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Experiences of family care during breast cancer: the perspective of caregivers*

Experiencias del cuidado familiar durante el cáncer de mama: la perspectiva de los cuidadores

Experiências do cuidado familiar durante o câncer de mama: a perspectiva dos cuidadores

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María Mercedes Moreno-González[1]
Dulce María Galarza-Tejada[2]
Luz María Tejada-Tayabas[3]

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[1] Universidad de Guanajuato, División de Ciencias de la Salud e Ingenierías, Campus Celaya-Salvatierra, Celaya, Guanajuato, Mexico.

[2] Universidad Autónoma de San Luis Potosí, Facultad de Psicología, San Luis Potosí, Mexico.

[3] Claustro Universitario de Chihuahua, Chihuahua, Chihuahua, Mexico.

ABSTRACT

Objective: To describe the experience of family care to women with breast cancer during treatment from the perspective of caregivers in the Mexican context. **Method:** Qualitative phenomenological study. In-depth interviews were conducted with caregivers of women who survived breast cancer. Participants were selected by intentional, cumulative and sequential sampling. A conventional content analysis was performed. **Results:** Participation of seven caregivers, who reported their positive and negative experiences when assuming their role as informal caregivers in the family context. On the strength of the reciprocity of care and its reward, prevailed critical moments, negative feelings, and lack of support resources during the experience. This enables the understanding of the informal care bond in order to enhance it with coping strategies and specific guidance from the nursing staff. **Conclusion:** Participants experienced a transformation in their identity as caregivers and by being aware of their experience, they could describe their qualities, which increased their coping strategies with the disease and the care challenges.

DESCRIPTORS

Breast Neoplasms; Caregivers: Family; Oncology Nursing.

Corresponding author:
Luz María Tejada-Tayabas
Claustro Universitario de Chihuahua
Av. División del Norte Nº 3104 Col. Altavista
31320 – Chihuahua, Chih. – Mexico
lmtayabas@yahoo.com.mx

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INTRODUCTION

In Mexico as in other countries, the family is the main context of development of the human being, and its members provide care to those in need in order to ensure their well-being(1). Family care for members in vulnerable conditions is based on common sense and personal experience. People exercising this role do not receive financial compensation, and distinguish from other family members for being the primary caregiver, mainly because of their affective and consanguineous ties. This role is commonly played by the female gender with a direct parental relationship, particularly by mothers or daughters(2-3).

Breast cancer is one of the chronic diseases with highest incidence in women that demands close family care(4). The diagnosis has great impact on people affected and their family, because women are the axis of family organization and play different roles, such as wife, mother, provider and caregiver(3). Therefore, when the caregiver par excellence in the family needs to be taken care of, the family dynamics is altered in an important way.

The care required during breast cancer treatment changes according to the path of the disease(4). In response to this situation, family members provide emotional support and physical care for women during hospitalization, the treatment process and rehabilitation without receiving specific training or guidance. Caregivers act as representatives and providers, offer support for the satisfaction of basic needs, take care of wounds, and also compensate the roles previously performed by women within the family dynamics. All these factors result in a series of changes that transform the lives of those who perform care(5-6). For this reason, and as this subject has been little studied(7), it is relevant to inquire women with breast cancer about their family care experiences. As health professionals are often unfamiliar with the family context of women with breast cancer, the limitations, difficulties and challenges faced by these women and their caregivers in their day to day with the disease are not taken into account. These are key issues for providing the necessary support and professional counseling both to women and their caregivers in order to strengthen women's well-being and facilitate the home care process.

Several qualitative studies have deepened the experience of caring for a family member with a chronic condition. Findings demonstrated the negative effects experienced by caregivers on their physical and emotional health as a result of the exhaustion felt for facing the deterioration and uncertainty of chronicity with scarce social support, which leads them to prioritize the welfare of their sick relative over their own(8-10). In Latin American countries such as Brazil, positioning the family as a unit of care is a possibility considered as a phenomenon of particular interest for the nursing profession(11). Aspects such as the caregivers' spirituality have been explored(12), as well as their psychological well-being(13) and experiences in relation to death(4). Caregivers of women with breast cancer have several characteristics. In countries such as Iran, family care falls on women, daughters or sisters(5). In Brazil(14) and Canada(15) studies report that women's partners perform this function(14-15). Understanding the experiences of family caregivers of women with breast cancer in different contexts and by taking into account that such experiences are affected by race, ethnicity, values, beliefs and cultural traditions of the family may help in the planning of effective interventions(5). The objective of this study is to describe the experience of family care of women with breast cancer during treatment from the perspective of caregivers in the Mexican context.

METHOD

STUDY DESIGN

Qualitative phenomenological study in which the interpretative sociology of Alfred Schütz was used as theoretical-methodological reference. His assumptions, knowledge and reciprocity of perspectives were adopted, and particularly his contributions about the actors, where he resorts to phenomenological criteria such as the awareness of the self and the intersubjective relationship of actors in everyday life(16-18).

SCENARIO

The study was conducted with family caregivers of female breast cancer survivors who had been diagnosed in a period of more than six months and less than five years. Men and women over 18 years of age were included.

In-depth, individual, face-to-face interviews were conducted(19) in the homes of caregivers.

DATA COLLECTION

During a semester, health promotion activities were performed with women participating in the organization called Recuperación Total (RETO A.C.) that is dedicated to the support of women diagnosed with breast cancer. Through these women, were identified the caregivers, who were invited to participate in the study by telephone, but some did not accept by claiming lack of time. At the first face-to-face contact, caregivers signed an informed consent form. An intentional, cumulative and sequential sampling was used until reaching the quantity and intensity of data that revealed confluence of meanings(19).

During in-depth interviews, data are constructed little by little through a continuous process to go into the life of interviewees and visualize their experience(20). In-depth interviews were conducted by the researcher PhD MMMG with seven caregivers of women survivors of breast cancer. Data collection started with the question: How has been your experience as a caregiver from the moment you were told about your relative's diagnosis of breast cancer? Techniques of recapitulation and exploration of new topics were used in order to encourage interviewees to expand, confirm and deepen their testimonies(20). Interviews lasted 40 minutes, were audio recorded with participants' prior authorization, transcribed in word processor by the first author MMMG, and reviewed by the second author LMTT in the period between February and October, 2017.

ANALYSIS AND PROCESSING OF DATA

A conventional content analysis was carried out[21]: The units of analysis were narrative texts understood as a social phenomenon of construction of identifications, which were processed under an initial coding in order to identify topics and subtopics of analysis. Later, families of codes were generated and was developed a scheme of findings. A second coding was performed based on the developed scheme, which allowed identifying the networks of relationships between codes and categories that facilitated the grouping of meanings units about personal experiences. The analysis process was performed simultaneously with data collection and the Atlas Ti 5.2 software was used as a tool. The analysis was performed and results were discussed until reaching consensus among all researchers.

ETHICAL ASPECTS

The study project was approved by the Research Ethics Committee of the Division of Health Sciences and Engineering of Campus Celaya-Salvatierra of the Universidad de Guanajuato under number CIDSC-29800204. Those who agreed to participate in the study read and signed the informed consent form. Participants were kept anonymous by granting the following codes: P1, participant 1; P2, participant 2 and so on.

RESULTS

CHARACTERIZATION OF THE PARTICIPANTS

The study included seven caregivers (three men and four women) residents of the state of Guanajuato, Mexico. They were aged between 25 and 68 years; Catholics; married (n=4), single (n=2), and in a stable union (n=1); occupation of employees (n=6) and homeworkers (n=1), educational level between primary and secondary school (n=2) and undergraduate degree or engineering degree (n=5). Kinship with the woman with cancer was daughter (n=3), husband (n=3) and sister (n=1).

The breast cancer stage most frequently diagnosed was stage II (n=4), followed by stage I (n=2) and stage III (n=1), and the time elapsed after diagnosis was of six months (n=1), two years (n=2), three years (n=2) and five years (n=2). Treatments received were conservative mastectomy (n=2), radical mastectomy and chemotherapy (n=3), radical mastectomy, chemotherapy and radiotherapy (n=2). Health care services were provided mainly in public institutions (n=6) and private institutions (n=1).

CATEGORY 1: CRITICAL MOMENTS OF THE EXPERIENCE

Searching for what we did not want to find: One of the most mentioned critical moments was the detection and diagnosis. The identification of “a lump” or “a small ball” in the breast, either through mammary exploration (n=1) or incidentally (n=6) generated alarm and anguish. From that moment, started the search for something they did not want to find, that is, cancer:

On one occasion, while lying down I embraced her, I passed my hand and I touched her here (points to the armpit and chest) and at that moment I said, you know, you have a small ball (P4).

Caregivers showed full knowledge of the signs and symptoms of breast cancer and the importance of their prompt attention. Consequently, they immediately sought an accurate diagnosis and went to the corresponding health service:

We went immediately to control (preventive medicine), they took the Mammogram, the doctor asked for a biopsy, they took a sample with a needle and put it on a glass slide (P2).

Caregivers demonstrated emotional impact upon receiving the diagnosis. Uncertainty and fear arose from the social meanings built around breast cancer as a condition that places the person near death, and because of the uncertainty about what will happen to the sick woman and within the family dynamics:

At first, when they tell us it is cancer, you do not know what will happen from then on, it only comes to mind, my mom is going to die, cancer is equal to death (P3).

Access to health services: After the diagnosis, when going to the health institution to initiate treatment, caregivers discovered they had to follow the care guidelines and processes of public care institutions. This implied waiting for a shift, adapting to the infrastructure, resources and care capacity of the institution itself, which sometimes involved a long waiting time for a definitive diagnosis. Caregivers expressed their anxiety and concern with the earliest possible treatment of women hence, many sought various strategies based on their economic possibilities and support networks. Their role as caregivers began with making urgent and sometimes drastic decisions. In this stage of the disease, the purpose of such decisions was to speed up the care process in private services that involved excessive cost. However, they deemed it necessary to accelerate the diagnosis and treatment of women. Saving their lives depended on them. This was expressed by some caregivers:

We got the money, it was an expense that was not within our reach, so we are still paying the loan, it was an anguish to raise the money for the operation, but it had to be done for her (P1). *The oncologist could provide care through social insurance (public services), but the appointment was going to be four or five months later, with the private health insurance, care was immediate* (P4).

Care after mastectomy: During the recovery of mastectomy, two particular situations were combined. Firstly, the impact of seeing the woman without a breast for the first time and seeing the wounds and sequels left by the surgery. Furthermore, there was the consequent emotional impact felt by the woman in relation to the meaning given to the breast as a sign of femininity. Secondly, was the need to face the wound that required care from those who were not trained, including dressings, bandages, medication administration, monitoring of catheters and drainage of liquids:

I put her in the shower to care for her and she got rid of the Drenovac (catheter for drainage), a lot of blood started coming out, then she got dizzy, she got really bad and we got scared and took her to the emergency department (P3).

In response to women's emotional distress, male caregivers stated that the absence of a breast did not interfere with the perception of their femininity or sexual attractiveness. For them, the important thing was women being well. They preferred women did not rebuild the breast if they had to go through the same process of pain and suffering again. Therefore, their care actions were aimed at emotional support in order to prevent women from getting depressed. The change of image seemed to affect caregivers more because of the emotional impact produced on women than on them:

Her first reaction was to tell me (I'm going to be without a breast). I did not care, I never saw it as a deformity, I never thought about leaving her, nor did I ever think that she was less of a woman because of that, I just want her to be well and feel good (P7).

Care during chemotherapy: The effects produced by this treatment significantly affect women's general state, which causes fear and despair in caregivers for not knowing how to alleviate women's discomfort. Women with cancer are socially recognized by loss of hair, eyebrows and eyelashes, and when caregivers observed these characteristics in their family members, they were more aware of the diagnosis received before:

I realized my mother was sick when I saw her without eyebrows and without hair and that was when I said, for God's sake, she has cancer and we have to help her overcome all this suffering (P3).

For one of the caregivers, the fact that his relative had no discomfort during chemotherapy was reassuring:

Actually, the chemotherapies did not affect her (...) we knew some women had vomiting and my wife did not have those symptoms, she really had chemo and led her normal life, and that was reassuring (P4).

CATEGORY 2: FEELINGS IN THE FACE OF CARE NEEDS

During their experience, caregivers experienced fear of the unknown and sometimes anger. These feelings are part of the answers to the situation experienced and the starting point for the decision of acting as caregivers.

Feeling angry: Anger was identified as part of the feelings expressed by participants. The situations that generated this feeling were mainly when knowing the diagnosis of breast cancer, not receiving the support from whom they expected, and the anger with the changes in their lives:

I got very angry with my sister, I told her, that's suicide, how did you leave yourself, why did you not exam yourself before (P5). *The support expected from the closest ones in those moments is with actions, because one also has to stop doing many things in order to take care of her and help is needed* (P7).

Feeling afraid: Throughout their experience, caregivers expressed fear of a bad prognosis, of the death of their family member, or fear of not doing the right thing in each moment of care:

Every day I fear her death (P2). *She was taking a shower and the drainage tube came out, I was scared, I thought it was my fault, I could barely take her out of the shower and I took her to the emergency department, I did not know what else to do* (P7).

The difficulty of doing it well: Despite feeling constant fear, participants used all their energies to do their best for their family member, but continually expressed it was difficult. On some occasions, the difficulty was related to performing a dressing or bandage. On others, they mentioned the difficulty of facing situations for which they were not prepared, for example, providing emotional support for their women and making effective decisions about their care:

It is difficult when it happens with someone of your family (...) at the hospital, they do surgeries and the chemo, but the difficult thing is what is done at home (P1). *It has been a difficult and painful experience (...) it is very difficult to do it alone without knowing how* (P2).

CATEGORY 3: SUPPORT RESOURCES DURING THE EXPERIENCE

The caregivers' response to the care demands was based on support resources available at each moment: their own resources were identified, such as previous experience and strategies used to maintain balance, as well as external resources, such as support received from the woman with breast cancer (reciprocity of care), family and social support.

Previous experience as a caregiver: In participants' testimonies, were identified differences in coping among those with previous experience, who used their previous knowledge and adjusted to the new experience:

For me, it was not hard to take care of my wife because I had also taken care of my grandmother (P4).

Those who did not have such experience had to assimilate the situation and build the meaning of caring for a woman with breast cancer:

I did not know what to do, I kept quiet, I prepared tea and that day we went to sleep without saying or doing anything else (P2).

Caregivers continually expressed the need to receive guidance at each stage of treatment in order to know who to contact and the best way to provide care.

We must be explained about what is cancer and the symptoms, as well as the basics of care provided at home (P3). *Having information helped us a lot, and knowing how one is going to feel after chemotherapy. Uncertainty is what kills you, not knowing what is going on and what you can do* (P4).

Freeing myself to maintain balance: Caregivers looked for strategies to maintain their emotional balance. Some of them looked for distractions or activities to set themselves free, relax or distract themselves, while others defined a position of accepting the disease and placing their faith in God for the recovery of their loved one:

There are many ways to set myself free and for me it was exercising, reading, taking refuge in my own daughters, improving communication with them (P7). *For us, the key was to accept the disease and place ourselves in the hands of God (…)* (P4).

Reciprocity of care: One of the important points identified as a support resource was the reciprocity of care. The care relationship between the caregiver and the woman with breast cancer is not unidirectional, it is dynamically transformed into a practice of intersubjective care, in which, at times, the caregiver needs support that in turn can be provided by the person being cared for:

(…) when she saw me unwell, she said (do not be like that), I need you to be well, we must give strength to each other (P6).

This reciprocity was motivated by the search for a retribution to the woman for the care provided when some family member became ill. In spite of the woman's vulnerable state, the strength and desire to stay alive were projected onto the caregiver:

I believe the family should participate and be there, we all have jobs, we all have things to do, but she is also everyone's mother, she took care of us and supported us when she could (P2).

Family support: Family participation in the care experience was important, not only the nuclear family but also the extended family. This was manifested by restructuring the family dynamics through reassignment of roles and distribution of tasks that could not be performed by the woman with breast cancer at that time. Each family member contributed according to their own capacities:

My sister-in-law fed my children because my wife could not cook, she was the one who supported us (P4).

A cousin lives in León (nearby city) near the Institute of Security and Social Services of State Workers and told us to come and stay there, so, in hospitalization days, we had family support (P5).

The fact of feeling dissatisfied with the support received had a negative impact on the experience:

My brothers do not help, they just talk and tell her to take good care of herself, as if that would help (P2).

Social support: The support received by significant people with whom there was no blood relationship was mainly directed to women with cancer. However, caregivers said this has indirectly helped them:

(…) when we arrived at RETO (organization dedicated to support the recovery of women with breast cancer), these were the first impacts we had, then, one of them asked me how I was, and this helps a lot (P7).

Social support was strongly linked to the recommendation of using alternative treatments, mainly to mitigate the effects of chemotherapy:

Her sister was giving her some royal jelly (...) she was taking it before chemo so that she did not have nausea (P4).

Regarding the support received from health professionals, caregivers expressed some positive experiences with the presence of follow-up and guidance, and doctors were the most frequently mentioned by caregivers. The participation of other health professionals was minimally identified, even though psychological support is also essential in the trajectory of breast cancer, and the lack of support was reported in some cases:

Nobody comes close to you, they only give you directions: stand up, leave, the doctor has no sensibility when he tells you your mom has cancer, the nurses go and put the medicines, measure the pressure and that's it, they do not tell you what's next and do not ask you what you need (P2).

CATEGORY 4: THE REWARD OF BEING A CAREGIVER

At the end of the experience, caregivers went through a process of learning that allowed them to know more about breast cancer and develop risk awareness. The fact that the woman who had cancer is alive, gave them a feeling of satisfaction, raised awareness on what it means to be a family caregiver, and identified their qualities and their intention to help others.

Risk Awareness: The female caregivers living this experience developed a greater perception of the risk of suffering from breast cancer, which favored their self-care by knowing about the timely detection.

You become more prone to explore yourself, one becomes a bit more scared and prefers to go to the doctor, we know we have more risks (…) (P3).

My identity as a caregiver: At the beginning of the experience, some caregivers were not aware of the role they were playing, and stated they were supporting their family member, but did not measure the importance of their role. Throughout their narratives and after reflecting on their actions, they developed greater awareness of their role of caring, including describing their own qualities, the importance of family caregivers and the willingness to help others:

I describe myself more as an emotional caregiver (P3). *One does not choose to be a caregiver you just feel it. Caring for someone is to love deeply* (P1).

For caregivers, the main reward is to feel lucky that their relative is alive. A greater union between the family was identified and it gave a new meaning to their daily life:

For me, being a caregiver is an honor and a pride, the respect between us has grew, and feeling the triumph of one as of everybody (...) I have the satisfaction of saying I have personal achievements, I feel very well (P7). *An opportunity of being closer to that person and knowing yourself, of being able to value life more (…)* (P3).

DISCUSSION

This work shows the relevance of detecting breast cancer in early stages, which favors women's survival and provides greater hope and certainty to caregivers, and consequently facilitates care(22). However, the process to obtain an accurate diagnosis and timely treatment follows a long path, as reported in another study also conducted in Mexico(23).

The experience of informal care is not limited to a set of actions, and involves a process of transformation in the lives of those who perform care. The demands and activities of care contribute to the reorganization or abandonment of daily tasks, which favor frustration, stress and overload, and directly affect caregivers' well-being.

As in other studies on family care(8-10) to chronic patients, negative experiences and critical moments are reported by caregivers, and differences are identified depending on the course of disease and the degree of significance that caregivers give to it. Critical moments have a profound impact, because they demand immediate decision-making, and caregivers are confronted emotionally to take responsibility for the health and well-being of women with breast cancer(24-25).

Every interpretation of this world is based on a collection of previous experiences, some of which are one's own, while others have been transmitted by other people. In a group, everything works as a reference scheme called "hand knowledge"(17). In this sense, cancer is socially linked to a threat of imminent death. In the case of participants of this study, when receiving the diagnosis of cancer, their first thoughts and concerns were not directed to the attention of the woman or changes they would have to make to provide care, but they focused on the imminent possibility of death, which kept them in negative emotional states.

Caregivers faced different feelings. They reported the feeling of "being stuck" by breast cancer for identifying it as a painful process for which they were not prepared(26), they did not know what it meant to be a caregiver and suddenly became one without knowing the reason clearly and without knowledge about how to help the other to satisfy their multiple needs. This coincides with some studies in which was reported that assuming informal care generated feelings of anger, sadness, incompetence, and sometimes impotence(24).

The experience of care in relation to critical moments associated with the disease and mainly the lack of social support from care institutions impacted on the daily life of caregivers and the relationship of the couple. This is in line with findings of other studies(12-13,27) in which strategies for coping with the disease were based on promoting family unity and collaborative work that required close support and guidance.

Schütz proposes the "we" notion, "understood as the possibility of socially interrelating"(17). In this study, was observed how the relationship of care allowed horizontal and intersubjective relationships between the caregiver and the sick person, and with other members of close social networks. The family was one of the main support networks of caregivers at the time of caring for women with cancer. A similar situation was mentioned in studies on the care of cancer patients(24).

According to Schütz's perspective, caregivers participating in the study are actors, "an actor is always in relation to the other, because of which emerges an idea that transcends an individual vision" and has an intersubjective character. "The actor is in relation to the other, the subjectivity of the actor is in attention to the subjective relationship with another actor"(17).

According to other authors, there is a duality in critical moments of a couple's relationship that combines situations of greater emotional closeness with others of distancing(14-15). In the present study, closeness and complicity were identified in each stage of treatment, where caregivers kept their needs and concerns in the background, in order that women were well and could overcome the disease and treatment. This is based on Schütz's perspective that tells us about how each experience is different in each person around the same phenomenon, and proposes an idealization of the congruence of meanings, in which both caregivers and women surviving cancer have different experiences and perceptions. However, they strive for a common good between both for the benefit of the family(17).

Likewise, a reciprocity of care is identified as a fundamental relationship between caregivers and women with cancer, which shows a different relationship of power than that between other binomials. For example, a caregiver and an older adult where the degree of dependence seems to allow the caregiver to make autonomous decisions. In the relationship between caregivers and women with cancer, power relationships change in each stage of treatment, and caregivers receive support from sick women in order to maintain their balance and face the situation. That is related to the idealization of reciprocity of reasons, in which any form of social interaction is based on constructions related to the understanding of the other and on the general scheme of action. Thus, there will be constructions based on the idealization that caregivers' reasons will become reasons for women who survived cancer and vice versa(17).

In the literature, were found favorable changes regarding self-care behavior. Either because of the greater sense of vulnerability to present the disease(5), for maintaining the balance between the commitment to care, leisure and rest, or for accompanying women during care of their health. Caregivers are concerned with performing the techniques appropriately for protecting and avoiding any damage. They mentioned feeling anxious and in some cases, satisfaction in demonstrating their creativity and ability(15). There is a tendency to look for answers in something divine, reference is made to a supreme being, in whom caregivers and their families trust and have faith, and from whom they will receive divine help. Their beliefs help them to find a bearable meaning for the illness and suffering and also provided the strength to face these, since beliefs are a form and a means of psychological defense(12,27). Caregivers are not prepared in advance for the experience of diagnosis and care of women, and throughout the process, they create strategies to face a challenging experience and not avoid it, in the best case.

Another finding was the transformation of caregivers' identity. At the beginning of the care experience, they did not fully identify with that role, in spite of having performed care actions on previous occasions. In a second moment, they recognized their duties as caregivers by expressing their characteristic features such as providing emotional support and physical care. Finally, by being aware of their experience, they manifested the intention to share and help other caregivers in need of it. Caregivers were aware of the role they play with the woman they cared for, and when care became part of their daily routine. However, this part of the study did not allow an in-depth analysis of participants' self-awareness as caregivers. Some elements can be outlined, namely the transformation of roles, the need for intersubjectivity expressed in the reciprocity of care and in the care experience as a collective act of the family, rather than an individual action.

The Mexican context shows the paradox between the accessibility and speed of the flow in public and private health services. The cost of advanced cancer treatment can be up to one million pesos (US$ 52,000)(28), which is an impossible situation for an average family and leads to the immediate access of public health services. Both the supply and demand for early detection services are scarce and insufficient(22), which can generate social and economic consequences both for the population and the health system. This was reflected in the present study, when caregivers of women with breast cancer looked for strategies to deal with the situation according to their economic capacity by mediating the rapidity of private services with the accessibility of public services. This situation can unfortunately determine the prognosis and recovery of women in treatment(22).

This work just outlines some categories of the experience of care for people with cancer. The transformation of daily life and transition of caregivers generate a series of actions and processes that may have different outcomes. This study shows constructive experiences, and leaves aside different contexts and events where the distancing, rupture between couples and family disintegration prevail. Such elements will be part of continuity of this study.

These findings reflect the need for nursing interventions based on the experience of patients and caregivers, with follow-up at each stage of the care process with clear and timely information.

CONCLUSION

The experience of caregivers of women with breast cancer generated profound changes in them through the discovery of their reach and limitations in difficult situations. Being a caregiver gave meaning to their lives and strengthened the ties with their women. Caregivers declared satisfaction with the work done and felt fortunate that their family member was well and had another opportunity to live. This aspect transcendentally modified their experience, so it is important to inquire caregivers of women who have lost their lives because of breast cancer with the purpose of understanding this phenomenon from another, but no less important perspective.

RESUMEN

Objetivo: Describir la experiencia del cuidado familiar a la mujer con cáncer de mama durante el tratamiento, desde la perspectiva de los cuidadores en el contexto mexicano. **Método:** Estudio cualitativo fenomenológico. Fueron realizadas entrevistas en profundidad con cuidadores de mujeres sobrevivientes de cáncer de mama seleccionados mediante muestreo intencional, acumulativo y secuencial. Se llevó a cabo un análisis de contenido convencional. **Resultados:** Participaron siete cuidadores. Los cuidadores refieren sus experiencias positivas y negativas al asumir su rol de cuidadores informales en el contexto familiar. Sobre la fortaleza de la reciprocidad del cuidado y su recompensa, prevalecen los momentos críticos, los sentimientos negativos y la falta de recursos de apoyo durante la experiencia. Ello permite entender el vínculo del cuidado informal para potenciarlo con estrategias de afrontamiento y orientación especifica por parte del personal de enfermería. **Conclusión:** Los participantes experimentaron una transformación en su identidad como cuidadores y al ser conscientes de su experiencia, fueron capaces de describir sus cualidades lo que incrementa sus estrategias de afrontamiento tanto de la enfermedad como de los desafíos del cuidado.

DESCRIPTORES

Neoplasias de la Mama; Cuidadores; Familia; Enfermería Oncológica.

RESUMO

Objetivo: Descrever a experiência do cuidado familiar com a mulher com câncer de mama durante o tratamento, do ponto de vista dos cuidadores no contexto mexicano. **Método:** Estudo qualitativo fenomenológico. Foram realizadas entrevistas em profundidade com cuidadores de mulheres sobreviventes ao câncer de mama selecionados por meio de amostragem intencional, acumulativa e sequencial. Foi realizada uma análise de conteúdo convencional. **Resultados:** Participaram sete cuidadores. Os cuidadores relatam suas experiências positivas e negativas ao assumir seu papel de cuidadores informais no contexto familiar. Sobre a força da reciprocidade do cuidado e sua recompensa, prevalecem os momentos críticos, os sentimentos negativos e a falta de recursos de apoio durante a experiência. Isso permite entender o vínculo do cuidado informal para potencializá-lo com estratégias de enfrentamento e orientação específica por parte do pessoal de enfermagem. **Conclusão:** Os participantes experimentaram uma transformação na sua identidade como cuidadores e, ao ser conscientes da sua experiência, foram capazes de descrever suas qualidades, o que aumenta suas estratégias de enfrentamento tanto da doença quanto dos desafios do cuidado.

DESCRITORES

Neoplasias da Mama; Cuidadores; Família; Enfermagem Oncológica.

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