

# Conceptions of quality of life, body and gender among Turkish breast cancer patients



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**Abstract** In accord with the increasing cancer rates, cancer became a highly visible illness, and cancer patients' associations became more active and popular in Turkey. Many of those associations emphasize the concept of "quality of life," and aim at inculcating a holistic and individualistic approach on health. That concept stresses the psychological and social factors, which affect the patients' illness experience, and aims at empowering the patients by suggesting ways to improve their lives. However, the discourse on quality of life, which is shaped by the medical scientists, health care providers and cancer patients' associations, often overlooks the patients' socio-economic status and environmental factors, which affect their illness. Therefore, the concept of quality of life, which recently became popular, has different meanings for different cancer patients,

**Resumo** Na sequência das crescentes taxas de incidência de cancro, esta doença adquiriu grande visibilidade e as associações de pacientes tornaram-se mais ativas e populares na Turquia. Muitas destas associações enfatizam o conceito de "qualidade de vida" e defendem uma abordagem holística e personalizada sobre a saúde. Este conceito realça os fatores psicológicos e sociais que afetam a experiência da doença e pretende capacitá-los, sugerindo-lhes formas de melhorar as suas vidas. No entanto, o discurso sobre a qualidade de vida, elaborado por médicos e outros profissionais da saúde, bem como pelas associações de doentes com cancro, ignora as condições socioeconómicas dos doentes e os fatores ambientais que influenciam a doença. Portanto, o conceito de qualidade de vida tem significados

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depending on their demographic and socio-economic background. For the breast cancer patients with a disadvantaged background, having cancer and a good quality of life creates an oxymoron, whereas the ones with a higher socio-economic status define having a good quality of life as an attainable goal for them. In this work, I will explore how the Turkish women with breast cancer define quality of life, and relate their conceptions of body, gender and health with that concept. My research took place in three different hospitals in Istanbul in order to canvass a broad range of cancer patients in terms of their demographic and socio-economic status. It includes semi-structured interviews with female breast cancer patients on their illness experience and conceptions of quality of life.

**Key words** Turkish breast cancer patients; quality of life; conceptions of body and gender; conceptions on health; patients' associations.

Cancer rates are constantly and rapidly increasing in Turkey since the late 1980s, and that is making cancer a more visible illness in the Turkish society. Similarly, the mortality rates due to cancer have also increased considerably and cancer became the second most lethal disease after heart diseases. The mean age for cancer diagnosis drops to 30s and 40s, and having cancer cuts across different socio-economic groups. Every

diferentes para cada um dos doentes com cancro, dependendo do seu background demográfico e socioeconómico. No caso das doentes com cancro da mama provenientes de meios desfavorecidos, ter cancro e uma boa qualidade de vida cria um óximoro, enquanto as pacientes com estatuto socioeconómico mais elevado ambicionam uma boa qualidade de vida. Este artigo explora o modo como as mulheres turcas com cancro da mama definem qualidade de vida e como a relacionam com as suas concepções de corpo, género e saúde. Esta pesquisa foi realizada em três hospitais distintos em Istambul, com o objectivo de angariar uma ampla gama de doentes, no que respeita ao seu estatuto demográfico e socioeconómico.

**Palavras-chave** Pacientes de cancro da mama turcas; associações de doentes; qualidade de vida; concepções do corpo e de género; cidadania biológica.

year around 25.000 people are diagnosed with cancer (The Turkish Ministry of Health, 2010). As a result of these developments, the social and medical conceptions of cancer are also changing, and the cancer patients relate their illness to their social identity and life in different ways. Cancer patients help the society to break the taboos about cancer, which becomes a more visible and discussed illness through the media, the

internet and the new grassroots patients' organizations.

Breast cancer is the most common type of cancer among Turkish women, similar to the United States and European countries (The Center for Disease Control, 2011). Turkish women with breast cancer became more vocal about their illness experiences, and several of them established patients' organizations, which aim at addressing the personal problems related to the illness and inform the society about cancer. Those grassroots organizations, which benefit from the media and the internet, are different from the more formal cancer associations, which are founded and directed by medical doctors. The patients who are actively working in those organizations often challenge the existing medical and social conceptions of cancer. Therefore, their organizations can be evaluated as an attempt to create a new concept of citizenship based on a biological condition, which can be named as biological citizenship, a term used by Adriana Petryna (2002). In this paper I will explain why biological citizenship and breast cancer patients' organizations, which are established within that framework, are vital to the patients, especially to the ones with a disadvantaged socio-economic background.

The health scientists throughout the world often use the concept of quality of life in their research, since it can be easily

measured through several standardized tests, and it allows cross-cultural comparisons of the health conditions of people with specific illnesses, such as AIDS and cancer, in different countries. The concept includes a more holistic conceptualization of health, where the patients' psychological and social problems are considered equally important as their physical problems. However, despite its practicality and broader conception of health, social scientists rarely use this concept and some of them are skeptical about it, since it is based on the neo-liberal, Western view of human beings, according to which people fully pursue their rights to know about health issues, to assess various risks and make the best decisions on their health by themselves. Therefore, the common claim that quality of life is a universal and value-free concept is invalid (Kaufman and Morgan, 2005). In accord with these problems, the social scientists prefer to use qualitative methods and interview people to understand their own subjective meanings, definitions and evaluations of quality of life, along with the quantitative methods (Jacobson *et al.*, 2006).

In addition, social scientists also find the health scientists' efforts to popularize this concept as problematic in the sense that it takes health as a matter of individual responsibility rather than a major human right, as it is stated in the charter of

the World Health Organization as early as in 1948 (Mann *et al.*, 1999). Accordingly, it is up to people to live their healthiest life, even though they may suffer from poor living or working conditions and experience problems in access to medical care or in interacting with the health care providers. The issues of poverty, inequality, genetic conditions and environmental health are downplayed during the process of popularization of the concept of quality of life, because this process takes place in a rather simplistic and discriminatory way.

Recently, the Turkish medical scientists, especially the public health specialists, oncologists and nurses, began to focus on the concept of the quality of life in their studies, especially when they do research on people with chronic diseases, such as cancer. They also try to create an awareness of the concept of quality of life in society, so that the “lay people” do their best to improve their quality of life in terms of health and sickness. As an anthropologist who shares the above mentioned concerns about the concept of the quality of life, I aim at exploring how the Turkish breast cancer patients attribute their own subjective meanings to that concept and to what extent they find it useful in evaluating their illness experiences.

I interviewed thirty breast cancer patients and survivors, who recently did the cancer treatment, and had five fo-

cus groups with 8-10 women each, in order to investigate how breast cancer patients with different socio-economic backgrounds and ages respond to that concept. I conducted my research in one private and one state university hospital in Istanbul. As a result, among all the patients who participated in my research, only six of them, who were younger (the ages varied between 35 and 55) and had a higher socio-economic background, approached positively to the concept of quality of life. Thanks to their private insurance, those women have the chance to be treated in a private hospital and enjoy a better interaction with the health care providers. They also have an easier access to professional psychological support and to supportive social interactions. From their point of view, having a high quality of life is an attainable goal by maintaining a positive and optimistic attitude towards the illness and the treatments and by trusting completely in the health care providers' professional skills. Those women also had an easier access to the media and the internet, and often followed the news about cancer closely. In contrast, the breast cancer patients with a disadvantaged background emphasize that their psychological and social problems, are even worse than their physical problems related to the illness and the treatments. They were either not familiar with the term “quality of life” or they reacted

against that concept. Having cancer and living a life with a high quality is an oxymoron for those patients, no matter how much they try to be optimistic about the outcome of the treatments. The crowded and chaotic public hospitals and the brief and tense interactions with doctors and nurses also affect their treatment experience negatively, and prevent them to think about their life in relation to the concept of quality.

The patients with a disadvantaged background find that concept rather simplistic and unrealistic. They argue that the doctors impose a certain way of living with a top-down approach, without understanding how the poor and sick people really live. One of those patients, who works in a factory, explains: *"The doctors on TV say that the open markets are the best places to buy fresh fruits and vegetables, but since I work during the day, I go to the market at the end of the day, when only bruised and rotten stuff is left. Those doctors also say that walking in fresh air is good for cancer patients, but they don't know that the air smells like a coalmine in my neighborhood, since we don't have natural gas"*. Four of those patients still have to work despite their ongoing cancer treatment, in order to pay some of their treatment expenses. Although those patients have a State insurance or a green card, which is given by the State to the poorest people who do not have any formal income, it does

not cover all of the expenses, or they don't want to deal with the tedious State bureaucracy.

The most important social problem which the patients with a disadvantaged background complain of is about the lack of social support or an "immense loneliness," in the words of a breast cancer patient in her 60s. Most of those patients' survived their husbands who died earlier than their diagnosis, or their husbands have their own health problems, such as chronic heart diseases, which prevent them from taking care of their wives. Moreover, there is a case of mutual exclusion in this topic, because the women also do not expect their husbands to provide help and support, since they internalized the generalized argument that "men are not expected to take care of sick people in Turkish culture". Most husbands stay away from the hospital, where their wives do their treatments, or in one extreme case, one of the husbands moved to the family's summerhouse during his wife's chemotherapy sessions, which lasted two months. If the husbands help, they do the light chores, such as using the dishwasher, or do "manly" activities, such as driving their wives to the hospital. As for those women's children, the women are sometimes reluctant to even share the diagnosis with them, since they do not want to affect their studies, and the children are often too busy with their ac-

tivities to help and support their mother. The female relatives, such as sisters and cousins, friends and neighbors provide the most help and support, but even in that case, they often do not know how to react against the patients' illness narratives. They either feel pity for the women or understate their physical and psychological problems, by saying, for instance, "You will be fine soon, don't worry" or "Oh, I have a headache too," and both type of reactions cause the women to be reluctant to share their problems with people around them.

Most of those women do not have much access to the newly established grassroots organizations, since the information about them can be mainly on the media and the internet, which they do not have much access to. Moreover, some of the organizations are based on private hospitals, which are rarely attended by the patients with a disadvantaged background, because of their monetary problems. Most of those women also evaluate having professional psychological support as a taboo, and they avoid having it, despite their psychological problems and social isolation, since they associate having this professional help with having a major psychological disorder, such as schizophrenia. The social isolation of elderly, disadvantaged breast cancer patients also stem from their routine physical problems related to the illness and the treatments, such as pains,

fatigue and nausea, and their economic impoverishment. Despite having insurance, all the extra treatment expenses of patients, which accumulate gradually during the long-term treatment, lead them to use all of their savings, which they have for their children's education, home improvement, or vacation and travelling plans. Because of their physical and economic problems, those patients go out and socialize much less, and rarely do the activities they enjoy such as shopping or go to a restaurant with their friends.

The patients with a disadvantaged background also reacted to the word "quality" saying that a poor breast cancer patient can have no such thing as "quality" in her life! For them, the words cancer and quality create an oxymoron when they are used together in relation to their own illness experience. One patient, who cleans houses for a living, talks about this contradiction in terms: *"When I think about quality, the first thing that comes to my mind, is a brand new washing machine, which is made in Germany. It works perfectly, it is rarely broken, and even if it is broken, the technicians come and repair it easily. In contrast, I feel like an old and broken washing machine. Instead of technicians who fix the German washing machine, the doctors deal with me for months now, and I have no clue when or whether I will be cured".* As this quote suggests, the uncertainty about the cancer treatments' effective-

ness also affects the patients' quality of life, since the patients cannot figure out whether the illness or its treatment cause those problems. The majority of Turkish breast cancer patients who do the surgery lose one or both of their breasts soon after the diagnosis, and they complain of nausea, fatigue, pain and weight gain which occur often during the treatment procedure.

### **The breast cancer patients' strategies in coping with their problems**

In order to deal with the uncertainty and other emotional problems related with the loss of a breast, many cancer patients often conceptualize their body or body parts in technical terms, and compare it to a machine. Besides that washing machine example, another patient talked about her body as a car, and her breasts as the car's headlights. She said that one of her headlights was broken after her breast removal surgery. The technical references that the patient invented, provide them with an emotional distance and also with an opportunity to produce an alternative discourse to the medical one. Additionally, Turkish breast cancer patients often talk about their breasts or removed tumors referring to fruits, vegetables and nuts, as part of their efforts to normalize what they are experiencing.

When compared to a cucumber or a walnut, the tumor becomes a more mundane, familiar and understandable entity rather than a scary and uncanny medical issue. One of the patients referred to her tumor removal as carving out the rotten part of an apple and claimed that thinking in those terms comforted her because it made her understand the surgical process better. However, she also felt uncomfortable, since she couldn't relate her radiotherapy experience to the apple metaphor. Again, another patient from a higher socio-economic background, referred to chemotherapy using a term she is more familiar with, as Camel Trophy, in order to emphasize its side-effects, tiredness and nausea, which are very difficult to cope with.

These technical and mundane references also help breast cancer patients to cope with the excessive medicalization of their daily life, and reclaim the ownership and control over their bodies. Independently of their socioeconomic and demographic background, the patients I interviewed often complained about how their body no longer belongs to them, but it belongs to the medical realm after the diagnosis. A patient, who is also a businesswoman in her fifties, explains that doctors do whatever they like to her body, and she cannot argue with them, since she can understand what is going on in her body only through the doctors' explanations. She described that

process in the following words: *"My body doesn't belong to me anymore, it belongs to cancer and doctors who fight with cancer. My body is like a war zone between cancer and doctors, over which I have absolutely no control"*. This excessive dependence on doctors and medicine disturbs many cancer patients, and that is why, through their illness narratives, they are trying to create an alternative discourse than the imposing medical one. Several patients also argued that they lost the control over their lives, most of which spent in the hospitals for various types of treatment, because of their physical problems and frequent visits to the hospital.

Secondly, the breast cancer patients try to control the effects of cancer on their bodies and lives, based on the decision about the amount of medical knowledge and discourse they will acquire and internalize. Most women in their thirties and forties, who often had an early diagnosis of cancer, claim that they want to learn every detail about their illness through the media, the internet and the discussions with doctors. They added that reading and talking about cancer is like a psychological therapy for them. In contrast, the older women who often had a late diagnosis of cancer avoid learning too much about their illness and argue that it is the doctors' job to know about cancer. They are also more resistant to the medical language and discourse, and try to come up with their own expla-

nations. In doing that, they challenge the cancer's taboo character and face the illness which is often associated with death in the Turkish society, despite the doctors' counter arguments about how the early detection of cancer saves lives. Moreover, in accord with the socio-economic inequalities, which prevent people from equal access to health care, many patients with a disadvantaged background cannot have access to adequate medical information, even if they need it. Their only opportunity for that is mostly the brief and tense interactions with doctors and nurses in the crowded public hospitals, and they try to fill the gaps in that information through the other patients' explanations, sensational pieces of news in media and their limited access to the internet. Therefore, the access of these patients to the newly established patients' organizations is crucial since they create a less hierarchical and pluralistic platform where the patients with a disadvantaged background acquire medical knowledge, and medical and social discourses on cancer can interact without the existence of barriers. However, this rarely happens since those organizations mostly cooperate with private hospitals.

The third strategy of patients in controlling the cancer's effects on their bodies and lives is to decide with whom and how much to share their illness experiences and illness narrative. The loss of control over their body and life points

to a major rupture in the patients' lives, which, according to the anthropologists Cheryl Mattingly and Linda Garro (2002), can be overcome by re-establishing a sense of continuity through creating and sharing a particular illness narrative based on each patient's experiences. These authors argue that creating and sharing an illness narrative are the first steps of healing for the patients, both in psychological and physical terms. Generally, the younger breast cancer patients with a higher socio-economic background have more people around them while the elder patients with a disadvantaged background often complain about loneliness. They said that they feel discriminated by the doctors and nurses in the public hospitals because of their socio-economic status, and, as explained above, that they lack adequate psychological support outside of the hospital context as well. They explained that the younger people around them are too busy with their studies or work, and the older people have their own health problems. Despite their complaints about loneliness, being self-sufficient is also a matter of pride for those women, since it also proves that they are not too poor or too sick to take care of themselves. They emphasize the importance of being strong and independent during and after the treatments, or at least doing their best to be like that, since it means that they are "winning the battle against cancer" for the time being,

in accord with the war metaphor Susan Sontag (1979) conceptualizes, which is also very popular in the Turkish health realm. They also suggested that having cancer lead them to achieve a new wisdom and achieve a better self in order to recompense their damaged body and interrupted lives. They emphasized that cancer taught them to evaluate what happens in their lives from a new perspective and not to care too much about minor problems, which do not affect their lives and health much in the long run. They also became more selective in their social relations, and maintained their friendship only with people who supported them during their treatments.

### **Breast cancer patients and biological citizenship**

Most breast cancer patients state that they can share their illness related problems only with the other breast cancer patients whom they met in the hospital. Again, they also feel the need of a patients' organization where they can express their problems as much as they want and find solidarity as a response. Breast cancer patients argue that their illness attacks their womanhood, since it leads to the loss of one or two breasts and hair during the treatments. In the case of younger patients, it

also leads them to delay their pregnancy plans for several months or even years during radio and chemotherapy. In order to cope with all the changes, those women often redefine their womanhood and motherhood, and emphasize that despite the cancer's attack, they try hard to prove to themselves and to the others that they do not have anything less than other healthy women. They develop certain strategies for that, such as learning new make-up techniques, buying natural looking wigs and changing the way they dress in order to look more feminine. They emphasize the social and cultural aspects of motherhood rather than the biological ones, by telling the young women in their family and social environment to have regular gynaecological check-ups and breast examinations in order to avoid breast cancer, and, in some cases, taking women to the doctor for that purpose. They become the unofficial spokespersons for breast cancer and warn every woman against it in "a quite motherly way" in their own terms. Independently of their age and socio-economic status, those women view being feminine and motherly as giving a public message about their health, body, gender and sexuality through their looks instead of having superficial worries. Moreover, by publicly discussing the most intimate and private aspects of their illness, they break the taboos about it, which made it impossible

to even utter the disease's name or talk about it in detail, since that is considered as "inviting the illness."

The grassroots breast cancer patients' organizations, which were founded in 2000s are the best places for the patients to create and share their illness experiences with other patients, as well as to collaborate to find strategies in coping with the physical, psychological and social problems caused by their illness. In contrast with the formal patients' associations, which are often founded by doctors, are based in hospitals, and which have a hierarchical top-down approach towards the patients, in these newly organizations, the patients dominate. The patients plan and organize various activities and try to reach as many people as they can, and also determine which medical experts they will invite to their activities and how they will benefit from that expert. Therefore, these organizations are more flexible, informal, pluralistic and radical than the institutional associations. They can be evaluated according to the concept of biological citizenship, which was first coined by Adriana Petryna (2002) and theoretically elaborated by Nikolas Rose (2007). The term biological citizenship is based on Foucault's concept of biopolitics which indicate the policies that are established and implemented in order to discipline, control and regulate a certain population's health condition. Several institu-

tions, such as governments, schools, hospitals and asylums, are involved in this process of defining who is “healthy” or “unhealthy” and “normal” or “abnormal” through newly established medical categories, charts, reports and statistics. Although Foucault referred to those policies in relation to the political and social dynamics in Europe in the late 18<sup>th</sup> and 19<sup>th</sup> centuries, the same policies are also dominant throughout today’s world (Rabinow and Rose, 2006). Nikolas Rose (2007) discussed the concept of biological citizenship in order to show how the hierarchical, top-down approach of biopolitics is negotiated and resisted by the lay people who want to contribute in shaping policies and discourses on the issues of health and illness with respect to their own perspectives and experiences.

Adriana Petryna (2002) used this concept to refer to the victims of the Chernobyl nuclear accident, who developed a new political and social identity, based on their biological condition of being exposed to radioactivity. Those victims demanded both discursive changes in terms of creating a new awareness about the Chernobyl accident’s effects on people’s health, and practical ones in terms of changing policies and demanding monetary compensations from the State. Nikolas Rose (2007) argued that the concept of biological citizenship is not only valid for the Chernobyl victims, but also for many contemporary grassroots

patients’ organizations that demand discursive and practical changes, such as the organizations of AIDS patients and the patients with genetic diseases. In this respect, the recently formed Turkish breast cancer organizations can be viewed as examples of biological citizenship, since they want to change the social and medical discourses on breast cancer by breaking the taboos about the disease and creating a new awareness about cancer and cancer patients. They also want practical changes, such as the increase in the coverage of the State insurance, especially for such surgeries as breast reconstruction, which is not merely a cosmetic detail as some people put it, but an essential part of the woman’s body integrity.

Through these patients’ organizations, the women help each other in fundamental issues and, for instance, provide advice about where to find natural looking wigs or silicone breast paddings to fill their bras. These organizations, which are mostly attended by the women with a higher socio-economic background, provide a platform where the patients can discuss a wide range of issues that they cannot discuss freely in a hospital setting, such as alternative or complementary medical treatments or ethical codes of internet chat and dating. Despite their democratic environment, I also observed that, in accord with the argument stated above, the interpersonal relationships

in these organizations follow a pattern similar to kinship, and the elderly patients behave in a way quite motherly to the younger ones, and they are being rather protective towards them. They often advise the younger patients on how to cope with the cancer and cancer treatments, and the younger patients accept this motherly attitude as long as they are not oppressive or intrusive.

Similarly, there is also a rather friendly competition with respect to who suffers more during the treatments and who copes better with cancer, as a woman in her fifties emphasizes: *"I said I never cried when I lost my hair after my first chemotherapy and I saw everyone in the group staring at me in a disbelieving and envious way. When they questioned me on that I told them that a friend of mine, who also had cancer, gave me the address of a store that makes great looking wigs, and thanks to her, I went there right after I lost my hair and solved that problem quickly without too much emotional drama. Then after our conversation, two young women from the group approached me in private, asked me the name and address of that store, and I helped them."* However, some tensions also develop within these groups, especially when the women compare the amount of support that they get from the people around them. A patient in her thirties explains: *"Some more traditional women expect that their daughter in law should take care of them fully during their*

*cancer treatments, but even though some of those young women do not work, they have a family and a life of their own too! Those women think that it is acceptable to complain constantly about their daughter in laws in our group, since many of those women are elderly and have married sons, but I honestly want to hear more of their cancer experiences than how their daughter in law neglects them. . . I don't even think that is true since I know that some of them always go to their treatments with their daughter in laws!"*

Despite these issues, the patients experience a communal empowerment by forming networks of help, advice and solidarity, and organizing social activities, which contribute to create a new awareness of cancer and cancer patients in the Turkish society. A woman in her sixties narrates: *"In this group, I learned that I can have a fulfilling social life despite cancer. My social life now involves laughing about how other, healthy people see us, crying about our suffering and sharing our most intimate secrets about the losses brought by cancer, and we do this all together. In addition, I see people who suffered much more than I did, but still remained strong, and those people really inspire me to be like them. So what else can I want from a cancer patients' organization? (She laughs)."*

The existence of these organizations is crucial not only for the patients' efforts to cope successfully with their illness, but also for the whole society, in terms

of breaking the taboos about cancer. The patients often mentioned that the people around them became surprised to see how they became a much happier and psychologically stronger person who can talk about their cancer more freely after they joined those organizations. Compared to hospitals, the organizations also provide less hierarchical platforms for the interactions between doctors and patients. The patients invite doctors or psychologists only to some of their activities, and the participating patients determine about the role of these experts in the activities, such as moderating the conversation, giving a talk on a specific issue and answering the patients' questions. It thus becomes clear that it is very important that these organizations increase in number and be more pluralistic in order to reach many cancer patients from different socio-economic and demographic backgrounds. In fact, they try to reach the elderly patients with a disadvantaged background, who have less access to the media and the internet, and some of them cooperate with the municipalities for that purpose.

To conclude, I argue that the concept of biological citizenship should be carefully analyzed in addition to the concept of the quality of life in order to understand the breast cancer patients' illness experiences and narratives, particularly with respect to the issues of body and gender. The concept of biological citi-

zenship is more helpful to explore the patients' social interactions and their identity rather than a limited and individualistic perspective of the quality of life, as it is popularized in Turkish society. The concept of biological citizenship also has the potential to embrace the experiences of people from all ages and backgrounds, in contrast to the concept of quality of life, which is more meaningful for the younger people with an advantaged background, a better access to the media and the internet, and a more medicalized everyday life.

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