

Biographic Strategies of Greek Women with Breast Cancer: From the “Injured” to the “Contributing” Body

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Abstract

This paper is based on a disciplinary qualitative research, grounded on fourteen biographical-narrative interviews with Greek women, experiencing breast cancer and mastectomy. These women have eventually participated in solidarity groups of self-help and voluntary action and describe the multiple ways they have coped with this new “alarm situation” that emerged in their biographies. The main purpose of the article is to understand and interpret the practises they employed, in as much as they record breast cancer as a turning point with respect to emotions, social relationships and activities. The main results of the research reveal that these particular women, members of a larger social group, tend to produce a special form of embodiment and politicization. This results in a complex, painful and struggling renegotiation of a social identity and a rather new form of relationships with the self and the significant others. The management of the disease – and the potential social stigma or everyday negativity - ultimately leads to a redefinition of the basic life values, within the framework of an energetic and combative, self-reflective project with an often contradictory content.

Keywords: Qualitative Health Research, Breast Cancer, Biographic Strategies, Politicization, Embodiment

1. Introduction

Every form of serious disease constitutes, in addition to any biological impairment caused, a complex and unique psychosocial phenomenon. These issues are closely connected to specific social, cultural and historical patterns. They are as well combined to inter-personal experiences and the intersubjective interpretation of health problems. The empirically oriented tradition that has been developed within the social sciences, namely the sociology of health and illness - and the sociology of the body - has systematically highlighted the social and experiential dimension of illness (Cregan, 2004). Sharing common grounds with the aforementioned sociological tradition, the contribution employs the concept of embodiment in understanding both the historical, dynamic, relationship we develop with our bodies and the role that its management retains in shaping individual, and certainly, social identities. Perpetuating that the body constitutes, especially in middle-class groups, the “core project of the self”, which mediates the social sphere and the political agenda, we systematically examine the multiple ways in which the injured body functions as a tool for political action and self-determination and as a medium of caring, nursing and resistance (Newton, 2003). Additionally, we seek to explore how the biographical experience that is attached to breast cancer and medical practices becomes an energetic mechanism for a technology of the self. This skill creates, through politicization, forms of collective action and gradually leads to the development of a bio-sociality, retaining concrete content and struggles (Chatjouli, 2013; Lerner, 2001).

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We particularly seek to understand how these women, who have undergone partial or total mastectomy, are subsequently mobilised in groups of self-assistance, solidarity and voluntary action, promoting nursing, caring and therapeutic intervention. This mobilisation is the final outcome of a particular experience that is grasped as a total experience. However, as this is demonstrated from the biographical interviews, this total experience is constituted gradually. Furthermore, it is uniquely based on certain social mechanisms that give to every subjective biographical pattern its particular form and content. This social feature is what finally enables the social subjects to cope with this new image of the self. This modified self-understanding forms and co-creates a new energetic, albeit struggling, identity that redefines the relations with the social others. Thus, this painful experience of coping with a serious illness and surviving death, a cultural process that the article aims to highlight, becomes a mean of politicization of the body and a source of solidarity and nursing activities. These social procedures tend to generate for these women moral obligations and rights alike. They as well give birth to a special sense of moral duty, forcing them to redefine their opinions regarding political participation and collective action as well as issues of nursing, caring and assisting each other. It has been argued that the emergence of a disease that threatens social identity, such as breast cancer, results, for the affected individual, in an overall reassessment of priorities and psychological effects, as a consequence of the severe intensity that leads to an existential agony. This stressful experience includes a wide range of emotions such as insecurity, vulnerability and alienation, leading to the redefinition of the self and of central life goals. Individual reactions notwithstanding, usually the first months after surgery are extremely difficult from a psychological point of view. Sadness, fear, shock, anger go along with a sense of relief that breast cancer was detected at an early stage and was intercepted plausibly (Lam & Fielding, 2003). However, what is crucial in the case of breast cancer is a new form of embodiment, which certainly occurs after mastectomy (Landmark & Wahl, 2002). The central research questions thus, can be posed as follows:

- a) What is the particular relation of the transforming and transformed materiality of the body to the experience of breast cancer?
- b) What is the connection between this experience of breast cancer and the biographical patterns followed?
- c) How are these patterns affected and modified in certain social and historical horizons?

From a biographical standpoint, the "injured" breast seems to result in an almost compulsory redeployment of the patient's personal horizons. The presence of breast cancer, the fear of possible death and permanent bodily change are presented by the participants as a severe rupture in their personal histories. This serious biographical disruption leads to a series of redefinitions regarding relations with others, the image of the self, sexuality and particular life values (Kayser & Sormanti, 2002). The appearance of mastectomy and the immediate threat of forming a new life situation seem to become unbearable for the majority of women diagnosed with breast cancer. The pressure experienced by medical tests gives rise to a forced reconstruction of everyday life (Redd et al., 2001). Based on our qualitative research, these biographical patterns, the politicization of the body, the development of a solidarity group of volunteers and the emergence of new forms of nursing and caring are at the same time determined by medical interventions and cultural perspectives.

2. Materials and Methods

This manuscript was based on empirical research that was conducted following all the required and appropriate ethical standard, as decided by the Senate of the University of Crete (Senate 229/22-3-2012, http://www.en.uoc.gr/research-at_uni/eth/ethi.html & <http://ec.europa.eu/euraxess/index.cfm/rights/index>). The contribution was originally grounded on 14 biographical-narrative interviews with women diagnosed with breast cancer and mastectomy, aged 45-55 years. All participants are enrolled in self-help programs and voluntarily offer practical and moral support in various solidarity groups. The interviews were conducted in three phases. The first, pilot phase, was experimental and involved contacts with psychologists at cancer hospitals and at women's breast cancer associations in Athens. At this initial stage, what was recorded, through semi-structured interviews, basically concerned their overall and more specific estimations and evaluations with respect to the key parameters of the disease. Besides, it addressed specific social parameters (i.e., social and marital status, educational level, budget, etc) and additionally focused on the patients' psychological needs during treatment. At this phase, we also conducted participant observation in the same institutions in order to preliminarily understand a variety of characteristic aspects of the relationship between women with breast cancer and health professionals.

The second phase of the research included the completion of six biographical narrative interviews and their systematic analysis, extracting the important themes the participants deemed as meaningful and crucial, in order to create a more comprehensive model of grasping all cases. Finally, the third phase involved the completion of eight additional biographical narrative interviews, following a similar research procedure and logic. The research was conducted in Attica, mainly in the city of Athens, Greece, during the period 2004-2009, a few months before the emergence of the severe economic and social crisis. The focus is on the first solidarity and self-help organization that was formed, still active and energetic in the area of Athens, whose name is not referred for reasons of anonymity and protection. The purpose was to understand the way in which the occurrence of breast cancer and mastectomy affects the women's lives, their biographical trajectories and their political participation in connection to the operation on their bodies.

The sample selection criteria were basically the following:

- a) The existence of mastectomy, as part of therapy concerning breast cancer.
- b) The expiration of a certain period of time after the completion of interventional therapies, i.e., mastectomy, chemotherapy and possibly radiotherapy, without the appearance of metastases.
- c) The voluntary participation in solidarity and self-help groups.
- d) Marriage and parenthood.
- h) Age, a decade before or after 50.
- g) The social stratification, i.e., belonging to middle social strata.

Breast cancer forces to a radical rethinking of the body and the constitutive values of life itself. However, the interesting feature is that women's participation in voluntary self-help groups, first as patients and consequently as active members who offer caring, nursing and assistance to new patients, highlights the ideological and political dimension of managing this type of cancer. Moreover, it gives to the research community access to some particular forms of assistance that have been developed in Greece, especially regarding the decline of the traditional middle-class, both on an economic and a cultural level. We as well assume that this study will possibly contribute to the deeper understanding of the way solidarity and caring can grow in situations of extreme economic crisis and collapse of the *sui generis* Greek welfare state. The common cultural background (petty or middle class people, living in the city) was necessary in order to highlight the common points of patients' biographical trajectories in our sample. The narratives are crucial in as much as they interpret the past, especially in cases of severe disruption. Consequently, this empirical material forms an appropriate tool to understand how breast cancer, nursing, caring and therapeutic interventions that follow lead to the reorganization of the horizons of the self (Lee et al, 2001). Women diagnosed with breast cancer, in our research, were invited to narrate their life stories. They were strongly informed that we were largely interested in the ways they experienced and managed this particular disease. The purpose was to examine how the experience of illness "invaded" their lives and how narration can reconstruct this "biographical disruption", which is closely connected with the sense of the "injured" and at the same time "resisting" body". Participants were preliminarily informed that their conversation would be recorded exclusively for research purposes and declared their agreement. The study followed the standards for the conduct of a proper and appropriate qualitative research. In this study, triangulation, an attempt to increase reliability and validity of qualitative results, was pursued (Savvakis 2014: 53-67). The three researchers involved in this study analysed the data separately in order to ensure that the identified themes were in accordance with the overall interview material. In qualitative research, it is also important to consider multiple ways to achieve stability and credibility of the produced data in order to increase its reliability. For this reason, the empirical material was passed through multiple times to reveal latent and profane qualities. Finally, all the narrators are protected through the use of pseudonyms.

3. Results and Discussion

In this section we systematically discuss the findings of our empirical research, which primarily but not exclusively, resulted from a methodical analysis of the fourteen biographical interviews. As we demonstrate, every stage that is proposed is linked with a step in the formation of embodiment, the political self and the significant others.

3.1 Early Phase

Regarding the early phase, we can highlight that the majority of patients strive hard to rationalize and attribute a concrete sense of meaning to the occurrence of cancer. This is an effort to assign a sense of continuity to the events of the past, as directly related to the emerging disease.

Thus, the participants report that, before the onset of the illness, they systematically experienced severely traumatic events and endured painful situations. Anna reckons: At some point in my life, my stepbrothers turned me down, they rejected me. They changed their attitude towards me. This rejection left me with a sense of bitterness too, and I think that this is one part of my illness. I assume that the rejection I suffered is part of the disease, so never let anyone dismiss you! Kalia is also an example of a person that has gone under constant pressure, referring to situations of psychological distrust and difficulty: I did not want to get married because I had my own car, being carefree. I had so much fun in my life, this is to say I didn't get married to leave my house. However, I would rather not get married in order not to change my life. And from the point I was the only child in my family, I got three children of my own. That made things more complicated and suddenly from working outside the house, I was locked up in a house with three children. Eventually, a nice cancer comes, because I really believe that the cancer comes after a squeeze, plus the family background, because my mom had earlier died of breast cancer. As mentioned above, cancer patients often claim that the most important factor in carcinogenesis is a chronic suppression of emotions and desires. Indeed, a common feature is that narrators are exceedingly worried about various issues. They furthermore develop anxiety and stress regarding situations that are subsequently assessed as unimportant (Ovayolu et al., 2013). The participants, in their effort to accept and rationalize the occurrence of this particular disease, reconstruct the past and consider it as a basic reason for the emergence of breast cancer in the present (Hsu et al., 2010). This interpretation creates a form of a retrospective construction that consequently problematizes the social conditions before breast cancer. Participants regard the appearance of breast cancer as a "particular and uneasy moment" of a biographical pattern that is valued from a present standpoint as incorrect and pathological. This particular pathology and frailty is grounded on a perceived personal inability to produce a happy and self-determined life.

3.2 Diagnosis

The way in which the narrators were informed that they suffer cancer varies. Thus, it appears to play a crucial role in dealing with the disease and the subsequent mastectomy. Joanne reports: Well, sometime after Easter, my family informed me. At that point I got extremely angry, extremely angry. I was never that angry about anything in my life before. My husband, my sisters, my own sisters, my friends, they had hidden it from me, they had no right to do something like that!! They hid it from me, while I had never shown them that I was afraid. "I'm leaving", I told them, I changed doctor. I went to another doctor, I told him the case: "I want to talk! I'm weak, I want to know what I have and soon to go under surgery if you suggest so, so that you remove, if this is the case, the rest of it. The other breast, if it has to, have it removed as well, I don't mind, I want to be done with it. I want to live!" In the latter case, we can perceive the patients' anger and negative emotions, caused by their families and medical personnel's attempt to conceal reality. The participant demands honesty and sincerity from the medical staff, since she claims that she can plausibly deal with and potentially overcome this predicament. We may suggest that the actual knowledge of her condition is absolutely necessary and significant. The participant proposes that only a brave and conscious attitude towards the breast cancer suits women, in general. She maintains that women energetically demand to have control over their situation. It seems like they stand against an enemy whom they want to know and meet, so that they will increase their chances to beat it. As stated in the previous extract, "I don't mind, I want to live." In this extract, we can also detect that the narrator presents a self merely controlled by a serious biographical uncertainty. This biographical difficulty leads to a conscious shift: the patient decides that she is willing to lose her other breast, as well, as long as she will manage to stay alive. The powerful desire to stay alive consolidates the two horizons that mediate and shape the struggling dimensions of the self. At the same time, it bridges the gap of physical loss. She decides that what actually matters is life itself and not the dominant, socially constructed, female sexual identity. As she characteristically states, I'm not interested, at all. Cut off the other one, too, if you have to, it doesn't bother me, I want to live!

3.3 Medical Treatment

At this stage, the important issue, as derived from the biographic material, is the awareness and the acceptance of the modified body after mastectomy. During this phase, women have fortunately escaped the danger of immediate death. Thus, they deal with the management of chemotherapy and its side effects. They as well strive to become reconciled with the new sense of the bodily self. Participants recall these situations and preserve a heroic, merely stoic, attitude regarding side effects.

Mastectomy assaulted their identity and self-confidence; however, it did not eliminate passion for living and their ability to plan for the future. This sense of biological continuity is interrupted by this feeling of biographical disruption, while narrations, as energetic products, bridge the two disparate components of the self, attempting to relativise the violent break. It is particularly the existence of the family and the significant others that empower this concrete decision to keep on living. As Kleio points out: *I don't allow myself to be harmed. It is an unnecessary luxury, I have two children who need me.* Children are the fundamental figures who offer the opportunity to conceptualize the present and the future, in relation to the past. The integration of the disease in the family routine and the repetition of daily actions, such as walking or everyday humor are some distinct key features. These manage to "domesticate" and "ease" the disease and promote a certain sense of continuity between the past and today. However, most women, after diagnosed with cancer, recall that they experience disagreeable emotions. More specifically, they feel fear, anger and guilt and seek support and encouragement from their relatives or families. This disagreeable experience mobilizes social action that is multiplied when women reckon themselves as survivors. These women perceive breast cancer as a challenge to their own being, and do not choose grief and sadness to portray their existence. Furthermore, they continuously strive to continue their activities, including some previous professional occupation, adopting a biographical sense of continuity. A typical example is that of Irene, who states: What helped me immensely in my self-medication was the fact that I kept my job. To put it otherwise, I'm against women who quit their jobs. I realized that I had to become more active and multiply my interests. I can say that after joining my club [club refers to self-help and support cancer patients] and this seminar, I certainly gained education for voluntary action. Frankly, I think that I lit not only a candle, but also a very powerful lamp, which reflected my own face. The narrators state that after the surgery and the proper treatments, they felt an intense need for emotional support. Through participation, they felt stronger and undertook action to provide support to other sufferers. In other words, they faced their illness as a motivation for participation and expression; this is to say, as an opportunity to share their personal experiences through their actions, oriented to others. Under this perception, the disease is conceptualized as a new starting point for action. The source of this affirmative action can be detected in the overall experience of the "injured body" and the "abused breast". Participants feel obliged to help other women and transform cancer from a source of biographical discontinuity to an inspiration for life.

3.4 Biographical Restructuring and Politicization

Participants intend to restore a stable relationship between continuity of the healthy (past) and ill (present) self and body (Henriksen & Hansen, 2009; Katapodis et al., 2005; Facione & Facione, 2006). As recorded, the "injured breasts" could result in a transubstantiation of the previous images of sexuality, particularly with respect to motherhood. This re-conceptualisation of the breast is part of a larger shift of the individual political perspective (Chang & Li, 2002). The ideological allies of this transformation of the political self are, in our case, the self-help associations and the groups of voluntary action that promote nursing, caring and therapeutic interventions. This turn to a more politicized and energetic self makes it possible to compromise with the new situation. In certain cases, some particular women even manage to symbolically overcome breast cancer. Thus, they bridge the biographical uneasiness, caused both by the disease and the plethora of medical intermediations. The empirical material indicates that breast cancer leads to "a deep personal dive", to a forced and mandatory self-reflection process, often described as "meaning attribution", "post-traumatic self-reflection and "personal journey" (Burke, 2012). This transforms the experience of the disease from an extremely negative change to a potential positive one. This radical shift regarding the perception of the self is advocated by the medical experts (Alexias et al., 2012). The specialists promote a new scientific normativity that encourages a lifestyle change and a positive engagement with the self (Bairati et al, 2006). It is no coincidence, therefore, that in the majority of the segments, a psychological vocabulary is retained in order to redefine the relation with the self and the familiar ones (Sparkes, 2012).

In some cases, cancer is idealized, rationalized and symbolically redefined. This assists, especially after a successful treatment, to the restoration of a positive view that leads to a "real" and deep understanding of life and to a paradigm shift. These women often emphasize that they realized the essential "meaning of life" and decided "to really enjoy life", forming meaningful relationships with others (Henriksen & Hansen, 2009). At this point, the changes in life are as well treated as a realization of the previous pathogenic social actions and behaviors. Ultimately, breast cancer leads to a recursive and biographical construction of the past. This meaningful retrospective construction project is healing the personal ruptures and it is, as well, related to the practical purposes of managing the high risks of the disease.

A typical example of this is Gianna, who even stated that cancer was a welcomed event in her life. She remarks: I arrived at a point to tell myself that cancer was a pleasant event. I felt happy that the disease came into my life! I know it sounds contradictory and paradoxical, but it is true. I said it, and I believed it. I wish it had come earlier! I had to escape and cease fights and misunderstandings, avoiding stabs in the back. I got to a certain point to say it was a good thing that this breast cancer entered and changed my life. What have I done with my life for so many years? Why not to love myself, why not to put limits to the others? Why I remained silent? Should cancer appear in order to stand up and talk about my needs? We can also highlight that the participants redefine the values and the goods of life whereas previously they claimed irreverence and nonchalance. Narrators claim that through the experience of the disease, they learned to love themselves and protect the blocking oppression within their environment. They also supported that they try to protect their internal harmony, attempting thereby to reconstruct a sense of biographical continuity, which was violated by the intrusion of breast cancer. The experience of illness - and the intervention of experts, professionals or voluntary groups - ultimately leads to an increased sense of self-awareness. Participants stress that they choose not to oppress themselves and not to allow embarrassing situations to persist for a long period of time. The empowerment of self-reflection mobilizes and orients social action to other sufferers, deemed as an extended political and symbolical family.

3.5 Discussion

Voluntary action emerges as a distinctive element based on self-awareness, promoting caring, nursing and self-empowerment. After the end of their adventure, participants confessed that they wanted to share their fears and concerns regarding the future with peers. Through personal experiences of participation in self-help groups, they choose to contributively share feelings and emotions. Research participants visit women who have undergone surgery, and strive to ease their pain, empower them, alleviate their fears and concerns and offer caring, nursing and companion. Thus, the disease, through this biographical restructuring process and the subsequent politicization of the self, produces some positive social results. Actually, it redefines social identity and highlights contribution and engagement as dominant categories of their existence. In other words, subjectivity does not acquire the form of an isolated individualisation or a turn to the inner self. On the contrary, it leads through the politicization of the body, to unique and specific forms of solidarity, caring and nursing. The analysis – based on fourteen biographical-narrative interviews - demonstrated that the consequences of breast cancer in the biographical course of these middle class Greek women have the main following consequences:

- a) Biographical disruption, accompanied by a severe threat on female identity and subsequent resistance or coping strategies.
- b) Forced, albeit energetic, renegotiation of the relationship with oneself and the significant others.
- c) Dramatic redefinition of the life values and priorities, in a reflective framework concerning the interpretation of the self.
- e) Mobilization and active participation in voluntary and solidarity programs.

The onset of breast cancer is extremely vital and significant because participants try to organize a plausible defence against the disease. Thus, they create a sense of continuity with their previous experiences and review their relations with their fellow men and women, assessing situations under a different perspective. What emerges is a new dimension of a “political” self. This project of energetic contribution, deeply rooted in self-help groups, does not promote an one-dimensional individualization, but a rather complex social mechanism, which might lead to new political paths for other social groups as well. The experience of alienation is partially redeemed through the politicization of the body, encouraging forms of solidarity. The “traditional female roles” - namely those of reproduction, motherhood and sexual obedience - are gradually replaced by those of the caretaker woman. This new social persona minds not only for her children but also for those, even unknown, who need protection and assistance. The “injured breast” seems to lead to a new identity that strives to marginalize the mere sexual element of the breast, transforming it into a symbol of maternity and caring. Thus, the biologically insulted body is restoring biographical continuity through social contribution and political participation. However, this “continuity” is not a reproduction of the traditional division of gender roles. They are not unequivocal returns to the traditional roles of the woman as a mother or a nurse, or to a person that is exclusively domestic or available. On the contrary, the performance of the caregiver roles results in the production of a constantly active reflection as an outcome of the disease.

This is a social mechanism that produces a politicized subject that advocates participation in other forms of collective action. This contributes to the production of a reflective project of the self in which the altered body becomes the vehicle for a new relationship with the self and the others. The intervention of medicine is often accompanied by a process of self-empowerment that participants retain regarding both the previous situation and the future (Tzanakis, 2014). Thus, the suffering female body becomes at the same time the object of medical institutions and of personal care (Chen et al, 2014). Voluntary action is precisely a concrete result of this experience of biosociality (Rabinow, 2008). Medical interventions tend to produce subjectivities that are involved in risk situations that promote new forms of co-existence and political demands. The objectification of the body, through medical intervention, is accompanied by a parallel process of individualization and subjectification (Rabinow & Rose, 2006). These two elements constitute a “practice of the self” (Foucault, 1988) and compose a form of biosociality; namely the development of voluntary action, self-help and mutual support. Finally, this is the outcome of the politicization of the “injured” body, oriented to a “contributing” one. The biosocial body emerges therefore as a field that encourages collective action. Through this action, a state of non-normality (i.e., breast cancer that threatens life, happiness and femininity) is converted to a mechanism of social integration and not deviation. The reconceptualization of the “injured breast” is the source of this mobilization, as biosociality incorporates the content of previous meanings. The individual project that tended to heal the biographic wounds is politicized through a biosociality that relies on nursing, caring, support, solidarity and images of normality. This is not however, a nostalgic return to a “healthy past” but an introduction to the public sphere of a form of sociality grounded on the experience of breast cancer. This process gradually transforms the “injured” female body and constitutes an area of claims and demands. These are particularly oriented in three main directions:

- a) The immediate family, expanding living space and claiming an accepted self and more balanced relationships, particularly with husbands,
- b) The medical institution, claiming a more democratic and simultaneously, effective therapeutically relationship, and
- c) The wider public place, articulating a demand for a normality that politicizes breast cancer.

The politicization of the body, through the experience of breast cancer, creates a potential pattern, albeit not followed by all women, which stands on the public sphere as a political alternative. This includes a new type of embodiment and biographical re-structuring towards issues of caring, nursing and helping the others and the self. The previous statement holds wider implications regarding the possible ways social sciences – and acting agents themselves – understand breast cancer and the suffering body with energetic, productive, meaningful, caring and inspiring ways.

4. References

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