

ORIGINAL ARTICLE

### PSYCHOSOCIAL REPERCUSSIONS OF RADIOTHERAPY TREATMENT FOR CERVICAL CANCER: A QUALITATIVE APPROACH

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### ABSTRACT

**Objective:** to understand the psychosocial repercussions of post radiotherapy treatment for cervical cancer. **Method:** qualitative study, with the participation of patients in post radiotherapy treatment for cervical cancer in an onco-gynecologic nursing outpatient clinic, located in the Municipality of Rio de Janeiro - Brazil. Data were collected during the months of March and April 2019 by means of open interview and submitted to content analysis. **Results:** four categories were defined: the construct of social roles: the loss of female identity; the sexuality of post-treated women for cervical cancer: marital repercussions; difficulties in adapting to the new life condition: rebuilding the body image; living with cervical cancer: rethinking life and rebuilding values through the support network. **Final considerations:** the results contribute to the direction of care, increasing the quality of life and helping these women reorganize their professional, social, and family lives.

**DESCRIPTORS:** Stress, Psychological; Psychosocial Impact; Psycho-Oncology; Radiotherapy; Brachytherapy.

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### INTRODUCTION

Cervical cancer is a serious public health problem worldwide, especially in developing countries<sup>1</sup>. According to the National Cancer Institute (INCA)<sup>2</sup>, 16,590 new cases are expected in Brazil by 2021, with an estimated risk of 15.43 cases per 100,000 women.

This type of cancer occupies the third position of primary location of incidence and the fourth cause of cancer mortality in women in the country<sup>2</sup>. These data show that this type of cancer has expressive social magnitude since it is responsible for high rates of morbidity and mortality<sup>1</sup>.

Despite advances in terms of treatment and control of the disease, most diagnoses of cervical carcinoma in developing countries occur in the advanced stage<sup>1</sup>. At this stage, curative surgery is no longer possible due to the involvement of essential structures adhered to the tumor such as bladder, bowel and rectum<sup>3</sup>. In these cases, pelvic radiotherapy alone or in conjunction with chemotherapy becomes the most effective treatment of choice<sup>4</sup>.

Although the administration of ionizing irradiation and the techniques for protecting adjacent areas have been improving, this treatment modality produces adverse events in the pelvic floor, causing late sequelae<sup>5</sup>. When it reaches the female pelvis, radiation can cause inflammation in the mucous membranes of the rectum and bladder, which can evolve to fibrosis, stenosis, and fistulas, which are responsible for chronic bladder and gastrointestinal dysfunctions and the consequent permanent use of urinary devices with significant repercussions in the work and daily activities of this population<sup>6</sup>.

Besides these organs, when radiation reaches the vaginal lumen it may cause irreversible alterations, leading to a series of sexual dysfunctions associated with the loss of elasticity of the vaginal mucous and consequent vaginal stenosis, causing interference in the conjugal life of women after the treatment<sup>7</sup>. Pelvic radiation can also lead to ovarian atrophy, inducing early menopause, thus contributing to the sexual dysfunction of women who require this therapeutic modality<sup>6</sup>.

Although the benefits provided by radiotherapy have been proven in terms of survival and local control of the disease, the search for a cure or better prognosis sometimes considers only the biological aspects of the woman's life after treatment, relegating the social, cultural, and psychological dimension in which she lives<sup>5</sup>.

In view of these reflections, health professionals should look at these women from a different perspective with an approach that considers the possible psychosocial repercussions inherent to radiotherapy treatment for cervical cancer, aiming at establishing quality care focused on humanization and comprehensive care. From this perspective, the following question arose: What were the psychosocial repercussions of the post-radiotherapy treatment for cervical cancer on the interviewed women?

Therefore, to answer this question, the following objective was defined: to understand the psychosocial repercussions of the post-radiotherapy treatment for cervical cancer.

### METHOD

This is a qualitative study, taken from a master's thesis and based on the consolidated criteria for reporting qualitative research (COREQ)<sup>8</sup>. The research was carried out in a nursing ambulatory of a hospital of national reference in gynecological cancers situated in the city of Rio de Janeiro - Brazil, anchored in the content analysis according to Bardin<sup>9</sup>.

The convenience sample aimed to capture all patients who returned for the first follow-up visit, which occurred 45 days after the end of radiotherapy in the outpatient clinic. All patients were in advanced stages (IIb, IIIa and IIIb) and underwent the same number of radiotherapy sessions. They were personally approached and invited to participate in the research after the nursing consultation in a private room, where they were explained the objectives of the research through the informed consent form.

Inclusion criteria were women over 18 years of age and undergoing primary posttreatment in the modality radiotherapy/brachytherapy for cervical cancer; and patients with severe discomfort associated with treatment such as extreme weakness, nausea, and pain at the time of the interview were excluded.

Data collection started in February 2020 and ended in April of the same year, considering the saturation point of the interview data<sup>10</sup>, totaling 28 participants. The method adopted for data collection was the open interview from a central question focused on the perception of possible psychosocial repercussions of post-radiotherapy treatment in daily life, daily activities, and marital, professional, and family relationships.

It is noteworthy that all interviews were recorded with the aid of a tape recorder and, subsequently, reproduced for the participants. After authorization for data disclosure, they were transcribed in full, and, to maintain anonymity and data confidentiality, the interviewees were identified numerically in a subsequent manner from (E1) to (E28).

The set of interviews made up the text corpus that was processed by qualitative analysis software Interface de *R pour les Analyses Multidimensionalnelles de Textes et de Questionnaires* (IRAMUTEQ)<sup>11</sup>. We chose to use the Descending Hierarchical Classification (DHC) method to classify the Text Segments (TS) according to their respective vocabulary words and divide them according to the frequency of reduced forms.

Thus, aiming at a better understanding of the results, the basic steps of content analysis according to Bardin<sup>9</sup> were observed, as follows: 1. organization and preparation of the data for analysis; 2. detailed reading and evaluation of the transcribed content; 3. analysis of the coding process performed by the IRAMUTEQ software; 4. Coding process to describe the ambience or individuals and the categories or themes for the analysis; 5. Elucidation of the peculiarities of the representation of the description and themes in the qualitative narrative, based on the current literature after the categorical analysis; 6. Segmentation of the data and presentation of the results after the analysis.

The research was approved by the Research Ethics Committee with Opinion No. 3,648,823 and No. 3,465,739.

### RESULTS

When coding the data, the IRAMUTEQ software recognized the separation of the corpus into 138 text segments (TS), and 106 (76.81%) were used. In addition, 4,633 occurrences of words were recorded (667 were distinct from each other and 71 occurred only once).

The segments used were divided into two groups and subdivided into five classes of meaning, presenting the most frequent active forms and the ratio of the percentage obtained in each class by means of the DHC as shown in Figure 1.

Class 5 17%		Class 1 20,8%		Class 3 17%		Class 2 23,6%		Class 4 21,7%	
Words	X2	Words	X2	Words	X <sup>2</sup>	Words	<b>X</b> <sup>2</sup>	Words	$\mathbf{X}^2$
lack	29,95	pain	32,78	bother	25,65	God	24,28	nephrostomy	18,94
home	16,77	intercourse	26,64	husband	19,86	die	19,61	look	14,47
activity	15,76	bleeding	20,16	shame	9,93	need	13,47	adapt	10,5
tidy up	14,78	close	20,04	menopause	8,58	strength	13,47	mirror	6,95
companion	9,93	vagina	20,04	understand	3,21	sad	12,6	disturb	3,67
get	8,54	pleasure	15,87			cry	12,6		
feel	8,39	burning	15,87	1		think	10,13		
tired	6,89	tight	11,79			son	10,08		
horrible	5,41	sexual	11,28			illness	10,0		
help	5,41	will	8,52			ask	3,18		
woman	3,21	lose	7,44			hold	3,18		
		difficulty	3,36						
		fear	2,82			S			S - 3

**Figure 1** - Dendrogram of the classes generated by the IRAMUTEQ software through the Descending Hierarchical Classification. Niterói, Rio de Janeiro, Brazil, 2021

It is observed, according to the reading from left to right of the generated dendrogram, a subgroup in the first class, which allows us to conclude the proximity of the vocabulary words between these classes. Thus, it becomes clear the affinity between them, demonstrated in classes one and three, for example, and the distance between classes two and four.

In view of the classes formed through the Dendrogram, it was possible to group the classes according to the approximation of meaning in thematic categories, namely: the first thematic category was composed of class five; the second category, composed of classes one and three; the third category, composed of class four; and the fourth category, composed of class two.

The naming and grouping of each thematic category occurred after careful analysis by the researcher, using the bibliographic reference analyzed and the content of the speeches according to their respective divisions and positions in each grouping. Thus, they were named: Category I: The construct of social roles: the loss of female identity; Category II: The sexuality of women in treatment for cervical cancer: marital repercussions; Category III: Difficulties of adaptation to a new life condition: rebuilding the body image; Category IV: Living with cervical cancer: rethinking life and rebuilding values through the support network.

### Category I: The construct of social roles: the loss of female identity

In this class, late systemic complications arising from radiotherapy treatment, such as fatigue, pain, tiredness, and infertility emerged as impeding factors in the execution of the social role attributed to women by society. The greatest concerns identified in the voices of the participants centered on the impossibility of performing domestic activities, generating, and caring for the children, the family, and the home.

The lack of these activities triggers feelings of incapacity, feeling "less of a woman", because these activities were tied by them as essential for the recognition of the roles of mother, caregiver, and wife, identified in the reports below.

I couldn't do the household activities, I felt weak, I didn't feel like the owner of my house, I felt useless. (I21)

I feel very depressed for depending on other people, I have a child to take care of, I am the mother, and I can't. (I22)

Still in this sense, considering the process of the adverse effects of radiation on the pelvic cavity, negative feelings linked to the interruption of the desire for pregnancy are perceived in the women's statements. For them, femininity is intrinsically linked to reproductivity, deconstructed by opting in the first place for the continuity of life.

The fact that I can't be a mother makes me sad, I took a long time to believe, I took a long time to think about having children, and this happened, the disease arrived. (I6)

Knowing that I won't have more children is very bad, I already have a son, but my new boyfriend has no children. (I15)

Regarding the role of wife linked to the continuity of the marital relationship, the study presented reports of divorce associated with the couple's difficulty in dealing with the repercussions of treatment. The highlighted speeches revealed that the family, then considered a support network, did not feel prepared to assume this care.

My partner abandoned me when he saw the reality of the problem, he said that I was no longer any use, that I became a hollow, empty woman, I could never find another person. (119)

I no longer have a family, they all left me, even my daughters abandoned me. (121)

# Category II: The sexuality of women undergoing treatment for cervical cancer: marital repercussions

This class includes the repercussions on women's sexuality arising from the process of transformation of the vaginal mucosa and induced menopause, resulting from radiotherapy in the pelvic cavity. Vaginal shortening after the end of treatment was considered the main complicating factor for sexual dysfunctions, causing pain during sexual intercourse and psychological alterations linked to fear of pain and of new lesions or bleeding with significant impact on the marital relationship.

I can't have intercourse, it closed, it was very tight, and it hurts, I don't feel like having sex, it's over, I don't feel any pleasure. (I3)

I was very afraid of feeling pain during intercourse, I became very dry, I don't feel like having intercourse. (I5)

I was so traumatized by everything that happened before I started the treatment that I can't relax, it is not something that brings me pleasure, it is as if I were a virgin again. (I8)

Until today I am afraid of intercourse, because I bled a lot, I am afraid to do it and bleed again and come back all over again. (I11)

In view of the reports that discuss the difficulty of adaptation to the new reality of sexual practice, one notices in the perception of the interviewees, that sexual practice should happen as an obligation, even without the desire of the woman due to the fulfillment of the role of wife or companion. The justification that men have a physical need for sex makes

them feel they must do it.

I don't feel like doing anything, I don't feel any pleasure, I do it because I must, for the partner's sake. (123)

I have a husband, it is a very boring situation not to do it, I don't feel like it. (124)

In addition to the issues listed, another aspect that emerged as enhancing sexual dysfunction was the induced menopause because of the loss of ovarian function post pelvic radiation. This was manifested with more severe symptoms than natural or spontaneous menopause, potentially impacting sexuality, and quality of life. The severity of menopausal symptoms and the stress inducing them affected the physical and mental wellness of the respondents and had repercussions on family and social relationships.

I already wake up in a bad mood, not even I can stand it, my mood oscillates a lot, and the partner suffers. (18)

With menopause my libido is reduced, and everything adds up, sometimes I run away from sex, it is very complicated, you must go through it to know. (126)

The menopause causes me unbearable heat, my husband complains a lot about sleeping in the same room as me, I must turn on the air conditioner and the fan. (128)

# Category III: Difficulties in adapting to the new life condition: rebuilding a new body image

This class revealed that in face of the gastrointestinal and urinary dysfunctions, arising from radiotherapy in the pelvic cavity, the withdrawal from work and social activities became increasingly evident in this group of women. The complications arising from these dysfunctions in the social life of the interviewees led to restrictions, such as going to public places, traveling, sleeping away from home, and returning to professional activities, implying the need to stay close to the bathroom, limiting activities and contributing to a lower level of functionality.

Moreover, such dysfunctions culminated in the routine use of diapers and pads, pointing to a significant impact on the deprivation of social interaction, generating embarrassing situations, in addition to changes in self-esteem.

I have frequent diarrhea, even to leave the house is complicated, I must think if there will be a bathroom nearby. (120)

After radiotherapy I started to release urine without realizing, I must use diaper all the time, it is difficult to adapt the clothes, it is very uncomfortable. (I14)

Regarding the difficulties related to the use of devices, nephrostomy forced the interviewees to make major transformations in several dimensions of their lives. Despite keeping their condition hidden under their clothes, the concern with body image and with possible leaks in the collection devices were also listed as limiting their daily activities. Being a nephrostomy patient implied not only the use of the collection bag, but also a new body image that needed to be rebuilt.

I feel dissatisfied with my body, sometimes I don't want to look at myself in the mirror, I even lost interest in having sexual relations. (I7)

Nephrostomy disturbs me, I think it disturbs anyone, I go to church the bag fills up, every hour I must go to the bathroom, stop my prayer. (I14)

The greatest difficulty with the nephrostomy was acceptance, I always tell my mother, I just

wanted to be normal again... I was not born with this; I was not born like this. (I15)

I donated all my pants, and I can no longer use them because of nephrostomy, only wide clothes, this makes me very sad. (119)

For these women, the loss of this body segment did not represent only the inability of the body to function as before, since the use of the device was expressed as a physical imperfection, culminating in feelings of little attractiveness by the partner and avoiding sexual contact. In addition, they revealed a feeling of maladjustment from standardized normality in the face of the need to adapt clothing to the permanent use of the devices.

## Category IV: Living with cervical cancer: giving new meaning to life and reconstructing values through the support network

In this class, the participants highlighted how positive the support network was during the process of coping with the disease. Faith, family, and children emerged as a source of hope and courage to face the repercussions of the treatment. In addition, the narratives point to the participants' need to be able to exercise their social roles as mothers, providers, and caregivers. Thus, the appealing speeches of attachment with God were witnessed in the face of the place occupied in the social dynamics.

I only ask God for strength to hold on until the end. (122)

I see myself as if I were hand in hand with death, it is sad to look at my son and not be sure that tomorrow I will be beside him. (126)

The stigma of cancer presented itself as a reason for subjection to prejudice and to cover up the situation experienced by the participants. Added to this is the insecurity about the course of the disease, its survival, and its impacts, which caused a series of changes in the way the participants see life. Faced with these facts, many sought to reflect, value, and experience life differently after treatment.

I evolved a lot as a person, I value the little things, especially the family. (18)

People look at you with pity, cancer did not kill me but left me with a very painful sequel. (119)

The way people look at you as if you were going to die makes me feel lower. (126)

### DISCUSSION

In coding the data, there was a 76.81% ST score. Evaluated, therefore, as a good utilization, considering the classification of results of the text corpus equivalent to 75% or more<sup>11</sup>.

The results revealed distinct repercussions in several contexts arising from radiotherapy treatment for cervical cancer. Regarding the loss of female identity, it was observed in the interviewees' reports gender-related issues, related to caring for the home and children, listed as characteristics associated with the female universe. Caring for the home and for others is a feminine event, complex and subject to intervening variables, among which, the social and culturally constructed attribution is experienced as a natural attribute, when they are social constructions that aim to regulate the power relations between genders<sup>12</sup>.

Another meaning that emerged from the interviews attributed to the female social

role is the exaltation of fertility as a woman's highest attribute and proof of her femininity, other words, maternity seen as inseparable from the feminine condition<sup>13</sup>. The uterus and its annexes, pregnancy and motherhood associated with the construction of female roles, considered not only as a biological event, but also as a virtue loaded with cultural meanings that bring latent the feeling of plenitude, power and self-esteem<sup>14</sup>.

It is noteworthy that, in face of the deconstruction of the identity of wife or companion reported by the participants, the companion's support is extremely important when it comes to creating a healthy environment so that the woman can feel integrated into the family context again<sup>13</sup>.

However, the results of the study in question indicated that the partner and some close family members could not stand the complex situation that involves the treatment and made the decision to move away. In this sense, it is important to understand that the way couples relate before the beginning of the treatment is a decisive factor during the process, in other words, unstable relationships that do not have a solid emotional connection tend to generate anguish, insecurity, and distancing of relationships due to the stress of the disease<sup>14</sup>.

Low sexual desire was prevalent in the interviews due to all the hormonal changes resulting from induced menopause, in addition to the physical changes that can occur in the vaginal mucous in the long term after radiotherapy treatment, leading to loss of libido and difficulties in arousal<sup>15</sup>.

This impairment was further exacerbated in the interviewees by fear of bleeding and pain during intercourse. The concern with pain during intercourse induces decreased arousal and, therefore, results in increased vaginal dryness and/or inadequate muscle tone and, consequently, culminates in increased perception of pain, making sexual intercourse more difficult<sup>16-17</sup>.

In association with the changes listed, the severity of the symptoms of induced menopause contributed to the drop in libido, affected the quality of life and mental wellbeing of the interviewees with an impact on family and social relationships<sup>18-19</sup>. In this context, a Brazilian study<sup>20</sup> corroborates the results found when it concluded that the practice of sexual intercourse after radiotherapy was reported by only 26.4% of the participants, and that the reasons for this low percentage were associated with the abandonment of women by their partners and the lack of guidance.

In the scenario in question, some women chose sexual abstinence, for the need to preserve intimacy or for rejection, since the partners cannot see them as a sexual partner, because the main sexual organ was compromised, resulting in the loss of sex and intimacy<sup>21</sup>. Still in this sense, in view of the difficulties revealed, it is highlighted in the participants' reports that the sexual practice happened as an obligation, even without the woman's desire due to the fulfillment of the role of wife or companion. Even after the feminine conquests over the centuries, a vision of sexuality linked to the historical-cultural concept of gender domination is noted, being unlinked from a natural expression of the human being, being experienced by these women as a social obligation, where there are no choices<sup>22-23</sup>.

As for gastrointestinal and urinary dysfunctions resulting from acute post-radiotherapy toxicity, these were reported as a source of anguish and suffering, mainly because of the need to always remain close to the bathroom, feeling socially incapacitated<sup>24</sup>. Studies<sup>23-24</sup> with women undergoing radiotherapy for cervical cancer pointed out that bladder dysfunction was the most frequent post-treatment adverse effect, in contrast to the records made by the health team in the analyzed medical records, which indicated vaginal stenosis as the most frequent effect. Thus, the authors concluded that bladder disorders bring suffering and anguish, as corroborated by the participants of the study in question and were not reported in the medical records at the time of medical consultation because they did not present visible clinical changes.

Moreover, such dysfunctions culminated in the routine use of diapers and pads with significant impact on the deprivation of social interaction and quality of life, leading to sensations such as frustration, shame, changes in self-image, concerns about possible leakage, loss of self-confidence, anxiety, and sadness<sup>23-24</sup>. Still in this context, regarding the use of urinary devices by nephrostomies, when facing the presence of the permanent device, the participants had difficulties in accepting their new life condition, the changes in their daily lives, which occurred not only at the physiological level, but also at the psychological, emotional, marital, and social levels, besides the new body image, which had to be rebuilt<sup>25</sup>.

These changes are closely related to the uncertainties about the future and the fear of experiencing frustrations with the new reality, since society exalts body image by exalting the beautiful and statuesque body, in addition to marital difficulties and shame of the partner, contributing even more to the difficulty of adapting to the new daily life<sup>26</sup>. In this sense, the participants revealed a feeling of maladjustment of the standardized normality in face of the need to adapt their clothing to the permanent use of the devices. It is noteworthy that clothing is a way to model the image that each being carries of himself. It is observed, then, that clothing is classified as an instrument of inclusion and, therefore, it is understandable that nephrostomies patients feel excluded<sup>27</sup>.

In view of the above, it is important to know how pelvic radiotherapy affects women in treatment, to obtain a better understanding of the psychosocial aspect's quality care with a focus on humanization and integrality, benefiting patients in the organization of their social integrality, benefiting patients in the organization of their social, professional, and family life family life during the treatment period<sup>28</sup>.

In parallel with this understanding, despite all the technological evolution and the forms of treatment, the stigma of cancer imprints its mark on the culture, and even today the crystallization of this stigma full of negative representations does not seem to dissolve<sup>29</sup>. A myth that cancer is an incurable disease hangs over our society, making it difficult for society to accept the disease and interfering with the hope of the patient and the family<sup>30</sup>.

As a way of coping with the situations reported, the participants sought something that would help in the new situation experienced. It was present in the speeches of the participants how positive the family support, religiosity and faith were, considered by them as a support network during the process of coping with the disease. Regardless of the forms of coping that the women interviewed resorted to, they sought to do or believe in something or someone that would make them overcome the possible repercussions resulting from the treatment, having the pillars of faith, family, and children as a source of hope<sup>29</sup>.

In addition, cancer treatment was perceived and taken as a learning tool to revalue the self and the family, and many sought to reflect, value, and experience life differently after treatment<sup>30</sup>.

Finally, it is worth mentioning that this study had the limitation that it was carried out in a single center, translating the reality of a public institution's clientele, which demands more extensive research encompassing other scenarios and other methodologies.

### FINAL CONSIDERATIONS

It was evident that the complexity of the female universe facing the disease goes beyond the physical and functional sequels associated with the treatment. The feelings of anguish and sadness come up against the impossibility of exercising the role of the woman as the provider for the home, the limitations of her sexuality, and the changes in her body image, becoming an impediment to her return to her professional, social, and marital activities. Thus, it is important to reflect on the performance of health professionals in oncology or even on the need to better understand the issues involved in the multifactorial context of cervical cancer treatment. Therefore, the study intends to contribute to stimulate the academic community to develop research to support the development of strategies that guide the care, increasing the quality of life and helping to reorganize the professional, social and family life of these women.

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