

Beyond biomedical classifications: breast cancer experience in Brazil, 1990-2015

Carlos Barradasⁱ

ⁱ Junior researcher, Centro de Estudos Sociais/
Universidade de Coimbra.
Coimbra – Portugal
orcid.org/0000-0002-2130-5095
barradascarlos@gmail.com

Luiz Antonio Teixeiraⁱⁱ

ⁱⁱ Professor, Faculdade de Medicina/Universidade Estácio de Sá.
Rio de Janeiro – RJ – Brasil
orcid.org/0000-0001-8871-0928
luiztei3@gmail.com

Luiz Alves Araújo Netoⁱⁱⁱ

ⁱⁱⁱ Postdoctoral researcher, Programa de Pós-graduação
em História das Ciências e da Saúde/Fiocruz.
Rio de Janeiro – RJ – Brasil
orcid.org/0000-0001-7965-2957
luizalvesan@hotmail.com

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Abstract

The paper analyses illness experiences of breast cancer in women undergoing treatment at the Hospital of Cancer III of the National Institute of Cancer. It argues that part of the interviewed women's experience was constructed from the interaction between family coexistence and the mobilisation of different cultural meanings of the disease and femininity, negotiating senses for biomedical entities. The study results from a qualitative research of ethnographic inspiration that interviewed women undergoing treatment from breast cancer during 2015. It draws on the accounts to discuss the interaction of society with biomedical entities for the significance of cancer in Brazil between the 1990s and 2010s.

Keywords: breast cancer; illness experience; biomedicine; Brazil; history.



Illness experience is a phenomenon at the same time individual and collective, lived within the family sphere and in other circles of the subjects' sociability, confronting different aspects that configure the subjectivity and personal trajectory of the sick person (Williams, 2000).¹ Being ill from chronic conditions adds fundamental aspects to the experience, such as the demand for long-term care that, in most cases, incorporates the need of multiprofessional teams, greater quantity of clinical and laboratory exams, and the use of medical technologies of higher complexity. Furthermore, it determines the continued coexistence with symptoms and signals of the disease and, most of all, the realignment of social interactions (Williams, 2000; Weisz, 2014).

Breast cancer is a disease that, besides the violence of its biological effects, brings with it a strong symbolic and emotional load, related to both the suffering that it produces and the possible transformations on the body and on sociability. Associated to different aspects that constitute social interpretations about women's place in society, such as sexuality (Emilee et al., 2010), mammary carcinoma is one of the main – if not the main – types of neoplasia in terms of presence in the social imaginary and in the mass culture (Bell, 2014).

Although there is a vast literature on illness experience in general as well as in the breast cancer scope (Dein, 2004; Inhorn, 2006; Kerr et al., 2018), it is necessary to conduct a localised analysis on the way women experience the disease in specific contexts (Denny et al., 2017). As an ontological perspective of history and sociology of medicine and disease has been pointing out, both the disease and the illness result from specific historical-social processes, and mobilise different beliefs, expectations, perspectives and interests (Brown, 1995; Young, 1982). In this sense, the different illness experiences have been marked, since the final decades of the twentieth century, by a strong participation of biomedicine, both in the definition of care practices and in the construction of meaning about infirmities.

Besides discussing illness experience in the private/family sphere, it is necessary to be attentive to the institutional aspects that involve the coexistence with breast cancer (Conrad, Barker, 2010). At this point, the understanding of the social process of illness is crucial to relate women's subjectivity to more general issues about the operation of health system and care networks. According to the literature (Rosa, Radünz, 2013; Barros et al., 2019), the illness experience of breast cancer is quite complex because it involves different procedures on the body, in its physical and psychic dimensions.

Often, patients with breast cancer undergo a therapeutic process that starts with surgery and extends with an adjuvant treatment – chemotherapy, radiotherapy or hormonotherapy (Bertos, Park, 2011). This process causes physical alterations, such as partial or total surgical loss of the organ and collateral effects related to chemotherapy, such as alopecia, skin problems and body weight modification. The physical modifications provoked by the disease and by the therapeutics can be traumatic. The possibility that women undergoing treatment feel different, with an altered physical aspect and, consequently, scared of being excluded from their daily social relations, makes them become identified as “having cancer” or “cancerous.” This is an identity to which various attitudes are attributed and among them stands out the social pressure to deal with the disease in a positive way (Berlant, 2011). This fact withdraws these women's agency capacity due to the social subordination motivated by the disease (Clow, 2001; Sontag, 2009).

Beyond its impact on body and sociability, the epidemiological dimension of breast cancer remains of concern. Considered as a severe public health problem, it is also a challenge to health systems due to the high costs of treatments and the difficulty to prevent it (Kaliks et al., 2013). Although risk factors associated to the development of breast cancer are known, the prevention of this neoplasia is mostly secondary, by means of early detection or opportunistic tracking in public or private health services (Parada et al., 2008). In Brazil, one of the main problems of secondary prevention of breast cancer refers to the health system hindrances to organise strategies of early detection and provide women with appropriate referral and follow-up (Teixeira, Araújo Neto, 2020a).

Among the epidemiological impact, care management hindrances and the heterogeneous set of values and symbols attributed to breast tumours, there are women of different ages, socioeconomic segments, educational level, ethnicities and life stories. Discussing these women's illness experience contributes to the understanding of the complex and tense interaction in connection with biomedicine, public health and individuals, users of systems and biomedical technologies.

Approaching the most recent discussions on illness and identity (Trusson, Pilnick, Roy, 2016; Biehl, Eskerod, 2007; Konrad, 2005), we argue that part of the experience of the women interviewed was constructed drawing on the interaction between family coexistence and the mobilisation of different cultural meanings of the disease and femininity (Helms, O'Hea, Corso, 2008), such as the fear of hair loss and impacts of the treatment on sexuality (Santos, Santos, Vieira, 2014). In this sense, we propose an analytical path that is distinct from the classical interpretations of stigma (Goffman, 1980) and biographical disruption (Bury, 1982), considering that the illness experience is not determined only by stigmas and enunciations formulated about illnesses and sick persons, but built up by negotiations regarding the senses of the condition of being ill in daily life.

This process of negotiation of senses about diseases is named by Rosenberg as framing, drawing on the assumption that naming the experience by means of the diagnosis has an impact on the ways by which people relate with diseases (Rosenberg, Golden, 1992; Rosenberg, 2002). An important aspect of this process of framing regards its ambivalence between the individual and the collective and between the illness and the sick person. At the same time, illness is framed by society and frames the sick person, as much as the illness experience is simultaneously individual and collective (Rosenberg, 1989).

Drawing on the narratives of illness experience of women undergoing breast cancer treatment at the Hospital of Cancer III (HC III), linked to the National Institute of Cancer José Alencar Gomes da Silva (Instituto Nacional do Câncer José Alencar Gomes da Silva, Inca), in Rio de Janeiro, this study will explore three important aspects of the experience of illness from mammary carcinoma: receiving the diagnosis; relationship with the family; impact of the illness and treatment on identity and self-perceptions. These three aspects are related to important reflections in the field of social and historical studies on illness experience (Good, 1994; Kleinman, 1992, 1988). To start with, it is important to understand illness as a social phenomenon, lived and constructed, or performed, among actors and institutions and its meaning in daily life (Martin, Spink, Pereira, 2018).

This study is the outcome of a qualitative research of ethnographic inspiration. Semistructured interviews were conducted in 2015 with women undergoing breast cancer treatment at the HC III, Inca's breast cancer treatment unity, situated at rua Visconde de Santa Izabel, 274, Vila Isabel district, in Rio de Janeiro. Fifteen women were selected to be interviewed. The criteria that based the selection were: aged 18 or more, with breast cancer, and with diagnosis transmitted by the medical staff more than two weeks before. This period was recommended by the unity's medical professionals as crucial so that, on the one hand, the interviews could be conducted with the lowest possible physical and psychological impact on the sick women and, on the other hand, so that it enabled the collection of a set of recent and trustworthy information, considering the new experience of transition from a healthy to an illness condition. All of the sick women were initiating the treatment at the time of the interview. The interviews were guided by thematic agendas according to the McGill Illness Narrative Interview (MINI) (Groleau, Young, Kirkmayer, 2006), focusing on the different perceptions of illness and their consequences in individual and collective terms.

The MINI is a schedule developed at the McGill University, directed to studies in the area of transcultural psychiatry, but, due to its great structural malleability, it can be used in other contexts and conditions of health research (Craig, Chase, Lama, 2010). The adaptation of its modules enables the reconstruction of illness experience narratives in great detail and complexity. The translation into Portuguese and the adaptation to breast cancer were conducted by the research team of the project "Assessment of the state of public knowledge on health and medical information in Portugal," developed by the Centre for Social Studies of the University of Coimbra, between 2010 and 2013, and in the realm of the Harvard Medical School Portugal Program on Translational Research and Information.

The MINI enables great freedom and flexibility of speech to interviewees. Considering its collaborative nature, the more the researcher is involved in the coproduction of these narratives of illness experience, the richer and more detailed will be the information produced, because, "above all, this interpersonal dynamics requires being a good listener, that one can listen empathically and without judgments" (Josselson, 2007, p.546). By means of the attention to details, mutual search for elements that are relevant to the sick persons, their therapeutic itineraries and associated stories and dynamics, the MINI attains the rearrangement of all events connected to the illness experience, such as the relationship with medical services, health information and communication, constructing a dense and ordered narrative (Barradas, 2020). Collecting the events and their sequence, it reconstructs the illness experience, providing total freedom to the sick women to manage them and talk about them according to their expressive and conceptual resources, hence assigning meaning to specific episodes. Thinking and verbalising the illness experience enables to rectify – in the sense of "realign" – the facts that were produced and/or altered by a "disruption" (Rabinow, 2003, p.16), i.e., the breast cancer diagnosis.

The interviews were conducted in cabinets at the hospital, ensuring the necessary secrecy and tranquillity. They had an average duration of sixty minutes and comprised six groups of questions, named modules, which compose the MINI, being recorded and later transcribed and codified. All methodological precautions suggested by Zoppi and Epstein

(2001) and Morse (2001) were considered, because “interviewing sick persons” involves a set of concerns that those who develop ethnographies in health systems and institutions should be based on (Weiss, 1994).

The first MINI module, designated exploratory, is open, asking the sick person about the manifestation of what they would perceive as an illness, the moments which they associated to this alteration in their health condition, how, when and by whom was made the search for health services, what is the relationship with the biomedical practices and their professionals, and what is their knowledge about health communication and information. This first module exposes with great distinction the competence of MINI to make evident the singularities of illness trajectories.

The second and third MINI modules, according to the initial version (Groleau, Young, Kirkmayer, 2006), refer to the identification of what in medical anthropology is designated salient prototypes and explanatory models. These modules are in general more structured.

In the first case, salient prototypes are constituted of references to current health problems that in some way are conceived from previous experience of the interviewee and/or friends and family members, and media or even popular representations (Kirmayer, Sartorius, 2007, p.833). In other words, salient prototypes are the modes by which the illness is apprehended/understood, drawing on internal or external past representations of the sick person.

In the second case, the module related to the explanatory model (Kleinman, 1973), refers to the way in which is identified the cause that the interviewee understands as having provoked her illness. This module may involve a discourse of strong biomedical anchoring, like an interviewee referring that she developed breast cancer due to the family’s genetic history, or a discourse in a certain way popular, teleological and with a strong moral economy, like thinking that she acquired cancer for not leading a good, tranquil life without addictions, or even in some cases, thinking that she acquired cancer because God wanted it so. In this module, there is often a retrieval of behaviours, attitudes and moments that the interviewees assume as determinant in the pathway of the illness. In another prism, it is also a module with prospective characteristics, because it convokes the perceptions of what in the future should or not be done in order not to contract an illness, treatment perspectives or even social expectations.

The other modules approached more specific themes, such as “medical services and response to the treatment,” “impact on the life of the sick person” and “sources of information,” thus enabling to deepen the knowledge about each of these, revealing divergences in the access to public health systems, impacts and the way the interviewees configure the information on health and the access to it (Barradas, 2020).

The interviews were recorded, transcribed and submitted to analysis of thematic contents. The research was approved by the Research Ethics Committee, under CAAE number 39179714.0.0000.5241. The transcriptions are identified by code so that patients are not identified by their real name, and were kept in an external storage unity, in the possession of the interviewer, encrypted and with a password to ensure anonymity and confidentiality. The recordings will be preserved for up to five years after the presentation of the research and after this period they will be destroyed.

The HC III is a unity of Inca specialised in the care of women with breast cancer. Its structure is directed to the care of this type of illness by a multiprofessional team and is integrally financed and managed by the Unified Health System (Sistema Único de Saúde, SUS). The unity was incorporated into the institutional design in 1992 and corresponds to the former Centro de Pesquisa Luiza Gomes de Lemos da Fundação das Pioneiras Sociais (Research Centre Luiza Gomes de Lemos of the Social Pioneers Foundation), linked to a long tradition of research and care in the field of gynaecological neoplasia (Teixeira, Fonseca, 2007). The reflections in this article draw on observation and research in a high complexity reference unit of SUS, associated to the country's main cancer control institution, which poses limits and possibilities to the discussion.

As limits, it is necessary to stress that due to the configuration of the available procedures and the efficiency of the care, the interviewees' therapeutic itineraries cannot extrapolate to a general analysis on breast cancer care in Brazil, not even in SUS. It is also important to highlight that the interviews with users undergoing treatment also pose certain directions to the perception of illness, distinct from that elaborated by "not ill" persons. However, if the scope of the analysis is restricted to a high complexity reference unity, its configuration enables a more general discussion on the relation between biomedicine, public health and illness experience, seeking points of connection and tension between these spheres.

Biomedicine and illness experience

A common point to all narratives about the interviewees' experiences is the negotiation regarding procedures, nomenclatures and biomedical concepts. Although not necessarily sharing principles and precepts of biomedicine, the process of constructing meaning for the own illness mobilised different biomedical entities (Keating, Cambrosio, 2003). Thus, it is also necessary to understand the therapeutic pathways from the perspective of medicalization (Zorzaneli, Ortega, Bezerra Jr., 2014). The discussion around the senses of medicalization helps to understand the way in which conceptions and medical norms start to control social relations and those of the individuals with their bodies; it also helps to build a society based on rules that determine the normal and the pathological (Canguilhem, 2009), often transforming them in social norms of what is acceptable or unacceptable, both in the sphere of aesthetic patterns related to the body and regarding behaviours and ways of dealing with adversities (Camargo Jr., 2003).

Brazilian studies, as that of Martins (2004), show the specificity of the historical process of medicalisation of women's bodies. At the end of the nineteenth century and first half of the twentieth century, the perception of women by medicine had a reductionist perspective, centred on the reproductive system. This way of thinking was generalised to conceptions in which the female body should be sexual, sensual and reproductive, and that in the sexual division of labour women were destined to simple tasks, in general related to the household.

In the debate on illness experience, the concepts of stigma (Goffman, 1980) and loss of identity (Bury, 1982), although seen in a critical perspective in this article, represent essential theoretical frameworks, especially for being central notions for a large set of studies in the field of human sciences. In both cases, Goffman and Bury depart from the

view that signals, processes and enunciations experienced as from the illness, a “damned citizenship” in the understanding of Sontag (2009), determine the subjects’ experience, essentially, excluding them from social life as abnormal beings.

Though the impact of stigmas is a recurrent topic in the sociology of illnesses, the agency of social subjects over their own lives and the capacity to re-signify symbols and statements in daily life cannot be ignored. In the same way, a critical understanding of the concept of loss of identity does not ignore the transforming aspect of illness in people’s lives. On the contrary, it considers that the identity is not ruptured, for the notion of rupture presupposes an ideal type to be broken, but rather it is realigned and reconstituted by the illness (Williams, 2000).

In this article, we also consider the collective dimension of the transformation provoked by illness. More specifically, we discuss the family reorganisation in relation to the illness experience, observing that the sick individual also alters the relationships with those who are close, not rupturing those relationships, but re-signifying them. According to Karkow and collaborators (2015), in an exploratory study with families of women diagnosed with breast cancer in the state of Rio Grande do Sul, cancer can be considered as a “family illness,” insofar as its occurrence tends to alter the forms of relationship among relatives.

Regarding the diagnosis, we take the perspective of the history of medicine that the differentiation of a specific entity results in more complex processes than the recognition of the disease. As Rosenberg (2002) discusses, the diagnosis is the central point in the interaction between doctor and patient and enables the social actors to mobilise themselves drawing on it. In this sense, the discussions by Aronowitz (2015, p.3) about the fear of the risk or of the illness contribute to think about what the author calls “a quest to cure the fear and the uncertainty.” The diagnosis poses to women a new range of possible experiences, dealing with the fear of stigmas produced around the disease, but also with the control, or lack of control, over their own life.

Experiences negotiated with biomedicine

The women selected for this study were between 25 to 75 years old, all of them presenting locally advanced tumours with the need of neoadjuvant chemotherapy and, afterwards, mastectomy. Some of the interviewees valued the family’s role in providing support to the suffering, while others highlighted the religious aspect. The posture regarding the diagnosis of cancer also draw attention, in that some of the women stressed the fear and uncertainty caused by the news, while others demonstrated that the diagnosis caused a lesser impact in their daily life.

Among the various topics raised in the interviewees’ speech, we elected the three categories of analysis mentioned in the introduction: receiving the diagnosis; relationship with the family; impact of the illness and treatment on identity and self-perception. The selection of these points relates more to the possibility of contributing to the reflections in the field of history and sociology of diseases and collective health, than to the fact of being a quantitative aspect in the analysed sample.

Receiving the diagnosis

One aspect highlighted by the historiography of medicine in the construction of cancer as a specific entity is related to its “damned statute” (Imbault-Huart, 1985). The narratives of physicians in the nineteenth and twentieth centuries placed neoplasia as an incurable ailment, incapable of being controlled by medicine, a death sentence. Actually, the death signal is also often attributed to perceptions of cancer outside the circle of academic medicine, and it is part of what Susan Sontag (2009) named the metaphor of illness. Several studies in the field of history and sociology of medicine have explored this characterisation of cancer, either by means of professional statements and the organisation of health services (Patterson, 1987; Pinell, 2002), or health education and communication materials (Teixeira, Gruzman, 2017; Araújo Neto, 2019).

This interpretive key is based on the general notion that cancer diagnosis is faced by individuals as an inevitability of death or suffering, which is socially acceptable and recognised, but does not necessarily conform as a rule. In daily life, the forms by which subjects give meaning to experiences vary according to the individuality or even to specific collectivities (Heller, 2008). These forms of re-signifying a common notion about a given topic can be considered an antidiscipline, breaching the control apparatuses, or at least subverting them.

Regarding cancer diagnosis, a subversion to what is connoted as a damned statute is to receive with relative calmness the news of the illness. This attitude was present in the accounts of some interviewees who stated they were not desperate with the discovery of the disease: “Look, I reacted, I reacted normal. I reacted normal. One gets nervous, how can you not. ... But I didn’t get desperate, do you understand? I was calm, waiting for the cure” (Joana).

Although in the continuity of the interview these women stressed the changes caused by the illness in their daily life, the news of the diagnosis did not activate, according to their reconstructions, the stigmas and damned statutes commonly associated to cancer.

This way of dealing with the identification of the tumour enables to raise hypotheses about the relationship of the interviewees with the illness. A possible reading, related to strategies of primary prevention and health communication, would attribute the “calmness” regarding cancer diagnosis to the population’s greater clarification. In this perspective, a positive result can be observed from educational campaigns for early detection of breast cancer, in that the disease became more “common” in daily life. Despite the plausibility of this hypothesis, it is necessary to be careful when assessing the impacts of educational campaigns without a more detailed study on people’s reception and the meanings elaborated from health communication materials.

Nevertheless, there are other elements presented by the interviewees regarding the diagnosis that enable a reflection about the non-recurrence to the disease’s stigmas and damned statutes. A first point to be highlighted refers to religiosity as instrument of comfort or care.

The women who reacted more serenely to the confirmation of the diagnosis, relativizing its impact, belong to the group of interviewees who declared their religiosity. They state that

the fact of having faith and religious activity has given them emotional support. McClain, Rosenfeld and Breitbart (2003) observe that among the strategies used by patients to face breast cancer diagnosis, spirituality assumes an important role, suggesting that spiritual wellbeing is a factor of protection against eventual death. In a similar way, Lorencetti and Simonetti (2005), in a study about coping strategies used by oncological patients in face of the disease and its treatment, observe that patients create different manners to relieve suffering and deal with the situation, and religiosity and spirituality have demonstrated efficacy in providing emotional support and balance.

I have much faith, this is why I stayed calm.

Because I think that my life is not mine, it is His. Do you understand? He does with it what He wants, He gives it, He takes, understand? So, I'm in His hands, I'm in the Lord's hands (Filipa).

When we put God into our lives, He takes care of us. Isn't it true? Even if it is a hard struggle, He is struggling with us, and helps to take us until the end. Isn't it true? Oh, doctor, I have much faith in God (Ana).

And when I left my house, the first thing I did, the only thing I did, first of all, I asked God: 'God, I don't know what is written on that exam, but you know. So, give me the strength, calm down my heart for when I receive the news.' And thanks to God I didn't have any problem. Because God prepared me. As I am until today. Do you understand? (Regina).

In a more general scope, it is reasonable to consider the diagnosis as a mechanism that promotes the sense of self-control over the illness experience. We agree with Aronowitz (2008, 2015), when considering that the articulation of religiosity in the promotion of relief regarding the pathway of the disease also relates to the fact that, once the problem has been identified, it is possible to mobilise a set of practices related to religiosity to achieve the cure of the disease. In this case, the diagnosis is not placed as a sentence, but it provides power to the sick person in her illness condition, enabling to act by means of framing.

One should not, however, understand these reactions as the rule. In the research's sample, other patients declared great fear and suffering regarding the breast cancer diagnosis. "And this was how my life went. ... In the beginning, when I received the news, it was very difficult. It's not easy. I cried all night long. ... I was afraid to die, right? And not seeing my grandchildren" (Roberta).

Finally, we observe something close to what Bell (2014) pointed out regarding breast cancer diagnosis. Receiving the news does not obey general conceptions about the disease, but results from the individual experience with biomedicine and health services, and the own values and expectations of the sick subjects.

Illness as a family experience

Another aspect highlighted in the literature and present in the interviews, regards the family experience of illness. As we have mentioned before, a segment of researchers who deal with the theme consider breast cancer as a "family disease" due to the impacts of the illness on the individual's more immediate and closer nucleus. Following the

direction of loss of identity and illness experience as a phenomenon of exception, the studies that discuss the relationship between the sick person and the family point to the radical transformations in their interactions, associated to a new perception of mortality (Ambrósio, Santos, 2011), or even to the practical challenges imposed to daily life, such as financial changes and rupture of life projects.

Again, it is not our objective to ignore or disregard the observations of researchers who study the illness experience adopting qualitative methodologies similar to the ones used in this article (analysis of semistructured interviews); our objective is to argue how the subjectivity of the experiences requires an accurate look at the relation biomedicine/public health/illness. In several interviews, patients reported situations of becoming close to relatives after receiving the news about their condition. Even though maintaining a feeling of suffering and failure about the own illness and its consequences for the family life, they considered this closeness as something positive in their lives.

Today, I went to live near my son, so I am not alone, do you understand? For them to take care of me, because I will need it, right? Everything... I have rented my house with three bedrooms, to live in a studio next to my son (Filipa).

The family becomes more united. When there is nothing, each one is at work, carrying on life. But when there is a disease, that's when one actually sees the union, the children one has. And I can't say anything about anyone of them, thank God, they are always by my side (Ana).

These designs of the family experience are conditioned by the family model to which each patient is linked. In some accounts, more traditional structures were mentioned, making references to husbands – some of them also ill – and to sons and daughters. However, other arrangements were observed, like that of a woman who takes care of three grandchildren, because her daughter died some years before. Her family structure is composed of the other daughter and five grandchildren, with the financial maintenance provided by the daughter's work and the pension.

It is important to differentiate the feelings of guilt and failure in the illness experience. Though both feelings involve a dimension of personal deviation that would result in the illness, they evoke distinct moral values. In guilt, the sick person interprets the surge of the disease as a punishment for not having followed certain normal standards of care. Failure, as commented by Sontag (2009), is the result of a frustration of expectation regarding the capacity to avoid or survive the disease, a consequence of the warlike metaphor adequate for cancer: if we fight against it, when dying or succumbing, we are defeated, we fail.

Other interviews pointed marriage as an important factor in the experience of illness, either by the support provided by the partner in the process of the disease, or by the fact that becoming ill strengthens bonds. This aspect refers to the consideration of Rosenberg (1989) on the double effect of the process of framing diseases: at the same time that the family relationship establishes a set of meanings and relations for the illness, the illness experience can establish or construct bonds and senses for social life. Therefore, the perception of the complexity of the experience is necessary. Adopting the perspective

of rupture or loss of identity can eclipse ways of living the disease that strengthen or reconstruct family interactions.

It is important to mention that the family dimension of illness is a central point in another facet of women's experience: identity and self-perception. In most accounts, part of the construction of meaning about the own body following mastectomy or chemotherapy was related to what relatives or other close persons commented about the interviewee's appearance. The interviewee who has five grandchildren, when asked about the way in which the family dealt with the alopecia, said that only one of the grandchildren noticed and "kept pointing: you are bald." The reconstruction or realignment of identity will be discussed later, but it is important to bound this dimension, at the same time individual and collective, of which the family is an essential element in the illness experience.

Finally, a point less present in the interviews, but well discussed in the literature, regards the fact that the illness of a person in the family represents a risk for the other members, one of the most impacting aspects of the notion of cancer as a "family disease." Some interviewees reported the reaction of surprise and fright, especially of women, fearing for themselves. Relating these accounts to the considerations of Aronowitz (2015) about the convergence between the experience of risk and disease, the occurrence of cancer in a family nucleus can, in some situations, effectively generate a collective illness experience, with the other individuals of the family living the risk of neoplasia as a specific disease. This sharing of the condition of risk/infirmity seems to be a crucial point in the reorganisation of family life, possibly bringing close or distancing certain individuals and contributing to the elaboration of meanings to biomedicine. This is the case explored by Bell (2014), of women whose relatives had breast cancer and, due to this, they adopted measures of vigilance or even prophylaxis to deal with the risk. In other words, the preventive strikes, as described by Ilana Löwy (2010).

Impact of the disease and treatment on identity and self-perception

Contemporary studies on identity and self-perception have increasingly pointed to the role of subjectivity and interaction between subject and society in the construction of meanings about the self and others (Hall, 2006). Regarding the illness experience, long historiographical and sociological debates place individual and collective dimensions in opposition; there are readings that highlight the role of structures (institutional, cultural, discursive) over the sick person (Goffman, 1980; Porter, 1985; Foucault, 2011), and others that seek to stress the subjects' agency in the construction of their own experiences (Williams, 2000; Palmeira, Gewehr, 2018).

In this paper, we seek to explore the possibilities of both analytical approaches in the collected accounts, observing how the patients related to the cultural, institutional and discursive structures that emulated senses about being ill and the own body. In our society, the woman's image is socially and culturally constructed as a symbol of beauty, and several aspects of her body, breasts included, are aesthetically valued. However, many women studied in this research did not have the sensation of loss of the breast as their main suffering, but rather the loss of hair.

Because a woman is as an entirety of vanity, right? And also a question that comes straight into our minds, cancer is chemotherapy. 'My God, I will lose all my hair.' My hair was this long, doctor! I've had it cut now to come here, because it was down to my waist. I was feeling like Rapunzel, do you understand? (laugh)
So then I get like this, it is so..., you see a bald person and it is so shocking. Do you understand?
And I think that people could be well prepared for this. So it wouldn't be a shock therapy! (Adelaide).

The loss of hair is a central component of the suffering engendered by the disease, especially due to its relevance in femininity and the fear of stigmatisation, for showing physical features that distinguish them from healthy women (Goffman, 1980). According to this author, the stigma, as a mark that promotes social discredit or disadvantage, produces impotence and devaluation in its victim. In the case of cancer, stigma amplifies the difficulty to face the disease.

From fear of not being socially accepted, the sick women who have their appearance modified due to chemotherapy often isolate themselves. On the other hand, the actual existence of stigma hinders many of them from remaining in their conviviality groups. The cases of women abandoned by their partners or spouses, under the justification that they are not able to deal with the disease, are no exception. In this sense, the fear regarding the impact of stigmas in daily life promotes a reformulation of self-understanding, an identity reconstitution.

It is important, though, to stress that this transformation in the way of perceiving oneself with the loss of hair from chemotherapy does not necessarily imply the isolation of the sick person or the determination of the experience from the stigma. The individuals are able to re-signify the emulations formulated about their "out of the norm" condition or can simply establish dynamics in absentia of stigmatisation. One interviewee, for example, when asked about people being surprised regarding the loss of hair, answered that it did not happen, because "I didn't hide with a headscarf, I didn't use it."

I didn't use anything on the bald. Didn't use anything! Hat, cap, wig, scarf. Didn't use anything! When I came here, the bald was shining... My son: 'Mother, put a hat on your head.' No. Leave my bald as it is. Why should I cover it? If I am, I was undergoing a treatment, everyone knows that I was undergoing a treatment, why should I hide it?... No! Let my bald be it! (Marília).

One starts to see because, today with the short hair... I can't wait to see my hair growing. But, I see myself differently, right? With the scarf I'm one person, without the scarf I'm another person. So much so, that I never used a wig. Because I've always said: 'I want to be me!' Not a person, a personality! Understand? I want to be me! I never used a wig, only a scarf (Roberta).

Other patients demarcated the loss of hair as a central phenomenon of the illness, transforming the way in which they saw themselves and causing considerable suffering. At this point, there was a strong presence in the accounts of the social and cultural construction of gender roles, especially regarding the aesthetic pattern to be followed by women. The older women did not seem to give much importance to the physical modifications resulting

from the treatment, justifying this apparent omission with the inexistence of expectations regarding the return to a sexual or affective life with new partners. On the other hand, the younger women showed interest in overcoming the physical characteristics of the treatment and re-establishing a more attractive aesthetic pattern, aiming at new affective relationships.

In this sense, it is necessary to understand the impact of the fear of stigmas not only in the pathological dimension of the illness, but also in fundamental aspects of daily life and the construction of the sense of self, as sexuality and the perception of the body. The association of stigmas to individuals may result in processes of exclusion from broader social circles, or even of belonging to other more specific circles – those of stigmatised persons (Silveira, Nascimento, 2018). The use of wigs and other prostheses as ways of minimising the social damage caused by the treatment appears as an attempt to maintain the symbolic aspect of femininity and the perpetuation of the control over the own trajectory.

The second aspect that has impact on the interviewees' identity construction regards the alteration or loss of breast following mastectomy. A central procedure in the therapeutic itinerary of women with breast cancer, this surgery has a long history of practice, referring to the very development of the surgical speciality and the trajectory of medical actions for the control of this type of neoplasia (Olson, 2002; Lerner, 2001). Until the mid-1960s, mastectomy was virtually the only possible therapeutics for Brazilian women, both due to the routine of the medical practice and the difficulty to access adjuvant technologies, such as radiotherapy (Teixeira, Araújo Neto, 2020b).

The medical discourse on mastectomy, since the early decades of the twentieth century, has been around the efficacy of the technique for women's survival. In the 1930s, the Brazilian surgeon Antônio Prudente (1939, p.178), an important actor in the organisation of the struggle against cancer in the country, qualified women's aesthetic concern with the body mutilation as a "smaller issue" in face of the years gained with the surgery. Until the mid-twentieth century, female wellbeing and life conditions in the post-treatment were rarely under consideration. As from the 1960s, the greater action of women's movements, at first the feminine leagues (Prudente, 1967) and later the feminist movement, brought women's experience to the fore. By the end of the century, as a result of curriculum changes in health professionals' education and in the health system (Edler, Pires-Alves, 2018), comprising the incorporation of multiprofessional teams with the participation of psychologists, nutritionists, physiotherapists, among other specialists, led to greater concern with women who underwent mastectomy.

Understanding the impacts of mastectomy not only on the post-therapeutic process, but also on the experience of women submitted to the procedure, is an important point of discussion about the tensions between biomedicine and individuals. The scar caused by mastectomy represents a definitive modification in the female's body structure, which can alter the forms of utilization and understanding of this body. In a way, it represents the mark of a treatment that never ends.

For me, the greatest difficulty was the reality after the surgery, when I left without my breast. ... Because until then I was undergoing a treatment, every time I went to the

doctor he gave a feedback. Look, now we'll schedule the surgery. Then I did it. But when you leave, and actually face the reality that you are without your breast and there is still another treatment to undergo... ... Until then, I think I couldn't see myself, not even in the mirror, how I was. I only started to actually see myself this way, mutilated, when the other things started to happen, that I saw myself, it was beyond what I could bear. Then I started to see my physical body too (Carolina).

There are people, right? Who say: 'Oh, I'll take the breast away ... I'll be without breast.' One finds it quite strange. I still find it strange. But also, I have no preference, I mean. Because when I started with the treatment, right? I already became aware of what I was going to go through. Until the day of the surgery arrived. We had a round-table, there. And the doctor, insisting, right? (Roberta).

'Oh, we are going to make a small quadrant. Mrs Erica, we can make the quadrant.' No, no, doctor! I would like, understand? Then I said: 'Oh, doctor, and if it comes back again?'

Then he was kind of... 'Listen, Mrs Erica, let's do the following? As you have already put in your life that if it comes back, it can come back. We'll do as you wish: we'll take it all away, do you understand?' (Doctor).

It is important to carefully analyse women's perceptions and constructions about their relationship with their breasts, as well as about the impacts of their loss. The weight of social institutions is clear in the way the interviewees understand their bodies and elaborate sense for the changes caused by the treatment, but subjectivity finds space in the individual trajectories, providing an own meaning to each experience of loss of breast. It is possible to visualise among the interviewees concerns with sexuality, family coexistence, public image, or even the little attention given to all these aspects.

The observation of these different experiences with mastectomy is crucial when questioning the concept of "loss of identity" proposed by Michael Bury (1982). Bury's reading on being ill is, in a certain way, close to Sontag's (2009), thinking the disease as a "damned citizenship." In these interpretations, the disease would end the person's life as it was known until then, break the identity and provoke a rupture in the trajectory. However, the empirical research with sick persons shows the complexity of the identity construction, traversed by reconstructions that are peculiar of each individual. An indicative of these various appropriations of the experience is in the decision to reconstruct the breast after mastectomy.

In the society's normative logic about the female body, it is expected that the woman wishes the breast reconstruction as a way of retrieving the identity ruptured by the illness, a passport to get away from the "damned citizenship" of the disease and its stigmas. However, among the patients in this research sample, the positions vary according to their own values, beliefs and expectations regarding their body and experiences. The choice is not necessary or evident:

So much so, that when I started the treatment, I already made it very clear that I don't want, I don't want to have an implant. I don't want! I want to stay like this, do you understand? This way I'm here. Because four years ago I had meningitis. I was in a coma for two weeks, between life and death. ... Then, I think: if God didn't take me

with the meningitis, why did I have to go through cancer today, right? If I had to go through cancer today, it is because I'm sure that He is with me in this struggle. If He permitted, besides going through cancer, having to lose a part of my body, then I'm not going to go against God's will. Do you understand? Truly. If He wants me without one [breast] there is no problem. The important thing is that I went through it with Him. Do you understand? I don't want to reconstruct, I don't want! And here they give us a small breast. To leave the place, right? But I don't like it, it bothers me. It's not mine. And I feel better without it (Roberta).

The fear of consequences of the new procedure as well as other concerns of daily life are present in the decision of women to reconstruct their breast, they are part of the process of reorientation of their identities. Choosing to carry on without breasts is a procedure of re-signification of the complex body; it may require, or not, considering social patterns, but, especially, weighing the impact of new biomedical interventions on the body, its impacts in daily life.

The reformulation of identity and the perception of the self, drawing on the experience of illness, places subjectivity in the centre of the discussion, showing that determining from the stigmas incurs in analyses that, despite the pertinence in several cases, overlooks the variety of forms by which women experience the disease and construct meanings around it.

Final considerations

This article discussed the experience of illness in women undergoing breast cancer treatment in a high complexity reference unit of SUS, the Hospital of Cancer III, of Inca. Drawing on the accounts and on a critical analysis of recent studies on the history and sociology of medicine and health, we argued that the experience of the women interviewed was constructed from the interaction between the family coexistence and the mobilisation of different cultural meanings of the disease and femininity, with the fear regarding the loss of hair and the impacts of the treatment on sexuality. From these aspects, we could problematize the complexity of the interaction between biomedicine, public health and subjectivity, throwing light on the diversity of elements that participate in the construction of meaning about the illness in the reformulation of the perception of the self.

If the perspectives of Goffman (1980) and Bury (1982) brought important contributions to a critical reading of the medical discourse and the demand for greater attention to the viewpoint of sick persons, more recent analyses, critical to the determinism implied in the concepts of stigma and loss of identity, highlight the agency of the sick persons over their own illness. This view does not mean ignoring or reducing the weight of biomedicine and the health structure on people's lives, but valuing and considering the capacity of individuals to elaborate their own meanings for the different aspects that compose daily life.

NOTE

¹ To ensure security and anonymity of the patients interviewed for this article, all their names were substituted by pseudonyms.

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