Chapter

Breast Cancer, Gender, and Body Experience. A Qualitative Study in Argentina on the Transit of the Illness, Femininity, and Sexuality at Stake

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Abstract

The chapter examines the transit of women through breast cancer by investigating the transformations in lifestyles and social behaviors that the experience of illness inaugurates. From the perspective of gender studies, we investigate the political technologies that operate on corporeality and the cultural matrices from which we signify, live, and account for this transit. These are experiences that, far from being reduced to singular events, have social roots. In particular, we focus on how the experience of illness acts as a regulating device for the notions of femininity and sexuality in play. This is produced by a reconfiguration of the gaze for oneself and for others, especially when going through certain treatments implies that the illness is "manifested" or becomes "public." With this aim in mind, we look at the different strategies that women adopt, as well as the vicissitudes and shared discomforts that occur in the face of the emergence of the diagnosis and the treatments. The results presented here are the result of research carried out in the Metropolitan Area of Buenos Aires (AMBA) in Argentina during the period 2015–2020, based on in-depth interviews with women between the ages of 25 and 75 who have been diagnosed with breast cancer.

Keywords: breast cancer, gender, femininity, sexuality, social behaviors

1. Introduction

This production is part of a qualitative research developed in the Metropolitan Area of Buenos Aires (AMBA) in Argentina during the period 2015–2020, from the development of in-depth interviews with women who have been diagnosed with breast cancer, aged between 25 and 75 years. We have used the study of biographical forms [1–3] to analyze the experience of women from their narratives and through the technique of in-depth interviews.

We start from the assumption that the experience of women diagnosed with breast cancer is not merely an individual and private aspect, but is always the effect

of social norms and ways of feeling. We question the biomedical nomination of the disease as a mere diagnosis, reduced to a sociodemographic or "biological" reference as an attribute or organic condition. In this direction and drawing on critical gender studies, mainly post-structuralism, we reflect on the processes of gendered subjectivation as a gendered and situated experience in specific ways of becoming ill [4–6]. Bodies live within the productive constraints of certain regulatory, gendered schemes that function as norms of intelligibility [7, 8]. We are therefore questioning how a disease whose clinical, epidemiological, and therapeutic aspects put social mandates weighing on women is perceived. Hence, the question revolves around the principles of social regulation of corporeality that are at stake in this experience and its derivations and implications, in the transformations and sensitivities it produces, where the materiality of bodies is inseparable from the norms that regulate their materialization and significance.

The chapter explores how the experience of illness acts as a regulatory device for the notions of femininity and sexuality in play. This is produced by a reconfiguration of the gaze for oneself and for others, especially when going through certain treatments implying that the illness is "manifested" or becomes "public." With this aim in mind, we will examine the different strategies that women adopt, as well as the vicissitudes and shared discomforts that occur when faced with the emergence of the diagnosis and the treatments, particularly with regard to the transformations related to the visibility at stake and aspects related to sexuality. This approach focuses on the social networks involved in the experiences and thus differs from other studies, predominantly from the field of psychology, on sexuality and corporeality [9–13].

2. Bodily transformations and illness: visibility for others and for oneself

Going through cancer, mainly as a result of treatment, brings with it physical changes. Chemotherapy tends to cause hair loss, but also skin changes and swelling: hormone therapy, weight changes, and menopausal symptoms. Surgery, depending on the type and medical guidelines, may involve a mastectomy; that is, the entire mammary gland is removed—including the nipple-areola complex—or a quadrantectomy, in which part of the mammary gland is preserved. This may be in addition to interventions in the axilla or emptying of the axillary lymph node chain, which may coexist with the abovementioned surgeries.

The way these body changes are handled varies. For some women, these transformations go very deep, producing a significant threat to subjectivity and femininity. Thus, a whole operation is set up to "invisibilising" the transition through the disease using resources such as wigs, hats, and makeup. For other women, on the other hand, it may be about aspects that, although not considered ideal, are not entirely problematic, without experiencing them with anguish, loss, and dismay. Many of them make visibility a reason to be able to talk about the subject.

In this process, we are interested in exploring the meanings, the negotiations, the ways in which women deal with the transformations, emphasizing how certain ways of seeing are configured, as signifying processes that produce ways of experiencing illness and which are governed by this external horizon and beyond the world. John Berger [14] is categorical about the centrality of the gaze, especially with regard to the cultural constitution of female subjectivity, as a central problematic axis in his work. In her photographic studies, she has upheld the historical female position in the gender order, characterized and positioned as an object for vision: "A woman

must continually contemplate herself. She must be accompanied almost constantly by the image she has of herself (...) From her earliest childhood she has been taught to observe herself continuously. And so she comes to regard the observer and the observed in her as two constituents, but always distinct, elements of her own identity as a woman" [14]. Throughout modern history, it has not been women who actively look, know, and judge but those who are observed, even by themselves. This exercise on oneself can be challenged by going through the treatments, promoting a subjective work, of bodily processing, in the face of the present transformations.

The fear of not knowing how to feel is part of the disruptive process that a surgical intervention exposes and which implies for women a singular type of work, lived intensely and from every detail. It is not only a question of being exposed to one's own fears, or at least not as the origin of them, but of dealing with them vis-à-vis the cultural legacy that permeates our being-in-the-world and our ways of seeing.

From a feminist reading, Lynda Nead [15] has historically investigated the place given to women in the field of the nude in art. She argues that this has been coextensive with the medical field, two fundamental discourses from which the body has been subjected to scrutiny and judged, regulated, and contained. In recent decades, she notes, there has been an intensification of the links between "good" femininity and physical health, "Desirable femininity has been constructed specifically in terms of both health and beauty" [15]. In the same vein, Georges Vigarello [16] does genealogical work on the history of beauty and points to the close link between beauty and health as contemporary gender regulatory ideals. If beauty was once only the privilege of a few women, in the democracies of the inter-war period, it is promoted by the increasingly refined idea that beauty is constructed [16]. The use of cosmetics, fashion, and surgical expertise, above all, guarantees the possibility of intervention. "Pure" surgery is reinvented by another, born in the First World War, "reparative" surgery. The one that should erase the scars, go unnoticed, hide any mark that could make the gaze "there" an undesirable place. Women's bodies gradually become the object of an increasing amount of knowledge and techniques aimed at beautification under the premise of a voluntarist body-object, in which there is no such thing as an ugly woman, but one who neglects herself: "This triumph of the voluntary body displaces the relationship with authority, just as it displaces the relationship with oneself (...) The order that is given ceases to be truly vertical, it plays more with guilt, involving the subject and her responsibility" [16].

This notion of the voluntarist body, but from a reading that articulates power in the processes of negotiation of visibility, allows us to reflect on the political technologies that act on bodies, as processes that are not necessarily conscious, the norm is acted upon, in Judith Butler's terms. Technologies that operate as generated power devices, as María Celia Labandeira [17] expresses, the effect of a specific dynamic of power relations from which we can understand the normativities inscribed on bodies in relation to what is expected, what is healthy, what is beautiful. In Vigarello's line of argument, not looking good is akin to perceiving oneself as ill. In this operation, wigs, makeup, and surgeries are located as *gender technologies* [18] that act on corporealities and from which it is possible to model this visibility of oneself for others after breast cancer treatments. Technologies are part of a sum of social technologies of institutionalized discourses, epistemologies, and critical practices, as much as of everyday life [18].

The negotiation of visibility, its modulations, must be considered here as a process which, as we have already noted, presupposes effort and work on oneself, on how to approach an experience that not only makes the body but also exposes it publicly.

However, beyond the voluntarism that makes this visible corporeality, in a certain way a project, we must consider that the alternatives have been barred by possibilities of access. A generalized reading that takes into account the operating intersectionality allows us here to understand that this performance of norms is part of a process that is biased by access to resources as elements that inevitably participate in the ways of experiencing the illness.

At the beginning of this section, we considered how hair loss following chemotherapy treatment is one of the circumstances that express the emergence of the disease for women. The loss of hair, even if it is a temporary effect of chemotherapy, is an event that many women experience with great anguish. Wigs, scarves, and turbans are undoubtedly elements that help to mitigate the associated feelings of discomfort. For women undergoing chemotherapy, shaving their hair is an almost obligatory step in an attempt to anticipate a more painful outcome, the loss of hair "by locks." It is also a matter of using it with a certain degree of comfort since, for most women, the use of a wig was "something annoying," "itchy," "hot," "heavy," an unhappy artifact, which in the case of synthetic wigs was exacerbated. The wig is mainly used for others and for oneself, when these bodily transformations cannot be dealt with, when one wishes to conceal one's transit in the home—for example, under the gaze of one's children—or to go unnoticed by others in public, in order to avoid giving explanations, to avoid feeling pitied, or to avoid looks of terror and fear. To sleep, they often wear scarves, and to be inside their homes, caps, hats, or turbans, devices are also used when the wig is not accessible or is "uncomfortable" in contact with the skin that is already extremely sensitive due to the drugs used for chemotherapy.

The negotiation of visibility, its modulations, must be considered here as a process that, as we have already noted, presupposes effort and work on oneself, on how to approach an experience that not only makes the body but also exposes it publicly. However, beyond the voluntarism that makes this visible corporeality, in a certain way a project, we must consider that the alternatives have been barred by possibilities of access. A generalized reading that takes into account the operating intersectionality allows us here to understand that this performance of norms is part of a process that is biased by access to resources as elements that inevitably participate in the ways of experiencing the illness.

In the accounts, the use of these artifacts prevails despite the discomfort they cause. It is in this direction that we included the artifacts as gender technologies, devices for the normalization of bodies, which produce discomfort but which operate satisfactorily mitigating other even greater misfortunes, linked to the ways of experiencing the visibility of going through the treatments. In the same direction, the analysis of breast surgery can be included, although it acquires a different subjectivity insofar as the ways of dealing with visibility are produced in the intimate sphere, as a woman states, "the mastectomy is something private, but the hair is something very public," producing other ways of dealing with the image.

Finally, we can also recognize other narratives in which the possibilities of re-signifying these dominant ways of seeing take on other forms. Some of our interviewees do not stop wearing wigs, scarves, or turbans; however, the modes of appropriation are different, and so are the alternatives as bodily dispositions.

As we have seen, the processes of visibility for oneself and for others are part of a complex operation that acts coextensively. That is to say, this reflexivity on oneself that inaugurates the gaze cannot be done outside of eyes that are the same eyes from which we also see ourselves.

3. Sexuality, links, and bodily dispositions

We read sexuality as a device of gendered power. Authors such as De Lauretis [18] and Butler [19] provide tributaries and critics of Foucault's [20] reading and read the body as signified in a context of power relations, where sexuality is a historical and specific organization of these relations. It is a politically complex zone in which affective states, pleasures, pains, fantasies are experiences of the body, but as we have already alluded to, it exceeds it. Sexuality in the face of the experience of illness not only alludes to bodily dispositions as ways of being with and toward the other, in which possibilities crossed by this contingency appear, but at the same time leads us to think about how it should be lived, which opens the field to the ethical dimension and to questions about meanings, choices, moralities, possible ways of linking, and the power relations that are established. These are the two aspects that we are interested in focusing on in this section and which are coextensively involved.

The passage through breast cancer, particularly during the course of treatment, produces transformations in women's ways of experiencing sexuality. Given the wide range of aspects from which the object "sexuality" can be approached, we refer here particularly to the dimension of eroticism, which deals with pleasure, in its different forms, enjoyment, and sexual desire without reproductive purposes [21]. We have already mentioned in the previous section that visibility is part of the experience of illness, although we will emphasize its participation in the modes of erotic-affective bonding with their partners.

Depending on the type of treatment, the transition through the disease involves "side effects" for the ways of dealing with sexuality, in which discomfort, pain, and the sensation of discomfort and weakness transform the ways of bonding that had previously remained unquestioned. To this we must add another type of effect, related to weight gain and the surgical interventions themselves, which can lead to a feeling of strangeness toward one's own body, an estrangement from oneself.

Drugs and radiotherapy can produce lesions such as burns, blisters, reduced vaginal elasticity, and genital pain, which is why it is understandable that women during this time find it painful to try to have sexual relations. To this we can add some of the consequences of treatment-induced menopause, which exacerbates the difficulties of "traditional genitalia." The passage through the treatments exposes many women to a new experience as a sexual being, which brings to "consciousness" aspects unnoticed in the incarnated everyday life.

Many women are concerned about a fundamental aspect of this transition in terms of erotic-affective bonds and find themselves faced with the dilemma of "giving in" or suffering from a "painful" sensation, also experienced out of guilt for their own experience of illness, which is inevitably shared by their partner. This aspect is highlighted by other studies, which addresses the guilt experienced by women with breast cancer when they feel unable to respond sexually to their partners [22, 23]. We can read here not only a bodily tension, but also a concern for the other that in most cases ends up disabling pleasure and sexual desire itself. Sexuality is challenged not only with respect to genitality and penetration itself, but also to the encounter itself.

As we mentioned, the moment when the interview was conducted—as a concrete point in the transition of the experience—and the treatments—the "side effects"—are part of the narration about the experience of sexuality. We are now interested in including other aspects that are also significant and that allude, on the one hand, to the type of erotic-affective link they maintain with their partners and, on the other

hand, to the treatments, but particularly, to the surgical interventions and to the production of a certain visibility. Some of these women had stable partners who knew and had experienced with them the first signs of what would later become a diagnosis of breast cancer. Faced with the difficulties and the new situation of going through the treatments, a game was established between the order of what was said and what was not said, between assumptions and aspects that they preferred not to be dealt with, and doubts and ambivalent instances where concern for the other prevailed. For this reason, the work of bodily processing is not limited to women, but forms part of a network that is produced in the links with their partners.

In stable couples, despite the difficulties, there was a tacit knowledge not only about the experience of breast cancer, but also about an erotic understanding as a bond. Even at the time of treatment, they possessed an important capital, which allowed them to anticipate. However, it is totally different for women who try or initiate a relationship during the illness, which speaks of greater difficulties and dilemmas for their subjectivities. For those who did not have a stable partner, starting a relationship can be problematic after surgery or mastectomy. For some, this implied an impossibility to establish any kind of erotic-affective links. For other women, undergoing surgery does not make them erotically and sexually inactive, but they do feel obliged to "warn," to anticipate, an aspect that can also be "traumatic."

The modes of sex-affective processing are largely mediated by visibility, where "negotiations" between partners are at stake, determining how the bodily disposition is experienced in relation to the other. For some women, having sex wearing a bra has been one of the ways of dealing with the transformations resulting from the surgeries. In these cases, an internalization of the norm prevails, which also does not allow visibility of the self without the possibility of anguish. The norm here operates by demanding compliance with certain esthetic patterns, as a dominant visual pattern that directs the gaze, even that of the women themselves who experience sexuality as a result of a loss.

In most of the accounts in our research, the types of bonds established by the women speak of loving care and respect for their partners, their decisions and possibilities, as ways of protecting and also being able to propitiate spaces that favor sexual pleasure and sexuality itself, even if traditional genitality is dispensed with. But we should also mention that not all women were able to be contained and accompanied in these moments of transformation and sensitivity. There are harsh accounts that speak of neglect, abuse, and violence, which are linked to the dynamics of the type of relationship they had. For both of them, this experience has affected them to such an extent that they have not been able to return to their relationships with men, extending this experience to all other possible experiences.

In the narratives recovered for this analysis, we can see a predominance of the gaze as an active participant in the modes of production of sexuality. However, it should be noted that for some women the transit of the illness has not been felt only on this level. Sensitivity is a fundamental aspect to be considered after undergoing surgical treatment.

There are mastectomies in which it is possible to preserve the nipple-areola complex, although this does not necessarily mean preserving sensitivity or the "nipple function," that is, sensitivity as an erogenous zone, breastfeeding the baby.

This also invites us to question the role of reconstructive surgery: reconstructive of what? This is the political question that opens up and which participates as a normative regulation of the materiality of bodies and of the ways of experiencing illness.

4. Conclusions

This chapter has dealt with the experience of women with breast cancer by considering the diagnosis as an instance that exceeds a strictly biomedical nomination and that is linked to life itself, to the conditions of being and thinking in the world. This experience is sometimes disruptive insofar as the unexpected interrupts and destabilizes habitualities. There are displacements, transformations in regularities, and also disputes experienced subjectively, but not for this reason, culturally and socially mediated. This operates as a matrix that acts on bodies and participates in ways of living.

In this chapter, we have focused in particular on some bodily transformations, as a figuration of modes of visibility for others and for oneself, but also on the experience of sexuality and the bodily styles that are put into play in the transition to the experience of illness. The generated modes regulate bodily matter [7] on the basis of dynamics of recognition/unrecognition, and these dimensions are settled as spaces of dispute, fully felt by the subjectivities of this study.

Visibility has been an important dimension during the transit of the disease, making the experience of cancer a public experience. The ways of going through bodily transformations have varied, but they are undoubtedly a source of concern for women. Visibility is adjusted on the basis of a work on the self that presupposes a voluntarist corporeality on which a project is based. From a critical reading, we have noticed here the effort that is made by subjectivities, from the use of different artifacts, to reach an invisibility, biased by access to specific resources and often experienced from the discomfort of such devices, which participate as gender technologies, modeling healthy, acceptable, beautiful corporeality, as a signifying chain that operates simultaneously. We could think of a microphysics of the gaze, paraphrasing Foucault [20], which is expressed in the ways of experiencing illness and must be understood in a larger horizon, from cultural regimes that permeate our experiences and ways of seeing. Undoubtedly, there are other possible dimensions of priority analysis, such as the dimension of the place of breasts in the cultural framework and the so-called reconstructive surgeries. This opens up new questions linked to how to approach bodily materiality, although we have decided not to deal with it here and to think about a future development that will give it greater depth.

The other of the questions addressed here dealt with the experience of sexuality, particularly during the course of the treatments. We referred here to the erotic dimension, as a work of bodily processing in the links themselves. What is said and what is not said, the ways of approaching visibility, the type of bond established, the discomfort caused after the passage of treatments linked to pain, the sensation of weakness, and the feeling of heaviness, were, in the narratives studied, some of the aspects that produce discomfort in the bonds.

We can conclude that the transit through the illness, and particularly the interventions and bodily transformations from the passage through the treatments and surgeries, is part of instances of normative regulation, privileged processes from which it was possible to materially explore these dynamics of power. The experience of illness from a significant contiguity with "the feminine" highlights the regimes of cultural intelligibility that mediate and produce bodies, undoubtedly influencing the ways of experiencing illness.

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Conflict of interest

The author declares no conflict of interest.

Notes/thanks/other declarations

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