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Female sexual medicine

How women with gynaecological cancer deal with treatment: Issues of visibility and invisibility

Appréhension des traitements chez les femmes atteintes d'un cancer gynécologique pelvien : problématiques concernant la visibilité et l'invisibilité

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ABSTRACT

Through the psycho-anthropological approach study of the experiences of women affected by pelvic gynaecological cancer who undergo surgical treatment, this paper explores how these women perceive their bodily aesthetic and the impact this has on their sexuality and their relationship with their partner. Gynaecological cancers impact women in several ways, including having an effect on the way that they feel their femininity and appearance are perceived by others. Indeed, gynaecological cancer affects a part of the body intimately associated with representations of desirability that are linked to sexuality. Surgical procedures can cause scarring which can result in having a visible, physical impact on the patient, whilst also affecting their sense of body image and sexual identity. Healing treatments are too often associated with the visible, aesthetic appearance and the physicality of body, and neglect to treat questions of subjectivity. As such, women are compelled to feel like they have an integral body image, and that they are obliged to have a perfect body and need to be physically attractive to their partner.

Mots clés :
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RÉSUMÉ

À travers une étude psycho-anthropologique sur l'expérience des femmes atteintes d'un cancer gynécologique pelvien induisant un traitement chirurgical, cet article explore la manière dont ces femmes perçoivent leur corps esthétique et l'impact que cela a sur leur sexualité et leur relation avec leur partenaire. Le cancer gynécologique pelvien impacte la pluralité de la femme, notamment sa féminité c'est-à-dire l'extériorisation au monde de son féminin. En effet, le cancer gynécologique affecte une partie du corps intimement associée aux représentations de désirabilité liées à la sexualité. Les gestes chirurgicaux peuvent provoquer des cicatrices qui s'inscrivent dans le visible du corps de la femme, affectant l'image corporelle et l'identité sexuelle. Les traitements sont trop souvent associés à cette dimension externe et visible, engageant le corps esthétique de la femme au détriment de la subjectivité, souvent négligée. Au final, tout cela contraint les femmes à investir une image corporelle « entière », « normale », afin de rester désirables pour leurs partenaires.

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1. Introduction

Through its psycho-anthropological approach, the FECAPSE[1] study, which concerns female sexuality and intimate relationships, aims to evaluate the issues associated with the impact of gynaecological cancers on a woman's body and her sexuality. Knowing that pelvic cancer, through its symptoms and its treatment, affects the body both internally and externally, we understand that there are specific issues concerning the visible and invisible, the aesthetic and mental. As much as the external effects can be observed, the internal can only be understood via subjective feelings and bodily manifestations of these effects.

As such, we consider the "visible" to be what a woman sees as the result of the disease and its treatments on her body, externally and objectively. Conversely, the "invisible" can be defined as what is felt internally as a result of the disease and its treatment, which may not necessarily be objectified, and which, therefore, can be said to belong to the realm of the subjective. In this context, the feminine aesthetic is what is shown and linked to the visible and to femininity, whereas the invisible concerns a woman's femininity and subjective point of view. If the differentiation of these two concepts provides some clarity, we must keep in mind that both the mental and aesthetic perceptions of femininity develop in conjunction with each other throughout life. Thus, in the last section, we discuss this transferential link between the mental and the aesthetic that seems, faced with the disorganization induced by gynaecological cancer, to find its expression through the body and the social. Also, we will see, through the experience of gynaecological pelvic disease and its treatments, the reasons why cancer can be both visible and invisible. Why does it cause aesthetic and mental consequences for women? And what are the responses and solutions of the women who are faced with these changes?

2. Method

The FECAPSE study explores certain issues revealed in women's discourses as a result of its specific methodology. Primary results were collected through the observation of medical gynaecological consultations at two clinics: a regional cancer treatment centre and a public hospital. Additionally, thirty patients who enrolled (with cervical, corpus uteri or ovarian cancers) were followed via interviews throughout the course of treatment, from diagnosis to the end of treatment. The interviews were held at three different intervals in order to follow longitudinally the therapeutic itinerary of women affected by cancer:

- first interview: prior to treatment;
- second interview: three months after the first treatment;
- third interview: three months after the end of all treatment.

These interviews were non-directive and conducted by anthropologists at each patient's home, while those conducted by the psychologist took place at the hospital. The psychologist also proposed two psychological tests (Sexual Activity Questionnaire/SAQ and Thematic Apperception Test/TAT) in order to evaluate the patient's sexuality and sexual relations. In parallel, some socio-demographical and medical data were collected by the epidemiological team. The methodology employed allowed us to collect numerous accounts, which will demonstrate our hypotheses.

[1] FECAPSE 1: longitudinal study on intimate relations of women with pelvic cancer: impact on sexuality (exploratory study). March 2009–June 2011.

3. Results

3.1. Surgery and other treatment: their repercussions on women

Through its often-intrusive treatment, gynaecological cancer, which is an internal disease, results in both visible (scars) and invisible (internal organs are affected by treatment) consequences. Sometimes diagnosis of gynaecological cancer requires removal of the affected organs through an opening in the abdomen. This medical procedure is common for a hysterectomy, and may sometimes be combined with a bilateral salpingo-oophorectomy (removal of fallopian tubes and ovaries). Celioscopy can cause small scars, while laparoscopy can cause scars along the entire length of the abdomen. Surgery is one of the most significant causes of stigma for patients. However, pelvic cancer can also impact the patient aesthetically when it is treated with chemotherapy, one of the results of which is hair loss.

Women's discourses show that gynaecological cancer interacts with society's view of what women should look like. Culturally, aesthetics are an important factor for these women who are subject to contemporary society's vision of female aesthetic codes. For most women interviewed (in our study but also in other studies on breast cancer in particular [1]), one of the most significant bodily impacts continues to be hair loss caused by chemotherapy. "These consequences are experienced as a regression, humiliation, loss not only of personal identity but also female sexual identity, of which one of the most important attributes is hair", [2] (which is more valued when long and voluminous). Thus, a woman deprived of her hair perceives her femininity to be threatened. Indeed alopecia may become "a disturbing sign of undesirability" [3] [4]. In this way, women feel deprived of their aesthetic values and show a desire to continue to show a perfect body and a need to be perceived as physically attractive by their partner. The visible stigma is particularly difficult to accept in a contemporary society that imposes standards of youthfulness and seduction often associated with physical and sexual performance: imperfection is forbidden in society's standardised vision of beauty. Indeed, women are subject to a social pressure to live up to contemporary society's view of beauty. If the margin of freedom for women "within society has increased markedly, they do however suffer from a tyrannical concern regarding their ability to seduce, that is to say a recognition over which they have no power, as it comes from the gaze of men around them. A woman is always on stage in some way, exposed to male judgment" [5].

Thus, visible anatomical and physiological changes may disrupt a female cancer patient's body image, because these changes can lead her to question her femininity and physical appearance. This is especially the case when treatments such as radiotherapy, surgery and chemotherapy expose the body through an opening of the sexual organs, causing them to lose their mysterious, hidden, precious and intimate qualities. The disease is a fracture in feminine existence and can result in a woman's sense of modesty being disturbed. Although modesty is usually associated with nudity, here it can be differentiated from basic modesty relating to the naked body due to it being a more general modesty relating to the effects, feelings and desires of the patient and also being a part of their relationships with other people. It is the other's gaze that informs and validates the game of modesty. This is illustrated by a patient who says, "*It's really stressful. I don't really like to show this part here [the genitals]. I don't really like that*". (patient n° 14, T2). As such, modesty is linked to sexuality, or more specifically to the sexuality attributed to, or concealed within, each body part. The body, nudity and–unavoidably–modesty are all involved during medical interventions. However, this is a specific type of modesty, "medical modesty" [6], which calls upon both sides