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Knowledge and expectations of women in the preoperative mastectomy

CONHECIMENTO E EXPECTATIVAS DE MULHERES NO PRÉ-OPERATÓRIO DA MASTECTOMIA

CONOCIMIENTO Y EXPECTATIVAS DE LAS MUJERES EN EL PREOPERATORIO DE MASTECTOMÍA

Pricilla Cândido Alves¹, Anna Paula Sousa Silva², Míria Conceição Lavinhas Santos³, Ana Fátima Carvalho Fernandes⁴

ABSTRACT

The objective of this study was to understand the knowledge, concerns and expectations of patients suffering from breast cancer in relation to mastectomy. Interviews were performed with 11 women before their being submitted to surgery at the Hospital das Clínicas in Fortaleza (Ceará state) on December 2008. The hermeneutic-dialectical method was used for discourse analysis, and three theme categories were defined: Knowledge about the surgery, Feelings and expectations surrounding mastectomy, and Removing the breast. It was found that women go through a stressful preoperative period, lack knowledge about the surgery, experience anxiety and fear of what they should expect, as well as feelings of panic and shock before their breast is removed. It is, therefore, observed that the health team caring for those patients has an important role in education and in providing emotional support so as to minimize the tragedy those women are experiencing.

KEY WORDS

Mastectomy.
Knowledge.
Emotions.
Preoperative care.
Perioperative nursing.

RESUMO

Com o objetivo de compreender o conhecimento, as preocupações e as expectativas de pacientes portadoras de câncer de mama em relação à mastectomia, entrevistou-se 11 mulheres internadas no pré-operatório da cirurgia, no Hospital das Clínicas de Fortaleza (CE), em dezembro de 2008. O método hermenêutico-dialético foi utilizado na análise dos discursos, sendo definidas três categorias temáticas: Conhecimento acerca da cirurgia, Sentimentos e expectativas em torno da mastectomia e a Retirada da mama. Constatou-se que a mulher passa por um pré-operatório estressante, com desconhecimento acerca da cirurgia, sente ansiedade e medo pelo que está por vir, além de sentimentos de pânico e choque diante da retirada da mama. Ressalta-se, portanto, a importância do papel educativo e do apoio emocional direcionados por toda a equipe que presta assistência a essas pacientes, de maneira a minimizar o drama que vivenciam.

DESCRIPTORES

Mastectomia.
Conhecimento.
Emoções.
Cuidados pré-operatórios.
Enfermagem perioperatória.

RESUMEN

Con el objetivo de entender el conocimiento, las preocupaciones y expectativas de pacientes portadoras de cáncer de mama en relación a la mastectomía, fueron entrevistadas en el preoperatorio de la cirugía 11 mujeres internadas en el Hospital de Clínicas de Fortaleza-Ceará-Brasil, en el mes de diciembre de 2008. El método hermenéutico-dialéctico fue utilizado en el análisis de los discursos, definiéndose tres categorías temáticas: Conocimiento acerca de la cirugía, Sentimientos y expectativas en torno a la mastectomía y Extirpación mamaria. Se constató que la mujer pasa por un preoperatorio estresante, con desconocimiento al respecto de la cirugía, ansiedad y miedo de lo que está por venir, además de sentimientos de pánico y shock ante la extirpación de la mama. Se resalta, por lo tanto, la importancia del papel educativo y el apoyo emocional brindados por todo el equipo que atiende a tales pacientes, de manera tal de minimizar el drama que experimentan.

DESCRIPTORES

Mastectomía.
Conocimiento.
Emociones.
Cuidados preoperatorios.
Enfermería perioperatoria.

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INTRODUCTION

Breast cancer is probably one of the diseases women most fear, due to its biopsychosocial effects, which deeply and significantly affect women's lives. It is the cancer type not only with the highest incidence levels in the female population, but also with the highest mortality ratios, turning into a true global public health problem⁽¹⁾.

According to INCA (Brazilian National Cancer Institute) estimates for 2008, 49,400 cases new breast cancer cases will be registered, that is, a gross incidence rate of 50.71 cases for every 100,000 women. In the Northeast, the incidence level for new cases is 7,630 cases, with a gross rate of 28.38/100,000⁽²⁾. Based on these data, it can be observed that this cancer type has continuously increased in the last decade, which can result from sociodemographic changes and health service accessibility.

Mastectomy is the most used treatment for breast cancer, responsible for a range of alterations experienced by the patients who face it, as it is an aggressive surgical process, accompanied by traumatic consequences for women's lives and health, exactly because it is an emotionally difficult experience that needs adequate and high-quality preparation during the pre-operative phase⁽³⁾.

The entire multidisciplinary team should be involved in this preparation, but especially during the pre-operative nursing visit, as this category is directly connected with the patient and can use the visit to provide information on all pre-, trans- and post-operative actions, thus reducing patients' anxiety level by addressing feelings like fear, apprehension and concern. These stand out in such a generalized way at the moments before these women's surgeries and directly indicate lack of information and adequate care for these patients, which can impair post-operative recovery after mastectomy⁽⁴⁾.

Thus, in this preparatory phase, dialoging, sharing feelings and reactions, exploring ideas in-depth and discussing relationships are extremely important as, when one acts to strengthen a relationship with other people, the immune system responds more actively and becomes stronger, while other organic systems start to act better⁽⁵⁾.

Hence, getting to know these women's concerns in the pre-operative phase of mastectomy is highly relevant in the attempt to understand the sense of communication in the pre-operative phase of mastectomy, as a lack of care related to information, disease and surgery, allied with lack of knowledge on these patients' expectations, is observed in the hospital environment.

This fact appoints the need for high-quality pre-operative visits, in which nurses adopt care strategies based not only on technical-scientific knowledge, but also on knowl-

edge about the patients' expectations and perceptions regarding the surgery, so as to attend to these women in their physical, emotional and social aspects and thus, systemize the care needed during this period.

OBJECTIVE

This research aimed to understand breast cancer patients' knowledge, concerns and expectations regarding the surgery in the pre-operative phase of mastectomy.

METHOD

Exploratory-descriptive study with a qualitative approach, involving 11 breast cancer patients, based on the following inclusion criteria: being older than 18, in the pre-operative phase of mastectomy, spontaneously accepting to participate in the research by signing the free and informed consent term.

Participants were hospitalized at the breast ward of a university hospital, where interviews were held in December 2008 through weekly visits, always during the morning shift, as this was the time before the surgeries.

Approval for the research was obtained from the Research Ethics Committee at Hospital Universitário Walter Cantídio of the Federal University of Ceará (HUWC-UFC), in compliance with Resolution No 196/96⁽⁶⁾ and registered under protocol number 074.11.08.

Data were collected until data saturation was obtained, a criterion adopted in qualitative research, in which convergences and divergences in the collected information point towards the end of data collection⁽⁷⁾. A three-part structured interview script was used for data collection: the first two parts addressed the participants' sociodemographic characterization (name, age, education level, civil status, occupation and origin) and data related to the disease, respectively (diagnosis time, tumor dimensions, previous treatments and presence of metastases), and the third referred to questions like: What type of surgery are you going to have? Do you know how the surgery is performed? What are your concerns and expectations regarding the surgery? How do you feel about the removal of your breast?

During the interviews, the interviewees' discourse was registered manually. Next, the statements were transcribed, preserving their colloquial tone.

Descriptive data analysis was used, according to the hermeneutic-dialectical method, in which the social actors' discourse is situated in its context with a view to a better understanding⁽⁷⁾, considering the following steps: 1) Data ordering, in which all information collected during the field work was mapped, including rereading of the material and

Mastectomy is [...] an emotionally difficult experience that needs adequate and high-quality preparation during the pre-operative phase.

organization of the reports; 2) Data classification, departing from inquiries based on theoretical foundations, using exhaustive and repeated reading of the texts to identify what is relevant and elaborate specific analytic categories, and the last step 3) Final analysis, attempting to establish relations between the data and theoretical frameworks from literature.

Based on the unit of meaning in the participants' discourse, three categories were identified: The woman's knowledge about the surgery, Feelings and expectations about the surgery and Removal of the breast. To guarantee the study participants' anonymity, the women received biblical names, due to cancer patients' general fondness of divine presence and spirituality⁽⁵⁾.

RESULTS AND DISCUSSION

With regard to sociodemographic data, the women's age range varied between 36 and 72 years, with a predominant group between 50 and 70 years old. As for civil status, seven were married, two single, one widowed and one divorced. Regarding education, one had finished secondary education, nine had not finished primary education and one was illiterate. Occupations included housewife, cook, trader, public servant, farmer and retired.

With respect to origin, seven participants came from the interior and four from the capital, in accordance with INCA estimates, in which most cases occur in the interior⁽²⁾. Diagnosis time of the disease ranged from five months to ten years after tumor discovery, and tumor dimensions ranged from 9x7mm to 12 cm. Most patients had not received any previous treatment before the surgery and metastasis was present in one patient only, who also presented lung problems.

The data related to the study questions revealed the category of patients' concerns and expectations about being mastectomized, identified and discussed next:

Knowledge about the surgery

The art of understanding is linked to the art of convincing (rhetoric) in those cases when communication involves decisions on practical issues. Thus, hermeneutics and rhetoric join, not only as a route to understand the message, but also to understand how action is oriented and modified⁽⁷⁾.

Hence, locating the woman in the meaning of the action through the hermeneutical-dialectical method, we attempt to identify the ideological illusion of the woman's release from the thinking standards she might be deeply imprinted with. In fact, this is way thinking produces rationality, as it is capable of accounting for an interpretation of reality, inserting discourse in its context, in order to understand it departing from its interior and in the field of the historical specificity it is produced in⁽⁸⁾.

Based on this principle, in dialectics, the human being is the starting point and hermeneutics is the search to understand the meaning language is given, which is what we considered and abstracted from the women's statements:

[...] I am going to have my breast removed, but I don't know the name of the surgery (Sara).

[...] I don't know if they're going to remove the whole breast or just work in the armpit, they are going to decide that when they open it (Rebeca).

The importance of information and knowledge about the disease is present in the decision process about the type of surgical procedure for women with breast cancer⁽⁹⁾.

When asked about the type of surgery they were going to have and how it would be performed, most patients only know that their breast would be removed, but neither the name of the surgery or procedure they would submit to, nor how it would be performed⁽¹⁰⁾.

Breast cancer surgery aims to promote local control through the mechanical removal of all malign cells presents in the primary tumor, enhance survival, direct systemic therapy, define surgical staging of the disease and identify the main risk group for distance metastases. Axillary emptying, in turn, is performed with a view to surgical staging and control of the disease in the armpit, assessment of local and distance relapse prognoses and orientation of complementary treatments⁽¹¹⁾.

The types of surgery depend on clinical and histological staging and can be classified as conservative: tumorectomy (tumor removal without margins) and segmental resection or sectorectomy (tumor removal with margins) and non-conservative: subcutaneous adenomastectomy (with removal of the mammary gland, preserving the skin and areola-nipple complex), simple or total mastectomy (breast removal, including skin and areola-nipple complex), mastectomy with preservation of one or two pectoral muscles and axillary lymphadenectomy (modified radical), mastectomy with removal of pectoral muscle(s) and axillary lymphadenectomy (radical)⁽¹¹⁾.

Thus, different factors have contributed to the safety of these surgical procedures nowadays, although most of these techniques ignore patients as subjects and persons in their treatment. This can be verified at the moment of the diagnosis and treatment definition, when patients rarely take part in the process, and evidenced through the study participants' discourse.

Information on the disease, treatment and its consequences is fundamental. This information and orientations, received from health professionals, communication media and people who experienced the disease, about the causes of breast cancer, aspects related to prevention, treatment and its implications for women's lives are considered essential to decrease anxiety and fear regarding diagnosis and treatment⁽¹⁰⁾.

Thus, for surgical treatment to become complete and more humane, patients need to be emotionally prepared and orientations should be comprehensive. This means not just mentioning the name of the surgery, but explaining each step, that is, what, why, when, by whom, how and the consequences, so that patients can know about their treatment and collaborate in their recovery⁽¹⁾.

The issue of women with breast cancer's participation in their treatment process, including the modes they will be submitted to, should be conducted within a proposed care model guided by the ethics of care delivery to citizens, allowing them to become subjects in their own care.

Feelings and expectations about the mastectomy

The experience of women who will submit to a mastectomy differs from women who do not submit to this process. The most common pre-operative feeling is anxiety, initially because they see the surgery as the possibility of cure and hope that, after its accomplishment, they will no longer need to worry. At the same time, there is fear of the unknown, the anesthesia and possibility of facing a body that will no longer be the same⁽¹²⁾, as observed next:

[...] I am concerned, nervous because I am going to have my breast removed, I am afraid of the anesthesia as well (Sara).

[...] I am afraid of the surgical center and the anesthesia (Rebeca).

[...] I am nervous and afraid of feeling sick at the time of the surgery and because of the anesthesia (Ana).

In these statements, hermeneutics shows us daily living conditions and clarifications about the deep structures of this world in the daily reality of feelings⁽⁷⁾.

Fear of the unknown is appointed as the main source of anxiety in patients with breast cancer suspicions who are going to be submitted to a surgical procedure. Countless factors have been identified as responsible for this anxiety surrounding the moment of the anesthetic-surgical act: concerns with possible injuries during the surgical procedure, fear of post-operative pain, separation from the family, loss of independence, fear of disability, fear of waking up in the middle of an anesthesia, fear of the diagnosis and complications⁽¹³⁾.

As hermeneutics-dialectics permits addressing the significant whole of the research phenomenon and, thus, the subjective and objective aspects of people's psycho-cognitive process⁽¹⁴⁾, the different factors mentioned that concern women in the pre-operative phase need to be perceived and worked at this moment, in order to avoid future complications.

In this phase, according to the study on nursing's role in pain control in cancer patients, it was demonstrated that nurses' actions should be clear and precise, not only in the control of this aspect, but also in educational orientations

and emotional support to these patients, who are in a state of complete frailty⁽¹⁵⁾.

Anxiety is a universal phenomenon and an emotional reality almost all surgical patients experience, which can influence their treatment response and negatively affect post-operative recovery. This feeling, in addition to patients' fear of the surgery, represents a bothersome feeling of discomfort or dread, accompanied by an autonomous response, that is, a feeling of apprehension caused by the anticipation of danger⁽¹³⁾.

Besides anxiety and fear, feelings of despair and anguish are common with regard to treatment. In most cases, the possibility of death, deriving from a disease like breast cancer, which causes mutilations and alters patients' body image, arouse feelings of depression and fear in view of the finiteness of life. It also causes disbelief in treatments and in a possible struggle for life⁽⁵⁾, as observed in the statements below:

[...] I am anxious and afraid of dying (Noemi).

[...] I did not want to do this surgery because I think it won't help, but the doctor convinced me (Isabel).

Fear of death does not seem to join patients' resources or increase their resistance against the disease process. This fear does not help them to expand their personality in order to put their potential to work, but restricts and limits them. Fear of death actually is an essentially negative emotion⁽⁹⁾.

This feeling of fear about death is experienced at the moment of the diagnosis and accompanies the being-with-cancer during their entire trajectory of coping with the disease. Hence, death constitutes the scariest fact of life, in view of which there is no control or prediction⁽⁹⁾.

Based on the above, nursing care while preparing the patient for surgery should include an individualized approach and one of its goals should be to reduce fear of the unknown, death and anesthesia, with a view to reducing possible complications to a minimum and enhancing patients' recovery⁽¹³⁾.

Some women in this study showed no concerns or low levels of anxiety. These attitudes can indicate a lack of introversion, also leading to resistance to understand and reaffirm themselves towards the experienced situation⁽¹³⁾.

[...] I am not concerned, I just want everything to work out (Judite).

[...] it's not that I'm not concerned, but I prefer not to talk about it (Madalena).

This behavior can also be understood and justified in the society we live in, as Western society raised communication barriers, with no place to express pain, love, to open up for other people, to break the silence, and the obligation to be or demonstrate that one is happy, even if the body or soul cries, suffers, is sick, needs help. Help should preferably be professional and impersonal⁽⁵⁾.

It seems, though, that many professionals do not know about therapeutic communication techniques, avoiding verbal contact with patients who experience the possibility of death, taking distance because they do not know how to process the feelings the situation of imminent death arouses. These facts become a source of concern when reminding that nurses and their team are the health professionals who interact with patients more direct and constantly during their stay at a hospital institution⁽¹⁶⁾.

With a view to improving this problem, nursing education courses or intensive training for these professionals would be needed, addressing care methods and techniques, didactics and interaction strategies with a view to effective and potential practice in oncology nursing care⁽¹⁷⁾.

Thus, the nursing team should adopt a broad and early approach of pre-operative patients before mastectomy, considering the possibility of detecting feelings and concerns these women present which, when not identified, entail consequences and complications both during and after the surgery.

Breast removal

In this hermeneutical reflection, we look for a given group's (mastectomized women) worldview at a present moment, so as to examine the feeling of loss about the breast removal⁽⁷⁾.

[...] I think it will be difficult to get accustomed to the new image, it will be difficult for my husband too (Sara).

[...] I think it's very bad to have a breast removed because I'm going to have a defect, with one breast missing (Isabel).

Losing a breast arouses feelings of shame, rejection and inferiority. This is explicable, as the body representation plays a noteworthy role in the construction of the self-image and body awareness, particularly the relation a person establishes with his/her own body, it is a component and essential element of individuality⁽¹⁸⁾.

Besides, the breast is considered the central object of desire and satisfaction, and a disease located in this object destroys all possibilities of symbolizing the woman as a feminine being. When she is threatened with the loss of this organ, the woman feels that her feminine identity is being questioned, as well as her breastfeeding capacity and sensuality⁽¹²⁾, as observed in the women's statements.

The breast removal modifies social and sexual aspects of the woman's identity, influencing her marital relationship. The effects of the mastectomy on the couple's life, however, greatly depend on their relationship before the surgical intervention, and also on the quality of the sexual relationship and emotional involvement⁽⁵⁾.

When confronted with possible breast loss, the women experience a very complex moment, with the actual feeling that life is ending, mutilation is certain while the fu-

ture is uncertain, leading to different reactions towards the fact.

[...] I felt very shocked initially when I knew my breast would be removed, but I think it's better to be alive and with one single breast than dead with both (Judite).

[...] I panicked first, but now I'm calmer (Madalena).

Feelings like sadness, depression, state of shock and panic about the breast removal are evidenced, characterizing the difficult experience of breast cancer and mastectomy, as the meaning attributed to this experience is often related to death and mutilation⁽¹⁹⁾.

Some patients see the breast removal as something unavoidable in view of the disease, manifesting acceptance and conformation with the fact.

[...] I think it's better to remove the breast than to remain ill (Rebeca).

[...] If it's for my health, losing a breast doesn't mean anything (Éster).

[...] I am prepared to lose my breast (Noemi).

For many women, the acceptance to lose their breast derives from the fact that there is no other way, but the only route towards the so awaited cure, that is, getting rid of evil. Thus, it is better to accept it than to die without at least trying⁽¹⁶⁾. For women, it is fundamental to face the disease with courage, without losing hope, they need to believe in the possibility of recovering and getting back to a normal life⁽¹⁸⁾.

With regard to the activities of daily living, the women are commonly concerned with its continuity after the breast removal. In most cases, they are accustomed to giving care and the feeling of needing care produces feelings of anguish, concern and anxiety⁽¹¹⁾, as observed in the following statement:

[...] I think it will be difficult for me to get accustomed to the loss of this breast, also because I'm a housewife, it's gonna be bad to do the housework (Ana).

The woman plays many roles: mother, wife, worker, family head and citizen. Many obstacles emerge in this universe for female role performance, mainly in situations when women get ill⁽¹⁹⁾. This arouses concerns like not wanting to be a bother, not depending on others, not getting in the way⁽¹¹⁾.

In view of the above, specialized emotional support is needed, which should always be offered as, often, the stress accompanying this moment makes it difficult to rationally absorb all information given⁽²⁰⁾.

In this respect, nurses need to contribute to the multidisciplinary team and their role is fundamental to help women in such a difficult and modifying process as breast removal, whose compromised self-image entails physical, emotional and social traumas that can negatively influence the evolution of their treatment and recovery.

CONCLUSION

After data analysis, it was concluded that the mastectomy provokes a whirlpool of doubts, anxiety and fear of what is about to come, mainly due to the patients' lack of information and knowledge about the surgery. Hence, the women end up facing a stressful pre-operative period, with anxiety, fear of the unknown and death as the main feelings regarding the surgery.

In the dialectic interpretation, it was observed that the women's behavior results from previous conceptions, given conditions, but also from the context they live in.

The researchers consider that the disease experience made some women acknowledge themselves as finite beings, taking hold of the possibility of death as part of their existence. The opportunity to have contact with these women enhanced their professional and personal growth, revealing

the fundamental importance of learning to listen, being present and respecting each person's singular moment.

Thus, in the pre-operative phase of mastectomy, multidisciplinary teams and nurses should physically, emotionally and socially support these women, so that the breast removal represents a moment of less shock, emotional commotion, depression and feeling of uselessness.

In view of the above, with a view enhancing women's adaptation and effective coping in this process, they should be oriented, receiving an information and care guide with the following data: type of surgery, care for the operated arm, handling the drain, changing dressings, moving the operated limb and return to the outpatient clinic. This study offered important support to construct an orientation manual for mastectomized women, which is being validated in a doctoral dissertation and will be made available at care institutions for these patients in the future.

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