








The (re)construction of female identity among women cancer survivors: a qualitative study

A (re)construção da identidade feminina entre mulheres sobreviventes do câncer: um estudo qualitativo

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ABSTRACT

Introduction: During and even after cancer treatment, changes related to patients' body image and concerns about their female identity can impact both their physical and emotional health. This study aimed to understand the (re)construction of female identity among women cancer survivors.

Methods: This was a qualitative study developed based on the concept of identity. Twenty-one adult women who had undergone or were undergoing antineoplastic treatment were interviewed.

Results: The data analysis process revealed three themes, namely: Femininity on the skin, Being feminine in the eyes of others, and Being feminine now.

Discussion: The identity of female cancer survivors was redefined after cancer treatment, since it leads to physical changes that affect the way they perceive themselves and present themselves as feminine to society. From this moment on, these women seek to assert themselves in socially and personally valued behaviors and actions that justify their femininity, building a new identity based on the illness experience.

Keywords: Femininity, Social Identification, Body Image, Cancer Survivors, Culture.

RESUMO

Introdução: Durante, e mesmo após o tratamento do câncer, mudanças relacionadas à imagem corporal das pacientes e preocupações relacionadas à sua identidade feminina podem impactar tanto sua saúde física quanto emocional. Este estudo teve como objetivo compreender a (re)construção da identidade feminina entre mulheres sobreviventes do câncer.

Métodos: Este é um estudo qualitativo desenvolvido com base no conceito de identidade. Vinte e uma mulheres adultas, que haviam sido ou estavam sendo submetidas a tratamento antineoplásico, foram entrevistadas.

Resultados: O processo de análise de dados resultou na produção de três temas, a saber Feminilidade na pele; Ser feminina nos olhos dos outros; e Ser feminina agora.

Discussão: As identidades das mulheres sobreviventes ao câncer foram re-significadas após o tratamento antineoplásico, uma vez que este leva a mudanças corporais que têm repercussões na forma como elas se percebem e se apresentam como femininas à sociedade. A partir deste momento, estas mulheres procuram se sustentar em comportamentos e ações valorizadas social e pessoalmente que justificam sua feminilidade, construindo uma nova identidade baseada na experiência da doença.

Palavras-chave: Feminilidade, Identificação Social, Imagem Corporal, Sobreviventes do Câncer, Cultura.

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INTRODUCTION

The connection between biological and social factors and between bodily aspects, the self and identity is a constant in the life experience of people with chronic illness.¹ From the onset of illness, body functioning changes, and self-conception and identity may also change.¹ The body, which in most social situations is taken for granted as part of the person, loses this status once physical malfunction sets in during illness.¹

In cancer, the physical changes resulting from the disease and its treatments are frequent in the illness process. The psychological impact of cancer on women is twofold: on the one hand, it is related to the social image of cancer represented by suffering and death, and on the other hand, it is related to the social image of the female body, sexuality, and motherhood.² For example, alopecia is a fairly common situation experienced by women undergoing chemotherapy treatment for breast cancer.³ Despite the numerous unpleasant side effects of antineoplastic chemotherapy, including vomiting, nausea, and fatigue, one study found that hair loss was considered the most traumatic by 46% of respondents.⁴ Trusson et al.,³ in their study on the role of hair loss in cancer identity, state that future research should consider the role of stereotypes in patients' experiences.

Haines et al.⁵ developed a mixed-method study to evaluate breast cancer education and prevention initiatives targeting young females. The researchers analyzed a selection of 32 English-language breast cancer messages and advertising campaigns that targeted this audience. A visual analysis of the messages indicated an explicitly gendered discourse within contemporary campaigns, which involves conflicting messages regarding breast cancer risk, health, and female beauty.⁵ The researchers therefore conclude that even though the intent may be to educate and empower young women to "fight" breast cancer, the messages paradoxically use images that sexually objectify young women's breasts and bodies, which may contribute to the reproduction of one-dimensional or stereotypical representations of gender and femininity.⁵

Women often make very negative statements about the change in their physical appearance after cancer. They often report that they feel a part of themselves is missing or that they no longer see themselves as women.⁶ In addition, they also report losses in marital relationships and social interaction.⁶

During and even after cancer treatment, changes related to body image and concerns related to their female identity can impact both the physical and emotional health

of women.⁶ A study on female identity reconstruction among female cancer survivors may provide a deeper understanding and improve nursing care for these patients. In this context, this study was developed with the aim of understanding the (re)construction of female identity among women cancer survivors in Brazil.

METHODS

Study Design

This was a qualitative study developed based on the concept of identity, understood as shared psychological perceptions and social relationships established by a given group, with a shift from "I" to "we", so that there is recognition, acceptance, and belonging of the subject,⁷ as in the shared illness experiences of female cancer survivors, which allows the construction of a new identity. Culture plays an important role in the construction of identity, since it recognizes the subject as a being who is aware of their thoughts and practices, and that these stem from the social world.⁸ Therefore, culture subsidizes the construction of identities. This article was structured according to the *Consolidated Criteria for Reporting Qualitative Research (COREQ)*.⁹

Participants

Participant recruitment was carried out using the snowball sampling technique. This technique includes the publication of the study in social media where participants can access and share the study information with others in their social networks.¹⁰ The dissemination of this study was carried out on the following social networks: Instagram, WhatsApp, and Facebook. An explanatory text about the research, the target audience, and an invitation to participate in the study was disseminated on these media. Women who met the proposed eligibility criteria and expressed interest by responding to the invitation through comments or direct messages to the research team member disseminating the study were approached. A research team member contacted the participant and scheduled a day and time to conduct the interview virtually via a video conferencing application. Furthermore, the study participants were asked to use their personal contact network to recruit other people with shared profiles.¹⁰

The established eligibility criteria were as follows: Brazilian adult women (aged 18 or older), who had undergone or were undergoing antineoplastic treatment, and who reported being clinically able to participate in the interview. As this investigation was guided by the concepts of identity and culture, we decided not to limit the type of neoplasm, stage of disease and treatments as eligibility criteria. The

reason for this is that, according to the adopted theoretical framework, the experience of illness is individualistic. In other words, individuals with similar characteristics in relation to the illness will have distinct experiences. The approach to these experiences will occur through culture, as it provides the foundation for decision-making. Thus, grasping these experiences will help to understand the identity constructed by a social group, as in the case of women with cancer.^{7,8}

Data Collection

Data collection was carried out from February 2021 to February 2022. The interviews were conducted by the research team, and all interviewers received appropriate training in qualitative interviewing from a research member experienced in this research design and in cultural studies. Data collection was supervised by the same researcher. Each participant was interviewed twice, with each meeting lasting approximately thirty-five minutes. The interviews were conducted and recorded for later transcription and analysis through the Google Meet platform.

When necessary, a second interview was conducted with some participants, so that the researchers could confirm what had been previously said. In such case, the interval between each interview was one month, as proposed by the participants according to their preferences. For six participants, the second interview was not possible for the following reasons: lack of availability, hospitalization, and compromised health. For these cases, it was decided to respect the situation and only use the information collected in the first interview for data analysis. Their reports were shared (without identifying the participant) with the other participants during their respective individual interviews to cross the experiences and deepen the data, thus seeking the validation of the reports.

For data collection, the research team designed the following questions, which were organized in an interview script, in order to answer the objectives of this research: "What does femininity mean to you?", "Is femininity important to you?", "What do you usually do to feel more feminine?", "Have cancer and treatments affected your femininity in any way? If yes, how?". In addition, other questions could be asked to deepen the interview, and a questionnaire was prepared to collect socio-demographic and clinical information from the participants, such as age, marital status, employment status, and tumor topography.

Data collection was interrupted when the data corpus obtained met the proposed objectives. The interviewers' impressions during data collection as well as other situations experienced during the course of the research were recorded in a field diary.

Ethics

This study was approved by the Ethics Committee for Research with Human Beings of the Federal University of Alfenas (UNIFAL-MG) on October 22nd, 2020 under Protocol No. 4.355.724 and Certificate of Ethical Appraisal Presentation No. 29155520.9.0000.5142. The participants consented to participate in this study by signing the Informed Consent Form, which was provided digitally. When cited in the text, the participants were identified by fictitious names.

Data Analysis

Data analysis and data collection were carried out simultaneously. Each interview was analyzed according to the inductive thematic analysis of the manual transcription and familiarization with the data.¹¹ Subsequently, data coding and recoding was performed, and the representative themes for the participants' universe were elaborated. These themes were revisited in the second interview with the participants (with the exception of the six participants mentioned above), therefore, the data socialization strategy was chosen.

Reliability

To ensure the methodological rigor of the study, the research team decided to follow nine strategies that ensure a high level of validity and reliability in qualitative research:¹² 1) before and during data collection, an attempt was made to identify and list the elements that could influence the results; 2) an attempt was made to recognize biases in participant selection; 3) the adversities experienced were recorded in a field diary; 4) the reported experiences were compared in order to obtain different perspectives of the phenomenon studied; 5) clarity was sought in the analysis process; 6) excerpts were selected from the participants' statements that substantiated the identified themes; 7) the data collected was discussed with the entire research team to reduce flaws in the investigation; 8) the participants' statements were validated by conducting more than one interview with some participants, or with the strategy of socializing the participants' information; 9) finally, an attempt was made to associate the interviews with the field diary entries in order to obtain consistent data on the participants' perspectives.

RESULTS

A total of 94 women responded to recruitment, but 51 did not attend the interview appointment. Thus, 21 participants remained throughout the data collection process (Table 1). All participants were residents of the southeastern region of Brazil.

Table 1. Participant characteristics.

Fictitious name	Age	Marital Status	Employment	Type of cancer
Violet	42	Married	No	Breast
Sunflower	30	Married	No	Breast
Lily	38	Married	Yes	Breast
Rose	52	Married	Yes	Breast
Mayflower	56	Divorced	Yes	Breast
Tulip	48	Divorced	Yes	Breast
Marigold	35	Married	No	Stomach
Azalea	39	Married	Yes	Breast
Clove	50	Married	No	Peritoneum
Orchid	30	Married	No	Kidney
Hydrangea	31	Married	Yes	Breast
Daisy	39	Married	Yes	Breast
Stellitia	37	Married	No	Breast
Bromelia	45	Married	Yes	Breast
Camellia	41	Divorced	Yes	Breast
Gerbera	29	Single	No	Breast
Dahlia	21	Single	Yes	Ovaries
Chrysanthemum	34	Married	No	Breast
Magnolia	26	Married	Yes	Neck
Begonia	39	Married	Yes	Lymphatic System
Amaryllis	46	Married	Yes	Breast

The data analysis process resulted in the production of three themes, namely: Femininity in the skin; Being feminine in the eyes of others; and Being feminine now (Figure 1).

Femininity in the skin

In this theme, the participants reported on the physical and daily repercussions that cancer and its treatments (surgery and chemotherapy) had on their lives.

Azalea: “Because sometimes people tell us: ‘Oh, but it’s just hair, hair grows back!’ No, it is not just hair, behind that hair are people with low self-esteem, behind that hair is someone facing a disease... When I shaved my head, one of the things I heard the most was: ‘You are lucky because you are beautiful!’ I think everyone has their own beauty, but what about a woman who doesn’t feel beautiful? How would she feel represented by a bald head? Because the hair is the frame of the face, and what do you do when you no longer have that frame? [...] It’s hard, I don’t recognize myself in this face, you know? I don’t recognize myself in this body. Early this morning, before I went out, I put on my eyeliner, because the eyes no longer have the lashes that framed them. No doubt this makes a difference, the eyebrows do, the eyelashes do, makeup does, but it is not just a question of vanity, it is really a question of trying to

find yourself in what you are not, I am not this person who is here with you, I do not find myself in her, and there is a whole meaning that you can give to this change [...] It is very sad, even though we know that there is treatment, that science is fighting to make it possible!”.

Orchid: “I’m not a particularly vain person, but when you start looking at yourself and not recognizing yourself, when you lose things that you were used to, then you start looking for things that make you more feminine [...] You are already emotionally shaken by the diagnosis, and then you start looking at yourself in the mirror and not recognizing yourself, then you start to suffer with that, right, there is no way not to be emotionally shaken [...]. The image was something that lasted longer, because I basically did not look at myself in the mirror for a while, because I did not like what I saw, so that made me a little frustrated... It seems that you are just a random person, you are not a woman, it seems that you only see a disease, you only see yourself like that, you simply cannot see your traits, what describes you [...] I thought I was very feminine and suddenly all that was lost, both physically and emotionally, psychologically, I think it all changed”.

Violet: “I am not what I used to be, I miss being what I used to be, being able to take care of my house work, take

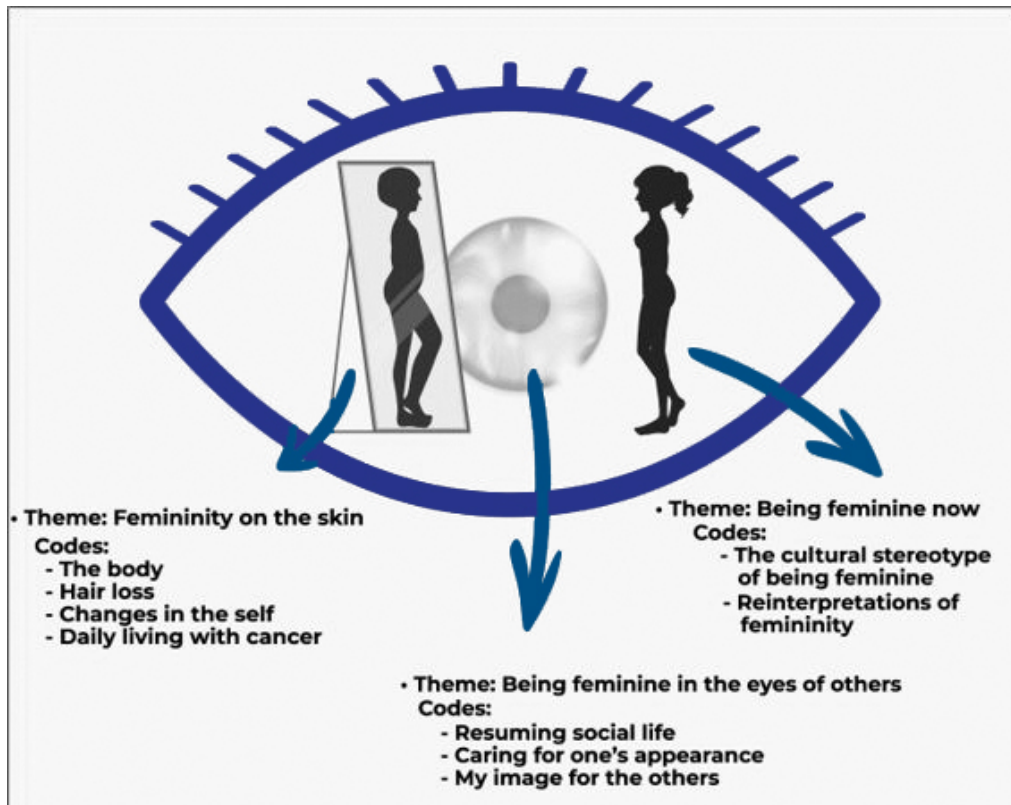


Figure 1. Representation of the data analysis process.

care of my husband, have a sex life, be able to work, study, concentrate, because these medications help us, but they also end up killing the good cells that are left. I think that I brought this upon myself, really messed up [...] It is the feeling of not being able to give back to the people that are around me, what they need, like affection to my children, and attention to my husband. I withdraw a little when I am in pain, because I don't like to see them watching me feel pain. Because it is clear, for those who know me in my daily life, they know that I am a lively and happy person, I'm talkative, I get angry with my children, this is my normal, but when I feel pain I withdraw a little, I get sad. That is why I avoid as much as possible not to feel this pain, this pain hinders me".

Being feminine in the eyes of others

The women interviewed disclosed how they felt when they returned to society and how they stood out because of their changed appearance due to the illness.

Lily: "I thought I could not wear normal people's clothes, today I dress up, I wear any kind of clothes, I wear makeup, I wear jewelry, I do everything normally. So, I'm a normal person nowadays, I don't worry about the opinion of others [...] The impression I have is that everyone is staring, everyone is commenting, this bothers me".

Sunflower: "... When people see that we are bald, they look at us with this pitying look, as if we were things, they think: 'Wow! Look, she's bald, she's having treatment'. When it starts to grow back, many people look at us and say 'Wow, how could she have the courage to get her hair cut like that? She's a little boy, isn't she?' Sometimes people don't know that she went through treatment, so... there is still this prejudice, you know? That people wear more masculine hair, like, let's say, a little boy's haircut".

Tulip: "People have prejudices, because nowadays the people who are close to me, who know about my treatment, about my disease, see me differently, but in the beginning, as soon as they found out that I had the disease, they looked at me with a pitying face, 'aw, poor thing, ah Tulip' they would verbally tell me, 'aw, be strong', but I realized that they were suffering more than I was, like 'aw, poor thing, oh...' I heard bizarre things, like 'you always took care of your body on the outside, now I want to see on the inside, you forgot to take care of yourself on the inside, now let's see whether you remain beautiful and hot, let's see if you keep up being hot without getting fat' [...] Before chemotherapy, Tulip was afraid of being judged, today Tulipa is not afraid of being judged [...] there are other factors, but this is the main one, before I was very afraid of being judged".

Being feminine now

In statements for this theme, participants try to explain the meanings they now employ for being feminine.

Hydrangea: *"Ah, I think that being feminine is what differentiates us from men, we are human, women, right?! Women are delicate people, more concerned with the family environment and making sure everything is in order, having a different role, and I also think that femininity has to do with the visual aspect of the woman, because when I lost my hair, I didn't feel so feminine, so I think that our softness, is... we can take care of our hair and regarding the body we have our differences too. When I lost my breasts, I felt the difference, so I think it has everything to do with what a woman really is, what differentiates her from a man [...]"*.

Violet: *"Ah, being a woman means having the authority to do what you want, to think about what you can and cannot do, what is right and what is wrong. It's you being able to come and go without anyone forbidding you from anything, without judging, without pointing fingers, which is what most people do. To me being a woman is this [...] I had to have my (breasts) removed, I had to learn to have other femininity values [...] This is very important, because we can't let a disease speak louder than who we are, and femininity is not just about having hair, breasts, or body, it's more than that. Your actions is what matters, and you can't let anything shake your actions, people from outside influence what you feel, I think that we change our thinking"*.

Rose: *"I think that femininity for me is keeping the feeling of being a woman, being able to preserve my quality of life, being able to stay active, is... being able to, even in the most difficult times, to find beauty in my image, to be able to put on make-up, to dress myself even in the most complicated times, I think that femininity during chemotherapy is... you get a little lost, you look in the mirror and cannot identify yourself, right?! It's you searching for your identity, finding your identity within all that you are living [...] Yes, this is a social stereotype, isn't it? People create a stereotype since we are children, we create a stereotype of what is beautiful, what is socially considered beautiful, and when you are faced with a total, 100% change in your life, you realize that this stereotype has nothing to do with it, that you have other things that make you much more beautiful, much more important, much more special, I think it is the change in the value of things in life, that's exactly it"*.

DISCUSSION

In the participants' experience, the physical repercussions of chemotherapy and surgery mark the beginning of changes in their perceptions of their femininity. They realize from

their bodies that they cannot visually be a feminine being, as their reports describe situations in which they distance themselves from the previously constructed representation of femininity.

Physical changes related to treatment affect the well-being of these women and their self-esteem. This is because many of them, self-esteem is based mostly on their perception of their own body, so a poor perception of their body can lead to a decrease in self-esteem.¹³

Through their statements, the interviewees give an indication of the extent to which cultural conceptions influence the interpretation of body image. Considering this, the way people with cancer view their own physical appearance and their actions regarding their bodies change remarkably, especially in terms of femininity and sexuality. In general, women constantly self-examine themselves in relation to cultural stereotypes of physical appearance.¹⁴

Therefore, appearance-related side effects change the perception of body image and lead to intense negative reactions. Body image is defined as the "internal representation of one's external appearance"¹⁵ that involves the psychic representation of one's body and the emotions related to the sense of their own body. The body image construct is indeed relevant because it directly impacts quality of life.¹⁴

When confronted with obstacles in society's representation of the so-called feminine bodies, the participants experience the feeling of being in a neutral point in gender representation, because their body attributes do not support the idealized feminine image, but also do not represent the masculine image. Culturally, women have been required to take care of their appearance since childhood, a demand that can overwhelm them if they focus only on the outside and consequently pay no attention to inner care.

Over the centuries, women's bodies have been standardized, signified, and shaped based on culturally produced social norms and impositions. This standardization, which leads women to conform to what is standardized and accepted as natural and biological, is a way of marginalizing their bodies in response to what is understood as correct, healthy, and beautiful.¹⁶

A Dutch group studied the changes in body image of women undergoing chemotherapy, in particular the problem of hair loss.¹⁷⁻¹⁹ These researchers observed that in designing their physical appearance, these women sought to represent themselves as deteriorated and sustained this image with expressions of negative feelings, revealing their difficulty in coping with esthetic changes to their bodies and consequently in presenting their female identity in the social world. The physical changes prevent them from representing their femininity in several dimensions, such as taking care of

their household, their husband, their children, their work, as well as themselves. Regardless of the scenario, the context of coping with illness includes the family and can affect family dynamics.²⁰ This ineffective role performance negatively affects their female identity, sense of worth, self-esteem, self-confidence, and body image.²¹

For this reason, the participants believe they stand out in the crowd, because even with make-up they feel different, they believe they embody the image of a woman deprived of her femininity or even recognized as sick. It can therefore be theorized that, by reinterpreting their psychosocial and femininity-related priorities, some women try to assimilate new attributes that help them feel more comfortable in their social reintegration and deal with the perverse or pitiful expressions in their daily lives. However, despite being socially valued, these attributes do not fully meet the esthetic aspects that are socially imposed. Some researchers²² describe that body image anxiety can lead to continuously and obsessively looking at oneself in the mirror, dressing to hide or correct a perceived flaw, and seeking reassurance from other people about one's appearance in order to find some kind of comfort in this behavior, while recognizing that one is different.

The change in the female external image is a significant episode during treatment, which is accompanied by a change in the internal image, that is, the image that the woman has of herself, which is subjective and corresponds to her identity.²³ Unlike other chronic diseases, cancer is a traumatic and conflicting illness for women, which brings with it effects related to body changes, sexual dissatisfaction, in addition to mood swings and difficulties in integrating into groups and the family, which can make all the difference in the outcome of adaptation to adversity.²⁴

In possession of this new body, women seek to bargain these changes by adopting elements that are culturally appreciated, such as being alive and with their affective bonds, and being delicate and independent. Besides, the participants list new elements to redefine themselves as feminine, but the challenge is not only to feel feminine, but also to expect others to recognize them as such. In this dilemma, they dedicate themselves to perform their femininity, even if this new body only represents a small part of them. For the participants, the process of rediscovering their femininity during the illness is an ongoing one, because with each chemotherapy session, surgery, or other procedure, there are new repercussions that require a new learning of the self. This lead to a reorganization of the attributes that compose their female identity.

By accepting their new condition, these women will improve their coping in relation to their negative experiences with the illness and consequently reinterpret their

femininity and their existence in a positive way, which will naturally improve their self-perception. Soon the perception that others have of them will be softened, since their identity has been constructed in an authentic and conscious way.²³

To understand the impact of chronic illness, including cancer, on identity and well-being a framework of 'biographical disruption' has been used. Bury²⁵ describes biographical disruption as an experience in which "the structures of daily life and the forms of knowledge that sustain them are disrupted". This can affect how people view themselves and how they believe they are viewed by others, involving a renegotiation of self and identity.²⁶ As mentioned earlier, women experience several changes throughout the illness, that is, new biographical disruptions emerge, which change their perceptions of self and add up in the composition of a new female identity.

Finally, it is understood that the reconstruction of the female identity for women cancer survivors begins when their bodies change during or after treatment. In this first moment, there is the self-recognition that one is no longer the same, and this is confirmed in their experience in society, so these women seek to manage their female identity to meet the representation of who they are now. The basis they use to understand themselves as different and establish their new identity is culture, that is, the senses and meanings embedded in the feminine gender that are present in their social group are replaced by others that are also worthy. Therefore, the new feminine identity for the participants is to be delicate, to care for themselves and for others, to be socially active, and to have the freedom to perform their femininity beyond stereotypes.

The limitations of the study are related to the difficulty of some participants in using web conference technology and the fear of exposure of their image, since the meeting would be recorded, which led to some women refusing to participate in this research. The interviews had to be conducted by video call because the data collection occurred during the COVID-19 pandemic, when face-to-face activities were not recommended, especially for people with chronic diseases. To address this limitation, participants were explained how the web conference platform worked prior to the interviews and were assured that their image would be protected for the research.

CONCLUSIONS

In this research, it was found that the identity of women cancer survivors was redefined after cancer treatment (surgery and chemotherapy), as these procedures lead to physical changes that affect the way they understand and present themselves as feminine to society. From this moment on,

these women sought to sustain themselves in socially and personally valued behaviors and actions that justify their femininity, thus promoting the construction of a new identity based on their experiences with the illness.

It is expected that the evidence produced in this study will contribute to the knowledge of the identities constructed during the illness, not only by women, but also by other social genders. The generalist or oncology nurse should be aware of the fact that the illness has repercussions that go beyond the physical dimension of the patients, reaching the psychosocial dimension, therefore these professionals must meet such care demands.

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