

REVIEW ARTICLE

Health-related quality of life of young women with breast cancer. Review of the literature

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Summary

Purpose: The purpose of the present article was to investigate the health related quality of life (QoL) of young women with breast cancer.

Methods: For the purposes of this article, we reviewed the literature via the electronic databases Pubmed, Scopus and Google Scholar. Key words used were breast cancer, young women, health related quality of life, and quality of life.

Results: Young women reported fatigue, pain in the breast and hand problems with lymphedema as the most frequent physical effects of treatment. Other physical problems were the not periodic and painful menses, vaginal dryness and loss of libido. Many young women had depressive symptoms such as depressed mood, helplessness, hopelessness, sleep loss, psychomotor retardation and disorders of appetite. There were often concerns about the health monitoring and self-image, while they were anxious if they will have a

baby in the future or if they can nurture the existing ones. Many problems arose in the career of young women. They faced discrimination in the labor supply and/or layoff because they were considered unable to do their job effectively. In addition, they reported isolation problems and feeling different from other women of similar age.

Conclusions: Young women consider that their health-related QoL is worse compared with older women. Young women worry about their future, with particular reference to their role as mothers and especially to children-bearing. The free screening and non-exclusion of young women is particularly important for breast cancer prevention and women's well-being.

Key words: breast cancer, functionality, quality of life, young women

Introduction

Breast cancer is the second leading cause (after lung cancer) for women's mortality, accounting for 13.8% of all cancer deaths in females. Death rates due to breast cancer adjusted to age for

women have declined since the mid-1980s, showing a relative reduction of 43% from 32 deaths per 100,000 women in 1986 to 18.4 deaths per 100,000 women in 2014 [1]. This is attributed to

the increased use of screening tests, i.e. mammography, combined with the use of targeted adjuvant therapy after surgery [2].

The family history of breast cancer has been recognized as one of the most important risk factors for breast cancer development [3,4]. Mammography has been shown as the most important factor for reducing mortality in the context of screening [5,6]. Women with family history of breast cancer are advised to undergo screening test for breast cancer annually with mammography, clinical breast examination and / or magnetic resonance imaging (MRI) before the age of 50 years [7].

Breast cancer can occur both in men and women, but it is very rare in men. The incidence of breast cancer in men is just 1% [8]. Breast cancer is the leading cause of cancer and the leading cause of mortality from cancer in women worldwide. It is estimated that 1.384 million women were diagnosed with breast cancer and 450,000 women had died of breast cancer globally in 2008 [1]. Breast cancer is the most frequently diagnosed malignancy in women, accounting for 26.1% of all newly diagnosed cancers in women. The incidence of breast cancer has increased since 1990, probably due to the increasing use of mammography as a screening tool [2]. From 1988 to 2004, the rates of breast cancer show fluctuations, probably due to changes in hormonal factors (i.e. age at menarche, pregnancy and menopause, breastfeeding practices, use of oral contraceptives and hormone replacement therapy [HRT]) [9].

Not all breast tumors are malignant. The benign breast diseases are responsible for small changes in the normal breast tissue which may indicate increased risk of invasive breast cancer or may behave as non-obligatory precursor lesion [10]. Specific histological abnormalities based on pathological examination have a relative risk range for subsequent invasive breast cancer [11]. The benign breast diseases generally are classified into three types of lesions according to their severity and the relative risk of subsequent breast cancer, as follows: (i) non-proliferative disease, (ii) proliferative disease without atypia and (iii) proliferative disease with atypia [12]. Non-proliferative breast lesions (i.e., mastitis, cysts, apocrine metaplasia and mild hyperplasia) are not associated with increased risk of breast cancer [13]. The proliferative breast diseases without atypia (e.g. fibroadenoma with complex functions, endoporic papillomas, sclerosing adenosis) are related to moderately increased risk (1.5 to 2 times) of developing breast cancer, while the risk of breast cancer is increased from 3.5 to 6 times in atypical

hyperplasia (ductal or lobular). While several studies have shown a higher rate of breast cancer after the diagnosis of benign breast diseases in ipsilateral breast, lesions with atypia also refer to an increased risk of breast cancer in the contralateral breast [13].

The QoL of patients with breast cancer has been investigated in several studies [14-29]. Although breast cancer and its treatments affect the physical, psychological and social functioning in various ways, it has been suggested that the QoL of patients with breast cancer is actually moderately high [14,19,25]. Patients with breast cancer have reported higher QoL in the family dimension [14,19] and lower QoL in health and functionality [14] and the psychological and spiritual dimension [19,30]. Overall, the findings of previous studies suggest that patients with breast cancer have a worse QoL than patients with other types of cancers [14,23], particularly in the dimensions of psychology, sexuality [14] and emotional functioning [23].

The purpose of the present article was to investigate the health related QoL of young women with breast cancer.

Methods

The current literature was reviewed via the electronic databases, Pubmed, Scopus and Google Scholar. We used as key words the words breast cancer, young women, health related quality of life, and quality of life.

Results

Quality of life of young women with breast cancer

Initially, health care professionals defined the QoL as the complete social and psychological well-being: the individual's assessment for the social function, mental acuity, emotional state, and the sense of well-being and his relationship with others. All these areas of life cover the extent to which the objective of a woman's situation and the expectations and hopes for the future are in line with each other. For example, two women could have the same objective health and welfare situation, but their quality of life may vary considerably according to their own personal perception for themselves, their identity and their health [31].

Changes in one dimension of QoL can also affect perceptions of the person in the other dimensions. Disturbances in body or physical dimension, for example, are likely to affect the psychological or social well-being of a woman. Consequently, the QoL can be perceived differently among people. Therefore, it is generally considered that the QoL is best defined in terms of the patient. It is

interesting to note that the quality of life can change over time, and depends mainly on the age and the experiences. Thus, it is generally believed that the elderly adjust their perceptions about their health while younger people have higher expectations about their physical and operational status [31].

In a quantitative study, Avis et al. [26] described negatively the dimensions of QoL of 202 young women with a mean age of 43.5 years, from 4 to 42 months after diagnosis of breast cancer. Of them, 44% had undergone mastectomy, while 75% underwent chemotherapy and 69% radiotherapy. The overall QoL and health-related QoL were measured by the Functional Assessment of Cancer Therapy - Breast cancer (FACT-BC), the medical history, the symptoms, the lost days of work / activity after diagnosis, the disorders in relationships, the sexual health and the body image, the coping strategies and the preparedness feelings. The results showed that the generalized pain and suffering to the appearance were reported in more than 70% of the participants. The young women rated the overall QoL significantly lower than the oldest. In general, few socio-demographic and medical factors were associated with QoL. The lost days immediately after diagnosis, the problems in relationships, the sexual health and body image and the coping strategies were related to almost all dimensions of QoL. Continuous treatment, vaginal dryness and feeling unprepared for breast cancer effects were associated with certain dimensions of QoL.

Similarly, Bloom et al. [31] investigated the QoL 5 years after the treatment from 185 women aged 50 years or younger who had breast cancer. Half of them (51%) had mastectomy while the rest (49%) followed conventional treatment. The majority of women had some form of adjuvant therapy, which consisted of either chemotherapy or radiation and / or administration of tamoxifen. The results of the study showed that at the point of 5 years without breast cancer, the young women enjoyed good health and improved QoL. However, the researchers reported that certain physical, social and psychological issues must be addressed so that young survivors can continue to have a good QoL as they become older.

Siegel et al. [32] in their qualitative study investigated the age-associated pain in 51 young women with breast cancer aged 35 years. All women had completed the treatment for breast cancer at least 6 months before the interview. The majority of participants (59%) were diagnosed with stage I or II cancer. The issues raised by the interviews were (1) the behavior when they learned

the diagnosis, (2) concerns about the impact of the disease from their husbands, (3) the sadness for the lost opportunity for childbearing, (4) the feeling to be different and isolated, (5) the uncertainty about their future and (6) concerns about their young children. These 6 areas of discomfort provided detailed information using the experiences of young survivors and consist a reference guide for further understanding of the painful issues faced after diagnosis of breast cancer.

Unlike the study of Siegel et al. [32], Dunn and Steginga [33] described the challenges faced by 23 young women aged 31-47 years with breast cancer. Of these, 9 women had conservative treatment, 13 had mastectomy and one underwent double mastectomy. The fears that women faced were that they will not survive long enough to see their children grow to adulthood, questions relating to sterility and fear of infertility due to possible recurrence of cancer. The majority of concerns which were described by women were related to the stage of their life, emphasizing the challenges specific to their age group. The participants highlighted the importance of mutual support, as well as meet and exchange experiences with other young women with breast cancer.

Four dimensions of quality of life in young women with breast cancer

QoL is not one-dimensional, but includes numerous aspects of life. Currently, there are four dimensions. These are the physical, psychological, social and mental dimension of QoL. Ferrell and Dow [34] defined the QoL for cancer survivors using these areas and creating a definition that includes all of them. Specifically, they defined:

1. Physical well-being: control or relief of symptoms and maintaining function and independence.
2. Psychological well-being: the attempt of a person to maintain a sense of control for the threatening of life disease characterized by emotional distress, changes in life priorities and fear of the unknown.
3. Social well-being: the attempt of people to deal with the effects of cancer, their roles and their relationships.
4. Spiritual well-being: the person's ability to maintain the hope and to derive meaning from the experience of cancer characterized by uncertainty.

Using this "all dimensions" definition, the review of the literature on the 4 dimensions of QoL of young-aged women with breast cancer showed:

Physical dimension. Thewes et al. [35] reported that fatigue, the pain in the breast and in the hand and problems with lymphedema are the most

frequently reported physical effects of treatment for young women. Other physical problems among younger premenopausal women include the limited movement of the arm / shoulder, the dry throat, and problems with the menstrual cycle. For many women, the current level of physical symptoms (fatigue, pain) were not perceived as debilitating and did not significantly affect the activities of daily life. Instead, many women worry about whether their symptoms were normal, and seek confirmation that their physical symptoms are not signs of relapse.

Young women also discussed how gynecological consequences of treatment affect their QoL. The most common challenges for women aged less than 50 years included the non-recurring or painful periods, the vaginal dryness and the loss of libido [31]. There is also consistent evidence of sexual dysfunction after treatment [31,36]. These problems have been reported to occur regardless of the treatment options [31]. Obesity and the increased weight are often reported in studies in young women with breast cancer. Among the studies that includes this variable, the percentage of women who reported increased weight or were annoyed by the increased weight after diagnosis ranged from 23 to 83% [37].

Psychological dimension. Depressive symptoms, such as depressed mood, helplessness, hopelessness, sleep loss, psychomotor retardation and appetite disorders are often reported by the youngest survivors of breast cancer [37]. Ganz et al. [38] found improvements in mood and overall QoL during the first year after treatment. However, no further improvement was found when the first year was compared with the 2nd or 3rd year of follow up.

Also, concerns about the future were positively associated with symptoms of depression and anxiety in younger women [37]. Concerns have also been reported such as nervousness about the health monitoring and self-image. In one study, Bloom et al. [31] found that even 5 years after diagnosis, 52% of women claimed to be generally "too anxious, nervous or worried" and 68% had concerns about the future. The main concerns, however, were for the future of the women [37].

The concept of having children is another important aspect of QoL for many young survivors of breast cancer. This concept is not only important in terms of the experience of pregnancy, child birth and motherhood, as well as the future confirmation of a woman [33]. In their qualitative study, Siegel et al. [32] found that stress faced by these young mothers was triple. Firstly, mothers

felt fear and sadness that they will not live enough to see their children reach adulthood. Secondly, they felt anxious about finding a suitable person to bring up their children in the case the cancer recurred and worsen their situation or die. Thirdly, these women try to minimize the daily impact of the disease on their children.

Moreover, there is enough evidence of the growing problems in sexual function after treatment. These problems occur regardless of the method of treatment. While the problems of sexual function are partly physical, they are also psychological. Some studies have reported that women feel to be rejected by men because they do not want to touch their affected breast. It is not surprising the fact that the problems of self-image and intimacy are often mentioned. Furthermore, the emotional and practical support by their partners during treatment, and after, was fundamental for an improved QoL. However, the women expressed guilt about the progression of their disease and the effect it has on their partners, and the relationship. This is a dimension that greatly reduces the QoL [31].

Social dimension. Many young women reported being distressed about the impact of their breast cancer to lifestyle and in their careers. Since the majority of young women are working full time and enter the peak of their career at the time of diagnosis, issues related to their job arise. This may include subtle distinctions in job offers and / or layoffs because it is believed to be unable to do their job effectively [31]. Women also reported lack of resources available to help them return to work [39].

Problems with self-image and their relationships are frequently reported among these younger women. In a study conducted by Thewes et al. [35], in which the authors interviewed a pre-menopausal woman who was not married, she described herself as an "obligation" for the prospective partners because of possibility of cancer recurrence and the issues with infertility.

An important issue that is addressed in many studies is the sense of isolation and the sense of difference from other women of the same age. In fact, even some women who lived in large cities reported that the available support groups cannot serve their unique needs and therefore they felt that it was due to their young age [32, 35]. Previous studies have shown that isolation feelings can occur in patient support groups, where younger women could not connect with other members of the group as the majority of participants were older, usually married for several years and their

children had been brought up. Consequently, the younger women feel even more isolated, uncomfortable and even depression when they participate to such groups. Feelings of isolation are not uncommon when they are socializing with friends [32].

Younger survivors have also reported a feeling of marginalized in the public health programs, which promote mammography in women aged over 50 years. These campaigns contribute to feelings of isolation and stigmatization, because women are “too young to have breast cancer” and is not “normal”. The stigmatization of young women reinforces the feeling of isolation and consequently, these women are more likely to draw away from the interaction with others, leaving their jobs and their social activities [40].

Spiritual dimension. While there is growing interest among researchers about the spiritual well-being of cancer survivors, there are no current studies to investigate only the spiritual well-being in relation to the young survivors of breast cancer. However, there is a study with older breast cancer survivors. In this study, Gall et al. [41] examined 52 women with a mean age of 55.2 years, from which requested to write in their own words how religion and spiritual factors played a role in the understanding and treatment of their breast cancer. The researchers found that spirituality and spiritual practices have had a positive role for the majority of them, including their faith in God, religious response activities (i.e. prayer), the spiritual meaning in their illness and social support in religious Organizations. Other studies have also

shown that an opening to spirituality among cancer survivors can lead women to post-traumatic stress and sense of affirmation of life [31,41].

Patients with breast cancer have reported that religious faith is an important source of support for the treatment of their disease [41] and that the cancer experience itself can lead to increased awareness of how to cope with. Spiritual well-being has also proven to be a long-term adaptation resource for cancer survivors to maintain self-esteem and confidence, providing a sense of meaning or purpose, providing comfort, reducing emotional distress and increasing inner peace and creativity, an overall sense of hope and a positive attitude towards life [41].

Conclusion

Among breast cancer patients, young women consider that their health-related QoL is worse compared with older women. The main symptoms reported were fatigue, pain in the breast and in hand and problems with lymphedema. Young women suffer mainly from depressive symptoms and anxiety and worry about their future, with particular reference to the motherhood. Prevention has a role of importance in case of breast cancer. Free screening is necessary, so all young women have to undergo preventive examination of their breasts in order to detect any cancer lesions and early treatment thereof.

Conflict of interests

The authors declare no conflict of interests.

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