

## **PATIENTS' CREATIVITY AS FACTOR OF OVERCOMING THE TABOO CONCERNING DISCUSSION OF CANCER PROBLEM. POLISH EXPERIENCES**

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Cancer increasingly often determines the direction of a life story of a contemporary woman. At the same time, until recently there was a taboo concerning discussion of cancer problems. For example, the breast cancer used to be a taboo topic, associated with a punishment, stigma and disgrace. In 1970s, as a result of breast cancer patients and survivors activism the situation started to change in the United States. Later, American experiences influenced on breast cancer activism and the situation of patients in Poland. However, there are significant differences between Western and Polish breast cancer activism. The article presents selected forms of activity carried out by Amazons in Poland which aim was to educate people in area of breast cancer. Additionally, it sets new challenges and tasks which should be considered by activists.

*Key words:* education, creativity, activism, patient, cancer.

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## **ТВОРЧИСТЬ ПАЦІЄНТІВ ЯК ЧИННИК ПОДОЛАННЯ ТАБУ ЩОДО ОБГОВОРЕННЯ ОНКОЛОГІЧНИХ ПРОБЛЕМ. ПОЛЬСЬКИЙ ДОСВІД**

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Онкологічні захворювання усе частіше визначають напрямок історії життя сучасної жінки. У той же час, ще донедавна існувало табу на обговорення онкологічних проблем. Наприклад, захворювання на рак молочної залози зазвичай було заборонною темою, пов'язаною з покаранням, клеймом і ганьбою. В 1970-ті роки у Сполучених Штатах у результаті активності пацієнтів, що залишилися в живих після лікування рака молочної залози, ситуація почала змінюватися. Пізніше американський досвід вплинув на активність пацієнтів, хворих на рак молочної залози, у Польщі. Проте, між західною й польською активністю таких хворих існують істотні розбіжності. У статті представлені деякі форми діяльності Польських Амазонок, спрямованої на просвіту людей з проблеми захворювання на рак молочної залози. Також у статті представлені нові виклики й завдання, які мають взяти до уваги активісти.

*Ключові слова:* освіта, творчість, активність, пацієнт, онкологічне захворювання.

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Breast cancer increasingly often determines the direction of a life story of a contemporary woman. Seventeen thousand new cases of breast cancer were diagnosed in Poland in 2012 based on the data of the National Cancer Registry (cf. National Cancer Registry <http://85.128.14.124/KRN/>). The diagnosis of breast cancer, long-term treatment and its consequences can affect women's health issues (i.e. early menopause, reproductive health, fertility, disability), as well as psychosocial conditions of their functioning (i.e. emotional distress, depression, lower quality of life, changes in body image, feminine identity, marital relationships, disturbances in social roles). Furthermore, cultural and social conditions affect the perception of patients and the meanings given to breast cancer. The situation of women afflicted with breast cancer and their families is difficult. For this reason, breast cancer patients and their relatives require supportive care. Education programs disseminating knowledge about breast cancer and exposing the taboo of this disease are an important part of patients' recovery. In Poland, many of them were invented and conducted by ill women.

*Social and cultural background of breast cancer activism*

Adriana Teodorescu highlights: 'The cultural history of breast cancer resembles the general history of cancer, and, despite being recent, is characterized by major changes from invisibility and stigma, to being brought to the fore, to acceptance and socially organized fighting against this disease' (Teo-

dorescu, 2014, p. 48). Until the 1970s in United States 'cancer was considered a disgrace'<sup>1</sup> (Ibidem, p. 48). Breast cancer was a taboo topic. Women after diagnosis fearing a negative reaction of other people, stigmatization or social exclusion did not admit to their disease. The situation started to change in 1970s when well known Americans (i.e. Betty Ford, then the First Lady of the United States<sup>2</sup>) admitted to the diagnosis of breast cancer. Edyta Zierkiewicz notes that 'their gestures appeared to be significant enough to change the status of cancer – from a low profile to a quite high one. People who decided to tell publicly about their cancer experiences wanted to question, then generally accepted, the 'disease ontology', and consequently the way the position of the patient was perceived – 'a victim of cancer': helpless, weak, illogical, sinful, all in all, a rightly punished woman. People suffering from breast cancer began to protest fiercely against social isolation and their stigmatization, also against being treated as substandard women' (Zierkiewicz, 2012, p. 36). During that time, the Reach to Recovery program adopted by the American Cancer Society was popularized. The main aim of it was to give practical and emotional support for women affected breast cancer. The idea of support was based on patients' volunteerism (Sulik, Zierkiewicz, 2014).

In the early 1980s, in the Western world appeared the first artistic photographs showing the postmastectomy scar (i.e. Jo Spence self-portraits for 'The Cancer Project', the series of photographs by Hannah Wilke recording her mother's struggle with breast cancer; the poster known as the 'Warrior' showing tattooed Deena Metzger's postmastectomy scar, the photo taken by Hella Hammid). In 1993, 'The New York Times' Magazine published on its cover the famous picture titled 'Beauty Out of Damage', showing the image of a former top model Matuschka uncovering the scar after mastectomy. It initiated the public debate about breast cancer patients and contributed to increasing financial resources for medical care and research. Those pictures were unique because they showed the aesthetic result of breast cancer treatment. Since that time there have been appearing more and more artistic projects showing mutilated body due to breast cancer (i.e. 'The SCAR Project. Breast Cancer is not a Pink Ribbon' by David Jay<sup>3</sup>, 'Reconstructing Aphrodite' by Terry Lorant in cooperation with Dr. Loren Eskenazi<sup>4</sup>, 'The Art of Reconstruction: Tattoo Artist Helps Breast Cancer Patients Reclaim Their Identity' by Michelle Gabel<sup>5</sup>). Additionally, there are calendars with pictures showing survivors (i.e. Pink Ribbon Pin-Ups calendar supporting Canadian Breast Cancer Foundation).

Since the 1990s, in the United States dynamically has developed a social movement with community-based organizations joining people fighting against breast cancer (Sulik, Zierkiewicz, 2014a). Many companies and organizations joined the Pink Ribbon Campaigns (see Sulik, Zierkiewicz, 2014b). The patients' activity focused on breast cancer was (and still is) based on supportive programs, education programs, publishing autobiographies of breast cancer survivors, fundraising for screening programs and research, and so on. Some of them are controversial (i.e. sale of gadgets bearing the pink ribbon is considered as a manifestation of commercialization of the disease, non-transparent rules of accounting income from the sale of products with pink ribbon) (see Ehrenreich, 2001; Sulik 2011; Sulik, Zierkiewicz, 2014a, 2014b).

American experiences connected with breast cancer activism have gone global. They influenced on breast cancer activism and the situation of patients in Poland. The Polish Amazons movement dates back to the 1980s of the twentieth century, when the specialists from the Warsaw Centre of On-

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<sup>1</sup> The perception of breast cancer has changed in developed and developing countries. There the disease commonly is not seen as a shame, punishment for sins, stigma. However, these changes have not occurred in all cultures of the world. For example, many women in Uganda keep their diagnosis of breast cancer and the ongoing treatment in secret, because according to the local belief, women with one breast are considered witches and cancer is considered a sickness caused by a witch. Furthermore, side effects of chemotherapy are similar to the signs of HIV, which further complicates the situation of the cancer patients. (Smith, 2014, p. 3).

<sup>2</sup> As a result of Ford's confession to breast cancer many women began performing self-examination, going for screenings. It led to an increase in the reported incidence of breast cancer. This phenomenon is called the 'Betty Ford blip' (Gibbs, 2011).

<sup>3</sup> The SCAR Project is a series of large portraits of young half-naked breast cancer survivors (18-35 years old) taken by David Jay. The mission of the project is: 'The SCAR Project is not about breast cancer, but the human condition itself; the images transcend the disease, illuminating the scars that unite us all' (<http://www.thescarproject.org/mission/>). The author's intention was to show scars caused by breast cancer treatment, as visible signs of the heroic struggle with the illness; to highlight the fact that this disease is nothing like an infantile pink ribbon, but rather a very painful experience that requires a heroic effort. The scars shown in the photographs are located on various body parts (not only in the area of breast amputation, but also on the reconstructed breasts, on the back after flaps of skin were to use in reconstruction). This shows that breast cancer dramatically cripples a woman's body, not just her chest.

<sup>4</sup> Women in age from 27 to 78 who chose the path of reconstruction after mastectomy took part in this project. In the book titled 'Reconstructing Aphrodite' there are photos with those women and their stories.

<sup>5</sup> In the United States, a trend of tattooing scars left by surgical treatment of breast cancer has been developing. The Amazons who have decided to tattoo their scars usually explain that they did it to hide or beautify them. Tattoos chosen by the patients usually have a symbolic meaning (i.e. ribbons, angels' wings, ivies). Photographs taken by M. Gabel capture moments and effects of work of Kim Leach, a former nurse who once a month, at the plastic surgery clinic, tattoos scars left by reconstruction surgeries.

cology, after returning from their scholarship in the United States, started adapting the idea of patient support in Poland (Zierkiewicz, Wechmann, 2013; Sulik, Zierkiewicz, 2014a). In Warsaw, the capital of Poland, they have established the first group of patients who had undergone mastectomy and were meeting for arm rehabilitation exercises. Only after four years, some women participating in the rehabilitation group began to form a support group. The actual development of the Amazons movement in Poland took place in the late 1990s, when new support groups started to form, so-called Amazons' clubs (presently, there are approx. 200 clubs spread all around the country). The Amazons support each other and provide support for other patients, who are not members of the clubs (including patient voluntary service in hospital wards). They also cooperate with hospitals and doctors, provide training and workshops (for patients and their spouses); jointly undertake various forms of physical activities; implement social and educational initiatives aimed at promoting healthy lifestyles, encouraging prophylactics and familiarization with breast cancer.

Despite the fact that the American experiences had an impact on the formation and functioning of the Amazons movement in Poland, there are significant differences between Western and Polish breast cancer activism. 'Polish Amazons – as opposed to American activists – are in fact, not at all rebel, do not publicly criticize anybody, do not look to blame others for their situation' (Zierkiewicz, Wechmann, 2013, p. 75). Their activities are focused on two main objectives: enabling the club members to realize their potential; and providing education about breast cancer (conducted in cooperation with medical specialists<sup>6</sup>) (Ibidem) .

*From exposing the taboo of breast cancer to taming with the disease*

In the literature, there are two ways to conceptualize the meaning of health. The biomedical model was based on the concept of the body as a machine, and the disease as a consequence of damaging it. Conceiving health solely in physiological terms meant neglecting the significance of the influence of social and psychological factors on the course of biological processes, thus leading to reification and depersonalization of the afflicted. The traditional paradigm was replaced by the holistic model, according to which health is 'a dynamic process aimed at restoring the constantly disturbed balance of the organism, resulting from the constant changes taking place within it and in the surrounding environment' (Dolińska – Zygmunt, 2001, p. 15). The essence of this approach lies in treating health as a sum of the mutually related dimensions (i.e. physical, mental, social and spiritual) of which it consists. The holistic paradigm of health puts emphasis on its subjective dimension, which is expressed through active and conscious participation of each human being in achieving a good psychophysical state. Humans are thus responsible for their health and body, while any difficulties influencing their psychophysical state 'may lead to a creative reaction of the organism, expressed through the processes of self-change and self-transcendence' (Ibidem, p. 16).

'It may seem that breast cancer, the disease which disrupts the course of an ordered life, leads to the creation of an existential void, a feeling of nonsense regarding taking up any activity by the subject of experience. However, life verifies the validity of this assumption, for it turns out that breast cancer, connected with a high risk of (premature) loss of life, may evoke reflections of an existential nature' (Mazurek, 2013, p. 75). Furthermore, traumatic experiences (such as breast cancer) may contribute to adoption of new forms of activity, learning and development (see Tedeschi, Calhoun, 1996, 2004; Mazurek, 2013). Taken activity may be beneficial in individual, as well as in social and cultural dimension.

Polish women diagnosed with breast cancer at the beginning of the 1990s (and earlier) did not know either the course of the treatment, or its consequences<sup>7</sup>, were not aware what medical treatment was offered to patients in the West, or where to seek help (also psychological), etc. Therefore many doubts and problems remained in the realm of conjecture. The main source of knowledge and support for a patient was their doctor. Health and emotional problems, experienced by patients, were further intensified by insufficient knowledge of the society's about cancer and their irritating beliefs with regard to this illness (i.e. cancer as a form of punishment). Many patients were ashamed of their ailment and did not admit it to their surrounding environment, hiding signs of undergoing the treatment instead. Those taking care of the patients were also going through a hardship not knowing how to talk to them, support them and help them, and what to tell others to avoid stigmatization.

The subject of cancer in Poland was being initially popularized by specialists, and only later saw activities of the patients who recovered and wanted to use their experiences to help others. Some of them joined the Amazons clubs, while others were taking individual actions – sometimes very innova-

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<sup>6</sup> American women, in order to avoid the medical primacy over breast cancer and patients' problems, based their breast cancer education program not only on medical expertise, but also on the patients' experiences. They have often criticized the medical procedures offered as a part of treatment, encouraging the search for alternative solutions (see Zierkiewicz, Wechmann, 2013).

<sup>7</sup> For example, mastectomy was the most commonly used surgical treatment, in spite of alternative treatments being available (i.e. conserving surgery). The problem of lymphedema, which can occur as a result of lymph node excision, was rarely discussed. Unaware patients did not exercise and neglect lymphatic massages, which led to painful swelling.

tive, creative and unconventional at that time. The media also became helpful, increasingly raising the subject of the “shameful” female ailment (see Zierkiewicz, 2013).

Actions initiated by the Amazons were focused on providing support to patients, often lonely in their fear and suffering; as well as on breaking the code of silence surrounding breast cancer and popularization of cancer knowledge. Initially, the activities of the Amazons club members were focused on building support networks for women who had just received the breast cancer diagnosis and also those undergoing the treatment. The activists were meeting in order to jointly undertake arm rehabilitation exercises after mastectomies and lymph node excisions, to talk to each other and to support each other. Then, following the Reach to Recovery concept, they have implemented the volunteer patient program, which involves volunteers (meaning Amazons who recovered from cancer and received a necessary training) visiting patients in hospitals. Volunteers’ convince the patients that they can beat the cancer and live a happy life, of which they are the best example. They also educate the patients about the course of the treatment and the convalescence; where to seek psychological help, etc. Except the volunteer patient program and the club ‘tea and cake’ meetings, the members of the Amazons club participate in the pilgrimage to the Jasna Gora Monastery in October, organize marches, convalescence camps, the Spartakiada sport event, psycho-educational workshops and conferences, as well as publish their own newsletters and establish cooperation with other patients organizations. Independently from the Amazons movement, there is also a rapid development of the internet forum devoted to breast cancer, which sees activities of both: the recovered patients, who do not need help themselves but want to offer their support to other patients, as well as women who have just received the diagnosis (rarely their family members) and seek some advice, information or support.

The education of the Polish society in the area of breast cancer is largely carried out by the patients (the club activists, as well as patients who are not the club members). Their actions are supported by media, medical professionals (mostly physicians), ‘the spokeswomen for the disease’ and ‘the breast cancer stars’ (Zierkiewicz, 2013, p. 171) meaning, celebrities who confessed their illness; however, there is hardly any support from the state institutions. The narratives of illness, published in the form of books or newspaper reports, and containing memories of the times of diagnosis and treatment (see Hawkins, 1993, 1999; Tembeck, 2009; Jurecic, 2012; Zierkiewicz, 2013; Mazurek, 2015), as well as photographic projects (some of them published as calendars) showing images of female bodies mutilated by surgical and oncological treatment, and images of dressed women (sometimes with their family members) who have undergone the treatment (i.e. ‘More than one with one’ by Dorota Kiałka and Agnieszka Kłos, ‘Amazons and maternity. Beautiful and healthy for children’ by Katarzyna Piwecka and Ewa Rzychniak) (see Mazurek, 2013, 2015; Zierkiewicz, 2013), deserve special attention. The main objective of these artistic projects is familiarization with the illness and scars that it causes, but also building the belief that despite the cancer, it is possible to look beautiful, be active, and enjoy life. They constitute a warning not to underestimate the checkups and breast self-exams and encourage undergoing these medical practices. This is why Polish photographic projects – as opposite to the US - show neat, deliberately stylized, models (patients) in elegant settings.

#### *Conclusion*

The research conducted by Edyta Zierkiewicz and Emilia Mazurek which main aim ‘(...) was to find out how both spouses cope with the wife’s illness and what kind of support they provide’ (Zierkiewicz, Mazurek, 2015) confirmed that ‘(...) members of the Polish society (here: patients and their families) are still deprived of support and help from public institutions and professionals. The general silence surrounding the issue of patient care firmly entrenches it within the family sphere only – both of the parties in question are isolated in their misfortune, their feelings of incompetence, overloaded, experience accumulated frustration and helplessness’ (Ibidem). For this reason, supporting patients and their families (also through the education of the healthy part of the society about breast cancer) is still the area that needs attention, research, and deliberate actions in response to real needs. Various patient and aid organizations, state institutions, specialists (i.e. physicians, psycho-oncologists) and media should certainly join such actions.

The practices concerning the popularization of breast cancer knowledge and support for patients and their families introduced in Poland are similar, in some respects, to the Western experiences. However, cultural, sociological and mentality differences do not always allow for a direct transfer of the solutions applied in the West. Besides, the solutions that worked there may not necessarily bring the desired effect in Poland. The actions of the Polish activists tend to be more cautious, reserved, and can sometimes excessively hide the horror of the illness, or deficits in the area of prophylactics, treatment and medical care, which are the state competence. However, over the past twenty years, which is the period of the rise and development of the Amazons movement, there have been many positive changes in the perception of breast cancer and those affected by it. This helps the patients

cope with breast cancer better; they no longer need to be ashamed or reticent about their illness. They can also count on receiving help and understanding (mainly from other patients and those who have recovered) at various stages of their recovery. Patients are becoming more competent in terms of their ailment: they know where to seek help (medical, psychological, financial), what to ask doctors and when, they know their rights and are able to enforce them better, they are able to cope with the emotional consequences of the illness better, even before treatment they can get familiar with the post-operative scarring.

Polish Amazons (especially members of the Amazons clubs) are facing new challenges, which may lead to the improved situation of cancer patients and better care for them, as well as in their better adaptation to life in so-called conditioned health. When considering the creativity of Polish Amazons in popularization of breast cancer, I would like to draw attention to two particularly important tasks. First is better identification of needs and problems experienced by family members of patients, in particular their caregivers (usually husbands) and development of support programs directed to them. This is especially important because in Poland, as opposite to the US, an organization focusing on spouses of breast cancer patients has not yet been constituted. It would be difficult here to even diagnose the existence of 'the brotherhood of breast cancer husbands' (Silver, 2004, p. xv). Whereas, they usually do not know too much about breast cancer and a care of the ill person, they are burdened with additional responsibilities during the wives' illness, they have their own unmet psychosocial needs (see Cardoso, Bese, Distelhorst, et al., 2013, Zierkiewicz, Mazurek, 2015). Psycho-educational interventions addressed to caregivers would be an important part of the good functioning of the family and patient recovery. There is a lack of these in Poland.

Secondly, the Polish Amazons could attempt to show the effects of breast cancer without masking, cover-ups, embellishing. The artistic projects implemented so far, which exhibit mutilated bodies, were aimed at familiarization with scars, warning against the illness, encouraging prophylactics, and finally proving that cancer patients can be beautiful, attractive and needed. Highlighting the beauty and femininity despite the illness was deliberate – it was not meant to frighten either healthy or sick women. However, it lacks alternative images, exposing the terror of the illness and the effort required from the patients to recover what has been lost, disfigured, mutilated. Also missing, are visual illness narratives (see Bell, 2002, Tembeck, 2009), showing changes that a body is going through, emotions experienced over time, while undergoing the long term treatment (see Mazurek, 2015). It is however difficult to say, whether patients and the public are ready for it.

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