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CUIDADOS E VIVÊNCIAS DAS PACIENTES NA FASE DA SOBREVIVÊNCIA PÓS-TRATAMENTO DO CÂNCER GINECOLÓGICO

Care and experiences of patients in the post-treatment survival phase of gynecological cancer

Cuidados y experiencias de los pacientes en la fase de supervivencia post-tratamiento de cáncer ginecológicos

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RESUMO

OBJETIVO: conhecer as experiências das mulheres na sobrevivência do pós-tratamento do câncer ginecológico. **Método:** estudo qualitativo, desenvolvido com vinte e cinco pacientes do Instituto Nacional do Câncer, com dados coletados entre fevereiro e abril de 2022, por meio de entrevistas norteadas por roteiro semiestruturado. As falas foram analisadas pela perspectiva da análise de conteúdo. **Resultados:** após o tratamento, a saúde hormonal e reprodutiva foi seriamente comprometida, além de outros problemas correlacionados, entre esses, destacam-se as limitações físicas e psicológicas que restringem suas atividades diárias e prejudicam a qualidade de vida. **Conclusão:** é necessário que o foco no investimento para o cuidado de suporte seja além da realização de atividades de tratamentos isoladas, e sim, uma estrutura multidisciplinar capaz de atender as reais necessidades e assim, ajudar nessa fase difícil de sobrevivência do câncer.

DESCRITORES: Neoplasias genitais; Feminino; Sobreviventes; Saúde sexual; Análise qualitativa.

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ABSTRACT

OBJECTIVE: to understand women's experiences in surviving post-treatment gynecological cancer. **Method:** qualitative study, developed with twenty-five patients from the National Cancer Institute, with data collected between February and April 2022, through interviews guided by a semi-structured script. The speeches were analyzed from a content analysis perspective. **Results:** after treatment, hormonal and reproductive health was seriously compromised, in addition to other related problems, including physical and psychological limitations that restrict daily activities and impair quality of life. **Conclusion:** it is necessary that the focus on investment in supportive care goes beyond carrying out isolated treatment activities, but rather, a multidisciplinary structure capable of meeting the real needs and thus helping in this difficult phase of cancer survival.

DESCRIPTORS: Genital neoplasms; Female; Survivors; Sexual health; Qualitative analysis.

RESUMEN

OBJETIVO: comprender las experiencias de las mujeres en la supervivencia del cáncer ginecológico post-tratamiento. **Método:** estudio cualitativo, desarrollado con veinticinco pacientes del Instituto Nacional del Cáncer, con datos recolectados entre febrero y abril de 2022, mediante entrevistas guiadas por un guion semiestructurado. Las declaraciones fueron analizadas desde la perspectiva del análisis de contenido. **Resultados:** después del tratamiento, la salud hormonal y reproductiva quedó seriamente comprometida, además de otros problemas relacionados, entre ellos limitaciones físicas y psicológicas que restringen las actividades diarias y perjudican la calidad de vida. **Conclusión:** es necesario que el enfoque de la inversión en cuidados de apoyo vaya más allá de la realización de actividades de tratamiento aisladas, sino de una estructura multidisciplinaria capaz de atender las necesidades reales y así ayudar en esta difícil fase de supervivencia del cáncer.

DESCRIPTORES: Neoplasias genitales; Femenino; Sobrevivientes; Salud sexual; Análisis cualitativo.

INTRODUCTION

Advances in early detection, treatment and rehabilitation have contributed to an increase in the number of gynecological cancer survivors.[1] In Brazil, cervical cancer is the third most common type of cancer among women, and 17,010 new cases have been estimated for 2023.[2]

Due to the nature and location of the disease, after the end of gynecological oncology treatment, women may have numerous sexual complaints such as decreased libido, vaginal dryness and shortening, as well as psychological and psychosocial impacts.[3]

Although surgeries and treatments have become less radical and invasive, they can still cause scars and mutilations that affect various nerves and blood vessels involved in important gynecological and urinary tract functions.[4]

In light of this, addressing issues of cancer survivorship, and interventions to improve quality of life is an ongoing challenge for research and health professionals, as complaints are distressing and can last for a long time, which can negatively impact people's health.[5]

Sexual health is an integral part of human life, and when it is compromised, it can cause numerous physical, emotional and psychological discomforts.[6] Despite the high prevalence of sexual complaints in the post-treatment survival phase, there are countless cases of patients who do not receive basic clinical care, and the reasons are diverse: embarrassment at broaching the subject, lack of time on the part of health professionals, priority on treating the tumor, and even ignorance of effective strategies that can be used.[7]

Given this scenario, it has become necessary to know the experiences of women in the survival phase of post-treatment for gynecological cancer, and thus to know the real needs in order to help and offer the health care that can be provided.

METHODOLOGY

Phenomenology was applied from Heidegger's perspective, which seeks to understand the meaning of being, considering its singularities and relationship with the lived context.[8] The Consolidated Criteria for Reporting Qualitative Research (COREQ) guide was used for the scientific writing of this study.[9]

The research was carried out with gynecological cancer survivors who had undergone treatment at the National Cancer Institute (INCA), a federal public hospital which is a reference in cancer treatment, located in Rio de Janeiro, Brazil.

The subjects of this investigation were patients who had undergone gynecological cancer treatment at INCA's hospital unit II, totaling twenty-five participants. Semi-structured interviews were used to gather the information and the patients were selected using the convenience sampling method, since the initial idea was to conduct the interviews on site, due to the availability of access to the interviewees, and because it allowed for a low operational cost for the research.[10]

The inclusion criteria were voluntary acceptance, being over 18 years old, having finished treatment for gynecological cancer (uterus, ovary, vulva, endometrium) and being followed up in unit II of the hospital. The exclusion criteria were having psychological or mental problems and being in palliative care.

After this, we opted for telephone contact, which was consulted in the patient's electronic medical records, and 35 possible participants were selected to be contacted. Of these, five did not answer the phone, three did not agree to take part in the study and two were undergoing treatment due to recurrence of the disease.

Thus, 25 women agreed to take part, and the interviews were scheduled in advance according to each participant's availability. The interview technique used an individual approach, and for the sake of convenience and privacy, the interviews were carried out in their respective homes, via Whatsapp video calls, and took place between February and April 2022, lasting between 45 and 60 minutes.

The main researcher, who holds a doctorate and is the first author of this article, was responsible for conducting the interviews and had experience in the data collection technique, having previously carried out similar work for her master's degree. She was also familiar with the research setting, as she works as a civil servant at the hospital. However, no prior relationship was established between the interviewer and the participants, since their academic and professional objectives are independent.

When the interviews began, the objectives of the study were explained to each participant. A sociodemographic characterization of the patients was carried out, with data being collected on the disease and treatments, followed by the guiding question "what challenges do you encounter as a cancer survivor"? The questionnaire was made up of open questions, and the interviewees were informed that they were free to answer the research question and that the intention was to listen to their perceptions and experiences. In this way, we were able to listen attentively and open up to the unveiling of "being" when trying to understand the patients' experiences, stripping away any opinion that the researcher might have in order to infringe on this perception.

The first stage was analysis, when the women's accounts of their experiences were listened to and read repeatedly. After the interviews, the field notes allowed us to recall and emerge from the stories told, in other words, revealing the way of being of those who tell about themselves, allowing for a theoretical-philosophical-methodological framework.[8]

In order to preserve the identity of the participants, they were identified by numbers from 1 to 25, according to the order of the interviews. The interviews were recorded on electronic media and later transcribed. No repeat interviews were carried out in this research. However, at each meeting with the participants, the researcher turned to the research team for any adjustments that might be necessary to meet the proposed objectives. The criterion for ending the interviews was data saturation when the information became repetitive and redundant.[11]

The study was approved by the Ethics Committee of the National Cancer Institute under No. 5.234.121 and CAEE No. 53733421.6.0000.5274.

RESULTS

The 25 participants were aged between 30 and 65, 9 of them had finished treatment six months ago (at the time of the interview) and 18 had been diagnosed with cervical cancer. Of the total sample, 20 were under 45 and said that after treatment, their hormonal and reproductive health had been seriously compromised, as well as other related problems. These include the physical limitations of the body, which guide and restrict daily activities that need to be carried out.

> *The pain in my joints is terrible [...] I have insomnia and sleep badly because I can't relax, the pain in my legs is unbearable. (patient 11)*
>
> *I feel a lot of pain all over my body, some days I can't get out of bed. (patient 7)*
>
> *In addition to the pain in my arms and legs, I have swelling, and sometimes it gets so big that it's difficult to move around. (patient 19)*

Pain, especially in the joints, legs and arms, causes numerous discomforts and complications such as stiffness, decreased range of motion and sensory changes, which can reduce the function of the upper and lower limbs and make simple daily activities a continuous challenge.[12]

In addition to a decrease in the intensity of activities that used to be carried out naturally, tiredness and fatigue are other complaints that accompany women, and activities that used to provide pleasure and well-being become difficult and even discouraging.[13]

> *I still can't do my daily activities and I feel very tired, which prevents me from doing small household chores. (patient 12)*

> *After treatment, there are times when I just want to sleep and do nothing else [...] I only get up because I have a small child who needs my care. (patient 25)*

In addition to physical limitations, there are other symptoms that can persist after treatment, such as depression and anxiety. [13]

> *At the end of my treatment, I sought help from a psychologist and psychiatrist because my anxiety was very high and I also had a compulsion for food, so I really had to seek medical help. (patient 22)*
>
> *I used integrative medicine to reduce my anxiety, because when I'm very anxious, I self-sabotage by not taking my medication properly, I eat badly and I don't do the physical exercises that are important to me. (patient 17)*
>
> *After all the suffering I've endured, I've had a lot of psychological scars [...] you're suffering from pain in your body that also affects your soul [...] I didn't want people to feel sorry for me, but rather a means or help so that I can actually reduce so much suffering. (patient 4)*
>
> *In addition to my health problems, I have a daughter who needs special care, and this made me more anxious, because I needed to look after her and myself [...] in short, I had to seek psychiatric medical assistance to cure my mind. (patient 13)*

Faced with episodes of mental and psychological issues, it is clear that these women must be assisted and listened to in their complaints and reports, since they seriously compromise their quality of life. Other survivors try to redirect their pain in various ways, which is a necessary step on the road to recovery and overcoming, even if they have a difficult condition that they need to learn to live with.[14]

> *I always tried to think positively, I told myself that the disease wouldn't get me down and I wouldn't lose to it. From diagnosis to the end of treatment I had this optimistic attitude and it was essential not to lose hope. (patient 14)*
>
> *I believe that family and medical support was essential for me not to have negative thoughts, and I always thought that everything would pass and that in the end everything would be fine. It was this support and God that made all the difference to me. (patient 16)*

In addition to the sequelae resulting from the post-treatment period, there are also other symptoms that can persist, such as vaginal dryness, lack of libido, vaginal shortening and other causes of compromised sexual health.[15]

> *After the treatment, everything got worse, I started to feel a lot of pain during sexual intercourse, I have vaginal dryness and shortening and no desire to have sex with my husband. (patient 2)*
>
> *I have a serious problem with vaginal stenosis and this affects my self-esteem and my relationship with my spouse [...] it makes me sad and very afraid that I will never be the same woman again. (patient 6)*
>
> *After the treatment, I began to experience vaginal dryness and stenosis, which is why I avoided sexual intercourse. I had to have a serious talk with my husband and told him that he could have another woman to satisfy him. (patient 4)*

Gynecological cancer survivors suffer an impact on their relationship with their own bodies, as mutilation and scarring negatively influence their perception of themselves and a sense of strangeness about their own bodies. In this sense, body image and self-esteem are an important issue in the condition of survival and are often associated with a variety of other emotional and interpersonal concerns that impact on the personal relationships and sexuality of survivors and their partners.[16]

In view of this, the provision of medical and multi-professional assistance has become essential, because through a thorough assessment of sexuality issues, actions can be developed to promote health and improve quality of life.[17]

> *I received help from the sexuality outpatient unit, where there is a nurse who explains, advises and with this I feel much better [...] the conversations I had with her made me understand that the disease can be better treated when we receive assistance. (patient 20)*
>
> *At the cancer hospital, I had all the support I needed, as did the nurses, who gave me all the necessary instructions about the symptoms I might have and how to minimize them. (patient 19)*
>
> *The medical staff were very communicative and helpful and immediately after treatment, I had a medical consultation which told me what symptoms I might have, including some that could persist for years. (patient 24)*

Women expect health professionals to initiate conversations about sexuality, as this bond can facilitate dialog about these issues and help survivors to better understand the care process.[18]

The profound intimate changes have an impact on women and make them change their way of thinking and seeing themselves, reinventing themselves in the face of the circumstances imposed on them, so that they can continue to fight for their identity, despite the constant presence of pain.[19]

DISCUSSION

The definition of survival in the clinical trajectory of cancer is highly debated, as it can be considered a threshold between the disease and cure, that is, patients still need medical care mainly due to the physical and emotional changes that result from the course of treatment experienced, and there are countless needs to be met, whether specific or complex, in order to minimize suffering.[20]

Specifically in relation to follow-up care support, studies have shown that patients may have moderate or severe unmet support care needs after treatment, and most of them had expressed concern about this, as cancer follow-up appointments prioritize "survival" over experiential issues of living with and beyond cancer.[21]

In this sense, the importance of doctor/patient communication is emphasized, since patients have many questions related to the disease in the post-treatment period, especially because most of them are not prepared for the countless changes that occur in their lives, and many end up being negatively surprised.[22]

In this study, the participants sought information on what forms of care they could have in the post-treatment survival phase; and another study corroborates this, since health professionals can be a valuable aid for patients to express their concerns and alleviate their emotional burden.[23]

To this end, communication skills need to be implemented, as this increases empathy and probably other aspects that can result in a strategy for building a relationship based on trust, and reducing the interpersonal barriers that may exist.[18] Therefore, training with a proactive approach is needed for oncology health professionals, and thus with adequate technical training, improve access for patients who need specialized medical care.[24]

The suffering caused by cancer not only puts patients through physical and psychological challenges, but also their personal and social relationships. A survey on marital sex life after gynecological cancer showed that many patients were afraid of being abandoned by their partner and worried that they were not meeting their spouse's needs, which caused difficulties in maintaining relationships and was a source of constant conflict between the couple.[25]

A study of Muslim women who had been diagnosed with gynecological cancer corroborates these findings by showing that after treatment, they had difficulties and lacked the will to have sex, and this was due to the fear of feeling pain or discomfort, and thus further damaging their health.[26]

On the other hand, a study to determine the predictive factors of sexual function and suffering carried out with Iranian women who had undergone gynecological cancer did not identify a direct relationship between these two factors, since the results showed that other elements such as unfavorable economic conditions and lack of support can have an even greater negative impact on the lives of surviving patients.[27]

Intimacy in married life after cancer can be considered one of the most stressful and painful experiences for the couple, so that after treatment therapy sessions, there can be a marked decline in libido and sexual pleasure and possible emotional distancing between them.[28]

In this sense, resilience as the human capacity to face and respond positively to life situations, as well as the social support received, are predictors of health quality; and based on this broader understanding, non-pharmacological interventions such as music therapy, therapies and support groups can be sources of care strategies that can be offered to survivors.[24]

It is important to note that in this study the patients were satisfied with the treatment received by the cancer hospital and the health professionals who work there. However, this is not a reality in the country's public hospitals, because with a low budget for health costs and precarious access to cancer care, they are unable to absorb the high demands of the population and, consequently, late diagnosis and treatment of patients.[29]

Finally, it should be emphasized that perceptions related to self-image can cause discomfort, as patients need to promote self-acceptance and approach the new identity of their bodies, and this process is involved with difficulties, and the psychological aspects are extremely affected, with frequent complaints of symptoms of anxiety and depression, which in the end, are not always adequately treated.[30]

FINAL CONSIDERATIONS

This study sought to understand the experiences and ongoing challenges faced by women survivors in the post-treatment phase of gynecological cancer.

Patient survivors, regardless of age, after undergoing treatment for the disease, have increased risks of sexual dysfunction and psychosexual suffering, and have experienced numerous problems that persist for a long period, which negatively impact on various aspects of their lives, be they physical, psychological or psychosocial.

In view of this, it is necessary to focus on investing in supportive care beyond carrying out isolated treatment activities, but rather a structure with a holistic and multidisciplinary vision of care.

As limitations of the study, although we tried to seek greater diversity in the sample group made up of women who have had cancer of the entire gynecological female tract, the results represent a small proportion of patients who suffer from these problems. It is therefore suggested that studies be expanded to other hospital units and other types of tumors so that new evidence can be obtained in different realities, in order to gain a better understanding of the subject.

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