

The Social Consequences of Identifying a Genetic Disease with an Endogamous Ethnic Group

The Kashubian Case

Anna Kwaśniewska, University of Gdansk, Poland, a.kwasniewska@univ.gda.pl

Development of genetics research has contributed to the detection of genetic diseases. One of them is the LCHAD enzyme deficiency, relatively common in the Kashubian population, and therefore by the media called the “Kashubian gene”. This article is a case study in which the social and cultural consequences of labelling a disease and problematising the ethnic nature of an illness are demonstrated. It is argued that a genetic disease can become a kind of stigma and spoiled identity, and that the collective identity created by biomedicalisation and geneticisation is either accepted, negotiated, or ignored because of its stigmatising properties. The *biosociality* built around the disease affects not only the carriers and their families, but also a wide range of people, who oppose the ethnic labelling of illness and the process of stigmatisation.



Introduction – Kashubians and the LCHAD enzyme deficiency

I first became interested in the social consequences of LCHAD deficiency, a rare genetic disease relatively common in the Kashubian ethnic community, while talking to a Kashubian activist and writer from Wejherowo (a town of about 50,000 inhabitants in northern Pomerania). During the field research I conducted in 2016–2017, he drew my attention to the potentially stigmatising nature of the disease in relation to the non-medical term “Kashubian gene” which was popularised by the media.

Kashubians are an autochthonous Slavic people of Pomerania who have inhabited the region for centuries. Their population, including persons with partial Kashubian lineage, numbers over 500,000 people (Mordawski 2005: 47; Latoszek 2001: 149). The basis of their identity has been the Kashubian culture, including Kashubian literature, and the Kashubian language. The Kashubian language has the status of a regional language, and it is the only language in Poland with this status. Based on the Act on National and Ethnic Minorities and Regional Language passed by the Polish *Sejm* (lower house of the parliament) on January 6, 2005, some Kashubians consider themselves a separate nation (Obracht-Prondzyński 2007; Mordawski 2005). Unfortunately, the number of speakers of this language is decreasing. Hence, the main concern of ethnic leaders is to stop the disappearance of the intergenerational transmission of the Kashubian language. This problem seems to overshadow other issues, including health. The main organisation representing Kashubians is the Kashubian–Pomeranian Association, founded in 1956. Formally a social and cultural organisation, in practice it is also a political actor, articulating the interests of this group.

Apart from language, an integral element of the identity of Kashubians has been their Catholicism. Religion has influenced and still affects many aspects of life, including the number of children. Both in the past and present, the area inhabited by Kashubians has been characterised by a high birth rate compared to other regions of Poland.

The Kashubians have lived in the same geographical area for centuries, since most of them were and still are engaged in agriculture and, in the northern parts of this territory, in fishing. Currently, some of them are also engaged in various services (construction, tourism, car repair). They are attached to their region and are conscious of the fact that by living within a compact, relatively homogeneous ethnic group, they will be able to retain their cultural and linguistic identity.

According to my interlocutors, until at least the 1970s, the selection of partners in this region was spatially confined to the boundaries of each village and possibly of the neighbouring ones. There was very little inflow of people bringing in “new genes” from outside. Endogamy was fostered by the cultural pattern prevailing in the Kashubian villages, which obliged men to marry women from their own village (instead of families

giving women away to “strangers”). Marriages were earlier contracted between people of similar social and financial status, but the economic criterion for partner selection lost its importance after World War II. The post-war impoverishment of the population, the nationalisation of larger farms and changes in cultural mentality all contributed to this change. On the other hand, the fact that the partner originated from a Kashubian family remained very important, even more so than before. Hence, everyone in their community and its surroundings were related to some degree, which has contributed to a higher incidence of genetic diseases and higher child mortality:

Here in Kashubia, there was a very small influx of... [people from the outside]. We lived on our own. There was a priest named Grucza, and he once said that, up to the sixth generation, we were one big family. And in my genealogical studies, I confirm this to the full extent. And that's why there is no doubt that this is a hereditary matter. The rules for these marriages used to be such that they took place in the nearest circle by principle. (W-08, M/c.70)¹

According to my interviewees, often only the father's genealogy was considered when establishing the family genealogy of marriage candidates. Sometimes it was only during an interview with a priest, who asked additionally about the mother's genealogy, that the candidates turned out to be already related:

[B]ecause no one paid any attention to the name of the mother here. They knew about kinship when it was through the father. The T. line was like that, from... well, near Tuchom, anyway. They had to have the Pope's permission to marry within the family, because they had the same surnames, and they didn't notice that they were most related to each other through their mothers. (W-08, M/c.70)

Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) deficiency is a rare genetic disorder caused by a deficiency in an enzyme responsible for fat metabolism, which was identified in 1989. This disorder is fairly common in the European Baltic Sea region, and especially in Denmark, Sweden, Estonia, and Finland (Immonen 2016; Tyni & Pihko 1999), as well as in Poland (Piekutowska-Abramczuk et al. 2010). In Poland, the first case of LCHAD deficiency was diagnosed in the 1990s. Studies conducted since 2008 have shown the highest frequency of the mutated gene responsible for LCHAD deficiency to be in the northern part of Pomerania, with a prevalence of 1 in 73 (Piekutowska-Abramczuk et al. 2010: 375). In the part of Pomerania inhabited by

¹ The code after each quotation stands for: W - interview, 08 - number, F/M - gender of the interviewee, c.70 - their age. Translations of the interviews and other sources were made by me.

Kashubians, it is 1 in 57 (Nedoszytko et al. 2017: 9). According to medical doctors who conducted research on the topic, frequent occurrence of the disease results from long-term occupancy of a geographic area, low influx of people (genes) from outside the area, and group endogamy:

We suppose that the disease [LCHAD deficiency] manifests itself because its carriers live in a small, closed population and connect with each other – says prof. Dorota Piekutowska-Abramczuk from the Department of Medical Genetics at the Children's Memorial Health Institute in Warsaw. (Katarzyńska 2008)

Kashubians are considered to be an isolated population since several lines of evidence suggest that they conform to the criteria of such a population: an old settlement, high rates of endogamy with consanguineous marriages between distant relatives, and slow population expansion with negligible immigration. (Nedoszytko et al. 2017: 11)

To some extent, the cultural explanation for the prevalence of LCHAD deficiency in the Kashubian population has contributed to the disruption of the positive image Kashubians have of themselves. Medical professionals were seen by activists from the Kashubian-Pomeranian Association to have undermined the Kashubian pride in continuity, as well as the reputations of the kin group families who have lived in a given village for 150 years and more.

This article asks, on the basis of this case study, what are the social consequences of rare genetic diseases when identified with particular social groups? What roles are played by the media and doctors in these social consequences? For the theoretical framework of the article, I have adopted the concept of biomedicalisation as presented by Adele Clarke et al. (2009). This complex, multi-level and ambiguous process is related to the development and application of new technologies. Through research and diagnostics (including genetic diagnostics), biomedicalisation contributes to the emergence of new techno-scientific identities. Transformations of techno-scientific identities at the population level often lead to the creation of *biosocialities* that reflect collective interests. Paul Rabinow (1996) notes that these new collective forms of socialisation cluster around the proliferating categories of bodily vulnerability, somatic suffering, genetic risk, and exposure to disease.

Research Data, Site and Methods

This article is based on empirical data obtained during the ethnographic field research that I conducted from June 2016 to December 2017, and from November to December

2018, among Kashubians living mainly in the counties of Kartuzy, Wejherowo and Puck in the northern and central part of Pomeranian Voivodeship. I deliberately chose this area because its Kashubian occupancy has been historically documented for centuries. Kartuzy County is considered to be the centre of the Kashubian territory – Kashubians along with people of partial Kashubian ancestry constitute 99% of the population in the Sierakowice municipality, 94% in the Przodkowo municipality, and 92% in the Kartuzy rural municipality. In the Wejherowo municipality (Wejherowo County), Kashubians and people with partial Kashubian descent constitute 85% of all inhabitants, and in the Puck municipality they constitute 94% (Mordawski 2005: 40–42). The area is characterised by considerably stable occupancy, cultural homogeneity, and a strong Kashubian identity of the inhabitants. Most of the Kashubian population inhabits villages and small towns, engaging in agriculture, crafts, services, and agro-food industry. In Puck County, which is situated by the Baltic Sea, tourism plays an important role.

The main data collection method was semi-structured in-depth interviews – I conducted 24 interviews with people from Kashubian families (aged 24–76, 11 women and 13 men) living in the villages of Kolonia, Staniszewo, Sianowo, Mirachowo, Sierakowice, Wilanowo (Kartuski County); Kosakowo, Swarzewo (Puck County); Bieszkowice and Szemud (Wejherowo County). A second group of interviewees consisted of members of the Kashubian-Pomeranian Association from Gdańsk, Gdynia and Wejherowo (4 interviews). I also conducted 2 focus-group interviews with a total of 9 people. I collected narratives about the disease among both Kashubians and non-Kashubians, and I participated in the reunion of a branched Kashubian family. The interviews were coded and analysed following the principles of grounded theory (Strauss & Corbin 1994) and qualitative data analysis (Silverman 2008).

My second method was participant observation, lasting several dozen hours in total. I participated in conferences addressing patients with rare diseases, including LCHAD deficiency, in Wejherowo, as well as in a conference of medical doctors working with LCHAD deficiency dedicated to the Kashubian scientific community.

My third research method was analysis of existing media data (Babbie 2006). I analysed the content of over 30 press articles on the LCHAD deficit in the Kashubian population which appeared between 2008 and 2017 in the regional and national press and on the internet. I have also analysed the diagnostic offerings of several genetic clinics and paediatric practices. These methods allow me to present various aspects of the case in study. I present both voices of the Kashubian people as well as the approaches of ethnic leaders, doctors, and the media.

Biomedicalisation and Biosociality

The issue of medicalisation emerged as an analytical interest in the 1970s, resulting from a concern with the growing role of medicine as a field that increasingly intruded on people's everyday lives (Zola 1972). In sociology, research on medicalisation was developed by Peter Conrad (1992), who viewed it as a sociocultural process that relied on defining a given problem in medical terms and using medical terminology to describe it – with or without the participation of medical professionals. Medicalisation is related to extending the category of illness to ailments that had previously been considered non-medical (Conrad 1992: 209).

Over time, two concepts have emerged alongside medicalisation: The first is *biomedicalisation*, associated with the technological advancement of medicalisation, and the second is *geneticisation* (Bell & Figert 2015). Biomedicalisation is related to the development of new scientific and research technologies that combine the results of biological research, computer science and information technology (Clarke et al. 2003, 2009). Biomedicalisation involves, through scientific and technological innovation, the expansion of the knowledge and methods, which enable the transformation of human bodies and lives. It results in medicine being transformed “from within” by the new sociotechnological solutions that enable biomedical sciences and technologies of intervention within the fields of health and illness, but also within the organisation of medical care (Clarke et al. 2009: 22). According to Adele Clarke et al. (2009: 22–23), biomedicalisation is composed of five interrelated processes:

- (1) a new biopolitical economy of medicine, health, disease, life and dying
- (2) an emphasis on health in a broad sense, not merely medical, but also sociocultural health, as well as on optimisation, improvement and management of risk and surveillance at the individual, group, and population levels
- (3) increased dependence on science and technology
- (4) the change in modes of production, distribution, and dissemination of biomedical knowledge and management of information
- (5) the creation of new identities based on transformations of bodies and the creation of new individual, collective, and population identities (or niche groups) of a techno-scientific nature. These new collective identities at the population level often lead to the emergence of *biosocialities* that are characterised by new modes of social relations profoundly linked to such identities.

The second concept that has emerged alongside medicalisation is geneticisation; features include diagnosis by means of screening and genetic testing, as well as a new

conceptualisation of diseases – not occurring at the level of cells as before, but at the level of genes. Geneticisation is a mechanism that facilitates biomedicalisation. Paul Rabinow noted that the new genetics will lead to the creation of new group and individual identities and practices: “These [biosocial] groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene in and ‘understand’ their fate” (Rabinow 1996: 102). Such groups form biosocialities that arise through biological self-determination and reflect collective interests (Rabinow 1996; also Clarke et al. 2009). They are organisations and associations founded and run by patients, shaping the conditions around their own diseases as well as shaping their own identities and subjectivities (Lemke 2015; Rabinow 1996). Nowadays, these patient and family organisations are becoming increasingly important, through either supporting research or (sometimes) conducting their own. Clarke and colleagues note that “[a]s forms of biosociality, embodied health movements reflect how ‘life itself’ becomes the stakes, and biomedicalisation the usual means of addressing them” (2009: 28). The goal of biosociality can be both the struggle for access to better treatment, as well as the raising of public awareness about the various problems faced by the group.

Biomedicalisation leads to the emergence of new techno-scientific identities. Such new identities are negotiated; they can be either accepted or rejected based on their stigmatising properties (Clarke et al. 2009: 23). Sometimes, the new identities can become a source of stigmatisation (Goffman [1963]2005: 34–35). The nature of meanings and values assigned to the stigma depends on many factors, especially sociocultural ones. In the process of stigmatisation, differences between people and groups are distinguished and labelled. Negative stereotyping then occurs through the association of these labelled individuals or groups with undesirable characteristics, and this leads to the loss of social status of the individuals labelled (Link & Phelan 2001). Bruce Link and Jo Phelan (2001) note that the necessary condition for stigmatising others is the possession of power – whether social, economic, or political power. This power may derive from one’s knowledge, position, or professional role.

Biomedicalisation has transformed the material world. It has led to economic polarisation and unequal access to medical research, medicines, and treatment (Moyer & Nguyen 2016). These processes are complex and multidimensional and involve communities in different parts of the world. Various case studies show that biomedicalisation perpetuates inequalities in social constructs such as race. In her study of heart disease in the African American community, Janet Shim has shown the constructs of race, social class, and gender to be common in cardiovascular epidemiology in the United States. The risk behaviours conducive to these diseases have been embedded in

notions of race and linked to it, being construed as natural rather than shaped by socially constructed intergroup relations (Shim 2010: 239). Similarly, Jonathan Kahn (2010: 264) illustrates the case of an “ethnic drug” used to treat heart failure in African Americans in the United States. BiDil is the first drug ever to be approved with a race-specific indication. The story of this drug raises concerns about the dangers of reifying the race in a manner that could lead to new forms of discrimination. This drug has become a point of debate regarding the category of race in biomedical research (ibid.: 264). This shows that biomedicalisation and geneticisation give new meanings to the notion of race, legitimise its social existence, and cause certain drugs and diseases to become “ethnic”.

A New Genetic Disease – LCHAD Deficiency

Since the end of the twentieth century, genetics has become the dominant paradigm and emblem of modern medicine. Ongoing genetic research has resulted in the discovery of new diseases, as well as in changing medical interpretations of their causes. In this process, behavioural and psychological differences have become partially defined as genetically determined. This results in the geneticisation of society, wherein, as Abby Lippman notes, the differences between individuals are reduced to their DNA, and most diseases and behaviours are identified as genetically determined (1991: 18–19).

Critics note that this new form of biological reductionism carries with it a new form of stigma and social inequality (Sontag 1999). The development of genetics transforms social relations and cultures, influences understandings of health and disease, and generates new forms of risk (Domaradzki 2012: 8). Emphasising the genetic basis of certain traits and behaviours can facilitate their “naturalisation” and thus reduce social stigma and responsibility (Shostak, Conrad & Horwitz 2008).

LCHAD deficiency is an autosomal recessive disease, and for a child to be born with the disease the parents must be carriers of the mutated gene. However, not every child of the gene-carrying parents is born with the disorder – the probability of developing the disease is 25%, and it is linked to the way the genes are inherited. The condition does not produce characteristic symptoms that would be easy to diagnose, but if it is not recognised early, it can lead to sudden death, severe disability, or blindness of the child (Immonen 2016; Piekutowska-Abramczuk et al. 2010; Sykut-Cegielska et al. 2011). The disturbed metabolism is caused by a deficiency in the enzyme responsible for the use of fat – provided in food and made up mainly of long-chain fatty acids – as an energy source. At the time of writing, there is no cure for this disease. It is treated with an appropriate diet, in which most important is replacement of long-chain fatty acids (butter, oil, lard) with complex carbohydrates and medium-chain fatty acids – in particular a special MCT (Medium-Chain Triglyceride) oil.

The frequent occurrence of the mutated gene in the Kashubian population caught the attention of journalists, who began to use the term “Kashubian gene” when writing about the disease. The power of the media caused this name to become a colloquial term for the LCHAD deficiency. Research conducted by doctors and geneticists in the following years has demonstrated that the mutated gene responsible for this disease is also relatively common among residents of other parts of Poland – especially in Silesia, and less frequently in Mazovia (Nedoszytko et al. 2017: 6). However, this fact has neither drawn media interest nor produced any discourses on the causes of the frequent occurrence of LCHAD deficiency in other regions of Poland.

A New Economy of Risk and Surveillance Methods

Biomedicalisation’s focus on health, risk, and surveillance has entailed the emergence of a new field of power interested in the health of citizens. Biomedicalisation also involves risk management. On the one hand, it aims to reduce risk through research and treatment, and on the other hand, it continuously confirms the existence of risk in the social sphere. As Clarke and colleagues point out:

Genetic susceptibility testing represents one powerful domain of the elaboration of surveillance through the identification of individuals and (sub)populations as “at risk”. Further, genetics may define individuals and/or specified (sub)populations as at differing degrees of risk, from “low” to “moderate” to “high” in cases where the relationship of inherited or acquired genetic mutations to disease susceptibility is cumulative. (2009: 24)

One surveillance method involves screening for early detection of various diseases. After medical practitioners determined in the years 2001–2006 that a large group of children diagnosed with the LCHAD deficit at the Children’s Health Centre in Warsaw were from Pomerania, pilot screening of new-borns for the disease was carried out in the area in 2008. At that time, the testing showed that in the hospitals of the Pomeranian Voivodeship, 41 children were born with a mutation in this gene – the majority of them (39 children) in the area inhabited mostly by Kashubians, with the highest number in Kartuzy (22), and lower numbers in Puck (8), Kościerzyna (6), Chojnice (2), and Wejherowo (1) (Piekutowska-Abramczuk et al. 2010: 375). Since 2015, these tests have become part of the mandatory screening of new-borns in Poland funded by the Ministry of Health. I have not found any mentions of the Kashubian parents refusing to allow the testing.

Genetic technologies are becoming a new way of managing the body, as the information provided by its tools changes individual experiences (Lippman 1991; Rose

2007, 2008). Genetics create a new form of fatalism wherein genes are taken to be responsible for individual diseases, while at the same time, genetic testing provides an element of control over one's own destiny (Rose 2008: 424). This control also applies to procreation. As a result, "reproductive medicine" is one of the areas of biomedicalisation that is becoming increasingly important (Shaw & Raz 2015: 4–5). Genetic technologies allow individuals to learn about "risks" and to mitigate them – for example, by avoiding procreation or choosing a partner who is free of the defective gene in the case of the LCHAD deficit. In the Pomeranian Voivodeship, medical doctors gave referrals to young people from families with a history of LCHAD deficit so they could participate in state-financed genetic testing to detect the mutated gene responsible for LCHAD deficiency.

The development of what Clarke and colleagues (2003) call the "Biomedical TechnoService Complex, Inc." is also linked to geneticisation. Private laboratories in Poland offer genetic testing to detect diseases carried by people planning to have a child. More recently, these tests include one for LCHAD deficit. This test is quite expensive by Polish standards (300.00–400.00 PLN = 68.00–89.00 EUR). On their websites, some laboratories report that the disorder is most common in Kashubia. They therefore suggest that people from this region with reproductive plans should consider testing to determine whether they are the carriers of the mutant gene. In this way, these laboratories create a new area of uncertainty and fear, as well as a new emphasis on risks associated with the origins of both partners from Kashubian families: "Before, you didn't know about this gene, about this disease, so you didn't worry, whereas now, there's this kind of anxiety in there somewhere" (W-12, F/c.40). Genetic testing, by enabling the informing and elimination of risks, acquires a moral value. It also shifts the responsibility for a child's health onto families and parents. One of the interviewees whose family has a child with the LCHAD deficit talked about the attitudes towards genetic testing among young people in her family:

We talk, but we'll never know what they will do. Whether they're going to want to get tested or not. Well, I think that they could, but maybe they need to mature on their own, and think by themselves, "Yeah, listen, maybe we'd better get tested, so we'd know. We know there's a sick one in our close family, and there's always the risk of this disease." (W-17, F/c.40)

The Influential Power of Journalists and Information Media

One effect of biomedicalisation is the change in the production, transfer, and dissemination of biomedical knowledge, as well as in the management of information (Clarke et al. 2009: 22–23). Due to digital developments, the results of scientific research can now be published

in online editions of medical journals. This enables access for medical professionals, but also for other interested parties. After the results of medical research on LCHAD in the Kashubian population were published in specialist journals, they attracted the interest of journalists. Between 2008 and 2017, more than 30 articles and news clips concerning the disease were published in the local and national press and on the internet. Initially, the texts had a sensationalising tone, with titles such as “The curse cast on the Kashubians” (Klątwa rzucona na Kaszubów) (Katarzyńska, March 19, 2008) or “The Kashubian gene killed little David” (Kaszubski gen zabił Dawidka) (Gromadzka-Andzelewicz, May 7, 2009). They later became more balanced: “What is the Kashubian gene?” (Czym jest gen kaszubski?) (Nadmorski24.pl, October 14, 2010). The media, including the internet, have popularised knowledge about this new and rare genetic condition. At the same time, they have popularised the non-medical term “Kashubian gene”.

This raises the issue of journalists’ responsibility for the quality and nature of the published content. Journalists are able to get their voices heard, select the content conveyed to their audiences, and at the same time attract attention with sensational titles and content. In an attempt to gain readers, they treat the genetic disease as a sensation, ignoring social consequences of attributing “bad genes” to the entire Kashubian population. The media’s message is not symmetrical or objective, but rather an expression of cultural hegemony (Gramsci 1971). Such hegemony is connected to the access of symbolic elites to valid channels of information distribution, by means of which they create a certain image within the media that diverges from reality. The power of the symbolic elites and the media’s pursuit of sensationalism cause coverage of the LCHAD enzyme deficiency to be presented as an almost universal disease of Kashubians, influenced by their culture.

On the other hand, the media discourse on the so-called Kashubian gene drew attention to the fact that knowledge about genetic risk extends beyond the private concerns of an individual. This broader knowledge implies that an individual who takes on a genetic responsibility towards future generations is under a moral obligation to submit to genetic testing and prenatal diagnosis (Domaradzki 2012: 14).

After the media had disseminated information about the LCHAD deficiency in the Kashubian population, posts appearing on internet forums (especially Facet WP) criticised Kashubians’ customs, accusing them of backwardness, incest, and marrying within the family. Internet user Aneczka writes:

It really is true that Kashubians only marry within family. That’s how it is in Sierakowice. In this way, they prevent their possessions from passing into other hands. People are very rich, and in this way, they increase their possessions compared to others. To a normal outsider, such things are gross. First cousins marry each other. (Facet WP 2010)

In response, one internet user stated that in some places in Podhale region, every other inhabitant has the same surname, meaning that they are also most likely interrelated – even though they have not been diagnosed with a genetic disease (Facet WP October 14, 2010).

At the same time, the internet has proven to be an important source of information for affected persons and their families. One manifestation of biomedicalisation is the use of the internet to search for diagnostic and therapeutic information, and to build communities (Clarke et al. 2009: 22). According to the interviewees, it is mainly younger Kashubians who use the internet to learn about the disease: “Nowadays, young people are more knowledgeable, they can find anything on the computers. There’s a lot of information about this Kashubian disease on the internet, and that’s where they are looking for it” (W-01, M/c.44). The internet serves to connect patients and families affected by the LCHAD deficit. Parents share experiences and recipes, since their children need to eat balanced meals prepared exclusively with MCT oil.

Another feature of biomedicalisation is the formation of patient associations. One association can bring together patients suffering from various diseases; an example is *Ars Vivendi*, which connects patients with phenylketonuria and other rare diseases, including the LCHAD deficiency. The association holds meetings for patients and their parents at which medical professionals give lectures presenting the latest state of knowledge. Much attention is given to diet since it is fundamental in treating this condition. This association was mentioned by the mother of a 16-year-old boy with LCHAD deficiency from the Wejherowo area:

We belong to an association called *Ars Vivendi*. It’s based in Warsaw. This is the only one with this disease, the only one that took us in as the LCHADs. There aren’t many of us, so they took us in [...]. We go there when there’s a three-day meeting in Warsaw. On these occasions, various doctors give lectures. That’s when we go. Once Dr Wierzba had a meeting, and she invited this cook, and Dr Cegielska was there, too. And then there’s a presentation of some progress in medicine, the news. (W-12, F/c.40)

The Social Power of Medical Professionals

Two opposing positions are discernible in scientific research on identity: essentialist and constructivist. In the first approach, identity is something permanent, existing in reality, everlasting and unchangeable in time. Here, as Barker (2005: 251) notes, identity is perceived as the universal and timeless essence of one’s own self that every human possesses. From the essentialist perspective, markers of identity are objective

criteria that allow the differentiation and classification of persons into given categories or groups.

In the second approach, identity is seen as a construct that changes over time and is fluid and unstable. Anthony Giddens (2001: 105) observed that identity is a reflective project, in which we are not what we are, but what we make of ourselves. In this approach, identity is a dynamic, constantly transforming creation that takes shape through negotiations.

The development of genetic research has meant that genes have begun to be seen as the basis and markers of identity. This has ushered in a return to an essentialist understanding of identity. Nikolas Rose observes that genetic essentialism lays the foundations for a new molecular ontology of life that reduces identity to the level of molecules and redefines persons as somatic units (Rose 2007; Novas & Rose 2000). An awareness of being a carrier of a faulty gene can become the source of a “spoiled” identity (Goffman [1963]2005). A significant role in the process of stigmatisation is played by language – by the terms and metaphors employed. For many Kashubians, the term “Kashubian gene” is particularly controversial. This theme came up quite often in the interviews:

The very term “Kashubian gene” is already stigmatising, since it indicates that the Kashubians carry a potential threat – so it’s better to stay away from them [...]. Some journalists described it as the “Kashubian gene”, [implying] that Kashubians marry among themselves and are not open to the outside world. (W-14, M/c.45)

Other Kashubians also pointed out that this commonly known name for the condition could result in all Kashubians being perceived as potential carriers of the mutated gene. As one female interview participant pointed out, “[t]his name, ‘the Kashubian gene’, suggests that many, or all of us Kashubians carry this gene, and this is not true” (W-24, F/c.30). While Kashubian sociologist Brunon Synak, former chairman of the Pomeranian Regional Assembly, supports the screening tests, he also expressed a concern that

[t]hose who don’t understand what it is all about will only remember the “Kashubian gene”. Such a mental stereotype could be dangerous. There’s already talk here and there of “the Kashubian curse”. Of how a Kashubian man would be better off not be marrying a Kashubian woman. (Gromadzka-Andzelewicz May 20/22, 2009)

Stigma is primarily a social process in which the reactions of others degrade the identity of both the individual and the group (Goffman [1963]2005: 34–35). The Kashubians I

spoke with feared that when passed on from generation to generation, the stigmatising label could become what Erving Goffman called *ethnic stigma* (Goffman [1963]2005: 33). Goffman observed that not all groups are concerned about the stigma imposed on them ([1963]2005: 37). However, in the case of Kashubians, and especially people associated with the Kashubian-Pomeranian Association as well as those with higher education, anxiety over the colloquial definition of the disease was evident during my research. Some interviewees reacted quite “allergically” when asked about the so-called Kashubian gene. Some were irritated by the question, or changed the topic of the conversation, while others said that they had heard about the disease, but since their families were mixed, the disease did not concern them.

Goffman notes that an individual stigma bearer, and more broadly a group bearing the stigma, can become the object of disputes and discussions regarding their identity. At the same time, professionals have the power to tell them what to do and what to think about themselves, all allegedly for their own good (Goffman [1963]2005: 168). In Foucault’s (1998) terms, this constitutes an element of biopower, whereby the state apparatus, through collaborating doctors, exercises control over various areas of social life. In the case of Kashubians, the opinions of some doctors led to press publications proposing that “greater openness by the Kashubian community may reduce the number of carriers of the so-called Kashubian gene” (Drewka 2016: 1). This suggests that Kashubians should change their cultural practices. Some researchers do not rule out the possibility that the mutation is of Kashubian origin, and thus suggest that this ethnic group might be responsible for its emergence and spread (Piekutowska-Abramczuk et al. 2010: 377; Nedoszytko et al. 2017: 11). This brings up the problem of responsibility on the part of experts – in this case, the medical community that speaks with authority to the media. By entering non-medical interpretations of the genesis of the disease, and by criticising the Kashubians’ selection of life partners, experts call into question the values important to this group.

In this case, medical community opinions about the social determinants of the relative prevalence of this genetic condition have contributed to a spoiled identity. As Christine Hauskeller, Steve Sturdy and Richard Tutton (2013) note, the strength of identity politics depends on who controls the use and meanings of biomedical technologies. Having at their disposal these technologies and research findings, medical doctors and geneticists imbue them with non-medical meanings. Biopolitics, in Foucault’s (2011) terms, is a form of domination and power, achieved through the control of a unified life process. Biopower usurps the right to manage populations by regulating and controlling life processes (ibid.). In a process of constructing subjectivity described as “making up people”, the unique knowledge systems of biomedicine shape social identities (Hacking 2007).

Kashubians and especially ethnic activists strive to counteract this genetic determinism and essentialism. Among those involved in this struggle is Bogusław Nedoszytko, a medical doctor from Kashubia. According to him, the gene mutation responsible for the disease “was probably introduced to the Kashubian population from Scandinavia. Therefore, it should rather be called, for example, a ‘mutation typical of inhabitants of the Baltic coast’. Using the term ‘Kashubian gene’ denigrates, stigmatises, and its use should be discontinued” (2018: 7).

As emphasised by Clarke and colleagues (2009: 22–23), new techno-scientific identities are negotiated both at the individual and group level – they can be selectively rejected, ignored, taken on or managed. An example of such rejection is the attitude of some people I interviewed who claimed that there was no such thing as the LCHAD deficiency because they had not encountered a case of this condition in their own family or among friends. One interviewee also initially rejected the fact that her own son had LCHAD deficit:

Before I accepted that my child was sick [with LCHAD deficit], I didn’t even go to Warsaw for my first appointment. I said no. This is impossible. I have a healthy child. And then he had the second crisis, if you can call it that, and I realised that my child was ill. And that he can’t go too hungry, and he can’t run too much, can’t run freely. He had this crisis, and we went to Dr Wierzba, and it was then that I realised that I have a sick child. (W-11, F/c.40)

An attitude bordering on dismissal of the disorder as unimportant because it was seen to affect only a few people was presented by a Kashubian Catholic activist with whom I spoke who belonged to the Kashubian-Pomeranian Association:

Before, children were dying, well, many, many more children were dying. Older people still remember this very well, so no one makes a general tragedy out of it. Obviously, it is a tragedy for the family, for a narrow group of people, or the whole family, but also for the local community [...]. However, this is not a general problem of the Kashubian society. We have too many various other problems that will sooner draw us to our graves, as Jan Karnowski² writes, taking our language along. (W-09, M/c.47)

For this activist, the ideological goals and the preservation of cultural identity overshadow the significance of the group’s health problem. I see this as a cultural defence against the perception of Kashubians through the prism of a genetic disease.

² Jan Karnowski (1886–1939) was a Kashubian activist, writer, and historian of the region.

An example of disease-related identity management can be found in activities aimed at disseminating knowledge about LCHAD deficiency and its causes within the Kashubian community. These include information campaigns, conferences, and popular lectures on prevention. They are prepared by local governments, schools, and Kashubian activists. Pro-health activities are sometimes conducted as part of local cultural festivals such as family picnics with band performances and children's competitions organised at the school complex in the village of Przyjaźń (Kartuzy County). The program included pro-health lectures on the "Kashubian gene" and breast cancer. The event was described to me by one of my interlocutors whose child attends the school. It was on this occasion that she had learned more about this disease.

Earlier in the same year, the county authorities in Kartuzy had organised a conference addressed to representatives of the local community such as village and town leaders, and other officials, entitled "The origins of our lineage – what the genetics says about the Kashubian population". The speakers mainly included medical professionals working with genetics and rare diseases. Eugeniusz Pryczkowski was the only speaker from outside the medical community. He is a Kashubian activist and journalist who in his talk challenged the medical hypothesis that the reason for the relatively frequent occurrence of LCHAD deficiency in Kashubia was that the population inhabited a small area for generations, had no influx of people from the outside, and had primarily marriages taking place within one group. He represented those Kashubians who resist medical interference in non-medical aspects of life – in this case, such important aspects as the choice of life partners, ways of living, and values related to family and identity.

The geneticisation of identity changes and reconstructs social relations (Rabinow 1996: 99). LCHAD has made some Kashubians pay more attention to genealogical links between families living for generations in one area. The identification of a genetic disease with no characteristic outward manifestations has meant that every Kashubian woman and man can be suspected of being the carrier of the mutated gene – hence a level of anxiety among parents with adolescent children. Especially in the Kartuzy area, parents have begun to pay attention to possible kinship links to people with whom their children have closer relationships, for example whom they date.

Discovery of the LCHAD deficit has meant that the amateur genealogical research which had already been popular among Kashubians has now started to pay more attention to connections between individual families. Websites and internet resources are used for this purpose: "there hadn't been the kind of genealogical systems like now. They really make it easier. That's why I'm saying, it really is down to kinship that this disease somehow lay dormant here" (W-14, M/c.72).

The new information has affected the children with LCHAD deficit and their parents in other ways as well. Children with the condition need to eat frequently (every 3–4 hours during the day, and often at night), and the need to limit energy expenditure to a minimum means that some children and adolescents do not participate in various forms of extracurricular activities such as sports or trips. This causes them to feel or be excluded from their school class community or peer group. Often they are home-schooled, which also affects their relationships with their peers. Illness affects the choice of group they socialise with, meaning that many children only meet children and families in the same situation. Due to geographic distances, staying in touch via the internet and telephone prevail.

Conclusions

Biomedicalisation is a complex, multi-faceted process with both positive and negative effects on many aspects of the lives of individuals and groups. Biomedicalisation and related genetic technologies have gone beyond the original goal of developing new forms of diagnosis and treatment. The development of genetics has led to the discovery of new diseases, including the LCHAD deficiency, and to the invention of new forms of treatment. As a result, it has contributed to saving many lives, either from death or from other consequences of the diseases. Progress in genetics is therefore a source for optimism, but on the other hand, its sociocultural implications extend far beyond its strict medical uses, and these implications generate areas of uncertainty. In the case of the Kashubians, the concern arose that a percentage of them might be carrying the mutated gene. In the views of some, this awareness has become a source of stigma and “spoiled” identity (Goffman [1963]2005). Members of the Kashubian-Pomeranian Association are worried that the stigma associated with the disease will negatively affect the image of the entire group and will become part of a negative ethnic stereotype.

The Kashubian case demonstrates that the social consequences of a genetic disease can represent a return of an essentialist understanding of identity. Many Kashubians with whom I spoke pointed out that the term “Kashubian gene” was highly stigmatising. It has been disseminated by the media, which took sensational interest in the disease. At issue is also medical professionals’ responsibility for the non-medical hypothesis concerning the cause of the high frequency of LCHAD deficiency in the Kashubian population. In their opinion, the prevalence of this disease results from population immobility, endogamy and a low influx of outsiders. Such developments have evoked different reactions from Kashubians – some have accepted this interpretation, some have outright denied the consequences of the disease, and still others have actively defended themselves against medical interference in such aspects of their lives as

their choice of marriage partners, non-migration to other areas of Poland, cultural distinctiveness, and discrete group identity. This demonstrates that the new identity arising from biomedicalisation and geneticisation is either accepted, negotiated, or ignored because of its stigmatising properties (Clarke et al. 2009: 23).

The social and cultural effects of biomedicalisation have affected many aspects of Kashubians' lives and have also influenced the perception and identity of this ethno-regional group. Although the internet is used to spread misinformation about Kashubians, the internet is also used by Kashubian parents to find information about the disease, and to build communities of patients and their families. Younger Kashubians use the internet to communicate, and to support the families of children affected by this disease. The internet is also used for genealogical research to find connections between Kashubian families and lineages. In the past, the identification of such connections served to construct large families, but since the discovery of the LCHAD deficiency, some Kashubians have acknowledged the negative side of endogamous marriages.

This case study of one ethnic group has explored the ways in which cultural and medical elites have influenced the dissemination of genetics knowledge to the general populace. In turn, genetic technologies have enhanced the sociocultural effects of how these same elites formulate and express the information they provide. Phrases and expressions communicated by people who occupy higher positions in the social structure due to their professions are never neutral, and in the case of the Kashubians, poorly thought-out language and assumptions adopted by these elites may have lasting and stigmatising effects for decades.

Acknowledgements

This research was conducted as part of the research project funded by the National Science Centre in Poland (Grant No. 2015/17/B/HS3/00107). Head of the grant: Małgorzata Rajtar, PhD.

References

Literature

- Babbie, Earl 2006: *Badania społeczne w praktyce* [The practice of social research], translation: Witold Betkiewicz et al. Warszawa: Wydawnictwo Naukowe PWN.
- Barker, Chris 2005: *Studia kulturowe: Teoria i praktyka* [Cultural studies: theory and practice], translation: Agata Sadza. Kraków: Wydawnictwo Uniwersytetu Jagiellońskiego.
- Bell, Susan E. & Anne E. Figert 2015: Introduction. In: Susan E. Bell & Anne E. Figert (eds.), *Reimagining (Bio)Medicalization, Pharmaceuticals and Genetics: Old Critiques and New Engagements*. New York: Routledge, 1–15. DOI: <https://doi.org/10.4324/9781315760926>
- Clarke, Adele E., Janet K. Shim, Laura Mamo, Jennifer R. Fosket & Jennifer R. Fishman 2003: Biomedicalization: Technoscientific Transformations of Health, Illness, and US Biomedicine. *American Sociological Review* 68: 161–194. DOI: <https://doi.org/10.2307/1519765>
- Clarke, Adele E., Janet K. Shim, Sara Shostak & Alondra Nelson 2009: Biomedicalising Genetic Health, Diseases and Identities. In: Paul Akinson, Peter Glasner & Margaret Lock (eds.), *Handbook of Genetics and Society: Mapping the New Genomic Era*. London: Routledge, 21–40.
- Conrad, Peter 1992: Medicalization and Social Control. *Annual Review of Sociology* 18: 209–232. DOI: <https://doi.org/10.1146/annurev.so.18.080192.001233>
- Domaradzki, Jan 2012: Genetyzacja społeczeństwa: Społeczne konsekwencje nowej genetyki, [Genetization of a society: social consequences of the new genetics]. *Studia Socjologiczne* [Sociological studies] 2(205): 7–26.
- Drewka, Wojciech 2016: *Gen kaszubski wciąż groźny, ale już pod kontrolą* [The Kashubian gene is still dangerous, but already under control], https://expresskaszubski.pl/pl/11_wiadomosci/22030_kartyzy-gen-kaszubski-wciaz-grozny-ale-juz-pod-kontrola.html (accessed November 5, 2016).
- Foucault, Michel 1998: *Nadzorować i karać: Narodziny więzienia* [Discipline and punish: the birth of the prison], translation: Tadeusz Komendant. Gdańsk: Fundacja Aletheia.
- Foucault, Michel 2011: *Narodziny biopolityki* [The birth of biopolitics], translation: Michał Herer. Warszawa: Wydawnictwo Naukowe PWN.
- Giddens, Anthony 2001: *Nowoczesność i tożsamość: "Ja" i społeczeństwo w epoce późnej nowoczesności* [Modernity and self-identity: self and society in the late modern-age], translation: Alina Szulżycka. Warszawa: Wydawnictwo Naukowe PWN.
- Goffman, Erving, 1963: *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall. Polish edition 2005: *Piętno: Rozważania o zranionej tożsamości*, translation: Anna Dzierżyńska & Joanna Tokarska-Bakir. Gdańsk: Gdańskie Wydawnictwo Psychologiczne.
- Gramsci, Antonio 1971: *Selections from the Prison Notebooks*, translated and edited by Quintin Hoare and Geoffrey Nowell Smith. New York: International Publishers.

- Hacking, Ian 2007: *Kinds of People: Moving Targets*. British Academy Lecture 151. British Academy: 285–318, <https://www.thebritishacademy.ac.uk/documents/2043/pba151p285.pdf>. DOI: <https://doi.org/10.5871/bacad/9780197264249.003.0010>
- Hauskeller, Christine, Steve Sturdy & Richard Tutton 2013: Genetics and the Sociology of Identity. *Sociology* 47(5): 875–886. DOI: <https://doi.org/10.1177/0038038513505011>
- Immonen, Tuuli 2016: *Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency in Finland – Earlier Diagnosis and Strict Diets Improve the Survival Rate and Clinical Course*. Academic dissertation. Pediatric graduate school, Children’s Hospital Helsinki. Helsinki: Helsinki University Hospital, University of Helsinki, <https://helda.helsinki.fi/bitstream/handle/10138/162724/longchai.pdf?sequence=1>.
- Kahn, Jonathan 2010: Surrogate Markers and Surrogate Marketing in Biomedicine: The Regulatory Etiology and Commercial Progression of “Ethnic” Drug Development. In: Adele E. Clarke, Laura Mamo, Jennifer R. Fosket, Jennifer R. Fishman & Janet. K Shim (eds.), *Biomedicalization: Technoscience, Health and Illness in the U.S.* London: Duke University Press, 264–285. DOI: <https://doi.org/10.1215/9780822391258-010>
- Latoszek, Marek 2001: Liczebność Kaszubów – kwestia metodologii [The number of Kashubians – a question of methodology]. In: Józef Borzyszkowski & Cezary Obracht-Prondzyński (eds.), *Badania kaszuboznawcze w XX wieku* [Kashubian studies in the 20th century]. Gdańsk: Instytut Kaszubski, 140–158.
- Leinke, Thomas 2015: Patient Organizations as Biosocial Communities? Conceptual Clarifications and Critical remarks. In: Peter Wehling, Willy Viehöver & Sophia Koenen (eds.), *The Public Shaping of Medical Research: Patient Associations, Health Movements and Biomedicine*. London & New York: Routledge, 191–207.
- Link, Bruce G. & Jo C. Phelan 2001: Conceptualizing Stigma. *Annual Review of Sociology* 27: 532–545. DOI: <https://doi.org/10.1146/annurev.soc.27.1.363>
- Lippman, Abby 1991: Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities. *American Journal of Law and Medicine* 17(1–2): 15–50. DOI: <https://doi.org/10.1017/S0098858800007917>
- Mordawski, Jan 2005: *Kaszubi u progu XXI wieku* [Kashubia at the beginning of the 21st century]. Gdańsk: Instytut Kaszubski.
- Moyer, Eileen & Vinh-Kim Nguyen 2016: Editorial Note: Is the 21st Century the Age of Biomedicalization? *Medicine Anthropology Theory* 3(1): I–VI. DOI: <https://doi.org/10.17157/mat.3.1.523>
- Nedoszytko, Bogusław 2018: *Tzw. “gen kaszubski” – prezentacja wielośrodkowych wyników badań* [The so-called “Kashubian gene” – a presentation of multicentre research results], <https://www.tvmed.pl/t/5149/Tzw-gen-kaszubski--prezentacja-wielosrodkowych-wynikow-badan> (accessed January 30, 2018).
- Nedoszytko, Bogusław, Alicja Siemińska, Dominik Strapagiel, Sławomir Dąbrowski, Marcin Słomka, Marta Sobalska-Kwapis, Błażej Marciniak, Jolanta Wierzba, Jarosław Skokowski Marcin Fijałkowski, Roman Nowicki & Leszek Kalinowski 2017: High Prevalence of Carriers of Variant c.1528G>C of HADHA gene Causing Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHADD) in the Population of Adult Kashubia from North Poland. *PLoS ONE* 12(11): e0187365. DOI: <https://doi.org/10.1371/journal.pone.0187365>

- Novas, Carlos & Nikolas Rose 2000: Genetic Risk and the Birth of the Somatic Individual. *New Genetics and Society* 29(4): 485–513. DOI: <https://doi.org/10.1080/03085140050174750>
- Obracht-Prondzyński, Cezary 2007: *The Kashubs Today: Culture-Language-Identity*. Gdańsk: Instytut Kaszubski.
- Piekutowska-Abramczuk, Dorota, Rikke K.J. Olsen, Jolanta Wierzba, Ewa Popowska, Dorota Jurkiewicz, Elżbieta Ciara, Mariusz Ołtarzewski, Wanda Gradowska, Jolanta Sykut-Cegielska, Małgorzata Krajewska-Walasek, Brage S. Andresen, Niels Gregersen & Ewa Pronicka 2010: A Comprehensive HADHA c.1528G>C Frequency Study Reveals High Prevalence of Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency in Poland. *Journal of Inherited Metabolic of Disease* 33 (Suppl 3): 373–377. DOI: <https://doi.org/10.1007/s10545-010-9190-7>
- Rabinow, Paul 1996: Artificiality and Enlightenment: From Sociobiology to Biosociality. In: Paul Rabinow, *Essays on the Anthropology of Reason*. Princeton: Princeton University Press, 91–111. DOI: <https://doi.org/10.1515/9781400851799-007>
- Rose, Nikolas 2007: *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century*. Princeton: Princeton University Press. DOI: <https://doi.org/10.1515/9781400827503>
- Rose, Nikolas 2008: Race, Risk and Medicine in the Age of “Your Own Personal Genome”. *BioSocieties* 3: 423–439. DOI: <https://doi.org/10.1017/S1745855208006339>
- Shaw, Alison & Aviad Raz 2015: *Introduction*. In: Alison Shaw & Aviad Raz (eds.), *Cousin Marriages: Between Tradition, Genetic Risk and Cultural Change*. New York & Oxford: Berghahn, 1–32.
- Shim, Janet K. 2010: The Stratified Biomedicalization of Heart Disease: Expert and Lay Perspectives on Racial and Class Inequality. In: Adele E. Clarke, Laura Mamo, Jennifer R. Fosket, Jennifer R. Fishman & Janet K. Shim (eds.), *Biomedicalization: Technoscience, Health and Illness in the U.S.* London: Duke University Press, 218–241. DOI: <https://doi.org/10.2307/j.ctv125jk5c.12>
- Shostak, Sara, Peter Conrad & Allan Horwitz 2008: Sequencing and its Consequences: Path Dependence and the Relationship between Genetics and Medicalization. *American Journal of Sociology* 114(Suppl. 1): 287–316. DOI: <https://doi.org/10.1086/595570>
- Silverman, David 2008: *Interpretacja danych jakościowych* [Interpreting qualitative data], translation: Małgorzata Głowacka-Grajper & Joanna Ostrowska. Warszawa: Wydawnictwo Naukowe PWN.
- Sontag, Susan 1999: *Choroba jako metafora: AIDS i jego metafory* [Illness as a metaphor: AIDS and its metaphors], translation: Jarosław Anders. Warszawa: PIW.
- Strauss, Anselm & Juliet Corbin 1994: *Grounded Theory Methodology*. In: Norman K. Denzin & Yvonna S. Lincoln (eds.), *Handbook of Qualitative Research*. Thousand Oaks: Sage, 273–285.
- Sykut-Cegielska, Jolanta, Wanda Gradowska, Dorota Piekutowska-Abramczuk, Brage S. Andresen, Rikke K.J. Olsen, Mariusz Ołtarzewski, Maciej Pronicki, Magdalena Pajdowska, Anna Bogdańska, Ewa Jabłońska, Barbara Radomska, Katarzyna Kuśmierska, Małgorzata Krajewska-Walasek, Niels Gregersen & Ewa Pronicka 2011: Urgent Metabolic Service Improves Survival in Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) Deficiency Detected by Symptomatic Identification and Pilot Newborn Screening. *Journal of Inherited Metabolic of Disease* 34(1): 185–195. DOI: <https://doi.org/10.1007/s10545-010-9244-x>

Tyni, Tiina & Helena Pihko 1999: Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency. *Acta Paediatrica* 8: 237–245. DOI: <https://doi.org/10.1111/j.1651-2227.1999.tb01089.x>

Zola, Irving K. 1972: Medicine as an Institution of Social Control. *Sociological Review* 20(4): 487–504. DOI: <https://doi.org/10.1111/j.1467-954X.1972.tb00220.x>

Press and Internet Articles

Facet WP 2010: <https://facet.wp.pl/klatwa-zapisana-w-genach-6002203044222081g/2> [A curse in the genes], October 14, 2010 (accessed November 10, 2014).

Gromadzka-Andzelewicz, Jolanta 2009: Gen, który Szwed zostawił Kaszubom [The gene that the Swede left for Kashubians]. *Polska: Dziennik Bałtycki* May 20/22: 4–5.

Gromadzka-Andzelewicz, Jolanta 2009: Kaszubski gen zabił Dawidka [The Kashubian gene killed little David]. *Polska: Dziennik Bałtycki* May 7: 1, 4.

Katarzyńska, Alicja 2008: Klątwa rzucona na Kaszubów [The curse cast on the Kashubians]. *Gazeta Wyborcza* March 19: 19.

Nadmorski24.pl October 14, 2010: *Czym jest gen kaszubski?* [What is the Kashubian gene?] (accessed October 10, 2018).

Anna Kwaśniewska, PhD (ethnology, history) is an associate professor at the Institute of Archeology and Ethnology, University of Gdańsk, Poland. Her research interests and publications focus on intangible cultural heritage, medical anthropology, national and ethnic minorities (especially Kashubians). A recent article is “Spatial, religious and national selection of marriages and the identity of Kashubians in the context of a genetic disease” in *Etnografia Polska* 65(1–2), 2021.

(a.kwasniewska@ug.edu.pl)

