

PARTICIPATING IN A SUPPORT GROUP: EXPERIENCE LIVED BY WOMEN WITH BREAST CANCER

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The goal of the study was to understand the meaning of support groups in the life of women with breast cancer. It is a qualitative study with 30 mastectomized women who belonged to six support groups in the city of Fortaleza, Ceará. Data were collected with semi-structured interviews, organized and analyzed based on the interactionism concept. The results characterized the support groups as a mechanism to cope with the situation and to overcome the suffering derived from the diagnosis and treatment of the breast carcinoma. The socialization of the experiences facilitated the search for assistance in the support groups, since sharing the problems with mastectomized women was a way to preserve a high self-esteem, have faith and overcome some difficulties. Participating in the group provided well-being and a differentiated care, since it was considered a way to know, accept and understand the disease and its cure, facilitating the socialization of ideas.

DESCRIPTORS: breast neoplasms; mastectomy; group structure

PARTICIPACIÓN EN UN GRUPO DE APOYO: EXPERIENCIA DE MUJERES CON CÁNCER DE MAMA

En este estudio, se buscó comprender el significado de los grupos de apoyo a las mujeres con cáncer de mama. Se trata de estudio cualitativo con 30 mujeres mastectomizadas pertenecientes a seis grupos de apoyo de la ciudad de Fortaleza-Ceará. Los datos recolectados por medio de entrevista semi-estructurada fueron organizados y analizados bajo el marco teórico interaccionista. Los resultados caracterizaron los grupos como un mecanismo para el enfrentamiento de la situación y de superación del sufrimiento que se originan en el diagnóstico y tratamiento del carcinoma mamario. La socialización de las experiencias facilitó la búsqueda de auxilio en los grupos de apoyo, ya que compartir problemas entre las mujeres mastectomizadas, era una forma de mantener la auto-estima elevada, de creer, de confiar y superar algunas dificultades. La participación en el grupo proporcionaba bienestar y un cuidado diferenciado, ya que fue considerada una forma de conocer, aceptar y comprender la enfermedad y su cura, facilitando la socialización de las ideas.

DESCRIPTORES: neoplasias de la mama; mastectomía; estructura de grupo

PARTICIPAÇÃO EM GRUPO DE APOIO: EXPERIÊNCIA DE MULHERES COM CÁNCER DE MAMA

Procurou-se compreender o significado sobre os grupos de apoio na vida das mulheres com câncer de mama. Trata-se de estudo qualitativo com 30 mulheres mastectomizadas, pertencentes a seis grupos de apoio da cidade de Fortaleza, Ceará. Os dados coletados por meio de entrevista semi-estruturada foram organizados e analisados sob fundamentação interacionista. Os resultados caracterizaram os grupos como mecanismo para o enfrentamento da situação e de superação do sofrimento, oriundo do diagnóstico e tratamento do carcinoma mamário. A socialização das experiências facilitou a busca de auxílio nos grupos de apoio, pois compartilhar problemas entre as mulheres mastectomizadas era uma forma de manter a auto-estima elevada, de acreditar, de confiar e superar algumas dificuldades. A participação no grupo proporcionava bem-estar e cuidado diferenciado, pois foi considerada uma forma de conhecer, aceitar e compreender a doença e cura, facilitando a socialização das idéias.

DESCRIPTORES: neoplasias mamárias; mastectomia; estrutura de grupo

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INTRODUCTION

In Brazil, breast cancer is the main cause of death among women. Of the 467,440 new cases of cancer diagnosis predicted for 2006, breast cancer was the second most incident, with 48,930 new cases. In the state of Ceará, 34.82 cases are estimated for every 100,000 women, with 1,460 cases in the state and 660 in the city of Fortaleza⁽¹⁾.

Breast cancer is characterized as a slow, silent and stealthy disease but, if it is diagnosed early and receives appropriate therapeutic intervention, the myths, grief and uncertainties that stem from the pathology and its treatment could be greatly diminished. In low-income social groups, women reaffirm the moral/religious connotation of cancer as a deadly and punitive disease⁽²⁾.

Regardless of the therapeutic process, "cancer" provokes negative feelings, making the woman see herself as different and excluded from society when struck by this disease. In order to minimize this image, it is possible for the person to join a support group, so that she may be able to share experiences with other women undergoing the same situation, and then understand that she will be able to face obstacles and overcome limitations. It will also help her notice that she is not alone, that she may exchange experiences and regain the will to live.

Despite the proven benefits of participating in support groups, it was observed that there are few spaces that propose these activities and that, when they exist, the people who need them may not become involved. There are several questions about the real reasons for such an attitude but, particularly, it would be of interest to know: what does "participating in a support group" mean for women with breast cancer? And how do they perceive it?

Some factors may inhibit the woman's insertion in support groups, among which the authors consider the many invasive procedures, whether in the hospital or outpatient environment; the fear of social and physical consequences/implications resulting from mastectomy; and the often poor socioeconomic conditions, which makes it impossible for them to participate in the group regularly.

Some women submitted to therapeutic procedures that lead to mutilation sought ways to live with their new health condition with dignity. For that, they seek help in institutions like associations, healthcare services, support groups or even their family⁽³⁾.

In the experience with women who participate in a support group, the authors have observed on several occasions that, at the moment they join the group, women feel solitary, isolated and ashamed, especially if they have to talk about issues regarding body image, health and disease. It was during this experience with a support group, by listening to their stories, that the authors became aware of the following questions: what do these groups offer for the socialization of women? Which contents structure the symbolic universe for women with breast cancer, considering the participation in support groups? Why do they seek and participate in the activities offered by the support groups?

With the goal of finding answers for these questions, the study aimed to understand the meaning of the support groups in the life of women with breast cancer.

METHOD

This is a descriptive study with a qualitative approach, under a sociocultural perspective that favored the understanding of the subjective world of actions, reactions, aspirations, beliefs and life experiences of women with breast cancer who participate in support groups⁽⁴⁾.

Thirty (30) women, mastectomized because of breast cancer, participated in the study, receiving assistance in the six support groups that exist in the city of Fortaleza. Each group was represented by five (5) women, with up to five years of mastectomy, able to be interviewed and participating in support groups for at least three months (12 sessions, when the group had weekly meetings, or three sessions in case of monthly meetings).

The six support groups for women with breast cancer are characterized as being non-governmental organizations, and/or associated to public and private institutions, offering patients psychological support and physical recovery. In some, a team of volunteers participates, made up by physicians, social workers, nurses, occupational therapists and physical therapists.

Data collection was performed with previously-scheduled, semi-structured interviews, lasting approximately 20 minutes, in a harmonic and relaxed atmosphere. One guiding question was used: What does it mean for you to participate in a support

group? This question was the stimulus for the beginning of the interview and made it easier for the respondents to socialize their life experiences.

The dialogues were recorded with the authorization of the interviewees, in an adequate place of their choice. The content of the interviews was transcribed integrally, noting expressions of feelings, crying and intonations, aiming to absorb all the information, pauses and noise contained in the recordings.

This approach helped the authors to amplify the researcher-subject relationship and create questions about experiences within the group and their repercussions in social and family life. Data collection was interrupted after interviews with five women of each group, because coincidences among their answers had been observed, which responded satisfactorily to the proposed goals.

The transcribed interviews were read several times, with the goal of ordering convergent and divergent ideas and contents, building a comprehension of the meanings of support groups in the perspective of women, and the meaning of the groups for their lives.

For systematic data organization and coherent description of the entire material obtained, the authors decided to use thematic content analysis according to Bardin⁽⁵⁾. Therefore, in the pre-analysis of the interview, the authors sought to separate similar from differentiated statements, representing basic units of meaning for the groups, in the respondents' views.

Units of meaning were identified in the exploration of the collected material, putting similar phrases together and symbolizing the interpersonal and intergroup relations the participants attributed as being significant for their personal, family and social development. The analysis was based on an interactionist approach, emphasizing the conscious interpretation of each woman and the meaning of group interaction⁽⁶⁾.

According to Resolution 196/96, the research project was approved by the Ethics Committee at the University of Fortaleza (UNIFOR). The study participants were informed about the importance of their participation in the research, assuring their anonymity and freedom to quit the interview without loss of participation in the group or other forms of healthcare. Those who participated in the research signed the Term of Consent and were informed that the data would be grouped, presented to them and published in scientific journals.

RESULTS AND DISCUSSION

The content analysis of the interviews and observations performed with the studied women allowed the authors to apprehend that participating in support groups meant the possibility of exchanging experiences, receiving and offering social support, staying away from social exclusion, receiving information and leisure activities.

According to reports from the studied women, the participation in support groups for breast cancer patients promotes the *exchange of experiences* with others undergoing similar problems, which enables them to realize that they are not alone in this route: *We see that it didn't happen to me alone, that there are many others with the same problem.*

The women reveal that the opportunity of sharing experiences with people suffering from the same problems is a way for them to feel included in the group, supported and, from there, be able to express feelings⁽⁶⁾. In the group, *we observe and see that one of those friends also had it and is strong, I mean, exchanging ideas, you cry, you discuss the common problems, we get stronger.*

Being part of a support group for women with breast cancer was also considered a source of social support when they noticed that the groups worked as a base for the continuity of the process of recovery and adaptation to the new condition, and also as a psychophysical and psychosocial environment of transformation. Therefore, the women added that *they are people who underwent the same thing as I did and that I have to live with today, there's a lot of support to help you when you feel that you're going to falter.*

Cancer is seen as an unpredictable disease, entailing uncertainties about a full cure, and this feeling is shared with other women during medical appointments, among the self-help group members and in the meetings of mastectomized women⁽⁷⁾.

The women evidenced the importance of this group experience, because they identify the ways of coping used by each participant besides freedom of speech. The women can express what they think, feel, desire and *you're not ashamed of speaking about your problem, everybody is there to hear you out* in the environment created by the support groups.

Experts on the topic say that the directional search for people in the same situation of anxiety is a consequence of the need to establish a social reality that might serve as the base to evaluate the justification of the anxiety they find themselves in⁽⁸⁾.

It could be observed, in the participants' reports, that many women identified the group as a

space where they can find people they consider as reference and role models for the elaboration of their own image and history: *it is the mirror that we have of the other, if we can see another person who had the problem, that we went through it well, then, I'll tell myself, tomorrow I'll be just like her, I'll believe and work hard to get there.*

As the socialization process goes by, the authors are exposed to people or groups that take the role of positive or negative references. In the present study, it was observed that women seek positive references and identities to motivate them to overcome the difficulties they have to face.

The value of the self-help groups lies in the fact of sharing common experiences, providing their members with an enormous amount of energy, which may be directed to the demands of life, to resocialization and recovery⁽⁷⁾. Therefore, *one of the things that really helped me was seeing that there were other women with the same disease who were helping the others.*

All studied women highlighted how significant it is to participate in a support group, not only for the emotional and social support they receive, but also for the possibility of leaving the situation of *social exclusion* and seeing themselves as included, becoming equal to one another: *here, despite the differences, some wear prosthetics, others had a reconstructive surgery, they're all alike.*

The symbolic universe, represented by sharing their lives with other women with the same experience of living with breast cancer and going through the same therapeutic processes, is represented, in the viewpoint of the women, by a reality experienced in the support groups that helps the reduction of suffering and *social isolation*. Such a fact is evident in the following expression: *They all speak the same language, the same problem and the same things, like this: when we're in pain and the other has a similar pain, we feel calmer.*

This feeling of sharing grievances is common in the statements of the women with breast cancer, and the physical pain is felt as a sensorial perception related to emotional phenomena and components of personality⁽⁹⁾.

The feeling of pain, usually felt by women, not only portrays physical suffering, but also self-esteem and self-image, which have been changed because of the problem that causes so much grief, i.e. being submitted to a surgery of breast removal – the mastectomy. The awareness of not being the only one to show such feelings, the possibility of dialogue, sharing feelings and reactions as well as exploring ideas are forms of therapy and of minimizing the suffering, shared in support groups⁽⁹⁾.

The personal interaction makes changes that turn greater individual development more feasible, and the fact of sharing experiences in support groups works as a facilitator of physical, social and emotional support⁽¹⁰⁾. It was verified that, out of 30 respondents, 17 mentioned the importance of a moment to share experiences. According to them, it makes interpersonal communication easier, enables group interaction and provides means of self-help and mutual aid. They state that the goal of the group is to complete itself mutually and constantly, and to learn with the other members from their personal experiences⁽¹⁰⁾. As such, the moments to exchange experiences are considered valuable for those who integrate these groups, regardless of their way of living, being and living with themselves and others.

The *information*, received and shared about the disease, their treatments, reactions and side effects, and the way of dealing with each situation are part of the symbolic universe of the studied women about the importance of the group as social support. The act of helping, clarifying, informing the women who will undergo treatment probably lowers the expectations and tensions that stem from their lack of knowledge. This act should be humanized, valuating an internal personal process, encouraged by a space for collective reflection, coping and mobilization⁽¹¹⁾.

According to the studied women, among the activities proposed by the groups, informative and educative actions were also included, providing knowledge about the disease and its treatments. Such activities reinforce the control over their bodies and the adoption of preventive or early diagnostic measures, using self-examination of the preserved breast⁽¹²⁾. The need for information was represented when women stated about the group: *there are many things, lectures, courses, and now there is going to be a course there, and it all ends up making a lot of things clear to us.*

They report that the group enables them to learn about possible complications, exposition to risk factors and clarifications about their rights as mastectomized women and access to healthcare services. This power, originated from acquired knowledge, also relieves the fears they experience, since the unknown scares them: *We had several questions, and many things were made clear in talks with the professionals.*

The topics, consciously assimilated, provide the authors with the capacity of establishing fair reflections and decisions, and also to minimize erratic behaviors that are so common in human nature. The common sense within a critical, plural and responsible process may then evolve to good sense. The informed

citizens become the transformers of their own lives, and this is also highly regarded by women, as seen in the following statements: *here they teach us many things, they teach us how to take care of ourselves. I come over to take part in the courses, the lectures of people who come here often. There are also some classes, we learn a lot about this disease, it relieves the fear, and there are always new people around.*

This information about the disease and the answers about the pathology and the treatment favor health promotion, making them more independent for self-care, for the execution of other activities related to the environment and the family. They also enable each woman to transform into a multiplying agent. *We try to make it work, to bring information to people, so that we can detect cancer earlier.*

The positive experiences are one of the strengths for the execution of actions needed for treatment, and they are useful to minimize the ever-present tensions and fears in these cases, besides favoring their egos and encouraging them to formulate a life project⁽¹³⁾.

When expressing meanings, the satisfaction each woman presented when talking about her participation in the group was remarkable: *knowing other women with the same problem helped me a lot. I had to meet people with the same problem as I had so I could feel safer. I improved a lot when I became part of the group, I feel more useful, I can help other people.*

The self-help groups aim to help people solve their problems, since they are homogeneous in terms of having members that experienced similar problems, which is a characteristic of support groups for mastectomized women.

Another element present in the symbolic universe of the studied women about the meaning of the groups for mastectomized women was their reference to social integration. This happens because a large share of these women expresses the idea that, by finding themselves integrated in the community, they retake their social activities, which makes them productive, able to help others and to value themselves. The group also enabled some decision-making, shown as: *I'm still afraid of going out, but the group has helped me a lot, after listening to some of them I felt brave enough, I go to the supermarket, take part in the group's festivities and walks.*

The participation in groups of women with breast cancer meant that they could inhabit a space that provides moments of joy and pleasure as they enjoy leisure activities, such as walks or trips. The group activities reduce social isolation and many times improve self-esteem⁽¹⁴⁾, as seen here: *I took part in the*

trip to Rio Grande do Sul, I had never been in an airplane and I had the chance to take this trip with the group. We do not grow by staying at home all the time, I was staying at home too much, but at home, all we do is take care of the house, here we feel renewed.

Leisure, configured as an activity that is aimed at having fun and entertainment, was highlighted as an element of great importance and repercussion in their lives, acting as a powerful therapeutic resource.

For them, leisure is a way of seeking the cure for the disease because, when they have these moments of fun, they fill their minds with pleasurable thoughts, moving away from persistently negative thoughts about the disease⁽¹³⁾. Regarding leisure itself, the women revealed that: *I come here, I spend the afternoon here, we talk a lot, it is very good, it makes me feel good. We walk, we play, we have fun, we meet a lot of people, it's always like that in the group. Here I don't feel alone, I have a lot to say and I also like to listen.*

They also configure dialogue among each other as a form of leisure and of spending time, reinforcing the idea that the group is perceived as a space for pleasure and meetings that favor their general well-being. In this group experience, the physical space of the support groups transforms into the social *locus*, destined to helping each of them to do activities. The experience in a group of people with similar problems provides the opportunity to develop a therapeutic value and new ways of coping with the disease⁽¹³⁾.

It could also be verified that, among the benefits that come from the support group experience, there are improvements in self-esteem and body image, recovering them for life, for the joy of living. Such stimuli emerged when they observed that *life does not end, it goes on, and when we find a group like this, which supports us, encourages our self-esteem, even though my self-esteem is not low, I've always been an optimist. For me, being a part of a group like this makes me live another life, I was eager to help someone, encourage people, there are many people who feel lonely.*

The building of a society is done, initially, by understanding its relations. Language, the formulation of concepts and the clear definition of thought are elements that facilitate the comprehension of information and cause actions of citizenship⁽⁶⁾. Therefore, the language used by the women as a tool to facilitate their interaction and relations was remarkable, changing behaviors and relieving their suffering, based on the experience with the other women of the group: *we talk and sometimes even describe how we felt, telling our story sometimes. When we are part of a*

group, we meet people with the same problem, and we communicate with each other and start to accept it.

The group experience causes a constant change in each individual, which is shown to be dynamic and continuous through the interaction with the others⁽¹⁰⁾; habits, thoughts and feelings change and become behaviors in a relationship of friendship, not one of dominance. These changes were identified in a healthy way: *I was staying home too much, holding myself back, taking care of the house and everything, and by coming over here, we get happier, it changes your life for the better. It's fantastic to participate in a group like this!*

Exchanging experiences in this group makes women acquire greater skills for coping with cancer-related difficulties, encouraging them to change attitudes and reactions, besides improving knowledge of the self.

FINAL CONSIDERATIONS

The results of this study allowed us to understand that, for those women who participate in support groups for mastectomy, such groups are of fundamental importance in the socialization of the participants, since they make it possible for the women to exchange experiences, offer social support, information and orientation about the disease and its

treatments, development of leisure activities, improvement of self-esteem, self-image and interpersonal communication.

The physical space, organized by professionals who are interested in helping in the process of recovery and rehabilitation of women with breast cancer, can be transformed into a social space full of possibilities for human transformations that lead to the well-being of the group that is being helped.

The authors verified that it is fundamental to implant support groups in municipal and state public health services in Ceará, similar to what happens in the cities of Sobral and Juazeiro do Norte. Added to the incidence of this type of cancer, the women reveal satisfaction and the need for continuity with the group, having seen improvements in their health.

Multiprofessional efforts can be valued and recognized, with events, campaigns and meetings that call local and state authorities' attention to the situation. Support groups for women with breast cancer are very important, because it is a way to reduce the barriers for these women to access recovery and rehabilitation services.

Other studies should be developed to identify and validate the results of the changes in quality of life, in the favorable conditions for the recovery of health and prevention of aggravations, along with the women who participate in this kind of support groups.

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