Assessment of quality of life in women five years after breast cancer surgery, members of Breast Cancer Self-Help Groups – non-randomized, cross-sectional study

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Aim of the study: To assess the quality of life in patients treated for breast cancer who were 5 years after diagnosis and were active members of Breast Cancer Self-Help Groups.

Material and methods: The study had a non-randomized, cross-sectional design. We enrolled 167 women who were more than 5 years after mastectomy and were active members of Breast Cancer Self-Help Groups (group A1). As a control group we enrolled 117 women after mastectomy – not members of such support groups (group A2). For the evaluation of the quality of life in both groups we used the following standardized questionnaires – EORTC QLQ-C30 and EORTC QLQ-BR23 as well the Mini-MAC scale for the assessment of strategies of coping with disease.

Results: Based on QLQ C30 scores, group A1 had better emotional functioning (p = 0.0005) and a higher general quality of life (p = 0.0259), whereas group A2 had better role functioning (p = 0.0042). Based on QLQ BR23 scores, there were statistically significant differences in body image (p = 0.0366) and life perspectives (p = 0.0313) in favor of group A1. In the control group, there was a greater use of destructive coping strategies and anxious preoccupation (p = 0.1957).

Conclusions: Membership in Amazon groups improves functioning in breast cancer patients that can also extend into a five-year period after treatment completion.

Key words: breast cancer, Self-Help Groups, quality of life, mastectomy, standardized questionnaires.

Introduction

Breast cancer is the most common cancer type in women in the developed countries, and according to the World Health Organization (WHO), constitutes one of the most important issues for public health. The mainstay of treatment for breast cancer is mastectomy or breast-conserving surgery. Mastectomy causes stress, a feeling of shame as well as depressed mood. These consequences are seen in patients regardless of the time after treatment completion. In addition to physical scaring, patients after breast cancer surgery experience mental trauma. For this reason, it is necessary to study various aspects of quality of life in such patients [1]. According to Antonovsky, cancer, oftentimes being a chronic disease, is one of the critical life events. The diagnosis of breast cancer causes stress, fear and is associated with a multitude of problems requiring adaptation to the disease. This negatively influences the general quality of life [2].

The notion of quality of life was introduced into the medical science in the 1970s. In the recent years, health-related quality of life has gained special interest, which is associated with a holistic approach to the cancer patient. Because of the systematic increase in cancer morbidity, the assessment of quality of life has become an important part of management of cancer patients [3]. WHO defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [4]. In medical science, quality of life assessment is based on evaluating the problems related to the disease itself as well as to the applied treatment in terms of changes in physical, mental and social functioning, and subjective well-being [5].

Breast Cancer Self-Help Groups play a very important role as support groups for women after breast cancer surgery. Initially, these groups were founded in order to provide mental support and motivation for further treatment to women with breast cancer [6]. Amazon groups are organized by women who were treated for breast cancer. Their tasks include providing information on various methods of rehabilitation as well as on social events such as excursions.

The aim of the study was to assess the quality of life in women after mastectomy, who were active members of Amazon groups. These women

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were compared to similar women who were not members of such groups.

Material and methods

The study had a non-randomized, cross-sectional design. The study was approved by the Bioethical Committee at the Collegium Medicum in Bydgoszcz (No. 110/2016). Informed consent was obtained from all individual participants included in the study at the time of the survey. We enrolled 167 patients after mastectomy who were active members (at least one meeting per week in the last year) of Breast Cancer Self-Help Groups – group A1). The studied patients were members of Amazon groups in the Kuyavian-Pomeranian Voivodeship. There are 8 such Amazon groups in this Voivodeship with 450 members. Of these 450 members, 200 met the inclusion criteria and 33 did not consent to participate in the study. Therefore, 167 patients were included. The control group included 117 women – consecutive patients reporting for follow-up visits at the Center for Oncology in Bydgoszcz from March 2016 to August 2016, who met the necessary inclusion criteria and were not members of Amazon groups. Subjects from the control group completed their questionnaires in a separate room, were accompanied by the researcher throughout the study, and were allowed to ask any questions during their participation.

The control group consisted of 117 women after mastectomy who were not members of such support groups – group A2.

Inclusion criteria:
- patients who had undergone a BCT or mastectomy procedure,
- patients who had had breast surgery 5 years before or earlier,
- patients who had completed their oncological treatment,
- consent to participate in the study.

Exclusion criteria:
- patients undergoing oncological treatment,
- bilateral mastectomy,
- other cancer now or in the past,
- psychiatric diseases,
- obesity (grade III – BMI < 40),
- other ASA IV severe diseases: patients with severe systemic diseases that present constant threat to their lives.

Study design:
- consent to participate in the study,
- data collection – sociodemographic data, clinical data (date of surgery, type of surgery, type of treatment [chemotherapy, hormone therapy, radiotherapy], place of residence, occupation, length of membership in an Amazon group),
- completion of quality of life questionnaires – QLQ-C30 and QLQ-BR23,
- completion of the Mini-MAC scale.

Patients completed the questionnaires on their own after a short demonstration.

Research tools

EORTC – QLQ-C30 (Questionnaire for Quality of Life Assessment in patients with cancer, version 3.0) – an international, standardized research tool consisting of 5 functional scales, 3 symptomatic scales, a scale for the assessment of general quality of life QLQ and 6 individual items. The questionnaire consists of 30 items and can be used in all patients receiving cancer treatment regardless of cancer type and its location. All scores form the individual parts of the questionnaire range from 0 to 100 points. Higher scores in the functional scales mean better functioning.

EORTC – QLQ-BR23 (quality of life questionnaire – breast cancer) – an extension to the QLQ-C30. It consists of 23 items and was created specifically for breast cancer patients. QLQ-BR23 covers the following areas – side effects of treatment, body image, sexual functioning, arm symptoms, breast symptoms, and additional individual items. All scores from the individual parts of the questionnaire range from 1 to 4 with higher scores corresponding to worse functioning.

Mini-MAC scale (Polish version) – consists of 29 items and measures four strategies of coping with cancer – anxious preoccupation, helplessness – hopelessness (destructive strategies), fighting spirit and positive redefinition (constructive strategies). Scores are computed for each strategy separately and higher scores correspond to higher intensities of respective strategies.

Statistical analysis

We performed the statistical analysis with the use of the PQStat ver. 1.6 software. The t-test was used for comparing age between the study groups. The remaining comparisons of quantitative variables between the study groups were performed with the Mann-Whitney U-test.

Qualitative variables were compared between the study groups with the χ^2 test.

P-value of less that 0.05 was considered significant, and highly significant if it was less than 0.001.

Results

We did not find significant differences between groups in terms of age, number of family members, education, place of residence, or type of treatment (CHTH, HTH).

We found statistically significant differences between the studied groups in occupation and adjuvant treatment (CHTH + RTH, RTH) – women from the A2 group were more frequently employed and had a lower frequency of adjuvant treatment than women from the A1 group. Sociodemographic and clinical data of the studied groups are presented in Table 1. We would like to highlight that all information regarding the history of neoadjuvant and adjuvant treatment was obtained from patient interviews and was not verified in patients' medical histories.

Table 2 presents QLQ-C30 quality of life scores in both study groups (A1 and A2). The general quality of life scores were significantly higher in group A1, corresponding to a better quality of life ($p = 0.0259$). Similarly, patients in group A1 had higher scores in emotional functioning and this difference was highly significant ($p = 0.0005$). Patients

Table 1. Sociodemographic and clinical characteristics of the study groups (A1 vs. A2) and between-group differences

Demographic data		A1 (n = 167)		A2 (n = 117)	
Age, mean year (SD)		63.67 (8.41)		63.41 (7.38)	
Student t-test/Mann-Whitney U-test		$t = 0.26, p = 0.7955$			
Number of family members (SD)		2.17 (1.04)		2.56 (2.21)	
Student t-test/Mann-Whitney U-test		$Z = 1.22, p = 0.2212$			
		Number	%	Number	%
Education	elementary	5	3.11	8	6.84
	middle	116	72.05	71	60.68
	high	40	24.84	38	32.48
	χ^2		4.73		
	degrees of freedom		2		
	p-value		0.0941		
Residency	village	29	18.01	27	23.08
	town up to 100,000	57	35.40	44	37.61
	town > 100,000	75	46.58	46	39.32
	χ^2		1.78		
	degrees of freedom		2		
	p-value		0.4116		
Occupation	full-time	19	11.80	27	23.08
	farming	4	2.48	1	0.85
	retirement	114	85.72	62	76.07
	χ^2		12.07		
	degrees of freedom		3		
	p-value		0.0071		
Adjuvant therapy, n (%)	CHTH, RTH	73	59.8	70	45.3
	χ^2		5.69		
	degrees of freedom		1		
	p-value		0.01		
	CHTH	37	22.9	22	18.0
	χ^2		0.707		
	degrees of freedom		1		
	p-value		0.40		
	RTH	29	18	11	9.4
	χ^2		4.07		
	degrees of freedom		1		
	p-value		0.04		
	HTH	83	51.5	59	50.42
	χ^2		0.03		
	degrees of freedom		1		
	p-value		0.85		

A1 – members of Amazon groups; A2 – control group; p – statistical significance; CHTH – chemotherapy; RTH – radiotherapy; HTH – hormone therapy

in group A2 had significantly higher scores in role functioning ($p = 0.0042$).

There were no significant differences between the study groups in terms of physical functioning, cognitive functioning and social functioning ($p > 0.05$).

With the use of the QLQ-BR 23 questionnaire, the following variables were measured – body image, sexual functioning, sexual pleasure, life perspectives, treatment side effects, breast symptoms, arm symptoms, and stress related to hair loss (Table 3). We compared the scores between the study groups. We found statistically significant differences in body image ($p = 0.0366$) and life perspectives ($p = 0.0313$), both in favor of members of Amazon groups. Moreover, breast symptoms were more intense in

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Table 2. Quality of life in both groups (A1 and A2) and between-group comparisons (A1 vs. A2) regarding the scores of the QLQ-C30 questionnaire

EORTC QLQ C-30 Functional scales (best score – 100 points)	Study groups	Arithmetic mean	Standard deviation	Mann-Whitney U-test
Physical functioning (1–5)	A2	68.49	24.12	$Z = 0.95$ $p = 0.3422$
	A1	66.05	24.82	
Role functioning (6, 7)	A2	84.62	19.84	$Z = 2.87$ $p = 0.0042$
	A1	77.74	21.81	
Emotional functioning (21–24)	A2	64.46	20.60	$Z = 3.48$ $p = 0.0005$
	A1	73.34	24.35	
Cognitive functioning (20–25)	A2	69.94	23.29	$Z = 1.19$ $p = 0.2346$
	A1	72.67	24.69	
Social functioning (26, 27)	A2	78.06	20.91	$Z = 0.89$ $p = 0.3724$
	A1	76.54	19.44	
General quality of life (29, 30)	A2	38.10	14.75	$Z = 2.23$ $p = 0.0259$
	A1	41.74	16.47	

EORTC QLQ-C30 – European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; A1 – members of Amazon groups; A2 – control group, p – statistical significance

Table 3. Quality of life in both study groups (A1 and A2) and between-group comparisons regarding the scores of the QLQ-BR23 questionnaire

EORTC QLQ-BR23 Symptomatic scales (best score – 1 point)	Study groups	Arithmetic mean	Standard deviation	Mann-Whitney U-test
Body image (9–12)	A2	2.19	0.78	$Z = 2.09$ $p = 0.0366$
	A1	2.01	0.79	
Sexual functioning (14, 15)	A2	1.63	0.74	$Z = 0.80$ $p = 0.4223$
	A1	1.55	0.71	
Sexual pleasure 16	A2	2.54	0.66	$Z = 1.19$ $p = 0.2320$
	A1	2.39	0.68	
Life perspectives 13	A2	2.78	0.90	$Z = 2.15$ $p = 0.0313$
	A1	2.53	0.96	
Treatment side effects (1–4, 6, 7, 8)	A2	1.73	0.52	$Z = 1.63$ $p = 0.1027$
	A1	1.81	0.49	
Breast symptoms (20–23)	A2	1.41	0.55	$Z = 3.24$ $p = 0.0012$
	A1	1.60	0.59	
Arm symptoms (17, 18, 19)	A2	2.09	0.72	$Z = 1.39$ $p = 0.1643$
	A1	2.20	0.68	
Stress related to hair loss 5	A2	2.26	0.94	$Z = 0.61$ $p = 0.5445$
	A1	2.37	0.97	

EORTC QLQ-BR23 – European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Breast Cancer module; A1 – members of Amazon groups, A2 – control group; p – statistical significance

members of Amazon groups as compared to the control group. This difference was highly significant ($p = 0.0012$; Table 3).

There were no statistically significant differences between the study groups in the following scales – sexual functioning, sexual pleasure, treatment side effects, arm symptoms, stress related to hair loss ($p > 0.05$).

We assessed coping strategies with the use of the Mini-MAC scale on the following sub-scales – anxious preoccupation, fighting spirit, helplessness – hopelessness, positive redefinition. Patients in group A2 had higher scores in the anxious preoccupation scale as compared to group A1. This difference was statistically significant ($p = 0.0284$). Although patients in group A2 had higher scores in the helplessness – hopelessness sub-scale, this difference was not significant ($p = 0.1957$). Although patients in group A1 had higher scores in scales assessing the constructive coping strategies (fighting spirit and positive redefinition), this difference was not statistically significant ($p > 0.05$; Table 4).

Discussion

In this study we used standardized questionnaires, namely, EORTC QLQ-C30, EORTC QLQ-C29 and the Mini-MAC scale. This allowed us to compare our results with studies on the quality of life in breast cancer patients performed earlier. Additional observations were made possible by dividing breast cancer patients into those who were members of support groups (Amazon groups) or otherwise, and by including patients with a long-term follow-up (5–10 years after surgery). Our results clearly indicate that members of Amazon groups experience significant benefits. These patients had higher scores in emotional functioning, general quality of life, body image and life perspectives. Moreover, patients who were not members of Amazon groups had greater emotional problems, as measured by the Mini-MAC scale.

According to de Boer *et al.*, patients treated for breast cancer usually resign from work. This results primarily from a long and debilitating treatment [7]. Although in our study women in the control group were significantly more active at work (23.08% vs. 11.8%, $p = 0.0071$), they did not have better quality of life scores except for the work sub-

scale. As in previous studies, patients with higher education level, who are satisfied with their work, showed a better quality of life [8, 9].

In our study, we found that members of Amazon groups had better scores in general quality of life, including emotional functioning as compared to the control group. The between-group differences were highly statistically significant. Similar observations were made by other authors [10, 11].

After treatment completion, there is a difference between the situation of women treated with mastectomy compared to those after breast-conserving surgery [12]. Because of a greater physical scaring, patients after mastectomy have various problems with their body image [12-14]. We found that members of Amazon groups had better scores in the scales of body image and life perspectives than the control group, as measured by the QLQ-BR23 questionnaire.

Factors that can contribute to a decreased quality of life in patients after mastectomy include physical symptoms such as restriction of movement in the shoulder or lymphedema of the arm. Such physical limitations are common reasons for job absence [15]. In our group, physical symptoms were present in patients even five years after diagnosis and were more pronounced in members of Amazon groups.

We used the Mini-MAC scale for the assessment of coping strategies. In both study groups, the constructive coping strategies prevailed. This is in line with previous studies that found that disease-related stress decreases with time after treatment completion [16, 17]. There was a statistically significant difference between the study groups in anxious preoccupation, which was more pronounced in the control group. In contrast, members of Amazon groups were able to use support of other people from the group. Consequently, members of Amazon groups used this particular coping strategy less frequently. Based on clinical trials, breast cancer patients after mastectomy who use constructive coping strategies had better survival rates [18, 19].

As already established in previous research, the environments created by members of support groups for breast cancer patients provide a friendly milieu. They are

Table 4. Coping strategies in both study groups (A1 and A2) and between-group comparisons regarding the scores of the Mini-MAC scale

Mini-MAC scale coping with disease	Study group	Arithmetic mean	Standard deviation	Mann-Whitney *U*-test
Anxious preoccupation	A2	2.28	0.63	$Z = 2.19$ $p = 0.0284$
	A1	2.12	0.64	
Fighting spirit	A2	3.26	0.42	$Z = 0.40$ $p = 0.6883$
	A1	3.29	0.44	
Helplessness – hopelessness	A2	1.86	0.55	$Z = 1.29$ $p = 0.1957$
	A1	1.77	0.48	
Positive redefinition	A2	3.12	0.42	$Z = 1.28$ $p = 0.2017$
	A1	3.16	0.47	

A1 – members of Amazon groups; A2 – control group; p – statistical significance

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places for a safe exchange of experiences and provide unconditional acceptance [20, 21].

The characteristic feature of our study was that it was performed among patients long after completion of cancer treatment. Studies assessing the effects of early intervention in support groups among patients treated for breast cancer often do not take into account the differences in quality of life between patients who are members of support groups and other patients [22]. Other studies assessed the role of support groups in patients just after diagnosis [23]. The research performed so far suggests that breast cancer patients benefit from support groups regardless of the time that elapsed after diagnosis.

According to Saegrove *et al*. and Coreil *et al*., breast cancer patients prefer the company of people with similar problems [24, 25]. This accounts for the popularity of support groups in Poland and in other countries. Such groups help breast cancer patients starting from the moment of diagnosis [21]. Owing to the technological advancement, support groups can function in various forms – through the Internet and teleconferences [26–28].

Our study had a non-randomized, cross-sectional design and had limitations. It was carried out in a small group and its results cannot be generalized for the entire population. We did not assess personality traits. It would be interesting to know whether members of Amazon groups develop the traits that promote better quality of life or whether they already have them before they enter these support groups. Information regarding the type of oncological treatment was obtained during the study directly from patients; due to the character of the study we were unable to access relevant medical records.

This was a major limitation of the study. Another limitation of our research consisted in the character of survey collection. Participants at Amazon Clubs were surveyed during club meetings while patients not affiliated with any club were surveyed during their follow-up visits at the Oncology Centre. Although the investigators did their best to ensure comfortable atmosphere of the meeting, the very fact of having to report at hospital and undergo a follow-up visit might be a source of stress for responders. It would be worthwhile to prospectively study patient outcomes depending on their personality types. Based on the work of other authors, women who receive psychological support have improved functioning during and after breast cancer treatment [29]. The physical activity of women after mastectomy is reduced. This may lead to the adverse event like body postural changes and limited range of motion [30-33]. Moreover, membership in support groups induces an optimistic attitude [34].

In conclusion, breast cancer patients who are members of Amazon groups have a better quality of life after completion of treatment in comparison to similar patients who are not members of such groups. This also applies to patients who received the diagnosis more than 5 years earlier. In this study, we confirmed that support groups play an important role in well-being of breast cancer patients. Members of Amazon groups had better emotional functioning, body image, life perspectives and general quality of life as well as a lower tendency towards destructive coping strategies in comparison to the control group. Our research suggests that breast cancer patients require environmental support regardless of the time that elapsed after diagnosis. Self-support groups provide breast cancer patients with the opportunity to both receive and provide help, which creates a feeling of being useful.

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The authors declare no conflict of interest.

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