

# The healing cost: comfort and discomfort experiences of women undergoing brachytherapy

*O custo da cura: vivências de conforto e desconforto de mulheres submetidas à braquiterapia*

*El costo de la curación: experiencias de comodidad e incomodidad de mujeres sometidas a la braquiterapia*

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## ABSTRACT

**Objective:** To describe the experiences of comfort and discomfort in women who underwent brachytherapy for the treatment of cervical cancer. **Methods:** Qualitative study carried out in 2013, based on Kolcaba comfort theory and conducted through semi-structured interviews with eight women who have completed treatment, at least, six months ago. **Results:** The following discomforts stood out: pain in the procedure and in the post-treatment effects, in the physical context; fear of the unknown and suffering; lack of a companion; stress due to embarrassment during treatment; low self-esteem; and post-therapy psychological trauma, in the psycho-spiritual context. Comfort measures consisted in dialogue with the professional, medication management and use of faith and spirituality. **Conclusion:** The results provide support for the practice of health professionals in relation to comfort and discomfort that deserve to be the target of intervention in terms of the assistance to women with cancer.

**Keywords:** Brachytherapy; Uterine Cervical Neoplasms; Nursing Theory.

## RESUMO

**Objetivo:** Descrever as vivências de conforto e desconforto de mulheres que se submeteram à braquiterapia para tratamento de câncer do colo uterino. **Métodos:** Estudo qualitativo, desenvolvido em 2013, embasado na Teoria do Conforto de Kolcaba e realizado por meio de entrevistas semiestruturadas com oito mulheres que concluíram o tratamento há, no mínimo, seis meses. **Resultados:** Sobressaíram os seguintes desconfortos: dor do procedimento e dos efeitos pós-tratamento, no contexto físico; medo do desconhecido e do sofrimento, falta de acompanhante, estresse por sentir-se constrangida durante o tratamento, baixa autoestima e trauma psicológico pós-terapia, no contexto psicoespiritual. As medidas de conforto consistiram no diálogo com o profissional, administração de medicações e uso da fé e espiritualidade. **Conclusão:** Os resultados oferecem subsídios para a prática de profissionais de saúde em relação aos confortos e desconfortos que merecem ser alvo de intervenções na assistência à mulher com câncer.

**Palavras-chave:** Braquiterapia; Neoplasias do Colo do Útero; Teoria de Enfermagem.

## RESUMEN

**Objetivo:** Describir la experiencia de comodidad e incomodidad en mujeres que se sometieron a la braquiterapia para tratar el cáncer de cuello uterino. **Métodos:** Estudio cualitativo realizado en 2013, basado en la teoría de comodidad de Kolcaba y realizado con ocho mujeres que completaron el tratamiento hace por lo menos seis meses. **Resultados:** Se destacan las incomodidades: dolor del procedimiento y de los efectos después del tratamiento, en el contexto físico; miedo a lo desconocido y al sufrimiento, el estrés por sentirse avergonzada durante el tratamiento y baja autoestima y trauma psicológico después de la terapia, en el contexto psicoespiritual. Las medidas para sentirse confortables consistieron en el diálogo con el profesional, administración de medicamentos y el uso de la fe y la espiritualidad. **Conclusiones:** Los resultados proporcionan subsídios para la práctica de los profesionales de la salud relacionada con las comodidades e incomodidades que merecen intervenciones en la atención de las mujeres con cáncer.

**Palabras clave:** Braquiterapia; Neoplasias del Cuello Uterino; Teoría de Enfermería.

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## INTRODUCTION

Considered a problem from the public health perspective, cervical cancer (CC) is a major cause of female mortality. It is the second most common cancer among women, with an estimated 15,000 cases for the years 2014/2015<sup>1</sup>. Brachytherapy is among the forms of treatment for the CC and it is a form of radiation therapy that uses radioactive materials near the tumor, through an intracavity system<sup>2</sup>. Despite its potential benefits this treatment produces significant side effects, which can gradually disappear or be irreversible<sup>3,4</sup>.

Brachytherapy may cause significant and challenging changes to the physical and emotional well-being of women who undergo this treatment, such as food, hygiene, sleep, rest, physiological eliminations, sexuality and sterility, work routine, and social relations<sup>3,4</sup>. Failure to realize the significance of these changes may result in losses in terms of adapting to treatment and even in improving the health condition of women. This fact requires attention from health professionals regarding the physical, emotional and socio-cultural aspects in a therapeutic process that aims at holistic assistance<sup>5</sup>, in which they take care of women with CC, not just the cancer.

Given these considerations, the question of this study that women who undergo brachytherapy may have various discomforts during and after the establishment of this therapeutic modality arises. Once known, these discomforts can be remedied or mitigated by certain interventions.

This study aims to describe the experiences of comfort and discomfort of women who underwent brachytherapy for cervical cancer treatment. According to the theoretical framework of Katherine Kolcaba, the term comfort is understood as the condition experienced by the person receiving comfort measures and experimenting the immediate and full experience of being strengthened to achieve relief, tranquility and transcendence. Discomfort, in turn, refers to the lack of such measures<sup>6</sup>.

Moreover, according to the reference cited, the comfort taxonomic structure establishes that this may occur in the physical, psycho-spiritual, socio-cultural, and environmental contexts, and for each there are states of comfort, called relief, tranquility and transcendence<sup>6,7</sup>.

Relief is perceived as the state of having an attenuated discomfort or a condition of satisfaction of a specific need. Tranquility is the absence of specific discomforts, is the state of calm and contentment. On the other hand, transcendence is the ability to overcome discomforts when they cannot be avoided, leading the individual to overcome their problems or suffering<sup>6</sup>.

Among the main assumptions of the comfort theory used in this study, we include:

1. humans have holistic responses to complex stimuli;
2. people struggle to meet their basic comfort needs or to have someone providing this satisfaction to them;

3. improved comfort encourages patients to engage in health seeking behaviors, according to their choice;
4. institutional integrity is based on a value system aimed at care receivers<sup>6</sup>.

## METHODS

This is a qualitative, descriptive and exploratory study carried out with eight (8) women who underwent brachytherapy, identified and selected according to the following inclusion criteria: have completed treatment at least six months ago and be physically able to participate. The study excluded women who were in phase of palliative care; who were still in treatment, or who had undergone brachytherapy for another condition other than the CC.

The Center of High Complexity in Oncology, located at the University Hospital of Maceió, was chosen to be the source of production of participants for being a benchmark for the treatment of cancer in the state of Alagoas, and being a part of the Expansion Program of the Oncologic Assistance (Expands) in Brazil. The approximation of participants was conducted through a survey of the records of nursing visits in 2011 and 2012, by which women who met the inclusion criteria were selected.

The objectives of the study were explained through phone calls and home visits, and the women were invited to participate in the research. The date and place for the interviews had been agreed according to the preference of women. The collection of testimonials was recorded in voice, it occurred between July and December 2013, and followed a script composed of questions regarding comfort and discomfort while submitting themselves to brachytherapy, in its different phases: before, immediately before, during therapy, immediately after, and post-therapy.

The information obtained was analyzed based on the theoretical and methodological framework of Katherine Kolcaba and were organized in her diagram, where she outlines the taxonomic structure of comfort and establishes the contexts in which this may occur.

In obedience to the ethical principles set out in Resolution 466 of 2012, of the National Council of Health, this study was approved by the Ethics Committee in Research of the Federal University of Alagoas (Opinion N<sup>o</sup> 305,171) in the year 2012. All participants signed the Informed consent Form (ICF) and, to ensure their anonymity in relation to the statements presented in this article, women are identified by numbers.

## RESULTS AND DISCUSSION

The study included eight women aged between 29 and 60 years, coming predominantly from cities in the state of Alagoas. By observing the marital status before and after treatment, we noticed that five women lived with a partner at the time of collection, while one was a widow, and two were single. As for education, half of them did not have completed elementary

school, one had never studied, two had incomplete high school and one had incomplete higher education. The professions were related to a lower financial income (kitchen assistant, seamstress, housewife and cash attendant), and two women were unemployed and one was retired. Regarding religion there was a prevalence (n = 7) of Catholic women.

The data analysis allowed describing the experience of comforts and discomforts lived in the different phases of the therapeutic route of the participants, as follows.

### Phase 1: Before brachytherapy

The stage prior to brachytherapy includes the period in which women are informed by the physician that they will undergo treatment until the arrival to the health service for the first session. All the women in this study were aware and started the brachytherapy procedures after having completed chemotherapy and/or radiotherapy, that is a time when they felt extremely fragile and sensitive, still experiencing the side effects of these treatments and their impact on their whole being.

The main effects caused by chemotherapy and radiotherapy, and therefore, possible to be found in women who are beginning brachytherapy are: radio dermatitis, mucositis, xerostomia, fatigue, mood swings, incontinence, nausea, diarrhea, constipation, hypotension, hypertension, venous fragility, alopecia in the genital region (to a lesser extent), anemia, anorexia, hyperpigmentation and photosensitivity of the skin<sup>3,4,8,9</sup>. The speeches of the participants reflect the bodily suffering, in the physical context, still at the beginning of treatment with brachytherapy:

*[...] When I finished radiotherapy and chemotherapy, I still got a little weak because of the radio. I felt very tired; it was that endless fatigue... [...] Even to walk. I walked with some difficulty because I was weak, and sometimes I walked holding on things. (Participant 2)*

*[...] This part was all black, you know? [She points to the hip], the skin peeled off. (Participant 4)*

A study performed in 61 hospitals throughout Brazil pointed out that in approximately 35% of services, brachytherapy sessions are held after teletherapy<sup>10</sup>. In a survey conducted in Florianopolis, women affected by cancer were also vulnerable since diagnosis, and in the course of the brachytherapy treatment the fragile condition was potentiated, fact that demands special attention of the caregivers involved in the treatment<sup>11</sup>.

It is important that women are prepared for the treatment and are informed of the number and frequency of sessions, and doubts concerning the procedure must be clarified, in order to avoid evasive answers.

*He [the doctor] just explained to me that it was a treatment that helps fighting the development of the cancer. (Participant 4)*

*He [the doctor] said "it is a simple gynecological examination". (Participant 1)*

When not prepared for the procedure, women can interpret it as a very simple treatment, a kind of truce in relation to what they had been through previously, which in practice does not occur. In this regard, there are currents that understand that telling the truth is an ethical obligation of professionals, regardless of the consequences. However, some authors show that not always the truth is revealed, depending on the moral position of the healthcare professional<sup>12</sup>.

For the participants of this study, the non-clarification of the therapy resulted in discomfort in terms of the psycho-spiritual context, generating fear before what was still unknown for them, associated with fear of going through other hardships again:

*[...] She [the doctor] said it didn't hurt; she said she was not going to hurt me, I was nothing, and yet I was afraid. (Participant 5)*

*[...] We were frightened because of the symptoms we've been feeling, because I bled a lot. (Participant 1)*

In the environmental context, women also suffered influences of people who have undertaken or would perform the procedure. This type of interference occurred in the exchange of experiences among the other patients and their families in the waiting room. Some reported that the conversations held before the brachytherapy comforted them, in the sense of bring relief to their tensions, but others reported having been even more anxious and scared, before the negative reports of some patients, causing discomforts:

*[...] While we waited, the girls talked and each one said something different. (Participant 5)*

The unavailability of companions made women feel lonely and displaced at moments during consultation scheduling related to brachytherapy, which caused discomfort in the socio-cultural context:

*[...] It is too bad, because we are not followed up... I felt very alone because I got there and did not know anyone. (Participant 8)*

This situation can be compared to those in which women felt comforted by having support and monitoring of the family and friends:

*[...] I always went there with my son, with my sister, sometimes with my husband... so, I didn't get much scared. (Participant 7)*

It is noticed that the discomforts were present in all the contexts defined by Kolcaba at this stage. In an attempt to generate relief to patients, the comfort measure consisted of the professional orientation that patients need not be afraid. Momentarily, some women felt calmer, but that relief did not extend to the other phases of treatment, since, according to the theory of comfort, it is dynamic and not always remains steady from start to finish. Transcendence begins to appear soon in this first stage, when women realize that, at any cost, they will have to undergo treatment to achieve the possible cure of the disease<sup>6,7</sup>.

### **Phase 2: Immediately before brachytherapy**

This phase, which had a short but inexact duration, includes the time from the women's preparation to start the procedure in the healthcare service, until their placement on the brachytherapy table. Women begin to have a sense of suspicion in terms of what had been informed to them regarding the treatment. In the psycho-spiritual context, she enters a phase of doubt and apprehension for perceiving that the procedure is more complex than it was informed.

*The nurse gave me a painkiller, I think it was dipyrone, and told me to use Xylocaine, that local anesthesia. Then I woke up and thought: so the problem will be serious. (Participant 1)*

It is recognized that this is indeed a complex procedure, and therefore it requires a psychological preparation of women so they will not feel surprised when brachytherapy actually starts. There is an increase in distress and the permanence of the fear of the not experienced procedure, although there have been efforts to eliminate such tensions. As a result, it is common to see high blood pressure in women, which in some cases resists the administration of medications, as well as increased sweating, cold hands, among other symptoms:

*Every time I went there, she [the nurse] kept asking if I was afraid. [...] I was cold, freezing, my hands sweated and I couldn't control myself. Every time she gave me some medicine, but the thing [the pressure] didn't lower at all. (Participant 5)*

As mentioned, at this stage the main discomfort is predominantly the psycho-spiritual nature that ends up creating physical discomforts through the manifestation of symptoms characteristic of anxiety, and it is essential to recognize such events, as they enable the planning of specific interventions for each patient.

The main measure of comfort for such a situation is the relaxation of women by talking to them and alleviating their physical symptoms with drug therapy. In the psycho-spiritual context, comfort refers to the self-concept, the vision that one has of oneself and the meaning that is attributed to him to life in its

relations with the world and with a higher being<sup>7</sup>. As every disease leads individuals to experience a crisis situation, in addition to breaking with the physical balance, the sick person demands a new psychological structure to support this moment, and this fact alone, generates anxieties that may become accentuated at the stage of treatment which follows<sup>13</sup>.

### **Phase 3: During brachytherapy**

This phase comprises the brachytherapy itself, namely, from the placement of the applicator into the vaginal canal by the physician until the moment when the machine is off. The patient, in reality, comes in contact with the procedure, realizes that she will have to be observed by professionals of the opposite sex, and at times by trainees, while remaining in gynecological position throughout the section. This discomfort is one more reason for distress and embarrassment, since women are subject to a moment of physical invasion of their privacy:

*[...] Now, the problem is that a woman at my age, old, is ashamed of everything, right?! Then I felt embarrassed. (Participant 5)*

After nurses prepare the patient and responsible technician position her, there was, in some cases, one more reason of intense discomfort before the brachytherapy was actually initiated: the wait for the physician:

*[...] Then, after that, I still have to wait for the doctor... and my legs up. My tailbone ached and I couldn't even move. (Participant 2)*

The comfort in terms of the environmental context depends on nursing care for the environment which is reflected in verbal and non-verbal communication with patients<sup>6</sup>, interventions to relieve anxiety, respectful treatment and the maneuvers aimed to calm them, in addition to external influences, including the ambient temperature, sounds and noises, aroma and luminosity<sup>14</sup>.

Another cause of suffering at this stage was the fear of the electric shock and the pain from the beginning to the end of the section, to almost all the women interviewed. Some compared this pain to the loss of virginity, a normal delivery and the fact that it extends throughout the body, as they have to keep themselves motionless in gynecological position.

*[...] But I stood there crying, feeling much pain, because I could not stand being there in that position, or attached to those metal devices, until the time it was over. (Participant 2)*

*[...] But I was afraid to shock! Because I knew that those devices were connected to the power, you know?! [...] I was afraid of burning myself, of receiving an electric discharge [...] (Participant 5)*

Fear can be defined as a fear of something that poses as a real danger to the physical or psychological integrity. It is not synonymous with anxiety, since this is characterized as fear; however in this fear there is no real object<sup>15</sup>.

When brachytherapy starts in fact, after the arrival of the doctor, the women feel disappointed because they are in great distress, without someone to accompany them:

*[...] But then I was wrong completely. I cried from start to finish. (Participant 2)*

*[...] I didn't like it, you know?! It was horrible! (Participant 3)*

*[...] I thought I wouldn't resist, because of the pain! (Participant 1)*

The theory of comfort states that people may feel discomfort and yet, feel calm, because the sensitivity to discomfort is related to each person and it also depends on factors such as the individual pain limits, past experience, and their life history<sup>6,7</sup>.

Perhaps the most complete concept that applies in this case is the "total pain" as it applies to pain a multidimensional view, the concept of Total Pain, where the physical component of pain may change under the influence of emotional factors, social and also spiritual<sup>16</sup>.

It is possible to observe some of the anguish of these patients when, because of stenosis for example, which is a common effect of brachytherapy, the cervix has to be broken manually by the professional. This is when women turn to a higher being, crying out for help, or seek within themselves for some force capable of helping them to overcome this situation:

*Then he [the doctor] put the collet; he tried to break the first time, but he couldn't, because I cried a lot, I couldn't stand it! I said, "Doctor, you're killing me! And he said: You have to go through this. (Participant 1)*

*[...] And I said, "Jesus, come here! I can't stand it anymore! (Participant 1)*

*I continue the treatment because I liked of my life... I liked to live, my family... and I still have some dreams to accomplish. (Participant 5)*

It is noticed that spirituality is an expression of identity and the purpose of life of each individual through his personal history, experiences and aspirations. The relief of suffering thus occurs as faith allows changes in perspective in which the patient and the community realize the seriousness of the disease<sup>17,18</sup>.

Similarly, the desire to be cured of the disease or the will to continue living provides power to patients, so that they complete the therapy.

#### Phase 4: Immediately after brachytherapy

This phase extends from the time when women leave the brachytherapy room until the subsequent days when they go

home and then return to perform the other sections. It is common to note that some participants felt anger and despair after the first great suffering experience in brachytherapy to the point of wishing to abandon the treatment:

*One day, when the doctor tried to touch me to examine me, I didn't let him do it! I had to relax... the psychologist came to talk, so I'd let him do it... and it was not just me! (Participant 5)*

*But then I had this psychological problem; the problem of going back there again, thinking I would feel the same, you know... That the same thing would happen again. (Participant 1)*

After the session, some effects of brachytherapy, from the simplest to the most complex ones, begin to emerge, making it difficult for women to carry out daily activities:

*You have diarrhea; the flatus are horrible! Rotten! It's like a rust... it gets rotten. (Participant 4)*

*[...] From the second on, my clit was flat, full of blisters! It was totally erupted, as if burned. (Participant 2)*

Fatigue and discouragement are common, as previously reported, and it was observed that, when patients had a loved one that strengthened and encouraged them to continue, they found another way and a motivation to continue insisting on treatment, despite of all the difficulties encountered:

*She (companion) came and gave me support; she gave me courage. She said, "Cheer up! Don't be like this! You will get through it! (Participant 1)*

*[...] Now, I went there because of her (mother) and because of my daughter. If it depended on me, I would have died, I wouldn't have gone there. (Participant 2)*

It is noticed that the main discomforts of this phase were physical. We can highlight the bleeding, burning, pain, blisters on the genitals, nausea, vomiting, urinary tract infection, weakness, among others; those which were found in a study that evaluated the quality of life of women with CC<sup>19</sup>. In addition, psycho-spiritual discomforts, such as stress, low self-esteem and trauma after the first section are characteristic of these women. The most used intervention by professionals and by family members consisted in encouraging women to reach a state of transcendence and continue treatment, despite the discomforts.

#### Phase 5: Post-brachytherapy

This phase comprises the exit of women from the brachytherapy room after the last section. Most discomforts observed in the phase immediately after brachytherapy remained. Problems such as vaginal stenosis, fistulas, incontinence and urinary tract

infection, pain, dyspareunia, vaginal bleeding, diarrhea, nausea, among others were highlighted:

*And I think that, sometimes when I fart, I don't do it through the anus; it comes through the vagina. Gosh, that's weird! (Laughs) (Participant 1)*

*After I finished the treatment I was very thin, because I had a lot of diarrhea! That's why today I don't have lunch anywhere; I get ashamed! (Participant 8)*

*Every time I have intercourse, it bleeds. I started to have a lot of urine infection. (Participant 4)*

Acute intestinal toxicity is manifested by nausea, vomiting, diarrhea and cramping pain, which disappear 2 to 3 weeks after the end of treatment. Approximately 6 months to 5 years after the end of radiotherapy, there may be diarrhea, cramping pain, nausea, vomiting, malabsorption, progressive fibrosis, perforation, and the formation of fistulas and stenosis<sup>3</sup>.

Other systemic discomforts that hitherto were not found in the literature were also observed in the interviewed women. These seem to be associated with neuropathic pain, which for being unusual, brought doubts and surprise both for patients and for professionals:

*After this treatment my feet seemed to have come out of an operating room at that time. It was so much pain; I could have even passed out from pain. (Participant 1)*

Neuropathic pain can be defined as a kind of pain arising from partial or complete lesion or abnormality of function in any part of the peripheral nervous system (nerve, plexus, or roots) or the central nervous system (brain or spinal cord). The same can be perceived superficially or profoundly and is often described as a continuous burning pain and burning or intermittent twinge, shock, which pierces in needful<sup>20</sup>.

It is also observed the interference of physical sequelae such as vaginal stenosis in the sociocultural context immersed in sexual relations. In the post-brachytherapy period various effects are directly related to women's sexuality, since they feel unable to perform the sexual act itself. Generally there are attempts to do it, however, little success is reported, causing great stress and suffering to women and their partners:

*As for sexual relationship, so far, if I have it, my goodness! I am married, but I cannot have it in any possible way! So I let it be. (Participant 8)*

*He is scared too, because he understands the situation. We dated like this: only at the beginning, but we cannot reach inside. And it still burns, so I use the cream and on the other day it gets better; so we carry on like this. (Participant 5)*

Vaginal stenosis seems to be the biological cause of sexual dysfunction related to radiotherapy in the female pelvis, as the dryness and the narrowing of the vaginal light lead to pain and bleeding during sex and the consequent decrease in libido and pleasure, which affects sexual response, including desire, arousal, orgasm and resolution<sup>4</sup>.

Thus, this is an important need that deserves attention from health professionals, since sexual activity is one of the indices by which the level of quality of life is measured, and therefore may be a reason for joy or sorrow with all its nuances in women's lives<sup>4</sup>.

After treatment women realize that some of the effects left by brachytherapy remain and there is no effective treatment capable of eliminating such discomfort. There is a sense of hopelessness hanging over patients, making them feel disillusioned by medicine, as they try in every way to find a solution for their discomfort, and cannot find anyone able to help:

*The walls are all resected because it burns, you know?! (Participant 8)*

The exit of patients from the top of the treatment process is as important as the treatment period and requires a multidisciplinary care that meets the needs of women holistically in order to assist them in adapting to their new lifestyle.

## **CONCLUSIONS AND IMPLICATIONS FOR PRACTICE**

It is considered that the objectives were achieved, since through the interviews it was possible to list the major discomforts in physical, psycho spiritual, sociocultural and environmental contexts experienced by the women interviewed in all phases of the brachytherapy procedure.

It is important to note that the moments of discomfort excelled when compared to those in which the woman has reached the relief, transcendence or tranquility. This disparity shows the gap in this type of assistance, which overestimates the "cure" and does not seem to offer sufficiently a support for the management of side effects from the treatment.

Thus, it is believed that these patients should be assisted holistically by a multidisciplinary team, contemplating the discomforts emphasized in the speeches of the participants in this study, so that they are heard at every stage of the process and their discomforts are assisted, especially by the nursing staff who witnesses most of the moments experienced by women with cervical cancer, either in the preparation for the procedure or in the post treatment follow-up.

The relevance of this study is also demonstrated by the fact that a nursing theory has been used for its implementation, which contributes to the spread of a part of the scientific knowledge, characteristic of the profession, aimed at the assistance with a view to its improvement.

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