

Breast Cancer in Contemporary Greece: Economic Dimensions and Socio-Psychological Effects

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Abstract - The main purpose of this article is to critically complete the economic perspective regarding breast cancer offering a more spherical understanding of the disease as well focusing on its socio-psychological effects. The contribution presents some specific socio-economic features of this particular illness in contemporary Greece, emphasizing on some of the core strategies these diagnosed women apply in respect with their professional re-orientation. It as well analyses the inter-subjective experience of breast cancer in as much as participants record it as a turning point regarding their economic status, socio-psychological state, biographies and overall relationships.

The paper is based both on qualitative research, grounded on fourteen biographical interviews with Greek women, experiencing breast cancer and mastectomy and on quantitative data provided by secondary inquiry. In an integrated view, it is possible to formulate some preliminary conceptual tools that can account for the economic dimensions and socio-psychological implications of the disease. Besides, we present the energetic strategies these women employ to mitigate personal suffering and transform their "harmed" body to an energetic source of professional re-orientations and biographical re-constitutions.

Keywords - Economic dimensions, Socio-Psychological effects, Applied sociological research, Mix methods, Breast cancer.

1. Introduction

Cancer is a very common disease in the contemporary world with extremely high direct and indirect economic costs and socio-psychological effects. It is estimated that cancer cost the EU Member States €126 billion in 2009, with healthcare accounting for €51 billion (40%). Across the EU, the healthcare costs of cancer were estimated at the equivalent to €102 per citizen, but varied substantially from €16 per person in Bulgaria to €184

per person in Luxembourg. Productivity losses due to early death were estimated to cost €42.6 billion and lost working days €9.43 billion. Informal care was estimated to cost €23.2 billion. Lung cancer had the highest estimated economic cost (€18.8 billion, 15% of overall cancer costs), followed by breast cancer (€15 billion, 12%), colorectal cancer (€13.1 billion, 10%), and prostate cancer (€8.43 billion, 7%). Researchers point out that these estimates are conservative, as some categories of health care costs, such as screening programmes, were not included due to the inability to obtain these data for all countries under study (European Commission, 2014).

The expensive financial cost emerges from the long hospitalization period, diagnostic tests, surgeries, however, mainly by the high cost of medication. Especially in Greece, all the previous costs are largely paid by the National Health System and it is roughly estimated that they count for almost a 6.5% of the total expenditure on health care in the country. In most countries of the world, as in Greece, cancer is the second cause of death after cardiovascular disease (Ministry of Health, 2008).

More specifically, breast cancer is one of the most serious and life threatening forms of disease that is the leading type of cancer in women, especially in the so-called developed world. As a result, this particular illness is connected to significant economic implications, social-psychological re-orientations and biographical consequences both on a global and on a national Greek level. It is furthermore responsible for a large number of death cases or severe health problems regarding lifetime (IARC, 2008).

Especially for women, breast cancer is the second type of cancer after that of the lung. Statistics account that more than 1.6 million women are diagnosed with the disease each year worldwide. According to recent research it is estimated that one woman in eight is affected by the disease, or

otherwise 13% of the world female population will become ill during lifetime. Besides, the disease affects all age groups from 20-90 years. The chances of a woman to get infected significantly increase through ageing, while the risk of developing breast cancer quadruples after menopause (Tzala, 2004; Ferlay et al., 2013). Particularly, in Greece, where breast cancer is the leading cause of cancer death in women, more than 4.900 women are diagnosed with breast cancer each year and more than 2.000 eventually die (IARC, 2008).

According to recent epidemiological data obtained from the Pan-Hellenic Archive of pathological-tumors laboratories in 2011 the incidence of breast cancer cases estimated in 6.454 (data from 97%-98% of laboratories). The interesting element is that 27%-28% of these women are under 50 years of age, while 45% of them - diagnosed with breast cancer - will proceed to mastectomy. The scientists emphasize that if breast cancer is early diagnosed and treated, the prognosis is very good. Besides, even the metastatic breast cancer - in the case of HER2 - can be treated satisfactorily (Ministry of Health, 2008).

Thus, a closer scientific examination of this phenomenon can account for the deeper economic consequences of breast cancer, especially in the contemporary Greek context. Is as well allows for a more promising socio-psychological individual management and treatment of the disease directed to an effective regulation and contextualization of its generating factors. This effort aims to reduce the potential costs of the disease on economic figures (macro level), socio-psychological dimensions (middle level) and biographical disruptions (micro level).

Breast cancer also results to a unique indirect economic cost due to reduced productivity of both the sufferer and the family that is burdened by homecare and by the loss of working days regarding at the same time the patient and the caregivers. Indirect costs are estimated to be at least twice the direct ones (Ministry of Health, 2008; Tzala, 2004). Also, the social-psychological cost of breast cancer is often quite unbearable. Sufferers undergo drastic consequences in their personal, family, professional and social-psychological lives.

Women diagnosed with the disease often encounter compassion or rejection by their friendly or family environment; an element that creates additional unbearable socio-psychological encumbrance on patients, who often incriminate and blame themselves (Sparkes, 2012; Lam and Fielding, 2003). At the same time, the social stigmatization affects the personality and dignity of these women and makes the psychological and biographical experience of breast cancer an extremely painful process (Landmark and Wahl, 2002). Moreover, patients are confronted with phenomena and characteristics of the Greek health care system that

additionally cumber them mentally and strain them physically (i.e. labyrinthine structures and bureaucratic obstacles in the health system, high costs of disease, unsatisfactorily operation of the National Health System, etc).

The individual socio-economic level is associated with the possibility of incidence of several cancers. Cancers of the lung, stomach and esophagus occur more frequently in the lower economic and social strata. Breast cancer is detected more often in the upper social strata, while the cervix into the lower. Generally, mortality from malignant tumors appears to be directly and strongly related to lower socio-economic status, chronic psycho-social burden and suffering situations such as unemployment and poor living conditions (Toundas, 2001). It has also been well documented that most cancers (i.e. lung, colon and breast) affect people with poor socio-economic status who have less access to health services, resulting in insufficient prevention, late diagnosis and improper treatment (Ministry of Health, 2008).

Socio-economic factors are crucial regarding both the appearance and the early diagnosis of breast cancer thus influencing the effectiveness of treatment in as much as psychosocial and vocational rehabilitation. For this reason contemporary health policies tend to take into account the social-psychological effects and the economic dimensions of breast cancer. These policies, at both European and national level, despite the very serious problems arising from the current economic crisis, aim to increase public participation in actions and screening programs. The recent epidemiological data indicate that the mammography screening can reduce mortality of breast cancer in women up to 35% (IARC, 2008).

However, only 40-50% of women, obliged to go through clinical testing for the disease, are controlled. Thus, and due to the high survival rate of the disease, the applied policies aim at managing the consequences of breast cancer. Despite the alarming increase with respect to the frequency of the disease, the improvement of the diagnostic equipments and therapeutic practices contribute to the gradual reduction in the absolute number of deaths. Specifically, mortality from breast cancer is reduced at a rate of 2% per year. These epidemiological data increase the scientific interest regarding the socio-psychological effects and the economic dimensions of survival these women retain (IARC 2008).

It is indicative that "Action 7" of the Greek national action plan for cancer specifically aims to improve the institutional framework and to strengthen the professional and social rehabilitation mechanisms for cancer patients, both the diagnosed and the cured ones (Ministry of Health, 2008). The above action aims to an effective and immediate biographical recovery. Is as well strives to social and vocational rehabilitation of cancer patients, because

although more than 50% of them are completely healed less than 10%, fully return to their former working and social activities (Ministry of Health, 2008).

The previous issues are closely connected to specific economic features that influence the entire social, psychological, cultural and historical patterns in relation to the disease. They are as well combined to inter-personal experiences and the subjective interpretation of health problems. For this reason, the article examines the consequences of breast cancer on the professional re-orientation of these women. It also explores the economic implications and the socio-psychological patterns these women follow. The crucial element is to focus upon every affected person and on the everyday practices these women discover in order to transform their socially, psychologically and culturally “disadvantaged” body into a meaningful source of biographical and professional re-orientation. The management of the disease ultimately leads to a redefinition of the basic life values, within the framework of an energetic and self-reflective social project with an often conflicting content.

2. Method

The fundamental findings of this paper was based on qualitatively empirical research, originally grounded on fourteen biographical-narrative interviews with women diagnosed with breast cancer and mastectomy, aged 45-55 years. It was also based on secondary research on statistics, reports and health regulations regarding breast cancer, on a European and on a national Greek level.

All research participants are enrolled in self-help programs and voluntarily offer practical and moral support in various solidarity groups. Women diagnosed with breast cancer were invited to narrate their life stories. They were strongly informed that researchers were largely interested in the ways they socially experienced and psychologically managed this particular disease (Alexias et al., 2015). The purpose was to examine how the experience of both illness and therapy are connected to biographical disruption (Savvakis and Tzanakis, 2004). Accordingly, we explore the ways this biographical discontinuity is connected to a plethora of economic issues (i.e. work, vocational opportunities, etc) and is related to specific professional re-orientations (Bury, 1982, 1997; Williams, 2001).

Research design roughly followed the general lines of grounded theory and the interviews were conducted in three phases (Strauss and Corbin, 1996). The first phase of research design 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. The

aim was an interactive relation to the research field, which would allow us a more sensitive and open conceptualization and question-posing process.

At the same time, this would take into consideration that participants themselves and professionals as well attribute meaning when engaging in a sociological research (Savvakis and Tzanakis, 2004). During this initial stage, we highlighted specific social parameters as the social and marital status, the educational level and the economic budget. We additionally focused on the patients’ economic, social and psychological needs during treatment. At this phase, we finally conducted participant observation at the aforementioned 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 project included the completion of six biographical narrative interviews and their systematic analysis, extracting the important themes that 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 as above research approach.

The research was conducted mainly in Athens and in the broader geographical region of Attica. The overall project lasted from 2004-2009; consequently it was completed a few months before the emergence of the, still lasting, severe economic and social crisis. The purpose was to understand the way in which the occurrence of breast cancer and mastectomy affects the women’s lives. More particularly, we focused on some economic dimensions of the disease and on the ways it affected their socio-psychological state, their biographical trajectories and their professional orientations.

The sample selection criteria included the existence of mastectomy, as part of a therapy concerning breast cancer, the expiration of a certain period of time after the completion of interventional therapies (mastectomy, chemotherapy and possibly radiotherapy) without the appearance of metastases, the voluntary participation in solidarity and self-help groups, the family status (i.e. marriage and parenthood), the average productivity age (i.e. a decade before or after fifty) and the overall social stratification (i.e. belonging to middle social strata).

Breast cancer forces to a radical rethinking of the body as a whole; its economic capacities, its productive abilities, its socio-psychological state 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 - as well highlights the economic dimensions and the socio-

psychological effects of coping with 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 on a cultural level (Alexias et al, 2015).

Participants were preliminarily informed that interviews would be recorded exclusively for research purposes and declared their agreement. During the overall research period, 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> and <http://ec.europa.eu/euraxess/index.cfm/rights/index>) were applied. All the narrators are protected through the use of pseudonyms. Besides, in this study, triangulation, an attempt to increase reliability and validity of qualitative results, was pursued (Savvakis, 2014).

3. From the Initial Shock to Professional Re-orientation

Regarding the early stage of the disease, namely the "shock situation" we can highlight - based on the overall empirical material - that the majority of patients strive hard to rationalize and attribute a sense of meaning to the occurrence of breast cancer. The participants, in their effort to accept and rationalize the diagnosis of this particular disease, reconstruct the past and consider it as a basic reason for the emergence of breast cancer in the present. This is an effort to assign a sense of continuity to the events of the past, as directly related to the disease.

Thus, the participants report that, before the onset of the illness, they systematically experienced severely traumatic events and endured painful situations. 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 heavily worried about various issues. They furthermore develop anxiety and stress regarding situations that are subsequently assessed as unimportant (Ovayolu et al., 2013).

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 is grounded on a personal inability to retain a happy and self-determined life. The participants demand honesty and sincerity from the medical staff, since they claim that can plausibly deal with and potentially overcome this predicament. We may suggest that the actual knowledge of the medical condition is absolutely necessary and significant. The participants in general propose that only a brave and conscious attitude towards breast

cancer suit women. They support that women energetically demand to have control over their situation. It seems like they stand against an enemy whom is vital to know and meet in order to increase their chances to beat it.

These biographical difficulties lead to a conscious shift: the patients decide that they ultimately want to stay alive. This powerful desire to "stay alive" gradually opens up the space for a transition from a "shock situation" to a struggling one that these women fight to cope with the gap of physical loss (mastectomy). At this second stage (mastectomy phase), the important issue, as derived from the data, is the awareness and the acceptance of the modified body after surgery. During this second 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 is a direct assault to their identity and self-confidence; however, it did not eliminate passion for living and their ability to plan for the future. In our research, it is particularly the existence of the family and the significant others that empower this concrete decision to keep on living. Through the interviews, it is also evident that these particular women seriously review their views on life, revise their goals and set new priorities, including professional re-orientation.

It is often remarked that women with mastectomy abandon their work because of physical weakness, particularly if this task requires manual work. This happens because of the dysfunction merely caused by the surgery to remove lymph nodes. In our research is evident that this choice is directly linked to the way in which the appearance of the disease is justified. Moreover, changes over the body are interpreted as part of an overall re-orientation of life projects and plans. Consequently, some typical alternatives emerge, which incorporate an altering professional perspective in a new biographical re-constitution. In what follows the analysis shall focus on three typical energetic types of professional re-orientation, as these were recorded in our research.

3.1 Retirement form Work

Withdrawal from work can be total or partial including even household and everyday shopping. This alternative can be passive and be characterized by a sense of powerlessness because of objective physical difficulties. These options, however, can be associated with an interpretative scope through which the appearance of the disease is explained, namely as a consequence of the lack of self-caring over the body. Thus, withdrawal from work may not exclusively be passively and connected to a "weak" body. It might as well be - especially in these cases

where work is replaced by alternative caring activities of the self and the others (yoga, participation in self-help groups, gymnastics, artistic activities, etc.) – quite energetic, voluntarily and enthusiastic.

The following extract from Mary is indicative:

After cancer I stopped working and it was something that was my choice. Why was my choice? I thought it is better to sit home to look after my children and do things without stress, because when you work and have a family you are constantly in a state of doubt whether to find time for household. And I was just a little bit strict in the way I did things. So I wanted to chill, to stay home, and do what I wanted to do. And what I wanted was to take care of my family. I liked very much to take care of my children, my husband.

In this case, housework acquires a moral dimension that did not previously retained, associated with a reorientation of values and a serious reevaluation of what is meant as essential to life.

3.2 Reassessment of Job Opportunities

However, the job prospects are often coupled with the assessment that the “harmed” body is affected and an adaptation should occur according to new conditions. In this case, as well, the adjustment may be rational aiming to actively prove that the “infected” body remains quite able to meet current and demanding conditions.

Joan is a characteristic example who manages the household simultaneously taking good care of her image towards her beloved ones:

I did not demonstrate that I was unable or depressed, that I could not do my work like I did it in the past. I was trying not to show it in order not to influence them, my family. I did not want them to think: look how our mom and husband ended up, in all the social roles to say so. I did not show it and I continued my life as before, as I could. Of course, there were some minor differences because as I said, I could not lift weight, was medically prohibited, I could not shake the clothes or the carpets outside. Of course I got used to it

(laughs) and gradually I did what I could do; however, I continued my life as before with some minor changes.

It is, in other cases, also often that household in combination with the previous profession take the form of the last line of defence in maintaining a positive and healthy image of the self.

Gogo accounts on this:

What helped me was the fact that I was alone and on my own in the house, I had no mom, I had no aunts, and I had no brothers or sisters. It was just my husband and I. During the chemotherapy an aunt of my husband was visiting me [...] with some friends and came and helped for two days. During the other days I was on my own. This did good to me because I had no time to play the sick-role, vomiting and so on. It was just impossible to think of chemotherapy and side effects since I had to feed my children.

3.3 Professional Re-orientation

In some cases of heavy surgery, patients are entitled to a low disability pension but as a consequence it is forbidden to work. However, it is normal, as this was reflected in our research, to supplement their income by additional part-time professional occupations, which are “black”, non typical, due to legal restrictions. In other words, profession is both a means of income support and of empowering a “damaged” self-image.

As Vivi reports:

I now get a disability pension that binds me, for I cannot work. I just do odd and part-time jobs whenever I can, without IKA (Institution social security), without anything because it is forbidden due to this disability pension.

A professional re-orientation is very common feature in our research. The example of Miriam is indicative of a typical choice. This professional strategy is adopted either de facto due to infirmity or it forms an explicit objective of policies aiming to vocational rehabilitation. Miriam had problems in her work because it was linked to operating hospital machines. However, she changed her professional direction and started writing of poetry and reports, a shift heavily assisted and supported by her colleagues.

Her account is as follows:

I was extremely helped from my colleagues thus I changed professional direction because I could not operate machines which were difficult to handle. These machines demand some pressure, some rhythm, which I cannot have anymore due to the surgery on my right hand. However, I eventually managed to succeed and to leave the scullery and move towards research. I compensated - and I really do not want to say that I won with my illness - but I account on my everyday life in a better way. Over these years that I have undergone this surgery I have written one or two collections of poems I think, apart from three hundred to five hundred research papers (laughs). I really think that I have taken a great pleasure to from this.

According to this logic, which is part of a typical professional and biographical re-orientation, the modification of working conditions is interpreted as a positive change. This transformation is in line with the new state of the body and is as well desirable to the extent that is assessed as compatible with the new relationship to the self. The interesting element is that this new relationship with the self is directly associated with a modified approach to the others that is far more energetic than the “healthy” past. This acquires sociological significance when this professional re-orientation is transformed into voluntary action and support to groups of peers.

The narrators state that after surgery and proper treatments, they felt an intense need for emotional support. Through participation, they felt stronger and undertook action to provide support to other sufferers. Under this perception, the disease is conceptualized as a new starting point for professional and biographic action. The source of this shift can be detected in the overall experience of the “damaged body” and the “abused breast”. Participants feel obliged to help other women and transform cancer from a source of biographical discontinuity and professional retirement to an inspiration for life.

4. Discussion

The experience of illness potentially acts as a mechanism for individualisation, connecting personal experience with general economic transformations and social developments (Bauman, 1997; Beck,

1999). Increasing complexity in western societies, Greece included, have contradictory effects on how people understand the past, live in the present and plan for the future. The opportunities for individual action seem to be multiplied; however, this takes place on a ground that is constantly characterized by economic uncertainty, social instability and psychological tensions (Giddens, 1991).

Every modern person – and this was evident in our research – is assigned with increasing responsibilities in relation to the organization of his/her life. He/she is as well, almost individually, accountable for the sufficient management of critical issues that affect economic prosperity, social organization and psychological happiness. This contradictory and struggling life project is everyday performed without reference to generally accepted, namely universally, criteria of life evaluation and without a material basis of a steady professional career, at least for a vast majority of people (Burke et. al., 2012).

This has certain results on personal biographies and on collective decisions forcing life to acquire, sometimes mandatory, experimental elements and improvisation. Therefore, every individual is carrying an unprecedented “moral weight”, since everybody, under a certain age, assumes responsibilities which enter the realm of the constitution of subjectivity and management of personal identity. Consequently, she/he is forced to employ new practices of the self, as defined by the late Foucault’s work (Foucault, 2008, 2009). Similar transformations are detected in our research and have already been described in other previous empirical sociological papers, regarding Greek society (Alexias et al., 2012; Serdedakis and Tsiolis, 2000).

More specifically, in our research, participants intend to restore a stable relationship between continuity of the healthy (past) and ill (present) self and body, on economic, social and psychological terms (Henriksen and Hansen, 2009; Katapodis et al., 2005; Facione and Facione, 2006). Breast cancer leads to a dialectical and biographical construction of the past. This meaningful, retrospective, re-constitution project is attempting to heal the personal ruptures and it is, as well, related to the practical purposes of managing the high risks of the disease, on economic, social and psychological level (Bairati et al., 2006).

It is precisely these radical individual changes that participants in our research are forced to go through, due to the experience of biographical discontinuity caused by breast cancer. Women of our sample thematise as “objective” the state of their disease. At the same time, they inexorably link it with individual challenges in all areas (economy, work, family social relationships, psychological stability, political action, etc). This eventually leads to a rational reflection of the capabilities, opportunities and constraints of the “damaged” body within a

particular economic and socio-psychological environment. Experiencing the loss of previous certainties leads to a severe and painful renegotiation of - taken for granted in time and space – general concepts and everyday practices. This process touches fundamental dimensions of existence and influences constitutive aspects of individual identity. Nevertheless, and this is vital, women, their relatives and families do not remain passive within the new situation.

For example, profession, a fundamental economic dimension of modern living, plays a key role in this radical social re-orientation process but does not shape an obvious choice. On the contrary it is dependant, every time, upon a particular social, cultural and economic milieu, which is activated within a framework of existential dilemma. This process is neither one-dimensional nor univocal and it is not absolutely based on voluntarily action or good will. On the contrary, it is a lifetime project grounded on calculations, cancellations and re-orientations. It is an ambivalent process that is materialized through the personal confrontation with social conditions and through interaction with significant others. It is a multifaceted process with different, partial, individual objectives (Serdedakis et al., 2003).

Thus, breast cancer, through this biographical restructuring process and the subsequent re-orientation of economic priorities based on professional re-settlement, produces some positive social results. Actually, it redefines social identity and highlights contribution and engagement as dominant categories of 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 is a project of energetic contribution, deeply rooted in self-help groups, which does not promote a one-dimensional individualisation. It rather constitutes a complex social mechanism, which might lead to new forms of economic exchanges, altered political paths and more psychological features.

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. Voluntary action is precisely a concrete result of this contradictory experience. Medical interventions tend to produce subjectivities that are involved in risk situations that promote new forms of co-existence. The objectification of the body, through medical intervention, is accompanied by a parallel process of individualization and subjectification.

These two elements constitute a practice of the self (Foucault, 2008, 2009) resulting to the development of professional re-orientation, voluntary action and self-help. Through this action, a state of

non-normality (i.e. breast cancer that threatens profession, family, social and psychological stability and life itself) is converted to a mechanism of social integration and economic re-capitulation. This assists, especially after a successful treatment, to the restoration of a positive view that leads to a deep understanding of life and to a paradigm shift.

This transformation is closely connected to a demand for a personalized treatment for each patient. The ultimate goal and philosophy of modern breast cancer treatment, is, as demonstrated, to have a specific treatment for each patient identity and not in general for the diseases. This goal, advocated by applied sociological research, ultimately forms a solid basis for moderate economic costs and for more balanced social and psychological effects.

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