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## Ocena realizacji potrzeb edukacyjnych i informacyjnych u pacjentek rozpoczynających leczenie z powodu raka gruczołu piersiowego

### Streszczenie

**Wprowadzenie.** Rak gruczołu piersiowego jest najczęstszym nowotworem złośliwym u kobiet w Polsce.

Diagnoza – rak sutka nagle zmienia optykę życia kobiety, stwarza wiele dylematów i powoduje pojawienie się wielu istotnych pytań. Pytania bez odpowiedzi skutkować mogą podjęciem przez chorą niewłaściwej decyzji – odmowa leczenia, przerwanie leczenia lub poszukiwanie alternatywnych metod terapii.

**Cel.** Celem pracy była ocena realizacji potrzeb edukacyjnych i informacyjnych związanych z rozpoznaniem 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.

**Wyniki.** Zdecydowana większość ankietowanych kobiet, w chwili ustalenia rozpoznania nowotworu, posiadała mierną lub zupełnie niesatysfakcjonującą wiedzę na temat choroby. Ponad 50% ankietowanych wyraziło przekonanie, że ich potrzeba wiedzy z zakresu istoty choroby, jakiszczeółówdotyczącychleczenia nie zostały zaspokojone. Ponad 1/3 ankietowanych kobiet wyraziła niezadowolenie z powodu dostępu do materiałów informacyjnych (broшуry dla chorych z rakiem gruczołu piersiowego), ponad połowa – z zakresu informacji przekazanych im przez onkologów. Ponad 40% ankietowanych było nieusatsfakcjonowanych z zakresu informacji uzyskanych od rehabilitantów, dietetyków i psychologów. Spośród wymienianych, najlepiej oceniana jest opieka duszpasterska (zaledwie 23% negatywnych opinii).

**Wnioski.** Kobiety z rakiem gruczołu piersiowego stanowią dużą grupę osób, które charakteryzują się wieloma specyficznymi, często niezaspokojonymi, potrzebami edukacyjnymi i informacyjnymi. Część z tych potrzeb może być zrealizowana poprzez zastosowanie lepszych procedur edukacyjnych i informacyjnych. Celowym wydaje się powołanie do życia nowej specjalności medycznej: opiekuna-edukatora zajmującego się pacjentami z chorobami nowotworowymi.

**Słowa kluczowe:** rak gruczołu piersiowego, rozpoczęcie leczenia, potrzeby edukacyjne, edukatorzy.

## The assessment of fulfilment of educational and informational needs of women who start breast cancer treatment

### Abstract

**Introduction.** Breast cancer is the most common malignant cancer affecting women in Poland. The diagnosis: 'breast cancer' – suddenly changes the perception of the entire surrounding world, creates serious dilemmas and brings to mind many important questions. Questions left without answers may create fear which, in turn, may cause rejection of treatment proposals, ceasing current treatment or looking for alternative methods of therapy.

**Aim.** The aim was to assess educational and informational needs of women who started treatment for breast cancer.

**Material and method.** The tested group consisted of 116 women – the members of the Lublin Amazon Women Association, aged 35-82, with breast cancer diagnosed within 16 years (1992-2008). The retrospective method was used. The original inquiry questionnaire was applied.

**Results.** At the beginning of the therapy, when the diagnosis was settled, almost all the tested women, presented moderate or really unsatisfying knowledge concerning breast cancers. All of them needed to broaden their knowledge and lots of them did not have sufficient information about the disease. More than 50% of women stated that their needs concerning information about the causes of the disease and details of treatment were not fulfilled. More than 1/3 of the polled women were dissatisfied with limited access to brochures addressed to patients with breast cancer; more than half of them – with consultations with oncologists. No less than 40% of the polled women were dissatisfied with the results of consultations with physiotherapists, dieticians and psychologists. The polled women highly appraised priests' care (only 23% women expressed negative opinions).

**Conclusions.** Women who start treatment for breast cancer are a large group of people with special educational, medical and psychological needs which are not fulfilled satisfactorily. Some of these needs may be fulfilled by applying better educational and information procedures. It seems advisable to establish a new medical specialty minder-educator – to take better care of patients with malignant diseases.

**Key words:** breast cancer, beginning of treatment, educational needs, educators.

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## INTRODUCTION

Malignant diseases are serious medical, life threatening problems that impact millions of individuals each year all over the world. The number of new cases registered yearly grows in all industrialized countries. The same medical phenomenon is observed in Poland. In 2006 there were registered 126,019 new cases of malignant diseases. Within six years (2000-2006) the incidence rate increased by 9.9% (increment by 11,372 cases). At the same time, the yearly recorded number of breast cancer incidences increased by 1,469, that is by 12% (Polish National Cancer Registry data).

Breast cancer is the most common malignant cancer affecting women in Poland.

For all the people receiving the initial diagnosis 'breast cancer' – it is something that suddenly changes them and their perception of the entire surrounding world. The information 'you have got breast cancer' – is a shock. For some patients it seems to be a death sentence. These people feel fear and anxiety. Some of them feel isolated. Some of the patients say that such a diagnosis makes them feel the presence of something like a wall around them or they feel as if labelled as damaged, sick and different. Such reactions are part of the emotional stages of breast cancer.

People affected by breast cancers have lots and lots of questions. First of all – 'why?' and 'why me?' Then questions about hazard to life, effects of aggressive treatment procedures, disfiguration caused by surgical treatment (mastectomy and axillar lymphadectomy), future ability to have satisfactory sexual life and also about disabilities (after-effects of long lasting therapy) are raised [1,2]. There are lots of questions but women with the frightful diagnosis are almost unable to think in a rational way. Simple information, simple routine answers and short time devoted by an oncologist to inform a patient about her cancer and suggested treatment are by far insufficient.

Patients with breast cancer are the group of people with many questions, serious dilemmas and suddenly appearing, significant and hard to solve problems (such as necessity to temporarily suspend their working activities).

Having these problems named means taking appropriate steps to solve them. Questions left without answers may create fear which, in turn, may cause rejection of treatment proposals, ceasing current treatment or looking for alternative methods of therapy. Methods such as alternative medicine (herbal remedies, homeopathy, treatment with the use of colours or so-called bio-fields) which seem to be less body-disfiguring, less uncomfortable or safer are just illusory hopes. Such decisions would be the worst ones and may affect the increase in cases of death from breast cancer.

## AIM

The aim was the assessment of educational and information needs of women who started treatment for breast cancer.

## MATERIAL AND METHODS

The tested group consisted of 116 women aged 35-82 years (mean 59.7; median 60.0; SD10.0) breast cancer survivors - members and supporters of the Lublin Amazon Women Association with breast cancer diagnosed within 16 years (1992-2008).

There were distinguished 2 subgroups of patients to find out what were (if any) the changes in the needs of the patients during the last 18 years:

- Subgroup 'a' – women who went down with breast cancer from 2003 to 2008 (69 subjects)
- Subgroup 'b' – women who went down with breast cancer from 1991 to 2002 (47 subjects).

The retrospective method was applied by using original inquiry questionnaire. This questionnaire contained 7 closed-ended questions. Among them:

- one-choice and multiple-choice questions concerning anthropometric parameters, course of the disease and obtaining information as well as educational needs at the moment of getting the breast cancer diagnosis and making preparations for treatment for breast cancer
- ranking scale question concerning the knowledge on the subject of breast cancer possessed by studied women at the time of setting the diagnosis.

The ranking scale questions referred to balanced rating scale models with equal numbers of favourable and unfavourable response choices and relative positions of items.

The used model was as follows: '0-1-3-4-5', where '0' meant no knowledge, '1' – poor knowledge, '2' – rather poor knowledge, '3' – rather good knowledge, '4' – good knowledge, '5' – full knowledge [1]. While analyzing questionnaires, the described scale was supplemented by the mark: 'Ø' meaning 'no answers checked'.

## RESULTS

The obtained results are presented in tables located beneath.

Almost all the interviewed women (94% of women from Subgroup 'a' and 87% of women from Subgroup 'b'), at the beginning of therapy, when the diagnosis was settled, had moderate or really unsatisfying knowledge concerning breast cancers (marks: score 0, 1, 2 or 3; Table 1). Twenty percent (25%) of women from Subgroup 'a' as well as 28% from Subgroup 'b' had no knowledge concerning such disease (marks: score '0' – Table 1).

All of them needed to broaden their knowledge and lots of them had not obtained such information (Table 2). More than 50% of women (from both subgroups) stated that their needs to obtain information concerning causes of the disease were not fulfilled (56% of women from Subgroup 'a' as well as 82% – from Subgroup 'b') and details of treatment at the beginning of cancer therapy (62% of women from Subgroup 'a' and 51% – Subgroup 'b') – Table 2.

No less than 40% of women were dissatisfied with the obtained information concerning duration of planned treatment (40% dissatisfied in Subgroup 'a' and 53%

**TABLE 1. The knowledge concerning breast cancers at the time of getting to know the breast cancer diagnosis**

| Knowledge concerning breast cancers at the moment of getting to know the breast cancer diagnosis.<br>Marks: [scale '0' = no knowledge; '5' = full knowledge]; Ø - no answer | Number of polled women giving marks             |  |
|---|---|--|
|   | Subgroup 'a'.<br>Diagnose settled 2-7 years ago | Subgroup 'b'.<br>Diagnose settled 8-18 years ago |
| Ø   | 1 (2%)  | 0 (0%)   |
| 0   | 17 (25%)  | 13 (28%)   |
| 1   | 7 (10%)   | 6 (13%)  |
| 2   | 12 (17%)  | 7 (15%)  |
| 3   | 29 (42%)  | 15 (32%)   |
| 4   | 0 (0%)  | 6 (13%)  |
| 5   | 3 (4%)  | 0 (0%)   |
| Number of polled women  | 69 (100%)                                       | 47 (100%)  |

**TABLE 2. Not fulfilled needs reported at the beginning of cancer therapy**

| Deficiency of information concerned with  | Number of polled women who reported not fulfilled needs.             |   |
|---|--|---|
|   | Subgroup 'a'.<br>Diagnose settled 2-7 years ago<br>(69 women = 100%) | Subgroup 'b'.<br>Diagnose settled 8-18 years ago<br>(47 women = 100%) |
| causes of the disease   | 39 (56%)   | 39 (82%)  |
| details of treatment  | 43 (62%)   | 24 (51%)  |
| duration of treatment   | 28 (40%)   | 25 (53%)  |
| risk of complications with appearance   | 41 (59%)   | 20 (42%)  |
| possible complications  | 43 (62%)   | 22 (46%)  |
| alternative methods of treatment  | 32 (46%)   | 19 (40%)  |
| the life risk caused by the presence of the malignant disease                   | 27 (39%)   | 18 (38%)  |
| further consequences of the disease as a result of applied methods of treatment | 33 (47%)   | 22 (46%)  |
| rehabilitation  | 25 (26%)   | 20 (42%)  |

**TABLE 3. Dissatisfaction with contacts with selected sources of information available at the beginning of cancer therapy.**

| Dissatisfaction with contacts with:                           | Number of polled reported not fulfilled needs.                       |   |
|---|--|---|
|   | Subgroup 'a'.<br>Diagnose settled 2-7 years ago<br>(69 women = 100%) | Subgroup 'b'.<br>Diagnose settled 8-18 years ago<br>(47 women = 100%) |
| brochures addressed to patients with breast cancer            | 26 (37%)   | 25 (53%)  |
| oncologists   | 57 (82%)   | 29 (61%)  |
| nurses  | 20 (28%)   | 13 (27%)  |
| dieticians  | 32 (46%)   | 21 (44%)  |
| physiotherapists  | 29 (42%)   | 19 (40%)  |
| psychologists   | 28 (40%)   | 21 (44%)  |
| priests   | 16 (23%)   | 11 (23%)  |
| persons being previously cured because of a malignant disease | 22 (31%)   | 19 (40%)  |

in Subgroup 'b'), possible complications (62% and 46% respectively), risk of complications occurrence (59% and 42% respectively), possible further consequences of the disease and applied methods of treatment (47% and 46% respectively).

When analyzing the answers given by the patients – one can notice high levels of dissatisfaction related to majority of available sources of information. It is noteworthy that women with breast cancer diagnosed 2-7 years ago seem to be more critical than those with cancer diagnosed 8-18 years ago (Table 2).

More than 1/3 of the interviewed women in both subgroups (37% of women polled in Subgroup 'a' and 53% – in Subgroup 'b') were dissatisfied with the limited access to brochures addressed to patients with breast cancer; more than half of the patients were dissatisfied with consultations with oncologists (82% of women from Subgroup 'a' and 61% – from Subgroup 'b'). No less than 40% of the studied women were dissatisfied with consultations with physiotherapists (42% of women from Subgroup 'a' and 40% – from Subgroup 'b'), consultations with dieticians (46% and 44% respectively) as well as consultations with psychologists (40% and 44% respectively). Looking at the data collected in Table 3 one can say that women in the study highly appraised priest's care (only 23% women expressed negative opinions).

## DISCUSSION

The diagnosis – breast cancer – means informing a patient about a potentially life-threatening situation and the perspective of applying long lasting, often mutilating and carrying high risk of complications therapeutic procedures.

The obtained data (Table 1) suggest that the level of oncological awareness have not changed significantly over the last few years. Recently, like 8-18 years before, more than 50% of women when informed about their cancers did not possess almost any knowledge concerning breast cancer (marks: 0-2 points with maximum 5 points possible; Table 1). At that time no more than 4% of respondents had sufficient knowledge of breast cancer (mark: 5 points - Table 1).

Women with newly diagnosed breast cancer are a large group of people with special educational, medical and psychological needs. Some of these needs were described many years ago [1,3] but lots of them still have not been solved in a satisfying way. The obtained data suggest that years have passed but the same problems of women treated for breast cancer remain unsolved.

When comparing the answers given by the interviewed women one can notice that the sense of dissatisfaction has changed – but in many cases in an unfavourable way (Tables 2 and 3).

The fact that the level of satisfaction is so low should make us do our best to find reasons and to take proper remedial measures.

Now is the time to diagnose the reasons. To do that we need further studies and more participants. But even nowadays one can draw some conclusions.

We think that the fundamental issue which underlies these problems is connected with organizational troubles (i.e., few psychologists and educators as well as educational means) insufficient financial outlays, insufficient activity of non-profit organizations, underestimating the scale of problems and financial troubles of medical centers.

Thinking about financial problems one can find a counter-argument that financial outlays on health service have raised. However, at the same time the number of patients and the cost of procedures raised as well. For many years the number of employees has not changed much in many oncology centres whereas the number of patients has increased considerably. To fulfil its educational and psychological role, oncology centres need more and more qualified employees. Patients with breast cancer need more information and more time for discussion and psychotherapy [4 - 7]. Some answers must be given by physicians – oncologists [8, 9]. Besides, lack of educational as well as information aid provided by oncologists had been the most irritating disadvantage for the women (82% of the women diagnosed 2-7 years ago and 61% of those diagnosed 8-18 years ago).

In 2006 there were 126,019 new registered cases of malignant diseases in Poland. At the same time there were 262 oncologists (Central Statistical Office data) professionally active in Poland. That makes: 481 new cancer cases per one oncologist yearly. There is the question about the amount of time they may devote to their patients and to conversation with them. Nowadays there can be observed a growing number of new cancer cases. Therefore, we need more and more oncologists. It is time to appeal to healthcare decision-makers to increase the number of oncologist education courses for new oncologists and to increase the number of employees in oncology centres. Facts remain that even in better-developed countries the number of such specialists is not satisfying therefore we must suppose that in many cases some educational and psychological problems should be solved by psychologists, priests and workers of non-profit organizations [10].

To save money, instead of excessive employment of many specialists such as dieticians, psychologists and social workers we need people capable of taking care of patients and fulfilling their important, non-medical needs. We think about a new specialty: minder-educators. By the term 'minder-educator' we understand workers educated to look after patients with cancer (tasks: nursery, education, dietetic advice, psychological care and help with adaptation to hospital conditions). Minder-educators should be assigned to small groups of patients and be active in taking care of them. They should accompany patients from the moment of announcing the diagnosis – 'You have got breast cancer' and do their duty until the treatment is completed. It is time to discuss the usefulness and business value of new type of staff training. We think that usefulness for patients is evident. But the question about the finances (too little money for almost all medical purposes) remains unanswered. Nowadays all managers of oncology centres must take under consideration all issues – those financial, too. So far, fulfilling psychological and education needs is not profitable enough (unfavourable contracts with NFZ (National Health Fund)).

## CONCLUSIONS

Women who start treatment for breast cancer are a large group of people with special educational, medical and psychological needs. Many of these needs are not taken care of in a satisfying way. Some of them may be fulfilled by using better educational and information procedures. It seems advisable to establish a new medical specialty: minder-educator – to take better care of patients with malignant diseases.

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