

An Overlooked Group in the Psychosocial Care in Breast Cancer: Spouses

Meme Kanserinin Psikososyal Bakımında Gözden Kaçırılan Kısım: Eşler

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Abstract

Breast cancer directly affects women physically, psychologically and socially in the process of diagnosis, treatment and post-treatment, leads to the deterioration of psychosocial adaptation, and affects the family and social relations negatively. The family, which is an important source of support in the breast cancer process, can face the same psychosocial troubles with women. The results of the research show that the most preferred source of support in families is spouses and their quality of life is lower than the other family members. Psychosocial care which is biasedly solely canalized to women by the healthcare professionals often overlooked their spouses, and leads to be received inadequate support by them. In this context with the awaring of the psychosocial problems spouses facing, it is important to include spouses to psychosocial care which healthcare professionals provide to women with breast cancer. In this article, it is aimed to raise awareness about psychosocial problems experienced by the spouses of breast cancer patients as a mostly neglected group and possible interventions.

Keywords: Breast cancer, spouses, psychosocial care.

Öz

Meme kanseri; tanı, tedavi ve sonrasındaki süreçte kadını fiziksel, psikolojik ve sosyal açıdan doğrudan tehdit ederek psikososyal uyumunun bozulmasına, aile ve sosyal ilişkilerinin olumsuz yönde etkilenmesine neden olabilmektedir. Meme kanseri sürecinde önemli bir destek kaynağı olan aile, kadın ile birlikte aynı psikososyal sıkıntılar ile yüzleşebilmektedir. Araştırma sonuçları, aile içerisinde en çok tercih edilen destek kaynağının eşler olduğunu ve diğer aile üyelerine göre yaşam kalitelerinin daha düşük olduğunu göstermektedir. Sağlık profesyonelleri tarafından önyargılı bir şekilde sadece kadına yöneltilmekte olan psikososyal bakım, eşleri sıklıkla göz ardı etmekte ve yeterli desteği alamamaları sonucunu doğurmaktadır. Bu bağlamda sağlık profesyonellerinin, eşlerin yaşamakta olduğu psikososyal sorunların farkında olarak meme kanseri olan kadınlara sağladıkları psikososyal bakıma onları da dahil etmeleri önemli olacaktır. Bu makalede, çoğunlukla ihmal edilen bir grup olan meme kanserli hastaların eşlerinin yaşadığı psikososyal sorunlar ve yapılabilecek müdahaleler konusunda farkındalık geliştirilmesi amaçlanmaktadır.

Anahtar sözcükler: Meme kanseri, eşler, psikososyal bakım.

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BREAST CANCER is the most common type of cancer in women both in the world and in our country. Breast cancer, the fifth most common cause of cancer-related deaths, appears to be in the first two together with lung cancer as far as women are concerned (Ferlay et al. 2015, American Cancer Society 2017, Şencan and Keskinlik 2017). Breast cancer, which affects the physical health of the woman in the diagnosis, treatment, and post processes, impairs psychosocial harmony of women by leading to psychological problems such as physical adjustment problems, anxiety, depression, hopelessness, fear of death, helplessness as well as problems with body image and sexuality and occupational and economic problems (Çam et al. 2009, Karakoyun-Celik et al. 2010, Aguilar Cordero et al. 2015, Chen et al. 2016, Jakobsen et al. 2017).

In this difficult process, family is one of the support mechanisms that help the woman with breast cancer to heal and adapt to the disease (Arora et al. 2007, Cebeci et al. 2012). However, the psychosocial problems that emerge with breast cancer lowers the life quality of women (Karakoyun-Celik et al. 2010, Cebeci et al. 2012, Curtis et al. 2014, Fonseca et al. 2014,) and leads to some interfamily problems and deterioration in family and social relationships as it adversely affects spouses, the family and close relatives (Çam et al. 2009, Tiryaki et al. 2010, Babaoğlu Akdeniz 2012, Yusoff et al. 2012, Neris and Anjos 2014, Aguilar Cordero et al. 2015, Chen et al. 2016). At every stage of illness, family also faces the same psychosocial problems together with the women (Baucom et al. 2009, Kraemer et al. 2011).

It is known that the primary care giver to the women with breast cancer is mostly the spouses. However, studies have shown that spouses who play a key role in the adaptation of women to the disease also have a lower level of life quality compared to the other family members (Fergus and Gray 2009, Lopez et al. 2012, Li et al. 2013, Segrin and Badger 2014, Borstelmann et al. 2015). Spouses who most experience the psychosocial problems that breast cancer leads to (Fletcher et al. 2010, Hasson- Ohayon et al. 2010, Silva et al. 2010, Avci and Kumcagiz 2011, Nasiri et al. 2012, Yusoff et al. 2012) are often neglected within the healthcare system (Hoga et al. 2008, Neris and Anjos, 2014). Studies have revealed that spouses try to deal with the disease-related problems individually, that they cannot receive adequate support, and that they suffer emotionally, psychosocially and physically (Hasson-Ohayon et al. 2010, Bigatti et al. 2011a, 2011b).

With the prejudice that breast cancer and the problems it causes only affect women, healthcare team are anxious to provide the psychosocial care directly to women (Neris and Anjos 2014, Kauffmann et al. 2016). However, it is known that these problems are not only experienced by women but also their spouses who share the experience of having cancer and who, thus, are affected negatively and need psychosocial care and support (Chung and Hwang 2012, Çömez and Karayurt 2016).

All health professionals have important duties so that women and their spouses can cope with the problems they experience in this process (Hoga et al. 2008, Remmers et al. 2010, Kauffmann et al. 2016). Psychosocial care provided by health professionals to women with breast cancer should also cover the spouses, addressing their psychosocial issues and needs. This study aims to raise awareness about the psychosocial problems experienced by the spouses of breast cancer patients as a mostly neglected group and about the possible interventions.

Role of Spouses

The family, who experience the disease-related problems with women, is the support mechanism that provides help to the women with breast cancer and contributes to the healing process (Arora et al. 2007, Borstelmann et al. 2015). It is known that patients living alone have worse psychosocial adjustment than those living with their wives and/or children (Çam et al. 2009). Research results show that the most important and preferred support for the women with breast cancer is the spouse (Kraemer et al. 2011, Borstelmann et al. 2015). Research has further indicated that women who receive the support they expect from their spouses have higher levels of psychosocial adaptation during the pre, while and post disease processes and they can cope with the disease more effectively (Fergus and Gray 2009, Tiryaki et al. 2010).

Spouses, who are the most important, preferred, and sometimes the only source of family support in the process of diagnosis, treatment and post-treatment, bear the burden of care that the community has attributed to them and which he believes he must do (Fergus and Gray 2009, Lopez et al. 2012, Li et al. 2013). Adaptation problems experienced by spouses, who struggle to cope alone with the consequences of the illness and who suffer from the difficulties of caregiving and due to the feelings of unpreparedness, may lead the family into a dead-end and may create a vicious circle by negatively affecting the couple relationship (Hocaoğlu et al. 2007, Fletcher et al. 2010, Kraemer et al. 2011). The results of the study conducted by Tiryaki and colleagues (2010) with 25 husbands whose wives had unilateral mastectomy show that they had high levels of anxiety and depression. In the light of that study and the literature, it may be argued that spouses are a very significant source of support for the patients during the diagnosis, treatment, and post-treatment processes. On the other hand, they also need support due to the heavy burden of caregiving and various psychosocial problems (Hasson-Ohayon et al. 2010, Çömez and Karayurt 2016).

Psychosocial Problems of Spouses

The diagnosis, treatment, and post-treatment processes of breast cancer are considered to be a threat both for women and their spouses. Spouses, who share the same experience with women, have physical problems resulting from the whole process and also anxieties over uncertainty about the future, the risk of recurrence of the disease, and the fear of losing their wives (Zahlis and Lewis 2010, Neris and Anjos 2014, Çömez and Karayurt 2016). Not knowing how to give care to their wives and feelings of inadequacy to support them increase their anxiety level and lead to feelings of guilt (Zahlis and Lewis 2010, Yusoff et al. 2012). The results of the study conducted by Lewis and colleagues (2008) to examine the predictors of the depressive mood of the spouses of patients with breast cancer reveal that spouses who felt unsure of the well being of their wives and who experienced uncertainties about their work performance and future show more depressive symptoms.

Fear of losing wife is triggered more often when spouses, who put effort to reestablish the family balance alone, realize the importance of women's role as the mother and the house manager. This situation increases their anxiety regarding household care and their future. Physical weakening of women particularly during the treatment process leads to imbalance at home and increases the responsibilities of men as they have to

assume the roles of the women as well. The increase in the roles played and the changes experienced may be a challenge for spouses (Silva et al. 2010, Bigatti et al. 2011a). In their study, Bigatti and colleagues (2011a) found that spouses experience role challenges with respect to sexual, professional, domestic and family relationships, with more challenges in roles related to social environment. In addition to the caregiver role, the new roles spouses assume regarding home and child care increase the burden on their shoulders, they start not taking enough care of their own roles and personal needs, and they may even experience economic problems as they lose their job. In a qualitative study by Silva and colleagues (2010) conducted with the spouses of patients who had mastectomy, one of the spouses stated that: *"I did everything right, as it should be, you know. I made all the arrangements. I felt that I must take care of her better than before. And I still do. I dedicated myself to her. I accompanied her on surgery, biopsy, examination, chemotherapy and radiotherapy days, I did everything necessary. I quit my job not to leave her alone."*

Alongside the changing family balance and the accompanying problems, mastectomy, which is frequently used in the treatment of breast cancer, brings with it many troubles that concern women and therefore the spouses. Some of these complaints stem from the unrealistic beliefs of couples about mastectomy, which are gathered under the name of mastectomy stigmatism. As a result of the surgical operation and consequently because of the changing body image perception and femininity and sexuality perception, women believe that their partners will evaluate them as inadequate, and thus they have difficulty establishing intimate relationships (Uçar and Uzun 2008, Freysteinson et al. 2012, Andrzejczak et al. 2013, Yıldırım and Batmaz 2013). On the other hand, spouses believe that they should subdue their sexual desires as they feel their wives may feel uncomfortable because of the wound site, they may feel hurt, and they may both lose their interest in sexuality (Silva et al. 2010). They also believe that they need to reassure their wives that they still love them and find them attractive despite the marks created by mastectomy (Zahlis and Lewis 2010). As having cancer is associated with death, the spouse who has the fear of losing his wife feels the necessity to support his wife more as he is also worried that their relationship will deteriorate due to mastectomy (Odigie et al. 2010, Avci and Kumcagiz 2011, Freysteinson et al. 2012, Andrzejczak et al. 2013). However, the worries they experience and the necessity to continuously show a protective and reassuring attitude may make them uncertain about how to treat their wives, may cause them to avoid contact or to be emotionally closed (Okanlı and Ekinici 2008, Zahlis and Lewis 2010). This situation, that is, the lack of information created by unrealistic beliefs and the naturally impeded communication leads to a decrease in the mutual sharing of the couple (Baucom et al. 2009, Kauffmann et al. 2016), causing deterioration by interfering with the sexual life and marital adjustment of the couple (Fobair et al. 2006, Helms et al. 2008). In their study, Kinsinger et al. (2011) report that perceiving the support from spouses as adequate plays a key role in the sexual satisfaction and marital adjustment of the women.

In the process of cancer, in which social support plays a very important role, the inability of the spouse to share feelings and thoughts clearly with his wife, and thus the inability of the woman to perceive the support that she expects may lead to feelings of anxiety, tension and anger (Fergus and Gray, 2009, Segrin and Badger 2014, Borstelmann et al. 2015). The study conducted by Okanlı and Ekinici (2008) on patients with

mastectomy and their spouses revealed this fact and also found that spouses repress their anger after mastectomy. In a qualitative study conducted with the spouses of 48 women with early stage breast cancer, Zahlis and Lewis (2010) found that in order to avoid conflict, protect their wives and other family members, and to remain strong, spouses repress their real feelings instead of sharing them with their wives or others. Furthermore, Zahlis and Lewis (2010) revealed that some spouses want to share their feelings with others and to receive support, while some spouses withdraw into themselves as they believe nobody will understand them or they do not want to open up their feelings.

The feeling that they need to be strong and/or people will not understand them, or the inability to express emotions clearly to avoid conflict increases the psychosocial problems that the spouses experience and reduces the satisfaction they get from life (Odigie et al. 2010, Bigatti et al. 2011b, Chung and Hwang 2012, Nasiri et al. 2012). The results of the study conducted by Bigatti and colleagues (2011a) indicate that when the spouses of women with breast cancer mainly use avoidance attitude as the coping strategy, it means that they have high levels of perceived stress and depressive symptoms. The results of the study further reveal that spouses have higher levels of psychological distress, anxiety and depression compared to their wives (Hasson-Ohayon 2010, Bigatti et al. 2011b, Duggleby et al. 2012). In their study conducted with 150 women with breast cancer and their spouses, Hasson-Ohayon and colleagues (2010) found that compared to the women with breast cancer, spouses defined more distress in the dimensions of psychological distress, anxiety and depression. Also, Fletcher and colleagues (2010) found that the spouses of women with breast cancer show more depressive symptoms.

As these studies reveal, psychosocial problems associated with breast cancer are experienced not only by women but also by their spouses. Spouses, who bear all the burden with the instinct to protect their wives and other family members, are overwhelmed by the intensity of the caregiver role, but at the same time, they force themselves to remain strong (Hocaoğlu et al. 2007, Yusoff et al. 2012). The spouses, who from time to time need to stay alone, to refresh themselves, to feel relieved and to breathe by sharing their emotions and thoughts with a person or with God, are on the other hand disturbed by their time away from their wives thinking that they have too many things to do (Zahlis and Lewis 2010, Duggleby et al. 2012). Thus, they try to comfort themselves in the short run through some methods such as accepting, ignoring, positive thinking, being hopeful, researching what works, and trying to avoid or stop bad thoughts (Duggleby et al. 2012, Yusoff et al. 2012). However, all these point to the fact that spouses try to find solutions alone to overcome the problems they are experiencing, support mechanisms are inadequate, and they mostly cannot deal with problems effectively and thus they need to be encouraged by being involved in the psychosocial care within healthcare system. A study conducted by Bigatti and colleagues (2011b) showed that spouses of the women with breast cancer had higher levels of depression compared to the healthy control group and that they use problem-oriented coping strategies less. They further revealed that depression experienced by spouses and ineffective coping mechanisms are associated with lower levels of social support. Thus, it is seen that spouses, who try to provide care to their wives without receiving enough support from the healthcare system and who try to deal with the problems that occur

while taking care of their wives alone and who suffer for this reason, need a strong support network (Hoga et al. 2008, Fergus and Gray 2009, Silva et al. 2010, Çömez and Karayurt 2016).

Role of the Health Professionals in Coping with Psychosocial Problem

Breast cancer, which is a family disease, causes the women and their spouses who are overlooked within the health care system to experience some psychosocial problems and also to the deterioration in life quality. Spouses who are sometimes the sole source of social support for women with breast cancer may also need a care receiver role by not being able to tolerate the burden attributed to the caregiver by the society and the inadequate social support (Arora et al. 2007, Bigatti et al. 2011b, Yusoff et al. 2012). In this process, it is important for health professionals to identify problems clearly and correctly and to provide appropriate psychosocial support so that both women and their partners can achieve adequate adjustment (Neris and Anjos 2014, Kauffmann et al. 2016).

Health professionals, who work with patients and interact with them so that patients and their spouses can cope with the problems they experience during this process, should adopt a holistic approach (Hoga et al. 2008, Remmers et al. 2010, Chen et al. 2016, Caldeira et al. 2017, Coyne and Dieperink 2017, Nwozichi et al. 2017). The holistic approach is based on the fact that the individual is physically, emotionally, socially, and spiritually an integral part of the family and the environment in which he lives (Kocaman 2005, McEvoy and Duffy 2008, Papathanasiou et al. 2013). Thus, the holistic care to be given to the women should also involve their spouses who are their biggest supporters. In this way, spouses may also adapt to the processes of this disease. The studies in the literature emphasize that the couples who experience the process of coping with breast cancer together may successfully overcome this challenging process through a successful adaptation process (Dorval et al. 2005, Babaoğlu Akdeniz 2012, Curtis et al. 2014). However, psychosocial care that should be provided in an integrated manner during the breast cancer process is often given only to women and the fact that their spouses also primarily need a care receiver role can be overlooked (Neris and Anjos 2014, Kauffmann et al. 2016). This situation causes couples not to cope with problems effectively and leads to the emergence of other problems in addition to the disease (Fergus and Gray 2009, Bigatti et al. 2011a, 2011b, Kinsinger et al. 2011). It is possible to prevent the problems from getting worse by increasing the awareness of health professionals regarding the problems women and their spouses can experience during the process, by making frequent evaluations with the patients about these problems, and by interfering with the problems determined through evaluations as early as possible (Moireira and Canavarró 2013).

According to some research findings, intervention into the psychosocial problems of spouses yields positive results and increases the life quality of couples within the scope of holistic care principle (Badger et al. 2007, Lewis et al. 2008, Baucom et al. 2009, Kauffmann et al. 2016). For example, the study by Badger and colleagues (2007) conducted with 96 women with breast cancer and their partners through telephone counseling and self-control exercise revealed that the anxiety and depression levels of the women with breast cancer and their partners were higher compared to those in the

control group. Another study conducted by Baucom and colleagues (2009) to improve the relations and functions between the women with breast cancer and their spouses revealed that the couples in the intervention group had better psychological functions and adaptation compared to the couples who received standard treatment protocol, and also, the results of one-year follow up showed that women had higher levels of growth in the post-trauma period. Lewis and colleagues (2008) conducted a study with the spouses of 20 early stage breast cancer patients. The spouses participated in a psycho-training program which was designed to improve the psychological functions, well-being and communication skills of the spouses so that they can better support their wives. At the end of the program, it was revealed that spouses had important improvements in their depressive mood, anxiety levels, skills, self-confidence and self-care. In the same study, the interviews conducted with the patients and their spouses to reveal the changes they went through following the intervention showed that spouses had lower levels of nervousness, while the couples reported that the quality of their relationship improved.

Conclusion

Spouses experience the challenges that breast cancer leads to with women and encounter some psychosocial problems. Spouses, who are mostly overlooked within the health-care system, cannot express their problems freely, and thus cannot receive adequate support, which affects their life quality negatively. It can be said that health professionals are in an important position to help women with breast cancer and their spouses, given the fact that they are trained to recognize the anxieties of the individuals they care during their vocational training and to communicate appropriately using their help skills. Thus, health professionals must be aware that during the cancer treatment process, spouses experience various psychosocial problems together with their wives and that they must thus be a part of care. Health professionals must also plan some activities in order to provide the necessary support. Health professionals may organize many activities regarding the psychosocial problems experienced by couples with the educational infrastructure they have. Some of these activities are determining the problems women and their spouses experience during the process through qualitative and quantitative research, and then conducting training, support and counseling activities regarding these problems, evaluating the efficiency of these activities through research, and improving the content of activities based on the results of the research. Thus, both the women with breast cancer and their spouses receive a holistic and quality care, they can cope with this difficult process more effectively, and they can even strengthen their relationships during the process..

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