"Technobonds" – the role of gene-related technologies in the redefinition of "care" and family among cancer patients in Poland[1]

***Hubert Wierciński,* Department of Ethnology and Cultural Anthropology, University of Warsaw**

Abstract: The growth and implementation of advanced medical technologies create knowledge, social needs, practices and responses. I argue, based on my ethnographic research conducted from 2009 to 2012 in Warsaw and Białystok (Poland), that technologies play a crucial role in the biographies and narratives of people suffering from cancer. This is especially clear when talking with and about a patient`s illness with family in the context of gene-related technologies.

In this article, I analyze a body of interviews conducted with the families of cancer patients. Their ideas and beliefs about care, aetiology and the character of disease were strongly medicalized. The definition of family and ties were under a strong influence of new language and technologies derived from gene-related medicine. As a result, "technobonds" – a new definition and representation of family relations can be observed. Techobonds might be perceived as a new form of "internal, familiar care" – a subjective project created by lay people confronted with biomedical knowledge and practices but also with life-challenging emotions like fear and uncertainty.

Keywords: medical anthropology, cancer, Poland, family, genes

Introduction

This article is the result of ethnographic study conducted in Warsaw and Białystok, Poland from 2009 to 2012. I collected 44 in-depth interviews with people diagnosed with malignant forms of cancer. The majority of my analyses are based on these interviews. However, my perspective has been significantly broaden by many informal conversations with psychologists, psychooncologists, oncologists and general practitioners.

The aim of the research was to explore patients' cancer-related experiences in the context of the Polish biomedical health system. My focus was the process of medicalization (perceived as a neutral phenomenon) and the role of new medical technologies in shaping patients' experiences and interpretations of illness.

At the beginning of my explorations, I was convinced that such research should be focused on a rather narrow group – I chose those diagnosed with breast cancer. However, I quickly discovered how difficult it is to only examine breast cancer – my informants suffered from various metastases to bones, lungs and other organs. Thus, oftentimes they were unable to name their condition ("cancer" was the right word). Also, a significant number of informants reported that their relatives suffered from various forms of cancer (before and after their own condition) and these experiences also played a significant role in shaping the informant`s ideas about cancer itself. Thus, I decided that the proper group for my research should be constituted of people who experienced malignant cancer.

The informants represented different ages, sexes and education levels. However, the majority of them were women over 40. All of them lived and worked in large cities and shared a body of common experiences inspired by a quite unified Polish biomedical culture.

Many of them received the same procedures the same hospitals, and oftentimes even met the same doctors at the same institutions. Interviews were anonymous and fully voluntary – none of my informants has been forced to participate in this research. All names have been changed and the collected materials has been coded. Despite this, in Poland there are no standard ethical procedure for ethnographic research, the unwritten set of rules shared by anthropologist working at the Department of Ethnology and Cultural Anthropology of University of Warsaw has been adapted. One of the primary rules is to never harm informants physically and mentally. This rule seems obvious, but interviews with cancer patients have proven that it is extremely difficult to judge where the emotional border which anthropologists should never cross is. Informants represented various attitudes to their experiences and mental condition. During every meeting informants were exposed to my main research goals and provided with information about their right to anonymity and to refuse to provide answers particular questions.

As I have already mentioned, my data was collected in two Polish cites. In Białystok, the largest north-eastern city in Poland, I worked with patients from a local GP (general practitioner) clinic. The majority of them experienced cancer some time ago. However, some of them were still under doctor`s supervision or had just left a hospital ward. All interviews were arranged with the help of doctors working in the clinic. They helped me find informants, encouraged them to take part in my research and arranged meetings, usually in the patients' apartments (or in a free room at the clinic). Such cooperation was highly inspiring – I`ve gained knowledge about patients' problems, demands and needs through the prism of medical doctors' daily practice. All information collected from doctors is anonymous and has not been used to prepare any public report based on this research.

In Warsaw, I worked with so-called "fresh" (an example of hospital jargon) patients in the biggest oncologic hospital in Poland –Centrum Onkologii [Centre of Oncology], and members of two key Polish patients organizations – Polskie Amazonki Ruch Społeczny (PARS) and Rak`n` Roll. Interviews collected at the hospital were significantly shorter and less detailed when compared to interviews from Białystok. I believe that this reflects the specific environment of big hospitals. The hospital is far from being a stagnant place – contrary, it is a sphere of dynamic actions, governed by strict time rules and other regimes. In such an institution anthropologists might simply fail to find a place for themselves. Polish biomedical culture is not helpful – its character is definitely dominant, with almost no place for "soft" sciences – even psychiatry and psychology are perceived as not fully "scientific." These factors played a crucial role in my efforts: I was refused (or ignored) numerous times when asking for research permission in hospital.

Fortunately, my research experiences were dramatically different when talking with patients' organizations, where I could easily find people eager to share their experiences. It should be stressed that one of the examined patients' organizations had its headquarters in Centrum Onkologii and worked with patients staying at the hospital.

My research and analyses were inspired by the theory of narrative. Authors like Arthur Frank and Cheryl Mattingly played a crucial role in my interpretation and perspective on collected data. Arthur Frank (1995) provided me with a framework for grouping collected interviews – or rather stories. His concepts of chaos and restitution narratives served as a map for a better and a more coherent final interpretation. Cheryl Mattingly (2007) helped me understand that ill people are still active and seek progress in their lives. According to her, disease is a serious and stimulating challenge resulting in emergent new orders, definitions and life narratives – the time of diagnosis and treatment is a "narrative moment." Overall, I perceived my informants as active people, seeking new solutions and capable of creating new narratives to describe and organize their worlds. To create such narratives, they needed a number of elements. I believe that medicine, medicalization and genetic discourse gave them

these "bricks" and helped to restore (at least partially) a sense of control and stability after a serious diagnosis.

The rise of genes

The majority of social scholars discussing the anthropological aspects of genes and the rapidly growing genetic sciences focus on issues of politics, ethics, and race. (See Fendos 2009, Fullwiley 2011, Lee 2008, Lock 2007) New treatment opportunities tend to be a secondary topic. Since the success of the human genome mapping project, the debate about genes and the potential benefits and threats of the rapidly growing gene-related sciences is quite vivid in Polish public debate. Authorities, including scientists and medical professionals, have emphasized that an intimate genetic code may be the key to a new understanding of the body. Gene therapies and genetic screenings have been widely discussed. However, the voice of researchers suggesting that only particular conditions might be explained through the prism of genetic inheritance have been far too weak to be heard.

The debate is more complex and goes beyond biomedical studies. Law specialists have suggested that new legal solutions must be proposed. (Boratyńska 2012) A gender perspective has been implemented into gene-related studies (Derra 2013) and bioethicists have discussed the potential risks and challenges for society, science, and culture. (Chańska and Różyńska 2013) Issues of genetic counselling and diagnostics were explored in 2012 during the conference "Bioethics and genetics. Challenges in genetic counselling and diagnostics." The conference was organized by the Committee for Bioethics (Polish Academy of Sciences) and Department of Philosophy of University of Warsaw and took place in Staszic`s Palace in Warsaw.

In the Polish gene debate, conservative voices play a significant role. This oftentimes emotional (and based on emotions together with political and religious convictions) voice is represented by conservative politicians, some social organizations, and the Catholic Church. These social agents depict gene-related technologies, including reproductive technologies (despite that there is a significant difference between them), as dangerous, unnatural, and posing a great moral threat to society, culture, and tradition. (Radkowska-Walkowicz 2013)

Overall, my informants could hear and learn about genes in many places and from numerous sources. The "positive" (chance, progress) and "negative" (threat, "playing-God") knowledge is easily accessible. Such knowledge can be gained from medical units, doctors, friends, other patients, and when queuing for periodic consultation and screenings. The character of such knowledge must be complex, as are the sources. In fact, it is quite difficult to speak about "knowledge" characterized by some degree of coherence and solid background. My informants' "knowledge" was a subjective mixture of ideas, fears, facts, and myths welded together and shared amongst the sick and their family members.

Despite the quite blurry character of genes and the polarized discourse strongly marked by moral issues, one of the most characteristic discoveries was the informants' reaction to my question about the aetiology of disease. "Nie możemy pozbyć się naszych genów" [You just can`t get rid of your genes], said one of my informants. Most of them, when searching for the answer about the genesis of their condition, looked at the medical history of their family. When they could not find any examples of cancer, the disease itself was depicted as a very mysterious and somehow "unnatural" event, beyond known aetiological patterns. A spontaneous onset, at least at the very beginning of treatment, was perceived as rather a curiosity.

These types of declarations correspond with Margaret Lock's (2013) reflections on a new form of identity: "individual genetically at risk." However, there are some substantial differences in Lock`s interpretations and my ethnographic data. According to her informants

– close relatives of patients suffering from Alzheimer`s disease – genetic testing and genetic discourse had little impact on their lives. Instead, they preferred to focus on family history, viewed as – as far as I understand –a better alternative to still uncertain genetic medicine. My data suggest that genetic discourse, including disease definitions, tests, statistics, risk assessment and preventive actions are quite closely related to family definitions and had a significant influence on family medicalization. Such medicalization resulted in the emergence of new awareness and identity, marked by potential risk. Thus, collected data correspond with the concept of "risky relations" described by Featherstone et. al. (2006).

A number of informants mentioned – in most cases spontaneously – that their condition was caused by genetic factors. Some sought an explanation directly in genetic inheritance, although, barring single cases, none of informants had heard from their doctors that the disease might be anchored in their genes. On the contrary, the most common explanation suggested by doctors was that the condition is the result of an "unhealthy" (according to biomedical standards) lifestyle: smoking, poor diet, stress, or just an unhappy accident.

Even when doctors denied the genetic background of the disease, some of the informants continued to suspect their genes and family history. This statement finds confirmation in the interview with Mrs. Leokaida (cancer in her family, both from her father's and mother's side, was quite common): "Lekarz mówił, że to nie jest z tym powiązane, ale może tam są jakieś geny" [The doctor said that there is no clear connection, but maybe there are some genes] – she said. It is worth stressing that her relatives suffered from various types of cancer, different from her own disease. Despite that, Mrs. Leokaida and most of the other informants perceived cancer as a homogenous type of disease – just "cancer", regardless of whether it was located in the bowels or in the brain. Such units could be passed from generation to generation and materialize in particular parts of the body under different circumstances.

Familiar medicalization

Advanced medical technologies, including genetic screening had a great potential to create new relations, body definitions, and health-oriented practices. During my fieldwork, I had the impression that some of my informants treated such tests as a form of fortunetelling. This observation corresponds with Margaret Lock's (1998) reflections on the nature of social reception of genes. She argues that a similar cultural pattern is responsible for clairvoyant practices, and trust in genetic testing is all about managing the future and the unknown. However, she argues that biomedical practices are far more reductionist and deny subjective knowledge together with culturally and socially based factors.

I suggest that this statement is only partially true. It is quite clear that incorporation of a genetic discourse can be understood as an example of medicalization and reduction. However, for my informants, the process of medicalization was a result of diligently working out their lives after their diagnosis. This was a conscious and voluntary choice, based on comprehensive calculations and influential discussions with relatives, friends, and loved ones. Choosing medicalization was safe, or rather safer (my interlocutors had never denied that a significant number of patients die because of cancer) than comparative medicine and alternative solutions. "No to jest kwestia życia i śmierci" [This is a matter of life and death], said one of my informants.

Choosing medicalization could also result in particular benefits, like access to experimental treatments, special programs for family members, and generally speaking a better quality of care. (Chapman 2002) After genetic tests (despite the results) the patients' body awareness and lifestyle changed. What is more, technological analyses of mysteries

written in kinship singled out some relations. Only those who were the closest to the informants – both "biologically" and emotionally – were encouraged to run the tests. It should be stressed that the distance between the informant's family members – even "biological" – was a subjective construction, more emotional and personal than "biological." Examining genes could also serve as a symbol for accentuating special relations with particular people. That might also be interpreted in the opposite way, there were people on the other side of the scale, in other words less important. Such direct declarations are absent in my collected material, but certain words used by my informants, their body language, and voice modulation suggest that that was the case. The experience of illness itself could shorten the distance between relatives. For example, a group of my informants realized that a distant "aunt" suffering from cancer became closer to them than other healthy and close (both biologically and emotionally) cousins.

Genetic testing together with associated practices and knowledge had a great impact on the informants' definitions of family and the nature of relations creating such a community. Biological definitions gained significance. I argue that thanks to genetic technologies a new form of bond had emerged – a "technobond". This bond can be described as highly medicalized and established under the influence of advanced medical technologies. The character of this bond is shaped not only by the technologies themselves, but also by associated meanings, social images, and practices. At the very basic level of technobond lies a sense of collectively shared and experienced fear of the disease and fear of family coherence and safety. The idea of a technobond is to create a joint family front against cancer and the associated sense of dread and uncertainty. In other words, such a bond is designed to eliminate all the chaotic elements that might lie at the core of chaotic narratives defined by Arthur Frank (1995). A technobond serves as a shield and portal through which new technologies, health-oriented practices, and habitats are implemented by the family. This portal keeps the family together and provides a basic sense of comfort. It also serves as a reminder: the future is still uncertain, so all the members of the family should keep an eye on each other and run necessary tests systematically.

Technobonds had a visible impact on the language informants' used to describe disease and associated experiences. The language was reshaped and adapted to medical standards. Many typical medical terms can be found in collected narratives, for example, "procedury" [procedures], "wyniki" [results], guz, [tumour], "masa nieznanego pochodzenia" [unknown mass], "medycyna nuklearna" [nuclear medicine], "chemioterapeutyki" [chemotherapeutic agents], "mutacja brca1" [brca1 mutation], "komórkowe podstawy dziedziczenia" [molecular basis for inheritance], and "dziedziczny rak piersi i jajnika" [hereditary breast-ovarian cancer syndrome]. These terms, quite awkward when used for example by a lower middle class woman from Białystok, age 50, with only a secondary school diploma, suggests that some medically defined phenomena, the style of description, reasoning, and general image of human body have been – both voluntary and involuntary – adopted into informant's every-day reality. Family was not an exception. The question is why? To answer this question, one should be aware that biomedical language is more complex than just a form of technical and jargon communication. It also serves as a medium for powerful stories (DelVecchio Good 1994) capable of transforming human experiences and offering a rich source of a bit old-fashioned, but still spunky, "explanatory models." (Kleinman 1981) These "modernist" (Le Fanu 2000) stories are not only full of hope, but they are also imbued with the profound idea of human progress aimed at controlling what was once beyond control: risk, the future, and the body`s natural limitations.

Gene narratives

My research indicates that this concept of genes, together with associated technologies, definitions, and knowledge have been inserted by patients to their life-worlds, both on the individual ("my cancer is caused by my genes") and the family level ("we all have some cancer genes"). Since genes are inherited, they are continuously present in invisible tissue, which constitutes family and kinship (according to biological definitions very popular among the informants). Some of the informants perceived cancer – contrary to Susan Sontag (1978) – as something originating from the body; something which has already been there. While Sontag emphasizes that in many cultural metaphors cancer is depict as external threat originating from the outside word and ravaging body like military raid, a significant number of my interlocutors seemed to present an alternative view. According to them, "cancer genes" or "cells" (or just "cancer") were somewhere there, hidden deep in their bodies. They were inherited and waiting to be activated. Thus, cancer was very probable or even inevitable. When analyzing some of my informants' narratives, one might get the impression that genes were not only social actors with almost full agency, but also they became an object of the "cult." (Le Breton 2004) These were genes where the future has been carved and genes were to decide what will happen and to whom. This type of attitude can be described as genetic fatalism.

Overcoming fatalism

Simultaneously, my research suggest that such fatalism can be overcame. Mrs. Maria`s family was acquainted with cancer, especially with female cancers. (Her mother suffered from ovarian cancer, her aunt struggled with leukemia and her cousin with throat and stomach cancer.) At the time of our meeting in 2011, her older daughter (Mrs. Maria has three daughters. They all live and work in Great Britain) had struggled with breast cancer for two years. Mrs. Maria was diagnosed with breast cancer in 2006. In 2010, a letter came from the Polish Academy of Sciences, department in Szczecin. It was an invitation to a special program which aimed to establish whether Mrs. Maria had "ten gen" [this gene]. That was a show of great favoritism for my informant. She claimed that such invitations (and advanced tests) are not offered to every ordinary patient.

Screenings done in Szczecin had not reviled any mutations, and Mrs. Maria was sent back home. Soon after her eldest daughter was diagnosed with breast cancer. Thanks to special insurance and the help one of Mrs. Maria's daughters who is a doctor, Mrs. Maria, and her two daughters (the youngest one "bała się" [was too scared] to run tests) were examined in Cardiff. Genetic tests confirmed that she and her daughters are "carriers" and that the disease is transmitted by the female line. "Jestem niebezpieczna! Trzeba dzieci badać!" [I am dangerous! Children must be under constant control], she claimed and sent back the results from Cardiff to Szczecin.

Taking the pains to receive special treatment for her and her family can be explained in a simple way. However, I suggest that Mrs. Maria efforts go far beyond this and can be perceived as a dramatic struggle for "prawdę" [truth] hidden in substance that bonds her family. This is a quest, a mystery waiting to be solved, and a struggle with destiny. This story also resembles wrestling with the problem of subjectivity. Cardiff's results accepted by the Polish institution would ensure a very special status for Mrs. Maria and her daughters. They would eventually join an elite group of patients with open access to the best units, tests, programs and technologies available in Poland.

This unique treatment offers more complex control of contemporary and future events linked to the disease. In Mrs. Maria's opinion this type of complex care reduces chances for

future onset or relapse. Her interpretation resembles almost mathematical or statistical character. Such reasoning can be viewed as an example of the incorporation of medically-based strategy and language. This phenomenon is not unique. Other informants adapted medical metaphors, langue, terms and reasoning (especially biomedical logic) to describe their condition and even personal experiences.

This can be viewed as a pure example of medicalization and social control (Conrad 1992, 2005, Illich 2000, Zola 1972) and it is worth stressing that Mrs. Maria has never challenged medical legitimacy and power. She believed her life and the life of her family will be more stable and predictable when under medical control. In this control she found a set of useful tools for managing risk and uncertainty. Thanks to them, Mrs. Maria was able to reconstruct her biography, which was severely damaged by the traumatic experiences related to her and her daughter`s cancer.

This story illustrates how access to particular technologies and medical programs might stimulate the storytelling and life-reconstruction processes. Emerging stories echo restitution narratives proposed by Arthur Frank (1995). The aim of such stories is to rebuild a broken or disrupted (Bury 1982) life, and in the case of Mrs. Maria this type of need – the need for safety and coherence – is evident. However, due to the reluctance of the Polish institution, Cardiff's results were never accepted. She found the solution for her and her family; she managed to overcome the handicapping impact of genetic fatalism and learned how to make use of genes, but in the end the local medical institution gridlocked her efforts. This shows that restitution pulses, especially those associated with biomedicine, are distributed by medical institutions. However, the mechanism of their distribution is not clear. One can say it is unpredictable and lacks a coherent pattern, even data from prestigious medical institutions like Cardiff might not be strong enough to open access to the world of advanced and socially valued medicine. In Poland, this type of hi-tech medicine is often viewed and treated as an extraordinary and overwhelming sphere where everything is possible and every patient is treated according to the most advanced "Western" standards.

I suggest that a very strong position of medicine and medical institutions in Poland allows them to distribute hope in an imbalanced manner. The strong authority of medicine and medical institutions is responsible for the financial and legislative background that allows medicine to create an unbalanced and unequal distribution of power and rights in the doctor – patient relationship. In this relationship, the patient is almost never perceived as a partner. It is worth stressing that the latter schema is simplified; in fact, patients visiting doctors and seeking help must cope with invisible forces and a conglomerate of knotty regulations and bureaucratic decisions determined mainly by financial, not pro-patient motivations. A good example comes from the field of cancer(s) therapy: state funding of some advanced or long-lasting therapies are limited in time and number. My informants oftentimes asked what it means that according to regulations, they no longer can participate in particular treatment. Such decisions not only challenged their trust to medical institutions and state, but also strongly shook up their self-description categories. They asked themselves: am I a patient or not? Do I deserve help? Am I cured? Additionally, the recent confusion caused by new rules and list of state-funded medicines received rather negative feedback from patients' organizations, patients, and the doctors themselves.

The data collected during my research stresses that such actions and verdicts – illogical and unpredictable, according to my informants – are the underlying cause of the disappointment and distrust of doctors and medical institutions. What is more, in some cases the unclear, limited, and changing access to treatment were perceived by patients as destabilizing phenomena responsible for chaotic and unpredictable experiences, even worse than cancer itself. Paradoxically, medicine and medical institutions designed to help were the

source of experiences similar to Arthurs Frank`s chaotic narratives (1995) – unstable, unpredictable, and paralyzing.

External or internal?

Despite their knowledge and trust in technologies and procedures, some of my informants mentioned that they had close relatives who decided not to run any genetic tests. The informants explained that – according to their knowledge – the reasons were in most cases related to fear of the final results. A case in point is Mrs. Maria's youngest daughter, who refused testing, because "she was too scared."

Other motives can be also distinguished. Mrs. Bianca and her sisters all suffered from malignant cancers:

> Rozmówczyni: Było nas sześć w domu i nowotwory były (...) Wszystkie mamy tendencję do guzków ale nikt nie robił żadnych testów.
> Badacz: Dlaczego?
> Rozmówczyni: Nikt nie chce ich ruszać (Researcher: Hubert Wierciński, informant: Mrs. Bianca, 12.04.2011).
>
> [Informant: There were six of us in the household, and we have encountered cancers (...) We all have a tendency for tumours. But nobody has run any testing.
> Ethnographer: Why?
> Informant: Nobody wants to provoke them].

Additionally, Mrs. Bianka's husband`s family was also "zaznajomiona" [conversant] with various cancers. This had a great impact on Mrs. Bianka`s son's mental condition. She described him as a "hipochondryk" [hypochondriac] and "sfiksowaną" [fixated] person who "nie widzi świata dookoła przez nowotwory" [can`t see the world around because of cancer]. Her son was terribly concerned about his "genetic inheritance" and potential risk of getting the disease. It should be mentioned that Mrs. Bianka definitely dissociated herself from her son`s experiences and fears. She claimed that the disease can`t only be related to genes. "W każdej rodzinie są przypadki" [There are a number of onsets in every family], she claimed and explained that the actual reason for cancers in her family is simply bad luck and a kind of statistical anomaly. According to her, cancer was a phenomena situated beyond the tissue creating family. It was an external threat, just like Susan Sontag (1978) has suggested.

The rest of the informants were not so certain about the external origin of their condition. Cases of cancer in their families provided some clues suggesting that the threat came from the body and family. And that was a bit complicated, Mrs. Cecylia's story proves that this type of perspective might provoke people to ask questions and simultaneously avoid the answers. Her sister suffered from cancer, probably non-malignant, but she refused to speak about this experience with anybody. Additionally, she was immune to genetic test propositions.

In this story, a case of genes and inheritance is even more complicated. Mrs. Cecylia's son suffered from a rare genetic condition which left him blind. After Mrs. Cecylia was diagnosed with cancer, her daughter ran double genetic testing. The results were negative. Mrs. Cecylia tried to encourage other relatives to run tests. She also planned to examine herself and to ask her oncologist for information about available genetic screenings. Here is a part of her speech:

> Jest przykład w rodzinie i znaczy to, że to jest możliwe. Dlaczego mam więc nie robić badań? To może pomóc moim dzieciom, może podnieść świadomość (Researcher: Hubert Wierciński, informant: Mrs. Cecylia, 24.02.2012).
>
> [There is an example in the family, so it means that such a situation is probable in the future. So, why should I skip testing? They can make my child safer, more sure and perhaps more aware].

"Przykład" [the example] she mentioned was her son's disease. It is worth noting that Mrs. Cecylia established a link between her son's experiences and her own condition. From her narrative, a picture of the illness perceived as a universal phenomenon emerged. The illness was able to diffuse through genes and materialize in particular bodies. There were no significant differences between cancer and other typically genetic diseases. Mrs. Cecylia's experiences mixed together with a kaleidoscope of popular and professional knowledge, a variant of "local health system" proposed by Arthur Kleinman (1981). In this worldview, family members were tied together by invisible threads. These threads served as "genetic hi-ways," routes by which various conditions could travel in carrier-genes and materialize in particular bodies under unpredictable forms.

Medicalization and hope

My research indicates that a process of medicalization had many positive aspects. One of them was great potential for creating a sense of hope and stimulating the emergence of new narratives. Medical authority and "medical proof" played a crucial role in my informants' stories. Medicine and medical authority, closed tightly with the high-valued category of "science", had a great influence on patients' biography and their subjective experience of safety. These types of "medical stories" – I believe that this is the correct term to describe what medical research, including genetic screening, has offered to laypersons – served as a source of hope for my informants, and a powerful weapon in their struggle with chaotic experiences: fear, uncertainty, and a sense of "bliski koniec" [close end]. That was a medicine, which, according to my informants, could help them and save their lives. Medicine offered not only treatment and testing, but also information, data, statistics, prognosis and technologies. Perceived by informants as "obiektywna" [objective], "stała" [constant] and "porządna" [solid], provided a palette of elements from which new restitution narratives could be created.

The act of creating these types of narratives is based on a subjective risk assessment covering a numerous categories, which are significant for individuals and social groups. A sense of hope and safety are key features. I suggest that restitution narratives are the products of an interaction between hope, self-awareness, and a risk assessment of the disease. These elements, when in a state of homeostasis, not only served as a spark for acting, but also effectuated a sense of control and potential stability in the informants' present and future lives. Even though this sense of control was limited, it was still strong enough to create a sphere where patients could once again recreate their disrupted biographies (Bury 1982) and arrange plans for the future.

This interpretation gains a stronger foothold when moving back to Mrs. Maria's story. After "positive" genetic tests she claimed: "I am dangerous! My children should be examined." Her declaration clearly resembles "risky relations" described by Featherstone and others (2006). Such relationships provoke actions and redefine daily experiences and definitions.

One of her daughters was already diagnosed with breast cancer and spent some time in a hospital in the UK. Mrs. Maria and her two daughters were aware of the risk, having already

experienced it. However, their awareness and experiences were quite specific, and shaped by a strong influence of biomedical discourse. All of the women underwent a series of medical procedures and preventive treatments. Mrs. Maria and her daughters have learned to observe their bodies in a new way. They introduced new habits, including diet and serious lifestyle changes. Most significantly, they carefully examined and calculated their future risk of cancer, and to do this, they adapted medical definitions of body and risk, oftentimes expressed in percentages: "trzydzieści pięć procent populacji ma ostrą postać tego raka, a 45% umiera przed pięcioletnim przeżyciem" [thirty-five percent of population has an acute form of such cancer and 45% dies before the five-year limit]. Their preventive actions and risk calculations included aggressive preventive surgical procedures – mastectomy and ovariectomie – offered to Mrs. Maria`s daughter living in Great Britain.

This radical solution was seriously taken into consideration by Mrs. Maria and her other daughter. Such decisions seem to be extremely influenced by the culturally defined female body, the images of beauty and gender identity. (Hansen 2007) However, in Mrs. Maria's family, the results of genetic tests questioned the canon of beauty and the popular definitions of the body. Mrs. Maria's sexual identity (and that of her two daughters') was strongly medicalized. The process of medicalization led to deconstruction of cultural patterns. In the analyzed story, breasts and the pubic region were no longer objects of sexual interest. They became a "drogi rodne" [reproductive tract] or an area of medical interventions, marked with scars. According to Mrs. Maria, the breast were a hotbed of cancer, a place where mutated genes engrafted disease, challenging not only sexual and gender identity, but also the family as a social unit. The latter issue was perceived by Mrs. Maria to be the most important. In her narrative, a strong "profit and loss account" motif can be found. When apprising priorities Mrs. Maria discussed planned actions and choices with her doctor. She also read a body of professional literature and paid for extra consultations. She spoke about her actions with great enthusiasm and engagement. I was surprised that a layperson, with the help of her ill daughter and trusted doctors was able to build such a coherent and meaningful story based on a conglomerate of facts, statistics, emotions, fears and experiences.

Mrs. Mirosława displayed a similar attitude (she and her daughter suffered from breast cancer). Cancer was a very common disease in her family. She suspected that a high rate of cancer incidence was related to her ancestors. "Może nasi przodkowie często chorowali? [Maybe our ancestors suffered a lot?], she claimed when I asked her to explain cancer incidence in her family. Her inklings have been affirmed. During our meeting, Mrs. Mirosława showed me her "pozytywny" [positive] genetic test results and explained all the records and symbols used to code the information. I must admit that her knowledge, despite her lack of a medical background, was quite impressive and convincing.

Another part of her narrative should be also mentioned. Mrs. Mirosława recalled a time when her husband suffered from cancer and eventually died after an exhausting struggle with the disease. However, his experience of cancer was different. Mrs. Mirosława pointed out that her husband was a heavy smoker and this "paskudny zwyczaj" [nasty habit] was a key factor in his condition. "To nie ma nic z nami wspólnego" [This has nothing to do with us], she claimed. But who are "my" [the "us"]? This short sentence echoes how Mrs. Mirosława and a number of other informants perceived the disease. Cancer could be "ours" – inherited and passed from generation to generation. Equally, it could attack the symbolic and emotional sphere of family relations. I would like to stress that the genetic definition of family is not deprived of emotions and symbols – genes, according to my informants – were a set of symbols representing a type of relation between them and their relatives. However, there is a substantial difference between the narratives that describe the disease as inherited and those which claim that cancer comes from the outside world and is not associated with elements constructing the biological definition of the family. It is hard to speculate about a

rule, but I suggest that at least some informants, when explaining their partner`s disease, looked beyond-biological factors to culturally and socially grounded issues, like smoking, poor diet, stress, and an irregular lifestyle. It is quite interesting that in this group of narratives the possibility of cancer's genetic inheritance in a partner`s family was rather doubtful. Thus, in narratives about relations where genes did not play a key role (marriage or cohabitation), one might find some lost in translation suggestions of a partner`s own responsibility for his/her disease.

A disease seen through the prism of genetic discourse clearly shows a specific of "familiar disease." This type of a condition is faultless; it is just a misfortune, a result of biological mutation beyond anyone's control. Unlike a disease caused by a "paskudny zwyczaj" [nasty habit], like Mrs. Mirosława used to say, inherited cancer cannot be discussed in terms of responsibility. Biological facts, in some cases verified by genetic tests, is an undisputed phenomenon. Perhaps this is one of the main reasons why a "genetic theory" of cancer was so popular amongst the informants. When talking about biological facts, significant problems like stigma and responsibility are solved. In a medicalized world, the responsibility has been transferred to individuals, who must obey a set of rules and accept particular definitions and practices. When they adapt biomedical definitions of body and family they are perceived as responsible and aware. People who are reluctant to accept medicalization are depicted as irrational, not responsible, immature, or simply cowardly. The case of Mrs. Maria youngest daughter clearly illustrates this. Mrs. Maria suggested that her child behaved in an irrational way, driven by fear and emotions.

Conclusion

Cancer does not just impact the individual, the disease almost equally concerns the patient's family. As my research has shown, the closest relatives, engaged most in the illness narrative. They have assisted in daily chores and routines, and actively participated in organizing the therapy including: arranging visits with doctors, gaining knowledge about cutting edge therapies, and leading medical units. What is also significant is that the relatives have shared the fears and emotions experienced by informants. Thus, we can say that cancer emotionally impacts the family, but who it impacts was determined largely by the characteristics and strength of the ties between particular family members. The pre-illness relations could be only strengthen by the experience of cancer, but equally, cancer had the potential to create or boost new relations between relatives who, before the diagnosis, had never been very close. However, this is only one side of the cancer's potential impact. My research has also shown the reviled and destructive power of cancer experience and it`s devastating impact on family relations. Luckily, such dramatic examples have been reported only sporadically.

In the collected interviews, it is quite visible that the lives of families came under strong pressure and became medicalized. The informants have suggested their families adapted to the rhythm of their disease and treatment. In the collected data, one can find numerous examples of biomedical jargon adapted by informants and utilized to describe their emotional state and general situation. The process of medicalization caused an even deeper phenomenon – the fundamental definition of family was also impacted. New advancements in medical technologies based on genetic screening encouraged my informants to treat and interpret their relationships in a more "biological" manner. This biological definition, based on genetic relationship, gained significance due to the incorporation of medical language and a style of reasoning in informant`s daily life. Thus, it might be perceived as a clear example of biological essentialism.

One of the most important issues – according to the informants – was their genetic inheritance and the related risk of recurrences and new cases of cancer in their family. Collected data suggest that genetic and biological essentialism gained significance and was one of the main forces propelling the informant`s actions and behaviors. "Techobonds" clearly resemble this phenomenon. These redefined and strongly medicalized bonds had a power to organize and stimulate new practices, definitions, and values, all focused on biomedical definitions of health, risk and prevention.

Scientific definitions and language were known to the informants. These elements delivered not only a particular kind of knowledge, but also served as a background for life reconstruction, including familial relationships, practices, and definitions. I believe that this type of outstanding role for biomedical discourses and knowledge displays the strong position of biomedicine and its institutions. Despite the recently observed erosion of doctors' authority in Poland, my informants still perceive medicine (in an abstract sense) as a "stable" "objective," and "strong" source of narratives, and a hope for a better future. Thus, the process of medicalization cannot be perceived as a negative and incapacitating phenomena. What should be stressed is that informants have demonstrated creative potential even when accepting a strong biomedical discourse in their life. Absorbed discourse, or some of its elements, have been creatively redefined and embedded into informant`s daily reality. This process clearly shows that lay people might use medicalization for their own purposes and according to their locally defined social and cultural patterns.

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