



## SURVIVAL FROM CANCER IN THE FAMILY PERSPECTIVE

### A SOBREVIVÊNCIA AO CÂNCER NA PERSPECTIVA DA FAMÍLIA

### SUPERVIVENCIA AL CÁNCER EN LA PERSPECTIVA DE LA FAMILIA

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#### ABSTRACT

**Objective:** recognizing the family experience facing the experience of the person with cancer falling ill and surviving. **Method:** an exploratory and descriptive study of a qualitative approach. The production of data was performed with three families of two surviving to cancer through semi-structured interviews, in the period from January to March 2012. Data analysis was carried out in three stages: ordering, classification and final analysis of the data. **Results:** it was possible to identify feelings such as anxiety, weakness and insecurity about the future of the family of the patient when discovering the disease. But the family with its unique way of thinking and acting was articulated in combating the disease, and also for care. **Conclusion:** the cancer survival is seen by family members on how to overcome the disease, being built from diagnosis to end of treatment. **Descriptors:** Family; Neoplasia; Survival; Nursing.

#### RESUMO

**Objetivo:** conhecer a vivência da família frente ao adoecer e sobreviver da pessoa ao câncer. **Método:** estudo exploratório e descritivo com abordagem qualitativa. A produção de dados foi realizada com três familiares de dois sobreviventes ao câncer por meio de entrevistas semiestruturadas, no período de janeiro a março de 2012. A análise dos dados foi desenvolvida em três etapas: ordenação, classificação e análise final dos dados. **Resultados:** foi possível identificar sentimentos como angústia, fraqueza e insegurança dos familiares quanto ao futuro do paciente na descoberta da doença. Porém, a família com seu modo singular de pensar e agir articulou-se no enfrentamento da enfermidade, e também, para o cuidado. **Conclusão:** a sobrevivência ao câncer é vista pelos familiares como a superação diante da doença, sendo construída desde o diagnóstico ao fim do tratamento. **Descritores:** Família; Neoplasia; Sobrevivência; Enfermagem.

#### RESUMEN

**Objetivo:** conocer la experiencia de la familia delante a enfermar y el sobrevivir de la persona con cáncer. **Método:** un estudio exploratorio y descriptivo con un enfoque cualitativo. La producción de los datos se realizó con tres familias de dos sobrevivientes de cáncer a través de entrevistas semi-estructuradas, en el período de enero a marzo de 2012. El análisis de datos se llevó a cabo en tres etapas: ordenación, clasificación y análisis final de los datos. **Resultados:** fue posible identificar sentimientos como la ansiedad, debilidad e inseguridad acerca del futuro de la familia del paciente en el descubrimiento de la enfermedad. Pero la familia con su forma única de pensar y de actuar se articuló en la lucha contra la enfermedad, y también para el cuidado. **Conclusión:** la supervivencia al cáncer es vista por los miembros de la familia como la manera de superar la enfermedad, se está construyendo desde el diagnóstico hasta el final del tratamiento. **Descriptores:** La Familia; Neoplasia; La Supervivencia; Enfermería.

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## INTRODUCTION

Cancer is recognized as a chronic degenerative disease that affects millions of people worldwide. Despite therapeutic advances allowing the improvement in the survival rate and quality of life, it is still considered in the perception of the patient and his family as a painful and deadly disease.<sup>1</sup> Still, the cancer stigma adds to the suffering of the person receiving this diagnosis, and also his family.<sup>2</sup>

In assistance to families in the context of falling ill from cancer, it is clear that the patient is following it. In this sense, the family is of great importance for the recovery of the health of the sick person.<sup>3</sup>

According to the Centers for Disease Control and Prevention, the term survival goes beyond the individuals that experience cancer and bringing as survivors those people who have their lives affected by the diagnosis, thus including family members, friends and caregivers.<sup>4</sup>

Through this perspective, nursing can and needs to understand the multidimensional impact of the disease on quality of life of each family member, and that will be through the comprehensive care that can early recognize the challenges and the potential difficulties faced by this.<sup>5</sup> Therefore the family needs to reorganize and adapt to new dynamics because of its functions need to be rethought and distributed, in order to assist in this process, taking into account that these changes are influenced by the meaning that the individual and his family attributed to the disease.<sup>6</sup> However, this may not be ready to take care of the sick person in need of information about the disease and treatment, and instructions on technical skills to take care.<sup>7</sup>

With this relevance, the family as coparticipants in the process of getting sick and surviving from cancer, since it experiences every stage along with the sick person, it is thought guiding question: What is the front family experience the sick and survive the person with cancer?

Given the above, the objective of this study is to forward family living and survive the sick person to cancer.

## METHOD

This is an exploratory and descriptive study of a qualitative approach, with a research subproject entitled << Resilience as a coping strategy for the cancer survivor >>. Such research, both quantitative and qualitative,

was approved by the Research Ethics Committee of the Faculty of Nursing/UFPel, under opinion number 31/2009.

The study in question was developed with three families of two people surviving from cancer in medical evaluation of follow-up in a university hospital in southern Brazil. The production data was carried out through semi-structured interviews from January to March 2012, and the meetings were scheduled in the families' homes for a total of two meetings with each. The impressions of the researcher after the interviews were recorded in field notes.<sup>8</sup>

Data analysis was carried out in three stages: ordination of data, which involved the transcription of the interviews, observations and field notes, allowing the development of a horizontal map of field discoveries, data classification, at which the researcher conducted a thorough reading of the texts, making it possible to identify the relevant structures and the central ideas of the discourse. Furthermore, at this stage a cross-reading was performed, identifying at each speech empirical categories, namely units direction. The final analysis, in which it held a reinterpretation of the meaning units, in parallel with the research objectives, integrating these senses with the theoretical assumptions and the context of the informants.<sup>9</sup>

The ethical principles that have supported this study are in accordance with Resolution number 196/96 of the National Health Council/Ministry of Health on Human Research.<sup>10</sup> Still, it was guaranteed to informers, anonymity, through its identification by the name initials followed by the degree of kinship with the person surviving to cancer, eg AB, LM's brother, the right to withdraw at any time from research and free access to the information when their interest. All respondents signed the Informed Consent (IC).

## RESULTS AND DISCUSSION

Participants were three relatives of people from cancer surviving. The characteristics are presented individually seen the existing particulars.

Informant 1: female spouse, 70, said black skin color, two children, home, practicing Catholic, 5<sup>th</sup> grade of elementary school, had no monthly income.

Informant 2: male, spouse, 66, mentioned mixed skin, two children, retired typesetter, made extra services, Catholic, 2<sup>nd</sup> year of high school, had an average monthly income of R\$ 1.000,00.

Informant 3: female, daughter, 35, said white skin color, single, one child, receiving sick pay, seamstress, evangelical, 2<sup>nd</sup> year of high school, had monthly income of R\$ 730,00.

The analysis of the interviews enabled us to identify how the family experiences the sick person and survive cancer. Thus, we present the results in relation to this thematic unit.

The family, when faced with the first signs of illness in one of its members, experiences the experience to accompany him to doctors of various specialties, perform various tests and sometimes hear that nothing was found wrong, but notice the problem aggravating.<sup>11</sup>

In this perspective, the family suffers in the face of uncertainty, and requires choose to pay visits and tests to clarify the diagnosis and start treatment immediately, as shown by the testimony:

*[...] we passed by some private doctors to expedite the thing and some private tests also [...] F.R.B.P, wife of D.R.P*

*The mother went there (hospital) and herself scheduled the consultation, took the exam (mammography) and was negative. But something told me, my intuition that it was not. So I went with her in the doctor's return and said to the Doc, "How can a person have problem of hormones and glands and the breast be spun so retracts inside?" And she told me that it was normal did not care. Then we went out there and I said "mother we'll have to look for a specialist!" [...] A.R.L, daughter of M.J.R.C  
[...] she felt a lump in the breast and went to the doctor. Then I know that the doctor said it was a lump, but did not need to be scared. But then she went to another doctor and did biopsy and then yes it was found that she had cancer. J.J.L, husband of M.J.R.C*

It is observed that respondents reported the search along with their families for medical examinations and with the intention of confirming the diagnosis of cancer and also to get the necessary treatment. In this dimension, for assistance and cure, the family looks for experts, often having to pay high-cost tests. In some situations, even with treatment expended by the Unified Health System there is no coverage for certain expenses.<sup>11</sup>

Since the beginning of the first symptoms, by identifying an oncology diagnosis and treatment selection, family members typically accompany their loved one on an emotional roller coaster, with implications for the quality of life and social well-being.

The reports can be seen the impact of the discovery of disease experienced by the family:

*The impact was so, how will I tell you, we always scare [...] F.R.B.P, wife of D.R.P [...] because the impact was the worst, because no one expects no one wants. J.J.L, husband of M.J.R.C*

Family members get frightened by the diagnosis of the disease, thus having a hard time accepting it, making it difficult to assist the person who needs their help. At that time, the family, despite the emotional difficulty that is, needs to support the sick member and accept the cancer in its immediate situation.<sup>12</sup>

Cancer diagnosis puts individuals and families in fragile condition, and there are difficulties to cope with the disease due to stigma. Thus, it is feared to be added to the idea of imminent risk of death and fear of aggressive and mutilating treatments. In this perception, cancer of stigma is reinforced, especially when the late diagnosis of the disease limits the possibilities of treatment and cure.<sup>13</sup>

Generally, cancer treatment is over, aggressive and intense for the patient, requiring a lot of it and the family. The frequent recurrence of complications demands strength and support from all people involved in this process so that it can overcome the crisis episodes and pain.<sup>14</sup>

It can be seen, therefore, the reaction of the family before the disease, and this view for its stigma of pain and inevitable, although they had the knowledge that if treated early, can focus on a remission.

*[...] we know that cancer is a painful disease, but we also know that if attacked with time comes curable. F.R.B.P, wife of D.R.P*

*[...] People think that you will ever die. It's automatic, already have that prejudice, because when it comes to cancer people think you are terminally ill and has not long to live. [...] When the mother was being treated I knew she was going to go through it and was overcome. A.R.L, daughter of M.J.R.C*

*Cancer is seen thus as a thing, as if an atomic bomb. But today we have lived already know that attacking with time can be permanently cured. J.J.L, husband of M.J.R.C*

Family members reported uncertainty before the diagnosis of cancer and also expressed their belief in the survival of their being. The daughter said people's reactions to the diagnosis of disease and treatment of the mother, understanding this as prejudice. However, it notes that in all family members there was present hope of cure.

In this process, the emotional aspects are decisive factors for coping with the disease, as aid in positive answer to every problem.

Thus, the sick person and his family understand the relevance of this fact, which benefits the overcoming of obstacles, with the hope of healing present in this context.<sup>11</sup>

The interviewees reported feelings of despair and anxiety during treatment:

*[...] I get desperate and think about many things, will it stop here, will the treatment, as they say, will stop the disease [...] always trying to stay calm not to demonstrate that worried we always got. Is the head will it get better? [...] But sometimes I was even scared, because she had an occasion when she had to return there urgently in hospital I do not remember what happened, I know it has a problem in the surgery she had to return there. J.J.L, husband of M.J.R.C*

*[...] so sometimes you become very distressed. [...] when the mother was much more painful than mine, I felt weak to help her, did not want to cry in front of her, just wanted to give strength. A.R.L, daughter of M.J.R.C*

Thus, one can see that his daughter and her husband MJRC demonstrated feelings of anguish, despair, weakness and uncertainty about the future and that one of his major concerns was to support the patient and family to demonstrate the concern and insecurity that were feeling before the treatment.

Anxiety is an unsettling feeling towards the unknown situation that unexpectedly man has to experience, leading her inner sense of agony.<sup>15</sup> Thus, it appears that family members revealed their sorrow not only for your loved disease, but also the changes that took place in the family context.

It is noteworthy that the diagnosis and treatment provoke feelings that lead to an imbalance in the family organization. The family experience is resized, their attitudes, their beliefs and values are considered from another point of view.<sup>14</sup>

The family of a person with cancer requires great attention because of the chronic nature and severity of the disease which it contains. The consequences of this extend to family structure, imposing the need to reorganize to meet everyday demands and care for the sick, and can also affect interpersonal relationships. The existence of the disease in the family also mobilizes positive and negative feelings that need to be understood by health professionals.<sup>13</sup>

Family members expressed the changes that happened in their lives during cancer treatment.

*Our life always changes, some changes, because we always had to be in the case, the willingness to meet her I could not make*

*an effort [...] to the people's house chores had to help her, that it is normal. During treatment I was in the market today me or her will, or our daughter. When she did the surgery I was still working, retired, but working, and there changes, have to go to work or have to seek an examination, any activity that she had to do, we did. J.J.L, husband M.J.R.C*

*There was a pretty big change I had to unfold me because at the time I was working and I could not miss service. The father took care of all day and when I came at six looked after [...] then, when the mother was under treatment who would market was me and dad, cook these things [...] A.R.L daughter of M.J.R.C*

*The only change that happened now was the care that we have to have with him, the health care. I did not leave anything, our life remains the same. F.R.B.P, wife*

The husband and M.J.R.C's daughter said what changes occurred in the family routine to provide care during cancer treatment, reporting that sometimes took over activities previously carried out by the person with the disease. Already the wife of D.R.P reported that the only change was in relation to the care of the family they needed to be more intense, but that his life routine remained the same. At this time, we see the difference in the demand for care as the gender of the patient, because there is a culture in relation to the woman as caregiver.

It should be mentioned that in the family, who often assume responsibility for and the habit of care is the woman. Thus, it is identified as a natural process that women are the caregiver of a family member affected by the disease. However, when women face cancer, there are adjustments in their life routine, because that now they need and want to receive help and care.<sup>16</sup>

Note, too, that the man in the "role" spouse carries the care of sick wife, as shown in the dialogues. Fact that corroborates a study conducted in northern Taiwan, where the husbands believed that the relationship between them and their wives with metastatic cancer was irreplaceable, and therefore the care of them could not be played by others.<sup>17</sup>

In this sense, it is evident that when the caregiver provides care to your family, this implies an overload of activities, related to the assistance to the patient and the fact that you cannot take advantage of everyday life by the lack of free time to rest and devote yourself the other tasks.<sup>15</sup>

Thus, facing the disease takes the family to reset its routine to live with the disease and the implications arising therefrom, since the

family dynamic is complex and each member plays a role and plays.<sup>14</sup>

In this regard, we emphasize the importance of nursing recognizes the patient's daily life and his family, giving importance to family organization, the quality of relationships, the role of the sick man in the family, the impact to the work activities of caregivers, the housing conditions and family income.<sup>13</sup>

Based on these observations a way to facilitate the process of adaptation to the new condition of family functioning, it is to encourage interaction between members, as this promotes changes in behavior of these.<sup>18</sup>

After treatment, when the patient and his family begin another phase in their lives, the body stabilization, with the decrease of the therapeutic effect and the resumption of their habits, it is observed that they are building a new identity for this saga: the surviving identity. Also, realize that the family return to living conditions that was before the disease even considering living with the after-effects of the therapy, in addition to frequent medical follow-ups, reminding them of the situation of his family member being a cancer patient.<sup>19</sup>

Family members exposed the medical monitoring that occurred after the end of treatment, with the hope of not having disease recurrence and a sense of calm to the situation that lived in spite of this restlessness in all return times to health services for periodic evaluation.

*[...] you know you have to always be alert, investigating making all examinations [...] he has done the dishes that doctors ask, exams, and so far it's always okay F.R.B.P, wife of D.R.P*

*[...] it is having follow-up, she goes to the doctor from time to time and makes all examinations and thank God for the time being did not show up anything and we get more quiet. I hope you do not return, it has not been any thing and we're always looking at it, let's wait to see what will happen. J.J.L, husband of M.J.R.C*

The families were on "high alert" regarding the monitoring of health status. In this new phase, in which they survived the cancer diagnosis, the significance of the change of appearance in the body ends up being more valued by family, since they have become more aware of health issues.<sup>16</sup>

The new phase experienced by the family is defined in order to attempt to modify the peaceful conduct and the victimized person, another active and hopeful in fighting the disease. Thus, survival is a path to be traveled; it starts with the discovery of the

cancer diagnosis and continues throughout life. Moreover, living after cancer treatment has different reactions and often brings challenging situations. Thus, people feel the need to make sense of this experience and develop ways to live in new condition, which means a way people are to adapt to the disease situation and continue to live.<sup>19</sup>

Thus, the cancer survival is seen by the family as an overcoming of its being:

*I think it's too much, I think it is an opportunity to live again [...] I think, because due to the stage of her illness we fought, but had that fear. And so everybody struggles, but she overcame! [...] A.R.L, daughter of M.J.R.C*

*Survival? Look, I'm not a trained person, but if I think so, we've been in this situation with several people, have the person who is brave that is warrior and wants to win [...]. I consider my wife as a cancer survivor, because this is a disease which if not treated in time, it kills, because we had with several people that happened this, and she had serenity, a so-quiet to rehabilitate this disease. J.J.L, husband M.J.R.C*

It is observed that the informants consider their family as cancer survivors. The reports one can see the different ways that each comprise survival, which is seen as overcoming the family to face the cancer process that involved surgery and other treatments. In the post-disease period considered their cured one.

Importantly survive the disease does not mean only be cured, it emerges from the need to recognize that the success of treatment transcends the biological sphere, extending to an existential dimension that includes the various spheres of human existence. It is understood still to know the meanings attributed to survival deserves attention of all health professionals, highlighting the nurse who takes care of these clients in different social contexts.<sup>20</sup>

In this sense, the fact of experiencing cancer enabled the family to understand the existential limits. However, the cure is seen as a hope for the future, which is being established by the people in the path of cancer survival.<sup>19</sup>

## CONCLUSION

The experience of family front cancer treatment is permeated by feelings that fluctuate depending on the stage where the family member is sick. It was observed that the family sees the disease as painful and fatal for the cultural stigma already established; however, it is clear that the family believed in healing.



It is observed that the family is organized to the care of the sick person; each member defines its role and articulates its routine as needed family dynamics. It is evident that before the discovery of the disease emerge the feelings of despair, anguish and uncertainty about the future.

It was found that the family experiences the survival of unique and dynamic way cancer, according to their beliefs and values. Thus, there is like family understands, interprets and experiences the stages of illness and surviving cancer.

In line with this, it highlights the importance of nursing in the face of cancer survival, in order to support, guide and provide the necessary assistance to the patient and his family, as he may not be prepared to take care. It is worth emphasizing that nursing needs to train its professionals in oncology, so they can provide the necessary support to the family before the disease.

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