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“(UN)NECESSARY CHANGES.” SELF-IMAGE TRANSFORMATIONS AND REORGANIZATION OF EVERYDAY LIFE OF WOMEN WITH ACQUIRED DISABILITIES AS A CONSEQUENCE OF NEOPLASTIC DISEASE

The aim of the article is to present, based on the author’s research, identity problems and conflicts of social roles experienced by women with acquired disability which is a consequence of cancer. The research shows that numerous tensions and dilemmas occur in relation to a conflict between being a disabled woman and her family, professional and social roles. Disability is connected with inability to perform all former roles and the need to reorganize everyday life, thus affecting the image of oneself. Therefore, the situation of becoming disabled is a critical moment which forces the redefinition of ‘Ego’, a change of former lifestyle, performed roles, and relations with other people. In order to cope with these challenges and adapt to change, women take up various action strategies.

Keywords: identity, the redefinition of ‘ego’, the conflict of roles, reorganization of everyday life, acquired disability, cancer

INTRODUCTION

The experience of a neoplastic disease and disability as its consequence is undoubtedly a turning point in the biography of an individual. It forces not only a change of lifestyle but also and perhaps first and foremost the redefinition of one’s way of thinking about oneself, the world, and relationships with others. Acquiring a disability leads to the stoppage of one’s former course of life. An individual loses control over their life for a period of time and feels disorganization of their identity, which introduces chaos and disorientation. They suffer, feeling painfully stricken and forlorn (Riemann and Schutze 1992: 104). In order to find oneself in a new situation, it is necessary to modify formerly performed social roles, revise

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relationships with others, and consequently correct auto-perception, life objectives, and ways of organizing and executing tasks.

‘Life after cancer’ or ‘with cancer’ requires not only the acceptance of limitations and incomplete physical fitness but also the acceptance of changes of identity (Scambler and Scambler 2010: 48; after Tobiasz-Adamczyk 2012: 95). In relation to the sense of individual and social identity, it is important to answer what it means to have cancer not only at the moment, but also in the past and the future. The completion of the stage of intensive treatment, which means leaving the dominating role of being a sick person behind, requires sufferer to confront the issue of how much the disease has disturbed their individual biography, how it has influenced their auto-perception, and to what extent it has stigmatized them socially (Tobiasz-Adamczyk 2012: 95).

Functioning during a treatment of neoplastic disease or during the period of remission generates a lot of contradictory feelings and internal dilemmas. Past experiences and auto-perception from before the disease overlaps with the fear for one’s life and the consequences of undergone treatment, which can result in disability and force correction or creation of a new picture of oneself, redefinition of previously performed roles, and reorganization of everyday life. Marcin Lubaś and Katarzyna Słaby (2017) notice, referring to Arthur Frank’s terminology (1997: 75–135, as cited in Lubaś and Słaby 2017: 403), that there are two dominating narratives in the stories of women about their neoplastic disease and life in the period of remission. The first is the narrative of restitution of health, where women concentrate on recovery and the disease is treated as a passing phase. The second is the narrative of searching, which takes into account less optimistic aspects as well, such as the loss of the feeling of being attractive and feminine, or the feeling of loneliness (2017: 401). Edyta Zierkiewicz (2012b) also refers to A. Frank’s typology in her analysis. She refers to this typology, because it reflects not only the ways of reacting to the disease but also makes it possible for women struggling with it to create and implement strategies to cope with the new situation. In the restitution narrative, possible limitations disappear or are sufficiently contained and adapted to. This way of perceiving the disease and disability (which is the consequence of cancer) makes individuals define themselves more by their former fitness and activity, which in turn makes the necessity to create a completely new identity and the implementation of new social roles superfluous. The narrative of searching or struggling is connected with the rejection of former auto-definition (from before the disease and disability) and with the construction of completely new picture of oneself. Women suffering from cancer learn new roles, adopt new identities, support other sufferers, and have a sense of mission. Finally, there is the narrative of chaos, which reflects confusion, powerlessness, and withdrawal (Zierkiewicz 2012b: 36), which disturbs or even makes impossible the construction of a coherent picture of oneself, leading to the fragmentation of identity, tensions among roles, increased chaos, disorganization, and internal mental conflict.

Auto-definition and adaptive problems as well as conflicts of roles, experienced by women (and also by men) with acquired disability are a subject of analysis by both Polish and foreign researchers, who consentaneously indicate the multidimensionality and strong individualization of identity and adaptive strategies implemented by individuals acquiring disability (Riemann

and Schütze 1992; Couser 1997; Fine and Asch 1998; Davis 2002; Chodkowska 1993, 2002; Świątkiewicz-Mośny 2010; Malec 2008; Tobiasz-Adamczyk 2012; Nowak 2012; Zierkiewicz 2012b; Gąciarz and Rudnicki 2014; Stojkow and Żuchowska 2014; Ostrowska 2015; Piątek 2018, 2020 and others). The process of adaptation depends on many factors: the course of disease, the suddenness of its occurrence, the kind and degree of disability, age, family situation, personality, social support system, and a number of other conditions.

Despite the progress in the field of medicine, neoplastic diseases remain a huge challenge for doctors and patients, causing fear and changing forever the lives of the ill and their families. Unfortunately, victory over cancer does not mean victory over fear of its recurrence, because it accompanies the cured and their families for a long time after successful treatment (Neoplastic disease – patients` experiences 2014: 50), which influences the way they function. Although, as noticed by Emilia Mazurek (2018), the ontologically ill experience a lot of compassion, care, and support, they also often experience difficulties in everyday contacts (2018: 81) and problems with adapting to new situations.

Explorations carried out by the author among women with certified physical disability as a consequence of undergone neoplastic disease also revealed that the researched women experienced identity problems, as well as tensions between social, family, and professional roles and the role of an ill and disabled person. Confronted by contradictory expectations and standards, the women implemented various adaptive mechanisms and new strategies. This article is dedicated to these very issues. Empirical bases for this analysis will be my own research conducted among women with disabilities.

METHODOLOGICAL-DEFINITIONAL DRAFT

The research presented here constitutes a part of a broader research project executed by the author in the Bielsko-Biała subregion of Poland among adult women with certified physical disability of moderate and severe degrees¹. The main aim of the research was to specify the determinants of adaptation and integration of women with physical disability in a local community. Selected issues covered in the research referred to, among other problems, the following research questions: Which social, cultural, and psychological factors facilitate and which handicap adaptation to the role of a disabled person? How does disability influence one's degree of self-acceptance and auto-perception? How are the social roles of disabled women performed and does disability influence redefinition of these roles? What changes occur in personal, family, and professional life as well as in the field of activity in a local community after the onset of a disability? In what area of life were changes the most radical after the onset of a disability? From what sources of support can women with disability benefit? How do women assess their situations, and how do they see their futures?

¹ The empirical data presented in the article constitutes a part of a broader research project titled *Psycho-social conditions of adaptation and integration of women with certified disability in a local community*, executed by the author in 2009-2014 (the first stage) and 2015-2017 (the second stage). The first stage was financed by an internal grant of the University of Bielsko-Biała (no. 13/I/GW/08).

In the research, in conformity with *The Professional and Social Rehabilitation and Employment of Disabled Persons Act*, a disabled person is defined as permanently or temporarily unable to perform social roles, as a result of a permanent or long-lasting damage to the efficiency of the organism (*The Professional and Social Rehabilitation and Employment of Disabled Persons Act* of August 27, 1997, article 2, point 10, Journal of Law of the Republic of Poland from 2011, no. 127, position 721). Taking into account social context, it is assumed that a disabled person is ‘an individual with impaired physical and/or mental ability that brings the functional limitation of life activity in a degree, which hinders the performance of their social roles’ (Kawczyńska-Butrym 1996: 16). Disability, as a social construct, was to a significant degree equated with inability to perform roles based on culturally dominating patterns (Malec 2008: 17). One important point of reference in the auto-definition of an individual has become the degree and scope of performed social roles and changes in this area.

Women with damaged locomotive organs (motorically disabled) and with chronic internal organ afflictions have been included in the category of physically disabled. The researched women held legally-valid certification of moderate or severe degree of disability. The group with severe degree of disability includes persons with damaged efficiency of the organism, who are unable to work or are only able to work under protected mode conditions, and who require, in order to perform social roles, permanent or long-standing care and support of other people due to inability to exist independently. The group with moderate degree of disability includes persons with damaged efficiency of the organism, who are unable to work or only able to work under protected mode conditions, or require temporary or partial support of other people in order to perform social roles (*The Professional and Social Rehabilitation and Employment of Disabled Persons Act* from August 27, 1997, article 2, point 10, Journal of Law of the Republic of Poland from 2011, no. 127, position 721).

The research material was collected in stages. In this analysis, empirical material from the first part of the research has been used. It was conducted with the use of a survey method with the application of a questionnaire². Four hundred and sixty women with acquired disability took part in the research. They fulfilled the following criteria: Age 18–65 years old, a physical type of disability, disability code – 05-R, 07-S, 08-T, 09-M, 10-N or 11-I, a moderate to severe degree of disability acquired for the first time within the period covered by the research, and having completed the process of certification. The Disability Certification Boards located in the Bielsko-Biała subregion helped in recruiting respondents.

² The questionnaire consisted of 52 questions, including: 32 closed, 10 half-open, and 10 open questions. The questions were divided into four parts, related to separate topics. The first part concentrated on changes which have taken place in the respondents’ lives after disability occurred (the following aspects were taken into account: self-reliance in performing self-serving actions, being mobile and in managing a household; the performance of roles in the areas of family, professional/educational life and in residential community, as well as the occurrence of problems, conflicts and changes in these areas). The second part focused on the system of support and on the quality of social interactions, as well as on communal factors, which were conducive to integration and adaptation in the local community after the occurrence of disability. The third area concentrated on issues linked with the ways of auto-perception and auto-definition by the researched women after the occurrence of disability, their fears and concerns, the degree of acceptance of current situation, as well as how they cope with new roles, relationships with others, and implemented adaptive strategies. The fourth focused on the social-demographic characteristics of respondents.

From the group of women with acquired disability, 198 individuals were selected for this article. Their disability was a consequence of undergoing neoplastic disease (152 – breast cancer and 46 – other types of cancer)³.

In the group of women whose disability was the consequence of undergoing breast cancer ($N = 152$), women with moderate degree of disability dominated (60%), with the remaining 40% having certification of severe disability.

As many as 78% of the respondents were in the age group of 50+, which is in conformity with the incidence of getting ill with breast cancer in the 50+ age group. Women in the age group of 40–49 accounted for 16% of cases, whereas women in the age group of 30–39 accounted for only 6%. 63% of the researched women lived in cities, and 37% in the countryside.

The professional situation of respondents presented itself as follows: 21% were professionally active, 12% were unemployed, 25% were disability pensioners, and 42% were retired (including 5% who were early pensioners).

As regards marital status, the situation presented itself as: 78% of the researched women were married, 11% were widows, 5% were unmarried, and 6% were divorced. Most often respondents had two children (39%), while 25% had one child, and 21% had three or more children. Only 15% of them were childless.

Describing their family situation, more than half of the women (56%) declared living in a small, two-generational family household, or that they lived with a husband or a partner without children (20%). In the rest of cases, they functioned in multi-generational families (9%) or lived alone (15%).

In the group of women with other kinds of cancer ($N = 46$) respondents with moderate degree of disability (58%) dominated. 42% of them had the certification of severe disability. The most frequently occurring types of cancer in this group were: ovarian cancer (33%), endometrial or cervical carcinoma (29%), and colorectal cancer (13%). Other types of cancer (among others lung, anal and blood cancer, malignant goiter, and renal cell carcinoma) accounted for 25%.

As many as 91% of respondents from this group were in the 50+ age group. Women in the age group of 40–49 accounted for 5% of cases, whereas women in the age group of 39 and under accounted for 4%. 71% of researched women lived in cities, whereas 29% in the countryside.

The professional situation of respondents in this group looked as follows: 29% were professionally active, 21% were disability pensioners, 42% were retired, and 8% were unemployed or jobless without having official job-seeker status.

Regarding marital status, the situation in this group looked as follows: 67% of researched women were married, 17% were divorced, 8% were widows, and 5% were unmarried. Most often respondents had two children (42%), while 38% had three or more children, and 8% had one child. In most cases, these children were already adults or teenagers. Only 12% of the women were childless.

Describing their family situation, half of the women (50%) declared living in a small, two-generational family household, or that they lived with a husband or a partner without

³ The domination of respondents with breast cancer is in line with general tendencies, because this type of cancer is the most common among women in Poland (<http://onkologia.org.pl/raporty/> [7.03.2020]).

children (21%). In the rest of the cases, they functioned in multi-generational families (17%) or they lived alone (12%).

To summarize, the analyzed sample of the researched women was dominated by individuals over 50 years old, city dwellers, pensioners and disability pensioners, and married women functioning in nuclear families with one or two (often adult) children. The dominating type of neoplastic disease was breast cancer (77%), while other types of cancer accounted for 23% (the most frequently occurring types were endometrial or cervical carcinoma, ovarian and colorectal cancer).

It was agreed that the key factor in selecting respondents would be those consequences of neoplastic disease which led to damage to the efficiency of an organism, and which in turn required permanent or long-standing care and support of other people in order to perform social roles. The choice of this category of respondents was dictated by the character of neoplastic disease⁴ and its psycho-social consequences for patients and their social environment.

Neoplastic disease is chronic and life-threatening. The basic criteria which allow including it to this category are the long-lasting course of the disease; the lack of unambiguous definition of its course and treatment; it results in disfunction or disability; the specialized rehabilitation process; and the need for supervision, observation or care (Markocka-Mączka and others 2016: 178). A chronic disease often leads to disability, which involves incapacity and limitations in performing social roles corresponding to age, gender and social and cultural norms (www.unic.un.org.pl). The common denominator of chronic disease and disability is the inability to fully perform former social roles and the appearance of new roles linked with the disease and limited ability. One of the key objectives for a person who has acquired disability becomes integration, which allows functioning normally in different social roles under the conditions of normalization created by society.

THE CONSTRUCTION OF SELF-IMAGE AND ADAPTATIVE STRATEGIES IMPLEMENTED BY RESPONDENTS

Adaptation to a chronic disease and its consequent disability takes place gradually. Nela Kerr (1977) claims that this process consists of six stages. The first five are: (1) shock (disbelief, surprise, anger, and pain); (2) the expectation of improvement (intensive treatment and the belief that the situation is temporary); (3) mourning (mood swings, loss of meaning in life, pessimism); (4) defending health (an ill person takes action in order to improve their situation, being fully aware of their disability); and 5) neurotic defense (this can involve deployment of defense mechanisms which ignore the fact of limitations related to disability. This kind of behavior can also be displayed by family and friends of the ill person). The fourth and fifth stages can occur one by one, or only one of them may be present. The sixth stage

⁴ The term malignant neoplasm covers the group of about 100 afflictions, which have been classified in the International Statistical Classification of Diseases and Related Health Problems. Neoplasms are second most common cause of death in Poland (National Neoplasms' Register <http://onkologia.org.pl/nowotwory-zlosliwe-ogolem-2/>).

is adaptation. (1997: 317–324). At the adaptation stage a self-image and an understanding of one’s capacities and limitations are formed. An individual determines consecutive objectives and organizes life from the beginning. The course of this process, its duration, and problems occurring at each stage are highly individualized.

Neoplastic disease brings about a number of negative consequences in various areas of life. From a biological point of view, it is linked with pain, disfigurement, and disability. From the psychological perspective, it brings suffering, fear of death, a change in the perception of one’s body, lowered self-esteem, and the feeling of losing control over one’s life. Socially, it forces the adoption of new roles and the reorganization of old ones. It also results in the disturbance of family relations and constraints in social life. From a behavioral perspective, it is connected with medical procedures, and changes in lifestyle and forms of activity (Ziarko 2014: 113). In all these areas, these consequences influence the preservation, reconstruction or creation of one’s self-image and future life. They force one to pose difficult questions such as: Who am I? What do I think about how others see me? What is my place in my family, workplace, or society in general? For this reason it is crucial, from the point of view of this analysis, to define the term ‘identity’.

Personal identity is understood as an image of one’s own person and this is precisely ‘what is the most relevant, characteristic and specific for auto-characteristics’ (Malewska-Peyre 1992: 19). It consists of the structure of feelings, values, and projections in relation to oneself. It is formed under the influence of social interactions and experiences connected with them. (Mielicka 2000: 28). Personal identity is anchored in the need for uniqueness, whereas social identity is rooted in the need for belonging and similarity to others.

Mirosława Marody (2014) claims that even if identity is chosen individually, it remains a ‘collective product’. ‘It is a product, not only and even maybe not so much, of our personal decisions, but also and perhaps even first and foremost, of our relationships with other people, their reactions to what we do, and their readiness to accept that we are, what we want to be seen as’ (Marody 2014: 196). Identity refers to individual and social auto-definitions of individuals. Basically, we are discussing a certain set of projections, judgments, and convictions held by a social actor about themselves (Bokszański 2002: 252).

From a psychological point of view, identity is closely linked with the structure of *ego*. Identity gives *ego* a sense of continuity in time and under changing circumstances, as well as differentiating us from other social actors. *Ego* includes the image and assessment of one’s body, self-knowledge, the ability, and inclination to make choices, the ability to undertake deliberate actions, and self-regulation. *Ego* is also influenced by people close to us, social norms, values, and performed roles. It can be accepted that *ego* is not only a loose structure of various roles and social identities, but also projections, judgements, values, and objectives linked with ourselves (Wojciszke 2006: 136–137). In the context of identity, *ego* performs a number of important functions. One of them is preserving and negotiating identity in relation with others. Self-knowledge and biographical memory are key indicators of the feeling of one’s own identity. The recognition of our identity by others is also a function of *ego* (Wojciszke 2006: 141).

Zbigniew Bokszański (2006) explains identity multidimensionally. These dimensions refer to dichotomies: prescriptivism-descriptivism, process-state, continuity-dissimilarity,

and conformism-rebellion (Bokszański 2006: 30–43). From the prescriptive perspective, identity means ‘the essence’ of a human being (the meaning of their existence), whereas from the descriptive perspective, it concentrates more on the description of identity structure, its origins and evolution. Process-wise understanding of identity, comprehended as the lack of a stable self-image and social acceptance, can be juxtaposed with structural understanding of identity’s characteristics. Especially interesting, from the point of view of this analysis, is understanding identity as a continuation of certain traits over time. In this perspective, identity is understood as the continuity of a person and their characteristics, despite the passage of time. It can be juxtaposed with dissimilarity, which means displaying traits and values, causing that a subject, continuing their identity, exposes their dissimilarity to others. Finally, the last dimension refers to the extreme forms of adaptation. From conformism, understood as a number of identity identifications which are in line with social expectations, to rebellion, which leads to the construction of new identities and to changes.

Referring to the authorial research used in this article, one can find common points with the dimension proposed by Zbigniew Bokszański (2006: 35), which differentiates the ways of constructing self-image, displayed by the opposition of continuity-dissimilarity. In answers given by the respondents one can find elements connected with the understanding of new identity as dissimilarity. It is understood as something exceptional that distinguishes the ill from others, those who do not have the experience of neoplastic disease and disability. This identity provides knowledge, experience, and strength, as it makes them someone completely different from who they used to be. In this new situation, one’s hierarchy of values, as well as ways of thinking and acting also change. Traces of continuity remained in this new self-image (the memories of oneself from before illness, referring to former fitness, outward traits and psychological characteristics – especially visible in answers to the question about undertaking activities before and after the occurrence of limited ability), although they usually generated dissonance, slowed down the adaptation process, and hindered the creation of a stable and unambiguous self-image.

Accepting a new situation (and making it meaningful) in a way that is not stigmatizing and does not negatively influence self-esteem is not easy. This is accompanied by another difficulty, resulting from the memory of life before the occurrence of disability and from coping with the new situation. It is associated with “the discomfort of belonging ‘neither here, nor there’” (Bednarczyk et al. 2015: 107–108). On the other hand, the practice of ‘auto-stigmatization’ provides an opportunity to adjust to the demands of society and the harmonization of identity (Lejzerowicz 2015: 102). “People, who are treated as disabled individuals, start to behave in a stereotypical way and they themselves begin to find traits ascribed to them by others. The label has been attached and one has to accept this fact” (Lejzerowicz 2015: 102–103).

Auto-definition of identity involves a number of selected traits: gender, physical appearance, family, local community, state affiliation, religion, social status, and social role (Kocik 2006: 131). In the context of the problems analyzed here, the key issues seem to be, from a bio-psychosocial perspective, those linked with gender and physical appearance, whereas from strictly sociological point of view, those referring to the scope of performed social roles (especially family and professional roles). Entering new roles (for example that of an ill or disabled person), the conflict of roles, and the loss of professional status or the suspension of

professional activity for the period of treatment influence self-perception and auto-definition. Disease or disability are ‘the state of negotiation’ and its result depends on the acceptance of changes which have occurred in an individual’s life, as well as on a new order of interaction ‘negotiated’ by them with their family and social circle (Tobiasz-Adamczyk 2012: 93).

The research conducted by the author of the article shows that women with acquired disability lose important points of reference. Notions such as femininity or attractiveness change their meaning in the face of the struggle with neoplastic disease. Key difficult moments are the period of treatment (chemotherapy, radiotherapy, hormonotherapy, and surgical interventions: the removal of breasts or ovaries, or sigmoid colostomy) and adaptation to changes and side effects which have occurred as its consequence. These side effects include scarring, disfigurement, hair loss, worsened skin condition, weight gain or loss, edema, and anemia. All this significantly alters a woman’s outward appearance, and thus influences their self-assessment. It is accompanied by long-term stress arising from uncertainty about the prognosis and the development of the situation. Moreover, during the period of remission, women experience the fear of relapse, which additionally negatively influences physical and mental wellbeing and self-image.

Almost all the respondents have clearly indicated that they experienced difficulty with the acceptance of their body after the occurrence of disability. The women had to deal not only with the stigma often linked with disability, but redefinition of notions such as femininity and attractiveness was also necessary. Beata Tobiasz-Adamczyk (2012) draws attention to the difficulty and specificity of the situation of women with disability caused by neoplastic disease. Discussing women with breast cancer she claims that on one hand they are perceived as people whose life is threatened by oncological disease, but on the other, because the disease involves the breast, an attribute of femininity, the loss of this attribute becomes an indicator of relationships with others, and ultimately a discriminating and stigmatizing social fact (Tobiasz-Adamczyk 2012: 93). Edyta Zierkiewicz notices that “breast cancer is a special disease, because of its power to ‘redefine’ the generic identity of a person afflicted by it” (2012a: 32). However, in the case of respondents suffering from other types of cancer, the consequences of the disease and disability also influenced their sense of femininity, attractiveness, and self-acceptance. It is a result of the fact that feminine identity is socially constructed by the body. A body with a stigma which cannot be removed constructs an identity with a stigma and it influences one’s ways of entering social roles and how they are performed.

It also has to be remembered that the consequences of cancer of the reproductive organs and breast, and of colorectal or anal (in cases of sigmoid colostomy) cancer influence not only feelings of attractiveness, but also the fulfillment of sexual and intimate needs (Ostrowska 2007). For these reasons respondents indicated difficulties and constraints in the area of intimate relations with a husband or partner. They partly resulted from the degree of acceptance of the current situation and self-assessment, as well as from the quality of marital relations (over 62% of the women in relationships indicated some tensions in this area). The scale of difficulties depended on the stability of the relationship before the occurrence of limited ability, as well as on the scale of change which occurred after the onset of disease and its consequences.

Additionally, referring to the period from before the occurrence of disability made the course of adaptation more difficult and slower. Many respondents indicated that they try to hide (camouflage) the consequences of a disease or disability even from the closest members of their family and social circle. However, on the other hand, when a woman was able to construct a positive self-image it was conducive to the acceptance of herself and her new situation.

Assuming that one of the key points of reference in defining oneself are performed social roles, another important problem linked with coping with the disease and limited ability was the experience of difficulties in performing those roles and conflicts among them.

Respondents had to face situations where they could no longer define themselves through previously performed roles. On the other hand, new roles arose, those of an ill and disabled person, as well as of a patient. They came with various new expectations and demands, but also with new privileges. Uncertainty about prognosis, the time for performing a given role and its influence on previously performed roles also had an impact on performing new roles. Consequently, this situation caused a number of tensions with which the researched women had to cope.

Assessing the scope and degree of performed social roles and the conflicts occurring among them, the indicators of the consequences of disability, such the degree of self-reliance in everyday life and independent existence, as well as constraints in performing social roles, have been taken into account. In the area of self-serving actions, 69% of respondents (among the whole sample of 198 persons) declared full self-reliance in maintaining everyday personal hygiene and dressing, 27% indicated the need for some help of other people, and 4% selected full reliance on others. When it comes to household management, 32% of respondents did not need any help and 49% required support in this area. 19% of respondents required support in hard household chores, shopping, and looking after security.

Parental roles in the area of fulfilling emotional and custodial needs were performed with the support of relatives. Responsibilities regarding organizing the performance of children's school and extracurricular duties caused the greatest difficulty. In this case, the researched women often benefited from the support of a spouse or grandparents. Because most of the women participating in the research had older or adult children, childcare issues did not pose serious or long-lasting problems. However, treatment and rehabilitation forced their withdrawal from full participation in family life for some periods of time. There are four main strategies of coping with conflicts in personal and family areas. They are listed below, in order of the frequency of their application: (1) the strategy of separating and segregating various expectations, resulting from performed roles and their gradation; (2) the strategy of delegating various duties to other people; (3) the strategy of limiting or breaking some relations of roles; and (4) sporadically expanding their relations, taking on too many roles and responsibilities to find, paradoxically, justification for not performing them (see Piątek 2018: 102–105). Great support in everyday activities and in performing roles in these areas was provided by respondents' relatives, mainly husbands and adult children. Partners' involvement in everyday activities positively influenced adaptation to the ensuing situation (compare with Zierkiewicz and Mazurek 2015: 95–116).

Roles other than those in the family, mainly professional, also became complicated in the face of the disease and disability. The majority of women of working age indicated changes

in their professional situation. These mainly involved obtaining a disability pension (and a break or termination of a professional career) or a continuation of employment but under new terms and conditions, specified by an employer and dictated by a certificate of disability and privileges resulting from it. There were also some cases of job loss or the necessity of changing positions or retraining (Piątek 2020: 98). The strategies of coping with role-based conflicts undertaken by the professionally active women came down to separating various expectations, resulting from performed roles and their gradation. They also involved delegating various duties to other people, when the nature of a position made it possible, or limiting or breaking some relations between roles. The prevalence of the application of these strategies depended on the degree of disability and the scope in which an employer respected privileges granted on the basis of a certificate of disability.

Disability also significantly influenced the roles performed in a local community. Over 60% of respondents experienced difficulties with contacts within their social circle, which, to some extent, could result from fears and awkwardness about interactions with a person suffering from cancer and disability. The respondents indicated that their contacts with people from outside the family became less intensive, as did their participation in various religious, cultural, and sporting activities. Emilia Mazurek (2012) notices that ‘cancer provokes anxiety among the healthy (undiagnosed) part of society’ (2012: 286). Hence, the risk of withdrawal of not only an ill or a disabled person from social interactions but also people from their closer and wider social circle. Many people are unable to deal with ill or disabled individuals. However, Marek Rembierz (2016) notices that “recognizing the fragility of the human condition, results in the fact that everyone is at least potentially marked by disability, which can at some point unexpectedly become present and real. In this case, the postulates, and imperatives of care for a disabled person, who cannot live fully independently, concern not somebody else but directly my own person [...] (2016: 24)”. This perspective is worth taking into account while entering interactions with disabled people.

The strategies applied by the respondents in their participation in the life of a local community mainly concentrated on limiting activity to the safe company of family and other disabled women. There were some variations in this area, resulting from the different causes of disability. The differences were linked with the type of cancer which caused the disability. The women who had suffered from breast cancer applied strategies differing from those taken by women who had suffered from other types of neoplastic disease. Respondents with types of cancer other than of the breast limited their activity in the local community, and a great majority of them limited their contacts to the safe space of domestic life (especially those after sigmoid colostomy), whereas in the case of women post-mastectomy an increase in participation in social life (especially in the Amazons Association) was observed. As many as 84% of respondents were involved (to various degrees of intensity) in the Association’s activities, while 80% of them indicated Amazons as a source of help and support, as well as a place where new friendships could be started (compare to Gajda 2007: 35–42). The women’s consolidation and activity after mastectomy helped in creating a new space for interaction and communal integration, but most importantly it was conducive for forming, on both individual and communal levels, a completely new definition of identity, known as the ‘amazon identity’ (Zierkiewicz 2012b: 52). The core of this auto-definition was the experience of a neoplastic

disease and the loss of breasts. It is worth noting that this identification can be so strong that many women decide not to have breast reconstruction, seeing such an operation as the rejection of their new identity (see Mazurek 2014).

In the case of the remaining respondents, the necessity of facing various, often new, and difficult situations after the occurrence of disability was conducive to the fragmentation of identity. It led to situations, where, depending on the circumstances, the women adopted many identities. Sometimes they revealed their disability, but at other times they wanted to be perceived as fully fit and healthy (Hebl and Kleck 2008: 394–395; Lejzerowicz 2015: 100). This strategy could bring short-term benefits and make life easier, but in the long-term perspective it led to identity crisis, confusion, and disorganization.

This unfortunate situation could stem from the fact that identity is not some constant and unchangeable construct, but rather a process, supported by an individual (Giddens 2001: 74). The consequence of this fact is that identity is constantly in a state of redefinition, carried out by a reflective individual in every extraordinary situation or by adopting a new social role. These new identity projects never take a final form; instead they become an auto-definition construct, created by individuals, who enter interactions with others and make current interpretations (Marody 2014: 196).

CONCLUSION

Acquiring a disability forces the reorganization of life on all its levels. The trauma linked with neoplastic disease and its consequences changes one's way of looking at what was and what will be and influences the definition of oneself in various social contexts. A person suffering from a chronic disease (not only cancer) has to face many problems, among others: a growing distance in social interactions, the necessity of defining oneself again in the context of a dependence-independence dichotomy, and finally the occurrence of disability (Ziarko 2014: 113). All these problems are important factors influencing an individual's auto-definition.

Additionally, the process of adaptation is closely connected with the stage an ill or disabled person is in at a given point in time. Adaptation to neoplastic disease can proceed in three stages. The first is the stage of disbelief, denial, or shock, as the reaction to diagnosis. The second is the stage of dysphoria, the realization that the diagnosis is real. At this stage strong tension and fear is intermingled with hope and optimism. Finally, the third stage involves the development of strategies of coping with the disease and disability as its consequence (Holland and Goen-Piels 2000 after Ziarko 2014: 30). At this stage, a new but not necessarily enduring identity is formed. 90% of respondents, despite temporary disorganization and chaos (especially during the period directly after diagnosis and during the course of intensive treatment – mastectomy, chemotherapy, hormonotherapy), experienced a reorganization of their lives. On average, this was a period of a few to several months, after which some sort of stabilization occurred, and the women and their relatives adapted to their new circumstances. During this period, a new self-image (in all or most aspects) was also created.

As the research shows, this new identity in the face of acquired disability can be constructed on the basis of different points of reference. It can involve previously performed

roles (e.g. family or professional), albeit in different forms than before, but it can also refer to new roles or activities, for example in the area of politics, culture, or sport (see Niedbalski 2015: 95–112). It can also involve social groups a woman joins when she acquires the status of disabled person (e.g. Amazon Associations or various self-supporting groups). These activities can often help in ‘creating oneself’ anew and seeing one’s place in society from a completely different perspective.

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„(NIE)KONIECZNE ZMIANY”. PRZEOBRAŻENIA OBRAZU SIEBIE
I REORGANIZACJA ŻYCIA CODZIENNEGO KOBIEC Z NIEPEŁNOSPRAWNOŚCIĄ NABYTĄ
BĘDĄCĄ KONSEKWENCJĄ CHOROBY NOWOTWOROWEJ

Artykuł na podstawie badań autorskich omawia problemy tożsamościowe oraz konflikty ról, jakich doświadczają kobiety z niepełnosprawnością nabytą, która jest konsekwencją choroby nowotworowej. Jak wynika z badań, pomiędzy rolami pełnionymi w sferze rodzinnej, zawodowej i społecznej a rolą osoby niepełnosprawnej pojawiają się liczne napięcia i dylematy. Niepełnosprawność wiąże się z niemożnością pełnienia wszystkich dotychczasowych funkcji i koniecznością reorganizacji życia codziennego, rzutując tym samym na obraz siebie. Sytuacja, w której jednostka staje się osobą niepełnosprawną, to moment krytyczny wymuszający redefinicję „Ja”, zmianę dotychczasowego stylu życia, realizowanych ról i relacji z innymi ludźmi. Aby poradzić sobie z tymi wyzwaniami i zaadaptować się do zmian, kobiety podejmują różne strategie działania.

Słowa kluczowe: tożsamość, redefinicja „ja”, konflikt ról, reorganizacja życia codziennego, niepełnosprawność nabyta, choroba nowotworowa

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