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## Ocena realizacji potrzeb informacyjnych i edukacyjnych kobiet w trakcie szpitalnego leczenia raka gruczołu piersiowego

### Streszczenie

**Wstęp.** Rak piersi jest najczęstszym nowotworem złośliwym u kobiet w Polsce. Liczba nowych zachorowań zwiększa się corocznie. Wspomniany wzrost zachorowań oraz stosunkowo późne rozpoznanie choroby nowotworowej warunkują coroczne pojawianie się dużej liczby kobiet wymagających opieki szpitalnej i obciążającego leczenia.

**Cel.** Celem pracy była ocena potrzeb informacyjnych i edukacyjnych kobiet leczonych szpitalnie z powodu raka gruczołu piersiowego.

**Materiał i metoda.** Badana grupa składała się z 116 kobiet – członkiń Lubelskiego Stowarzyszenia Amazonek będących w wieku 35-82, z rakiem piersi rozpoznany w okresie: 1992-2008. Badanie miało charakter retrospektywny. Zastosowano autorski kwestionariusz wywiadu. Pytania dotyczyły realizacji potrzeb związanych z adaptacją i pobytem w szpitalu w trakcie leczenia raka gruczołu piersiowego.

**Wyniki.** Analiza udzielanych odpowiedzi wskazuje, iż istnieje wiele, od lat nierozwiązanych problemów informacyjnych i edukacyjnych dotyczących pobytu w szpitalu i przebiegu leczenia raka piersi. Przed 8-18 laty nie mniej, niż 1/3 pacjentek odczuwała niedostatek wiedzy na temat: objawów ubocznych i powikłań leczenia, diet zalecanych podczas leczenia choroby nowotworowej, możliwości rehabilitacji, bezpieczeństwa stosowania leczenia alternatywnego oraz radzenia sobie ze stresem. Wspomniane bolączki były także aktualne 2-7 lat temu. Z czasem pojawiły się nowe, nurtujące i niezaspokojone pytania, jak chociażby pytanie o nowy typ leków wspomagających leczenie – o prebiotyki i probiotyki.

Ponad 1/2 ankietowanych kobiet uznała, iż najbardziej cenionymi przez nie źródłami niezbędnych informacji były: broszury przeznaczone dla osób z chorobą nowotworową, kontakt z onkologami, psychologami i rehabilitantami oraz byłyimi pacjentkami, czyli osobami uprzednio leczonymi z powodu raka gruczołu piersiowego.

**Wnioski.** Kobiety z rakiem piersi stanowią dużą grupę ludzi charakteryzujących się specyficznymi potrzebami edukacyjnymi, medycznymi i psychologicznymi. Obecnie, wiele z tych potrzeb pozostaje nierozwiązanych. Część z nich może być zrealizowana poprzez zastosowanie lepszych procedur edukacyjnych i informacyjnych.

**Słowa kluczowe:** rak gruczołu piersiowego, potrzeby edukacyjne, niezadowolenie, organizacje non-profit.

## An evaluation of the execution of the educational and informational needs of women during hospital treatment for breast cancer

### Abstract

**Introduction.** Breast cancer is the most common type of malignant cancer among women in Poland. The number of new cases increases annually. The aforementioned rise in the number of new breast cancer cases and the fact that the tumour is usually diagnosed relatively late are the main causes behind the large number of patients who require hospital care and aggressive treatment annually.

**Aim.** The aim of the study was the evaluation of informational and educational needs of women undergoing hospital treatment for breast cancer.

**Material and method.** The tested group consisted of 116 women – the members of the Post-Mastectomy Women's "Amazons" Club in Lublin aged 35-82, who had breast cancer diagnosed within the 1992-2008 period. The examination was retrospective in character. An original questionnaire was applied. The questions concerned the execution of needs in relation to the adjustment and hospitalisation of women treated for breast cancer.

**Results.** The analysis of the answers given in the questionnaire indicates that there are a lot of informative and educational problems which have not been solved for many years, concerning the hospitalization of women with breast cancer. It is noted that 8-18 years ago, no less than 1/3 of polled patients were satisfied with their knowledge on the subjects of: the side effects and the complications after the therapy applied, dietary recommendations for patients treated for cancer, the possibilities for rehabilitation therapy, the safety of applying an alternative therapy as well as coping with stress. The same worries were also relevant 2-7 years ago. Over the years, some new pervading and disquieting questions have appeared – such as the question concerning the new type of medications, prebiotics and probiotics which aid the cancer treatment.

More than 1/2 of polled women enumerated the following sources of necessary information as most valuable: brochures aimed at women with cancer, contacts with oncologists, physiotherapists and psychologists, as well as former breast cancer patients. These opinions had remained almost unchanged for many years.

**Conclusions.** The women suffering from breast cancer constitute a large group of people with specific educational, medical and psychological needs. Currently, many of these needs remain unfulfilled. Some of them may be met by the application of better educational and information procedures.

**Key words:** breast cancer, educational needs, dissatisfaction, non-profit organizations.

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## INTRODUCTION

Breast cancer is the most common malignant disease affecting women in Poland. Data taken from the Cancer Registry Centre enumerate 13 322 new cases registered in 2006 (at that time the number of all new cases of malignant tumours in females was equal to 61 927), that means 21.5% of all newly registered neoplasms in women.

During 6 years (2000-2006) the number of breast cancers registered annually increased by 1 469, that is by 12% (Polish National Cancer Registry).

Partial data collected during the last 3 years suggest that the alarming trend still lasts.

The Polish Ministry of Health expects that:

- every 14th woman in Poland will suffer from breast cancer during her lifetime
- almost a quarter of Polish women who will go down with any type of cancer, will suffer from breast cancer.

Poland is a country where there is a registered average value of the coefficient of breast cancer cases (approximately 30/100,000) as well as the growth rate of the mortality caused by the malignant disease. There are problems with late tumor diagnoses in Poland and, as a consequence, the effects of treatment are not satisfying. The aforementioned rise in the number of new breast cancer cases and the fact that the tumour is usually diagnosed relatively late are the main causes behind the large number of patients who annually require hospital care and aggressive treatment. The number of people who are at risk for complications, physical disability (including the consequences of intensive chemotherapy and axillary lymphadectomy) and psychological complications, goes up into thousands.

Most of them require a long-term psychological and orthopaedic rehabilitation and orthopaedic supplies. Moreover, they have specific needs resulting from living under constant danger, the uncertainty of the future, hospitalizations, sense of disfigurement (mastectomy, therapy with the use of drugs blocking ovary functions), problems and complications caused by the cancer therapy and a deterioration in their financial situation (some of them must temporarily suspend their working activities) [1,2].

Patients with breast cancer are, therefore, a group of people with many significant and often unsolved problems. Malignant breast diseases affect women of different professional and social status, education degrees, medical knowledge and intellectual capabilities. These diseases affect people with different skills in managing stress, with different resourcefulness and willingness to be educated and broadening their knowledge.

How do they deal with such problems? How can we help them realize what their special needs are? These are questions of fundamental importance. The answers should provide important guidelines for all people who have the welfare of such women at heart.

## AIM

The aim of the study was the evaluation of informational and educational needs of women undergoing hospital treatment for breast cancer.

## MATERIAL AND METHODS

Between April and August of 2009, a survey study was conducted. The study involved women - breast cancer survivors – who were members and supporters of the Post-Mastectomy Women's Club "Amazons" in Lublin. The examination was retrospective in character.

The tested group consisted of 116 women aged 35-82 (mean 59.7; median 60.0; SD 10.0) who were diagnosed with breast cancer within the period of 1992-2008.

To establish the changes in needs of women over the period of the last 18 years, 2 subgroups of patients were distinguished:

1. subgroup 'a' – women who went down with breast cancer within the period of 2003-2008 (69 subjects)
2. subgroup 'b' – women who went down with breast cancer within the period of 1991-2002 (47 subjects).

An original questionnaire was applied which consisted of 8 close-ended questions. Among them were:

- single-choice and multiple-choice questions concerning the anthropometric parameter, the course of the diseases and the lack of fulfilment of the informational and educational needs during hospital treatment for cancer.
- questions with a ranking scale that dealt with the usefulness of different sources of information during the hospital treatment of cancer.

The questions with a ranking scale referred to the balanced rating scale models with an equal number of favourable and unfavourable response choices and a relative position of items.

The model used was as follows: '0...5', where '0' meant no satisfaction whatsoever, '1' - poor satisfaction, '2' - average satisfaction, '3' - high satisfaction, '4' - very high satisfaction, '5' - full satisfaction [1]. While analysing the questionnaires, the described scale was supplemented by the mark: 'Ø' meaning 'no answers checked'.

## RESULTS

The results obtained in the study are presented in tables located below.

Table 1. presents the unfulfilled informational and educational needs during the hospital stay caused by breast cancer.

Table 2. presents the usefulness of different sources of information available for patients during the hospital course of breast cancer therapy.

When comparing the answers given by the women belonging to both subgroups, one can draw a conclusion, that many of the problems remained unsolved for many years. It is obvious that the degrees of such problems in hospitalized patients have changed, but they have not disappeared and many of them are still significant.

It is noted that 8-18 years ago, no less than 1/3 of patients (subgroup 'b') were dissatisfied with their knowledge of dealing with postoperative scarring and the problems with upper limbs mobility (38% of polled), the side effects of the used therapy methods (51% of polled), the symptoms suggesting the risk of any complications (38%), dealing with the side effects and complications after the used therapy

(38%), the dietetic recommendations (40% of polled), indication for and the possibilities of applying rehabilitation procedures (38%), the safety and the possibilities of applying the so-called alternative therapy (42% of polled), managing stress (51%), the safety and the principles of applying some cosmetic procedures such as manicure and pedicure (42%) and the possibilities of obtaining psychological help (31%) as well as social benefits (48%) – Table 1.

The problems with the information on dealing with the postoperative scarring and the reductions of the limbs mobility, the possibilities of applying rehabilitation

procedures, as well as obtaining psychological assistance, seem to be less essential, but there are other problems which became more disturbing, for example the deficiency of information concerning the use of probiotics and prebiotics (39% of polled from subgroup 'a' and 21% from subgroup 'b') – Table 1.

No less than ½ of polled women, who were diagnosed with breast cancer 2-7 years ago, were dissatisfied with their knowledge of the side effects of the applied anti-cancer therapy (59% of polled – subgroup 'a'), the symptoms of possible complications (53%), managing stress (59%),

**TABLE 1. The informational and educational needs which are not met during the hospital stay of breast cancer patients.**

Deficiency of information on:	Number of polled patients who reported unfulfilled needs.	
	Subgroup 'a'. Diagnose settled 2-7 years ago (69 women)	Subgroup 'b'. Diagnose settled 8-18 years ago (47 women)
the principles of personal hygiene	14 (20%)	12 (25%)
the manicure and pedicure safety	23 (33%)	20 (42%)
the special rules for cleaning dishes, cutlery and appliances for daily use	19 (27%)	16 (34%)
dealing with drains and dressings	12 (17%)	6 (12%)
dealing with the postoperative scarring and the reduction of the limbs mobility	21 (30%)	18 (38%)
the side effects of the applied methods of cancer therapy	41 (59%)	24 (51%)
specific means and appliances used to facilitate personal hygiene	19 (27%)	10 (21%)
the possible complications after the cancer therapy	37 (53%)	20 (42%)
the symptoms suggesting the risk of complications	37 (53%)	18 (38%)
dealing with unexpected medical problems	29 (42%)	18 (38%)
the necessity of purchasing wigs, bedpans, incontinence sheets and other medical supplies	12 (17%)	0 (0%)
dealing with problems such as pains, nausea, constipation	10 (14%)	10 (24%)
diets recommended for patients treated for neoplastic diseases	35 (50%)	19 (40%)
the recommended probiotics and prebiotics	27 (39%)	10 (21%)
the safety of applying the so-called alternative treatment methods	35 (50%)	20 (42%)
the possibilities of applying rehabilitation procedures	15 (21%)	18 (38%)
the procedures associated with obtaining the social service assistance	19 (27%)	23 (48%)
managing stress	41 (59%)	24 (51%)
psychological assistance	13 (18%)	15 (31%)
pastoral help	9 (13%)	1 (2%)

Symbols:

-no less than ⅓ of polled expressed such an opinion.

**TABLE 2. The usefulness of the following sources of information during the course of breast cancer therapy.**

Source:	Group of polled women													
	Subgroup 'a'. Diagnose settled 2-7 years ago (69 women)							Subgroup 'b'. Diagnose settled 8-18 years ago (47 women)						
Mark:	Number of patients giving marks							Number of patients giving marks						
	Θ	0	1	2	3	4	5	Θ	0	1	2	3	4	5
brochures aimed at patients with breast cancer	1	0	2	5	3	0	58	7	0	0	0	3	2	35
oncologists	6	0	0	0	0	3	60	6	0	0	0	2	5	34
nurseries	7	0	0	10	12	8	32	16	0	0	4	7	6	14
dieticians	9	6	0	2	14	3	35	13	2	0	0	2	9	21
physiotherapists	5	0	0	0	2	13	49	4	2	0	0	2	7	32
psychologists	7	10	3	0	0	5	44	11	2	0	0	4	5	25
priests	9	8	4	3	6	13	26	18	4	0	0	2	8	15
former cancer patients	3	2	0	6	10	2	46	10	0	0	1	2	3	32

Symbols:

Θ - no marked answers

- no less than ⅓ of polled expressed such an opinion.

dietetic recommendations (50%) and the safety and the possibilities of applying of the so called alternative therapy (50% of polled from subgroup 'a').

More than 1/2 of polled women indicated the following sources of information for patients hospitalized because of breast cancers as the most valuable: brochures aimed at women with breast cancer (58 women from subgroup 'a' – that means 84% and 35 from subgroup 'b' – that means 74%), consultations with oncologists (the answer was given by 60 women from subgroup 'a' – that means 87% and 34 women from subgroup 'b' – that means 72%), physiotherapists (49 women from subgroup 'a' = 71% and 32 from subgroup 'b' = 68%), psychologists (the answer was marked by 44 women from subgroup 'a' – that means 64% and 25 from subgroup 'b' – that means 53%) and former breast cancer patients (respectively – 46 women (67%) and 32 ones (68%)) – Table 2.

## DISCUSSION

The women suffering from breast cancer are a large group of people with special educational, medical and psychological needs. A number of suggestions for helping these patients was already put forward many years ago [1,3,4] but they are still not fulfilled to a satisfying degree [1].

At present, the questions which require the most urgent answers are those concerning the side effects of the applied therapy, managing stress, the indications for and the safety of applying the so-called alternative treatment. The majority of polled women emphasize the lack of such answers. However, it also indicates that they get hardly any satisfaction from the accessibility to other necessary information. More than 1/3 of polled women were dissatisfied with the limited availability of information on the possibilities of dealing with unexpected medical problems, the symptoms suggesting the risk of complications, managing stress, the recommended probiotics and prebiotics, the safety and the possibilities of applying the so-called alternative therapy as well as the dietary recommendations for patients treated for breast cancer (Table 1). It is within the competence of oncologists, surgeons, dieticians, psychologists, active members of non-profit organisations, etc. to answer such questions. [5,6]. Patients with breast cancer need more information and more time for discussions as well as for psychotherapy [7-9]. The medical staff is aware of these needs which, unfortunately, remain unmet. So, what is the reason for this? It may be due to organizational problems.

Almost all the polled women considered oncologists to be an essential source of necessary information (Table 2). However, there is a question of the factual availability of such specialists. Nowadays, a growing number of new cancer cases can be observed. In 2006 there were 126019 new registered cases of malignant diseases in Poland (data from National Cancer Registry). At the same time there were only 262 oncologists (GUS data) being professionally active in Poland. It makes a total of 481 new cancer cases per one oncologist yearly. A question arises about the time each oncologists may devote to a patient. We need more oncologists to meet the needs of patients with malignant diseases. It is the time to make an appeal to the health service

decision-makers to increase the number of postgraduate oncology courses and the number of oncologists in oncology centres.

The polled women confessed that they had also had problems with the access to other sources of information. The usefulness of advice given to patients by dieticians, psychologists, physiotherapists (Table 2) and social workers is evident. The deficiency of necessary information is most likely caused by the insufficient employment of medical personnel in hospitals and the limited amount of time such specialists can devote to consultations with patients.

The insufficient number of such workers is tightly connected with financial reasons. Nowadays, there is too little money available for medical purposes. Therefore, the managers of oncology centres must choose between the interests of hospitals and the interests of patients. Acknowledging the psychological and educational needs of patients has not given any satisfying profits so far.

In some cases the educational and psychological problems may be solved by priests, volunteers and members of non-profit organizations such as the Polish 'Amazonki' [8,10,11]. This may currently be the best possible solution. Non-profit organizations such as 'Amazonki' should be treated as an essential element of oncological care. A better partnership between 'Amazonki' and oncological centres should enable patients to get in touch with 'experienced' former patients, who suffered from such a disease, survived it and, consequently, know a lot about the problems of women treated for breast cancer. We are aware of the fact that such an idea is not the ultimate solution but it should be taken into consideration as the most profitable one, until better days (and better financial condition of oncology centres) come.

## CONCLUSIONS

The women suffering from breast cancer are a large group of people with special educational, medical and psychological needs. Many of these needs are not fulfilled satisfactorily. Some of them may be met by the introduction of better educational and informational procedures.

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