



## REPORT ON THE PERCEPTION OF WOMEN SURVIVORS OF BREAST CANCER ABOUT SELF-CARE

### ORIGINAL ARTICLE

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### ABSTRACT

Objective: to understand the perception of women survivors of breast cancer about self-care and its barriers or facilitators. Method: qualitative study, in which ten women who underwent surgery for breast cancer participated, carried out from May to September 2018, in Juiz de Fora, Brazil. The semi-structured interviews were analyzed using Bardin's Content Analysis, originating the category "*Autocuidado: motivação para a vida*". Results: given the effects of the treatments, the women reported facing a readaptation process, in which they develop coping strategies based on the motivational factors provided by the support network, encouraging the performance of self-care practices. Conclusion: although therapies for breast cancer bring negative impacts on women's lives, they tend to reframe their vision of health care and strengthen affective bonds, fundamental elements for motivation for self-care and continuity in the trajectory of combating cancer.

Keywords: Self-care, Breast neoplasm, Women's health.

## 1. INTRODUÇÃO

Cancer is considered a worldwide health problem, especially in developing countries, with breast cancer being the type with the highest incidence and mortality in females. Its incidence is 23 million (11.7%) of new cases in the world, followed by lung cancer



(11.4%), colon and rectum (10.0%) and prostate cancer (7.3%). Looking at the Brazilian scenario, according to the *Instituto Nacional do Câncer* (INCA), for the three-year period 2023-2025, 73,610 new cases of breast cancer are expected to occur per year (BRASIL, 2022).

Among the risk factors, the Ministry of Health (BRASIL, 2022) highlights genetic aspects and family history, reproductive and hormonal factors (nulliparity, non-breastfeeding, early menarche, among others), as well as environmental and behavioral factors (exposure to ionizing radiation, alcoholism, smoking, sedentary lifestyle, inadequate diet), these factors being considered modifiable. The main forms of treatment are surgery, which can be partial removal (segmental mastectomy) or total breast removal (mastectomy), with or without removal of axillary lymph nodes, as well as radiotherapy, chemotherapy and hormone therapy (BRASIL, 2020). The therapies are considered traumatizing and can cause sequelae that affect various aspects of women's lives (OLIVEIRA *et al.*, 2019).

Self-care was a concept inserted from the theory of Dorothea Orem, being defined as decisions and strategies that the individual develops with the purpose of maintaining life, health and well-being, with the intention of making him/her participatory and responsible for their own health (SILVA *et al.*, 2020).

In addition, the body is seen as an important factor for the individual's inclusion in society, with the breasts characterized as: femininity, sexuality, beauty and bond with motherhood. Changing this region of the body affects body image, generating anguish and depression (ALMEIDA; FILGUEIRAS, 2018; JURADO *et al.*, 2019; OLIVEIRA *et al.*, 2019). Thus, in the case of women undergoing mastectomy, whether total or partial, they felt mutilated, with a decrease in self-esteem and a feeling of femininity (OLIVEIRA *et al.*, 2019).

With the social and emotional impact of breast cancer treatments and their side effects, women prefer to remain reclusive, avoiding social interactions (ALMEIDA; FILGUEIRAS, 2018). They start to face other sources of suffering, which generates the need for changes in daily life, reorganization of the female role and a family



restructuring regarding domestic and professional activities (CARVALHO *et al.*, 2018). The deficit in functionality can result in the abandonment of some daily activities under the dimensions of self-care, domestic activities, entertainment, leisure, work and social participation, causing a feeling of incapacity and affecting the quality of life (LIZE *et al.*, 2021).

Therefore, for self-care to be carried out, it is necessary to awaken the individual to the need to carry out activities aimed at care in situations of fragility of health and disease, such as breast cancer (MACHADO; SOARES; OLIVEIRA, 2017 ). To face the situation, women adopt strategies, such as religious belief and faith, or even the insertion of a routine of physical or therapeutic exercises, namely physiotherapy and participation in support groups, factors that demonstrate the disposition for carrying out activities of daily living and reducing functional limitations, favoring care for one's own health (DIAS *et al.*, 2017; CARVALHO *et al.*, 2018).

Thus, a measure that can help promote self-care is the development of motivations and strategies, carried out by health professionals, aimed at raising awareness that each individual is responsible for knowing their needs, changing their habits (BRASIL, 2020).

Given these assumptions, the objective was to understand the perception of women who survived breast cancer about self-care actions, and the factors that facilitate or hinder their implementation.

## 2. METHOD

This was an exploratory descriptive study, with a qualitative approach, developed at the physiotherapy clinic of the teaching hospital of the *Universidade Federal de Juiz de Fora*, located in Juiz de Fora, Minas Gerais, carried out between May and September 2018. The sample consisted of intentionality, composed of women with breast cancer. The following were included: women who underwent mastectomy (total or partial), with or without breast reconstruction, aged over 18 years. Those with any cognitive impairment that interfered with data collection were not included. Data were



collected through individual interviews with a semi-structured script, recorded and transcribed. The script consisted of personal identification data, such as, for example, name, address, age and education, as well as questions about health habits, knowledge about breast cancer, possible complications of treatments, lifestyle habits related to health and self-care related to protective factors for breast cancer or aggravation in the illness situation. The script went through experts in the health area and was tested, prior to the research, with women affected by breast cancer, but who would not be part of the study.

This article is part of the research entitled “*De peito aberto: percepção das usuárias e da equipe sobre o adoecimento, o tratamento e assistência no câncer de mama*”, already approved by the ethics committee. Recruitment began through direct contact with the women at the outpatient clinic, with a view to inviting them to participate in the research. The interviews were scheduled individually and held on the premises of the hospital. During the reading of the Term of Free and Informed Consent (TCLE)[7], doubts were resolved, clarifying the research objectives and the option to participate or not in the study. Data collection ended with 10 interviews. The recurrence and complementarity of information was observed, reaching a saturation criterion to respond to the research objectives. Bardin's Content Analysis was applied, including three stages: pre-analysis; exploration of the material; and treatment of results, inference and interpretation (BARDIN, 2020).

The project was approved by the Research Ethics Committee of the *Universidade Federal de Juiz de Fora* (Opinion No. 1,047,539), observing the ethical aspects of the investigation, in accordance with Resolution No. 510, of May 27, 2016, of the National Health Council/Ministry of Health. It should be noted that, upon acceptance to participate in the research, the TCLE was signed, with one copy remaining with the responsible researcher and the other with the research participant. For the privacy of the participants, it was decided to identify them by the letter “E” (interview), followed by Arabic numerals (E1, E2, E3, for example), according to the occurrence of the interviews.



### 3. RESULTS AND DISCUSSION

#### 3.1 SOCIODEMOGRAPHIC AND CLINICAL PROFILE OF THE PARTICIPANTS

Regarding the sociodemographic data of the research participants (Table 1), it was found that the age group ranged from 47 to 70 years, with a predominance of white color/race (70%). As for education, 60% of the participants had completed high school. As for marital status, 30% were married, 20% divorced, 20% widowed, 20% in a stable relationship, and 10% single. As for religion, 90% of the women reported being practitioners, with the prevalence of the Catholic religion (70%).

Table 1. Sociodemographic profile of participants

	Age	Education	Color/Race	Children: Age	Situation marital	Family Composition	Income*	Religion
E1	62	incomplete fundamental	White	Three: 40/40/36 years old	Widow	1 person	1 minimum wage	practicing Catholic
E2	53	Complete Elementary	White	One: 26 years	Single	2 people	3 minimum wage	practicing Catholic
E2	49	incomplete fundamental	black	Two: 21/14 years old	Married	3 people	3 minimum wage	practicing Catholic
E4	60	Complete high school	brown	One: 16 years	Married	3 people	3 minimum wage	Practicing Evangelical
E5	48	Ensino médio completo	White	One: 23 years	Married	3 people	3 minimum wage	Practicing Evangelical
E6	48	Complete primary education	Yellow	One: 18 years	Divorced	3 people	1 minimum wage	Non-practicing Catholic
E7	70	Complete high school	White	Two: 45/35 years	Divorced	1 person	1,5 minimum wage	Practicing Catholic



E8	47	Complete high school	White	Two: 25/20 years	Stable union	3 people	3 minimum wage	Practicing Catholic
E9	58	High school	White	Two: 34/28 years	Widow	3 people	1 minimum wage	Practicing Catholic
E10	39	Complete high school	White	None	Stable union	1 person	2,5 minimum wage	Has no religion

\*Salt. minimum = minimum wage in force in November 2018.

Source: author himself.

With regard to the clinical profile of the research participants, in relation to the duration of surgery, there was a variation from 1 to 20 years, with a predominance of total mastectomy (90%). All participants underwent axillary dissection and only 30% reported not having undergone breast reconstruction. All interviewees needed complementary therapies to surgery: chemotherapy (70%); radiotherapy (40%); and hormone therapy (90%), many of which were combined therapies (Table 2).

Table 2. Clinical profile of participants

	Type of surgery	Surgery time	Breast Reconstruction	Complementary therapies to surgery
E1	Total Mastectomy	8 years	Não	Chemotherapy / Hormonal Therapy
E2	Total Mastectomy	5 years	Yes	Chemotherapy / Hormonal Therapy
E2	Total Mastectomy	5 years	Yes	Hormone therapy
E4	Total Mastectomy	7 years	Yes	Chemotherapy / Radiotherapy
E5	Total Mastectomy	10 years	Yes	Chemotherapy / Hormonal Therapy
E6	Total Mastectomy	5 years	Yes	Hormone therapy
E7	Quadrantectomy	20 years	No	Chemotherapy / Radiotherapy / Hormonal Therapy
E8	Total Mastectomy	5 years	Yes	Hormone therapy



E9	Total Mastectomy	5 years	No	Chemotherapy / Radiotherapy / Hormonal Therapy
E10	Total Mastectomy	1 years	Yes	Chemotherapy / Radiotherapy / Hormonal Therapy

Source: author himself.

## 3.2 ANALYSIS OF INTERVIEWS

From the content analysis of the interviews, the category "*Autocuidado: motivação para a vida*" emerged. Throughout the description of the results, each recording unit is exemplified with excerpts from the interviewees' statements.

### 3.2.1 AUTOCUIDADO: MOTIVAÇÃO PARA A VIDA

Analyzing the perspectives of self-care, this emerges as a result of acceptance and maturation of the new scenario imposed by the disease, comprising strategies acquired by women aimed at living in a healthy way, adopting health protection attitudes, from eating healthy and maintaining the mental well-being to practicing physical activities regularly and avoiding lifestyle habits considered harmful to health (MONTEIRO *et al.*, 2021).

Cuidados com a alimentação, exercícios físicos, e o que eu acho que é mais importante, é o exercício psicológico. Manter sempre em alta, sempre em dia porque senão tudo tende a cair (E2).

Tomar muita água, que eu tomo demais. E me alimentar. Eu como comida que eu faço. Eu não como fora. (...). Então eu considero isso saudável. Gosto de legumes. Gosto de frutas (E9).

Among the reports, it is observed that fatigue was highlighted as one of the most disturbing reactions to chemotherapy, accompanied by pain, nausea and changes in body image (FERREIRA; FRANCO, 2019; BARBOSA *et al.*, 2017). According to the study participants, fatigue reduces physical performance, triggers weakness and extreme tiredness, heaviness and slowness, poor concentration and ability to solve problems (LOYOLA *et al.*, 2017; CUNHA, 2018).





Varrer casa... eu tenho dificuldade... que eu sinto que eu vou varrendo e parece que eu canso. Aí eu tenho que parar para depois começar de novo (E6).

To manage the physical effects of fatigue, the women adopted some self-care practices: rest, as physical rest; energy conservation, such as carrying out tasks according to your disposition, limits and priorities; and dietary care, such as the consumption of certain fruits and other foods that alleviate undesirable reactions (CUNHA, 2018).

Agora, tudo que eu fazia, não posso fazer mais igual eu fazia. Eu tenho que fazer mais 'maneirado' e poucas coisas. Capinar eu não posso, né? (E1).

Most women reported still being treated, specifically hormone therapy, pointing to symptoms resulting from this therapy, which, like the others, causes changes in the woman's body, such as hair loss, changes in appetite and body weight (LIZE *et al.*, 2021).

Another limitation often mentioned in the interviews was dysfunction in the arms, especially on the side of the surgery, which can occur due to scarring or lymphedema, among other factors caused by the treatments. These restrictions disrupt the performance of daily tasks and self-care actions (CARVALHO *et al.*, 2018).

O esvaziamento da axila me trouxe várias limitações, por conta de fraqueza nos braços. Eu não consigo torcer um pano. Não consigo, igual eu falei, limpar uma geladeira. Trouxe muitas limitações (E8).

Due to the fragility in which she finds herself due to the illness and treatments, the role of home and family caregiver is often reversed. In general, women find it difficult to understand their role both within the family and in society, which can lead to feelings of incapacity and frustration. The limitations caused by the treatment as a whole interfere with the quality of life of these women, since many daily activities that were previously performed without major difficulties by them, currently, need to be developed with effort. Sometimes, these activities are abandoned or carried out only with the help of other people (DIAS *et al.*, 2017; BARBOSA *et al.*, 2017; CUNHA, 2018).





Olha, o peso eu não pego porque quando eu faço compras, por exemplo, é meu marido quem traz (E4).

Difficulties in carrying out activities of daily living create embarrassment, due to the fact that women do not feel capable of taking care of the home and family. There is also a reduction in the diversity of interpersonal relationships, considering work an environment in which conditions for socialization can be created (CARVALHO *et al.*, 2018; DIAS *et al.*, 2017).

Na mastectomia, a dificuldade do braço é muito grande. Para mexer, fazer o serviço do dia a dia, ainda, é muito grande. É assim... varrer casa, às vezes, eu varro, tenho que parar um pouquinho... igual eu falei a questão de levantar o braço... ainda não é 100%, entendeu? (E6).

The benefits arising from women's participation in groups with professional guidance were highlighted in the reports, demonstrating that, through guidance on cancer, the body and the benefits of health care, there was an improvement in dedication to self-care. In addition to knowing more about the disease and their body, women focus more care on themselves, prioritizing their own lives, evidencing self-care (LOYOLA *et al.*, 2017).

Fritura, evito, não como fritura. Eu não como carne gordurosa. Eu como muita fruta, coisa que eu não comia. Como muita salada, entendeu? Coisa que eu não tinha tempo, porque eu trabalhava, hoje eu paro, eu fiz esse tempo pra mim (E2).

Eu tenho monitorado a minha alimentação. Tem algumas coisas em casa que eu já estou fazendo, com mais cuidado. Eu sempre fui agitada. Depois da cirurgia, eu fiquei um pouco parada. Agora, estou voltando dentro do meu limite, a fazer as coisas (E10).

Even knowing the benefits of physical activity, most women do not adhere to this practice, claiming lack of time or consequential limitations to treatments. However, they report that the presence of a family and professional support network act as motivational factors (CARVALHO *et al.*, 2018).

Ah, eu precisava ficar menos preguiçosa. Estou precisando, urgentemente, de fazer uma caminhada. Começar a animar a fazer a caminhada de manhã (E7).



Eu tenho muito apoio. De profissional, eu tenho apoio. Participo (...) [grupo de apoio]. Tem a psicóloga e a assistente social. Elas são uma bênção na minha vida (E8).

Among the coping strategies used, women try to carry out the guidelines given by professionals and consider carrying out tests and consultations as part of self-care actions. The bond established in the relationships between women and professionals favored adherence to treatment and the adoption of healthier habits (CUNHA, 2018).

Não, eu faço todas [as orientações] que me passam. Nesse tempo todo, tudo que me ensinam, eu faço. Tenho cuidado com o meu braço, com o meu corpo... não pego peso, mais. Não faço nada que vai me prejudicar (E5).

Educational actions aimed at promoting self-care, as well as family and professional support, are essential to welcome mastectomized women in this difficult period (MONTEIRO *et al.*, 2021). An exercise program provides an increase in the feeling of energy, which decreases the feeling of fatigue, tension and depression (LIZE *et al.*, 2021). From this perspective, health education emerges as an interesting tool to minimize complications and suffering and as a motivating element for the implementation of attitudes that contribute to relative autonomy in self-care (MONTEIRO *et al.*, 2021).

On the other hand, some barriers may arise, even in the functions performed by the woman who assumes the role of caregiver and responsible for various domestic activities. She tends to prioritize the needs of other family members to the detriment of her own needs, including health care actions, Carvalho *et al.* (2018), as observed in the following excerpt:

Eu preciso de um pouco mais de tempo para cuidar de mim e da minha saúde... me dedicar mais... então, assim, como no caso da minha mãe... como eu vivo para ela, então meu tempo vai todo para ela. Então, nesse período eu vou esquecendo de mim. Então, quando eu vejo que está acontecendo alguma coisa, quando eu percebo mesmo, já aconteceu. Então, fica muito difícil (E6).

In addition, a change in lifestyle is added as a protection strategy, as it is necessary to add demonstrably healthy attitudes to the routine, such as the practice of physical



activity, balanced diet and socialization, that is, actions aimed at caring for health itself (MONTEIRO *et al.*, 2021). Performing physical exercises during cancer treatment contributed to improvements in psychological, social and physical aspects, thus favoring an improvement in quality of life (LIZE *et al.*, 2021).

Cuidados com a alimentação, exercícios físicos, e, o que eu acho que é mais importante, é o exercício psicológico. Manter sempre em alta, sempre em dia porque senão tudo tende a cair (E3).

As part of the coping process, women use spirituality to adapt to the changes caused by breast cancer, which is also a source of hope and motivation for life (CARVALHO *et al.*, 2018).

Olha, eu tenho muita fé em Deus. E, quando eu estou com alguma dificuldade, eu procuro ver o lado melhor. Se eu não posso resolver, então, eu coloco Deus em primeiro lugar (E4).

Health professionals acquire a very important status as a vehicle of information about self-care actions. This information ranges from basic care with the arm on the ipsilateral side of the surgery to the suggestion of participation in support groups, covering all health care that, in some way, was compromised by cancer (DIAS *et al.*, 2017).

In this sense, support groups emerge as a significant tool. They stand out as an environment for listening, learning and welcoming through the sharing of experiences and feelings, favoring the adoption of self-care practices. Faced with the effects of therapies for breast cancer, women face a readaptation process and develop coping strategies based on the motivational factors provided by the support network, namely dialogue with family members, integration into support groups, living with health professionals, and spirituality as a source of faith and perseverance.

#### 4. CONCLUSION

The study had limitations regarding the number of participants, the heterogeneity of the sample and the diversity of the treatment period, as it was an intentional sample. It was also restricted to the population of the coverage area, assisted in a university



hospital that serves the region of the Zona da Mata of Minas Gerais, therefore, it is not possible to generalize the results.

From the meanings expressed, the research allowed a better understanding of the coping strategies used by women in the face of the repercussions triggered by breast cancer treatments and the influences - negative or positive - on self-care actions. It was observed that the effects of therapies proposed to combat breast cancer can be devastating and cause impactful adverse effects that limit daily activities and self-care.

In contrast, the perspective of coping with the disease with a view to recovery was observed, as well as the adoption of healthy practices, strengthened by the support of the family and professionals to minimize the complications of treatments and improve health care.

The study's findings reinforce the need to structure a health care line for women who have survived breast cancer to act as a facilitator and support in guiding and carrying out self-care actions. In this thinking, health education stands out as an important strategy for promoting self-care. Care for one's own health should be encouraged by professionals and health services that assist these women, in order to favor coping with and overcoming the difficulties imposed by illness from cancer and its treatments.

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## APPENDIX - FOOTNOTE

7. Termo de Consentimento Livre e Esclarecido (TCLE).

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