	A process of constant reflection was made, both during the formulation of the project and during the process of data collection and analysis. The main researcher made the interviews, transcription, analysis, and interpretation of the data. A methodological advisor accompanied and orientated the process of project formulation, collection of information, analysis, and interpretation. The interviews were recorded on an audio device and transcribed in a word processor. A validation process was made for the results from the participants.
Auditabilidad	Workshops about methodological processes were done with other researchers. Presentations were made for academic communities. The Project was submitted to evaluation by the Ethics Committee.
Transferibilidad	An analysis and reflection were made about the applicability of the results in other scenarios

Source: Analysis and development of criteria for the rigor of qualitative research

Resultados

En la Tabla 3 se describen las características socio-demográficas de los participantes. Como se observa,

predominaron las mujeres, con una edad media de 40 años. Según el grado de parentesco, la mayoría de los cuidadores familiares fueron hijos.

Table 3. Characteristics of the participants

Participant	Characteristics of the caregiver			Characteristics of the person being cared for			
	Gender	Age	Relationship	Age	Type of family	Type of cancer	Treatment
E01	Female	31	Daughter	50	Nuclear	Breast cancer	Palliative care
E02	Female	30	Daughter	57	Single parent	Breast cancer	Ambulatory chemotherapy
E03	Male	35	Son	55	Single parent	Lung cancer	Ambulatory chemotherapy
E04	Female	45	Wife	60	Nuclear	Chronic myeloid leukemia	Hospital chemotherapy
E05	Female	35	Daughter	63	Single parent	Pancreatic cancer	Palliative care
E06	Female	45	Mother	25	Single parent	Acute lymphoblastic leukemia	Hospital chemotherapy
E07	Female	40	Mother	18	Single parent	Acute lymphoblastic leukemia	Hospital chemotherapy
E08	Female	45	Mother	18	Composed	Acute lymphoblastic leukemia	Hospital chemotherapy
E09	Female	50	Sister	45	Nuclear	Breast cancer	Follow-up
E10	Male	48	Brother	60	Extended	Multiple myeloma	Hospital chemotherapy

Source: From the sociodemographic data of the participants

From the data analysis, it was identified that family caregivers of people with cancer face a new way, organize themselves to care for their loved one and suffer from transformations for the rest of their lives

Facing a new way

When the news break about a loved one having cancer, it marks a turning point for the family caregiver, since everything starts to be different. From that moment on facing new challenges, dynamics and situations derived from the care, which are perceived as burdens that influence on a physical, mental, emotional, and social level, and if prolonged, could drive the caregiver to a state of burnout or caregiver stress syndrome. In that sense, these burdens correspond to a personal cost that is imposed on the caregiver by the cancer disease of the relative.

For the caregiver life is no longer the same, even, considering it is no longer their own, since the light that shines their way goes away to give way to a new one that leads them to recognize themselves as someone completely different, as stated by the following caregiver: *“Life fades away, one is no longer the same”* (E04). The new path taken by the family caregiver, is characterized by a devotion for their ill relative, up to the point of neglecting and forgetting about themselves, as recognized by the following participant: *“(…) I was, on*

that sense totally neglecting, well (… myself” (E02). As told by one of the family caregivers, these changes come with the loss of concentration, mood changes and melancholy: *“Obviously the mood, the mood changes, so there obviously was, well (… more crying, more low state of mind, of melancholy”* (E02).

On the other hand, on a physical level, the caregiver perceives a decrease and exhaustion of their overall health associated to changes such as insomnia, fatigue, musculoskeletal pain and lack of appetite, since the care of a person with cancer demands physical effort and time, as described by the following participant: *“It is very exhausting because finally (… let’s say (… an ill person demands efforts, demands time”* (E03). This exhaustion can be expressed in a significant and abrupt loss of weight, as told by the following participant: *“In clothes I feel (… it’s big. Maybe, maybe, I lost around six kilos”* (E10).

The image of cancer as a sign of death contributes for the family caregiver to perceive, simultaneously, multiple emotions, thoughts and expectations, which tend to be negative and catastrophic about the future of the ill relative, as recognized by the following caregiver: *“(…) one said…cancer!… and it was already death (…)”* (E08). In that sense, only the word “cancer” generates fear and uncertainty, as observed in the following account: *“(…) the fact of saying its cancer is (…)*

the word cancer scares” (E09)

Within the emotions perceived by the family caregiver are found sadness, fear, crying, anger, defeat, uncertainty, and frustration. These emotions, which are intense and exhausting, are associated to a contradiction between a compassionate attitude of the family caregiver towards the ill person and the inability to give comfort and solutions to everything that ails the person, as described by the following family caregiver: *“the hard stays for me (...) are seeing him in the conditions he manifests himself, for example, aggressive pains, which make him cry, make him feel completely uncomfortable and he asks me to take away that pain, to help him take it away (...) how do I do that? (...) I can't, there is no way, no, you would have to be a magician. For me, enduring that (...) imagine it (...) is a weapon going through me”* (E10).

Therefore, the care of a person with cancer constitutes a challenge, since the family caregiver does its role in the midst of a situation that is framed by disappointment, deterioration and progression of their ill relative towards death, as recognized by the following family caregiver: *“(...) they start to run out of life, how much pain they suffer, their will to live fades, how their bodies deteriorate (crying and silence), how they want to stop living”* (E01).

In the social setting, the family caregivers tend to change leisure and recreation activities to dedicate themselves to the care of their ill loved one, as observed in the following testimony: *“But going out with friends or to eat, no, I'd much rather stay at my house”* (E01). These activities decrease because the caregiver does not have enough time to do them, as told by the following participant: *“(...) I have felt more limited because obviously (...), let's say, you restrict yourself (...) let's say from arriving late to let's say to your house (...)”* (E03).

Similarly, gradually distancing from social life can lead the caregiver to social isolation, as mentioned by the following caregiver: *“(...) initially I isolated myself a lot, still do, still do”* (E02). At the beginning they distance themselves of their own families, later from friends denying socialization with other people, as described by the following participant: *“I have distanced myself a lot from my family”* (E04); *“(...) I also worked, so I had a group of friends there, but it is not the same anymore”* (E08).

Organizing to care

The role of a caregiver tends to be new and unknown, which demands dedication and effort to learn, which should be done in a short time and with their own resources. By the circumstances in which it happens, having to adapt with the roles they already had, as observed in the following accounts: *“While I was organizing my house, my two nieces were already here, so*

I took care of them and well (...) of everything in the house” (E01); *“(...) I feel that now my priority is my university and my mom”* (E02).

Therefore, to achieve an organization of their activities, family caregivers, create new routines and establish support networks that allows them to assist their ill patient and continue with their own life. .

In relation to routines, these should be understood as activities that have a similar development and are done repetitively, which allows to accommodate and reduce the complexity imposed by day-to-day care of the ill loved one. There are preparation routines, which start early, before meeting with the patient and have the purpose of organizing the day, benefit the ill person and the rest of the family. These routines allow to get ahead in household chores to then oversee the patient for the rest of the time, as described by the following participant: *“(...) I always wake up around four in the morning when I don't sleep here. I have to make lunch to them and then get ready to come here all day”* (E08).

Another aspect to consider is that the routines that the caregiver establishes for the rest of the day, depend on the place where the person with cancer is, whether at the hospital or at home.

It is convenient to note that at home, the family caregiver dedicates more time to household chores such as: organizing the house, preparing food, cleaning clothes, and providing comfort, as observed in the following testimony: *“A routine for every day? (...) my dear (...) do, clean the house (...) sweep (...)”* (E07). These chores meet the objective of making home an adequate environment for the patient, by being comfortable, pleasant and above all, clean, as told by the following family caregiver: *“The food also I try to make it with boiled water or water (...) I mean, with a lot of care. Once it's done, serve it, not letting it sit for a long time and leaving it there, all that”* (E08); *“Being careful with their clothes, the clothes are handwashed, I don't wash it with the clothes of others, with ours either, always separately”* (E07).

It should be added that routines at the hospital focus on what the ill relative requires, as well as support and contribution. In some cases, assuming the function of informing the nurses about novelties related to the treatment of the patient, as observed in the following account: *“I was looking for the medicine the nurse told me (...) when it was on a certain number (...) to let her know”* (E06). Also, giving support in the bathroom, mobilization and cleaning of the ill relative as well as protecting and verifying the adequate working of the devices that are connected for the treatment, as indicated by the following participant: *“Yes, I have to cover her, I have to clean her carefully (...) to avowing getting the catheter wet”* (E08).

Similarly, it is very important to establish support networks since these facilitate the organization of the family caregivers. Support networks are constituted by relatives, next of kin, institutions, and some health-care professionals. These support networks help to distribute the workloads that are associated to care, as observed in the following account: “*There was a very polite friend in his church, he is studying at the university and so, (...) let’s say Thursdays and Tuesdays, he came and stayed with him*” (E06). Likewise, they serve as a support to minimize the emotional impact caused by being a caregiver, since the support network is useful for the caregivers to express themselves, share their anguishes, distract themselves and feel motivated to continue with their role, as told by the following participant: “*Thank God I had him as my support, he was a lot of support, very big in that moment, because if I didn’t have him, then I would have (...) gone crazy!*” (E05). In this sense, the support network helps the family caregiver to have strength during hard times and get encouragement to keep going.

Life transformations

The life of the caregiver suffers changes that transform their way of thinking, acting, and facing life circumstances.

These life transformations are related to the learnings obtained when caring for their loved one, as described by the following family caregiver: “*(...) I see it more like a learning, these are everyday learnings, there are hard days, others not much, but it is more like learning*” (E02). These learnings motivate the caregiver to change their perspective about life and how to act, as observed in the following testimony: “*It is an experience that (...) well, I had to with my daughter, and no, you don’t want that for your children, I think it’s an experience where you learn from life, you learn (...) to love and like (...) have greater appreciation for life*” (E07).

Similarly, caregivers recognize the experience of caring for a person with cancer as something difficult that leads them to reflect about their own lives, their position in the world and their way of facing adversities. This way, seeing it as a moment of truth that defines and determines who are the people that surrounds them, as mentioned by the following family caregiver; “*(...) one learns to live, to control yourself and recognize who is who. Yes, because again, well, in good times everyone is around, but in hard times is where you know who is who*” (E10).

As mentioned the relationships with the ill loved one also suffer transformations, since it is an experience that they live together at all times, which contributes to a closer bond, even, when relationships have been hard in the past, as observed in the following account: “(...)

it was a beautiful experience because I got much closer to her, I got closer and closer to her and she did too and she became attached to me (...)” (E05).

It should also be mentioned that a relationship arises between the relative and the patient where there is a big demonstration of affection, gratitude, empathy, and union which appear and are strengthened every day, as told by the following participant: “*(...) I’ve felt proud of being with her, of being able to attend her, being with her everywhere, I’ve felt happy, joyous*” (E03). Through constant interaction achieving a relationship between them with a connection that gets stronger with the experience of care, as described by the following family caregivers: “*We got her a thermal bandage but no, It didn’t work because she said that she wanted to feel my hands*” (E01); “*We let’s say caress each other, well (...) we hug, sometimes I grab her and kiss her on her head, or things like that*” (E03).

Meaning, that the strength that this relationship acquires leaves great satisfaction to the family caregiver, since they consider that the time invested in caring and supporting their ill relative, is precious time that will be forever remembered with a clear conscience, as told by the following participant: “*I shared a lot of time with her and its time that will not come back, its time that won’t come back and that I earned. From knowing her, seeing her pain, nobody, nobody will take those memories from me and yes obviously I have conscience that I was there for her the whole time and yes, that doesn’t take away the pain, but it gives me peace*” (E01).

Therefore, the family caregiver gets a series of positive attitudes that allows to see the situation they are facing from a different perspective. This is achieved with courage to continue with life and keep going, as observed in the following testimony: “*(...) very positive (...), no, let’s do it that we will get through this and, so on (...) let’s say that in some periods yes, there are periods where I have had to take courage, right, and keep going as they say*” (E03). This way positively facing the disease for the ill patient, generating strength to transform the emotions that are less favorable and minimizing them for the benefit of the patient and the caregiver, as described by the following participant: “*(...) we can’t cry in front of her, we have to be strong, demonstrate her that she is capable, that life continues, to see how many people move forward, keep being functional*” (E05).

Finally, the family caregivers give a different meaning to their life, since the fact of living this experience, makes them face similar situations through their thoughts and actions to serve and help the other, as described by the following family caregiver: “*(...) now things are different (...) because it’s a thing when you have a son in the circumstances I did, like (...) me inside a clinic and I see the whole world and me, I think*

about going to help. Or if I'm walking on the street and I see someone stranded (...) I feel like, like (...) doing something for them, I feel a lot of compassion" (E07). Being aware of the experience lived by the ill loved one makes the family caregiver be more sensitive to the pain of the other and understand better the person who suffers, as observed in the following testimony: *"(...) we all need each other and at the end we are all weak. Maybe I am powerful because I am healthy and (...) I could maybe do a favor to a person that needs it and I don't (...) let's see (...) maybe my health does not allow me to see that, but now that I am here I have to look for that"* (E10).

Discussion

Mesa et al. (15) and Espinoza et al. (16) consider that the loads that relapse over a caregiver are negative consequences that derive from care. On that subject, describing two types of loads, the subjective load, which corresponds to the attitudes and emotional reactions towards the experience of caring; and the objective load, which refers to the level of changes in various aspects in the domestic setting and in the life of the caregivers.

It should be mentioned that for the family caregivers, in the present study, the workloads are imposed from the moment that the news about their relative with cancer are known. This statement coincides with the findings of Hashemi et al. (3) who found that when the caregivers learn about the diagnosis of their relative, they associated it to a catastrophic disease and the imminence of death, which contributes to make the disease process painful and hard to take, especially because they do not know what it means to care for a person with cancer and the new role that must be suddenly assumed.

Rezende et al. (17) set out that the loads of the caregiver could surpass their physical and mental capacity, making the caring labor a stressful and chronic event that wears out the caregiver to the point of developing caregiver stress syndrome. This syndrome affects has repercussions in all the spheres of the person and is characterized because the caregiver can present lack of self-control, alterations of physical and emotional health and negative repercussions in social and economic aspects (18). This can limit their ability to change behaviors that are necessary to develop their role as caregivers (19).

On the other hand, Mesa et al. (15) found that the most significant changes on a physical level are problems related to burnout, changes in sleep, pain or changes in appetite. Which goes in line with the results from this study, since family caregivers recognize having a deterioration in their overall health, reflected as insomnia, fatigue, musculoskeletal pain and lack of appetite.

In addition, the mental load that family caregivers for people with cancer are exposed to, is related to the perception of emotional burnout, stress, fear, exhaustion, anxiety, and less satisfaction with life (18, 20). In this sense, Han et al. (21) found that family caregivers may feel guilt because they consider that they contributed to the onset of cancer and ask themselves what they could have done to make things better. On that subject, Shannon (22) identified that the feeling of being unable to assist the needs of the relative with cancer created an emotional load on the caregiver when assisting the relative. Regarding the stated by this author, the family caregivers in the present study had difficulties to concentrate and experienced frequent mood changes, even suffering from depression. In that sense, Rodríguez et al. (23) recognized that 19% of ill people oppose, even aggressively to their caregivers. This aggressiveness significantly increases the workload of the caregiver.

Mesa et al. (15) determined that family caregivers can socially isolate themselves, which contributes to the feeling of solitude and abandonment, as they lose their ability to interact, converse and divide their suffering with others (24). In that regard, Otis and Juarez (25) expose that, even though having family support, family caregivers can continue to report feelings of greater isolation, which can contribute to the presence of anguish and impact their quality of life.

It should be noted that human beings, to confront the stimuli in the environment in which they develop, organize their answers according to their beliefs, opinions, stereotypes, attitudes and representations, which generates an attitude that the person unconsciously assumes and acquires to confront the stimuli of the environment (26). In the concrete case of the family caregivers, organizing themselves is a way of confronting the experience of caring for their ill loved one and this begins with the learning and knowledge of the tasks and specific functions of this family role.

From another perspective, Hashemi et al. (3) discovered that the role of the family caregiver of a person with cancer, tends to be assumed unexpectedly. Therefore, for the caregivers it is like entering an unknown world. In concordance with the results from this study, it was found that the family caregivers acquire this role without willingness, preparation, knowledge of familiarity with the tasks that they will perform. In this sense, Hashemi et al. (3) expose that caring for a patient with cancer is associated to unexpected and hard tasks that the caregiver must recognize and adapt to. Hence, the caregivers must organize themselves to face the situations that arise and that alter their everyday life.

In that regard, Fernandes and Angelo (27) pointed out that providing specific assistance and support to a dependent person, which is characteristic of the caregiver, corresponds to a new role that they must learn and de-

velop. For this reason, the authors expose that the new role of caregiver, generates the need to simultaneously manage multiple that cause weigh and conflict to those that must face them.

On the other hand, the establishment of routines by the caregiver, emerge as a way of adapting to the multiplicity of tasks that are derived from the role of being a caregiver, which according to Morale et al. (28) contribute, as time goes by, to take control of the situation. Moreover, suggesting that routines favor the development of a more precise idea of the situations they must face, since the caregiver gets to have more information, external resources and support available that translate into tools to face the care of their ill relative.

Precisely the family caregiver support network benefits the organization of the caregivers to the extent of allowing them to be supported and relieved from their tasks. For Han et al. (21) family constitutes the main support network of family caregivers, who assume complementary functions depending on the situations and the context around the ill person. On that subject, Montford et al. (29) stated that, in various situations, friends can become in an important support network for the family caregiver, since they can be considered as part of the family. The previously mentioned, coincides with the results of the present study, where family caregivers recognize that having a support network helps to reduce the care loads.

Another factor to consider is that life transformations are related to the changes experienced by the family caregiver, derived from the process of learning to care for a person with cancer, the effort to overcome adverse situations and adapt to the changes that the process of care implies. This contributes to create a new perspective of life (19).

Likewise, the combination of experiences of serious or complex risks, such as caring for a person with cancer, and a relatively positive psychological result despite those experiences, contributes to develop and strengthen the ability to resist and recover from significant challenges that threaten the stability and viability of the person (30). Therefore, family caregivers live a process of accommodation that transforms their lives, since, regardless of facing their negative emotions and radical changes, they stand upright to overcome the difficulties they encounter (28, 31).

For their part, Martínez and De la Cuesta (32) pointed out that family caregivers report that after caring for a relative with cancer, their lives are not as they were before, since throughout the time they have cared for them, their life is no longer as before in terms of activities and assets, and their strength and abilities have been reduced. Also, their health problems and the progressive disease of their relative they care for requires

more effort and dedication from them, therefore leading to losses related to their abilities, their personal freedom and their social life (16). However, the effort to adapt to the dynamics and the situations imposed by the care and the continuous interaction between the family caregiver and the care of their ill relative, contribute to successfully overcome the hard experience they have lived (28, 31).

In short, the life transformations made by the family caregiver are reflected in a life of dedication to their ill loved one, since the losses and resignations they have made over the time they have been caring, change a significant part of their lives, wishes, purposes and aspirations that they had for themselves (32). This life of dedication allows the caregiver to strengthen their relationship with their loved one, which coincides with the results from Mosher et al. (33) where it is determined that caregivers and their relatives report a common positive change in their relationships which results in a greater appreciation of life; since caring for a person with cancer leads to a greater conscience about the shortness of life

Conclusiones

- The experience lived by the family caregivers of people with cancer represents a life of dedication to their ill relative, where the new path they face, the organization of their life to care and the transformations they undergo occur around the disease and the care demanded by the person with cancer. This fact makes the family caregivers to resign their own life to live it according to the needs and expectations of their ill relative.
- The findings obtained in the present study provide supplies that should be considered for the development of public policies of health related to the assistance and care of people with chronic diseases like cancer; likewise, family caregivers should be included, without forgetting their experiences, which, benefit the creation of a dyad between the caregiver and their relative to cope with the disease. In the same way, the family caregiver can become a support to the health system for the care of the person with cancer in an outpatient and homecare setting
- Therefore, it is relevant to do research that goes in depth on the most significant needs for the family caregivers, since this could be a starting point to create more awareness about comprehensive care for patients with an oncological disease and their family. Thus, including the family caregivers in the care of a patient helps to diminish the uncertainty generated by the disease and allows to create strategies of health promotion that stimulate the caregivers to also care for themselves

Conflict of Interest

The authors declare that they have no conflict of interest.

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