ILLNESS NARRATIVES – BETWEEN PERSONAL EXPERIENCE, MEDICAL DISCOURSE, AND CULTURAL PRACTICE

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Abstract: *This article provides an overview of selected academic studies of first-person narratives of illness. The review splits between a discussion of literary and visual representations of illness. It presents the causes of growth in the number of illness narratives that are available in the public space. Furthermore, the paper deals with the problems of representing breast cancer in written stories and photos. It analyzes selected problems of illness memoires written by women afflicted with breast cancer and published in Poland, as well as Polish photographic projects which show the Amazons after treatment.*

Key words: *illness narrative, photo narrative, (auto)pathography, breast cancer, Poland.*

INTRODUCTION

Each somatic problem – and surely a chronic or terminal illness – is one of life's experiences which cause intense and negative emotions. In Polish, in order to determine a somatic problem, one term: "choroba" is used; whereas in English, depending on the context, it can be called a "disease" (a medically defined disease unit, an objective "phenomenon"), "sickness" (a reference to the social role of the sick person), or "illness" (the individual experience of illness, a subjectively felt state). The latter three ways of understanding illness are in accordance with the biopsychosocial paradigm of health, which – as opposed to the biomedical paradigm – assumes that a sick person, pursuant to a medical diagnosis, but also based on their own feelings and convictions, as well as information obtained from other sources (not necessarily medical), creates their own understanding of their problems and gives subjective meanings to them. The fact of the irremovability of the existential nature of the illness and its cultural presence, makes it a "hermeneutical phenomenon in nature" (Kwiatkowski, 2001, p. 18). Its meaning goes beyond the strictly scientific, medical explanation, and thereby it becomes the subject of a deeper consideration of the person experiencing it and the reflection of representatives of the humanities and social sciences.

Chronic illness can lead to the rethinking, or even reconstructing, of a person's biography and self-concept. In Michael Bury's perspective, this is a consequence of "biographical disruption" (Bury, 1991). The moment of crisis favours telling stories about one's life concentrated around the experienced trauma, hence formulating an illness narrative. Describing the experiences connected with an illness helps to rebuild the lost biographical continuity, define the meaning of the critical event, and by this cope in a better way –in both the psychical and the pragmatic dimension – with suffering and anxiety.

The main aim of this article is to review selected academic studies of first-person narratives of illness. The review splits between the discussion of literary and visual representations of illness, specifically breast cancer. Furthermore, the paper also aims to present selected problems of illness narratives written by women afflicted with breast cancer and published in Poland, as well as Polish photographic projects which show the Amazons after treatment.

BREAST CANCER CALLS FOR STORIES

Stories containing the memories of ill people from the periods of the occurrence of the symptoms of an illness, learning about the diagnosis and the course of treatment, and recovery are referred to in the literature with several names: illness narratives, suffering narratives, pathographies, or autopathographies. According to Arthur Kleinman, “The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core mataphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. (…) The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering” (Kleinman, 1988, p. 49). According to this approach, illness narratives are created by a patient during a conversation with a doctor, and their main aim is to specify the symptoms of the disease based on which it is possible to make the right diagnosis and prepare the plan of treatment. At present, the understanding of the notion of the illness narrative is becoming broader. Illness narratives are defined as “autobiographical accounts of illness spoken or written by patients” (Jurecic, 2012, p. 2).

As observed by Arthur Frank, in modernist times patients would formulate the stories about their indisposition using first of all the terms taken from medical science. “The physician becomes the spokesperson for the disease, and the ill person’s stories come to depend heavily on repetition of what the physician has said” (Frank, 1995, p. 6). This changed in the post-modern era. “The *post-modern* experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell” (ibidem, p. 6). Hence, in post-modern times, patients formulate illness narratives taking not only from the medical discourse (though it is still significant), but also from the available models and adopted practices in the culture and society in which they live. They talk about their experiences connected with the loss of health not only during visits to the doctor’s, but also in the waiting room, in the hospital room, sharing with other patients, and during talks with family members, friends, acquaintances, and strangers. Each time, their story is different, adjusted to the conditions of the situation and the profile of the recipient. Medical and cultural discourse formulate certain frames which set the limits of what is allowed, what is commonly accepted, and what can be assessed in a negative way or rejected, even leading to the stigmatization or exclusion of the author of the narrative. These frames refer not only to what to speak about, but also to how to say it, what vocabulary to use, etc.

Ann Jurecic (2012) believes that specialists such as psychologists, psychiatrists, nurses, and doctors should be considered precursors of illness narratives. At the beginning of the twentieth century, it was they who published stories about illnesses in medical journals or in the press. In the 1920s and ’30s, patients suffering from tuberculosis, who were isolated from society, began writing and publishing so-called sanatorium narratives (Rothman, p. 226: cited by Jurecic, 2012, p. 5), in which they mostly described their stays in impersonal, objectifying medical institutions and their relations with the personnel and other patients. In the second half of the twentieth century in the United States and Western Europe a dynamic growth of book-length illness narratives was observed. Anne Hunsaker Hawkins (1993, 1999) calls written illness narratives pathographies. She defines pathography as “an extended single-author narrative, situating illness and treatment within the author’s life and linking them with the meaning of that life. Pathographies provide the story of illness from the perspective of the individual patient” (Hawkins, 1999, p.128). Many authors use the term “autopathography” to emphasize that the author of a narrative is an ill person (the experiencing entity). These (auto)pathographies which constitute the record of consecutive stages of the dying of an ill person are termed “(auto)thanatographies” (cf: Tembeck, 2009). It is worth noting that Frank objected to the adoption of the term “pathography”, arguing that there is “no ill person [who] has ever called her story a ‘pathography’. (…) To call people’s stories ‘pathographies’ places them under the authority of the medical gaze: medical interest in these stories is legitimated, and medical interpretations are privileged. Medicine certainly should be attentive to ill people’s stories (…) but physicians must be attentive on ill people’s own terms” (Frank, 1995, p. 190-191).

Literary representations of illness usually take the form of diaries, novels, and tales. They are a kind of handbook – they tell how to cope with a somatic problem and the treatment. Personal narratives of patients have an educating potential – they provide the knowledge derived from pragmatic experience. Personal confession (see: Tembeck 2009) usually is not the objective reflection of reality. The border between truth and fiction, between authenticity and creation, is blurred in stories about illness (cf: Bury, 2001; Zierkiewicz, 2013). "In this sense chronic illness narratives might be called 'factions' rather than either fact or fiction" (Bury, 2001, p. 282).

The majority of illness narratives tackle the problems of HIV, AIDS, and cancer (especially breast cancer). According to Thomas G. Couser (1997), since the mid 1970s there has been a rapid and systematic increase in the number of stories concerning breast cancer in the United States. In Poland, however, such publications started to appear only much later, at the beginning of the twenty-first century (Zierkiewicz 2013). At present, many publications are available on the Polish market – both by Polish authors as well as translations from other languages – presenting the experiences of women battling against breast cancer[1]. "The new processes (of the so-called autobiographizing of suffering) were revealed first in women's magazines, then in book pathographies, and then on the more and more numerous blogs about having cancer" (Zierkiewicz, 2013, p. 203).

The increasing number of illness memoirs written by lays "(…) is the consequence of a variety of changes in culture, medicine, media, and literacy over the past century, which include medical professionalization; the rise of modern health care; the emergence of the women's movement (…); the inability of master narratives to give meaning to suffering in the modern era; and technological advances that promote self-publication and the global distribution of information" (Jurecic, 2012, p. 10). It is predicted that such publications will be more and more numerous because the ill are encouraged to tell stories about suffering and recovering health. The cultural and social permission for revealing such confessions – so-called cultural authorization (Couser, 1997, p. 12) – also contributes to the increase in the competence of the ill in the scope of creating illness narratives. They have a broader knowledge about what and how to write. However, primarily, creating illness stories has a therapeutic function – it helps the ill to find or give meaning to the experienced suffering, understand and interpret the changes occurring in their biography and in the world in which they function, to cope in a better way in a life marked by chaos and anxiety.

Authors dealing with different forms of illness narratives create their classifications simultaneously, indicating certain distinctive features of this genre. The most well-known classification was prepared by A. Frank, who distinguished among three narrative types of illness stories: the restitution narrative, the chaos narrative, and the quest narrative. "The plot of restitution has the basic storyline: *Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again*" (Frank, 1995, p. 77). The narrator focuses on presenting the symptoms of an illness, the circumstances connected with making the diagnosis, the conducted medical tests and their results, the doctors' competence, and alternative treatments. All this is in order to emphasize the triumph of medicine allowing for recovery. The chaos narrative is the opposite of restitution. Its author cannot see the possibility of recovery, and has a feeling of total loss of control over their life, health, and body. In the last type of illness stories, the loss of health "is the occasion of a journey that becomes a quest" (ibidem, p. 115). The narrator accepts the disease and at the same time perceives it as a chance, challenge, and stimulus for internal change.

Another typology of illness narratives, defined as pathographies, was prepared by A. Hunsaker Hawkins, who distinguished among four narrative types: didactic pathographies, angry pathographies, alternative pathographies and ecopathographies. Didactic pathographies "are motivated by the explicit wish to help others. Often they blend practical information with a personal account of the experience of illness and treatment" (Hawkins,

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[1] Eg. K. Kofta (2003), *Lewa, wspomnienie prawej. Z dziennika,* Warszawa: Wydawnictwo W.A.B.; A. Mazurkiewicz (2003), *Jak uszczypnie będzie znak,* Warszawa: Prószyński i S-ka; J. Grzelka-Kopeć (2007), *Pokonać smoka,* Kraków: WSiP.

1999, p. 128). This type is a special guide for a confused patient. The second type, the angry pathography, is motivated by the strong need to point out deficiencies in various aspects of patient care. It is a special voice against the dehumanization of the patient that is noticeable in medical practice. The alternative pathography is also critical of the medical system, but in contrast to the previous type, this one is focused on finding alternative treatment. The fourth type was named ecopathography. Authors of ecopathographies connect the personal experience of illness with global problems in the environment, politics, and culture. The illness is presented as a result and a sign of those problems.

In Poland, until the 1990s handbooks were written by experts in certain fields. Then gradually, publications started to appear whose authors were non-experts sharing their experiences in the scope of solving life-related problems (Zierkiewicz, 2012). The majority of illness stories about breast cancer available on the Polish market have a similar plot. They mention the moment of noticing the symptoms of an illness, the diagnosis, and the reaction to it, the undergoing of a difficult medical treatment, the use of various sources of social support, making the decision about breast reconstruction, the transformation of the ill woman under the influence of the critical event and coming close to death, recovery, and living within the so-called condition. These are usually restitution narratives or quest narratives, according to Frank's typology. Their authors present themselves as heroines who not only won their battle against an illness, but women whose lives had acquired a new value and depth through the illness. Edyta Zierkiewicz (2012, 2013) observes that Polish readers only have access to didactic and alternative pathographies according to Hawkins's typology. The authors of didactic pathographies, in recounting their experiences, teach and instruct readers, giving them useful advice and tips. However, they are far from criticizing doctors and medical care, and they do not formulate any significant claims towards politicians, the society, or the representatives of the medical community. Alternative pathographies are enriched by the search for new ways of treatment in the area of conventional and unconventional medicine. Angry pathographies and ecopathographies are not commonly available to Polish readers (Zierkiewicz 2012).

It is difficult to determine the exact reasons for such absence. It may be caused by the lack of competence of the patients to resist the medical profession and all they represent. The medicalization of breast cancer reinforces the belief that this illness is not a cultural or social problem, but a medical one, and as such requires medical intervention, which is the only method of treatment. Therefore, it is difficult to express anger towards medicine and doctors without having an alternative ally. It is also worth mentioning that the Polish Amazon movement cooperates with the medical environment, avoids open confrontation with doctors and medical institutions, does not make any claims, or engage in difficult discussions (e.g., on the impact of environmental pollution or living conditions on the risk of breast cancer), and finally avoids the use of alternative images of women after breast cancer treatment (i.e., showing the enhanced effects of the illness) in various artistic projects. "Polish Amazons – as opposed to American activists – generally do not rebel, do not criticize anyone publicly, and do not seek people responsible for their situation" (Zierkiewicz, Wechmann, 2013, p. 75). The attitude of Amazons being members of certain clubs has had an impact on illness narratives written by the patients, both those engaged in the movement and those not participating in it.

It is also worth mentioning that the goal of all illness narratives present on the market is to instruct patients in how to deal with losing their health psychologically and socially, as well as in contacts with doctors and medical institutions (e.g., how to prepare for a visit to the doctor's, how to talk to them, where to find information on various medical centers and their offerings). Such narratives also provide patients with information about what alternative treatments are available. They are therefore practical guides: they raise the patients' spirits, teach them, and show them how to be competent. This might indicate that the authors of those narratives feel their actions mean something – that their effects are visible. Rebelling against medicine, the country's health policy, or the cultural presentation of breast cancer in the media might seem pointless, because one voice cannot change much.

PHOTOGRAPHS TELL STORIES: THE PHOTO NARRATIVE

More and more frequently, the ill record and publicize the course of their illness and recovery not only orally and in writing, but also visually. According to the old adage, one picture is worth a thousand words. Photographs showing an ill person and the microcosm of the ill may also be regarded as a narrative of an illness. However, certain conditions for this have to be met. Susan E. Bell defines narrative as a sequence of ordered events that are presented to a particular audience in order to represent the featured world and people's experiences. "Narrative discourse is bound off from other discourse with a complicated set of codes that are recognizable to members of a culture. Pitch, tone, silences, non-lexical utterances, and structural features, distinguish narratives from other forms of discourse" (Bell, 2002, p. 6). Narrating orally or in writing is related to creating and receiving a message in visual form. Like in the case of an oral or written narrative, its author suitably chooses the means of expression just as a photographer decides what will be included in a photograph, what moment they will capture, what will be placed in the foreground, etc. A recipient participates in decoding what they are seeing and they may read the picture presented to them in many different ways. However, it should be noted that one photograph is not enough to be read narratively. During an international conference which was held in Spain in 1993, the participants for the first time defined the term "photo narrative" in a comprehensive way. The photo narrative was defined as "a set of photographs arranged to create a storyline within the constraints of a particular format" (Baetens and Ribiere, 1995, p. 314 cited by: Bell, 2002, p. 10).

The photo narrative became a new way of telling a story about an illness and the process of recovery or recording the consecutive stages of dying. In Tamar Tembeck's adoption of the term, "autopathography refers to a given aesthetic form through which an experience of illness is related firsthand" (Tembeck, 2009, p. 7). It may take visual, performative, or narrative forms. The author named these forms visual (auto)pathography, performative (auto)pathography, and literal (auto)pathography. With reference to the visual presentation of an illness, the following terms are used: autopathographic depictions, autopathographic paintings, and autopathographic photographs.

In the case of photo narratives, the process of reconstructing an illness's history by the recipient is difficult to predict. The author of photographs usually presents only the photographs recording the course of an illness and treatment, though sometimes they are accompanied by captions or short sentences – while the reading and interpretation of what is in the picture lies with the recipient. Their interpretation of the emotions and physical and mental states of the ill person shown in a photograph and the context of events may be far from reality, and this is why their story about an illness may greatly differ from the actual one experienced by the author of a photo narrative. However, the interpretation of every illness narrative – regardless of its form (literal or visual) – is not an accurate / literary reflection of the world described by the ill. The recipient decodes the message, gives it a subjective meaning, reads it in their own unique way, and creates their own interpretation of the illness. The number of narrative recipients determines the number of possible interpretations.

For some time now, well-known and anonymous people who have suffered from an illness or disability have been making their image public through artistic projects which should be considered photo narratives, and as understood by T. Tembeck, as visual or performative autopathographies. Examples can include pictures of Frida Kahlo, immobilized after a communication accident, the photographs of Jo Spence suffering from breast cancer and leukaemia, the diary "Under Construction" prepared by artist Jo Beth Ravitz in cooperation with her husband, and the series of photographs of the ill Hannah Wilke and her mother.[2] The pictures of photographs created by the ill constitute a series which show the sequence of events presenting the consecutive stages of an illness, treatment and recovery or dying (so-called (auto)thanatographic images/photos, as in the case of the creativity of J. Spence). The ill show themselves in different moments of therapy; they present the fulfilled roles, expose the chang-

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[2] Detailed analysis of the creativity of these women can be found in texts written by S. E. Bell (2002) and T. Tembeck (2009).

ing external appearance (e.g., a body before mastectomy and after breast amputation, an emaciated and ruined body due to chemotherapy), etc. These projects are a peculiar form of auto-therapy of the ill person. The precursor of the phototherapy sessions was J. Spence (1995) who argued that taking photographs may be a great method of self-healing.

The photo narratives created by J. Spence (self-portraits for "The Cancer Project") in Great Britain or the photographs by H. Wilke recording her mother's struggle with breast cancer taken in the United States were published at the beginning of the 1980s. These works were unique because they showed the aesthetic result of breast cancer. At that time, the scar left after mastectomy could only be seen in medical photographs, created for the purposes of doctors. As observed by Lisa Cartwright, in the United States up to the early 1990s, the typical image of a woman suffering from breast cancer showed a woman of higher or middle social class, white, educated, smiling, completely dressed, with a symmetrical chest (Cartwright, 1998, p. 123). This was in contrast to the voice of Audre Lorde, who in "The Cancer Journals" published in 1980 criticized the attitude of women hiding their asymmetrical chests after mastectomy with the use of external prosthesis or by means of breast reconstruction surgery. According to the author, such actions contributed to the tabooization of breast cancer and to the political and cultural absence of ill women. The way of presenting breast cancer in the media has changed since 1993, when on the cover of *The New York Times Magazine* there appeared a photograph titled "Beauty Out of Damage" showing the image of Matuschka uncovering her scar after mastectomy. According to L. Cartwright, "this portrait foregrounds the scar as a physical and aesthetic transformation of the body that is as significant to the experience of breast cancer as these other techniques and their more conventional (and familiar) results" (Cartwright, 1998, p. 128). Since that time, more and more photographs have appeared showing ill, mutilated bodies different from the ones we are used to seeing.

Similar to the literary representations of illness, photographs showing nudes of women suffering from breast cancer appeared in Poland at the beginning of the twenty-first century. The calendar for the year 2005 prepared by members of the Wroclaw Amazons Association Femina - Fenix – of women after mastectomy – encouraged by the photographer Izabela Moczarna–Pasiek[3], can be considered a pioneering project in this respect. The photos for consecutive months show the half-acts of Amazons bravely exposing the mark of their illness – the scar after mastectomy, and one of them their breast after reconstructive surgery. The photographs are images of mature women (aged 45-60 years), most of whom are happily looking directly into the lens (two of them cover their faces). All the photographs were taken in sepia. However, the project did not arouse much social or media interest. Perhaps the project's promotion was too poor, or at that time Polish society and the Polish media were not yet ready to become interested in the problem of women suffering from breast cancer (Zierkiewicz 2013). Dorota Kiałka and Agnieszka Kłos, inspired by this undertaking, worked on another calendar in 2008 (the project called "More than one with one"[4]). This time, young Amazons, aged 25-34, were invited to take part in photographic sessions. The women posing for the pictures, properly prepared by the stylist, are feminine and flirtatious, with frivolous looks on their faces. Some of them show not only their scar but also a different side of their illness: baldness (sometimes hidden under a wig or a scarf). One photograph presents a woman after a bilateral mastectomy being hugged by her daughters holding their hands on their mother's scar. The photographs are colorful and draw the attention of the recipients. These pictures expose – in accordance with contemporary ideals of beauty – the beauty and femininity of the models. They are presented in such a way as to emphasize that, despite their illness, a woman may be attractive, sexy, and beautiful. These undertakings triggered an explosion of new photographic projects – not necessarily calendars – showing women suffering from breast cancer (e.g., the series of portraits "AMAZONS 2011"[5] and "Amazons and maternity.

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[3] http://www.moczarna-pasiek.com.pl/projekty/amazonki.html [opened: 12.01.2015].

[4] http://foto.com.pl/wystawy/60-niejedna-z-jedna [opened: 12.01.2015].

[5] http://amazonki2011.blogspot.com/ [accessed: 12.01.2015].

Beautiful and healthy for children”[6] by Katarzyna Piwecka and Ewa Rzyczniak, the photograph exhibit by Edyta Leśniak). Also, women suffering from other types of cancer have followed the Amazons' actions (e.g., the project “Four Lashes”[7] by Teresa Szczęsna-Grotowska). These works are usually assigned an artistic function (they show the beauty of a woman's body mutilated as a result of an illness, but they do not show the real nightmare of the illness) and an educational function (they inform healthy people about an illness and the risk of developing it, educate them about prevention, prove to the ill that, despite their illness, one can live “in a normal way” and look beautiful, etc.).

Photographic projects carried out by members of Polish Amazons' clubs or other patients' organisations are done in accordance with the aesthetic canons accepted in the mass media. Ill women shown in the photographs are beautiful, attractive, sexy, and they are the objects of men's desire. Their impeccability is only disrupted (and not always, at that) by the scar left after their mastectomy, the uncovered breast after reconstruction, the mark on the body after a skin graft for reconstruction surgery, the lack of hair (sometimes hidden under a scarf or a hat), etc. What is missing among them are alternative photographs – so the ones similar to the already mentioned works of J. Spence and H. Wilke – showing women without make-up, in everyday hair and outfits, exhausted by their illness, and subjected to medical treatments. The causes of the absence of such types of photographs need to be sought in the lack of or insufficient cultural authorization (Couser, 1997) of such visual messages; but also in the lack of or insufficient consent of the Amazons themselves to publicize the “real” face of the illness and the image of an ill woman. Additionally, Polish Amazons do not want to confront medical representatives. For this reason, in their artistic projects they do not publish photos with the unsuccessful effects of breast reconstruction. A confirmation of the opposing views of Polish Amazons in this respect was the discussion held by the users of the forum for women suffering from breast cancer during which many women reacted critically to the artistic project “The SCAR Project” by David Jay, which showed dark and quite shocking images of the ill (e.g., a pregnant woman after a bilateral mastectomy). During the promotion of new Amazon projects, their authors usually stress that the aim of the campaign is to show that breast cancer does not lead to the loss of femininity, that despite the illness one can be a beautiful, active and smiling woman. Through their actions, they also want to encourage healthy women to take part in preventive screenings. Showing unretouched realities of the illness could scare them away from doing this.

It is difficult to consider the Polish photographic projects quoted here as photo narratives or visual pathographies according to the previously given definitions. In spite of the fact that the series of photographs within one project show women suffering from breast cancer, and these series have some leading motifs, these photographs do not show the sequence of events comprising the history of an illness of one ill woman. It would be hard to recreate an illness narrative on their basis. Surely, many from among the ill have photographs recording the course of the illness and recovery in their personal files, but these files are not made public. It seems that this is one of the challenges which may be taken up by the Polish Amazons.

CONCLUSION

Up until recently, conversations about chronic somatic illnesses were conducted primarily between the ill person and their doctor, their nearest family members, and their friends. Public sharing of intimate feelings connected with experiencing an illness was considered inappropriate (Zierkiewicz,

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[6] The heroes in these photographs are both young and mature women diagnosed with breast cancer (sometimes before giving birth to a child). Such photographs show fully clothed women accompanied by their children, who are adults, youngsters, or little babies. The scenery reminds us of palace halls. Women pose in elegant clothes and with smiles on their faces. The pictures symbolically emphasize the relationship between the mother and her children, e.g. three sons hold their mother with their hands, a woman talks with her son, who is sitting on a windowsill, a mother holds the hand of her little daughter, a mother looks out of the window with her daughter by her side.
http://epoznan.pl/news-news-32825-Wystawa_zdjec_-_%E2%80%9EAmazonki_i_macierzynstwo._Piekne_i_zdrowe_dla_dzieci%E2%80%9D [accessed: 12.01.2015].

[7] http://dcpir.pl/data/uploads/pliki/prezentacja-zdj-kobiet.pdf [accessed: 12.01.2015].

2012). In fact, the ill did not indicate such a need. Due, however, to the weakening of the authority and the paradigm of biomedicine, easier and easier access to information about illnesses and treatment, social consent, and the need for messages pertaining to coping with situations of the loss of health, illness narratives appeared and have remained in the public space. There are now literary, visual, and performative representations of illness. One can notice a positive impact on the process of healing in the psychological dimension of an ill person. Writing memoirs or taking photographs of a scarred body have a therapeutic function; it helps the ill to find or give meaning to the experienced suffering and understand and interpret the changes occurring in their biography; it helps them to cope with the disease better.

Authors of illness narratives are not the only group who can benefit from creating verbal and visual representations of their illnesses. The following people are among the other recipients: the ill and their relatives (family members, friends), professional and non-professional workers who provide support for the ill, medical representatives (mostly doctors, nurses, and physiotherapists), as well as the people making medical and social decisions. Every recipient looks at the pathographies for information relevant to their point of view.

Illness narratives “negotiate the authority of experience versus the authority of expertise” (Wohlmann, 2014, p. 19). Such narratives become guides, sources of help, alternatives (a form of addiction for the ill and their relatives) to institutionalized and professional sources of help. However, they are also sources of knowledge for people who provide support for the ill (professionally and non-professionally). Due to the memories of ill people, other patients and their relatives get to know the world of people suffering from the same or similar diseases, their problems, means of coping with them, the next stages of treatment and recovery, etc. Narratives with happy endings bring hope to others. They are also a guide for how to move in the world of healthcare institutions, effectively communicate with doctors, and deal with dehumanization. Readers learn to talk about their illness, what language to use and find out how other people see the illness and suffering (see: Zierkiewicz, 2013). Due to such narratives the patients’ relatives and people supporting them learn about the needs and expectations of the ill, learn to cope with their suffering, and are better prepared for the next stages of treatment. Visual representations of the illness help people get used to the image of a mutilated body, to see what is usually hidden, made taboo, and never spoken of.

The voice of patients – as an alternative to the voice of biomedicine – should also be heard by medical practitioners. “For physicians, pathographies can provide a unique *window* into the experience of their patients, often revealing aspects of patient experience that remain unarticulated in the medical encounter” (Hawkins, 1999, p. 129). Illness narratives help doctors learn about how the patients place their medical experience in the entire biography (see: Mazurek, 2013) and give it subjective meaning. They also help them get to know their patients’ emotions and dilemmas (e.g., connected with the need to confront the sometimes incomprehensible or contradictory information presented by doctors), which trigger rebellion, anger, frustration, but also the feeling of uselessness and resignation. Learning and understanding the situation of the ill may change the asymmetrical relations between the doctor and the patient. The language of the patient creating a narrative is also important. Analysis of illness narratives may be a perfect teaching method during training courses for doctors and students of medicine.

The last distinguished group of recipients are the people who influence the country’s policies. By sharing their experience as patients, the ill reveal the flaws of the healthcare system and social policies. They unmask dysfunctional aspects of the system, which should be used to help people. Their narratives are therefore a form of protest and a call for change. The patients’ voice may help begin the transformation both of state institutions and the solutions adopted by them.

Since the beginning of the twenty-first century, in Poland more and more illness narratives by women suffering from breast cancer have been appearing. There are Polish pathographies, as well as those translated from other languages present on the market; the press publishes reports on the fate of the Amazons (see: Zierkiewicz 2013); more women tell their stories on blogs and forums; and they are more willing to share their memories with other ill people (e.g., as volunteers in oncological departments in hospitals) or researchers. Some Amazons who have joined clubs prepare photographic projects, where the image of an ill person is made public. Such projects are usually accompanied by a message: "when you beat breast cancer, you can still look beautiful and live your life to the fullest," and an image of an ill/healthy woman is a perfect example of this. Those photographs are not part of a cycle that could constitute a narrative. The goal of both Polish pathographies and photographic projects is mostly didactic – their purpose is to familiarize people with cancer, and therefore, there are no alternative forms of illness narrative – revealing the true side of the illness. The ill tell their personal stories, "but they compose these stories by adapting and combining narrative types that cultures make available" (Frank, 1995, p. 75). Social and cultural changes will influence changes in those narratives. It seems that, in the future, Polish Amazons will face new challenges in this aspect.

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NARACIJE O BOLESTI – IZMEĐU OSOBNOG ISKUSTVA, MEDICINSKOG DISKURSA I KULTURALNE PRAKSE

Sažetak: *Članak pruža pregled odabranih akademskih studija autobiografskih naracija o bolesti, uključujući raspravu o literarnim i vizualnim reprezentacijama bolesti. Razmatraju se uzroci porasta broja naracija o bolesti u javnom prostoru te pitanja reprezentacije raka dojke u pisanim pričama i fotografijama. Analiziraju se odabrani problemi memoarskih zapisa žena oboljelih od raka dojke u Poljskoj, kao i poljski fotografski projekti koji prikazuju Amazonke nakon tretmana.*

Ključne riječi: *naracije o bolesti, fotografske naracije, (auto)patografija, rak dojke, Poljska*