

Piece torn from me: women with alopecia through antineoplastic chemotherapy

Pedaço arrancado de mim: mulheres com alopecia por quimioterapia antineoplásica

Pieza rotada de mí: mujeres con alopecia mediante quimioterapia antineoplásica

ABSTRACT

Objective: To know the perceptions of women about the altered self-image after alopecia by antineoplastic chemotherapy. **Method:** Descriptive, qualitative study carried out in an oncology hospital in the state of Pará. Thirty women with alopecia from antineoplastic chemotherapy participated. Data were produced from July to August 2021, through individual interviews with a semi-structured script. Data were analyzed under the precepts of Content Analysis associated with the IRAMUTEQ software. **Results:** We identified 17 women aged between 44 and 56 years (56.66%), with a steady partner (66.66%); Catholic (89.99%); with household income below one and up to two minimum wages (63.33%). Among the five classes generated by IRAMUTEQ, two will be analyzed in this article “the woman’s perception of hair loss” and “the hair as a meaning of femininity”. **Conclusion:** Women with altered self-images after alopecia are protagonists of physical and psychological confrontations that can negatively impact perceptions about appearance

Descriptors: Alopecia; Neoplasms; Oncology; Women’s health

RESUMO

Objetivo: Conhecer as percepções de mulheres sobre a autoimagem alterada após alopecia por quimioterapia antineoplásica. **Método:** Estudo descritivo, qualitativo, realizado em um hospital oncológico no Pará. Participaram 30 mulheres com alopecia por quimioterapia antineoplásica. Os dados foram produzidos no período de julho a agosto de 2021, por meio de entrevistas semiestruturadas. Analisaram-se os dados sob os preceitos da Análise de conteúdo associada com o *software* IRAMUTEQ. **Resultados:** Identificaram-se 17 mulheres com idade entre 44 e 56 anos (56,66%), com parceiro fixo (66,66%); católica (89,99%); com renda familiar menor que um e até dois salários mínimos (63,33%). Dentre as cinco classes geradas pelo IRAMUTEQ, duas serão analisadas neste artigo: a percepção da mulher sobre a perda do cabelo e o cabelo como significado de feminilidade. **Conclusão:** As mulheres com autoimagens alteradas após a alopecia são protagonistas de enfrentamentos físicos e psicológicos que pode impactar negativamente as percepções sobre a aparência.


Descritores: Alopecia; Neoplasias; Oncologia; Saúde da Mulher.

RESUMEN


Objetivo: Conocer las percepciones de las mujeres sobre la autoimagen alterada tras la alopecia por quimioterapia antineoplásica. **Método:** Estudio cualitativo descriptivo realizado en un hospital de oncología en el estado de Pará. Participaron 30 mujeres con alopecia por quimioterapia antineoplásica. Los datos fueron producidos de julio a agosto de 2021, a través de entrevistas individuales con guión semiestructurado. Los datos fueron analizados bajo los preceptos de Análisis de Contenido asociados al *software* IRAMUTEQ. **Resultados:** Se identificaron 17 mujeres con edad entre 44 y 56 años (56,66%), con pareja estable (66,66%); católica (89,99%); con renta familiar inferior a uno y hasta dos salarios mínimos (63,33%). De las cinco clases generadas por IRAMUTEQ, dos serán analizadas en este artículo “la percepción de la caída del cabello por parte de la mujer” y “el cabello como significado de la feminidad”. **Conclusión:** Las mujeres con autoimagen alterada tras la alopecia son protagonistas de enfrentamientos físicos y psicológicos que pueden impactar negativamente en las percepciones sobre la apariencia.

Descriptores: Alopecia; Neoplasias; Oncología; Salud de la mujer


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INTRODUÇÃO

Non-communicable diseases and complications represent the main causes of illness and death in the world population. Among these, it is estimated that malignant neoplasms will be the greatest cause of death in the coming decades. Neoplasms are a group of more than a hundred non-contagious diseases that appear silently and are characterized by a dysfunction in the cellular multiplication of the functional units that compose the organs, which, without control and proper treatment, may progress to a metastasis⁽¹⁾.

According to the World Health Organization (WHO), in 2018 there were 18 million new cases of cancer (CA) worldwide (17 million, plus non-melanoma skin cancer cases). In that same year, cancer caused the death of 9.6 million people, thus being considered the second leading cause of mortality worldwide⁽²⁾.

Considering the social, economic, and clinical magnitude of cancer, its early diagnosis is configured as a primary strategy to help combat new cases, which can be suspected through the occurrence of signs, symptoms, and predisposing risk factors. Thus, one can institute control measures and treatment in adequate time, increasing the chances of cure and patient survival⁽¹⁾.

For the definition of oncological treatment, it is valid to highlight that its choice will depend on some factors, such as age, histological type, presence of metastases, and lymph node dissemination. Given these factors, the choice is made for the forms of treatment, such as chemotherapy, hormone therapy, radiotherapy, and surgery, which can be used individually or together, varying according to the susceptibility of the tumors and the clinical staging⁽³⁾.

Chemotherapy is characterized as a form of systemic treatment for cancer through the use of drugs called “chemotherapy” or “antineoplastics”, dosed at regular intervals according to the therapeutic schemes. This type of treatment presents side effects throughout its use, such as dermatological alterations, diarrhea, constipation, nausea, vomiting, inappetence, fatigue, and peripheral paresthesia. Such effects go beyond the

merely biological and physiological aspects of the patient and reach the psychosocial, causing long-term damage⁽⁴⁾.

Among the dermatological changes is hair changes, which vary depending on the type of antineoplastic indicated. These changes include hair depigmentation, changes in hair texture, and alopecia. Although they are not risk factors for the health of cancer patients, they cause a great psychosocial impact on self-image and self-esteem, affecting the quality of life, especially for women^(5, 6).

Alopecia disfigures a woman, taking into account that long hair is seen as a symbol of femininity. Therefore, hair loss is one of the most representative, traumatic, and disturbing side effects of alopecia because it externalizes the disease to others⁽⁷⁾.

Hair loss appears two to three weeks after the start of chemotherapy and results from partial or total atrophy of the hair follicle, causing the hair shaft to fall out. This process acts negatively on the woman’s daily life, on emotional aspects, on the elaboration of self-esteem, on the process of self-image, and her sex life⁽⁷⁾.

Thus, even if hair grows back after chemotherapy ends, a woman’s relationship with her hair is remarkable and its absence causes a devastating and psychologically stressful, and painful impact⁽⁸⁾.

Studies⁽⁹⁻¹⁴⁾ refer to the feelings experienced by women during chemotherapy treatment against cancer, such as fear of dying, sadness and anguish due to the side effects caused by chemotherapy. The results show that the suffering they experience during chemotherapy goes beyond the physical limits and reaches psychosocial aspects, compromising their social identities.

Other authors^(7, 15-19) allude to the change in self-image and self-esteem of women facing alopecia and the consequences of this process in their lives, stating that this is one of the most representative side effects for those undergoing chemotherapy because hair is synonymous with femininity. Thus, their loss negatively affects the image that women have of themselves, leading

them to seek ways to cope with this loss such as wigs or scarves.

In consideration of this, the great relevance of the topic is inferred. In addition, it is noted the scarcity of articles based on the experience of women undergoing treatment with antineoplastic chemotherapy and how they deal with alopecia since no study conducted in the northern region was identified. Thus, these results denote a scientific gap regarding the object of this study, reiterating the need for literature on the subject, as it is a regional reality, given the high rates of morbidity and mortality from cancers in women in the Amazon⁽²⁰⁾.

The importance of the study for the participants and health professionals lies in the fact that the results may lead to reflections on the care provided to women who undergo chemotherapy and suffer from alopecia, reflecting on their ways of relating to other people and on their body image, supporting reflections and care actions aimed at their real biopsychosocial needs during chemotherapy treatment and the process of hair loss.

Given the above, the object of study was defined as: the self-image of women with alopecia due to antineoplastic chemotherapy. Herein lies the relevance of this study, which seeks to fill scientific gaps by answering the following guiding question: What are the perceptions of women with alopecia due to antineoplastic chemotherapy on their self-image? This article aimed to know the perceptions of women about their altered self-image after alopecia due to antineoplastic chemotherapy.

METHOD

This is a descriptive study, with a qualitative approach, developed in a reference hospital for oncologic treatment in the North of Brazil, located in a municipality of the State of Pará.

Qualitative research is characterized as a result of a process of personal reflection on experience, and its object is summarized by relationships, representations, and intentionality, delving into the universe of meanings

attributed by the subjects, whether in their individuality or as part of a group of belonging. It is determined as experience, living, subjectivity, common sense, and action, elements that contribute to the process of communication and guidance of behaviors⁽²¹⁾.

Women enrolled in the oncology service who met the following inclusion criteria participated in the study: older than 18 years, from any location in the northern region in oncological outpatient treatment, being treated with chemotherapy protocol that had alopecia as a side effector undergoing radiotherapy treatment with alopecia installed by previous chemotherapy. Fifty participants were excluded for not meeting the inclusion criteria, as well as for the presence of cognitive impairment, affecting the ability to read, understand, and speak. There were also some participants who complained about pain or other discomforts during the approach, resulting in a final sample of 30 participants.

The collection of information occurred in July and August 2021. The specific information, inherent to the object of study, was collected through individual interviews with a semi-structured script, which lasted approximately 30 minutes. As an instrument for data collection, we used a script composed of closed and open questions, which addressed socio-demographic aspects and the daily life of the participants after alopecia, letting emerge perceptions about themselves, their knowledge, fears, and attitudes towards hair loss.

Through the non-probability convenience sampling method, the women were approached according to their days of attendance at the hospital, not interfering, therefore, in the work routine of the team or the participant. The choice of participants was made by means of a prior conversation with the nurses responsible for the sector, who informed the patients scheduled for the day who had alopecia as a side effect of chemotherapy, referring them, before or after the visit, to the office requested for the interview. At the interview location, the patients were informed what the interview was about, what for,

why, how, and when it would be conducted, and the importance of their participation in the study was stressed.

The organization of the data from the socio-demographic form was performed by tabulating them in Microsoft Office Excel 2016, calculating the absolute frequencies, and organizing them in a table to characterize the sample.

Data analysis was designed by applying content analysis associated with the software IRAMUTEQ®, version 0.7 alpha 2. The analysis procedure followed the respective steps: pre-analysis; investigation of the material and treatment of results; inference and interpretation⁽²²⁾. Content analysis was used to designate affinities between semantic or linguistic arrangements, as well as between psychosocial structures. This form of analysis is based on the disintegration of the textual unit, which targets the secondary nuclei incorporated in the communication process with the participants and, subsequently, performs the reunion into classes or categories of ideas that express similar messages⁽²²⁾. As a support in data analysis, the IRAMUTEQ® software enabled different statistical analyses of texts. In this study, the analysis was developed through the interpretation of the Descending Hierarchical Classification (DHC), of the text segments (TS), based on Reinert's method and discussion with the literature on the subject.

Data were collected after clarification about the study and signature of the Free and Informed Consent Term (FICT), in compliance with resolution 466/2012. The confidentiality of the participant's identity was guaranteed according to the use of alphanumeric codes composed of the letter M (Mulher in Portuguese which means Woman) followed by the sequential number of the interview, as well as clarification of the right to withdraw at any time from the study and request all their recorded or written material, as well as refrain from answering questions that would cause discomfort or embarrassment and the measures that would be used to prevent such risks.

The study was submitted to the Research Ethics Committee (REC) of the State University of Pará (UEPA) (Opinion No. 4,766,290). All information was used for scientific purposes and there are no conflicts of interest related to the study.

RESULTS

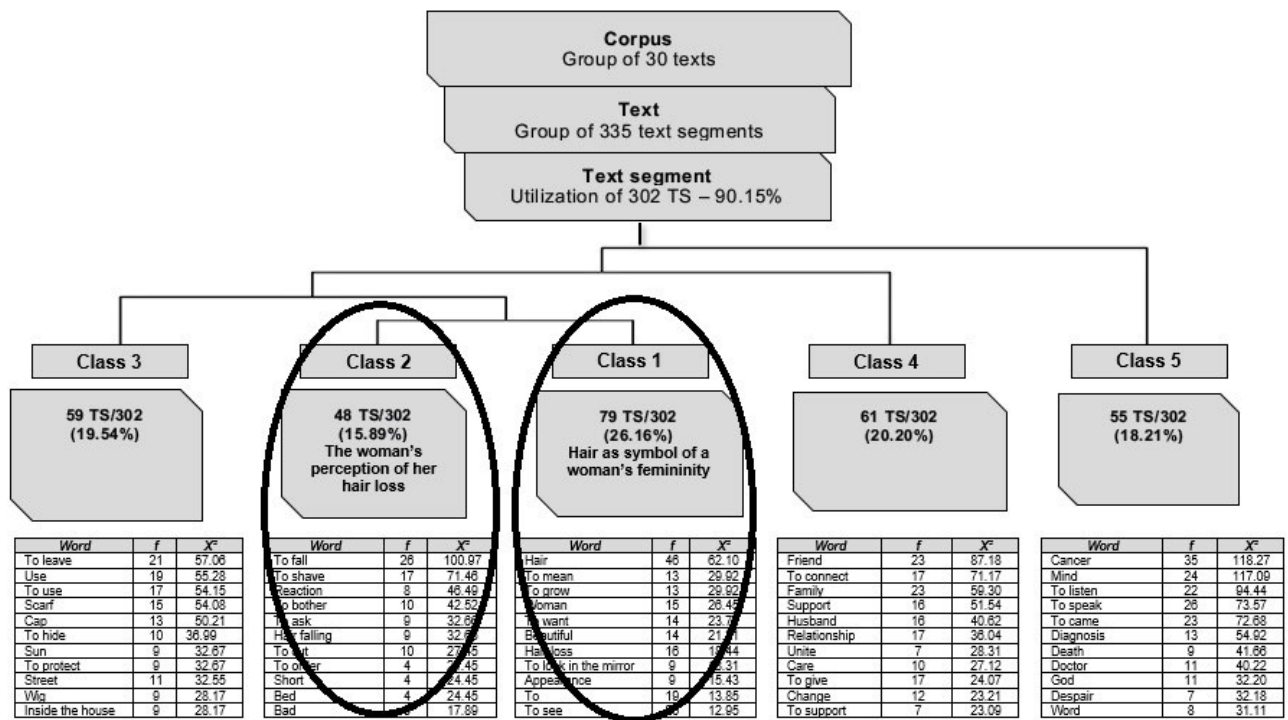
The sociodemographic profile of the participants indicated that 28 (93.33%) belonged to the state of Pará; 17 (56.66%) were between 44 and 56 years of age; 20 (66.6%) reported having a steady partner; 11 (36.6%) had incomplete elementary school education; the majority was catholic among 21 (70%) participants; 17 (56.66%) worked, and 19 (63.33%) had family income between 1 and 2 current minimum wages. Regarding the clinical-epidemiological variables, breast cancer was most evident in 17 (56.66%) of the participants.

As for the interviews, the IRAMUTEQ software processed the corpus of 30 texts into 335 text segments (TS), with utilization of 302 TS (90.15%). The class analysis based on DHC and TS originated a dendrogram with five classes. To meet the objective of this article, classes 1 and 2 are discussed, which are sub-shared in the same block, but with different meanings, denoting that, even though they have affinities among themselves, they are different, hence they have been separated.

The semantic content of class 1, formed by 79 TS/302 (26.16% of the corpus), refers to the feelings aroused by the alopecia and its impact on self-image. As for class 2, formed by 48 TS/302 (15.89% of the corpus), it points to the impact of the perception and feelings generated since the first signs of alopecia, resulting from the iatrogenic effects of chemotherapy treatment.

In this sense, the words of these classes highlight the psychosocial aspects resulting from the alteration of self-image and self-esteem. These classes are the result of questions regarding the meanings attributed by women to hair and the perceptions of these alterations since the first signs. Figure 1 presents the dendrogram with the descending division of the classes, showing the connection and affinity between them.

Figure 1 - Dendrogram: organization of the classes from the IRAMUTEQ analysis



Source: IRaMUTEq Report (2021).

In the lexical analysis of class 1, it is observed that the most representative words were “hair”, “to mean”, “to grow”, “woman”, “to want”, and “beautiful”, denoting the importance and significance of hair in the view and life of these women, which goes beyond the purely aesthetic aspects and the psychosocial, cultural, and identity issues.

“Hair means a woman’s vanity. It is part of her body, it influences whether she will feel beautiful or not” (M6). “For me, hair means that you as a woman feel beautiful. It means vanity and femininity. Hair represents all of that” (M7). “I still get low self-esteem, since it was my hair, my eyebrows, and my eyelashes anyway. All are important for a woman” (M8).

The changes that occur with antineoplastic chemotherapy can lead to mischaracterization, strangeness, and denial of the new image, causing negative feelings due to the visual and temporary distortion of being and being in the world.

“When I saw myself without my hair I felt strange as if I didn’t see myself anymore. When I looked in the mirror I felt like another person” (M2). “When I look in the mirror I feel

a sensation that I can’t even explain, but it’s like I feel diminished, another person” (M8). “A woman’s beauty and vanity are in her hair. So, a bald woman is ugly. I felt less of a woman and with low self-esteem” (M11). “When I am in front of the mirror I question myself if I am myself or who is this woman that is in front of me because I do not recognize myself, I really want to go back to normal, have hair, and groom myself” (M23).

For other women, alopecia is something temporary, just a phase, and therefore does not have much impact on their self-esteem. Some seek strength in religiosity to face the disease in a positive way, aiming to improve their health condition and the consequent iatrogenic effects of chemotherapy treatment.

“Later I understood that hair grows with time and I reassured myself, I have my cancer care, but I live my normal life” (M2). “I try to have strength and think that this is just a period that will soon pass, and that my hair will grow back” (M20). “I seek to get back on my feet little by little, thinking that the Lord God will heal me and give me new hair once all this is over” (M27).

I feel that at some point my appearance as a whole will improve. It is just a phase” (M28).

In the lexical analysis of class 2, the most representative words were “to fall”, “to shave”, “reaction”, “to bother”, “to ask”, and “hair falling”, indicating that in order to get rid of the suffering of seeing their hair falling, some women chose to cut it or even shave it. This is an extreme action for the great majority, a need to overcome their own pain, a way of coping with the disease, deciding for themselves, for their protagonism, in their own time and in their own way, instead of waiting for the how? And when will this loss happen?

“The hair loss bothered me, because every day when I woke up there were several hairs on the pillow, on the floor, in the shower, everywhere, it bothered me” (M1). “I asked my sister-in-law to cut it and leave it very short, it bothered me when I ran my hands through it and felt a large amount of hair, not only on the bed but spread all over the house, this cut relieved me in a way” (M4). “I prepared myself for this moment, I went to the hairdresser for a very short haircut to get used to it, and when I realized that the locks were falling out even with short hair, I decided to shave it. I felt better after shaving” (M19).

Women’s perception of the physical and visible reality of alopecia is related to the externalization of the disease in the eyes of others, ratifying their condition of being sick and causing feelings such as commiseration and strangeness of their appearances by others.

“When it started to fall off I was sure I was sick because, until that event, I was living my normal life” (M5). “I knew that when I walked down the street, bald or with a scarf, everyone would know that I was sick” (M6). “Now, with alopecia, people keep asking ‘is she sick?’ or ‘does she have some contagious disease?’ To have hair is to have health, the lack of it is a disease” (M23).

In this context, the looks and comments of others may recognize or reject the altered image of these women, having negative repercussions on the lives and daily lives of the participants.

“People stare at me with pity or fright and it makes me very uncomfortable and embarrassed” (M22). “Once, when I arrived at a bank, everyone in the queue turned away as if I had a contagious disease. That made me feel really bad because prejudice leaves bigger wounds than the very illness the person is facing” (M23). “I don’t want anyone to hinder my treatment by making me sad with comments about my current appearance” (M25).

DISCUSSION

Cancer has a characteristic profile according to each study region; therefore, it is classified as a variable aspect⁽¹⁾. There was a predominance of cases of alopecia whose primary site of cancer diagnosis was located in the breast, in agreement with another study⁽⁹⁾. There was a predominance of age between 44 and 66 years, which agrees with the results of other studies^(9,14). The determination of this age range may be correlated with the progressive increase in the risk of incidence of new cases of cancer from 40 years of age onward^(1,23).

The predominance of Christian women who experience cancer and have steady partners was similar to the results of other studies^(14,16). It happens that, although marital relationships are not presented as a determining factor for the development of the disease, the companion is characterized as a key player who should be inserted into the network of support for women with her family, as well as a fundamental element with regard to active participation during treatment, such as in the rescue of married life^(16, 23).

The representation and importance of hair differ between the different genders. For women, hair assumes a position that characterizes female identity, as they are considered crucial aspects of appearance in the social environment because they facilitate recognition and allow for personal characterizations, such as: female or male, young or old, and healthy or unhealthy. This categorization directly influences how individuals behave in a

certain context and how they interact with each other. Awareness of the human body (of oneself, of one's body) increases with social interactions since it is these interpersonal relationships that notice changes in body image (appearance), such as alopecia⁽¹⁹⁾.

Long hair is represented in society as a social and cultural symbol of femininity and as a reflection of sexuality. Therefore, alopecia acts negatively on body image and can also interfere with the sex life of patients who require chemotherapy, since this loss may be associated with the absence of individuality and attractiveness⁽⁷⁾.

In view of the above, the evidence of care with beauty is emphasized, especially with regard to hair. Thus, the clinical signs of alopecia result in the excessive concern of women when they observe the development of their new life condition⁽¹¹⁾.

Although self-image is a complex concept, it can be understood as the mental representation that a person has of his/her own body. In this case, the term image is not restricted only to the specific sense of vision, but also encompasses the affective and physiological experiences that have repercussions and interfere with the way the subject perceives himself, interacts, and reacts to the social environment. This construction and perception of image occurs in the interaction of the subject with the world around him/her⁽²⁴⁾.

Nowadays, people suffer increasingly from the influence of advertising in social media. These information and communication vehicles sell, indoctrinate, and dictate a stereotyped image of beauty that generates direct impacts on the formation of genders, especially in their visualization before society. It should be noted that the vast majority of people in the world do not have these standards of beauty shown whose features are practically unattainable, especially for people who are being treated for malignant neoplasms and often undergo a process of body change^(6,25).

In addition, women undergoing cancer treatment go through several changes in their way of life, ranging from discomfort to pain by the loss

of their hair, the disfigurement of their image, the limitation or loss of independence, the loss of self-esteem, by the prejudices and fears triggered by the ideas of incurability and death⁽⁶⁾.

In face of these losses, a range of negative feelings is generated in the woman in relation to herself. The body transformed by hair loss due to the chemotherapy drug nurtures anguish and sadness, and both feelings are responsible for generating a self-conception that she is outside the standards that are imposed and accepted in the social environment⁽¹⁹⁾.

The relevance of hair for women emerges in the segments of texts in which they expressed the perception of themselves marked by the pain of seeing their hair falling out, the altered self-image, and other emotional changes experienced, such as the non-recognition of themselves and the emergence of negative feelings towards themselves caused by strangeness and disfigurement of their body image⁽¹⁶⁾.

In the experience of young women with breast cancer and mastectomized, alopecia is cited as the stage of greatest difficulty in overcoming, denoting more representative feelings than the mastectomy^(22,25). On the other hand, alopecia may be perceived as something momentary, without much emotional damage. This occurs due to the conception of chemotherapy treatment as the only way to achieve a cure, thus, they cling to this conception as a way to face and assume the current health condition⁽⁹⁾, with no damage to their self-esteem and femininity, emphasizing the fact that they are alive⁽⁸⁾.

Cancer, even with the numerous forms of treatment, is still seen by many people as an incurable disease that is close to finitude, so seeking means of refuge in the face of so much suffering is something necessary. In this context, faith plays an important role during this process of seeking healing and well-being, since faith has significant repercussions and provides a condition of peace and optimism. Faith offers support and closeness to subjectivity, even if only momentarily, reflecting directly on how these women

understand and face not only the disease but also the iatrogenic effects of chemotherapy^(6, 26).

In short, most of the participants had prior knowledge about alopecia and therefore chose to be proactive in reducing the length of their hair, either gradually or abruptly, shaving it, in view of understanding the process of hair loss as an adverse effect of chemotherapy for cancer treatment. Starting from the premise that what the eyes don't see, the heart doesn't feel, the previous cut is a way to mitigate the level of psychic suffering related to the gradual hair loss⁽³⁾.

This prior knowledge of alopecia as one of the adverse effects of chemotherapy may be associated with the guidance that this woman received from the health team since the beginning of treatment. It is noteworthy that nursing acts as an important player in the dissemination of information and guidance in advance to women about the changes that experiencing and treating cancer can cause^(7, 16).

In this study, some women reported having received, since the beginning of treatment, guidance from health professionals working in the oncology sector of the hospital on questions related to hair loss, such as: When will hair loss start? What to do? How to care for or disguise it? And what resources are available for this? On the other hand, for other women, prior knowledge about alopecia was linked to previous experiences lived by family members, friends, or people close to them.

The visual nature of alopecia affects the biopsychosocial dimensions of women, since it encompasses numerous physical and psychological changes, as well as behavioral and social ones, and may lead to a rupture in life patterns⁽²⁶⁾. Experiencing alopecia can trigger a whirlwind of emotions, including the most aggressive ones for fear of family and social environment not understanding her health status, since alopecia exposes the disease and generates a view of an unhealthy person^(8, 27).

Thus, through the current condition of life, changes occur in these women's lives, and they are often forced to give up their routine activities as well as their interpersonal and affective relationships for fear of others' judgment or shame of their self-image, contributing to the development of feelings such as loneliness and depression, thereby impairing the quality of life of these women⁽²⁷⁾.

Therefore, society becomes a stigmatizing agent of women with cancer, since the looks directed at these women with alopecia, in most cases, may indicate pity, disapproval and curiosity, causing damage to their self-image and self-esteem, suffering, and loss of identity⁽¹⁹⁾. The exposing of alopecia highlights the pathology, which may culminate in rejection from others or from themselves^(11, 16).

FINAL CONSIDERATIONS

Perceptions of women about their self-image after alopecia due to antineoplastic chemotherapy vary according to the importance attributed to hair in their lives and the consequences of the lack of hair in the mental construction of altered and distorted images of themselves, even if only momentarily, with conflicting feelings emerging in the face of the strangeness of their mirror images.

The limitation of this study is methodological in nature because it was developed in a single oncology hospital. The expansion to other institutions will allow the densification of the data with more robust results regarding the sociodemographic analysis of the participants.

Additionally, the results of this study may contribute to the theoretical and practical field of nursing care for women with alopecia due to antineoplastic chemotherapy, since it may bring out subjective experiences of those who experience this process, revealing that these women do not get sick only because of cancer, but because of a range of psychosocial factors that interfere with their ways of being, existing, and relating to themselves and others.

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