

'I WAS WORSE OR SOMEHOW DIFFERENT?'

ETHNOGRAPHIC EXPLORATIONS OF THE TABOO AND STIGMA OF CANCER IN POLAND

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ABSTRACT

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In the article¹ I explore the taboo and stigma attached to cancer in Poland. I argue that they are linked and play a major role in experiencing the disease in the country, despite numerous social and medical campaigns. Taboo and stigma in Poland, perceived through the lens of cancer, relate to exclusion (and self-exclusion), social pressure, fear, displacement, and shame, and push ill people to numerous elaborate practices aiming to hide the disease and its signifiers. I analyze the informants' narratives, in which I have found a body of information on how cancer is experienced by individuals, who complained about stigmatization, and concealed it in families. The key role in constructing these narratives is played by local metaphors, cultural motifs, and the culturally constructed sick-role, which distinguishes the collected material from other studies on cancer.

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Keywords: cancer, stigma, taboo, stories, ethnography, Poland

Cancer in Poland, despite a series of vibrant, complex and frequently unorthodox social campaigns is still 'the' disease. This particular, highly characteristic condition (or set of conditions) is embedded in social and cultural mythology and shaped by popular imagery, interlaced with fragments of biomedical discourse. The most common images associated with it cluster around concepts of misfortune/curse, rapid or unavoidable death, emaciation, exclusion from social worlds, solitude, long stays in dehumanized medical institutions, and bodily degradation. While these images are also present in other societies, in the Polish context I distinguish at least three factors that play a crucial role in shaping patients' experiences and stories. These are the local metaphors and narrative motifs, the unified biomedical culture due to the limited number of specialist hospitals and practitioners, centrally planned medical education and services, and the dominant role of state medicine in cancer treatment, and the taboos and stigmatizing practices associated with the disease.

Consequently, it seems that no matter how well created and clear the efforts of various social actors, including the media, celebrities, patients' organizations and medical practitioners, cancer in Poland is still perceived and experienced as a condition like no other. In the article I analyze the informants' narratives, in which, although oftentimes of

a metaphoric and allegoric character, I have found a solid body of information on how cancer is experienced and concealed by patients in daily life. I suggest that the taboo and stigmatizing practices associated with cancer are a grave problem for a significant group of Polish patients. I believe that in Poland, when speaking of cancer, these two social phenomena—taboo and stigma—are tightly linked together, creating a complex net of interactions and social practices leading to patients' exclusion, and experiences of social pressure, stress, isolation and dissembling.

However, I argue that taboo and stigma have a dual effect. They are the main reasons for restricting actions and activity in the social world, whilst simultaneously causing changes in peoples' lives. The exclusionary power of taboo and stigma pushed my informants into seeking new paths of behavior, modes of thinking and action, by which they attempted to reconstruct life shattered by their diagnoses. To achieve their goals they constructed complex narratives, detailing experienced and, frequently, embodied taboo and stigma.

Taboo, stigma and medical anthropology

Taboo and stigma are classical anthropological ideas which have been conceptualized by numerous researchers. They hold a significant place in the history of anthropology (Douglas 1966: 1–8; Wasilewski 2010: 9–39; Goffman 1963: 1–41), especially in the study of religion, magic, rituals, social behavior and kinship (Leavitt 2013). Both taboo and stigma have been criticized, mainly for the tendency to generalize social reality and practices but also because of their ambiguous definitions and spheres of impact (Link & Phelan 2001). These 'total' concepts are deeply rooted in specific intellectual and historical periods of cultural anthropology which have depicted culture as a set of shared rules, prohibitions, actions and responses; but for contemporary anthropology such descriptions might no longer be tempting.

Despite this, I believe that taboo and stigma still provide fertile analytical subject matter, especially for medical anthropology, when exploring ephemeral and complex cultural phenomena like cancer. These two major themes often create a subtle net and have a significant influence on each other. Stigma can be the fundament for taboo practices and vice versa: taboo might result in stigma. Wasilewski (2010: 9–39) in his brilliant work *Tabu* asks whether taboo still just a matter of magic, ritual behavior, and prohibition, or if it has been transformed and spread over other aspects of daily reality in contemporary life. I believe the answer is yes: the notion of taboo has changed; as it is not immutable and timeless it follows cultural shifts and transformations. One can say taboo has lost its magical-ritual context, but its mechanism has persevered. Now, taboo is no longer just a prohibition beyond which an enigma is located. It has broader meanings and one of them focuses on dissembling, avoidance and stigmatizing particular medical conditions and suffering people.

Tabooing and stigmatization of health conditions are well-recognized phenomena (Ablon 1981). In a culture dominated, as Ronald W. Dworkin (2000: 77–82) would say, by 'the new gospel of health', where wellbeing and a healthy lifestyle have become a new religion, cancer challenges socially defined and experienced categories like body, aesthetics, locality, social norms, vitality and safety (McMullin & Weiner 2008: 7–14; Balshem

1991: 91–124; Bloom & Kessler 1994; Boonmongkon et al. 1999). Thus, it is a form of social experience which brings to local worlds a set of elements encompassed by taboo. It symbolizes death (including social death) and dirt and has the power to transform the human body into an object of revulsion and horror (Kristeva 1982: 1–32). Cancer is a ‘cultural black hole’, a sphere beyond control and rationality, a forbidden experience because it embodies the primordial, ‘biological’ face of life. Thus, as James T. Patterson (1987: 12–137) states, it is justified to say, that Western society is deeply embedded in ‘cancerophobia’. This phobia leads to organized social responses—‘anticancer alliances’, including the implementation of complex prevention programs, the organization of self-help groups, and anti-cancer policies. These actions aim to restore a sense of control and social coherence in the face of the overwhelming pressure related to cancer’s symbolic capacity.

Taboo perceived through the lens of cancer encompasses fear, suppression and mystery. This taboo affects the dark sides of patients’ emotions, experiences and actions, and also relates to exclusion, stigma, fear, displacement and shame (Malta et al. 2007: 6–8). It is an element of practices leading to the exclusion of the sufferer from local, public environments, and macro and micro realities, while also directly influencing patients’ narratives. If we assume that narrating is a way of acting and being active (see Høybye & Tjørnhøj-Thomsen 2014: 319; Littlewood 2003; Mattingly 2007: 72–170; Frank 1995: 1–25; Kleinman 1988: 3–56; Hyden 1997: 49–53) taboo represents the opposite process—it encourages the taming and restraint of action and narration. Thus, the cancer taboo directly affects the recognition of the self: a set of rules and ways in which individuals recognize and understand themselves through agency and narratives (Ricoeur 2005).

The cancer taboo affects the afflicted body and obeys no limits; it impacts on social and doctor-patient relations (Markovic et al. 2004: 330–335; Salander 2002: 721–723, 729–731), as well as those between family members and loved ones (Gordon 1990: 276–280; Gregg 2011: 70–71, 76–81). Furthermore, the cancer taboo undermines the relationship between anthropologists and the people they work with. Almost all of my meetings with patients were loaded with the ‘what can I say about this intimate issue to this stranger in front of me’ question. Thus, all participants having a role in the illness must struggle with the elusive, not to say ephemeral, phenomenon that is the cancer taboo.

Different societies share a body of stereotypes, images and excluding practices leading to social inequality concerning suffering people (Chavez 2009: 147–155). These culturally shaped and shared images focus on ill bodies and ill souls. The general, ‘Western’ picture of a person suffering from cancer, as Susan Sontag (1978) states, is rather gloomy as it is a condition that destroys the socially visible and ‘external’—the body—and simultaneously the ‘internal’—personality, the self. Suffering people might experience processes and practices which Erving Goffman (1963: 41–140) calls ‘stigma’. These phenomena appear as reluctance, fear and disgust focused on ill and wounded bodies which are situated at the very margin of social reality—they question social coherence and order. The suffering person recognized as ‘different’, ‘dangerous’ or ‘beyond normal’ is unable to fulfill social demands and, as a consequence, is stigmatized. So—as Goffman states—stigma is an extremely discrediting experience.

However, the concept of stigma can have a broader definition. As Veena Das shows (2001), stigma is not only associated with the body—its core is embedded in the virtual

net of social relations. According to Das, stigmatizing practices and stigma itself directly result from a weakened individual's relations within this complex net of social relations; those whose position seems to be unstable experience responses that include exclusion, limitation and marginalization. Following Das, severely ill people lack strong authority, and their position in the social net of relations is impaired. These people are—temporary or permanently—socially less active, sidelined and consequently lonesome. They might join groups or follow support environments such as self-help organizations and patients' movements; however, this does not guarantee release from social oppression.

The concept developed by Das gains significance when the issues of responsibility and 'proper behavior' arise. For example, smokers are often blamed for their illness (Stuber 2008: 421–423) and one can often hear claims that these people are fully responsible for their suffering and—what is even more tragic—for the cancer experienced in their families. Similar stigma might be imposed on people suffering from cancer located in sexually-related body parts. Jessica Gregg (2011) presents a case in point in her study of Brazilian women suffering from cervical cancer. These women have been socially condemned, as their illness, as Gregg suggests, was depicted as a consequence of immoral sexual behavior.

Stigma resulting from both body-oriented oppression and disadvantaged social relations ultimately leads to moral judgments and asymmetrical relations of power. In this article I examine both concepts—taboo and stigma—as I believe that the collected data delivered a body of examples for body-oriented stigmatizing practices and those which are more elusive, resulting from impaired social relations. Stigma is also an inseparable aspect of taboo practices: those who are tabooed are simultaneously stigmatized or vice-versa: stigmatized people are under the influence of taboo. Thus, I argue that it is justified to apply both categories to the following data analyses.

Research group and ethical standards

This article was preceded by ethnographic research conducted among malignant cancer patients in Warsaw and Białystok, Poland. The study took place between 2009 and 2012. A total number of 44 in-depth interviews were collected, together with field notes and observations made in hospital wards and GP surgeries. Whilst conducting the research, I established a cooperative relationship with a major Polish cancer patients' organization which allowed me to explore how and why people seek help and understanding in support groups. I argue that two main factors play a role: a search for access to better and more advanced/experimental treatments,² and the experiences related to taboo and social stigma accrued as a consequence of the cancer diagnosis.

The informants spanned different ages, sexes and education levels. However, the majority of them were women over 40. All of them lived and worked in big cities (Białystok is a regional city with a population of about three hundred thousand and Warsaw about two million) and shared a body of common experiences fostered by a relatively unified Polish biomedical culture. Many of them underwent the same procedures in the same hospitals, often under the care of the same doctors. The collected interviews were anonymous and fully voluntary—none of the informants were coerced into participating in the research.

All names have been changed and the collected materials have been coded. Despite the fact that no standard ethical procedure for ethnographic research exists in Poland, the informal set of ethical rules common to Polish anthropologists has been adopted. These standards include the notion of respecting an informant's privacy, along with ensuring the prevention of any physical or mental harm to the informant. The issues related to cancer are both intimate and emotional. Thus, during the research, I fully respected informants' wishes, never pushing them to answer any sensitive or overly-private questions.

Hospital ethnography and narrative research

Polish hospitals are a new field for anthropologists. This situation provokes a number of yet unsolved methodological issues. First of all, access to hospitals in Poland is very restricted. As my experiences show, authorities, doctors and medical personnel are usually reluctant to accept or participate in ethnographic research. They have a very limited knowledge of anthropology and often discredit the social sciences, especially those with a mainly qualitative approach.³

Generally, hospital wards are organized in a specific way, and are 'artificial' worlds with a highly limited number of possible social roles (Wind 2008: 79–83). In Polish hospitals this is even more visible—one can be a health worker, a patient, a relative or a visitor—so where is the place for anthropologists and their qualitative tools, usually unappreciated by the biomedical sciences? The limitations are especially visible when considering participant observation. Is it possible to apply classic 'proper ethnography' methods to hospital conditions? I believe not. Thus, in the project which is under discussion here, the standard ethnographic tools have been reshaped and constrained.

This limitation has two reasons. The first is rather mundane: the rhythm of the hospital ward and the GP's surgery do not allow spending of a lot of time with patients—and consequently it is a challenge to become a 'participant' in their reality. Anthropologists in Polish health institutions are still strangers and their presence is often unwanted. However, it is worth noting that this significant field obstacle is not only specific to Poland (see Long, Hunter & van der Geest 2008). Secondly, it seems unlikely that a healthy anthropologist can fully understand and participate in the world of people diagnosed with malignant cancer. These people have to confront one of life's biggest challenges: a struggle for life and living with devastating physical and mental experiences, including pain, suffering, stress, stigma and uncertainty. The dramatic scale is something fundamentally different to issues of ethnic or social diversity and no anthropologist would choose to experience patients' trajectories firsthand.

Considering everything—the specific hospital settings, field demands and the extraordinary character of the informants' worlds and experiences—I chose to exchange standard participant observation for the negotiated interactive observation proposed by Gitte Wind (2008), where the imperative of 'becoming one of them' is eliminated. The goal of such observation is to capture interactions, actions, meanings and practices emerging in the field—meaning that it is still a highly qualitative approach. As Wind states:

The concept of negotiated interactive observation captures what happens when you are doing fieldwork without at the same time assuming that you become one of 'them'. (...) A new concept could open our eyes and minds to what it means to do fieldwork and to grasp the critical dialogical relations we create with people we study, regardless of whether we do fieldwork in the mud of the street or amongst the blood and the stainless steel of the hospital. (Wind 2008: 87)

As I have already mentioned, a narrative approach is essential to the proposed analyses of collected data. At the beginning of the research I aimed to use a semi-structured questionnaire; however, after the first interviews I realized that the informants were quite reluctant to answer my questions. Quickly they started telling their own stories, which included numerous issues and topics beyond the questionnaire. Our meetings gradually changed from arranged interviews into longer and more complex conversations with a strong reflexive character. The informants discussed many issues during our meetings, which also provoked them into almost 'reliving' particular aspects related to their illness. Thus, I decided to apply a far more open form of narrative interview and simultaneously a narrative perspective on collected data.

The concept of narrative is relatively common in contemporary anthropology, including in the medical area (see Frank 1995; Garro 2000; Hyden 1997; Kleinman 1988; Mattingly 2007; Skultans 2000). Despite not being a medical anthropologist himself, Nigel Rapport (2000: 71–83) suggests that a narrative might serve as a kind of stable shelter—a perfect meeting place in an ever-changing world. Although this might sound rather idealistic, I agree that, in the rather turbulent worlds of the hospital ward and the doctor's consulting room, narratives might serve as a sphere of contact between the anthropologist and his informants, a place where stories stimulated by this contact come together (Jackson 1998). However, I argue that such meeting places are far from stable. In fact, they are all about not being firm—narratives are fluid and plastic structures, which cannot and do not withstand the intrusion of the dynamic external world and its galloping daily realities. Narratives do exist in such environments, depicting changes and perfectly responding to shifting conditions. Plasticity is their hallmark.

As a result, in my research I have focused on methodology recently rediscovered by social scientists focused on health (Saillant 1990: 81–84): unstructured, in-depth interviews, which I believe should be treated as stories composed of metaphors, interpretations and symbolic records of life after the diagnosis. These are the stories of people confronting life's biggest challenge—overwhelming, embodied mental and physical suffering, coupled with the threat of death. By analyzing such narratives I aimed to understand how people depict a world which has been compromised: a threatened world, where pain, fear, social stigma and taboo play key roles. I aimed to grasp the sense and motives for narrative building. I believe that the underlying sense of taboo and stigma experienced by informants has driven them to pick up the gauntlet and attempt to reconstruct and reorder their lives with or after cancer. The collected interviews are ideal samples of restitution narratives (Frank 1995: 75–97), narratives pointing towards the reconstruction and rearrangement of lives disrupted by illness and trauma (Bury 1982: 167–174).

By creating narratives rich in new-time structures, order and meanings, informants were able to struggle and cope with the sense of taboo and stigma. They could feel that a life stalled was once again set in motion (Mattingly 2007: 154–170). Without these

new stories, the escape from chaotic areas, dark and blocked by taboo and stigma, would be impossible. Thus, these stories are a form of self-treatment (Frank 1995: 75–97, 115–137; Kleinman 1998: 31–56; Trzebiński 2001: 115–151, 221–259) and a tool for coping with oppression and chaos. They are akin to cancer itself—sometimes stable and rather coherent, sometimes rugged and tragic—but their main feature is their metaphoric character: they do not depict the disease in a mimetic manner (Mattingly 2007: 25–48).

Cancer-related metaphors, stigma and taboo practices

In research focusing on taboo and stigma, metaphor has a significant role to play. Metaphors, as academics suggest, are ways of arranging and expressing everyday reality. They serve as keys to symbolic and social orders, as portals to culture, and modules explaining experiences (Erickson 2007). As McMullin and Weiner (2008: 9–11) suggest, in the case of cancer, metaphors play a special role: they are the tools used to struggle with fear and oppression. Through the use of metaphor, individuals can connect the individual parts of their life which seem to be contradictory. Metaphors might be utilized as connectors in the complex processes of reconstructing an individual's self-image which has been impacted by cancer and the associated cultural pressure and social stigma. Finally, metaphors have the power to express and grasp that which is situated at the very edge of the language field: the impact of taboo and stigma on daily life.

The classical study of the interplay between metaphor and cancer has been written by Susan Sontag (1978), and still inspires a generation of researchers. Cancer from Sontag's perspective is a metaphor in itself, encompassing the world and the experiences related to the illness. Cancer is the condition of melancholic and uptight people, often unable to control and defuse their emotions. It is the state of deep fear and internal suppression, where spontaneity is absent. Thus, cancer is the consequence of one's lack of self-control and its sources might lie in one's moral makeup. The condition almost takes on a persona of its own, becoming a social actor whose finger points towards introverted or highly-emotional people, whose lives do not fit within socially-accepted norms. Cancer is also a taboo, a reason for shame and concealment. Cancer is a difference and creates differences. In popular images it advances slowly, acting like a sneaky killer inflicting pain along the way. As Sontag points out, diseased bodies dry out and shrink. Such images of suffering challenge our sense of existence and feelings of social safety and coherence. Cancer produces unwilling bodies, hushed stories and people marginalized and enclosed in isolated spaces—hospital wards, hospices or care homes. Ill people, as Sontag suggests, might be compared to the icon of death: their thin faces and bald heads stir emotions and are themselves emotional.

These practices show that metaphors are a far more complex phenomenon, and go beyond oral statements and spoken language. Metaphors are situated between embodied experience, narrative, and verbal expressions (Kirmayer 2000: 153–157); their messages are hidden in the construction of particular narratives, their rhythm, prosody, internal structure, and applied language techniques. The voice modulation, scale and general resonance also have deep metaphoric meanings, only legible for people sharing a set of cultural and social clues by which metaphoric messages can be decoded and interpreted.

This is also clear for visual aspects of culture, body language, particular actions and human behaviors, which all transmit hidden, symbolic messages. What is more, the act of interpretation of metaphors is not free of metaphoric potential itself. One can say that metaphors are decoded by metaphors only to create and disseminate other metaphors, embedded in images, speech, voice, worlds, body language, actions and behavior. As Cheryl Mattingly states (2007: 129–154), human life is a complex set of metaphors and interpretative responses embodied in narratives and actions; however, some moments in one's life have more narrative and metaphoric potential than others. These special moments, provoking intense experiences (Abrahams 2005: 55–62), include particular conditions like socially and culturally distinguished cancer. Thus cancer, as Sontag has demonstrated, is a metaphor in itself, but also, as Mattingly suggests, something which creates a very special metaphoric environment, where not only words have hidden meanings: images, actions and practices also matter in a special way. However, these 'emergent narratives' (Mattingly 2000: 181–182, 188–190) and actions do not reflect and reconstruct the world in mimetic manner. As Mattingly concludes, they are transformed and allegorical, never depicting reality in a straightforward way.

One could claim, however, that there are significant differences between narratives and actions, between experiences and narratives, between life and narrative. So why are people so eager to create metaphoric stories about the events and experiences which have taken place in their lives? One fact can shed more light on this issue: people often construct stories about events which could have not been predicted or controlled. These, I believe include narratives about the stigma and taboo associated with cancer. The aim of such stories, as researchers suggest (Frank 1995: 53–75; Mattingly 2007: 1–25, 72–104; Hyden 1997: 48–53), is to order and give at least basic meanings to unpredicted, uncontrolled, and often undesirable experiences.

The ability of cancer to accumulate an emotional and symbolic charge, as my research has revealed, clearly corresponds with the above statements. The very emotional experiences cancer-sufferers have undergone have pushed both the sufferers themselves and their loved ones to hide the illness away in private spaces. They have developed numerous practices and narratives focused solely on concealing cancer and its effects on the body, relationships, and personal lives. My informants have often adopted metaphors and local cultural patterns of expressing emotions, turning their narratives into deep, metaphoric stories. This strategy is especially visible in a small number of narratives collected among members of the Orthodox Church (in Białystok) who used religious motifs to express their feelings, fears, and—in some cases—to provide an etiology of the illness. The most profound example of such metaphoric interpretation was delivered by a taxi driver, who incorporated into his narrative various biblical parables and motifs linked to greed, hubris, blame, and punishment, interlaced with local sayings and lore. Here is the part of his story:

It was God's punishment for me because, instead of going to pray, I was on Thursday, Friday, even on Sunday, going to work, because I was afraid I wouldn't earn anything. My wife asked me: where are you going? Don't we have enough money? It is enough! The kids are adults, and we have money! But the more you have, the more you want. But it is God's will that it should not be just like that... The doctor from Choroszcz lives above us. Every Sunday he used to fix his car. Every Sunday! So

I say, what we see: every Sunday he fixes his car. The doors, the lock, every Sunday. But there is [pause for reflection]. When there is Sunday, they say—what belongs to God, belongs to God, what belongs to the tsar, belongs to the tsar. Here there is no chance for discussion with this. One must be humble, keep your head very low and that is it. I tell you—I have experienced this myself. This is this situation, and I have never thought [about punishment], but there is the punishment.

Another popular metaphoric motif is the ‘lamentum’ narrative. Complaining about faith and depicting one’s life as cursed is often regarded as very specific to Polish society. The lamentum and complaint have a long historical tradition, with some researchers believing that they resemble a contemporary manifestation of ‘peasant’s grouching’, ‘peasant’s fate’—a form of expressing and experiencing life difficulties among Polish peasants deprived of personal freedoms and property rights between the sixteenth and early twentieth centuries (Kędziołek 1996). In many of the collected narratives a clear motif of complaint and grouching was present. Informants specifically complained about bad faith, generally depicting their everyday reality in a rather fatalistic manner and underlining the insecurity and general lack of control over life. In these narratives the future—as a concept and motif—is absent or transformed into a desultory and underspecified mirage. The informants did not have any plans and their interviews were dominated by reflections on experiences in both past and present. Some informants intentionally avoided talking about any future, despite my repeated attempts to elaborate on this issue. This provided the impression that the time structures applied in these interviews effectually slowed down the plot, making the narratives literally split after the present and head to nowhere. Such narrative structures, I believe, aim to illustrate the authors’ general attitudes to a life experienced as halted by the condition. However, other reports suggest that a fatalistic perspective is a more general phenomenon. Martha Balslem (1991: 13–55), in her study of cancer in a Philadelphian community, quotes numerous examples from literature describing American working class’ life perceptions (including health-related issues like cancer) through the prism of fatalism. Barbara Powe and Ramona Finne (2003: 454) point out that in popular accounts ‘death is inevitable when cancer is present’. Cancer fatalism, as Elaine M. Drew and Nancy E. Schoenberg state, ‘tends to be used extensively when examining traditionally underserved populations, including ethnic minorities, rural residents, and individuals with low socioeconomic status’ (Drew & Schoenberg 2011: 165).

Moreover, researchers focused on narratives (including cancer stories) point out, that ‘slow’, and futureless stories are not rare (Frank 1995: 97–115). Thus, collected narratives suggest that fatalistic motifs cannot be recognized as a unique Polish phenomenon. The social impact of cancer fatalism should be also redefined: none of my informants were rural residents or members of an ethnic minority, or occupied social margins. This clear difference between other reports might suggest that in the Polish context the fatalistic approach to cancer is perhaps a more general phenomenon, not limited to social minorities and rural populations. However, one should be aware that the historical context of Polish demography might have a significant impact on the dissemination of the fatalistic approach among other social groups and classes. The rapid urbanization of Poland is a rather recent phenomenon, mainly limited to the post-World War II period, and prompting massive migrations from the rural areas and small towns to depopulated cities.

Surprisingly, collected data correspond with Helle Ploug Hansen's (2007: 19–25) discussion of cancer in Denmark. Despite Danish society appearing to be more open and tolerant than the rather conservative Polish society, Hansen in her anthropological study of the suffering and stigma experienced by women diagnosed with breast cancer has revealed that the illness and the effects of treatment might be the reason for social stigma and concealment practices. Hansen points out that the abnormalities, deformities and mutilations of culturally significant body parts such as hair, faces or breasts might provide the stimulus for stigmatization and the emergence of taboo practices. Hair or breast loss results in reduced social status and decomposition of the sexual and body identity, and Hansen's informants experienced an indefinite sense of cold and nakedness, commenting that their appearance has strongly inhibited social relations. Consequently, they have adopted numerous coping strategies, including wearing heavy makeup, wigs, and clothes that cover body parts touched by cancer and its treatments.

In my collected narratives I have found numerous similarities with the aforementioned research. Changes located in the most visible parts of the body—the head and face—were strongly associated with identity crisis, which I believe is the result of the unique status of the face and head in global culture. Faces express emotions, and communicate about social status and self-identity (Goffman 1959; Ho 1976). This group of patients reported a sense of isolation, stigmatizing looks, shame and personal practices aimed at masking the effects of illness and treatment. The majority of these stories has been told by women, and represent—I believe—an example of sexualized and gendered images of the body as perceived by Polish society. Informants' experiences belong to the space of socially constructed and mediated stereotypes describing an attractive and healthy female body. The worst experiences have been reported by women who have undergone a mastectomy and lost their hair during treatment while some narrators even claimed that the decision to start treatment was a difficult one: many of them were in two minds about undergoing surgical procedures, chemotherapy or radiotherapy. In numerous stories one can find traumatic memories of the period of hair loss, or the feeling of something missing after the removal of a breast. Sufferers felt not only disfigured, but simultaneously experienced shame and annoyance at the stares of other people.

One of the informants tried to hide her bald head under a wig, especially when she was about to leave home for shopping trips and other everyday activities. She always tried to 'slide invisibly around', before returning home as soon as possible. Another interesting narrative about masking baldness was told to me by Zofia. She tried to come to terms with wearing a wig, but found it uncomfortable, suffering an unidentified 'allergic reaction' as a result of it. I believe that this allergic reaction relates to more than a medical fact, that it might well be a metaphor for the informant's rejection and resistance to her body's stigmatization. This belief is backed up by other parts of the interview in which Maria told me how she managed to overcome her sense of shame and distanced herself from the taboo and social stigma surrounding cancer. She presented a critical analysis of a 'retarded' Polish society, unable to understand the meaning of cancer. 'Let them stare! Damn all these people!' she thought after receiving strong support from her gynecologist, who encouraged her to 'get rid of the wig', a symbol of social oppression.

Zofia, in her speculations about social pressure, talked of her experiences in England, where her daughters had been living. There, nobody paid much attention to her bald

head. She claimed that if she was to fall ill again, she would prefer to stay in England, because in Poland 'there are no conditions in which to be ill'. It should be stressed that her main criticism of Poland centered on her social environment rather than the quality of healthcare.

The narrative presented by Dominika shed even more light on the interplay between sexual identity, body deformities and shame. After the removal of her breast, she claimed: 'the worst thing is my conviction that I am no longer attractive'. She only ever really felt comfortable fully-clothed. What surprised her was that even the removal of her scarf during medical examinations was a source of shame. The only place she felt 'normal' was the oncology ward and with the support group she participated in. 'There, all the people are the same, there is no place for amazement; there, everything is just normal'—she claimed.

What is significant is that physical deformities and changes in relation to the body were a significant source of tension and sense of unwanted otherness, even some considerable time after diagnosis and treatment. This tension was further exacerbated by the strange, hard to accept behavior of friends and acquaintances. Here is an example:

When I returned to work I felt terrible, just awful, because I had the impression, that... I don't know, I was worse or somehow different? I was deeply affected by this (...) I had the feeling that everyone was staring at me with great pity, right? Oh look—she's suffering from cancer, the poor woman—she can't have much time left. I had this feeling that something had changed, but I don't know why. I didn't want anybody to know. I thought that if nobody knows about it, that I have cancer, then maybe nobody will want to talk about it with me, but I met people who, for instance, asked: how are you? These were the older and younger people, and I was wondering, what's the point? I'm here, I'm talking to them; it seems that I'm in good shape.

A narrative in which social stigma was a key theme is Alicja's account. She lived in a small town in Podlasie (a region where I conducted part of my research), which she described as a rather tight-knit community, where 'people knew each other well'. However, after coming back home from hospital she began to see and feel that the friendly environment had changed its attitude towards her. The 'ubiquitous eyes' were everywhere: in shops, the post office and other public places. Despite a lack of any clear physical signs of cancer, the woman knew that she was constantly being observed and that people were starting to gossip about her. One day her young son returned from school crying and told her that the neighbors 'are gossiping that I look absolutely terrible and that I'll die very soon'. This oppressive atmosphere was a daily feature, and when it reached its peak, the informant and her husband decided to leave the town they lived in. They moved to Białystok, the capital of Podlasie, where she had better access to doctors and was anonymous. She quickly made contact with other ill people, whom she met in a clinic. In this new place, surrounded by a group of fellow sufferers, she felt comfortable and 'normal'.

However, times were tough. After moving to Białystok, the informant's son was faced with a new and difficult situation. He was frequently the victim of physical assaults and was mocked by his peers for his small-town origins. This abuse followed soon after the woman's troubling experiences, and during a time of intensive and painful medical treatment. I suggest that these stories are closely related and represent the struggle of emotionally and physically related people—a mother and son under great social pressure. Subsequent tests

of this deeply emotional relationship resemble the classical anthropological concept of *rite de passage*: in the narrative the tests were always accompanied by severe changes in the informant's body and signs of physical abuse on her son's face.

In these stories it is worth noting the recurring themes of escape and seeking shelter in alternative environments, in which the narrators felt anonymous or merely normal. In stories about stigma and taboo another distinct theme arises: the need to participate in a group where emotions related to illness will not be treated as a burden. Informants often suggested that they have tried to avoid saddling their relatives and family with their suffering while places where narrators felt anonymous or shared common experiences with others were depicted in the collected narratives as refuges, open-minded spaces free of social stigma that allowed emotions to be experienced on various levels: biographical, micro and macrosocial, political, economic and moral. In such places it was possible to offload the heavy emotional burden and share with others fears, plans and hopes. However, such spaces—hospitals, support groups, clinics and psychological help units—are in reality relatively closed and isolated worlds. Admittedly they are a part of the social and cultural landscape, but equally they are autonomous and separated from the public sphere by symbolic and institutional barriers. These places—especially medical units—are 'little islands' (Cosser 1962), in much the same way that real islands are separated from the external world. Thus, I argue that despite offering clear examples of positive influence, such places paradoxically reassert the power of taboo and social stigma, serving as socially constructed isolation wards or quarantine units where culturally unwilling and dangerous phenomena, processes, body images, stories and emotions can be carefully stored and controlled. Thus, these are the institutions which actively help in clearing the social sphere of all unwanted, taboo elements. In reality, they symbolize the taboo itself, never more so than in the case of hospital wards and hospices—damned places of death, suffering and pain.

Cancer, family and taboo

Some of my previous suggestions might imply that the family setting is a taboo and stigma-free sphere where cancer patients can feel comfortable and safe. This is not, however, entirely true. I have heard numerous accounts in which—not without some effort—informants have admitted that their illness in the family context was blanketed in silence. Other researchers also report such practices leading to suppression, growing anxiety, neglect and silence (Balshem 1991: 55–91, 125–141). As Holly F. Matthews et al. (1994: 789) suggests, in such families the lack of support and understanding might be the reason for personal dramatization or a stimulus for seeking other sources of support:

This struggle for understanding is made more difficult by the lack of natural contexts for discussion about the nature of the disease since cancer, for a majority of these women, is a taboo topic to be concealed from others, even family and friends.

As with Matthew's research, for a significant number of informants, our meetings were probably the first and possibly the last (at least in the near future) chance to share

their problems and experiences. These narratives were often dramatic and loaded with powerful emotions, accompanied by outbursts of crying and accusations directed at family members. Simultaneously in these stories, one can find numerous justifications and attempts to rationalize the family's passivity and imperviousness. Thus, they resemble Arthur Frank's (1995: 97–115) chaos narratives: stories lacking a clear structure, riddled with contradictions, silence and emotional outbursts.

During my research I have heard—more than once—that informants have hardly ever tried to talk about their illnesses with their relatives. Their motifs were rather based on empathy and altruism: they assumed that nobody deserved to be burdened with such heavy emotional and mental ballast. Here, the concealment might be interpreted as an act of care. However, I argue that this is not always the case: the informant's declarations might be equally perceived as attempts to rationalize their family's 'ambiguous'⁴ behavior. This suppression also serves as a good example of self-imposed taboo practices. As I have already argued, cancer might be the cause of weakened social relations and, according to Das (2001), it also might result in one's degradation within a social net, including family. Some of the collected narratives suggest that their authors suffered not only from cancer, but also from an unspecified social dysfunction which I believe resulted from the 'biological' disease experiences (body dysfunctions, temporary or permanent disability), but equally is a culturally defined form of experiencing cancer, the condition which often is perceived as the end of social life (Sontag 1978). Thus, patients, after incorporating a culturally defined role of cancer victim, began self-imposing taboo practices leading to their further stigmatization, exclusion and concealment.

Cancer, while none of informants directly described the condition in such manner, is a form of very special disability, a self-disability that encompasses physical and mental limitations but also prompts people to self-stigmatization, self-exclusion and self-dissembling by fulfilling the culturally and socially shaped roles of cancer victim. This sick-role victim discourse pushed informants to hide their experiences and emotions in a sterile, isolated and non-expressive sphere located at the very margins of family life to which, in some cases, only selected people were granted access; in the main these were adults, and then only the informant's closest relatives. Thus, exclusion—denied access to information, ignored questions, absence—affected a particular group of people, determined by their relationship to the ill persons, their age and—quite surprisingly—their health condition.

Most informants claimed that they did not inform all of their relatives about their condition, preferring, instead, to keep this knowledge to a limited circle of people. Thus, the cancer served as a factor in defining the type and closeness of relationships between family members. Only selected and initiated people were permitted to assist the informants, helping and caring for them, as well as taking on some of their duties. The narrators—often together with other relatives—strove to hide their illness from their children and grandchildren, particularly when they were not of adult age. What is noteworthy is that some informants also avoided telling their parents about their diagnosis, fearing their emotional reaction, and the influence on their health. But this is not the only reason. I have spoken to a number of people where one of their parents had suffered with or died from cancer. As a result, they adopted behavior which led to their concealing their condition, with the aim of protecting those who had already had an

exceptionally rough time because of the disease. Therefore, the reasons for the emergence of spheres of taboo and related practices—including the avoidance of particular people, situations and topics, the concealment of medical documentation, and disappearance for the period of chemotherapy—are not homogenous and depend on the context and type of relationships within each family.

Now, let me present some stories I believe are meaningful. These will provide more detailed descriptions of parent-child relationships. The first narrative I would like to analyze is that of an elderly woman—Mrs. Mirosława—suffering from breast cancer. Fifteen years previously her daughter was diagnosed with the same condition. During our meeting the daughter was preparing dinner, and her presence had a great impact on the interview. The informant was fraught and the whole conversation was conducted in a palpable atmosphere of secrecy. She spoke in a hushed voice, sometimes almost whispering into my ear. At the beginning of the meeting I was warned how things would look, and why: ‘because my daughter does not want this’. At this point it was obvious that cancer in this family was taboo.

The woman had been diagnosed quite recently, not long after she had detected a small lump during a bath. She felt terrified and her daughter immediately sensed what it was all about. The backbone of this complex interview is a story about disrupted relationships between a sick mother and her sick daughter interspersed with the figure of the daughter’s child/informant’s grandson. This is how the child was introduced into the story: ‘For fifteen years she has been struggling with cancer. She is very optimistic, she wears good clothes, buys everything, and does not think about it at all. Because she has a child.’

In the following part of the story the figure of the child plays a key role. Both informant and her daughter made enormous efforts to hide the information about their cancer from him. Her grandson, according to Mrs. Mirosława, was a clever child and would often ask some difficult questions. His unusual character and intelligence, suggested the informant, were somehow related to her daughter’s cancer. The boy was born into rather extraordinary circumstances: at first the doctors thought that informant’s daughter’s cancer had spread to her ovaries, but after further, more detailed tests, they discovered she was pregnant—a symbol of a new life. Despite this hope, the doctors suggested a termination: ‘The child was born against the will of her doctors. They told her that she must abort the pregnancy, otherwise the child would be born without a head.’ The abortion date was put back several times because of some ‘strange events and coincidences’—the term coinciding with other medical examinations or informant’s daughter breaking her hand. ‘It was a miracle’, she claimed. The boy was not just an average child: ‘the boy is very excitable’ and has emotional problems which Mrs. Mirosława linked to her daughter’s condition and punishing course of treatment.

The rest of the interview followed a standard pattern: the informant presented a selected series of events and information, always related to her daughter and grandson in some way. The narrative can be described as rugged, emotional and interspersed with periods of silence or whispering. I learned that despite being close to her daughter, Mrs. Mirosława has never told her how much she was concerned about her disease. It is difficult to find a clear answer to why the informant has been avoiding open and honest conversation with her daughter. This story is even more complicated—cancer was a fairly common disease in the interlocutor’s family, and tests have proved that the women’s cancers were

genetically related. And, as if all that was not enough, Mrs. Mirosława's husband—a heavy smoker—had died of cancer of the larynx a few years previously.

In this narrative all the cancers blend together, and the stories of the struggles with the disease are stretched out over time, having begun many years before. All the more difficult to understand was why this burning issue had been hidden away and cocooned in silence and evasion. However, what this serves to illustrate is what a powerful and agentic force taboo is, even able to demand emotional suppression among family members and concealment of the reality of the disease. Despite my best efforts, I was never told precisely how this fact was kept hidden and what practices and actions were involved. However, I suggest that this might not be by accident. The informant's avoidance of answering this question indicates that this sphere was also under the powerful influence of taboo.

I have the impression that taboo here was a phenomenon invoking its primordial, enigmatic character. Taboo, as Wasilewski (2010) states, is an enigma, an overwhelming, agentic force spread over social institutions, practices and deeply anchored in individual's minds. Taboo encompasses dirt and defilement, and emerges where particular phenomena shake structured and transparent reality (Douglas 1966). I believe that the fundamental breach in the informant's world was strongly related to genetic screening results. The factor responsible for suffering was the invisible, abstract unit: the mutated gene transferred in the family. Thus, the reason for cancer was not external, nor even just a result of misfortune. It was there, in the basic unit creating affinity: in blood, or using more medicalized language, in genes. These genes, the foundation of the kinship bond, transpired to be the medium for a mystery, a mutation, dirt. So, when the basic sense of family was affected (Mrs. Mirosława's definition of family was strongly related to biological concepts, perhaps under the influence of the screening results and associated biomedical discourse), the more elusive and softer sphere of relations also came under strong pressure. The cancer in Mrs. Mirosława's story afflicted the sphere which should have never been touched, which was beyond informant's perception and reception. Genes became dirt, a tabooed mystery unwillingly present in the bonding tissue of the family. These dirty genes impacted not only the present family relations, but suddenly unraveled the hidden past. As Margaret Lock (1998: 7–9) would say, they became the omens for the—now—dangerous future.

Now, to the second narrative, which was related to me by woman aged 30, named Gosia. She complained that relations with her mother could definitely not be described as perfect, especially through the lens of her illness (melanoma) and her associated experiences. Her mother's reaction to the informant's diagnosis was influenced by many factors and previous experiences, including the loss of her husband to cancer. In this narrative what especially draws the attention is a strong echo of family taboo-concealment practices followed by both Gosia and her mother. The following part of the interview sheds more light on the informant's strategy of hiding her diagnosis:

In this context, I decided that I would not tell my mother for as long as was possible. I am a very late child, my mother is in her seventies; she has suffered a lot in her life and my father suffered from cancer for five years before he died in terrible pain. So I was afraid that this would—you know—almost wipe her out.

Below is the part of the story describing her mother's reaction to the diagnosis and the upcoming surgical procedure:

In my opinion she reacted in the worst possible way—I just hate such reactions. So, she claimed that I did not have cancer. And such information and such a diagnosis made me quite rebellious. It meant that somebody completely belittled my fear. And it does not mean that I want somebody to cheer me up, and—you know—be brave and so on. And you say—all right, but you do not know how it's going to be, because there are no precise results and the surgery is coming. I don't know how it's going to be, neither does the doctor—nobody fucking knows! And now I need someone to be with me, but I don't need anybody to neglect my condition, because I felt like an idiot.

Gosia described her mother's reaction as a 'complete syndrome of suppression'. She ignored any information about her daughter's disease and refused to speak about her husband's death. She behaved as if 'nothing has ever happened', exactly as if her daughter had never been to hospital, as if the domestic space was not full of tension, fear and a chilling sense of uncertainty. Despite being disappointed, the informant tried to accept and understand her mother:

I think she just simply could not look at her youngest daughter through the lens of all that she had been through when my father was ill. And I think that if she would ever try to imagine me in this context, she would probably go crazy. I don't know, that was her way to deal with all this.

This narrative is a powerful example of how suppression and silence can be used to rework and rethink the nature of family bonds and the history of the family itself. The 'lack of natural context' (Matthews et al. 1994: 789) in the family encouraged Gosia to examine her father's cancer story more carefully. A significant part of this interview was nothing more than a complex and reflexive analysis of the informant's memories and feelings associated with her father's cancer. Here is a short example:

I was a kid and my father had a hardcore cancer. He had five different tumors in his bowels, terrible operations and damn hard will to fight, so he encouraged doctors to give him some extra doses of medicines, though his treatment should have been rather a palliative at that time. I mean they should have been helping him to die in dignity, not in pain, but he chose the second option—he thought that he could still get something from life. We were with him, and we saw everything.

The last words seem to be the key to the rest of this story which focused on the profound changes in Gosia's life after diagnosis, including long periods of hospitalization. The time in hospital was very difficult: hospital was a place like a hell, where people suffered terrible pain and were repulsive because of the visible body deformations and wounds resulting from cancers and therapy. In such a horrible space Gosia suffered mentally and physically, away from home, disappointed with her mother's reaction, but with a strong need to survive and to learn something from the disease. Here, once again, a classic motif of *rite de passage* emerges. Gosia described her mother's suppression, concealment and hospitalization as a set of ensuing challenges. In the long and lonely periods of hospitalization she made herself—not without an effort—understand her mother's behavior and reexamine relations with her deceased father:

You know what? First of all, finally I made myself to look at the past, at my father—our relationship. This was something that I had thoroughly hidden somewhere and then, once again, I found it. Actually, my father died in 2001 and I've never cried about this. You know, I just started running and running and I had the feeling that this will never reach me. But at that time, when I went to the oncologic ward, when I felt the smell and when I saw all that people in the shape of my father, with attenuated faces, these doctors, and palms burned out with chemo... Then I said to myself: good morning girl, now we gonna gently rewrite this. You know, we gonna challenge this. Sure this will last for years, to solve everything that I have in my head. But I think that my life said stop. Now stay here and solve everything in you, because otherwise you will always follow the wrong direction.

This reflexive transformation helped Gosia to understand and accept mother's attitude but what seems to be the most important is that it helped her to find her own way to struggle with cancer. Her father's suffering and attitude was a role model of dignity and positive obstinacy in cancer treatment. However, Gosia was also critical about her father. She claimed that, despite his bravery, he was too much focused on himself, too closed off and limited in his suffering. As Gosia concluded, her father's cancer and his suffering could not expand beyond him, could never reach his family and loved ones. By refusing to share his experiences, he refused to share his story with the rest of his family, leaving it with the open wound.

Conclusions

Cancer is a challenge for anthropologists. This highly unique group of conditions resembles a mixture of lay and professional knowledge, and embodies socio-cultural fears and emotions. On the other hand cancer patients often seek new life-solutions, and subjective forms of expression, actions and agency, creating a cancer subculture in motion. In a complex kaleidoscope of meanings and practices, one can easily become lost in the search for repeatable rules of action and modes of reasoning. My research suggests that narratives created by cancer patients are diverse and characterized by their subjective context, encompassing the narrator's individual biography, cancer type, stage of illness, and the family role. The field context—hospital or GP surgery—could also significantly impact the structure and content of collected interviews.

However, I believe that in Poland, when speaking of cancer, these two social phenomena—taboo and stigma—are tightly linked together and create a complex net of interactions and social practices leading to a patient's exclusion, social pressure, stress, isolation and need to dissemble. Collected data suggest that tabooing and stigmatizing practices related to cancer are still a challenge for a significant group of Polish patients and this social response and oppression are the clear sources of discussed issues here. I have observed similar processes as reported by Gregg (2001), Hansen (2007), and Chavez (2009). The female respondents delivered numerous examples of experienced stigmatizing and tabooing practices, especially when their condition was linked to the sexually prominent parts of the body—breast, face, and reproductive system. The most common complaints focus on the stigmatizing gaze, exclusion, the need to dissemble, and the sense of being treated (in the workplace, among family and friends) in a 'different'

way. A significant number of these narratives were collected among members of patients' organizations. This should not be surprising—as Holly F. Mathews (1994: 797–799; 2000: 394–403) suggested, such organizations attract people who have suffered disappointment and bad experiences, who seek alternative solutions and perspectives on their condition.

Despite the fact that treatment reported as 'different' was usually limited to rather subtle and non-harming practices (reserved and lukewarm attitudes or a sense of pity), the informants perceived such behavior as leading to undesirable distinction and revilement. However, in some cases the social pressure that arose around the informants pushed them to radical actions, including moving to another city or otherwise changing the social environment. The stigma and taboo practices were less visible in men's narratives, although one of the most prominent motifs in these narratives was a general fear of being recognized as unable to fulfill masculine duties: the ability to work, and to be active and self-reliant. Thus, male respondents frequently listed all the activities they still undertake such as work in the garage, do-it-yourself practices, and helping their relatives in daily duties. I believe this strong focus on presenting oneself as active, despite the obvious impact of illness and therapy, might be interpreted as an attempt to avert the impact of social stigma: 'there's life in the old dog still', some said. Similarly, firm, 'masculine' statements were made by the male informants when talking about their experiences related to the illness. Respondents were very reluctant to admit that the cancer was a mental challenge, as they believed such a confession might be interpreted as an act of weakness leading to stigmatization. This short quotation from the interview with Mr. Adam is a good example:

Cancer never kills prematurely those who live their life and are happy about their existence. These are the laws of evolution. Only the individuals who are soaked with fear and distrust, who give up and feel no longer needed, pass away. These are the individuals dominated by negative thoughts and emotions.

What is surprising is that I have found numerous examples of self-imposing taboo, stigma and restrictions resulting from the local concept of the sick-role. As researchers report, especially in the United States context, the strong intersections between cancer and 'the discourse of hope' (Del Vecchio Good et al. 1990: 60–62) impacts the Western sick role; in the Polish context, however, elements based on a sense of misfortune, acceptance of victim-style behavior, and social isolation, should be taken into consideration. These self-limiting practices might be the result of the still strong religious background in Poland. While, except in a few cases, informants have not made any significant references to Christianity in their narratives, the strong focus on accepting and enduring suffering and anguish in the Roman Catholic and Orthodox Churches might be the crucial cultural background stimulating Polish patients' sick-roles and narratives. Here motifs like fatalism also play a role. Even though Elaine M. Drew and Nancy E. Schoenberg (2001: 174–178) and Martha Balslem (1991: 125–149) have shown that the concept of fatalism is strongly stereotyped and should be perceived as a more complex strategy for coping with cancer, I suggest that in my collected data fatalistic motifs resemble the local pattern of experiencing and talking about misfortune more generally.

In recent years many efforts have been made by different social actors, including the state, medical practitioners, non-government and patient organizations to change

this undoubtedly unfavorable situation. The results of these actions are visible: cancer patients have gained significant attention and voice. Their needs have been articulated and emphasized in numerous social campaigns, and special medical programs. However, some of these solutions—especially the so-called ‘oncological packet’ (the state program for cancer patients)—have been widely criticized by doctors (mainly oncologists and primary care practitioners) and other social actors.⁵ The main points of criticism focus on superfluous bureaucracy and lack of foundations, but some voices have also suggested that the new solutions favor cancer patients and discriminate against others who suffer from different life-threatening conditions (mainly chronic illnesses—diabetes and cardiological disease). As a consequence, despite the obvious drama of people suffering from cancer, according to some socially influential groups they have become inequitably privileged. This study, together with collected data, however, signalizes a major discrepancy between the efforts made by different agents and the social response to these efforts. Cancer is still a spiky condition, shaped by a range of emotional discourses, stigmatizing practices, tabooing and concealment.

Based on research I argue that taboo and stigma have a dual effect. They are the main reasons for the restriction of actions and activity in the social world, whilst simultaneously causing major changes in people’s lives. The exclusionary power of taboo and stigma pushed my informants into seeking new paths of behavior, and modes of thinking and action, through which they attempted to reconstruct lives shattered by their diagnoses. To achieve their goals they constructed complex narratives, detailing experienced and, frequently, embodied taboo and stigma. The observed ubiquitous need for telling and retelling one’s story finds a strong support in numerous reports delivered by other researchers (Frank 1995; Hyden 1997; Mattingly 2007). This condition has a variety of faces, including stigma and taboo, along with a brighter face, in which one can find many examples of cancer patients as active people, seeking new solutions and narratives, describing in a reflective manner their lives and realities. This claim is supported by examining a short part of Monika’s narrative:

After all, the illness gave me some kind of awareness about myself, the awareness of my power, which I’ve discovered quite suddenly. I realized that we should really appreciate daily life. Life is unpredictable but now I know that if something happens, I can cope with it. Before the cancer I have never had this kind of awareness.

Such examples of activism and reflection hold more complex meanings than just narrative potential. As Das suggested (2001), a lack of social engagement resulting from a weakened social position in one’s net of relations is one of the main reasons, and equally a consequence, of stigmatization and social oppression. I suggest that this ubiquitous need by informants for telling, doing and changing should be seen as a struggle for emancipation and empowerment, leading to the reconstruction of weakened social relations. This is also a powerful example of establishing individual voice and language to express experienced changes, encouraging informants to once again restart their life trajectory and equipping them with—as Cheryl Mattingly would say—‘the therapeutic emplotment’ (2007: 72–104).

Finally, the impact of taboo and associated concealment was visible in the context of family. As the family is one of the fundamental cultural pillars in Poland, the impact of cancer on it can be perceived as vital in the local context. Many stories focused on family response to the condition as the family, next to biomedicine, is the key area where cancer is 'happening'. A significant number of informants found themselves stuck in taboo space or had to cope with awkward situations: family members could not help them (cancer was too overwhelming an experience), or, in some cases, they were simply not interested in the sufferers' stories and problems. The concealment is even more characteristic to the group of narratives collected among people in whose families the illness was a special experience—exceptionally ubiquitous or already present in the past. In these stories a strong need for sharing experiences and emotions was visible. After all, cancer is not an ordinary event: it has the power to exhort ill people and their relatives to reshape their lives and daily realities. My observations suggest that ignoring ongoing processes and their consequent emotions must have resulted in increased anxiety and tension among informants, and a greater need for support. Some people managed to defuse the tension during meetings with doctors or therapists (although not very often), or joined support groups and patients' organizations. However, there were still individual, who could not find any suitable source of support. These people, disappointed or suppressed by the family, told the most detailed narratives describing experienced stigma, sense of exclusion, suppression and life-crippling concealment.

NOTES

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² The organization I was cooperating with had a visible impact on Polish public debate on cancer and cooperated with different agents, including private persons, institutions, healthcare outposts and pharmaceutical companies. Thus, at least some members had the chance of extra services and treatment.

³ This lack of appreciation is clearly seen in the Polish context: methods characteristic to the social sciences and humanities are often perceived as unscientific and not objective, especially the qualitative approach. Polish biomedical discourse strongly emphasizes the need for objectivity and statistical measurements, which also applies to non-medical research conducted in hospital settings.

⁴ My aim is not to accuse or moralize—the term ambiguous was often used by informants.

⁵ <<http://www.polskatimes.pl/artykul/3784929,naczelnia-izba-lekarska-krytykuje-pakiet-onkologiczny-tylko-utrudnia-sytuacje-pacjentow,id,t.html>>

<http://wyborcza.pl/1,75478,17400319,Dyrektorzy_krytykuja__pakiet_onkologiczny___Biurokracja.html>

<<http://www.wprost.pl/ar/497973/NRL-krytykuje-pakiet-onkologiczny-NFZ-nie-przewidzial-ze/>>

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