

RELATO DE EXPERIÊNCIA: GRUPO PARA MULHERES COM CÂNCER DE MAMA EM RADIOTERAPIA

AN EXPERIENCE REPORT: GROUP FOR WOMEN WITH BREAST CANCER IN RADIOTHERAPY

INFORME DE EXPERIENCIA: GRUPO DE MUJERES CON CÁNCER DE MAMA EN RADIOTERAPIA

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RESUMO

Objetivo: relatar a experiência da criação de um espaço de acolhimento que promovesse o diálogo sobre os impactos que o diagnóstico do câncer traz para a vida das mulheres, o compartilhamento de sentimentos e o esclarecimento de dúvidas sobre o tratamento radioterápico. **Método:** trata-se de um estudo qualitativo, tipo relato de experiência realizado por acadêmicas de Enfermagem durante a construção de um grupo de ajuda mútua para mulheres com câncer de mama. O encontro ocorreu semanalmente, com duração de cerca de uma hora e iniciava com a apresentação das participantes. A seguir, duas perguntas norteadoras: “Como foi a descoberta da doença?” e “Quais são os sentimentos sobre o estado de saúde atual?” incentivavam o processo para o compartilhamento de vivências. **Resultados:** constatou-se que diversas pacientes não tinham recebido informações sobre os efeitos adversos e os cuidados durante a radioterapia. Além disso, foi possível compreender a dinâmica familiar e perceber a reflexão que as mulheres faziam sobre si mesmas e suas vidas durante o tratamento. **Conclusão:** a realização desse grupo foi fundamental para que os questionamentos manifestados fossem elucidados e para que as mulheres se tornassem mais fortalecidas, unidas e providas de conhecimento sobre o tratamento e o autocuidado.

Descritores: Neoplasias da Mama; Radioterapia; Oncologia; Enfermagem; Saúde da Mulher; Saúde Mental.

ABSTRACT

Objective: To report the experience of creating a welcoming space that promotes dialogue about the impacts that the diagnosis of cancer brings to women's lives, sharing feelings and clarifying

doubts about radiotherapy treatment. **Method:** this is a qualitative study, experience report type carried out by Nursing students during the construction of a mutual-help group for women with breast cancer. The meeting took place weekly, lasting about an hour, and began with the presentation of the participants. Then, two guiding questions emerged: “How was the discovery of the disease?” and “What are your feelings about your current health status?” encouraged the process of sharing experiences. **Results:** it was found that several patients had not received information about adverse effects and care during radiotherapy. In addition, it was possible to understand the family dynamics and realize the reflection that women made about themselves and their lives during treatment. **Conclusion:** the creation of this group was essential for the questions raised to be elucidated and for the women to become more empowered, united, and provided with knowledge about treatment and self-care.

Descriptors: Breast Neoplasms; Radiotherapy; Medical Oncology; Nursing; Women's Health; Mental Health.

RESUMEN

Objetivo: relatar la experiencia de crear un espacio acogedor que promueva el diálogo sobre los impactos que el diagnóstico de cáncer trae en la vida de las mujeres, compartiendo sentimientos y aclarando dudas sobre el tratamiento con radioterapia. **Método:** se trata de un estudio cualitativo, tipo relato de experiencia realizado por estudiantes de enfermería durante la construcción de un grupo de ayuda mutua para mujeres con cáncer de mama. El encuentro se llevó a cabo semanalmente, con una duración aproximada de una hora y comenzó con la presentación de los participantes. Luego, se realizaron dos preguntas orientadoras: “¿Cómo fue el descubrimiento de la enfermedad?” y “¿Cuáles son sus sentimientos acerca de su estado de salud actual?” alentó el proceso de compartir experiencias. **Resultados:** se encontró que varios pacientes no habían recibido información sobre efectos adversos y cuidados durante la radioterapia. Además, fue posible comprender la dinámica familiar y darse cuenta de la reflexión que las mujeres hacen sobre sí mismas y sus vidas durante el tratamiento. **Conclusión:** la realización de este grupo fue fundamental para dilucidar las cuestiones planteadas y para que las mujeres se empoderaran, se unieran y se les dotara de conocimientos sobre el tratamiento y el autocuidado.

Descriptores: Neoplasias de la Mama; Radioterapia; Oncología Médica; Enfermería; Salud de la Mujer; Salud Mental;

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INTRODUCTION

Breast cancer is the most common among women in Brazil and the world, representing about 28% of new cases per year¹⁻². In 2017, there were 16.16 deaths per 100,000 Brazilian women, in which the South (73.07/100 thousand) and Southeast (69.50/100 thousand) regions had the highest rates³. Breast cancer has multifactorial causes such as age, environmental, genetic, and endocrine aspects. Endocrine factors are related to the length of exposure to the estrogen hormone, such as early menarche, late menopause, first pregnancy after the age of 30, and nulliparity. Habits such as alcohol consumption, smoking, obesity, lack of physical activity, and mutations in the BRCA 1 and BRCA 2 genes are conditions that increase the risk⁴. The age group between 50-59 years old is the most prevalent. It is estimated that 66,280 new cases of breast cancer are diagnosed each year in the triennium 2020-2022³.

Radiotherapy is one of the therapies used for treatment, which consists of the application of ionizing radiation to the site of the tumor, present or not, which acts on the DNA of cells and inhibits their proliferation⁵. The duration of treatment is approximately 2 months, usually performed in an outpatient clinic with daily sessions. The most frequent side effects of radiotherapy sessions reported by patients are skin changes, burns, fatigue, pain, and decreased self-esteem⁶.

The diagnosis and treatments for cancer are reflected in the daily lives of these women and significantly impact their mental health. Upon receiving the diagnosis of the disease, they immediately refer to the idea of a “death sentence” and feelings such as fear, anguish and anxiety begin to awaken⁶.

During the treatment and coping with the disease, many women have the phases described by Kübler-Ross⁷.

There is the stage of shock and denial, which refers to the moment when the patient is aware of her situation but refuses to accept it. The stage of anger for being sick, bargaining

negotiations for healing with the professional team, family members, or divine entities, melancholy, and depression, manifested by signs of hopelessness and withdrawal are observed. Finally, acceptance following the inevitable disease and possible death⁷.

Nurses have a fundamental role in active listening and in welcoming negative feelings, providing individualized care for patients undergoing radiotherapy treatment. Nursing consultation allows professionals to get to know the patients, identifying the main problems and defining interventions for the best possible outcome⁸.

In addition to routine nursing consultations, other support tools can be adopted. Mutual help groups are spaces where participants have the opportunity to create bonds with professionals and with people who are experiencing similar situations, sharing experiences and knowledge⁹. This type of group is carried out voluntarily, openly, and composed of individuals who identify themselves through their experiences¹⁰. In the case of mutual help groups aimed at coping with cancer, it seeks to assist in coping with the disease and encourage women to seek their autonomy and be protagonists of their recovery⁹.

For professionals, this activity can bring relevant information that was not identified in the Nursing consultation or by the health team, constituting a differential to improve care and meet the needs reported by the participants in the groups⁹.

OBJECTIVE

To report the experience of nursing students from the Federal University of Health Sciences of Porto Alegre, during the creation, execution, and conduction of a space that enabled to offer mutual help groups for women with breast cancer undergoing radiotherapy treatment at Hospital Santa Rita, from the Santa Casa de Misericórdia Complex in Porto Alegre.

METHOD

The experience report is a qualitative methodology whose crucial factor is the articulation between practice and theory, approaching experiences that generate reflections on a theme cohesively and succinctly to share pertinent themes. Therefore, we present an experience report lived by nursing students in the fifth semester, about the mutual help group developed for women undergoing radiotherapy treatment, in the assisted practice of the Mental Health Nursing Discipline of the Federal University of Health Sciences of Porto Alegre (UFCSPA). The setting of this activity was in the outpatient clinic of the Hospital Santa Rita Radiotherapy Service, belonging to the Santa

Casa de Misericórdia of Porto Alegre, which is a reference hospital for the treatment of cancer. The group took place from April to June 2018, weekly, lasting one hour.

This practice was conducted by a professor from the Department of Nursing, from the women's health center with experience in oncology, groups, and nursing consultation, together with nursing students. Nine meetings were held with a total of 36 participants, women with breast cancer, aged 24 to 75 years old. The group came about as a result of a request from the nurses of the Radiotherapy Service given the large demand of patients and the team's difficulty in providing assistance aimed at the needs of these women. As requested, the students began to work on viable alternatives for the execution of the groups under the coordination of the responsible professor, without the direct input of the nurses in the sector.

Because of the methodology used (experience report), there was no need to submit it to the Research Ethics Committee (CEP) ⁽¹¹⁻¹²⁾. Regarding the descriptors used, the platform of the Virtual Health Library was searched for those that best represented the topic addressed. To identify the participants, the letter P will be used, indicating participants, followed by Arabic numerals.

RESULTS

Activity planning

The organization of the activity began with visits to the radiotherapy service, allowing for the integration of the academic group with the local nurses. In this way, we identified the demands of patients and the need to improve the reception service. The possibility of a mutual-help group was considered, as the women undergoing treatment remained in the waiting room for two to four hours, without a space for listening and exchanging experiences. The students created posters inviting them to participate in the group, which were posted in the waiting room and at the entrance to the service, containing information about the place, day, and time of the activity.

Group development

When starting the group, there was a moment of presentation between the women present in the group and us, nursing students. Next, we asked trigger questions to encourage reporting and exchange of experience.

We started by asking “What was it like to discover the disease?”. At this moment, a change in the patients' facial expressions was noticed, some smiling and others with a distant look. Many reported that it was a shock, that the disease was very bad. P1 reports that “I didn't want that result”, “I was scared”. Some women pointed out the sadness experienced as a triggering factor for the disease, as well as the lack of attention to their health. On the other hand, others said they had no reason to develop the disease, P2 reports as “Something I have to go through here (in this life)”.

Family participation has always been a frequently mentioned aspect. Some women reported that they received great family support, which offered them support and helps in difficult times, as P1 “I was scared, but everyone supported me”, P3 says that “Upon learning about the disease, my children took a plane from São Paulo and in the other day they were already here”. While others stated that family members were not ready to help and they, although sick, needed to remain responsible for household chores; P4 reports that “I take care of my family more than me”, P5 says “I'm feeling a nuisance for them” and “No one helps me at home”, P6 states that “My husband does nothing”. These statements show how the society we live in is shaped by patriarchal faces, still reproducing gender roles and making women responsible for domestic activities. The discovery of breast cancer, in most cases, was made by the patients in the self-examination, where they identified small “lumps” and then sought care from a health professional for examinations.

The second guiding question is, “How do you feel about your current health?”. According to P7 “It's great to be alive, even though the treatment was tiring, it was worth fighting for your life”, P8 states “I want to live”, P9 reports “I want to be well to live with my family, who I love a lot”. The predominant feeling was one of resilience. Patients stressed the importance of fighting the disease and restoring their health. This motivation and hope were shared with the women who were in the first radiotherapy sessions. We noticed in their reports how P10 refers “I didn't know I was so strong”; P11 reports “I discovered something very important, I didn't know I had this courage” and “A strength appeared that I didn't know I had”. Women, when faced with the disease, reflect on themselves and create a perspective of change in their attitudes in the future; P12 refers to “I must not 'swallow' everything”; P13 reports “I must think more about myself”.

“I thought the poster was aggressive, the word cancer does not concern me”, this expression was brought up by P14, one of the participants who was undergoing treatment and felt offended when reading the group's promotional poster. She claimed not to have the disease, showing a process of denial in the situation she was going through. Because of this scenario, the advertising poster was changed and the word “Cancer” was removed, as other women could be experiencing the same feeling and not attending the group.

We observed that part of the participants did not demonstrate a full understanding of the treatment they were undergoing, as in the case of P15, P16, P17, P18, and P19. Many questions related to the functioning of radiotherapy were mentioned, especially regarding the purpose and side effects. P15 states “Nobody told me anything about it” (exercises to improve the mobility of the arm that underwent axillary emptying), P16 reports “I did not receive any information about food”, P17 states, “Nobody told me about skincare”, P18 asks “How is the marking done?” and P19 asks “What is emptying?”, showing a gap in the process of education, health promotion and self-care.

DISCUSSION

Importance of nursing care

As we experienced, a study carried out at the Federal University of Rio Grande do Sul with women who attended the Radiotherapy Clinic¹³, also exposes a situation in which women lack information about the treatment. Thus, the need and importance of care provided by nurses are highlighted since by implementing measures to guide these women, there is a significant impact on the prevention of adverse effects of treatment, such as radiodermatitis¹⁴.

Ahead of these findings, we realize the importance of quality care that promotes health education, recovering the autonomy of patients, making them independent for their self-care and appropriate knowledge about their health and disease process.

Nursing constitutes a link between the team of professionals, the patients, and the family⁹. This interaction is important to strengthen the care network these women receive, making the journey of treatment more welcoming and humane. Nursing professionals are the ones who stay with the patient the most, their perception and knowledge of the different feelings these women experience to add value to the work of the multidisciplinary team, with the possibility of offering more qualified and comprehensive care ^{9, 15}. We noted that the treatment and care of breast cancer must be multi-professional and articulated, allowing women to receive guidance and information about the disease they are experiencing. Thus, it allows women to become protagonists in the health and disease process and develop strategies to overcome the adversities of the moment they are going through¹⁶.

Benefits perceived with the formation of the group

The formation of the group has become an extremely important tool to restore women's self-esteem, build bonds of support and inform them about the treatment. Positive group therapy can enhance the effectiveness of breast cancer treatment, also helping in the process of self-knowledge of the disease, and establishing stronger bonds between patients and the leader¹⁷.

During radiotherapy sessions, many women end up facing different feelings⁷, many of them negative and which make the treatment even more painful¹⁷. Therefore, the group was able to alleviate these sensations and create a welcoming environment. After the activities, the women expressed feelings of acceptance, renewed hopes, and solidarity with the other group participants. Information and the exchange of shared experiences were also fundamental for women to seek to become protagonists of their self-care, aware of the possibilities of treatments offered and their current health situation. As in other studies⁹⁻¹⁹⁻²⁰, the acquisition of information and the bond created enabled the demystification of cancer by the patients, motivating them to help each other. Some statements demonstrate this: "How good it is to share our experiences, we can help each other", "Here I saw that I'm not alone".

Limitations found

During the performance of the group, some problems appeared. We observed difficulty in adapting the time to the activity because the radiotherapy sessions took place simultaneously. This fact generated great fear in women to participate in the group and be placed to fit during treatment. As a result, in the first few weeks, few women attended the meeting. To handle this situation, the unit nurse drew up a list of patients who would go to the Nursing Consultation and referred them to the group. After the activity, the information of the patients was passed on to the unit nurse as a way to share the needs.

Another barrier that contributed to reduced adherence to the group was the concern of women with transportation. Many patients came from inner cities and depended on transportation provided by the city of reference, and generally, it was not flexible with other activities beyond the fixed time of the radiotherapy session.

Another aggravating factor was the change in the unit's routine, to a new possibility of assistance such as mutual help groups. This situation demanded that professionals leave their comfort zones and allow to perceive other forms of care.

CONCLUSION

The mutual-help group was a watershed in the treatment of patients, as it allowed them to feel belonging to the group and important for being there, in contrast to what they previously reported, when they felt alone and being just another number to be assisted. It is important that professionals have expertise in the oncology area and skills related to nursing consultation and working with groups. Health education, one of the pillars of nurses' work, is extremely necessary as many patients look for ways to combat radiotherapy symptoms from unreliable sources without scientific evidence, available on the internet, which can end up causing side effects to the treatment, such as damage.

For us as students, this experience was perceived as unique and extremely important for our education. We acquired new knowledge, skills, and attitudes, improving our care, seeking comprehensive, safe, and quality care. We also have overcome the adversities encountered and expanded the welcoming culture on other fronts, with possibilities of returning to the Radiotherapy Service for the work carried out.

CONTRIBUTIONS

All authors contributed equally in the design of the research project, data collection, analysis, and discussion, as well as in the writing and critical review of the content with intellectual contribution and the approval of the final version of the study.

CONFLICT OF INTERESTS

Nothing to declare.

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