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COUPLES DEALING WITH BREAST CANCER: THE ROLE OF HUSBANDS IN SUPPORTING THEIR WIVES

Aim: The main goal of the article is to showcase how husbands performed the role of caregivers for their wives after breast cancer diagnosis. The researchers analysed this issue by comparing the perspectives of the male caregivers with their wives' opinions. The wives were active members of Amazon clubs. **Background:** Partners of women with breast cancer are expected to assume responsibility for taking care of their wives. Simultaneously, however, they are not prepared to fulfil their new duties, nor are they being provided with any professional support in this regard. **Method:** Semi-structured interviews were conducted with eight married couples, separately with wives and husbands. **Results:** Husbands perceive their role in their wives' struggles as primarily supportive and channel any negative emotions via undertaken actions. They support their wives in four ways: by focusing on their wives' feelings and caring about her, taking part in the healing process, managing the household during the period of their wives' recovery, and by bringing back normalcy into their lives. **Conclusions:** Limited knowledge about oncological diseases, deficiencies in the assistance services offered to husbands of women with breast cancer and stereotypes about gender roles contribute to the difficulties men face when taking care of their sick wives. Even the wives active participation in the Amazon movement does not seem to mitigate their problems.

Keywords: breast cancer survivors, spouses, men as caregivers

INTRODUCTION

Seventeen thousand new cases of breast cancer were diagnosed in Poland in 2012 (cf. Krajowy Rejestr Nowotworów; *National Cancer Registry*, <http://85.128.14.124/KRN/>). Consequently, however, the crisis affects at least twice as many people (i.e. the closest relatives), due to their engagement in helping those bearing the heaviest burden of the disease. Somatic affliction, similarly to a multitude of other critical life events, affects not only the life of the

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person who endures it. Cancer is a “family disease” *par excellence* (Ussher, Sandoval, Perz, Wong et al. 2013: 900; cf. Budziszewska, Piusińska-Macoch, Sulek, Stepień et al. 2005; Zagroba, Staśkiewicz, Zielińska and Sendek 2008; Świętochowski 2010), a medical condition inflicting disturbances on the lives of everyone belonging to the immediate family. By this virtue it is sometimes referred to as the “we-disease” (Kayser, Watson and Andrade 2007: 404)¹.

On account of heightened stress levels, upset sleeping patterns, abject fatigue, eating disorders and other factors, the cancer patient’s family members may be regarded as “second-order patients” (Lederberg 1998: 981, cf. Bigatti, Brown, Steiner and Miller 2011: 193). Moreover, they are prone to depression, burnout or becoming overburdened due to an exponential increase in daily responsibilities, as well as anxiety stemming from growing costs of medical treatment and a decrease in familial standards of living (Wagner, Bigatti and Storniolo 2005). Bearing this in mind, one can observe that it is the partners of breast cancer patients who seem to be positioned in an especially peculiar situation, and who are usually expected to assume responsibility for providing care and support to the patients.

Western researchers pay particular heed to three salient themes characterizing the situation of breast cancer survivor’s husbands: emotional problems as a reaction to the stress induced by the illness (also, to its treatment); coping strategies (including the search for social support); and burdens and benefits (the latter occurring rarely) stemming from the cancer’s emergence within the family.

Breast cancer triggers a spectrum of emotions in the woman patient as well as in her husband. The very appearance of breast cancer and the necessity to undergo a biopsy constitutes a stressogenic situation for both spouses (Northouse, Jeffs, Cracchiolo-Caraway, Lampan et al. 1995). Participating in a long-term therapy engenders elevated tension, uneasiness, fear, anger, a sense of losing control, helplessness, and/or uncertainty, and the intensity of each emotion varies at different stages of the disease’s trajectory (Northouse 1989; Northouse, Mood, Kershew, Schafenacker et al. 2002; Wilson and Morse 1991; Hilton 1993). Studies confirm that the stress experienced by caregivers of cancer patients is sufficient enough to heighten the risk of their premature death (Schultz and Beach 1999). Active participation in the decision-making process related to their spouses’ treatment (such as choosing the type of surgery) (see Morris and Royle 1988), being engaged in the treatment process itself (Wilson and Morse 1991) and receiving support (Ciambone and Allen 2002; Mireskandari, Meiser and Thewes 2006) might suppress or assuage the fear, help restore a sense of control over one’s life, and reduce the stress level.

The subject matter literature presents coping strategies chosen by men struggling with their wives’ health crisis from a variety of angles: in relation to the stages of cancer treatment (detection/diagnosis, surgery and/or adjuvant therapies, remission, recurrence/metastasis; see Picard, Dumont, Gagnon and Lessard 2005, Kim and Given 2008, Volker and Wu 2011); adopted orientation (namely focusing on the wife and taking care of her, or on the family and

¹ This term corresponds to the idea propounded by Karen Skerrett (“we-ness”), according to which the couple constructs a shared narrative – about their relationship and related events, thus also about the illness of one of the partners. Couples who adhere to the “adaptation philosophy” (deemed resilient couples) describe cancer as “our problem” (Skerrett 2010: 505).

restoring the familiar order of things; Hilton, Crawford and Tarko 2000); the prevailing style of dealing with problems (Naaman, Radwan and Johnson 2009); and the demand for specific support (Given, Given and Kozachik 2001). When assaying the ways of adaptation to a life with an ailing family member, it becomes clear that coping strategies can be categorized not only as individual or shared by both spouses, but also as positive or negative (cf. Shiozaki, Kei, Atsuko, Hiroki et al. 2011).

The emergence of a cancer diagnosis disrupts the way a given family functions – the healthy adult must take over responsibilities heretofore attended to by the other partner for an undetermined amount of time. The illness seems to be particularly troublesome to cope with for men in traditional relationships. Numerous articles highlight the difficulties men encounter while coming to grips with the necessity to shoulder more household chores – interestingly, it is less a matter of the increase in the amount of responsibilities *per se* and more of their incongruence with the models of masculinity internalized by these men in the course of socialization (cf. Ciambrone and Allen 2002; Hagedoorn, Buunk, Kuijer, Wobbes et al. 2000; Seymour-Smith and Wetherell 2006; see also: Hanlon 2009). Apart from these two types of burdens, also mentioned in the literature are the costs associated with taking care of the sick partner (including the inability to meet one's own needs, social isolation, physical fatigue, elevated negative emotions that beleaguer the person assuming the caregiver role) and adverse changes to the relationship with the person suffering from cancer (including a sense of underestimation of one's role as a carer) (Sercekus, Buyukkaya Besen, Partlak Gunusen and Durmaz Edeer 2014; Drabe, Wittmann, Zwahlen, Büchi et al. 2013; Ussher, Sandoval, Perz, Wong et al. 2013; Hagedoorn, Kreicbergs and Appel 2011). Curiously, the illness itself seems not to have any deleterious effects on the marriage (Dorval, Guay, Mondor, Masse et al. 1999); in fact, researchers come to the conclusion that breast cancer may even be conducive to bolstering the marital bonds (Dorval, Guay, Mondor, Masse et al. 2005; cf. Stępień and Wiraszka 2011). Other benefits – usually serving as a buffer protecting the carers from all the unpleasant aspects of the role they perform – include acknowledging one's efficacy, developing empathy, sharing more time together, and a greater appreciation of life (Lin, Fee and Wu 2012; Ussher, Sandoval, Perz, Wong et al. 2013).

When compared with their western counterparts, Polish researchers devote much less attention to the issue of men's performance as cancer patients' carers. Breast cancer survivors' husbands, let alone partners, are scantily mentioned in the Polish subject-matter literature, and typically as a potential source of support (not necessarily the most efficient one; see Deręgowska 2012; Zabłocka-Żytka 2010). At times it is suggested that they might actually aggravate the trepidations already experienced by their wives, in cases when they do not or cannot accept the treatment-related change in their wives' physical appearance and sexually reject them, when they fail to evince understanding and distance themselves emotionally from them, or when they outright abandon them (cf. Zagroba, Jędrzejewska, Marcysiak, Ostrowska et al. 2012: 406).

It seems, however, that the middle of the last decade saw a noticeable breakthrough in the way Polish subject-matter literature described the breast cancer survivors' husbands' situation. Paweł Izdebski and his co-workers (2008) have examined – by making use of a carefully designed questionnaire – the demand of patients' husbands for social support (and compared

their results with answers elicited from the partners of healthy women). The issue of providing care to cancer-patients by their spouses as unprofessional carers warrants immediate attention precisely because of the nature of the Polish social reality². Unlike the Western health-care systems, the Polish one does not only fail to help patients meet their informational, instrumental or emotional needs, but also renders their loved ones barely noticeable. Women with breast cancer find respite from their predicaments in a number of ways, including by getting involved in a variety of support groups (such as the Amazon-volunteers in hospital wards and/or the members of patients' associations), conversing with female colleagues or relatives, seeking information in women's magazines (which eagerly put out articles on medical topics), reading pathographies (i.e. printed illness narratives; cf. Zierkiewicz 2012), and engaging in "consultations" on online forums. Only a small number of them have access to psycho-oncologists and/or feel entirely satisfied with the support received from the health professionals' community. Their husbands are likely to have even fewer opportunities to obtain help or gain a complete understanding of the circumstances thrust upon them – truth be told, virtually none of them participate in the Amazon discussion forums (Koronkiewicz 2014), and a web portal or a support group bringing together husbands whose wives have undergone breast cancer treatment has yet to be created³. Furthermore, it is typical for media outlets perceiving men as their target group to neglect the issue of coping with the illness of a family member, and, to make matters worse, friends and distant relatives, finding themselves dumbfounded in the gruelling reality reshaped by the occurrence of cancer, withdraw themselves from any relationship with these men. Finally, access to professionals dealing with their partners' illness is excruciatingly limited. Paradoxical as it may seem, their main, if not only, source of support is their ailing wives (Izdebski, Matusik and Tujakowski 2008).

This brief overview of issues and selected writings makes clear that men who take on the responsibility of caring for their sick partners face difficulties of a considerable quotient – in some respects their situation seems to be more exacting than the one faced by the sickness. Inasmuch as one considers three resources indispensable to fend off any crisis: social support, hope and self-efficacy (in this context, influencing the course of the illness; see Zabłocka-Żytka 2010), it seems obvious that male carers exhibit deficits in each of the aforementioned areas. Also, that they lack direct access to them. It has already been said that men do not readily experience social support, let alone exert any control over the course of their partners' treatment/recovery or be capable of inducing hope (they often lack information conducive to the formation of such attitudes). Women may take an active part in the treatment process or deliberately abandon it. They are the ones who give or refrain from giving consent to medical interventions (in case of doubts, they can discuss them with other specialists or

² For now, there is a deficit of such research initiatives, but publications addressed to patients and their families have begun to appear more often. Among others, the Polish Society of Clinical Oncology (and acting under the auspices of the Oncology Centre in Warsaw "There and Back" Foundation) under the Oncology Education Program provides electronic – translated from English – handbooks instructing how to live in so-called conditional health: "When Someone You Love is Being Treated for Cancer. Support for Caregivers" (2014).

³ "Men Against Breast Cancer" is one of such groups, established in 1999 in the US as a non-for-profit organization for Amazons' husbands. It deals with providing relevant support to the husbands during their struggles with their wives' ailments (<http://www.menagainstbreastcancer.org/>).

their peers going through similar hardships). Options available at their husbands' disposal are of an entirely different kind: they can plead, persuade, or make attempts at controlling their wives' behaviour. Being aware of the inability to effectively influence their partners' behaviour can further lead to a sense of helplessness, frustration or anger. Some questions regarding these "deficiencies" inevitably arise, like: what percentage of the population of men struggle with such "deprivations"? Which factors can facilitate and which impede undertaking any care-related tasks? Does the approach towards the new role (whether a personal choice was involved while taking it up, or it was forced upon the carer, or it was a necessity) impact the degree of involvement in providing care to a partner?

METHODS AND SAMPLE

The aim of the research was to find out how both spouses cope with the wife's illness and what kind of support they provide. In particular, we were interested how men whose wives struggle with breast cancer, and are active members of Amazon clubs as well, take up and perform the role of their carers, and how this effort is actually perceived by the ill. We also attempted at identifying gender-dependent differences between the spouses in responses to the illness and the choice of ways of coping with it.

In order to explore the ways in which men support their ailing wives, we conducted semi-structured interviews (Rubacha 2008) with eight married couples who had partaken in a series of clinics organized by the Amazon Federation of Associations in September 2014 (two pairs declined to participate in the research)⁴. We conducted sixteen interviews with wives and husbands separately. This particular group was chosen intentionally, as we were interested not only in revealing how men take on their new roles, but also whether their wives, active members of their respective clubs, assist them in confronting problems brought about by the illness and imposed mercilessly on the entire family.

We wondered if the fact that wives receive different kinds of support from the social association (i.e. emotional, from their colleague activists and psychologists collaborating with the club; instrumental, from the employed physical therapists; and informational, from the invited physicians' lectures) and perceive their cancer in different ways (i.e. as a liberator or as an occupation; Herzlich 1973 via: Larsen 2009: 29) impacts favourably on their husbands and constitutes an idiosyncratic resource men can rely on while performing the role of a caregivers.

All of the interviews were recorded and transcribed afterwards. The interview questionnaires were comprised of 20 open-ended questions (some of them were different for wives and for husbands) raising the following issues: the ways of rationalizing the onset of an illness; emotions and thoughts brought about by the diagnosis; the hardships of treatment and the ways

⁴ The Federation is an umbrella organization bringing together approx. 200 clubs spread all around the country (with approx. 25 thousand affiliates). Since its inception (since 1993) it provides training services to the Amazons, especially those that permit them to take up the role of volunteers in hospital wards. In addition, it trains club leaders and organizes psychological workshops (for young patients and those with metastasis). Starting last year, it offers courses for married couples (four editions had already been conducted; ten couples took part in every edition).

of coping with the new situation exhibited by the wife/husband during its course; received social support (from specialists) and its evaluation; mutual support provided by spouses and its evaluation; the wife's expectations concerning her husband's support; the impact of the illness on the marriage (sex life, emerging conflicts); the ideal support for women with breast cancer and their carers; the attitudes of other patients' husbands; and participation in clinics for married couples organized by the Amazons Federation of Associations.

Men participating in the interview fell in the 52–73 age range, while women were between the ages of 46 and 71. The average age of the men and women was 59 and 54.5 respectively. One of the men had acquired higher education, two secondary education, four vocational education and one primary education. Six were still working, two were retired. Six women declared finishing secondary education and two vocational education. The longest marriage amounted to 50 years, and the shortest was 5. The average length of marriage in the research group was 27 years. All of the respondents were parents; the youngest child of the interviewed couples was 14 years old, and the oldest 49. Three couples lived in a big city, three in an average-sized city and two in the countryside.

The youngest age of breast cancer onset was 37, and the oldest was 59. The longest duration of actively participating in the Amazon movement was 8 years for one person, and the shortest was 2, also for one person (in total, the average was 5 years for the entire research group). One of the persons interviewed actively participated in the movement in the USA and later in Poland. Six women undertook mastectomy (of which two a bilateral mastectomy), and two breast conserving treatment (BCT). All of the interviewees agreed to adjuvant therapy. Two of the respondents underwent breast reconstruction surgery.

A qualitative analysis, with a focus on interview data, was deployed. Two key categories (and four subcategories) formed its framework. Questions included in the interview guide pertained to: (1) giving meaning to the illness and (2) responses to its appearance and unceasing presence within the relationship. We had assumed that in their struggle for better understanding of the illness, people would attempt to (1a) find its cause, and fathom why it has happened to them, and subsequently (1b) discern its impact on their lives and identify the scope of changes that need to be considered. When it comes to receiving information about the diagnosis of illness in one of the spouses, it elicits different, oftentimes diametrically opposite, emotional responses (2a), and prompts the couple to take certain steps (more or less well-thought-out; [2b]). Our respondents (both women and men alike) considered these issues personally important to them, as they were willing to share information about providing and/or receiving assistance with the illness.

RESULTS: CARING FOR A BREAST CANCER SURVIVOR BY HER SPOUSE

GIVING ILLNESS A MEANING

Typically, the appearance of breast cancer induces the patient and her family to reflect on the reasons why they have lost their good health. Frequently their voice, typical – as it seems – in such situations raises questions such as: Why has it happened to me? How did I deserve

it? (see Mazurek 2013). The ever-changing cultural currents bring new answers with them.

Gone is the era of tabooing cancer, and with its demise all the religious-cum-colloquial ideas of illness as punishment for sins, a form of atonement or a sign of impending doom seem to be entirely outdated, and not befitting the current public discourse. Media outlets publish numerous medical reports and documentaries about breast cancer survivors, and the public sphere serves as a platform for a number of social campaigns, with celebrities bringing a range of illnesses into the spotlight (Zierkiewicz 2013). Representatives of advanced medicine have managed to instil in the minds of their audiences a conviction that cancer has biological roots and eradicating it does not necessarily entail finding out the exact reasons behind its occurrence – locating and annihilating the clusters of mutated cells is sufficient. Other contemporary experts, psychologists, complement these recognitions with the concept of cancer as a disease induced by accumulated stress or individual susceptibility (having a “Type C personality”; Temoshok 1987 or “Type D personality”; see Pinker and Bidzan 2014)⁵. Civil servants overseeing public health affairs voice their opinions as well, arguing that cancer simply stems from personal carelessness, i.e. choosing an inappropriate diet or refraining from physical exercise, smoking and drinking, adhering to an improper lifestyle (including: shrugging off check-ups and screening (Zatoński 2012). All of these professionals suggest that in order to solve the cancer problem one needs to abide by health professionals’ recommendations and thoughtfully manage her or his own health.

Interviews conducted with cancer patients and their partners reveal which disease concepts enjoy the greatest popularity, are socially sanctioned and are also deemed credible. Against this background a question can be posed: does embracing a particular frame of reference with regard to cancer by the men, facilitate or hamstring efforts to effectively assume their role of a carer of their ailing wives?

GENDERED WAYS OF EXPLAINING THE CAUSES OF AN ILLNESS

Sixteen people took part in our research, hence making any generalizations on the entire population would be stretching a point. Notwithstanding these limitations, our results reveal a tendency in the respondents’ answers. As it transpired, the women were prone to perceive cancer as a result of overexposure to stress, while the men were inclined to attribute the illness to genetic factors or a random chance (understood also as a “population” or “civilization” factor) (Gotay 1985).

In the eyes of men, cancer takes on an ideologically neutral meaning (even though medicine and epidemiological data interpretations were repeatedly accused of being slanted; Lerner 2001; Jasen 2003; Fosket 2004); their wives’ interpretations, however, unequivocally evoke anti-feminist connotations – the women surveyed pinpointed their career (or more broadly: an emancipated life style) as the major source of the tribulations they have to grapple with.

⁵ Critical analyzes of the concept of cancer personality can be found, in Anne Harrington’s book *The cure within* (2008: 89–91) and in the articles: “The role of psychosocial factors in the development of breast carcinoma” (Price, Tennant, Smith, Butow et al. 2001) and “Personality traits, health behavior, and risk for cancer” (Hansen, Floderus, Fridriksen, Johansen et al. 2005).

Certainly they were not conscious of the possibility of reading statements in such a manner. A deeper look at the social context sheds light on this paradox: both the preponderance of the Amazon movement representatives, and the society at large, still nurture patriarchal values (Sulik and Zierkiewicz 2014: 124–127).

Apparently the public sphere is infused with discourses propounded by the aforementioned experts, which in turn changes the range of interpretations readily available for people who strive to find the causes of their ailments. However, laypeople tend to take these discourses for granted, mindless of the limitations and intricacies they entail. By serving mainly as a useful “tool” for the adequate, i.e. in line with the *zeitgeist*, the categorizing of situations experienced in life, the ideological underpinnings of all these discourses, remain undisclosed, thus still implicitly rendering women as culpable for their maladies (due to their psychological frailty and/or feeble bodies). Crucially, the now dominant interpretational repertoire (by and large, medicalized) does not provide any justifiable excuse to leave one’s wife. Asked directly if cancer can be the cause of a marital breakdown, respondents replied:

It’s hard to explain such things to oneself. How can one explain that we come down with flu? Statistic. For sure no one chooses it. [Piotr]

I think that breast cancer in one’s life can’t be the reason for breaking up, because this is like with any other illness. Among woman it’s virtually a flu, right? So everyone will break up, because someone’s sick? An illness at this age..., everyone has something... [Andrzej]

About breaking up I haven’t even thought of it. For me it was [important] just to do everything, to recover. But to come to mind, to leave, never in my life. I pledged love and fidelity to my wife, to be till the end, till the last moment. End, that’s how it will be. I absolutely don’t think of leaving. Such things don’t even come to my mind. [Tadeusz]

The new (medicalized) approach to explaining the causes of breast cancer seems to make it easier for men to assume the role of a caregiver for their wives. From this perspective cancer can be seen as a typical, somatic phenomenon, much like flu or ageing-associated diseases. The medical connotations evoked by oncological diseases are far from conveying any moral judgements – hence leaving relatives or friends without any stigma. Conversely, the latter are expected to show concern and engage in helping the patient with her recovery.

IDENTIFYING AND NEGATING THE IMPACT OF THE ILLNESS ON THE RELATIONSHIP

The impact of cancer on an individual’s life has never received as much attention as finding its cause has. If anything, it has been portrayed as a personified brute force laying waste to one’s life: an invader, whose only aim is to bring misery and destruction. In the case of women affiliated with patients’ associations, who construct their identity around a common goal of heroically standing up against the cancer-assailant or coming to terms with its quotidian presence (and at the same time enjoying the privileges and opportunities offered to those assigned a “not entirely in health” status⁶), this approach may be considered as a problematic

⁶ In this context it seems appropriate to recall the concept of the “sick role” developed by Talcott Parsons (1991).

one. By refusing to be pigeonholed as helpless victims and becoming Amazons or survivors, they gain social recognition. Their partners, especially those who do not oppose any form of social engagement on behalf of their wives, also need to transgress previously held attitudes towards cancer and assume new roles. Respondents' replies suggest that they either focused on their sick partners (fully aware of the responsibilities that come with the role of a carer), or gave priority to preventing the familial status quo from collapsing – also by reining in any emotional volatility of other family members that might ensue after becoming aware of the cancer diagnosis (men become responsible for restoring normalcy).

Our observations correspond to the results obtained by a research team headed by Ann Hilton (2000). A more detailed account of the strategies preferred by our respondents when confronted with the problems brought about by cancer will be presented later on, but at this point it is important to underscore that a choice of a particular role (of a carer or a restorer, so to speak) has not influenced the way men perceived the outcomes of the illness, nor their marital relationships. All the interviewees concurred that cancer was not a source of conflicts within their relationships, nor did it shatter the intimacy between them and their wives. However, the conciseness noticeable in their responses is thought-provoking – as if they wanted to avoid exploring this specific topic. A different interpretation also merits mentioning: it was hard for these men to talk about something that “never happened”; they succinctly asserted that they are under pressure, kept away from confrontations, tried to tone down their wives moods, calmed them and explained their indisposition to themselves as stemming from the illness:

When she was hot under the collar, I tried to tone it down. [...]. She was angry because of the pain and everything. I could keep silent, wait. [...] But to argue? No, it's pointless. [Krzysztof]

Like their husbands, the wives did not notice a change in the amount of marital friction: quarrels, if any, stemmed exclusively from the general economic situation of the family. All of them confirmed, however, that the illness adversely influenced their love life, even if only at the initial stages of treatment and at their own volition: they felt ashamed of their wounds and chemotherapy effectively stifled their libido.

The answers provided by the respondents suggest that they either sought to consciously limit the impact of the illness on their relationship (by passing over the issue) or gainsay any impact in the first place (thus calling into question the very importance of this “event” to their lives). Hoda Badr dubbed these attitudes “avoidance” and “preventive buffering”, but saw them as specific only for ill women (2004; see Fergus and Gray 2009). In our research, it was the men who exhibited these dispositions, which might lead to an assumption that both spouses intentionally play down the significance of the problem by not raising any cancer-related topics. This assertion seems to be corroborated by the gathered data, or more precisely, by the way in which both the men and the women described their feelings and how they turned a blind eye to their own responses.

However, more adequate to understanding the situation of women with breast cancer seems Gerald Gordon's idea of “impaired roles” (1966 for Bury, Newbould and Taylor 2005: 6; cf. also Larsen 2009: 26–27). According to the latter, the chronically ill are not capable of meeting the standards of full recovery, but still take upon themselves a lot of the so-called “normal” activities and responsibilities.

INDIVIDUAL AND SHARED RESPONSES TO THE ILLNESS

Immediately after receiving a cancer diagnosis the patient is ushered into the realm of cancer. Unexpectedly, a person considering him/herself as being in good physical condition is forced to reassess his/her health status – from now on the ill person is being expected to take on the patient role, and, more importantly, he/she begins to think of him/herself as an ailing patient (Kagawa-Singer 1993)⁷. The diagnosis is an event so extreme that it is sometimes referred to as a rupture or torn biographical continuity which results in an orderly course of life being replaced by a trajectory (Riemann and Schütze 1991; Giddens 1991, see also Mazurek 2013). One begins to feel helpless, controlled by external forces beyond his/her control. When confronted with the tragic diagnosis, only one aspect of the entire situation conjures up similar, negative emotions in both spouses – the just revealed somatic disorder. All the rest, their affective reactions to the disease, experienced mood, and coping strategies will often differ (see Fergus and Gray 2009). The woman suffers both physically and mentally; she goes through the unpleasantness of treatment; she experiences changes in her own body and concurrently her sense of attractiveness; and she begins to fear an imminent death. At the same time their spouses have to deal with the accumulated stress coming from the need to care for their wife and from the necessity to take over some part of the household duties (like the need to look after the children); they fear changes in their wife's appearance and think of appropriate responses to these changes; they fear losing their loved ones and premature loneliness. The type and intensity of the particular emotions change at different stages of the disease trajectory and are subject to many factors.

EMOTIONS IN THE LIGHT OF THE CANCER EXPERIENCE –
LIVED THROUGH TOGETHER, BUT NEVER DISCUSSED

Numerous examples of research have proved that one's gender impacts on the choice of coping strategies to tackle the illness (Hagedoorn, Buunk, Kuijer, Wobbles et al. 2000; Kiss and Meryn 2001; Kluczyńska – current issue of this journal). Our work further supports the assertion that gender determines reactions to spousal illness.

When asked directly about the most difficult period following the disease diagnosis, all the husbands unanimously singled out chemotherapy, justifying their choice by describing how debilitated their wives felt after the treatment (mainly physically, because of vomiting, extreme weakness and loss of appetite, but also mentally, due to the trauma engendered by their change in appearance) and how little they could do to alleviate the suffering. They have also pointed out some systemic factors which frustrated and enervated them (interruptions in therapy because of the unresolved financial problems of the hospital or terrible conditions while undergoing chemotherapy, such as crowds of people, anonymity, and an

⁷ The secondary process of redefining one's health status, which is also infused by a number of different emotions, takes place when the medical treatment is over. It is rarely pointed out, however, that this time can be conducive to arising confusion and conflict between the spouses. Typically, men assume that their wives have been cured, so the family can function normally again. For the breast cancer patients a new stage of illness begins – life in what is called conditional health (in remission), marked by hope, but also uncertainty, insecurity and fear of death (Fergus and Gray 2009: 1317).

unfriendly attitude of the medical staff towards the patients). The initial stages of treatment were referred to as the most anguishing, leaving the deepest, most indelible marks on their memories. Against this background, the respondents spoke of their shock, loss, frustration, rebellion, and fear of death.

Conspicuously, both the men and women preferred to speak about the ill spouse's psychological state. The emotions of the men were rarely seen as an issue worthy of further discussion. Sometimes they recounted them implicitly or drew vague comparisons to their partners' feelings. Some respondents shunned their own emotions and stated that it is pointless to waste time and energy on thinking about feelings – only actions taken for the benefit of the patient may bring tangible results (shying away from any conversations on this topic seems to distract them from their own fears and reduce the feeling of helplessness), for example:

What can one think about? To help, help, help, and hope for the things to turn for the better. That kind of thinking or giving up won't help. Help as much as one can, and support the person who is sick [Andrzej]

I've [experienced it like my wife], some kind of fear for the future. [Piotr]

Oh, what can one think about? [...] Enormous stress, thinking, pondering about everything, how to overcome this period in life. [...]. Now I'm helping her in all the household chores. I had to do everything by myself before. [Krzysztof]

The men had not disclosed their emotional states in their wives presence, which forced the latter to make conjectures about their feelings by searching for cues in their behaviour:

He surely was afraid, but didn't show it. [Teresa]

It was very hard for him, but he never let anyone notice it. [Halina]

He had to be devastated, because he asked her sister for help. [Elzbieta]

He surely felt great shock and fear that he would be left alone, because he constantly searched for something to do, just not to think about the illness. [Beata]⁸

We can justifiably conclude that our respondents gave credence to a belief that emotions are not the domain of men. Social norms and stereotypes of masculinity prevail at large in Polish society and make it difficult, or even outright impossible, for men to talk openly about their emotions, since such conversations are regarded as a sign of weakness, a proof of not successfully dealing with a given problem. On the other hand, expressing the socially accepted "male" emotions and attitudes (such as aggression, anger, rage, domination, and brutality) seems inadequate when faced with a potentially deadly illness of one's wife.

Our research shows that spouses did not confer with each other about the experienced emotions. On the contrary, they deliberately avoided this topic. When the wives were on the

⁸ All the respondents were somewhat displeased about the classes carried out by psychologists during the clinics in Sieraków. On the other hand, they appreciated the time spent with a physical therapist who showed them new techniques of massaging someone's arms on the operated side.

verge of a mental collapse, the men tried to distract their attention from the disease, to refute the negative emotions they felt or to encourage them in a perky, “male” way. They did not seek explanations for their wives’ emotional states, to understand whether they resulted from becoming aware of a potentially fatal disease, from the fear of painful, difficult and long-term treatment, the fear of mutilation and losing their sense of femininity, the fear of being rejected by their husbands, or from the change in lifestyle (including the need to take on the role of the patient and resigning from work).

Such “muted” (limited to organizational matters) co-experiencing of the disease constitutes a serious threat to men in their endeavours to successfully cope with the loss of health by their partners. Numerous studies have shown that open communication between spouses plays a significant role in how effectively both of them cope with the onset of a disease (see Carlson, Bultz, Specia and Pierre 2000).

ACTIONS TAKEN IN AID OF WIVES AS A STRATEGY FOR COPING WITH AN ILLNESS IN THE FAMILY

Difficult life situations trigger negative emotions and lead people into taking measures aimed at regaining a sense of agency and control over their lives (Taylor, Lichtman and Wood 1984). It is safe to assume that a two-way relationship exists between how the woman with breast cancer and her immediate family cope with the illness, and the ability to provide mutual support: the better a particular family member copes with the difficult situation alone, the more support he/she is able to provide to others. Furthermore, the more support they give to each other, the more quickly they adapt to the new situation and more efficiently operate in it. In our study we have made an attempt at revealing how the couples coped with the illness of one of the spouses, and what kind of support they provide to one another.

Male respondents perceived their role in their wives’ struggles with the disease as primarily supportive. In their statements one can notice four main forms of assistance provided to the breast cancer patients, discerned by other researchers as well (see Hilton, Crawford and Tarko 2000; Kluczyńska in this issue). The first one can be described as *focusing on the feelings of one’s wife and taking care of her* (merely being present, hugging her, holding her hand during doctor check-ups or treatment, evincing love and sensitivity). The second one underscores *participating in the recovery process* (taking the wife to the hospital, massaging her arm, helping with finding the right specialist, attending a pilgrimage to the Jasna Góra Monastery). The third form of assistance pertained to *organizing the household during the time of one’s wife’s infirmities* (cooking, shopping, cleaning and caring for the children). The fourth type of support was *restoring normalcy*, i.e. considering the disease a typical element of life and refraining from excessively focusing on it – but, crucially, the men did so in the belief that this will help their wives in returning to full health. Respondents’ responses indicated that such an approach to the illness of their wives was something consciously sought for and desired by them:

We wanted to limit any change of our style of being. Not to devote oneself totally to it, not showing that the illness is most important right now. No, the illness is [important], but it can’t change our lifestyle. That’s what we tried to do. [Adam]

Husbands not only tried to mitigate their wives day-to-day struggles, but were also heavily involved in the processes of constructing their wives' own coping strategies. Men emphasized their role in overcoming the cancer – they saw themselves as a companion, as the organizer of time, as the arranger of travel (commuting to the hospital). That being said, some of the wives' statements about fending off the disease seem puzzling – only two unequivocally mentioned obtaining assistance from their husbands, the others spoke about “clenched fists”, “not focusing on oneself” and “being with other people”, undertaking psychotherapy, displaying self-control and submission to the recommendations of doctors. The discrepancies in the perception of the degree of commitment to helping one's wife may stem from the nature of the problem itself, i.e. from the unique perspectives of a sick wife and her husband, and specific traits the disease becomes infused with for both the former and the latter. One can be sure, however, that men carefully watched their partners and, within their capacities, tried to facilitate, or at least not hinder, the development of their wives' personal survival strategies. The first strategy of coping with an illness can be defined as *maintaining focus on the illness and the healing process* (i.e. adapting to a new life situation by acquiring information, meeting other patients, joining the Amazon clubs, developing certain routines or treatment regimens). The second group of strategies pertained to *making use of the available aid* (consulting one's condition with specialists such as doctors and psycho-oncologists, para-professionals, and non-professionals like other women suffering from similar diseases, as well as family members and friends). The third group of strategies covers *adopting a progressive perspective on life* (orienting oneself on the positive aspects of life, intentionally “forgetting” about the disease). The fourth category of strategies is comprised of actions *oriented on maintenance/recovering of normalcy in life* (not giving up on existing duties; if possible achieving important, personal goals in life, filling in the available time with meaningful activities).

The male respondents accompanied their wives closely during the illness and recovery periods. However, not always were they capable of interpreting the situation correctly and understanding the expectations of their wives. The issue of their intentions and the needs of their partners failing to converge was clearly visible with regard to social support. Using and providing support forms the cornerstone of strategies deployed to deal with a given problem. Due to the multifaceted nature of the matter discussed, we have considered it separately in our research. Analysis of the collected material prompted us to assume that our respondents perceive using/providing support in a traditional fashion. The men primarily focused on actions undertaken by them, such as instrumental assistance, or an immediate response to emergency situations, while simultaneously downplaying the emotional support. This stands in sharp contrast to the statements given by the woman patients who underscored the reassurance of love, caring, thoughtfulness, and the sheer presence of their husbands as quintessential. During the interviews, they repeated some of the words they regarded comforting:

He said that I shouldn't be ashamed of the physical discomfort. That everything will be alright, that we'll survive this somehow. He helped me as much as he could. [Maria]

He assured me that this doesn't change anything. He said: even if you lose both of your breasts it wouldn't matter, your presence is the most important. [Teresa]

Only two mentioned participation in household chores and taking on additional responsibilities. There are at least two ways of interpreting the differences in the responses between the men and woman with regard to the types of aid: the husband's help at home (instrumental support) is already self-evident and widespread, thus not worthy of mentioning; or it could also be that women in the study did not feel attractive and/or secure about their husbands' feelings (this would render any declarations of affection as invaluable and worth remembering).

The men and women participating in the study had different views on the type of provided assistance, but they shared the same conviction when it came to pointing out the "support recipient". Giving comfort to women is perceived by both parties as indisputable. Therefore, it came as no surprise that the men responded with undisclosed astonishment to a question whether they were receiving support from their wives and/or others following the cancer diagnosis:

It's hard to expect from someone sick to cheer you up. [Jan]

If she fell ill, how could she support us? [Tadeusz]

Our respondents did not seem to realize that they were also suffering the consequences of their wives illness by bearing the burden of changes in the organization and structure of their family life (especially after assuming the role of the informal carer). Only one of the respondents admitted that he expected emotional support from his wife. Her presence, a conversation, a smile, some help in coming to terms with the changes happening to her body and help with tending her ailing body, neutralized his anxiety:

Maybe I've expected this kind of spiritual emotional to better deal better with everything that happened to me. But a smile, help is also support. Dry out this, cook, peel or something. After the illness, after the surgery, when she got home, during her chemo, we've learned to help each other all the time. [...]. We've dealt with it. When I changed her bandages she said: don't be frightened, touch, rub. A man is just afraid when he sees fresh wounds. Stitches and everything. She says: don't be afraid, touch, that's the way it should be. Maybe this is a kind of support as well. This is how it's supposed to be. One is scared of offending, accidentally hurting. [Krzysztof]

In the eyes of the husbands, the division of responsibilities in the family obliged the men to become an unwavering source of support. Therefore, the husband has to somehow cope on his own, or perhaps with the help of his children. Our respondents spoke about doctors and psychologists with reluctance, with distance, sometimes deliberately mentioning examples of their incompetence when it came to providing any kind of support. It can be assumed that men do not want to (or feel ashamed to) admit that they enjoy someone's support or are willing to benefit from it, as it may be interpreted as a weakness or a sign of incompetence. The wives confirmed that their husbands are deprived of professional and non-professional assistance. When asked directly whether they provided support to their husbands, they denied it and started speaking about their feeling of helplessness and involvement in their own healing process. One of them admitted that despite her illness she tried to maintain the status quo in both the marital relationship and everyday family life. In retrospect, however,

she assesses the chosen strategy as having been inappropriate – any new type of situation demands a change, and persistently adhering to previous habits and patterns of action prompts putting on masks, posing, which is tiresome in the long run and does not bring any of the results one might come to expect:

He knew, and he knew that I wanted to, that I wanted to try to leave everything as it is. Now I know that it was a mistake! [Halina]

Three admitted that they had helped their husbands with overcoming the crisis brought about by the cancer. However, each one of them deployed a different strategy:

I've tried to put on a mask. [Elżbieta]

I've tried not to cause extra work and I've tried to smile, just to make him think that it's alright. [Beata]

I've been explaining to him that they removed my cancer, that it's gone and everything will be ok. [Jolanta]

The problem of misunderstandings related to using/providing support is extremely important because it influences how men find themselves in the role of a carer and how much satisfaction they derive from it. One might expect that in extreme cases it could lead to withdrawal from the relationship, or even breakup of the marriage. Women, when not provided the expected support, become irritated and/or disappointed. On the other hand, when men recognize that they are not able to properly help their partners, they tend to feel frustrated and/or unappreciated (Fergus and Rose 2009). Our research shows that the reason behind not meeting specific expectations resided in the lack of knowledge about their partners' needs – the husbands had to decipher ambiguous messages to guess what would make their wives pleased. Additionally, the husbands were usually not certain if they could actually satisfy the specific needs of their wives:

I've tried. Did I do well? It's hard to say. One would need to ask my wife. Surely I could do better, but... [Adam]

[I've helped] as much as I could. Did I do it well? I think so. Everything that needed to be done in the house, I had to do it for her. Everything was done somehow, right? Once better, once not so good. It's never the same. Life is life. [Jan]

It seems that wives do not only fail to inform their husbands about their needs, but neither openly praise their efforts nor complain about what has been done. Because of unclear expectations of their wives, job-related issues, and being ineffective in restoring normalcy (i.e. completely eradicating the disease from family life) the men quite critically assessed the support received from their partners. Their self-esteem was lower than what could be expected if one looked only at their wives assessment of the received support – this could be due to forbearance on behalf of the women, a tendency to lower the demands placed on their husbands or appreciating even small gestures performed by the latter.

CONCLUSION

In our research we have focused our attention on the situation of men taking care of their wives with breast cancer. Lack of research on this topic in the Polish social sciences may be traced back to a common belief that it is the man who should always provide assistance to his partner – both in health and in sickness. The intricacies of this phenomenon remain undisclosed under this stereotype. In our study we have tried to draw attention to how complex and multi-layered the circumstances are in which husbands provide assistance to their wives. Also, we wanted to take part in the at least decade-old discussion taking place in Western literature.

The results presented above allow us to formulate four general conclusions. Firstly, members of 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, over-loaded experience, accumulated frustration, and helplessness. Moreover, a commonly shared belief about “specializations” within gender roles precludes men from preparing themselves to take care of their sick wives and under-aged children. Stereotypical as it may sound, this approach remains ubiquitous in Poland.

Secondly, recent years in Poland have seen the medical interpretation of a cancer etiology gaining momentum. This often life-threatening disease no longer raises religious fear, nor are those suffering from it surrounded by taboos. Cancer has become one of the many lifestyle diseases affecting specific parts of the population. Moreover, there is no excuse, nor social acceptance, for men leaving their suffering wives. The emergence of cancer in the family forces all of its members to change in terms of their attitudes, emotions, roles, relationships and responsibilities. Acknowledging the increasing rate of cancer does not mean, however, that a surge in general knowledge about the disease is taking place as well (including information about its impact on family life, or about the situation of patients and the requirements that need to be met when performing the role of a caregiver).

Thirdly, the spouses shared experience of cancer, as suggested by, among others, Skerrett (2010), has to be founded on a shared discourse about the experience of the disease. Our research shows that men exhibit a reluctance to construct any kind of common narrative – they generally do not want to talk about emotions (neither their own, nor their wives), preferring instead to take certain actions and provide instrumental support to their partners. This does not mean that they do not experience negative emotions like fear, shock, mental collapse, helplessness, or hopelessness, or that their wives emotions escape their attention. Each of them individually acts out the stress they endure. Furthermore, the other side notices everything, but tactfully avoids addressing the problem. In the end everyone is left alone with their difficult emotions. Contrary to what one might instinctively suppose, such behaviours are interpreted by the respondents as a form of support: avoidance is interpreted as showing concern for the well-being of the partner (i.e. avoiding overburdening him/her with troubles they “don’t need” right now). Inability to converse about emotions triggered by the disease, transforms itself into an ability to look after each other. In this context, the respondents described turning

each other's attention away from the disease as a form of assistance, perceived as a more practical or reasonable action to undertake than other available choices.

Lastly, the fact that the women with breast cancer were members of the Amazon association did not seem to affect their husbands' situation. Being a breast cancer activist manifests itself in the general approach to the disease, and in access to professional and paraprofessional support (also to information on the coping strategies deployed by ex-patients). This, however, does not seem to affect the attitude of women towards their husbands-cum-carers. One could reasonably assume that if the activists were both substantively and emotionally better prepared to cope with the disease, they would also notice the significance of their roles in supporting their husbands (who, as it seems to be the case, also experience major tribulations). Unfortunately, this has little to do with what our respondents experienced – the wives were unable to support their husbands, or did not realize that this can be expected of them. Husbands accepted the social ties carefully weaved by their wives – they were, after all, participants in training organized by the Amazon Federation of Associations. Furthermore, they have consciously begun constructing their caregiver identity by deepening their knowledge on the psychology of relationships, learning about changes in the sexual sphere after oncological treatment and about rehabilitation issues their wives will have to struggle with after the surgery. That being said, they seem to be reluctant in transforming their social role, especially when it comes to reshaping their male identity. And it is the latter issue that should be seen as key to understanding how men cope as caregivers of woman with breast cancer – this, however, means that further research is most surely welcome (Zierkiewicz and Mazurek 2015).

Research results referred to in the earlier paragraphs prove useful when planning and implementing educational programs and social campaigns initiated by public institutions, patients' organizations (the Amazon Federation of Associations) and professionals assisting the sick and their loved ones. Four prime areas of application can be identified: the sensitization of public opinion to the needs of husbands caring for their ill wives and the problems they have to face; the inclusion of the Amazons' caregivers in the offer of social support proposed by professionals (psycho-oncologists); raising awareness among the ill of various problems their husbands have to face: negative emotions, the overwhelming sense of hopelessness and incompetence pervading their struggles to bring help and relief to their wives, and thus their often unfulfilled need of attention, understanding and support; and the implementation of educational programs aimed at improving communication efficiency between the spouses in the face of an illness.

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MAŁŻEŃSTWA MIERZĄCE SIĘ Z RAKIEM PIERSI: ROLA MĘŻÓW WE WSPIERANIU ŻON

Cel: Głównym celem artykułu jest zaprezentowanie, jak mężowie kobiet chorych na raka piersi, aktywnych członków klubów amateurek, pełnią funkcję ich opiekunów. Autorki analizują ten problem, konfrontując perspektywę mężczyzn-opiekunów z opinią ich żon. Tło: Od partnerów kobiet chorych na raka piersi oczekuje się przejęcia odpowiedzialności za opiekę nad pacjentkami, a jednocześnie nie przygotowuje się ich do wypełniania obowiązków wynikających z nowej roli i nie zapewnia im się profesjonalnego wsparcia w tym zakresie. Metoda: Indywidualne wywiady na półstrukturyzowane zostały przeprowadzone z ośmioma parami małżeńskimi, osobno z żonami i mężami. Wyniki: Mężowie spostrzegają swoją rolę w zmaganiach żony z chorobą przede wszystkim przez pryzmat wspomagania jej (szczególnie w wymiarze instrumentalnym), traktując podejmowane działania jako możliwość skanalizowania negatywnych emocji. Stosują cztery główne formy wspierania chorej żony: skoncentrowanie się na uczuciach żony i na trosce o nią, udział w procesie zdrowienia żony, organizowanie sprawnego funkcjonowania gospodarstwa domowego podczas niedomagania żony, przywracanie „normalności” w ich życiu. Wnioski: Ograniczona wiedza na temat chorób onkologicznych, deficyty w ofercie profesjonalnej pomocy dla mężów kobiet chorych na raka piersi oraz stereotypy dotyczące ról płciowych powodują, iż mężczyźni mają trudności z podejmowaniem opieki nad chorymi żonami. Nie pomaga im w tym nawet aktywność żon w ruchu amateurek.

Słowa kluczowe: przeżytniczki raka piersi, małżonkowie, mężczyźni jako opiekunowie