

**FAMILY EXPERIENCES IN CANCER SURVIVAL: BETWEEN HOPE OF
HEALING AND FEAR OF RELAPSE****VIVÊNCIA DA FAMÍLIA NA SOBREVIVÊNCIA AO CÂNCER: ENTRE
ESPERANÇA DE CURA E MEDO DA RECIDIVA****VIVENCIA DE LA FAMILIA EN LA SUPERVIVENCIA DEL CÁNCER:
ESPERANZA DE CURA Y MEDIO DE LA RECIDIVA**

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ABSTRACT

Objective: to know the experience of the family on surviving cancer. Methodology: qualitative and descriptive research carried out in October and November 2017, with ten relatives of patients with recurrence of cancer in chemotherapy treatment at the Oncology Service of the School Hospital of the Federal University of Pelotas, EBSEH. The semi-structured interview was used as a collection instrument and for interpretation of the results Bardin's content analysis. Results: the study found that family members considered the difficulties related to role reversals between the person with the cancer and their family. For them, the diagnosis of the disease and later relapse caused psychological, social, familial and spiritual changes. Final considerations: the cancer survival is a process that is being built daily and each family experiences in a unique way, being the adoption of coping strategies necessary to overcome the barriers imposed by the disease.

Descriptors: Neoplasms; Family; Recurrence; Survival; Nursing

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RESUMO

Objetivo: conhecer a vivência da família na sobrevivência ao câncer. **Metodologia:** pesquisa qualitativa e descritiva realizada nos meses de outubro e novembro de 2017, com dez familiares de pacientes com recidiva de câncer em tratamento quimioterápico no Serviço de Oncologia do Hospital Escola da Universidade Federal de Pelotas filial EBSEH. Utilizou-se como instrumentos de coleta a entrevista semiestrutura e para interpretação dos resultados a análise de conteúdo de Bardin. **Resultados:** o estudo revelou que os familiares consideraram as dificuldades relacionadas às inversões de papéis entre a pessoa com o câncer e sua família. Para eles, o diagnóstico da doença e posteriormente a recidiva provocaram mudanças psicológicas, sociais, familiares e espirituais. **Considerações finais:** a sobrevivência ao câncer é um processo que vai sendo construído diariamente e cada família a vivencia de forma única, sendo a adoção de estratégias de enfrentamento necessárias para superar as barreiras impostas pela doença.

Descritores: Neoplasias; Família; Recidiva; Sobrevivência; Enfermagem.

RESUMEN

Objetivo: conocer la vivencia de la familia en la supervivencia al cáncer. **Metodología:** investigación cualitativa y descriptiva realizada en octubre y noviembre de 2017, con diez familiares de pacientes con recidiva de cáncer en tratamiento quimioterápico en el Servicio de Oncología del Hospital Escuela de la Universidad Federal de Pelotas, EBSEH. Se utilizó la entrevista semiestructura y el análisis de contenido de Bardin. **Resultados:** los familiares consideraron las dificultades relacionadas con las inversiones de papeles entre la persona con el cáncer y su familia. Para ellos, el diagnóstico de la enfermedad y posteriormente la recidiva provocó cambios psicológicos, sociales, familiares y espirituales. **Consideraciones finales:** la supervivencia al cáncer es un proceso que va siendo construido diariamente y cada familia la vive de forma única, siendo la adopción de estrategias de enfrentamiento necesarias para superar las barreras impuestas por la enfermedad.

Descritores: Neoplasias; Familia; Recurrencia; Supervivencia; Enfermería.

INTRODUCTION

The increase in life expectancy in developing countries in recent decades, coupled with public policies for prevention and health promotion, is associated with the increase in prevalence rates and incidence of chronic and degenerative diseases, especially cancer. Cancer accounts for approximately 12% of all causes of death in the world, accounting for more than six million deaths each year and treated as an important public health

problem in developed and developing countries.¹

In Brazil, the National Cancer Institute (NCI) estimated for 2018 that the most common cancers, with the exception of non-melanoma skin cancer, will be prostate (68,220 new cases) in men and breast cancer (59,700 thousand) in women. They also complete the list of the ten most incidental cancers, ie: colon and rectum, lung, stomach, cervix, oral cavity, central nervous system, leukemia and esophagus.²

With this information, it must be considered that cancer is a disease surrounded by stigmas, which affects emotionally the people who experience it, as well as their families. In this sense, receiving the diagnosis of cancer causes various feelings, worries and worries in people, precisely because the future becomes obscure and often without prospects, because the threat to life seems to become closer when the disease is established.³

The discovery of cancer does not happen without sharing, especially with the family and the social support network that is closer, as it triggers changes throughout the family context, so that all members, to a greater or lesser extent, are affected by the situation. In this way, each member of the family reacts in a way, with feelings of fear, anguish, sadness and insecurity, due to the stigma attributed to cancer as a painful and incurable disease. Family members also suffer when dealing with the emotional needs of the member affected by the disease. It is in this sense that cancer can be considered a family disease, since it has seen the impact it causes in this sphere of conviviality.⁴

A study conducted in the southern region of the country found that the family's experience with cancer treatment is surrounded by diverse feelings, in a unique and dynamic way, according to

their beliefs and values and depending on the stage in which their sick family member is. The family sees the disease as painful and fatal by the cultural stigma imposed, however, it believes in healing and organizes itself in caring for the sick person, articulating their routine according to the need of family dynamics.⁵

In view of the family's experience in the process of family illness due to the presence of cancer, this study is justified by the importance of seeking knowledge about the survival permeated by the hope of healing and, at the same time, the fear of relapse. Based on the above, this article aims to know the experience of the family in the survival of cancer.

METHODOLOGY

This is a qualitative and descriptive study conducted with ten family members of patients with cancer recurrence on chemotherapy in an oncology department. The data were collected at the household and at the oncology service of the School Hospital of the Federal University of Pelotas, a subsidiary of the Brazilian Hospital Services Company (EBSERH), in October and November 2017.

By means of the acceptance of the participant and the signing of the Free and Informed Consent Form, a semi-structured, recorded interview was conducted to collect the data, containing questions

related to the characterization of the participants and the experiences related to the cancer of their relative. For the maintenance of anonymity, participants were identified by fictitious name followed by age (Example: Maria, 49 years).

The research data was analyzed in accordance with the precepts of the Bardin content analysis proposal, which consists of stages 6, organized in three phases: 1) pre-analysis, 2) exploration of the material and 3) treatment of results, inference and interpretation.

This research obtained a favorable opinion from the Research Ethics Committee (CEP) of the Faculty of Nursing of UFPel under number 2,296,004. It is also worth noting that the ethical guidelines related to research with human beings determined by Resolution 466/2012⁷, as well as the Code of Ethics of Nursing Professionals.⁸

RESULTS AND DISCUSSION

The study comprised ten relatives, six women and four men, aged between 21 and 64 years. In relation to the degree of kinship with the patient, four were daughters/sons, four were wives/husbands, one was a mother and one was a niece.

The level of schooling of the participants ranged from incomplete elementary education to full tertiary education, with incomplete elementary

education (six) standing out. As for the profession, the following were found: student (one), domestic (one), carpenter (one), home (four), retired (one), porter (one) and psychologist (one). The time of living with cancer of the family member varied from one year to 14 years.

The data of this research corroborate with studies, in which it was found that the majority of family caregivers of cancer patients are female. It was evident that spouses and children were the main members of the family who took on the role of caring and that the majority of these caregivers had low educational level.⁹⁻¹⁰

From the analysis of the data, two ontological themes were constructed, which will be presented below.

The family in the context of cancer: learning to cope with the disease

The family, when faced with the diagnosis of cancer, goes through several moments, from surprise or disbelief, and they also fear the worst, since they understand that this disease causes suffering and can lead to death.

Cancer is a disease considered devastating, and its diagnosis generates diverse feelings in the person affected by the disease, as in the family. When taken to recall the moment of diagnosis, relatives

reported feelings of surprise, sadness and fear.

It was a great surprise for us, in the family there was no one with this disease. So it was a big surprise (Pedro, 57 years old).

Very sad for the whole family, our world has crumbled (Maria, 49 years old).

The discovery was very bad, very sad. We have two children, they were annoyed, afraid that he would die. (Paula, 62 years old).

I was very tense, afraid, I was worried about him. Cancer is a very bad disease (Cristina 64, years old).

When the cancer diagnosis is established, the family caregiver has an impact on their lives, changes occur in their daily lives and they are also subject to illness or feelings such as fear, distress and impotence. In a study also, it was evidenced that at the moment the diagnosis of cancer is revealed, feelings of surprise, despair, fear and sadness arise.¹¹

Understanding that cancer can lead to death, relatives expressed concern about the future of their loved one.

The diagnosis is devastating, a very devastating news, we take a "creep" when we receive the news. It's very painful, everything she feels, I feel! If she feels pain, I feel pain for her. Look, it's not easy to think my wife could die (Beto, 53 years old).

When we discovered cancer, I thought this disease would destroy our family. It was a great pain to think that someone in my family would die (Elsa, 57 years old).

It was very complicated when we discovered the diagnosis. It was well on her birthday, it was quite shocking. We took the result of the biopsy and there we discovered that it was a malignant tumor, which was relatively large, had already consumed some bones of the face, which was very aggressive. It was horrible, very complicated, it shakes the emotional and the structure of the whole family (João, 21 years old).

These results on the impact of the diagnosis go to a study that revealed that the receipt of a diagnosis of cancer causes a number of feelings, concerns and concerns in people, as the future becomes obscure and often hopeless, as the threat seems to become closer when the diagnosis is established.¹²

The diagnosis of cancer in the family causes an emotional upheaval, since it is a dreaded and unwanted illness, being an unexpected event within the family nucleus. When this diagnosis occurs, family members face feelings of fear, insecurity in the face of a disease so stigmatized.

Relatives facing the possibility of death call into question their own lives, with their fears, anguishes and possibilities. When talking about a serious chronic disease, such as a cancer, death

becomes a present subject since diagnosis, permeating and extending even after treatment. In this context, families often need to reverse roles within the family circle, finding strategies to deal with the disease.¹³

Thus, the roles within the family that experiences cancer change, and the way in which its members deal with the transformations, can affect how they cope with the disease in the future.

She changed a lot, a lot of things she did before, now she cannot do it, so we took on this role, taking care of everything she cared for. A lot had to change, it was a drastic change even (Pedro, 57 years old).

There have been changes in the routine of the house, we have to divide to perform the tasks that today she can no longer do it (Bruna, 32 years old).

I did internship, I do physiotherapy, I stopped my internship so I could take care of it, my father stopped working. So we always gave the time and energy to take care of her in the best way possible (João, 21 years old).

Cancer has made me a better person, it made me think about life and now I really need to take care of a person, something that I had never done in my life. I have to take care of a being that I love, the time has come to help, to prove to myself that I am capable (Paulo, 60 years old).

In the reports, one can identify the changes that occurred in the family routine. In this sense, in the face of illness, care

also arises with the reversal of roles, since the caregivers feel the need to reciprocate what they have received from their mother, father, husband or other family member throughout their lives, and that in the face of illness end up depending on the other and needing attention.

Thus, after cancer diagnosis, family members routinely engage in the care and follow-up of the sick person, leading the family to change their daily living habits to help each other. In this perspective, when a family member is affected by a serious illness, the family can forget and ignore their own problems, starting to attend as a matter of priority the needs of the sick person.¹⁴

Thus, it is understood that the family, in addition to being surprised by the presence of a disease that causes great emotional impact, is often asked to cope with the changes caused by the disease. And, in this way, it builds its own way of day-to-day care and learns to deal with the experience of this disease.

Cancer Survival for the Family: Between Uncertainty and Hope for Cure

The experience of the cancer for the relatives of the study caused moments of uncertainty, but also of hope, since they believe in the cure of the disease. However, relapse and metastasis put the family on the alert for what must be faced,

leading them to adapt and live life while their family member survives that disease.

The cure unfortunately for my mother is just to say, increase her life span, but unfortunately the cure has no way. But we always look for the best for her, without straining. Always struggling and the doctors giving the treatment, never guaranteeing the cure, but always doing what is possible, what is available to them. Look, it's not easy, it's like the ground comes out from under our feet (Pedro, 57 years old).

You imagine, pull life, you have to do everything to be together, because soon after that the person you love, you will not be able to see, you will not be able to speak, you will never be able to touch, it is never again. It is a deep immensity, at first we were obsessed with healing, imagining that we could achieve healing, but to our disappointment, we know that there is no cure (Paulo, 60 years old).

Through the statements, it was possible to perceive in family caregivers, the fear and uncertainties regarding the diagnosis of cancer. The family suffers, if it distresses, it despairs, it animates, it is depressed, it is moved. It is in this mixture of feelings that the safety in life disappears in the face of the innumerable uncertainties that emerge after a diagnosis of cancer.¹⁵

In the existence of uncertainties, hope is present because it is the component that keeps the family firm and persevering. Thus, just as many family members reported negative feelings, others reported

hope, positive thinking, and attachment to religious beliefs.

It is a struggle in the day to day, we know it, know that the disease is not easy, but that there is always hope. It has the expectation of a miracle of God (Pedro, 57 years old).

As I said, we had a life expectancy of three months, we have been in this fight for four years, and I expect to do eight, twelve, maybe sixteen (Paulo, 60 years old).

Thank God, he did the treatments and is still here with us, let's take as long as possible, with faith in God. Maybe a miracle! (Elsa, 57 years old).

Hope is what drives the person to move forward because it has a beneficial effect, while it strengthens their ability to cope with crisis situations. The expectation of a miracle has also been expressed by family members through faith, as it may be seen that some bear within themselves the belief that someone is looking for them.

Therefore, patients and relatives, facing the despair and suffering caused by cancer, seek in spirituality a meaning for life. It is observed that the diagnosis of cancer changes the life of any person and it is in these perspectives that families cling to the existence of a supreme being who is watching over them and this fact makes them continue their daily walk.¹⁶

After getting the much-sought cure of cancer, most people go on living with a constant ghost: fear of relapse. At the end

of the treatment, the sick person and his or her family members usually suffer from anxiety and are faced with a difficulty in making plans because they are afraid of receiving the news of a relapse at each new examination.

In this scenario, the fear of recurrence is often present in clinical evaluations, at the time of re-examination and in the return of the consultation. A topic considered unpleasant since no family member or patient wants to have their expectations of healing frustrated or imagine that their efforts were in vain. In this research, it can be observed how some relatives experienced the moment of the news of the relapse.

Go take a routine exam and come back again, then start over. It is to suffer twice, not easy (Pedro, 57 years old).

It is a very negative thing, because this was not to return. It was to be treated and to disappear, it is a very negative thing (Lara, 53 anos).

He did the surgery, treated it and it looked good, but last year in April, the disease came back. I wondered, why is it happening again? What have we done wrong? Unfortunately this disease is treacherous (Elsa, 57 years old).

Not a month ago we discovered that the disease came back, she began to feel the same symptoms she felt when we first discovered the cancer. Then we went to do some tests and it was seen that the tumor had returned in the same place,

bigger than the previous one and more aggressive, it was a defeat (João, 21 years old).

It is observed that the finding of relapse is traumatic for the patient and for the family, being similar to a second diagnosis of cancer. For the family, the possibility of losing a loved one again emerges, causing feelings of uncertainty and fear to return. Relapse of the disease may be more difficult to cope with, since all the difficult times experienced in the previous treatment are again worrying.

Relapse is a particularly stressful event because it signals a decisive reversal in the patient's condition, and usually results in a less optimistic prognosis. Worry, anxiety, uncertainty, and fear that the sick relative is dying are ideas that are always present in the minds of family members. This moment can be accompanied by feelings of sadness and frustration of expectations of healing, vulnerability and lack of control over events.¹⁷⁻¹⁸

Cancer is represented by a metaphor for the meaning of a "treacherous disease" that can affect anyone regardless of age, social class and sex. This figure of language inherent in everyday communication is used in health by cancer patients and families to express clearly and precisely what they feel.¹⁹

Relapse can occur a short time or a long time after the first tumor is cured and requires a new perspective on the pathology and treatment of the patient and the family. Then begins a new "battle" against cancer in the hope of healing again.

It was possible to identify that family members of cancer patients survive the cancer daily since the diagnosis was established.

It is a struggle for her daily and for us as well. After all, we never gave up! We fight a lot, we live one day after another (Pedro, 57 years old).

Surviving is everything, we have to try to the end, cannot give up ever (Lara, 53 years old).

After she got sick, my life was like this, ups and downs, but we survived everything (Elsa, 57 years old).

Surviving cancer, I think it's you to stay there, not abandon the treatment, is to live one day at a time, not to let up easily (João, 21 years old).

We have to every second, every minute, everything in life now. Imagine waking up every day in the morning and being alive, looking to the side and your partner still breathing, that is to survive (Paulo, 60 years old).

In the meantime, it is emphasized that the experience of cancer is one of the most transformative that one can live. From one moment to another, the person is faced with the imponderable and his whole life begins to be rethought. Survivor is the

one who can live with cancer, despite the daily struggle that is waged against the disease.

In this way, cancer survival refers to a distinct phase of care that happens to the primary treatment and lasts until the cancer relapses or the end of life.²⁰ Cancer survival is therefore seen by family members as overcoming the disease, being constructed from the diagnosis to the end of the treatment.⁵

Still, it is understood that cancer survival is a process that begins at the time of diagnosis and does not stop until the end of life, and is associated with several changes that impact people's lives. Therefore, in order to survive cancer, the families of the present study had to face and adapt to this new life during the coexistence with the chronic condition, despite concerns about the recovery of health and the prognosis, they sought to rescue their routine and plan the future beyond cancer.

FINAL CONSIDERATIONS

From this study, it is observed that the trajectory traversed during the family experience in the survival of cancer, has been accompanied by feelings and concerns from the moment of diagnosis, and search in the treatments, the cure. These moments involve social and daily changes resulting from the treatment and

care given to the sick person. This process of caring for a family member with cancer is permeated by a series of implications in the physical, emotional, affective and professional spheres.

However, fear of relapse is a constant concern in the lives of families living with cancer. The news of cancer recurrence is always painful and difficult to understand and brings a series of questions and fears to family members. At this moment, there are feelings of disappointment, sadness, since there was an effort of the whole family to fight the disease, and this one still remains. The family has, among its many characteristics, the protection of its members; since it is in it that the main caregivers of sick people find themselves, and in front of the cancer is not different.

In this context, it is understood that suffering does not only affect the person who is sick, being a matter of the family. Thus, multiprofessional support to family members of cancer patients is considered important, through attentive and welcoming listening, leaving aside the pre-judgments, the understanding to the relatives who arrive with doubts, questions and uncertainties, should be part of the care offered by the entire health team.

It is considered that the time in the execution of the research was a difficult factor for the deepening of the inherent

issues in the survival of the family in the cancer survival, and that possibly new results could serve to point out paths for nursing care to the families that experience this process. Finally, the purpose of this study is not to finalize the knowledge on the subject, but to collaborate with new discussions and to qualify the nursing care provided in the oncology scenario.

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