Praca Oryginalna Zdr Publ 2011;121(1):37-42 Original Article

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# Ocena poczucia bezpieczeństwa zdrowotnego kobiet, które zakończyły leczenie z powodu raka piersi

## Streszczenie

**Wstęp.** Liczba osób, które ukończyły leczenie z powodu raka piersi zwiększa się corocznie. Mimo oficjalnego zakończenia terapii, osoby te zmagają się z licznymi problemami przez pozostałe lata swojego życia.

**Cel.** Celem pracy była ocena poczucia bezpieczeństwa zdrowotnego zgłaszanego przez pacjentki, u których zakończono leczenie szpitalne z powodu raka piersi.

**Materiał i metoda.** Badana grupa składała się z 116 kobiet, członkiń Lubelskiego Stowarzyszenia Amazonek będących w wieku 35-82 lat, z rakiem piersi rozpoznanym w okresie: 1992-2008. W badaniu użyto metody kwestionariusza wywiadu. Zastosowano autorski kwestionariusz zawierający pytania kierowane do kobiet, które ukończyły leczenie szpitalne z powodu raka gruczołu piersiowego.

**Wyniki.** Uzyskane dane sugerują, iż badane kobiety miały wiele zastrzeżeń do stanu opieki medycznej, psychologicznej i socjalnej.

Najmniej zastrzeżeń dotyczyło dostępności i treści broszur skierowanych do kobiet po mastektomii, dostępu do bezpłatnych procedur rehabilitacji (56% badanych) i bezpłatnych porad medycznych z zakresu onkologii (46%). Tylko 28% ankietowanych pozytywnie oceniło dostępność opieki zdrowotnej sprawowanej przez lekarzy innych specjalności. Mniej niż 50% kobiet było w pełni usatysfakcjonowanych dostępem do bezpłatnych badań laboratoryjnych. Najbardziej negatywne opinie dotyczyły możliwości skorzystania z pomocy psychologicznej i socjalnej.

**Wnioski.** Kobiety po leczeniu raka piersi to grupa osób o specjalnych potrzebach medycznych i społecznych. Realizacja wielu z tych potrzeb jest niesatysfakcjonująca. Należy wprowadzić istotne zmiany w zakresie funkcjonowania opieki zdrowotnej i społecznej w celu poprawy istniejącego stanu rzeczy.

**Słowa kluczowe:** rak piersi, kobiety, bezpieczeństwo zdrowotne, potrzeby medyczne, potrzeby socjalne.

# The assesment of women – breast cancer survovors' sense of health security

## Abstract

**Introduction.** The number of breast cancer survivors increases annually. Despite the official completion of the therapy, cancer survivors contend with numerous problems throughout the remaining years of their lives.

**Aim.** The aim of this study was to assess the sense of health security reported by patients who had finished hospital therapy for breast cancer.

**Material and methods.** The tested group consisted of 116 women – members of the Amazon Women Association-Lublin, aged 35-82, with breast cancer diagnosed in 1992-2008. A questionnaire-based method was used. A special original survey questionnaire with questions directed to breast cancer survivors was applied.

**Results.** The obtained data suggest that the surveyed women have got many reservations about the state of medical, psychological and social care.

The fewest reservations were expressed about the availability and content of brochures addressed to women after mastectomy, access to free rehabilitation procedures (56%) as well as to free medical advice in the field of oncology (46%).

Only 28% of respondents were satisfied with the availability of medical care provided by other medical specialists. Less than 50% of women were fully satisfied with the access to free laboratory tests. The most negative opinions concerned the availability of psychological and social care.

**Conclusions.** Women after breast cancer have got special medical as well as psychological and social needs. Many of these needs are not fulfilled. Significant changes in the functioning of health and social care must be provided to improve the status quo.

**Key words:** breast cancer, women, health security, medical needs, social needs.

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## INTRODUCTION

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

The number of new cases increases annually. According to the data from the National Cancer Registry [1] in 2005 there were 13, 385 new cases of breast cancer and 5, 112 deaths caused by such malignant disease. The standardized incidence ratio was 44.5 per 100, 000, while the standardized mortality rate amounted to 14.9 / 100 000.

The improvements in both early detection and treatment of breast cancer make the mortality rate following such a malignant disease, especially in cases diagnosed at their early stages, decrease. Progress in the war against breast cancer has been made, but many challenges still remain. These challenges are connected with the increment in the number of long-term survivors.

The overall 5-year survival ratio observed in Polish breast cancer patients, estimated as 63.1%, means that annually the number of breast cancer survivors increases by 7-8 thousand people.

This is quite a large group of women with special social, psychological and medical problems.

The completion of the therapy is only the end of a period of the survivor's life when the first but maybe not the last episode of the cancerous disease was noticed. Moreover, the use of multi-agent, intensive therapies that improve survival is potentially very harmful to people. So, the feeling of victory over the malignant disease can be achieved at the cost of disfigures, lymphoedema, restriction of shoulder movement and deforming scars being after-effects of applied surgical procedures, as well as it may be accompanied by a loss of some vital potential and sometimes disabilities resulting from drug- or radiation-related multiple-organ, damages. The treatment for breast cancer increases the risk of numerous medical problems. Some of these complications may significantly impinge on the quality of life in patients declared as cured of cancer [2].

That is why such women, despite the official end of the therapy, are persons who should be provided with easy access to medical, psychological and sometimes social care [3, 4]. They should be, but there is a question about the status quo. The answer to this question should become the guideline for social as well as health care decision-makers and urge politicians as well as civil servants to discuss the maintenance of the proper balance between economy and interests of people in need.

## AIM

The aim or this study was to assess the sense of health security reported by patients who had finished hospital therapy for breast cancer.

## MATERIALS AND METHODS

### Selection of respondents

Between April and August 2009, a survey study was conducted in cooperation with a non-profit organization – Amazon Women Association – Lublin, Poland.

The study involved women-breast cancer survivors – the members and supporters of Amazon Women Association – Lublin.

The polled women were former patients of different oncology centres in Lublin. All of them had completed planned stages of treatment and had no apparent evidence of active disease.

The group of respondents consisted of 116 women aged 35-82 years (mean 59.7; median 60.0; SD 10.0) who had been diagnosed with breast cancer within the period 1991–2008. To find out some potential changes in needs within the analysed period two subgroups of participants were distinguished:

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

### Content of the questionnaire

To protect individual privacy of respondents, there was no means of identification included in the questionnaires. The questionnaire contained 15 close-ended questions. Among them:

- one-choice and multiple-choice questions concerning anthropometric parameters, course of the disease as well as applied treatment
- ranking scale questions concerned satisfaction resulting from the availability of free of charge both medical and psychological care, social assistance as well as teaching materials and information bulletins for women-breast cancer survivors
- the one-best-answer question concerning the sense of health security relating to free access to specialized medical care, access to free laboratory testing, medicines and treatment.

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 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 [5]. While analyzing questionnaires, the described scale was supplemented by the mark: 'Θ' meaning 'no answers checked'.

### Methods of data collection

The method of written surveys was used.

It met all requirements necessary to protect individual privacy of the respondents during conducting survey research. The surveys were conducted in the registered office of Amazon Women Association – Lublin.

## RESULTS

The obtained results are presented in Tables 1, 2 and 3.

The data shown in Tables 1 and 2 present the levels of satisfaction (measured by using balanced rating scale: ‘0..5’) with medical, educational, psychological and social needs realization felt by the polled women. The data in Table 1 suggest a high dispersion of the levels of satisfaction resulting from the realization of polled breast cancer survivors’ needs. Relatively, the highest satisfaction (checked levels ‘4’ or ‘5’ out of 5) was felt because of the accessibility to free rehabilitation procedures, too (56% of women checked levels ‘5’ or ‘4’ – that means 33% of them felt full satisfaction, 23% – high satisfaction).

Nearly half of the respondents were really satisfied with the availability, as well as the quality, content and comprehensibility of the text found in the brochures addressed to patients after mastectomy – 47% of the polled (level ‘4’ –18%, level ‘5’ – 29%) and 55% of the polled (level’4’ – 33%, level ‘5’ – 22%), respectively.

Less than 50% of the polled women confessed that they were really satisfied (levels ‘4’ or ‘5’) because of the access to free medical advice in the area of oncology, only 28% – because of free accessibility to other medical specialists (level ‘4’ –14%, level ‘5’ – 14%).

Less than 45% of the women expressed their full or very high satisfaction (levels ‘4’ or ‘5’) because of possibilities of getting orders that enable their having free lab tests performed (level ‘4’ – 24% of the polled cancer survivors, level ‘5’ – 20% of the polled ones).

The opinions on the availability of free psychological assistance and social care quality (possibilities of getting any financial help) were much less positive– respectively 38% and 15% of the polled women checked levels “4’ or ‘5’ (when asked about the access to financial assistance – 51% checked level ‘0’).

**TABLE 1. The level of satisfaction resulting from possibilities of realizing medical, psychological and financial needs reported by breast cancer survivors.**

| Needs<br>Level of satisfaction | Number (%) of respondents giving marks | | | | | | |
|---|---|---|---|---|---|---|---|
| | Θ | 0 | 1 | 2 | 3 | 4 | 5 |
| Access to brochures addressed to patients who completed treatment for breast cancer | 13 (11%) | 20 (17%) | 6 (5%) | 4 (3%) | 17 (15%) | 22 (18%) | 34 (29%) |
| Quality of content and comprehensibility of text of brochures addressed to patients after mastectomy | 25 (22%) | 8 (7%) | 0 (0%) | 5 (4%) | 15 (13%) | 38 (33%) | 25 (22%) |
| Access to free medical advice in non-oncology areas | 19 (16%) | 14 (12%) | 16 (14%) | 4 (3%) | 31 (27%) | 16 (14%) | 16 (14%) |
| Access to free medical advice in area of oncology | 13 (11%) | 9 (8%) | 15 (13%) | 2 (2%) | 23 (20%) | 27 (23%) | 27 (23%) |
| Access to financial assistance | 17 (15%) | 59 (51%) | 11 (9%) | 6 (5%) | 6 (5%) | 7 (6%) | 10 (9%) |
| Access to free psychological assistance | 22 (19%) | 17 (15%) | 4 (3%) | 7 (6%) | 21 (18%) | 11 (9%) | 34 (29%) |
| Access to free rehabilitation procedures | 17 (15%) | 6 (5%) | 6 (5%) | 4 (3%) | 18 (16%) | 27 (23%) | 38 (33%) |
| Possibilities of getting orders that enable having free lab tests performed | 15 (13%) | 12 (10%) | 6 (5%) | 6 (5%) | 26 (22%) | 28 (24%) | 23 (20%) |

Data present the number (percentage) *of* **respondents** declaring selected level of satisfaction
Θ – no answer checked

**TABLE 2. The level of satisfaction resulting from possibilities of meeting medical, psychological and financial needs reported by women who have completed hospital therapy for breast cancer – data concerning subgroups of polled women.**

| Needs | Subgroups of polled women | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Subgroup ‘a’ (69 women) | | | | | | | Subgroup ‘b’ (47 women) | | | | | | |
| | Number of respondents giving marks | | | | | | | Number of respondents giving marks | | | | | | |
| Level o satisfaction | Θ | 0 | 1 | 2 | 3 | 4 | 5 | Θ | 0 | 1 | 2 | 3 | 4 | 5 |
| Access to brochures addressed to women who have completed treatment for breast cancer | 7 | 18 | 4 | 4 | 11 | 11 | 14 | 6 | 2 | 2 | 0 | 6 | 11 | 20 |
| Quality of content and comprehensibility of text of brochures addressed to patients after mastectomy | 12 | 8 | 0 | 5 | 10 | 23 | 11 | 13 | 0 | 0 | 0 | 5 | 15 | 14 |
| Access to financial assistance | 9 | 42 | 3 | 4 | 1 | 7 | 3 | 8 | 17 | 8 | 2 | 5 | 0 | 7 |
| Access to free medical advice in non-oncology areas | 7 | 12 | 10 | 3 | 17 | 14 | 6 | 12 | 2 | 6 | 1 | 14 | 2 | 10 |
| Access to free medical advice in area of oncology | 7 | 9 | 12 | 0 | 15 | 16 | 10 | 6 | 0 | 3 | 2 | 8 | 11 | 17 |
| Access to free psychological assistance | 11 | 17 | 2 | 4 | 7 | 10 | 18 | 11 | 0 | 2 | 3 | 14 | 1 | 16 |
| Access to free rehabilitation procedures | 7 | 6 | 2 | 2 | 9 | 20 | 23 | 10 | 0 | 4 | 2 | 9 | 7 | 15 |
| Possibilities of getting orders that enable having free lab tests performed | 7 | 10 | 0 | 1 | 16 | 20 | 15 | 8 | 2 | 6 | 5 | 10 | 8 | 8 |

Data are the number of respondents declaring selected level of satisfaction
Θ – no answer checked
_ – the underlining means that no less than 1/5 of polled respondents marked this answer.

**TABLE 3. The perceived level of meeting health needs among polled breast cancer survivors.**

| Perceived level of meeting health needs | Subgroup of cancer survivors | | |
|---|---|---|---|
| | Subgroup ‘a’ (69 women)$^{n}$ | Subgroup ‘b’ (47 women)$^{n}$ | Both subgroups (116 women)$^{n\%}$ |
| 1.’I know that the doctors care for me in the best way. For my part, I used to go for check-ups and take prescribed drugs regularly’ | 24 * | 22 * | 46 (40%)* |
| 2.‘Any free access to medical specialists is difficult so I take drugs and have check-ups irregularly’ | 30 * | 20 * | 50 (43%)* |
| 3.‘My family doctor does not want to refer me to a medical specialist or give me laboratory orders so I try to cure myself with medicines bought by myself (at the chemist’s or in a market)’ | 10 | 6 | 16 (14%) |
| 4.’I do not know where and to which specialists I should go so I cure myself with medicines bought in a market’ | 0 | 0 | 0 |
| 5.’I do not know where and to which specialists I should go so I do not control my health at all and do not use any drugs’ | 4 | 0 | 4 (3%) |

$^{n}$ – data are number of respondents checking selected description of perceived level of meeting of their health needs
$^{n\%}$ – data are number (percentage) of respondents checking selected description of perceived level of meeting of their health needs
* – the asterisk means that no less than 1/3 of the polled marked this answer.

While comparing feelings expressed by cancer survivors from the two subgroups, it may be noticed that such impressions clearly differ with respect to the access to brochures addressed to women who have finished treatment for breast cancer, access to non-oncology and oncology specialists as well as to psychological assistance. In general, in respect to the organizational aspects of health care, cancer survivors diagnosed with cancer in 1991-2002 (subgroup ‘b’) took less critical look than women with cancer diagnosed in recent years (subgroup ‘a’).

The analysis of the assessment concerning the access to brochures addressed to women who have finished treatment for breast cancer reveals that the respondents from subgroup ‘a’ most often checked levels ‘0’ and ‘5’, the respondents from subgroup ‘b’ – levels ‘4’ and ‘5’.

In subgroup ‘a’, the level of satisfaction due to the access to free psychological assistance was mostly considered as giving no satisfaction or giving full satisfaction (levels ‘0’ and ‘5’) while in subgroup ‘b’ – as giving high or full satisfaction (levels ‘3’ and ‘5’).

When assessing the access to free medical advice in non-oncology areas, the respondents from subgroup ‘a’ most often checked levels ‘3’ and ‘4’, while the respondents from subgroup ‘b’– levels ‘4’ and ‘5’. In subgroup ‘a’, the level of satisfaction because of the access to free medical advice in the area of oncology was mostly considered as a high or very high (levels ‘3’ and ‘4’), while in the subgroup ‘b’ – as very high of fully satisfied (levels ‘4’ or ‘5’).

Table 3 reveals the relationships present in cancer survivor – health care structures and allows for carrying out the assessment of the real access to medical care services. It presents real aspects of the functioning of the health care system in the context of women – breast cancer survivors’ needs. Only 40% of these women have been satisfied with medical care. For the majority of them (60% checked answers numbered from 2 to 5) the health service structures do not guarantee proper health care and do not provide them with the feeling of wholesome safety. Fourteen percent (14%) of breast cancer survivors confessed that they used to cure themselves with the medicines bought at the chemist’s or in a market, 3% of them just ceased caring for their health at all.

## DISCUSSION

The increment in the number of long-term breast cancer survivors means the increment in the number of people who need special care [6,7].

Our observations suggest that Polish women who were previously cured due to breast cancer are people with many unfulfilled needs. In short, their needs are both existential and practical. Of course, it is not only a Polish problem [8-11], but this does not mean that Polish health services or public assistance may be justified.

Among the unfulfilled needs mentioned earlier, there are those directly connected with health care, such as the access to medical advice in both oncology and non-oncology areas, possibilities of getting free laboratory orders, access to free psychological care and to free rehabilitation procedures and to social assistance, as well as those related to the availability and quality of information printed in books, magazines and brochures targeted to women who have undergone treatment for breast cancer. The opinions that sound particularly alarming are those concerning problems with the access to free medical care, especially difficulties with making appointments at the doctor’s (access to both oncologists and non-oncologic specialists), and difficulties with realizing systematic free health checks by repeating necessary laboratory tests. Problems concerning the access to free medical advice in non-oncology areas were reported by 29% of the respondents (levels of satisfaction defined by marks ‘0’-‘2’) (Table 1), problems with access to free medical advice in area of oncology were checked by 23% of the polled women (marks ‘0’-‘2’) and lack of necessary orders that enable having free lab tests performed, was reported by 20% of the polled (marks ‘0’-‘2’) (Table 1). It means that not less than 1/5 of cancer survivors may feel that their health and lives are not adequately protected and that instead of enjoying their lives they are under constant threat.

In many countries, cancer survivors may find some support offered online. Such support is realized with survivor on-line services (such as websites of both Picker Institute Europe and American Cancer Society, as well as the Cancer Survivors Network) popular in Canada, the USA and many

European countries, as well as with so-called cancer support groups [12, 13]. USA is one of the examples. In this country in 2008, almost 39% of cancer patients used the Internet for information on cancer topics [14].

These means of education and support for cancer survivors may resolve many important everyday problems reported by these women and by the realization of educative as well as psychotherapeutic roles, they could cheer survivors up and relieve physicians from excessive work making queues for specialists' advice shorter and reducing the demands for laboratory orders.

In our country, due to economic conditions and delays in the broadband Internet access , the role of this medium in organizing support and exchanging information necessary for women – breast cancer survivors, is not so significant.

It seems that forcing through the development of broadband Internet in Poland, making women over 50 years of age (this group of survivors was most strongly represented among the study participants) warm to accept this means of education and information exchange, skilfully advertising newly-formed Internet support groups as well as providing appropriate financial support by justifying public monies, would be the major steps forward towards better realization of the survivors' needs [15].

For the time being, however, in Poland, the most important and the most popular are traditional forms of supporting cancer survivors and enabling the necessary information exchange. The help of non-profit organizations, including Amazon Women Association, implements such tasks. Amazon Women Association, instead of promoting web consultancies, psychological support and online information exchange, offers support mainly by the use of conservative methods which include lectures, speeches, meetings with doctors and psychologists working as volunteers, as well as publishing and distributing books and brochures addressed to cancer survivors.

While appreciating the role of Amazon Women Association and their activists' dedication to the problems of cancer survivors, it is necessary to note that such an organization cannot meet all the needs of the people traumatized by diagnosis, treatment and possible late complications resulting from a malignant disease. This non-profit organisation, for the financial and organizational reasons, cannot substitute official health care structures.

It is worth emphasizing that most of the reservations expressed by the polled women concerned those aspects of health and social care which are the responsibility of the Ministry of Health as well as structures funded by the National Health Fund and local government bodies.

A striking example are difficulties with keeping the highest standards of complex medical services offered for such patients (not limited to cancer care only), including full free of charge access to necessary and regularly repeated laboratory tests. The fact that no more than 45% of the polled women expressed their full or very high satisfaction resulting from a possibility of getting orders that enable having free lab tests performed (level '4' – 24% of the polled cancer survivors, level '5' – 20% of the polled) and 20% of them were really unsatisfied (levels '0'-'2'), confirms this thesis (Table 1). Doctors-volunteers cooperating with Amazon Women Association may not be fully helpful to cancer-survivors. Free laboratory orders can be written/printed only by those authorized medical practitioners who have got signed contracts with the Polish National Health Fund or work in health centres bound by such contracts. In the latter case, physicians may admit a limited number of patients so queues are long and women must wait for their turn. It is also important that the number of orders as well as the scope of tests are not unlimited. They depend on funds described in the contracts.

It is crucial to consider survivors' financial situation. Financially stable women can afford both to be provided with private medical care and to finance their own screenings. Women who live in want are condemned to be waiting patiently for their turn to see a doctor and for deserved, limited number of free lab test orders.

It would be good if breast cancer survivors suffering from financial problems had opportunities to receive official financial support. Meanwhile, the polled women assessed social assistance and financial support as the least satisfactory (when asked about having access to financial assistance – 51% of them checked level '0') (Table 1).

The deterioration of financial situation among such women can lead to dietary restrictions as well as to attempts to economize on drugs and reduce the costs of trips to clinics distant from their place of residence. Economizing on drugs may lead to self-modifying patterns of treatment of any coexisting medical problems (women refrain from buying expensive drugs) or to applying alternative methods of treatment [11]. This may cause squandering effects of the previous therapy (overlooking any possible recurrences of the malignant disease), worsening of body functioning (improper treatment of co-existing medical problems), deterioration of the quality of life, and – who knows – it may also shorten the time of their lives [16].

A detailed analysis of the data presented in Table 3 suggests that such events and problems are real. The fact is that only 40 % of the respondents (checked option '1') do believe that the actual health system will guarantee their safety and proper care. Other women express reservations about their medical safety. Actually, not less than 43% of women apply medicines and monitor their health status irregularly (checked option '2').

On top of all that, another 20% of them do not provide themselves with proper health care. Such women are used to applying medicines on their own and control their health status on their own in a manner they deem appropriate (Table 3; options: '3' and '5').

Such attitudes and such situations may be also observed in countries with high national income and better economic situation of health system budget [16].

Comparing the costs of diagnosing as well as treatment of breast cancer and costs of further care, the costs of treatment sometimes seem to be even higher. The idea of economizing on routine laboratory tests, on secondary medical care as well as on social assistance seems to give some profits to health service budget but, on the other hand, may lead to wasting good effects obtained by early diagnoses and high costs of applying modern methods of treatment. An improvement in early diagnoses and favourable trends in epidemiological indices, such as mortality, death and cure rates) are causes for pride but they shouldn't be reported as facts taken out of context. This context should be named: better life, good life, satisfaction of living. If not, any improvement in mortality, death and cure rates will only means the Pyrrhic victory.

## CONCLUSIONS

1. Women with breast cancer in medical history have got special medical as well as psychological and social needs.
2. Many of these needs are not fulfilled
3. Significant changes in the functioning of health and social care must be provided to improve the status quo.

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