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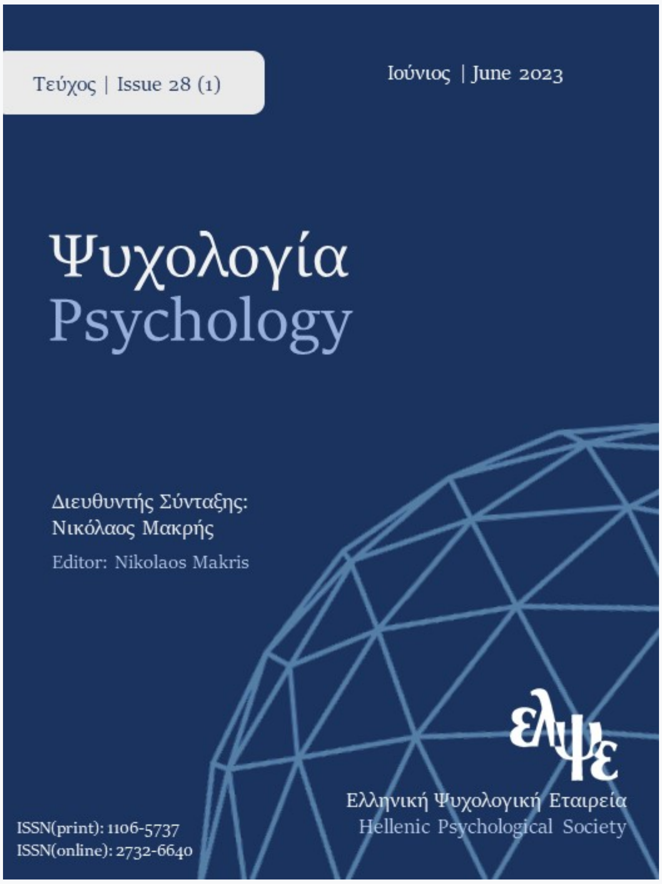

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Despoina Ziliaskopoulou, Evrinomy Avdi

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ΕΜΠΕΙΡΙΚΗ ΕΡΓΑΣΙΑ | RESEARCH PAPER

Gender identity, embodiment and liminality in women΄s experience of mastectomy

Despoina ZILIASKOPOULOU[1], Evrinomy AVDI[1]

[1] School of Psychology, Aristotle University of Thessaloniki, Thessaloniki, Greece

KEYWORDS

Mastectomy,
Phenomenology,
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CORRESPONDENCE

Despoina Ziliaskopoulou
School of Psychology, Aristotle University of Thessaloniki
Address University Campus,
Thessaloniki, 541 24
dziliask@psy.auth.gr

ABSTRACT

In addition to a potentially life-threatening illness, women with breast cancer also face several challenges related to the effects of medical treatment on their bodies and their embodied identity. Mastectomy, as a highly invasive treatment, has significant impact on women's lives. This study aims to investigate the experience of mastectomy and the subjective meanings that it holds for women, in relation to their identity and relationships. The research questions were explored through a phenomenological approach in order to better understand the role of the body in this experience, and a gender perspective was adopted in order to critically examine the socio-cultural background that shapes women's experience. Seventeen women, aged between 26-57, who had undergone mastectomy following a breast cancer diagnosis, participated in the study. The research material was collected through semi-structured interviews and analyzed using phenomenological analysis. The analysis also drew upon a gender perspective, given a focus of the study on the gendered dimension of embodied identity. Findings indicate that a core element of the experience of mastectomy concerns the alteration of embodied identity and a sense of liminality, an unresolved state of being in between the previous normal life and life post-diagnosis. The analysis highlighted the need to expand the concept of liminality in psycho-oncology, to include the ambiguity associated with women's self-identification as "normal women", in relation to embodied experience and the socio-cultural constructions of the female breast. Interestingly, liminality in relation to gender identity characterizes many women's experience, despite the use of silicone pads and/or plastic reconstructive surgery to manage the altered body. The findings enrich our theoretical understanding of the experience of mastectomy, broaden the concept of liminality, highlight the gendered dimensions of identity and the role of the socio-cultural context in shaping the experience of mastectomy. Moreover, they point to useful directions for the design and delivery of individualized support to women who have undergone mastectomy.

Introduction

Breast cancer is the most common cancer in women worldwide (Ferlay et al., 2015). In recent decades, preventive screening, early detection, and the development of more effective treatments have led to an increase in the survival rates of women following diagnosis in the developed world (Ferlay et al., 2015). As a result, research interest has shifted towards exploring issues around post-cancer survivorship such as the effects of the illness and its treatments, including mastectomy, on women's quality of life. Over the last decades, mastectomy is increasingly used as a treatment for breast cancer, despite evidence that it may not be more effective than breast-conserving surgery in stage I-II cancer (Poggi et al., 2003). Breast cancer is significantly more prevalent in women and affects a body part that is strongly implicated in socio-cultural representations around femininity, sexuality and motherhood. As such, women face additional difficulties to those associated with a life-threatening disease (Kunkel et al., 2002). In this paper, we present findings from a phenomenological study on women's experience of mastectomy, taking into account the role of the socio-cultural context in shaping women's subjective experience and embodied identity.

The psychosocial impact of mastectomy

Although few studies focus exclusively on the impact of mastectomy on women's life, it is evident that it can have significant psychosocial effects. Breast loss has been associated with several interrelated difficulties, such as physical (Boehmke & Dickerson, 2005; Thomas et al., 2015) and psychological symptoms (Fann et al., 2008; Thewes et al., 2004), negative body image (Helms et al., 2008; Rosenberg et al., 2013) and loss of femininity (Anagnostopoulos & Myrgianni, 2009; Lundberg & Phoosuwan, 2022), effects on sexuality (Hill & White, 2008; Ussher et al., 2012, 2014), fear of cancer recurrence (Thewes et al., 2016; Vickberg, 2001), loneliness (Rosedale, 2009), stigma (Björkman et al., 2017; Broom, 2001) and fear of death (Thewes et al., 2004), difficulties with the use of silicone prosthesis (Brunet et al., 2013; Glaus & Carlson, 2009; Thomas-McLean, 2005) and breast reconstruction (Fallbjörk et al., 2012; Harcourt & Frith, 2008; Truelsen, 2003).

A key issue in this literature concerns the effects of mastectomy on women's body image, and findings focus on the loss of femininity as the most important consequence of mastectomy for many women. There is evidence that women who undergo mastectomies tend to have worse body image than those with breast-conserving surgery (Den Oudsten et al., 2012; Martins Faria et al., 2021; Nano et al., 2005; Rosenberg et al., 2013) and poor satisfaction with the aesthetic result of the mastectomy is associated with reduced psychological well-being (Al-Ghazal et al., 2000), negative self-image and reduced self-esteem (Berterö, 2002; Berterö & Chamberlain Wilmoth, 2007), stress (Yurek et al., 2000), and a reduced sense of self-efficacy with regards to managing illness (Pikler & Winterowd, 2003). The effects of mastectomy on body image seem to be mediated by women's investment in their body image and this relationship is stronger in younger women (Moreira & Canavarro, 2012). With regards to the effects of age, some studies find no differences in body image satisfaction in different age groups (Engel et al., 2004; Monteiro-Grillo et al., 2005), but most suggest that women under the age of 50 tend to experience more difficulties with their body image following a mastectomy (Avis et al., 2004; Härtl et al., 2003). Moreover, when women participate actively in the decision-making process regarding treatment, women undergoing mastectomy do not have more body image concerns than those with a lumpectomy (Covelli et al., 2015; Fancher et al., 2009; Hawley et al., 2009).

Another key issue examined concerns the effects of mastectomy on women's sexual life. Many women with a mastectomy feel less desirable and exhibit reduced self-confidence in sexual behavior (Ashing-Giwa et al., 2004; Crouch & McKenzie, 2000; Landmark & Wahl, 2002) and this is true, especially for younger women (Avis et al., 2004; Fobair et al., 2006; Hill & White, 2008; Kinamore, 2008; Thewes et al., 2004). Long-lasting changes in women's sexual mood, arousal, and satisfaction, as well as a reduction in the frequency of sexual contact, have been reported (Ussher et al., 2012, 2014). Despite this, the effects of mastectomy on women's sexual life are rarely discussed by health professionals (Sheppard & Ely, 2008) and this lack of recognition renders women's sense of loss and mourning delegitimized (Pillai-Friedman & Ashline, 2014). Post-mastectomy, several single women report anxiety and shame at the prospect of meeting a new partner and believe that they have limited chances of forming a relationship (Gluhoski et al., 1998; Hill & White, 2008; Thewes et al., 2004), although body shame and fear of rejection are also frequently reported by women in long-term relationships (Ussher et al., 2012; Ussher et al., 2014). The quality of the relationship is a strong predictor of improvement in women's sexual functioning following a mastectomy (Gilbert et al., 2010) and the partners' support plays an important role (Wimberly et al., 2005). However, many women have internalized cultural norms regarding beauty, femininity, and sexuality and these representations often contribute to feelings of exposure, vulnerability, and shame in sexual relationships following a mastectomy (Crouch & McKenzie, 2000).

The role of the socio-cultural context in shaping women's experience is also implicated in the experience of using silicone pads and breast reconstruction (La et al., 2019). After mastectomy, very few women do not use silicone pads, even though they are uncomfortable and are a daily reminder of the cancer (Gallagher et al., 2010; Harcourt & Rumsey, 2001; Roberts et al., 2003; Thomas-MacLean, 2005). The use of silicone pads can be understood as an attempt to hide and control the body, serving women's desire to avoid stigma. It is worth noting that both professionals and relatives tend to urge women to maintain an unchanged body image following a mastectomy (Wilkinson & Kitzinger, 1994). Research on breast reconstruction contradicts the prevailing medical view that this marks the completion of breast cancer treatment (Cobb & Starr, 2012). It appears that satisfaction with breast reconstruction is not related to the objective aesthetic result as assessed by medical personnel (Beesley et al., 2012), but rather to the degree to which it allows women to feel normal according to social and cultural definitions (Denford et al., 2011). In addition, although reconstructive surgery may provide relief from the practical difficulties of using silicone pads, it does not fully restore the image or the sensation of one's "real" breast (Beesley et al., 2012; McKean et al., 2013; Truelsen, 2003).

In sum, the studies presented above demonstrate the significant impact of mastectomy on female identity and highlight the important role played by socio-cultural representations in shaping women's experience. However, research on the effects of mastectomy has been criticized from a feminist perspective as over-emphasizing issues of body image and femininity whilst sidestepping other important aspects of the experience (Hill & White, 2008; Yalom, 1997), thus reproducing dominant patriarchal representations of femininity. Most studies, for example, exclude older women, women with disabilities, lesbians, and women from minority cultural backgrounds (Ziliaskopoulou, 2017). As such, important aspects of the mastectomy experience, such as concerns about the loss of health and fear of death, limitations on work life, issues around motherhood (e.g. breastfeeding, negotiating child rearing), and changes in interpersonal relationships remain understudied (Avdi et al., 2012; Langellier & Sullivan, 1998; Thomas-McLean, 2004, 2005).

Studies that explore meaning-making following mastectomy highlight the varied and often contradictory aspects of women's experience. Phenomenological studies on the effects of mastectomy on identity suggest that physical changes are experienced as a threat or an attack to the whole of one's existence (Bredin, 1999; Van der Riet, 1998). Physical deformities after mastectomy may challenge the coherence of one's sense of self (Rosenblatt, 2006) and alter the taken-for-granted perception and experience of the world (Breaden, 1997); these processes have been described as leading to an "identity crisis" (Kasper, 1994) or "identity deconstruction" (Piot-Ziegler et al., 2010). Several studies have shown that changes in women's embodied identity are associated with the sense of lost femininity (Rosenblatt, 2006), and several women report feeling "inappropriate" as women (Avdi et al., 2012; Piot-Ziegler et al., 2010; Thomas-McLean, 2005; Ucok, 2005). Other studies suggest that existential concerns and fear of death are more important dimensions of the experience of mastectomy, as the deformed body is a reminder of cancer that can no longer be trusted (Breaden, 1997; Cohen et al., 1998; Piot-Ziegler et al., 2010; Waskul & Van der Riet, 2002). With regards to the long-term impact of mastectomy on identity, some studies suggest that it shatters women's identity (Fallbjörk et al., 2012) and can never be completely forgotten (Carter, 1993), others suggest women incorporate breast loss in their lives, and identity following a period of grief (Wyatt et al., 1993), whilst in fewer studies women describe breast loss as "no big deal" (Fallbjörk et al., 2012). In addition, some women seem to experience mastectomy as a "medal" or a sign of maturity associated with the completion of treatment (Grogan & Mechan, 2017; Parton et al., 2016).

In sum, research evidence regarding the psychosocial effects of mastectomy is mixed, and some aspects of women's experience seem to be overemphasized and others marginalized. Mastectomy is both an intimately personal embodied experience and is strongly associated with the dominant socio-cultural representations of cancer and female identity (Thorne & Murray, 2000). Research on this topic in Greece is quite limited, with some studies confirming the negative impact of mastectomy on body image and sense of femininity (Anagnostopoulos & Myrgianni, 2009; Markopoulos et al., 2009), possibly reflecting patriarchal values characterizing the Greek socio-cultural context, and a few have focused on changes in identity following breast cancer (e.g., Koutri & Avdi, 2016; Theofilou, 2022).

Based on the above, this study aimed to: a) describe the essential elements of the experience of mastectomy, b) explore the role of the body in the way women attribute meaning to changes in their identity post-mastectomy, and c) explore how socio-cultural values, norms and ideals of femininity, health and illness shape the experience of mastectomy. In order to capture the complex meanings women attribute to their experience, we adopted a phenomenological approach drawing on Merleau-Ponty's body theory. A key concept in this work is that of "embodied identity", whereby the body is recognized as an integral part of one's self, through which individuals perceive and understand their self and connect to the world (Bullington, 2013). Merleau-Ponty (1945, as cited in Bullington, 2013) distinguishes the "subjective" body, which is perceived pre-reflectively, from the "objective" body, which is observed by others or can be investigated through science. The objectification of the body can also happen by the individual under certain conditions (Finlay, 2006), such as when receiving a medical diagnosis, whereby changes in one's body turn one's attention to it (Carel, 2011; Crossley, 2000). In such occasions, the body fails to do what we normally expect it to do, and is transformed into the "objective", physical body. In this framework, illness is not approached solely as a dysfunction of a bodily subsystem but as an experience that essentially changes the way one exists in the world (Carel, 2013). In addition to phenomenology, we draw upon a feminist perspective, with the aim to understand the experience of mastectomy in the context of socio-cultural representations of female identity, health and illness, and critically examine the influence of context in shaping gendered experience. By drawing upon a gender perspective, we hope to highlight the female voice, re-evaluate the female experience around mastectomy and breast loss, with a broader aim to produce knowledge that may contribute to women's empowerment in relation to issues surrounding health and illness (Wilkinson, 2004). Before turning to the study itself, we briefly outline the concept of "liminality" (Little et al., 1998), which emerged as a key analytic tool in our attempt to capture the complex and contradictory meanings that women attribute to mastectomy.

Liminality

The concept of liminality stems from the anthropological studies on rites of passage conducted by ethnographer Van Gennep (1960) and subsequently by sociologist Turner (1967, as cited in Little et al., 1998). Van Gennep (1960) proposed that rites of passage, associated with changes in social roles, comprise an integral part of an individual's development in their social context. Rites of passage accompany important life events such as pregnancy, marriage, or death and can be divided into three stages. During *separation*, the individual distances himself from society and is prepared by "purification". In *transition*, the person has left the previous status behind but has not yet entered the new one and thus he is in an ambiguous state, which Van Gennep (1960) termed as liminality. In the final phase, *aggregation*, the individual is reintroduced into society as a member with a new status. Turner (1967, as cited in Blows et al., 2012) argued that liminality is a state in which individuals are structurally invisible, no-longer and not-yet classified, on the "threshold" or in the margins.

The concept of liminality was introduced in the field of psycho-oncology by Little and his colleagues (1998), in their attempt to interpret their findings regarding the experience of colorectal cancer. They described liminality as a condition in which the patients remain in a liminal state between the previous normal life and the life post-diagnosis. They suggest that patients enter liminality from the time of diagnosis, but in contrast to Van Gennep's view, they do not necessarily pass through three distinct phases. Liminality can last for the rest of their lives and remains a fundamental aspect of life with cancer. They argued that it proceeds through two phases. The *acute phase* starts from the time of diagnosis and is characterized by disorientation, loss of control and ambiguities. The *sustained phase* is more lasting and is characterized by the search for meaning and significant challenges to identity. The experience of liminality in cancer includes three core components. The first, cancer patientness, refers to the immediate impact of the cancer diagnosis and the persistent identification as a cancer patient. During the acute phase, it is linked to the threat of death and the awareness of mortality. During the chronic phase, the identity of the cancer patient is preserved through the sense that life has changed irreversibly, fears of cancer recurrence, and frequent checkups. The second, communicative alienation, describes a state of alienation from social familiars. Early in the illness, it is associated with the existential loneliness and the patient's difficulty in sharing their experience. During the chronic phase, it is reflected in patient's sense of isolation that may result from loss of social relations or by others' expectations that they should remain unscathed by the illness. The third theme, boundedness, concerns the limitations experienced by patients in terms of space and time availability, sense of autonomy, and ability to fulfil social roles (Little et al., 1998).

Methods

Participants

Seventeen women living in Greece, aged between 26-57, who had undergone a mastectomy after being diagnosed with stage I-III breast cancer one to nine years earlier and had no relapse or metastasis, participated in the study. Nine women had undergone breast reconstruction surgery, whilst eight were using a silicone prosthesis. There were no other selection criteria for participants, as heterogeneity of participants -in terms of age, relational and family status, socioeconomic background etc.- is considered an asset in obtaining rich data, in line with the principles of phenomenological research.

Procedure

Information on the study was provided to women attending two self-help organizations for women with breast cancer in Greece. Interested participants were contacted by the main researcher and informed about the study. If they decided to participate, interviews were arranged with them at a convenient place and time. Semi-structured interviews were used in order to gain a better insight into women's experience (Wilkinson et al., 2004). The interview schedule entailed several issues, including women's experience around the diagnosis and the process of treatment, physical changes and changes in their body image following the mastectomy, their experience with breast reconstruction surgery or the use of the silicone prosthesis, the effect of the mastectomy on their sexual relationships and on issues regarding their role as mothers (e.g., breastfeeding, relationships with children) and issues they may find difficult to share. The interviews were audio-recorded, and transcribed verbatim by the first author.

Ethics

Ethical approval for the study was obtained from the Scientific Council of the two participating self-help organizations. All participants gave their written consent.

Data analysis

The research material was analyzed using phenomenological analysis as described by Moustakas (1994) and aimed to provide an in depth description of women's lived experience of mastectomy and the meanings they attribute to their experience. Initially, multiple systematic readings of each interview were made by the researcher with the aim to achieve a better understanding of each participant's personal experience. Next, each interview was analyzed separately with the following process: The researcher collected all the main expressions of participants' personal experience (horizontalization) and then categorized those elements that shared common meanings (reduction-elimination). Elements that were not related to the basic research questions, were unclear, repeated or overlapping, were excluded. Subsequently, the researcher checked the constant elements of each experience based on the original text of each interview, in order to confirm that they are contained in each interview and those elements that were not validated in this way were removed from the analysis. Next, the researcher constructed an individual textural description of the experience of every participant including representative excerpts. Based on the individual textural description and through the process of *imaginative variation,* the researcher created the personal *structural description* for each participant, again including representative excerpts. Then, a textural-structural description of the experience was constructed for each participant, which included the invariant constitutes and themes. Following this process for each individual participant, a composite description of the experience was constructed, representing the group as a whole. In this paper, we present only some of the findings that concern the experience of mastectomy and its effects on participants' embodied identity.

Results

A core element of the experience of mastectomy centers on a sense that one's embodied identity has been permanently altered, to the extent that one is no longer able to identify as a "normal woman". The analytic concept of liminality was found to capture the ambiguity, ambivalence and contradiction that characterize women's experience and is used as an integrating framework for the analysis. In this section, we present the main aspects of women's experience related to female identity (liminal femininity), close relationships (social alienation), love relations and coping with changes (managing liminal femininity). All names used below are pseudonyms to protect the participants' anonymity.

Liminal femininity

Cancer diagnosis marked participants' entrance into the acute phase of liminality, as they faced their vulnerability and mortality (Arman & Renhsfeldt, 2003; Covelli et al., 2015). Participants described how they identified as cancer patients and began to recognize the limitations that cancer imposes on their lives, which centered on limits in their ability to project themselves in the future and their capacity to fulfil their social roles. It seems that dominant socio-cultural representations of cancer as a terminal disease (Broom, 2001; Sontag, 1979) framed participants' responses of shock and fear; threat to life rendered mastectomy a necessary "sacrifice for life" for many women (Covelli et al., 2015). At the same time, however, mastectomy was experienced as an act of violence that destroys a part of a women's body that comprises a key symbol of femininity. The ambivalent and painfully conflicted representation of mastectomy is powerfully illustrated in the following extract, whereby the participant's breast is represented as 'not functional', and therefore easily given up to save one's life, whilst at the same time remains a crucial element of femininity, eroticism and motherhood.

> Vicky, 37 years: "first you face death, so [you think] what can save me from death? Removing a part, your breast, it's ok, [it would be the same] even if it had to be the leg or the hand; also, it is not a functional part, that is, I think the breast is something "psychogenic", how can I explain, it is not functional; OK I can still do everything, but my femininity, it [the breast] is erotic, a very basic part, but at that time, it was practical, I could not see that (.) also, for me, I was breastfeeding and they cut my breast off, a breast full of milk, I suddenly stopped breastfeeding, that was also cut off, and so now when I want to leave for 24 hours I think to myself "how can I leave my daughter?", you cannot call that weaning, everything was done violently"

After the surgery, the meaning of the mastectomy seems to shift for many participants from that of being a necessary, life-saving sacrifice to that of a violent and cruel amputation. The altered body raised intense feelings of pain, anger and repulsion for the participants, and many were unable to recognize the deformed body as their own and rather felt alienated from it. From a phenomenological perspective, the way women experience their altered bodies demonstrates the objectification of their body, which is thought to lead to a change in the essence of their female identity (Carel, 2013; Finlay, 2006).

> Joanne, 43 years: "when you see your breast missing, first you are – it's an amputation, you miss a part of your body, a very basic part, and the image is not nice, you can't love your body from one moment to the next, I didn't like my body, I just didn't like it, I didn't want to see it"

As they began to acknowledge the loss of their breast, women transitioned to a new phase, adopting the identity of a cancer patient (Little et al., 1998). In this phase, participants expressed their sense of being in a limbo in relation to their identity as women, and talked about feeling unattractive, somehow "flawed" and "inappropriate" as women. This is in accordance with similar findings in the literature (Hill & White, 2008; Lindop & Cannon, 2001; Piot-Ziegler et al., 2010; Van der Riet, 1998). Given that gender is a central element of embodied identity, we would argue that women's experience of altered femininity is associated with a broader sense of ambiguity of existence (Piot-Ziegler, 2010). From a phenomenological perspective, this experience highlights the crucial role of the body in the perception of women's self (Bullington, 2013). Moreover, the important role of the body in one's sense of gender identity is illustrated in the examples that follow:

> Vicky, 37 years: "look, I think, you lose the core elements of femininity: hair, breast, eyelashes, gaze, things that are basic to a woman's femininity, we want long eyelashes, long hair, don't we? Big breasts um all this is lost, I came to see my image at one point and it was like a ghost like a disfigured creature"
>
> Hara, 26 years: "I have always liked to be so well-groomed, to be 100% female, I had a nice body, I had long hair, I had my breasts, and suddenly a part of me is missing, my hair is missing, my eyebrows are missing, you have the pale face of the cancer patient, you have bones that hurt from chemotherapy, you have so many other side effects, it's hard, very hard it is very difficult to accept yourself in the first place"

The extracts presented above strongly reflect cultural representations of what it means to be a woman as having specific –and visible- bodily characteristics. Vicky's references to seeing herself as a 'ghost' and a 'disfigured creature' are clear examples of a liminal identity, as both reflect a sense of being in-between, neither quite alive nor quite dead, and not-quite-human. Moreover, the experience of liminal femininity is reinforced by the values of the socio-cultural context (Wilkinson & Kitzinger, 1993, 1994) and by the absence of available discourses that reconceptualize female identity in alternative terms and without breasts (Crompvoets, 2003).

Several participants spoke in contradictory ways about the socio-cultural focus on bodily characteristics as a core element of femininity, and these tensions reveal a difficulty in regaining their sense of femininity as well as a difficulty in constructing a new, “normal” female identity. As is illustrated in the extract below, women challenged dominant constructions of femininity, claiming that they never invested in their body image to derive a positive self-image (Helms et al., 2008; Moreira & Canavarro, 2012), whilst at the same time considering it necessary to undergo reconstructive breast surgery to restore their body as that of a woman’s.

> Marina, 43 years: “I consider that a person’s image is not necessarily represented by their body, but by what their inner self expresses and this is not related- there are people who are awesome even with only one breast [laughter] or with only one leg, so this is my view and I had it before, my views have not changed now because of what’s happened, and it was very, very important for me to have these views, this value system, because this was a, how can I put it, a legacy, a background on which I depended throughout the treatment [...] I want to have this reconstruction because, as I told you, I don’t want my daughters to have this image of me, I don’t want them to feel that their mom is differ-, I want them to accept it and to say ‘yes, she’s had cancer’ but without them feeling disadvantaged and I don’t want them to get the wrong message that this is the image of the female body”

In the extract above it is interesting to note that Marina imagines her daughters accepting her status as a cancer patient but not as a woman who has undergone a mastectomy. Marina’s extract illustrates the ideological conflicts faced by several participants, where on the one hand they challenged the focus on women’s bodies as a core element of their identity, and on the other hand, still consider their body after mastectomy as not ‘really’ female.

Next, we turn to another key element of liminality that concerns changes in women’s social relationships and roles.

Social alienation

Another important aspect of women's experience relates to the inability to express thoughts and feelings resulting from the mastectomy. Participants talked about concealing their mastectomy and not sharing their concerns about the loss of their femininity, because of deep feelings of shame, worries about burdening others, and fears of being objects of pity. Shame is associated with the sense of lacking some essential and valued element, and concealing one’s feelings and experience of a shameful body may have been a way for women to lessen the potential of stigma. This difficulty was sometimes reinforced by others’ responses, who tended to underestimate the effects of the physical changes brought by the mastectomy, as illustrated in the next extract:

> Tanya, 52 years: “I didn’t talk to anyone about femininity (...) I didn't talk to my mum about it not because, I don't know, maybe it just didn’t happen, and I thought my mum I didn’t want to burden her with that as well, she was already in charge of my care and with all, this she wasn't- then with a friend who was close to me and who also took great care of me that summer, uh, this issue didn't come up, my friends in general were of the opinion that ‘you are very lucky that your type of cancer is a difficulty that will pass’, so this was my friends’ approach in general at that time, so the issue of femininity was not included”

In addition to each woman’s personal history, participants’ responses could be understood as also rooted in an ‘ideological dilemma’ (Billig et al., 1988), i.e. a contradiction at the level of ideology in relation to breast loss and its meanings. In both professional and lay discourses, the effects of mastectomy are primarily conceptualized in terms of loss of femininity, which is recognized and deemed ‘acceptable’, much more so than, say, fear of death (Goldenberg et al., 2006; Grabe et al., 2005). At the same time, however, it seems that breast loss is an issue that women are not entitled to mourn or share with others. In this way, the experience of having an imperfect, defective and therefore shameful feminine body intensifies the communicative alienation experienced by women, and this alienation is an important element in their sense of liminality (Little et al., 1998).

Love relationships

The sense of defective femininity seemed to bring about significant changes in women’s intimate relationships. The socio-cultural representation of the female breast as a primary symbol of femininity and female attractiveness (Arroyo & Lopez, 2011), considered necessary in intimate and sexual relationships, seems to reinforce the ambivalence experienced by many women regarding their sexuality. Women talked about their breastless body as an obstacle that interferes with spontaneous interaction and contact with the other sex. According to phenomenological research, this means that the female body fails to do what we would normally expect and this shift fundamentally changes the way women experience their female identity and their relationships (Carel, 2013).

As illustrated in the extract below, women in long-term relationships expressed strong concerns about whether they remained acceptable and attractive to their partners, while those not in a relationship reported that they withdrew from flirting and worried that they would be rejected if they engaged in a love affair. These findings are in line with similar findings in the existing literature (e.g., Ussher et al., 2012, 2014).

> Konstantina, 55 years: "I was thinking about it, it goes through your mind, of course it does, you think, okay until now we were fine, thank God, we were having a good time, we were a good couple, we had no problems, and I wondered if things will go wrong in the future, maybe, he won't like me anymore"
>
> Joanna, 43 years: "how would I have intercourse with someone, yes, it was tragic, I was so anxious, what can I say, how will he see me? what will he think about it? what will he say? I was very ashamed, I was ashamed (...) for a period of time, yes, I had withdrawn completely because I was so ashamed, I didn't know how the other person would respond"

Most participants reported not being able to resume their sexual life as it was prior to diagnosis and struggled to form a new way of contact with current or potential sexual partners. It is worth noting that all participants in our study were in heterosexual relationships, so possible differences in homosexual relationships could not be explored.

The breastless body and the sense of liminal femininity have a significant impact on women's sexual life. While the side effects of chemotherapy and hormone therapy are a problem mainly in the initial period of treatment, breast loss seems to lead to difficulties for several years. Women reported doubts about their attractiveness, experienced intense shame, and several felt intense ambivalence about sexual intercourse and touch more generally (Gilbert et al., 2010, 2013; Ussher et al., 2014). Studies have shown that the emotional support of partners can facilitate the resumption of sexual functioning, and this is also affected by the quality of sexual relationship and the degree of sexual satisfaction before diagnosis (Gilbert et al., 2010; Speer et al., 2005; Ussher et al., 2012). In this study, it was not clear what helped women resume their sexual life post-mastectomy.

> Vicky, 37 years: "you lose your sexuality if I can say that [laughter] you don't have sex without a top yet, uhm, no I can't, I don't want to lie to you or be silly, also his move to caress my breast is still, [I don't like him touching] even the good one [laughter], I think there's an issue there (.) I think that things are getting slightly better, this is purely my issue, I don't see my partner being bothered by something or approaching it negatively"

For some women sexual difficulties following mastectomy were linked to pre-existing relationship difficulties (Sheppard & Ely, 2008). Finally, in some cases the inability to return to the previous normal sexual function before cancer seems to be linked to the extent to which women themselves internalize the dominant socio-cultural norms around female beauty and attractiveness (Arroyo & Lopez, 2011).

It is worth noting that the majority of participants only spoke of their own sexual difficulties in passing, and mainly talked about the effects on the sexual satisfaction of the couple. Their talk reflected a focus on how their partner sees them, while issues relating to their own sexual desire and satisfaction were silenced. This bias is in line with dominant socio-cultural representations around female sexuality, according to which the sexual objectification of women continues to serve male sexual satisfaction (Hollway, 1998).

Managing liminal femininity

The use of the silicone patch and breast reconstruction surgery seems to be central elements in women's efforts to restore their damaged female identity. All participants considered the use of the patch imperative, as it helps their body look whole, normal and symmetrical (Gallagher et al., 2010; Roberts et al., 2003). At the same time, however, the patch is experienced as a foreign "body" that fails to restore the previous sense of normality; participants talked about how patches are ill-fitting, cause difficulties with dress choice, and require daily care (Crompvoets, 2012). In addition, although the use of silicone patches aims to conceal breast loss and avoid the stigma associated with it, their disclosure is of great concern to women (Berterö, 2002; Gallagher et al., 2010; Thomas-MacLean, 2005). In sum, despite the fact that most women talked about gradually becoming familiar with wearing a silicone patch, its use did not really help their wish to return to their normal state and this contributed to their experience of liminality.

> Anna, 42 years: “it was horrible, I had big breasts, very big breasts and they were heavy, it was quite something, if your breasts are heavy you don't realize it because it is you, however, when there is something foreign on you, inside your bra, which falls out when you lean forward, this made me feel very uncomfortable, carrying it on me, I couldn't have it for life, I couldn't, it wasn't a part of me, I'd rather cut the other breast than have such a thing on me uh and then the back pain started”

The decision to undergo reconstructive breast surgery is also linked to the desire to restore physical deformity and female identity (Piot-Ziegler et al., 2010). In this sense, women's wish to return to normality is translated into returning to an acceptable appearance in line with social representations of femininity (Denford et al., 2011).

> Marianthi, 57 years: “under no circumstances would I leave a mastectomy without reconstruction, under no circumstances (...) I was born a woman, I will die a woman and (.) I have to reconstruct this amputation, if I had lost my leg, I would have a prosthetic leg, I would do something, because, I wouldn’t - undress and see here a scar and there hanging a breast, well then I would surely go crazy, in that case, the mastectomy would really have a great impact on my life, it was clear from the beginning that I would reconstruct my breast”

However, after reconstructive surgery, the breast remains a source of discomfort for most women, as it looks and feels unnatural, differs from their ‘own’ breast and is experienced as incomplete, deformed and foreign. As such, women’s experience that they deviate from healthy, normal, feminine women remains despite reconstructive surgery, and they often compare the breast they had before the mastectomy and after reconstructive surgery (Abu-Nab & Grunfeld, 2007; De Boer et al., 2015; Fallbjörk et al., 2012; Paff Ogle & Ullstrup, 2006). As the phenomenological approach suggests, women experience their reconstructive breast as an obstacle to performing their female roles (Carel, 2013).

> Marianthi, 57 years: “it still bothers me, it's a foreign thing and once I, uh, I hugged a friend I hadn't seen in a while and she pulled back, this breast is like concrete, when someone comes in contact with this thing, either with their hand or when they hug you, they touch a concrete block, a wall, on something hard and you think ‘what is that?’, and if you don't know, it feels odd, even today I'm not used to this thing, I was told I would get used to it in time, but I haven’t got used to it, there are moments that, it's a foreign body, and I sometimes want to take it in my hand and pull it off my body, because it bothers me, it bothers me, it's a fake thing, it will never be part of my body until the day I die, it will always be a foreign thing and it will always remind me of what I went through (...) I am not the same woman and no woman is the same after a mastectomy”

Reconstructive breast surgery may allow the projection of a healthy and feminine image towards others when clothed and alleviates the practical difficulties of using a silicone patch, but women still feel not-normal and incomplete in terms of femininity. They often experience shame and dislike for their breasts (Abu-Nab & Grunfeld, 2007; Avdi et al., 2012; Nissen et al., 2002) and this seems to keep the chapter of the disease open for many years after diagnosis (Spector et al., 2011).

> Irene, 45 years: “every time you look at your body uhm you see it in front of you, no matter how much you want to hide it with clothes, when you see yourself in the mirror, you see it in front of you just uh (.) that the intensity this feeling causes lessens with time, and now many times I feel that my body <u>is not</u> feminine, that it <u>lacks</u> something (...) it is not as intense now but you <u>always</u> feel it”

Discussion

In sum, the experience of mastectomy is a complex and multifaceted experience; its meaning evolves over time and includes aspects that women find difficult to express. These non-verbalized aspects of the experience can be seen to be reflected in conflicting descriptions and meanings, insinuations as well as through silence, i.e. through the absence of reference to certain issues (Thorne & Murray, 2000; Wilkinson, 2000a). Initially, mastectomy is recognized as a necessary "sacrifice for life" as well as a highly invasive treatment, which changes in an essential manner the way participants identify as women. This experience can be described in terms of liminality as, in essence, it does not allow women to either return to their previous 'normal self' (i.e., their self and life prior to the diagnosis) or to transition to a new state (Little et al., 1998). An important element of the liminal sense is social alienation, as deep feelings of shame, concerns around burdening others, and fears of being stigmatized lead women to avoid sharing their concerns about breast loss and their wounded femininity. Liminality also characterizes women's encounters with sexual partners. Participants reported feeling "inappropriate" as women and ashamed of their body that fails to do what a "normal" female body is expected to be like and do, and they consequently maintained an ambivalent attitude towards new or existing sexual partners. Moreover, despite the use of the silicone patch and breast reconstruction surgery it seems that this liminal sensation persists for many years following a mastectomy.

The results of this study are consistent with some previous findings describing women's inability to return to normal life after breast cancer (Koutri & Avdi, 2016; McKenzie & Crouch, 2004; Thomas-MacLean, 2004). Moreover, the findings highlight liminality as a distinct response, which is characterized by a sense of being 'in-between', an oscillation between an attempt to continue one's life as if unaffected by breast cancer and a sense that one's life and sense of self have been irrevocably altered by cancer. In this sense, the concept of liminality underscores the decisive effect that mastectomy can have on women's bodies, their identity and social relations. In addition, the findings of this study theoretically enrich the concept of liminality as originally described by Little and colleagues (1998), by including the gendered dimension of embodied identity and the important role that social representations of femininity play in shaping women's experience following mastectomy.

Moreover, the phenomenological approach we adopted offers a more comprehensive understanding of the experience of mastectomy. The concept of embodied identity captures not only the altered body image, but the fundamental changes in women's female identity, highlighting the important role of the body in the construction of self and in being-in-the-world. For many women, mastectomy deconstructs the way they experience their bodies, the way they talk about breast loss and the way they interact with their familiars and partners. The body after a mastectomy is transformed into the "objective" body, which seems to be experienced as an obstacle that fails to live up to the expectations of the normal female identity and roles, which is, at the same time, constantly observed by others (Carel, 2011; Finlay, 2006).

In addition, the results of our study demonstrate the impact of the socio-cultural context on women's experience. The feminist perspective we adopted provided a framework within which the ways that the Greek socio-cultural context shapes Greek women's experience of mastectomy could be examined. Specifically, it became apparent that the experience of women is influenced by the way they perceive (and expect) the reactions of those close to them as well as the wider social context, and is framed by the available social representations about femininity (Crouch & McKenzie, 2000; Wilkinson, 2000a, 2000b). The Greek socio-cultural context is dominated by patriarchal values that recognize the female breast as an integral part of femininity and sexuality. Women, in some cases, seem to have internalized the dominant socio-cultural norms around female beauty and attractiveness, which seems to be linked with their inability to return to the previous normal sense of femininity or to enter a new normal state after a mastectomy, and thus remain in a liminal state.

These observations demonstrate the usefulness of research approaches that allow the study of experience holistically, capturing its complexities and tensions, and relating personal experience with the wider context (Avdi et al., 2012). In exploring deeply personal and complex female experiences, such as that of a mastectomy, we argue that the adoption of a phenomenological approach in combination with the gender perspective is particularly useful, as it offers ways of understanding the very personal physical experience in relation to cultural values and dominant social institutions.

A better understanding of the experience of mastectomy in the context of Greek society can contribute to the practices of medical care, the creation of support services, as well as mutual support movements. The concept of liminality, beyond describing many women's subjective experience, reflects the prevailing socio-cultural representations of the Western world around the "normal woman" after breast cancer. Existing representations regarding return to normality may hinder women's full reintegration into Greek society; in this sense, challenging such representations and offering alternatives could facilitate women's adjustment to life after mastectomy. Drawing upon our findings, we would argue that women should be encouraged to acknowledge and accept the ambivalent aspects of their experience as normal and to freely take decisions about their bodies. Therefore, the emergence of liminal femininity as a "normal" aspect of women's experience can lead to the recognition of a "new normality" (Trusson, 2013) and a different way of being and living with the disease and the altered body.

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ΕΜΠΕΙΡΙΚΗ ΕΡΓΑΣΙΑ | RESEARCH PAPER

Η εμπειρία της μαστεκτομής: ταυτότητα φύλου, ενσώματη ταυτότητα και “ζωή στο μεταίχμιο”

Δέσποινα ΖΗΛΙΑΣΚΟΠΟΥΛΟΥ[1], Ευρυνόμη ΑΥΔΗ[1]

[1] Τμήμα Ψυχολογίας, Φιλοσοφική Σχολή, Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης, Θεσσαλονίκη, Ελλάδα

ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

Μαστεκτομή,
Φαινομενολογία,
Φεμινισμός,
Ζωή στο μεταίχμιο,
Ενσώματη ταυτότητα

ΣΤΟΙΧΕΙΑ ΕΠΙΚΟΙΝΩΝΙΑΣ

Δέσποινα Ζηλιασκοπούλου,
Τμήμα Ψυχολογίας,
Φιλοσοφική Σχολή,
Αριστοτέλειο Πανεπιστήμιο
Θεσσαλονίκης,
Πανεπιστημιούπολη, 541 24
Θεσσαλονίκη
dziliask@psy.auth.gr

ΠΕΡΙΛΗΨΗ

Πέρα από μια απειλητική για τη ζωή ασθένεια, οι γυναίκες με καρκίνο του μαστού αντιμετωπίζουν σημαντικές προκλήσεις εξαιτίας των επιπτώσεων της ιατρικής θεραπείας στο σώμα και στην ενσώματη ταυτότητά τους. Η μαστεκτομή, ως μια ιδιαίτερα παρεμβατική στο σώμα θεραπεία φέρει σημαντικές επιπτώσεις στη ζωή των γυναικών. Η παρούσα έρευνα στοχεύει στη διερεύνηση της εμπειρίας της μαστεκτομής και των νοημάτων που οι γυναίκες αποδίδουν σε αυτή αναφορικά με την ταυτότητα και τις σχέσεις τους. Τα ερευνητικά ερωτήματα διερευνήθηκαν μέσα από τη φαινομενολογική προσέγγιση με στόχο την καλύτερη κατανόηση του ρόλου που διαδραματίζει το σώμα στην ασθένεια, ενώ υιοθετήθηκε η οπτική του φύλου, ώστε να εξεταστεί κριτικά το κοινωνικοπολιτισμικό πλαίσιο μέσα στο οποίο διαμορφώνεται η εμπειρία των γυναικών. Στην έρευνα συμμετείχαν δεκαεπτά γυναίκες, ηλικίας 26-57 ετών, που είχαν υποβληθεί σε μαστεκτομή μετά από διάγνωση καρκίνου του μαστού. Το υλικό που προέκυψε από τη διεξαγωγή ημιδομημένων συνεντεύξεων αναλύθηκε σύμφωνα με τις αρχές της φαινομενολογικής ανάλυσης. Η ανάλυση εμπλουτίστηκε από την οπτική του φύλου, καθώς δόθηκε ιδιαίτερη σημασία στην έμφυλη διάσταση της ενσώματης ταυτότητας. Τα ερευνητικά ευρήματα δείχνουν ότι κεντρικό στοιχείο της εμπειρίας της μαστεκτομής αποτελεί η αλλοίωση της ενσώματης ταυτότητας και μια αίσθηση μετεωρότητας, μιας ανεπίλυτης συνθήκης ύπαρξης ανάμεσα στη ζωή πριν και μετά τη διάγνωση. Η ανάλυση κατέδειξε την ανάγκη για διεύρυνση της έννοιας “της ζωής στο μεταίχμιο” στην ψυχο-ογκολογία προκειμένου να συμπεριλάβει την ασάφεια γύρω από τον αυτοπροσδιορισμό των γυναικών ως “φυσιολογικών γυναικών”, η οποία συνδέεται με την ενσώματη εμπειρία και τις κοινωνικοπολιτισμικές κατασκευές του γυναικείου στήθους. Ενδιαφέρον είναι, επίσης, ότι η “ζωή στο μεταίχμιο” γύρω από την γυναικεία ταυτότητα βιώνεται και από τις γυναίκες που χρησιμοποιούν επίθεμα σιλικόνης ή έχουν υποβληθεί σε επανορθωτική επέμβαση του στήθους. Τα ευρήματα εμπλουτίζουν τη θεωρητική κατανόηση της εμπειρίας της μαστεκτομής, διευρύνουν την έννοια της “ζωής στο μεταίχμιο”, αναδεικνύουν την έμφυλη διάσταση της ταυτότητας και τον ρόλο του κοινωνικοπολιτισμικού πλαισίου στη διαμόρφωση της εμπειρίας των γυναικών. Επιπλέον, προσφέρουν χρήσιμες κατευθύνσεις στον σχεδιασμό και στην παροχή εξατομικευμένης υποστήριξης σε γυναίκες που έχουν υποβληθεί σε μαστεκτομή.