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Marinho, Diana da Silva; Costa, Thatiane Pinheiro; Vargens, Octavio Muniz da Costa

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REVIEW

The experience of breast cancer under the perception of women who underwent mastectomy: an analysis held from scientific publications

A vivência do câncer de mama na percepção de mulheres submetidas à mastectomia: uma análise a partir de publicações científicas

La vivência del cáncer de la mama en la percepción de mujeres submetidas a mastectomia: un análisis a partir de publicaciones científicas

Diana da Silva Marinho¹, Thatiane Pinheiro Costa², Octavio Muniz da Costa Vargens³

ABSTRACT

Objective: to analyze, based on Systematic Literature Review, the perception of women who underwent mastectomy due to breast cancer about their relationship with their social group. **Method:** it is a descriptive study, which is classified as a Systematic Literature Review, performed in 2010, in which the following steps were conducted: the protocol construction; the definition of the guiding question of the study; the search for studies; the selection of studies; the critical assessment of studies; and the synthesis of data. Ultimately, we have selected 15 papers. **Results:** in most of the families, due to the situation of the mastectomy, it was verified a great union among the family members and, consequently, a better confrontation of the situation. Nevertheless, it was also verified the existence of family disaggregation, withdrawal of friends, sexual partner or of the woman itself, since there are no understanding and comprehension of the problem. **Conclusion:** The research has revealed that the dialogue among people who are significant for the woman contributes in the treatment and in the perception about the lived experience. **Descriptors:** Oncological nursing, Women's health, Breast neoplasms, Gender and health.

RESUMO

Objetivo: analisar, com base em Revisão Sistemática de Literatura, a percepção de mulheres mastectomizadas em decorrência do câncer de mama sobre sua relação com seu grupo social. **Método:** estudo descritivo, do tipo Revisão Sistemática de Literatura, desenvolvido em 2010, no qual foram desenvolvidos os seguintes passos: a construção do protocolo; a definição da questão norteadora do estudo; a busca dos estudos; a seleção dos estudos; a avaliação crítica dos estudos; e a síntese dos dados. No final, totalizamos 15 artigos. **Resultados:** na maioria das famílias, devido à situação da mastectomia, constatou-se maior união e, consequentemente, melhor enfrentamento da situação. Verificou-se, no entanto, a existência de desagregação familiar, afastamento dos amigos, do parceiro, ou da própria mulher, pois não existem entendimento e compreensão do problema. **Conclusão:** A pesquisa revelou que o diálogo entre as pessoas importantes para a mulher contribui no tratamento e na percepção sobre a vivência. **Descritores:** Enfermagem oncológica, Saúde da mulher, Neoplasias da mama, Gênero e saúde.

RESUMEN

Objetivo: analizar, basado en la Revisión Sistemática de Literatura, la percepción de mujeres mastectomizadas sobre la relación con su grupo social. **Método:** estudio descriptivo realizado en 2010. Los pasos realizados fueron: la construcción del protocolo de investigación; la definición de la pregunta de investigación; la búsqueda, la selección y la evaluación crítica de los artículos; y la síntesis de los datos. Se analizaron 15 artículos. **Resultados:** en la mayoría de las familias, debido a la situación de la mastectomía, se verificó un sentido de unión entre los familiares y, por consiguiente, mejores condiciones para enfrentar la situación. Sin embargo, también fue verificado, en algunas situaciones, la desagregación familiar, el distanciamiento de amigos o del compañero, como consecuencia de entender mal el problema. **Conclusión:** La investigación señaló que el diálogo con personas cercanas importantes para la mujer, contribuye en el tratamiento y en la percepción sobre la experiencia que están viviendo. **Descritores:** Enfermería oncológica, Salud de las mujeres, Neoplasias de la mama, Género y salud.

¹Nurse for Universidade do Estado do Rio de Janeiro. Instituto Fernandes Figueira/FIOCRUZ. E-mail: dianamarinho@ibest.com.br. ²Nurse for Universidade do Estado do Rio de Janeiro. Universidade Federal do Estado do Rio de Janeiro. E-mail: thatipinheiro@hotmail.com. ³Obstetric Nurse. Doctor. Professor at the Faculdade de Enfermagem da Universidade do Estado do Rio de Janeiro. Coordinator of Studies and Research Nursing, Women, Health and Society (NEPEN-MUSAS). E-mail: orientavargens@bol.com.br.

INTRODUCTION

Breast cancer is the malignant neoplasm of highest incidence among women in many countries. In Brazil, this is the first or second most frequent illness, depending on the region to be considered.¹

When faced with breast cancer, the woman experiences many feelings that bring out contradictory representations of vulnerability and determination that interfere in the perceptions of the woman itself and of people associated with her daily life.²

When faced with breast cancer, the woman experiences many feelings that bring out contradictory representations of vulnerability and determination that interfere in the perceptions of the woman itself and of people associated with her daily life.³

By understanding the importance of the meaning attributed by the woman to the mastectomy and its relationship with the nursing care, the following guiding question was delimited: "How the woman who underwent mastectomy perceives the relationship with her social group after surgery?". From these considerations, we have formulated the following objective: to analyze, based on the Systematic Literature Review, the perception of women who underwent mastectomy about their relationship with their social group.

The study aims at bringing contributions for the teaching, the care and the research through updated records on the issue at stake.

Literature Review

Epidemiological aspects of breast cancer

International researches report that cancer is not related to the hereditary factor is estimated at more than 90% of cases of breast cancer across the world. Epidemiological, clinical and experimental data have identified that the development of breast cancer related to the hereditary factor has a connection with the production of sex steroids. As examples, early menarche, late menopause, pregnancy and use of exogenous estrogens are considered risk factors for the development of breast cancer. Moreover, the studies have found that the lifestyle of people, including dietary changes and insufficient physical activity, might ease the incidence of cases of breast cancer worldwide.⁴

According to the data of the program Surveillance, Epidemiology, and End Results (SEER), of the National Cancer Institute from the United States, throughout 10 years, the incidence rate of breast cancer increased by approximately 3% per year. This increase was related to the development of the disclosure of screening programs for breast cancer. Nonetheless, since 2003, the incidence of the disease has been suffering decline. This decline has primarily occurred due to two factors: the reduction of the incidence in the groups of women over 45 years old, being that there is an effect due to the saturation of the tracking system for such a disease, and the reduction in the group of women between 50 and 69 years old, due to the decreased uncontrolled use of the hormone replacement therapy.⁴

In other countries, such as Brazil, the increased incidence has been followed by an increased mortality rate, which might be mainly attributed to a delay in diagnosis and institution of a suitable therapy. Among the units of the Brazilian Federation, the mortality by neoplasms presents large variations that, in addition to reflecting incidence, relationship with the risk factors, ways of life and

quality of information, are influenced by differences in access conditions, use and performance of the health services - important components of the living conditions of the Brazilian population.^{1,5}

It is important to obtain knowledge about the biological characteristics, the skills about breast cancer and the availability of technological resources. For that reason, it is crucial to trace the disease through clinical breast examination held by the physician or the nursing professional (in the course of a routine consultation or not, annually, from the age of 40 years) and the screening by means of mammography (every 2 years, in women between 50 and 69 years old, with no family history). As to the women at high risk, for example, those with family history, clinical examination and mammography are suggested (annually, from the age of 35 years old), as it was recommended in the Brazilian Consensus for combating Breast Cancer performed in the year 2004.¹

The purpose of these screening programs for breast cancer is to identify asymptomatic women (impalpable nodules) or early stage cases of this disease (palpable nodules of up to 2 cm). Thus, the therapeutic resources are, consequently, more effective, enabling less crippling treatments, which are also more likely to control. It should be highlighted that the self-breast examination is no longer recommended by the Brazilian Ministry of Health as an isolated method of tracking. Currently, its recommendation is focused on the self-care.¹

From the foregoing, it is possible to consider breast cancer as a public health problem in Brazil that deserves a special attention and a differentiated approach by a multidisciplinary staff, in order to provide a comprehensive treatment to the patient.

Psychological aspects related to women affected by breast cancer and underwent mastectomy

One of the first concerns of women with newly diagnosed breast cancer is due to the chemotherapy, because of its aggressive and stressful side effects, as well as of generated physical and psychological imbalances.⁶

Another concern is related to the mastectomy, which is one of the procedures to what most women with breast cancer is underwent, whose consequences might also reach them physically, emotionally and socially. The postoperative of this surgery enables the emergence of several issues throughout the life of women, especially those related to their self-image.⁷

The plastic surgery of the breast is recognized by the psychological and esthetic benefits, resulting in a better life quality for women who make that choice. The knowledge received during the preoperative period is important, by reflecting the relationship that is established between the client and the health care team, contributing to the identification of potential problems during the period of illness and surgery.⁸

Since the health-disease process involves not only the biological questions, it becomes important having knowledge by the nursing professional about the psychological aspects experienced by the woman subjected to a mastectomy surgery. Thus, with a view to providing a quality care, this professional should be trained not only to conduct technical and biological aspects of breast cancer.

The nursing role in the care of women who underwent mastectomy

In relation to the health care professionals, it is essential to emphasize the importance of nurses who value the clinical examination as a non-isolated strategy for early detecting the breast cancer. This is because the frank approach of problems with the patients allows them to express their fears and values that, often, prevent adhesion of the practice of health promotion and prevention. The participation of community members in educational activities might be one of the strategies for the information and dissemination of control measures of breast cancer.¹

The actions of the interdisciplinary team are started through the diagnosis, and they have a joint action to women and their social core. The interventions aim to gather the knowledge of occupations, favoring the return to physical, social and professional activities in the best possible way. The nursing is one of the most important occupations that integrates this team.⁵

The multidisciplinary team should consider as important the issues that might emerge at different times of the treatment, but an important situation is the phase prior to the mastectomy. In the preoperative, through the nursing consultation, the nursing professional identifies problematic situations to treat them before the surgery. In the postoperative, one should assist in the rehabilitation whose self-image changes might result in trauma related to physical, emotional and social aspects, influencing in the prognosis in a negative manner.⁹

The nurse should also possess communication skills to promote a better adaptation to the disease and the treatment. Importantly, the effectiveness of communication significantly favors the elaboration, the planning and the implementation of a quality care; besides creating bonds. Nevertheless, there are difficulties regarding the implementation of an effective communication, due to the lack of time, personal limitations of women and nurses, besides the unpreparedness of some nursing professionals to make this practice possible. Accordingly, one of the ways to reverse this situation is the continuous process of professional training.¹⁰

Another important role of the nursing professionals is to participate in the supportive groups, where supports for the growth, development and exchange of experiences are offered to women. Thus, it is possible to bring relevant contributions in the health promotion and rehabilitation, offering a comprehensive and humanized care.⁶

In the construction of the support group, the dialogue contributes to the deconstruction of myths and construction of new knowledge and positive attitudes before the breast cancer. The ways of group conduction enable the development of the collective responsibility in relation to the health of the group participants. This space aims at strengthening the self-esteem and the social reintegration, allowing professionals to get a community approach, thereby contributing to the development of the relationships. It is believed that by searching for a space that aims at stimulating the exchange of experiences, one should foster the self-awareness, as well as prepare these women for experiencing their daily lives in a more positive manner.¹¹

METHODOLOGY

The study is a Systematic Literature Review (SLR) that aims not only to solve evidence-based clinical problems, but also describe studies/surveys of nursing education, in a given period, seeking to gather skills related to a specific topic.¹²

We have opted for this type of research, because it allows the survey, the critical analysis and the synthesis of records related to the chosen theme found in the literature. Furthermore, it allows the quantification of existing studies and the identification of knowledge gaps in certain areas. For its preparation, we have followed the steps stipulated by Galvão, Sawada and Trevizan, with regard to the construction of a SLR, namely: the protocol construction; the definition of the guiding question of the study; the search for studies; the selection of studies; critical assessment of studies; and the synthesis of data.¹³

Thus, initially, we built up a protocol for the research with the goal of assuring that the review was conducted with the rigor of a research. For this purpose, we have used the protocol components suggested by Galvão, Sawada and Trevizan, namely: the question of the review, criteria for inclusion and exclusion; strategies to seek researches; mode of critical assessment of the researches; mechanism for collecting and synthesizing data.¹³

The second step corresponded to the definition of the guiding question, which is: “How does the woman who underwent mastectomy realizes the relationship with their social group after surgery?”.

In the third step, we performed the search of studies published in the period from 2000 to 2009, through the selection of papers related to the issue at stake. For this purpose, the papers were selected from the electronic search of the databases manager belonging to the Virtual Health Library (VHL), the SciELO database and the data of the Brazilian Journal of Oncology.

In the fourth step, we selected studies from the following inclusion criteria: belonging to the database manager of the VHL, SciELO or Brazilian Journal of Oncology databases; having one of the designed descriptors (mastectomy and self-esteem or mastectomy); having full-text papers in Portuguese; published in national journals in the period from 2000 to 2009; not duplicated and that were fitted to the context of the monograph. It is noteworthy that it was not necessary to use the descriptor for the selection of papers in the case of the Brazilian Journal of Oncology, because it does not have descriptors in its database.

In the fifth step, we performed a critical assessment of the selected studies with regard to their methodology and appropriateness to the objectives, achieved results, and conclusions.

The sixth step corresponded to the phase of data collection, where each selected paper was submitted to an analysis with the aid of an tool specifically designed for this purpose, in order to assure that all information pertaining to the study were obtained; reducing the risk of errors during transcription; guaranteeing accuracy in checking the data; and, finally, serving as a record. For this purpose, we have applied a relevancy test. This test was elaborated with the aim of bringing out the most significant data to answer the guiding question.

From that, we drew up tables to distribute the papers obtained by means of databases in the period from 2000 to 2009. In total, 15 papers were selected for the systematic literature review.

In the last phase of the review, we conducted a synthesis of the data by means of a descriptive analysis, in order to provide an assessment of the effectiveness of the investigation.

RESULTS AND DISCUSSION

The results were obtained from the analysis of the selected papers. We have used a form that served as a relevancy test for each paper. The results also sought to answer “How does the woman who underwent mastectomy realize the relationship with her social group after surgery?”.

It was found that the issue of social coexistence, the record of the perception of the woman who underwent mastectomy and the approach of the nursing role during the care are observed in most of the analyzed papers.

Thus, in relation to the social coexistence, it was observed that the family was identified as social support network of the woman who underwent mastectomy, before, during and after surgery, constituting, therefore, an important element in the experience of breast cancer.² This might be evidenced in the speeches extracted from one of the papers:

My whole family was important. All of them prayed for me. (Adália)^{6:22}

My daughter was the one who assumed my house, being that she was very young at that time, but she was my angel. (Rosa)^{6:22}

On the other hand, after mastectomy, women might present many obstacles when trying to resume her social life. Such obstacles begin already within the postoperative period, noting that, with the resumption of social relationships, concerns regarding their own bodies might be raised up. With this resumption, women are faced with the reality, reassessing and reworking their different ways to relate to their own bodies and with other people, such as, for example, their sexual partners, besides reassessing their potentialities.¹⁴ This might be proved by the following statements extracted from the analyzed papers:

You get afraid to look at the mirror, and the image is really scary, since you are deficient. (Vera)^{14:160}

When I was at the time of chemotherapy, when the hair falls, it's horrible! I went to the front of the mirror and began to cut it. The hair has a great meaning. (Maria)^{14:160}

After mastectomy, women might present many obstacles when trying to return to their sex, family and social lives. Although there is a security status before the discovery of breast cancer, factors such as pain, emotional stress, body image change and low self-esteem will emerge. Accordingly, it was noted that the difficulties related to the situation require family support, relational restructuring, patience, and differentiated dedication from a society that places too much emphasis on the appearance. Thus, the reaction of the partners will interfere with the recovery of the body and sexual identity, besides the restoring itself of these women.¹⁵ This might be proved by the following stretches extracted from one of the papers:

My husband and my kids are everything to me. He (her husband) was very good, supported me and gave me strength. It was he who went with me to all places, to the doctor's office, to the vaccine (chemotherapy) and to the light bath (radiotherapy). (Flor)^{6:22}

However, new roles might be performed as a way of adaptation after mastectomy, becoming relevant having the presence of social support for the performance of these roles. The new assignments require special qualities, which are obtained through skills, efforts and, mainly, by the interaction with other people, being quite significant.⁶ This might be proved by the following stretches extracted from one of the papers:

I grew a lot. Today, I make money selling jewelry that I learned to do here in the group (GEPAM). (Violeta)^{6:22}

Before, I was just a housewife. Today, I sell jewelry and straw bags. I earn much more than selling my clothing. (Flor)^{6:22}

Some partners of women who underwent mastectomy offer support, not expressing discomfort with the lack of the breast, even during sex intercourses. However, some move away from the time of diagnosis of breast cancer, generating insecurity. This situation makes many women opt for seeking an immediate breast reconstruction, whether for simple satisfaction of the spouse, for avoiding the prejudiced gaze by the society or for re-recognizing their femininity.¹⁶ This might be proved by the following stretches extracted from one of the papers:

Not for my husband, but it was bad for me, I already remained using a small T-shirt; for example, when I was wearing a baby doll or a nightdress, I didn't take away the top. He touched on my normal breast, because here there was nothing for him to touch, it was smooth (...) he saw it as a normal thing, that condition has not changed anything for him, okay? For him, it made no difference, could also remove the two that, for him, such a condition didn't make no difference. (Elza)^{14:161}

He stayed with me, but, soon after, we ended up, of course!(emphasizes), but, he did not come to talk to me why he did not accept, could not live with me due to this problem and said to my sister that I did not deserve this! (cried) (Júlia) ^{14:161}

I cannot stop thinking about the plastic surgery; we are born perfect and die with defective. ^{7:302}

With the prosthesis, we feel like a woman again. ^{7:303}

Despite the impact that a disease like the breast cancer provokes in people, it was observed, in most families, the presence of loving relationships, besides a greater security in the union, seeking a better confrontation of the problem. The type of reaction of people is associated with the level of family's relationship prior to the disease, i.e., the disease will be a contributing factor to the interpersonal relationships within the family context, making them stronger or weaker.³

With regard to the registration of the perception of women who underwent mastectomy, we have found that the most commonly awakened feelings are: fear, rejection, guilt, powerlessness, self-loathing and loss, since the breast is defined as a symbol of femininity, sexuality and motherhood. This is because the experience of breast cancer is wide and covers different times, with different meanings, implications in daily life and in relationships between women and people belonging to their social context. These meanings deeply affect the way in which the women perceive their illnesses and the responses of other people in relation to their new condition.^{2,15} This might be proved by the following stretches extracted from one of the papers:

It takes a piece of our body; I felt strange after surgery. ^{7:301}

I feel strange, I miss my breast when I look at the mirror...; when we strip our clothes and see that we no longer have one breast, it is tough. ^{7:302}

There's no way to escape surgery; I'm afraid of cancer because it can go to anywhere in the body; you must do what you think that is better, you are the only who know; I cannot stop thinking about the disease. ^{7:302}

With regard to the admission, there are reports that many women believed that the period of dependence in relation to the care of other people would be something normal and, after resume their lives, normally could assume their roles. Nonetheless, they found difficulties:⁷

When I got home, I came across the problem of not being able to do all home services. ^{7:303}

The arm, when I make efforts, it hurts, it is very swollen. ^{7:303}

Regarding the approach to the nursing role in caring of the woman underwent mastectomy, it was found that this treatment is one of the most accomplished, given that it could lead to results that would emotionally, physically and socially commit them. Such concerns are related to the care to this clientele in an individualized and comprehensive manner, especially in their daily lives. Before this situation, it becomes relevant to produce nursing interventions with the aim of contributing to the maintenance of life and its integrity, besides assisting in living with their own bodies and with other people.⁷ This might be proved through the following stretches:

I'm glad you came here to hear me, because we're nervous, and people who come here say that it's all right, that this is really like this, there are people who have had surgery 10 years ago. Then, I stop and wonder, but what about me, no one will listen to me? ^{7:304}

That's very good! You're here for me to talk to you, so you can talk about all this matters, do you know? ^{7:304}

To perform a comprehensive and individualized care, it should be emphasized the importance of the nursing to try to rescue the concept that the woman who underwent mastectomy has about herself, and, from that, to hold more qualified interventions.¹⁵

Some examples of interventions are: offering supportive information; supplying some opportunities for women to report and share their doubts; providing comfort and tranquility; stimulating the women's participation in group activities; encouraging the contact with their social network and stimulating the expression of feelings of these women towards the other people.¹⁷

The nursing work is of utmost importance for that the experiences of women subjected to mastectomy are mitigated and faced in the less traumatic possible way. However, nurses have been produced little with regard to care strategies that contribute to a better life quality of women who underwent mastectomy, highlighting the group activities as the main identified strategy.¹⁶

As to the group activities, there are results pointing their effectiveness for the patient with cancer, in order to improve the psychosocial adjustment before this disease. Furthermore, the support group allows the exchange of experiences among women with breast cancer, favoring the confrontation of this disease and of their uncertainties.² This might be proved by the following stretches:

*Here, they teach us a lot, teaches us to take care of ourselves. I come to participate in the courses, the speech of the people who always come here. Here, there also has some classes, we learn a lot about this disease, which relieves us a little in relation to the fear, and new people always come here.*¹⁸

*Meeting other women who had the same problem, this fact alone helps a lot. I needed to live together with people who had the same problem as me, in order to feel safer, after all. I improved a lot when I joined to the group, I felt more useful, now I can help other people.*¹⁸

Importantly, at the time of insertion in support groups, these women feel isolated and embarrassed, especially in talking about their obstacles related to health, disease, body image, family and society. They search for help not only in the support groups, but especially in the family, health care services, associations, among others. However, there are factors that can prevent their entrance, such as, for example, the physical, social and economic implications.¹⁸ This might be proved through the following stretches:

This disease has only one solution, God plus the love of people. (Violeta)^{6:23}

It was at the time of my illness that I got in a prayer group in my parish. God is everything, the rest comes after Him. (Jasmim)^{6:23}

It was also observed that the nursing care in oncology has evolved a lot, being that the tasks of the nursing professional in the current days are: caring with quality; providing psychosocial support; offering the recommended therapy; helping with the rehabilitation; and providing comfort and individualized care. This is because the women who underwent mastectomy, when are in daily contact with the nursing procedures, feel more secure and have a desire to share their uncertainties, ideas, sorrows and anxieties. At this point, they have the desire to receive a support for coping with the disease and its treatment.¹⁹

One of the main goals of the care to women who underwent mastectomy is to allow a recovery not only in relation to the health of the body, but, above all, to recover the unity of the person and its social identities affected by disease and the mutilation. It is suggested having an understanding of the whole process (from diagnosis of breast cancer until the mastectomy itself), looking at the experiences of these women with sights to assimilate the elements that define and characterize them.^{20,2}

Whereas the situation of disease and the mastectomy might affect the interpersonal relationships within the family environment, it also becomes convenient having an interdisciplinary care towards the family. This might be developed by deepening the knowledge about family relationships, besides the approach of actions that include aspects related to the family, not being limited to the postoperative event.^{3,21}

Therefore, for the interdisciplinary team, the goals should be guided by the strategies for dealing with the problem. This means to strengthen the coping strategies that facilitate the coexistence with the problematic situation, as well as to help the woman and her family to transform or abandon those actions that are ineffective for them both. On the other hand, the focus of attention of the professional should be the woman who underwent mastectomy, who, after breast surgery, usually presents changes in her self-image and, consequently, a change in her perception.²²⁻²³

CONCLUSION

For the study, we have selected 15 papers coming from the manager of the VHL database, the SciELO database and data of the Brazilian Journal of Oncology. The follow-up of the survey took place from steps for the elaboration of a SLR.

With that in mind, it is believed that the objective was achieved, as it was possible to analyze the perception of women who underwent mastectomy due to breast cancer about their relationship with their social group. In addition, we have observed the relevance of the nursing role in the care to the woman with breast cancer who was subjected to mastectomy, as well as the question of social coexistence of this woman.

The survey results showed a greater unity in the majority of the analyzed texts and, consequently, a better confrontation of the situation. It was found, however, that there are situations in which the opposite might happen, since there are no understanding and comprehension of the experienced situation. The survey has also revealed that the dialogue among the people considered important by the woman contributes to the treatment and the perception of her situation.

Regarding the nursing care, this study has brought contributions, because we sought to expose data that improve the care to be differently provided. Importantly, the nursing action should not be restricted to technical skills, but also covers the communication process, highlighting the importance of support groups.

With regard to the contribution to the scientific community, we have identified records where knowledge gaps were observed in the SLR modality, demonstrating a possible misunderstanding about this method that is destined to synthesize skills from researches; highlighting evidence-based nursing results; or synthesizing research expertise.

For the teaching, it has brought an updated synthesis of the knowledge produced and made available to the academic community about the issue at stake. Therefore, it represents an important contribution and indicative for future studies.

We conclude that it is extremely relevant having further qualification in the nursing care in oncology, in order make these professionals more able to actively participate in the treatment and the rehabilitation of oncological women, guiding about the possible side effects of therapies in a proper way; removing doubts; assisting in the exposure of fears and anxieties; and also supporting the social core of these women.

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Endereço de contato dos autores:

Fabio Fortes de Araujo

Rua sem nome, 00 - Rio de Janeiro - Cep 20000-00

