Self-Care Experiences and Practices of Women with Breast Cancer in Colombia

Abstract

Breast cancer affects physical, emotional, spiritual, social- familiar and behavior components of the women with this pathology. These changes occurred during phases: diagnosis and after-treatment.

Objective: The objectives of this study refers to the description of women's breast cancer living and practice in every stage mentioned, identifying conditional basic factors (age, educative level, etc), describing universal self-care requirements (familiar and social relationship), deviation health requirements (general knowledge of cancer) and identifying practices and self-care necessities.

Design: It is an ethnographic qualitative study carried out with ten women, five on them in treatment and five on ambulatory control. The information was recollected from semi-structured and open interviews, clinical histories and camp diary; adjusted to self-care deficit Dorotea Orem’s theory.

Results: suggest that acquaintance breast cancer are deficient, it continue being a taboo disease, synonymous of suffering, pain, disfiguration and death; it generates changes on way and quality of life making process slowly and difficult. Procedures that patients must carry out constitute an obstacle in the process.

Conclusion: Doesn't exist a standard integral attention pattern for women with breast cancer, the treatment are exclusively clinical and doesn't include psycho-social aspects own of breast cancer.

Keywords: Self-care; Practices; Breast cancer; Experiences

Introduction

Breast cancer is the most common neoplasm in women worldwide. In Colombia, it is the second cause of mortality by among women, after cervical cancer [1]. With the entry of the Law 100 in 1993 at the country, the general health and social security system and the regulation of programs of promotion and prevention (Resolution 412 and 3384 of 2000), the era of the early detection of breast cancer begins in Colombia. However, women with greater vulnerability still continue to consult in later stages, for reasons such as disaffiliation to health system, fear, cultural beliefs, indifference or underestimation of health agents to a finding in their body [2]. A reality that reveals the fragility of the health system, where 85% of the diagnoses are performed in late stages III with therapeutic results tending to alleviate symptoms and improve the quality of life, distinctly different of developed countries where the diagnosis is done in the early stages of the disease.

The diagnosis of cancer, radically modifies the women’s lifestyle, generates negative feelings that lead her to evaluate her social, family and work position and function [3]; responding to different phases of bereavement that will allow them to adapt to their new reality. Based on the experiences of women with breast cancer, it was intended to describe the experiences and practices of self-care during the different phases of treatment and control, adjusted in Dorotea Orem’s theory of self-care deficit: factors of basic conditioning (sociodemographic factors), universal self-care requirements (family and social relationships) and deviation health requirements (cognitive-perceptual, emotional, spiritual and behavioral aspects). Once, the main needs were identified, nursing diagnoses were proposed, which will serve as a guide to provide care and self-care actions that will allow the women to recognize and value the capacities they have to take care of themselves.

Materials and Methods

The research was carried out through the ethnographic method, were included women with breast cancer confirmed by pathology, in treatment or control at any stage, which came to the public hospitals in Popayán. The sample consisted of 10 key informants who voluntarily accepted to participate in the study. As exclusion criterion, was included to change of residence by pathology, in treatment or control at any stage, which came to the public hospitals in Popayán. The sample consisted of 10 key informants who voluntarily accepted to participate in the study. As exclusion criterion, was included to change of residence outside the urban perimeter.

Collection of information

The collection of information was done by the researchers, through the search in the databases of the hospitals of the public network and in the centers of care. Subsequently, women with residence in the city of Popayán were selected. The approach was performed in clinical consultations, treatment centers and cell phone. Subsequently an invitation was made specifying the purpose of the research and was sent to the participants to invite...
them to study and they consented to authorization for joining to the study. Clinical data were obtained from the hospital history supplemented with a copy of the patient’s clinical evolution. The instruments were based on the three categories of Dorotea Orem’s self-care deficit theory. A structured survey was conducted adjusted to the basic conditioning factors, an open interview adjusted to the requirements of universal self-care and health deviation, and at last, was used a field diary. Four interviews were carried out by key informants; the material was recorded on tape, transcribed, analyzed and supplemented with data from the field diary. Each interview lasted 45–90 minutes.

Categories

The analysis was determined according to the type of data collected: The quantitative data corresponding to the basic conditioning factors were tabulated in Microsoft Excel. The requirements of self-care and health diversion were adjusted in categories and subcategories as follows: universal self-care category and as subcategories (family and social referent, family relations and relationship with health personnel) and category of deviation health requirements and as subcategories (perceptual cognitive, emotional and spiritual and behavioral reference) (Table 1) to finally perform a triangulation of instruments.

Table 1: CATEGORIES: experiences and self-care practices of women with breast cancer according to Dorotea Orem’s self-care deficit.

<table>
<thead>
<tr>
<th>Basic Conditioning Factors</th>
<th>Universal Self-Care Requirements</th>
<th>Deviation Health Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family and social background</td>
<td>Family relationships</td>
<td>- Knowledge: definition, causes and prevention</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
<td>- Myths, taboos and beliefs</td>
</tr>
<tr>
<td>Socio-demographic variables</td>
<td>Family relationships</td>
<td>- Legal aspects and tramitology.</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
<td>- Perceptions about treatment and rehabilitation.</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
<td>- Spirituality and religiosity.</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
<td>- Adaptation and adjustment: attitude towards illness and self-image.</td>
</tr>
<tr>
<td></td>
<td>Health group relationships</td>
<td>- Changes lifestyle.</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
<td>- Complementary medicine.</td>
</tr>
</tbody>
</table>

Results

Basic conditioning factors

The women diagnosed with breast cancer, were between 44 and 71 years old, with a mean of 54 years. With respect to marital status, 50% were married, followed by 20% divorced and 10% single, in stable union and widows (Table 2).

Table 2: Percentage distribution according to marital status.

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Stable union</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Divorced / Separated</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>Widower</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>100</td>
</tr>
</tbody>
</table>

About the occupation -at the time of the interview-, 40% of the women worked like housewife and 60% were pensioners, public employees, chefs and merchants, with 20% each one. Related to education, 40% of women had incomplete primary education, 10% complete primary education, 10% incomplete high school, 40% of them had university studies and 30% of had a postgraduate degree (Table 3). For 90% of the women interviewed, the family relationships that they establish with people who live in their house are good. Only 10% considered that the relationship with their relatives was conflictive.

Table 3: Percentage distribution according to occupation.

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housewife</td>
<td>4</td>
<td>40%</td>
</tr>
<tr>
<td>Public Employee</td>
<td>2</td>
<td>20%</td>
</tr>
<tr>
<td>Chef</td>
<td>2</td>
<td>20%</td>
</tr>
<tr>
<td>Merchant</td>
<td>2</td>
<td>20%</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4: Percentage distribution according to stage of breast cancer.

<table>
<thead>
<tr>
<th>Stage</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>II A</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>II B</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>III A</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>III B</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>IV</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>100</td>
</tr>
</tbody>
</table>

Health deviation requirements

Cognitive component

Knowledge about definition, risk factors and general aspects of breast cancer: The women do not know fundamental aspects of their disease, although they clearly describe the risk factors, they argue that it is a multi-causal disease, which can metastasize and suggest the importance of taking an active role in care and treatment to avoid it "this is cancer and is painful "IC3," it’s a disease that can give us all" IC2.

Knowledge of prevention mechanisms: Five women agreed that before the diagnosis they had some kind of information about the disease and the mechanisms of prevention, but considered that educational campaigns were not enough to reach the majority of the population. They also warn that some of this information was acquired by the mass media, leaving little recognition for the participation of health agents. According to the National Demographic and Health Survey (ENDS): “Most Colombian women know or have heard about self-examination, but very few do it; 80% of women surveyed know what it is, but only 25% of that 80% do it every month” [4]. Fear of having a malignant tumor and an unfavorable diagnosis; resulted in late consultations in seven of them, in the other three cases there were early consultations. Many of them assume more responsible self-care behavior after diagnosis, all of them reiterate the importance of self-examination and mammography to detect the disease and improve prognosis.

The most frequent reason for consultation was the presence of painless lumps in the breasts that they found accidentally while taking a shower. “In breast cancer, it is usually the patient who accidentally discovers a lump when bathing or dressing” [3] and in the other three cases, non-classic symptoms motivated the consultation as pain and functional limitation of the shoulder and hyperpigmentation of the skin in the mammary area.

Myths, taboos and beliefs about breast cancer: Regardless of sociodemographic conditions, cancer is seen by women in the study as synonymous of suffering, disfigurement and death, “Cancer is synonymous with death” IC3. Awakening sensations of impending disaster and the need to live. “When I knew that I had cancer, I started to cry, I prayed God. I didn’t want to die because I have my son and two grandchildren who need me” IC4.

Many of the belief was derived from their own experiences and uncertainty about survival with this diagnosis. Many witnessed how cancer was killing the lives of family or friends, in a slow, painful and distressing way. “The death of someone close to him reminds them that they are destined to die” [5,6].

Even though the experiences, social environment, their prejudices and the information provided by the media, shape the significance of cancer. Some women consider it as a disease of every human being, with a gradual clinical evolution characteristic of each person: “It is a disease that can give to any person, we all have the disease, but only one develops more than others” IC2.

Legal aspects and tramitology: The financial resources and the medical coverage exert a great influence in the access to the attention and the quality of the services supplied. Eight women reported having had several impediments to support orders for medication, medical appointments and diagnostic tests, even from the time previous to the confirmation of malignancy, which delayed the start of treatment. Situations that delayed diagnosis and treatment increase the severity of problems and costs [7]. Resolution 5261 of 1994 includes chemotherapy and radiation therapy as a treatment for cancer [8]. “In Colombia, the burden of processing falls on institutions and patients, integral treatment is not guaranteed, surgery, chemotherapy and radiotherapy are authorized in different places. The lack of continuity cause complaints to protected their rights. In the country it is estimated that every three hours tutelage for cancer is interposed” [8], not outside this national general view, three women filed a guardianship action and one used “influence” to receive an appropriate treatment. Faced with these difficulties, four of the women surveyed said they felt like “charge accounts and under a mercantilist system”.

The requirements for access to health are seen as obstacles and dehumanization. Despite the disadvantages, women recognize the importance and need to take care of their health, regardless of the number of actions they must take.

Emotional and spiritual referent

Most common adverse effects and perceptions about treatment and rehabilitation: After the impact generated by the diagnosis, women take the treatment as a path towards restoring their health. When fears and uncertainty reappear, women renounce their fears, and face this stage with optimism and the illusion of finding peace and tranquility. Faced with different therapeutic modalities, seven of the ten women consider chemotherapy the most complicated to deal with.

Among the side effects that most afflicted women undergoing chemotherapy were: headache, dizziness, nausea and vomiting, dislike of food, general malaise, gastritis, back pain, weight loss and hair loss, ecchymosis in nails, nail drop and phlebitis. The most common side effects caused by radiotherapy were burning sensation, burning in the irradiated area, cough and general malaise. However, adherence to this last type of treatment was greater and is considered more bearable.

Adaptation and adjustment

Emotions and attitudes towards disease

Breast cancer mainly affects the emotional component, having to face a disease fraught with fatalistic meanings, which give rise to a series of negative emotions (fear, anger, pessimism, anxiety and suffering) externalized in their state of mind.

Initially, women assumed a negative attitude and defenselessness, losing interest in the activities of daily life. Any moment of loneliness represented a space prone to the appearance of thoughts of pain and death, increasing the anguish and impeding to make decisions or assuming a passive role in the recovery process. With the treatment, they expressed feeling shattered, fearing a possible metastasis and although they found it difficult to express their feelings with the passage of time began to adopt a more enthusiastic and positive attitude. The “fighting
spirit” was not equal in each case, depending on factors such as age, clinical stage, prognosis, treatment and support networks. The coping patterns have shown a clear relationship with the level of emotional disturbance and general psychological morbidity. The most effective strategies seem to be the confrontation of the problem and its redefinition emphasizing the positive of the situation, the search for social support (including medical information) and the distancing (distraction and rationalization) temporal [9].

Six of the women returned their usual rhythm of life, assuming a positive attitude, changing the initial carefree behavior by conscious actions like the follow-up to treatment and care activities aimed at maintaining their health. In the process of adaptation, the support of the family and the health group were determinant to reestablish their emotional state. Words of encouragement, complete, honest and timely information cleared the doubts about the illness, keeping alive the faith and the hope to maintain his health.

6.3.2.2 Situations that affect the self-image of women with breast cancer

Hair loss and partial or total removal of the breast were the two aspects that markedly affected the participants’ self-image, six were mastectomized and four had hair loss. For the mastectomized women, the extirpation had repercussions on their emotional and physical state, affirming that their body image was compromised. The mastectomy attacks one of the most significant parts of the woman, overwhelming her femininity, physical integrity and her sexuality.

Differences were observed in the way mastectomy was approached by younger women, who were affected by the possible rejection of their partner compared to those who had formed a home, had children and had a stable relationship. The women said that the fall of the hair was presented little by little while they combed. Some made the decision to cut it before, and when the fall was total, they wore scarves, hats or wigs to hide the baldness, claiming to feel shame by the new change. The self-consciousness of being deformed often prevents proper social relations and can produce a continuous state of alert about one’s appearance, even if the deformity is not obvious to others [10].

Spirituality and religiosity

Spiritual and religious beliefs helped women gradually accept their illness and change their behavior by sharing with others about their health status, serving as a source of support for newly diagnosed women. The new way of thinking and feeling are the pillars that sustain and guide the aspects of daily living, provide satisfaction, are a source of support and inner strength, promote it towards an optimal level of well-being, allow them to plan their future and lead them to fulfill desires before was too late.

Breast cancer show the duration of life, impotence and complications of treatment, and a strong impact on their family and social environment [12].

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Behavioral references

Use of complementary medicine

The American Cancer Society defines complementary medicine or methods like group of practices, systems, and health care products that are used in conjunction with conventional medical care. If these treatments are carefully administered, they may contribute to their well-being and comfort [11].

Eight of the ten women interviewed used complementary medicine after diagnosis. With the intention of contributing to their well-being, they used herbs and medicinal remedies such as: water of anamu and fading; pollen, wheat bran, molasses and barley; blackberry juice and grape; aloe vera with honey and a glass of cognac; omega; B complex plus brewer’s yeast; neural therapy; flower essences and Echinacea.

Although many believed the plants to be safe, some consulted with their physician before initiating any therapy, claiming that many people came up with “magic formulas” that would heal them, raising hope amid their vulnerability. The social and family support provided by complementary medicine facilitates self-care practices that improve in some women their mood, diminish partial symptoms, but that until now have not had a scientific support.

Universal self-care requirement

Family and social background

The family support system is the set of people who provide an affective environment during treatment. Breast cancer is an experience that not only affects the women, also their family, as expressed by the all people in the study, who felt that the diagnosis was a difficult test, modified their lives in a transcendent way and the their relatives and friends. The support received by the patient allowed her to affirm her role. Social support as part of the psychotherapy that cancer patients should receive, is very useful as it provides a space to express feelings and emotions, which facilitates adaptation to the disease, establish a social support network and acquire better skills to solve the problem [12].

Family support was one of the most important factors in initiating treatment, reducing fear and resistance to chemotherapy, under the perception that treatment was the only source of hope that would prolong their life and allow them to share more time with their loved ones. Likewise, it is common for a potentially serious illness such as cancer to generate high levels of stress in patients who suffer from it, for this reason, it is common for cancer patients to experience fear, social isolation, inability to handle the complications of treatment, and a strong impact on their family and social environment [12].

To five women with breast cancer, the disease, in addition to strengthening emotional and religious bonds, built a solid bridge
of trust, mitigating the stigma of society and the aftermath. Women perform their treatments and attend to their controls, even though they know that they do not have much time to live for example in three of them, but they know that they have the unlimited support of their family, and that with a positive attitude will facilitate their recovery.

Relationship with health group

The women who participated in the study agreed that the process of adaptation to the disease and the changes in daily life would be more bearable if the health staff made a constant accompaniment to them and showed more interest in their state of health. The lack of confidence and the fear to ask about aspects related to the disease and its evolution, contributed to disinformation. The treatment received by the health staff was good, according to the women participants. Most of the doctors who attended them did so politely and respectfully, using optimistic words that encouraged them to move forward; however, some of the doctors were characterized by their haughtiness, indifference and disrespect. “The doctors are prepared to assist you but not to accompany you; to inform you, but not to make themselves understood, and they hear you but they do not listen to you” [13] “It seems that everyone believed that we know everything about the disease and it is not like that” IC3.

In some cases preferences were evidenced, so they affirm that treatment and care should be equitable and non-discriminatory, such as difference when treated as a private patient and as an emissary of a health entity. The women expressed their nonconformity by the lack of information on the disease and its treatments. In addition, they consider that the language used is very technical and incomprehensible, not enough time is spent to explain the procedures to be performed and / or they do not ensure that the information has been understood. “The doctor as a professional seems good to me, but he is very bad people and one needs to be listened to and heeded. He’s like he hears but he does not listen and if he listens he does not listen, he’s very uncommunicative” IC2.

There are members of health group who do not provide a service with human quality, respect for the dignity and rights of patients. With respect to the nursing staff and the treatment offered, some consider it adequate, while another group expresses that it is necessary to be more attentive to the needs of the patients and their family.

Discussion

Like other people diagnosed with cancer, the women in the study experience feelings of loss, helplessness, and impotence. The impact of breast cancer on women and society is very complex as it is perceived as a threat to their lives, uncertainty about the future of their relationship and sexuality, child care and employment. They also face difficult situations such as: detection of a breast problem, confirmation of diagnosis, the period before treatment, surgery and subsequent therapy. The diagnosis of cancer modifies the woman’s lifestyle, generating negative feelings that will lead her to evaluate her position and social, family and work function [4], inducing in them, specific responses of the different phases of grief that will allow her or not to adapt to its new reality. Learning from his illness was not easy, especially when his current health condition depended on his prognosis. To reduce the annoying effects of treatment, they accepted alternative formulas, which they shared with other women in the same situation. They tried to remove fear by turning it into security and using autonomy to achieve the recognition of their rights, although to achieve this they have had to wander through eternal morning ranks in search of a support order, receive an incomplete drug, accompanied by a guardian or request a mammogram to which he was entitled after age 50 years.

The study emphasized the appreciation that women received support received by health agents, each woman, would have wanted a space to explore and express their thoughts, feelings and concerns, regarding their emotional and spiritual aspects [14]. However, it leaves them feeling that they dedicated the right time to inform them about their illness and procedures to follow.

They perceive health personnel as the giver of knowledge and solution and not as the person who directs their own care. Lerner (1993) found that patients who had reported poor communication with their physician reported more problems during their illness and presence of moods such as distress. Other investigators, on the other hand, found that patients reporting satisfaction with how they had reported bad news reported a better short-term (3 to 13 months) psychological adjustment, but not in the long term (6 years) [15].

Once diagnosis was confirmed, the women experienced the mourning that allowed them to gradually accept the new reality. As the treatment was introduced, the first changes in her femininity and sexuality, such as hair loss, removal of her breasts, annoyance to odors, anatomical changes in her body and side effects to the existing therapeutic modalities; experiences that had repercussions on family, social and couple relationships. They assumed the disease as a necessary suffering or as a divine/God test. They took refuge in religion and in the hope of a kind God who would remove them from danger. In individual and collective prayers, they found the support and the strength to overcome adversity. In the study by Feher and Maly (1999), religious or spiritual beliefs in women with breast cancer were maintained or increased during the illness, serving as an emotional support for 91% of them. Of the ten women in this study, nine adhered to religion and only one felt that it no longer fulfilled their expectations. All agree that positive attitude and struggle, coupled with prayer brings great benefits. Studies indicate that belonging to a religious group is positively related to the longevity of patients and to healthy lifestyles: they have better adherence to treatment and are more obedient with their medicines [15].

Religiousness and spirituality, as front facing strategies, were associated with better mental health and adequate adaptation to stress and allowed them to face the situation with courage, wisdom and positivism.

Faced with an unexpected crisis that abruptly broke the daily lives of people and the family, the closest social support was the family, with whom they built the first care and a social network of learning. In Colombia, there are still no policies and conditions that guarantee integral care for women; they continue to observe long lines, dawns, negative answers, false promises. Special consultations are the privilege of some women and although they receive priority attention, it is not what they really want. “Many health care companies consider service coverage from...
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The present study allowed to visualize the perceptions that the woman has with diagnosis of breast cancer, and to manifest the administrative and human failures of the health system. It is important to highlight the strength of women and their families, to seek alternatives for health care, despite the adversities encountered. As a limitation, it was found that many of the key informants died during the course of the investigation.

Conclusion

A. Basic conditioning factors: women with breast cancer, average age 54 years, marital status and household occupation, the diagnosis of stage of disease was IIIB in 30%, stage IIIA, IIA YB with 20% each.

B. Family and social referent: in any process of adaptation to a catastrophic illness, family support and health people are determinant to reestablish their emotional state. The accompagniment strengthens them and the complete, timely information clears many of the doubts they have about their illness.

C. Relations with health personnel: health professionals provided good treatment, however, women diagnosed with breast cancer, disagreed over the lack of communication during the consultation and treatment.

D. Perceptual cognitive reference: hair loss and partial or total breast excision are the two aspects that most deteriorate the body image of women with breast cancer.

E. Emotional / spiritual referent: spiritual support, influences grieving processes and confer the emotional support necessary to transit through the treatment and control of the disease.

F. Behavioral reference: the search for other complementary health methods, marked profound changes in their lifestyle, and marked the beginning of a network of social and family support in search of self-care practices to recover their health.
It is important that nurses assume a more dynamic role of educators by planning, implementing and evaluating intervention programs to facilitate the development of people, with the aim of helping to maintain self-care actions to preserve health and life, using the help methods proposed by Dorotea Orem: to act by compensating for deficits, to guide, to teach, to support and to provide an environment for development.

Acknowledgement

You live life, how to live to live, when you are diagnosed with breast cancer, you have to stop and say: we cannot go on like this! We must be responsible for our health and involve ourselves in our care ... we must seek information.

To women diagnosed with breast cancer, since without their unconditional support and collaboration it would not have been possible to perform this research work. You are our reason for being! This work constitutes the first step towards the transformation of health care to cancer patients and marks a milestone in the struggle of women for a more just and humanized care.

Conflict of Interest

There is no conflict of interest

References

10. American Cancer Society.