

Assessment of knowledge of cancer and lymphoedema among breast cancer survivors

Aleksandra Krzywonos¹, Katarzyna Ochątek¹, Anna Krzywonos-Zawadzka², Kamil Pitala³

¹Department of Rehabilitation in Traumatology, Clinical Rehabilitation University School of Physical Education, Cracow, Poland

²Department of Clinical Chemistry, Medical University of Wrocław, Wrocław, Poland

³Cracovian Center of Orthopedy and Rehabilitation, Cracow, Poland

Abstract

Aim: To evaluate the knowledge of breast cancer and lymphoedema symptoms among mastectomy survivors.

Material and methods: The research was carried out in the Centre of Oncology Branch in Cracow. The survey comprised 60 hospitalized patients as well as 30 healthy subjects from the Małopolska region. The scientific method used was a specially designed questionnaire.

Results: Women with a history of cancer demonstrate a health-oriented approach. The subjects known as the experimental group perform breast self-examinations, regularly visit a gynaecologist, are aware of the most severe mastectomy complication – lymphoedema, and recognize the impact of physical activity on it. Breast cancer operation survivors have a good knowledge of breast cancer and lymphoedema, however, existing shortcomings in practical issues are worrying. On the contrary, the control group neglects regular check-ups, evaluates its own knowledge as negligible and, most surprisingly, is not interested in the subject of breast cancer and lymphoedema, even though the subjects of the group believe that arm swelling is connected to all types of breast cancer surgeries.

Conclusions: Breast cancer survivors have a good knowledge of their disorder but are still lacking some essential information. Respondents from the control group have a limited knowledge in the field of cancer and lymphoedema, are not interested in breast cancer matters and are not encouraged by gynaecologists to perform breast self-examinations. Educational prevention programs should develop a health-oriented approach among all women and emphasize their basic role in therapy.

Key words: breast cancer, lymphoedema, knowledge, education, prevention.

Introduction

Nowadays, breast cancer is the most common cancer among Polish women. Breast cancer is the main cause of death among Poles between 40 and 55 years old. According to the Ministry of Health forecast, every fourteenth Pole will have breast cancer during her lifetime [1]. Standard treatments including surgery (axillary node dissection) and radiotherapy are consequently causing lymphatic system disorders [2-4]. Antineoplastic treatment is the main cause of lymphoedema that is not only associated with long-term physiotherapy, psychological damage, and deterioration of the quality of life, but also increases the risk of concomitant disorders (such as infections, inflammations or erysipelas) [5-11]. The statistics reflect the occurrence of lymphoedema associated with breast cancer surgery, reaching up to 50% of all cases (depending on the type of operation) [12]. According to the current knowledge, most of the breast cancer risk factors as well as the number of lym-

phoedema-causing factors are modifiable [10, 13-18]. As reported by the European Code Against Cancer, even 80-90% of all types of cancer cases in Western populations can be assigned to environmental factors, such as eating habits and socio-cultural behaviours. Elimination or limitation of the exposure to risk factors should result in a reduced number of breast cancer incidences and subsequently, reduced number of lymphoedema incidences. These are all goals of early prevention, primary prophylaxis and educational programs that participants declare to be familiar with. The aim of this work was to evaluate the knowledge of breast cancer and following lymphoedema, among breast cancer survivors.

Material and methods

The survey was conducted among 90 women, taking as a criterion the minimum age of 25 years (suscep-

Corresponding author:

Aleksandra Krzywonos, Katedra Rehabilitacji Ruchowej, Akademia Wychowania Fizycznego im. Bronisława Czecha w Krakowie, 78 Al. Jana Pawła II, 31-571 Kraków, Polska, e-mail: aleksandrakrzywonos@wp.pl

Submitted: 19.05.2014

Accepted: 8.09.2014

tibility to breast cancer starts before the age of 24 years old) [19].

The subjects ($n = 90$) were divided into two groups: an experimental group of 60 women and a control group of 30 women with a non-random sampling method.

The experimental group (EG) was comprised of the consecutive patients from Małopolska treated for breast cancer at the Centre of Oncology Branch in Cracow and were one week after mastectomy surgery. The sample size was estimated on the grounds of the number of patients who underwent mastectomy in the Centre of Oncology Branch in Cracow during the previous year, taking under consideration the confidence level and the confidence interval. The control group (CG) included consecutive patients from gynaecological wards in Cracow (residents of Małopolska). To obtain basic data and trends regarding the pilot study, convenience sampling was used among consecutive patients who declared no cancer history.

The research method was the author's questionnaire designed on the basis of relevant literature. The survey consisted of 26 closed questions concerning breast cancer and lymphoedema. The interviewer administered the questionnaire to the participants and then, the 100% anonymous surveys were analyzed. The surveys were linked to the participants via an identification number. The author did not need to receive ethics approval for the study because of the nature of the method used. The time frame of participants' recruitment was 3 months.

All of the approached participants from the Centre of Oncology agreed to take part in the survey.

Statistical analysis was performed using Statistica v.8.0 (StatSoft, Cracow, Poland) and Microsoft Excel. The Pearson χ^2 test was used for a multi-variant analysis. P value of < 0.05 was considered to be significant.

Results

The study group was diverse in terms of age, place of residence and education.

The average age of the women was 58.7 years old. The youngest respondent was 37 and the oldest one was 82 years old. The women in the control group were on average three years younger. The standard deviation (SD) of age in the study group was $SD = 9.76$ and in the control group $SD = 7.37$.

Most of the respondents (64.4%) live in urban areas, the rest of the respondents (35.6%) live in rural areas. Higher education was declared by 30% of the subjects, 32.2% had a vocational education: 27.8% – secondary education, 10% – primary education.

The analysis concerned the knowledge of breast cancer risk factors and lymphoedema. The results obtained in the experimental group were compared with the ones from the control group (Table I). The women

were asked whether they had performed breast self-examination at least once in their lives. In the EG, 81.7% of the respondents reported that they performed the examination, while in the CG, up to 66.7% of the respondents never practiced it. Another question was related to gynaecologist check-ups. Sixty three point three percent (63.3%) of respondents in the EG declared regular visits, while in the CG most women (56.7%) visit their gynaecologists irregularly. A small number of women do not visit any gynaecologist.

Subsequently, the participants of the study were asked if the gynaecologist had ever asked them about breast self-examination and had showed them how to correctly perform it. The responses in both groups were similarly distributed – there were no statistically significant differences. Fifty-five percent (55%) of the EG and 50% of the CG, respectively, have never been questioned by the doctor about breast self-examination and have not received any instructions. Only 20% of the women in the EG and 6.7% in the CG were both requested and instructed. Knowledge of the most serious breast cancer surgical treatment complications turned out to be good in the EG – 60% of subjects indicated lymphoedema. On the contrary only 13.3% of the respondents in the CG indicated lymphoedema. The awareness of the lymphoedema treatment centres existence is significantly higher in the group of the operated women. Such centres are practically not known in the CG. Another question was aimed at assessing the subjects' knowledge concerning breast cancer and lymphoedema. Over forty-three percent (43.3%) of the respondents in the EG claimed to have a good level of knowledge while 40% considered their knowledge as sufficient. The answers in the CG were different – none assessed their knowledge as very good or good, 46.7% considered it as sufficient, 16.7% as insufficient and 36.7% declared a negligible level of knowledge. Sixty-five percent (65%) of respondents in the EG admitted that the lack of physical activity after breast cancer surgery may be due to the lack of knowledge. On the contrary, in the CG, 63.3% did not believe that lack of knowledge was the reason for the lack of activity in the group. The majority of respondents in both groups claimed that they have no knowledge concerning the impact of diet on lymphoedema treatment after breast cancer surgery.

Majority of subjects in both groups declared their knowledge of preventive actions (78.3% in the EG and 56.7% in the CG). Additional sources of information about breast cancer and lymphoedema for the EG are health care professionals (35%), medical sources (25%), internet portals and medical services for "amazons" (30%), and other media (10%). Six percent (6%) stated that they did not seek such information. The results in the CG show that 16.6% of respondents asked medical staff to get such information, 23% derived their

Tab. I. The survey questionnaire

Question	Answer	Group				χ^2 test
		Experimental group (EG)		Control group (CG)		
		n	%	n	%	$\alpha < 0.05^*$
Performing breast self-examination at least once during the life time	Yes	49	81.7%	10	33.3%	$\chi^2 = 20.69$ $p < 0.05$
	No	11	18.3%	20	66.7%	
Gynaecologist check-ups	Yes, regularly	38	63.3%	11	36.7%	$\chi^2 = 6.34$ $p < 0.05$
	Yes, but irregularly	21	35%	17	56.7%	
	No	1	1.7%	2	6.7%	
Gynaecologist asking women if they perform breast self-examinations or giving instructions how to perform the self-examination correctly	Yes, the doctor asked and showed me how to do it correctly	12	20%	2	6.7%	NS
	Yes, the doctor asked but he/she did not show me how to do it correctly	15	25%	13	43.3%	
	No, the doctor did not ask and did not show	33	55%	15	50%	
Attitude towards mammography	I feel uncomfortable, but it is worth doing	16	26.7%	7	23.3%	NS
	I am doing mammography willingly as taking care of my health	33	55%	19	63.3%	
	Unconcerned	10	16.7%	4	13.3%	
	I am too embarrassed to do it	1	1.7%	0	0%	
The most severe complication after breast cancer operation	Scar	8	13.3%	10	33.3%	$\chi^2 = 20.60$ $p < 0.05$
	Lymphoedema	36	60%	4	13.3%	
	Weakening of the body	7	11.7%	7	23.3%	
	Psychological damage	8	13.3%	5	16.7%	
	Pain	1	1.7%	4	13.3%	
Knowledge about treatment centres for breast cancer survivors	Don't know	16	26.7%	15	50%	$\chi^2 = 24.86$ $p < 0.05$
	There are no places like this	6	10%	12	40%	
	There are places like this, but I do not know them	16	26.7%	2	6.7%	
	There are places like this, I know them	22	36.7%	1	3.3%	
Self-assessment of knowledge about breast cancer and lymphoedema (in 1-5 scale)	Very well	5	8.3%	0	0%	$\chi^2 = 38.96$ $p < 0.05$
	Well	26	43.3%	0	0%	
	Enough	24	40%	14	46.7%	
	Insufficiently	5	8.3%	5	16.7%	
	Hardly know	0	0%	11	36.7%	
Lack of knowledge can be the cause of low physical activity in breast cancer survivors	Yes, if women knew that physical activity is important, they would exercise	39	65%	11	36.7%	$\chi^2 = 6.50$ $p < 0.05$
	No, lack of knowledge is not the reason for low physical activity	21	35%	19	63.3%	
Impact of diet on lymphoedema after breast cancer operation	Yes	12	20%	1	3.3%	$\chi^2 = 11.41$ $p < 0.05$
	No	20	33.3%	4	13.3%	
	Don't know	28	46.7%	25	83.3%	

Tab. I. Cont.

Question	Answer	Group				χ^2 test $\alpha < 0.05^*$
		Experimental group (EG)		Control group (CG)		
		n	%	n	%	
Knowing about preventative educational actions about breast cancer (in the mass media/health centres/from medical staff, etc.)	No	13	21.7%	13	43.3%	NS
	Yes	47	78.3%	17	56.7%	
Information source about breast cancer and its complications	Health professionals	21	35%	5	16.7%	$\chi^2 = 33.68$ $p < 0.05$
	Specialized media – medical magazines	15	25%	0	0%	
	Internet – the Amazon web portals and medical portals	18	30%	0	0%	
	Non-specialized media	6	10%	7	23.3%	
	Don't search for this kind of information	10	6%	19	63.3%	
Importance of physical activity as a prophylaxis and treatment of lymphoedema	Yes	57	95%	5	16.7%	$\chi^2 = 57.58$ $p < 0.05$
	No	0	0%	5	16.7%	
	Don't know	3	5%	20	66.7%	
Overexertion has a negative influence on arm lymphoedema	No influence if performed rarely	6	10%	20	66.7%	$\chi^2 = 49.49$ $p < 0.05$
	No influence even if performed often	1	1.7%	2	6.7%	
	No influence at all	0	0%	4	13.3%	
	Yes, overexertion should be avoided	53	88.3%	4	13.3%	
Special cosmetics for lymphoedema affected arm may impact the size and degree of the oedema	No, there is no need to use some special cosmetics	33	55%	22	73.3%	NS
	Very little influence	17	28.3%	3	10%	
	Yes, significant/insignificant influence if used for a short time only	2	3.3%	0	0%	
	Yes, significant impact, special cosmetics should be always used	8	13.3%	5	16.7%	
Lymphoedema appears after every breast cancer operation	Yes, it is common after this type of treatment	9	15%	19	63.3%	$\chi^2 = 21.80$ $p < 0.05$
	No, it does not appear always, it depends on the type of operation	51	85%	11	36.7%	
Use of contraceptive pills	Yes	1	1.7%	1	3.3%	NS
	No, never used them	45	75%	22	73.3%	
	No, but I used them some time ago	14	23.3%	7	23.3%	
Contraceptive pills can be a risk factor for breast cancer	Yes	23	38.3%	6	20%	$\chi^2 = 9.90$ $p < 0.05$
	No	6	10%	11	36.7%	
	Don't know	31	51.7%	13	43.3%	
Exposure to risk factors (radiation exposure, ionizing radiation, high magnetic field) during your current or previous job	Yes	2	3.3%	1	3.3%	NS
	No	55	91.7%	25	83.3%	
	Don't know	3	5%	4	13.3%	

knowledge from non-specialist sources of information and media, up to 63.3% did not seek any information concerning this topic.

Ninety-five percent (95%) of the women in the EG confirmed the importance of physical activity in the treatment and prevention of lymphoedema, while 5% had no knowledge concerning this topic. In the CG, only 16.7% confirmed the beneficial effects of exercise, as many women questioned the positive impact of activity but the majority of women (66.7%) did not know whether the physical activity affected the swelling. At the same time, 66.6% of the CG believed that strain, if rare, does not affect lymphoedema. In contrast, 88.3% of EG said that overexertion should be avoided.

Different answers were obtained regarding the use of special cleaning agents and their impact on the quality and size of the swelling. Eighty-five percent (85%) of the Oncology Centre patients acknowledged that swelling occurrence depends on the type of procedure in contrast with the CG, where 63.3% consider lymphoedema to occur irrespectively of the operation type.

Both groups have a similar distribution of responses concerning the contraceptive pills intake. However, the groups differ significantly in their opinions regarding the pills as a risk factor for breast cancer. Another question was related to exposure to risk factors such as ionizing radiation or high magnetic fields at work. In the EG, 3.3% declared to be exposed to such stimuli, 91.7% of the women were not exposed, 5% did not know. In the CG also, 3.3% were exposed, 83.3% were not exposed and 13.3% did not know if the work environment exposed them to this type of stimulus. In addition, in the EG, 73.3% of women confirmed suffering from lymphoedema. Over sixty-eight percent (68.3%) of patients from the EG received education on and prevention of further treatment after the mastectomy surgery.

Discussion

An individual sense of responsibility for one's own health is a factor that determines regular medical appointments and examinations, monitoring alarming symptoms and participation in preventive actions. It is mainly the medical personnel who is responsible for the development of the health-oriented approach by educational activities in providing information to patients as well as in eliminating the prevailing false stereotypes about health and diseases. In the context of this study, one of the manifestations of pro-health approach is breast self-examinations, despite the fact that the benefits in reducing mortality are uncertain.

Regardless of the research centre, the results concerning breast self-examinations are similar – Paździur *et al.* demonstrates that 70% of the surveyed patients performed examinations [20], while Lewandowska *et al.* concludes that such examinations were declared by

a total of 82% of the respondents – she indicates, however, that only 20% practice them regularly [21]. The author's own results are inconsistent. Nearly 67% of the women in the CG have never practiced breast self-examinations. The potential answer to why women do not check their breasts can be found by analyzing the results of the questions related to the visits to a gynaecologist. The women in both groups, although they are under the control of a gynaecologist – in the EG more regularly than in the CG – have never been asked by a gynaecologist about breast checking and have not been instructed how to properly perform the test (50% and 55% in the EG and CG, respectively). In her study Cichońska *et al.* presents results showing that as many as 82% of the subjects during their visits to the gynaecologist have never had their breasts professionally examined [22]. It should also be noted that an important factor influencing the quality of breast examination is the phase of the menstrual cycle – a woman should control her breasts on the second or the third day of the menstrual cycle. In the cited study by Paździur *et al.*, up to 42% of the women practicing the examination conduct it on any day of the cycle [20].

Przysada *et al.*, in his study, emphasizes a broader knowledge of the research and the information related to the disease among the people with genetic predispositions to neoplasm [23]. Similarly, in the author's own study, women with a history of disease have a greater knowledge and awareness regarding examinations and possible complications. Sixty percent (60%) correctly indicate lymphoedema as the most serious complication of the surgical breast cancer treatment. However, the women in the CG feared postoperative scars the most (34%) and they indicated lymphoedema only in the last place on a par with pain (13%).

Although the majority of mastectomy survivors perceive their knowledge in the field of breast cancer and lymphoedema as good, it is impossible not to notice that it is fragmentary. Nearly 60% had no idea of the treatment centres for women after cancer treatment, or they did not know where to find such places. What that means in practical terms is that most patients after mastectomy do not know where to look for help in the postoperative period.

What is more, patients in both groups were not able to assess the impact of diet on swelling.

Women in the CG assess their knowledge as sufficient, incomplete or negligible, while the latter two responses were given by the majority of the respondents. The question about the reasons for such a low cancer awareness among women from Małopolska appears in the last two questions. Firstly, it may be due to poor sources of information concerning breast cancer and its complications, indicated by the respondents in the CG. There is a low topicality and quality of information presented in the popular press and television. On the

contrary, the EG receive the necessary information from the medical staff, look for it in medical magazines or on the internet on specific websites, including portals for “amazons” and they respond rather well. Cichońska *et al.* confirms that the expected source of information concerning cancer disease prevention is the medical staff, but also people with a history of disease. The best way of providing the information, according to the surveyed persons, is a direct interview [22]. Nevertheless, as it was stated in the Florek-Łuszczki’s study, only 25% of women receive information on cancer from gynaecologists while TV is the source for 60% of the respondents [23].

According to the study of Przysada *et al.*, doctors are a source of information only for 4% of the respondents. What is more, 60% of women during their medical visits sporadically have their breast controlled and over one third of women have never been advised to perform ultrasound or mammography [24]. It is obvious to point to the fact that gynaecologists still insufficiently participate in health promotion and disregard the subject of both cancer and lymphoedema, despite the strong emphasis on the importance of the educational activities in “Recommendations on the prevention and early diagnosis of changes in the mammary gland” issued by the Board of the Polish Gynaecological Society [25]. The importance of dialogue between the medical staff and patients is also emphasized by Ridner in his comprehensive study on the impact of education on lymphoedema among breast cancer women [4]. Nevertheless, medical professionals’ educational task is not as easy as it may be thought while there is not much interest among healthy Poles in the most killing cancer [1]. This issue is also highlighted by Cichońska *et al.* who claims that some women deliberately postpone examination, some of them are not interested in it, and some underestimate the problem and believe that they are not affected [22]. The described approach is similar among the women in our study who admitted that they do not seek cancer-related information, they are also not aware if during their work they are exposed to risk factors. However, these are attitudes that cannot be accepted, firstly for health reasons and secondly from an economic point of view. Women need to understand that the process of therapy depends mainly on their attitude and on observing their own body, controlling distressing symptoms and compliance with the examination calendar. It is essential to remember that to achieve a therapeutic success there is not only a need for well-prepared and professional medical staff but as also for an aware, involved and participating patient.

Taking into consideration that knowledge of the risk factors and implementation of preventative behaviour can minimize the risk of cancer and consequently the risk of lymphoedema, educational programs to prevent cancers have been designed. The question is if they

could expand women’s knowledge, bring some essential facts and prompt women to change their lifestyles. The survey shows that healthy women from Małopolska are not interested enough in expanding their knowledge in this field. That forces us to think about the changes that need to be done to improve awareness of women, modifications that will fill in huge information gaps. The author’s findings suggest that such a program can be designed to overcome the knowledge gaps.

In the future, possible confounding factors such as medical education and cancer history in the family of participants should be taken into account to improve the survey. Results will be more valuable if the survey group is enlarged in the future.

Disclosure

Authors report no conflict of interest.

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