

Quality of life and the level of knowledge and utilization of lymphedema prevention principles among mastectomized patients

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ABSTRACT

Introduction: Breast cancer is the most prevalent female malignancy in Poland. Oncological treatment and its adverse effects diminish quality of life of breast cancer patients, which is determined by a number of somatic, psychological and social factors.

Purpose: To assess the quality of life and the level of knowledge and utilization of lymphedema prevention principles among women after surgical treatment of breast cancer.

Materials and methods: The study included 145 breast cancer patients after radical mastectomy. The respondents were examined with the validated EORTC QLQ-BR23 questionnaire and a custom-designed survey.

Results: Examination with the QLQ-BR23 questionnaire revealed that mastectomized women scored low on the body image scale. The most

frequently reported ailments were arm and breast symptoms. While the respondents showed high level of knowledge with regards to lymphedema prevention, they poorly adhered to the prophylactic guidelines. The participants were well aware of the risk factors of lymphedema, and most of them declared avoidance of their harmful effects.

Conclusions: Quality of life assessment should constitute an integral component of rehabilitation in every breast cancer patient, as mastectomy exerts significant effect on the outcome of perioperative period. Apart from specialist physiotherapy, also education of patients with regards to principles of lymphedema prevention and autotherapy constitutes an important component of complex management of lymphatic insufficiency.

Key words: Breast cancer, mastectomy, quality of life, lymphedema, prevention.

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INTRODUCTION

Breast cancer is the most prevalent female malignancy in Poland. According to the most recent data from the National Cancer Registry, the yearly number of newly diagnosed cases of this malignancy exceeds 16 500 (age-adjusted prevalence rate: 52 per 100 000), and increased by about 10 000 during the last two decades. For a few years, breast cancer remains the second (after lung cancer) leading cause of mortality among female oncological patients in Poland (5 226 deaths annually, age-adjusted mortality rate: 13.7 per 100 000) [1]. Older age is the most important risk factor of breast cancer, followed by carriage of some genetic mutations (mostly in *BRCA1* and *BRCA2* genes), familial history of this malignancy (especially diagnosed at younger age), early menarche, late menopause, late age at first childbirth, long-term use of hormone replacement therapy (HRT), exposure to ionizing radiation, and some benign proliferative diseases of the breasts [2, 3].

Typically, patients with pre-invasive ductal carcinoma or early clinical stages of invasive breast cancer are subjected to primary resection of the tumor, sometimes combined with radiotherapy and/or systemic treatment. At highly-advanced local stages, the surgical treatment and/or irradiation are preceded by the systemic treatment [4-6]. The choice of local or systemic treatment modalities used at various stages of breast cancer is based on the results of clinical and pathomorphological examination. The determinants of therapeutic decision include histological type and grade of the cancer, expression of ER/PgR and HER2, characteristics of the primary tumor and axillary lymph nodes, presence, location and volume of distant metastases, ailments associated with the tumor, presence of life-threatening conditions, time elapsed between primary treatment and recurrence, characteristics of previous treatment and therapeutic response, menopausal status and age of a woman, performance status, past and present comorbidities and their treatment, opinions and preferences of patients, etc. [7-9]. Decisions regarding a strategy of radical treatment should be made before the onset of the therapy, by multidisciplinary teams including a surgeon, radiotherapist, clinical oncologist, and optimally also radiologist and pathologist being specialized in breast malignancies. All the therapeutic decisions should be discussed with a patient, who should be informed about all available treatment options. Surgical treatment involves the affected breast and regional lymph nodes. The surgery should be radical and provide maximum information on the locoregional stage of breast cancer. Either a part of the breast (conserving treatment) or the whole breast (mastectomy) can be removed; similarly, all

the regional lymph nodes (axillary lymphadenectomy) or only one or more sentinel lymph nodes can be resected. The choice of surgical treatment of the breast and regional lymph nodes is determined by a number of clinicopathological factors, and should be always discussed with a patient. Postoperative radiotherapy constitutes a vital component of therapeutic protocol in all patients who were subjected to the breast-conserving treatment, as it is associated with several-fold decrease in the risk of recurrence. If an adjuvant chemotherapy is indicated after the breast-conserving surgery, it usually precedes radiotherapy. The decision on implementation of systemic adjuvant treatment should be based on analysis of potential benefits offered by various therapeutic modalities and the risk of recurrence in a given case (determined on the basis of established prognostic factors). Also potential adverse effects of systemic treatment should be considered, as well as a performance status, comorbidities and preferences of a given patient [6,10,11].

A number of breast cancer patients suffer from lymphedema. The condition can be a direct consequence of the neoplastic process or an adverse effect of breast cancer treatment. The swelling of tissues results from lymphatic congestion caused by congenital defects or acquired injury of lymphatic vessels [12]. The impairment of lymphatic drainage is observed whenever the volume of interstitial fluid exceeds the transporting potential of the lymphatics. Cancer is one of the most frequent causes of lymphedema. In the case of oncological patients, lymphatic insufficiency can result from neoplastic involvement or compression of lymphatic vessels and lymph nodes, enlargement of internal organs, or elevated pressure in body cavities [13]. Moreover, lymphedema can develop as an adverse effect of anticancer treatment (lymphadenectomy, radiotherapy) [14]. Physiotherapy plays vital role in the management of lymphedema. The aim of physiotherapy is to rehabilitate patients at various stages of the disease (i.e. during inpatient, outpatient or sanatorial treatment). The detailed objectives include prevention of secondary lymphedema of the arm at the operated side, complex conservative management of already developed edema, and complete restoration of the shoulder girdle mobility after surgical treatment of breast cancer [15-17].

Oncological treatment and especially its adverse effects diminish quality of life of breast cancer patients. The quality of life is determined by a number of somatic, psychological and social factors. The quality of life of breast cancer women is a subjective parameter. Treatment undoubtedly affects body image of breast cancer patients, alters their self-esteem, and impairs physical performance (mostly due to limited mobility of the upper limb and risk of secondary lymphedema). Questionnaire

survey is an established method for quality of life assessment. The subjectively-perceived quality of life of breast cancer women can be determined with highly reliable, validated EORTC QLQ-BR23 questionnaire. Thus, quality of life assessment should constitute an integral component of rehabilitation process in every breast cancer patient [18,19].

The aim of the study was to assess the quality of life and the level of knowledge and utilization of lymphedema prevention principles among women after surgical treatment of breast cancer.

MATERIALS AND METHODS

The study was conducted in 2012, included 145 breast cancer patients treated at Maria Skłodowska-Curie Memorial Oncology Center in Białystok and at the Hospital of Ministry of the Interior and Administration and Warmia and Mazury Oncology Center in Olsztyn, as well as the members of Białystok and Olsztyn “Amazonki” clubs for mastectomized women. All the participants had a history of radical mastectomy with no signs of recurrence. The respondents were examined with a core 26-item quality of life scale for breast cancer patients (QLQ-BR23) and with a custom-designed questionnaire. The protocol of the study was approved by the Local Bioethics Committee at the Medical University of Białystok (decision no. R-I-002/629/2012). The results were subjected to statistical analysis, and presented as arithmetic means and their standard deviations. The significance of intergroup differences was verified with the Mann-Whitney U-test. All the calculations were carried out with STATISTICA 10.0PL software, and the threshold of statistical significance was set at $p < 0.05$.

RESULTS

Mean age of the surveyed women was 60 years (± 22). Individuals aged between 60 and 69 years ($n=60$; 41%) constituted the largest fraction of the respondents (Figure 1).

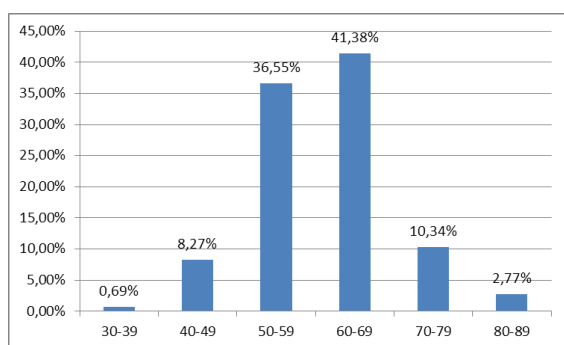


Figure 1. Age structure of the study participants.

Married women (85%) and maidens ($n=3$; 2%) constituted the largest and the smallest fraction of the study group, respectively (Table 1).

Table 1. Marital status of the study participants.

Answer	n	%
Married	123	85
Maiden	3	2
Widowed	15	10
Divorced	4	3

A total of 112 (77%) participants were subjected to chemotherapy and radiotherapy, and 90 (62%) patients had a history of hormonal treatment (Figure 2).

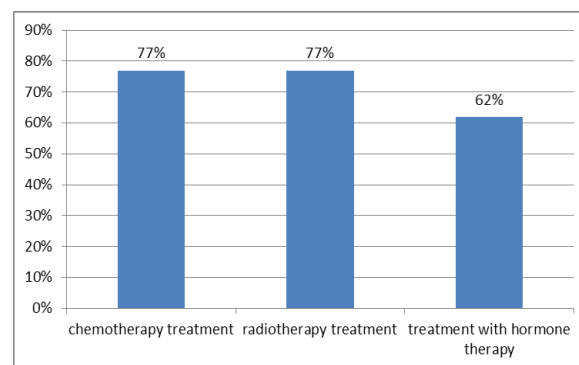


Figure 2. Distribution of treatment modalities within the study group.

Our respondents scored the highest on the sexual functioning and sexual enjoyment scales of the QLQ-BR23 questionnaire (77.2% and 73.4%, respectively). Only 57.6% of the participants assessed positively their body image. More than one-third of the respondents were concerned with regards to future perspectives (35.0%). Upset by hair loss turned out to be the least frequently reported problem of our participants (35.6%). The most frequently reported ailments included arm symptoms at the operated side, associated with edema and decreased mobility (43.1%), and breast symptoms, such as pain hypersensitivity of surgical scar (41.3%) (Table 2).

Most of the patients ($n=114$; 79%) obtained information on lymphedema prevention from their physiotherapists.

However, a considerable fraction of the respondents (74%) declared obtaining this information from other patients (Figure 3).

Table 2. Quality of life of mastectomized women, determined with the QLQ-BR23 questionnaire.

Quality of life scale	(n=145)				
	(%)	Min	Max	SD	Me
Functional scales					
body image	57.6	0.0	100.0	21.9	51.7
sexual functioning	77.2	0.0	100.0	22.3	94.3
sexual enjoyment	73.4	0.0	100.0	28.9	91.2
future perspective	35.0	0.0	100.0	34.7	32.3
Symptom scales					
systemic therapy side effects	39.8	0.0	85.0	19.8	41.0
breast symptoms	41.3	0.0	100.0	33.7	41.3
arm symptoms	43.1	0.0	100.0	23.0	44.1
upset by hair loss	35.6	0.0	100.0	43.6	32.6

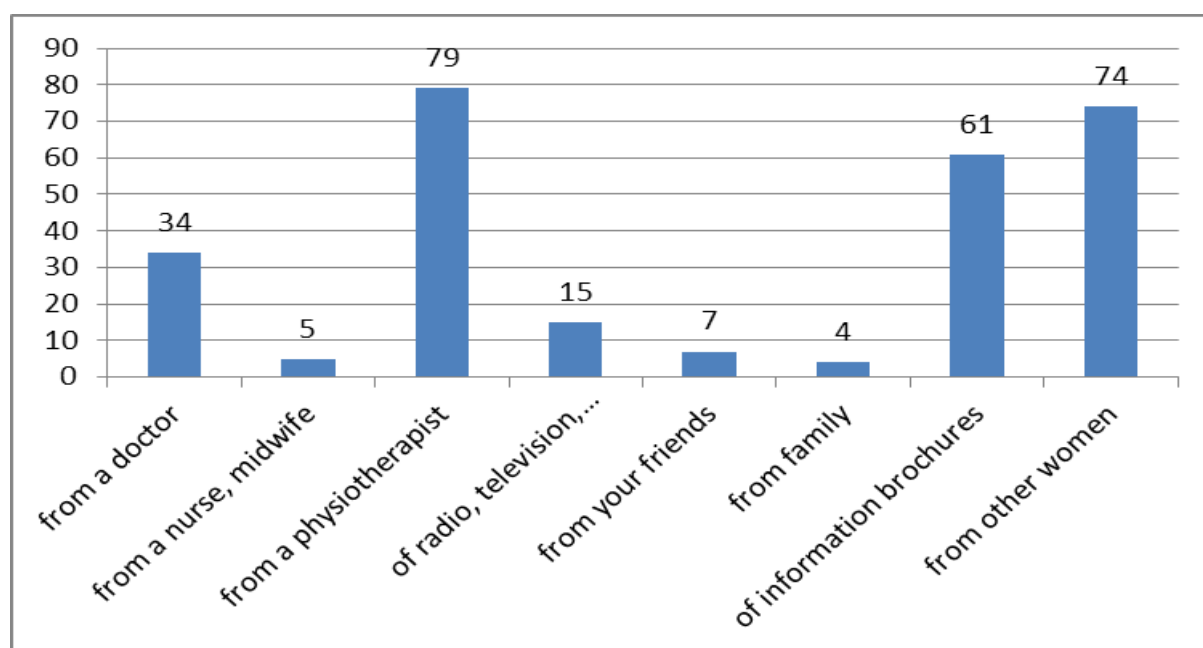


Figure 3. Declared sources of information on lymphedema prevention.

While elevation of the upper limb (n=116; 80%), physical exercise (n=108; 74%) and lymphatic autodrainage (n=76; 52%) turned out to be the best-known preventive measures of lymphedema among our participants, appropriate hygiene of the skin and nails (n=32; 22%) and maintenance of due body weight (n=15; 10%) were considered markedly less often. A total of 71 (49%) surveyed women declared frequent adherence to prophylactic guidelines of lymphedema; the

remaining participants complied with these guidelines only sometimes (n=31; 21%) or rarely (n=16; 11%) (Table 3). Most of the surveyed women were aware of the risk factors of lymphedema. The most universally known risk factors included iatrogenic factors (n=123; 84%) and overload with physical work (n=118; 81%). Our participants knew that lymphedema can be caused by more than one etiological factor, and declared that they avoid these factors often or even always (Table 4).

Table 3. Knowledge and adherence to the principles of lymphedema prevention among the study participants.

General knowledge of the principles of lymphedema prevention				
Yes n (%)		No n (%)		
121 (83%)		24 (17%)		
Knowledge of the specific principles of lymphedema prevention				
Frequent elevation of limb n (%)	Physical exercise n (%)	Autodrainage n (%)	Skin and nail hygiene n (%)	Maintenance of due body weight n (%)
116 (80%)	108 (74%)	76 (52%)	32 (22%)	15 (10%)
Adherence to the specific principles of lymphedema prevention				
Always n (%)	Often n (%)	Sometimes n (%)	Rarely n (%)	Never n (%)
6 (4%)	71 (49%)	31 (21%)	16 (11%)	3 (2%)

Most of the surveyed women were aware of the risk factors of lymphedema. The most universally known risk factors included iatrogenic factors (n=123; 84%) and overload with physical work (n=118; 81%).

Our participants knew that lymphedema can be caused by more than one etiological factor, and declared that they avoid these factors often or even always (Table 4).

Table 4. Knowledge and avoidance of etiological factors of lymphedema among the study participants.

Etiological factors of lymphedema	Knowledge of etiological factors of lymphedema n (%)	Avoidance of etiological factors of lymphedema n (%)				
		always	often	sometimes	rarely	never
Iatrogenic (blood pressure measurement, injections)	123 (84%)	108 (87%)	3 (2%)	5 (4%)	5 (4%)	2 (2%)
Overload with physical work	118 (81%)	2 (2%)	99 (83%)	9 (8%)	5 (4%)	3 (3%)
Lifting heavy objects	103 (71%)	3 (3%)	85 (82%)	10 (10%)	3 (3%)	2 (2%)
Wearing too tight underwear	92 (63%)	79 (86%)	3 (3%)	4 (4%)	4 (4%)	2 (2%)
Mechanical injuries	83 (57%)	67 (80%)	6 (7%)	3 (4%)	3 (4%)	4 (5%)
Sunbathing	82 (56%)	5 (6%)	62 (75%)	5 (6%)	6 (7%)	4 (5%)
Thermal injuries	74 (51%)	68 (92%)	2 (3%)	1 (1%)	2 (3%)	1 (1%)

DISCUSSION

Quality of life assessment provides information on the influence of a disease and its treatment on various spheres of patient life. High quality of life is one of the main determinants of therapeutic success in modern oncology [20-23]. The loss of a breast exerts devastating effect on one's sense of femininity and self-perceived ability to fulfill maternal role. Although surgical removal of the breast is not classified as a physical

impairment, it represents a form of psychological injury. Women, especially the younger ones, are concerned about losing their attractiveness [24].

Both our respondents and the participants of previous studies conducted by Han et al. [18] and Tomalska et al. [25] scored low on the body image scale. According to Ridan et al. [26], although mastectomy affects body image of a breast cancer patient, it does not markedly alter her intimate relationship if the latter is long-term and established. The fact that most of our patients were

married and aged above 60 years may reflect stable character of their intimate relationships. According to Tasiemski et al. [27], sexual enjoyment is the principal determinant of overall satisfaction with life in mastectomized women. This hypothesis seems to be supported by high scores of sexual functioning and sexual enjoyment scales of the QLQ-BR23 questionnaire, documented in our study. Also women examined by Han et al. [18] and Tomalska et al. [25] scored high on the sexual functioning and sexual enjoyment scales. The quality of intimate relationship can be favorably affected by positive self-assessment and self-acceptance to one's body image. In turn, the quality of life is considerably diminished due to side effects of treatment, presence of breast symptoms (pain and hypersensitivity of surgical wound), arm symptoms (decreased mobility, lymphedema), and loss of hair.

According to the International Society of Lymphology (ISL), the so-called complex decongestive therapy (CDT) should constitute a principal method of lymphedema treatment. CDT includes manual lymphatic drainage (MLD), multi-layer bandaging, exercises that improve lymphatic drainage, and hygiene of the skin [28]. The treatment is aimed at improvement of patient's life quality. This goal can be achieved not only by reduction of the edema, but also due to decreased fibrosis of tissues, improved mobility of joints in the affected limb, and overcoming psychological problems [29,30]. Also education with regards to prevention and autotherapy is an important component of complex physiotherapy for patients with lymphatic insufficiency. The prophylactic activities should involve both the patients being at risk of the lymphedema and those who already developed this form of lymphatic insufficiency. The most important preventive measures are appropriate hygiene and protection of the skin, and avoidance of factors that can cause the edema or enhance its severity [31, 32]. The latter factors include overload with physical work, overheating and injuries involving a region of lymphatic insufficiency [30, 34]. The information on the principles of lymphedema prevention should be offered by properly trained healthcare professionals (physicians, nurses and physiotherapists) [35].

Our participants identified physiotherapists and other patients as the principal sources of prophylactic education. The prophylactic activities should begin immediately after mastectomy, at a hospital ward where this procedure was conducted, and constitute a component of complex care coordinated by an oncologist. Also nurses may serve as a good source of prophylactic information due to large amount of time spent with breast cancer patients [32].

Dziura et al. [36] analyzed knowledge of patients with regards to etiological factors of

lymphedema. As many as 80% of their respondents declared knowledge of lymphedema prevention; noticeably, more than a half of the study group obtained the respective information from other patients, volunteers from the "Amazonki" clubs and from Internet, rather than from healthcare professionals. This suggests that the issue of prophylactic education of patients being at risk of lymphedema is frequently neglected by medical environment. The preventive measures of lymphedema are known for years; if implemented early during postoperative period, they may decrease the risk of this condition or at least postpone its development. The beneficial effects of physical exercise, autodrainage and frequent elevation of the upper limb at the operated side are often emphasized in literature [31, 37]. These forms of prevention were popular and frequently used by our patients. Appropriate hygiene of the skin and nails is particularly important preventive measure of infections of the lymphedema-endangered limb. Peri-nail and skin infections frequently constitute direct etiological factor of lymphedema [32, 38].

Therefore, the fact that our respondents rarely considered the skin and nail hygiene as a preventive measure of this condition, is alarming. Moreover, our patients rarely pointed to control of due body weight as a form of lymphedema prevention; in turn, excess body weight is associated with increased risk of lymphedema and worse therapeutic outcome [39, 40].

Despite possessing knowledge on the prevention of lymphedema, most of our patients did not adhere to the prophylactic guidelines of healthcare professionals.

These findings are consistent with the results published by Mathews et al. [41]; also these authors showed that despite having satisfactory knowledge on the prevention of lymphedema, mastectomized women do not comply with therapeutic recommendations and are poorly motivated to lifestyle modification. The fact, that our respondents were well aware of factors that may induce lymphedema and avoided them on a regular basis, should be considered optimistic. Reasonable level of physical activity, avoidance of mechanical or iatrogenic injuries and overheating of the affected limb was shown to be reflected by lower morbidity rates and reduced risk of lymphedema [40].

CONCLUSIONS

1. Quality of life assessment should constitute an integral component of rehabilitation in every breast cancer patient, as mastectomy exerts significant effect on the outcome of perioperative period.
2. Apart from specialist physiotherapy, also education of patients with regards to principles

of lymphedema prevention and autotherapy constitutes an important component of complex management of lymphatic insufficiency.

Conflicts of interest

The authors declare no conflict of interest.

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