Lymphology 39 (2006) 185-192

DISABILITY, PSYCHOLOGICAL DISTRESS AND QUALITY OF LIFE IN BREAST CANCER SURVIVORS WITH ARM LYMPHEDEMA

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ABSTRACT

The aim of this study was to assess disability, psychological distress and quality of life in Polish breast cancer survivors with arm lymphedema. One thousand sets of questionnaires consisting of WHO-DAS II, GHQ-30, EORTC QLQ-C30 and QLQ-BR23 were sent to members of the Polish Federation of Breast Cancer Survivors Clubs "Amazonki." The response rate was 28.3% of whom 31.70% reported arm lymphedema. The WHO-DAS II survey showed that patients with arm lymphedema had a higher overall disability score (45.04 versus 38.80 in group without arm lymphedema; p=0.01) and higher mean values in the scales of understanding and communicating, getting around, life activities at home, getting along with people, participating in society. The EORTC QLQ-C30 survey showed that patients with lymphedema had lower mean values in physical (0.55 versus 0.65; p=0.001), emotional (0.47 versus 0.57; p=0.01), social (0.59 versus 0.73; p=0.002), cognitive and role functioning, increased fatigue, pain, insomnia, dyspnea, nausea/vomiting and financial problems. The EORTC QLQ-BR23 data demonstrated worse future perspectives and an increase in breast and arm symptoms, and the GHQ-30 survey produced higher psychological distress (scores 15.18 versus 11.24; p=0.004).

In conclusion, breast cancer survivors with arm lymphedema were more disabled, experienced a poorer quality of life and had increased psychological distress in comparison to survivors without this condition.

Keywords: mastectomy, secondary lymphedema, breast cancer treatment, body mass index, quality of life, cancer survivorship

Breast cancer is the most frequently occurring cancer in women. This disease has to some extent been transformed into a chronic condition due to the continuous advances in treatment resulting in ever longer life expectancy (1). Therefore, the issue of the quality of life of breast cancer survivors becomes more and more important.

Lymphedema is a consequence of lymph stasis secondary to the obstruction or dysfunction of lymphatic vessels. Breast cancer treatment is the most common cause of secondary lymphedema in high income countries (2). Lymphedema may occur any time after breast cancer surgery (3). Recent studies report that arm lymphedema occurs in about one-third of all women treated for breast cancer (4,5). Although the risk factors for lymphedema are not well understood, it is well documented that a higher number of removed axillary lymph nodes (sentinel node versus regular level II dissection) and irradiation increase the risk of arm lymphedema. Other factors that predispose to arm lymphedema include: age >60 years, obesity, hypertension, and history of upper limb infection (2,6-9).

Arm lymphedema may significantly

affect physical and psychological well being. It causes deformity, functional disability, and pain in the affected arm (2,10,11). In addition, lymphedema also predisposes to recurrent infections (dermatolymphangitis) (10,11). In comparison to controls, patients with lymphedema have increased rates of anxiety, depression, psychological distress, and adjustment problems (12,13). Lymphedema may also be the cause of social isolation (12,13).

The quality of life of breast cancer survivors has been assessed in several studies. Despite its importance, lymphedema has received much less research attention than many of the other problems and non-lethal complications faced by breast cancer survivors. The purpose of our study was to assess disability, psychological distress, and quality of life in breast cancer survivors with arm lymphedema in comparison to breast cancer survivors without this complication.

MATERIAL AND METHODS

We sent 1000 sets of questionnaires to 33 chairwomen of the clubs "Amazonki" belonging to Polish Federation of Breast Cancer Survivors (each club received about 30 sets of questionnaires). Chairwomen then asked members of each club to fill in the questionnaires and to send them back to us. We did not mail or telephone any of the women to encourage them to send us back the questionnaires. The information about the purpose of the study was attached to the sets of questionnaires, and all the women were asked to give written consent to their participation.

The set of questionnaires included: questions about demographic and medical data, World Health Organization Disability Assessment Schedule II (WHO-DAS II), EORTC QLQ-C30 version 3.0 and the breast module: EORTC QLQ-BR23 (both developed by the European Organization for Research and Treatment of Cancer) and the General Health Questionnaire (GHQ-30).

Demographic and medical data included: age, education in years, marital and occupational status, height and weight, history of arm lymphedema, hypertension and diabetes mellitus. Body mass index (BMI) was calculated using the formula: BMI= weight [kg]/ height^2 [m^2].

Disability was assessed using the World Health Organization Disability Assessment Schedule II (WHO-DAS II), 36-item self-administered version. The WHO-DAS II measures disability in 6 domains: understanding and communicating (cognitive), getting around (mobility), self care, getting along with people, life activities (domestic responsibilities, leisure, work), and participation in society. Weighted scores of the scales were added to calculate the overall disability score (14).

Health-related quality of life was assessed with questionnaires: EORTC QLQ-C30 version 3.0 and the breast module: EORTC QLQ-BR23, both developed by the European Organization for Research and Treatment of Cancer. The EORTC questionnaires are commonly used to assess the QOL in cancer patients. EORTC QLQ-C30 consists of a global QOL scale, five functional scales (physical, role, cognitive, emotional, social), three symptom scales (pain, fatigue, nausea/vomiting) and five symptom items (dyspnea, insomnia, loss of appetite, constipation, diarrhea, financial difficulties). The EORTC QLQ BR-23 is a module meant to be used among breast cancer patients, varying in stage of disease and treatment. It consists of four functional scales (body image, sexual functioning, sexual enjoyment and future perspective), three symptom scales (systemic therapy side effects, breast symptoms, arm symptoms) and one symptom item (distress caused by hair loss) (15-16).

Authors have received permission from the European Organization for Research and Treatment of Cancer (EORTC) to use the EORTC QLQ-C30 and EORTC QLQ BR-23 in this study.

Psychological distress was measured

using the General Health Questionnaire (GHQ-30). This is a well-known instrument used to measure a patient's current psychological well-being and minor psychological distress. We used the version with 30 questions (GHQ-30) and the GHQ (0-0-1-1) scoring method (17).

Respondents were divided into two main groups: with and without lymphedema. The division into groups was based only on the reports given by responders. The group with lymphedema did not receive any objective measurement or clinical evaluation of their lymphedema status. The mean values of disability scores (WHO-DAS II), of global, functional and symptoms scales scores of quality of life (EORTC QLQ-C30, QLQ-BR23) and of GHQ scores were used to compare the groups. The higher BMI can facilitate development of lymphedema, so the influence of BMI was also assessed using the ANCOVA method. Differences in demographic variables were assessed using the chi-squared test and Student's t-test. The analysis of EORTC QLQ, WHO-DAS II and GHQ scores was performed using the ANCOVA method. Statistica for Windows version 6.0 was used for statistical analysis.

The study was approved by the Bioethical Commission of the Wroclaw Medical University.

RESULTS

We received 283 completed sets of questionnaires back (28.3% response rate). 84 breast cancer survivors reported to have arm lymphedema, 181 reported not to have it. 18 breast cancer survivors did not answer the questions relating to lymphedema status and were thus excluded from the analysis. 31.69% of responders reported having arm lymphedema. The prevalence of lymphedema in our study is similar to other reports (4-5).

The groups: (with and without lymphedema) did not differ in age, marital status or in the frequency of being afflicted with diabetes mellitus. They differed in place of dwelling, in median years of education, in occupation status, in the frequency of being diagnosed with hypertension, and in BMI. The basic demographic and health-related parameters of the subjects are presented in *Table 1*.

The group of breast cancer survivors with arm lymphedema when compared to the group of breast cancer survivors without this condition was found to have increased mean values in overall disability scores (WHO-DAS II). The differences in mean values adjusted for BMI between groups in disability, quality of life and psychological distress are presented in *Table 2*.

DISCUSSION

Physical Impairment

The group of breast cancer survivors with arm lymphedema (LE group) when compared to the group of breast cancer survivors without this condition was found to have higher overall disability scores (WHO-DAS II) and higher scores in the following scales: getting around and life activities at home (scale 2 and 51 of WHO-DAS II). The LE group also had lower mean values in scales for physical functioning (scale PF of EORTC QLQ-C30) and had more arm and breast symptoms (symptom scales BRAS and BRBS of EORTC QLQ-BR23).

Development of arm lymphedema resulted in increased physical disability in breast cancer survivors. This effect was independent of BMI. Disability as a result of decrements in physical capabilities and functioning when arm lymphedema is present is not in itself surprising. The affected limb can become dysfunctional due to increased size and weight, arm pain, weakness and decreased range of motion. In addition, arm lymphedema is associated with recurrent skin infections. It results in progressive functional impairment, significantly limiting domestic as well as job activities (2,10,11). In our study, women with arm lymphedema were less

TABLE 1
Basic Demographic and Health Related Parameters for Study Subjects

Characteristic	Women with lymphedema (n=84)	Women without lymphedema (n=181)	Statistics (*statistically significant)
Median age (range)	57 (40-77)	57 (31-80)	p=0.60
Dwelling (frequency %):			
- independent	46 (64%)	127 (78.9%)	
- assisted	26 (36%)	31 (19.3%)	Chi^2=1.54
- hospitalized	0	3 (1.9%)	p=0.005*
Median years of education (range)	12 (6-19)	13 (7-22)	z=2.19 p=0.03*
Marital status (frequency %):			
- single, never married	5 (5.9%)	12 (6.6%)	
- married	60 (71.4%)	111 (61.3%)	
- separated	0	3 (1.6%)	Chi^2=8.69
- divorced	74 (10.7%)	16 (8.8%)	p=0.12
- widowed	10 (11.9%)	38 (20.9%)	
- living with friend	0	1 (0.6%)	
Occupation (frequency %):			
- employed	7 (8.3%)	27 (15%)	
- self-employed	0	1 (0.6%)	
- volunteer	2 (2.4%)	2 (1.1%)	
- student	0	3 (1.7%)	Chi^2=14.71
- housekeeping	47 (55.9%)	86 (47.8%)	p=0.04*
- retirement	25 (29.8%)	59 (32.8%)	
- disease pension	2 (2.4%)	0	
- unemployed	1 (1.2%)	2 (1.1%)	
Diagnosis of hypertension (frequency %):	59 (22.7%)	39 (15%)	Chi^2=4.37 p=0.04*
Diagnosis of diabetes mellitus (frequency %):	12 (4.6%)	7 (2.7%)	Chi^2=0.07 p=0.79
median BMI	28.55	26.12	z=-3.09 p=0.002*

TABLE 2
Mean Values, Standard Deviation and Statistics for WHO-DAS II, EORTC QLQ and GHQ Scales in Groups of Breast Cancer Survivors With and Without Arm Lymphedema, Adjusted for BMI (*Statistically Significant)

Scale	Group with arm lymphedema mean (standard deviation)	Group without arm lymphedema	F value	p value
WHO-DAS II				
General overall health (H1)	3.03 (0.67)	2.74 (0.76)	6.87	0.01*
Understanding and communicating (DAS1)	42.80 (1.93)	37.20 (1.56)	4.97	0.03*
Getting around (DAS 2)	48.18 (1.89)	41.48 (1.53)	7.43	0.007*
Self Care (DAS 3)	33.10 (1.66)	30.50 (1.34)	1.46	0.23
Getting along with people (DAS 4)	42.38 (1.71)	37.37 (1.42)	4.91	0.03*
Life activities at home (DAS 51)	54.31 (2.13)	42.32 (1.72)	18.71	0.00002*
Life activities at work (DAS 52)	47.57 (5.57)	37.47 (3.67)	2.19	0.15
Participating in society (DAS 6)	51.21 (1.58)	43.96 (1.28)	12.43	0.0005*
Overall disability score	45.04 (1.43)	38.80 (1.17)	11.22	0.001*
EORTC QLQ-C30 (means in brackets)				
General QOL	0.49 (0.02)	0.55 (0.02)	4.45	0.04*
functional scales				
Physical functioning (PF)	0.55 (0.02)	0.65 (0.02)	11.79	0.001*
Role functioning (RF)	0.65 (0.03)	0.74 (0.02)	5.11	0.03*
Emotional functioning (EF)	0.47 (0.03)	0.57 (0.02)	6.59	0.01*
Cognitive functioning (CF)	0.56 (0.03)	0.68 (0.02)	11.76	0.001*
Social functioning (SF)	0.59 (0.03)	0.73 (0.03)	10.24	0.002*
symptom scales				
Fatigue (FA)	0.57 (0.03)	0.47 (0.02)	13.83	0.0003*
Pain (PA)	0.55 (0.03)	0.41 (0.03)	11.63	0.001*
Dyspnea (DY)	0.39 (0.03)	0.28 (0.03)	6.54	0.01*
Insomnia (SL)	0.66 (0.04)	0.51 (0.03)	8.52	0.004*
Appetite loss (AP)	0.24 (0.03)	0.19 (0.03)	1.53	0.22
Nausea/vomiting (NV)	0.16 (0.02)	0.08 (0.02)	9.39	0.003*
Constipation (CO)	0.38 (0.04)	0.27 (0.03)	5.98	0.02*
Financial problems (FI)	0.59 (0.04)	0.42 (0.03)	11.55	0.001*
EORTC QLQ-BR23				
functional scales				
body image (BRBI)	0.53 (0.04)	0.61 (0.03)	3.14	0.08
sexual functioning (BRSEF)	0.82 (0.02)	0.78 (0.02)	2.29	0.13
sexual enjoyment (BRSEE)	0.23 (0.04)	0.29 (0.03)	2.35	0.13
future perspectives (BRFU)	0.74 (0.04)	0.65 (0.03)	3,93	0.049*
symptom scales				
breast symptoms (BRBS)	0.37 (0.03)	0.20 (0.02)	20.89	0.00001*
arm symptoms (BRAS)	0.71 (0.02)	0.33 (0.02)	159.39	0.0000*
GHQ-30				
GHQ	15.18 (1.04)	11.24 (0.84)	8.48	0.004*

frequently employed than women without this complication.

Social Problems

Although breast cancer treatment can significantly alter body image, the swelling of the upper limb may be even more troublesome than living without the breast. Lymphedema causes arm disfigurement that could be difficult to hide, while the lack of a breast is visible only in intimate situations. Besides this, cosmetic surgery and prosthetics now make it easier to keep the lack of breast private. The visibility of lymphedema and characteristic arm garments causes women to feel different or even stigmatized. Furthermore, the enlarged size of the affected arm may prevent woman from wearing their usual clothing. In addition because lymphedema is difficult to keep hidden and private, it frequently causes social anxiety and constantly reminds the patient of their cancer experience. Therefore, isolation may become the defense mechanism employed to avoid negative emotions arising from social contacts (12,13).

In our study, the arm lymphedema group suffered from more social problems in comparison to group without this condition. The lymphedema group showed lower mean values in the following scales: getting along with people and in participating in society (scales 4 and 6 of WHO-DAS II), and in social and role functioning (scales SF and RF of EORTC QLQ-C30).

Psychological Distress

In the arm lymphedema group, psychological distress, measured using GHQ-30, was found to be significantly higher and emotional functioning (scale EF of EORTC QLQ-C30) was significantly lower when compared to women without lymphedema. Moreover, the lymphedema group reported to have worse future perspectives (functional scale BRFU of EORTC QLQ-BR23).

Development of lymphedema may almost be seen as a second blow from the disease. Women who went through the stressful diagnosis and treatment of cancer want to get back on track with their lives. Unexpected lymphedema, which develops months or even years after breast cancer treatment brings back many of these past emotions of being ill. Our results confirm earlier reports that psychological problems are more common in breast cancer survivors with lymphedema than in those without this complication (10,12,13).

Significantly greater mean values of reported bodily pain (symptom scale PA of EORTC QLQ-C30) found in the lymphedema group may be connected with the increased weight of the arm resulting in joint pain and cervical radiculopathy. However, emotional distress may in itself be felt as physical pain, muscular tension or may decrease a pain threshold (18). Similarly, greater mean values of breast symptoms (symptom scale BRBS of EORTC BR-23) in the lymphedema group may be the result of coexisting edema within the breast, but may also result from psychological distress causing increased awareness and an overemphasizing of benign symptoms.

Greater disability in understanding and communicating (scale 1 of WHO-DAS II), decreased cognitive functioning (scale CF of EORTC QLQ-C30) and an increased prevalence of fatigue, dyspnea, insomnia, nausea/vomiting (symptom scales FA, DY, SL, NV of EORTC QLQ-C30) reported by survivors with lymphedema in comparison to the group without this complication may also be a sign of psychological distress (18).

Financial Problems

Women with lymphedema reported more financial difficulties (scale FI of EORTC QLQ-C30). The presence of lymphedema may cause decreased ability to work, sometimes inability to continue employment, with decreased financial outcomes. However, the majority of our respondents were retired or did not work because of this disability.

Therefore, the main cause of financial problems of women with lymphedema assessed in our study can be related to the costs associated with treatment of this condition. The treatment of lymphedema is currently not covered by the Polish national health insurance plan (Narodowy Fundusz Zdrowia – NFZ). In addition, there are few lymphedema treatment facilities in Poland. Therefore, women have been trying different, often very expensive, but ineffective therapies before they manage to contact a qualified specialist.

Overall Health and Global Quality of Life

The arm lymphedema group was found to have significantly lower mean values in auto-estimation of the overall health (scale H1 of WHO-DAS II) and in global quality of life (scale QOL of EORTC QLQ-C30). Luoma and Hakamies-Blomqvist (19) noted that global quality of life is often expressed by cancer patients in terms of leading normal life, continuing to carry out roles and responsibilities, and controlling the disease experience. They emphasized the strong association between the meaning of global quality of life and the role functioning. Our study confirmed this observation. The lymphedema group in our study had a lower mean value of role functioning (scale RF of EORTC QLQ-C30) compared to the group without this condition.

Limitations

The findings of this study must be considered in light of its limitations. Firstly, the study population was limited to the members of the breast cancer survivor support groups. The general population of breast cancer survivors may be psychologically different from our responders. Besides, the response rate and sample size were low, and the women who responded may be psychologically and physically different from the women who chose not respond. The low response rate could result from our two-step questionnaire distribution process. We do not exactly know if all questionnaires were distributed among club members, so some questionnaires could be left not delivered and the real response rate could be higher. We did not have direct contact with participants and non-responders and weren't able to follow up with postcards or telephones. In spite of that, the 30% response rate is not unusual for mail-out surveys without follow-up (20).

The other limitation of the study was the lack of an objective measurement or clinical evaluation of lymphedema status. The categorization into groups with or without lymphedema was based only on self-reports given by respondents.

CONCLUSION

Breast cancer survivors with arm lymphedema were more disabled, experienced a poorer quality of life, and had increased psychological distress in comparison to survivors without this condition.

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