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# The experience of the partners of women with breast cancer*

A experiência do companheiro da mulher com câncer de mama
La experiencia del compañero de la mujer con cáncer de mama

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## ABSTRACT

**Objective:** To understand the experience of partners of women with breast cancer. **Method:** This was a qualitative study, based on the theoretical-methodological framework of existential and phenomenological psychology, and carried out with the partners of women with breast cancer who attended a center for rehabilitation after mastectomy. The data were collected in interviews between June and November 2014, based on a guiding question. **Results:** Ten partners participated in the study. On discovering the disease, the partners experienced emotional distress caused by the fear of losing their partners. Before this suffering, they demonstrated the ability to react: willingness to provide care, to comfort and to support the women in search of treatment, and together, seek to reverse adverse situations. They also showed sensitivity and recognized the intense emotional suffering of the women caused by the challenges faced throughout the course of treatment. **Conclusion:** The present study showed the intense suffering of the partners of women with breast cancer and their difficulty to ask for help. Thus, health professionals must be alert, addressing their needs throughout the treatment process to mitigate suffering.

## DESCRIPTORS

Breast Neoplasms; Marital Status; Caregivers; Existentialism; Oncology Nursing.

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## INTRODUCTION

In 2016, the Brazilian National Cancer Institute (INCA – *Instituto Nacional de Câncer*) estimated 300,870 new cases of neoplasia, of which 57,960 were breast cancer, with an estimated risk of 56.20 cases per 100,000 women(1). These projections make breast cancer the most common malignant neoplasia and also that which causes the most deaths among the female population(1). In contrast, the development of new technologies and more effective drugs to treat breast cancer, in addition to improved health care delivery, has contributed somewhat to controlling the disease and increasing patient survival(2). The physical consequences of treatment cause psychological suffering, which in turn trigger emotional and social difficulties, often leading to social isolation(3). These are the consequences of the stressful events associated with the bodily changes induced by treatment, together with other stressors, relative to the transformations experienced in different aspects of life, such as social relationships, functional capacity, work status, and the psychological universe of patients(4). Some effects are felt for a specific period, such as the duration of each procedure chosen for treatment, while others extend throughout a lifetime, such as lymphedema-related prevention and care.

As with all severe diseases, especially chronic and degenerative ones, at the same time, breast cancer procedures and treatment represent deprivation and opportunity for reformulation. Over time, women realize that they need to reinvent their lives and reclaim their social and family contexts, adapting to the bodily and emotional changes that stem from surgery and other treatments they underwent.

The main social contact of women with breast cancer, in addition to their healthcare providers, is with their family. Families are considered the main social nucleus of individuals and are the basis of socialization and the transmission of ethical, aesthetic, political, cultural and religious values. Families are at the center of the concerns and joys of women with breast cancer, one of the most commonly recurring themes in their discourse, because in the family routine, they experience their anguishes from the time of diagnosis, during treatment, and throughout the psychosocial rehabilitation process(5).

Thus, on assessing the interdependent relationships of breast cancer patients with others, a study showed that they placed greater emphasis on their marital and family relationships, as their spouses and family members were considered their significant others and/or their main support systems(6). Therefore, these persons represent the first and main social links to measure these women's actions and reactions.

In this direction, partners are considered a special member of the family, with specific characteristics that, in terms of intimacy, surpass relationships with all other family members. Women and their partners represent caregiving roles and the forces that maintain the cohesion of family relationships. Partners play an essential role in several phases of the treatment, and women need their support after receiving the diagnosis and undergoing surgery, and throughout the entire rehabilitation process(7).

A study with the partners of women who experienced breast cancer showed that spouses, when receiving their wives' health diagnosis, experience emotions just as intense as theirs, but in contrast, express feelings of hope. Over treatment, some partners had to change jobs, while others adopted more flexible work hours to be available to meet the needs of the women(8).

A review study showed that spouses and other family members valued being well received by health professionals and receiving guidance during the breast cancer treatment period, even if encounters were brief and mediated by the patients(9). In this regard, another study conducted in the United States showed that the partners of women diagnosed with breast cancer who were able to receive psychoeducational counseling improved their capacity to communicate and provide interpersonal support to their wives, in addition to improving self-care, depressing humor, anxiety and marital adjustment, including issues relative to the couple's sexuality(10).

Listening to what the partners of women with breast cancer have to say can help professionals perceive them as potential resources to aid in psychosocial rehabilitation(11). The literature about the relationship between mastectomies and sexuality recommends that further research focus on the viewpoint of partners, with the objective of complementing the many studies conducted on women with breast cancer.

Thus, the objective of the present study was to provide a more comprehensive view about the environment and social lives of women with breast cancer, focused on their partners, and considering the need to clarify the limits and possibilities of their role in supporting their sick spouse. The objective of the study was to understand the experience of being the partner of a woman with breast cancer from their own standpoint, considering the period between diagnosis and the rehabilitation process.

## METHOD

The choice for a qualitative method was based on the authors' interest in understanding the experiences of partners of women with breast cancer. This research approach focuses on particularities and not general explanations, and its goal is to recognize the intrinsic, contextual and personal nature of each experience. The present proposal is based on Phenomenological and Existential Psychology, grounded in the philosophical thinking of Martin Heidegger(12) and its notions of humankind and science for data analysis.

The study was developed at a center for rehabilitation after mastectomy at a public university in the state of São Paulo, Brazil. This service was provided by a multiprofessional team that delivered comprehensive care to women with breast cancer and gave guidance to their family members, all free of charge.

The following inclusion criteria were adopted: adult males, in a stable partnership since at least the time of the women's breast cancer diagnosis; whose wife was at least 18 years old and registered with the service, and absence of communication impairments. Potential participants were only contacted if the women gave their permission. They were asked to verify their partner's interest and availability to participate in the study, and once this double consent was secured, the partners were contacted and invited to participate. The women's consent allowed the researchers to use some data from their patient charts, such as date of surgery and types of treatment carried out. The exclusion criterion was the presence of communication and/or comprehension impairments that would affect understanding of the interview questions.

After consulting the rehabilitation center's database, the researchers contacted the women during their scheduled visitations. At this time, they were asked whether they were involved in a relationship with a single partner (either married or in common-law marriage) since their breast cancer diagnosis. If the answer was "yes", the researchers presented the study, its objectives, and the data collection procedures to the patients, who were then asked to consult their partners about whether they agreed to let the researcher contact and invite them to participate in the study. After the women obtained their partner's permission to be contacted, the researcher made their first approach, either by phone or at home, to schedule the interviews. Thus, two informed consent forms were drafted and signed: the first for the women who used the health service, and the second for their partners. The interviews were conducted in an isolated room at the health service, on a previously established day and time, when partners accompanied the women to their regular visits at the rehabilitation center, or at the couple's residence, according to their preference. The data were gathered between June 30 and November 27, 2014, and the interviews lasted an average of 50 minutes.

The data were collected through phenomenological interviews, based on the following guiding question: *What has been your experience as the partner of a woman with breast cancer?* The aim of this question was only to direct the focus of investigation, leaving the respondent at ease to talk about the topic. The researcher was free to interact and embrace the participants as deemed necessary, based on his experience as a health professional and psychologist. The interviews were audio recorded and 10 partners of women with breast cancer participated.

To maintain the participants' anonymity, the interviews were coded according to the number of the interview (I1, I2, I3...I10).

The present study abided by the recommendations set forth in Resolution 466 of the Brazilian National Health Council for research with human subjects. First, the researchers requested and were granted permission to conduct the study at the health service, and the data were collected after approval from the Research Ethics Committee of the Ribeirão Preto School of Nursing at Universidade de São Paulo (protocol CAAE no. 30819814.6.0000.5393 and official letter CEP-EERP/USP-098/2014).

## RESULTS

Ten male partners participated in the study. Four units of meaning emerged from their interviews, allowing the researchers to observe the phenomenon both chronologically and in terms of its development. First, the men were asked about the understanding that emerged at the time of the breast cancer diagnosis and the impact of the news, and then the development and repercussions of the disease in their lives. The categories encompassed the family microcosm, the marital relationship, the development of intimacy, and issues that emerged from the encounter with human finitude, the partner's suffering, and the social irruption of the experience, with its specificities, in community, religious, and technical-scientific contexts.

### EXPERIENCING THE IMPACT OF THE DIAGNOSIS AND EMOTIONAL DESTABILIZATION

The moment they received the diagnosis was described as that of the greatest impact on the lives of the partners', causing great suffering and emotional destabilization.

*Well, I'd say that it's like falling apart, everything that you planned for your family life, at first, it all comes crashing down. It's a reconstruction, a reconstruction. At first, we're lost, completely lost* (I4).

Despite their initial destabilization, the partners displayed an ability to react, expressing their willingness to support and motivate the women with regards to treatment. They sought to help their partners, reverse the adverse situation and find a new path to follow.

*It was quite a shock, but we had to gain awareness and realize that today, things are more advanced. If the woman gets down, and the man gets down too, then both collapse* (I6).

### SHARING CARE FOR THE WOMEN WITH OTHER FAMILY MEMBERS

In the family context, despite the impact of the diagnosis, the partners were able to share care dedicated to the women with other family members. These members were mainly the children, who were mobilized to strengthen their bonds with their mothers, expressing concern through caring affection.

*Even the girls, our daughters, they never leave her alone: "Mom, let's go here, let's go there, and I don't know what else, but the intention is to get her mind off the disease* (I2).

The participants also mentioned providing care together with other family members. Thus, the family joins forces in the coping process, expanding the possibilities of support provided by the partners.

*Some days she'll be really quiet, then I call the girls, especially the youngest, and she'll call her, "Mom, you're coming with me to the mall, come with me to this other place." Then, when she comes back, she's a new person, she's opened up her mind* (I2).

Sometimes, however, converging and sharing of care with family members does not occur, and only partners are responsible for providing care to the women.

*Today, what most contributes to her state of mind are her children. I have a son with a psychological problem, who we're trying to help, but he has bipolar disorder, which contributes to our current state* (I4).

### Sharing coping with the disease within the couple

The participants described the closeness enabled by dialogue as one of the main ways to display their concern:

*At first, I wanted to be with her all the time, I wanted to know what was going on, if she was okay, if she wasn't. Very sappy couple stuff* (I5).

When attempted dialogue was not effective, they used some alternatives. Contributing to the housework was also mentioned as an efficient way of supporting their partners:

*I clean the house, I take the heavy clothes out of the washing machine, but she still does some of it, because lying in bed all day increases the organism's disease. When she started getting out of bed, going out, I started feeling better* (I6).

However, sharing house chores did not prove to be the best way to handle problems for all the partners. For some, this method did not help them become closer to the women:

*Yes, sometimes, she doesn't think it's good. She'll tell me I should do it differently. The other day she pointed out what I had done wrong and it even upset me. I told her, if she's going to keep pointing things out, why doesn't she do it herself? And she said she couldn't. And then I told her to be quiet and stay in her corner, that I would do it my own way and I was sure I was doing it correctly. Jeez, she put on a face and we didn't say a word to each other for five or six days* (I7).

### Coping with treatment and its effects on conjugal intimacy

This unit of meaning includes the excerpts that demonstrated the limitations of corporeity, lack, guilt, and pain resulting from the cancer treatments and, primarily, the surgery. The partners expressed the repercussions of these consequences on the couple's intimacy. The difficulties emerged when they referred to issues from physical touch to sexual relations.

*After her surgery, she didn't want to have sex anymore, and I didn't care very much, you know? Because we begin to see it in a different light, to do it another way. So, I didn't seek her out anymore. She rejected me saying that she had breast cancer and etc. I think she died to everything, everything died to her. And since then, we haven't had any more sex. I stopped seeking her out, because it's no use* (I10).

The potential of being of the body also opens up the possibility of experiencing pleasure in the condition of power, and through the same indigent condition of need, it is possible to find satisfaction in the pleasurable experience.

*I also think it's a normal situation, because a woman who used to have two breasts and suddenly is mutilated, her psyche is affected, even if you don't want it to, it's shaken. So, at first, there were changes, but then she got better and healed* (I4).

Among the women who had had access to breast reconstruction, the partners observed that it had helped them re-valorize their bodies and feel satisfaction with their new body image before others. Women often request reconstruction for reasons relative to self-image and self-esteem. In the present study, the partners also expressed interest in the women's breast reconstruction.

*I even think she should have done breast reconstruction. I would've liked it if she had reconstructed her breast* (I4).

Limitations of the present study include the selection of partners of women with breast cancer who attended a healthcare center for rehabilitation after mastectomy. This sample did not allow the researchers to investigate the perceptions of other partners who live with women who do not have access to this service. The service in the study provided accessible and open-door services, with outpatient and multiprofessional care delivered by numerous professionals. It is highly regarded in the community and has provided support to many patients for almost three uninterrupted decades. The participants expressed gratitude and recognition of the unconditional support provided by the service to the women.

Another limitation of this study is that it did not conduct interviews with men who were not willing to care for their partners. This perspective could help provide a clearer understanding of what it is like to be the partner of a woman with breast cancer and not feel committed to their partner's treatment.

## DISCUSSION

The partners perceived that although the emotional suffering of the women hindered the couple's quality of life substantially, the anguish and difficulties faced by both throughout the course of coping with the disease also positively influenced how to face the new situation.

On commenting about how they felt on receiving the news, they showed intense commotion. They expressed vulnerability and a mixture of high emotionally dense feelings, such as despair and anguish before uncertainty and the reaction of fear noticed in the women. These feelings were enhanced each time the news of the diagnosis was told to other beloved ones.

When the perspective of the future is significantly altered by the confrontation with the possibility of finitude, so is the way of coping with the situation. The first feeling that emerges is that of being before an imminent loss, which indeed did occur, because the couple's dreams, life projects and plans for the future were concretely shaken. Thus, the partners felt prisoners to this new condition and saw their possibilities of *becoming* limited. Up until the time they were told about the diagnosis, they had led their lives in such a way that did not include the appearance of such a palpable threat to their survival. After confirming the diagnosis, everything that was taken for granted and that seemed to be in a certain way, was no longer so. Doubt and uncertainty installed themselves in their being, which was threatened in terms of the continuity of its existential project(13).

The partners found it hard to perceive their own frailties and justified their defensive experience of trying to show themselves impermeable to negative feelings by alleging that they could not accept to be fragile. They had to be strong in order to support and meet the needs of their wives.

Witnessing the women's disease requested that partners immediately adopt a certain outlook towards all those around them. They sought out people who could help their distressed family due to the altered course of their lives. Breast cancer installed altered temporality, which required new dispositions and attitudes from all, including *solicitude* toward each other, because everyone is impacted, and it was clear that the women depended on the support of their loved ones during this difficult time(14).

The world of family is the circumstantial context which surrounds the situation experienced by partners and that extends into a temporal/historical and spatial continuum. The temporal or historical sense is defined as the current nature of the characteristics experienced due to the woman's condition of illness and health recovery. Spatiality does not refer to physical space, but to the setting against which everything happens and how the partners perceived their role as caregivers. This characteristic corresponds to what is described as *Being-in-the-world*, essential to understanding the existential condition of man. In *Being and Time*(12), Heidegger described the concept of *Being-in-the-world*, and posited that "*the world of Dasein is a with-world*" and this means that in essence, humankind is constituted based on a network of shared meaning with others in the world(12).

Based on the landmark created by the news of the diagnosis, families sought out guidance regarding immediate care, which is necessary to make decisions relative to treatment. This is when family members take on their protective and supportive roles, helping women to overcome moments in which they feel impotent and incapable of controlling the events in their lives. Together with the support provided by their partners, the attention of their children can foster harmony in how the family members correspond to the requests of the partner and mother.

Sometimes, however, when convergence of care does not occur, those who express solicitude voluntarily can become burdened and even present emotional suffering. In fact, in the present study, the participants did not report this situation very frequently. However, we observe that even though the women's overall medical condition had evolved positively, the burden on the partner generated severe repercussions on their lives, such as the lingering fear of loss and of being surprised by recurrence.

Joint participation of the family members in the caring process helps everybody, including the partners, whose time-space reference has been disoriented, thus diluting the burden placed by the contingency of the woman's recovery from the disease and its treatment. Thus, everybody suffers, but they face the adversities of each step of treatment together.

The participants said that when they found themselves before their wives' illness, the first resource they used was dialogue. They tried to be close to their partners, supporting them and supporting each other not only in practical actions, but in words and conversations, motivating them to move onward, making themselves available and willing to help them cope with the disease and the entire rehabilitation process.

However, maintaining dialogue was not always a feasible alternative. Some partners avoided to blame themselves for not being able to maintain satisfactory dialogue and distanced themselves from the focus of the problem, while others expressed guilt relative to the difficulty in closeness and dialogue between them.

Regarding the couples' intimacy, the partners expressed feelings of estrangement and discomfort before the new situation triggered in the lives of the women. However, they also commented that the women distanced themselves because they did not feel "normal" after the surgery. Cancer can destabilize a couple's sexual life in many ways(15). The dynamics of the couple's relationship that was at play before the diagnosis, preexisting conditions, including depressive disorders, in addition to financial problems, among others, also appeared as important factors in the sense of aiding or hindering the revival of the couple's intimate relations during the treatment period(16).

What was considered simple before, such as the act of touching or having intercourse with their partners, changed in perspective and meaning, and the men underwent the bodily condition of indigence, limitations and restrictions generated by the disease and by the treatments, especially mastectomy. In some cases, these conditions lingered beyond treatment, convalescence and the recovery period. These results are consistent with the results of other studies, which point to the possibility of long-lasting physical and psychological sequelae of breast cancer(17-18).

In contrast, some of the participants reported that the potential of being for the body opened up new possibilities for experiencing pleasure in the condition of power and, through the same indigent condition of need, they were able to find the possibility of satisfaction through the pleasurable experience(19). Thus, far beyond the mere relief of tension, sexual needs can also be lived as an experience of plenitude carried out corporally. According to the participants, after breast cancer, exchanging physical caresses and sexual intercourse acquired a new meaning, indicating the possible resignification of life and of the mutilated female body.

The participants expressed living both the indigent and the powerful condition, and their interviews showed the limiting conditions they experienced when faced with the difficulties of their wives' illness. Similarly, close contact with the women's finitude also instigated them to re-dimension the power of their bodies, as they were not restricted to the difficulties, overcoming them in a certain way, by modifying how they handled sexual relationships and the women's bodily changes.

Regarding the issue of sexuality and sexual relations, it is worth noting that health professionals still face almost insurmountable barriers to identify needs relative to the affective-sexual lives of women with breast cancer and their partners. Interventions must be carried out taking into account the need for opening space for the couple to freely talk about these issues, because treatments, such as chemotherapy and radiotherapy, not only affect female libido, but can also trigger depressive symptoms that hinder treatment adherence(20).

## CONCLUSION

According to the participants, being the partner of a woman with breast cancer led them to experience the facticity of the diagnosis together with her. In their interviews, they revealed that at first, they experienced emotional disorganization, with the sad and grim surprise of the illness, followed by the unpredictable consequences of treatment. This made them feel confused when having to immediately choose a course of action, together, to face up to the challenging situation.

Discovering the disease caused an abrupt change in the life routines of the partners, who were captured by the fear of losing their wives. However, they demonstrated the capacity to react, making themselves available to provide comfort, motivate their partners to seek treatment, and seek to reverse the adverse situation. They also demonstrated that they needed considerable time before becoming familiarized with the situation and envisaging the possibility of finding new paths.

The results display the suffering of partners on sharing the hardships of invasive treatments and their dramatic consequences due to side effects. However, even though they were willing to care for the women, they found it difficult to perceive their own frailties.

The experiences reported by the participants show that when caring for women with breast cancer, healthcare providers must be aware not only of the patients' needs, but also those of family members and partners, since the time of diagnosis. They must also be included and embraced throughout the patients' entire treatment process.

It is necessary to hone data collection and technical care in the field, based on the improvement of professional education, in order to include in care the emotional condition of the partners of women with breast cancer. The present study demonstrated the need for professionals to direct their gaze and specialized care also to the partners of mastectomized women.

## RESUMO

**Objetivo:** Compreender a experiência de ser companheiro da mulher com câncer de mama. **Método:** Estudo qualitativo, com fundamentação teórico-metodológica na Psicologia Fenomenológico-Existencial realizado com companheiros de mulheres com câncer de mama que frequentavam um núcleo de reabilitação de mastectomizadas. Os dados foram coletados por meio de entrevistas, de junho a novembro de 2014, a partir de uma questão norteadora. **Resultados:** Participaram do estudo 10 companheiros. Com a descoberta da doença, houve uma desorganização emocional dos companheiros devido ao medo da perda das parceiras. Diante do sofrimento, demonstraram capacidade de reação: dispondo-se a cuidar, a consolar e a apoiar suas mulheres na busca do tratamento e procurando, junto com elas, reverter as situações adversas. Também se mostraram sensíveis e reconheceram o intenso sofrimento emocional de suas mulheres em razão das dificuldades enfrentadas no curso do tratamento. **Conclusão:** O estudo mostrou um sofrimento intenso dos companheiros das mulheres com câncer de mama e sua dificuldade em buscar ajuda, sendo necessário que o profissional de saúde esteja atento, acolhendo-os em todo o processo de tratamento, de modo a atenuar-lhes o sofrimento.

## DESCRITORES

Neoplasias da Mama; Estado Conjugal; Cuidadores; Existencialismo; Enfermagem Oncológica.

## RESUMEN

**Objetivo:** La experiencia del compañero de la mujer con cáncer de mama. **Método:** Estudio cualitativo, con fundamentación teórica metodológica en la Psicología Fenomenológica Existencial realizado con compañeros de mujeres con cáncer de mama que acudían a un núcleo de rehabilitación de mastectomizadas. Se recogieron los datos mediante entrevistas, de junio a noviembre de 2014, a partir de una cuestión orientadora. **Resultados:** Participaron en el estudio 10 compañeros. Con el descubrimiento de la enfermedad, hubo una desorganización emotiva de los compañeros en virtud del miedo de la pérdida de la pareja. Ante el sufrimiento, demostraron capacidad de reacción: disponiéndose a cuidar, consolar y apoyar a sus mujeres en la búsqueda del tratamiento y tratando de revertir, junto a ellas, las situaciones adversas. También se mostraron sensibles y reconocieron el intenso sufrimiento emotivo de sus mujeres en razón de las dificultades enfrentadas en el trascurso del tratamiento. **Conclusión:** El estudio mostró un sufrimiento intenso de los compañeros de las mujeres con cáncer de mama y su dificultad en buscar ayuda, siendo necesario que el profesional sanitario esté atento, acogiéndolos en todo el proceso de tratamiento, de modo a atenuarles el sufrimiento.

## DESCRIPTORES

Neoplasias de la Mama; Estado Conyugal; Cuidadores; Existencialismo; Enfermería Oncológica.

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