



ATTENDANCE AND SUPPORT: STRATEGIES TO HELP THE WIFE TO FACE BREAST CANCER

PRESENÇA E APOIO: ESTRATÉGIAS PARA AJUDAR A ESPOSA A ENFRENTAR O CANCER DE MAMA

PARTICIPACIÓN Y APOIO: ESTRATEGIAS PARA AYUDAR A LA ESPOSA A CARA EL CÁNCER DE MAMA

Eleandro do Prado¹, Josane Rosenilda Costa², Diego Raone³, Debora Cristina Barbosa⁴, Catarina Aparecida Sales⁵, Sonia Silva Marcon⁶

ABSTRACT

Objective: to learn from the perspective of women with breast cancer, how do they and their spouses face the disease and its repercussions in their daily lives. **Method:** an exploratory and descriptive study, conducted with eight women in cancer treatment. Data were collected in August and September/2015, through semi-structured interviews and analyzed qualitatively. Previously approved by the Research Ethics Committee from the Superior Studies Center in Apucarana, under Protocol nº 1.281.824. **Results:** from the content analysis emerged three categories that allowed understanding that receive the familiar support, mainly from the husband is fundamental to those women. **Conclusion:** This study revealed that marital support makes the experience with this disease less traumatic. The results prompted a reflection on new approach possibilities for this binominal, and encourage further studies aiming the spouse inclusion, as part of the treatment, who plays a key role in facing strategies. **Descriptors:** Breast Cancer; Family Relationships; Adaptation Psychological.

RESUMO

Objetivo: apreender, na perspectiva de mulheres com câncer de mama, como elas e seus cônjuges enfrentam à doença e as repercussões deste no seu cotidiano. **Método:** estudo exploratório e descritivo, realizado com oito mulheres em tratamento oncológico. Os dados foram coletados em agosto e setembro/2015, através de entrevistas semiestruturadas e analisadas qualitativamente. Previamente aprovada pelo Comitê de Ética em Pesquisa do Centro de Estudos Superiores de Apucarana, sob o Protocolo, nº 1.281.824. **Resultados:** da análise de conteúdo emergiram três categorias que possibilitaram compreender que receber o apoio familiar, principalmente do marido é fundamental para essas mulheres. **Conclusão:** este estudo revelou que o apoio conjugal, torna a vivência com essa doença menos traumática. Os resultados instigaram a reflexão sobre novas possibilidades de abordagem a esse binômio, e fomentam novos estudos, que visem a inclusão do cônjuge, como parte integrante no tratamento, o qual assume um papel fundamental nas estratégias de enfrentamento. **Descritores:** Câncer de Mama; Relações Familiares; Adaptação Psicológica.

RESUMEN

Objetivo: aprender de la perspectiva de las mujeres con cáncer de mama, como ellas y sus cónyuges enfrentan a la enfermedad y sus repercusiones en sus vidas diaria. **Método:** estudio exploratorio y descriptivo, realizado con ocho mujeres en el tratamiento del cáncer. Los datos se recogieron en agosto y septiembre/2015, a través de entrevistas semiestructuradas y analizados cualitativamente. Previamente aprobado por el Comité Ético de Investigación del Centro de Estudios Superiores de Apucarana, por el protocolo nº 1.281.824. **Resultados:** de los análisis de contenido emergieron tres categorías que permiten comprender que recibir apoyo de la familia, especialmente del marido es crucial para estas mujeres. **Conclusión:** Este estudio reveló que el apoyo del cónyuge, hace que la experiencia con esta enfermedad sea menos traumática. Los resultados provocaron una reflexión sobre las nuevas posibilidades de enfoque para este binomio, y promueven a otros estudios, dirigidos a la inclusión del cónyuge, como parte del tratamiento, que desempeñan un papel clave en las estrategias de afrontamiento. **Descriptores:** Cáncer de Mama; Las Relaciones Familiares; Adaptación Psicológica.

¹Nurse, Master Graduate Program of Nursing, State University of Maringá/ UEM. Maringá (PR), Brazil. E-mail: leandro_unicentro@yahoo.com.br; ²Nurse, Master Student, Graduate Program in Nursing, State University of Maringá / UEM. Maringá (PR), Brazil. E-mail: josanerc@gmail.com; ³Nurse, Master Student, Graduate Program in Nursing, State University of Maringá / UEM. Maringá (PR), Brazil. E-mail: enf.debora@ig.com.br; ⁴Nurse, Providence Hospital Intensive Care Sector. Apucarana (PR), Brazil. E-mail: raonediego@gmail.com; ⁵Nurse, PhD in Nursing, titular professor, Graduate Program in Nursing, State University of Maringá / UEM. Maringá (PR), Brazil. E-mail: casales@hotmail.com; ⁶Nurse, PhD in Nursing, Full Professor, Graduate Program in Nursing, State University of Maringá/UEM. Maringá (PR), Brazil. E-mail: soniasilva.marcon@gmail.com

INTRODUCTION

Breast cancer can occur in both sexes, but it is the most prevalent cancer in women, with the exception of the non-melanoma skin tumors, accounting for a quarter of all cancers diagnosed in women and the first cause of death among them.¹ The epidemiological characteristics lead most studies related to breast cancer to primarily focus on the diseases and patients.²

Receiving the diagnosis of a disease like cancer, which in the popular imagination is often associated to suffering and death, causes a large impact to patients and their family. So, in front of the diagnosis, women often have difficulties in social and familiar relationships³, producing a devastating effect on their life, causing disturbances in their everyday life organization and in the roles distribution within family and partners.⁴

However, the number of people affected by this diagnosis certainly exceeds the number of patients, because family members, friends and even same co-workers suffer directly or indirectly with this situation. Considering this statement, we see that we unfortunately know just a little about a diagnosis of breast cancer consequences to family, friends, and loved ones.²

Entering the family context, a member who deserves special attention is the spouse of the women with breast cancer. Because him, despite seeing cancer as a threat to his mate's life, he also needs to provide emotional and structural support to her. However, it may be that he does not have sufficient and appropriate emotional resources to deal with the situation.³

In this context, they need to resume their commitments, formally or informally, to keep themselves together in health or disease. So the mate in an almost imposed situation, assumes the caregiver role, helping them not only in their physical needs, but also providing care, attention and emotional support.⁵

The Ignorance of the related reactions to the breast cancer weather takes the spouse to feel hopelessness, helplessness, unrest and fear among many other possible feelings that undermine their own life, the offered support, the family and affective relationship, as well as the support and care to the sick woman.^{3,6-7}

Although the primary objective is to get the treatment and be healing, concerns related to these issues, also take account of the women's thought, emerging doubts about the future, mutilation, and especially the fear of being stigmatized or rejected by their

husband. Thus, the living with the spouse, can be permeated by some changes that involve the ways of how do women see their companions, as well as the way that they see their wives, this is a major step that requires attention so that the balance between them is not very affected.³

Considering this binomial's vulnerability conditions and facing the challenges posed by the disease's diagnosis, arises this study guiding question: How is it for the couple, to live with the disease and its consequences in family and marital daily.

In this sense, this study's objective to learn from the perspective of women with breast cancer, how do they and their spouses face the disease and its repercussions in their daily lives.

METHOD

This study consists of a qualitative and descriptive research⁸. It was conducted with eight women who underwent to treatment for breast cancer in an oncology clinic in a philanthropic hospital located in northern Parana State.

Data were collected in August and September 2015, through semi-structured interview, using a script including questions about the diagnosis period, treatment and its physical effects on marital relationship before and after diagnosis.⁸ Participated in the survey, women with breast cancer treatment, facing with their spouse the anticancer therapy.

The choice of the participants followed the following inclusion criteria. Be 18 years or older, be in anticancer treatment for at least three months, have a husband before diagnosis and had remained with him throughout the treatment course.

The interviews were conducted in an institution private room, to ensure the women's privacy and recording quality. Open questions were used, such as: How was for you and your husband to be diagnosed? Was there any change in family or marital life? Regarding the physical changes, how did you deal with them? All of them in order to rescue the feelings, that assisted them during the disease facing and have been raised from their diagnosis, as well as its influence on their marital relationship.

The interviews were recorded on digital media, fully transcribed and analyzed as proposed framework. Data analysis was made through the Bardin thematic analysis methodology, developing it in the main steps: Pre-analysis, careful listening and floating

reading of the collected material; material exploration, where the data were narrowly coded, and finally, the treatment and interpretation of the obtained results.

Aiming to maintain their anonymity, participants were coded with pseudonyms using M1; M2 to M8, according to the interviews chronological order. This study was conducted with the participants' consent by reading and spontaneously signing the Term of Consent considering the ethical and legal principles regulated by the Resolution nº 466/2012 from the National Health Council⁹; after being approved by the Ethics Committee Research Center for Superior Studies in Apucarana, under Protocol nº 1.281.824.

RESULTS AND DISCUSSION

Women with breast cancer in this study are aged between 20 and 75 years old, all are literate, and have at least one child, six are married at the civil marriage and two live together in a stable relationship with their partner. All of them had the presence of their spouses during the treatment, which allowed us to seize and explore the meanings about breast cancer and its implications in married life.

Following are presented the three categories that emerged from the treatment units during data analysis:

♦ The cancer impact on the personal and marital life

Despite scientific advances in medical areas, cancer is still linked to a disease associated with pain and suffering due to the aggressive and mutilating treatments, in addition to its characteristics and high mortality, for these reasons, it has been strongly associated to negative feelings, with many consequences for the patient, because besides the physical suffering, it also brings a moral and spiritual burden, causing intense reformulations in the patient and their family's¹⁰ These prerogatives originated the first category, in which, it was observed that the impact of the breast cancer diagnosis, is associated to the disease discovery and to the fear of death.

Suddenly the first thing that comes to the patient's head is that she may (or will) die due to the disease. Thereby, the moment when they receive the diagnosis is the harder and also the principal moment. The great part of the women thinks they are going to die.

It is not easy (sigh) to receive that news, it looks like a dream, or worse, it looks like a nightmare, it is not just a dream, because the dreams are full of good things and what

I was passing through was a real nightmare. (M1)

It is hard, isn't it? You see others women passing through this problem, but we never see ourselves passing through this, I was scared, frightened and I almost got crazy, thinking this was my end. (M2)

[...] At that time the floor begun to open, we get scared, scared to die. (M3)

It was sad, really sad [...] we think about everything at this time, everything goes on your mind, you don't think about the treatment, you don't think that everything is going to be alright, at that time we think only about the death (M7).

My God, I remember when I heard that it was really a cancer, I was terrified, and for a while I thought I couldn't deal with it, I was terrified (M4)

In parallel to the fear of death also comes the fear of physical changes resulting from the chemotherapy, especially when one breast or both are extirpated. For many, these changes go beyond the bodily changes also reflecting on their social life, including family, friends and work.

Even before the diagnosis confirmation, breast cancer is a precursor of feelings such as fear and anxiety, both on women and on their spouses, being often accompanied by depressive symptoms and life quality changes.¹²

Thus, it is important for those women to feel that they have a network of social support, which does not allow them to give up, making it easier to cope with the disease. Usually the family and specifically their husbands who occupy this place.¹⁴ This support helps them to have a positive confrontation against the disease, and contributes to the patient to not feel alone at this moment.

When I underwent by the first chemotherapies [...] He (husband) was there, if I went to the bathroom, He would after me, He didn't let me do anything, He helped me a lot (M5)

I had a lot of support [...] I hadn't any difficulties, didn't feel helpless, and my kids had always gave me a lot of support [...] with them it was easier (M6) [...] I had him (husband) by my side and a lot of people with me to give me strength, to help me, it was important. (M1).

The reactions expressed by the participants are determined for their personality traits, for the disease stage and for the variables related to treatment and to environmental factors.¹¹ Faith appears in these women's speeches as a shadow of an immense will to live, and as a fundamental impulse to face this battle, being

for many of them the refreshment and breath point.

My strength I took from God, I started to go to the church with more frequency, I think that God didn't send this disease to take my faith but to make it stronger. There are people who do not believe, but I believe in this, you know, and that was what held me (M7)

I've always had a lot of faith and this was what helped me a lot, my friends helped me a lot, they formed a group and came every days to pray for me at the church, this side of the faith was very important for me, helped me a lot, kept me on foot and strong with high astral (M8)

It is noticed in the preview speeches, that even with an intense progress in science around the oncologic treatment, with much technology in science, we have many examples to show that even with a increasing technology in science, they have many examples to show that the faith has still a crucial role on their treatment, that even with an intense scientific progress around the cancer treatment, with so many scientific technology there are many examples to demonstrate that the faith continues to play a crucial role on the patients treatment, being put as a powerful ally to combat the disease, being categorizing as a vitamin supplement that makes the patient feel strengthened.

A Large portion of the studies related to female breast cancer highlighted the physical changes in patients as a broad conflict factor in the couple's relationship. Conflicts arise as change results in the female body, impacting especially on the spouse who in most cases, will become the primary caregiver, as soon as it is with him that the woman shares her intimacy.¹³⁻⁴

In the reports' analysis, we identified that a cancer's impact can be minimized when you have a consolidated supporting network, especially when the support comes from those in which the woman puts her love and trust, their spouses. This support seems to be reassuring and with it, the woman seems to face safely and smoothly the treatment.

♦ The companion presence and support Paramount

Family members who often experience breast cancer, experience a considerable distress since the moment they are faced with the diagnosis and the treatment extends to the chemotherapy or to surgery. However, family members show a large importance in this process, especially spouse.

This family support encourages the women to face the challenges treatment and helps

them to accept more positively the situation, resulting in a better adaptation to the disease process.¹⁰

The union and encouragement are strategies to help the marital balance maintenance. These strategies are manifested through the constant companion presence, thereby strengthening the couple unity and reinvigorating them to cope with the disease.

He's always with me, always coming along; no letting me down (M5).

My husband is helping me a lot, we are having a lot of interaction, since the exams' beginning, [...] He is participatory, gives me strength and is always with me (M1).

Since when we discovered the disease he was always with me, never left me, he is always here with me (M4).

The caregiver's support and affection allow us the stability for the patient to fight against adversity, it is an ongoing hope investment, establishing the conviction of the ability to control the life destiny, providing their emotional necessities and achieving a better acceptance in the diagnosis and treatment.^{10,15} Considering their claims, this study's participants showed in their reports that they have received constantly family support, characterizing them by affection and attention gestures.

♦ The self-image and the marital relationship

A woman with breast cancer experiences during the treatment feelings of loss and adversity symptoms, leading to uncertainties about the future. The fear for the mutilation and especially for abandonment can trigger traumatic effects beyond the disease itself. In addition, women live with the possibility to have an incurable disease, accompanied by discomfort that comes from the treatment, and fear of losing a body part that for them is full of representations.¹⁵

This fear that is triggered, becomes understandable because the body image is closely related to their perceptions, thoughts, feelings and experiences, therefore it is a subjective question, which is constantly determined and socially influenced. In this reality the mastectomy impact, can affect the people' psychosocial in general, and especially of the women who had mastectomies.¹⁶

Many women experience such mishaps as a breast surgery result, the radiotherapy and chemotherapy. Most of them feel invaded in their most intimate dimensions, and will need to rebuild not only their bodies, but the sense and the feeling of "being a woman".¹⁸ Some speeches of the participants shed light on

important aspects regarding these experiences' emotional impact that confront the identity physical core and affect the "feel like a woman":

When I was without breast, I never let him (husband) see it, I always hid it, I didn't accept He seeing me without breast, I didn't let him (M3)

We suffer prejudice, you know, don't you?, the people look at you in a different way, and it hurts, much more in a little city [...] and I stopped doing things that I liked, what I am sorry (M5)

When people saw me bald, they didn't talk about cancer, "ohh, you have that disease", they had a lot of prejudice, wow! (M6)

The mastectomy and the chemotherapy's adverse effects is itself an aggressive and traumatizing character to women's life and health, this impact has just reflected also in their spouses' lives in general, are surprised with this diagnosis, and start to experience uneasiness and the fear of their wives' death, but they tend to stay positive about the prospects.¹⁷ The women in this study reported that their colleagues demonstrated a unconditional support to them in this process, encouraging them in the treatment and self-esteem.

He was with me all the time, the disease didn't change anything, neither in home neither in our routine [...] never treated me as "poor", when He saw me sad, He did everything to see me well (M4)

He always followed me for everything, always with me, He and our son, at the chemotherapy was all my family. (M6)

He cares about my feeding, don't let me to take Sun bath, this and that, I think that is in overkill [...] didn't change anything, He only says that He miss my hair (M2)

Even without verbalizing the suffering, the women reported the spouses' concern in silence, these inhibition strategies of suffering and fears, were emphasized in the speeches, showing that their companions did not verbally demonstrate their feelings in order to protect them.

I know that for him it was much harder, but He always said that it wasn't anything, but I know that for him the blow was intense, was huge (M3)

When He knew, He get despaired, He had asked so much to God to not let this happen [...] He cried a lot, but I consoled him, today he is calmer, but I know that He is still really worried (M2)

It is evident that these speeches that in an attempt to save the patient, the spouses try to act as if there were no problems regarding the diagnosis and treatment. It is evidenced that beyond this impact, some men strive to

be physically present and to support emotionally their wives which usually results in an exaggerated wear.⁴

Although such statements are somehow positives, there is the possibility of changes in the family dynamic, moreover, the experience of living with a woman with breast cancer can be considered as physical and emotional overload factor for the family, considering that the provided care can cause changes in family daily life and structure, being a potential source of stress.¹⁵⁻⁷

CONCLUSION

Opposed to those explanations commonly discussed, about esthetic preferences and "male insensitivity", the results seen herein, showed that the spouse remains beside his wife, and together they seek forces and subsidies to combat the disease.

However the results described in this work is far from being a conventional love history, here the cancer appears as a villain, stealing the protagonists' remnants romanticism, who even without a happy ending guarantee, joined forces to combat this disease, and together, explicit the struggle for life and the strength of joint.

The union experienced by the studied participants revealed that the shared support among them is the best way to face the disease, helping the stress reduction and promoting a better life quality for the woman and her family.

In the participating couples, the illness psychic consequences were associated with terms like: "Worry", "fear", "anguish", aiming to express their feelings, however, in the other hand, terms like "courage", "move on" and mainly "union" were expressive regarding the recovery and the fight against the disease.

This study also revealed, according to the patients that despite their spouses kept present and encouraging, they often feel helpless and alone in this situation, adopting protective attitudes toward their partners, not sharing their anguishes and concerns, what leads us to believe that there is an increased physical and emotional burden on them.

It is noteworthy that this disease affects the entire cycle and familiar structure, so in this context, the spouses were fundamental and participatory, and especially important throughout the breast cancer treatment course. Therefore, it is considered that they also need assistance in their doubt and uncertainty moments, given that they often are the most direct patient's support.

Even with a large number of scientific publications assessing the cancer impact in women's life, it was noted during this work course that there is a lack of studies involving these women's spouses, not including the impact that the disease can also trigger on their lives.

Finally, we emphasize here the importance to involve the whole family, especially the spouse in the treatment process in order to mitigate the disease's effects and negative feelings that it brings, making its impact being experienced in a milder form.

REFERENCES

1. Brasil, MS, Instituto Nacional do Câncer. Estimativa 2016: Incidência de câncer no Brasil [Internet]. 2015 [cited 2016 Jan 20];11:122p. Available from: <http://www.inca.gov.br/estimativa/2016/estimativa-2016-v11.pdf>
2. Hasset MJ. The full Burden of câncer. The Oncologist [Internet]. 2010 [cited 2015 Dec 16];15(ed):793-5. Available from: <http://theoncologist.alphamedpress.org/content/15/8/793.full.pdf>
3. Neris RR, Anjos ACY dos, Experiência dos cônjuges de mulheres com câncer de mama: uma revisão integrativa da literatura. Rev Esc Enferm USP [Internet]. 2014 [cited 2016 Jan 14];48(5):922-31. Available from: http://www.scielo.br/pdf/reeusp/v48n5/pt_0080-6234-reeusp-48-05-922.pdf
4. Guimarães AC, Lipp MEN. Um olhar sobre o cuidador de pacientes oncológicos recebendo cuidados paliativos. Psicologia São Paulo [Internet]. 2011 [cited 2015 Dec 16];13(2):50-62. Available from: <http://pepsic.bvsalud.org/pdf/ptp/v13n2/v13n2a04.pdf>
5. Anjos ACY dos, Zago MMF. Ressignificação da vida do cuidador do paciente idoso com câncer. Rev Bras Enfem [Internet]. 2014 Sept-Oct [cited 2016 Jan 20];67(5):752-8. Available from: <http://www.scielo.br/pdf/reben/v67n5/0034-7167-reben-67-05-0752.pdf>
6. Blum k, Sherman DW. Understanding the experience of caregivers: a focus on transitions. Semin Oncol Nurs [Internet]. Nov 2010 [cited 2015 Dec 16];26(4):243-58. Available from: [http://www.seminaroncologynursing.com/article/S0749-2081\(10\)00052-5/pdf](http://www.seminaroncologynursing.com/article/S0749-2081(10)00052-5/pdf)
7. Bardin L. Análise de Conteúdo. São Paulo, 70ªed. 2011.
8. Brasil MS, Resolução Conselho Nacional de Saúde nº 466. Brasília, DF, Gabinete Geral do Ministério da Saúde [Internet]. 2012 [cited 2015 Dec 16]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html
9. Nascimento AN do, Castro DS de, Amorim MHC, Bicudo SDS. Estratégias de enfrentamento de familiares de mulheres acometidas por câncer de mama. Cienc Cuid Saude on line [Internet]. 2011 [cited 2016 Dec 2015 18];10(4):789-94. Available from: <http://periodicos.uem.br/ojs/index.php/CienCuidSaude/article/view/18324/pdf>
10. Almeida TR de, Guerra MR, Filgueiras MST. Repercussões do câncer de mama na imagem corporal da mulher: uma revisão sistemática. Physis [Internet]. 2012 [cited 2016 Jan 14];22(3):1003-29. Available from: <http://www.scielo.br/pdf/physis/v22n3/09.pdf>
11. Cecilio SG, Sales JB, Pereira NPA, Maia Netto LLQC. A visão do companheiro da mulher com histórico cancer de mama. REME rev min enferm on line [Internet]. 2013 Jan/Mar [cited 2016 Jan 22];17(1):23-31. Available from: <http://www.reme.org.br/artigo/detalhes/576>
12. Ramos WSR, Sousa FS de, Santos TR, Silva Junior WR da, França ISX de, Figueiredo CAL de. Sentimentos vivenciados por mulheres com câncer de mama. J Health Sci Inst [Internet]. 2012 [cited 2016 Jan 20];30(3):241-8. Available from: http://www.unip.br/comunicacao/publicacoes/ics/edicoes/2012/03_jul-set/V30_n3_2012_p241a248.pdf
13. Silva G da, Santos MA dos. Estressores pós-tratamento do câncer de mama: um enfoque qualitativo. Rev Latino-Am Enfermagem [Internet]. 2010 [cited 2015 Dec 16];18(4):688-95. Available from: http://www.scielo.br/pdf/rlae/v18n4/pt_05.pdf
14. Ferreira BD, Farago PM, Reis PED dos, Funghetto SS. Nossa vida após o cancer de mama: percepções e repercussões sob o olhar do casal. Rev Bras Enfem [Internet]. 2011 May-June [cited 2016 Jan 14]; 64(3):536-44. Available from: <http://www.scielo.br/pdf/reben/v64n3/v64n3a18.pdf>
15. Comin FS, Santos MA dos, Souza LV e. Vivências e discursos de mulheres mastectomizadas: negociações e desafios do câncer de mama. Estud Psicol (Natal) [Internet]. 2009 Jan-Apr [cited 2016 Jan 20];14(1):41-50. Available from: <http://www.scielo.br/pdf/epsic/v14n1/a06v14n1.pdf>
16. Salci Aparecida M, Marcon SS. Após o câncer: Uma nova maneira de viver a vida. Rev. RENE on line [Internet]. 2011 Apr-June

[cited 2016 Jan 22];12(2):374-83. Available from:

<http://www.revistarene.ufc.br/revista/index.php/revista/article/view/168/77>

Submission: 2016/02/04

Accepted: 2016/06/14

Publishing: 2016/11/01

Corresponding Address

Eleandro do Prado

Rua Rui Barbosa, 714, Ap.013, Zona 07

CEP 87020-090 – Maringá (PR), Brasil