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Percepção dos cônjuges de mulheres mastectomizadas com relação à convivência pós-cirurgia
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The perception of mastectomized women's partners regarding life after surgery

PERCEPÇÃO DOS CÔNJUGES DE MULHERES MASTECTOMIZADAS COM RELAÇÃO À CONVIVÊNCIA PÓS-CIRURGIA

PERCEPCIÓN DE LOS CÓNYUGES DE MUJERES MASTECTOMIZADAS EN RELACIÓN A LA CONVIVENCIA POSQUIRÚRGICA

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ABSTRACT

The objective of this study was to understand how the partners of mastectomized women perceived life after the surgery. The study is both descriptive and exploratory, and was conducted in 2006 with five men who lived with mastectomized women in Fortaleza, Brazil. Semi-structured interviews were performed and the results were grouped into three analytic categories. We identified a level of misinformation about the illness, tranquility attributed to a faith in God, and a strong conviction that cancer and death are synonyms. Nursing/health professionals are responsible for providing knowledge about breast cancer and for fostering for integration between the woman and her partner, prioritizing a healthy life together.

KEY WORDS

Breast neoplasms.
Mastectomy.
Family relations.
Spouses.
Oncologic nursing.

RESUMO

Esta pesquisa teve como objetivo compreender a percepção dos cônjuges de mulheres mastectomizadas em relação à convivência pós-cirúrgica. Estudo qualitativo, realizado em 2006, no domicílio de cinco homens que viviam maritalmente com mulheres mastectomizadas, em Fortaleza-CE. Utilizamos a entrevista semi-estruturada. Os resultados foram agrupados em três categorias de análise. Identificamos um nível de desinformação quanto à doença, tranquilidade atribuída à fé em Deus, e a forte convicção de que câncer e morte são sinônimos. Cabe aos profissionais de enfermagem/saúde favorecer o conhecimento sobre câncer de mama, e abrir um painel de integração marido/esposa, priorizando uma convivência saudável.

DESCRITORES

Neoplasias da mama.
Mastectomia.
Relações familiares.
Cônjuges.
Enfermagem oncológica.

RESUMEN

Esta investigación tuvo como objetivo comprender la percepción de los cónyuges de mujeres mastectomizadas respecto de la convivencia posquirúrgica. El estudio fue de carácter cualitativo, realizado en 2006, en los hogares de cinco hombres que convivían maritalmente con mujeres mastectomizadas en Fortaleza, Ceará, Brasil. Se utilizó el sistema de entrevista semiestructurada, los resultados fueron agrupados en tres categorías de análisis. Identificamos un nivel de falta de información respecto de la enfermedad, cierto grado de tranquilidad atribuible a la fe en Dios y la fuerte seguridad de que cáncer y muerte son sinónimos. Corresponde entonces a los profesionales de enfermería y otros profesionales de la salud favorecer los conocimientos respecto del cáncer de mama y abril un panel de integración esposo/ esposa, apuntando como prioridad a una convivencia saludable.

DESCRIPTORES

Neoplasias de la mama.
Mastectomía.
Relaciones familiares.
Esposos.
Enfermería oncoloógica.

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INTRODUCTION

Breast cancer is the main cause of death in the female population[1]. The most common therapies include: chemotherapy, radiotherapy and hormone therapy, which are based on the disease's clinical stage. Regardless of other therapeutic interventions, mastectomy is a common practice, especially in the Brazilian population, in which breast cancer is usually diagnosed in more advanced stages.

Studies, mainly nursing studies, have evaluated the impact of the surgical treatment, that is, positive and negative changes that follow this therapy in women with breast cancer. Mastectomy causes an important psychological and social impact due to fear and taboos surrounding the disease[2-3]. It causes a mental image associated with mutilation, pain, loss of sexual appeal and impotence, which are manifested through feelings of sexual mutilation leading to difficulties in interpersonal relationships[2].

Psychological disorders that accompany the breast cancer diagnosis and treatment begin at the moment the woman suspects there is a nodule. The family dynamics is altered because of the disease and fear becomes part of the daily routine[4-5].

In terms of a psychological point of view, based on the daily routine of nursing professional practice, the husband starts to adapt during his visits in the post operative period. It is observed that husbands feel very anxious about their wives' disfiguration caused by the mastectomy.

At the same time, if living with cancer causes uncertainty for women, we can conclude that all those who live with these women, especially children and husbands, who are essential in the coping process, are also affected by the problem.

We believe that family members, especially husbands, are more capable of providing emotional support to the woman, as they develop a moral, emotional and affective support, which leads to a better adaptation of the woman to her new health condition. However, it is worth noting that husbands have to be included in the context as an object of care, since they experience the same feelings of fear, uncertainty and anxiety. When husbands share the disease experience with their wives they can either become closer or, when they do not have mechanisms to adapt and strengthen coping strategies, distance themselves from their partners.

Given these considerations, we have to take into account the characteristics developed by husbands in the face of a crisis, the development of attitudes and behaviors to cope with problems, with a view to develop a growing interpersonal relationship in which emotions, doubts and concerns are shared.

Husbands are more capable of providing emotional support to the woman, as they develop a moral, emotional and affective support, which leads to a better adaptation of the woman to her new health condition.

Knowing the experience of these husbands in the health/disease process, in all the phases of treatment, can enable other people who experienced, experience or will experience the same problems to develop constructive alternatives.

Hence, this study aimed to understand the perceptions of the breast removal for husbands of women who have undergone a mastectomy.

METHOD

This is a qualitative study because it focuses on the individual, seeking to understand the studied phenomena. Qualitative studies seek discoveries and cause the researcher to pay attention not only to assumptions but also to new elements in the course of the study.

The subjects were five men who met the following inclusion criteria: living in the same house with their wives at the time of the diagnosis and agreement to participate in the study. The exclusion criteria were: husbands/partners of women who had undergone mastectomy in less than one year, widowed, divorced and women who did not regularly attend the Association of Mastectomized Women (AMW).

Interviews were carried out in April and May of 2006. The participants were interviewed at their own houses because their jobs restricted their availability during day; time was scheduled according to their convenience.

The data collection instrument was a script with two parts: the first was the participants' identification data and the second was subjective questions related to their reactions in the face of the disease, marital relationship and coping mechanisms to cope with the mastectomy. The reports were recorded on k-7 tape. The semi-structured interview was chosen because it enables the researcher to establish with the interviewee the freedom and spontaneity necessary to enrich the study, while at the same time keeping to the proposed objective.

After detailed listening to the recorded interviews, the reports were transcribed and submitted to an exhaustive and repetitive reading and then organized according to the identified units of meanings.

The transcribed results were organized into three categories: understanding the diagnosis, living with the disease and marital relationship, taking into account the answers of the participants and analysis supported by content analysis[6].

Content analysis is a set of communication techniques that aims to obtain through systematic and objective pro-

cedures the description of the content of messages, indicators (quantitative or qualitative) that permit to infer knowledge related to the conditions of production, and reception (inferred variables) of these messages[6].

In compliance with the ethical-legal aspects of research with human subjects recommended by Resolution 196/96 of the National Council of Health, approval of the Ethics Research Committee at the Federal University of Ceará was obtained and participants signed Free and Informed Consent Forms. They were informed their participation was voluntary and that they could withdraw from the study at any time. Fictitious names were used so to ensure confidentiality.

RESULTS AND DISCUSSION

Sociocultural characterization of subjects

The participants were 45 to 56 years old. Most of them were from the middle-low class with a minimum level of education. Only Marcelo had a bachelor's degree; all of them lived in an urban area. The majority was self-employed. All of them lived with their wives for more than 20 years and with their disease for more than five.

The results are discussed according to the identified categories: Understanding the diagnosis; Living with the disease; and marital relationship.

Understanding the diagnosis

A lack of knowledge is observed among the interviewees when they attribute cancer to several ungrounded concepts. It shows they are not aware of the real dimension of the problem since a mastectomy presents repercussions on the physical, psychological and social spheres.

We observed that the meaning attributed by these men to cancer is compromised due the historical stigma of the disease. The belief that cancer and death are synonymous is still very strong and most people view cancer as something incurable. It is as if everything the individual does after the diagnosis is in vain, feeling powerless to reverse the already established condition[5,7].

At the same time, the coping strategies used by husbands are positive as well as their determined behavior and actions in the face of reality, seeking care delivery to deal with the established situation.

> My way of dealing with the situation, my behavior was to make her to believe and acknowledge that she had to care for herself because the problem was already there (Carlos).

> Now, my reaction was, if it is really cancer, if it is malignant, she might die, because there's no way out; so I run to the physician (Fernando).

The literature reports how important a positive reaction of husbands in view of cancer is, stressing that the protection and safety demonstrated by them enable the creation of options to cope with problems, the establishment of a growing interpersonal relationship and sharing of emotions, doubts and concerns[7].

Living with the disease is permeated by knowledge (ideas), beliefs (holding a proposition as true), values (feelings that encourage human behavior), standards (rules that indicate the way to act) and symbols (evaluative realities) enabling people to use acquired knowledge (implicit and explicit) to interpret an experience and generate a social behavior[7].

At the beginning, Marcelo, Hugo, Carlos and Diogo seemed calm, which they attributed to their faith in God, a support for coping with the disease according to the following reports:

> I really trust in God and I know He doesn't give you a load heavier than you can handle. That was something I understood He allowed to happen (Marcelo);

> He allowed it to happen, to see how we'd behave in the face of the situation. I didn't see it as a misfortune or something she or I didn't deserve, no (Hugo);

> No, nothing has changed. Because we understood, you know. We understood, especially, God you know, we acknowledge it. Like, today I am in the same way we are in this acknowledgment. God gives us conformation and we acknowledge it normally (Carlos);

> I didn't do anything, nothing, God was the One who is doing it. So, I thank Him for this recovery… Because I'm not capable of doing anything else, anything I do, any recovery is God… It is God who acts in me and does things. Because we were, I was at her side; Our Lord was at her side. And so we keep walking until today (Carlos).

> What I did was to hold in God, to have hope and faith. God gave me faith. Because I thought that the world was mine, you know? Then, my wife got sick and I saw that I was nothing (Diogo).

Women with breast cancer seek in spirituality and in complementary therapies a new sense for life. Holding on to religion in moments of hardship is a common practice in Latin society. The rationale is that religious therapies heal as they impose order on the chaotic experience of patients and families. However, the religious symbols need to be shared by the healer, the patient and by the whole community of reference in order to work[5,8-9].

Religion is a strong ally of women with breast cancer to fight depression and to neutralize tension[2,10]. Faith in the cure is based on the patient's belief in a superior power, such as God, who gives them hope and credit. This form of perception induces a relaxation that neutralizes tension and often times offers the key to recovery. Thus, religion provides them support and through spirituality they seek a cure[2-5].

Reports indicate that faith and belief in God, in the same way that they provide women a adaptation process and

coping mechanism, also provides their partners the same strength in this process, strengthening understanding, hope and helping them to cope with the problem and to support their partners.

Despite the faith in God that works as a support to cope with the problem, the spouses revealed embarrassment, shock, and pessimism due to the impact caused by the diagnosis and fear and impotence to reverse the condition, which is mainly observed in the reports of Hugo and Marcelo:

> It felt really bad because of her mother, you know, who died due to the same problem, but she is a fighter, she's a person who fights, wants to live (Marcelo).

The disease spread very rapidly and, consequently, the urgency of the surgical procedure was mentioned by all of them, which is evidenced mainly in the Hugo's narrative. Such facts signify that the couple maintained marital communication, which helped them to cope with the crisis, to discover facts and express feelings.

> I was very shocked at the time when her cancer appeared... It was three months, she took the exams in September, in December she had the nodule and it was practically me who discovered it (Hugo).

We have demonstrated the importance of communication in a marital relationship. Couples who do not communicate do not maintain intimacy and loving cooperation, an element so important in love, is extinguished.

Living with the disease

The wife's disease evidenced the importance of a stable relationship of trust, partnership and mutual respect. The family is pinpointed as the most important element in the recovery process of women with breast cancer because it provides help and/or a support system, which contributes to their recovery[11-12]. However, husbands should also be an object of care because they get sick jointly with their wives. They show insecurity, concern over the death of their spouses and sometimes uncertainties in the performance of household chores and care delivered to their wives.

The family's development of positive coping strategies ensures great protection of their loved one, enabling the woman to find in her family ways to strengthen herself because she receives help and affection[13].

The manifestation of mutual sickness due to the wife's disease can be observed in this report of Fernando:

> I got sick also, so I went to physicians and tried to diagnose my disease and never found it out. When I finally learned it was that thing psoriases caused by stress… so I figured out that the stress… it was the stress caused by having to take care of her… so she would not die for lack of care (Fernando).

Hugo and Diogo were unanimous in showing more dedication in their reports:

> I did everything right, as it had to be, you know. I made all the arrangements; I felt it was my obligation to take care of her better than before. And I still do. So I devoted myself. I accompanied her to surgery, biopsy, spent the days at the hospital, took her to chemotherapy, radiotherapy, I took care of everything, I left my work to accompany her (Hugo).

> I can say that I fight for her, I tried to help her, take her... I could have done much more, but this is it... it's life, you know? We don't choose how it happens (Diogo).

Diogo notes that their children were supportive, and also reported the importance of the woman in her role of mother and as the home's administrator:

> The children are an incentive, I have difficulties raising the children, and without their mother it'd be worse. Because she is the one who takes charge, she screams, demands, pushes things to happen. Can you imagine raising children without a mother? It's difficult, right? I think that this is nothing without her, it's the end of everything (Diogo).

The partners become fragile when they experience their wives' cancer. They are afraid of not being able to stand it, to lose their wives. It is not only fear of the concrete loss, but also the abstract, subjective loss, and mourning[14]. Thus, they need support and should receive care in health services. They should be included in support groups to help them to strengthen themselves, to inform them about the disease and treatment and help them in their psychosocial needs.

The children represent an important network of emotional support, essential to disease recovery. The archetypes of father and husband, the home breeder, define what they have to perform socially in an unquestionable way[2].

The husband's devotion is essential to the woman, especially in the initial stages of the disease and even after the mastectomy, because the woman has the need to be accepted, needs affection, understanding and love. In the lack of these feelings, the sexual relationship in a women's view, is total discouraging[2]. In this respect, it is acknowledged that husbands have the important function of supporting their wives, especially to deal with the emotional stress and the breast cancer treatment, but they should also be supported in their needs so they can develop positive coping strategies.

The marital relationship

We highlight the marital relationship of the individuals before and after the surgery. All of them report that the marital relationship before the surgery was *normal* or *good*, concepts that, according to the reports, can be understood as the absence of serious arguments or fights. They had a stable relationship:

> It's always been very good, always a very harmonious thing, calm and peaceful, because of our nature, we never went through periods of crisis and marital hardship, no (Marcelo).

> We never fight. First, because I don't like to fight, and she doesn't either. We like peace. We disagree about something, but we don't fight. Not before nor after (Carlos).

Marcelo, Hugo and Diogo denied they experienced any difficulties in their marital relationship because of the surgery:

> I confess that there wasn't any changes in terms of marital relationship, I felt no difficulties. What we can't avoid, we have to learn to live with and I don't have any difficulty in relation to her because of the cancer she has, no (Marcelo).

> No I didn't fell anything, I didn't feel anything at all, for me it even got better, I didn't abuse of her, I wanted to love her even more because of the disease, I supported her in every way I could, I had no prejudice (Hugo).

In relation to changes occurred in the marital relationship after surgery, two of the interviewees reported they had not experienced any changes, rather their marital life improved due to greater partnership and friendship:

> Boy, it didn't change anything and it is getting better, you know. And it is the same love… It got better because I acknowledged it. I started to treat her not like an ill person, but as a person who needed me increasingly more. I started to live better with her because she needed me (Hugo).

> I could even say that it got better because from that point on I started to see her and treat her as a person who deserves a closer support and from whom? From the person who is closest, in the case the husband, who is living with the situation (Marcelo).

Carlos, Fernando and Diogo expressed difficulties because of their spouses' physical limitations due to the surgery. Their spouses could no longer perform their domestic roles.

> Well, the most difficult thing was not, I mean still is that she became, I live with her so I can say that she became deficient. Deficient because she, all her agility, everything she did, home chores and other things, she doesn't do anymore (Carlos).

> The most difficult thing between her and me was this, it is because she can't do anything at home, nothing. And my salary is too little to pay for someone to help her (Fernando).

> When I get home earlier from work I do things at home because she can't, so I have to solve it. It's something, to put clothes on the line, get clothes, I always do something, help, do the dishes, it is not a dishonor, we share, you know, we never think about leaving each other, this idea never crossed our minds (Diogo).

When they face their physical limitations, women have to face social parameters such as dependency and change of roles; they no longer perform everyday tasks, work, take care of the children and the house. Personal relationships and friendships are also shaken; in some cases, social isolation set in[15].

A well-structured marriage provides social support and/or stops the effects of stress whereas a poor relationship, the loss of a partner or even the fact of being divorced hinders a good organic functioning. In the opinion of authors previously mentioned, marriage influences health, social position and survival, supporting many procedures and psychological paths[16-17].

For Fernando, the event led to a rupture in the couple's sexual life:

> It changed, yes it did, because the relationship becomes something else, it's different. So, there's no more, how can I say, a relationship as we had before… She's• always sick, she doesn't seek me and I don't seek either a relationship with her or anything. Now, friendship is the same, I don't have fun or anything (Fernando).

For some women, the relationship is viewed as something irrecoverable when they find themselves in the face of situations of disease and which have repercussions on both partners' sexuality in which the marital relationship is characterized by conflict, especially when the couple already had a previously difficult marriage[2].

The existential experience of a marital relationship has been expressed as difficult, especially when the couple already had a difficult relationship and which, when in the face of a disease that affects the sexuality of both, seems to women to be irrecoverable[18]. During the rehabilitation phase, the sexual partner is one of the most important sources of care for women with breast cancer.

Couples who do not communicate with each other do not manage to keep intimacy, an element considered so necessary in love, which is lost when there is no communication[19].

FINAL CONSIDERATIONS

Based on the husbands' reports , despite all the advancements oncology has achieved in terms of diagnosis, treatment and rehabilitation, the stigma that cancer is an incurable disease and that invariably leads to death is still very present in society and, therefore, leads to difficulties in dealing with the problem at personal and family levels.

In terms of coping with the problems, we show that the husbands attribute the basis to deal with the problem in a satisfactory way to faith in God , supporting their wives and overcoming their own difficulties.

On the other hand, they sought to overcome obstacles in the process of coping with the disease at the same time as they established strategies that permitted them to strengthen their marital life, showing dedication, support and accompanying the treatment, while the stigma of having a breast removed led to the couple's sexual disruption.

The construction of coping strategies presented in this study demonstrates that the partners of these women had to fight through their own obstacles in relation to their wives' mastectomies by themselves. They had to carry, themselves, the great responsibility of supporting their

wives in coping with the difficulties that emerge post surgery, without any support from the health system.

From this perspective, the husbands need to receive additional information about the disease, treatment and their needs related to intimacy and sexuality, since the disease and altered self-image tend to be an obstacle to sexuality after the mastectomy. It is clear that husbands of mastectomized women need a support network from health professionals, considering the various aspects and problems they have to cope with when dealing with the disease and their partners.

The importance of an integral healthcare delivered to mastectomized women by a multiprofessional team is essential to establishing a bond between the health system and the family with a view to deliver care considering the social context of these women, including the family and, consequently, their partners.

It is imperative that nurses establish an open channel of communication, a necessary condition to provide health care to the family in the operational structure of the therapeutic process, as well as emotional and sexual counseling.

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