

Winning the lottery and fearing for the prize: experience of rural families surviving the mamarian neoplasm

Ganhando na loteria e temendo pelo prêmio: experiência de famílias rurais sobreviventes à neoplasia mamária

Ganando la lotería y temiendo por el premio: experiencia de las familias rurales que sobreviven a la neoplasia mamaria

ABSTRACT

Objective: understanding the experience of rural families who have the surviving mother/wife of breast cancer. **Method:** qualitative research based on the theoretical basis of Symbolic and methodological interactionism of grounded data theory. Forty-one members of six rural families participated. The data were produced through an open interview with circular questions and the construction of the family genogram, being analyzed by the Constant Comparative Method. **Results:** the Theoretical Model was defined by two central categories: recognizing itself as a victorious family and (not) believing in the cure of breast cancer, symbolizing the trajectory of the experience of rural families. **Conclusion:** the experience can be described as a constant, interactive, and integrated movement in which the family recognizes itself as victorious, which “wins the lottery” when the mother/wife is considered cured, but “fears losing the prize” due to relapse.

Descriptors: Family; Rural Population; Breast Neoplasms; Survivorship; Nursing.

RESUMO

Objetivo: compreender a experiência de famílias rurais que têm a mãe/esposa sobrevivente de câncer de mama. **Método:** pesquisa qualitativa fundamentada no referencial teórico do Interacionismo Simbólico e metodológico da Teoria Fundamentada dos Dados. Participaram 41 membros de seis famílias rurais. Os dados foram produzidos mediante entrevista aberta com questões circulares e construção do genograma familiar, sendo analisados pelo Método Comparativo Constante. **Resultados:** o Modelo Teórico definiu-se por duas categorias centrais: reconhecendo-se como uma família vitoriosa e (não) acreditando na cura do câncer de mama, representando simbolicamente a trajetória da experiência das famílias rurais. **Conclusão:** a experiência pode ser descrita como um movimento constante, interativo e integrado que a família se reconhece como vitoriosa, que “ganha na loteria” ao ter a mãe/esposa considerada curada, mas “teme perder o prêmio” pela recidiva.

Descritores: Família; População Rural; Neoplasias da Mama; Sobrevivência; Enfermagem.

RESUMEN

Objetivo: comprender la experiencia de las familias rurales que tienen la madre/esposa sobreviviente del cáncer de mama. **Método:** investigación cualitativa basada en el marco teórico del interaccionismo simbólico y metodológico de la teoría de datos fundamentada. Participaron cuarenta y un miembros de seis familias rurales. Los datos fueron producidos a través de una entrevista abierta con preguntas circulares y la construcción del genograma familiar, siendo analizados por el Método Comparativo Constante. **Resultados:** el Modelo Teórico fue definido por dos categorías centrales: reconocerse como una familia victoriosa y (no) creer en la cura del cáncer de mama, representando simbólicamente la trayectoria de la experiencia de las familias rurales. **Conclusión:** la experiencia puede describirse como un movimiento constante, interactivo e integrado en el que la familia se reconoce victoriosa, que “gana la lotería” cuando la madre/esposa se considera curada, pero “teme perder el premio” por la recidiva.

Descritores: Familia; Población Rural; Neoplasias de la Mama; Supervivencia; Enfermería.

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INTRODUCTION

In the daily life and health conditions of rural families, the bond and friendship between those who are part of a given community, constitutes a support network to deal with difficulties, especially when the family experiences a serious illness of one of its members. This unique way of living for rural families and of being in solidarity with each other can be considered a symbolic and culturally constructed value, meeting the health care needs of those who share experiences⁽¹⁾. In situations of illnesses, especially in the diagnosis of cancer, the rural family defines this experience of having a family member with cancer as a threat to their world since they feel helpless and the disease is a gradual and continuous process⁽²⁾.

The families of women with breast cancer become the main source of support and psychosocial support during the diagnosis and treatment. This support provided by the family and, especially, by her partner, contributes to encouraging the woman to face the disease and to adhere to therapy⁽³⁾.

In the context of rural life, the illness of the woman/mother/wife has an impact on the organization of life in the family unit, work activities, and parental functions. The role of women (mother/wife) is quite present in the dynamics of rural life, and the illness from breast cancer interferes with the performance of the functions performed by her, which can cause disorganization in the family's daily life and reflect on the limits of their subsystems, requiring flexibility and ability to promote and adapt to changes in family dynamics.

Considering that breast cancer currently has a good prognosis and has the possibility of cure, families whose mother/wife is a survivor of this disease also live a new experience and may need to restructure and reorganize the family functioning. According to the National Coalition for Cancer Survivorship, the family is also considered a cancer survivor, experiencing expectations, feelings, and difficulties together with the sick family member. That is, family members or even friends who are involved in the care during the process of illness until the cure for the neoplasm, experience survival through the disease⁽⁴⁾.

In this study, family means the members they state⁽⁵⁾, conceived as a group of people united by affective, biological, affinity, and a sense

of belonging, sharing values, beliefs, and knowledge⁽⁶⁾. The terms survive/survivor/survival is related to the diagnostic condition of those people who underwent cancer treatment and did not present clinical manifestations of the disease for five years or more, or those people who completed the treatment for at least two years⁽⁷⁻⁸⁾.

Regarding women with breast cancer who live in rural areas, the study showed that social support is essential because, in addition to the repercussions among family members, women experience negative experiences both in social and emotional factors⁽³⁾. Thus, social support associated with cultural issues needs to be considered an important component during professional assistance to this specific group for the role that women play in the family group⁽³⁾.

Therefore, investigating the experience of the rural family in situations of survival of the mother/wife with breast cancer can contribute to broadening the understanding of this stage of the illness process and its repercussions within the family. This contribution is expressed in the production of a few studies developed in Brazil on the health of the rural family and the role of women in this context, including the family group as a unit of care in nursing^(2,9-11).

Given the context, the guiding question of the research is: What is the experience of rural families when their mother/wife is a breast cancer survivor? The study aims to understand the experience of rural families whose mother/wife is a breast cancer survivors.

METHOD

This is a descriptive study with a qualitative approach, anchored in the theoretical framework of Symbolic Interactionism^(12,13) and the methodological framework of the Grounded Theory of Data (GT)⁽¹⁴⁾. Symbolic Interactionism focuses on the perspective of interactions, on the dynamics of social activities between people, on the meanings of events, on the natural environments of their daily lives, and on the actions that are developed by people^(12,13). GT is a qualitative method of analysis used for the construction of categories and that enables the development of a theoretical description of a certain reality; it is a method that gives rise to theoretical explanations for events in human experience⁽¹⁴⁾.

The people present at the time of the

interview were: a father, a mother, four spouses, 11 daughters, six sons, a son-in-law, four daughters-in-law, two granddaughters, a father-in-law, a mother-in-law, a sister-in-law, a niece, and a neighbor. In this study, the family was represented by the participation of at least two of its members at the time of data collection, one of them being the mother/wife, and the others who she would like to be present. Thus, six rural families participated in the study, totaling 41 people.

To select the possible families that could participate in the study, we sought to locate, three Family Health Strategies (ESF) of municipalities belonging to the 6th Health Coordination of the state of Rio Grande do Sul/Brazil, corresponding to the region covered by the municipality of Passo Fundo/RS/Brazil. The inclusion criteria were mothers/wives registered in the ESFs, living in rural areas and who had completed cancer treatment for more than two years.

Theoretical saturation was obtained when the data became repetitive and allowed the understanding of the identified concepts due to the depth and richness of the content, composing three sample groups: families whose children had already left home, were independent and lived far from their parents, living together, then, only the elderly couple; families in which children were dependent and lived in their parents' house; and families in which three generations (father, mother, children, and grandchildren) lived in the same house.

Data were produced through open interviews with circular questions⁽⁵⁾, lasting approximately three hours, carried out from March to September 2013. During each interview, the family genogram was prepared. The interviews, conducted by a single researcher, a master's student, were carried out at the rural families' homes, on a day and time established by them, recorded, and later transcribed in full. The questions used to produce the data were: "Tell me what it's like for you to have your mother/wife cured of breast cancer? What did you think when you learned that the mother/wife was considered cured? What do you think helped make that happen?"

Data analysis was performed according to the steps proposed in the Constant Comparative Method. The method was applied following the four stages: open coding (building codes),

theoretical coding (building categories and subcategories), theory delimitation (building the central categories), and theory writing⁽¹⁴⁾.

The research project was approved by the Research Ethics Committee of the Federal University of Santa Maria under Opinion number 250,567 and was conducted following the required ethical standards. To identify the participants guaranteeing anonymity and characterizing the speeches, we chose to use the letter "E" to identify the interviewed family member and the letter "F" to identify their families. The letters are followed by a cardinal number that represents the family member's number and the sequence in which the interviews were carried out, for example, "E1, F2".

RESULTS AND DISCUSSIONS

From the data analysis, we could understand the experience of rural families when their mother/wife is a breast cancer survivor, representing a process during several facts and events, even before the woman's illness. The theoretical model representative of the experience was defined by the organization of eight categories and three subcategories and two central categories, enabling the analysis, the interrelation, and the integration between them, understanding the trajectory of the rural family experience.

The categories and subcategories that support the phenomenon of the study are: 1) Reliving illness experiences; 2) Trying to perform the treatment as soon as possible; 2.1) Having difficulty; 2.2) Experiencing cancer treatment; 2.3) Receiving help; 3) Keeping the diagnosis secret; 4) Having to deal with mixed feelings; 5) Having repercussions on family life; 6) Defining cancer illness; 7) Resorting to spiritual and religious beliefs, and 8) Waiting for five years. The two central categories are: RECOGNIZING ITSELF AS A VICTORIOUS FAMILY and (NOT) BELIEVING IN THE SURVIVAL OF BREAST CANCER.

Reliving illness experiences refers to the memories of experiences that are somehow reflected in the current illness trajectory. While the family has its experiences, it goes back in time, seeking, in the rescue of lived situations, to seek explanations for the events to understand the present reality, in a constant coming and going to/from the lived context. Thus, the experience of families occurs in a timeline, moving along the course.

"I didn't just spend it with my mother. I also spent time with my father-in-law who had cancer" (E6, F1). "If I hadn't gone at the beginning, it would have been complicated, because that's how it was with my sisters. The first one stopped taking the exam because at that time everything was more difficult. It's been a long time since she passed away. She was giving up. She felt this, felt that, but she kept giving up because no one said: Go! And it happened: she died" (E1, F3).

When the family experiences the diagnosis of breast cancer of the mother/wife, it refers to the experience of illness of other women in the family, other relatives, neighbors, and known people who died from cancer. The social interaction that took place in the family group with previous experiences of illness and death from cancer influences the way the family experiences the diagnosis of the mother's/wife's breast cancer in the family nucleus. This social action makes the family seek cancer treatment as soon as possible. In this therapeutic trajectory, both the mother/wife and the family went through many difficulties for the woman to successfully carry out the treatment.

Thus, driven by the fear that this might happen in the family nucleus, the families are organized so that the mother/wife could start the treatment of the disease as soon as possible. This stage of illness, seeking to carry out the treatment as soon as possible, causes the family to face difficulties in experiencing the therapy and assigning meanings to it from the experiences of the past projected and interpreted in the present and for the future.

"At that time, I didn't have much to think about. It was to start soon! There wasn't much to organize. It was to go after and it happened! It appeared and, in a few days, I had to do the treatment! I didn't have time to organize myself. There's no way to plan. You have to go as soon as possible" (E5, F6). "What counts is also the stage at which you discover the disease. How far along it is. When we feel anything, we have to go to the doctor right away, it's not to wait. When you waited, you wasted time. Gotta go soon!" (E6, F4).

The concept that the start of cancer treatment should be performed as soon as possible is associated with the interactional context and the experiences lived by the family in different social spaces and with people affected by cancer, especially breast cancer. These experiences have repercussions on how the

families will look at the situation experienced by the mother/wife and how they will proceed during the illness. To these previous experiences, new experiences are added along the way.

The home environment of families is considered the ideal place for care when a member becomes ill. However, this scenario is configured according to the illness experiences lived before the diagnosis of the mother's/wife's breast cancer. That is, the social interaction of the group is directed to the facts of life sustained and supported in the face of chronic situations that the family has had to face. Thus, the family is constituted according to the care needs of each situation of their daily life and in the very personal way of each member⁽¹⁵⁾.

Due to the course of therapy, the mother/wife and her family faced some mishaps, such as difficulties related to the distance between the residence and the city of treatment, the limitations of transportation and the time available to travel to the treatment site, the side effects caused by cancer therapy and the financial implications to be able to carry out the therapy and have access to the specialized health service.

"We had difficulties because we had to take transport in the city and we had nothing to go there with. At that time, it was very difficult! So, if it were today it would be different!" (E8, F1) "There was no transportation at that time. It used to not be like it is now, allowed to take it to a place and get it. It wasn't like that before." (E4, F4). "The treatments today have changed. But at the time, I had to sell everything I had. At the time, we paid R\$300,000.00. So today it is certain that it has changed, but at the time I had to sell everything I had. They were very expensive! And then chemo? That was per session!" (E5, F6).

"I had mouth sores and couldn't eat or sleep at night. I finished chemotherapy in June and went until the end of the year to recover. It was long!" (E5, F5). "What impressed me the most was the chemotherapy. Nothing worse than chemotherapies! Those chemotherapies were killer. Those can't be forgotten! God! I couldn't even put water in my mouth. That was disgusting, God! I hate everything, you know? I don't know if there's anything worse than chemotherapy, oh God!" (E2, F6).

A study showed the two biggest difficulties pointed out by cancer patients along the therapeutic itinerary as fatigue and discomfort due to moving from their homes to the place to

perform the treatment and the side effects of anticancer therapy. In addition to these difficulties, patients still faced long waits to return to their homes, lack of financial conditions with food during treatment, changes in family dynamics with home activities, and continuous exposure to invasive procedures⁽¹⁶⁾.

The experience of the mother/wife of cancer treatment in the family context was specifically associated with the mastectomy surgical procedure and hospitalization. The meaning of a woman's submission to surgery is attributed to situations experienced in the social interactions in which the woman finds herself, whether within the family, in the community, or in the municipality in which she lives. Given all the risks involved in surgery, the surgical act assumes a somewhat frightening meaning for the family, and surgery is seen more as a negative than a form of treatment. This negative view of the surgical procedure may, on the other hand, have been influenced by how the health professional informed the family about the type of treatment that the mother/wife would need to perform and the need for hospitalization.

"The doctor told her that she was going to remove the breast and she would live for about 40 days. It was a scare for everyone! When we got home everyone was like that, not knowing what to do. She didn't want the breast taken away. She said that she would rather die than remove the breast" (E2, F4). "She had the surgery on Friday and I went on Saturday. She was in the room. My God! That day for me was the worst day of my life!" (E8, F1).

From this perspective, the experience of breast cancer treatment is related to the life context of families and the meanings they attribute to therapy, which are influenced by the social life of the community where they live and by people from other locations with whom they relate.

Research carried out with women survivors of breast cancer found that after receiving the diagnosis of the disease, a new stage begins in the experience of illness: the performance of surgery, chemotherapy, and/or radiotherapy, establishing new difficulties to be faced. The stage of experiencing cancer treatment is understood by women as traumatic and frightening, possibly linked to cultural constructions about breast cancer in the myths and stigmas that this diagnosis socially represents⁽¹⁷⁾.

As a way to alleviate these difficulties, the family received help from other family members, neighbors, and friends. The main forms of help that the mother/wife received, mentioned by the families, were directed to the two difficulties experienced to be able to carry out the treatment of breast cancer: transportation and financial condition.

"Without the help of a neighbor, she wouldn't have gone! Because he was the one who always took her. He couldn't go, she had no one to go with. Thanks to the neighbor at that time, she would not have completed the treatment" (E8, F1).

"The neighbor stopped going to work to take me for the dressing. This man to me is like a son! Sometimes he took me twice a day. He helped me, supported me, like a son! At that time, if the neighbor hadn't helped me, I wouldn't have had any treatment. That I'm sure! He didn't take me for money, he took me for goodwill because we're good friends and I consider him like a son. I wouldn't leave him for the world. He might even do something wrong, that if I know, I'll pretend I don't. I consider him my son! I will never say anything against him and he knows that" (E4, F1).

This family action is constituted as self-care and an integrated care system that does not refer only to blood family ties, but to people who belong to that place, such as neighbors, friends, and the community. Thus, the family is constituted as a social support network and a health care system where everyone moves, helping each other⁽¹⁸⁾.

In addition to the social support of family and friends, rural women who survived breast cancer also considered the assistance received by health professionals to be important, as many wanted to keep the diagnosis a secret as a way to protect their family and friends from suffering⁽¹⁹⁾. This evidence is configured oppositely in this study, that is, family caregivers of the mother/wife who wish to keep the diagnosis of breast cancer a secret from other members and from the rural community where they live.

Considering the meaning negatively attributed to cancer in the socio-cultural context of the rural environment, keeping the diagnosis a secret explains the strategy adopted by the family to protect the woman from interference coming from the community or even from the family nucleus. This secret is kept interactively, within family relationships, because socially, cancer

arouses prejudice, fear, afraid, and stigma in people and those involved in the mother/wife's illness process.

"We agreed with the mother that we would not tell the father anything. We lied and say it was a normal surgery! A regular surgery! And when the mother started chemotherapy, her hair would start to fall out, we had no way to hide it from her anymore. Then we had to tell" (E6, F1). "It's not that we lied to her, we were relieved! One thing we know could be worse for her, we take a breather first. This may not be our family's fault; it may be a strength!" (E2, F5).

"At the time she got sick, around here, you couldn't even talk about cancer, you couldn't even hear about it: "Ah! There is such a place there is a person with cancer". Or: "Oh! That person over there has cancer." And when it happened, we didn't know what to do. At first, nobody said anything, everyone hid that she had the disease. It only started to appear after a while" (E5, F6).

The secret happens in family situations that can involve either a single member or almost the entire family. These events, within the family, mean that they are often experiencing negative feelings and experiencing difficulties. On the other hand, secrecy represents an important dimension of protection, care, and preservation of individual and family privacy, which makes the family experience positive feelings.

When the family has new experiences in its environment, in the case of a chronic disease such as cancer, it represents a certain concern about the situation among its members, generating fear and having an impact on the way to face it. In this context, the family keeps the diagnosis secret, trying to protect the sick family member from a possible reaction to society or from something that until then was an experience unknown to the family unit⁽²⁰⁾.

Keeping the disease secret is a strategy used by families as a possible way of mediating social coexistence. Each family has its secrets to preserve privacy and autonomy, both for the family group and for each member.

Dealing with contradictory feelings corresponds to another stage of the trajectory experienced by families. The feelings experienced by the family were diverse and contradictory, including denial, anger, guilt, suffering, sadness, shame, worry, fear, courage, hope, joy, and relief. These feelings permeated the family nucleus due to the meaning that the illness of the mother/wife

acquires along the way.

"When I came here, when I was with my mother, I was fine, but when I got home, I would wash myself crying. I had to be the strongest! I was the oldest! I had more responsibility! I thought so!" (E6, F1). "I always tried to stay calm and when I met with them, I tried to act like it was okay, but it wasn't okay. I was affected inside, but I tried to give them strength! Be their base!" (E2, F1).

The will to fight a negative experience in the family provides members with positive feelings of overcoming, developing greater confidence to take active measures to deal with and overcome the family problem⁽¹⁷⁾. On the other hand, women survivors of breast cancer consider that living with fear becomes something permanent, justified by the fear of experiencing a recurrence of the disease at some point in their lives⁽²¹⁾. A study showed that the rural family had repercussions on the nucleus during the illness process, causing several positive and negative feelings instantly, both in the patient and in their families⁽¹⁰⁾.

After living that experience, with the absence of the woman at home or her inability to carry out agricultural and domestic tasks during the period of treatment in another municipality, the family reorganizes itself to maintain its proper functioning, with greater interaction between the members of the family nucleus.

In this context, family members assume the role of women in the family nucleus, performing agricultural and domestic tasks, which until then were performed by the mother/wife before her illness, causing changes in roles in the family group. Thus, they need to divide tasks to reorganize the functioning of the family, creating repercussions on family life.

"The milk cows, I had to make the cheese and I had to go to the farm" (E3, F2). "I had to go to work on the farm because at that time we grew tobacco and there were the children to take care of" (E7, F6). "She was always like that, always managing, leading everything! She had her children when they were still small and in addition to taking care of the children, she plowed and moved the land. So, in addition to taking care of the food and the small children, she still worked in the fields" (E5, F5).

The treatment stage of the experience of becoming ill with breast cancer has significant repercussions on family dynamics. This

repercussion occurs mainly in domestic activities, as the woman assumes the role of responsible for performing these tasks, which is considered inherent to the female figure in the home.

When the woman starts the treatment for breast cancer, the family's daily life changes. Their domestic activities change with difficulties in carrying out household chores due to the need to reduce the movement of the arms, the woman feels discomfort when sleeping, driving, performing routine tasks, and disturbances in body posture, which reduces their abilities⁽²²⁾. These limitations cause psychological discomfort because women daily relive the presence of the disease and the difficulties of obtaining the full physical capacity to perform household chores, as well as to take care of their bodies, and eat independently^(17,22).

When a rural family experiences an illness from cancer, it compromises the symbolic elements that configure the meanings that make up rural living. The illness process makes everyone involved change their tasks, increasing the demands of care for the sick member and they feel threatened with issues related to dealing with the land and animals⁽²⁾.

Throughout their experience, the family attributes positive and negative meanings to the disease, the difficulties, and the strategies used by the families when experiencing the diagnosis and treatment of the mother's/wife's breast cancer. Such an experience is revealed by the perspectives that occurred when dealing with the illness, starting with the way of believing that cancer has no cure until the way of believing that cancer can be cured.

"Before, cancer was a ghost. Cancer meant death. People just thought they had no more cure. And it has! Look at that time and now? It's the past as an era! Because if it was like the old days, there would be few people left. Today it has changed a lot, but you need to find out early, find out soon" (E6, F6). "When the news finally arrived, it wasn't easy because there was always a lot of association between cancer and death. So, there were things that seemed as if there was no efficient treatment to be able to cure" (E2, F3).

The path taken at each stage of the rural families contributed to the meaning of the illness of the mother/wife, representing the cure or not of breast cancer and inducing family members to resort to spiritual and religious beliefs during the experience lived in the family environment.

This perspective of (not) believing in the cure for cancer makes the family find strategies to strengthen throughout the experience. At the time when family members seek to strengthen themselves, they resort to spiritual and religious beliefs.

"What matters a lot is having faith! One made a novena for a Saint; another made a prayer for another. We also made a lot of promises" (E6, F6). "I think it was almost a miracle! We prayed, we went to the novena, we did novenas, and the children came together. They came together with us and said prayers. At the time, they had it written and they wrote it. They prayed the rosary, said prayers, they asked for their grandmother's health" (E4, F4).

"There was a day when our neighbor took Jesus' mother to her room and I said: "Am I going to die Holy God"? Will I die? Because Jesus' mother always stayed here in the kitchen and that day the neighbor took her into her room and started praying, praying, and praying for her, which scared me! It's a thing of God what he sent me! I always, always said that it was something that God sent me, there is nothing else. How do you say, "He saved me!" (E6, F2).

Studies show that in the experience of cancer diagnosis and treatment, spirituality is considered a foundation for coping with the illness process, contributing to the understanding of the meaning of both illness and suffering. Also, spirituality helps patients to have strength and courage, from diagnosis to the end of treatment, helping with adherence, adaptation, and successful completion⁽²³⁾, especially in rural families, due to their uniqueness.

In the context of rural families, religiosity plays an important role in everyday life, contributing to the strengthening of social life and the construction of concepts and values. Spiritual and religious beliefs help these families to overcome difficulties and problems from serious diseases such as cancer and integrate a care system into the community⁽¹¹⁾. Thus, influencing the quality of life of rural families who experience the process of becoming ill with cancer, and their health outcomes and survival.

Strategies, linked to religious practices and spiritual manifestations, added to the end of cancer treatment for breast cancer in hospital institutions, help the family to remain confident, "waiting for five years". The family members want this time to pass soon, becoming one of the most

desired moments of the entire timeline that makes up the experience of rural families when having a mother/wife who is a breast cancer survivor. Thus, the family can celebrate the woman's survival as a victory for everyone involved in her illness process.

"We had that anxiety that the five years would end soon to say: "Bah, it's cured"! That wish for that time to pass. Because we were sure of some things and had doubts about others. And those exams, you know, every six months were very sad, very boring" (E6, F1). "And it passes quickly! And it's gone faster after five years because it's already eight years now. We forget. Now it was water that passed. It was a flood that went away with the water. We forget because it passes so quickly that he can't even imagine" (E1, F6).

The trajectory of the experience reflects the wait of rural families for five years after the completion of cancer treatment in the hospital environment when the mother/wife could finally be considered cured of breast cancer. After this period, the families recognize themselves as victorious families, as if they had won the lottery, but at the same time they live in fear of losing the prize, as they feel insecure about the future and, fearing relapse, tend not to believe in curing cancer. However, the passage of time, stability in the results of exams performed periodically and the confirmation that the mother/wife is healthy and performing their tasks well are factors that lead them to believe in the cure of cancer.

RECOGNIZING ITSELF AS A VICTORIOUS FAMILY and (NOT) BELIEVING IN THE CURE FOR BREAST CANCER are the two central categories that represent the trajectory of the experience of rural families, experiencing facts from the past (people who had the disease), the present (experienced illness) and in the future (uncertainty about the prognosis of the disease). This trajectory makes the family realize how much it is capable of facing and dealing with the unknown illness of the mother/wife from breast cancer.

"For the mother and for us, to have overcome this, I would say it was a victory! Knowing that this was one of the worst cancers I had and that the mother survived, I think it's a huge victory! An overcoming! Can you imagine?" (E4, F4). "It's like you have a debt. After you paid off the debt, it did! Go rest later. It's the same thing! It was a lottery for us at that time to see

her healed! It was like winning the lottery! It's the same thing! But it was a lottery-like I told you! She was born again!" (E6, F4).

"Once you go through this, you're never sure if you're cured or not. Anything you think you can have again. I feel good! But guarantee, guarantee that I'm cured, I don't guarantee. Why should I say, "Oh my God, I'm cured, I'm cured"! Because sometimes I feel pain very similar to the one that we went through before having the surgery. So how can I say: "I cured myself of this disease"! I'm fine, but sure, sure I'm cured, I'm not!" (E4, F1).

The survival of women in families involved the entire social context and the thinking of people as human beings in continuous interaction, as people think about the way they live, about life experiences, and about what brings value to them. On the other hand, when people attribute positive values to the experience of having the mother/wife a survivor of breast cancer, the meaning of cure goes beyond what was expected, beyond what the family believed and expected to happen, making the cure something unbelievable for the woman and the family.

Research carried out with women who survived breast cancer with evidence of comparison by rural-urban residence and age, found that women in rural areas were more likely to follow up related to breast cancer from the beginning, showing expressive care about their health and their family members with examinations or investigational tests than urban survivors. It was evident that older women sought support groups in the community as social support after the end of treatment, representing an alternative to sharing the experience⁽²⁴⁾.

The end of cancer treatment is presented as a meaning related to the idea of recognizing oneself as a victorious family. This recognition is because the family members, together with the mother/wife, have successfully reached the end of the therapy. However, concomitantly with this recognition, the family continues (not) believing in the cure for breast cancer.

Thus, we highlight the importance of training and practical preparation of nurses to work with families who experience cancer of one of their members, in different scenarios of professional practice, especially in spiritual issues⁽²⁵⁾.

Above all, we highlight the relevance of

additional research aimed at rural families, their way of life, and the meanings arising from this unique scenario, as the disease threatens the group as a family unit, interfering with the dynamics of rural work in the face of the demands of health care and dealing with the land⁽²⁾. From this perspective, studies that address the relationships of rural families with the experiences of illness that permeate the family and social context in which they (co)live can contribute to a more humanized practice in the health area, as well as research on the performance of teams in the scenario of rural ESFs, family nursing, and oncology nursing.

FINAL CONSIDERATIONS

This study aimed to understand the experience of rural families whose mother/wife is a breast cancer survivor and, through the data obtained, we showed that this experience constituted a process that is included in the trajectory of families even before they experience the illness of the mother/wife.

Understanding the influence that reliving past experiences exerts on the present life of families contributed to the interpretation of the way they interact with what they experience and the way they project the future. With this, the set of lived experiences and the sense of threat attributed to the diagnosis become relevant for families to decide to carry out the treatment of breast cancer as soon as possible, especially in the fear of losing the mother/wife even before starting cancer therapy or not being able to carry out all the treatment successfully.

It was also evidenced how much the solidarity of neighbors and friends, in rural areas, becomes even stronger when a member of the community needs help or goes through any type of difficulty. The help and support that the mother/wife and the other members of the family group received from neighbors and friends confirmed that the rural setting is a place where people live as families, helping each other wherever necessary, even if the neighbor's family needs to reorganize his domestic chores and work with the agriculture.

The trajectory taken by families when having to deal with contradictory feelings and the repercussions on family life challenged them to face, in addition to illness, other aspects, which required the mobilization of strength and courage already existing in the family nucleus.

During the experience, the families faced several challenges and difficulties, but they managed to face them by resorting to spiritual and religious beliefs. The dimension that is present in spiritual manifestations and religious practices presents a subject that needs to be addressed not only in nursing practice but also in the training of health professionals in general.

Thus, the experience of rural families when their mother/wife is a breast cancer survivor can be described as the result of a constant, interactive, and integrated movement, in which the family recognizes as a victorious family, but, at the same time, lives the dilemma of (not) believing in the cure for cancer. It is important to understand the difference between the scenario in which these families live and the scenario of the urban area since the process experienced by the families in this study was directly influenced by the cultural characteristics of the rural environment, which makes up their family and social lifestyle.

This study represents an addition to strengthening knowledge in the area of family health, as well as raising reflections to rethink the practices developed by nurses and other health professionals who interact with the rural population, especially with women survivors of breast cancer and their families.

The limitations of this investigation are directed at the discussion of data with research, specifically, developed with the rural population and that addresses the relationship of these families with the experiences of illness that permeate the family and social context in which they live. In this perspective, studies in this direction are suggested to contribute to a more humanized practice and with greater attention from the nursing perspective for these families, in particular, emphasizing the strength of the family in a situation of illness and the need to involve it in the care that the nurses provide in their professional practice in rural areas. With this, we can contribute to the understanding of the illness process in families that belong to the rural scenario.

REFERENCES

- 1 - Burille, A, Gerhardt TE. Experienci(a)ções de reconhecimento e de cuidado no cotidiano de homens idosos rurais. *Physis*. 2018 [citado em: 14 de jul. 2021]; 28(3):e280307. Disponível em:

<https://www.scielo.br/j/physis/a/rsGvLkKHvDyJwZCb9LKg6nh/?lang=pt>.

2 - Girardon-Perlini NMO, Angelo M. A experiência de famílias rurais frente ao adoecimento por câncer. *Rev bras Enferm.* 2017 [citado em: 14 de jul. 2021]; 70(3):577-84. Disponível em: <https://www.scielo.br/j/reben/a/P7gX7GLpPFFyk69MmFGsCFz/?format=pdf&lang=pt>.

3 - Mattias SR, Lima NM, Santos IDL, Pinto KRTE, Bernardy CCF, Sodr e TM. Câncer de mama: sentimentos e percepções das mulheres diante do diagnóstico. *R pesq cuid fundam online.* 2018 [citado em: 26 de mar. 2022]; 10(2):385-390. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/6057/pdf_1.

4 - Nekhlyudov L, Ganz PA, Arora NK, Rowland JH. Going beyond being lost in transition: a decade of progress in cancer survivorship. *J Clin Oncol.* 2017 [citado em: 03 de ago. 2021]; 35(18):1978–1981. Disponível em: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5676953/>.

5 - Wright LM, Leahey M. *Enfermeiras e famílias: guia para avaliação e intervenção na família.* 5ª ed [Reimpr.]. São Paulo: Roca; 2018.

6 - Girardon-Perlini NMO, Hoffmann JM, Begnini D, Mistura C, Stamm B. A família frente ao adoecimento por câncer de mama. *Rev enferm UFSM.* 2016 [citado em: 03 de ago. 2021]; 6(3):360-370. Disponível em: <https://periodicos.ufsm.br/reufsm/article/view/20893>.

7 - Schneider IJC, D'orsi E. Sobrevida em cinco anos e fatores prognósticos em mulheres com câncer de mama em Santa Catarina, Brasil. *Cad Saúde Pública.* 2009 [citado em: 10 de ago. 2021]; 25(6):1285-96. Disponível em: <https://www.scielo.br/j/csp/a/b8MSzB9LsYJSW4sNXdZxmck/?lang=pt>.

8 - Zebrack BJ, Chesler MA. Quality of life in childhood cancer survivors. *Psycho-Oncology.* 2002 [citado em: 03 de ago. 2021]; 11(2):132-41. Disponível em: <https://onlinelibrary.wiley.com/doi/10.1002/pon.569>.

9 - Costa FA. Mulher, trabalho e família: os impactos do trabalho na subjetividade da mulher e em suas relações familiares. *Revista da*

Graduação em Psicologia da PUC Minas. 2018 [citado em: 15 de abr. 2021]; 3(6):434-452. Disponível em: <http://periodicos.pucminas.br/index.php/pretexto/article/view/15986/13632>.

10 - Begnini D, Girardon-Perlini NMO, Beuter M, Silva L, Van Der Sand ICP, Misko MD. Experiência de famílias convivendo com neoplasia avançada: um olhar à população rural. *Rev bras Enferm.* 2020 [citado em: 10 de ago. 2021]; 73(4):e20180895. Disponível em: <https://www.scielo.br/j/reben/a/Zq37WCg4rPRLwVDfTKPVhZx/?lang=pt>.

11 - Ceolin T, Heck RM, Menasche R, Martorell-Poveda MA. Sistema de cuidado à saúde de famílias rurais. *Rev Recien.* 2021 [citado em: 10 de ago. 2021]; 11(33):14-26. Disponível em: <https://doi.org/10.24276/rrecien2021.11.33.14-26>.

12 - Blumer H. *Symbolic Interactionism: perspective and method.* Englewood Cliffs: Prentice-Hall; 1969.

13 - Charon JM. *Symbolic Interactionism: in introduction, an interpretation, an integration.* 8th ed. Eighth Edition: New Jersey; 2004.

14 - Glaser BG, Strauss AL. *The Discovery of Grounded Theory: strategies for qualitative research.* New York: Aldine; 1967.

15 - Moreno-González MM, Galarza-Tejada DM, Tejada-Tayabas LM. Experiencias del cuidado familiar durante el cáncer de mama: la perspectiva de los cuidadores. *Rev Esc Enferm USP.* 2019 [citado em: 26 de mar. 2022]; 53:e03466. Disponível em: <http://www.revenf.bvs.br/pdf/reeusp/v53/1980-220X-reeusp-53-e03466.pdf>.

16 - Teston EF, Fukumori EFC, Benedetti GMS, Spigolon DN, Costa MAR, Marcon SS. Sentimentos e dificuldades vivenciadas por pacientes oncológicos ao longo dos itinerários diagnóstico e terapêutico. *Esc Anna Nery Rev Enferm.* 2018 [citado em: 10 de ago. 2021]; 22(4):e20180017. Disponível em: <https://www.scielo.br/j/ean/a/hD37vTgjp7zMmJnPbJNCG9G/?format=pdf&lang=pt>.

17 - Cardoso DH, Muniz RM, Arrieira HO, Viegas AC, Arrieira ICO, Amaral DED. Mulheres sobreviventes ao câncer de mama: estratégias para promoção da resiliência. *Rev Pesqui (UFRJ).*

2018 [citado em: 21 de ago. 2021]; 10(2):474-484. Disponível em: <http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/6094>.

18 - Piriz MA, Lima CAB, Souza ADZ, Mendieta MC, Lima ARA, Heck RM. Autoatendimento em saúde rural: perspectivas de cuidado por mulheres agricultoras. Ciênc cuid Saúde. 2019 [citado em: 21 de ago. 2021]; 18(2):e45044. Disponível em: <https://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/45044>.

19 - Adams N, Gisiger-Camata S, Hardy CM, Thomas TF, Jukkala A, Meneses K. Evaluating survivorship experiences and needs among rural african american breast cancer survivors. J Cancer Educ. 2017 [citado em: 21 de ago. 2021]; 32(2):264-271. Disponível em: <https://link.springer.com/article/10.1007/s13187-015-0937-6> doi: [10.1007/s13187-015-0937-6](https://doi.org/10.1007/s13187-015-0937-6).

20 - Neves FB, Noguez PT, Guimarães SRL, Muniz RM, Pinto BK. Decisões contraditórias: motivos que levam o familiar cuidador a omitir o diagnóstico de câncer. Rev enferm UFPE. 2017 [citado em: 26 de mar. 2022]; 11(2):591-600. Disponível em: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/viewFile/11978/14530>.

21 - Pembroke M, Bradley J, Nemeth LS. Breast cancer survivors' unmet needs after completion of radiation therapy treatment. Oncology Nursing Forum. 2020 [citado em: 22 de ago. 2021]; 47(4):436-445. Disponível em: <https://onf.ons.org/onf/47/4/breast-cancer-survivors-unmet-needs-after-completion-radiation-therapy-treatment>.

22 - Reis APA, Panobianco MS, Gradim CVC. Enfrentamento de mulheres que vivenciaram o câncer de mama. Rev enferm Cent-Oeste Min. 2019 [citado em: 22 de ago. 2021]; 9:e2758. Disponível em: <http://seer.ufsj.edu.br/index.php/recom/article/view/2758/2079>.

23 - Barbosa RMM, Ferreira JLP, Melo MCB, Costa JM. A espiritualidade como estratégia de enfrentamento para familiares de pacientes adultos em cuidados paliativos. Rev SBPH. 2017 [citado em: 10 de maio 2021]; 20(1):165-182. Disponível em: <http://pepsic.bvsalud.org/pdf/rsbph/v20n1/v20n1a10.pdf>.

24 - Weaver KE, Nightingale CL, Lawrence JÁ, Talton J, Hauser S, Geiger AM. Preferences for breast cancer survivorship care by rural/urban residence and age at diagnosis. Suporte Care Cancer. 2020 [citado em: 23 de ago. 2021]; 28(8):3839-3846. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/31834516/>.

25 - Siler S, Mamier I, Winslow BW, Ferrell BR. Interprofessional perspectives on providing spiritual care for patients with lung cancer in outpatient settings. Oncology Nursing Forum. 2019 [citado em: 23 de ago. 2021]; 46(1):49-58. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/30547964/>.

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