

## QUALITY OF LIFE OF WOMEN WITH BREAST CANCER AND SUPPORT OF SELF-HELP GROUPS: PILOT STUDY

### JAKOŚĆ ŻYCIA KOBIEC Z RAKIEM PIERSI I WSPARCIE GRUP SAMOPOMOCOWYCH: BADANIE PILOTAŻOWE

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- A. Study design/planning  
zaplanowanie badań
- B. Data collection/entry  
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- C. Data analysis/statistics  
dane – analiza i statystyki
- D. Data interpretation  
interpretacja danych
- E. Preparation of manuscript  
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wyszukiwanie i analiza literatury
- G. Funds collection  
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#### Summary

**Background.** Assessment of quality of life (QoL) is important for cancer survival and can be influenced by positive social support. The aim of the study was to compare the QoL of patients with breast cancer in terms of using the support of a self-help group (SG) in relation to quality of life.

**Material and methods.** The research group consisted of 135 respondents, who were the patients with malignant breast cancer. The first comparative sample of respondents, who did not attend the SG, was numbered 70. The second comparative sample of respondents, who attended the SG, consisted of 65 patients.

**Results.** In mental health QoL, body image was rated better in patients who attended the SG; in relationship QoL, positive significance was shown in the sphere of sexual life and social support in the SG patients. In the environmental area, QoL was statistically significant in the availability of health services in favor of the SG patients. When comparing the individual domains of the questionnaire, we found more significant differences in the sphere of mental experience and social relationships for the SG patients.

**Conclusions.** Social intervention has a positive effect on treatment outcome, length of life and the life quality of breast cancer survivors and contributes significantly to coping with changes in social ties, sexual intimacy in marriages and partnerships, family relationships and has a positive effect on improving mental and physical health.

**Keywords:** social support, breast cancer, oncology, quality of life, nursing

#### Streszczenie

**Wprowadzenie.** Ocena jakości życia (JŻ) jest ważna dla przeżywalności nowotworu i może być kształtowana za sprawą pozytywnego wsparcia społecznego. Celem badania było porównanie jakości życia pacjentek z rakiem piersi w zakresie korzystania ze wsparcia grupy samopomocowej (GS) w odniesieniu do jakości życia.

**Materiał i metody.** Grupa badawcza składała się ze 135 respondentek, które były pacjentkami z nowotworem złośliwym piersi. Pierwsza próba porównawcza respondentek, które nie uczestniczyły w GS, liczyła 70 osób. Druga próba porównawcza respondentek, które uczestniczyły w GS, składała się z 65 pacjentek.

**Wyniki.** Jeśli chodzi o JŻ w aspekcie zdrowia psychicznego, postrzeganie własnego ciała było lepiej oceniane przez te pacjentki, które uczęszczały na spotkania GS, a jeśli chodzi o JŻ w aspekcie relacji, w grupie pacjentek z GS wykazano pozytywne znaczenie w sferze życia seksualnego i wsparcia społecznego. W sferze środowiskowej JŻ była statystycznie znacząco lepsza wśród pacjentek z GS, jeśli chodzi o dostępność świadczeń zdrowotnych. Porównując poszczególne partie kwestionariusza stwierdziliśmy bardziej znaczące różnice w sferze doświadczeń psychicznych i relacji społecznych u pacjentek z GS.

**Wnioski.** Interwencja społeczna ma pozytywny wpływ na wynik leczenia, długość życia i jakość życia osób, które przeżyły raka piersi i znacznie przyczynia się do radzenia sobie ze zmianami więzi społecznych, intymności seksualnej w małżeństwie i związkach partnerskich, relacji rodzinnych, jak również ma pozytywny wpływ na poprawę zdrowia psychicznego i fizycznego.

**Słowa kluczowe:** wsparcie społeczne, rak piersi, onkologia, jakość życia, pielęgniarstwo

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## Introduction

Breast cancer is the most common malignant tumor in women worldwide. Breast cancer in women has become the most frequently diagnosed tumor and, for the first time, has overtaken lung cancer, mainly due to its high prevalence in low- and middle-income countries [1]. There are 1,900 new cases in Slovakia every year; the incidence is rising, especially among younger women. At the age of 25-45, the incidence has increased by 30% over the last 20 years. The disease itself has been known for more than 4,000 years [2]. The incidence and mortality of the disease are specifically dependent on ethnicity and geographical distribution. The highest incidence of breast cancer is in North America, Western Europe, New Zealand, Australia, Israel, Malta, South America, particularly in Uruguay and Argentina. The lowest incidence of the disease is in some locations of Africa: Congo, Rwanda, in some locations of Asia: Mongolia, Vietnam, Thailand [3]. The success rate of treatment is 90-100%, provided the disease is detected in time and treated correctly. However, negative changes in the emotional, cognitive, and social spheres persist in the surviving patients.

Until 2014, the highest prevalence of breast cancer (2.3%), compared with other health conditions, had been in the USA [4]. Nowadays, breast cancer is gaining a higher prevalence among young women. In the United States, approximately 7% of breast cancer patients are women under the age of 40 [5]. In 2017, the American Cancer Society estimated the incidence of the disease at 12,150 cases of breast cancer in women under the age of 40, and 26,393 of the women were under the age of 45. The WHO estimates that there were as many as 627,000 deaths from breast cancer in 2018, corresponding to 15% of all cancer deaths in women worldwide [6-8].

As in other European countries, in Slovakia, patients with breast cancer form the biggest group of people with a diagnosis of cancer. Two thousand newly diagnosed cancers every year means that there is an increasing number of patients who live in fear and uncertainty for the future, feeling the threat of premature death, loss of sense of femininity, frustration, and other emotional disparities, which significantly reduces their quality of life. The psychosocial burden persists even in patients who have undergone breast-conserving surgical treatment with minimal physical intervention [9-11]. Many studies confirm the vital influence of family, support groups and society in improving the quality of life of people with this malignant disease. For these reasons, multidisciplinary management, especially in young women, is appropriate to optimize clinical outcomes, with a focus on support through support groups [12-14].

The quality of life in context, influenced by self-help groups, is measured only singularly, and this question has not been addressed in the field of health care. A self-help group is a small, voluntary organization, which is made up of individuals with similar health, social or everyday concerns. Self-help groups are made on the assumption that an affected person is most able to be helped by a person who is experiencing or has experienced similar situations [15-17]. Health science is beginning to have an important place, even here in self-help organizations.

The World Health Organization suggests that the strategy "Health for everyone until 2000" continues with "Strategy for health for everyone in the 21st century", and that health care providers become involved in self-help groups and organizations [17].

The aim of nursing is to help a patient satisfy his or her needs. The health staff therefore has the responsibility to find appropriate means to support self-care physically, socially, spiritually, and psychologically. According to information about patients, the nurse considers whether or not a self-help group would be effective [17]. Health care should be oriented to the use of opportunities for different forms of social support. Social support is a broad term, which includes the supportive ways that different people behave in the social environment. Structural measures of the environment deal with the existence of social relationships. Functional measures refer to the resources that people within an individual's social network provide [18]. Many studies confirm the

vital influence of family, support groups, and society in improving the quality of life of people with a malignant disease. For these reasons, multidisciplinary management, especially with young women, is appropriate to optimize clinical outcomes, with a focus on support through support groups [12-14].

The aim of the study was to compare the quality of life of the patient with the malignant breast tumors in terms of the use of self-help support groups in relation to quality of life.

## Material and methods

### Study design

This was a cross-sectional study.

### Participants and data collection

The research group consisted of 135 respondents. It was a pilot study. These were the patients with malignant breast cancer. Due to the comparison of two groups of respondents, depending on the use of self-help group services, two comparable groups in terms of age, treatment, and duration of the disease were deliberately created. The study was conducted in Slovakia in the towns Košice, Prešov and in Vranov nad Topľou, in selected oncology clinics and self-help groups. The first comparative sample of the respondents, who did not attend the self-help group (NSG), was numbered 70. The second comparative sample of the respondents, who attended the self-help group (SG), consisted of 65 patients. In Table 1, the characteristics of the respondents are presented. The average age in the NSG was  $51.2 \pm 13.73$  and in the SG, it was  $55.01 \pm 15.2$ . The duration of the disease was approximately the same (NSG  $5.79 \pm 1.22$ ; SG  $6.02 \pm 2.11$ ). Most respondents in both groups underwent oncology treatment (chemotherapy, radiotherapy); only 8% of women in NSG had not had oncology treatment, and in the SG group, this was 12% of women. Women attending the self-help group were followed for 3 months (January-April 2020). The group was a personally-based support group led by a healthcare professional. The women attended a personal session once a week for 90 minutes. Women also used web meetings (chat) for the purpose of sharing personal experiences, emotions, providing valuable advice, and organizing social activities without the presence of a health professional. Family members also had the opportunity to participate in this self-help group. During the follow-up, meetings took place in a self-help group on the following topics: difficult emotions, uncertainty and helplessness, strategies for coping with difficult life situations, current state of breast cancer treatment and rehabilitation, job opportunities, body perception and sexuality, self-love and body image, family and friends, life in society, cancer patient claims. These topics were presented by experts with many years of experience in the field.

**Table 1.** Characteristics of respondents

Characteristics	SG n=65	Ratio	NSG n=70	Ratio
<b>Education</b>				
Secondary vocational	6	9	3	4
High school	48	74	55	79
University	11	17	12	17
<b>Age (M ± SD)</b>	55.01±15.2	-	51.2±13.73	-
<b>Duration of the disease (M±SD)</b>	6.02±2.11	-	5.79±1.22	-
<b>Treatment</b>				
Chemotherapy	42	69	55	79
Radiotherapy	6	9	4	6
Chemotherapy and radiotherapy	9	14	5	7
Without oncological treatment	8	12	6	8

Characteristics	SG n=65	Ratio	NSG n=70	Ratio
<b>Type social support</b>				
<b>Family and friends</b>	26	40	35	50
<b>Family</b>	20	31	20	29
<b>Friends</b>	19	29	23	33
<b>Self-help group</b>	65	100	0	0

Notes: SG – respondents attending a self-help group, NSG – respondents not attending a self-help group.

A standardized multidimensional instrument EORTC QLQ-C30 and a specific module EORTC QLQ-BR23 were used in the study. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (Breast Cancer Module) was used to determine the quality of life (Quality of Life – QoL). These questionnaires adequately correspond to the options of analyzing the given issue. Besides these tools, a standardized questionnaire, the World Health Organization WHOQOL-BREF (short version), was used [19].

### Statistics

Statistical methods of descriptive statistics were applied to process the research results: calculation of abundance (n) and percentage values (%), calculation of mean scale value (M), standard deviation (SD). For the statistical comparison of the monitored groups, t-test was used in the statistical program SPSS 18 (Student's distribution t). This statistical methodology allowed us to determine statistically significant differences between groups in the monitored parameters.

### Ethical aspects

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Institutional Ethics Committee of Jan Adam Reiman University Hospital with Polyclinic in Prešov (protocol code 62/EK/2020).

### Results

Through the EORTC QLQ-C30 and EORTC QLQ-BR23 questionnaire, the perception of overall health and functional condition of patients were assessed, as well as the incidence of the symptoms that characterize the breast cancer. Table 2 presents the final average score achieved in the sphere of functional condition of the respondents in terms of the five functional domains EORTC QLQ-C30.

**Table 2.** QOL in terms of overall quality of life and functional domains (EORTC QLQ-C30)

Functional condition	SG n=65		NSG n=70		p
	M	SD	M	SD	
<b>1. General health condition</b>	56.55	22.01	57.95	22.01	0.852
<b>2. Physical functionality</b>	76.28	20.11	76.79	20.11	0.442
<b>3. Performance, fulfilment of the role</b>	71.08	22.33	70.88	22.33	0.523
<b>4. Emotional functionality</b>	70.29	22.91	70.21	22.91	0.668
<b>5. Cognitive functionality</b>	85.49	15.47	84.94	15.47	0.486
<b>6. Social functionality</b>	65.58	28.51	65.71	28.51	0.732

Notes: SG – respondents attending a self-help group, NSG – respondents not attending a self-help group.

The SG respondents achieved mean score 76.28 points (SD=20.11) in the domain of physical functioning. When evaluating the emotional functionality, the SG respondents achieved an average score of 70.29 points (SD=22.91). In the domain of performance and role fulfilment, the respondents rated at an average level of 71.08 points (SD=22.33). In the domain of social functioning, the average was 65.58 points (SD=28.51). In terms of individual indicators, we did not find significant differences in the compared groups using the statistical methodologies.

Table 3 below presents the assessment of the most common symptoms of breast cancer, using EORTC QLQ-C30, from the perspective of women surveyed in both groups. The resulting values confirm that the most common symptom is insomnia ( $p=0.047$ ). The least common symptoms of breast cancer in the SG group were loss of appetite ( $M=16.8$ ), nausea and vomiting and diarrhea.

**Table 3.** QOL in terms of symptoms (EORTC QLQ-C30)

Symptoms	SG n=65		NSG n=70		p
	M	SD	M	SD	
1. Fatigue	36.5	22.11	37.15	20.81	0.645
2. Nausea and vomiting	12.62	20.01	12.48	18.97	0.342
3. Pain	35.69	15.89	35.79	24.55	0.282
4. Shortness of breath	22.9	25.96	23.2	20.15	0.645
5. Insomnia	38.3	31.12	39.44	31.44	0.047*
6. Anorexia	16.8	24.41	16.78	23.41	0.476
7. Constipation	17.65	16.22	17.78	16.23	0.409
8. Diarrhea	9.95	9.21	10.44	9.45	0.125
9. Financial difficulties	40.45	32.78	40.2	32.11	0.578

Notes: SG – respondents attending a self-help group, NSG – respondents not attending a self-help group, \*  $p<0.05$ .

In terms of comparing the responses of the respondents, the difference in the sphere of quality of life was confirmed in sleeping (insomnia), where the SG patients showed better scores ( $p<0.05$ ). We did not find significant differences in the other areas assessed.

In terms of comparison of the observed groups of respondents, we found differences in the perception of quality of life in body image ( $p=0.028$ ) and sexual functioning ( $p=0.038$ ) (Table 4).

**Table 4.** QOL in terms of functional status (EORTC QLQ-BR23)

Functional status	SG n=65		NSG n=70		p
	M	SD	M	SD	
1. Body image	67.58	22.11	73.52	25	0.028*
2. Sexual activity	19.24	20.01	18.94	21	0.452
3. Sexual satisfaction	18.55	15.89	19.01	15.79	0.147
4. Sexual functionality	57.25	25.96	59.92	25	0.038*

Notes: SG – respondents attending a self-help group, NSG – respondents not attending a self-help group, \*  $p<0.05$ .

A comparison was made in terms of the perception of quality of life in the patients with the breast cancer, who attended self-help group (SG), and in patients who did not attend a self-help group (NSG). The physical results are presented in Table 5.

**Table 5.** Results QOL – WHOQOL-BREF

Physical area	SG n=65		NSG n=70		p	PN
	M	SD	M	SD		
Q3 Pain and discomfort	3.11	0.68	3.44	0.68	0.271	4.03
Q10 Energy and fatigue	3.28	0.83	3.41	0.87	0.645	3.62
Q16 Sleep and rest	3.33	1.08	3.00	0.95	0.342	3.61
Q4 Dependence on medical care	2.78	0.94	3.13	0.92	0.282	4.16
Q15 Mobility	3.78	0.81	3.65	0.86	0.645	4.27
Q17 Daily activities	3.39	0.85	3.18	0.88	0.476	3.76
Q18 Work performance	3.00	1.03	3.24	0.90	0.487	3.76
Mental area	M	SD	M	SD	p	PN
Q5 Positive emotions	3.78	1.00	3.81	1.05	0.913	3.83
Q7 Concentration	3.39	0.85	3.60	1.06	0.543	3.55
Q11 The image of one's own body	4.11	0.47	3.59	0.94	0.046*	3.9
Q19 Self evaluation	3.11	0.90	3.29	0.77	0.521	3.57
Q26 Negative emotions	3.33	0.97	3.29	0.92	0.900	3.47
Q6 Meaning of life	4.44	0.62	4.13	1.02	0.292	3.86
Social area	M	SD	M	SD	p	PN
Q20 Personal relationships	3.56	0.86	3.29	0.99	0.409	3.75
Q21 Sex life	3.40	0.99	2.57	0.99	0.028*	3.64
Q22 Social support	3.89	0.47	3.41	0.87	0.047*	3.85
Environmental area	M	SD	M	SD	p	PN
Q8 Safety and security	3.29	0.69	3.40	0.91	0.721	3.24
Q9 Environment	4.44	1.25	4.06	1.18	0.371	2.85
Q12 Financial situation	2.94	1.11	2.88	1.11	0.872	2.87
Q13 Access to information	3.78	0.43	3.59	0.94	0.459	3.87
Q14 Possibilities of leisure activities	3.22	0.94	3.53	1.12	0.385	3.33
Q23 Environment	3.83	0.38	3.41	0.87	0.087	3.54
Q24 Availability of health services	3.89	0.83	2.82	0.81	0.000***	3.70
Q25 Transportation	3.28	0.89	3.24	0.66	0.872	3.19

Notes: \*  $p < 0.05$ , \*\*\*  $p < 0.001$ , SG – respondents attending a self-help group, NSG – respondents not attending a self-help group, PN – population standard [19].

NSG women reported medical aid dependence and fatigue, and reported work performance in terms of pain and discomfort. The quality of life was rated better by the patients, who did not attend a self-help group. Patients in the SG group rated their quality of life better in terms of sleep and rest ( $3.33 \pm 1.08$ ), mobility ( $3.78 \pm 0.81$ ), and the performance of daily activities ( $3.39 \pm 0.85$ ). Compared with the population norm, oncology patients have impaired sleep and rest (3.61), mobility (4.27), and need a higher level of assistance in performing daily activities (3.76) and work activities (3.76). We did not record significant differences in the monitored groups using statistical analysis (Table 5). Positive emotions were found in both groups (SG=3.78, NSG=3.81), confirming that they are at almost the same level. Significant differences were not seen even in negative emotions and concentration when comparing these three groups. Body image was rated better by patients of SG group ( $p=0.046$ ). We found more significant differences in the sphere of sexual life. The SG patients rate their sex life better ( $3.40 \pm 0.99$ ) than the NSG patients ( $2.57 \pm 0.99$ ). Positive results were found in the areas of sexual life ( $p=0.028$ ) and social support ( $p=0.047$ ). Differences between the two surveyed

groups were recorded in environment and access to information ( $3.83\pm 0.38$ ) in favor of the SG patients. We recorded statistical significance in the availability of health services ( $p=0.000$ ). The SG patients have a higher degree of satisfaction with the availability of health services ( $3.89\pm 0.83$ ). Table 6 points out the differences in all quality of life domains in patients with breast cancer (SG and NSG).

**Table 6.** Differences in the domains of the monitored groups QOL – WHOQOL-BREF

Aspect	SG n=65		NSG n=70		p	PN
	M	SD	M	SD		
Domain 1 Physical health	13.18	2.9	13.06	2.95	0.721	15.55
Domain 2 Mental health	15.22	3.12	14.62	3.11	0.034*	14.78
Domain 3 Social relations	14.25	2.22	13.84	2.31	0.027*	14.98
Domain 4 Environment	13.98	2.84	13.9	2.91	0.825	13.30
Q1 Quality of life	3.69	0.83	3.28	0.79	0.132	3.82
Q2 Satisfaction with health	3.29	1.06	3.06	0.86	0.410	3.68

Notes: \*  $p<0.05$ , SG – respondents attending a self-help group, NSG – respondents not attending a self-help group, PN – population standard [19].

When comparing the individual domains of the questionnaire, we found more significant differences in mental experiences ( $p=0.034$ ) and social relationships ( $p=0.027$ ). In these spheres, their quality of life was rated better by the SG patients in comparison with the NSG group. In the other domains, the differences in the observed groups were minimal.

## Discussion

Breast cancer is a progressive disease that has a high prevalence in younger age groups. This cancer greatly affects the quality of life of patients and their families. The support of the family and loved ones is important for patients with breast cancer. Social support of patients who share the same fate forms a crucial form of assistance in the process of adaptation to the cancer, but also in improving the quality of life of patients. We investigated the effect of the disease on personal relationships, how the cancer influences the sex lives of patients, and the degree of social support in the social quality of life of patients with breast cancer. We compared SG patients and NSG patients. We found significant differences between the observed groups in experience, social relationships and sex life.

In our study, we cannot say unequivocally that there is clear significant evidence of support for a self-help group. Although we sought to create homogeneous and comparable groups of respondents in terms of treatment and disease, we could make comparisons; using other variables such as the level of human health, the level of understanding of the disease and many other factors. In terms of oncological symptoms, we could better evaluate the quality of life for women visiting their support group in the area of general health, physical functionality, performance, and task fulfilment, cognitive and social functions only at the level of average values. These ratings have not been significantly confirmed.

Insomnia was better assessed in patients attending the self-help group at a statistical level of  $p<0.05$ . Other areas of the EORTC QLQ-C30 questionnaire were not statistically proven. The sexual area of the respondents not attending the SG was evaluated for differences in the EORTC QLQ-BR23 questionnaire compared with the WHOQOL-BREF questionnaire. Among the important factors influencing the quality of life of women in our group was the availability of health services, where this issue was better evaluated by patients visiting a self-help group.

Žiaková and Maštenová [20] claim that belonging to self-help group in oncology patients significantly influences the improvement of the quality of interpersonal relationships in women with breast cancer. The research was conducted on a sample of 44 cancer patients, 39 of whom had breast cancer and 5 women had other oncological diseases [20]. In their study, Kornblith and Liqibel [21] point out that the image of one's own body and the sexual life of breast cancer patients are closely linked. Based on the outcomes of a paper, we may confirm that SG patients have a better sex life than NSG patients [21]. Many studies confirm that patients who attend self-help group, whether in the form of personal meetings or on-line meetings of support groups, have a higher degree of social support in comparison to female patients who do not attend self-help groups in any form [22-24]. The given finding is also confirmed by the study of Sowa et al., which showed statistically significant differences in the areas of body image ( $p=0.037$ ), life perspective ( $p=0.031$ ), as well as symptoms of breast cancer ( $p=0.001$ ) in favor of female members of self-help groups compared with the control group [24]. When comparing the psychological health of patients with breast cancer, we found more significant differences in the rating of perception of the image of one's own body, where the quality of life and ability to cope with changes in body image were rated better by the SG patients ( $p=0.046$ ). SG patients achieved better results than NSG patients in self-appraisal. In their research, carried out on a sample of 44 oncology patients, Žiaková and Maštenová also state that better results in the rating of their life and the discovery of a new energy in life are reported by SG patients [20]. Various studies report that between 25 and 99% of cancer patients experience fatigue, and that it is at its worst during chemotherapy treatment. In addition, breast cancer is often associated with high levels of distress and co-occurs with other symptoms such as pain, sleep disturbance and depression. The disease itself affects quality of life and reduces engagement in social activity and work [25,26].

In a study by Bencová, Krajčovičová [27], in a sample of 127 patients diagnosed with breast cancer, they assessed nine variables: physical, familial, cognitive, and emotional functionality, fatigue, pain, nausea and vomiting. The analysis of the variables showed that psychosocial distress played the biggest role in the poor quality of life of all patients [27]. Outcomes confirmed that a significant increase of psychosocial distress in patients for three years after the treatment ( $p<0.001$ ) comprised predominantly of emotional dysfunction (anxiety, nervousness, irritability, loneliness, perception of the future). Emotional psychological dysfunction, together with some social variables (financial concerns, threat, or job loss), significantly worsen the quality of life of these women. Many published studies [28-30] report a prevalence of anxiety and depression in the range of 22-27% in oncology patients at the beginning of treatment. Similarly, moderate to severe stress occurs, which assumes an increased incidence of stress-related disorders among other psychological problems, especially within 6 months after diagnosis [31]. The results point to the need to develop a support system for oncology patients, which should include and consider psychological aspects in addressing the physical needs of women with breast cancer.

## Conclusions

Our pilot study had a non-randomized, cross-sectional design with 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 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.



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