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HEALTH MATTERS, PATIENTS AND DOCTORS THROUGH THE LENS OF MEDICAL ANTHROPOLOGY

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HEALTH MATTERS, PATIENTS AND DOCTORS THROUGH THE LENS OF MEDICAL ANTHROPOLOGY. INTRODUCTION

DANUTA PENKALA-GAWĘCKA

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The articles included in this thematic section of "Ethnologia Polona" are written mainly by Polish anthropologists whose work has made medical anthropology an important and well visible sub-discipline of socio-cultural anthropology in Poland. In addition, we have invited two medical anthropologists from abroad (working in Saint Petersburg and Oslo) to submit their papers which complement the topics raised in this issue.

The emergence of medical anthropology in Poland was a slow process, because, for a long time it was largely folk medicine or its "remnants" that attracted researchers. Pioneering studies which paved the way for medical anthropology were conducted in the 1970s and 1980s at the University of Wroclaw, where ethnologists' interest concentrated on ethnobotany and new approaches to studying folk medicine, and at Adam Mickiewicz University in Poznań, with the focus on complementary medicine and medical pluralism[1]. However, until the beginning of this century only a few Polish scholars had developed an interest in medical anthropology. The situation has significantly changed in recent decades, which was perhaps precipitated by earlier publications aimed at popularisation of this anthropological sub-discipline in Poland (e.g. Penkala-Gawęcka 1983, 1994), and then by well attended conferences and seminars. Among these events, a workshop organised in Poznań in 2009 gathered a group of young Polish anthropologists who had started their studies on health, illness and medicine, and a conference in Będlewo, in 2011, was attended by anthropologists and

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[1] For a comprehensive overview of the sources and paths to medical anthropology in Poland see Penkala-Gawęcka 1995; for an outline of its further development see Bartoszko and Penkala-Gawęcka 2011.

scholars representing related disciplines[2]. Other important, international conferences took place in Warsaw: MAYS (Young Scholars Medical Anthropology) meeting in 2011 and the 3rd HIT (Health in Transition) Conference in 2013[3].

Scholars working in medical anthropology conduct research both at home and abroad; outside Poland, most researched areas are Central Asia (e.g. Penkala-Gawęcka 2006, 2016) and Latin America (e.g. Wądołowska 2010; Kujawska 2016; Kujawska and Pardo de Santayana 2015), as well as Ukraine (e.g. Kołodziejska-Degórska 2016). In addition to more traditional topics of research, such as medical pluralism or complementary and alternative medicine, Polish anthropologists study, among other issues, people's health-seeking strategies in diverse socio-cultural settings (Penkala-Gawęcka 2016; Main 2018), new reproductive technologies and women's experience of in vitro fertilisation (Radkowska-Walkowicz 2013), the medical choices of Jehovah's Witness patients in Germany (Rajtar 2013), experiences of people suffering from cancer (Wierciński 2015), or rare diseases in Poland and Finland (Rajtar 2017). In recent years, there has also been increased interest in Poland in studying various aspects of biomedicine (Radkowska-Walkowicz and Wierciński eds. 2014) and psychiatric anthropology, popularised and developed by Anna Witeska-Młynarczyk (ed. 2018, 2019) and Andrzej Perzanowski (2018).

The development of Polish medical anthropology is also connected with the activities of the Interdisciplinary Research Team for Childhood Studies at the University of Warsaw. As a result of studies conducted by the members of this team, a number of valuable works have been published, including volumes on children and health (Radkowska-Walkowicz and Reimann eds. 2018), the perceptions of "in vitro children" and their own experiences (Krawczak, Maciejewska-Mroczek, Radkowska-Walkowicz eds. 2018), child and adolescent psychiatry (Witeska-Młynarczyk ed. 2018; 2019) and, recently, on Turner Syndrome (Maciejewska-Mroczek, Radkowska-Walkowicz, Reimann eds. 2019). The activities of this group provide evidence of the advantages of collaboration between medical anthropologists and representatives of other social sciences, humanities and natural sciences.

The observed proliferation of research output – including articles and special issues in leading journals (Speier, Šmídová, Wierciński eds. 2014; Penkala-Gawęcka and Rajtar eds. 2016), participation in international conferences and seminars, invited lectures at home and abroad, and cooperation of medical anthropologists with foreign institutions and international organisations, interdisciplinary collaboration, as well as courses in

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[2] As a result of these meetings, two edited volumes were published: Penkala-Gawęcka (ed.) 2010; Penkala-Gawęcka, Main, Witeska-Młynarczyk (eds.) 2011.

[3] Articles based on the presentations from the latter conference were published in *Czech Sociological Review* (Speier, Šmídová, Wierciński eds. 2014).

medical anthropology at some Polish universities – may be regarded as visible signs of the current strength of this subdiscipline of anthropology in Poland[4].

This special issue provides an insight into the ways medical anthropology is currently developing in the country, though, of course, it cannot present the whole panorama of these studies. In the articles contained in this issue, we can trace the intersections of various research areas, topics and concepts, such as childhood, reproduction, biomedicine, biotechnologies, medicalisation, institutionalisation, commercialisation, standardisation, normalisation, guidelines, agency, ethics, disability, addiction, patients, biomedical practitioners, healers, complementary medicine, indigenous medicine, etc. While referring to anthropological theories and concepts, the authors all ground their studies in thorough ethnographic research.

Several articles offer anthropological analyses of diverse biomedical technologies used in the diagnosis or treatment of children's health problems, and/or examine the children's own views on such interventions, as well as opinions and attitudes of parents and other actors. These texts show the complex "social work" of such technologies, whose impact goes far beyond biological action.

Magdalena Radkowska-Walkowicz discusses Turner Syndrome, treated not only as a biological phenomenon, but a "multidimensional cultural fact". She focuses on the growth hormone used in the treatment of girls with TS, and examines it, on the one hand, as a kind of flexible biotechnology, and on the other hand, as "the hormone of hope", a substance which gives a person the prospect of achieving "normality" and avoiding stigmatisation. The specificity of this hormone also raises questions regarding biomedicalisation, bioethics and body enhancement.

The article of Ewa Maciejewska-Mroczek deals with another kind of technology – assisted reproduction, and more specifically in vitro fertilisation (IVF) – and presents a wide ideological, political and legal context of assisted reproductive technologies (ARTs) in Poland. Of particular value is how she reveals how a silent subject, an "IVF child" is being created in the anti-IVF discourse, and gives special attention to the voices of these children. The author highlights children's active role in building their own meanings of in vitro, but also the ways in which negative discourses of ARTs permeate into the worlds of children, and she argues strongly for considering their attitudes.

Anna Klepikova's research is based on interviews with parents of children with developmental – mainly intellectual – disabilities and autism. She shows that a medicalised, professional approach to disabilities, which dominates in Russia, is also shared by the majority of parents. In her article, Klepikova examines popular biomedical and

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[4] Today, the main university centres of medical anthropology in Poland are the Institute of Ethnology and Cultural Anthropology at Adam Mickiewicz University in Poznań, with the Research Group "Medical Anthropology", and the Institute of Ethnology and Cultural Anthropology at the University of Warsaw, with the Unit of Medical Anthropology and Corporeality.

alternative methods of treatment and rehabilitation adopted for children with disabilities, and argues that parents' assessments of their outcomes can be analysed with the use of the placebo effect theory. From this perspective, such factors as the price, prestige, foreign origin, exclusiveness and popularity of treatment enhance the placebo effect, which, in turn, fosters the commercialisation of disability rehabilitation sphere and proliferation of its institutions.

Anna Witeska-Młynarczyk focuses on practices of diagnosing ADHD among school children in Poland and analyses a new tool used for identifying this disorder. The author emphasises the biomedicalisation of ADHD and the development of "diagnostic cultures", clearly seen in the example of the ADHD scanner, as a new instrument of neurotechnology. She comments on the process of commercialisation of such tools and reveals how screening programmes of this kind create a special category of "patients-in-waiting" – those with the liminal status, waiting for the final diagnosis.

Małgorzata Rajtar, in turn, shows the process of normalisation of eating and constructing dietary guidelines for "healthy" people, and compare them with dietary regimens regarded as suitable for persons with a rare metabolic disease – LCHAD deficiency. According to her argument – grounded in fieldwork conducted in Poland and Finland – while healthy individuals are required to know the guidelines and make informed choices about their eating habits, this model is also extended to people with rare diseases, including LCHAD deficiency. However, as the author stresses, in this case there are no universal standards of proper nutrition and dieticians' recommendations may significantly vary; in addition, they are further appropriated by parents and patients themselves.

Some of the articles presented above tackle ethical issues connected with the use of biotechnologies, especially in the case of children. In another text, Aleksandra Rzepkowska deals with the dilemmas and problems of fieldwork among people with autism, including the ethics of this type of research. On the basis of her in-depth study, the author highlights the unique nature of work with autistic people, applied methods, and questions of responsibility and empathy, and concludes with a claim of the importance of traditionally understood fieldwork, in spite of difficulties and ambivalence of this particular field project.

Two further articles focus on drug addiction and the agency of drug users/addicted patients. Aleksandra Bartoszko describes patients' participation in a Norwegian heroin-addiction treatment programme and thoroughly examines the complex issue of their agency. She shows how patient agencies are made, and how patients and clinicians negotiate and expand them in practice inside and outside the clinic, which demands navigation between policies, treatment protocols and legal regulations. In her paper, Zuzanna Sadowska discusses the problem of drug users' agency. Based on fieldwork conducted in Warsaw, she problematises current dominant approaches to drug addiction, arguing that regular users are not deprived of agency. The author describes diversified and changing trajectories of people's drug use and analyses the processes of negotiating agency between the user and the substance.

Biomedical professionals, working during a period of intense healthcare system reforms, are at the centre of the next two articles. Hubert Wierciński examines the roles of Polish primary care doctors and focuses on their activities as social entrepreneurs. However, his aim is to show how this role influences encounters between doctors and patients, creating the space for deeper interactions and cooperation with patients, although – as the author argues – these opportunities have been undermined by an increasing bureaucratisation of healthcare system. In the next paper, Danuta Penkala-Gawęcka presents specific features of Soviet and post-Soviet mental healthcare in Kyrgyzstan, including the current efforts by representatives of "new psychiatry", who strive to implement globally approved standards of community-based and culturally sensitive treatment of mentally ill people. The author shows how these directives have been adapted to the local environment, where psychiatrists have recognised the value of traditional Kyrgyz healers' interventions and have started cooperating with them, despite radical differences in their ontologies and cognitive principles.

The issue of differences between ontologies of biomedicine and traditional medicine, and their possible reconciling is also tackled in the last article of this special section. Monika Kujawska underlines the complexity of the medical landscape of the Ashaninka people from the Peruvian Amazon and examines the coexistence of biomedicine and indigenous medicine within the area of women's reproductive health. Her analysis presents the Ashaninka as a resilient society that preserve their traditional practices connected with childbirth and birth control and at the same time adopt elements of biomedical knowledge.

This collection is intended to give the readers an insight into the main subjects and areas of research for Polish medical anthropologists, which are compatible with the contemporary studies of world medical anthropology. At the same time, it attests to the development of this anthropological sub-discipline in our country.

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THE HORMONE OF GROWTH AND HOPE. THE CASE OF TURNER SYNDROME

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Turner Syndrome (TS) is a condition that affects only girls and women and involves a partial or complete absence of the X chromosome. It is a well recognized medical condition and a multidimensional cultural fact that has appeared in specific historical, social and geographical contexts. TS is characterized by, among others, short stature, and ovarian failure. Girls with TS are put on estrogen replacement therapy and growth hormone treatment, which means a daily injection, starting at around 5 years of age or later and usually continuing until around 15. Without this treatment, girls suffering from it would be on average 20 cms shorter than women unaffected by it. In this text, I intend to look at the biosocial work of the growth hormone. I examine the purpose of it, and describe the work of hope being carried out in reference to hormone treatment. It is a technology, which is adaptable and flexible and from my perspective, hormones are "fluid objects". I present both the daily regimes and the regular biomedical controls taking place regarding GH treatment, describe the private and public histories of growth hormone therapy, and analyse an experience of the materiality of hormones, focusing on a pen injector device.

* * *

Zespół Turnera (TS) jest stanem, który dotyka jedynie dziewczynki i kobiety i obejmuje częściowy lub całkowity brak chromosomu X. Jest to uznana jednostka medyczna oraz równocześnie wielowymiarowy fakt kulturowy, który pojawia się w specyficznym kontekście historycznym, społecznym i geograficznym. TS charakteryzuje się między innymi niskim wzrostem i niewydolnością jajników. Dziewczęta z TS są poddawane estrogenowej terapii zastępczej i leczeniu hormonem wzrostu, co oznacza codzienną iniekcję, począwszy od około piątego roku życia lub nieco później, zwykle kontynuowane jest do około piętnastego roku życia. Bez tego leczenia dziewczynki z TS byłyby średnio o 20 cm niższe, niż kobiety bez TS.
W niniejszym artykule badam biosocjalną pracę hormonu wzrostu i jego cel. Prezentuję działanie nadziei związane z leczeniem hormonami. Jest to rodzaj technologii, którą można elastycznie dostosowywać. Z mojej perspektywy hormony są „obiektami płynnymi". Przedstawiam codzienne reżimy i regularne kontrole biomedyczne podyktowane leczeniem hormonem wzrostu, opisuję prywatne i publiczne historie terapii tym hormonem oraz analizuję doświadczenie istotności hormonów, koncentrując się na urządzeniu do wstrzykiwania.

Keywords: growth hormone, Turner Syndrome, technology, materiality

TURNER SYNDROME, AN INTRODUCTION

Turner Syndrome (hereinafter referred to as TS) is a condition that affects only women and involves a partial or complete absence of the X chromosome. It is estimated that 1 in 2,000–2,500 people are born with TS in a population (Gawlik *et al.* 2013), which means that there are approximately 10,000 women and girls with this genetic disorder living in Poland. These data are only estimates as no national register of persons with TS exists in Poland.

Physical- trait- characteristics of TS include most often short stature (without hormonal therapy women with TS are on average 20 cm less in stature than those without TS[1]), low set ears, low posterior hairline, small fingernails as well as the possession of a flat, broad chest (Gravholt, ed. 2009; Kucharska 2019). From Wikipedia[2] and other websites from which many persons with TS have easy access to, it can be ascertained that women with TS can also have lymphedema (swelling) of the hands and feet as if a newborn, gonadal streak (underdeveloped gonadal structures that later become fibrotic), increased weight, obesity, shortened fourth metacarpal bone, small fingernails, characteristic facial features, a webbed neck from cystic hygroma in infancy, aortic valve stenosis, coarctation of the aorta, bicuspid aortic valve (most common in cardiac problems), a horseshoe kidney, visual impairments, ear infections and hearing loss, high waist-to-hip ratio (the hips are not much bigger than the waist), attention deficit hyperactivity disorder, nonverbal learning disabilities (problems with maths, social skills, and spatial relations) and pigmented moles[3]. The majority of girls with TS will not have all of these symptoms but they and their families will be exposed to this information on popular websites. Therefore, over the course of diagnosis and therapy, people will not only have to face particular physical and psychological problems (Skuse 2009, Lagrou *et al.* 2006) but also something I would like to call – the effect of monsterization (see Radkowska-Walkowicz 2012 in the context of IVF children). Based on information and illustrations available online in regards to TS, the image which emerges is that of a disfigured, aesthetically non-normative person which is ungrounded in reality. In my research[4], on which more below, I have met with many

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[1] The first randomized research from 2005 demonstrated that the final height of girls treated with the growth hormone over a period of 5.7 years was 7.3 (5.7 years was 7.3 cms)cm more than those from the control group (Gawlik *et al.* 2013, 59).

[2] Wikipedia is not given here as a source of my knowledge about TS. The reference to this worldwide used encyclopedia indicates which TS image is being built through the most popular sources of knowledge, to which also persons with TS have access.

[3] See: https://en.wikipedia.org/wiki/Turner_syndrome. Access: 10.02.2019.

[4] **Acknowledgment:** I would like to thank Małgorzata Rajtar, Anna Krawczak, Ewa Maciejewska-Mroczek, and Maria Reimann for inspiring discussions, mutual support, and collaboration on the project. I am particularly grateful to all girls and women with TS, their families, and physicians who

girls and women with TS who were not physically disfigured. They were just like the rest of us – women who do not bear the stigma of a genetic disorder. In fact, many of them were taller than me.

One of the most stiking symptoms of TS is gonadal dysgenesis, in which supplementation of the female sex hormone is needed. Estrogen therapy is usually introduced around the age of 12 (Gawlik *et al.* 2013). To minimize the unfavorable effects of estrogen on long bone-growth, growth hormone therapy is simultaneously undertaken, beginning as early as just a few years of age, providing the patient was diagnosed early enough. One of the major problems for women with TS and their families, which has become apparent through conversations with people affected by the syndrome (affected directly or through the illness of their daughter), is infertility (Sutton *et al.* 2005; Świątkiewicz-Mośny 2010).

It is important to note that TS does not affect intellectual capabilities and only a small fraction of people with TS have some intellectual dysfunctions or learning disabilities (Kastrup 2009; Teilmann *et al.* 2009; Skuse 2009; Hong *et al.* 2009). However, psychologists have pointed out some psychological characteristics typical of people with TS, although they do not necessarily affect everyone (Skuse 2009). These include: ADHD or ADD in childhood and behaviour on the autism spectrum in adolescence and adulthood. Katrien Lagrou (2017) also speaks of low self-esteem as well as some emotional and social immaturity.

TS became undoubtedly a multidimensional cultural fact that has appeared in specific historical, social and geographical contexts. It manifests itself in bodies that become entangled in certain social concepts concerning issues such as gender, body, biology and ways of moving and expressing oneself. It is as much a biological phenomenon as a cultural one. Moreover, TS can be seen as a lens, through which one can look at various social phenomena, such as education, womanhood, medicalization etc. TS also challenges anthropology and its key dichotomies, including nature-culture, essentialism-constructivism, nature-nurture, and body-mind.

METHODS

In this article, I would like to look at the biosocial work of the growth hormone, one of the most important actors in the lives of TS girls and their parents. My main research questions are: What is the purpose of the action and giving of growth hormone? What is its social role?

agreed to participate in this project. The research is funded by the Polish Ministry of Science and Higher Education/National Program for the Development of Humanities (grant No.: 2bH 15 0137 83).

The research presented here is conducted as part of a Turner Syndrome research project: *Socialization patterns and the management of the embodiment in chronic disease. An interdisciplinary approach*[5] by scholars associated with the Childhood Studies Interdisciplinary Research Team, University of Warsaw. Our research includes TS women as well as their families and specialists who work with them, such as nurses and doctors as well as activists involved in TS support groups. The main tools that were used are classical anthropological methods which include in-depth interviews and participant observation. In situations where our subjects are children (girls with TS), depending on the interviewee's age methods that were more age-appropriate were used (see Maciejewska-Mroczek 2018). Additionally, we participated in summer camps and other activities organized for girls with TS. Our research is based on multi-sited ethnography (Marcus 1995), in which we not only examine the phenomenon as a complex network of dependencies, but also try to see its connections with other phenomena. Discourse in regards to TS was analyzed, all the while observing Marcus' postulate to be mindful of where a subject may take the researcher and be ready to follow. Analysis was also conducted of websites related to TS, press articles about TS as well as mentions of it on TV and in film.

In reference to this article, particular significance must be attributed to the in-depth ethnographic interviews with 21 people with TS, 10 physicians working with people with TS and 19 TS girls' parents which were conducted. Participant observations were made during training sessions for TS girls and their parents on the administration of the growth hormone, meetings of the Coordinating Team supervising the use of the growth hormone (which decides when to induct a patient into hormone therapy), as well as three summer camps organized by the Warsaw office of the Turner Syndrome Patients Support Society for girls with TS.

As many researchers were involved in the project, investigator triangulation was used (Denzin 2006). This did not mean only a division of labour, but rather a systematic comparison of the findings and results of research, and exploring how different researchers influenced the field. All collected materials were shared among the research team members. Our findings were presented and discussed during team seminars, organized every week. Data from different sources – including in-depth interviews, semi-structured interviews, participant observation, and discourse analysis – was triangulated.

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[5] The research is funded by the Polish Ministry of Science and Higher Education/National Program for the Development of Humanities (grant No.: 2bH 15 0137 83). The research is conducted by M. Radkowska-Walkowicz (PI), A. Krawczak, E. Maciejewska-Mroczek, M. Rajtar, M. Reimann.

THEORETICAL BACKGROUND

The starting point of my research is constructionist theory indicating the social dimension of illness and corporeality. From this perspective, hormones are constructed in social relations, and in discursive acts. As social actors, hormones affect the girls with TS in indirect ways, via language and social constructions. However, in my research, the biological and medical dimensions of hormones' work are very important, too. Thus, while still appreciating the value of social constructionism as a theoretical orientation, I propose to perceive TS and hormones in accordance with the paradigm of new studies on materiality (e.g. Barad 2007, Coole and Frost 2010), which emphasize the role of objects in the social structure of the world. They state the need to address objects, including human bodies as well as parts or substances belonging to them, as important actors, thus moving away from a language-centric perception of reality. It is not all about naively returning to deterministic concepts of existence. As Sari Irni indicates:

> "According to the new materialists, what is needed is a new account of biology, which understands it as actively producing variations in society, instead of merely linking it to the notion and critique of biological determinism" (Irni 2013, 41–42).

In this context, TS becomes a multidimensional experience of the body and language, an action of hormones and the gazes of other people. It is a chromosomal, hormonal and social phenomenon. Although I emphasize the social nature of disability, illness, and bodily condition, I underline the biological significance. Thus, it can be seen that TS is a bodily-social phenomenon and a biopsychosocial reality. However, I am not set on treating biology solely as an external fact but rather as a certain entanglement in social processes. What is social can provoke the biological and the biological, in turn, affects social positions (Irni 2013; Roberts 2007).

ON HORMONES

The concept of hormones as a substance regulating physiological processes was developed at the beginning of the 20th century (Tata 2005). It was fundamental in changing the way of thinking about human beings and the way their bodies function (Medvei 1982). In the 1920s, hormones became the fundamental chemical signaling agent, and endocrinology became an important scientific field. Hormones, as such, have had quite a successful career in the 20th century. In fact, Ilana Lowy calls the 1920s, 30s and 40s "the age of hormones" (2019) and compares their significance to that of genes at the beginning of the 21st century. It is my belief that along with genes, hormones can be considered the most significant biosocial agent that has decisive power over our bodies, social relations, our place in the world and happiness. What is more, from an anthropological point of view, hormones are far more interesting than genes. Although genes are perceived as a solid determinant, they are unchangeable and non negotiable (Le Breton 2004) whereas hormones are "fluid objects" (Sanabria 2016; de Laet and Mol 2000) that allow human interference. Genes are stable while hormones have incredible mobility. They are responsible for sex differences (Roberts 2007), for mood and behaviour. They exceed the boundaries of body where they behave in a particular manner and for example find their way into the water supply. They induce particular actions and moral panic connected with the levels of estrogen in the water supply, which is said to decrease sperm quality. But hormones are also the world's resident boogeyman. Chicken meat is full of hormones, which is supposed to accelerate puberty – leading to another moral panic connected with premature puberty serving as another proof of hormones' fluidity, their unbridled and "excessive" behavior (Roberts 2015). Hormones are thus complicated and complex biosocial elements where they are a material and discursive component of the biosocial universe (Barad 2007).

There are many mentions of sex hormones in literature, particularly in feminist literature. Researchers have noted their role in gender differentiation. Celia Roberts has dubbed them the "messengers of sex" (Roberts 2007). This is very apparent in Turner Syndrome when femininity becomes questioned – one X chromosome is missing and estrogen is required to supplement it. The aim is to turn girls into women and induce a monthly blood flow out of childish, unformed and gender unspecified bodies (Radkowska-Walkowicz 2019).

We can definitely read less about the growth hormone (hereinafter GH), whose journey and mobility follow different paths than those of sex hormones. From being prescribed to short statured girls and boys hormones have found their way to bodybuilders who, today, are the main customers in the GH trade. But in either case they operate in the field of aesthetic perceptions. They serve notions of beauty and wellbeing which may be subjective but have become prescriptive in culture to varying degrees.

RECOMBINANT HUMAN GROWTH HORMONE. A HISTORY

Human GH therapy began in the late 1950s. At first, the hormone was obtained through autopsies from a cadaver's pituitary glands. It turned out however that this process carried the risk of Creutzfeldt-Jakob disease and a search for new solutions ensued. In the early 1990s, the production of the recombinant human growth hormone (RhGH) began in laboratories employing genetic engineering methods (Ayyar 2011). The availability of using growth hormone therapy has helped patients with variying short stature problems, including girls with TS. According to our research, those, who due to time or economic restraints, were not able to benefit from GH therapy, believe that their lives could have been different had they received the hormone. They attribute many of their failures to short stature. Ewa, who was interviewed by Maria Reimann, one of the researchers on our team, is certain that her height has caused discrimination at work and is preventing her from living a happy life:

> "Short height, I am 136 cm tall and a friend of mine is about the same, 140 cm max, this is the average if you don't receive GH treatments. And well… that's how it is… we don't get a disability benefit, you need to work, to make a living, employers stare at you from the beginning… even if they don't say anything it's obvious what's going on and they don't want to hire us. Or then the things they say. I'll never forget, I haven't even entered the room properly yet and they go "but you're too short, if we had known how short you were we would've never called (…) so it's obvious we won't hire a little person. We'll take someone taller. Why hire someone little when you can take someone… prettier, no, taller. And that's how it is".

Short stature becomes crucial in how people define themselves. It is a cause for stigmatization and self-stigmatization. Maria Świątkiewicz-Mośny was right (2010) when she wrote about stigmatized identity in this context.

The beginning of GH therapy often changes the lives of people with TS a lot. According to the mother of an adult woman with TS, receiving GH was:

> "You know, like a trip to the moon, a trip to the moon. You can't describe it in any other terms, it was simply a trip to the moon".

Starting GH therapy can become a turning point in people'spersonal history. In most cases, it is a positive event and although the first shots may come with a variety of fears such as the fear of side effects as well as fear of the skin being punctured along with a child's or caregiver's fear of pain; they are also accompanied by hope. In addition, this marks the beginning of something that in the individual's private history of the disease can be considered as the onset of treatment of TS (which of course cannot be cured, as it is a genetic disorder).

The growth hormone, like most medical technologies, is a tool of hope. It allows people to believe that what is commonly referred to as "normality" (see Rajtar 2019) is within reach – although, as it turns out, it is not the only factor. At the same time it denotes another success story in the history of medicine. This means of hope makes it harder to deal with the costs that may arise during therapy. This is what happened in Marta's[6] story according to her mom:

> "Well, then it started (…) our daughter wasn't diagnosed with TS until she was 12. And that's when the whole procedure started and she was given that growth hormone (…) And it was such a shock to the system, I mean she started developing very quickly, when she transformed from a girl's body into a woman's body, developed curves, breasts, everything. She transformed from a little girl into a woman, although I think it was some kind of a shock to her body. I just don't know, a dose of estrogen and the growth hormone – in that year Marta's grades just plummeted. Not that she stopped studying,

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[6] All names have been changed.

> it's just that her potential… It's as though she was unable to take anything in. Psychological changes also appeared, she developed (…) an obsessive-compulsive disorder (…) it was as though I was unable to reach her. […] and Marta ended up in hospital for 10 months of therapy".

Personal stories are always immersed in economic and historical-political contexts. Maria's mother told Ewa Maciejewska-Mroczek from my research team about her search for a therapy for her daughter which became interestingly intertwined with the process of political transformation:

> "Just imagine, we were after transformation [after the fall of communism] and pharmaceutical companies were rushing into Poland and one of these aforementioned pharmaceutical companies was giving away GH for four patients with TS".

At first, she managed to get her daughter into a yearly GH treatment program. When that supply ended, she got lucky again as there were a tiny number of cases of mushroom-consumption related poisoning among children for whom there was a reserve of GH – as she told us – and there was enough GH for her daughter for another six months. When it seemed that the therapy would have to come to an end, the family received support from a German foundation. Working in the West, Maria's mom was able to earn money for more growth hormone injections.

> "I did not get the hormone but a promise of money, as it was possible to buy GH at the Children's Health Memorial Institute. I received 300 million Polish zloty. I packed it into a plastic bag, took my then-partner as security and said'let's go'. I withdrew the money from the cash desk at the embassy and we went to the Institute to make the payment. And of course there was a little cashier window with a female cashier and I just pushed the bag towards her and said: 'here you go, that's 300 million for the growth hormone'. She licked her finger and started counting. Everything was in order. That was back when a cashier would take a pencil and write out 'deposit accepted' on a small strip of paper and she wrote down that she accepted 300 million Polish zloty because I needed to have proof that the money went where it was supposed to go".

A turning point occurred in 2000 when the Ministry of Health began to reimburse growth hormone therapy for girls with Turner Syndrome in Poland who fulfilled clearly defined clinical criteria (Świątkiewicz-Mośny 2010).

THE MATERIALITY OF THE RECOMBINANT HUMAN GROWTH HORMONE

A plastic bag filled with money serves to demonstrate that the success of GH can be attributed to many agents, human and non-human. Apart from people who work in labs, there are also the mothers, their bodies and the finance involved. Nowadays the therapy is reimbursed, someone else is busy carrying bags filled with money and the very existence of these bags is questionable today. Other forms of tangible objects are important today, such as the stack of papers and documents that need to be handed in to the Coordinating Team Committee on Growth Hormone Treatment at the Children's Health Memorial Institute in Warsaw. Details which need to include personal contact information, precise biomedical measurements, family history and pregnancy history, all which need to be supplied in a standardized request form submitted to the committee:

> "Applications that do not at least contain a karyotype description, TSH, fT4, and IGF-I levels, carbohydrate metabolism evaluation, as well as x-rays for bone age assessment, cardiovascular, abdominal and pelvic imaging and growth charts will not be considered"[7].

However, when the requirements put forth by the Commission for the future beneficiaries of the GH are met, a daily routine begins, marked by regular injections into various body parts. GH must be stored in a fridge and injected every night in a very specific manner which is taught at the hospital. Every three months the patient reports for follow-up visits where the doctors take precise body measurements, particularly height. Hormone levels are verified and most importantly, empty GH ampoules will be counted and a new dose will be issued for the following months. In order for the therapy to continue, the body must be responding to the hormone (it needs to grow).

Each shot for our respondents and their parents represents hope for additional millimetres in height. And it would seem that every millimetre is of utmost importance. Despite the absence of unambiguous indications that it can be of therapeutic significance, some parents keep their daughters at home from school trips, even two-day ones, if there is the slightest doubt that the administration of the hormone could become a problem. Others try special diets. The parents that we met during our research were much more detailed in carrying ou the therapy than the doctors, although doctor informed us about many patients who did not follow their recommendations. Perhaps, that is why a doctor who was instructing a daughter and her mother in one of the hospitals emphasized the possibility of stopping the injections for a short period of time. In a note from another observed training I wrote:

> "It seems that doctor gives a little less information about side effects, but some still are noticed. Everything is OK. There's mention of school trips but Dr. X is focusing on saying that it's worth considering if they ought to be missed. Sometimes people need to consider if going somewhere is more important socially than hormone injections. But it can't happen too often. It is important to take the doses. The doctor isn't talking much about access to a fridge and the things which can be organized. According to the doctor it all boils down to either injecting or going on a trip".

Some of our respondents never went anywhere. Others always did. Teenager Mariola, who could never imagine missing a dose, went on school trips but hid the fact that

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[7] The application is available here: http://hormonwzrostu.czd.pl/index.php?option=com_content&view=article&id=99&Itemid=79. Access: 10.09.2019.

she needed to take injections from her peers. She did not reveal her illness. In another case, described below, the opposite happened where the illness was hidden by being in plain sight. Nonetheless, today the hormone is far less visible as its tangibility and bio-medical origin are hidden away in an injection pen. Ewa Maciejewska-Mroczek wrote in a note from a summer camp:

> “We are talking to Ewa about heating the pen, something I heard about from Justyna, Iga’s mother, in that it should be removed from the fridge sometime before the injection. Ewa says this is one of the new myths about administering GH, which wasn’t around back in her days. She talks about ‘her days’ a little and how she started out with normal syringes with a long needle, then a shorter needle. She recalled that for some time there was an awkward needle free device that pushed the hormone through the skin using high pressure (it caused nothing but problems and she failed to administer properly a dose three times). Lastly she had an injection pen, much like the ones being used on this trip”.

The transition from a thick-needle and a syringe to a delicate injection pen, just as in the case of other medical technologies, can be described as a process of miniaturization, normalization, obscuring/concealing[8] and blurring the boundaries between technology and the body and its everyday reality. Something crass and bulky (emphasized by Maria’s mom in her story about a plastic bag and thick needles) transforms into something more delicate. A wad of cash has turned into a transfer of information and medical documents. From obtaining the hormone from pituitary glands of cadavers we have moved on to recombinant DNA in a lab employing specialised genetic engineering.

Pen injector case (photo: E. Maciejewska-Mroczek)

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[8] Of course not always does the shift occur from the visible to invisible: estrogen tablets are increasingly frequently replaced with patches and therefore a great example that sometimes the opposite happens.

A thick needle has been replaced with a thin needle. A syringe has been replaced with an injection pen that hides the fact that it represents medical technology at all.

The young patients that we have met during our research, are following the intuition of pen and growth hormone producers, who know that daily entanglement in medical procedures should be habituated. Hence, injection covers are decorated in pink unicorns, hearts and cats (see photo 1). Technology, according to the cover of a well-known book *Care in Practice: On Tinkering in Clinics, Homes and Farms* (Mol *at al.* 2010), is not the opposite of care. It "is not cast as a functional tool, easy to control – it is shifting, changing, surprising and adaptable".

HEIGHT

Growth is a key issue in Turner Syndrome, which in itself is incredibly interesting. Some other symptoms of the syndrome become socially invisible, while others play no significant role in the personal and public stories of the patients. The issue of height and growth hormone therapy in nearly all forms of communication – be it Wikipedia, medical textbooks or personal stories – is key and appears centre stage. Nowadays somatotropin therapy is able to provide girls with a height that is often close to average. Nonetheless "low" height is still prevalent and is perceived as the main problem of people with TS. One of our interlocutors said:

> "It was apparent that at first the only thing I really knew about the Syndrome was that I will be short! And that I will need to take growth hormones. That was the knowledge I started out with. My parents explained something about it by stating that there was something wrong with my genes".

Anna Krawczak, from my research team writes:

> "Interestingly, despite these fundamental clinical and social variables, the theme of height in their narratives remains just as important as in conversations with women with short stature. The danger of short height – actual or internalised is the fear of a prophecy that may come true – which constantly appears in the girls' narratives (…). Getting the girls and teens accustomed to the issue of short stature is a significant part of pamphlets and studies by patient support organizations although since 2000 supplementary therapy covers each short statured girl with TS. The parents of girls who receive GH supplementation raise concerns about their daughters' short stature and their future in the context of physical dissimilarity" (Krawczak, forthcoming).

People with TS are often perceived as out of place to some degree. Too short, too small, initially too fast, then – during puberty – too slow. One of the mothers told us about her now adult daughter:

> "She has these little legs and weaker muscles. Aside from that, her legs are so short. Her body is not entirely proportional. She has long arms, a long body and quite short legs".

Some of our interlocutors find this peculiarity difficult to identify. It is not always apparent whether this peculiarity really pertains to differences in the behavior of TS girls and women or whether it is a reflection of complicated relations where family, biomedicine, school and social expectations towards women's bodies all meet.

Małgorzata Rajtar has noted:

> "It turns out that the use of GH serves not only as an improvement on the metric scale but is rather a strategy for reaching a state of 'normalcy' which would allow for equality of treatment in social and professional relations and in effect, for instance, would increase people'schances of landing a job that matches their qualifications and to establish peer and romantic relations" (Rajtar 2019).

The main tool that supports the notion that it is necessary to grow is the growth chart. It is the dream tool of modern biopolitics and Foucauldian power-knowledge. It is a tool for disciplining parents and children alike and a way of controlling the human body through "unhuman biomedicine". Mothers are particularly disciplined in this case. They are trained to do this from the moment of childbirth – it is clearly visible when analysing the discourse and practices concerning the feeding of newborns (see Sachs *et al.* 2006; Radkowska-Walkowicz 2014). A child's weight and height projected onto a relevant chart have become an indicator of good or not good enough motherhood.

SECRETS AND UNDERSTATEMENTS

And yet, the growth hormone which is supposed to satisfy the requirements of a growth chart can also be used for other purposes. Anna Krawczak (forthcoming) points out that this focus on growth is only part of broader processes concerning TS girls connected with infantilization and socialising to disability. In my opinion, another function of measuring height and the GH itself is more important in covering other problems. This is perfectly evident when we examine TS from the perspective of secrecy and furtiveness[9]. Girls are usually informed they have a genetic disorder called Turner Syndrome once they begin their growth hormone therapy. That is what happened in Klara's case:

> "[B:] Klara, do you remember how it happened? Did you even know what was happening then or were you too young?
> [R1:] Not really because no one wanted to tell me.
> [B:] Aha. Maybe at first your parents were protecting you a little from this information, no?
> [R:] Maybe yes, she didn't ask much, we didn't tell her much, there was no…
> [R1:] I only knew that I had to take some kind of shots and that's all I knew"
> (interview with an 18 year old and her mother).

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[9] I am referring here to an idea of Ewa Maciejewska-Mroczek, which was presented during a conference *Secrets, half-truths, understatements. What is said and what is left unsaid around children?*, Warsaw 2018.

At one of the summer camps, our researchers were observing relations between Justyna and Iga. The mother admitted about her five year old daughter:

> "Right now she sort of knows that something is going on but she doesn't really know what it's about, she doesn't know at all. She knows she's taking a hormone".

In her research journal Anna Krawczak describes the following situation:

> „'Iga, tell the lady what your biggest problem is'. I was surprised because from our conversation it transpired in no way am I interested in 'problems' or that I perceive TS as a problem. [...] Iga became embarrassed and hugged her mom and the question was repeated, again without the child reacting. Then the mother said 'Iga's biggest problem is her short height'".

The question of what to tell children with TS and when to tell them the truth about the illness is a recurring topic in our interviews. TS girls and women agree unequivocally that children should be informed as early as possible. Also, psychological research demonstrates that not informing children about their TS may have negative effects on their psychological development (Lagrou 2017). Still many parents choose to delay sharing this information. Paradoxically the growth hormone is an ally in this secrecy. Children find out they have to visit doctors and that they have to take shots due to their short stature. The problem of infertility and other possible setbacks resulting from TS as well as the fact that we are dealing with a genetic disorder are delayed in time by parental concerns. I agree with Anna Krawczak who writes:

> "The growth hormone helps to deal with the main visible distinguishing feature of this condition, while, at the same time, it does not require the use of dangerous terms such as: *Turner syndrome, genetic syndrome or illness, disorder.* However, this does have side effects. Together with the growth hormone, the girls' bodies are injected with fear of otherness and the conceptualization of this otherness, as symbolised by short stature".

But looking at how GH works in a social space, one also has to note that it changes daily habits and rituals. This daily regime includes the right injection time, the right injection location, correct storage of the hormone and ofempty ampoules. It is interesting that the responsibility is discreetly shifted onto the patient (or her mother) which is not surprising in the context of modern medical practices and the culture of individualism (Nowakowski 2015, 103–112; Jacyno 2007). I saw it clearly during growth hormone injection training.

> "A lot depends on you, girl – the doctor says convincingly. How much you'll benefit from it, is entirely up to you. The next two years are key, well the next year actually. You need to take this every day, before going to sleep. (...) I can tell from your mom's face that it won't be easy. I know, says the doctor, homework, etc. Yes, the mom confirms. But it is important. And she needs to fall asleep at 9:30 pm at the latest, explains the doctor. It's not just about the certain amount of hours of sleep required but also about going to sleep early and getting up late. It's important to be sound asleep before midnight. 'You grow when you sleep – it's been proven'. Period".

Therefore the final result depends on a person's response to what advanced medical technology has to offer. This technology, the growth hormone, is not external to the patient and her family. Positived results arise when accompanied by good care (Mol *et al.* 2010) and some self-discipline. In many contexts, the existence of this technology may also have negative social results, such as strengthening the belief in non-normality or even in the disability of short statured people (Murray 2008) as well as rare side effects the body experiences, something that is mentioned to the parents of children who are starting GH therapy and also during GH injection training. However, appropriate synchronization of technology and embodied person, technology and care leaves no space for discussion on the point of GH treatment as a body enhancement technology. As Linda F. Hogle points out:

> "Enhancements exist in a nexus of complex social, political, and historical relations, media representations, and medical and legal definitions of disorder and well-being." (Hogle 2005, 696; see Rajtar 2019).

Małgorzata Rajtar notes:

> "In striving for additional centimeters, which in fact represent an opportunity (perhaps an uncertain one) to live a fuller and more dignified life, ethical considerations, such as the inability of the little girls who undergo GH therapy to provide informed consent (…) and questioning the point of the therapy itself due to its duration and costs (Murray 2008) get pushed aside" (Rajtar 2019).

CONCLUSION

What then is the purpose of the growth hormone and what is its social role? It helps in the growing process, in positively responding to the requirements of growth charts and in meeting subjective perceived beauty standards. It can thus help in achieving what is subjectively defined as "normal". It also helps in avoiding discussing Turner Syndrome and redirecting everyone's attention to the issue of height. It also changes everyday habits, rituals and through the necessity of regular checkups it becomes a longer lasting presence in TS women's relationship with biomedicine. The growth hormone defines another success in the history of medicine and provides bio-ethicists with incentives to ask questions about the ethical side of therapy and body enhancement, while providing ethnographers with incentives to ignore it.

The growth hormone is the promise of a better future. It is also a tangible product that belongs to the body but has to be delivered from the outside. It is a fluid, mobile object, supporting various discourses and aspirations.

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SILENT SUBJECT: THE CHILD IN THE DEBATE ON ASSISTED REPRODUCTION IN POLAND

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This article explores the social construction of the "IVF child" in Poland. In this country where Catholicism is the dominant religion, attitudes towards in vitro fertilisation (IVF) and, more generally, assisted reproductive technologies (ARTs) are clearly mirroring and reproducing the nation's values. Based on official church teachings, the "IVF child" is a new subject of concern. Research conducted with children who were conceived in this manner proves that they are important actors, whose voices need to be included into the anthropological analysis of ARTs. The ways in which they articulate their understanding of ARTs shows both the pervasiveness of anti-IVF voices and the active roles children play in producing their own meanings.

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Artykuł dotyczy społecznego konstruktu „dziecka z in vitro" w Polsce. W kraju, gdzie katolicyzm jest dominującą religią, stosunek do zapłodnienia in vitro (IVF) i, szerzej, technologii wspomaganego rozrodu (ART), odwołuje się do wartości narodowych i reprodukuje je. W oficjalnym nauczaniu Kościoła stworzony zostaje nowy podmiot, „dziecko z in vitro". Badania z dziećmi, których przyjście na świat było możliwe dzięki pomocy medycyny, dowodzą, że są one ważnymi aktorami, których głosy powinny być brane pod uwagę w antropologicznych analizach ART. Sposoby, w jakie artykułują one swoje rozumienie ART, pokazują z jednej strony siłę głosów przeciwników IVF, a z drugiej – aktywną rolę dzieci, które tworzą własne znaczenia w tym obszarze.

Keywords: IVF, assisted reproduction, children, Poland

INTRODUCTION

Children take centre stage in regards to Polish debates on assisted reproduction. In public discourse, their existence is discussed, health scrutinised, best interest protected, and dignity respected. Social reality and the lives of children, however, are being neglected. The figure of "IVF child" is a juxtaposition of the way it is presented in Polish public debate and the way these children who come from families with histories of infertility, understand and negotiate their experiences.

In this article, I examine how the social image of the "IVF child" is constructed, contextualised and used in Poland. In addition, I unpack the set of values, norms and beliefs that are attributed to both Assisted Reproductive Technologies (hereinafter ARTs) and children and present how they are instrumentalised in public debate within a society that is predominantly Catholic. The number of Poles who attend religious services has consistently been decreasing, but 91,9% of Poles still declare themselves to be Catholic (*Życie religijne w Polsce* 2018). Moreover, 92.8% of all newborn children in Poland were baptised as Catholic (Mariański 2010). This means that membership of the Catholic Church is culturally significant, allowing this church to fill a very forceful position in Polish society. The power of the Church is also based on its institutional and material resources and connections with politicians at different governmental levels (Hall 2012).

In my efforts to understand the cultural forces shaping the current status of ARTs, I examine the main controversies fuelled by the official Catholic stance on reproductive technologies and the strong position of Catholic actors on the local political scene. I show how Catholic discourses have created the "IVF child" as a subject, which is both politically powerful as a concept and weak, muted (Ardener 2007) as a representative of a certain group.

Based on interviews and participatory research, I examine how discourses on IVF are negotiated and re-interpreted by the children themselves. Research with these children, who are rarely recognised as being among the main actors in the literature concerning ART, adds a new perspective to the anthropological understandings of assisted reproduction[1]. Including children's voices confirms how powerful the dominant discourses are, but also sheds light on the active roles being pursued by the young in their efforts to produce their own meanings. By exploring the connection between public discourse and children's narratives, this paper presents how Polish society's values are performed and reproduced (Weiner 1980).

CHILDREN IN ETHNOGRAPHY

This article is based on a larger multi-sited ethnographic project (Marcus 1995) entitled, "New Reproductive Technologies – a perspective of childhood studies"[2]. The ethnographic material for this part of the analysis comes from two types of sources.

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[1] With the development of ARTs, a new subject has emerged on the stage: a person who was born as a consequence of an embryo or gamete donation. However, donor-conceived child is analysed mainly in relation to third-party reproduction and its consequences for meanings of identity, kinship, etc. Although the subject of this paper may seem similar, my main focus is on those who are "IVF babies" in the national and religious context where assisted reproduction as a whole is widely debated and opposed.

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Firstly, texts from mainstream Polish media: newspapers, magazines and popular Internet portals are used. The main focus is on publications from the years 2007–2015. The second type of material comes from interviews with children and young people that were conducted in Poland between 2014 and 2016. The participants came from families who experienced infertility at some point, and most of them were conceived through ARTs. Participants were informed of the research aims using leaflets and web page information addressed to the children, as well as to the parents. Most of the interlocutors were from middle class families who had the financial wherewithal to afford expensive infertility treatment.

In this project, 29 children and young people (aged 5–28) from families who had experienced infertility took part. Participants were recruited mostly with the help of the Polish patients' organization, The Society for Fertility Treatment and Adoption Support 'Our Stork', along with assistance from personal contacts. Focus group discussions were organized in child-friendly spaces, suitable for private discussions. These were either children's homes, or a workshop space provided by a non-governmental organization in Warsaw. An ethics- committee permit was not required in regards of this research, but the researchers were extremely aware of the ethical dimensions involved and thus worked under a psychologist's supervision and adhered to the ethical rules as outlined in the Code of Good Practice in Social Research Involving Children (Maciejewska-Mroczek and Reimann 2017).

As we recruited children participants for our project, the research team's members encountered some methodological and ethical problems. We met criticism concerning the essentialisation of children who were conceived with IVF, ostensibly a reiteration of strategies used by IVF opponents in Poland. The contention was that these children are no different from others, who were not conceived without the help of IVF. However, comparison was by no means a focus of this study.

The research was conducted either in individual interviews, or, in most cases, group discussions. The latter method gave the participants an opportunity to share their experience with others with similar family histories. The presence of others, as methodological research suggests, facilitates the verbalisation of some problems through the process of sharing and moving from the personal to a more abstract level (Hennesy and Heary 2005; Hunleth 2011; Morgan *et al.* 2002). I was inspired by a broad body of literature in interdisciplinary childhood studies, especially by the view of children as active social actors, both in the research and in a broader social life (see for example Mayall 2008; Vaele 2005; O'Kane 2008; Gallacher and Gallagher 2008; on anthropological research with children Hardman 2001; James 2007). I was also influenced by feminist participatory research, with its "openness, reciprocity, mutual disclosure" (Reinharz 1992, 181). The idea of the research grew out of the concern that current anthropology is entitled and in a way obliged to give voice to the voiceless and marginalised, which obviously is the case for children, especially those who were intended participants.

This approach was inspired by the adamant stance taken by Nancy Shepher-Hughes (2004), who shows how this perspective is important especially in research conducted within the area of medicine.

In my research, children became not objects, but subjects of inquiry and their experiences and viewpoints produced valuable knowledge. According to Nick Lee (2005), most data about children's well-being comes from majoritarian knowledge, and insights from children, who have experiences differing from those of adults, are seen as pathological. In this context, it is important to acknowledge children as a social group which as a whole can be treated as a minority group (James, Jenks and Prout 1998), deprived of the position of active social participants (Jans 2004).

Of special concern was the methodology. Although anthropology has never limited its sources of knowledge to the verbal or discursive, research with children needs some new methodological approaches, shifting the focus from "what was said" to various modes of non-verbal expression. This is due to children's specific characteristics of interaction, related to their narrative skills, their position in society, and their special competencies, which are not equal to those of adults (Alderson and Morrow 2011; Christensen and James 2008; Emond 2005). Thus methods employed in the research were designed in a manner that would facilitate communication, such as making use of drawings, collages, playing with Lego figures, photography, and film-making.

Children's input into the social construction of debate on IVF is not recognised in Poland. Their voices may, however, throw a new light on the relationship between moral and religious concepts, revealed through the formation of the "IVF child" in the public debate Analysis of what they know and how they talk, draw or play about assisted reproduction (which is a part of their family history) may unveil the power of certain discourses and show how they are embraced, opposed or negotiated.

IVF AND CHILDREN IN POLAND: HISTORICAL, POLITICAL AND LEGAL ASPECTS

In order to better understand how the subject of the "IVF child" is produced and used in Polish debate, this concept needs to be embedded in the wider historical, political and legal context of ARTs in Poland (see Radkowska-Walkowicz 2014; Mishtal 2015). As Magdalena Radkowska-Walkowicz notes,

> "To understand the current debate on IVF in Poland it is necessary to place it in the wider context of Polish transition after 1989. And in turn, to understand the Polish transition to democracy it is helpful to follow the Polish debate on reproductive rights and health" (Radkowska-Walkowicz 2014, 2).

The roots of contemporary Polish debates on IVF can be traced back further than the transformation of 1989. According to Andrzej Leder (2014), it was in the late communist era, the late 1970's and 1980's, when a conservative-liberal alliance was established. Because of extensive support for anti-communist movements given by the Catholic Church, the victory of the anti-communist opposition in 1989 can also be seen as a victory for the Church, which took an active role in shaping the young state's political agenda. As Leder writes, the "cultural capitulation" of the left took place, which opened the way for a situation in which the Catholic thought gained a quasi-monopoly in the naming major moral dilemmas (Leder 2014, 187).

One of key issues in the country was assisted reproduction. In the first years of the new political order, assisted reproduction was not discussed in the same manner as other reproductive rights. Controversies appeared in the public arena gradually, with a significant rise in 2007, when the Minister of Health proposed funding for in vitro fertilisations, which are not included in the national health insurance system. ARTs were available for and used by those who could afford the very costly treatment. The situation changed when the Ministry of Health introduced a special program for the years 2013–16, in which three IVF procedures were funded by the state for couples that fulfilled a number of specific social and medical requirements. In 2014, another special program, for the funding of medicines used in ART procedures, was introduced. State-funded procedures were realised in both private and public clinics until 2016. The new conservative government, which came to power in 2015, withdrew state funding for ARTs. Presently, some local municipalities provide IVF funding, but the scope of this support is very limited. Funding is only one of the areas, in which the state intervenes in the domain of ARTs. Another key involvement of the state is in the regulation of the law concerning ART.

The medical procedures of ARTs usually precede their legal regulation (Pashigian 2012). Regulations are created in accordance with local values and institutional processes (Banchoff 2011). This also holds true for Poland, but in a specific way. Unlike the situation in many other countries, for almost thirty years fertility treatment procedures were performed with no regulations concerning ARTs being in place. There was conflict over ARTs, which led to deadlock between the opposing sides. This eventually led to a situation where all assisted reproduction procedures were allowed without any external control or limitations.

In July 2015, the first law regulating assisted reproduction in Poland, the Fertility Treatment Act, was enacted. In its first article it states that the main goal of the Act is the protection of embryos. Its main organising principles are the primary position of the embryo with the state being a guarantor of order pertaining to all aspects of ARTs, the secrecy and anonymity of third party reproduction, the primacy of heterosexual couple over other forms of parenthood, and no recognition of infertility based on social grounds. Embryos are allowed to be cryopreserved and stored for 20 years. Their "right to life" is so primary that, if not used in this time, they must be donated to other couples. They are therefore attributed with personhood and viewed as vulnerable. Embryos are presented in this scenario as weak citizens in need of protection by the state, and the order of articles in the act suggests the primacy of embryo protection over protection of the patient, which is characteristic of countries where there is a strong Catholic influence on the law-making process (see Zanini 2011). In this respect the creation of an unborn is similar to that adopted in Polish abortion law, where a new type of "foetal personhood" of the "purest democrat" was created. This refers to a phenomenon widely present in the literature: a "construction of foetus as a privileged legal, medical, and cultural subject, and consequential disfranchisement, disembodiment, and marginalization of women" (Holc 2004, 758).

Under the Polish Fertility Treatment Act, only anonymous gamete/embryo donation is allowed, and very limited data on donors are collected; no extended profiles of donors are made available for the recipients. Also gamete donations between family members are not allowed. The new law imposes an obligation on the doctor to choose donors on the basis of phenotypical similarities to the receivers. The Act does not recognise in any way a child's right to information or the future parents' right to participate in the process of choosing gametes/embryos. The process of third-party reproduction is framed as a purely medical issue.

The legal framework for assisted reproduction in Poland is still unsettled. For many decades it was unregulated by the law, which led to the strengthening of ART service-providers, who could freely decide which procedures were acceptable and to be applied, and which were not. However, some provisions of a more general character were applicable to fertility treatment (for example the Patients' Bill of Rights and the Patients' Ombudsman Act). At the same time, a lively debate in the media on IVF was taking place, which had an influence on the legislative process. Representatives of the Catholic Church took part in this process, formally, through bioethical commissions and informally, through sermons, articles in the press, religion lessons at schools, and private connections. It also used its institutional power (Mishtal 2015). The final shape of the Fertility Treatment Act was presented in the media as being "liberal" or "far-reaching", with regard to the above-mentioned circumstances. However, the presidential and parliamentary elections of 2015 brought the Law and Justice Party (a conservative-nationalist party) to power, who declared some restrictions on IVF in their campaign. This situation shows the fragility of the status of ARTs in Polish law.

Another important dimension of the picture of the IVF child in Poland is social acceptance for fertility treatment. Large-scale national surveys have been conducted on Poles since 1995, which show that IVF has gained broad social approval: in 2015, 76 percent of people accepted in vitro fertilisation for married couples, while 62 percent did so for heterosexual unmarried couples (*Opinie o dopuszczalności*… 2015). The least accepted model was in vitro for single unmarried women, which gained the approval of 44 percent. These numbers were similar to previous editions of the survey and they are meaningful because they reveal certain inconsistencies. The rates of acceptance are relatively high, given the fact that Poland is a country where Catholicism is the dominant religion, the Catholic Church openly opposes IVF, and Catholic clergy and journalists hold great sway in public debate. At the same time, these figures reveal the upholding of traditional attitudes of Poles towards the model of family. The majority of Poles believe that children should be born into traditional families, formed by heterosexual couples, preferably married. The acceptance of IVF correlates negatively with attendance of religious services. Those who attend church several times a week are the only group in which a majority (57 percent) does not accept IVF even for married couples. But among those who attend church every week, only 20 percent oppose IVF. The model of the IVF child is then shaped in relation to two contradicting social phenomena: the widely known opposition to IVF of the Catholic Church and its broad approval by ordinary citizens (of whom most are also Catholic).

CONTESTING IVF, CONSTRUCTING A SILENT SUBJECT: THE CATHOLIC POSITION IN THE POLISH CONTEXT

A very strong Catholic position towards ARTs and the "IVF child" in Poland is to be found in the teachings of the Catholic Church and in the activities of its local representatives. It is based on official documents released by the Congregation of the Doctrine of the Faith and is rooted in Catholic tradition and theology. Its main line can be traced back to the debate over abortion that took place in the early 1970s. In 1974, the Congregation issued a *Declaration on Procured Abortion*, where it was directly stated that personhood is attributable as early as when the ovum is fertilized.

> "From the time that the ovum is fertilized, a life is begun which is neither that of the father nor of the mother, it is rather the life of a new human being with his own growth. It would never be made human if it were not human already"[3].

The notion of personhood and the dignity of an embryo, posed clearly in the context of abortion, was continued and reinforced when Catholic authorities were forced to react to the fast-developing reproductive technologies.

The basic document which expresses the Catholic stance on IVF is *Donum Vitae, The Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation,* issued in 1987 by the Congregation for the Doctrine of the Faith (*Donum Vitae*… 1987). In this document, in vitro fertilisation is compared to abortion, and presented as an outcome of "civilization of death", thus assisted reproduction is enmeshed into a broader range of problems with modernity. As written in *Donum Vitae*:

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[3] http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19741118_declaration-abortion_en.html. Access: 15.09.2015.

> “The facts recorded and the cold logic which links them must be taken into consideration for a moral judgment on IVF and ET (*in vitro* fertilization and embryo transfer): the abortion-mentality which has made this procedure possible thus leads, whether one wants it or not, to man’s domination over the life and death of his fellow human beings and can lead to a system of radical eugenics” (*Donum Vitae*… 1987).

The parallel between abortion and assisted reproduction is, however, not confined to Catholic theology, but may also be seen as a pattern that is employed in different social, national and religious contexts (Banchoff 2011). In the case of Poland, however, this parallel results in the creation of a silent subject, the IVF child – innocent survivor of the Holocaust of embryos and at the same time a threat to the social order.

The ideological basis for all judgments of ARTs is the idea of marriage being the sole space for the creation of new life, and sexual intercourse within marriage as the only legitimate way to conceive. In Catholic bioethical discourse, the separation of conception from a physical “conjugal union” is defined as the “pathology of family life”, caused by “false prompts coming from the field of science” (Wojaczek 2011). Unlike in some other socio-religious contexts (see for example Kahn 2000, on Judaism, or Garmaroudi Naef 2012, on Shia Islam), Catholic thought understands sexual intercourse as essential in the process of family-making, and its lack thereof is a crucial argument against the permissibility of assisted reproduction. Concerned about the violation of this rule, IVF is presented not as an act of creation, but of destruction. Being an act against God’s and nature’s laws, it destroys family ties. This is defined in terms of children’s rights. As the authors of *Donum Vitae* claim,

> “The child has the right to be conceived, carried in the womb, brought into the world and brought up within marriage: it is through the secure and recognized relationship to his own parents that the child can discover his own identity and achieve his own proper human development. The parents find in their child a confirmation and completion of their reciprocal self-giving: the child is the living image of their love, the permanent sign of their conjugal union, the living and indissoluble concrete expression of their paternity and maternity. By reason of the vocation and social responsibilities of the person, the good of the children and of the parents contributes to the good of civil society; the vitality and stability of society require that children come into the world within a family and that the family be firmly based on marriage” (*Donum Vitae*… 1987).

Thus, according to this document, the appropriate model of conception is through sexual intercourse in a married couple, because this is the only model that allows for the child to be a sign of “reciprocal self-giving” of the couple. Alternatives of this model allegedly pose a serious threat to the social order. In the case of “IVF children”, the category of best interest is used: if IVF is destructive, it is considered in the best interest of the child not to be born with the help of ARTs. This implies yet another paradox, which is it is in the best interest of the child not to be born at all. This shows the vagueness of the notion of a child’s best interest, which is socially constructed in such a manner allowing different actors to use the term to suit their own purposes (Monk 2008; Stainton Rogers

2008). ARTs are therefore presented as posing a risk to one of the most important of modern values: the protection and well-being of the child. Allison James and Adrian James show that the notion of risk, when defined as natural in relation to a certain group (for example young people), allows control to be exercised over this group (James and James 2008). In the aforementioned context this concept is well applicable, as defining in vitro fertilisation as a "natural" risk to a family, is an endeavour to exercise control over modern people in society where traditional family patterns are collapsing.

The conceptualisations expressed throughout *Donum Vitae* and other official Vatican documents are in force for Catholics worldwide. What seems unique in the Polish context is the fact that a substantial number of politicians support anti-ARTs views. It is Catholic-affiliated politicians in Poland's aim to enforce the implementation of bioethical regulations with the ultimate goal of either banning IVF in its entirety, or restricting access to ARTs. Paradoxically, despite the strong acceptance of IVF in Poland, the anti-IVF side is very influential in public debate. The bishops of the Catholic Church are very powerful actors, and regularly raise assisted reproduction. This mechanism is in line with an overall model of Polish Catholicism. Despite a high rate of affiliation, a substantial portion of Poles is not religious in terms of practices and worldviews. This is why, in order to exercise control over reproduction and families, Polish Catholic authorities concentrate their efforts on trying to influence policymaking from the top down, including shaping the public discourse on ARTs. Although there are exceptions in this language of disapproval for ARTs, the message from the local Catholic authorities against assisted reproduction is clear. This message finds further realisation in conservative journalism, in Internet communication, and anti-IVF activism.

OF BARRELS AND DEWAR FLASKS: A "TEST-TUBE CHILD" IN THE ANTI-IVF DISCOURSE

The Polish debate on IVF in recent years has become more and more heated. It has also gained rising attention in scholarship (Radkowska-Walkowicz 2012, 2013; Krawczak 2014; Korolczuk 2011; Mishtal 2015). I focus here on the "IVF child", who in my opinion is created as distinct, but muted subject. In accordance with other scholars, I regard this process as part of a broader political project, pursued by conservative politicians and supported by high-ranking clergy. In order to gain the political goal, that is maintaining the Polish nation's attachment to "traditional" values, various strategies are being employed in shaping the public debate. Most of them are believed to be workable because they are embedded in the nation's moral agenda.

A somehow dramatic passage, written by Tomasz Terlikowski, an influential Catholic-affiliated journalist, recounts the story of a woman who was born from a donated embryo:

> "She's aware of the fact that she, unlike thousands of children, who still are kept in barrels, was given a chance to survive and she's aware of the fact that she, unlike her genetic siblings, was given the opportunity to live her life. (…) It is worth noting that the girl was saved by her parents from the big barrels with liquid nitrogen, to which she was sentenced to un-death and un-life by her genetic parents and doctors. Her parents decided to rescue her and give her love and acceptance, but still she feels she's been rejected" (Terlikowski 2014).

According to the author, the woman has undergone some serious psychological problems, related to the history of her conception, as she feels rejected by her genetic parents. The emotional and powerful language found in this text is a good example of how the debate on assisted reproduction is being shaped nowadays in Poland.

To understand the actual meaning of the above-cited fragment, it is necessary to know about a case that happened in Poland in 2012. In a small village, the Police found the bodies of six dead newborns. Further investigation proved that the perpetrator of the crime was their mother, then a 41-year old woman, who hid the bodies in plastic barrels. She was described in the press as an uneducated alcoholic, with poor moral standards and diagnosed as having a psychopathic personality. "Children in barrels" became a symbol of the harm caused to innocent children, adult moral deprivation and degradation, as well as the weakness of the state (the family was allegedly under the supervision of social services). This symbol soon started to be used as a widely recognised idiom.

The history of this case throws new light on the story about frozen embryos evoked by Terlikowski, which were also kept in barrels. In fertility clinics, embryos are cryopreserved in dewar flasks which are barrel-shaped containers with liquid nitrogen. In Terlikowski's narrative, no distinction is made between embryo and child, therefore embryos are also "babies in barrels". This rhetorical trick creates an association between notions of degradation and deprivation from "babies in barrels" to cryopreserved embryos in dewar flasks. It also shows them as innocent and vulnerable, needing of rescue, which is the typical conceptualisation of an embryo used in Polish conservative discourse (Krawczak 2014). The representation of "babies in barrels" is used in relation to IVF embryos, thus attributes to the latter characteristics of being innocent and deprived human beings.

Another strategy employed by IVF opponents is their dehumanisation of IVF children and their parents by equating them to animals, especially cattle, and comparing the procedure to veterinarian ones. The fact that embryology is rooted in veterinarian medicine is a widely used argument against IVF in Poland. This concept finds further development on the internet: one popular meme presents a cow, photographed from the back, with the inscription: "I have had a child from in vitro. A cow-specialist insemination did it". The word "did" is used here and in many other anti-IVF narratives in order to strengthen the concept of the dehumanisation of the process.

In relation to parents, anti-consumerist language is used, in which infertile couples are depicted as consumers, who shop for a child, similar to the way they would purchase goods in a supermarket. This reification views IVF children as products to be bought and sold. A good case in point is a widely cited and broadly discussed interview conducted with one of the key bishops in Poland, Tadeusz Pieronek, who deemed IVF to be an exclusively mercantile transaction: "love is not expressed at the counter of a shop". This and other similar statements relate to anxieties evoked by the separation of sexual and reproductive activities, as well as adding a mercantile aspect to the process of procreation (Kahn 2000). The shape of these anxieties manifests itself in blaming parents for improper way of conceiving, which is against the dignity of the child.

When this side of the debate employs biomedical language, it does so in order to portray IVF children as monster-like. Possible malformations are mentioned as the probable outcomes of assisted reproduction, and are presented in an exaggerated, "monstrous" way. Bishop Pieronek made a famous statement: "What is the literary representation of Frankenstein, a creature brought to life against nature, if not a prototype of in vitro?" (*Pierwowzorem…* 2009). This, as Radkowska-Walkowicz notes, is in line with the role of monsters in culture in general. They are seen as the result of sin or a bad omen. She sees the figure of Frankenstein as

> "a reference point in today's debate over biotechnology, especially new reproductive technology. So it is not without reason that Frankenstein's creature appears in debates on IVF in Poland. It is invoked to express fears of biotechnology and support the argumentation of its opponents" (Radkowska-Walkowicz 2012, 31).

The creation of surplus embryos and the fact that not all of them will be used is compared, following *Donum Vitae*, to abortion or even murder. During a debate in the Polish parliament, one parliamentary member, representing a conservative party, addressed his words directly to children who were conceived with the help of IVF, saying that their existence was paid for by the lives of their "brothers and sisters" (the other embryos that were not transferred). Assisted reproduction is also compared to the Holocaust: in both cases millions of innocent beings were murdered. Such a comparison is exceptionally powerful in Poland, where the Nazis located their biggest concentration camp, Auschwitz, and where the population of Jewish citizens was almost entirely exterminated. Moreover, those who manage to be born, are said to suffer from a "survivor syndrome" – a term used mainly in the context of the Holocaust. The previously cited conservative Catholic journalist Terlikowski, analysing the situation of a child who was born as a result of assisted reproduction through gamete donation, says: "I am not a psychologist, but it is hard to not recognize in her words a survivor syndrome" (Terlikowski 2014). Therefore, statistics of failures in IVF procedures are being presented as statistics of the innocent lives that were sacrificed in the name of other people's desire for reproduction.

Conferring the characteristics of children on embryos is not limited to Catholic-oriented discourses (Banchoff 2011). In Poland, however, in public debate this continuum is being employed in order to transfer it to a political subject, and to achieve the goal of banning IVF. In 2009, the prominent politician and parliamentary member, Jarosław Gowin, stated in a similar manner in a widely-discussed interview: "I almost hear the screams of despair of those tens of thousands of frozen embryos and I feel their distress. In my eyes, they are children abandoned by their parents" (*Aborcja zarodka*… 2009). The personification of embryos and their attribution with the traits of an innocent child has found its way into mainstream debate through such powerful politicians. It is also observable in political mobilisation. In 2014, over 28,000 people signed a petition given to the Polish government, opposing the introduction of a law regulating fertility treatment. They appealed in words such as: "thousands of children are asking for help! Help us to save their lives and battle for their dignity!" (*Tak dla leczenia niepłodności*… 2014). On 8th March 2015, on the streets of Warsaw the annual Manifa feminist march was held. As every year, it was surrounded by opponents representing various conservative groups. One of them, *Pro Prawo do życia* (Pro Right to Life), showcased a large banner, which asked: "What is being done to in vitro children?". And the answer was: "Frozen in barrels, abandoned when ill, killed when defects are revealed. Only 5% have the chance for a life and family". The text was illustrated by the pictures of: dewar flasks, a crying newborn and a fetus post abortion. This banner sums up most of the radical views of IVF children, who are presented as the victims of an "abortion mentality", unloved, treated as instruments and with cruelty by those who dare to play God.

All above-mentioned ethnographic examples reveal the specific construction of the "IVF child" in the Polish anti-IVF discourse. It is created and called into existence by these discourses. It is, however, silent subject, who is not allowed a voice. All the possible arguments have been expressed in this matter, but the children, the final "outcome" of IVF, remain unheard. The powerful use IVF children as discursive arguments, but neglect the very existence of them as real human beings, because it is counterproductive for them to do so. In the next section I will show how the children themselves construct their own meanings.

HOSPITALS AND CAMERAS

My approach in this research with children derives from an understanding of the category of embodied memories, which relates to the phenomenological concept of embodiment as espoused in current re-readings of Maurice Merleau-Ponty. Body, in this perspective, is a source of cognition and unique subjectivity, and family memory is preserved and revealed not only through narratives, but also through its members' bodies (Diasio 2013). Therefore, in families with a history of infertility treatment, a child's body represents the private, intimate history of the family. Children who hear family stories, often told several times, incorporate them and make them elements of their personal identity. As I will show later on, sometimes this identity can be built on a bodily matter, dating back as far as to the embryonic phase of existence.

The children whom I interviewed paid little attention to the hardships pertaining to the history of infertility treatment, of its emotional, medical, or financial character. The whole process was viewed in a positive light. The participants said that they were "awaited" and that their parents were "happy" to have them. They probably were not very aware of the difficulties surrounding infertility and assisted reproduction, as their parents did not stress this aspect in family narratives. Positive connotations of assisted reproduction in family histories may be also related to the very negative presentation of IVF in public debate and may be seen as a way of balancing the possible detrimental comments that children may encounter. The children I interviewed therefore have a different perspective to what is recounted in numerous studies of infertile adults: a history of a painful, often silenced experience (see for example Becker 2000; Radkowska-Walkowicz 2012).

Some focal points of the discussion over IVF children were raised by the children who took part in the study, but again, with no reference to, and probably no awareness of, their controversial character in the public debate. A case in point being the cryopreservation aspect, which may be related to the children as a personal life story, without the notion of humiliation or degradation to be found in anti-IVF discourses. For example, a girl, aged 10, asked about the history of her family, says:

> "I know I was for over three years in a hospital or somewhere, because… first I was supposed to… I might have been the same age as my brother, but my parents couldn't straightaway, my mom, give birth to me, at the same time".

Unlike in the public debate, cryopreservation is free from controversy and viewed as simply a fact in a family story. What is interesting is the extension of identity as far as to the embryonic phase, although children do not explicitly use the term "embryo". This form of awareness of being "oneself" would not be possible without the development of assisted reproduction. The "identity link" here is based on a continuity of matter and on an embodied understanding of self. In literature, the status of an embryo is widely discussed and shows that due to the development of new diagnostic techniques (ultrasonography) and assisted reproduction, the embryo has become a new kind of entity of ambiguous status and thus a new player in the social debate (see for example Dubow 2011; Steinbock 2011; Banchoff 2011). The notion of liminality is used in order to grasp the vague and fragile status of embryos (Merill Squier 2004). This perspective – of a child who is aware of her "embryonic past" and who includes this phase into her personal history – throws new light onto the debate. Embryonic heritage, inseparable from life course as a whole, strengthens and at the same time changes the meaning of the first stage of human development. It becomes something meaningful personally, thus an embryo becomes not only a political actor in the public discourse, or the personal “treasure” of parents, but also a cornerstone of individual identity. This can be only recognised when the perspective of a person who was conceived in this manner is taken into account.

When children from families who have experienced assisted reproduction are given space to express their views on their family and its history, they prove that it is neither negated, nor overemphasized. A girl, who told me previously that she and her brother are “from in vitro”, when asked what this means, says (with another joining in to further explaining the subject to the researcher):

> “[girl 1] They as if couldn’t immediately…
> [girl 2] …from a laboratory.
> [researcher] A laboratory?
> [girl 2] As if. […]
> [girl 1] Mom and dad wanted to have children but couldn’t do it normally, so they had to do it in another way, because […] …cause those little sperms from dad didn’t want to merge with that something from mum”.

The children had some knowledge about some basics of IVF, such as the role of science/medicine (represented by “as if laboratory”) and the difference between spontaneous (“immediate”) conception and assisted reproduction. The sounds of adult voices can obviously be heard in these narratives, but children actively construct their own meanings, such as by merging the language of science with the personal. And, again, assisted reproduction is presented as part of their family history.

Children also build their own understanding of in vitro, based on elements from family talks and the public debate they encounter. A 10 year-old boy, who is the son of an activist from the patients’ organization, told us:

> “There are priests who want to close a hospital called in vitro, and my parents are fighting along with others so that it’s not closed”.

This quote proves that there is awareness by some children (especially the older ones) of the negativity in some circles about IVF in Poland, and is yet another example of their active construction of meanings. Knowledge taken from the adult world is actively merged with the child’s efforts to understand and define the reality of assisted reproduction.

Here a rather lengthy fragment of research with a group of four children, aged 10–12, is given which illustrates the moment when the participants were asked to play scenes with Lego blocks and figures, showing how they came into the world. It shows the children’s understanding of and response to the debate in the public sphere. As the discussants are older children, they have an awareness of the main positions held and the participants in the debate.

"[child 1] A new series should be released: Lego Duplo Children or Lego Duplo In Vitro [laugh].
[researcher 1] Lego Duplo In Vitro, I wonder what would be there.
[child 1] There would be such… A priest, who's yelling.
[child 2] Yes, there would be the figurine of a priest, there would be a syringe and a sperm with a… with a kind of string, attached. And a ball, it would be fun. (…)
[researcher 1] Yes, brilliant concept for a toy. And is this priest an important part of this set, T.?
[child 1] Oh yes. (…) Could be a priest yelling in front of camera [laugh].
[child 2] Exactly, a camera could be there.
[researcher 2] So if there were figurines, there would be the figurine of a priest. What about other figurines?
[child 1] Children.
[researcher 2] Children. What other figurines would be in the Lego Duplo In Vitro set?
[child 1] Probably us.
[child 2] Probably a woman and a man, but a woman should be a little naked, not entirely, I mean… [laugh]. …because doing in vitro completely dressed…, she should have, I don't know, panties?
[researcher 2] A kind of shirt. Hospital shirt.
[child 2] Hospital shirt and there should be a little syringe.
[researcher 2] What other figurines? Who would be there?
[child 1] A father.
[child 2] A doctor.
[researcher 2] So there is a man, a woman, a priest, a child, a doctor.
[child 2] Right, a midwife should be there.
[researcher 2] That's kind of an idea. Maybe one should write to the Lego company [laugh]".

Children themselves proposed the course of this discussion. What is striking in this fragment, is the discrepancy between the atmosphere of freedom, laughter, openness and play, and the serious subject of the discussion. It shows that children have interiorised some elements from various sides of the discourse. From the medical aspect they took some props (syringe), medical terms (sperm), and an awareness of the actors involved (doctor, midwife, parents, children). But the "anti-IVF" part of the debate provided them with other props (a camera), actor (a priest who is yelling), and the overall notion that there is something wrong with the method that helped them (or their siblings) to be born. This fragment clearly shows the way in which discourses present in the world of adults permeate into the worlds of children and are interpreted by them. Cryopreservation, discussed in Polish anti-IVF discourses as relating to dignity, may be understood as a purely private fact of a child's own history. Meanwhile, Catholic-driven controversies may be well observed, defined and actively transformed through the mediums of humour and play.

CONCLUSION

A child who was born as a result of IVF is a crucial figure in the Polish debate on assisted reproduction. Her or his existence would not be possible without the development of science, which by some is interpreted as a blessing but by others as a curse. His or her position is, however, limited to being representative of some well-established discursive arguments. Caught in the crossfire of medicine and religion, their actual existence and experiences are neglected.

Children's voices are generally barely heard in the public sphere and their low participation in the public debate is connected to their social exclusion (Kay *et al.* 2008). While the debate on ARTs in Poland is shaped to a great extent by conservative Catholic viewpoints, and the "test-tube child" is made an important subject of it, IVF children are subjected to multiple exclusion. They are talked about, but not talked to, as one of our interlocutors said. They are muted. This group is also very directly affected by reproductive technologies; maybe more so than any other actors in the process of ARTs and thus, this group may be interpreted as radical examples of what Susan Merill Squirer calls "liminal ourselves": those who are living in and affected by the era of ongoing biomedical negotiations and interventions (2004). This intervention has marked their very existence and how they understand and interpret this intervention is an important indication of the new power relations produced by the proliferation of biomedical technologies and religious discourses pertaining to the changing reproductive constellations. The research conducted with these children shows that ART discourse can reach their world, and that they grasp some of its elements. The creative ways in which children conceptualize and refer to the debate on assisted reproduction mean it is crucial that their voices be listened to.

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CURING DISABILITY IN CONTEMPORARY RUSSIA: REHABILITATION PRACTICES AND THE PLACEBO EFFECT

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The paper is based on the materials of an ethnographic research project involving interviews with parents of children with developmental disabilities, primarily intellectual disabilities, multiple disabilities, and autism. Though in contemporary humanistic pedagogy and psychology developmental disabilities are viewed in terms of difference and diversity, Russian public and professional discourse on disability is dominated by a medicalised approach and the majority of parents adhere to this view. This article analyses the patterns of rehabilitation and treatment of children with disabilities in the family context. It views the effectiveness of various popular therapies offered to children with disabilities through the lenses of the placebo effect theory. It shows that the assessment of both biomedical and alternative treatment outcomes by parents of children with disabilities are subject to the placebo effect, and this effect is maximized by various symbolic elements of treatment, such as price, prestige, or popularity of a certain drug, method or institution. The placebo effect, together with other factors, accounts for the commercialization of the disability services sphere.

* * *

Artykuł powstał na podstawie materiałów zgromadzonych w trakcie realizacji projektu badawczego, w ramach którego prowadzono wywiady z rodzicami dzieci z niepełnosprawnościami rozwojowymi, szczególnie intelektualnymi, wielorakimi oraz autyzmem. Mimo że we współczesnej pedagogice i psychologii humanistycznej niepełnosprawności rozwojowe postrzegane są w terminach różnic i różnorodności, rosyjski dyskurs publiczny i profesjonalny o niepełnosprawności jest zdominowany przez zmedykalizowane podejście, podzielane przez większość rodziców. Artykuł analizuje wzorce rehabilitacji i leczenia dzieci z niepełnosprawnościami w kontekście rodzinnym. Rozpatruje skuteczność różnych popularnych terapii dzieci z niepełnosprawnościami poprzez pryzmat teorii efektu placebo. Pokazuje, że ocena rezultatów leczenia, tak biomedycznego, jak i alternatywnego, dokonywana przez rodziców dzieci z niepełnosprawnościami, podporządkowana jest efektowi placebo, a efekt ten potęgują różne symboliczne elementy terapii, takie jak cena, prestiż bądź popularność danego leku, metody czy instytucji. Efekt placebo, wraz z innymi czynnikami, przyczynia się do komercjalizacji sfery pomocy osobom niepełnosprawnym.

Keywords: disability, developmental disabilities, autism, medicalisation, biomedicine, alternative medicine, placebo effect

INTRODUCTION

This paper analyses the practices of rehabilitation targeted at children with intellectual disabilities, multiple disabilities and autism in present-day urban Russia commonly used by their parents in order to treat them. It aims at viewing the effectiveness of various therapies, rehabilitation methods and curative procedures, as perceived by the parents, through the lenses of the placebo effect theory[1].

The introductory part the article will discuss the connections of the placebo effect theory to anthropology. Afterwards it will describe the current approaches to and discourses on disabilities in Russia, highlighting medicalisation trends, and then, based on the ethnographic material, analyse the popular therapeutic strategies and methods applied to children with developmental disabilities. It will discuss the role of the level of trust for certain institutions in parents' choice of therapies and the commercialization of the disability rehabilitation sphere. This article lies within the framework of medical anthropology, and does not touch upon pedagogical methods of rehabilitation, focusing on the use of official biomedicine and non-biomedical or alternative medicine methods. It also leaves aside the topic of physical rehabilitation.

In the narrow medical sense, the placebo effect is understood as the non-specific effects of biomedical therapies, usually treated as something to be controlled and minimized in clinical research (Thompson *et al.* 2009). In the 19th and the beginning of the 20th century the word "placebo" itself was used as a pejorative term referring to an inert and inactive drug or substance. The medical interest towards the placebo effect started to grow in the 1920–1930s accompanied by the development of pharmacology. It was then that it became clear that the results of clinical trials depended on the participants' awareness of whether the patients were receiving an active drug or a placebo, and the first double-blind experiments were then conducted (Shapiro and Shapiro 1997b, 28–174).

The far-reaching consequences of placebos were first demonstrated by Henry Beecher in his well-known paper "The Powerful Placebo" (Beecher 1955). He showed that placebos could produce powerful therapeutic effects, and they are especially high in the treatment of pain (see also Morris 1997). They can also bring about side effects analogous to the supposed side effects of an active drug. Papers cited by Beecher, as well as later research, have shown that numerous medical conditions, among them nausea, cough, "common cold", headache, blood pressure, asthma, gastritis, ulcers, nervous and psychiatric disorders, and others, are subject to therapeutic placebo effect.

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Beecher, as well as other researchers (for example, Lasagna *et al.* 1954), then suggested that the psychological constitution of the patient played the key role in the manifestation of placebo effect. However, later it became clear that such psychological factors were not as relevant.

Further research demonstrated that the very context of treatment and its social characteristics contributed to the effect. Patients' sex, age, diagnosis, clinical records, or psychological constitution were not as important here as the levels of belief they exercised towards the treatment, which in turn depended on the doctor's communicative style, enthusiasm, and persuasiveness. The doctor-patient relationship and interaction, on the whole, influence the results of therapy tremendously. One of the placebo effect theories suggests that the effect is due to attributing natural positive changes, or changes that are due to any other factors, to certain medication or medical procedures (Shapiro 1969; Frank and Frank 1973; Gibbons and Horhmuth 1981; Ross and Olson 1981).

Thus, through an anthropological perspective the placebo effect can be perceived as a broader phenomenon than the therapeutic effect of saline solution, sugar pills, or sham surgery. It involves the effect produced by any therapeutic interactions and the symbolic elements of treatment. As Daniel Moerman puts it, "participating in any healing process, regardless of its content, can lead to healing" (Moerman 2000, 52). The effectiveness of therapeutic methods used within religious healing and rituals, ethnomedicine and other medical systems alternative to biomedicine are believed to be mostly built on the placebo effect. As Arthur and Elaine Shapiro claim, the history of medicine, prior to modern evidence-based biomedicine, involving the Hippocratic-Galenic theory or animal magnetism with its methods of theriac, blood-letting and dehydration, or fat of puppy dogs, is largely the history of placebo effect (Shapiro and Shapiro 1997a, 2). However, the results of biomedical treatment can also be highly related to the placebo effect.

The words and actions of a shaman or healer are infused with symbols and meaning. As Claude Levi-Strauss has shown in his classic essays "The Effectiveness of Symbols" and "The Sorcerer and His Magic" (Levi-Strauss 1963), the effect of a shaman's ritual is to a large extent rooted in its performative elements, including the performative linguistic elements of the text he pronounces. Sham surgery or laying on of hands show effective results due to the performativity, but the same happens in the modern biomedical clinic. The white coat, the organization of a medical room or a hospital, the order of actions and interaction in the medical room are interpreted as strong symbolic elements in the framework of the modern urban culture. The doctor's prognostic speech acts and her verbal instructions to a large extent determine the patient's expectations and behaviour, and thus the results of the treatment, because the results are largely mediated by a patient's beliefs and expectations. For a patient who does not belong to modern urban culture and usually goes to a healer when she is ill the symbolism of the biomedical clinic might not be as effective (see Hahn and Kleinman 1983; Thompson *et al.* 2009).

Apart from the doctor's role, her status, reputation and authority, various other symbolic elements might be important in the therapeutic process. Placebo trials have shown that the colour and size of a pill, the price of the medication or the popularity of the brand played the role in the outcome of treatment. Thus, during the experiments, the placebo branded as a famous aspirin brand resulted more effective than unbranded placebo aspirin (Moerman 2002, 47–48; Moerman and Jonas 2002)[2].

Any medical system is a symbolic system (see Kleinman 1973) that affects an individual's state of bodily or mental health not only through particular medications, but through the cultural meanings embedded in the healing encounters and processes. Medical practices, healing methods and the effectiveness of these methods are rooted in the cultural ideologies and are related to the cultural ideas on body, mind and self, social organization, religious and moral notions, rituals and mythology, and so on. Thus treatment is aimed not just at particular individual and her body, but rather at the social system an individual is incorporated into (see Scheper-Hughes and Lock 1983). Our own materials, presented further, are illustrative in regard to these theoretical points.

It is worth mentioning that anthropologists first described a phenomenon polar to placebo effect. It was called the nocebo effect and referred to the facts of death or illness induced by social suggestion (Mauss 1926; Cannon 1942). This effect also includes the phenomenon of mass hysterias, pseudo-epidemics, and self-diagnosis based on folklore symptoms (see, for instance, Hahn 1997, Justman 2015 for an extensive exploration of the nocebo effect). The nocebo effect, as well as the placebo effect, are directly related to the subject of this paper, particularly to the epidemiology of autism.

Thus, autism as a diagnostic category was included into the International Classification of Diseases and came into medical practice in the 1980s. It can still be considered a "new" diagnosis, in comparison with, for example, "mental retardation", which in medical classifications had been distinguished from "acquired" mental disorders like schizophrenia since the first half of the XIX century. Children who were previously mostly diagnosed with learning disabilities or "childhood schizophrenia" in many cases now tend to receive the diagnosis of autism. These diagnostic trends have partly determined the statistical growth in autism among the child population in recent years, which in turn triggers the mood of panic among the parents' community. According to the popular folk data that can be easily found in the social media, by 2025 every second child will be diagnosed with autism. The wide-spread reflections about the causes of autism often entail eschatological narratives on vaccination, toxic food,

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[2] More interdisciplinary research on placebo phenomenon can be found in Harrington 1997.

or environmental pollution. Together with another popular diagnoses like ADHD, autism thus falls into the category of modern epidemics, partly brought forward by the nocebo effect.

The situation in Russia partly reflects these trends. On the other hand, autism, according to psychiatrists, neurologists and other expert informants, is highly underdiagnosed in Russia, as community psychiatrists remain hugely unaware of its symptoms and manifestations. At the same time, it is gradually becoming a "fashionable", "romantic" and more desired diagnosis in comparison to highly stigmatized "mental retardation". According to some experts, autism in Russia is sometimes overdiagnosed because parents talk the psychiatrists into diagnosing their child with autism instead of mental retardation. Self-diagnosis, which in this case refers to when parents diagnose their child with autism, plays an important role here.

MEDICALISING DEVELOPMENTAL DISABILITIES

This paper is based on a year-long ethnographic research conducted in three major Russian cities, during which we collected approximately 100 interviews with parents of children with developmental disabilities (most of them were biological parents, but we included several adoptive families too), as well as 40 interviews with specialists and experts who work with children with disabilities or their parents (special education teachers, psychologists, psychiatrists, and others). Our study focused on families with children or adolescents and adults diagnosed with learning disabilities, Down syndrome, cerebral palsy and autism, mostly accompanied by intellectual disabilities, and severe multiple disabilities. We mostly reached the families through NGOs and rehabilitation centres that provided support for people with disabilities and their parents, which of course meant that the selection was rather specific: thus, we could not reach families who lead a more isolated life, minimizing their contact with public or private disability services.

Such diagnoses are chronic conditions that usually imply and lead to disability status. From the point of view of modern humanistic approaches to children and people with disabilities, such conditions cannot be cured or "corrected", though various educational methods and environmental adjustments can improve a person's functionality. The humanistic approach suggests that such disabilities should be perceived and treated in terms of differences, rather than deviations from the norm, and appreciation of diversity. It claims that disability is an essential, integral part of a person's identity, that should be rather subject to social adaptation and inclusion, than to medical rehabilitation. In Russia such ideology is shared and promoted by a number of professionals who work with people with disabilities, including some psychiatrists and neurologists, disability activists and self-advocates. Contemporary activist discourse in Russia, in line with the international trends, follows the diversity model approach to disability and tends to view developmental disabilities as permanent conditions that are related to a person's selfhood.

In parents' narratives, however, a child's disability is primarily constructed as illness, a diagnostic category that needs to be established and cured. With some exceptions, a parent's story is usually a story of struggle for appropriate or desirable diagnosis, dodging between different specialists and rehabilitation methods, and searching for "the magic pill" that will eliminate the disease once and for all. The fact that their child is not capable of fulfilling expected life scenarios and thus does not correspond to social norms is a source of extreme stress for parents and extended family. The situation is exacerbated by quite high levels of stigmatization experienced by children with disabilities and their families, absence of any systematic psychological or informational support for families raising children with disabilities in Russia, and a lack of possibilities for integration and inclusion for people with disabilities, especially in the spheres of education and employment. Thus, rehabilitating the child up to the point that they become "normal" is the idea that underlies the help-seeking strategies of many parents.

According to anthropological theory, knowledge and notions about the causes of disease or disability have a crucial impact on how the disease or disability is conceptualised, constructed and cured. It has something to do with the levels of stigmatization and exclusion a person and their family suffer, because the causal theories can be related to the ideas of blame, sin and moral punishment (Foster 1976; Kleinman 1980, 71–118; Kleinman 1988; Whyte 1995). Thus, the idea that a child could be "corrected back to the norm" is more characteristic of parents who have children with cerebral palsy or autism, than with Down syndrome or other diagnoses with a known and clearly established reason, which is a chromosome mutation in this case. Cerebral palsy is often viewed as a pathology that developed as a result of birth trauma or medical error, while the reasons for autism are still unclear, a single gene or mutation, responsible for it, has not been discovered, and the fact that it usually starts to clearly manifest itself when a child is around three years old provides fertile ground for various causal theories to proliferate. In both cases parents often presume that a child has experienced a period of normative development, at least prenatally, as with cerebral palsy, which gives rise to the idea that the child could be reset to "the norm" again.

A medicalised approach to disability is also characteristic of medical professionals, naturally, system of special education, various disability services and Russian society at large. Contemporary Russian society offers children with disabilities and their families a variety of medical and rehabilitation practices, proliferating the point of view that disability might be repaired and fixed, and further reconstructing it as a medical, rather than a social, problem. This paper will further discuss several institutions popular among parents that offer rehabilitation and therapies for children with developmental disabilities.

REHABILITATION PRACTICES AND INSTITUTIONS

When family learn that there is something wrong with the child, either they have some obvious impairments, or vague behavioural deviation from the conventional norm, they tread upon the rehabilitation road by visiting a variety of different specialists who could, as they hope, could clarify the nature of the impairments and determine the "correct" diagnosis. The long chains of specialists who propose or disprove diagnoses may include paediatricians, special education teachers, psychologists, speech therapists, massage therapists, and they never fail to include psychiatrists and neurologists.

Psychiatrists and neurologists usually tend to immediately prescribe children with intellectual and behavioural problems biomedical drugs, such as, on the one hand, antipsychotics, tranquilizers and antidepressants, and nootropics on the other. The first group of drugs are aimed at alleviation of symptoms, such as agitation, hyperactivity or "stimming"[3], that are usually seen as socially disturbing, or aggression or self-aggression that, apart from being perceived as a violation of social norms, might be dangerous or harmful. The aim and effect of nootropic drugs is usually described as "boosting the neurons", "nourishing the vessels", "stimulate the brain cells", and so on. Both groups of drugs are described by psychiatrists or neurologists as remedies to prompt speech, improve attention and concentration and "pull the child together".

One of our experts is a private psychiatrist and a representative of humanistic psychiatry and distances himself from the current trends in mass psychiatry, that are partly determined by the Soviet legacy. He comments that using the abovementioned popular explanations of drug effects psychiatrists and neurologists are enacting,

> "the quasi-medical, pseudo-scientific rhetoric. There are dozens of nootropic drugs, it's an extensive drug class, and the only thing that they actually have in common is that they don't work at all".

Our expert claims that metaphors and "mythological notions" that are used by doctors to explicate how the drug works have a prognostic effect, and the drugs are in fact placebos.

The same expert, as well as other experts interviewed, including one high-level representative of public psychiatry, also object to "ubiquitous" prescription of antipsychotic drugs to small children. These drugs, as they claim, are meant to help adult people with acquired mental disorders like schizophrenia. They demonstrate numerous side-effects and can hinder a child's intellectual development and have a detrimental impact on their personality. Their administration might be efficient or inevitable to a small percentage of children with disabilities who experience severe psychotic behaviour. However, community psychiatrists in Russia, according to our experts, demonstrate

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[3] Auto-communicative self-stimulation using movements and gestures that look "strange" and socially inacceptable, but is thought to be a means of self-comfort for a child with autism.

negligence towards these nuances, tend to over-medicalise children with developmental disabilities and remain hugely unaware of educational methods of rehabilitation.

Some parents, however, link positive changes in child's development with the intake of antipsychotics, stating something like "Risperidone[4] has boosted speech at once". Many notice the effects linked to nootropics intake:

> "He got injections [of nootropics]. The active ingredient was of **high purification degree**. The drugs were **from Italy or the USA**. […] Professor prescribes himself! He's an active member of **the New-York Academy of Science**, a citizen of honour in **the Maryland state**. He's got **patents everywhere**! But this guy he works in Yoshkar-Ola[5] […] We were sceptical at first. But the child started to progress. He became more independent, more active. Like he didn't eat with a spoon himself, and now he does, actively! The self-care skills get rolling!" (Eugenia[6], mother of a child with autism).

As the highlighted phrases illustrate, the effectiveness of an antipsychotic or nootropic drug is usually recognized when it is prescribed by a "famous", high-status or foreign doctor, or when the drug itself is foreign or exclusive (compare with branded aspirin mentioned in the introduction). Further progress in a child's development are seen as the results of such treatment.

More often, however, in case of antipsychotics, tranquilizers, anticonvulsants and the like the story of drug intake is told as a story of never-ending, interlacing side-effects, of chaotic administration of medication by the doctor, of restless experimentation with dosage regimen. The motivation behind the administration of this or that drug or dosage by the doctor remains vague for parents, prescriptions often seen as unreasonable. It often leads to a situation where parents completely refuse to give their child any drugs or improvise with dosages without consulting with any representatives of biomedical professionals, thus invoking the self-treatment practices. In case of self-administration or self-cancellation of drugs by parents the effect is viewed as immediate and maximized.

The parents' stories are usually built on the criticism of Russian psychiatry and neurology, and medical services at large. Thus, the administration of antipsychotic drugs is in many cases seen as useless and harmful, ruining a child's "normal" intellectual development or even the supernatural abilities they are claimed to have possessed.

As a rule, all parents of children with disabilities pass through a period of trust towards official psychiatry and biomedicine, and follow all the instructions and prescriptions. However, when their child fails to show expected improvements, when various undesired symptoms, interpreted as medical side-effects, start to manifest themselves, and when doctors fail to explain to parents what is going on, what logics stands behind the treatment, what

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[4] Popular atypical antipsychotic

[5] A town with a population of about 200 000 people in the central part of Russia.

[6] All names used are pseudonyms.

consequences to expect, a period of doubt and hesitation sets in. Parents start to distrust official biomedicine and psychiatry, as well as biomedical treatment, or refuse it completely and turn to alternative methods of rehabilitation.

Usually parents learn about the alternative methods of rehabilitation and healing by surfing through the internet, mostly at specialised parents' forums or Facebook pages. The discussions at such forums often look like a flow of advice that list a whole spectrum of doctors or institutions, including centres, offering non-biomedical therapies. However, it is not uncommon that some such methods are advised by representatives of official medicine, like paediatricians or neurologists, and it is relatively often that they are also recommended by special education teachers. Such popular methods include the Tomatis procedure, "bioacoustic correction" of the brain and dolphin therapy.

The Tomatis procedure is a type of sound or music therapy that has become popular across the world as a method for improving speech and language skills by stimulating the connection between the middle ear and the brain. Bioacoustic correction is a similar method, it can be called a cultural variation of Tomatis, developed and popular mostly in Russia, Ukraine, Belarus and other post-soviet countries. The description of this method states that the electroencephalogram activity of human brain can be transformed into sound, and thus during the procedure a patient is made to listen to "the music of her own brain", which leads to the "involuntary self-regulation" of the central nervous system[7]. As we see, the rhetoric, explaining how the procedure works is very close to the description of the nootropics' effect. It is presented and described by its proponents as a "scientific" method, while the "evidence-based" research claim such methods are unreliable. One of our experts, a representative of official public psychiatry, comments:

> "What about Tomatis? It's very popular in our region. It's intoxicating the whole country! The problem is that we can't control private services. There are now laws that would allow us to enter these organizations with check-ups. The laws must be changed, the very therapeutic approaches must be changed. People suffer!"

Thus the official psychiatry tries not only to establish control over the "unreliable" methods and organizations, but to retain and bring back the patients it has lost as a result of low level of trust towards the institution. Centres offering such services, have recently started to offer special education classes, speech therapy, and massage to avoid criticism and attract more clients with more "verified" methods. Parents, however, tend not to claim they "suffered from" or felt disappointed after bioacoustic correction, Tomatis or similar procedures.

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[7] See for instance: http://www.logopedprofi.ru/bak (accessed 20.06.2019) in Russian, https://impulss.eu/en/methods/bac in English (accessed 20.06.2019).

Even if simultaneously with Tomatis and bioacoustic correction a child attends numerous other institutions and specialists, their progress would be attributed to the effect of these new and fashionable procedures, rather than to the efforts of special education teacher or to naturally occurring development. According to popular belief, one the best devices for procedures like these are located in St. Petersburg, the second largest and second most important city in Russia. Usually parents have to invest a lot of money and overcome a substantial distance to visit St. Petersburg, so that their child could attend a month-long course of therapy. The perceived effects of the procedures are maximized when one has to invest more money or effort to obtain the service, or when it is offered by a prestigious institution.

Animal-assisted therapies are said to boost a child's physical and intellectual development because they involve physical exercise and trigger positive emotions. The dolphin therapy, however, stands out in this category, because on top of these elements that it is claimed to have a healing effect due to the "natural ultrasound" the dolphins produce. This is a typical dialogue recorded during a focus-group with mothers of children with Down syndrome:

> "[Vera:] We mustn't take anything but dolphins now, doctors say!
> [Sofia:] Dolphins are no go, I hear, because this therapy…
> [Victoria:] It's the same bioacoustics!
> [Sofia:] I've read somewhere, that hippotherapy or dolphins don't have therapeutic effect…
> [Victoria:] Reading is one thing, but you should see your child citing the Boldly Buzzing Fly Poem[8] just ten days after the ten days' course! It's not just swimming! Dolphins talk with each other through ultrasound, and this ultrasound heals all organs. Dolphins have biolocation glands, and they are the natural source of ultrasound, not electronic, nothing like that. It's natural stimulation of brain cells".

The "natural" source of ultrasound is of value to parents, and it is often, at least at the level of discourse, preferred to "artificially constructed machines", as another respondent says, like the bioacoustic correction machine. "Natural" automatically means "safe" and "harmless", which makes the procedure especially desired in the eyes of the parents. The best dolphin therapy centre, according to parents' opinion, is located in one of the Russian resorts at the Black Sea coast, and the dolphins there are said to be "former military dolphins", who emit "unique" ultrasound.

The price of a month-long course of dolphin therapy reaches 2000–4000 Euro for one child, which is at least ten times more than an average monthly wage in Russia. The costs of stay at the resort city are also high. However, though some parents doubt the effectiveness of the therapy, as we see in the quotation above, many of them try to save money so that their child could take the course at this Black Sea centre, and any progress, for example, the emergence of speech a month later, is attributed to dolphin therapy.

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[8] A famous Russian poem for children.

The majority of professionals, who support the evidence-based paradigm, deny the possibility that the dolphins' ultrasound can have an effect on speech development. Some, however, take on a more holistic and agnostic approach, saying that the emotions and sensations a child experiences during the therapy might serve as a developmental trigger, because, according to the words of one of our experts, a psychologist, "even if we're all for evidence-based methods, we can't be sure what finally worked, when a parents do this and that and that".

Another popular type of alternative therapy, that also exploits the rhetoric of naturality and toxicity, is based on various dietary theories. These alternative methods include, for instance, "chelation" and "biocorrection" methods that are meant to remove heavy metals like arsenic, mercury or lead from the organism, other detoxifying diets, gluten-free and casein-free diets, and naturopathy.

The idea behind these methods is that certain toxic substances have penetrated into a child's organism with contaminated food or vaccines, and poison their brain. The wide-spread notion underpinning this idea is that the functioning of the bowels directly influences the functioning of the brain, as one of our respondents, a mother of a boy with autism, formulated: "Bowels are the leading edge of the brain".

The normalisation of the digestive system and the elimination of poisonous substances are often seen as a prerequisite for restoring the brain cells, which in turn will lead to recovery. These notions spread partly due to the efforts of various centres and organisations of alternative medicine that sell detoxifying medication or offer expensive courses of treatment, sometimes online. For instance, the idea that autism was a disorder caused by external toxins and certain foods in combination with low immune response was once popularized by the "Defeat Autism Now" project launched by the Autism Research Institute in the USA. The project has been closed down, but there are still numerous web-sites, claiming that they adhere to this movement and advertising medication for chelation and detox. As one of such website states:

> "The central nervous system is not an isolated system. Its activity is based on three other systems: immune system, digestion system and detox system. It is in the bowels that food, and all necessary vitamins and minerals are absorbed, it is in the bowels that the hormones regulating the central nervous system, are produced"[9].

This kind of body image or body / psyche interaction model is also sometimes disseminated by the representatives of official biomedicine:

> "Our gastroenterologist said that his bowels are in a very bad state. And the bowels are directly connected with the brain, so it would pay to take diet. […] The bowels, the gut flora are underdeveloped, and the gluten absorption is upset. The ferments are insufficient, and gluten poisons the brain" (Natalia, mother of a child with autism).

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[9] http://www.autmedic.com/ (accessed 20.06.2019).

Similar arguments can be easily found in numerous tabloid articles on the Internet, and parents eagerly adopt them and disseminate them to various forums and discussions in social network communities. Sometimes parents themselves are involved in the marketing of dietary, detoxifying or naturopathic medication. At their personal web-pages they usually advertise certain drugs through telling the story of their child's "miracle recovery". An outsider might not notice the traces of recovery, like in the case of one of our respondents, who advertises the bee product medication "Tentorium" through the story of treating her daughter[10]. Her adolescent daughter remains completely socially and physically maladapted, spending all of her time at home, in an outdated wheel-chair by her mother's side. For the parents themselves, however, the effects of taking the drugs are obvious. The marketing strategies usually use the rhetoric of eschatology narratives and conspiracy theories, manipulating people's fears of environmental pollution and ecological catastrophe or risks of protein over-eating.

Some commercial centres, or clinics as they call themselves, specialise in conducting tests on detecting casein (milk protein) and gluten (protein found in grains) intolerance, as due to the causal theories described above, gluten and casein intolerance is not just a sensitivity for certain foods, but a trigger for autism or other developmental disabilities:

> "At first, we had taken the gluten and casein intolerance test here, in Russian, in In-vitro labs, and they didn't show anything bad, both were within the norm. And then we found a woman, from a Defeat Autism Now clinic, we chatted on Skype with her. She said we'd rather send Mike's pee to France, to the Phillip Augustus clinic, and it would show with a hundred percent accuracy if there was gluten or casein intolerance. We sent his pee, and the tests proved Mike had both gluten and casein intolerance" (Anastasia, mother of a child with autism).

The medical test offered by the alternative medicine representative and taken in the "Phillip Augustus clinic" in France, whether it exists or not, should look more convincing for parents, then a test in a biomedical lab in Russia, and the aim of it is to sell the service, or later on dietary goods, to parents. In a similar clinic Mike was diagnosed with "candida" disease, and to stop its growth he was prescribed a strict diet and certain medication. According to Anastasia, the doctors claimed that the autism symptoms, like stimming or stereotypical behaviours, would decline with the decline of "candida".

Anastasia set Mike on a casein-free and gluten-free diet, and she noticed improvements in both the functioning of her son's digestion and the normalisation of his behaviour. When Mike managed to steal some prohibited pastry from the kitchen, she found him stimming more and laughing nervously, due to gluten. Many parents see

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[10] See http://www.dcp-recovery.ru, in Russian (accessed 20.06.2019).

connection between the casein- and gluten-free diet or a certain ferment intake with positive behavioural changes and developmental progress as absolute.

Such therapy offered by numerous commercial alternative medicine organizations resonates with parents' hopes for finding the magic pill after investing time and effort into visiting various biomedical specialists. The way the alternative medicine specialists or web-sites elaborately explain how the therapy works, which is usually not the case with the representatives of biomedicine, is also attractive and looks trustworthy.

Anastasia, however, managed to keep Mike on a diet for a year only, though she found the therapy successful. She admitted that soon she felt tired of constantly baking gluten-free bread, and it was impossible to guarantee that Mike would not eat the same products as other family members. It is usually the case that family routines finally fail to be organised in such a way as to incorporate strict dietary schemes. Besides, many parents take their child off the diet because their negative emotional reactions to the restriction of habitual or delicious foods override the positive effect of the diet that parents notice.

In the case of Anastasia and some other parents, the fact that they turn to numerous and diverse specialists, including dubious online services, might be due not so much to their belief that therapy would work. It is rather a result of the desire to fulfil the role of good and responsible parents, who do everything possible to rehabilitate their child, and in this manner to try to make up for the blame they feel for their child's non-normative development.

It should be said that children with developmental disabilities, autism in particular, often have problems with digestion, which is sometimes due to the limited assortment of foods they choose to eat, and problems with digestion, like in any children, may cause mood changes. Children with developmental disabilities might have gluten and casein intolerance or any other food allergies, as often as other people might have them, and keeping casein-, gluten-, lactose-, and-so-on-free diets might be necessary for them. There are also certain diseases that are caused by metabolic problems, where special diet is the only therapy. For instance, in the case of phenylketonuria such problems might lead to central nervous system damage and cause intellectual disability. Our experts, the representatives of biomedical evidence-based science, deny the same scheme in case of autism and other popular developmental disabilities. Families with children with disabilities form a whole market for the manufacturers of dietary products supported by the mythology around certain foods.

Though these cases demonstrate that rehabilitation of a child with disabilities usually blends various approaches and methods belonging to different systems of knowledge, the divergence of the biomedical doctors' and parents' points of view and medical systems they adhere to, sometimes lead to conflicting interpretations of children's behaviour. Thus in our materials there is an illustrative case. Christina, mother of Nina, interprets her unruly behaviour as, in the first place, the side-effects of antipsychotic drugs, prescribed by a public psychiatrist, and in the second place, a result of violations of gluten- and casein-free diet, that she administered to her daughter herself. The public psychiatrist, who is in charge of Nina's treatment, claims that her psychotic attacks are a direct result of a restrictive diet, imposed by her mother, when Nina became deprived of her favourite food. Christina is also experimenting with the dose regimen of antipsychotic drugs because she does not trust the public psychiatrist's prescriptions and she is critical of the public psychiatry at large. Such cases of self-prescription and self-medication, according to Sylvie Fainzang, are socially meaningful, rooted in certain cultural ideologies and can be interpreted as political acts (Fainzang 2013).

DISCUSSION AND CONCLUSION

In his blog, targeted, among others, at parents of children with disabilities, Russian child psychiatrist Elisey Osin (Osin 2012) reviews several research papers describing autism placebo trials related to secretin (for English see, for instance, Sandler *et al.* 1999; Sandler, Bodfish 2000; Esch, Carr 2004). At the end of the 1990s there was a big buzz around the new medication that helps to cure autism. Secretin, a hormone that regulates secretion in the digestive system, was noticed to instantly improve a child's behaviour and boost their progress. Clinical trials were organized.

The medical personnel, scientists, and parents were all agitated and nervous, families were sharing their expectations and hopes, and everyone had the feeling that something very extraordinary was going on because the long-hoped treatment for autism was finally about to be discovered. The atmosphere of the experiment was solemn, the drug was slowly injected into children veins, one after another, the liquid with the new magical drug was flowing through the tubes, and for the parents it was more than just a liquid, but a promise that their child would be cured. Consequently, parents were asked several times to assess the children's behaviour and progress, and thirty percent of the families who participated in the experiment noticed positive physical and psychological changes, as well as improvement in mood and communication skills. However, all those changes could not be explained by the effect of secretin, because in fact children were injected with saline solution. The results the parents recorded were due to placebo effect. Their aspirations and belief in the new miracle drug, the expectation of physicians, the atmosphere of the experiment and the buzz around secretin determined the results. Parents started to notice naturally occurring behaviour and progress, and perhaps they began to pay more attention to children, and the children were emotionally responsive to their positive stance. This is also an example of the work of the symbolism of the modern biomedical clinic, which is similar to the effectiveness of shaman's symbols in the famous Levi-Strauss essay.

The results of the therapies described in this paper are in many cases also due to the work of the placebo effect, and the nocebo effect, when parents notice negative changes in child's behaviour, like in examples of breaking the diet. The example of parents and children with disabilities undergoing therapy illustrate that placebo is in the first place a social, and socially distributed, rather than a psychological effect. In a similar way the ritual healing of the cattle is effective because its target is the owner, rather than the animal itself.

The placebo effect is maximised when the therapy is expensive, fashionable, or offered by a prestigious specialist or organisation, especially foreign, or residing far away. The more money or effort the parents invest, the more obstacles they overcome, the more effect they see. The performative elements of the therapy and detailed explanations of how it works might also be relevant. Like with secretin, parents tend to attribute the natural progress in their child's development and positive changes that might have been triggered by pedagogical intervention or other factors, to the work of the therapies, specialists or institutions they trust most, and the trust is to a large extent based on price, status, exclusiveness and popularity.

The existence of the placebo effect is a condition for the existence and proliferation of numerous institutions around disabilities, and popular psychiatric and neurological diagnoses in children, autism among them, seem to create a whole industry of services, resulting in the disability rehabilitation sphere becoming highly commercialized. In the context of the lives of families raising children with disabilities in present-day Russia disability becomes a means of making commercial profit, rather than an object of care and support, as presented in the public social policy and prevailing paternalistic discourse.

The materials presented in this paper also show that in everyday practice the boundaries between biomedicine and alternative medicine are blurred. Thus, a paediatrician might advise a parent that her child should take up the bioacoustic correction procedure, while the typical neurologist would prescribe a nootropic drug to a child with autism or Down syndrome, though there is not enough evidence that it is effective in these cases, and would use the same patterns and metaphors to explain how the drug works, as web-sites selling the bioacoustic correction service. This is not to say that the work of biomedicine and its symbolism are equally bound to the placebo effect.

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NEUROTECHNOLOGY GOES TO POLISH SCHOOL. AN ETHNOGRAPHIC STORY ABOUT SCANNING ADHD[1]

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In a public primary school in a middle sized Polish town, research was conducted in which a number of children were diagnosed with a new tool for identifying ADHD. This situation serves as the point of departure for an ethnographic reflection devoted to contemporary practices of diagnosing children's mental health. The screening programs, which are more frequently permeating Polish schools, generate a category of "patients-in-waiting", who can be defined as children, who remain in an intermediate position between illness and normalcy. It is they who are the potential recipients of further diagnostic acts and therapies and they co-constitute a dynamically developing area of neuroeconomy.

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W jednej z publicznych szkół podstawowych w średniej wielkości polskim mieście przeprowadzono badania dzieci przy użyciu nowego narzędzia służącego do diagnostyki ADHD. Sytuacja ta stała się punktem wyjścia dla refleksji etnograficznej na temat współczesnych praktyk diagnozowania zdrowia psychicznego dzieci. Programy wczesnego wykrywania zaburzeń, które coraz częściej wkraczają do przestrzeni szkolnych, generują kategorię „pacjentów-w-oczekiwaniu" – osób, które przez dłuższy czas znajdują się w pozycji liminalnej pomiędzy chorobą a normalnością. Są to potencjalni odbiorcy dalszych działań diagnostycznych i terapii, współkonstytuujący dynamicznie rozwijający się obszar „neuroekonomii".

Keywords: ADHD, neurotechnology, diagnosis, medicalisation, Poland, patients-in-waiting, neuroeconomy

> "Scientific objects may not be invented, but they grow more richly real as they become entangled in webs of cultural significance, material practices, and theoretical derivations" (Daston 2000, 13)

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This paper[2] is about ADHD[3], and a diagnostic tool, namely an ADHD scanner that was used in a local school in Poland to preliminary diagnose children. The ADScan system was initiated in Germany as a result of cooperation between a commercial company and academic institutions with the common aim of creating a tool for an objective diagnosis of ADHD. The diagnostic process requires space of a particular dimension, a chair, a measuring apparatus, analysis software, as well as a person to diagnose and one to be diagnosed. The diagnosis comprises two steps. The first part includes a Continuous Performance Test (CPT) used to assess attention processes, impulsivity and reaction time. A child, following instructions, is required to press a button on a sphere which he or she holds in his/her hand when specified symbols appear on a small device placed in front of him or her. The second part of the test employs Doppler radar technology which measures the frequency and intensity of a child's bodily movements. The child is expected to obey the instruction to sit still until the diagnostician announces the end of the test. The collected data is then analysed by software called an ADScananlyzer which produces both graphic and numerical representations of the data. This is then compared with a short questionnaire filled out either by a parent or by a teacher based on the Diagnostic Statistical Manual[4] – psychiatric technology widely used in the medical diagnosis of ADHD. A diagnostic summary is eventually written by the person who conducted the test.

What will follow here is an ethnographic description of the materiality and the practices that stabilize ADHD through the application of this particular diagnostic tool in one Polish school. This study hints at the gradual appearance of standard regimes that enable the circulation of biomedical and neuroscientific knowledge and capital in the Polish schooling system (see Lakoff 2005), turning increasingly exposed to medical knowledge and practice, Polish families into potent consumers of diagnostic and therapeutic practices and situating school personnel as active agents in diagnostic processes. Relating the ethnographic story of introducing the scanner into a local school in Poland, I take a closer look at the ways ADHD is being embedded in a local context,

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[3] ADHD stands for Attention Deficit Hyperactivity Disorder. It is a psychiatric diagnostic category which describes a neurodevelopmental disorder diagnosable in childhood involving symptoms of hyperactivity, inattention and impulsivity. ADHD is included in such diagnostic manuals as the International Classification of Diseases (ICD) and the Diagnostic Statistical Manual (DSM) issued by the American Psychiatric Association. A standard therapy involves cognitive-behavioural programmes and pharmacotherapy.

[4] The information is taken from the Biomed website, a Polish company which uses this technology for conducting preliminary ADHD diagnoses in children (https://www.biomed.org.pl/adscan.html#breadcrumb; access 5.03.2019).

material and practical networks and support systems, among others, through the usage of specific equipment and procedures (Latour 2000). As noted by Lorraine Daston:

> "The persistence of scientific objects depends on the institutionalization of practices and an impressive array of apparatus" (Daston 2000, 12).

The tool I wish to talk about is just one example of a newly institutionalized practice intersecting commercial and academic interests, as well as the bureaucratic machine that embeds ADHD in the Polish educational system.

Interpretation of my ethnographic material will take place in relation to recent discussions concerning: the medicalization of child development, the encroachment of diagnostic cultures into schools, the influence of neuroscientific discoveries on contemporary society and models of normal child development advances in self-diagnosis, the infiltration of neurodevelopmental expertise by various actors representing divergent economic and non-economic interests, as well as the commodification of diagnostic and therapeutic technologies and services. Finally, light will be shed on the uncertainty and disorientation generated by the usage of the scanner in primary schools in the town where I conducted my fieldwork.

ETHNOGRAPHIC FRAGMENT 1

In the winter of 2016, the local Department of Education in Malden[5] organised a conference entitled "Diagnosing and preventing psychiatric problems among school children". A number of experts were invited to give lectures to an audience composed of school personnel, mainly psychologists and pedagogues. One of the contributors was Professor John Markovitch[6] from a local university who talked about ADHD and a new diagnostic tool that would identify the disorder in children through an objective measurement. He publicly announced a future research project in which he would test the device, already available on the Polish market, on children and inviting local primary schools to participate. The proposal appeared to be a screening programme that would help single out children suffering from hyperactivity. Shortly after the conference, the staff of the local educational office placed a short website notice inviting schools to contact the aforementioned academic if they were interested in taking part in the project. No mention was made about the commercial origin of the diagnostic technology to be employed. The research was introduced as being under the auspices of the university. In an interview I conducted with Professor Markovitch, he told me that interest on the side of the schools was immense, so much so to the extent that the

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[5] Malden is a pseudonym given to a middle size Polish town.

[6] All names used in the text are pseudonyms.

email address announced on the website jammed. This jammed inbox confirms the craving which exists for firm psychiatric diagnoses in children among Polish- school-personnel. It further evidences an ongoing transformation of medical knowledge and practice and its gradual encroachment into educational spaces[7].

I learned about the conference in the course of my fieldwork from Alina – a pedagogue working in a primary school in Malden. Alina is in her forties and has extensive experience working with children and she seems engaged in her work and perceptive of children's problems. Her school was the first I visited regularly during my fieldwork and I came to her office twice a week to talk and observe. I was also afforded the opportunity to interview the teachers and conduct a participant observation in a class in which one of the pupils had an ADHD diagnosis. That day, in an animated voice, Alina tried to explain to me about the ADHD scanner and stated hopefully it would be possible to have it in every school so that psychologists and pedagogues could identify children in need of support and surveillance. She shared with me one more important message that she had brought back from the conference: "I imagined that children can outgrow ADHD" – she confessed.

> "At the conference, there was a lady who drew our attention to the fact that a child who has such a disorder can later suffer from depression, easily become addicted, commit suicide and cause accidents" – she enumerated the ailments in a worrisome tone (*from fieldnotes*).

The research

This article is based on fieldwork conducted between 2015 and 2017 in Malden. My aim was to understand children's experiences of the ADHD diagnosis in one location in contemporary Poland. I followed ADHD practices through different field sites in Malden (schools, homes, medical spaces and psychological centres). With different intensity, I gathered material focussing on a number of children. I used a mixed methodology depending on what was possible in each case, conducting ethnographic interviews with carers, family members, teachers, school directors, psychologists and psychiatrists. In a number of specific cases, I regularly visited some of the children's homes. In five cases, I carried out participant observations in schools and in two cases I conducted research in focus groups with the focal child and his/her classmates. With one teacher and one mother, I worked using autoethnographic diaries. Over the course of six months, I took part in a therapeutic group for ADHD children run in a public psychological centre. In this centre, I participated in educational meetings organised

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[7] See Dominique Béhague's work on the historical and contemporary expansion of psychiatric knowledge and practice (2008), Nikolas Rose's article about the expanding scope of psychiatry (2006), a volume edited by Zsuzsa Millei and Eva Bendix Petersen focused on the ways in which the psy-complex plays out in contemporary educational spaces (2016) or Valerie Harwood and Julie Allan's work on a similar topic (2014).

for parents and teachers and where possible in diagnostic, therapeutic meetings or consultations with parents and/or children and kept abreast of academic research conducted in this town on ADHD when it spilled over into the educational space. I also interviewed the limited number of child psychiatrists working in Malden. Finally, but no less significantly, I worked with the diagnosed children using participatory methodology derived from new childhood studies and I followed "The Code of Good Practices in Research with Children for Social Sciences" written by the Childhood Studies Interdisciplinary Research Team at the University of Warsaw (Maciejewska-Mroczek *et al.* 2015; Maciejewska-Mroczek and Reimann 2017)[8]. The ethnographic material described in this paper was gathered after receiving written consent from the adults involved and oral consent for my presence during the diagnostic procedure received from the school principal and from the parents of children undertaking the test. The children participating in the diagnostic procedure were not asked for their consent by the researcher conducting the scanning procedure since it was desirable, according to protocol, not to inform the children about the purpose of the test. I had to follow suit and only queried each child whether they minded my presence in the room. My decision was an act of *ethics in practice* against my commitment to *procedural ethics,* whereby informing children about the research and procedural aims is a priority. However, in this instance for the sake of being able to observe a differently constructed research practice, I gave up on these standards[9].

Diagnostic cultures

In medical anthropology and in the sociology of medicine, ADHD is strongly associated with the concepts of medicalisation and overmedicalisation (Conrad 2007)[10]. On a very general level, medicalisation means to make medical what was not treated as such previously[11]. This was certainly the case with hyperactive, impulsive and inattentive behaviours in children which first started to be described in medical language in the eighteenth century. The ADHD label has a long and well-studied social and conceptual history (see Gorzkowska and Smachowiec 2012) and the biography of

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[8] The methodology of the research and ethical principles guiding it are described in detail in my monograph (Witeska-Młynarczyk 2019).

[9] For a discussion about pragmatic research to ethics in research practices with children see the work of Cindy Dell Clark (2011), Marilys Guillemin and Lynn Gilliam (2004), Anna Witeska-Młynarczyk (2018b).

[10] Ilina Singh has noticed that ADHD in Social Sciences is surrounded by a discourse of suspicion and worries about the social construction of disorder. She has postulated a more constructive approach to biomedical practices evolving around ADHD (Singh 2011, 889).

[11] For a detailed discussion of the concept of medicalisation in the context of ADHD see the works of Peter Conrad (1976, 1992, 2007). A similar concept, that of biomedicalisation, was proposed by Adel Clarke *et al.* (2003). In Polish literature, a solid discussion of both concepts can be found in Michał Nowakowski's book (2015).

this diagnostic category is illustrative of a wider trend involving the transformation of contemporary psychiatric knowledge and practice (see Béhague 2017; Béhague and Lézé 2015; Mills 2014; Witeska-Młynarczyk 2018a) into a more neurobiologically oriented one (Choudhury 2010), more reliant on pharmacotherapy (Mills 2018, 2014) and inclusive of younger and younger populations (Hollin and Pilnick 2015). What I describe in this text reveals much about the very local context of Malden, and about the larger processes of reformulation of contemporary childhoods.

Svend Brinkmann called a contemporary situation in which human suffering is being increasingly interpreted in terms of psychiatric conceptions and diagnostic categories as "diagnostic cultures" (Brinkmann after Nissen and Bech Risør 2018). Both enlarged disease definitions[12] and the increasing use of testing enabled by new technological developments constitute the key stimuli feeding diagnostic cultures (Nissen and Bech Risør 2018, 19). The medicalisation of human life is no longer understood as a top-down project (Clarke *et al.* 2003; Nowakowski 2015). It is developing on many fronts with different depth and pace as a consequence of actions taken by many medical and lay actors, as well as being sustained by newly emergent concepts and artefacts (Clarke *et al.* 2003). The encroachment of contemporary diagnostic cultures on childhoods necessarily brings about ethical and political concerns, resulting in alterations in human self-understanding, a redirection of attention and action, as well as the instigation of changes in the way both children and care are conceptualized. For Brinkmann, one of the main questions to reflect upon is whether

> "there is indeed a growth in ill health, or whether the proliferation of diagnoses, supported by new diagnostic practices and technologies, reflects a tendency to pathologize certain behaviours as disease" (Nissen and Bech Risør 2018, 12).

Overdiagnosis remains one of the main issues discussed in sociological literature in relation to ADHD (see Wessely and Singh 2015). Further investigation needs to be undertaken into the disorderly diagnostic process beginning at school with a preliminary scanning programme which results in a number of children entering a grey zone holding uncertain diagnoses.

The story of the ADHD scanner is a story of a tool which promises certainty and objective measurement to people who in their everyday work face a growing number of children whose behaviours can be categorised as impulsive, hyperactive and inattentive[13]. Particular care must be taken in making diagnostic tools and psychiatric

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[12] See for example Peter Conrad's and Deborah Potter's work on the expansion of ADHD diagnostic category to adults (2000).

[13] In interviews and small chats which were conducted with teachers during my research one motif came up repetitively – that of an ADHD epidemic. People I talked to often reflected upon differences between generations claiming that contemporary children have changed, that it has become more difficult to work with them and that many of them seem inattentive and hyperactive.

labels available in educational spaces for a number of reasons such as stigma, ableism[14], sanism[15] and adultism[16] (Liegghio 2016; LeFrançois 2008; Witeska-Młynarczyk 2019). Other reasons for care include the fact that labels tend to stick to disadvantaged kids (Blum 2011) and also because they strengthen the binary opposition of normal and abnormal (Liegghio 2016). My aim here is not to offer to the reader an anti-medical or anti-technological text, as I find contemporary neurobiological explorations fascinating and valuable. What I want is to shed light on the social life of the new knowledge and to propose a critical reading of real life situations. The role of the ethnographer is to describe how new technological developments change people's lives, among others, by providing new interpretative frameworks (Penkala-Gawęcka 2017, 185). In this text, how an expanding diagnostic culture thrives in one locality and how new technological solutions are entangled with commercial interests, academic careers, educators' search for solutions, and individual biographies will be highlighted ethnographically.

ETHNOGRAPHIC FRAGMENT 2

It was early June 2017 in Malden, nearly eight o'clock in the morning when I parked my bicycle in front of a large educational compound comprising of a primary, middle and secondary school. I had scheduled an appointment with three people: Anette – a woman in her thirties who works as a school psychologist, Marek, same age as Anette, who works as a school pedagogue, and Magda – a student in her twenties, pursuing an MA degree at a local university. The latter is a member of Professor John Markovitch's research team and the day in question, she was due to test a new device for diagnosing ADHD in children in this school. The kids were chosen by elementary education teachers as those "suspected of ADHD". The parents had already signed a consent form given to them by the educators. Magda agreed for me to observe her conducting research. She entered the building not much later than myself, carrying a laptop bag over her shoulder, a black suitcase in her left hand and a long leather case in the other. These intriguing items later turned out to belong to the neuroscientific world. Anette led us to the room where the examination was to be conducted. Magda rearranged the tiny classroom according to her research protocol and together with Marek removed the tables and chairs in order to create the empty space of specified dimension required by the test protocol. On one end of the room they placed a desk

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[14] Ableism –prejudice and discrimination against disabled people.

[15] Sanism – prejudice and discrimination against people recognised as suffering from mental illness or being neuroatypical or those who are recognised by society as unhealthy.

[16] Adultism – discrimination against young people based on the conviction that adults are rational, wise and mature while children and young people are immature and incapable of making rational decisions.

with a laptop. On the other side, Magda fixed a chair for children. A young researcher set up the apparatus – the ADHD scanner based on Doppler radar technology which was to examine attention and the ways in which children react to specific stimuli, as well as their propensity to move. Alas, it is impossible that everything be arranged according to the protocol when research is being undertaken in schools.

> "A chair was required to be a certain type, but schools do not have such chairs, so, sometimes they tried to give the child something to rest its legs upon"
> – Magda complained when inspecting an adult chair on which six and seven years old children were expected to sit.

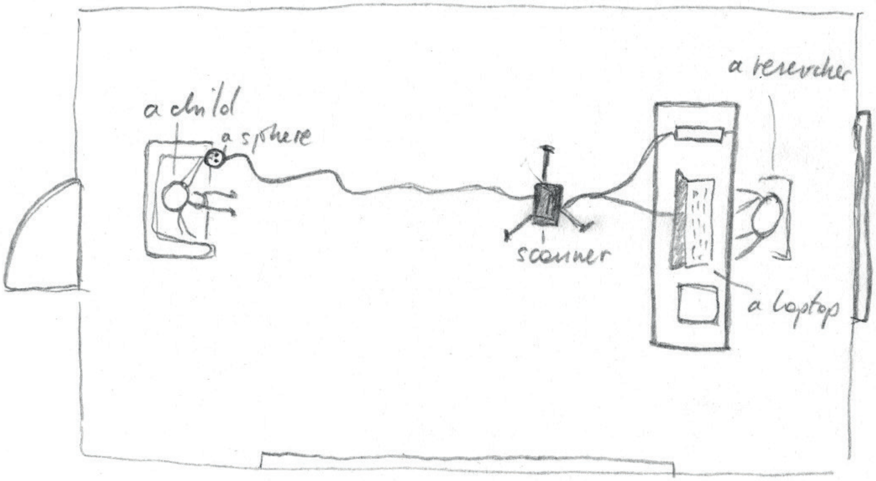

Figure 1. The arrangement of space for the test (a drawing from fieldnotes).

Diagnoses go to school

One important element of medicalising childhoods and human development is the growing involvement of non-medical personnel in diagnostic processes, in particular, the involvement of schools in spotting developmental disorders (see Meckel 2013; Armstrong 1983, 1994) and thus prompting further diagnoses. It is evident from other ethnographic contexts that in the case of ADHD, lay people play an increasingly significant role in accomplishing the routine work of medicalisation (Conrad and Bergey 2014; Malacrida 2004). Valerie Harwood and Julie Allan characterise the contemporary moment as one in which there is no hesitation:

> "[T]he current climate in education is one of acceptance and promotion of psychopathology as the default explanation of problems" (Harwood and Allan 2014, 18–20).

The jammed mailbox of Professor Markovitch confirms this hypothesis.

Mary Ebeling (2011) studying Premenstrual Dysphoric Disorder (PDD) and the promotion of self-diagnosis within pharmaceutical marketing campaigns in the United States discussed ways in which the commercial promotion of self-diagnosis and efforts on the side of pharmaceutical marketing reconfigure patients into consumers "who actively seek out diagnosis and treatments based upon their self-assessments of symptoms" (Ebeling 2011, 826). The idea behind the ADHD scanner, as submitted to school personnel, was that in the future, with the aid of this device, screening practices would possibly take place in schools and they would be run by staff members. Following this line of thinking, I suggest considering the encroachment of preliminary diagnostic practices into Polish educational institutions in the light of sociological literature concerned with the contemporary increase in self-diagnoses (Clarke and James 2003; Ebeling 2011; Stockl 2007) and biomedicalization (Clarke at al. 2003). Self-diagnosis normally refers to the patient's preoccupation with his or her health. Yet, in the case of children, it is commonly adult carers who take the diagnosing steps. In the case of school children, a triangle consisting of parents, teachers and psychological experts play a key role in fuelling the demand for a medical diagnosis. Yet, some larger actors (including transnational and governmental ones) are also involved in this process.

Before the scanner was tested in the school, a number of actions were taken in Poland by various commercial actors (pharmaceutical companies and companies selling neuroscientific know-how and technology, entities providing complementary products used for treatment) allied with non-commercial entities (doctors, officials and lay activists). The actions taken by these actors were meant to increase knowledge about ADHD in Polish society, promote self-diagnoses and legitimize particular treatments. Following Lakoff (2005), I recognize these as an integral part in the process of the creation of standard regimes that would allow the emergence of zones of potential circulation of the scientific object I am interested in.

Christine B. Philips (2006), in her short article, calls teachers "brokers for ADHD and its treatment", because they are the ones who single out children with "abnormalities" in the first place. Such was the case in the school in Malden, where teachers proposed pupils for testing. Yet, in order to become brokers, teachers have to gain knowledge about the disorder. Philips draws attention to the role of the pharmaceutical industry in this process. In Poland, the formulation of professional education about ADHD for teachers has come as a concerted effort of leading Polish child and youth psychiatrists, pharmaceutical companies, NGOs and the state including local bureaucracies (Witeska-Młynarczyk 2019)[17]. A good example is the educational programme "Dziecko i świat za pan brat" ["A child and the world-brothers in arms"] implemented by Janssen-Cilag – a company producing and distributing a pharmaceutical product named Concerta used in treating ADHD in children. The programme kicked off in 2010 under the auspices of the Ministry of Education and the Ministry of Health. It was planned as a long term project whose aims were to organise complimentary lectures and workshops for Polish-school-personnel by major expert figures in ADHD in Poland. Furthermore, the plan included the printing of educational materials about the disorder for teachers and parents, as well as the launching of an educational campaign in the mass media (Witeska-Młynarczyk 2019). During my research, I met teachers who were enthusiastic about the programme, such as a pedagogue from a primary school in Malden:

> "[Pedagogue:] There was a lot of valuable materials! For the teachers, for the school, for the parents. I even made available booklets which I gave to the parents of children I knew were facing such problems. (…)
>
> [Me:] How did the programme reach you?
>
> [Pedagogue:] Well… I follow what happens in Malden, what is available. I cannot recall now, but I was reading a variety of websites run by the Ministry of Education or by the Centre for Education Development or the local centre organising professional education for teachers, I met colleagues on sessions devoted to this methodology and there were materials available there too. (…)
>
> [Me:] Did you get the materials?
>
> [Pedagogue:] Not only did I attend the workshop. (…) but we also met in a larger circle, where there were psychologists, educators working in schools and psychiatrists. The workshop was led by a psychiatrist. (…) Obviously it was sponsored by a pharmaceutical company. (…) Even this year, I gave such a booklet to a parent".

Another pedagogue spoke about the meetings organised as a part of the same programme:

> "There was a very important part devoted to the consequences of ADHD and what the potential risks are if an ADHD child is not properly managed. They mentioned the percentage of suicides and the need to support the children pharmacologically".

Teachers' role in diagnosing is actually written into psychiatric technologies such as the DSM[18]. Diagnostic standards demand that the symptoms typical of ADHD are

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[17] "Dziecko i świat za pan brat" has been described on the websites of local educational departments as a long-term educational campaign targeting school personnel. Its broad aim was identified as the dissemination of knowledge about ADHD (see www.kuratorium.waw.pl. Access: 06.09.2018).

[18] Andrew Lakoff uses a term "liquidity" to enable a discussion of ways in which illness is made abstract and therefore exchangeable. He underlies the power of the diagnosis to produce an equivalence and allows for an emergence of an epidemiological population, which has potential of constituting a market segment (Lakoff 2005).

observed in a child in at least two different environments, which typically implies family and school. Philips noticed that the diagnostic criteria "accord teachers a formal role in diagnosis through specialised assessment instruments such as the Conners Teacher's Rating Scale" (2006, 433) – which is a list of questions about a child's behaviours that teachers have to choose an answer for. This scale is also used in diagnostic practice in Poland as a one- page- long form which lists eighteen questions concerning the symptoms of hyperactivity, impulsivity and inattention[19]. The space for the educators' voice, as it is crafted in psychiatric diagnostic technology, does not imply an open collaboration or active participation. Teachers fill out the forms brought by the parents and parents serve as intermediaries between the medics and educators. A conversation with an educator is not a part of the diagnostic standard[20].

As argued by Harwood and Allan:

> "Contemporary assessments of child mental problems are (…) informed by psychiatric categories from the DSM, with this system increasingly used in schools, and especially in the determination of the identification of problems that require financial support" (2014, 18–20)[21].

Such a questionnaire was also a part of Professor John Markovitch's research scenario. The DSM element rooted the research project in legitimate psychiatric knowledge and technology. It allowed for inclusion into the experimental diagnostic procedure an element of the standard one.

Yet, teachers also play a more informal role in preliminary diagnostic work (Dew and Jutel 2014) and are called by Philips "disease-spotters" (2006, 434)[22] – i.e. the initiators who push families onto their diagnostic journeys. The role of Polish teachers and their influence on the increase of diagnoses, has yet to be researched. My ethnographic work suggests that the role of school personnel in singling out children with ADHD increases, yet, the picture seems inconclusive, as the label is also often contested by educators (Witeska-Młynarczyk 2019). Philips described the entire process as an "organized penetration of the pharmaceutical industry associated with ADHD into the education domain" (2006, 434). She underlines that the materials provided by these companies "channel the reader toward medical therapy with pharmaceutical substances" (2006, 435). However, the story of the ADHD scanner reveals that the processes involved in

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[19] Examples of questions for which possible answers are –„agree, quite agree, disagree" are the following: a child is excessively talkative and a child is forgetful in everyday life.

[20] I saw during the research rare cases in which a psychologist diagnosing ADHD in a public psychological centre went to the school to observe children during classes.

[21] See Michał Wróblewski's work about the infiltration of the Polish educational system with neurobiological definitions of ADHD and the Americanisation of Polish psychiatry (2017).

[22] A similar reflection was developed by Claudia Malacrida for Canada and Great Britain in the context of ADHD, where teachers, special educators and school psychologists "identify, assess and administer medication to «problematic» children" (Malacrida 2004, 61).

the medicalising of children's behaviours are more nuanced. The penetration of educational spaces with psychiatric knowledge is regulated by bureaucratic measures and it involves many actors whose interests sometimes converge and sometimes depart.

The brain project

The term neuropsychiatry emerged in the 1920s and became popular in the 1950s. Its purpose was to indicate that "the future of psychiatry lays in the integration of insights from genetics and neurobiology into clinical practice". The neuro-prefix was to designate "a novel explanatory framework" (Rose and Abi-Rached 2013, 6). Horwitz and Grob note that:

> "In contrast to much of medicine, where physicians can often use laboratory procedures, imaging devices, and objective observations, psychiatric definitions typically involve ambiguous, uncertain, and contested definitions; many treatments for mental illness are correspondingly unspecific and general (…). The high degree of indistinctness among psychiatric symptoms means that the development of accurate diagnostic systems is especially problematic (…)" (Horwitz and Grob 2016, 522).

In psychiatry, where the diagnosis is still based on patient-reported information (and in the case of children, carer-reported information) sometimes complemented by clinical observations, the craving for more specificity and accuracy is robust. Uncovering the biomarkers[23] for specific disorders seems particularly significant for child and adolescent psychiatry, because of the discourses of risk and early prevention. The cultural tendency to treat children-patients as incompetent is not irrelevant here. Genetic screening and neuroimaging (the main techniques for identifying biomarkers) "could be used to access children before the symptoms appear". Early diagnosed childhood disorders already function as "biomarkers" used for identifying children at risk of more severe ailments (Singh and Rose 2009, 202). In this sense, scanning children for ADHD can be understood as a screening programme singling out kids who will be in need of long-termed assistance.

The presence of the ADHD scanner in this particular school is part of a more general shift in biomedical sciences, and in psychiatry in particular, but more so in the societies of the West, where "our brains are becoming central to understanding who we are as human beings" (Rose and Abi-Rached 2013, 2). Jonathan Rowson (2011) calls our age one of "neurological reflexivity" meaning an incorporated imperative of being conscious of ongoing neurobiological processes, feeling obliged to learn how to manage them, taking responsibility for oneself and ones' children, changing one's condition and increasing one's chances for a successful life by acting upon the brain. Rose (1999) suggests that such a focus is typical for contemporary neoliberal societies where the so called "pedagogies of brain awareness"

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[23] A biomarker is a certain pattern of brain activity.

constitute a part of the contemporary practices of perfecting the self (Rose and Abi-Rached 2013). Thus far, mental processes were a preoccupation of behavioural and psy-sciences, yet with technological developments which allow for the looking into of the molecular level of people's lives, mental states and behaviours became explicable "in material ways as the outcome of biological processes in the brain" (Rose and Abi-Rached 2013, 10). This forecast includes a discovery of biomarkers for each disorder and the possibility of early screening and intervention (see Hollin and Pilnick 2015).

The focus on small children based on the discourse of early intervention is an integral element of the "brain project". Rose and Abi-Rached argue that "futurity is central to contemporary problematizations of the brain" (2013, 14), and for this reason much of the research and designed interventions focus on children. Ilina Singh and Nikolas Rose note that

> "many pathologies are now reframed as developmental and hence amenable to early detection and ideally to preventive intervention" (Singh and Rose 2009, 15).

The aim is "governing the future through the brain". The molecular is slowly turning into the trademark of contemporary biopolitics (Rose and Abi-Rached 2013, 12).

Neuroeconomy

One of the elements of encroaching medicalisation as called by Adele Clark and others (2003) is the commercialisation of research and an enlarging market for biotechnology. The diagnostic tool, the usage of which I have described was introduced onto the Polish market by a commercial company whose main preoccupation were electroencephalography (EEG) tests and neurobiofeedback therapy (a non-drug treatment in which people learn to control bodily processes, such as attention)[24]. This enterprise sells both technology and know-how. In fact, to a certain extent, it is competing on the therapy market with pharmaceutical corporations. On the company's website can be read:

> "based on measurements taken by the ADHD scanner, it is possible to objectively state whether the patient suffers from the syndrome of attention deficits (ADD) with hyperactivity (ADHD) or without it".

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[24] The method rests on the assumption that human brain is malleable. The aim is to teach the brain to work better through the usage of neurotechnology. Technically, during a session, a client is attached to an EEG machine by electrodes placed on his/her head. A real-time scan of the client's brain waves appears on the screen. A therapist gives instructions based on this image which are meant to adjust the brain waves. Frequently, this involves playing a video game and performing assigned tasks. This is done to bring changes in the brain's output which are hoped will translate into changes in behaviour. The results depend on the frequency of the sessions and the length of the period the training lasts.

The diagnosis is described as being as accurate as the Conners' tests (questionnaires created for diagnosing ADHD for parents and teachers, and most recently also for children). Reference to "objectivity" and "accuracy" are important, in particular if they are compared with actions taken by one of the pharmaceutical companies selling drugs used in ADHD related therapy. During my fieldwork, this corporation disseminated a poster on which neurobiofeedback was described as "a non-verified method of treatment", in psychiatric and psychological centres for children (Witeska-Młynarczyk 2019). The company selling the ADHD scanner in Poland however promotes biofeedback claiming that the therapy is as effective as drugs[25] while additionally being non-invasive. This sounds convincing, taking into consideration the anxieties felt by parents in regards to pharmacotherapy (see Witeska-Młynarczyk 2019). The clashes amongst various entities making a profit from selling biomedical technologies – drugs, diagnostic tests, scanners, all take place in the background of projects focusing on the psychiatric health of children.

Visible here is also the convergence of commercial and academia interests. The research team of which Magda is part of aims at discussing the significance of the ADHD scanner for the objectivisation of the diagnostic practices in academic journals. Their positive conclusions may be significant for the future usage of the apparatus. Both Magda and another student also part of the research team claim that the tool they were testing allows for "objective" measurement which would eliminate uncertainty and human error often made by medical personnel.

Rose and Abi-Rached (2013, 18) coined the term "neuroeconomy" to name the described occurrences. They underline that the academic and industrial components intersect, especially when linked with the entrepreneurial spirit on the part of universities. Such a convergence of interests has resulted in me having been afforded the opportunity of observing how a number of children walk into a small classroom one by one to take part in the test in one of the public schools in Malden.

ETHNOGRAPHIC FRAGMENT 3

"[Magda:] Your name is George, yes?
[George:] Shakes his head].
[Magda:] Sit down here on this chair. You have amazing underground passages in this school. One can easily get lost.
[George:] I do not get lost.
[Magda:] Do you remember your date of birth?

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[25] More specifically they refer to Ritalin, which is a name under which psychostimulant drugs are sold in the USA.

[George:] 17th of September.
[Magda:] And what year?
[George:] I do not know.
[Magda:] And how old are you?
[George:] Six.
[Magda:] And what is your last name?
[George:] Marcinkiewicz.
[Magda:] I will explain everything in a minute. Are you nervous?
[George:] No.
[Magda:] Oh, that's great, there is nothing to be nervous about. Now, I have a sphere for you. Lean back in your chair comfortably. Your task is to press this button when there appears a square and a plus, ok?
[George:] Ok.
[Magda:] Let's have a trial run first.

They undergo a trial run.

[Magda:] And you see, here, at the end there was a square followed by a plus and you have to press very fast. Your task will be exactly the same, only longer, so you will have to focus, ok?
[George:] Ok.
[Magda:] Can we start?
[George:] Yes.

The task starts. Magda walks to her place in front of the laptop. She does not speak any more. She does not maintain eye contact with the boy. She does something with her phone. After ten minutes she speaks again.

[Magda:] Was it difficult or easy?
[George:] Difficult.
[Magda:] It was long, wasn't it? And now there will be a second part of the task. Lean back comfortably in your chair, put your hands here. You will sit like this for a while, ok?
[George:] Ok.
[Magda:] The task will end when the apparatus will squeak, ok?
[George:] Ok.

The boy, very lively, brisk and talkative now sits in an armchair without moving. He approaches the task very seriously. He does not move his feet until the last minutes of the research. After ten minutes Magda speaks again.

[Magda:] Ok, this is the end. You made it.
[George:] Yes.
[Magda:] Wait a moment, I will walk you to the class [from fieldnotes]".

Diagnosis as a process

A diagnosis is often understood as a critical moment leading to a healing procedure. It can be understood as a term or a category which puts the world in order. You get to know that your child is suffering from ADHD, learn about the disorder and how to help resulting in a gradual improvement. Yet, the diagnosis can be also understood as a process (Jutel 2018). Anthropologists and sociologists increasingly imagine it as a "diagnostic work" and as a "disorderly process" (Goodwin and McConnell 2014; Jutel 2011; Nissen and Bech Risør 2018) engaging various actors, things, ideas and places, a "doing the disease" (Mol 2002). Also, a diagnosis is no longer understood as predominantly associated with healthcare situations. It can happen in various spaces both medical and lay, as well as being capable of being shaped by expert and non-expert voices and judgements (Büscher, Goodwin and Mesman eds., 2010). Nissen and Bech Risør note that:

> "Processes of a diagnosis include any activity surrounding investigations, assessments and negotiations pertaining to clinical and non-clinical judgements of ill health. Different actors with their skills, experiences and sensing bodies are involved in these processes, in conjunction with technology and instruments of measurement. Studies of such processes have explored the enactment and the making of a diagnosis with particular focus on subtle intersubjective processes between health professionals and patients" (Nissen and Bech Risør 2018, 15).

The diagnostic work performed using the ADHD scanner in various schools in Malden involved many actors, most directly the local educational office, the school, teachers, parents, the local university and the commercial company. When the act of scanning is looked at as one of many events in a longer diagnostic process, its preliminary character is clearly visible.

The grey zone

Current biomedical developments push many individuals into a grey zone – at the edge of disease or at risk of developing one. As noted by Nissen and Bech Risør (2018, 20), new technologies, biomarkers and the desire to know, play a key role in shaping the diagnostic work. The same authors envisage the role of anthropologists to be those critically studying the diagnostic landscape as perforated by risk discourses, an abundance of screening programmes, testing and the use of new technology (Nissen and Bech Risør 2018,19). I suggest viewing the described assessments as actions transforming children into "patients-in-waiting" – a form of liminality which is characteristic of contemporary healthcare (Timmermans and Buchbinder 2010). Patients-in-waiting is an umbrella term coined by Stefan Timmermans and Mara Buchbinder "for those under medical surveillance between health and disease" (2010, 1). In their article, the authors worked on ethnographic evidence referring to the screening of newly born children, yet, they also suggested that the characteristics of patients-in-waiting may be found in other populations. One of the groups they mentioned were children with suspected developmental disabilities undergoing broad assessments.

Patients-in-waiting inhabit a liminal state between pathology and a state of normalcy. The assessments these people undergo do not necessarily result in a certain diagnosis but they may hint instead "at something" while leaving "ambivalent whether patients-in-waiting are already sick, are going to become sick and, if so, what their sickness will entail" (Timmermans and Buchbinder 2010, 417). The authors suggested that the uncertainty of disease is imposed on the patients and should be understood as a by-product of the logic of the population screening programmes in which "for every true positive case there are many more cases with uncertain results" (Timmermans and Buchbinder 2010, 417). They argued that:

> "The production of patients-in-waiting relates to the way screening and testing is implemented with shifting alliances between vocal patient groups, testing companies, and public health programs, combined with varying heuristic practices for interpreting results" (Timmermans and Buchbinder 2010, 418).

ETHNOGRAPHIC FRAGMENT 4

In a school corridor, nine-year-old Steven is waiting to be the first to take part in the test. He is the only one accompanied by a parent today. When Steven walks into the room to undergo the test, I ask his mom how it happened that they were there. She recounts a story of a very calm and gifted boy, who, when he started school, knew how to read and knew much more than other kids.

> "Steven was very obliging and mannerly in the first grade. Later, he started to, maybe not be rude, but to differ from the pattern she [the teacher – AWM] envisaged (…). And problems started – he did this, and he disturbed other children".

The mother never thought of Steven as in need of tests or psychological assistance. When I asked her about her knowledge of the disorder, she said:

> "The notion appeared a while ago [the ADHD – AWM] and I heard it somewhere – this is how all naughty children are labelled. They do not know how to deal with them and the easiest way is to say that a child has ADHD. Yet, whether these children have ADHD for real or if they are simply, I do not know, whether this is solely a question of an abundance of energy (…)".

Steve's mother's words display a lack of medical knowledge about the disorder or may even be interpreted as an anti-medical stand. Yet, even with such a starting point, the woman seems ready to enter the diagnostic process proposed by the teacher. Steve's mother holds the teacher responsible for her child's problems at school. Her motivation for making Steve participate in the test is to show the teacher that the latter has been mistaken about her son and that she should have given him more tasks if he was bored because he did everything faster than the rest of the class.

> "[Steven's mother:] She [the teacher – AWM] also told me that (…) it was not only her who complained – the teacher of religion, the English teacher – they all say that Steve disturbs, that he cannot focus, that he starts one action and fails to finish it. She wrote me once (…) that there would be such and such an examination and whether I would like my child to participate. I suppose that this was done to show my child up and indicate that he is abnormal, autistic or something of that sort. But he is simply different, has more energy, does things faster, and maybe he needs more incentives, so I said – 'So what have I got to lose in the circumstances?' (…) If it turns out that Steve has ADHD, well, I do not know what it means for later, for his adult life, or for his teens and whether I indeed should worry and do countless tests. I assume that the psychologist will tell me".

During our short conversation, there also came a moment of transition, when the woman started to look for symptoms:

> "It is true that when he does homework, he does not do it alone, because he does not want to stay in the room by himself. He prefers to stay with me. I am doing things in the kitchen and he sits at the table. I am working and he sits. When he sits down and something piques his interest he will sit and do it".

This day marked the beginning of Steve's ADD story.

The results

After a few months, the school received a "psychological opinion" about each participant. An affirmative diagnosis, such as the one below, constitutes the beginning of a diagnostic journey and the conferring of an identity on a patient-in-waiting meaning for one of the children who took part in the diagnostic procedure:

> "Based on the research that took place on 3rd of June 2016 employing an ADHD scanner and a questionnaire for the evaluation of ADHD symptoms, the following can be stated:
> - In terms of hyperactivity measured in a state of inaction, the child did not reveal any malfunction, which means that he is able to restrain from physical movement when required. In a task situation the physical activity remained at a normal level.
> - In terms of evaluation of attention deficits, the child revealed serious difficulties;
> - In the questionnaire-based evaluation the child revealed severe disorders both in terms of attention deficits and hyperactivity;
> - The outcomes of the objective measurements confirm that the symptoms indicated by the teacher were present.
>
> The discrepancy of the outcomes based on objective and subjective measurements of hyperactivity may suggest that the unwanted behaviour of a child results, to a significant extent, from environmental factors. The appropriate treatment of a child in its surroundings can decrease the exacerbation of the disorder in everyday life.
> To put it succinctly, it was possible to diagnose this child with ADHD attention deficit type".

The opinion given bares an official university stamp and the signature of Professor Markovitch. This paper marked one child as suffering from ADHD but many more questions arise including what the real consequences of this situation are, is this opinion already a diagnosis and how should it be interpreted and what to do about it?

ETHNOGRAPHIC FRAGMENT 5

On an autumnal day, at the psychological centre on Meadow Street in Malden[26], I asked a psychologist and a pedagogue working there about a mother, who stepped into the room during our conversation asking about the possibility of attending some help session in regards to her son diagnosed with ADHD. The personnel looked at me and said:

> "A strange story. A child was examined by someone from academia. The mother came with a piece of paper stating the child has ADHD. Yet, what are we to do with it? To acknowledge this diagnosis? But on what basis? How was this diagnosis made? No, I do not see it – ADHD. Anyhow, he changed school. We will see how he will now function [from fieldnotes]".

In autumn of the same year, I met Maria (– a speech therapy student pursuing a PhD on the topic of ADHD and speech problems) at the same psychological centre. She had come to the centre because she was searching for kids who had already been diagnosed to involve them in her research project. A psychologist working there alluded to Professor Markovitch's teams' diagnoses as a possible pool of research participants. Almost immediately, a discussion ensued about the validity of these diagnoses. People working there recounted a number of stories about children who had come to the centre with these diagnoses stressing the difficulty of their situations, in particular, because Professor Markovitch was a well-known specialist. Maria eventually took the position of inviting, only those kids who received diagnoses from a psychiatrist or from the psychological centre on Meadow Street – where a team of psychologists trained by Warsaw psychiatrists performed diagnostic work, to participate in her research. Nonetheless, a number of parents and their kids remain in limbo, looking for proper support for their children, post the issuing of a preliminary diagnosis issued as a result of scanning.

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[26] This institution specialising in diagnosing ADHD was one of my field sites.

CONCLUSION

From the 1960s onwards, an increased focus on neuronal functioning at a molecular level which, in turn, has fuelled technological innovations can be observed. One of the motives behind this was the search for reliable psychiatric diagnoses based on biological and physiological markers. The ongoing processes of biomedicalisation translated into the entrance of diagnostic technologies and knowledge into non-medical spaces, as well as their commercialisation and appearance under multiple forms (one of them being the ADHD scanner). Bearing in mind "the screen and intervene" logic characterising this "neuro project" and state health policies, schools have become a natural ally in testing new concepts and tools. They have become a natural laboratory, in which, as the ADHD scanner story reveals, various interests intersect and clash resulting in palpable tensions rising to the surface. Through the promotion of instruments capable of being used by a lay person, "diagnostic power is removed from the exclusive purview of medical authority" (Ebeling 2011, 831) and placed in the hands of adult carers on whom the child patient depends. This move does not only "redistribute power within medically mediated relationships" (Ebeling 2011, 831), but also sets in motion a complicated process of negotiation and meaning making, involving many actors and machines under which no one really holds control and the result of which is in each case uncertain. This generates feelings of anxiety and confusion in children and their families who get drawn into the process of the diagnosis of ADHD (Witeska-Młynarczyk 2019).

Some social scientists have signalled that the processes involved in the biomedicalization of childhood are not neutral and require much more ethical consideration. As noted by Nikolas Rose, new technologies may be used outside the laboratory and medical context "with consequences that ignore the multiple problems of interpretations and reliability that are inherent in these new technologies" (Rose 2014, 1214). Such a state of affairs seems to have arisen with the diagnoses produced by Professor John Markovitch's team, which have brought about a lot of ferment, despite the claim being made that they are simply an objective measurement and a helpful guide bringing parents closer to legitimate diagnoses.

The main concerns mentioned by Singh and Rose (2009) point to both the social and ethical problems posed by the use of biomarkers in psychiatry and include a focus on individual-level risk factors rather than on environmental and social issues. Laurence Kirmayer and Ian Gold would call this a reductionist perspective (2012). Singh and Rose postulate retaining complexity (2009), while Kirmayer and Gold put forward the postulate of "resocializing psychiatry" (2012) which has become overtly biologized. Furthermore, more questions need to be addressed such as those about the commercialisation and marketing of biomarker data in regard to child development, psychiatric conditions, emotional and cognitive capacities, as well as their consequences for the decisions taken by families (Singh and Rose 2009). In the case of the ADHD scanner, what is worrying is the fact that the research process was understood by both school personnel and parents alike as an actual diagnosis, when in fact it was no more than an uncertain screening procedure that turned children into patients-in-waiting. The ADHD diagnostic processes I have followed in my research project were fundamentally social in the sense that they resembled patchwork-like diagnoses (see Gardner at al. 2011) involving numerous actors, instruments, knowledges and social spaces. Preliminary diagnoses that have been undertaken with an ADHD scanner have proved particularly problematic as they have not been recognized by actors who are routinely involved in the diagnostic processes of children dealing with problems of children retaining attention, hyperactivity and impulsiveness. It seems that the zones of potential circulation of medical knowledge and practice are in place in Polish schools, yet, the regulatory regimes are somewhat lacking (see Lakoff 2005).

Finally, a crucial ethical issue concerns the ways in which children are treated in such semi-diagnostic and semi-academic situations. They are not provided with information about the purpose of the test, about the reasons why it is being conducted and what getting tested means for them. In addition, they are not even directly asked whether they want to participate, nor is respected their capacity to make decisions about the complex issues that often rise as a result considered (see Singh and Rose 2009).

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NORMALISED EATING AND DIETARY GUIDELINES IN LCHAD DEFICIENCY

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Dietary guidelines have become a ubiquitous feature of nutritional landscapes in a growing number of countries. Issued by departments or ministries of health and implemented by dietitians and health professionals, such guidelines are intended to govern the health of children and adults by regulating both the content and quantity of what they eat. While these dietary guidelines are intended for kids and adults who can and want to eat, they often serve as a reference point for the dietary treatment of patients whose appetites are considered abnormal, and/or who do not or cannot eat. Drawing from ethnographic research being carried out in Finland and Poland on LCHADD, a rare disease, this article juxtaposes dietary treatments prescribed for this disease with state and biomedical rationalities that govern “normal” dietary patterns and normalised eating. Treatment for LCHADD differs from general dietary recommendations for “normal” growing children. Despite stringent dietary guidelines for LCHADD, dietitians admit that there are no global standards in place regulating the consumption of prescribed nutrients; thus, recommendations may vary by country.

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Zasady dietetycznego odżywiania nieodłącznie wpisały się w krajobrazy żywienia coraz większej liczby krajów. Wydawane przez departamenty lub ministerstwa zdrowia zasady, wprowadzane następnie w życie przez dietetyków i profesjonalistów zajmujących się zdrowiem, mają na celu zarządzanie zdrowiem dzieci i dorosłych poprzez regulacje tego, co i w jakiej ilości spożywają. Zasady dietetycznego żywienia kierowane są do dzieci i dorosłych, którzy mogą i chcą jeść. Pomimo to, stanowią punkt odniesienia dla terapii dietetycznych pacjentów, których apetyt odbiega od normalnego i/lub którzy nie jedzą lub nie mogą jeść. W niniejszym artykule, opierając się na badaniach etnograficznych rzadkiej choroby, jaką jest niedobór LCHAD, w Finlandii i Polsce, zestawiam leczenie dietetyczne stosowane w tej chorobie z racjonalizacjami państwa i biomedycyny, które stoją za wzorcami „normalnego” żywienia i normalizacji jedzenia. Leczenie niedoboru LCHAD odbiega od ogólnych rekomendacji dietetycznych skierowanych do „normalnie” dorastających dzieci. Chociaż zasady odżywiania dietetycznego dla pacjentów z niedoborem LCHAD są bardzo restrykcyjne, dietetycy przyznają, że brakuje globalnych standardów lub norm, które regulowałyby konsumpcję składników odżywczych. W rezultacie rekomendacje mogą odbiegać od siebie w różnych krajach.

Keywords: dietary guidelines, standardisation, food, rare diseases. LCHADD, Finland, Poland

INTRODUCTION[1]

During our discussions of food and nutrient related issues, Dr. Aurinko[2], a dietitian working with LCHADD children (**L**ong-**C**hain 3-**H**ydroxyacyl-Co**A** **D**ehydrogenase **D**eficiency) at one of the university hospitals in Finland, often consulted a large volume titled *Clinical Paediatric Dietetics* (Shaw, ed., 2015). Along with her desktop computer, mountains of documents, bookshelves overwhelmed with literature and boxes laden with medicinal products, the volume was part and parcel of that spacious, well-lit and child-friendly university hospital office. As it turned out, the volume, which Dr. Aurinko virtually treated as the "bible" of metabolic diseases, enumerated dietary treatments for a large number of disorders. Written by UK based dietitians, it presented concise and universally applied dietary knowledge. But just how "universal" and "scientific" are the dietary guidelines recommended in this volume? And how are they implemented and contested in practice?

This article draws from research being carried out by three researchers among patients with LCHADD, their family members, physicians and members of patient advocacy associations in Poland and Finland since 2016[3]. Along with participant observation at patients' homes, culinary workshops and conferences on rare disorders in Poland, illness narratives and life history interviews were conducted with 21 and 6 patients and/or families in Poland and Finland respectively. Additionally, semi-structured interviews with 9 and 7 medical professionals (physicians, dietitians, geneticists, a psychologist and a speech therapist) were carried out in Poland and Finland respectively. Moreover, a few members of patient advocacy associations were interviewed

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[2] All names of the interviewees have been anonymised; additionally, age and gender details pertaining to patients with LCHADD have been altered to protect their privacy. Interviewees gave their verbal consent to participate in the research project. The majority of interviews were audio-recorded and transcribed.

[3] The project titled "Socio-Cultural Dimensions of Rare Diseases: The Case of LCHAD Deficiency. A Comparative Study of Poland and Finland" (2016–2019) is funded by the National Science Centre in Poland (Grant No: 2015/17/B/HS3/00107, PI: Małgorzata Rajtar, PhD).

in Finland[4]. As further ethnographic research in Finland is envisaged, in this article, I primarily scrutinise the Polish case. This project focuses on LCHAD deficiency, a rare metabolic disease. Our research is being conducted in Finland and Poland, which are both located in the Baltic Sea region. LCHADD belongs to fatty acid oxidation disorders (FAODs), which are among the most common inborn errors of metabolism. They exhibit overlapping symptoms that often occur in connection with fasting and may cause hypoketotic hypoglycemia, failure to thrive, cardiomyopathy, liver involvement and even sudden death in infancy (Fahnehjelm *et al.* 2016; Haglind 2016, 8–9; Immonen 2016). Additionally, LCHADD often leads to retinopathy.

After a short introduction to rare disorders, and specifically LCHAD deficiency, in the following, I juxtapose dietary treatments prescribed for this disease with state and biomedical rationalities that govern “normal” dietary patterns and normalised eating. I examine how “norms” guiding dietary treatment for patients with LCHADD are constructed and work in practice.

RARE DISEASES AND LCHAD DEFICIENCY

Rare diseases (RDs) make up a large group of diseases (up to 8,000) that are characterised by a low prevalence in populations (≤5: 10,000 in Europe). Nevertheless, they affect 6%-8% of the population during their lifetime. It is estimated that the total number of people affected by rare diseases in the EU is between 27 and 36 million (Council of the EU 2009; European Commission n.d.; EURORDIS 2017). RDs are often severe, chronic, disabling and possibly lethal conditions; they not only decrease patients’ (and their families’) quality of life, but also pose a challenge for public healthcare (Libura *et al.* 2016; The Council of the EU 2009).

First described in 1989, LCHAD (Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase) deficiency (LCHADD) is a rare, albeit life-threatening metabolic disease. It is caused by mutations in the HADHA gene, the most common being c.1528G>C (Immonen 2016; Piekutowska-Abramczuk *et al.* 2010; Sykut-Cegielska 2006). Before newborn screening for LCHADD was introduced in 2015 and 2013 in Finland and Poland respectively, the

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[4] This research project also attends to processes of “geneticisation” (Lippman in Heath *et al.* 2007, 152) and examines how people make sense of genes and incorporate them into “older” cultural categories, such as “blood” and “curse” that have been ascribed to their social and group identities, in this case the Kashubian identity. Some biomedical literature (e.g. Piekutowska-Abramczuk *et al.* 2010, S373; see also Sykut-Cegielska et al. 2017, 269) argues that the prevalence of LCHADD is strongly connected with Kashubian decent. Kashubians populate Northern Poland, specifically the Pomerania region. Apart from interviews with families of LCHADD patients from this region, 18 semi-structured and/or life history interviews with members of the Kashubian community were conducted by one of the researchers in the project (see, for instance, Kwaśniewska 2017).

mortality rate attributed to this disease was high; it was estimated that approximately 40% of children with LCHADD died in the early days or years of life (Autti-Rämö *et al.* 2005, 1130). While this disease is extremely rare in Australia and Northern America[5], it is relatively frequent in Europe, around the Baltic Sea in particular. More specifically, Poland and Finland probably have the highest number of LCHADD patients worldwide. In Finland, LCHADD is the most frequent mitochondrial fatty acid β-oxidation (FAO) defect. (Immonen 2016). It is worth noting that Finland has already implemented EU recommendations for establishing National Plans for Rare Diseases (Council of the EU 2009), but Poland still has not. Available data on LCHAD deficiency indicates that between 1976 and 2014, a total of 47 patients with LCHADD were diagnosed in Finland; of those, 27 died (Immonen 2016). In Poland, a total of 59 patients with LCHADD were diagnosed between 1986 and 2009; of these, 20 died (Sykut-Cegielska *et al.* 2011). In comparison, between 1990 and 2012, 16 patients were also diagnosed with LCHADD in Sweden (Fahnehjelm *et al.* 2016).

As is the case for other rare diseases (e.g. Featherstone and Atkinson 2012; Larotonda 2016; Paul and Brosco 2013, 111–139), there currently are no drugs available that "cure" patients with rare metabolic disorders, including LCHADD. Treatment itself is clinically challenging (Haglind 2016, 9, 45; Fahnehjelm *et al*. 2016, 1459) and it subjects patients and their family members to a dietary regimen for the rest of their lives. As Jolanta Sykut-Cegielska and her colleagues argue (2017, 266), when it comes to treating inborn errors of metabolism, "dietary treatment" (*leczenie dietetyczne*) is the right term. Dietary treatment "is based on the usage of foods in specified quantities, in specified composition, and with the addition of nutrients necessary for the organism; [it is aimed at] excluding harmful or badly tolerated [nutrients]" (Sykut-Cegielska *et al.* 2017, 266). For LCHADD, dietary treatment entails consumption of low-fat and high-carbohydrate foods, frequent feeding (every 3 hours for small children and every 6–8 hours for adolescents) and avoiding long periods of fasting and physical exertion (Dixon *et al.* 2015; Haglind 2016; Immonen 2016; Sykut-Cegielska 2006). Unfortunately, adherence to this does not spare patients from hospitalisation; they are prone to episodes biomedically known as metabolic crises that may be triggered by illness, physical activity and stress, and may cause symptoms like poor feeding or loss of appetite, lack of energy and vomiting, among others. Additionally, feeding problems that often occur in children and adolescents with rare metabolic disorders

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[5] It is, for instance, listed in the Arizona Newborn Screening Panel that includes bloodspot screening for 28 "relatively rare," "rare" and "very rare" disorders. LCHADD is considered a "rare inherited disorder" which means that it "occurs in greater than 1 in 50,000 US births" (Arizona Department of Health Services n. d.). A newborn screening program has been implemented in the US since the 1960s; however, individual states have been allowed to decide which conditions to screen for. By 2000, the number of diseases screened for differed widely by state: some states (e.g. Utah) screened for 3 conditions, others for up to 36 conditions. In 2006, the American College of Medical Genetics recommended screening for 29 primary and 25 secondary conditions (Timmermans and Buchbinder 2013).

necessitate tube feeding, which can be accomplished with devices like nasogastric or gastrostomy tubes (Rajtar 2017).

NORMALISED EATING AND DIETARY GUIDELINES

Anthropological and historical scholarship shows that dietary normalisation for children and patients has been part of state management techniques and interventions in hospitals, schools and childcare facilities dating back at least to the second half of the 18th century (e.g. Coveney 2006; Foucault 2014; Scholliers 2017). For instance, according to historian Peter Scholliers (2017, 340) who analysed documents referencing what he called “the actual diet” in two public general hospitals in Brussels during the 19th and 20th centuries, “children’s diets improved more rapidly than adults” due to “the paradigmatic transformation of dietetics” at that time. As a result of this transformation “children emerged as a distinct group that was readily targeted by physicians (the so-called new pediatrics)” (Scholliers 2017, 340). A similar shift occurred in other European hospitals, specifically in England, France and Germany. Scholliers further noted that hospitals throughout Europe both “increasingly” used food as a part of their treatment and commonly “wished to serve food that was similar to the fare the patients had before entering the hospital” (2017, 340). Dietary recommendations in hospitals were constantly scrutinised by physicians, assistants, students, nursing staff and even the patients themselves; any deviation from the dietary rules (e.g. supplying and/or eating non-prescribed food) was forbidden. These experiences were codified in the first batch of treatises published in the 1880s. According to these, young patients between seven and fourteen years of age were to “receive milk, eggs, meat, rice pudding, cheese, butter, rice, bread (*pain fin*), potatoes, beans and peas, fruit, coffee with milk, and light beer (for poor children, lard, herring, and lots of *legumineuses* would replace the meat and cheese)” (Scholliers 2017, 349–350, emphasis in original). Scholliers emphasised that eggs, and particularly milk, were seen as “ideal food” for children between the ages of 2 and 10. Finally, he highlighted that beginning in the 1870s, special attention was given to the diets of young hospital patients in Brussels. Along with the increased purchasing power of the working classes, this may have even transformed child nutrition outside the hospitals (among the working classes in particular). Scholliers argued that hospitals contributed to “transforming children’s diet by emphasizing the consumption of milk, eggs, and wheat bread, and eating à *discretion*” (2017, 354, emphasis in original).

Dietary regimes of 19th and early 20th century Europe, as analysed by Scholliers, demonstrate a “politics of health” that involved “at least partial integration of medical practice with economic and political management, which aimed at the rationalization of society” (Foucault 2014, 114). These dietary regulations were devised by a diverse body of state agents, including physicians, and were approved by municipal authorities, e.g. the Brussels city council. Occasionally, the costs of any additional food (e.g. refined bread, fresh fish, fruit, or smoked ham) were audited. The "actual diet" in the hospitals of Brussels was further evaluated by both surgeons and members of the city council. Such evaluations examined "the timetable of meals; the cooking and distribution of food; and its quantity, quality" as well as its taste. Ultimately, such evaluations revealed an "interest in food issues beyond mere cost" (Scholliers 2017, 346).

Scholliers documented dietary regimes that could be viewed as the precursors to current nutritional guidelines issued by departments or ministries of health and implemented by dietitians and health professionals. Both then and now, the "well-being" of the population, to which a panoply of management techniques has been applied, is of paramount importance to health politics and biopolitics (Foucault 1979, 2014; see e.g. Greenhalgh 2012). As John Coveney put it,

> "knowledge of the «good» diet becomes the central focus for the modern subject of food choice. As a complex form of power, nutrition became a practice of analysis, reflection, calculation and tactics on food" (Coveney 2006, 64).

Although the dietary treatments for LCHADD and other rare metabolic diseases substantially deviate from what could be considered normal guidelines, I argue that the LCHADD diet is monitored and scrutinised by dietitians and physicians in a similar way.

In the following, I present the "scientific" or "medical" model of "good nutrition" (Coveney 2006) embedded in dietary guidelines prescribed for "healthy" populations[6]. I further address two issues that differentiate the dietary treatment for LCHADD significantly from "traditional nutritional recommendations for normal children" (Haglind 2016, 44). These include the breastfeeding of infants and the consumption of particular fats.

WHAT FOODS ARE SUITABLE FOR BABIES AND CHILDREN?

Research in Poland has documented that the Polish Ministry of Health endorses breastfeeding, which is heralded as the "golden standard" in neonatal and baby nutrition by the European Society for Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), the European Food Safety Authority (EFSA) as well as the World Health Organization. (Weker and Barańska, eds., 2014, 12; see Kramer and Kakuma 2001). Similarly, the Nordic Nutrition Recommendations (NNR) 2012, on which

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[6] Beata Tobiasz-Adamczyk (2013, 11–83) provides a comprehensive overview of the sociology of health and nutrition with an emphasis on the elderly and the relationship between nutrition and obesity that may be of interest to Polish readers.

Finnish dietary guidelines are based, recommend exclusive breastfeeding "for around the first 6 months of life and partly breastfeeding until 12 months of age" (Nordic Council of Ministers 2014, 96; 28; 85–102)[7]. According to these, breast milk provides the optimal nutrient combination of proteins, fats, carbohydrates and both micro and macro elements, and is thus highly beneficial for the development of infants. Ultimately, breastfeeding should constitute the sole source of food for up to 6 months. Whereas breastfeeding is recommended for babies in general, this is not the case with LCHAD deficiency (Dixon *et al.* 2015; Sykut-Cegielska *et al.* 2017, 270; interviews with dietitians). When neonatal screening yields positive test results for LCHADD, breastfeeding should be ceased because breast milk contains "bad" fats, i.e. long-chain fatty acids, which are to be avoided by anyone afflicted with this metabolic disorder. Currently, babies are typically switched to one of two powdered formulas: Lipistart®, a formula produced by Vitaflo (Nestlé Health Science), a UK company that produces, among others, medical foods for metabolic diseases; or Monogen®, a powdered feed produced by Nutricia (Danone)[8]. As I was told by Ms. Kowalska, a dietitian employed by a large Warsaw hospital, both formulas are high (80%) in MCTs (medium-chain triglycerides) and low in LCTs (long-chain triglycerides), hence they are suitable for LCHADD patients. Like MCT oil, which is equally essential in the LCHADD diet, they are available on prescription, imported via pharmacies and reimbursed by the Ministry of Health[9].

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[7] These recommendations are often referred to as having "*the scientific basis* for the planning of diets for population groups and for the development of food-based dietary guidelines in the Nordic countries". They are suitable for "groups of *healthy individuals* and for developing national and regional nutrition policies, nutritional educational programs, food regulations, and action programmes" (Nordic Council of Ministers 2014, 43; emphasis added). Nonetheless, they also prescribe that "for individuals with diseases and other groups with special needs, the dietary composition and energy content might have to be adjusted accordingly" (Nordic Council of Ministers 2014, 43).

[8] Both Nutricia and Vitaflo regularly sponsor events (e.g. conferences and meetings, cooking workshops, etc.) for patients, their families and physicians, which are sometimes coordinated by patient organisations. In fact, a physician told me that without such sponsors, it would be virtually impossible to hold such meetings free of charge for participants of various socioeconomic statuses. This issue is beyond the scope of this article.

[9] In Finland and Poland, the costs of medicinal foods, such as infant powder formulas that contain MCTs as well as MCT oil, MCT procal, etc., that are part and parcel of dietary treatment, are reimbursed. Nonetheless, models of reimbursement in the two countries differ. Expenses above 600.00 EUR/year are reimbursed in Finland, however parents still pay a nominal fee of 2.50 EUR per can. In Poland, once their application for reimbursement is approved by the Ministry of Health, parents pay a nominal fee of 3.20 PLN (less than 1.00 EUR) per can. The "Polish model" has been much more frustrating to parents and patients as well as more time-consuming for medical personnel than for their Finnish counterparts. In order to ensure that patients have uninterrupted access to these products, parents are required to regularly- every 3 months on average – apply to the Ministry of Health for reimbursement.

Breastfeeding is a source of concern that compounds the stress LCHADD parents endure. For one Polish mother I spoke with, breastfeeding her infant had never even been an option. Later in infancy, her child was diagnosed with LCHADD. She told me, "now they're saying that breast milk should not have been recommended after all. And bitterly, she reflected,

> "Well, now some are saying that we are bad mothers because we don't breastfeed, we don't want [to breastfeed], but, well … sometimes you can't. You just can't".

In another instance, a newborn had been screened before LCHADD was added to the newborn screening panel; subsequently, it was diagnosed in light of a metabolic crisis. Her mother, who had breastfed up to the time of diagnosis, spoke of the practice with regret:

> "If I were on a diet during my pregnancy, nothing would have happened. If I had known that she was already sick when she was in my belly… But who could have known that? I harmed her because I was breastfeeding her; my milk was fatty. Well, unfortunately, I harmed her".

Over tea in her office, Ms. Kowalska provided me with a thorough overview of the diet she prescribes for her patients; she even delved into the specifics of individual cases.

> "This diet [she began] may be diversified (*rozszerzana*) according to the dietary guidelines (*schemat żywenia*) for healthy children. (…) [She further continued:] Starting from 6 months of age we introduce mashed vegetables and mashed fruits, including mashed vegetables with meat, but we emphasize that this must be the leanest meat possible".

With the exception of breastfeeding, these recommendations follow the dietary guidelines for "normal" children which suggest that

> "from 6 months of age, the gradual introduction of a diversified diet is recommended. Breast milk as a part of the diet is recommended throughout the child's first year, and partial breastfeeding can be continued for as long as it suits the mother and child" (Nordic Council of Ministers 2014, 98; see also Szajewska 2017).

Ms. Kowalska gives her patients (or the parents of infants and small children with LCHADD) a list of allowed foods that includes, among others, chicken or turkey breast, and low-fat fish or egg whites, all of which provide the required dietary protein[10]. The youngest patients as well as those with nasogastric and gastrostomy tubes should still be fed with powdered formula. Expanding the diet means, as the dietitian

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[10] Patients and/or their parents receive special charts showing allowed and forbidden foods. In Poland, these charts are often produced by Nutricia, a Dutch company that specialises in products for babies, including clinical nutrition for babies with inborn errors of metabolism, among others. Nutricia produces, for instance, MCT oil that is required in the diet of LCHADD patients.

explained to me, reducing the powdered formula enriched with MCT. In its stead, MCT oil itself must be introduced into the diet. The amount of MCT oil (or MCT ProCal powder) to be consumed depends on the patient's age, test results and dietary guidelines for the general population regarding what Ms. Kowalska and other physicians termed "classic fat".

The problem with the "classic" fat found in most vegetable oils, butter (and many dairy products), red and fatty meats, fatty fish and some fruits and vegetables (e.g. avocados and olives) is that it contains long-chain fatty acids that should not be consumed by LCHADD patients, but are of value to healthy individuals. Highlighting "strong scientific evidence", the Nordic Nutrition Recommendations 2012, for instance, emphasise the consumption of

> "plant foods such as vegetables, fruits and berries, nuts and seeds, and whole-grain cereals [that] are rich in dietary fibre, micronutrients, and potential bioactive constituents".

Such a diet should also include

> "fatty fish, nuts, seeds, and vegetable oils [that] provide different kinds of unsaturated fatty acids. Seed oils such as rapeseed and flaxseed oils are rich in both n-3 and n-6 fatty acids. The very long-chain n-3 fatty acids found in fish are of special health importance" (Nordic Council of Ministers 2014, 21–22).

Additionally, the NNR 2012 warn against "high consumption" of beverages with added sugars, refined grains (i.e. white bread and products made with sifted flour), sweets, sugar-rich drinks and desserts. Generally, among its recommendations to "promote health and wellbeing among the Nordic populations", the NNR 2012 encourages individuals to "*decrease energy density, increase micronutrient density, and improve carbohydrate quality"* (Nordic Council of Ministers 2012, 22; emphasis in the original). This goal should be achieved by following diets based on "naturally fibre-rich plant foods" that are generally lower in energy density than those dominated by animal foods. Products high in added sugar or refined grains that are high in energy density should not be consumed as they are linked to increased risk of a number of chronic diseases, such as diabetes. Unable to consume "classic" fat, but in need of products that are high in energy density, LCHADD patients, however, have to consume low-fat sweets (such as candy, Haribo jellies, jelly beans, etc. that contain 0%-1% fat) and starchy foods (often potatoes, breads and cornstarch before both exercise and sleep) in quantities that far exceed the above recommendations. One mother, for instance, told me that her teenager consumes up to one kilogram of Haribo-like jellies daily.

Ms. Kowalska recounted her individual crucible: accommodating the requests of one of her patient's mothers. According to her, "there are some schematic ways of thinking that parents use". She continued: "To them, it is common knowledge that children eat sausages (*parówki*). Or that children like sweets or children don't like vegetables". Drawing from her research on children and food in Warsaw, Zofia Boni noticed that "ideas about, and practices of feeding might and often do differ from those about eating, and *vice versa*" (2018, 107). Locked into "schematic ways of thinking" about foods "suitable" and "liked" by children that are often perpetuated by the advertising industry, the mother was convinced that children absolutely have to eat sausages. Even the leanest links, however, are not suitable for LCHADD children due to their fat content; thus, the dietitian was strongly opposed to her patients consuming them. Despite this, the obdurate mother persisted, still demanding a recipe. Finally, they concocted a recipe for home-made sausages that would contain a permissible amount of fat, but at the same time resemble the food item that "normal" children allegedly love.

> "It does not taste like a classic sausage of course – the dietitian conceded – but it provides some [food] variety for the kid. So if the mother is willing to make such a meal, why not?".

This dietitian belongs to the highly creative individuals who work at (university) hospitals in Finland and Poland. It is evident in the "recipe for sausages" example that such dietitians try to accommodate the wishes of patients and their parents while still holding true to the dietary guidelines for a specific disorder. Some parents prefer such an attitude over what they called an "overly textbook approach" (*strasznie książkowo podchodzi*) and – informed by experience, no doubt, – know that one square of chocolate or even one cookie should not be cause for concern. Others, however, favour the more legalistic or "strict" dietitians that would rebuke them for even the slightest dietary transgression. Nonetheless, the dietitian's role in treatment success is to manage the well-being of their patients by scrutinising what foods are consumed and how often their patients eat and/or are fed:

> "to devise the appropriate diet; to evaluate menus; to monitor the implementation of dietary recommendations, and to identify nutritional issues" (Sykut-Cegielska *et al.* 2017, 266–267).

Along with "regular monitoring" of dietary treatment, dietitians are also responsible for "training parents of the sick child in nutrition, [especially] in case of an acute metabolic decompensation" (Sykut-Cegielska *et al.* 2017, 267).

MONITORING AND SELF-SURVEILLANCE

Monitoring plays an important role in the biomedical management of rare metabolic disorders, such as LCHADD, as well as in (self-)surveillance that is intended to police the body, especially the eating body (e.g. Kimura *et al.* 2014; Trainer *et al.* 2017; Tobiasz-Adamczyk 2013, 63–77; Yates-Doerr 2013). The introductory chapter to *Clinical Paediatric Dietetics* emphasises that the "assessment and monitoring of nutritional status should be included in any dietary regimen, audit procedure or research project where a modified diet has a role" (Shaw and McCarthy 2015, 3). *Clinical Paediatric*

Dietetics (Dixon *et al.* 2015) distinguishes three kinds of monitoring: clinical, biochemical and dietary. While clinical monitoring[11] measures the weight, growth and development of patients' bodies; biochemical monitoring focuses on the measurement of acylcarnitines, fat soluble vitamins and so on. Both should assess adherence to or deviation from established norms, either concerning bodily development or the "nutritional adequacy of the diet" (Dixon *et al.* 2015, 607). Of course, the latter plays an important role in dietary monitoring. However, the notion of "dietary monitoring" far exceeds both the measurement of nutrients in the patient's diet and the focus on the individual body. Here, families, and specifically parents, enter into the picture as those who "need continued support and advice" once an infant or child is "established on dietary treatment" (Dixon *et al.* 2015, 606). Moreover, regular dietary monitoring encompasses not only diet-related issues, such as making sure that "the overnight feeds provide adequate CHO (or energy) for age" or checking "the intake of long and medium chain fat" (Dixon *et al.* 2015, 606). "Support and advice" offered to parents within this regime requires providing "new ideas and information on low fat manufactured foods" (Dixon *et al.* 2015, 606).

While clinical and biochemical monitoring can be carried out regularly in a clinic (every 3 to 6 months depending on the patient's age and health condition), dietary monitoring is more difficult to conduct even if physicians and dietitians argue that these test results ultimately show whether a patient is following dietary guidelines. One established way of dietary monitoring is the "food diary".

Prior to check-ups, parents are requested to keep a detailed record of all items (including the brand names of food products) their kids have consumed in the past 2–3 days. The food diary is subsequently presented for inspection during their checkup. However, as the mother of a primary school pupil in Poland told me, keeping a food diary is pointless for her because her child perpetually consumes a diet consisting of the same items. Nonetheless, she still begrudgingly complies, however redundant it may feel to her.

Food diaries exemplify (self-)surveillance that instills (self-)discipline, responsibility and medical adherence (Kimura *et al.* 2014; Trainer *et al.* 2017). According to Kimura and her colleagues "documenting eating habits puts the eater in the position of understanding their health as a scientific project, and of having to explain deviant data points as bad behavior" (2014, 38). Though some parents question the necessity and purpose of conducting food diaries, they nonetheless strictly adhere to quantities and metrics while applying MCT oil and other nutriceuticals or functional foods

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[11] Other authors in this volume put "clinical monitoring" into the "clinical assessment" category. The latter "involves a medical history and a physical examination. The medical history will identify medical, social or environmental factors that may be risk factors for the development of nutritional problems. Such factors may include parental knowledge and finance available for food purchase, underlying disease, treatments, investigations and medications" (Shaw and McCarthy 2015, 7).

(Dumit 2012; Scrinis 2013) into their kids' frequent meals, even employing a syringe for more accurate and precise measurement.

CREATING NORMS IN PRACTICE

In a survey conducted among US metabolic dietitians on "nutritional strategies" utilised in the treatment of fatty acid oxidation disorders (FAODs) (including LCHADD), Solis and Singh (2002, 1800) emphasised that medical nutrition therapy is considered a "standard treatment for FAODs". They determined, however, that along with "diverse approaches used to manage" FAODs, there was "a lack of evidence supporting the protocols in use; and a need for comprehensive, clinical research studies to determine optimal, patient care". The survey showed, among others, that there were no uniform recommendations regarding the frequency of meals (ranging from 2–4.4 for infants and 3–7 for children with LCHADD). Neither was there agreement regarding an "optimized" fat intake for each disease, i.e. the percentage of dietary fat for LCHADD patients ranged between 10% and 33%. Authors strongly advised "the development of standardized treatment and monitoring strategies and product formulations tailored to the needs" of LCHADD patients (Solis and Singh 2002, 1803).

I am not sure if my interviewees were versed in the Solis and Singh article, but they certainly raised the same concerns regarding the lack of standardised dietary treatment for LCHADD patients. Popular and derogatory usage characterizes standards and standardisation as homogenising and dehumanising, and as such, they are contested (see e.g. Timmermans and Epstein 2010; Yates-Doerr 2013). Nonetheless, my interviewees believed – although "hoped" may be a better term – that standards may "provide the optimal technical solution for particular problems" (Timmermans and Epstein 2010, 73–74), such as the percentage of dietary fats to allow in the LCHADD diet. Thus, they would probably agree with Stefan Timmerman and Steven Epstein who define standardisation "as a process of constructing uniformities across time and space, through the generation of agreed-upon rules" (2010, 71). This does not mean, however, that standards would not be subject to change. Just the opposite, standardisation "is an active process that aspires to stability and order" (Timmermans and Epstein 2010, 84; see Yates-Doerr 2013, 284). When I asked Ms. Kowalska about the "norms" she follows for designating the percentage of MCT oil to be consumed for energy intake, I was surprised by her response:

> "They [the norms] come from above (*odgórnie ustalane*) and are repeated by many associations, at many conferences. But I know that there are differences too. Every country has its customs so to speak. According to our norms, the percentage amount of MCT fat is to constitute 10–20% of dietary energy [intake]. Classic fat can account for up to 10%, so if we combine both fats together, the fat norm would not cause any deficiencies. The only deficiencies it could cause regard fat soluble vitamins

> because MCT only carries energy, but no vitamins. So, vitamins are supplemented. (…) According to American norms, however, MCT fat can go up to 24% [of energy intake]. I heard somewhere that if you exceed 20%, it [MCT] can be transformed into long chain fats that are toxic, so there shouldn't be more than 20%. To tell you the truth, opinions differ. We stick to 10–20%". (see also Sykut-Cegielska *et al.* 2017, 270).

In light of the varying expert opinions and lack of global standards, the ultimate criterion for truth and validity for the norms she has been following is the health of her patients. She argued "I prefer to utilise our [norms] because our patients are well balanced (*dobrze wyrównani*), they have good results, so I don't see any point in changing anything".

Not only physicians and dietitians in countries like Finland and Poland have to balance the health of their patients against elusive "norms". A close reading of the "bible" of metabolic disorders mentioned earlier in this paper: *Clinical Paediatric Dietetics* shows that the seemingly authoritative voice present in the volume is constantly undermined by phrases that expose the lack of sufficient knowledge for determining optimal amounts of certain nutrients. Here are some examples that refer to dietary treatment of FAODs, particularly LCHADD:

> "Treatment recommendations have been published for ß-oxidation defects based mainly on expert opinion from a European workshop. (…) The safe upper limit for long chain fat intake is unknown and varies with the severity of the disorder. (…) For severe defects of LCHADD and MTPD it is recommended to restrict LCT [Long chain triglycerides] to as low as practically possible (5%–10% energy intake). (…) It has been suggested that patients should maintain a high intake of MCT [Medium chain triglycerides] throughout life (10%–20% energy intake). [However] (t)he optimal amount or ratio of C8, C10 fatty acids to provide is not known".

Finally, the same text admits that long-term usage of MCT "in humans has never been systematically studied, so it is not known if there are any detrimental effects" (Dixon *et al.* 2015, 596). Additionally, despite general agreement on the necessity of frequent feeding in LCHADD and some other FAODs, "the safe duration of fasting for different disorders and ages has not been well-defined and practices differ between countries and centres" (Dixon *et al.* 2015, 598). Neither is there agreement on overnight feeding: "In the USA no consensus on overnight feeding could be reached by an expert panel". In the UK, however, "children with severe defects are fed 3–4 hourly during the day and by continuous nasogastric or gastrostomy feeding overnight (or the child is woken for feeds during the night)" (Dixon *et al.* 2015, 598). Nonetheless, overnight feeding "is not standard practice" (Dixon *et al.* 2015, 598). It is worth emphasising that all parents we have spoken to in Finland and Poland practiced (and were obliged to practice) overnight feeding of their kids.

Unlike national and international dietary guidelines for "healthy" individuals that reference a "scientific basis" and "scientific evidence", dietary treatment of rare metabolic disorders, such as LCHADD, is primarily based on the personal experiences of physicians and dietitians along with "expert opinion" (see Timmermans and Epstein 2010, 81).

CONCLUSION

A decade ago John Coveney (2006; see Scrinis 2013) noted that public health nutrition has become rife with tension when it comes to the ideology of health promotion, which he argued, oscillates between medical/scientific and social/community models. Despite the differences between these two models, they are similar when it comes to what they consider to be "good" food and nutrition. As he puts it,

> "in each, the subject, or the collective subject (the community) is required to be self-reflexive and self-regulating in order to make «proper» and informed decisions" (Coveney 2006, 19).

Dietary guidelines in Finland (and Nordic countries in general) and Poland for "healthy" individuals subscribe to the scientific model in which

> "individuals are required to make informed choices about their eating habits after having learned and considered the scientific facts about food and health" (Coveney 2006, 18; see Yates-Doerr 2013 for Guatemala).

Moreover, such guidelines operate on the premise that healthy individuals are willing and able to eat, in other words, that eating is a "norm". By calling for the "adjustment" of dietary recommendations for individuals with diseases (Nordic Council of Ministers 2014, 43), however, public health authorities implicitly require not only healthy individuals to be "self-reflective, self-regulating individual(s) with the correct concern for themselves" (Coveney 2006, 18). This medical model extends to rare metabolic disorders, fully disregarding the paucity of sufficient scientific knowledge concerning both rare diseases and the results of dietary treatment. Additionally, infants and children with LCHADD commonly face feeding problems and are regularly fed through nasogastric or gastrostomy tubes for months, if not years of their lives (Rajtar 2017). Faced with insufficient "scientific evidence" (e.g. random control trials) and lacking in global standards, physicians and dietitians treat "norms" as "tools" that are to be translated into dietary practices based on their own personal experience, expert opinion and patient test results. These dietary recommendations are further appropriated by both parents and the patients themselves, who cannot or would not follow them to the letter.

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ANTHROPOLOGICAL RESEARCH ON AUTISM. REFLECTIONS FROM THE FIELD

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For a long time, people on the autistic spectrum were doomed to social marginalisation. They often spent their entire lives kept in homes or were sent to closed institutions where they were treated like passive objects of custodial care. Their developmental potential and creative possibilities were generally questioned. Since the 1950s, this has slowly been changing. Individuals with autistic syndrome and their relatives have obtained access to a variety of forms of aid. A network of specialist institutions supporting them through early diagnosis, therapy, care and education have been expanding as well. One such facility, located in Łódź, became for two years my research field. Stepping over the threshold of this institution I was not a novice since I had already met autistic people in the context of my private life. Still, I had never met such an abundant and diversified group of individuals on this spectrum (in terms of symptom level and age). During the course of my research, a number of issues needed to be addressed such as issues related to research method, my behaviour towards people with autism, some organisational matters as well as professional and ethical dilemmas, all of which will be written about in this article.

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Przez długi czas ludzie ze spektrum autyzmu skazani byli na społeczną marginalizację. Bardzo często spędzali swe życie uwięzieni w czterech ścianach własnego domu lub trafiali do ośrodków zamkniętych, gdzie byli traktowani jako bierny przedmiot dozoru i działań opiekuńczych. Na ogół wątpiono w ich potencjał rozwojowy i możliwości twórcze. Począwszy od lat pięćdziesiątych dwudziestego wieku, powoli się to zmienia. Osoby z syndromem autystycznym i ich bliscy uzyskują dostęp do rozmaitych form wsparcia. Rozrasta się również sieć placówek specjalistycznych, oferujących im możliwość wczesnej diagnozy, terapii, opieki i edukacji. Jedna z takich placówek, działająca na obszarze Łodzi, stała się dla mnie na dwa lata terenem badawczym. Przestępując próg tej instytucji, nie byłam nowicjuszką, ponieważ stykałam się wcześniej z autyzmem w życiu prywatnym. Mimo to, po raz pierwszy weszłam w kontakt z tak liczną i zróżnicowaną (pod względem objawowym oraz wiekowym) grupą osób z tego spektrum. Decydując się na aktywność w tym specyficznym i wrażliwym środowisku, musiałam także podjąć próbę odpowiedzi na wiele pytań dotyczących zagadnień badawczych, organizacyjnych oraz etycznych. O wszystkich tych kwestiach opowiadam w swym tekście.

Keywords: Autism Spectrum Disorders (ASD), disability, fieldwork, ethnographic observation, communication, empathy, ethics, research responsibility

INTRODUCTION

For a long time, all society could offer autistic persons[1] – just as to the people with many other disabilities – was not much more than a segregated education, rejection of them as individuals and confining them to standards of mediocrity and stereotypically established social roles. People with autism often spent their lives kept in homes or were sent to closed centres, so-called asylums, where they were treated like passive objects of custodial care (Goffman 1961; Woodill 1992; Barnes 1997; Barnes, Mercer 2003; Andreoli 2004; Zakrzewska-Manterys 2015, 2017). As was claimed by Ivan Brown and John P. Radford, particularly in the Western world

> "It was widely agreed that, in a perfect society, all such people would be «put away», and it was often said of those who remained in the community that they «belonged in an asylum»" (2015, 13).

Also, they were usually seen as "incurable" and "defective". Their developmental potential was questioned in general and their perceptions and experiences were not explored. Since the 1950s, this has slowly been changing. Attempts to understand these people and to connect them, in a friendly manner, with their socio-cultural environment have been made (Abberley 1987; Gałkowski 1997; Żuraw 2016). The foundation of these efforts is a belief that both disabled and able-bodied people have many more common characteristics than separate ones and that no person can live on his/her own and function in diverse society being isolated from it. In the case of ASD, the value of this strategy also consists in the fact that it contributes to engaging people from this circle with spontaneous social situations. Thus, it supports the development of creative and reflective thinking of these minority group members and equips them with the skills necessary to give their own opinions. As a result, they can learn to live based on their personal experiences and not under external control or pointless, automatic imitation.

Nowadays, the network of experts and specialist institutions supporting people with autism is expanding as well. Their aid programs include a variety of actions, but the priority is precise diagnosis, early intervention, (re)habilitation and personalised therapy. Time plays a key role in this context since an early diagnosis allows for early treatment and because the human nervous system decreases in plasticity with age, this results in better effects in the future, a higher quality of life and lower costs related to both social and medical care (Chojnicka and Płoski 2012, 250). The importance of early detection and treatment is indicated by the research data. This data shows that a wide group of autistic persons, estimated at even sixty per cent, have an intellectual

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[1] Being aware of all semantical differences, in this text I use interchangeably such terms as "autism", "ASD (Autism Spectrum Disorders)", "person(s) with autism", "autist(s)" etc. I do it for stylistic reasons.

retardation lower than an IQ of fifty, but this percentage is less in the population of children with early clinical diagnosis (Goldberg Edelson 2006; Pużyński, Rybakowski, Wciórka 2010, 591–597; Dykens and Lense 2011; Kika 2014). Even if normalised intelligence tests are considered to be not an excellent tool to assess developmental potential and that this potential should be regarded individually, dimensionally and dynamically, it is beyond any doubt that the group of people most threatened with a lack of autonomy and permanent dependence on others is relatively wide among autists. The emerging network of specialist facilities which have sprung up have contributed to improved ASD prevention and, at least partially, counteracts the situation when the families of children with extensive developmental disorders are left on their own and not provided with even basic support or guidance. Unfortunately, such facilities exist mainly in big cities. One of them, located in Łódź, became for two years my research field. I entered this institution[2] in 2013, transgressing my own world and opening the risk of tensions related to exceeding the boundaries of other communities. Borys Cymbrowski and Dorota Rancew-Sikora both noted that leaving *orbis interior* and delving into the field usually entails researchers communicating with otherness, with unexpected social issues and launching a cascade of experiences to which they are not fully prepared but which they need to address (Cymbrowski and Rancew-Sikora 2016, 11, 14). This is exactly what happened in my case, although, it needs to be stressed that I was no 'freshman' entering the field since I had already met individuals with ASD in the contexts of my private life. Still, I had never met such an abundant and diversified group of people with this disorder (ranging from its severest forms to ambivalent manifestations defined as only containing autistic components)[3]. What is equally important, my field research was combined from the very beginning with voluntary service to the foundation. It was my way of thanking the local community for them consenting to my stay in the place and a way of more deeply exploring the environment (Męcfal 2016, 96). Doing voluntary service allowed me to have deeper contacts with the studied group and to accompany its members in different circumstances: during their studies, meals, play time, rest periods, sporting activities and therapy (both individual and group). Thus, I gained wide access to the so-called direct or embodiment channels of knowing the other person. The only limitations in this respect were situations during which my presence could disturb a person's intimacy (nappy changing, or situations where physiological needs required satisfying) and also situations in which my presence could be unfavourable due to organisational or therapeutic reasons.

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[2] This was a foundation serving children and adults with disabilities.

[3] It was a diversified group in terms of age ranging from children and youths from nursery schools to middle schools.

IN THE FIELD: MY AIMS, ASSUMPTIONS AND RESEARCH POSITION

As is well known, field projects never guarantee the certainty of gaining any interesting and satisfactory data. This happens not due to a lack of nimbleness or poor preparation on the researcher's part but simply because this is the logic of the research procedure and the nature of his/her activities. Fortunately, this state of affairs did not arise in my project. The period I spent in the field and the experiences I gained were very instructive. As has been previously mentioned, conducting this study involved several specific dilemmas and problems which I now wish to discuss.

I shall start from a primary issue, notably my mode of presence in the field. In general, it is assumed that in the case of traditional fieldwork there are at least two types of procedure. The first one consists in the participants of the research knowing the whole situation and fully cognisant of the researcher's intentions and often fully consenting to his/her plans. The other type of procedure involves people not being aware of what is being studied and conducted without their permission. This is not the rarity it might seem (Bielska 2016, 71–72). Much depends in these cases on the projected cognitive goals and the specificity of the penetrated environment. Important also are the individual characteristics of the researcher, his/her cognitive skills and axiological background (interiorised conceptual categories, thinking structures, hierarchies of importance, values as well as ethical and aesthetic standards). All of these factors define the frames in which the researcher operates and builds a basis for his/her assumptions. For my project, the deontological perspective, assumed as my reference point, turned out to be essential. According to this perspective, the well-being of the participants of the study is the priority, which means that no goals or arguments can be considered against this (Geisler 2007, 24; Jagiełło and Modnicka 2011, 106–107, 111). Adopting such a position meant that I decided to be fully open about my activities. I believed that concealing my own professional identity would disturb the fundamental rules of social relations (especially the human right of self-determination, personal freedom and control of information about oneself) and maybe would be close to "anthropophagy". Consequently, my fieldwork was preceded by a direct conversation with the heads of the foundation during which I submitted a covering letter containing my personal data, institutional affiliation and a description of my study. Then, the heads turned to the legal guardians of the persons cared for by the institution and asked them for their consent to my research at the place as well as organising a meeting with me. The meeting was a way of informing people and of familiarising me with them and vice versa and it created a space for open dialogue. Only after gaining the acceptance of its members, did I take my first research steps.

An important cognitive doubt arises here. Did my self-disclosure affect the course and the results of the study? Did it limit my resources of observation? I believe this occurred to some extent. After all, the natural human reaction is to aim to build and maintain a positive image of oneself and one's membership group. It leads, among others, to the staging of behaviour and the censoring of information considered inconvenient or damaging. Therefore, it can be presumed that if I had somehow camouflaged my professional identity, I would have found out more about the world I wished to explore and would have been allowed to know its secrets. As an ordinary volunteer, however I would be more transparent to my environment, which would weaken the embedded socio-cultural tendencies to self-creation and self-control. Being guided by the deontological perspective, I decided maintain standards of openness.

At the same time, I must admit that fulfilling this standard turned out to be impossible among all participants of the study. This resulted directly from the attributes of the group, especially the fact that a large part was represented by people with severe intellectual disabilities who were unable to communicate in a conventional or generally available way (including alternative and supporting methods of communication). Therefore, despite best intentions, I could not explain to them who I was and why I was staying with them.

Another important question I needed to answer entering the foundation was to choose the research method. For obvious reasons, the answer was not completely free but limited by three basic considerations: legal, ethical and practical. Taking them into account, I decided to choose ethnographic observation but excluded the use of audio-visual techniques for recording the research situations. I also gained the consent of my 'gatekeepers' to make field notes although not while communicating with those under care but, so to speak, after hours. Here I must point out that this self-imposed limitation to the ethnographic observation was not troublesome to me and that my research in the foundation was only one of my areas of activity and interests in the world of autism (concurrently, I studied written stories related to this theme). As such, my presence in the field was merely to support my already undertaken analytical work and enrich my empirical experiences. I must further mention that due to the specific nature of the reality I was studying, my observations were not fully participant but could be classified as so-called negotiated interactive observations (Wind 2004; Wierciński 2016, 89–90). As claimed by Hubert Wierciński, in this version of ethnographic fieldwork *in situ*

> "(…) the researcher constantly absorbs the field, is present in it and experiences it with the whole self but does this without the imperative of experiencing what is felt by the «natives» and who they are since the access to their perspective is limited" (Wierciński 2016, 89–90).

Thus, emphasis is placed on the interactions, activities and practices in the field which are subjectively observed and analysed by the researcher. A consequence of this type of exploration may be the special awareness of the essence of the world he/she is interested in. This awareness is not equivalent to participating in this universe since no paths available to the ethnographer lead to it. The said theoretician uses in this context the metaphor of a wall which can be seen, tapped, identified through touch but which retains the properties of a barrier – in that it rather suppresses and closes than opens (Wierciński 2016, 90). Such an understood formula of negotiated interactive observations relates to many field projects within which the observer finds it difficult to understand the rationale and feelings of the people under study (especially when this goes beyond the sphere of typical ethnic or social distance). It also applies to my actions as I was not a novice since I had already had dealings with autism in my private life. Also, what needs to be stressed, is that the experience turned out to be very important for my study in the foundation. It meant that in the initial stages (as well as the following) of my visits to the field, I was capable of preventing myself from what is defined as being in a state of being totally blinded and even traumatised by the sense of otherness. This state is often encountered by scientists during first contact with the explored completely new reality. The intensity of this experience is sometimes so strong that it distorts the researcher's perception and in extreme cases leads to a deep mental crisis that may last for years and dangerously transform the person[4]. My already gained empirical knowledge of ASD protected me from this effect and also permitted me to avoid some difficulties that might have occurred in my relations with persons on this spectrum. For example, being aware that autism is in general a permanent and strongly fixed condition, I was able to cope better with certain situations in the field that I encountered such as the lack of noticeable reaction of many children to my person, the non-establishment of eye contact by the children and their non-reciprocity or desire for isolation.

To continue in this vein, I would like to indicate another benefit I derived from having had private experience in dealing with ASD people. My research and voluntary activities in the foundation were not limited to passive ethnographic observation and typical service actions but also took the form of dialogue and partnership with the facility's employees. If I felt that I could help in solving any issue or sudden problems which arose, I immediately offered ideas, which, in many instances were acted upon. For example: one day, one of the people under study showed high irritability and increased level of psychomotor excitation as this person was incessantly running,

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[4] The situation is particularly distinctive of research studies conducted in difficult and vulnerable communities that pose special risks for researchers (Hart 1995; Harris 1996, 1997; Byrne 2005; Quina *et al.* 2007; Arditti *et al.* 2010; Kafar 2013). Examples include prisons, juvenile detention centres, shelters for people in crisis, hospital wards for seriously ill patients, hospices and other minority settings. It seems that trauma is almost inherent in these projects, especially if they are undertaken by a (highly) sensitive person and/or by a novice. Nevertheless, it is still comparatively rare that authors include descriptions and analyses of intense emotions experienced in the course of their fieldwork. It is a sorry state of affairs that this is the case, because feeling is a way of knowing. Consequently, emotions can be a powerful analytic tool which can provide worthy insights into a topic and relevantly enrich research reports and writings (Kleinman 1991; Kleinman, Copp 1993; Bourne 2005; Lalor, Begley, Devane 2006; Johnson 2009).

squeaking, crying and could not be calmed down. Members of the caring and tutoring staff were left largely confused by the child's behaviour. I looked closely at the child and noted that he would not permit anyone to make him wear shoes or socks which he took off right after entering the play area. I thought that perhaps the boy had had his nails clipped and as a sensory hypersensitive person felt much discomfort. I told his guardians about this presumption and they contacted his mother who confirmed my "theory" and informed all that she would be more careful next time to make sure that her son's nails were not cut too short since this irritates him.

Another similar incident happened in the dining room during dinner. One of those being cared for absolutely refused to eat. I thought that maybe his aversion was caused by the specific texture of a dish which made it difficult for him to put his food on the fork. It turned out to be true and the situation was quickly resolved.

In no way are these details provided to undermine the professional expertise at the institution of the foundation's staff. The point which I am trying to make is that even the temporary presence of the anthropologist within some social and/or institutional sub-world may be beneficial for its operation. With a willingness to adopt an adaptive fieldwork approach, an openness to others and sensitivity towards the local context, which are peculiar to anthropological approach, the researcher can bring a positive contribution to the communities being studied and described, on condition however, that the field preparation includes a versatile and deep reflection on the features of the analysed group. In the case of my exploration, especially important was undoubtedly the reflection I underwent on my behaviour towards the studied people. Most of all, I had to be aware that in spite of appearances, autists have a very fragile psyche and are very sensitive to the emotions, moods and the intents of people they interact with. This means that even if an individual with ASD does not show it, he/she may truly suffer in interactions with people whose behaviour concerns, hassles or distracts him/her. It is an important thing in terms of therapy. (It needs to be remarked upon that, according to contemporary standards, the main goal of treatment is not to break and reassemble the patient to match dominant norms and conventional expectations but to achieve his/her maximum self-reliance in his/her daily life, to achieve non-conflicting co-operation with the environment and to foster the ability to make conscious judgements. All roads behind these therapeutic activities is, or should be, to lead to as high an independence as possible of the person with autism[5]. It is indeed known that being in a nursing home, in isolation from the world, most often causes the psychophysical degradation of any human and a state of chronic, progressive dementia. Every coercive aim of making people with ASD become the same as the neuro-normative majority is an attempt to control them and thus an act of violence.)

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[5] Briefly, the primary aim is competence, not correction.

STAYING WITH AUTISTS: HOW TO BEHAVE AND WHY?

Today, there are different treatments for ASD but the truth is that therapeutic success is almost random. The reasons behind this are unknown. It seems, however, that two factors are favourable for positive results to be gained. Firstly, there are activities which contribute to the gaining of a higher trust of the patient in other people and secondly, activities which are used to strengthen the patient's belief in his/her own efficiency and self-agency (Mahrer and Nadler 1986). Of equal importance within a given therapeutic method are the so-called soft aspects of therapy such as the creation of a good atmosphere in a meeting and the manifestation of respect and support to the patient. Indeed, any spontaneous reaction and any contact with an autist may trigger his/her potency which in turn will bolster the person and stimulate his/her development.

I tried to put these into practice in the field which translated into trying to be maximally calm, patient and predictable in my interactions with those under study. This was important because of any possible chaotic or expansionist effect on people with ASD which could engenders a lot of fear and uncertainty which may lead further deterioration of the disease and intensify the existing mechanisms of it. Additionally, I had to bear in mind that individuals with an autistic syndrome usually choose different paths of communication than their neuro-typical counterparts. While the latter have high sensitivity to visual and auditory signals, the former are more skilled in using touch data, (micro)kinesthetic and proxemics (Wroniszewski 1993, 12; Kliś 1994). Therefore, during my fieldwork, I attempted to use the kinesthetic way of communication more than normal. I did this through keeping my body still, through a delicate and controlled touch, through the illustration of information conveyed verbally with motions and by the avoidance of any violent and invasive spatial behaviour. I endeavoured to pay attention to the body language of the children too. Their minds were mostly distant and "closed" to me, but their bodies became nearer and more "open". I had the opportunity to closely observe the children's faces, glances, postures and movements. Obviously, I do not know whether all these behaviours were significant but sometimes they were so suggestive that I recognised, personalised and remembered the child just by his/her intense or particular way of using his/her body as way of expression. Often, it was also the only tool available to create a kind of bond between us. I knew many of these young people not through their thoughts, dreams or views but through their physical contact with me: tapping, stroking, embracing, gazing, pinching and pushing etc[6].

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[6] Body and bodily-sensual events are only one of the components of typical relationships. In the case of autism these spheres not infrequently take centre stage. It seems that sometimes we can speak about a kind of "hyper-embodied" contact in this context. This is a broad, compelling topic which requires separate elaboration.

Most authors agree that one of the defining features of ASD symptoms is occupied by failures in understanding and an inability to form statements, all of which occur in many patients. These problems negatively affect all spheres of personal development. There is a widely held view that linguistic processes form the basis of people's growth into the structures of society and culture – they help in intraception[7] and are an important way of reaching others and influencing them[8]. During my study, I endeavoured to support all attempts at using language by those with autism but it was far from easy. I tried to speak slowly, calmly and articulate every syllable of every word clearly and expressively. Often, I kept uttering the same thing over and over again. Despite this, what I said was frequently not understood by the children and/or did not arouse any noticeable reaction and sometimes it was I who failed to grasp their messages. This is related to the specific character of verbal communication in autism which is composed of such features as: atypical pace of speech, echolalia, inversion, producing stereotypical sounds, repeated parts of words, shortcuts or sudden mental leaps (Vicker 2009; Eigsti *et al.* 2011; Boucher 2012; Ray-Subramanian, Ellis Weismer 2012; Kominek 2014). I need to say that this failure to comprehend on my part was one of the most

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[7] Intraception is a concept developed by H. A. Murray to describe those who process the world primarily through their feelings or emotions (https://psychology.wikia.org/wiki/Intraception, access: 10.11.2019).

[8] Some people claim that with the development of language abilities other talents which may occur in ASD can be destroyed. They think that an autist, as he/she makes progress in the process of verbalising, loses mastery in some areas and that he/she inevitably becomes an ordinary, handicapped person, although capable of speaking (a bit) but irrevocably robbed of his/her uniqueness. Sometimes, these people also believe that it is better for an autistic person to be incapable of saying anything, even his/her own name, asking for a glass of water or exchanging a few words with his/her parents than to be typical, or average. “Anything but ordinariness, it is so vulgar!” – they are strongly convinced. Quite apart from the fact that such elitist views are questionable, the opposite is true. Therapeutic and educational practice prove that an increase in language skills does not curtail an autist's or an autistic savant's talents at all. Stephen Wiltshire is a spectacular example (https://www.stephenwiltshire.co.uk/, access: 10.06.2019). He is a brilliant urban artist who is capable of drawing almost the entire of London (after having only a cursory observation of its building). This man developed, both artistically and linguistically. At first, unable to speak a word of the language, he later communicated with the environment using his drawings. He was nonverbal during his early childhood and finally learned to talk only at the age of nine. Today Wiltshire is considered a great architectural innovator and was awarded The Most Excellent Order of the British Empire for services to the art world in 2006. His work is known and valued all over the globe, and his drawings are held in a number of important collections. Indeed, individuals with autism occasionally lose their aptitudes but it is often due to other factors. They become bored with some activities or certain biological changes in their bodies take place. At other times something happens to them – this can be a sudden loss of a significant loved one, the birth of siblings, moving to an unknown place, a change of school etc. (During the life cycle of every human a variety of unexpected events such as trauma, a trajectory process, epiphanies and life changing situations occur which can result in transformation.) In general, people on the autism spectrum will only benefit by improving their intellectual abilities in every field, especially in the field of language because it is an imperfect but powerful human instrument of cognition.

emotionally demanding moments of my fieldwork, being unable to respond to the initiative of the other side and accept that person's invitation to meet in the space created by the word – considered the main medium of meaning in human culture. In such situations, I tried to answer with a friendly gesture or smile but these were only substitutes. Encountering such language difficulties, I also tried to pay particular attention to their prevocalic or vocalic signals (squeals, shouts, peculiar exclamations and vocatives, etc.). All these behaviours may be an important means of communication, be a sign of the structure of social relations and may contain the characteristics of the performer, inform about his/her detachment and be a manifestation of pleasure or sympathy to the other person. On the contrary they may be a manifestation of displeasure, irritation and even of hostility. The literature has supported for a long time the view that many more negative and neutral emotional behaviours (such as: shouts, cries and a lack of interest) rather than positive ones (screams of happiness and murmurs of satisfaction and so on) are observable in autism. (Minczakiewicz 1994, 103). This fact may discourage some from interacting with people with ASD, organising activities for them or including them in social situations. However, it should be noted that the reaction of those with autism is dependent on many factors, such as their familiarisation with the people involved, the structure of the local space (many autists have a bad reaction to sensory complicated or crowd settings) and equally to weather. During the course of my study, it became apparent to me that even subtle changes in the environment (such as slightly turning up a ventilation in a room, or the darkening of a room), the playing of some music or a food break may affect the autistic people's mood, their willingness to interact and attitude to reality.

PENALTIES AND REWARDS. SOME ETHICAL DILEMMAS

Another issue is the use of penalties and rewards for sufferers of ASD. In general, it is assumed that in relation to these individuals no penalties should be administered. It is a very ethical assumption but in the light of what has already been said, it needs to be recognised that we do not always know what a penalty for a person with autism is and is not. In fact, physical and mentally felt displeasure-activities are still being carried out. These include making the cared one inactive and isolating him/her. These methods are especially practised in cases of (self)aggressive, destructive behaviours and tantrums. Most often these take the form of physical holding, relegating from a group activity or taking the sufferer to another room so that the individual may rest from excessive, overwhelming emotions and stimuli (sometimes, a specially equipped hall is used for this purpose where the person can release their tension by, for example, punching a mattress or throwing soft objects against walls). It needs to be noted that this exclusion may, paradoxically, be viewed as a reward since due to the act of aggression and further isolation, the person may avoid stressful situations thanks to this exclusion. Being given a time-out, the person will avoid the activity he/she does not like but one which could inspire and strengthen him/her socially or mentally. In such cases, regular appliance of this technique may disturb or even inhibit the development of the individual. Questions arise as to how effective "punishment" is but also to its ethicalness. A definitive answer to this dilemma is, I believe, not available, since one is dependent on the concrete cultural context, diverse situations and individual aspects.

Another technique used in relation to those with ASD is hypercorrection. It is applied in particular in relation to children when they cause some damage. If, for example, a child soiled the floor, he/she would be required to clean it and in addition, wash something extra. Sometimes, hypercorrection goes hand in hand with a positive exercise. For example, if the sufferer draws on furniture, his/her drawing skill is tested on the board or on a sheet of paper. However, often it cannot be specified as to whether the damage caused by the child is a conscious act or is due to other reasons. It may happen that a child drops a plate with food and breaks it because he/she is incapable of tolerating the smell due to his/her neurophysiological condition. It is equally probable that he/she may do such an act on a completely unchecked impulse, such as becoming frightened of some sound which would remain unnoticed to a man from the circle of "normals". When an individual with autism seems to be "absent" and does not communicate in the usual manner, it is very difficult to identify his/her motivations, intentions and current mental-emotional condition. Helpful tools here in the deciphering process are empathy, intuition, observation and an ability to think logically and strategically but sometimes these are not even enough. This is because no two human experiences are the same. Despite attempts to categorize them as so, they are still essentially indivisible and unique. That is why the other person always remains a kind of mystery – particularly if he/she differs in some way which is the case in autism.

CONCLUSION

Fieldwork is slowly losing importance in Polish ethnology and cultural anthropology (Kaczmarek 2016, 123). In spite of this, it remains a valuable method of collecting data. At the same time, the concept of field is understood in many ways (Buliński and Kairski eds. 2010), including the spheres of no "contact with a living human" (Buchowski 2012, 96): studies of artefacts apart from their creators and places of origin, some ethnohistorical and ethnolinguistic research, exploration of media spaces, textual and literary analysis etc. Some representatives of the discipline declare outright a farewell to the field (Żerkowski 2015) whilst others assess this idea to be premature and misleading (Sikora 2015).

In my study on autism, I have always employed a variety of sources and methods of analysis. By doing so, I consider my presence in this traditionally defined field to be an important way of acquiring knowledge and legitimising my conclusions. I have always assumed that the experiences I gained will help me to better understand the phenomena of my interest and will be helpful in the process of interpreting different research materials (such as written accounts, data, internet content and so on). This preliminary assumption has been positively verified during my field explorations which have largely expanded my cognitive horizons. Through contact with a wide and diversified group of sufferers I have encountered many faces of autism – in respect of individual characteristics and how these people function in their daily lives (from the people requiring total care, to those seemingly "absent" and to individuals capable of undertaking certain decisions and actions on their own). With my relatively long stay at the foundation, I could observe how a person with ASD may develop and change, improve in skills and gain more autonomy. I have also seen many opposite situations, where severely disabled people require permanent care and are incapable of achieving any high degree of independence[9]. Given the specific nature of the environment I entered, my field project was to some extent characterized by ambivalence. On one hand, I was very close to the studied individuals coming into contact within their sphere of intimacy. I held their hands, put their shoes on, passed them toys, helped them to eat, drink and reach the toilet; I was also the witness to many of their spontaneous behaviours and emotions. I was sincerely pleased with their achievements and worried about their failures. On the other hand, I could never bridge the distance – as a representative of the neuro-normative majority I could not become one of them and assimilate their points of view (Malinowski 1922, 25; Mead 1977, 6). I could attempt comprehension but I was not able to make myself similar in terms of mental and psychophysical condition. During my stay with them I sensed the clear distinction between "knowing" and "knowledge" which constitutes the distinction between "native experience" and "expert perspective". For obvious reasons, it was also impossible for me to cross the border of closeness in the field, beyond which begins human (reciprocal) friendship or intimacy (Wax 1971, 373; Hendry 1999). I felt that many sufferers did not even recognise and notice me. Being physically present I was in a way somewhere else, far away, rather than next to or among them. Nevertheless, I consider the empirical sensation of this intensified quasi-closeness as a fundamental experience that has helped me to enrich my anthropological imagination and awareness of autism.

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[9] Such situations may be regarded as extremely negative and sad but this belief is not fully justified. Taking care of another person is indeed a natural human behaviour. Sometimes, we can give others nothing more than respectful, sympathetic care (Sośnicka and Dobrołowicz eds. 2011).

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FALLEN AGENTS: NEGOTIATIONS OF PATIENT AGENCY IN NORWEGIAN OPIOID SUBSTITUTION TREATMENT

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Based on an ethnographic fieldwork, this article explores how patients in a Norwegian heroin-addiction treatment program negotiate their agency, navigating between policies, medical guidelines, and their own lived experiences as they seek what they perceive as appropriate medication. Outlining these patients' participation in treatment inside and outside the clinic, I illustrate that different types of agency are involved across these domains. I argue that patient agency is not something one has or does not have, but rather involves the institutional interpretations of these mobilised elements: What kind of agency is appropriate to exert in the Norwegian healthcare system? The analysis highlights the social constructions of the "addicted patient" and raises questions of the value of patient subjectivity and the politically tinged ascriptions of agency manifested in patient rights and guidelines for clinical decision-making.

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Niniejszy artykuł, oparty na etnograficznych badaniach terenowych, ukazuje, w jaki sposób pacjenci objęci norweskim programem leczenia uzależnień od heroiny negocjują swoją sprawczość w staraniach o odpowiednie dla nich leki. Opisuję, jak pacjenci, nawigując między polityką, wskazaniami medycznymi oraz własnymi życiowymi doświadczeniami, aktywnie uczestniczą w leczeniu zarówno *wewnątrz*, jak i *na zewnątrz* kliniki. Przedstawiam, w jaki sposób w tych dwóch kontekstach aktualizowane są różne typy sprawczości. Argumentuję, że sprawczość nie jest czymś, co pacjent posiada bądź nie posiada; wiąże się ona raczej z interpretacją instytucjonalną, a więc tym, jakiego rodzaju sprawczość jest uznana za odpowiednią w norweskim systemie opieki zdrowotnej. Analiza kładzie nacisk na społeczne konstrukty „uzależnionego pacjenta" i stawia pytania o wartość jego podmiotowości oraz politycznie nacechowanych przedstawień sprawczości manifestowanych w prawach pacjenta i wytycznych dotyczących decyzji klinicznych.

Keywords: agency, addiction, noncompliance, opioid substitution treatment, patient involvement, Norway

INTRODUCTION

Agency, more specifically patient agency, is a central underlying element in the discourse of patient involvement that became a buzzword in national and global health strategies, plans and regulations of human services (Andreassen 2004, 2016; Gubrium *et al.* 2016). During the last decade, politically tinged ascriptions of agency have figured centrally in debates about patient role in medical decision-making. Increasingly, international bodies and national health authorities have invited to break down the traditional paternalistic relation between patient and physician advocating patient-centered care as a vehicle to improve health care. For instance, World Health Organization drafted a major policy brief recognizing patient engagement as "a fundamental plank of health policy" (Coulter *et al.* 2008). Similarly, the United States' Institute of Medicine emphasizes "care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (2001, 6).

As the understanding of addiction as a disease has gained political attention, solutions and treatments have increasingly been defined through medical lenses. Consequently, the discourse of treatment and patient agency penetrated the field, shaping actors' subjectivities and expectations in new ways (Bartoszko 2018b; 2018c). However, patients with substance addictions or dependencies[1] face serious constrains when demanding participation in clinical decision-making. These demands evolve from clinico-political ideologies advocating for individual sovereignty and a model of patient involvement based on normative visions of responsibility and compliance. But a culturally constructed clinical image of the "addicted patient" as irresponsible, noncompliant, and ambiguous challenges that vision.

Based on a one-year-long ethnographic fieldwork among patients in opioid substitution treatment (OST)[2], this article asks: What kind of patient agency is appropriate to exert in the Norwegian health-care system? The article explores how patients receiving treatment for addiction negotiate their agency in such tense conditions, navigating

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[1] Addiction is understood as an overwhelming involvement with any pursuit whatsoever (including but not limited to drugs or alcohol) that is harmful to the addicted person, to society, or both. Under this definition, opioid use "can take up every aspect of the addicted person's life – conscious, unconscious, intellectual, emotional, behavioral, social, and spiritual" (Alexander 2008, 35). On the other hand, dependency denotes non-overwhelming involvement with opioids, and persons who use opioids in this way are "dedicated to living stable, socially approved lives. Their drug use gives them pain relief, energy, or composure that they find indispensable for coping with the obstacles that they must face in their normal lives – although they must often endure harmful side effects" (Alexander 2008, 43).

[2] Patients in OST are diagnosed with opioid dependence syndrome according to ICD-10, which define the syndrome as "a cluster of physiological, behavioural, and cognitive phenomena in which the use of a substance or a class of substances takes on a much higher priority for a given individual than other behaviours that once had greater value. A central descriptive characteristic of the dependence syndrome is the desire (often strong, sometimes overpowering) to take psychoactive drugs (which may or may not have been medically prescribed), alcohol, or tobacco. There may be evidence that return to substance use after a period of abstinence leads to a more rapid reappearance of other features of the syndrome than occurs with nondependent individuals" (World Health Organization 1992). The ICD definition of dependence encompasses elements of both overwhelming (addiction) and non-overwhelming (dependence) engagements with substances ignoring the qualitatively essential difference between these two phenomena.

between policies, medical guidelines, and their own lived experiences as they struggle for what they perceive as appropriate medication for their ailments.

I define patient agency as individuals' capacity to act to influence their treatment situations according to their will. These negotiations include *all* actions and behaviours concerning the treatment situation. Outlining patient participation in treatment inside and outside the clinic, I illustrate that different agentive elements are mobilised and resisted, and different types of agency are involved across these domains. Thus, patient agency is not something one *has* or does *not* have, but rather involves the interpretations of these mobilised elements.

NARRATIVE AND NON-SOVEREIGN AGENCY

In social sciences, notion of agency is employed in heterogeneous ways. In anthropological literature, it is used for two main reasons: to explain human creativity and to account for changes in social structure (Rapport and Overing 2000, 8–9). For instance, Leach (1977) saw agency as manifestation of criminality inherent in humans (Leach 1977, 19). He writes:

> "All of us are criminals born by instinct. All creativity (…) contains within it a deep-rooted hostility to the system as it is" (Leach 1977, 19).

Human action, in other words, is driven by a desire to challenge established societal rules simultaneously producing new ones. In the same vein, Lavie, Narayan, and Rosaldo define creativity as "human activities that transform existing cultural practices in a manner that a community or certain of its members find of value" (1993, 5). I follow this strand of thinking in my approach to agency drawing further on Lucas' (2017) concept of narrative and non-sovereign agency.

The premise for my use of agency in this article is this: As individuals, we enter social situations equipped with the culturally shaped ideas of possible lives in a given social context at a given time, and we are constantly in quest for creating our future and living out multiple possible futures (Bruner 2004; Mattingly 2009). Therefore, people are meaningful agents who are both constituted by a complex matrix of stories and have any number of stories of their own to tell *and* enact (Lucas 2017; Mattingly 2009). According to Lucas:

> "Often we are blinded to the agency of others by an assumption that agency is equivalent to perfect freedom of choice or to the absence of coercion. We are prone to see people, as Hutchings (2013) puts it, as "choosers or losers" rather than as consistently beset *both* by the capacity to act and a number of factors that compromise this capacity (…) And each of us, though certainly some much more than others, *is* subjected to harmfully reductive narratives. [Yet,] everyone is both embroiled in inescapable power relations and capable of moments of recognition" (Lucas 2016, 10, 12).

Inspired by feminist theory, Lucas is interested in

> "uncoupling the notions of agency and autonomy to defend a definition of agency that is resilient in the face of coercion, oppression, and systematic marginalization" (Lucas 2016, 12).

Her perspective accounts for structural inequalities and injustice, but does not frame these as invincible obstacles to agency. Following Lucas's (2017, 12) suggestion, I dispense with the idea that we are either free or unfree, either agents or victims, either "choosers or losers" so as to challenge the tendency to think of patients or "drug addicts" as passive victims of biopower or coercion, and of biomedical professionals or law enforcements agents as self-legislating, wholly autonomous individuals. This approach acknowledges *all* human beings as "agents capable of unpredictable action" (Lucas 2016, 13), instead of defining them according to received social categories and dominate narratives.

Agency, therefore, is a relational and interactional concept, rather than an innate or transcendent capacity which the self-governing subject may exercise. It is

> "the capacity to appear to another within a plurality of subjects and selves, each of whom is constituted by shared norms and narratives" (Lucas 2017, 28).

Resting on this kind of inter-subjectivity, the narrative concept of agency can provide a strong sense of uniqueness, individual freedom, and meaningfulness. Therefore, I define agency as the capacity to make sense, to meaningfully act (Lucas 2017).

OPIOID SUBSTITUTION TREATMENT IN NORWAY

In Norway, a country of 5.3 million inhabitants, approximately 8,700 and 12,700 persons are estimated to be injecting drug users (predominantly heroin) (Bretteville-Jensen and Amundsen 2009; Amundsen and Bretteville-Jensen 2010). In the past, users of illicit drugs could be divided into subcultures based on their drugs of choice. Lately, however, the prevalence of poly-drug use has evinced a rise. Combinations of opioids (heroin, methadone, buprenorphine, morphine and other morphine-like substances) and benzodiazepines are most common. Amphetamine and other central nervous system stimulants are widely used in combination with opioids. Norway has 300 fatal overdoses annually (European Monitoring Centre for Drugs and Drug Addiction, 2017), a fairly consistent number over the last decade. To address this challenge, the national OST program existing since 1998, has relaxed its admission criteria and introduced new medications. At the end of 2017, 7,622 patients were in Opioid Substitution Treatment (OST). The average age of these patients was 44.9 years and approximately 70% were men (Waal, Bussesund, Clausen, Lillevold, & Skeie, 2018).

In OST, patients with heroin addiction receive long-lasting opioid substitutes for – usually illegal – heroin under controlled conditions. The substitution medications, such as methadone or buprenorphine, are said to eliminate heroin withdrawal symptoms, reduce cravings, and block the effect of heroin. Treatment of opioid addiction with substitution medication has shown an increased patient survival rate, along with a diminution in health damage, criminal behaviour, and somatic diseases, compared with psychosocial treatment alone (Hedrich *et al.* 2012; Riksheim *et al.* 2014; Skeie *et al.* 2011).

According to the national guidelines for OST, the aim of substitution treatment is:

> "to improve [patients'] life quality and to assist them in altering their life situation by improving their optimal coping and functional levels. The objective is also to reduce the harmful effects of opioid addiction and the risk of death from overdose" (Helsedirektoratet 2010, 3).

The OST program encompasses social service centres, general practitioners, and specialised healthcare. The treatment is mainly outpatient, with medication supplied free of charge at the local pharmacy or through the OST centre. The OST system aims at a rather high degree of control. Medication must be taken under daily supervision until patients are determined to have stabilised and gained sufficient control over their drug use, as measured through urine samples indicating no evidence of non-prescribed drugs. Once patients stabilise, they may be allowed to self-administer medication at home. Medication lasting for up to a week or more, depending on preapproved travel plans, may be available.

The guidelines recommend three medications for treatment: methadone, high-dose buprenorphine (Subutex), and a buprenorphine-naloxone (Suboxone), with buprenorphine the recommended first choice. However, the guidelines emphasise that "patient's preference should be emphasised in the choice of medication" (Helsedirektoratet 2010, 51–52).

Patients respond differently to prescribed medications. Some are satisfied, while some experience disabling side effects, persistent cravings, or just do not feel well. Switching treatment modality requires negotiations between the patient and the OST program, and these negotiations are the context for this study. I focused on choice of medications because it is the most contentious issue in debates on patient involvement in OST and illustrates the power asymmetries in the clinical setting while casting new light on patient agency.

SUBSTANCE TREATMENT REFORM AND LEGAL PATIENTISATION

In 2004, Norwegian authorities extended public goods, such as better health provision and rule of law, to groups previously excluded from these benefits, such as OST patients. Incorporating OST patients into the "ordinary" patient community was a form of inclusion and a recognition of their agency. This inclusion was to be achieved through Substance Treatment Reform, formal medicalisation of addiction, and an increasing use of legal structures to assign treatment. Responsibility for treatment was shifted from social welfare services to the healthcare system, with addiction treatment redefined as a specialised health service along the lines of somatic and psychiatric care. The reform guaranteed OST patients access to specialised healthcare and established patients' rights to safeguard this goal.

Patients' rights were central for my interlocutors' understanding of their new position in the clinical landscape, which changed their expectations for involvement in treatment. Following the global rise of ideologies advocating active patient engagement, Norwegian health authorities have ascribed increased significance to patients' experiential knowledge, formalising it through treatment protocols and legal documents. For instance, the Norwegian Patients' Rights Act states:

> "The patient is entitled to participate in the selection of available and prudent examination and treatment methods. The service offer should be as far as possible designed in cooperation with the patient and […] patient's opinion should be strongly considered" (§ 3–1).

Thus, as I read the expression "as far as possible", this act extends agency to patients. The question is not *whether* patients should have agency, but what kind and on what premises. The act offers a space for multiple legal and clinical definitions, and thus, for negotiations and normative judgments. Norwegian law and the literature do not clearly define patient involvement, but they chart a clear image of a desired patient: one who is active, autonomous, competent, and responsible. Therefore, clinicians and patients must strike a balance between two main policy documents: the Patients' Rights Act that regulates patients' involvement in choice of treatment modalities and recognises patient agency and individual needs, and the OST guidelines that focus on control and express "cautiousness" regarding patients' agency. Thus, OST treatment is built on a tension between *the responsible subject* assumed in patients' rights discourse and *the irresponsible drug user* assumed in OST program's disciplinary practice.

METHOD

My overall objective during fieldwork was to explore the experiences of OST patients in the context of the Substance Treatment Reform of 2004, which granted patients' rights to persons diagnosed with dependence. Increasingly, I focused particularly on patients' experiences of changes in treatment modalities that appeared to be contentious. Patients who wished to switch or keep their prescribed drugs had to negotiate with the OST interdisciplinary treatment team, usually represented by social workers. Some OST patients chose to take legal action, filing a complaint with the County Medical Officer. The length and intensity of this process varied depending on the patient's situation, preferences, negotiating capital, and relationship to the treatment team, as well as the prescribing physician's preferences.

I followed closely six patients who wished to switch or keep their medication during a 1-yearlong (2013–2014) ethnographic fieldwork in several Norwegian municipalities. OST patients are a heterogeneous group of persons: those leading very "stable," mainstream lives; those actively engaged in open drug scenes; and those in between these two extremes. The interlocutors who participated in my study belonged to all categories, fluctuating among them, as I will show. They all used different combinations of medications depending on their situation and geographical location. They were recruited through a traditional snowballing method beginning with my initial contact with an OST patient recruited through a personal network. Participation in the study was based on an informed consent procedure approved by the Norwegian Centre for Research Data. The Regional Committees for Medical and Health Research Ethics evaluated the project and found no reason to apply the additional regulations that are specific to medical and health research.

Participant observation was a key fieldwork component. Among other things, I accompanied the patients during OST consultations, prehospitalization meetings, and meetings with their treatment teams, lawyers, or patient associations. I also followed them through their everyday OST activities such as visits to pharmacies, low-threshold health clinics, detoxification units, and urine collection sites. While the most intensive relationships were developed with these six patients, I also met their friends, friends of friends, and other OST patients, who shared their stories. Many of them were satisfied with their treatment.

Altogether, I collected around 40 treatment stories. In addition, I participated in relevant events such as patient gatherings, workshops, local professional addiction conferences, seminars, and courses, which yielded insight into the main narratives and rationales in the field. I also conducted over 60 in-depth interviews with representatives of patient organizations, addiction researchers, OST physicians, OST consultants, social workers, general practitioners, health bureaucrats, the patient ombudsman, and lawyers.

Ethnographic field notes and transcripts from interviews and documents (e.g., health records, OST guidelines, and white papers) were coded and analyzed for key empirical themes emerging from the material. These themes were further analyzed against key words from policy documents, clinical guidelines, and bills of rights (such as "individualized treatment," "patient involvement," "patient agency" and "quality of life"), and for how these ideological and political intentions corresponded to the ideas and experiences of patients and clinicians in treatment practices.

PATIENTS' SUBJECTIVE AGENCY

Barrows and Pickell formulate the aim of treatment recommendations as:

> "changing a patient's existing unacceptable situation into a preferred one [such as] a cure, a relief of pain, an improvement in health status, a prevention of impending illness or complication, or a reduction of distress or concern, depending upon the patient's and [the clinician's] objectives" (Barrows and Pickell 1991, 163).

Already at this point, the negotiations of patient agency are explicit: What is the goal of OST and according to whom? Is the goal to stop heroin use entirely or to reduce it? Is it to enable the patient to work or study? Is it to eliminate the patient's "highs" or to allow the patient to feel "highs" on a legal or safer medication? Is it to avoid overdoses and possible death or to enable the patient to live better despite risks? Patients and clinicians often disagree on these desired outcomes as policies of harm reduction and goals of abstinence clash. Patients who prefer a shorter life span challenge the clinical imperative to prolong life (Bartoszko 2018a). Ideas of a good life including "highs" contrast with the ideal of living in non-altered ways (Bartoszko 2018b). The plethora of patients' subjectivities, past experiences, and dreams for the future challenge the vague goal of OST to "improve life quality". Disagreements concerning these goals result in treatment recommendations that often override patients' wishes and disregard their personal, social, and clinical experiences.

As a creative capacity, agency can be engaged to influence the state of the world. Here, as Fischer pointed out, "the importance of realised effectiveness is unclear: exerting power so as to influence the world does not necessarily mean that the world is so influenced and changed" (Fischer 2014, 152). In this respect, Fischer coined a term *subjective agency*, referring to the individual's internal ability to make choices and control procedures (Fischer 2014, 153).

Studies document that patients experience diminished subjective agency in OST, which is described as a hostile system, fostering suspicion and distrust, while reproducing social stigma and exclusion (Bartoszko 2018a; 2018b; Bourgois 2000; Friedman and Alicea 2001; Harris 2015). Other scholars emphasise OST's capacity to monitor and control patients' bodies requiring them to forgo pleasure (Moore 2008) by consuming medications that stabilise withdrawal symptoms yet may not bring patients the desired effect or a better quality of life (Bartoszko 2018a).

My interlocutors experienced an inability to influence their situations and felt discredited and disrespected. They feared sharing their real stories, such as relapses, with their treatment teams because of the restrictive consequences. Patients reported an "bureaucratic indifference" (Herzfeld 1992, 1) among clinicians who treated them as cases, not individuals. For instance, they experienced degraded agency when clinicians imposed urine testing rather than simply asking them to report any drug use. Clinicians tended to rely on testing because of underlying mistrust of patients and time constraints that limit opportunities for constructive dialogue with patients. A conversation with Oscar, a 40-year-old patient, illustrated this experience:

> "[Oscar:] They say they look at us as humans. Talking so much about psychiatry, change of mindset; that they take us seriously and with respect. But when you get in there [OST] it's just: 'What have you taken? How much? When?'
>
> [Aleksandra:] But isn't it important …?
>
> [Oscar:] Well, yes. This too. But nobody asks how I am. Or no, do you remember the social worker lady. Sweet and kind. She asked, but now it's that with the youngsters. They have no clue. And then it is just like, 'Hello, how are you?' And you're not waiting for answers. Like for real answers. (…) So all the meetings, they are so technical, it becomes so technical. So little of all the mental and social they are talking about".

In such cases, patients experience an imbalance between what they provide (bodily fluids and answers to uncomfortable questions) and what they receive (the desire to be "really heard and seen"). The imbalance is disempowering and leaves patients stripped not only of subjective agency but also of the possibility of getting well. As a result, individuals' agency *as* patients with needs and right to talk, share, and be involved is undermined.

At the same time, patients are very cautious of what they say during their consultations. As 50-year-old Ina expressed:

> "The main focus […] can quickly be directed toward something that patients can't really say anything about, such as consumption of [non-prescribed] drugs. Because it would lead to restriction of personal freedom and desires. Well, then you have to lie. And then OST understands that you are lying, so you have to lie more and so on. The worst here is that those who work in OST don't stop this. God, so much waste of time and energy".

This example highlights relational nature of agency. On the one hand, patients experience diminished agency because they have to hide their "true stories", fearing consequences of their "confessions", as patients often call these consultations. On the other, lying as an attempt to deceive (Barnes 1994) in order to achieve goals within limited conditions is a way of exercising agency and a means of control.

AGENTIVE DISABILITY AND AMBIVALENT AGENCIES

Every treatment is initiated by a set of negotiations, negotiations of roles, of symptom management, of knowledge, meanings, and life forms (Strauss *et al.* 1963; Kleinman 1980). Studies suggest that patients can easily be swayed by physician authority when choosing treatment options, and that patients are willing to follow physicians' recommendations even if they are contrary to their own wishes (Gurmankin *et al.* 2002; Karnieli-Miller and Eisikovits 2009). In OST, the situation is often the opposite, and physicians struggle to maintain authority. As most OST patients are experts in "lay pharmacology" (Webster *et al.* 2009), the clinical negotiations may be more explicit and, often, dramatic. The vast majority of OST patients enter the clinic with specific ideas about their treatment, in particular, their preferred medication. My interlocutors argued that they *knew* which medication worked best for them and attempted to get OST professionals to acknowledge that experiential knowledge. In other words, they demonstrated patient agency by requesting specific services or by responding to given recommendations (Gill 2005; Koenig 2011).

Often patients' requests went against the doctors' opinions, such as: "No, I don't want Subutex because it gives me anxieties" or "I think morphine would be a better option to keep me healthy". In response to the prescriber's biopower, patients wield counter power, the strength of which lies in their pharmacological reasoning based on lived experiences unavailable to clinicians. At stake here is not the recommendation itself, but what it reveals about power relations in the clinic, about the social treatment of patient agency when medical knowledge is questioned, and about the social and clinical understanding of addiction and pharmaceutical enhancement of life quality.

Patients understand patient agency as the ability to take effective action to get what they want, but clinicians and health bureaucrats see limitations to this understanding for two reasons: first, institutional constraints often hinder fulfilment of patients' requests, and second, clinicians and health bureaucrats tend to ascribe to these patients what I term *agentive disability*, a diminished capacity to take the rational action that would comply with the institutional imaginaries of a competent patient. When patients express their wishes for particular medications, clinicians often attribute this kind of agency to their treated condition – addiction – and thus distinguish between desired and problematic agency. One prescriber described the challenge of differing views of agency:

> "[H]ealthcare professionals become quite uncomfortable with a situation in which they see that the patient is very well informed. Especially when you have, perhaps, very tight rules binding you so that you can see that what the patient says makes quite a bit of sense. Yet I have to adhere to these rules. Then you can see that the doctor comes to a point where he has to, kind of, defend a reality with which he doesn't necessarily agree completely. […] Nevertheless, the fact is that there is an elephant in the room, which doesn't make things easy to discuss. This is because it sometimes implies discrediting the patient's motives. […] By saying that… OK, when you say that you now want heroin as a substitute medication or something else, then I know that one of the problems is that it is a drug (*rusmiddel*). I don't want to contribute to your intoxication (*rusing*). This is often difficult to talk about, because it could mean suspecting the patient, I think. [I]n some cases, we don't agree and it is me who gets to decide. But then it is important that we keep people in treatment. There is such a dilemma regarding what we can accept without perceiving it as unsound and what the patient accepts".

During discussions of the choice of modality in OST, patients' experiences and in-depth knowledge of pharmaceuticals are often their weakness. The idea of involving them in treatment becomes a dilemma, and therefore, the formulation "patient's wish" (*ønske*) in OST guidelines may be a slightly unfortunate way of mirroring the patients' competence and involvement. During my fieldwork, clinicians tended to interpret the "wish/preference" in various ways, and these terms often bore normatively negative associations. I could spot this through the context in which they frequently used the words wish or preference: "[Patients] *prefer* [morphine] because they can get high"; "Some [of the patients] have their, you know, *preferences*"; or "We can't give [into] their *wishes*". With these statements, practitioners questioned patients' motives and interests. Clinicians dismissed patients' experiential knowledge, aligning it with value-laden images of the addicted patient having distorted agency, which the disease model of addiction and neuroscience strongly promotes (e.g. Hyman 2005). Because the line between the preferred effect of OST medications and so-called "drug seeking behaviour" is indistinct, the clinical appreciation of patient agency is tested.

OPPORTUNITIES STRUCTURES AND "FRUSTRATED FREEDOM"

Agency is not a totally free choice, and neither are patients free to choose whatever treatment they wish. Choice is conditioned by local clinical cultures, legal regulations, and available and authorised research *at a given time* and expressed in treatment protocols (e.g. Bartoszko 2018b, Gjersing *et al.* 2011). For instance, 53-year-old Siv was in treatment with morphine for three years, with good results according to OST, and she did not want to switch to Suboxone, which the new guidelines recommended. She filed complaints to avoid the compulsory conversion. Before her final and successful complaint to the Norwegian Board of Health Supervision, the following dialogue took place between her and the physicians during a pre-hospitalisation consultation:

> " [Detox physician:] You feel that you are pressurised, but it seems that [OST does] not have a choice because of the guidelines and regulations and all of this…[…].
> [OST physician:] At the same time, it is not wrong to have this feeling, to be pressed for something you don't want…
> [Siv:] Yes, this is a duress situation.
> [OST physician:] Now, we have tried all the instances… they have written that it appears you can't appeal any more. This is tough for you, no doubt about it.
> [Detox physician:] The situation is pretty much set in concrete. As long as you live in this country, the case is closed. So everything is already decided […].
> [OST physician:] We have no authority. We are as stuck as you are".

In this meeting, the clinicians spoke with many voices. We hear an authoritarian voice that patient experienced as disempowering. There are "higher authorities that decide". At the same time, the clinicians acknowledged the patient's perspective, but expressed their own powerlessness. With treatment protocols restricting their clinical responsibilities, they expressed hopelessness regarding these constraints and the patient's fears.

In their descriptions of patient cases, clinicians emphasised institutional hindrances that limited their ability to consider the individual's situation. A physician shared her thoughts on compulsory conversion of OST patients to Suboxone, which was introduced to the program to prevent injections and diversion to illegal markets:

> "Well, it makes a difference if you are in charge in the Directorate of Health or the government, or if you are a legislator. Then you are able to say that 'there are so many people who die of this drug and that one. We have now seen that more people die from buprenorphine as well. Overdoses. We have to do something about this. Everyone needs to get on to Suboxone, which is less dangerous'. That, in a way, becomes the perspective when you carry the systemic view with a sense of responsibility for a third person. But then you also have this one-on-one relation between the clinician and patient, which is a slightly different setting. Unfortunately, this is a dilemma. Sometimes, in order to achieve something at the system level it has to be harder for some patients and a little more difficult for some single patients. For instance, [it requires] taking a medication that they may not have required in the first place".

Precautions are made in the clinic because of the medications' risk profiles and patients' assumed unpredictable conditions; however, the precautionary practices limit patients' subjective agency as patients are not even given the chance to "prove that they are not guilty" of selling, injecting, or abusing the drug. Patients tend to express their experiences as individual and personal problems to be appreciated, but these often conflict with institutional and political needs and obligations.

Exposed to the clinico-legal promises of "involvement", patients expect satisfaction. In the above situation, Siv left the meeting disillusioned and frustrated. Meetings in which patients' preferences are suspected and dismissed because of treatment protocols dash patients' expectations of being active participants in treatment, triggered by the new law. According to Fischer,

> "The effectiveness of aspiration and agency is often limited by available opportunities structure […]. The *will* is important, but there also has to be a *way*" (Fischer 2014, 6).

Opportunities structures encompass formal and informal social norms; class, gender and other systematic distinctions; and legal regulations, treatment protocols, and other institutional factors that define what is possible. Individual agency acts on choices, but those choices are structured through socio-political processes that transcend the individual. When subjective agency far exceeds available resources and opportunities, we find "frustrated freedom". This kind of freedom permeated my interlocutors' experience with OST. As Fischer wrote:

> "Individual[s] [may] possess the subjective agency to achieve more than their material resources and opportunity structure can enable. In such a condition, opportunity and resource deficits frustrate their perceived capacity to successfully make the decisions and choices that they believe would enhance their well-being" (Fischer 2014, 156).

Resistance outside the clinic

So far, I have shown that patient agency, in its narrow sense, can be troublesome in the landscape of diverging policies, guidelines, and lived experiences; and as a result, patients experience clinical disempowerment. Yet, actively negotiating their treatment, patients appear as creative and resourceful social agents, exercising more agency than is typically assumed.

I now focus on how patients enact and negotiate their agency as they exert the right to refuse the recommended OST modality and to engage in various life strategies outside the clinic. Through their non-acceptance, understood as a form of active resistance (Stivers 2005, 52), patients actively participate in clinical decisions and create the opportunity to shape treatment and future outcomes.

Legal action

Before participating in yet another consultation, Siv said to me: "If it doesn't work here [in the clinic], let's try elsewhere". She was prepared for OST to reject her desire to keep her preferred medication, and planned to file a complaint with the Norwegian Board of Health Supervision. The Substance Treatment Reform granted patients the right to complain, and those with sufficient capital use the law to change the course of their treatment (Bartoszko, 2018c). Thus, patients' agentive space has expanded beyond the clinical setting as the law provides another new pathway in a contentious landscape.

Anthropological accounts of biological citizenship (Petryna 2002) emphasise that patients' agency elicits changes not only to medical classifications, but also to the ways in which claims are made on the state. In the field of addiction, too, I argue, increased intersections between medicine and the law have created new subjects that threaten clinical authority in new ways. Patients' rights may serve to enable patient agency, which has been diminished in the clinic, and thus shape, to paraphrase Hacking (1985), a new kind of patient – the patient-citizen – who, not only seek specific medical treatment, but also fulfilment of their rights. The Substance Treatment Reform mobilised legal consciousness among former "drug addicts" who are now patients with a diagnosis (Bartoszko, 2018c), giving them a novel opportunity to make meaningful decisions about compliance. Under the treatment reform, a central feature of patient agency is to challenge potential medical wrongs, thus empowering disadvantaged patients, but also laying the foundation for further corrosion of medical authority. The following situation illustrates this situation.

One of the OST program reports about Siv's long legal process notes:

> "The patient was very much focused on rights in her statement and there was much talk about laws and rules, and, unfortunately, little room to assess her health condition".

Yet, each time the patient asked for an individual health evaluation, she was referred to guidelines that were treated as "law-like". During the consultations, no one thoroughly evaluated Siv's situation, an omission that the Norwegian Board of Health Supervision noticed and documented. This example of OST's structural ambiguity (Best 2008, 356) highlights the ironic and confounding character of bureaucracies (Hoag 2011, 81). Expectations towards patients as active agents are blurred, and although patients are expected to turn to the law, such engagement can be viewed as a burden to the clinic (Bartoszko, 2018c). As patients enter the realm of powerful bureaucracies, they engender a potent force of clinicians, illustrating the disaggregated character of power and of the state. In Siv's situation, the clinicians appeared "petty empowered… the dominated segment of the dominant" (Marcus 2000, 3). They were complicit with the powerful institution of law, yet antagonistic to it when it disturbed the established patient-clinician dynamics. In this context, patient agency expressed through legal mobilisation threatened medical authority, generated fragmented governance, and thus initiated possibilities for patients but also potential conflict in the clinical relation.

Precarious agents

During my fieldwork, patients who wanted to switch from buprenorphine products to methadone or from methadone liquid to methadone pills had a difficult time. Pending OST decisions, they employed various strategies to deal with their situations. Patients who were dissatisfied with a treatment regime often engaged in "non-adherent practices" which the clinical narrative discourages. In addition to experiencing diminished subjective agency, patients often felt that OST acted against their interests. In an attempt to reclaim self-control and self-regulation, patients devised strategies of resistance toward the system, such as diversion, unsupervised weaning, self-prescribed split dosing, or cheating with urine samples (Bartoszko 2018a). To curb side effects and achieve a better quality of life, some of my interlocutors manipulated the system or supplemented their medications. The following examples illustrate this behaviour.

Jon

Jon had been with the OST for 13 years. Six years ago, he began experiencing harsh side effects of the methadone liquid he had been consuming since he started treatment, including stomach and intestinal spasms, nausea, and severe vomiting. He asked to switch to pills, which he tolerated much better. OST refused his request using the diversion argument, citing the guidelines. They wrote in their response to Jon's application,

> "According to the guidelines, 'methadone may be given in a form other than liquid mixture only in exceptional cases and in terms of sufficient control of [patient's] drug habits'".

Jon filed a complaint with the County Medical Officer. Pending a decision, he continued to use the liquid mixture, until he felt too sick to ingest the medication and injected it, exposing himself to medical and social risks. In addition, he used cannabis to curb nausea and exchanged the liquid methadone with tablets on the black market. His “pill days” gave him some relief from the disturbing side effects and time to recharge his energy to continue his fight.

Jon’s situation not only caused him to doubt OST’s concern, but also hindered his social rehabilitation and challenged his identity. He wavered between a new “rehabilitated life” that he had sought when he joined OST and his old “junkie life”. To cope with the unsatisfying medication, he continued to visit the illicit drug environment in town to make exchange arrangements, opening himself to suspicion and fulfilling OST’s low expectations of him. In addition, he was challenged to restrain from using other drugs during these visits, and his use of cannabis made it difficult to prove to OST that he was “reliable” and “stable” enough to get methadone tablets on a weekly basis (according to OST, only stable patients were permitted to get methadone tablets).

Oscar

I accompanied Oscar to a downtown pharmacy where he picked up his 12 mg of Subutex every Wednesday. Back at his place, I saw him take 10 mg of his dose and hide the rest in a box under his bed. I questioned why he did not the entire dose.

> “[Oscar:] Well, I am trying to taper off. If I tell them [OST] that I went down, they will give me just 10…
> [Aleksandra:] That’s fair, I suppose, isn’t it?
> [Oscar:] Well, no. Because if someday I feel that I need more [Subutex], they will not give me any.
> [Aleksandra:] Like if you have a bad day and cravings and stuff, you cannot call them and get a bit extra?
> [Oscar:] Nope.
> [Aleksandra:] That’s why you keep some away for a rainy day?
> [Oscar:] Yep”.

OST deems such stockpiling as irresponsible. First, it contributes to a larger cache of “OST medications floating on the streets”, and the media has repeatedly reported theft in the rehabilitation centres where Oscar lived. Second, unsupervised weaning and “tinkering” with strong medications involves medical risks (Helsedirektoratet 2010). Yet, as Oscar’s story illustrates, OST patients live in an uncertain system that is not geared for “emergencies” or to facilitate rehabilitation. Rather, the system is geared to maximise crises, spare some quantities of medication, and risk theft or sale.

Based on these stories, I argue that the OST system is built on technologies of suspicion and is neither designed nor organised to facilitate *rehabilitation of thought,* thus leading to clinically disapproved actions. The various creative ways in which patients deal with mistrust while coping with precarious treatment situations serve to maintain harmful, unwanted behavioural patterns. The control measures lead to patients’ engaging in risky behaviours including hazardous administration, poly-drug use, and illegal tapering of prescribed medication (see also Bartoszko 2018a; Dahl 2007; Harris and Rhodes 2013; Mjåland 2015).

The precarious treatment left my interlocutors to circulate between worlds, identities, and possibilities, neither patients nor addicts and without genuine agency in the dominant discourse of patient involvement.

COMPLIANCE AS IDEOLOGY THREATING PATIENT AGENCY

Trostle (1988) argued that compliance should be regarded as an ideology supporting the authority of medical professionals, rather than the only right therapeutic route. Yet, he noted, the assumption is that in exchange for a physician's services, a patient owes fees, cooperation, and compliance; noncompliance is usually the patient's fault (Trostle 1988, 305). Clinicians interpreted Jon's and Oscar's actions accordingly. As these two manipulated the system to cope with unsatisfying treatment, they fulfilled the OST clinicians' pre-existent perceptions of OST participants as noncompliant, irresponsible, and ambivalent patients. In addition, their noncompliance was seen as lack of self-control which clinicians attributed to the "addict's" distorted agency stemming from a compulsive desire to use and "a force other than his own". Indeed, clinically, addiction is characterised by a loss of control over drug use despite negative consequences. This characterisation frames addiction as a condition in which the capacity for autonomous agency, control, and decision-making is completely undermined. Kirmayer (1992) pointed to the narrative misreading in clinical situations in which patients do not seem to accept clinical reasoning which can lead to their being categorised as noncompliant. He wrote,

> "When this sort of education fails to change the patient's behaviour – even though the patient can recite the biomedical facts and seems to understand the doctor's line of reasoning – the physician suspects some hidden perversity of the patient's mind" (Kirmayer 1992, 326).

I found this kind of misreading common in the clinical and social imaginaries about noncompliant OST patients.

However, some forms of noncompliance are inherently rational and logical (Conrad 1985; Fainzang 2014; Trostle 1988). Indeed, my study documents that

> "what appears to be noncompliance from a medical perspective may actually be a form of asserting control over one's disorder" (Conrad 1985, 29).

The way patients acted were examples of asserting control over one's clinical and social situation, a *tactical agency*. Tactical agency refers here to how patients "cope with the concrete and immediate conditions of their lives" (Honwana 2005, 49). However, patients' actions come from a position of disempowerment. Thus, tactical agency, as "an agency of the weak", includes vulnerability and an ability to cope. The way Jon and Oscar administered their prescribed and illicit drugs was as an active engagement of patient agency within the given conditions and with available resources.

GOOD AND APPROPRIATE AGENCY?

The provided examples highlight that the agentive nature can be ambiguous. I use Durham's term "ambiguous agency" (2000, 116) to refer to examples of agency that contrast starkly with established, normative ideas about autonomy, responsibility, and the kind of behaviour patients should demonstrate, the activities they should engage in, and the spaces and places they should inhabit.

If patients' agency is considered negative, challenging, and problematic, then clinicians more likely question it and attempt to curtail it. Institutional constraints become more significant and explicit when resistance is present. Such negative agency has to be overcome through modes of disciplinary control or precautionary practices designed to bend patients' conduct towards morally and socially approved goals, transforming social agency into "responsible agency". On this issue, Hoggett remarked:

> "[T]here is a danger that we […] slip into equating agency with constructive coping, as if the two were synonymous. The point is that there is nothing necessarily constructive about agency and we should beware of smuggling normative assumptions into our thinking here, as if agency is good and absence of agency is bad" (Hoggett 2001, 42–43).

Patients' resistance reveals the contradictions between the sociological notion of agency and that promoted by policies and the practical field of medicine. The notion of agency as something inherently positive fails when we deal with actions that go "against the grain", that have goals inconsistent with political ideals of freedom, the principles of "universal reason", or "self-interest" (Mahmood 2001); in other words, that counter normative assumptions about the reasonable patient.

My fieldwork reveals precisely how, in the practice of medical interventions, the agency of "out-of-place" patients is often considered inappropriate, and may be identified as an obstacle to the clinical intervention itself. OST patients are allowed – moreover, they are praised – for being "agents", but their agency must be of the "right" kind. In other words, the negotiation of patient agency in OST is not about agency being acknowledged, but rather about what kind of agency is deemed appropriate.

CONCLUSION

This article calls into question ideologies promoting "patient involvement" and "individual treatment" when the daily practice of clinicians requires a more pragmatic, tacit kind of thinking that accounts for structural conditions and patients' perceived ambivalence. My investigation of patient agency inside and outside the clinic shows that policies, treatment protocols, and legal regulations may serve as both "thinners" and "thickeners" of patients' agency (Klocker 2007) by constraining and expanding patients' range of viable choices.

Although the OST system can leave patients feeling trapped and powerless, they are not passive or docile in their dealings with OST and the health-care bureaucracy. They demonstrate the ability to influence events in their social worlds, which emphasises that clinicians do not necessarily hold all the power in social relations. Patients' actions, although illustrating the "agency of the weak", testify to the decreasing status of the physician and the erosion of medical authority.

Patients and clinicians find their own paths between policies, treatment protocols, and patients' lived experiences. Tracing these, they negotiate the narrow form of "patient agency" and shape new and broader forms. In other words, patient agencies are *made* and cannot be assumed in clinical reality. Their form, role, and significance change according to opportunities structures and how individuals engage with them. Thus, agency is not something a patient *has*, but rather a cascading series of contingent actions a patient *does*, as a temporally embedded process of social engagement informed by the past but oriented toward the present and the future.

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BETWEEN THE SUBSTANCE AGENCY AND THE USER'S CONTROL. INSTRUMENTAL DRUG USE AMONG DRUG USERS IN WARSAW

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The focus of this article is on instrumental drug use and the problem of agency in interaction with psychoactive substances. Most of the Euro-American discourse formed around drug use stresses the individual loss of self-control related to drug use. This paper is located within those critical studies of drug use, which challenge the notion that regular drug users are deprived of agency in their interaction with psychoactive substances. During my fieldwork among drug users in Warsaw, I got the impression that psychoactive substances can be treated as a tool for altering the state of the human mind, which can be employed in various ways and controlled by the user. Still, this tool is a dangerous one and cannot always be fully subject to human agency. Based on case studies, I analyse the functions of drugs for the users and their intentions regarding use. The ethnographic exploration of individual drug use trajectories is a starting point for the further consideration of the process of negotiating agency with psychoactive substances.

* * *

W artykule podejmuję próbę analizy zjawiska instrumentalnego zażywania substancji psychoaktywnych i problemu sprawczości w interakcji z narkotykami. Większość euroamerykańskich dyskursów łączy zjawisko zażywania narkotyków z utratą kontroli. Niniejszy artykuł usytuowany jest w obrębie nurtów badawczych związanych z zażywaniem substancji psychoaktywnych, które kwestionują przekonanie, że regularni użytkownicy substancji psychoaktywnych są pozbawieni sprawczości w interakcji z nimi. W trakcie moich badań terenowych przeprowadzonych wśród użytkowników substancji psychoaktywnych w Warszawie zauważyłam, że substancje psychoaktywne można traktować jak narzędzie służące do zmieniania stanu ludzkiego umysłu, które może być w różnorodny sposób wykorzystywane i nad którym użytkownik może mieć kontrolę. Jest to jednak narzędzie niebezpieczne, które nie zawsze w pełni poddaje się ludzkiej sprawczości. Na podstawie studiów przypadku analizuję, jakie funkcje spełniają narkotyki dla użytkowników, a także jakie są indywidualne powody ich konsumpcji. Etnograficzna analiza empirycznych trajektorii zażywania substancji stanowi punkt wyjścia do dalszych rozważań nad procesem negocjowania sprawczości z substancjami psychoaktywnymi.

Keywords: substance use, drug instrumentalisation, neural model of addiction, the Nida model, agency, control

INTRODUCTION

Psychoactive substances might be treated as a tool for altering the state of the human mind, which can be used in a variety of ways. One of my interviewees said:

> "I would like to live in a world where if I found myself in a certain mood I could go to a pharmacy and choose a mind-altering substance that would fit my current state".

Although there is a broad range of psychoactive substances with different effects, in the laboratory of the streets, drugs are not an ideal mind-altering machine. Psychoactive substances are an instrument that can easily go beyond the user's control. Still, the present research suggests that not every case of regular drug use develops into addiction; quite the contrary. Situations where users do find a balance between their needs and dreams and the potentialities provided by particular drugs are relatively common. In spite of this fact, most Euro-American discourse formed around drug use stresses the individual loss of self-control related to drug use (Garriot and Raikhel 2015; Weinberg 2013). The following research is located within those critical studies of drug use (Cloud and Granfield 2015; Granfield and Reinarmar 2015; Garriot and Raikhel 2015; Müller and Schumann 2011; Lilienfeld and Satel 2014; Waldorf *et al.* 1991; Zinberg 1984), which challenge the notion that regular drug users are deprived of agency in their interaction with psychoactive substances. According to the model of drug instrumentalisation proposed by Christian Müller and Gunter Schumann (2011), being the theoretical basis of this study, psychoactive substances are consumed for their ability to change mental state and are instrumentalised in order to achieve specific goals. In this approach, psychoactive substances can be treated as a tool for altering the state of the human mind, which can be controlled by the user. Still, this tool is a dangerous one and cannot always be fully subject to human agency.

The aim of the paper is to analyse how the agency relations within drug use depend on the function of a drug for the user and his/her intentions regarding substance use. In the first section of the article, I present a brief history of how the notion of the loss of self-control is linked with the concept of addiction and current frameworks for controlled drug use. Then, on the basis of my fieldwork conducted among drug users in Warsaw, I analyse individual drug use trajectories with regard to the changing function of a drug for the user and the process of negotiating agency with psychoactive substances. The paper concludes with a discussion of how agency, the functions of a given drug and the reasons behind their use are interlinked with each other.

ADDICTION *VERSUS* CONTROLLED DRUG USE

The loss of self-control related to drug use is the key criterion of addiction (Weinberg 2013), which in many Western societies in the 21st century is said to be a disease (Granfield and Reinarman 2015). This understanding of dependency can be traced back to the late 18th century; it was also then that the notion that substance use causes a loss of self-control became widespread. The early understanding of addiction conceptualised it as a "disease of the will" (Granfield and Reinarman 2015; Levine 2015). The popularisation of the disease concept is strongly related to the activity of Alcoholics Anonymous. Within the AA movement created in the 1930s, alcoholism was seen as a person-specific disease and was also attributed to a loss of self-control (Levine 2015). In the 20th century, the disease concept has been reconceptualised using neurological models of addiction (Courtwright 2010; Granfield and Reinarman 2015; Levine 2015; Lilienfeld and Satel 2014). New neuroimaging technologies made it possible to visualise brain activity, which led to a consolidation of those scientific approaches which assume that changes in brain activity are the key to understanding drug dependency (Campbell 2010; Courtwright 2010; Kalant 2015; Raikhel 2015; Vrecko 2010). The biggest impact was made by the so called "NIDA model", postulating that addiction is a chronic, relapsing brain disease, first formulated by Alan Leshner (1997) and then promoted by the American National Institute on Drug Abuse. It assumes that substance use causes permanent changes in the structures and functioning of the brain, which makes addiction, fundamentally, a brain disease. The NIDA model assumes that substance use begins voluntarily, but over time drug users lose control and become compulsive users (Leshner 1997; NIDA 2008).

The brain-disease model provided a moral argument for destigmatising addiction, as it started to be seen as something beyond the individual's control (Room 2015). The War on Drugs created and promoted the view of addicts as dangerous criminals (Courtwright 2010, but within the disease paradigm the problem of addiction was translated into medical terms and placed within the realm of public health rather than criminal law. Instead of being perceived as criminals, addicts gained legitimacy as patients suffering from a mental illness (Courtwright 2010). But this was a double-edged sword as it could deny the drug addicts the agency to stop using drugs without medication.

Although the processes taking place in the brain are important for understanding phenomena of dependence, the biomedicalisation of drug use meets with opposition on the part of many social scientists as a reductionist approach that belittles the importance of social and cultural factors in the shaping of dependencies (Campbell 2010; Courtwright 2010; Kushner 2010; Lende 2012; Levy 2013; Lilienfeld and Satel 2014; Raikhel 2015). Moreover, addiction as a disease models do not take into account the user's agency in interacting with psychoactive substances and narrow considerably the role of the choices made and the possibility of a conscious response to stimuli. There are many studies showing that a significant proportion of the users of psychoactive substances are not addicted, and even those who have gone to the stage of compulsive consumption find ways to reduce or stop further drug use without any therapy (e.g. Chen and Kandel 1995; Cloud and Granfield 2015; Granfield and Reinarman 2015; Raikhel and Garriot 2015; Müller and Schumann 2011; Lilienfeld and Satel 2014; Waldorf *et al.* 1991; Winick 1962; Zinberg 1984).

Drugs have addictive potential because they strongly stimulate the so-called reward system of the brain, responsible for processes related to the feeling of pleasure and desire, and also cause neuroadaptation, which makes many users susceptible to relapse (Robinson and Berridge 2003). However, all psychoactive substances directly or indirectly affect the reward system; the particular mechanisms vary depending on the type of substance, with different short- and long-term effects, as well as differences in the potential for addiction (Blätter *et al.* 2011). Although it is the drugs' pharmacologic attributes that partly dictate their effect and controllability, a number of other factors mediate the effects of particular drugs. Therefore, the same substance can have different effects depending on the user and the context of use. Moreover, it can be radically different for one user across the trajectory of drug taking (Müller and Schumann 2011; Zinberg 1984).

Norman Zinberg (1984: 8) distinguishes three variables that determine the subjective effect of psychoactive drugs: drug (the pharmacological action of the substance), set (user's attitude and personality structure), and setting (social sanctions and rituals connected with drug use). There is a wide range of factors that have to be present before drug use becomes chronic and disturbs routine brain functioning (Granfield and Reinarman 2015). First of all, the user has to learn how to take pleasure in the effects of a drug (Becker 1953). Furthermore, the user has to start taking drugs regularly and increasing amounts consumed over time (Granfield and Reinarman 2015). Although some regular users become addicted, some studies provide evidence of controlled drug use or natural recovery (Becker 1953; Chen and Kandel 1995; Müller and Schumann 2011; Robins 1993; Waldorf *et al.* 1991; Winick 1962; Zinberg 1984).

Of these, Lee Robins' classic study among American veterans of the Vietnam War is particularly noteworthy. The researcher suggests that many soldiers who regularly consumed heroin during the war stopped using the drug completely after returning to their ordinary life, despite the availability of the drug in the USA (Robins 1993). His research shows that it was primarily the social context that influenced the continued use of heroin by some soldiers, and not the changes in the brain caused by the substance. Craig Reinarman, Dan Waldorf and Sheigla Murphy, in *Cocaine Changes: The Experience of Using and Quitting* also suggest that some users can consume a very strong addictive substance such as cocaine in a controlled manner and combine this habit with daily functioning (1991). Moreover, those who became heavy users often quit the habit the moment drug-related losses outweighed the benefits. As their research suggests, the more a user is rooted in everyday life, the greater the chance of maintaining control in interacting with a psychoactive substance. Norman Zinberg suggests that drug use can be a stable practice, subject to the user's control (1984). According to his approach, a controlled consumption of psychoactive substances is subordinated to social sanctions and rituals, which distinguish it from compulsive use. Social sanctions define acceptable patterns of use in a given circle of users; identify potentially dangerous effects; and are designed to limit the use of substances to selected social contexts. Social rituals are specific practices that accompany controlled substance use. They concern methods of substance use, the choice of the social environment in which use takes place, actions taken during intoxication, as well as ways of preventing unwanted effects (Zinberg 1984).

Many social science researchers emphasise the fact that social factors and the personal reasons for drug use are determinants which, to a large extent, account for the addiction of a given user to a substance (Lende 2012; Lilienfeld and Satel 2014). Therefore, controlled drug use is also partly associated with functional and instrumental drug use. Psychoactive substances fulfil certain functions for users, which affect the purposes and the frequency at which the substance will be used (Müller and Schumann 2011). Determination of the function of a drug allows one to determine why a given user continues to use it and why he/she chooses to take this particular substance (Lende *et al.* 2007). An example of a functional analysis of drug use is Daniel Lende's research among users of methamphetamine, during which the researcher identified the reasons why they continued to use this substance. Lende noted that the function of drug taking depends not only on the possibilities of stimulation provided by a given substance, but was also closely related to the values shared in a given user culture (Lende *et al.*, 2007).

The theoretical basis of my research was formed around Christian Müller and Gunter Schumann's theory for non-addictive drug use. Müller and Schumann suggest that even habitual drug taking can become a stable and widespread behaviour in its own right which does not necessarily develop into addiction. They suggested that people use drugs because they can instrumentalise their effects. During the period of experimentation, people learn how they can use the optimal substance; the appropriate dose and a setting in which drug use would help them reach their goals. The instrumental effect of drugs is the result of their ability to change mental state and the fact that a proper mental state can be necessary to achieve certain goals through appropriate behaviour. Throughout initial experimentation, the user learns a drug's effects depending on the type of substance, its doses, or a particular mix of drugs in a particular set and setting. Müller and Schumann identify three types of drug consumption: experimental, instrumental, and compulsive. Experimental consumption refers to a state where the consequences of drug use are yet unknown. An individual learns what state of mind can be induced by a drug in different doses, as well as how to use a certain mental state and how to control the drug consumption. Drug instrumentalisation is the state where the individual can foresee the effect of the drug, control its influence and benefit from it in order to reach certain goals. These goals may change in the course of life, and instrumental consumption may turn into addiction. Drug addiction according to this model is compulsive seeking and consumption of a drug, usually associated with a steady increase in the intake of psychoactive substances. Compulsive consumption cannot be subject to user control, nor does it serve any instrumental purposes, because at this stage of use, the side effects of drugs outweigh the benefits that result from their use (Müller and Schumann 2011).

The empirical ethnographic evidence I have gathered largely overlaps with the instrumentalisation model proposed by Müller and Schumann. My research among drug users in Warsaw shows that many persons in the drug users' milieu use drugs habitually for a period of time without becoming hard-core users, and even those who "mature" to become compulsive users find ways of limiting their drug consumption or ceasing to take drugs at all without therapy. Moreover, involvement with addictive drugs is preceded by a stage of non-addictive use. My observations have shown that during the initial stage of use, users learn what effects can be achieved using a particular substance in a given dose and in a specific social context, and to some extent begin to control its effects and adapt them for their own purposes.

METHODOLOGY AND STUDIED GROUP

In the period 2011–2014 I conducted anthropological fieldwork in Warsaw among groups of people who took psychoactive substances and incorporated them into their day-to-day lives. The main criterion for my choice of interviewees was their ability to perform their daily duties in spite of taking psychoactive substances and functioning in different social situations while under their influence. Another aspect that I took into account was their engagement in drug taking over the years, as well as experiences with different types of psychoactive substances, including psychedelics. My interviewees were students and professionals between 20 and 35 years old, both men and women. The gender proportions were similar. I studied two groups of friends who took psychoactive substances more closely. Both of the groups were formed around long-term drug use in their twenties; one of the groups also included a few small scale drug dealers. The exact numbers of people belonging to those groups, as well as their composition, were rather fluid. In both cases, the groups consisted of 3–4 friends who lived together and formed the core of the group, and their acquaintances who would just drop by, usually to share an experience of intoxication. Taking psychoactive substances was the main pastime they had in common; it was the drugs that defined them as a community. The more experienced members sometimes introduced new acquaintances into the drug taking; they showed them where and how to buy substances, which drugs suit a particular setting and what the appropriate dose is to achieve the desired effect and avoid overdosing. In the case of a group containing small scale drug dealers, many people were passing through their apartments just to buy drugs. However, the convention of being friends was usually created around the transaction, and they spent some time together sharing a joint or having a drink. The core of this group also consisted of more hard-core users than in the other group. At the time of the research, they were using drugs more intensely and had started to experiment with them in their early teens. In both cases, stronger substances were usually consumed during holidays and weekends, and that was also the time when more friends gathered together to party. Drug users belonging to those groups were usually able to attend to their duties, even though some of them took drugs on a daily basis. In the course of drug taking they learnt how to manage the appropriate dose and the type of substance to be able to function under their influence in every-day situations.

In both of those groups they attributed different meanings to different substances. Substances like opiates[1], stimulants[2] or emphatogens[3] were considered rather as hedonistic drugs which they used for relaxing, clubs or in a sort of attempt at self-medication. Psychedelic and dissociative[4] substances were treated more as a tool for broadening perception and enabling spiritual experiences. There were also different rituals associated with their use. Psychedelics and dissociatives were usually taken in an intimate and safe environment and in a well thought-out and planned setting – in someone's flat or in the countryside. However, they were also consumed during special music events prepared for psychedelic experiences such as, for example, trance parties. The other substances (stimulants, empathogens like amphetamine, cocaine or MDMA) were consumed mainly during club parties, on a daily basis (opiates, stimulants, cannabis) or as a remedy to get rid of the negative effects of another substance (mainly opiates, alcohol or cannabis). It needs to be pointed out, however, that this is a generalisation because, as analysed in the case studies below, each user in the process of drug instrumentalisation found a substance which he/she used in a particular set and setting to achieve specific goals. The attitude toward drug taking was also one of the

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[1] Opiates are drugs used as prescription pain-relievers. They reduce stress, fears and evoke a state of bliss. Examples of this type of substance are morphine, codeine, heroine, tramadol.

[2] Stimulants are a group of substances that are experienced as increasing physical and cognitive activity and reduced fatigue. Examples of substances belonging to this kind are cocaine, amphetamine, methamphetamine.

[3] Emphatogens are a class of psychoactive drugs that produce a very strong experience of euphoria as well as emotional communion, openness and empathy. The most common substance belonging to this group is MDMA.

[4] Psychedelics and dissociatives are a class of psychoactive substances causing so called altered states of consciousness characterized by thought, visual and auditory changes. Examples of this group of substances are LSD, psilocybin mushrooms, DMT, ayahuasca, metoxetamine, kethamine.

aspects that distinguished the interviewees I chose for my research from other drug users I met in the course of my fieldwork. They considered psychoactive substances not just as hedonistic tools used for pleasure, but also as an instrument which can serve for self-development and broadening of perception. They were strongly involved in drug-taking and found it to be a meaningful activity that distinguishes them from the rest of society.

The use of particular substances is partly dictated by the market and interlinked with their availability and price. For example, the popularity of amphetamine in Poland is mainly an outcome of its low price and easy availability, which is caused by the fact that this drug is produced in Poland. In the period when the research was conducted, designer drugs were semi-legal in Poland and available online, which accounted for their commonness. Some of my respondents also used to buy legal medicines, the likes of the cough medicine Thiocodin[5] or Acodin[6] and overdose them to achieve the desired effect. My interviewees purchased psychoactive substances via the internet, from dealers or in a pharmacy.

The main tools of my fieldwork were participant observation and recorded in-depth interviews. The idea of conducting research in the drug users' milieu emerged when I met a few drug users over the course of my studies. Then, using a snowball technique, I developed a network of interviewees and was gradually allowed to take part in their every-day activities including those related to drug taking. During my research, I was observing a number of drug-related practices and rituals; I engaged in many off the record conversations regarding experiences with psychoactive substances; I also participated in club parties and culture-specific festivals. Due to the illegality of most psychoactive substances in Poland, an essential condition for carrying out in-depth research interviews was building longer term relations with and winning the trust of the interviewees. Observation of individual persons over the years has given me a deeper insight into how they changed their attitude to the use of psychoactive substances and how they redefined their approach and ways of referring to them.

During all the stages of research, participants were asked for their consent to participate. Confidentiality and anonymity was ensured for all interlocutors. However, during the research I was observing practices related to psychoactive substance use which are illegal in Poland. The anthropological research ethic in this case requires loyalty toward the interlocutors[7].

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[5] Tiokodin is a cough medicine containing codeine which belongs to the group of opiates.

[6] Acodin is a cough medicine with an active substance dextromethorphan which in higher doses works as a dissociative drug.

[7] Research in the form of an interview is published under the *expressis verbis* provision that the source of the interview remains anonymous.

DRUGS AS AN INSTRUMENT

While observing the practices of drug users, the first aspect that drew my attention was the fact that they treat drugs as an instrument which can fulfil a specific function that each user discovers on their own during the process of learning the drugs' influence and gaining control over their effects. As one of my responders said:

> "You can treat it as a spice […] I don't like feeling the same all the time, I take many things, I don't like to stay in the same mental state, let's say that's my way of spicing my life".

As there is a broad range of psychoactive substances with different effects, the users allot them to different social situations. For instance, the higher concentration levels produced by amphetamine could be used to study more effectively, while the lack of tiredness and the sensitisation of the senses produced by cocaine could multiply experiences during clubbing. The flow of synesthetic elements during a psychedelic session can increase one's creativity, while opiates can be used to reduce tension in order to alleviate stressful situations, etc. During my fieldwork I observed that users at the first stage of drug taking learn what outcomes a particular substance could induce in the specific set and setting and realise that, to a certain degree, they start to control the effects. The drug users in my research treated psychoactive substances as mind altering tools, and many of them have been using drugs for years without ever reaching the compulsive consumption stage or significantly changing their lifestyles. However, some of them lost control over their drug use and after a period of instrumentalisation of the drugs went into the compulsive consumption stage.

In order to be able to treat drugs as instruments, one must assume the possibility of controlling their effects. Reflecting on the experiences of the users of psychoactive substances, I have concluded that the notion of control when applied to drug use can refer to two significant factors – the control of the intensity of consumption, and the control of the effects of the substance.

The consumption intensity, comprising the dosage and frequency of use, is the object of social regulations which aim to protect users against overdose and addiction. The circles of users develop various rituals and practices in their community which are supposed to enable users to work out moderate dosages and frequencies which do not lead to addiction. They are passed on within the user networks and worked out by individual members who acquire new experiences. In the studied groups, the method of ingesting the drug could be considered as this kind of ritual. Sniffing powder or swallowing pills was appropriate and socially acceptable, but using syringes would be seen as crossing the metaphorical line. Another important ritual, aimed at controlling consumption intensity, was the use of substances in the appropriate social setting and combining their use with daily duties and other social roles.

The object of the effect control is acquisition of the skill of influencing the action of the psychoactive substance, directing it towards a concrete activity, avoidance of bad trips, and the ability to control one's own body and behaviour, or of entering into a social interaction. Different social situations require a different degree of control over one's body or behaviour. While spending time with other drug users, the disturbance of motor skills could be accepted but during an everyday social situation like being at work, attending classes or interacting with one's family, the user has to maintain control over his/her body and behave according to the shared rules of society, even under the influence. Although drug users generally manifest fewer inhibitions, the rules connected with the substance effect in the studied group would concern, for instance, no tolerance of aggressive behaviour. The control of the effect in the observed environment was also directed toward avoidance of bad experiences while under the influence of substances. Psychoactive substances cause emotional sensitivity and require appropriate set and setting in order to benefit from the drug's effect. More experienced users, who had discovered how to instrumentalise the substances, were aware of how to manipulate their choice of substance, as well as set and setting, in order to get the experience they desired and avoid unpleasant ones.

In my opinion, it is this ability to control the effects of a substance that allows one to treat it as an instrument. In the interaction with psychoactive substances, the agency and control are distributed between the drug and its user; therefore, as I try to show below, drugs can only be instrumentalised to a certain degree.

The agency of the substance is understood here according to the combined perspective of Don Ihde's notion of postphenomenology and Lambros Malafouris' framework of Material Engagement Theory. This theoretical orientation is situated within those approaches which expand the notion of agency on non-human entities and postulates that people are constituted not only through biology or culture but also through the use of material forms and techniques. Humans have a predisposition towards technological embodiment and because of this fact material forms can shape their minds and extend their bodies. Technological artefacts can mediate our perception and interpretation of the world, transforming the way we experience and, as a consequence, ourselves (Ihde and Malafouris 2018). In the case of my research, psychoactive substances can be seen as a technical mediator because of their ability to influence the human nervous system and cognition. Substances and their users create hybrids; drugs can give them certain features, change their emotions, alter the perception of reality and its phenomena. The substance is not a passive instrument used by the user but an actant. The agency of substance is its ability to change the human state of mind and co-constitute the user's experience of the world. However, the change that emerges from the substance effect is also subordinated to human agency. During the experimentation and instrumentalisation states of drug-user interaction, the non-addicted drug user can operationalise agency over aspects of the experience. This agency includes the choice of setting, the selection of the drug itself, the ability to use the mental state evoked by the drugs to achieve certain goals and even how the drug is subjectively experienced (the "set"). However, drug use takes place in the particular socio-cultural context where an individual participates in social relations, thus the user's agency is not just a product of his/her individual choices, but operates within the social structure. Therefore, it might be conceptualised within the framework proposed by Pierre Bourdieu. According to his theory, people's actions are guided by socially built-up expectations, assumptions, and dispositions to react, which emerge from particular social experiences and conditions (the habitus). The individual agency is constrained by the social field, but still able to operate "freely" within that field (Bourdieu 2000). In the case of drug use, the political and economic realities constrain, for example, the choices of "setting" or substances. The illicit psychoactive substances, due to their juridical status, might only be used in the socio-cultural niche in which drug use is socially accepted. In a social setting which does not accept drug taking, the user has to maintain a high degree of control over the drug's effect and his/her body, which influences the choices of substance or dose. The established discourses and narratives also constrain the range of meanings and interpretations that can be associated with the stories told about drug experiences.

CASE STUDIES

In the following section of the paper, I analyse two case studies from my research which illustrate narrations of subjective experiences during long-term drug use. Natalia was part of one of the groups of friends taking psychoactive drugs which I described at the beginning of the paper. Anna wasn't connected with any of them; I met her over the course of my research using the snowball technique. Based on their narratives, I examine how the functions of drugs change depending on the users' intentions toward drug use and meanings attributed to it in the individual drug use trajectory. Natalia's and Anna's stories are the starting point for analysing the process of building relations and negotiating agency with psychoactive substances with reference to Müller and Schumann's theory.

Natalia's story

Natalia began her experience with drugs by trying to smoke marijuana when she was sixteen. Initially, she smoked marijuana for social purposes without experiencing other effects of the substance, apart from improvement in her mood. Over time, she began to take more and more pleasure from the effect caused by the drug, and also learnt to control its consumption to such an extent that she was able to function under its influence in everyday situations. She then smoked marijuana to alter her perception of the world and deepen her experiences.

> "The original reason for taking drugs was, for me, curiosity, but also the fact that despite my enthusiasm for life, I did not quite see the meaning of it, I felt that it was not lived fully. Because you always want to see something more and you develop to some point as a human being and the whole world seems like an interesting place to you, but then you get the impression that you understand everything and I did not like that feeling because it made me feel bored".

At the beginning of high school she started experimenting with another substance – amphetamine. Initially, she used it for typical entertainment purposes as a stimulant used during parties, but changes in her life situation made her change the function of the drug.

> "I was exhausted with school, I started to take it to be able to function faster, I took it at work, at school, and then I started going to clubs. It was the time when I moved out of my family home and started living in Warsaw. Previously, my friends kept dropping by all the time, I never suffered from loneliness, and now in Warsaw I did not have such friends, my situation, in general, was hopeless, and drugs improved my mood and generally made me feel very strong".

In the past, Natalia had taken amphetamine only when someone offered it to her, now she began to seek it. This gradually intensified the consumption of the substance until it became part of her daily routine. Amphetamine served as a means of helping her to cope with more duties resulting from paid employment, and was also a way to deal with loneliness. The influence of the drug made her more productive, and helped her to overcome hyperactivity:

> "Amphetamine gave me a better understanding of the current moment, as well as greater enjoyment of it. It must be added that it acted differently on me than on other people. I am a very chaotic person, I was certainly this way because of my hyperactivity, I have never behaved with caution, but under the influence I exercised a lot of it, I took in everything that was going on a lot more slowly and I did not have to talk and do everything so fast, but was able to think first. My friends could not understand why I liked it so much or how I could use it on a daily basis. But being high on amphetamine I could totally control myself, so I knew that no one was aware that I was under the influence".

Natalia took amphetamine almost daily for a period of two years. With the intensification of consumption, the drug slowly ceased to bring the earlier benefits and began to induce psychotic states in Natalia. One day, when travelling, when she could not take amphetamine with her across a border, she took all of her supply at once. Since then, she has practically stopped using the drug, and has slowly replaced it with other substances primarily belonging to the group of psychedelics and dissociatives, the effects of which transfer Natalia to unreal worlds created during her narcotic visions:

> "I started to live in such a fairy-tale reality, the wind that was blowing was the best wind in the world, just amazing, everything was amazing, the point was that everything was super nice to you, gave you so much pleasure, I would say, you walked and there it was this asphalt you walked, or a blade of grass".

With the increasing importance of drug-related practices, Natalia began to get to know more experienced users of psychoactive substances who showed her drugs which she had never had the opportunity to experiment with and which opened up a new spectrum of experiences. She decided to rent a flat together with two of them. They were often visited by other users of psychoactive substances, and the rituals associated with their use became the main focus of the time they spent together. They primarily used substances belonging to the group of psychedelics and dissociatives, such as methoxytamine, LSD, dexamethasone and 2CP but after a while they started to experiment with every substance which was available:

> "Though I had taken some stimulants before, now I took literally everything, all that year I did not say no to any of them. Collecting every experience going along the way, it was not important whether it was good or bad, enough that it was new, new, new, I wanted to get the most out of all sensations. Then I reached this moment when I thought I had tried all the substances and decided that now the whole mastery was to mix them properly. People who use drugs have such an insatiable desire that they always want more and more experiences. You have this impression that what we are experiencing may be cool, but not loud enough when it should be blasting".

After half a year of intensive use of a variety of psychoactive substances, during which she still did not neglect her daily duties and enjoyed the drug experience, Natalia found herself alone in the apartment after the friends she was sharing it with had moved out. Then she began to take drugs in solitude, gradually turning away from other life activities, and the psychoactive substances, instead of bringing the intended effect, began more and more often to evoke nightmarish sensations:

> "I did not go to school any more so I did not get out of bed, and at some point I got so muddled in my head that I did not know whether I had taken anything or not, and so I was not getting what was going on, and at times it seemed a pleasant condition, but it kept on going forever in this empty apartment. This flat started to run away from me, maybe I wanted to leave it so badly. I was under the influence of methoxy and the buildings around me were moving, I was sitting in this apartment, and this apartment was swinging, I was sitting there and it was all rocking, sometimes I was inside the apartment, sometimes outside, sometimes in it and it continued on and on…"

Following this event, Natalia stopped using psychoactive substances for a year. Currently, she takes them occasionally.

> "Once I was very scared, before I met drugs, of what would happen to me, what thoughts would come to me, now I have no such fears at all. And the most horrible scenarios were that I was alone, and I don't want to be, I have this bad streak right now and I really had these panic attacks, I know I had some deep problems. If you've experienced bad trips, you may not be afraid of anything, you have already met the most terrible things that can be in your head. It is a very good moment in my life and I am very happy with the kind of person I am becoming. I do not feel any more this need to do something every day, what I like most is the fact that I remember those times when I got up and the first thing I wanted to do was to be influenced by a substance. I think I'm just happier now. Drugs give me joy, but this is not my first and only happiness, not the one most important in my life".

Natalia, in her course of drug taking, was using drugs for self-medication, treating attention disorder, enjoying herself more at the party or trying to enhance productivity. Although the use of drugs started to get beyond her control, the environmental clues of losing control was enough for her to cease using drugs in a compulsive way without medication. Today, as she states, she has passed through the personality-disorder problem, so now she is able to use drugs occasionally, mainly to remind her of the new perspective they brought. The change in the instrumental goals attached to the drug was mainly modified through the change in meanings connected to them and her engagement to the social setting of the drug-user.

Anna's case

Anna, when I met her in the course of my fieldwork, was 28. At 22 she experienced drugs, LSD, for the first time. However, the psychoactive substance which she continued to use the longest and most intensively was methoxetamine, a dissociative drug. The main effect of the drug is based on sensory deprivation and a feeling of dissociation, often described as depersonalisation. With larger doses, methoxetamine produces hallucinatory visions, a sense of levitation and out-of-body experience.

To analyse the interaction between Anna and methoxetamine, we have to go back to her first contact with hallucinogenic substances. The fact that her experience was a result of a mere coincidence makes it unusual in comparison with other cases from my research. There was no previous expectation about the effect of the drug; there was no previous influence of the community, no curiosity pushing her to try this drug. Anna had a blurred idea about how drugs work, one based on morality stories from school and the message spread by the mass media. During the Burning Man festival in the United States, somebody gave her mint drops. Until the moment she felt changes in her perception, she did not have the slightest idea that her first psychedelic trip had just begun:

> "I had thought that it was just a breath freshener, then when I went to a toi-toi I started to see the air in multi-colours and it was in waves, and the walls started to move away, and when I left the toi-toi everything outside was totally different than before. It was so colourful, everything had multiple dimensions and I found it difficult to go back to my caravan, which was just a few meters away, but for me it seemed a galaxy away and with the remains of my conscious mind I thought, oh I have just taken some drug. That was the first time I tried a psychoactive substance. It was a really strong acid".

This first psychedelic experience was for her an amazing one; she was not at all terrified of this unknown mental state. When the psychoactive substance stopped working, she decided to find that substance again. After coming back to Poland she started to seek the company of people who took drugs. She also began to experiment with different psychoactive substances which she used for different purposes.

> "The first acid was just a coincidence, but on all other occasions I took it consciously, motivated by this curiosity: what more could happen here, what other boundaries could I cross. With other substances it was for some practical purposes: such as antidepressants, or I took speed to clean my apartment quickly before my dad's arrival, because there was just two hours left, so it was often for such practical purposes, without this or other hedonistic pleasure, always for something".

To conclude, psychoactive substances which are not classified as hallucinogenic were used by her for practical purposes, whereas acid was a way to discover the world in all its dimensions, a pursuit of sensation, and a means of broadening her perception.

> "I didn't take them for pleasure, listen, You can't foresee what will happen on an acid trip, it can become the worst bad trip, for me it was education, education about man and the world, about the whole Universe, micro and macro cosmos, for me it was science. […] That was the best period of taking anything, the healthiest and the most developing".

At the beginning she would prepare herself for each acid trip like she would for a "real" journey; she would take it only on special occasions. Later, acid taking started to be an aim in itself, motivating enough to make her travel hundreds of kilometres and spend lots of money.

The methoxetamine period of Anna's life lasted from December 2010 to March 2012. Anna herself makes distinctions between several stages which she labels as "psychedelic", "heroine" and "the black whole"; each one lasted a few months. The early dose of one shot was gradually diminished (100–80–50 mg).

> "December 2010 was my first methoxy, which didn't impress me too much; in general I died 3 times, ok, fine so I experienced how to die. But the following experiences with methoxy, added to acid, ok, maybe it was not a true acid, the boom in research chemicals had begun, so these acids probably weren't real acid but kind of 4-aco-dmt, 2c something all the 2c something[8]… And this exact combination was fantastic!"

Although Anna did not like her first experience with methoxetamine, she tried it again just because it was easily accessible. That way she discovered that methoxetamine could work differently with the well-known LSD (or its new replacements). So after a few unsuccessful experiments she learnt how to use this drug to achieve specific goals.

> "Well, I really like music**.** There is no other stuff that makes music sound so good as methoxy. My beginnings with methoxy were just so innocent, I took it to listen to music, it was like you had some fucking great earplugs. I had never taken methoxy without music, it was always with music, I used to lie or sit locked in my room, someone close to me could be with me to listen to music, just in the evening, like, for example, people have a beer to relax in the evening, so I went to bed, with music and methoxy […]. And then it became more and more frequent, I would start a day without music but with methoxy".

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[8] Substances belonging to the group of new designer drugs which were semi-legal at that time in Poland. They have a similar influence to the well-known psychedelics like LSD or psilocybin mushrooms.

During this stage, labelled by Anna as “psychedelic”, methoxetamine served as a means of deepening the perception of music and of producing visions. Another change in her way of using methoxetamine started when Anna began to notice the first symptoms of depression. While on drugs, she was still able to function in the social environment.

> “I felt like a mentally healthy person, I could do things, I could go to town and take care of every-day duties, I realized that being intoxicated with methoxy I felt actually better, it was an antidepressant for me, other medications didn’t work for me or I felt even worse after taking them […] I simply treated methoxy as my antidepressant”.

When Anna started feeling the first symptoms of depression she did not yet understand what was going on with her. She felt demotivated all the time and found it difficult to manage the simplest things. She wanted professional help to cure depression, but as she was a drug user her doctor referred her to the detox ward where she spent ten days. Then she went to therapy in the “Monar”. She said that during that therapy she became a “real junkie”, and following a detox therapy she became seriously drug dependent.

> “When I was attending those meetings I was taking drugs the most, because when you are among junkies, being one of them, you just perceive yourself as a drug addict, and what do drug addicts do? They do drugs. So I felt justified in doing drugs, because I had it documented that I was a drug addict, so I was allowed to do that. […] There was such an atmosphere of doing drugs, they gave us needles, and they gave us syringes so I would not have to buy them”.

With the continuing depression, a new function of methoxetamine appeared. It started to be a way to escape from reality for Anna, a way to self-cure, and a soporific.

> “I also discovered when I was suffering from really strong depression, that methoxy, especially when injected intramuscularly, was just a puff, and a few minutes later I was no more, I took it because it made me sleep well, the last methoxy of the day was to fall asleep. […] I felt warm, safe, calm, I could leave the entire world behind”.

Around that time she started a relationship with a recently met boyfriend who suffered from alcoholism. After a New Year’s Eve party, where they met, he asked Anna if he could stay at her place. She did not mind anything then. That way they spent the next few months lying in bed, she would take methoxetamine and he kept drinking beer from early morning. A secure financial situation provided access to intoxicants for both of them. Her parents gave her an apartment and paid the rent, she also had savings from an Erasmus student exchange.

Anna is not able to recall much from the winter months of 2011–2012. She would spend whole days lying in bed injecting methoxetamine, no longer understanding why she was doing that. That made her feel even worse, and “the planet Earth became an alien place” for her, as she recalls. Even epileptic seizures did not stop her. Then came the turning point which, after William Burroughs, we could call "the naked lunch" (1991). It is the moment when addicted people experience a lucid moment during a cycle of drug use. One March day, opening her eyes during a continuous methoxetamine trip, Anna saw her boyfriend wobbling at the window frame.

> "And this ended in March, with his delirium I mean, when I was somewhere between doses of methoxetamine and I saw him standing on the window sill (I live on the 5th floor), actually outside the sill, on this little sheet metal roof, I sobered up in an instant, I grabbed him, I don't even know how, it was so shocking, and it was so shocking that I got such an adrenaline rush that could wake up the dead. I called the ambulance; they took him to a mental hospital. He had delirium with awfully scary hallucinations, what happened was that he'd had it even the day before but I was constantly intoxicated with my substances I didn't realise that he had been drinking since January, and he had been drinking incessantly! […] Then, after his delirium, I sobered up, too, and I stopped doing methoxy. He was in hospital for a week or 10 days and when he came out he visited me, sat down close to me, and I felt like he was a stranger. I remember asking myself who he actually was, what we talk could talk about, both so sober, he also didn't talk, he just stared at me, it was so weird, and that was the moment when we slowly started to get to know each other".

Although she quit methoxetamine that day, she took it twice afterwards. Nowadays, she still occasionally takes drugs for certain purposes. Thus, we may assume that she has returned to instrumental use.

THE SUBSTANCE AS THE AGENT

The metaphorisation of the loss of control in the case of Anna can be found in her very personal drug experience. She says that being intoxicated in some way seemed to mean for her an interaction with some kind of intelligence. She was even able to describe how methoxytamine looks: "a middle aged woman with blond hair, in my aunt's style, so warm". However, when she began to lose control over her drug consumption, and when the drugs ceased to satisfy her in any way anymore, she felt the symbiotic relationship with the drug as being parasitic.

> "When I was on methoxy, I felt that I was going crazy, that my person had been trampled, crushed by this substance, this alien, like it wasn't just a drug but some kind of an intelligent entity. My own body would because an empty vessel, like some kind of astral bodies would use it, leech on it. Waking up I would feel exhausted".

According to her own interpretation, this was a metaphor of addiction:

> "That's the metaphor of the addiction […] I experienced it a few times when I was addicted to something, it made me act unlike the real me, I subordinated my life to feed this "something": it was like a parasite which was able to live somehow, thanks to my body, thanks to my life, I let it live at my own cost".

Looking at Anna's story we could conceptualise addiction as a type of internalised power that comes from the sense of being controlled by a substance. As Anna herself puts it: "It is a compulsion that feels as if there is someone inside of you, an alien that moves your hands, as if pulling the strings".

"HIJACKED" REWARD SYSTEM VERSUS DRUGS INSTRUMENTALISATION

Regarding the changing functions of drugs in Natalia's and Anna's stories, I will discuss how each period of their drug use corresponds to the three types of drug taking Müller and Schumann distinguish: experimental, instrumental and compulsive.

Experimental consumption is related to the period when Natalia and Anna, as beginner drug users, experienced the effects of various substances for the first time and were not yet able to predict their effects. During this period, they tried different types of psychoactive substances and slowly learnt what state of mind they could trigger, and how to derive pleasure from it. Together with subsequent experiments with the same substance in different sets and settings, they also discovered how their actions could be used to achieve specific goals depending on the dose and context of their use. Gradually, they began to control the drug-induced altered states of mind and give them functional purpose.

The instrumental stage of drug use begins when the effect of specific substances is already predictable for Natalia and Anna, and their use is accompanied by specific rituals. The instrumentalisation of substances is closely related to the fact that they are able to control drug-induced altered states of mind and use this state for specific purposes (as a tool to change perception, deepen stimuli, increase productivity, transfer oneself to a visual reality, self-creation, or for a therapeutic effect). With the intensification of consumption and changes in the life situation, their drug use goals also change: before taking methoxetamine to anaesthetise herself "because her life was so painful", Anna used to take LSD to deepen her life "which she liked and enjoyed so much". But when the consumption of drugs began to be compulsive, the use of psychoactive substances ceased to serve specific purposes, it became a habit difficult to control, an end unto itself.

The analysed cases also reflect the ever-changing relationship between man and substance. During the "instrumental" stage of drug taking, Anna and Natalia could form a sort of "hybrid" relationship with drugs. The substances were changing their mental state in the way they wanted and allowed them to experience sensations which are impossible to achieve without drugs. Psychoactive substances partly dictated their mental state, but they learnt how to instrumentalise this state for their own goals. When they stopped bringing the desired effects, the relationship started to become parasitic, and Natalia and Anna felt the substance taking control of them. The moments that became turning points for both of them are interesting. For Natalia, it was the horrible experience caused by the drug, as well as the fact that she had ceased to perform her duties. For Anna it was the experience of seeing her boyfriend standing outside the window which broke her somnambulistic dream of continuous intoxication. In those moments they regained their agency.

Involvement in the drug use setting and the sense of belonging to a group are some of the motivators that pushed Natalia and Anna towards further drug taking. When they started using drugs they also found their niche, people who shared their experiences. They found interesting people who were very different from the public image of junkies who prostitute themselves at a train station, or aggressive criminals. They became part of the environment of users of psychoactive substances, where their agency could be realised via "doing drugs". The perception of their first drug experience remained in strong opposition to their image of drug effects based on cultural background. When the official culture offers you a scenario that is totally incompatible with your own experience, you will probably reject all the warnings which the culture tries to instil in you. The public discourse in Poland and the health/education campaigns often take an unambiguous and simplified approach to illicit drug use, because their illegal nature makes them unambiguous in the jurisprudential nature of these substances. Many drug users who I met in the course of my research emphasised that the naive public narratives about the harmfulness of drug taking and the view of the loss of self-control attributed to substance use were based on "urban legends" rather than on the real-life experiences of drug users and their actual problems. The public view of drugs as "evil" in nature was rejected by the groups I studied. They shared an opinion that drugs may cause someone to lose control, but this loss was not attributed to the substances *per se,* but rather to the particular way they might be used. The loss of self-control is a cultural construct (Room 2015) and it is the culture that informs social actors about what it means to lose control over one's body or life. In many western industrialised societies, including Poland, productivity, work and family are important social values and, in the public discourse, drugs are seen as leading to the negation of those values. However, many drug users perceive drugs as a tool that helps them find meaning in the world, to construct themselves; they do not have to be connected with the negligence of other social roles. As Craig Reinarman, Dan Waldorf and Sheigla Murphy (1991) point out, the more a person has a stake in conventional life, the greater the chance of maintaining control over drug use.

As Daniel Lende (2012) emphasises, addiction cannot be treated as a phenomenon reduced only to the level of biology (changes occurring within hard-wired pleasure circuits and chemical imbalances caused by drug use), it is also socially constructed. A full explanation of how the transition from learning to take drugs to habitual use happens lies in the dynamics of community and socially-derived meanings. In Anna's story, the new social context of drug taking appears during her stay in Monar. The constant presence of stimuli producing craving, the availability of means, the structure of the environment, the sense of belonging to a group that supported drug consumption, influenced the formation of new patterns of drug use. In this social context, using psychoactive substances may have had no purpose; it was a goal unto itself. Moreover, the doctors' granting her the status of an addict also granted her permission to become one. As Anna puts it: "among junkies, being one of them, you just perceive yourself as a drug addict, and what do drug addicts do? They do drugs". The change in the consumption context and the resulting change in drug use habits illustrates the essential point made by Daniel Lende (2012): addiction is not solely an interaction between the substance and the brain, but also a social process.

CONCLUSIONS

Drug use is a long term process of learning how to manage psychoactive substances to reach the desired results: how to take advantage of them and how to control the consumption. During a trial and error period, the user creates his/her own way of using drugs: he/she finds the substance that meets his/her expectations and observes its effects in certain settings and contexts. He/she also discovers whether it is possible to channel those effects through appropriate steps. In my opinion, the first stage of instrumentalisation is the discovery that a psychoactive substance is able to change a mental state and that this change may lead to many different directions. The next stage of instrumentalisation is trying to direct that flow and adapt it to one's own objectives. The field observation has shown, however, that a constant interaction of a person with his/her environment causes alterations in his/her needs, and subsequently, the goals of taking drugs. Therefore, the type of drugs used, intensity of use, and the significance attributed to them are never fixed.

According to the analysed material, the process of instrumentalisation is a reciprocal interaction between person, substance, set and setting. In the drug–user interaction the substance and user's agency is in the process of constant negotiation and is interlinked with the function of the drug for the user, his/her intentions toward use and the socio-cultural context.

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ARE POLISH PRIMARY CARE PRACTITIONERS SOCIAL ENTREPRENEURS?

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In this article I explore the range of entrepreneurial roles played by doctors working in Polish Primary Health Care [Podstawowa Opieka Zdrowotna – POZ]. I use the division into social and strictly business entrepreneurship – whose source comes from economic sciences – in order to examine what entrepreneurial values rural/small town doctors and their city colleagues recognise and use in their practices. POZ is mainly carried out in private clinics contracted by the National Health Fund [Narodowy Fundusz Zdrowia – NFZ], therefore I look at the values associated with entrepreneurship. I consider these values as visibly altering doctor–patient encounters, thus I analyse doctor's strategies for establishing his/ her formal and informal relations with patients. I focus my attention on the specific forms of experiencing time in primary care, namely short and long time structures, which I recognise as crucial for interactions between practitioners and their patients. Finally, I put forward the thesis that much of the interaction in POZ offices has the characteristics of symbolic exchange – the reciprocal forms of doctor–patient interactions transfer these encounters beyond purely medical interventions to spaces of mutual cooperation, attachment and trust.

* * *

W artykule analizuję spektrum ról odgrywanych przez lekarzy pracujących w polskiej Podstawowej Opiece Zdrowotnej (POZ). W tym celu posiłkuję się podziałem na przedsiębiorczość społeczną i *stricte* biznesową, którego źródło pochodzi z nauk ekonomicznych. Ponieważ POZ realizowana jest głównie w prywatnych przychodniach kontraktowanych przez Narodowy Fundusz Zdrowia, przyglądam się, jakie wartości związane z przedsiębiorczością przyświecają lekarzom pracującym na wsiach i małych miasteczkach oraz w dużych ośrodkach miejskich. Uważam, że te wartości kształtują relacje pomiędzy lekarzami a pacjentami. Analizuję więc strategie lekarzy, przy pomocy których tworzą oni oraz utrzymują formalne i nieformalne relacje z podopiecznymi. Przedstawiam tu dwie podstawowe struktury czasowe („długą" i „krótką"), pomocne lekarzom POZ w nawiązywaniu relacji w pacjentami. Wreszcie, stawiam tezę, iż znaczna część interakcji w gabinetach POZ ma cechy wymiany symbolicznej, która przenosi kontakty lekarzy z pacjentami ze zmedykalizowanej i sformalizowanej przestrzeni, do świata wartości takich, jak współpraca, przywiązanie i poczucie zaufania.

Keywords: Poland, primary care, social entrepreneurship, doctor-patient relations

Researchers have proved that relations between patients and doctors visibly alter the quality of diagnosis and treatment (Piątkowski 2015; Piątkowski and Nowakowska 2012). Many conditions require not only equipment and doctors' skills, but also stimulating impulses that build a sense of trust and care between patients, on the one hand, and practitioners and the institutions they represent, on the other.

The considered relations and experiences are vulnerable to political and economic reconfigurations of late modernity, which doubtlessly shape doctor's values and roles (Rylko-Bauer and Farmer 2002; Mulligan 2015; Keshavjee 2014; Piątkowski and Nowakowska 2012). Thus, inspired by Lorna's Rhodes (1996) reflections on biomedical culture and Sławomir's Czachowski's (2002, 2005) studies on "family doctors", I aim to look at the roles played by practitioners in a medical sector distinctive to majority of contemporary healthcare systems – primary care. As the "Health for All" strategy announced in Alma Ata in 1978 and the WHO's "Ljubljana Charter" state (Cueto 2004; Janes *et al.* 2006), primary care is fundamental to contemporary global health. Extensive multidisciplinary research has revealed complex primary care tasks and contexts. As Cezary Włodarczyk demonstrated, it is more than just a form of medical practice – more than anything, it is "a category of health policy" (Włodarczyk 2000, 213). Public health and social researchers recognize primary care practitioner's cooperation with state institutions and their engagement in providing social aid and prevention (Czachowski, 2002, 2005, Kowalska-Bobko 2017). However, the quantitative perspective employed by most of the above-mentioned academics, although informative, does not exhaust all primary care matters. Patient-doctors encounters have their unique cultural scenarios, gestures, and rhythms that frame the reciprocal process of diagnosis, treatment, and knowledge transfer. Together, these constitute an ethnographically thick ritual of care based on empathy and trust, whilst simultaneously introducing relations of power. Moreover, ethnographers like Jane Farmer and Sue Kilpatrick (2009), Sue Kilpatrick *et al.* (2009), and Lisa Iversen (2002) have demonstrated, that primary care practitioners are also rooted in local communities and possess a cultural capital, potentially turning them into socially engaged medical professionals – "social entrepreneurs" working for the community.

However, I am not entirely sold by these enthusiastic declarations. I see the latter research as inconclusive and, although conducted in various geographic and cultural settings, not covering all primary care economic and political contexts. To illustrate this, I focus my attention in this paper on Polish primary health care – the *Podstawowa Opieka Zdrowotna* (POZ) – which since 1997 has been decentralised and – to some extent – opened up to the market, turning many doctors into entrepreneurs, but presumably not "social". These doctors revealed a strong attachment to private property and business entrepreneurship. Only a portion of them perceived their roles closer to Farmer (2009), Kilpatrick, (2009) and Iversen's (2002) concepts of social entrepreneurship.

I consider this state of affairs to have its roots in Poland's recent socio-political history. Since 1989 the country has been undergoing massive reconstructions – first the transition and later EU accession. These reconfigurations clearly altered the doctors' values, which were exposed to new economies and policies favouring entrepreneurship and independence from the state. Thus, I ask how and what entrepreneurial roles POZ doctors recognise in Polish post-transformation healthcare. I explore the socio-economic frameworks establishing doctors' duties and analyse the factors shaping their work views. Later, I seek strategies – revealed by rural/small town doctors and their city colleagues – of maintaining formal and informal relations with patients. Here I focus my attention on the specific forms of experiencing time in primary care, namely short and long time structures establishing frames for relations between doctors and patients. Finally, I investigate the observed reciprocal forms of doctor-patient interactions, which I consider as a *sine qua non* for doctors' social, although not fully entrepreneurial, engagement. I argue that the observed symbolic reciprocity transfers patient-doctor encounters beyond purely medical interventions, into spaces founded on cooperation, attachment, and mutual trust.

THE METHODS, THE FIELD AND THE STUDY GROUP

The ethnographic research with practitioners working in POZ clinics was conducted from 2014 to 2018. The research encompassed POZ clinics in Podlasie and Mazowsze voivodeships. The majority of these clinics were run by two to four doctors, with the exception of one bigger in Warsaw and two in Białystok. The surgeries usually served a population of up to six thousand patients, with doctors sharing administrative duties. The larger clinics had their own supervisory board coordinated by the doctor-owners.

Forty five interviews were conducted in seventeen different clinics, three of them in Warsaw, one in a rural area nearby Warsaw, seven in Białystok, and six in a rural/small town area of Podlasie. Due to legal restrictions and the owners' reluctance, the observations were limited to only two surgeries – one in Białystok and one in Warsaw. More fruitful observations resulted from participation in the surprisingly socially vibrant gatherings of the *Porozumienie Zielonogórskie* ("Zielona Góra Agreement"), an association of healthcare employers representing the collective interests of POZ doctors. There, I observed how doctors interacted, exchanged knowledge, and shared experiences related to their jobs, patients, and finally lives inseparably tied to their profession.

The clinics, despite being to some extent standardised thanks to rigid state contracts, are also diverse and dependant on regional demography, economic competitiveness, and human resources (Holecki *et al.* 2013). Warsaw is commonly highlighted by the medical community as a place with a weaker state role in providing care. The local healthcare system is augmented by the private sector based on voluntary insurance contributions and pay-per-visit appointments. In this area I observed a high turnover of patients and doctors sharing job duties between independent institutions and those offering state-refunded services. Consequently, the doctors rarely displayed an attachment to a particular clinic and its patients. Surprisingly, almost none of the Warsaw doctors had ever spoken about this uneasy fact for POZ practitioners. Moreover, in the investigated clinics – literally entrepreneurial medical companies – as well as primary care services, patients could attend pay-per-visit secondary care consultations and lifestyle consultations with cosmetologists, psychologists, and diet counsellors.

In Podlasie the state plays a much more dominant role in providing healthcare, although some minor independent clinics offer competitive services. In the investigated clinics the doctors' personal attachments were strong, with almost all my interlocutors occupying full-time positions in primary care. Consequently, the turnover of patients is notably lower than in Warsaw. Informants, especially those who worked in the rural/small-town area, claimed that POZ clinics still play a distinguished role in the local communities, thereby evoking some references to Farmer's and Kilpatrick's (2009) findings. The similarities between their conclusions and the data under discussion here, are mostly visible in the long-lasting, deep-rooted doctor-patient relationships and practitioners paying more attention to patients' social and personal matters. Many doctors lived in the vicinity and shared neighbourhood relations with patients. In some cases, the doctors were attached to the land by property rights or affinity.

Before taking up positions in POZ, many informants had worked in hospitals. Some of them occupied consulting positions in pharmaceutical companies. In the 1990s, these doctors were unable to find permanent positions in healthcare. Instead, they took advantage of a rapidly expanding pharmaceutical sector, where they were exposed to culture of capitalism.

Such diverse professional experience resulted in doctors occupying different economic positions. Most of the older practitioners were the owners of medical centres, holding economic capital. Consequently, a majority of the younger practitioners were salaried employees. Some of the respondents occupied the weakest position of "resident". This, however, did not prevent them from sharing similar economic values with their experienced colleagues, as well as perspectives on healthcare and relations with patients. They often spoke about the healthcare system as a healthcare market, rather than as an institution of social welfare.

ENTREPRENEURSHIP(S) AND PRIMARY CARE

Entrepreneurship is a term commonly used outside the field of anthropology – predominately in economy and management studies. Nevertheless, it is a phenomenon universally present across the globe. Consequently, there are many culturally-grounded ideas for entrepreneurship reaching beyond narrowly understood business activity. Entrepreneurship inspires deeper human relations of trust and affinity. It serves as a *modus operandi* for ritualised behaviours, establishes hierarchies, and creates spaces for dynamic cultural activity. However, entrepreneurship, as non-anthropologists suggest, is an intentional act of identification, evaluation, and exploitation of opportunities for introducing new products or services in order to accumulate wealth (Certo and Miller 2008). Entrepreneurs consequently aim to sell their offer, and focus their actions on generating profit and building their status.

Hence, how should social entrepreneurship be defined? The theory of social entrepreneurship lacks the characteristic of accuracy that is found in the economy (Thompson 2002). The term is open to critical interpretation, however, two aspect are crucial, namely: references to business entrepreneurship and socially oriented approaches making social entrepreneurship a unique form of socially engaged activity. As Trevis Certo and Toyah Miller propose, it

> "(…) involves the recognition, evaluation, and exploitation of opportunities that result in social value – the basic and long-lasting needs of society – as opposed to personal and shareholder wealth" (Certo and Miller 2008, 267).

John L. Thompson complements this definition:

> "Many social entrepreneurs, then, are people with the qualities and behaviours we associate with the business entrepreneur but who operate in the community and are more concerned with caring and helping than with "making money". In many cases, they help change people's lives because they embrace important social causes" (Thompson 2002, 413).

In order to achieve social changes, social entrepreneurs play the roles of agents of innovation, adaptation, or knowledge distribution. As the latter one requires long-lasting evaluation and careful observations, the measurements of socially-oriented performances differ from those of business activities, which prefer standardised and calculable methods (Austin *et al.* 2006).

How then, does the concept of social entrepreneurship work in the field of medical anthropology and primary care? The most informative seem to be ethnographically grounded reflections brought by Farmer and Kilpatrick (2009), Kilpatrick *et al.* (2009) and Iversen *et al.* (2002). Farmer and Kilpatrick state as follows:

A social entrepreneur is someone who formally and informally generates community associations and networking that produces social outcomes (Farmer and Kilpatrick 2009, 1652).

Although concise, this definition is more flexible than previously quoted concepts, which see social entrepreneurship as a voluntary form of activity, although formalised and implemented by dedicated institutions. They miss the broad range of informal engaged actions, peoples' interactions, and intentions, all evidently matching the sense of pro-community commitment. What is not missed, but less exposed, is social entrepreneurs capabilities of generating associations where culturally-grounded actions and ideas emerge. These abilities, as Farmer and Kilpatrick (2009), Kilpatrick *et al.* (2009) and Iversen *et al.* (2002) suggest, result from socio-cultural and geographical contexts in which people with a certain capital (education, authority, trust) work. Rural primary care doctors seem to perfectly illustrate this thesis. They are supposed to be intensively devoted to their practice, as contrary to city doctors, they have intimate knowledge about people who are often not only their patients, but friends, neighbours, or relatives. As Kilpatrick *et al.* (2009) argue, they occupy a double-position: professional-external to the community, and native-internal, allowing them to comprehend community matters. They are able to diffuse and navigate through two separate social dimensions, mixing strong personal relationships and weaker ties with more distant people and their needs.

As WHO states, primary care is the set of procedures which aim to cover people's common health-related needs to keep them healthy and happy in their communities. This is especially visible in smaller communities, where doctors must be fluent in elements of secondary care, psychology, and even mediation, as institutions relevant for the latter are usually located in cities. Thus, as Iversen *et al.* (2002) point out, rural doctors must cope with number of medical/non-medical/social challenges and carry more responsibility within the community – they are not explicitly primary care doctors, but "specialists-generalists", whose work is socially vital. Iversen revealed that doctors' actions and decisions are socially visible and commented by the surrounding social environment, exactly as their professional roles, duties and commitments. Rural societies' expectations are demanding, leaving no space for practitioners to take their minds off the community. Practitioners working in institutions as vibrant as rural clinics play the roles of social entrepreneurs, or in other words "boundary crossers" (Farmer and Kilpatrick 2009),

> "who live in the rural community and are employed in the health system and so are able to use the lens of a community member to analyse and lead actions to build and use community capacity for health development. They can do so, because they operate in, and across, two or more social fields, including health" (Kilpatrick *et al.* 2009, 286).

However, I am not entirely sold by these enthusiastic declarations. How should we look at modern medical practice, taking into account the above mentioned research and a vast body of critical literature, revealing progressive and globally universal liberalisation of healthcare systems? Are the primary care doctors an exclusion or perhaps anthropologists should look more carefully for hidden agenda in primary care?

REFORM AND ENTREPRENEURSHIP(S) IN POZ

Since 1997 the Polish healthcare system has been undergoing intensive reconstruction. As Peggy Watson (2013) critically remarks, the considered reforms, although necessary, have provoked massive inequalities among Polish patients exposed to fiscal regulations. These reconfigurations, however, have also confused doctors. The reforms, as doctors and researchers have revealed, have been inconsequent and in many aspects socially unjustified or simply misguided (Kowalska-Bobko 2017). After series of changes, the 1997 reconstruction plan, seen as a long-awaited liberal transition in healthcare, has lost its original aims. As a consequence, practitioners have had to continually invent new strategies for familiarising themselves with the incoming concepts of healthcare. But what exactly has changed in healthcare and how has it affected primary care?

The key person here is Jerzy Buzek, whose government in 1997 initiated reconstructions in healthcare system. Similarly to other countries in the Eastern Bloc Before, and for a while after 1989, in Poland almost all medical units were centralised and state-dependent. Although guaranteeing free access to procedures, the bureaucratic and ineffective system was eroded by corruption, cronyism, poor standards, and social inequalities, which together translated into a phenomenon I call "a culture of disappointment".

The goals of this undoubtedly difficult reform centred upon social insurance reconstruction, decentralisation, debt reduction, and the introduction of new healthcare providers – non-public, private agents headed by medical professionals, who were contracted by the newly-established paying institutions (Kowalska-Bobko 2017). Since 1997, the core of the healthcare budget has been made up of new social insurance contributions. In the period between 1997 and 2003, healthcare insurance, which is a component of social insurance, was managed by 16 regional *Kasy Chorych* ("Health-insurance Funds"), which were the paying institutions responsible for contracting medical services. In 2004, after a spate of criticism focused on unequal budgets and unclear bureaucracy, the *Kasy Chorych* were replaced by the *Narodowy Fundusz Zdrowia* (NFZ, "National Healthcare Fund") which is now the sole public institution financing medical services. Each January/February the NFZ signs contracts with healthcare providers. The NFZ's regulations set a price for each medical service and regulate the amount of money transferred to a healthcare provider. Additionally, the NFZ transfers a basic rate for each patient referred for surgery to contracted healthcare providers (for example to POZ). This rate is called the *stawka kapitacyjna* ("capitation rate"), and it might differ each year as well as for patients of varying ages and with distinct conditions.

Most significantly, however, the reform introduced new a primary care system based on Western models. The system – the *Podstawowa Opieka Zdrowotna* (POZ) – was opened up to the market, as the state was no longer able to cover the high costs of organising care at all levels. Practitioners were encouraged to establish partnerships, operating on the basis of contracts signed with the paying institution.

Simultaneously, previously state-run surgeries were gradually transformed into partnerships. This process was completed in 2004. The contract's value varies between each surgery. The final sum results from the number of patients assigned to a surgery, multiplied by the value of a capitation rate linked to each "type" of patient. Additionally, contracts include separate capitation rates for the services of doctors, nurses, and midwives. Surgeries must cover all of their costs, including outsourced medical and laboratory examinations, fixed costs, taxes, and salaries, from budgets made up from the above-mentioned contributions. After settling all debts, the rest of the money is the doctors' income, divided up differently in each clinic. In some clinics, self-employed doctors with an independent medical practice issue a bill to the clinic for their services on a monthly basis. In others, the final income is divided between the doctors according to internal regulations outlined in a particular partnership's agreement. Consequently, many medical practitioners have become managers and employers, balancing costs and competing with other clinics. This competition is becoming heated, as the big-name medical companies are systematically taking control over the primary care market.

It seems, therefore, that the reconstruction of Polish primary care was – contrary to the Alma Ata declaration – ultimately focused on economic and legal aspects, with only a secondary focus on community matters. Thus, Poland fits well into a process, which Craig R. Janes describe as follows:

> "Over the past twenty-five years the community-focused principles of comprehensive primary health care, set forth in Alma Ata declaration of 1978, have been replaced by efficiency lead reforms which advocate for a universally available but minimum package essential health care and public health services" (Janes *et al.* 2006, 6).

This appears to be confirmed in my research. Many times doctors rationalised the need for more economic freedom in healthcare, apparently undervaluing other goals of their practice. How, therefore is it possible to understand entrepreneurship in POZ? Based on the collected data, I suggest this entrepreneurship should be divided into two distinguished approaches. I consider them as a consequence of the series of succeeding healthcare reforms, and, although the proportion between them lacks the balance postulated in Alma Ata, they should be investigated together. The first approach, characteristic to a vast majority of informants, regardless of their educational background and location, manifests in the discourses and practices revealing doctors' attachments to liberal values. Here, two elements attracted my attention:

1. doctors as people of business, balancing costs, planning, and earning money;
2. the "cult" of private property, considered by doctors as liberation from the state's unfavourable gaze.

This is not surprising after taking into account the ethnographic testimonies denuding progressive liberalisation in global healthcare systems (Rylko-Bauer and Farmer

2002; Mulligan 2015; Keshavjee 2014; Janes 2004; Janes *et al.* 2006; Stone 1997). As Deborah A. Stone critically states,

> "In the late twentieth century, the doctor has been reconceived as an entrepreneur who is no in the business of insuring patients as well as caring for them. […] As medicine become professionalized, the role of money in the doctor-patient relationship became highly controversial" (Stone 1997, 534).

I partly agree with her criticism, although I consider it as generalising one. The US healthcare system in Stone's work, cannot be treated as a reference point for the Polish context. Thus, I recognise a second entrepreneurial approach in POZ, albeit rarer and less obvious than the business-oriented ideology. It is manifested in the form of mostly informal and spontaneous attitudes, actions, and intentions of doctors who, as well as business activity, appreciated pro-community aspects of their work and maintained a variety of non-professional relations with patients. However, these relations rarely were used by doctors to fulfil their roles as social entrepreneurs who stimulate communities or implement social innovations. The geographic context, contrary to Farmer and Kilpatrick's (2009), Kilpatrick's *et al.* (2009) and Iversen's *et al.* (2002) revelations, was also less distinctive. Indeed, doctors in Warsaw were mostly (except one informant) embedded in strictly neoliberal discourses and practices, leaving community matters almost completely aside. This does not mean, however, that similar attitudes were unheard of in other locations, including rural areas. Doctors there were also attached to liberal values, as their clinics operated under the same conditions as those in urban settings. And yet, in rural areas I met and observed practitioners who more often devoted themselves to patients and community matters. However, their actions were limited to spontaneous and unstructured activities or to non-medical relations based on reciprocity. Despite that, I consider these interactions as unique. Based on the collected data, I suggest that they should be investigated as local manifestations of social entrepreneurship – admittedly not fitting any of the mentioned definitions – but nonetheless contributing to the variety and depth of doctor-patient relations.

PEOPLE OF BUSINESS

The business roles of doctors has been often investigated as a global threat (Janes 2004; Janes *et al.* 2006; Stone 1997; McKenna 2012, 2010). Healthcare systems and doctors, researchers argue, gradually turn from patients' suffer and channel their attention on standardisation and market-grounded care (Abadía-Barrero 2015; Mulligan 2015, Czachowski 2002, 2005). The data under consideration here seems to support this thesis, however, I consider the process of liberalisation in Polish healthcare as still less radical. This is clear in doctors' declarations, where calls for more profound reforms could be outlined. Here is an example:

> "The reform is to upgrade something, to upgrade financing. According the last reform, money is supposed to follow patients. Perhaps this is the case somewhere in secondary care surgeries, but not here" (man, 63, owner, Podlasie).

Most practitioners, with no difference between urban and rural, expressed their perspectives on healthcare in a neoliberal language. With few exceptions, they talked about a "healthcare market" rather than a welfare system, favoured limitations on insurance or postulated co-payments for consultations. "If she had to pay five *zloty*, then she wouldn't be here so often" – said a rural clinic owner, when asked about patients who often visit doctors. Practitioners often complained about insufficient progress by successive governments, who have been unable to implement "real" (doctors' terms) reconstructions, with the aforementioned co-payment as a flagship idea. The doctors' position was clear – the costs of medical services are higher than the health insurance rate, thus some constraints or additional payments are simply inevitable.

Generally, practitioners perceived the 1997 reform as "normalising", where normalisation – a process implementing a liberal economy – should be read as a crackdown on the remnants of "unfair socialism". A new form of medical practice – based on private ownership, economic activity and contracted services – as the doctors told me, was warmly welcomed, since it was the only reasonable idea for organising primary care and ensuring a high standard of services. Shortly after 1997, running one's own business became the right way to be a "modern" doctor, whose social and economic capital corresponded with heavily idealised images of "Western" doctors earning a lot of money and occupying a key position in healthcare systems. Thus, the successive reforms clearly altered doctors' identities, which are now based on attachment to private ownership and business entrepreneurship. As one of the doctors said:

> "Now, doctors know that they have a budget, they know what they manage, they know what they can do. In the past everything was unclear, the money was different, the salaries low. Now, doctors, like in every country, earn according to their scope of duties and responsibilities" (woman, 54, co-owner, Białystok).

Founding a POZ clinic, or even working in one, empowered doctors authority and enriched them with a new vision of medicine. The doctors gained access to additional training. Some respondents participated in coaching sessions and many completed postgraduate management studies. Doctors can implement some innovative medical, organisation and management solutions in their practices. Nevertheless, all these amenities cost money and doctors must balance their budgets. Consequently, the reform, apart from "normalisation," also brought a "price revelation". Doctors discovered medicine costs – prior to 1997, the centrally distributed money was an abstract issue managed by people in administrative institutions. Now, practitioners are forced to control spending, as their clinics are companies prone to financial turmoil:

> "If I were supposed to do this *lege artis*, then I would spend all of my money. Let's say I have somebody with hypertension and I going to examine him with the whole battery of examinations – then, with such approach to every single patient, I would run out of money. It is simply impossible" (woman, 64, owner, Podlasie).

This discovery has had profound consequences for doctors, who must now be fluent in accounting and socio-economic factors affecting their profits. Nevertheless, business entrepreneurship has opened up many new possibilities to doctors and offered them a certain independence from the state. They consider themselves as practitioners and businesspeople having more responsibilities than just treating people. As one of my informants said,

> "It is just as in every other business, but, as the owner and the employer, I have certain duties. I must keep an eye on my nurses, on their social insurance, I have to follow labour laws, and besides, like every employer, I must take care of health and safety issues. In the big surgeries there was a director and his or her deputy, taking care of everything. And here, I am a director and deputy, I am the owner, stockist, hauler, literally everybody!" (man, 50, owner, Podlasie).

Summing up, becoming a doctor-businessperson in a non-public surgery was a "cultural revolution" – a new way of practising medicine in Poland. As Stone (1997) pointed out, the practitioners who are often entrepreneurs preoccupied with monthly income and the costs of running their businesses, introduced market economics to their daily practice. Such intrusions entail new concepts of understanding medical practice. As my observations revealed, doctors (even contracted) rarely treated patients lacking social insurance. They explained this with alleged difficulties in recovering their costs from NFZ or were concerned about potential consequences (mostly financial) of serving patients without the right to state-refunded healthcare. Furthermore, they referred patients for examinations only in "justified situations" (doctors' term), even under the threat of accusations of parsimony. The doctors are not afraid of asking "market questions" and defending their economic position, which was demonstrated during strikes in 2003–2005 when they successfully blocked the state's attempts for further reconstructions in POZ. The emergence of the *Porozumienie Zielonogórskie* ("Zielona Góra Agreement"), an association of healthcare employers representing the collective interests of POZ doctors, has significantly reshaped the health-policy scene. By criticising government activities, practitioners articulated their objection to "distorting" (doctors' term) the essence of the 1997 reform, namely unhampered entrepreneurship and market pricing for services.

SOCIAL OR RECIPROCAL ENTREPRENEURS?

"Not only market mechanisms, statistic or however we name it, decide the quality and significance of this job" – said one of the informants. So, what else does? First, the quality, intensity and durability of professional relations that doctors maintain with patients. Secondly, the variety of non-professional interactions between doctors and patients. And finally, the doctors' potential – unique to Polish healthcare – for switching between medical and non-medical interactions, resembling Farmer's and Kilpatrick's (2009) "boundary crossing".

The Polish healthcare system is commonly described as a treadmill, where powerful institutions dwarf vulnerable patients (Watson 2013; Piątkowski 2015). Many of my informants left hospital jobs, frustrated with the intense nature of the work and poor contact with the ill. Moving to POZ was, then, a chance for better relations with patients. Despite doctors' complaints about the institutionally imposed rush, in POZ they have more time for patients; if necessary, they may prolong consultations and this practice was common among practitioners – more often in rural areas – whose patients required non-medical support:

> "The rural doctor was like a priest – you could have a word with him. The older people still do this. I have a patient abused by her daughter-in-law. Nobody knows, but I know. She comes to me and doesn't want to leave, cries, wants to talk. Do you think this consultation lasts ten minutes? No. It lasts for half an hour" (man, 63, owner, Podlasie).

Thus, time determines the intensity and depth of relations in POZ. The collected evidence suggests that there are two distinctive forms of experiencing time by doctors. I consider them as structures of experience (Mattingly 1998), as they introduced an order in the narratives and revealed how practitioners conceptualised their work. The time established frames for relations with patients and channelled doctor's attention on their needs. Time is the agent powering doctors' actions and turning them into meaningful socio-cultural practice – into care.

The first time frame was commonly mentioned as "ten minutes". This institutionally standardised period, according to NFZ, is a sufficient period for a consultation in POZ. "Ten minutes" establishes the rhythm of doctors' work and specifies a number of daily admissions. Doctors used this measure to depict intensive interactions with patients, mostly deprived of meaningful contact with their stories, bodies, and expectations. For many, such consultations, overloaded with bureaucracy, were a symbol of failure of the idea of primary care, where personal interactions are essential. Is also appears that "ten minutes" is the optimum period of interaction commonly reached by quantitative researchers, whose conclusions easily percolate into Polish public and scientific discourses. Here is an example:

> "The research has revealed that most of the admissions in POZ are official. Establishing polite relations, explaining the disease's background, and dialogue about the right treatment are rare. Moreover, negative interactions, like lack of eye contact, limited information, complex language, criticism, lack of empathy, showing off, or shortening the consultations by doctors increase the level of patients' disappointment" (Holecki *et al.* 2013, 151).

The second time frame, rarer and thus more elusive, is a long perspective through which doctors looked at patients' biographies, conditions, body-mental changes, and family and personal environment. This form, much harder to grasp in quantitative inquiry, cements the quality and durability of relations. It lays a foundation for doctors' non-medical involvement and interaction with patients. This was observed predominately in rural and small town settings, however, informants working in Białystok also spoke about how such deep structures bring significant knowledge about patients:

> "We are the doctors *sensu stricto*, because, after so many years, we know people. I see them in a different way. The patient comes in and I ask – why are you so thin? She said, she was nervous because of surgery. No – I said. How much have you lost on weight? Miss, you don't lose weight just like that, what about your thyroid? Then, quickly she had surgery and later some fits due to thyroid hyperactivity. A [hospital] doctor didn't know her. But I know many generations, it is enough to me to just have a single look" (woman, 64, owner, Podlasie).

This knowledge, as informants argued, is the essence of primary care. To successfully perform their duties, doctors must transform it into practice of "knowing", which was possible only after a long period of "ten minute" interactions, ineffective in and of themselves, but informative when accumulated. Thus, a key to deeper mutual relations was in doctors' mental processes of relocating patients from the short time frame and placing them in the longer axis. Although, in the majority of narratives the long-lasting relations were presented as crucial to efficient medicine, simultaneously they designated a space for deeper interactions between practitioners and patients. In this space the informants offered their knowledge, views, and experience – as the social entrepreneurs or "bounder crossers" do – to their patients in need. This commitment was more visible in rural areas, where patients usually received more help than defined by the contracts. Although they complained about "the system, which doesn't see their commitments", the practitioners voluntary offered their patients secondary care, which is often hard to access for rural communities:

> "I do this for my patients. I do this for Mr X, as he can't go there, he has no money, he will never be admitted to a surgeon. […] I am a small-scale surgeon, a small-scale gynaecologist, a small-scale oculist, a small-scale dermatologist" (man, owner, 61, Mazowsze).

Such doctors established deeper connotations – often founded on the principle of exchange – with their patients. Although it would seem fundamental to cultural activity, these forms of interactions are rare in the field of healthcare. Known examples of bribing and controversial gifts cannot be treated as reciprocity, which – in contrast to bribery – favours long mutual relations and meaningful communication between involved parties. The reciprocity is not a literal form of social entrepreneurship, however I see it as business-independent example of doctor's social involvement. In contrast to Farmer's and Kilpatrick's (2009) interpretation, I do not place the reciprocity interactions among the examples of boundary-crossing practices. I would rather propose to consider these relations as primary to any further commitments, as a pact initiating mutual cooperation and establishing new and intense relations of trust and attachment. Thus, I would call practitioners who establish reciprocal interactions with their patients "reciprocal entrepreneurs". This identification corresponds more accurately with the data under consideration here and below I provide some examples.

Case study 1

Mrs. M. owns a clinic in Białystok, which she has been running for fifteen years. She is well known to her patients who sometimes – in gratitude – bring her sweets and food. Usually, she shares the gifts with her nurses or gives them to poorer patients. Sometimes, however, she uses them to initiate a reciprocity. M. brought me the story of her unusual relationship with D. – a patient working in the court archives. M's husband is a keen gardener, growing vegetables which require special twine to support them. As D. has access to "a high-quality string to binding files and perfect for gardening", M. has established an exchange with D. – sweets/food for string. Such string can be bought for pennies, contrary to delicious home-made food brought by patients. But the price is not the point here. M. and D. entered the interaction where goods are exchanged – as in Malinowski's *kula* [ring] – symbolically and coalescent relations of mutual trust, respect, favours, and commitment. The circulation of goods brought them closer and enabled a complex exchange of knowledge, gossips, gestures and favours. They exchange books and recipes. They share knowledge about the neighbourhood and useful contacts for their professional and personal lives. Clearly, M. crossed a boundary, and came down from a level of professionalism, but – as I have learned observing her other reciprocal interactions – she reached the daily life and matters of her patients.

Case study 2

Mr. S. is a doctor living in Warsaw but working in the rural part of Mazowsze. He painted a vivid picture of a contemporary rural community, where primary care doctors are still respected and help those in need. However, these needs can be surprising. One evening he received a call from a poor couple, who were patients, asking for medical assistance. Although he was not obliged by the contract, he drove out to the patients' home only to discover that this time the patients were unusual. Two pigs – a sole precious possession of these people – were ill. After his initial shock, S. gave them some analgesic medicine and drove back home. The next day the pigs felt better and their owners came grateful with some gifts of food. S.'s conclusions about this story were truly "ethnographic". He realised how much he was respected, but also how much social responsibility he had. Additionally, he recognised the social context of this event – after receiving small gifts of food, which he couldn't refuse for fear of causing insult, he entered a relation of trust, favours, reciprocity, and care with his patients, who passed on the news about the selfless doctor to other community members, enforcing his position and giving him – a newcomer from Warsaw – a chance to establish much deeper relations with them, people of a rural area sharing local worldviews.

CONCLUSIONS

Contemporary Polish primary care sits between two "clashing civilisations": a neoliberal and standardised biomedicine competing with healthcare understood as a public system of social welfare (McKenna 2012). I consider the commodification of global healthcare and transitional context of medicine in a post-socialist state as the key factors responsible for this major split. Today, POZ doctors must run their clinics-companies as businessmen do, and simultaneously remember about the pro-community goals of their practice. Thus, they are squeezed between distinctive forms of entrepreneurial activity. As my research has revealed, balancing the two was not easy. Therefore, I am not persuaded by research revealing an idealised picture of doctors voluntary devoting themselves to their community. Perhaps true for the other countries' field context, however, such conclusions sharply contrast with the picture I found among Polish primary care professionals, apparently confused with the conflicting discourses, laws, and expectations shaping their work – or perhaps mission. They did not have any coherent idea about how to combine a pro-community "Health for All" strategy (partially reflected in the goals of the 1997 reform and in public expectations) with an attachment to market-based values. As one of the informants said, "the clinics are social companies", however, she failed to explain, how much they were "social" – and how much they were "companies".

I do not blame the doctors for their business orientation. I believe the reasons for a certain failure of a pro-community approach in POZ lie elsewhere. Polish healthcare is far from stable. Shifting politics and economies are reflected in cyclically changing health policies, exposing patients and professionals to incoherent institutional discourses and requirements. In such chaotic settings the doctors were unable to establish their professional identities and identify the core values of their work. My observations suggest that this conflicting situation is additionally exacerbated by POZ doctors' unclear social perception. "Traditional" concepts of a free, state-provided "family medicine", and "modern", neoliberal settings of medical practice clash here, however, the former seems to currently be prevailing, and yet is not meeting the economic and legal frames of contemporary healthcare in Poland. These remarks find support in the doctors' critical conclusions about patients lacking knowledge about the rules regulating the healthcare system. However, as they pointed out, there are no places where patients can educate themselves, nor there are institutions encouraging them to do so.

Although doctors focus on business entrepreneurship, I still consider primary care practitioners as unique in Polish healthcare. I found many of them eager to establish deeper relations with patients, and some of them maintained unobvious and surprisingly "ethnographic" interactions of reciprocal commitment with them. The latter were usually enriched by doctors' reflexive approaches to primary care and community matters – as M.'s and S.'s examples have demonstrated. Doctors operated with complex time frames and performed elaborate mental processes of transferring interactions with their patients from meaningless consultations, reduced by institutional limitations, to spaces filled with "knowledge" about patients and their dilemmas. This knowledge was crucial to reaching further than merely seeing to temporary body conditions. It was a cornerstone of multigenerational and long-lasting insights into patients' life trajectories, body-mental transformations, and changes in their social environment. Here, the informants recognised a space for fulfilling the social mission of primary care. Nevertheless, according to my respondents, the recent standardisation and bureaucratisation in healthcare has significantly reduced opportunities for such commitments. This adverse shift manifests itself as a transition from a subjective approach, where patients' stories and descriptions of symptoms, along with the physician's interpretations were fundamental, to time-compressed and standardized procedures reflecting bureaucratic patterns of treatment. This, as respondents suggested, undermines community and patient-oriented care. In the bureaucratic healthcare of today, they argued, the opportunity for deeper doctor-patient relationships has been limited. The long time frames are now difficult to maintain, as NFZ's overwhelming standardisation questions their value, or simply ignores them. Despite this, the practitioners still made efforts to enjoy "knowing" rather than "serving" the patients, although it is hard to estimate, how long they can persevere in this institutionally unwelcome bridgehead of voluntary flair.

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“NEW PSYCHIATRY” AND TRADITIONAL HEALING IN KYRGYZSTAN: ATTEMPTS TO DEVELOP CULTURALLY SENSITIVE AND COMMUNITY-BASED TREATMENT

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Healthcare in post-Soviet Central Asian countries, and mental healthcare in particular, has still preserved many characteristics of the previous Soviet system. In the Kyrgyz Republic, a wide-ranging reform of the healthcare system, which started in the second half of the 1990s, has not included psychiatric services in its priorities. In the face of severe deficiencies in the system, such as an over-institutionalisation of mental healthcare and a lack of adequate financing, a group of local psychiatrists, aware of the standards of contemporary psychiatry, have tried to implement an approach promoting culturally sensitive and community-based treatment of mentally ill patients. They notice a great popularity of traditional healers and their role in local communities, based on a worldview shared with their patients and competence in values and norms of social life. Moreover, these psychiatrists understand that healers’ interventions can be effective in the cases of non-psychotic mental health disorders, and attempt to develop some kind of cooperation with Kyrgyz healers, especially in crisis situations. In this article, grounded in the publications of this group of psychiatrists and my own fieldwork in Bishkek between 2011 and 2013, I discuss these achievements and show how globally promoted ideas and directives of contemporary psychiatry have been adapted to the local conditions.

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System opieki zdrowotnej w postsowieckich krajach Azji Środkowej, a w szczególności system pomocy psychiatrycznej, zachował wiele cech medycyny sowieckiej. Reformy systemu medycznego, prowadzone na szeroką skalę od połowy lat 90. ubiegłego wieku w Republice Kirgiskiej, w niewielkim stopniu objęły sektor zdrowia psychicznego. Wobec poważnych niedostatków systemu, takich jak nadmierna instytucjonalizacja opieki psychiatrycznej i brak odpowiedniego finansowania, grupa miejscowych psychiatrów, świadomych standardów współczesnej psychiatrii, zaczęła promować i wprowadzać w życie idee kulturowo wrażliwej i opartej na współpracy społeczności opieki nad chorymi psychicznie. Dostrzegli zjawisko wielkiej popularności tradycyjnych uzdrowicieli i ich rolę w lokalnych społecznościach, której podstawą jest podzielana z pacjentami wizja świata, a także znajomość wartości i norm życia społecznego. Ponadto przyznali, że praktyki uzdrowicieli mogą być skuteczne w przypadku niepsychotycznych zaburzeń psychicznych, a także podjęli pewne formy współpracy z kirgiskimi uzdrowicielami, szczególnie w sytuacjach kryzysowych. W niniejszym artykule, opartym na publikacjach tej grupy psychiatrów oraz własnych badaniach terenowych prowadzonych w Biszkeku w latach 2011–2013, rozważam te osiągnięcia i pokazuję, w jaki sposób promowane w skali globalnej idee i dyrektywy współczesnej psychiatrii adaptowane są do lokalnych uwarunkowań.

Keywords: psychiatry, mental healthcare, traditional healing, culturally sensitive treatment, community-based treatment, cooperation between psychiatrists and healers, Central Asia, Kyrgyzstan

INTRODUCTION

During anthropological research in Kyrgyzstan, shortly after starting my fieldwork in Bishkek in 2011, I learned about some psychiatrists who were interested in the practices of local traditional healers[1], observed their work and recognised the abilities of particular healers to help people. Examples of such an attitude, which sometimes leads to attempts at cooperation between psychiatrists and healers in various socio-cultural settings, can be found in the existing literature, mainly within the field of transcultural psychiatry. I wondered, however, how this trend had emerged in Kyrgyzstan's psychiatry, what its specificity in the local context was and whether any forms of cooperation with healers had developed.

Those issues did not lie at the heart of my research, which focused on people's perceptions of health and illness, and their health-seeking strategies and practices in the context of urban medical diversity. I spent three fieldwork seasons in Bishkek between 2011 and 2013[2], conducting ethnographic research based mainly on talks and to a lesser extent on semi-structured interviews with "ordinary" people, healers, doctors and other biomedical professionals. However, as my interest in the above-mentioned questions developed, I found an opportunity to talk with two female psychiatrists – professors, belonging to different age categories (one was retired, although still worked part time, the other was younger and fully active). This article is partly grounded in the information that I received from them[3], partly in the literature on Soviet psychiatry and especially in the articles describing the contemporary status of psychiatry and psychology in the Kyrgyz Republic. I was particularly interested in new approaches in Kyrgyzstan's psychiatry, which give attention to socio-cultural particularities, including certain features of local healing.

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[1] The word "traditional" should, in actuality, be placed in quotes, since healers' ideas and practices are highly hybridised. I decided to omit quotation marks in the text for reasons of convenience.

[2] This research was supported by the National Science Centre in Poland [Narodowe Centrum Nauki], grant No. NN109 186440.

[3] We mainly talked about the role of healers and psychiatrists' attitudes towards them.

First, I briefly present main characteristics of Soviet psychiatry, while being aware of the danger of unjustified generalisations and stereotyping. The next section shows the picture of psychiatry and practices of mental healthcare in post-Soviet Kyrgyzstan, focusing on its current problems, efforts to implement reforms and the constraints encountered, which hinder the fuller implementation of standards of contemporary psychiatry. Subsequent parts of the article deal with its main topic – local responses to the globally prevailing trends which promote culturally sensitive, community-based treatment and social support for mentally ill patients. I discuss the standpoint and practical efforts of a group of psychiatrists in Kyrgyzstan who stress the importance of social and cultural factors in shaping people's attitudes to mental disorders, and call for implementing new approaches within mental healthcare services. I focus on interesting examples of such endeavours, namely appreciation of the role of healers in the locally-provided care for people with mental health problems and attempts to develop cooperation with these non-biomedical practitioners in particular situations. These developments reveal how global ideas about community-based treatment of the mentally ill have been adopted to the local circumstances. This process should be viewed in the wider context of the social, economic and political changes following the collapse of the Soviet Union.

SOVIET PSYCHIATRY – COMMON FEATURES AND LOCAL DIFFERENCES

Several specific features of Soviet psychiatry are commonly presented in the literature discussing its development and subsequent changes after the dismantling of the USSR, in Russia and other newly independent countries. In general, psychiatry and mental healthcare conformed to the Soviet model of highly centralised, hierarchical and administratively organised medicine, (Field 2002; see also Borovitz and Atun 2006). Among the main, often mentioned characteristics of Soviet psychiatry, there are: the centralisation of psychiatric policy[4]; the use of psychiatry as an instrument of political repression; a prevailing Pavlovian and anti-Freudian conceptual orientation; work (or "occupational therapy") considered as a primary means of treatment; isolation from the trends of western psychiatry (Raikhel and Bemme 2016, 155). In addition, it is pointed out that Soviet mental health care was based on large, specialised psychiatric hospitals which, "with some exceptions [were] overcrowded, understaffed, and in poor repair" (Probes *et al.* 1992, 69). Much scholarly attention has been paid to psychiatric hospitals of the "special type", resembling penal facilities and operated by the Ministry of Internal Affairs, meant for political dissidents who were given psychiatric diagnoses. Although researchers have indicated that psychiatric abuse observed during Soviet times

[4] Not only for the Soviet Union, but also the Eastern Bloc (Raikhel and Bemme 2016, 155).

should not be understood as the result of bad psychiatry, but of bad politics (Probes *et al.* 1992, 75) and many questions regarding the political use of psychiatry remain unanswered, this issue strongly affects the field of psychiatry's reputation in the former USSR (Raikhel and Bemme 2016, 158–159)[5].

Importantly, recent studies show that "sciences of the mind and brain" – the so called psy-ences or psy-disciplines (psychiatry, psychology, among others) – were "surprisingly heterogeneous" under socialism, and the changes observed in Soviet times were "shaped not simply by political interference in science, but by a range of conceptual and social dynamics" (Raikhel and Bemme 2016, 155–156). For example, even during the dominance of Pavlovian psychiatry of the 1950s – represented mainly by the Moscow school – competing theories and "schools" emerged, such as the Leningrad school, "which placed a greater emphasis on environmental and psychosocial factors in the development of mental illness" (Raikhel and Bemme 2016, 157)[6]. This approach was closer to the ideas of social (or socialised) medicine, which were characteristic of the early years of the Soviet Union (see also Field 2002).

It is often stressed in the literature that psychology did not get much attention during Soviet times and it remained on the margins of dominant psychiatry. As Lawrence Probes *et al.* state, "there were comparatively few psychologists in the USSR (…) and they played only a minor role in clinical psychiatry" (1992, 68). It was a "clinical-diagnostic" approach that permeated Soviet psychiatry and it was only in the final years of perestroika that psychology began to receive more recognition (Raikhel and Bemme 2016, 157, 164). One of my interlocutors – a psychiatrist and psychologist, Galina Mikhailovna[7] recalled that after completing a course in psychiatry at the Medical Academy in Frunze (today's Bishkek) she was lucky to have been directed to Moscow to undertake specialisation in psychology in the early 1970s, when it was treated as a discipline entirely separate from medical studies. Generally, psychotherapy was considered a part of "small psychiatry", which dealt with "mild" psychic disorders, such as neuroses or personality disorders, while "big psychiatry" treated schizophrenia, dementia, etc. (Molchanova, Kim *et al.* 2009, 271).

When discussing Soviet "psy-disciplines", we should consider the differences in their trajectories in various parts of the USSR. Although a lot of research accentuates the uniformity of healthcare in all the constituent Soviet republics, due to the highly

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[5] Editors of the first, significant book on the history of psychiatry under communism in the Soviet Union and Central and Eastern Europe, Mat Savelli and Sarah Marks, point out that "the intensity of debate regarding the issue of psychiatric abuse has (…) deflected attention away from attempts to understand the development of psychiatry in Eastern Europe and the USSR in a wider context" (Savelli and Marks 2015, 6).

[6] Lawrence Probes *et al.* (1992, 70) also notice that even at that time some branches of psychiatry progressed in the USSR, e.g. hypno-suggestive therapy for psychosomatic disorders or alcoholism.

[7] I have changed the names of my interlocutors to preserve their anonymity.

centralised and standardised policies (Field 2002, 68), a closer look at particular cases might reveal local specificities, despite common characteristics. Such differences could be observed in Central Asia, especially during the earlier stages of Soviet rule. An interesting and particularly thorough overview, provided by Alisher Latypov (2010), shows the transformations of mental healthcare in Tajikistan, from the time of the Russian Empire, through the long Soviet period and into the first decades of independence. The author discusses, among other things, severe difficulties in the establishment of the psychiatric profession (and biomedical healthcare in general) in Soviet Tajikistan, not only because of the lack of physicians trained as psychiatrists, but primarily because of people's distrust of non-native doctors, and the authority of *tabib*s, religious and spiritual healers among Tajiks (Latypov 2010, 426–427). After harsh attacks against mullahs and healers during the Soviet anti-religious and modernisation campaign, the first state psychiatric hospital was established in 1941, close to Stalinabad. Similar processes took place in other regions of Central Asia, such as Kazakhstan (see Michaels 2003) and Kyrgyzstan.

It is necessary to emphasise the importance of the evacuation of leading Russian physicians, including psychiatrists, to Central Asia during World War II. In Kyrgyzstan, older people still remember and highly value doctors who were transferred to Frunze during the war. Latypov points out that the arrival of experienced psychiatrists enabled "the formal foundation" of psychiatry in Tajikistan (Latypov 2010, 428). It might also have led to the increased uniformisation of mental healthcare[8]. The author comments on this, describing standardised psychiatric education, therapeutic methods and institutions which developed between 1960s and 1980s, as well as psychiatric abuse, not only in its political dimension, but also in the everyday practices of the hospital's personnel (Latypov 2010, 432–434). In another article he reveals the ways in which psychiatry was used by the Soviet regime in political campaigns in Central Asia, and focuses on the construction of a psychiatric category called *narkomania* (drug addiction) presented as a regional problem, specific in the "backward" peripheral areas of the USSR (Latypov 2015; see also Latypov 2011).

In the Kirghiz Soviet Socialist Republic, according to Molchanova, Kim *et al.* (2009, 271–272), psychotherapy was developed within the field of "medical psychology" in the 1960s and 1970s, thanks to Nikolay Kantorovich, a follower of the Leningrad school and the head of the Department of Psychiatry at the Medical University in Frunze. The methods of treatment included hypnotherapy, meditation and so called rational therapy (a Soviet version of cognitive therapy). Jenishbek Nazaraliev, a psychiatrist who

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[8] However, among various therapeutic methods introduced by evacuated specialists, the author mentions "cross-cultural psychiatry". As he explains, Professor Mark Sereisky, the most influential person from the transferred psychiatrists, had explored cross-cultural psychiatry in 1930s among various ethnic groups in Northern Caucasus (Latypov 2010, 429).

designed his own, original methods for treatment addicts in the 1990s, notes that in the late 1970s and early 1980s a local school of therapy for drug-dependent and alcohol-dependent patients, grounded in psychotherapy, was taking shape in Kyrgyzstan. In his words, a group of local scholars

> "put forward, for the first time in the Soviet Union, a comprehensive programme for the prevention of alcoholism, drug addiction, toxicomania and smoking among the young people" (Nazaraliev 2003, 73).

Hence, it can be claimed that apart from universal features, there were also particular trajectories of Soviet psychiatry in Central Asian region.

PSYCHIATRY AND MENTAL HEALTHCARE IN THE KYRGYZ REPUBLIC – AN OVERVIEW

After the disintegration of the Soviet Union the newly independent post-Soviet countries encountered enormous economic and social difficulties connected with fundamental political changes. A dramatic deterioration of the inherited Soviet healthcare system belonged to these pitiful consequences. However, researchers have emphasised that deficiencies of this system were already apparent earlier, during the "late socialism" and perestroika. In fact, it can be compared to a statue with feet of clay: highly centralised, underinvested – as a "non-productive" sector, with big hospitals, over-specialisation and weak primary care, shortages of equipment and pharmaceuticals, and prevailing quantitative indices (Field 2002; Borowitz and Atun 2006). Following the breakup of the USSR, a drastic decrease in funding led to the collapse of the healthcare infrastructure and a severe worsening of epidemiological situation and health outcomes in many regions, including Central Asian republics. The need for substantial improvement was obvious, and Kyrgyzstan was one of the first countries in the region to start wide-ranging healthcare reform. The results of three subsequent reform programmes, such as the development of family medicine and new financing mechanisms, have been positively assessed by international experts (Borowitz and Atun 2006, 434; Ibraimova *et al.* 2011a, 2011b). Despite this, many problems in the healthcare system of Kyrgyzstan are still noticeable, including underfunding, uneven distribution of medical personnel and institutions in the country, poor quality of training, corruption and mass economic emigration of doctors and other medical staff. In addition, as I observed during my own research in Bishkek, there was a striking contrast between the positive evaluations of the reforms by specialists, on the one hand, and people's assessments on the other hand, which were generally negative, and distrust of doctors evidently prevailed (Penkala-Gawęcka 2014a, 2016).

With regard to the situation of psychiatry and mental healthcare in the Kyrgyz Republic, the reform in this sector has not been successful thus far. Programmes of reforms implemented between 1996 and 2016 did not include mental health services in their priorities (*WHO-AIMS Report…* 2008, 31). It is significant that the report on Kyrgyzstan's healthcare system in the *Health in Transition* series devoted only a few pages to mental healthcare, and the overall assessment was: "the quality of mental health care remains poor" (Ibraimova *et al.* 2011a, 93)[9]. Local specialists complain about continued government neglect of numerous problems affecting psychiatric care. With the dissolution of the Soviet Union the situation of mental healthcare in Central Asia drastically worsened and among the wide range of pressures, a lack of funding was the most intense. While reporting on the collapse of psychiatric care in Tajikistan, Latypov used the wording "the humanitarian catastrophe in mental institutions" (2010, 434). Actually, the situation in this country has been perhaps the worst in the region, due to unrest and a civil war between 1992 and 1997 and its consequences[10]. The collapse of the previous system had, however, also severe consequences in Kyrgyzstan – for instance, it was noted that the mortality rate among patients at the Chim-Korgon psychiatric hospital near Bishkek increased by 50%[11].

As Eugene Raikhel and Dörte Bemme (2016, 161) note, mental healthcare has remained highly institutionalised in most of the former Soviet states. With regard to Kyrgyzstan, Ainura Ibraimova *et al.* (2011a, 93) point to an overemphasis on large inpatient facilities, which work inefficiently[12]. This issue is also discussed by local psychiatrists who likewise notice deficiencies of the inherited system. For example, Molchanova *et al.* (2015, 13) write that it is "overly centralised (…) and still resembles the mental health care system in the Soviet Union", and complain about the lack of adequate financing for improving its structure[13]. Krassimir Kanev, the author of one of the reports, maintains that the opinion on excessive institutionalisation as the most significant problem of mental healthcare system in Kyrgyzstan was shared "almost

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[9] Strikingly enough, in an earlier report on healthcare in Central Asia "mental health" was mentioned only once, in the article on reforms. The authors note that the rapidity of social change in the region "is (…) likely to have an impact on levels of mental health, although there has been no specific analysis of this issue" (Savas *et al.* 2002, 81). Another report, by Ibraimova *et al.* (2011b), which describes Kyrgyzstan's success in healthcare reform, does not mention mental healthcare at all.

[10] Latypov provides a broad list of the challenges that faced the mental health service and concludes that, as a result, "those unfortunate enough to have been inpatients at psychiatric facilities during this period, stood only a 50% chance of surviving the conditions" and adds that "this period saw an increase in the incidence of such conditions as post-traumatic stress disorder, anxiety and depression" (Latypov 2010, 437–438).

[11] According to statistics from 1991 to 2013, quoted by Molchanova (2014a, 23, 26).

[12] It is exemplified by a low bed occupancy rate – 66% in 2007 (Ibraimova *et al.* 2011a, 93).

[13] As they stress, "the majority of psychiatric services (…) remain concentrated within the general area of Bishkek, and particularly beneath the umbrella of the Republic Center of Mental Health" (Molchanova *et al.* 2015, 13).

unanimously by government representatives, users and the progressive professional community", whom he interviewed (Kanev 2012, 6).

The inadequate number of psychiatrists poses another challenge to the functioning of mental healthcare. According to the data reported by Molchanova *et al.* the number of psychiatrists in the Kyrgyz Republic decreased from 250 in 2001 to 53 in 2015, and among them there were only six child psychiatrists (down from 33 in 2001). Such a dramatic decrease is mainly due to the mass emigration of medical doctors, including psychiatrists, and the low popularity of this specialty among medical students (Molchanova *et al.* 2015, 13). The WHO report on mental healthcare in Kyrgyzstan also noted that "psychiatry lost a majority of qualified specialists (migration to other countries, leaving for other structures)", while the demand for psychiatric aids increases (*WHO-AIMS Report…* 2008, 30, 31). What is striking is that local psychiatrists often lament the very low prestige of their profession. In Molchanova's words "mental health care specialists in KR [Kyrgyz Republic] are stigmatized even more than patients with mental disorders" (2014a, 26). Supposedly, this is the result of the political abuse of psychiatry in the Soviet times, as Reikhel and Bemme argue, claiming that its

> "aftereffects for the profession's reputation in Russia – and elsewhere in the post-socialist world – have been longstanding and profound" (Reikhel and Bemme 2016, 159).

In addition, this problem should be considered in the wider context of a significant decrease in the level of trust for doctors in general, which is evident in Kyrgyzstan (Penkala-Gawęcka 2014a, 2016) and other countries of Central Asia, and observable in different post-Soviet states as well (for Russia, see e.g. Aronson 2007). As Molchanova puts it, "increased stigmatization of psychiatrists and psychiatry itself" is also due to the activities of several NGOs, fighting against psychiatrists under the slogan of human rights protection (Molchanova 2014a, 24). She opposes the "radical" approach represented by those activists, who advocate for the abolition of all mental health institutes (Molchanova *et al.* 2015, 13), and discusses the position of psychiatrists from the academic sphere, critical of the system but unable to develop a detailed plan for its improvement (Molchanova 2014a, 24)[14].

One often addressed problem is the use of outdated treatment schemes, which is mainly caused by the lack of adequate funding. Although the psychiatrists working at the departments of psychiatry at the Kyrgyz State Medical Academy and the Slavonic University in Bishkek have developed clinical protocols recommending innovative models of treatment, only old-fashioned treatment programmes are available in mental health hospitals (Molchanova *et al.* 2015, 16). However, according to Ibraimova *et al.*

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[14] In Molchanova's words, the situation of mental healthcare in the Kyrgyz Republic "by the end of 2005 could be described as an active destruction of the old system without a construction of anything new instead" (Molchanova 2014a, 24).

(2011a, 93–94), the availability of psychotropic medicines has improved, largely because in 2006 the Additional Drug Package of the Mandatory Health Insurance Fund was introduced for insured citizens.

Another challenge to mental healthcare in Kyrgyzstan, mentioned by local specialists, is "the influx of international experts", which, in their opinion, often results in mutual misunderstandings and discrepancies between the needs of patients and "the globally prescribed interventions" (Molchanova *et al.* 2015, 16). This is in line with what Raikhel and Bemme (2016, 161–162) write about the tensions between local understandings of the effective psychiatric and psychological interventions – especially in crisis and conflict situations – and models offered by external experts, promoting global standards[15]. On the other hand, psychiatrists in Kyrgyzstan do admit that a number of successful projects have been supported by international institutions (the Mental Health Initiative of the Open Society Institute, the Soros Foundation Kyrgyzstan, UNICEF and others). For example, outpatient rehabilitation programmes have been developed by NGOs with the support of several external agencies (Ibraimova *et al.* 2011a, 94)[16]. In addition, thanks to the pressure of such organisations as the WHO or the Open Society Foundations, some efforts have been made on the part of the government to improve the system.

Among the positive changes that have been introduced, adoption of the law "On Psychiatric Care and Citizens' Rights to Receive It" in 1999, should be noted. However, according to the authors of the report of the Mental Disability Advocacy Center, based on research conducted in Kyrgyzstan in 2003, the review shows that "unless serious measures are taken to meaningfully implement the 1999 Psychiatric Care Law", the mental health system remains overly centralised and based on institutions. Specialists warn that it would continue to deteriorate and the current crisis would even become catastrophic (*Mental Health Law…* 2004, 5). They argue that "the law has often been inconsistently implemented and in some cases virtually never implemented" and quote examples of violations of basic standards of care and patients' rights in particular mental health institutions (*Mental Health Law…* 2004, 13; see also Shields and Kabak eds. 2008). Another evaluation, issued later, also points out that these reforms "remained largely on paper" and reports on "systematic violations of patients' rights" (Kanev 2012, 6, 7).

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[15] For example, as Raikhel and Bemme state, "calls for further deinstitutionalization often elicit scepticism from local clinicians and observers who fear the result will be an increase in homelessness" (Raikhel and Bemme 2016, 161).

[16] Several projects providing non-institutional services to psychiatric patients were implemented by the Kyrgyz non-governmental organisation Mental Health and Society, supported by Caritas-France and the Open Society Foundations (Kanev 2012, 4). Until 2010 the Open Society Foundations were called the Open Society Institute.

Despite chronic underfunding, some efforts – which included, first of all, increase in out-patient services, educating primary care doctors and integrating psychiatrists into family medicine institutions – have been, at least to some extent, successful (*WHO-AIMS Report*… 2008; Molchanova *et al.* 2015, 13). These challenges were recognised in the "Mental Health of the Population of the Kyrgyz Republic in 2001–2010" national programme which was launched by the government in 2000. One of its main goals was to reform over-institutionalised psychiatric services and develop community-based mental healthcare, in accordance with the WHO guidelines (Thornicroft and Tansella 2003). Due to shortages in funding, this programme was suspended (Molchanova *et al.* 2015, 13)[17], however, thanks to psychiatrists' initiatives and external support, the activities aimed at community-based care have been stimulated. The model of psychosocial support for patients, with the long-term goal of integrating them into their communities, has been developed. This "therapeutic plan" has been implemented by multidisciplinary, mobile teams, which consist of a psychiatrist, a psychologist, a nurse and a social worker. They are involved, among others, in exploring family and clan relations, and family counselling. Importantly, members of the team usually belong to the same ethnic group and often to the same clan as the patient, but in spite of this, as Molchanova (2014a, 26) claims, it is not easy to reach an agreement between both parties because of widespread resentment towards psychiatrists. Organised since 2006, such teams work in Bishkek, Osh, Karakol, Talas and Naryn and are supported by the Soros Foundation Kyrgyzstan (Molchanova 2014a; Sadykov and Hosák 2016).

NGOs play an important role in the development of community-based mental health rehabilitation in Kyrgyzstan, especially those which are family-based, i.e. founded by relatives of patients with mental disorders. In Molchanova's words, they "might serve as groundwork for a new set of a culturally-sensitive out-patient and community-based rehabilitation system" (2014a, 26). The director of the "Family and Society" NGO was one of the founders of first multidisciplinary mobile teams in Kyrgyzstan. Another NGO, "Mental Health and Society", has strongly advocated for mental health patients' rights and helped patients establish their own self-advocacy group.

Psychotherapy and counselling have developed gradually in post-Soviet Kyrgyzstan. However, as specialists point out, "the state psychotherapeutic service is still perceived to be a part of psychiatry", whilst psychological counselling did not exist here until the mid-1990s (Molchanova, Kim *et al.* 2009, 272, 276). There are psychology

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[17] The authors added that the next national programme was under development and would be, hopefully, supported by the World Bank (Molchanova *et al.* 2015, 13). Actually, the government programme for mental health care of the population of the Kyrgyz Republic for 2018–2030 started in 2018. A new programme on Public Health Protection and Health Care System Development for 2019–2030, called "Healthy Person – Prosperous Country" was launched in 2019 and is supported by the World Bank. According to the government statement, mental health is one of the priority areas in this programme (http://zdrav2030.med.kg/index.php/en/. Access: 15.06.2019).

departments at some universities (albeit with a focus on theories rather than practice) and specialisation in psychotherapy is offered as a 2-year postgraduate training course at the Kyrgyz State Medical Academy[18]. It is significant that psychologists are rarely found in mental healthcare institutions. Molchanova refers to the Ministry of Health's initiative to introduce posts of psychologists at psychiatric hospitals, which, "attractive in theory, in practice turned into a caricature" because of "an outrageously low salary" (Molchanova 2014a, 24). Reflecting on the possible future of counselling in Kyrgyzstan, the same author and her colleagues conclude that – despite many challenges – it may increase in importance

> "because it is less stigmatized than psychiatry or psychotherapy and it integrates aspects of folk counseling [traditional healing practice] and Western approaches" (Molchanova, Kim *et al.* 2009, 277).

CULTURALLY SENSITIVE APPROACH AND PSYCHIATRISTS' ENCOUNTERS WITH HEALERS

Those psychiatrists and psychologists from Kyrgyzstan who are aware of the trends in contemporary global psychiatry and current recommendations of the WHO and other international institutions (Killaspy 2006; *Guidance for Commissioners…* 2016), have been trying to propagate and implement a "culturally sensitive approach" in their own practice. As I understand from their publications, as well as conversations with two psychiatrists, they place particular emphasis on gaining a thorough knowledge of local cultural traditions and social relations, which is important, in their view, for effective treatment of mentally ill patients.

In the articles dealing with more general issues (e.g. Molchanova, Kim *et al.* 2009; Molchanova 2014a), and especially those which describe particular mental health disorders in Kyrgyzstan (e.g. Dobryakov *et al.* 2012; Molchanova and Agazade 2016), the authors provide quite comprehensive accounts of traditional Kyrgyz ideas and practices connected with health and illness, and characterise the specificity of local family relations and wider social organisation[19]. They consider this knowledge necessary for understanding people's attitudes to persons with mental disorders. For instance, great respect for the elders in the family and clan – a deeply rooted and still very important trait of Kyrgyz traditions – is described as a reason for the extremely low number of reported cases of Alzheimer's disease and other forms of dementia,

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[18] According to Molchanova, Kim *et al.* (2009, 274), there is no specialisation in counselling at the departments of psychology, except for the American University in Central Asia (AUCA) in Bishkek.

[19] It should be added that these are almost exclusively accounts of the Kyrgyz culture and society. Apart from the Kyrgyz (67%), the other major ethnic groups in Kyrgyzstan are Uzbeks (14%) and Russians (10%).

especially in rural areas. As Molchanova points out, someone with Alzheimer's disease stays with the family and is treated with care and attention. On the other hand, the low social position of younger women, daughters-in-law (Kyrg. *kelin, kelyn*) in the family hierarchy, and the youngest one in particular[20], explains why their disorders are often neglected – in such cases they are rather treated as "bad wives" and may be divorced by their husbands. Whereas, generally, the patriarchal structure of the society results in more attention given to men, older women also usually get support and care (Molchanova 2014a, 25).

It might be assumed that some of the psychiatrists' accounts, which present lists of particular cultural traits and refer them to attitudes and practices of care for the mentally ill, can lead to the essentialisation of "culture" and support of stereotypes – dangers that are often mentioned by medical anthropologists who discuss the issue of "cultural competency" in the field of healthcare (e.g. Kleinman and Benson 2006). However, when focusing on specific mental disturbances, the authors give much more detailed and nuanced analyses. For example, an interesting paper on depression among pregnant women in Kyrgyzstan (Dobryakov *et al.* 2012) takes into account substantial differences between the situation of women in the cities and in rural areas, and shows how the strength of traditional family and gender structures in the latter settings makes for a higher incidence of depression among young Kyrgyz village women. In addition, the authors describe and discuss various, still flourishing "traditional Kyrgyz rituals" connected with pregnancy and birth, pointing out that these rituals attract the attention of perinatal psychologists and psychiatrists, because they function as "specific coping mechanisms" which may prevent depression and anxiety (Dobryakov *et al.* 2012, 47). Further evidence of such a culturally sensitive approach can also be found in the articles on post-traumatic stress disorder (PTSD) and its "culturally shaped manifestations" in Kyrgyzstan (Molchanova 2014b; Molchanova and Agazade 2016). According to the observations of the authors who worked with victims of ethnic clashes in Osh and Jalal-Abad regions in 2010, the patients did not usually meet all required criteria for PTSD diagnosis and presented different symptoms (especially somatisation). Explanations for difficulties in applying ASD (acute stress disorder) and PTSD diagnoses have been found in the specific traits of Kyrgyz culture, such as *esi* (i.e. following strict traditional rules of behaviour), which impose obligations on men of hiding their feelings, not complaining or showing fear (Molchanova and Agazade 2016, 274).

Among often reported cultural peculiarities of the Kyrgyz (similar to other Turkic groups of Central Asia) is their attitude to the world of spirits. It is stressed both in

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[20] In the patrilineal Kyrgyz society with patrilocal marital residence, a daughter-in-law comes from another clan and lives with her husband and his relatives. The *kelin* is obliged to do all the housework and obey the other members of the family. In addition, while the older sons with their wives and children may eventually move out and live on their own, the youngest son and his wife must stay with his parents and take care of them.

anthropological reports and psychiatrists' accounts, that local understandings of the causes of illnesses often refer health disorders to the influence of evil spirits, especially *jinn*s (mentioned in the Qur'an) and *albarsty*. The latter is a mischievous spirit, known and feared in all Central Asia as a kind of nightmare that torments young women in particular. I was often told about such experiences of my interlocutors or their friends and relatives in Bishkek. Molchanova and Nazim Agazade (2016, 276) describe the characteristics of this creature and the course of its visits, resulting in unpleasant sensations at night, and reveal that patients diagnosed with PTSD after the tragic Osh events[21] tended to interpret their nightmares just as *albarsty*'s visit.

Locally shared ideas about ancestor spirits (Kyrg. *arbak*, plur. *arbaktar*) deserve particular attention. It is striking that from the Kyrgyz point of view, spirits of the dead are continuously present in the lives of their descendants as helpers and protectors, but they can also punish them for improper behaviour or neglecting responsibilities towards *arbaktar*. As Gul'mira Aldakeeva argues, "respect for the spirits of the dead and relations with them are observed in everyday life and form the core of folk religiosity" (2009, 259). These beliefs, expressed in special rituals conducted for *arbaktar*, together with pilgrimages to sacred sites (Kyrg. *mazar*) and spiritual healing, constitute what is locally understood as the traditional form of lived, everyday Islam[22].

In this context, the role and position of spiritual healers, as mediators between the people and the world of spirits, is better understandable. Despite many years of persecution of shamans during Soviet times, shamanic and other healing practices did not disappear, they existed underground and a considerable revival in their popularity has been observed in independent Kyrgyzstan, as well as in the other Central Asian countries (see Duyshembiyeva 2005; Tulebaeva 2009; Penkala-Gawęcka 2014b, 2017a, 2017b; Pelkmans 2017)[23]. Evidence of their popularity has been provided not only by anthropologists, but also by psychiatrists working in Kyrgyzstan[24]. They point out that according to their statistics,

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[21] Violent ethnic clashes between the Kyrgyz and Uzbeks took place in southern Kyrgyzstan in 2010, in Osh and Jalal-Abad in particular.

[22] For a thorough discussion on the place of ancestor spirits in the Kazakh religiosity see Privratsky 2001; about the living role of ancestors in Kazakhstan see Dubuisson 2017. There is also extensive literature (e.g. Aitpaeva 2006 for Kyrgyzstan) dealing with *mazar*s in Central Asia, as sacred sites where close contact with the supernatural (including ancestor spirits) is enabled.

[23] It should be noted that this process has occurred during the course of an overall rehabilitation and support for cultural traditions of the titular nations of these countries. See, for example, Sophie Hohmann's in-depth examination of these issues with regard to Uzbekistan (Hohmann 2007, 2010).

[24] It is important here to mention that, according to a study conducted in eight post-Soviet countries in 2001, in Kyrgyzstan 25% of respondents (from the sample 2000) admitted that they had asked healers for help, which revealed the highest level of healers' popularity in this country (Stickley et al. 2013).

> "89% of patients who visit the Psychotherapeutic Clinic and approximately 100% of patients in the other mental health wards of the Kyrgyz Republic Center of Mental Health have met traditional healers prior to seeking psychotherapy" (Molchanova, Kim *et al.* 2009, 267)[25].

The authors admit that what they call "Kyrgyz folk psychotherapy" is more popular among the Kyrgyz people than official psychotherapy. They state that the help-seeking behaviour of the Kyrgyz is predictable: "the first (and often the last) person they would like to see is a traditional healer" (Molchanova, Kim *et al.* 2009, 270).

It is noteworthy that a group of psychiatrists collaborated for some time with the Aigine Cultural Research Centre in Bishkek, whose mission is to revive and enhance Kyrgyz cultural traditions[26]. They took part in expeditions organised by Aigine to sacred sites in several regions of Kyrgyzstan and had an opportunity to talk with healers and observe their practices, often conducted in *mazar*s, since healing proceeded there is considered most effective (Adylov 2007; Tulebaeva 2009). During that research the participants interviewed local people and, for instance, the results of a survey done in the Talas *oblast* (administrative region) showed a high level of people's trust in healers and their capability to contact spirits of the dead (Molchanova *et al.* 2011, 38). Psychiatrists were also invited to participate in the activities of a special commission created by the Ministry of Health in 1990s, which worked at the "Beyish" Centre of Folk Medicine with the aim to select healers with extraordinary abilities, who then received some additional training at the Centre[27]. These encounters certainly influenced perceptions and attitudes of this group of psychiatrists to Kyrgyz traditional healing.

Duyshenkul Adylov, a "very talented psychiatrist", as Galina Mikhailovna, the older of my interlocutors, called him, was the first to start researching Kyrgyz healers. She added that it was just at the beginning of perestroika, so

> "our brains were designed and oriented at Marxist-Leninist ideology. [Therefore] we thought that a very large percentage of healers were unhealthy".

In Adylov's book, already published (in Russian) in 1999, entitled *Psychiatric and Psychotherapeutic Aspects of Healing in Kyrgyzstan*, he presented the results a10-year study of various types of Kyrgyz healers, altogether 358 persons. He used methods of psychiatry, striving to reveal those who suffered from mental illness and, as a result, he found 40 people among the healers with severe psychotic disorders and a number of individuals

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[25] This survey was conducted in all wards of the Republican Centre of Mental Health in 2005 and 2006.

[26] http://www.aigine.kg/?lang=en. Access: 12.10.2018. The Director of Aigine, Gulnara Aitpaeva and her colleagues published several books – collections of articles based on interdisciplinary research on sacred sites and healing in Kyrgyzstan.

[27] I write more about the "Beyish" Centre in another article (Penkala-Gawęcka 2018) – its years of prosperity, then crisis and, finally its dissolution – which reflects the changing political and socio-economic conditions. The psychiatrists who were my interlocutors also briefly participated in the commission mentioned above, but they were rather sceptical about the value of its activities.

who had other mental disturbances or neurological problems (Adylov 1999, 88). However, he was also interested in the traits of the healers' personalities and the mechanisms of their influence on patients. He discovered similarities between their techniques and those used by professional psychotherapists, first of all suggestion, and noticed that applying "specific attributes", characteristic of a particular "ethno-cultural context", strengthens psychological influence (1999, 107). The author admitted at the beginning of his book that while he had started his work with healers as a psychiatrist, further studies showed him many elements of their practice which were interesting for a psychotherapist. Adylov tried to catalogue the variety of Kyrgyz healers, and differentiated the following categories: *kuuchu* (resembling a shaman) and *bakshy* (a shaman – according to the author, strongly Islamised), *közü achyk* (a clairvoyant), *tabyp* (*tavyp*) (uses pulse diagnostics and hot/cold classification of illnesses) and *synchy* (combines traditional Kyrgyz and extrasensory methods)[28] (Adylov 1999, 80–82, 2007, 381–383). According to Galina Mikhailovna, Adylov headed the commission responsible for selecting healers at the "Beyish" Centre. Besides, for some time he collaborated with the Aigine Centre and his findings were subsequently quoted by the authors of other publications, including psychiatrists who valued his work. What is worth mentioning, he observed healing séances and asked the healers, among other things, about their motivation behind the decision to practise and tried to obtain detailed accounts of their way into the healing profession.

Adylov and then other psychiatrists became particularly interested in the phenomenon of the emergence of a future healer. For specialists, the problem of differentiation between those healers who have psychiatric disorders and the others was crucial, and they tried to develop differential diagnosis (Adylov 1999, 36–43). However, they noticed the strength of local beliefs about the appointment of the healer by spirits, and a specific illness which marks such predestination. This is a variant of the "shamanic illness", well known from ethnographic accounts, not only in Central Asia, but also in many other regions. Anthropologists working in Central Asia point to the importance of a "shamanic/healer's illness" in the career of contemporary spiritual healers (e.g. Biard 2013; Penkala-Gawęcka 2013; Pelkmans 2017). Such sufferings are usually taken (especially when supported by the authority of an experienced healer) as a sign of the call of spirits, ancestor spirits in particular, choosing a person who should become a healer. If someone who has been appointed does not want to accept this calling, he or she would be punished with further suffering or even death. So, this specific illness

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[28] Other types of healers are also presented in the literature, e.g. *bübü*, described as a female shaman. Ethnographic research shows that the terminology is not stable and healers often do not overtly name their specialty. Pelkmans (2017, 152) for example, claims that Kyrgyz healers do not call themselves *bakshi* mainly because they do not aspire to be like the great, powerful shamans living in the past. For a discussion on Kyrgyz spiritual healers' initiation, sources of legitimacy and authority see Penkala-Gawęcka (2017a, 24–29).

is treated as the result of misapprehension or disobedience of the person chosen by spirits (Molchanova, Aytpaeva *et al.* 2009, 209).

Psychiatrists from the discussed circle have also used and elaborated the concept of *kyrgyzchylyk* (Kyrgyzness), which was popularised by members of organisations engaged in reviving the Kyrgyz cultural heritage, especially Aigine Cultural Research Centre. This concept, also described in contemporary ethnographic accounts, is characterised by Aitpaeva and Molchanova as "the totality of characteristics and qualities inherent to the Kyrgyz ethnic group" (2007, 395). In this sense, it can be understood as a culturally defined Kyrgyz national identity, which is closely connected with *musulmanchylyk* (Muslimness) (Toktogulova 2007)[29]. At the same time, this term is used in a narrow sense too – according to the authors, people relate it to various forms of spiritual healing and clairvoyance, which require possessing supernatural abilities. Such extraordinary individuals are treated as "having a gift of *kyrgyzchylyk*"[30] (Aitpaeva and Molchanova 2007, 398). In the article referred to above, Molchanova tried to explain this phenomenon from the standpoint of transpersonal psychology. But in the other, later text (Molchanova and Agazade 2016, 276–277) the authors interpret *kyrgyzchylyk* as connected with a psychotic episode – a kind of "pre-*kyrgyzchylyk*", with hallucinations and dissociative signs, namely what is called in ethnographic literature the "shamanic/healer's illness". The psychiatrists notice, however, that because of widespread ideas about the call of spirits, "an initial psychotic episode is usually considered a 'spiritual emergence', and a patient generally has to visit a number of traditional healers before a psychiatrist takes care of him or her" (Molchanova, Kim *et al.* 2009, 270).

PSYCHIATRISTS AND HEALERS – MUTUAL RELATIONS AND ATTEMPTS AT COOPERATION

Existing evidence confirms the great popularity of traditional healers in various parts of the world, where they often act as strong rivals or significant partners of biomedical professionals in the local contexts of medical pluralism. Such situations prompt a search for some forms of "peaceful coexistence" or even cooperation with non-professional practitioners. Transcultural psychiatry, concerned with the relationship between culture and mental health, has made significant efforts directed towards rapprochement between psychiatrists and healers. The classic work of E. Fuller Torrey (1972) is a good example of this approach. He showed that shamans or witch doctors

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[29] Irina Antonovna, the younger of the psychiatrists I talked to, expressed her fear that the idea of *kyrgyzchylyk* would acquire a chauvinistic tinge.

[30] One of the variants of *kyrgyzchylyk* is *manaschylyk*, i.e. a special gift of telling the great Kyrgyz epic "Manas". Manas tellers are considered, similar to healers, persons chosen and led by spirits, and their initiation has similar characteristics.

can sometimes be as effective or even more effective than psychiatrists, and revealed similarities in methods and techniques used by both parties[31].

Attitudes of psychiatrists and other biomedical professionals to local traditional healers in post-Soviet Central Asia varied, depending on many factors. Latypov showed that although in Tajikistan mental health care was in a "dormant" phase, representing "the widespread neglect of mentally ill people" (Latypov 2010, 444) and healers had been extremely popular, psychiatrists and other medical personnel were overtly hostile towards them. In Shymkent (southern Kazakhstan), Botagoz Kassymbekova noted a different approach in a similar situation of distrust of psychiatrists and authority of healers among people with mental health disorders:

> "Doctors (…) often shunt "no-hope cases" off to healers. They view *taeyips* as a cultural tradition that people in Shymkent and other communities created, protect, and are comforted by. Some even suggest that *taeyips* should consider getting formal training, so they can offer more professional help" (Kassymbekova 2003, 4).

My observations from Kazakhstan, where I did research in the second half of the 1990s, revealed that a number of psychiatrists and other physicians who had contact with healers at the centres of complementary medicine in Almaty, tended to accept their abilities and they even included some of the healers' treatment methods into their own practice (Penkala-Gawęcka 2018, 60–61).

Obviously not all psychiatrists and psychologists in Kyrgyzstan appreciate the practices of traditional spiritual healers[32]. Adylov pointed to the "confusion" of the majority of doctors, including psychiatrists, whose lack of knowledge and experience, together with inflexibility, hindered the understanding of the role of healers in the society (Adylov 1999, 23). In his later article he argues that in the early post-Soviet period, representatives of official medicine experienced a kind of "cultural shock" when they observed the expansion of healing, however the perspective of many specialists has changed then (Adylov 2007, 379). According to the opinions of the psychiatrists I talked to, healers can help in specific cases[33]. Irina Antonovna, the younger of my interlocutors, said that among the healers whom she had met, several had easily visible signs of

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[31] An example of a newer publication that focuses on integration of traditional healing with psychiatric treatment in various regions of the world, is the book entitled *Psychiatrists and Traditional Healers* (Incayawar *et al.* eds. 2009).

[32] The attitude of biomedical professionals in Kyrgyzstan to traditional healing seems varied, but perhaps most of them tend to deny their practices and treat the majority of healers as charlatans (see Pelkmans 2017). On the other hand, such segments of complementary medicine as acupuncture or apitherapy, which are mainly practised by physicians, are accepted and officially supported.

[33] Similarly, psychologists who conducted research on healers in the north of Kazakhstan have argued that their methods were effective in diverse neurotic and psychosomatic disorders (Jumageldinov *et al.* 2015, 209).

mental illness, but some, possibly, had a kind of special gift. In her opinion, a psychiatrist and a healer may complement each other. Galina Mikhailovna mentioned that she is not a "categorical" psychiatrist who would deny any unconventional methods. She also gave an example of a "very reasonable" healer who was trained in western psychotherapy, and although she did not use it in her practice, in Galina's words this knowledge might somehow help her.

Molchanova, Kim *et al.* have wondered what the future of psychotherapy in Kyrgyzstan would be:

> "There have been movements to render the official mental health service the dominant approach in Kyrgyz society and relegate traditional healing practice to the past. Given the popularity of traditional healing in Kyrgyzstan, however, this seems to be an impossible aim for the near future" (Molchanova, Kim *et al.* 2009, 276).

As I mentioned earlier, some traditional methods have already been used in counselling in Kyrgyzstan. The authors maintain that there is "a unique prototype of Kyrgyz psychological counseling, which is a product of both psychotherapy and traditional healing" (Molchanova, Kim *et al.* 2009, 276). Besides, a portion of psychiatrists claim that certain aspects of folk healing may be included in psychiatric practice. Adylov writes that presently

> "those medical doctors, who discovered the rational[e] in folk healing practice, adopt its elements in their work. Some of them are practising even at mazars. (…) Folk healing can add [supplement] treatment with natural elements, culturally sensitive social and rehabilitation activities in therapeutic practices" (Adylov 2007, 379).

He emphasises the similarities between particular healers' practices and psychotherapeutic techniques, for example hypnosis (Adylov 2007, 390). Other specialists also recommend appreciating the "positive aspects" of folk healing and using them in mental healthcare. They notice, however, that this should be done with caution, because, for example, if a psychiatrist would like "to use the rhythmic knocks of an *asatayak* (special stick) in therapy, he or she may not be taken seriously" (Molchanova, Kim *et al.* 2009, 276).

In this context, my interlocutors mentioned the Medical Centre of Dr. Nazaraliev, the largest private psychotherapeutic institution in Kyrgyzstan, specialising in alcohol and drug addiction treatment. In his book entitled *Fatal Red Poppies*, Zhenish Nazaraliev refers to the achievements in substance abuse therapy, which was developed by local psychiatrists and implemented for the first time in the Soviet Union (Nazaraliev 2003, 73–74), however, he focuses then on a search for his own methods of treatment. In his words, what he invented is a "highly scientific method of psycho-pharmaceutical treatment", patented by the Centre. The core of this approach is a "deep-level psychotherapy" (or stress-energetic psychotherapy, shock therapy) (Nazaraliev 2003, 82).

The Nazaraliev Medical Centre has substantially developed and now consists of two big facilities in Bishkek and its vicinity (the second building, a rehabilitation unit, is located in the foothills of Tian Shan). They have two departments: one of narcology and the other one of psychiatry. Treatment is divided in three stages: detoxification (psychopharmacological therapy), "mindcrafting" and a "powerful finale" called stress energetic psychotherapy[34]. The Centre's website claims that "yearly remission success rate for drug addicted patients is 83% and alcohol addicted patients is 92%"[35].

Interestingly, Nazaraliev and his personnel have included some elements of Kyrgyz traditions into the second stage – "mindcrafting". This method is presented as

> "a psychotherapeutic synthesis of eastern spiritual and philosophical approaches to medicine and western pragmatic scientific techniques".

As we can read on the site:

> "just above the rehabilitation facility, on the mountain of salvation called 'tashtar-ata', a handmade pile of stones and four pagodas (Christian, Muslim, Buddhist and of Judaism) have found its accommodation"[36].

However, these "pagodas" have apparently been added later, when the circle of international clients of the Centre widened. Earlier, as the above-mentioned book suggests, more stress was put on Kyrgyz traditions, with Tashtar-Ata treated as their sacred mountain. During the rehabilitation, patients climbed up the mountain and, "in keeping with local traditions" took stones with them and later left them on the pile. They also "left behind them (…) 'ribbons of hope' tied to the bushes at the summit" (Nazaraliev 2003, 385). This was obviously related to the old tradition, still alive in Central Asia, of fastening cloth ribbons to tree branches and making a wish (see Montgomery 2007). Galina Mikhailovna stressed that in this context the reason for this practice was "to tie up the addiction", get rid of it. These practices formed a part of the programme called "The Seventh Sky", whose results, according to Molchanova, Kim *et al.*, were "very encouraging" (2009, 273). Today, stones are still used during the "ritual of liberation" on Tashtar-Ata, and this procedure is named "lapidopsychotherapy". The use of stones is presented as a "transcultural ritual". Besides, mindcrafting includes living in traditional, "comfortable handmade yurts" near the beautiful Issyk-kul lake, using the Russian sauna (*bania*) and practising meditation, as well as "Dervish dance" and "Aum [Om] chanting"[37].

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[34] As explained, it includes elements of imperative influence and neurolinguistic programming.

[35] http://nazaraliev.com/en. It should be added that this treatment is available only to well-off patients and, in addition, also VIP services are offered: http://nazaraliev.com/en/pricing-policy. Access: 13.11.2018.

[36] http://nazaraliev.com/en/treatment-and-rehabilitation. Access: 13.11.2018.

[37] http://nazaraliev.com/en/treatment-and-rehabilitation. Access: 13.11.2018. Such hybridisation of methods and techniques is also characteristic of complementary medicine in today's Central Asia.

A possible rapprochement of traditional healing and official psychiatry and psychology is also seen from the different angle. In the opinion of some psychiatrists, a solution might be the acceptance of parallel interventions of psychiatrists (or psychologists) and healers. The former can remove symptoms of illness, while only the latter – according to the prevailing illness aetiologies – are able to fight a deep, hidden cause of health disorder. In fact, patients often seek help from both traditional healers and doctors. This kind of parallel treatment, according to specialists, may be especially effective in the case of non-psychotic patients "with a traditional worldview" (Molchanova, Aytpaeva *et al.* 2009, 215; Molchanova, Kim *et al.* 2009, 276). In addition, psychiatrists point out that healers usually refer patients to medical doctors when they recognise serious psychotic symptoms whose treatment is beyond their competence (Adylov 2007, 391; Molchanova, Kim et al. 2009, 271).

The attitude of the same group of psychiatrists to traditional spiritual healers seemed to become even more positive after the bloody ethnic clashes between the Kyrgyz and Uzbeks in the south of Kyrgyzstan, in 2010. Medical professionals and psychologists worked as members of teams established in order to help the survivors of these events. As I mentioned before, the specialists recognised difficulties in diagnosing people who apparently suffered from post-traumatic stress disorder. Because of locally shared beliefs about the causes of their sufferings, patients preferred to ask for help a traditional healer rather than go to a psychiatrist. Medical professionals noticed that "culturally-shaped features of stress disorders" among the Kyrgyz decrease the effectiveness of psychiatric treatment. In the face of this, they advised using local mediators between patients and psychiatrists and establishing an "effective communication between traditional healers and mental health professionals" (Molchanova and Agazade 2016, 277).

Further experiences, connected with assistance provided to the victims of gender-based violence during the Osh and Jalal-Abad events, also showed that cooperation between the two parties is possible. In a very interesting article based on encounters with the local healers and their patients, Molchanova *et al.* (2017) reveal why these practitioners were so often asked for help in such cases, and explain the causes of their effectiveness. In accordance with the shared cultural norms, raped women tried to hide their "shame", therefore the majority of survivors preferred not to seek psychiatric or psychological help. The authors write:

> "taking into consideration the cultural context, victims of GBV [gender-based violence] often are more likely to look for assistance from traditional healers than from crisis centers" (Molchanova *et al.* 2017, 8).

The examples from their field research illustrate the approach of healers, who are thoroughly familiar with the worldview and social constraints experienced by their patients. The sufferings of those survivors who had signs of sleep paralysis or difficulties in breathing at night were usually interpreted as *albarsty*'s visits and traditional healers – *bubu* (*bübü*) or *kez-achyk* (*közü achyk*) – were considered competent in those cases. Healers often saw victims of gender-based violence who had "unexplained bodily symptoms", such as pains in various parts of the body, which psychiatrists called "somatoform symptoms". In one such case, quoted in the article, the *bubu* suspected that her patient had been raped in 2010, which she had subsequently hidden from her husband and his family. The healer told the *kelyn*'s mother-in-law that her illness was caused by *korkuu* (great fear) and performed special purifying rituals. In addition, "the *bubu* did not take any money from the young woman and told her mother-in-law that it was an honor for her to see such a 'clear soul' in the young *kelyn*", which resulted in much better treatment of the woman from her husband's relatives (Molchanova *et al.* 2017, 9).

The authors conclude that due to socio-cultural factors, consequences of gender-based violence in Kyrgyzstan often remain beyond the reach of the mental healthcare professionals. Therefore, as they claim, "psychiatry, unlike other medical specialties, might greatly benefit from cooperation with traditional healing, and patients with stress-related disorders can receive help from a wise traditional healer" (Molchanova *et al.* 2017, 8).

CONCLUDING REMARKS

The fact of the great popularity of healers, especially traditional spiritual healers, among the inhabitants of Kyrgyzstan, which has been observed since the 1990s, certainly influences the attitudes of biomedical professionals to their practices. It is apparent that the position of doctors towards their non-biomedical rivals is mostly negative, although it differs depending on the kind of complementary medicine practice. Nonetheless, they tend to enhance the boundaries between biomedicine and "folk" medicine and often treat healers as charlatans (Penkala-Gawęcka 2018). The perspective of psychiatrists, discussed in this paper, is different. At least a portion of them take into account the importance of people's deep distrust of psychiatrists and psychiatric institutions, marked by strong negative emotions, which hinders the effectiveness of mental healthcare. For example, Adylov points out that the commonly shared negative image of psychiatrists and their abilities makes healers' services more attractive (Adylov 1999, 18). Stigmatisation of persons with mental disorders is among the often quoted reasons for people's avoidance of psychiatric assistance, especially in the villages (Molchanova *et al.* 2017, 8; Kanev 2012, 7; Sadykov and Hosák 2016, 35). Various problems of mental healthcare in Kyrgyzstan (organisational deficiencies, underfunding, insufficient and uneven distribution of specialists), presented in the first part of the article, create further barriers to the access to professional help.

However, in my opinion the most important element is the shared worldview of traditional healers and their clients, particularly their beliefs concerning the spiritual world and illness aetiologies. In addition, Kyrgyz healers are fully competent in local cultural values and norms, hierarchies in the extended family and clan structure, gender roles, etc. In fact, as members of the local Kyrgyz communities, they are "culturally sensitive". These factors have been noticed by the psychiatrists; for example Molchanova *et al.* write that a healer may be effective because he/she "can operate in the same cognitive schema as his/her patient by mixing traditional rituals, prayer and cognitive behavioural techniques, even while a healer is unaware of using them" (Molchanova *et al.* 2017, 4). As I tried to show, in this context, and especially in critical circumstances such as the consequences of tragic events in the south of Kyrgyzstan in 2010, some form of cooperation with traditional healers has become a vital issue for the local psychiatrists. It might be argued that pragmatic goals have prevailed over radical differences in "cognitive schemes" and ontologies of psychiatrists and healers. What is apparent is that the former quite often refer to the similarities between a number of professional psychotherapeutic techniques and healers' practices, which may be seen as a kind of self-justification.

In the opinion of local psychiatrists, global standards offered by external specialists often turn out to be inadequate and lack the necessary cultural sensitivity. When appealing for effective measures in dealing with patients who suffer from PTSD, Molchanova and Agazade mention, among others, "training of visiting specialists on cultural competence, including, primarily, respect and loyalty towards representatives of other cultures" (Molchanova and Agazade 2016, 277). Evidence of an appreciative attitude of psychiatrists in Kyrgyzstan towards traditional healers and efforts aimed at cooperation with them, presented in this article, demonstrate how globally promoted ideas about community-based and culturally sensitive treatment and rehabilitation of people with mental disorders can be adopted to local socio-cultural conditions.

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DIFFERENT SYSTEMS OF KNOWLEDGE FOUND IN THE REPRODUCTIVE HEALTH OF ASHANINKA WOMEN FROM THE PERUVIAN AMAZON[1]

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Indigenous Ashaninka people from the Peruvian Amazon operate within their communal reserve and autonomous native communities, where biomedical health posts and biomedical practitioners are present. This article analyses how the two systems of knowledge and practice i.e., indigenous medicine and biomedicine, coexist in the Ashaninka territory and how they are articulated in childbirth, birth control and other aspects of reproductive health. Their medicinal cosmology privileges the medicinal plant use and midwifery. At the same time, these practices are compatible with biomedical thinking. The childbirth techniques widely shared by the Ashaninka women and midwifes do not change substantially after biomedical training. Instead, Ashaninka women complementarily add new practices to their own pre-existing array of contraceptive and labour techniques, without shifting their ontological basis. The Ashaninka seem a resilient society, one which is capable of "absorbing" novel biomedical knowledge, practices and technology into their medical landscape, while remaining within their cultural boundaries and thus preserving their specific features.

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Aszaninka – rdzenna ludność Amazonii peruwiańskiej mieszka i działa w obrębie wspólnotowej rezerwy i w ramach autonomicznych społeczności (hiszp. *comunidades*), w których znajdują się biomedyczne punkty zdrowia i działają praktycy biomedycyny. Artykuł analizuje, w jaki sposób oba systemy wiedzy i praktyki, tj. rdzenna medycyna i biomedycyna, współistnieją na terytorium Ashaninka i jak są artykułowane w praktykach związanych z porodem, kontrolą urodzeń i innymi aspektami zdrowia reprodukcyjnego. Medyczna kosmologia Aszaninka traktuje ziołolecznictwo oraz położnictwo w uprzywilejowany sposób. Jednocześnie te praktyki etnomedyczne są kompatybilne z biomedycznym sposobem myślenia. Techniki porodu powszechnie stosowane przez kobiety i położne Aszaninka nie zmieniają się znacząco po

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treningu biomedycznym. Zamiast tego, kobiety Aszaninka rozszerzają swój wcześniej istniejący zestaw technik antykoncepcji i porodu o nowe techniki, nie naruszając zasadniczych podstaw ontologicznych. Społeczność Aszaninka wydaje się być odporna i jednocześnie elastycznie działać (*resilience*) w obliczu zachodzących zmian w krajobrazie medycznym. Jest w stanie „wchłonąć" nową wiedzę biomedyczną, praktyki i technologię, pozostając w swych granicach kulturowych i zachowując swoje specyficzne cechy.

Keywords: medical pluralism, medical landscape, resilience, medicinal plants, midwifery, indigenous Amazon

INTRODUCTION

In the ethnographic literature the Ashaninka have been described as a resistant society; one which has managed to adapt to the diverse "historical solicitations" while always preserving the features enabling them to identify themselves as members of Ashaninka society. Historical memories of their struggle and resistance are, beyond human tragedy, symbols of Ashaninka identity and a historical metaphor (Sahlins 1995). During the pre-conquest period, the Ashaninka served as middlemen in the trade of goods between lowland Amazon and the highlands, never losing their independence from the Incas (Heckenberger 2005). They knew also how to be flexible in front of the conquerors, missionaries, and landowners, adapting to the new conditions. They resisted the call of subversive groups such as *sendero luminoso* and cocaine producers, instead organising themselves into self-defense groups (Span. *autodefensa*). Nowadays they are in the process of engaging themselves in the modern economy by cultivating several cash crops. This ability to maintain their ethnic identity, together with a high degree of resilience and flexibility in social organisation, can explain, at least in part, their successful resistance to the aggression of the colonial and national powers (Varese 2006, 30–31).

The Ashaninka case offers a complex picture of medical landscape in which we find, 1) indigenous Ashaninka medicine, which is not only a referential source of home and expert healing but also a form of articulation of Ashaninka identity and a powerful form of resistance (see derivative function of medicine – De Burgos 2014); 2) biomedicine with its modernist idea of progress and improvement (Baer 2003). And yet Ashaninka everyday dwelling in the world is intimately related to the knowledge and use of plants. This paper will attempt to demonstrate that the use of medicinal plants by the Ashaninka goes beyond symptomatic response to health conditions, instead it shows strong people, animal and plant relations and interactions. Under ontological scrutiny, the Ashaninka can be labeled as an animist society, the one which has established social relations with non-humans, namely animals, plants, rocks, water bodies and, what we call in Western naturalist ontology – spirits (Descola 1996). However, their social relations with other human groups and non-humans are better explained within Amerindian perspectivism framework (Viveiros de Castro 1998). According to this paradigm and to Ashaninka experience, plants and animals are endowed with not only senses and instincts, but also with intensions and agency and all non-humans see themselves as humans.

Medical pluralism (Baer 2003; Crandon-Malamud 1991; Johannessen and Lázár 2006) is a useful framework to understand people's array of possibilities from which one can make his/her medical choices. Medical landscape is another concept, which, according to Kołodziejska (2016, 155)

> "better defines the complexity of everyday behaviour (…), because people do not deliberately choose one option from the bunch of possibilities, but they rather act in accordance with the relations they have with, e.g. other people, institutions, medicines, medicinal plants, political power and many others".

The medical pluralism highlights choices people have and uses they can make of them, while medical landscape or health landscape / healthscapes (see Gold and Clapp 2011) pays attention to biophysical and social space in which the interaction of various medical systems take place. In my opinion, both frameworks are suitable to explore the relations between different system of knowledge and accompanying practices in the reproductive health of Ashaninka people. I would like to pay attention to both health-seeking practices of Ashaninka people, choices they make, and also to the coexistence of two parallel systems of indigenous and biomedical knowledge and technology. I hypothesise that these systems are manifested with unequal strength and within unequal power relations. My question here is whether this coexistence of two knowledge traditions in birth control and childbirth may be socially resilient.

Social-ecological resilience has been defined as the capacity of a system to absorb changes and still remain within its boundaries or maintain the same stable state (Holling 2001). Social resilience is often understood intuitively and different definitions exist. The core idea is that societies experience threats, risks and challenges which inevitably lead to responses. These responses may bring adaptation, transformation and change. Resilience is measured in the capacity of a given society to: 1) cope with risks and overcome/adjust to adversities, 2) learn from the previous experiences for the sake of future threats, shocks or uncertainties, 3) transform, which encompasses people's ability to obtain assets and help from government organisations and/or civil society, to participate in decision making and to create institutions that increase their agency in the future crises (Keck and Sakdapolrak 2013). It should further be noted that in intercultural contexts resilience does not imply a merely adaptive process or a passive incorporation of foreign cultural elements. A resilient society is one which is capable of "absorbing" disturbances and crisis via a complex re-arrangement of the previous equilibrium. Resilience is related to risks, shocks, and unforeseen unrest, and therefore in medical anthropology has been used mainly in the analysis of health risk

(Leipert and Reutter 2005; Obrist, Mayumana and Kessy 2010), but not only (see e.g. Zank, Araujo and Hanazaki 2019). I will attempt to show that it can be useful too in explaining indigenous peoples' capacity to absorb and react towards changes induced by the presence of biomedicine in their communal territories, for example, in dealing with biomedical obstetricians in locally rooted practices such as birth control and childbearing.

To sum up, the aim of this contribution is to describe medical landscape of the Ashaninka in respect to their reproductive health. The description and analysis of the Ashaninka choices may be slightly biased by the fact that I conducted the research mainly from medical-ethnobotanical perspective. By using the concept of resilience, my scrutiny revolves around power relations between Ashaninka indigenous medicine and biomedicine. Finally, I attempt to answer the question whether the coexistence of two systems of knowledge related to family planning and childbirth leads to the biomedical practice becoming Ashaninka (Span. neologism *ashaninkar*) or does the Ashaninka way of doing things acquire a biomedical way of thinking.

THE ASHANINKA ETHNIC GROUP AND THE STUDY AREA

The Ashaninka ethnic group belongs to the Arawak linguistic family. The Ashaninka groups as a whole constitute one of the largest remaining indigenous Amazonian groups in Peru. They inhabit the areas along the Apurímac, Ene, Perené, Tambo and upper Ucayali rivers and their tributaries in the region called *Selva Central*. Groups of Ashaninka are also found throughout Gran Pajonal highland savannas and the eastern bank of the Pachitea river (Varese 2006). As such their settlements and living style show a degree of diversity that ranges from scattered bands to large settled communities along the riverbanks which are well connected to Peruvian society (Killick 2009, 702–703).

The Ashaninka Communal Reserve is located along the Ene, Tambo and Apurímac river valleys and it covers 184,468 ha of tropical highland forest in Peru's central Amazon (Caruso 2011, 610). According to Peru's Protected Areas Law no. 26834 of 1997, these are "areas destined for wildlife conservation for the benefit of neighbouring rural populations" (art. 22(g), after Caruso 2011, 608). Communal reserves were set up at the request of indigenous groups wishing to secure territories, both ancestral and for current use (Caruso 2011, 608). These territories are co-managed between the state and the local indigenous groups. Ashaninka people have managed to capitalize on this land category in addition to the *comunidad nativa* (native community), recognized in the *Ley de Comunidades Nativas* no. 20635 (1974). The creation of native communities increased the importance of the formal leadership, such as *presidente de la comunidad*, *asamblea general*, etc.

For Ashaninka people, as for other Arawak groups the main unit of society is the nuclear family: one married couple with their unmarried children (Johnson 2003, after Killick 2009). According to my field observations the examples of polygyny and polyandry are extremely rare. Ashaninka people have shown a preference for uxorilocal residence especially in the first years after marriage (Varese 2006). However, over time even those houses connected by close kinship ties move further and further apart (Killick 2009). Since the emergence of native communities and legal rights to their own territory, the Ashaninka enacted a rule, which claims that in the case of a mixed marriage between a non-Ashaninka outsider and an Ashaninka man or woman, the one who takes a non-Ashaninka as a partner must leave the community and live outside the Ashaninka territory. This new law of "traditional" promotes Ashaninka racial, linguistic and cultural uniformity.

METHODS

The information was collected during three stays among the Ashaninka people, who live along the Tambo river, in 2016, 2017 and 2018. During the first field campaign in 2016 I worked together with Joanna Sosnowska, PI of the project. The material was collected in the following ways. First, walks to the forest, fallow agricultural areas and agriculture fields (Span. *chacras*) were taken, where Ashaninka people showed and described the use of medicinal plants. During the course of the fieldwork, 30 walks of this kind were made. Secondly, medicinal plants in 60 Ashaninka home gardens were catalogued. Thirdly, I interviewed 15 specialists/experts of Ashaninka traditional medicine: midwives, bone setters, shamans and steam-bath makers or other healers (*curanderos*). Other semi-structured interviews were conducted among lay Ashaninka and experts and concentrated on illnesses and forms of treatment, which could be useful for the analysis of health seeking behaviours. These interviews were complemented with talks with doctors (general practitioners and obstetricians) and nurses in each visited village/community. Altogether 90 adult Ashaninka people participated in the project (N respondents = 90): 60 women and 30 men, living in 10 different communities along the Tambo river. During the fieldwork, I lived with different families in communities sharing their daily routine. The chosen native communities were: Otica, Oviri, Anapate, Poyeni with its three hamlets: Shikapaja, Savareni and Selva Verde, then Vista Alegre, Capitiri, Charauaja, Shevoja, Marankiari and Chembo. They are situated along the Tambo river, a tributary of the Ucayali river, in the tropical Selva Central, Peru.

Herbarium specimens of each mentioned plant was collected – provided it was in a flowering or fruiting phase – then press-dried and deposited in the Herbario de San Marcos del Museo de Historia Natural (USM) in Lima. In the plant identification participated Joaquina Albán Castillo, our Peruvian collaborator. The permission for collecting herbarium specimens was granted by SERFOR, № 252-2017-SERFOR/DGGSPFFS. This permission also concerned the issue of conducting fieldwork among the Ashaninka people. In order to obtain it, the Ashaninka had to sign an informed consent form. The project itself did not go through any ethics commission either in Poland or in Peru, as the data were based on voluntary interviews with adults.

MEDICINAL LANDSCAPE OF THE ASHANINKA

I will refer to Ashaninka medicine interchangeably as indigenous or traditional medicine. The latter is a more formal version of the former one, recognized by international bodies, such as World Health Organization. Both indigenous and traditional medicine may be distinguished from biomedicine as autonomous, although likely to have incorporated certain practices from the Western medicine (Gold and Clapp 2011, 94).

For the Ashaninka people home medicine and the expert level of treatment are very much intertwined and rest on a shared ontological basis. The home sector of traditional medicine is a part of an egalitarian stream of knowledge and practice related to health prophylaxis and treatment. Home medicine implies the use of medicinal plants, animal parts, minerals, and magical practices, but not formulas/charms. Practices from expert spheres, like bone setting, massages and midwifery are also part of home medicine. The difference between these two sectors is not a total behavioural change but rather the extent and intensification of the performed healing treatment. However, shamans and steam bath makers have more knowledge and power than lay Ashaninka people to counteract the malevolent spirits (Ash. *kamari*) and evil caused by other people. A shaman (Ash. *sheripiari* – a tobacco eater) is a healer *par excellence* in this society. In reproductive health, the *sheripiari* plays a limited role. He may be consulted on when a couple cannot conceive a baby and sometimes a shaman is also approached during the pregnancy to recommend an adequate diet. Steam bath makers (Ash. *shipokantatsiri*; Span. *evaporadora*) are usually women who share some aspects of apprenticeship with shamans – especially months or even years spent on a special diet and observing sexual abstinence. Their role in reproductive health is minimal – pregnant women may be given steam-baths as a form of prophylaxis or to diagnose a certain health problems. Some women combine bone setting or massage with midwifery. In practically every community there are between one and three midwifes who help pregnant women and assist in the delivery. There exists a gradient between lay midwifes, who help women in their immediate surrounding and the capacitated ones – who are willing to serve the whole community. The Ashaninka midwifes do not keep accounts of the number of pregnant women they helped or the number of labours they assisted, but when asked of how many labours they had assisted the previous year, four to five childbirth were mentioned. This relatively low number can be explained by the fact that midwifery is a service that is free of charge, but not a full time job. Five midwifes I spoke to had attended at least one workshop with doctors, called *capacitación*. Training workshops have been organized by both international NGOs, such *Medicos sin Fronteras* or *Save the Children*, but also by the Peruvian Ministry of Health with financial help of Repsol YPF (a Spanish oil company) and by the *Centro Amazónico de Antropología y Aplicación Práctica* (CAAAP). Among the capacities gained during these workshops, Ashaninka midwifes enumerated: administering injections, checking of the fetus position, examination of the placenta, and general hygiene protocol. Post-workshop the midwifes introduced subtle modifications to their work, especially related to hygiene. However, these training sessions did not substantially influence their obstetrical knowledge and practice. Indeed, knowledge content of the workshops was secondary to what they learned through experience and from elderly women. Nonetheless, the interviewed midwifes were not disappointed with the courses and workshops. Rather, they felt that their abilities and knowledge had strengthened and had been legitimized through these events. They also felt that they could better understand the doctors' point of view.

As in other developing countries, Peruvian government has put in place biomedical systems not only because of their therapeutic worth but also in the name of social and economic advancement and development (Baer 2003). A similar idea, in the name of progress, have motivated Ashaninka leadership in obtaining funds for constructing adequate infrastructure and keep biomedical staff on their territory. There are three types of health centers (Span. *centro de salud*) along the Tambo river. Only three *centros de salud* have a category I–III, in Puerto Ocopa, Poyeni and Betania – the three largest Ashaninka communities. This means that there is one general practitioner there, one obstetrician, one dentist, several (five to eight) nurses and a laboratory technician. Most communities, however, merely have a I–II category health post (*posta de salud*), which means one obstetrician and two or three technicians and/or nurses. In the smallest communities and hamlets, which have fewer than 200 inhabitants, there is only one technician or health promoter, who has an access to a *botiquín* – a dispensary with free of charge basic medicines. A doctor pays a visit once a month to these smallest settlements. From this short description, it can be seen that the obstetrician is a privileged biomedical representative in indigenous communities. Their privileged position and high accessibility in indigenous communities stems from a World Health Organization (WHO) policy, which supported the attention given to pregnant women and small children in developing countries. This policy partly stems from the statistics – the Pan American Health Organization results from 1990s showed major inequalities in infant mortality and morbidity for indigenous peoples than for national societies. According to these estimates, the Ashaninka had an infant mortality rate of 99 per 1000 infants (Montenegro and Stephens 2006, 1863). Several decades after the implementation of the aforementioned policy, positive results can be seen. Viewed from the statistical point of view, the mortality of parturient women and small children has decreased in indigenous groups. On a local level, this policy brought a new agent into indigenous communities – doctor and nurses. On top of this, NGOs supporting indigenous medicine have counterbalanced the efforts of biomedical infrastructure installations in indigenous groups areas by strengthening the role of local health experts and reviving the use and management of medicinal plants. Such actions in Peru have been carried out since the 1990s by e.g. the *Asociación Interétnica de Desarrollo de la Selva Peruana* (Aidesep) amongst the Ashaninka, Yinnes and Shipibo (Montenegro and Stephens 2006, 1863).

REPRODUCTIVE HEALTH AND THE USE OF PLANTS

Plants are present in all spheres of the Ashaninkas' life. Their role and their healing properties stem from their position in an overall network of relations between humans and non-humans (see also Lenaerts 2006). The etic division between medicinal and non-medicinal plants should be treated more as an convention made for analytical purposes, rather than a reflection of these people reality. Medicinal plants are often linked to diet and food proscriptions and are used to counteract the malicious behaviour of many different kinds of insects. The latter, especially ants, are seen as troublemakers by the Ashaninka. Many etiological concepts of illnesses are built around malevolent insects. The widely held assumption is that when a husband or a wife has extramarital sexual relations, she/he becomes infected with "bugs" (*bichos*). Table 1 contains details about plant use in cases of partner infidelity, as well as information about plant *pusangas* – love potions related to love magic (see also Figure 1).

Figure 1. Leaves of *Xanthosoma* cf. *sagittifolium* which resemble vagina. The starchy tuber of this plant is used as a *pusanga* (photo: M. Kujawska).

A proper diet

Ashaninka people understand that the body is built through an adequate diet and physical activity. The idea of adequate food permeates the whole life of these people, a feature characteristic to other Amerindian groups, who have processual approach to becoming and being a person (e.g. Århem 1996; Rival 2002). Here I will just point to the diet and food proscriptions during gestation and childcare. Other food proscriptions relevant to Ashaninka reproductive health can be found in the Table 1.

Pregnant women put greater attention to food taboos than they do to a balanced diet, so promoted by nurses and teachers in recent years (starting from early age at school). Here it is important to introduce a Spanish term *cutipar*, which means to copy, gain or assimilate the characteristic of an other. In most cases these are animals and plants which can *cutipar*, i.e. a person gains the characteristic of a given species of animals or plants. Especially unborn children and infants are vulnerable to being *cutipado* (passive form of the verb *cutipar*) by animals and plants. The general idea is that a child will take the characteristic of fruit or animals, which his/her mother ate while being pregnant. Therefore, pregnant women, especially from the seventh month of gestation onward, are very careful with what they eat. Once I stayed with a couple whose youngest son had not starting walking by the age of four. According to the parents, that might have been due to the fact that his mother had eaten water turtle when she was pregnant with him. The parents seemed helpless and the child had not had any medical tests or shamanic examinations done. In this situation, manioc, plantains and some species of fish, which constitute food *par excellence,* is the safest food for pregnant women. However, some women get tempted by game meat, as well as prohibited kinds of fish or fruit, which they should avoid. For these occasions some women cultivate *ibenki* (*Cyperus* sp.) and *ibinishi* (mostly *Justicia* spp.) in their home gardens, and given to counteract the effects of the proscribed food. Both *ibenki* and *ibinishi* are generic names, in most cases they have their proper names (see Table 1). Forest plants are also consumed when a food proscription has been broken. Perinatal dietary and activity restrictions are mostly limited to a pregnant woman. Her husband may be involved, however, and they both perform couvade (see also Rival 1998).

Even more food and activity restrictions are put upon parents of a new-born child – most game animals and birds should be avoided. Even a simple activity, such as hunting in the forest may affect the baby, as the spirit of the child accompanies his father. For example there is a small black partridge, called *shianti* that when the parents eat it, it affects (*cutipa*) the baby. It makes the child cry, disturbs him/her, and the baby follows its voice. If parents break the diet, and eat this partridge there is a special forest plant, *shiantishi* (*Peperomia* sp.) to remedy the situation.

Birth control with plant agents

The Ashaninka get married when they have the capacity and the confidence to care for themselves and their families. Indeed, the desire to display this ability seem to be part of the reason for marrying (Killick 2009; 705). As in other Amazonian societies the main goal of a marriage is to have and raise children (Rival 2002; Cayón 2013). Through child rearing, real and lasting bonds between spouses are built. The average number of children in the families I worked with was 4.4, with a minimum of 1 (adopted) and a maximum of 12. Couples who have lots of children are the subject of gossip and disdain by their neighbours, who claim that children cannot have a suitably good upbringing in such families.

Ashaninka women have a number of ways to control the number and spacing of children by contraception and abortion and their practice includes the parallel use of natural (plant) and synthetic (biomedical) agents. For example, plants are used in order to delay ovulation and make a woman sterile for a period of time. In these cases, plants are always used at the end of the menstruation cycle. Several species were determined, which were claimed to be effective by the Ashaninka women (Table 1). Different authors, describing plant contraceptives used by the Amazonian groups, have taken different positions in deciding whether plants can be effective or not. According to Hern (1994), plants used by indigenous women are not effective – and the fact that these people have relatively few children is due to numerous periods of sexual restraint during their lives. In contrast, both Maxwell (1972) and Belaunde (1997) describe the "sacred plants" used for contraception by indigenous women from the Amazon. Maxwell supports their effectiveness, which is sustained by the women's testimonies, while Belaunde claims that no tests had been performed that could prove their effectiveness. Contrary to the description of Maxwell and Belaunde, the knowledge about contraceptive plants amongst the Ashaninka is not treated as secret or privileged. Apart from the previously mentioned *Cyperus* sp., whose compounds and properties are described below, the other identified plant used for this event is *Pseudelephantopus spiralis*. The only known activity of this species is antiplasmodial and antileishmanial (Girardi *et al.* 2015).

Voluntary miscarriage is also practiced and women talk about it discreetly yet openly. Women claim that plant abortifacients are effective when used in the very early stages of pregnancy because they are not very strong. When a woman finds out that she is pregnant later, she is normally afraid of inducing abortion by the means of plants, which may bring complications to her or to the fetus, and as a result, the child may be born with a defect. On the other hand, those women who cannot get pregnant visit shamans, and steam bath makers and take advice from elderly women. During our walks in the forest I recorded a few plants which were used to improve women's fertility. They are known under an umbrella name *bairontsiki*. *Tectaria incisa* and *Desmodium adscendens* are consumed in a way that a woman may choose the sex of the baby: When long leaves are ingested, it is for a boy (*chirampari*) and whereas round leaves will result in a girl being born (*tsinane*) (Figure 2).

Figure 2. Leaves of *ohoairontsiki* (*Tectaria incise*) used to improve women's fertility. They are consumed in a way that a woman may choose the sex of the baby: when long leaves are ingested, it is for a boy (*chirampari*) and whereas round leaves, it will result in a girl being born (*tsinane*) (photo: M. Kujawska).

Childbirth

Ashaninka women find out that they are pregnant when their menstruation does not appear. Other known symptoms are that the nipples become stiff and small, and some marks and spots appear on the face. If the woman wants to keep the baby, she carries on her daily routine.

Women use plants to facilitate the labour or to make it less painful. These plants are both wild species growing in the forest and cultivated in home gardens. Here, I will concentrate on the cultivated plants. The most frequently used ones are sedges (*Cyperus* spp.), known as *ibenki*, which have extremely diverse medicinal applications. These *ibenki* are used to accelerate labour contractions. According to phytochemical findings, this is not the plant itself that produces this effect, but a parasitical fungus found on it (*Balansia cyperi*) (Plowman *et al.* 1990). These fungi produce ergot alkaloids, which are most probably responsible for the medicinal properties ascribed to sedges by the Ashaninka. The highest concentration of the fungus is found on rhizomes, and this part is always used by the Ashaninka. It is either chewed, with the juice swallowed, or a decoction is prepared and drunk. Very similar use of *ivenkiki* has been reported among the Matsigenka, belonging to the same Arawak family (Shepard 1998). Another widely used species for soothing pains and accelerating labour is a perennial herb, with the generic name *ibinish* (*Justicia pectoralis*). It contains betaine, which is a non-specific anti-convulsive agent (Freed, Gillin and Wyatt 1979). The species contains secondary metabolites, such as coumarin and umbelliferone (Macrae and Towers 1984). At doses approaching toxic level, coumarin has a sedative and hypnotic effect (Macrae and Towers 1984: 107). These properties could explain the persistent use of *Justicia* spp. during labour.

FERTILITY CONTROL AND CHILDBIRTH FROM THE PERSPECTIVE OF PARALLEL SYSTEMS OF KNOWLEDGE

As was explained above, Ashaninka women use both plant and synthetic contraceptives. Young women seem to be more inclined towards the use of pills and vaccines than middle aged women. Obstetricians give contraceptive pills every month to young women, due to lower amount of hormones. Women in their late twenties and older may receive a vaccine every three months. Use of intrauterine devices (IUD) is never practiced and doctors explained that women carry heavy loads of manioc and logs, so it could move inside and as a result prove ineffective. While plant contraceptives are used openly, synthetic ones are used covertly, without the consent of a husband, who could be suspicious that his wife is cheating on him.

Ashaninka women reluctantly report vaginal infection to biomedical staff due to the widely shared concept, according to which there exist a direct relation between such infections and extramarital sexual relations. Therefore, women exclusively use medicinal plants for such events. Moreover, women avoid hand examinations by obstetrician as they are seen to be both painful and shameful.

According to obstetricians, women are more and more often visiting health posts or centers to take a pregnancy test. If they are pregnant, they are registered and they attend periodic check-ups. Pregnant women obtain mineral supplements, folic acid and vitamins free of charge from the health posts.

From the seventh month of pregnancy onwards a woman will start checking the position of the baby with the assistance of a midwife or an experienced woman in her family. Everybody is afraid of breech delivery – only the most skillful and experienced midwives are capable of assisting them. Nearly all births occur at home, with only a fraction being performed in a health center or a post where an obstetrician has a dedicated space for births. Caesarean delivery is never performed in any of the health centers of the Tambo river, due to a lack of proper sterile conditions. These centers are poorly equipped – ultrasound scans are never performed, neither are rudimentary blood tests. Obstetricians use a stethoscope and hands to examine the position of the fetus. Women do not want to be attended by obstetricians during labour because they reportedly "put their hands inside too much". However, some women do not mind if an obstetrician is present during the domestic delivery, albeit not as the main assistant, but rather as a watchful observer. The main assisting person is more likely to be the mother or a mother-in-law, husband or, in some cases, a midwife. Midwifes are called when they are part of a family or when a woman is left on her own and cannot be assisted by her family, or when she and her partner are inexperienced. Birthing is done in a vertical position and women support themselves with a pole or a rope. Normally the husband stays behind to physically support the woman. The Ashaninka, midwifes, or obstetricians do not make vaginal cuts, but when the vagina is broken, obstetricians or nurses will sew the stitches or, in their absence, a midwife will do so.

From the doctors and nurses' point of view, it is their duty to assist domestic childbirth; if they turn down a request and something goes wrong during the labour, they may be in trouble. Doctors and nurses are generally aware of the plants taken by the woman before the labour begins. Obstetricians claim that these plants are taken wrongly and make parturient women push when the aperture is just six or seven, and so they are already exhausted when the proper labour starts (when the aperture is ten). Therefore, on a declarative level, their aim is to correct the inadequate use of plants by the Ashaninka, not to discourage them from using plants.

From midwifes' point of view, the workshops they have participated in, along with their loose collaboration with biomedical staff in the community, have contributed to an increase in hygiene during labour. Midwifes can get alcohol and gloves from the health post. Once they are in a hut to attend the labour, they insist on using boiled water. Cotton strings used to wrap the naval are also boiled in water. My own findings stay in line with another piece of research performed in low technology birthway scenario in the neotropics (tropics of the New World), and indicate that the influence of biomedicine on midwifes does not substantially alter their obstetric knowledge and practice, which is deeply embedded within their hands-on experience (Sesia 1996).

RELATIONS OF POWER AND RESILIENCE OF ASHANINKA MEDICINE

Streams of legitimized knowledge

There is a clear distinction between Ashaninka and biomedical practice concerning birth control and childbirth. These two systems dispose of their own means and experts. Nonetheless, the Ashaninka women have a choice and they can pick practices from both systems which are convenient for them: some practices are resisted and others are welcomed. The Ashaninka system of knowledge has a greater legitimacy than biomedicine. It is empowered by the fact that the Ashaninka are on their own land and within their social milieu, where they speak their own language, and share their cosmovision and lifestyle. The Ashaninka not only outnumber biomedicinal staff in their communities, but they also make use of two sectors of knowledge transmission and exchange – an egalitarian stream of knowledge based on the recognition and use of medicinal plants, animal and mineral derives, as well as an expert level of knowledge confined to some individuals but based on a widely shared ontological basis. The required plant and animal resources are within easy access, in home gardens, fallow fields and in the forest. On the other hand, biomedical staff rely on only the expert level of knowledge, which may be transmitted in a limited space, i.e. in health posts and health centers. During home childbirth obstetricians and nurses may give limited advice and be of help, however the whole procedure of labour is managed by the Ashaninka.

Between community members and outsiders

The Ashaninka exhibit a double standard of behaviour and approach towards their own people and outsiders, respectively. They highly prize individual autonomy and harmonious social interactions, which often require curbing personal ambitions and resentments, as was observed in other Arawak societies (Izquierdo 2005). On the other hand, outsiders, represented in Ashaninka communities by teachers and biomedical staff, are approached with a demanding attitude. Although the social interactions with outsiders living in the community tend to be peaceful, nonetheless, the Ashaninka's effort focused towards obtaining measurable benefits from them. Outsiders, after all, are "goods bringers". This way of socialising with outsiders could be perfectly explained from an Amerindian perspectivism conceptual framework (Descola 2013). However, here I will limit my argument only to the possibilities of knowledge exchange and social interactions, as well as influencing other systems, without diving into the deeper motivations of the Ashaninka.

Ashaninka agency and sovereignty is strengthened during frequent community meetings and social gatherings, during which people discuss what is good and beneficial to them. Doctors and nurses are usually excluded from these social gatherings and are only occasionally invited to community meetings – always as an "external body". There exists a whole protocol which determines the rules of engagement between biomedical staff and the community. It is usually the *presidente de la salud* (health president) – a person chosen from the community, who acts as an intermediary between the community and the biomedical staff, to plan and organize health campaigns, vaccinations etc.

It is Ashaninka women and their families who decide whether the childbirth will be held at home or not, what kind of contraceptives to use, etc. In these circumstances, it is the obstetricians and nurses who must adapt to the situation to a greater extent than the Ashaninka do. Does the coexistence of two systems of knowledge related to family planning and childbirth lead to the biomedical practice becoming Ashanink

(Span. neologism *ashaninkar*) or does the Ashaninka way of doing things acquire a biomedical way of thinking? In my opinion neither occurs. Thanks to the presence of biomedicine in the Ashaninka communities the extent of choices has become greater. Biomedical knowledge, resources, and technology are added to the array of ethnomedical practices, but they do not change the underlying Ashaninka ontological basis. Some practices are omitted – especially hand examinations performed by obstetricians. On the other hand, biomedical staff cannot openly question people for their use of medicinal plants, and neither are midwifes criticized for doing so. Rather, their practices are corrected by placing greater concern on hygiene and people are encouraged to consult on their health problems at an early stage with doctors and nurses, not just with shamans and other experts. These findings are in line with the conclusions of Lenaerts concerning Asheninka ethnomedicine, that

> "[t]he borrowing process partially means going toward the Peruvian world (…). The result is a clear proximity to urban people, though keeping very clear indigenous features" (Lenaerts 2006).

Herbalism and midwifery – resilient practices

Herbalism and midwifery are two elements of the ethnomedical systems in Latin America which are recognized as compatible with biomedical thinking (Heckler 2007; Sesia 1996). According to Heckler (2007), the declining importance of shamanism amongst the Piaroa indigenous group from Venezuela has occurred in parallel to the promotion of herbalism by Christian missionaries and has subsequently been strengthened by biomedicine. Although, I have not conducted a longitudinal study on the use of medicinal plants amongst the Ashaninka, the whole discourse built around medicinal plants is striking. The Ashaninka want to promote their phytotherapy and plan to have a book published, one that would safeguard their intellectual property rights about medicinal plants, and which would bring healing oriented tourism. They thus want to capitalize on their "deep knowledge of plants", as recognized by mainstream western society. Yet at the same they do not express a similar willingness towards promoting their shamanism. There are only a few shamans still active along the whole Tambo river. On the other hand, knowledge of medicinal plants is prominent and complex. Plants are inexpensive, locally available, and embedded in Ashaninka cosmovision and are thus recognized as their own agents of treatment. My findings differ with those of Heckler in the sense that medicinal plants are not used to treat merely symptoms by the Ashaninka but very often, as was shown in this article, are intertwined with deeper ontological relations between humans and non-humans.

Therefore the persistent use of medicinal plants and midwifery are resilient practices – ones which are privileged by Ashaninka medical cosmology, and which at the same time are validated by biomedical practice, especially in the low technology contexts of indigenous communities.

CONCLUSIONS

The Ashaninka people operate within their own communal reserve and within their own autonomous communities, which create the conditions for the biomedical practice, which is characterized by low technological input in which doctors, obstetricians and nurses have limited options to exercise their practice. Ashaninka people do not see this as a major obstacle in interacting with biomedical staff. They simply want to maintain relations of power in which it is for them to decide how the methods of birth and birth control will be performed. They see biomedical obstetric practices as complementary to their own. The imposition of relations of power by the Ashaninka epitomises their resistance towards melting with general mainstream society, and their awareness of their distinct cultural features.

Midwifery and labour techniques are widely shared between lay Ashaninka women and expert midwifes. The use of plants is prominent and complex and permeates all spheres related to reproductive health. Although the Ashaninka may see midwifery and herbalism as a distinctive feature of their society, and one which is privileged by their medical cosmovision and supported by the long tradition of trial and error practice, in fact these aspects of their ethnomedicine are also compatible with, and hence validated by biomedicine, which sees them as complementary with their own practice. Perhaps, this is for this reason that the frictions and tensions between biomedical staff and the Ashaninka are almost invisible and oriented towards consensual rearrangements.

The Ashaninka seem a resilient society, one which is capable of "absorbing" novel biomedical knowledge, practices and technology within a complementary approach, while remaining within their boundaries and preserving their specific features. Ashaninka birthways and birth control cope with the presence of biomedicine and with the changes it introduces: the Ashaninka are learning and selectively transforming.

Table 1. Medicinal plants used in reproductive health by Ashaninka people from the Tambo river valley.

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Alternanthera sp. Amaranthaceae, [MK482]	similar to ibinishi	Childcare	When a child cries; this is caused by parents consuming game, which affects the baby	The child is bathed in a decoction of leaves	herb	cultivated in home garden
Amaryllidaceae sp.	cebolla niro	Partner's fidelity	*Pusanga* for women. It makes the pubic mound nice and round. It is used by both girls and adult women.	The plant is grated and placed on the pubis	herb	cultivated in home garden
Aphelandra aurantiaca Lindl. Acanthaceae [MK454]	tsorishi [leaf of *paucar*]	Childcare	When a child cries; this is caused by the parents consuming *paucar* (*Cacius cela*) meat	The father searches for leaves and brings them to his wife. She baths the baby in a decoction of leaves	herb	secondary forest
Bignoniaceae sp.	timakorentsishi [leaf of a childbirth]	Childbirth	To accelerate the labor. This helps when the woman does not take care of herself and, for example, eats shapaja (*Attalea phalerata*), this increases pains and delays the labor	A sweet tuber is eaten	perennial herb	cultivated in home garden
Bignoniaceae sp. [MK445]	emotsanki	Childcare	The symptom is a sound coming from the child's belly, due to intestinal parasites. The cause is the infidelity of one of the parents. Bugs (*bichos*) enter the partner when one of the parents has extramarital sex. The parasites are then transmitted to the child	A root is chewed and juices are released, which are passed to the child's mouth	herb	fallow fields

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Brunfelsia grandiflora D. Don, Solanaceae [MK465]	chirisanango	Menarche	This is used during the menarche, induces vomiting	A root is ingested, which produces vomiting	shrub	cultivated in home garden
Bryophyllum pinnatum (Lam.) Oken Crassulaceae, [MK451]	banteshi, siempreviva	Postpartum	A women will take this during after birth in order not to lose too much weight	A decoction of leaves is drunk	succulent herb	protected in home garden
Centropogon cornutus (L.) Druce Campanulaceae, [MK466]	tsomitsishi	Childcare	Used for the weaning of the baby	The water of the flower is placed on the nipple and the milk is no longer sweet	herb	ruderal
Chromolaena laevigata (Lam.) R. M. King & H. Rob, Asteraceae [MK368]		Postpartum	When a woman gets a chill and fever after childbirth	Leaves are used in a bath	shrub	ruderal
Costus sp. Costaceae	caro	Childcare	Galactagogue	The liquid from stems is ingested; the stems are also used in form of a cataplasm on the breast	succulent herb	fallow fields
Cyperus sp. Cyperaceae	irajantsibenki [herb of menstrual blood]	Menstruation	When a woman is menstruating and eats game brought by her husband – this leads to the husband having bad luck when hunting	The woman cures her husband's shotgun by spitting a chewed rhizome on the cannon	perennial herb	cultivated in home garden

Botanical name	Ashaninka name	Category of use	Use	Preparation	Life form	Habitat
Cyperus sp. Cyperaceae	itonkibenki [bone herb]	Pregnancy	When a woman does not stick to a diet during pregnancy and eats every kind of food	Rhizomes are boiled and taken as an infusion	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	shiobana	Childcare	When a child already has teeth, approx. 15th months, weaning starts	The mother passes a chewed rhizome into the child's mouth	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	ibenki	Menstruation	When a woman eats a wild bird during menstruation	The woman chews rhizomes and spits them onto the hands of her husband	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	atsanontsibenki	Childcare	Chest hoarseness and a cough that affects a child when one of the parents has had extramarital sexual relations	A rhizome is chewed and put straight into the child's mouth	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	shiobana	Contraception	Contraceptive	A rhizome is crushed and cooked, red water comes out like blood, and it is taken at dawn. One must diet as well: the woman is not allowed to eat salt, chili, pineapple – or sweet food in general, because the blood can follow suit. After three months the woman has to take it again. It is usually taken with the first menstruation after the childbirth and continues to be taken until the woman wants to have another child	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	atsanantsibenki [herb of egoism]	Childcare	Chest hoarseness and cough that affects a child when one of the parents has extramarital sexual relations	The unfaithful parent chews the rhizome and puts it into the child's mouth	perennial herb	cultivated in home garden

Botanical name	Ashaninka name	Category of use	Use	Preparation	Life form	Habitat
Cyperus sp. Cyperaceae	emokibenki [herb of *suri* – edible larvae]	Childbirth	When a woman cannot give birth because she is *cutipada* – affected by what she had eaten – she takes it before the labor	Rhizomes are cooked and taken in infusion	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	irajantsibenki	Menstruation	Against excessive blood flow during menstruation	Rhizomes are crushed and drunk with water during menstruation	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	ibenki	Menstruation	When a woman is menstruating and eats game, it may bring bad luck to her husband when hunting. Thus, when a woman is menstruating she should not eat meat from a person other than her husband, because she can cure her husband, but she cannot cure another person	The wife spits chewed rhizomes on her husband's hands and elbows and on his shotgun	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	shiobana	Woman's fertility	Woman's sterilization	It is chewed at the beginning of menstruation and is repeated with every following menstruation	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	bairontsibenki	Woman's fertility	To improve fertility	Rhizomes are chewed and mixed with other plants from the forest. It can be done during or outside of menstruation	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	atsarentsibenki	Childbirth	To accelerate labor. When a woman eats certain game or fruit it can affect the fetus (*cutipar*) and thus the parturient woman has problems when giving birth	A rhizome is chewed and eaten	perennial herb	cultivated in home garden

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Cyperus sp. Cyperaceae	ibenki	Pregnancy	For a pregnant woman, when she likes to eat game. Eating meat with bone can affect (*cutipar*) a pregnant woman	A rhizome is chewed and the juice is ingested	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	tsomontebenki [herb of pregnancy]	Childbirth	To ease pain during labor	The husband, who assists the labor, chews a rhizome and spits it on the back of his wife	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	ibenki	Menstruation	When a man becomes unlucky at fishing. This occurs because his wife has eaten fish during her menstruation	The wife chews rhizomes and spits on the fishing net. It is left for a week without any use. After this period the man can go fishing again	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	manonkabenki	Menstruation	When a man becomes unlucky when hunting. This is because his wife has eaten game during her menstruation	A man takes rhizomes to the forest and he chews them. He then spits it into his hands and blows it into the air	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	atsarentsibenki	Childbirth	When the labor is painful and difficult, which is due to the pregnant woman's lack of dieting as well as eating different kinds of meat and fruit	A bath with rhizomes is prepared for the parturient woman; when the resource is scarce an infusion is taken instead	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	aimentantsipini	Childcare	Chest hoarseness and cough that affects a child when one of the parents has extramarital sexual relations	A rhizome is chewed and passed directly into the child's mouth	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	ibenki	Extramarital sex relations	A symptom is a pulsing navel; the cause is extramarital sexual relation of one of the spouses, a bug penetrates his/her body	A rhizome is chewed and the juice is ingested	perennial herb	cultivated in home garden

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Cyperus sp. Cyperaceae	atsanatsibenki	Childcare	Chest hoarseness and cough that affects a child when one of the parents has extramarital sexual relations	A rhizome is chewed and passed directly to the child's mouth	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	bairontsibenki	Woman's fertility	To improve fertility	Three rhizome are cooked and mixed with honey, pollen and a herb that has a tuber [Bignoniaceae]. The mixture is placed in a bottle. The bottle is buried in the middle of the path. After 3 days it is dug up. It is taken daily when menstruation is about to end. One must avoid having sex for a month	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	shiobana, eiroabantatsi [„not to have children"]	Contraception	Contraceptive	Given to a girl during the menarche. Three or four cooked rhizomes are taken. A forest plant is admixed to it. This potion produces sterility for several years	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	motitsibenki [herb of a pregnant woman]	Childbirth	To accelerate the labor and ease pain	Rhizomes are crushed and rubbed on the belly of the parturient woman. It is mixed with a companion plant – ibinishi [*Justicia* sp.]	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	timakorentsibenki [herb of the labour]	Childbirth	When a baby is about to be born, this plant is for the husband who accompanies the labor	The husband chews rhizomes and spits on the head and spine of his wife before assisting her labor	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	irajantsibenki	Childbirth	Against hemorrhage	After labor, the parturient woman is bathed in rhizomes	perennial herb	cultivated in home garden

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Cyperus sp. Cyperaceae	pirijabenki [herb of dryness]	Contraception	Contraceptive. When a woman takes this plant, she becomes sterile. She will have menstruation but she will not fall pregnant again	A decoction of rhizomes is taken when menstruation is about to finish	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	atsorentsibenki [dilator herb]	Childbirth	To accelerate the labor. The problem with giving birth and the accompanying pain may be caused by the lack of diet during the pregnancy	A decoction of rhizomes is drunk by the parturient woman just before labor	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	ibenki [*intimantiari intsipaite* – to accelerate the labor]	Childbirth	To accelerate labor	Rhizomes are crushed and chewed, and the juice is then ingested	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	irajantsibenki [herb of menstrual blood]	Menstruation	When the wife is menstruating and eats the meat her husband has hunted with a shotgun, when he returns to the forest he will have no luck hunting. When a woman has a small baby, it can also affect her husband's luck in hunting	When the man goes to the forest and does not hunt, he goes back to his house and tells his wife – she then excavates the rhizomes, crushes them and spits them on his hands and elbows	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae	timakorentsibenki [„for a child to be born"; herb of childbirth]	Childbirth	When the parturient woman already has labor pains; used to accelerate the labor	Rhizomes are crushed and put on the head of the parturient woman	perennial herb	cultivated in home garden

Botanical name	Ashaninka name	Category of use	Use	Preparation	Life form	Habitat
Cyperus sp. Cyperaceae	atsarentsibenki	Childbirth	To accelerate labor	Rhizomes are taken in a decoction	perennial herb	cultivated in home garden
Cyperus sp. Cyperaceae [MK404]	charijabenki [herb of a fishing net]	Menstruation	When a menstruating wife eats fish, her husband will be unlucky when fishing	The wife chews rhizomes and spits on her husband's fishing net	perennial herb	cultivated in home garden
Desmodium adscendens (Sw.) DC. Fabaceae, [MK481]	tsireiroki	Woman's fertility	When a woman wants to choose whether she is going to have a son or a daughter – it influences the sex of the baby	Many leaves are chosen: the long ones for a boy and round ones for a girl. They are cooked and taken when menstruation is about to end.	herb	ruderal
Desmodium adscendens (Sw.) DC. Fabaceae, [MK481]	tsireiroki	Partner's fidelity	For a woman who suspects that her husband wants to leave her	The woman takes a bath in the evening without her husband seeing, they then have sex	herb	ruderal
Dichorisandra ulei J. F. Macbr. Commelinaceae, [JS168]	bairontsiki	Woman's fertility	To improve fertility	A root is cooked and drunk	herb	ruderal
Dracontium plowmanii G. H. Zhu & Croat Araceae, [JS142]	ponto, marankianto	Woman's health problem	Ovarian cancer	A root is crushed (it resembles placenta), it is left outdoors for a night and drunk in the morning for a fortnight	herb	secondary forest

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Elephantopus mollis Kunth Asteraceae, [MK395]	jetorishi [spider leaf]	Partner's fidelity	When one of the spouses has extramarital sexual relations, the other person transmits bugs (*bichos*) to the person's body. A man passes bugs similar to tiny *carachama*s fish (*Pseudorinelepis genibarbis*) into his urine.	A decoction of roots is drunk	herb	ruderal
Fridericia florida (DC.) L. G. Lohmann Bignoniaceae [JS160]	tampishiri, clavowasca	Man's sexual potency	Male sexual potency	A bark is grated and macerated in alcohol, then drunk	liana	fallow fields
Gossypium sp. Malvaceae	algodón rojo	Childbirth	Taken to counteract hemorrhaging during labor or caused by abortion	Rhizomes are cooked, together with *achote* leaves (*Bixa orellana*) and drunk	small tree	cultivated in home garden
Justicia aff. *rauhii* Wassh. Acanthaceae [MK433]	aimentantsishi	Childcare	Chest hoarseness and cough that affects a child when one of the parents has extramarital sexual relations	A decoction of leaves is given to the child	herb	secondary forest
Justicia comata (L.) Lam Acanthaceae [MK448]	tsimerishi [leaf of the night]	Childcare	Used when the father goes hunting in the forest, so a child does not cry	When a child is born, he/she is bathed in the decoction with leaves	perennial herb	cultivated in home garden

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Justicia pectoralis Jacq. Acanthaceae, [MK417]	emokishi [leaf of *suri* – adible larvae]	Childbirth	Taken to counteract labor pains which may be due to the fact that during pregnancy a woman didn't stick to a diet and she has been affected (*cutipada*) by game or fruit she ate	Leaves are drunk in an infusion with *emokibenki* (*Cyperus* sp.)	perennial herb	cultivated in home garden
Justicia polygonoides Kunth Acanthaceae [MK450]	karentsashi	Pregnancy	For a pregnant woman; what the pregnant woman eats can affect a fetus. By ingesting this plants she can omit proscriptions	The woman takes it daily in form of infusion from the fourth month of pregnancy	herb	cultivated in home garden
Justicia sp. Acanthaceae	atsarentsipini	Childbirth	To counteract labor pains	An infusion of leaves is drunk	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	ibinishi	Partner's fidelity	This plant is used as a *pusanga*, when the husband has a lover. It makes him return to his wife.	The wife prepares a bath in decoction of leaves, she also places some leaves on her husband pillow. After bathing, she should have sex with her husband straight away	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	ibanteshi [mouth leaf]	Childbirth	To stretch the vagina, in order to facilitate the labor. It is used when the labor starts	Infusion of leaves is drunk	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	tonkamentontsishi [shotgun leaf]	Menstruation	Used when a woman in the household (wife or daughter) is menstruating and eats game	Chewed leaves are spat into the hollow of the barrel of the shotgun	perennial herb	cultivated in home garden

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Justicia sp. Acanthaceae	atsarentsishi	Childbirth	It helps the placenta to come out in one piece	A leaf decoction is given to a woman in labor. When the woman takes it, the placenta is expelled fast. It is only given when placenta does not come out easily. This happens when the woman eats rice, *suri*, fruit – *caimito*, or coconut. The fruit peel or *suri* which affected the woman must be cooked together with leaves of *atsarentsishi*. This may be replaced by *malva* (*Malachra alceifolia*) or green cocoa – they contain phlegm	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	tsimerishi [leaf of the night]	Childcare	It is used when a child is affected (*cutipado*) by what his parents eat. He/she then cries	The child is bathed in a decoction of leaves	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	atsarentsishi [„so as the baby is born"]	Childbirth	To accelerate labor and ease the pain	An infusion of leaves is drunk together with *malva* (*Malachra alceifolia*); it can be taken early in a pregnancy	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	ampeakotantiari [„to forget"]	Partner's fidelity	When a man or woman leaves his/her partner, to forget about this person, not to suffer.	Leaves are squeezed in hands, the juice is released and put in eyes	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	charijashi [fish leaf]	Pregnancy	When a women is pregnant and she is affected (*cutipada*) by the fish she has eaten	The woman's belly is rubbed and washed	perennial herb	cultivated in home garden
Justicia sp. Acanthaceae	jananikishi [baby leaf]	Childcare	When a father denies a child is his	When the baby is bathed in a decoction of leaves, the father will return and stay with his wife and a child	perennial herb	cultivated in home garden

Botanical name	Ashaninka name	Category of use	Use	Preparation	Life form	Habitat
Justicia sp. Acanthaceae	atsarentsishi [according to Antonio is cloth leaf]	Childbirth	To accelerate labor and ease the pain	An infusion of leaves is drunk together with *ivenki* (*Cyperus* sp.)	perennial herb	cultivated in home garden
Lantana trifolia L. Verbenaceae, [MK484]	orégano	Woman's health problem	Menstrual pain	Infusion of leaves is drunk	aromatic shrub	protected in home garden
Malachra alceifolia Jacq. Malvaceae, [JS164]	malva	Childbirth	To ease labor and pains	Taken daily, before childbirth; leaves are soaked in cold water. The leaves contain a lot of phlegm	shrub	cultivated in home garden
Malachra alceifolia Jacq. Malvaceae, [JS164]	malva	Childbirth	To make the placenta come out entirely	A decoction of leaves and flower is drunk	shrub	cultivated in home garden
Mangifera indica L., Anacardiaceae	mango	Postpartum	Postpartum, when a woman gets a chill and fever after childbirth	Mango leaves are macerated in water with palta (*Persea americana*) leaves and rhizomes of ginger (*Zingiber officinale*)	tree	cultivated in home garden
Marcgravia sp., Marcgraviaceae [JS162]	shironitsanke	Partner's fidelity	It seems that the illness "eats" the person from inside. This is because one of the spouses has had extramarital sexual relations and the other person transmits a bug. The person has an itching sensation all over the body	A decoction of leaves is drunk	climbing fern	secondary forest

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Orchidaceae sp.	bairontsiki	Woman's fertility	To improve fertility	The stems are crushed and drunk with water at the end of menstruation. A long stem is ingested for a boy (*chirampari*), and a round one is ingested for a girl (*tsinane*)	epiphyte herb	transplant from the forest to home garden
Palicourea sp., Rubiaceae, [MK423]	panabashi [*panaba* – a kind of partridge]	Childcare	When parents eat game it affects the child and he/she cries at night	The child is bathed in a decoction of leaves	herb	secondary forest
Pariana bicolor Tutin, Poaceae, [JS172]	tabankirishi	Childcare	Healing of the baby's navel	Leaves are burned and turned into ash, then thrown over the navel, which then dries and heals	herb	ruderal
*Peperomia pilos*a Ruiz & Pav. Piperaceae, [MK438]	totsishi	Woman's health problem	Vaginal infection and itching	The vagina is washed with a decoction of leaves	herb	fallow fields
Peperomia rotundifolia (L.) Kunth, Piperaceae, [JS123]	pashitotsanke [tick plant]	Venereal disease	Venereal disease	The entire plant is cooked and drunk	climber herb	secondary forest
Peperomia sp., Piperaceae [MK415]	shiantishi [leaf of a black partridge]	Childcare	When the parents eat it a small partridge (*eritoki*), this affects (*cutipa*) the baby. It makes him/her cry and the child refuses to eat; the partridge disturbs the child and the baby follows the bird's voice	A child is bathed in a decoction of leaves	herb	secondary forest

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Polygala spectabilis DC. Polygalaceae, [MK480]	tsavitsipentaki [vagina]	Partner's fidelity	Swelling and irritation in the vagina, due to a woman's extramarital sexual relations	The vagina is washed with a decoction of leaves	herb	fallow fields
Polygala spectabilis DC., Polygalaceae [MK355]	tsavitsishi [vagina's leaf]	Childcare	When a new born baby has green diarrhea; this is caused the relationship between parents. The green-black stool is the rest of the semen of the male	Leaf juice is put to the new born baby's mouth	subshrub	fallow fields
Pseudelephantopus spiralis (Less.) Cronquist, Asteraceae [JS185]	ineneshiotsiti [leaf of dog's tongue]	Contraception	Contraceptive	Five leaves, together with *chupa-sangre* (cf. *Amaranthus spinosus*) are taken in an infusion one day before the end of menstruation. This postpones the menstruation for three months. It can be repeated every three months.	herb	ruderal
Psychotria poeppigiana Müll. Arg., Rubiaceae [JS122]	sharonishi [leaf of a partridge *sharoni*]	Woman's health problem	Breast wounds	Leaf juice is put on the breast	shrub	secondary forest
Rubiaceae sp. [MK474]	intishi	Partner's fidelity	When one is unfaithful to their partner, a bug penetrates their ear. It is used to remove this bug, which produces itching	It has a tuber inside, which is removed, grated, wrapped in cotton and placed in the ear. This is done at night. Only a small amount is used because the tuber is itchy	shrub	fallow fields

Botanical name	Ashaninka name	Category of use	Use	Preparation	Life form	Habitat
Ruellia cf. caroliniensis (J. F. Gmel.) Steud., Acanthaceae [MK389]	eritokishi [leaf of one kind of partridge]	Childcare	When the parents eat it a small partridge (*eritoki*), this affects (*cutipa*) the baby. It makes him/her cry and the child refuses to eat; the partridge disturbs the child and the baby follows the bird's voice	A child is bathed in the decoction of leaves	shrub	transplant from the forest to home garden
Sabicea villosa Willd. ex Schult. Rubiaceae, [MK479]	shiopaitoki [a fruit of *shiopa* – an edible larva]	Partner's fidelity	When a person has extramarital sexual relations a bug can penetrate the skull – one feels as if something were entering his/her head. However, it is only a sensation, because nothing can be seen	The head is washed with an infusion of leaves	climbing herb	fallow fields
Scleria melaleuca Rchb. ex Schltdl. & Cham., Cyperaceae [JS121]	imerishi	Abortion	Abortive plant, its use can cause tumors	Its use is not recommended by the Ashaninka women	herb	secondary forest
Solanum acuminatum Ruiz & Pav., Solanaceae [MK400]	akajeniantoke [itch]	Partner's fidelity	When the vagina is irritated due to extramarital sexual relations	A decoction of leaves is used to wash the vagina	small tree	protected in home garden
Stachytarpheta cayennensis (Rich.) Vahl, Verbenaceae [MK472]	tsivetashi [leaf of rayfish]	Childbirth	To accelerate labor	A decoction of leaves is drunk	subshrub	fallows

Botanical name	**Ashaninka name**	**Category of use**	**Use**	**Preparation**	**Life form**	**Habitat**
Tectaria incisa Cav., Tectariaceae [JS134]	bairontsiki	Woman's fertility	To improve fertility	Leaves are chewed and juice is ingested. Long leaves are ingested for a boy (*chirampari*), and a round ones are ingested for a girl (*tsinane*)	fern	secondary forest
Tetrathylacium macrophyllum Poepp., Salicaceae [JS157]	muitontsishi	Childcare	To heal the new born child's navel	The grated root is placed on the navel	tree	fallows
Vernonanthura patens Asteraceae (unresolved name) [MK388]	pijoro	Abortion	To protect the fetus, against miscarriage	The heart of the trunk is scraped and mixed with the liana to make baskets. Four knots are cut [where the interval is shorter], cooked and taken until the woman no longer has pains	shrub	ruderal
Xanthosoma cf. *sagittifolium* Araceae	falsa pituca / tipo cajento	Partner's fidelity	This is a special *pusnaga* for women. It is used in order to keep the husband, so as he never becomes interested in other women	A root (tuber) is scraped, cooked and the intimate parts are washed. A talc can also be made and placed into the vagina before the sexual intercourse	herb	cultivated in home garden

Legend: Initials MK and JS stand for Monika Kujawska and Joanna Sosnowska, respectively. The numbers which follow show the position in the botanical collection of each of the researchers.

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List of table and figure captions

Figure 1. Leaves of *Xanthosoma* cf. s*agittifolium* which resemble vagina. The starchy tuber of this plant is used as a *pusanga* (photo: M. Kujawska).

Figure 2. Leaves of *ohoairontsiki* (*Tectaria incise*) used to improve women's fertility. They are consumed in a way that a woman may choose the sex of the baby: when long leaves are ingested, it is for a boy (*chirampari*) and whereas round leaves, it will result in a girl being born (*tsinane*) (photo: M. Kujawska).

Table 1. Medicinal plants used in reproductive health by Ashaninka people from the Tambo river valley.

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POLISH ROMA MIGRATIONS – TRANSNATIONALISM AND IDENTITY IN ANTHROPOLOGICAL PERSPECTIVE

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Until recently, the migration of Polish Roma has not been a subject of an academic inquiry. This article aim is to shed light on some issues related to transnational living and identity of Polish Roma in anthropological perspective[1]. The findings of our research suggest that Roma migrations from Poland are not categorically different from non-Roma population and in fact are integral and socially connected part of history of migrations from Poland on local and national level, determined by same processes of structural forces rendering people to seek opportunities abroad. Our study has demonstrated how crucial and important is for Polish Roma their connection to Poland – on social, personal, cultural and economic level. This calls for a more careful and nuanced approach in future research to Polish Roma identity seen in relational terms. Finally, our article calls for a need to a more ethically informed research with the Roma whose Polish identity needs to be recognized in its own right, in particular in migratory context. This means also few policy recommendations that we offer at the end of the article.

* * *

Do niedawna migracja polskich Romów nie była przedmiotem badań naukowych, stąd też celem tego artykułu jest rzucenie światła na niektóre kwestie związane z ich transnarodowym życiem i tożsamością w perspektywie antropologicznej. Wyniki naszych badań sugerują, że migracje Romów z Polski nie różnią się zasadniczo od migracji ludności nieromskiej i w rzeczywistości stanowią integralną i społecznie powiązaną część historii migracji z Polski na poziomie lokalnym i krajowym, zdeterminowaną przez te same warunki strukturalne, które motywują ludzi do wyjazdów za granicę. Nasze badanie

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[1] Founding source: Polonez NCN "Continuity or change – Anthropological analysis of Polish Roma migration paths to Great Britain", grant No. 2015/19/P/HS6/04125. The project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 665778.

pokazało, jak ważna dla polskich Romów jest ich łączność z Polską – na poziomie społecznym, osobistym, kulturowym i gospodarczym. Wymaga to ostrożniejszego i bardziej zniuansowanego podejścia do przyszłych badań nad polską tożsamością Romów. Wreszcie, nasz artykuł wzywa do potrzeby bardziej świadomych etycznie badań z udziałem Romów, których polska tożsamość nie może być kwestionowana, w szczególności w kontekście migracji. Oznacza to również kilka rekomendacji w tym obszarze, które proponujemy na końcu artykułu.

Keywords: Roma migration, transnationalism, identity, Polish Roma, ethics

INTRODUCTION

This article presents some findings from a research project which explored international migration of Polish Roma since 1989. For many observers it may come as a surprise that a group stereotypically associated with mobility and nomadic lifestyle has never been the subject of interest from Polish migration scholars. Also, despite its rich traditions, the Polish Romani studies never looked at the issue. We explore the reasons behind that academic discursive silencing of Roma mobility elsewhere (Fiałkowska, Garapich, Mirga-Wójtowicz 2018) aiming at bringing together two strands of scholarship together – migration studies and Romani studies. This article continues this attempt but through a more empirically and ethnographically grounded argument on the need to frame Polish Roma migration culture, their agency and structural determinants governing their mobility as part of broader processes of migration from Poland. In consequence, Roma are brought from the outside or periphery of Polish social sciences to its core.

The study looked at international migration of Polish Roma from perspective of social anthropology with elements of social history. Since that area has never been systematically studied, the main aim was to fill this scholarly gap both in migration and Romani studies as well as to contextualize these migrations as part of overall international mobility from Poland post-1989. The gap in scholarship is particularly surprising since European scholars in the last decade produced an array of studies of migration of Roma within the EU with a notable silence on Roma from Poland. We aimed therefore to construct a picture of Polish Roma migration from selected localities since 1989 and capture similarities and differences between various groups of Roma under study as well as between them and their non-Roma (Gadjo) neighbours. Inevitably the research questions were broad, further specified during fieldwork. We were then focusing on issues traditionally explored in migration research such as: when and why did Roma begin to migrate? Are the reasons the same as non-Roma inhabitants of these towns? How migrations impact Roma communities in terms of shifts and changes in their identity, perception of the outside world and Roma culture?

At the same time we aimed at looking into the other end of migration process and chose Great Britain – where according to very few publications on the issue (Acton and

Ingmire 2012; Staniewicz 2011) Roma from Poland move since mid-90s (apart from other destinations, such as Ireland, Germany or Canada). We aimed also at analysing what is the impact of living in Britain on Roma culture, tradition, family relationship but also what can be said about their relationship with other groups they encounter during their migration trajectory – other groups of Polish Roma, Roma from other countries and other ethnic minorities.

Broadly speaking the study aimed at conceptualizing Roma as a transnational community which over long period of time has dealt with various structural and political factors such as collapse of the Berlin Wall, European integration, post EU enlargements intensification of intra-EU mobility. The aim was to determine how these impact on Roma communities, their life strategies and perceptions of the world. In this case, the concept of transnationalism is understood as a multi-layered "double orientation" of immigrants (Vertovec 2004, 970) resulting from the fact that communities, groups, families and individual lives span more than one nation states (Glick Shiller *et al.* 2004). A more precise and empirically viable concept of translocal connection is suggested and used by Anne White in her studies on migration from Poland (2011, 2014), pointing to the fact that migrants through their lives connect two specific localities, towns, villages rather than abstract nation–states. In this report both concepts are used depending on what aspect of life strategies of respondents needs to be emphasized.

Our key arguments in this article stem from the broad aim to link two abovementioned so far separate fields of Polish scholarship. The findings of our research point first, to the fact that Roma migrations from Poland are not categorically different and "exotic" linked with their alleged nomadic past, but are an integral and socially connected part of history of migrations from Poland on local and national level, determined by same processes of structural forces rendering people to seek opportunities abroad in the context of communist system in Poland as well as post 1989 political and economic transformations. Second, the article argues for a more careful and nuanced approach to Polish Roma identity seen in relational terms. Our study has demonstrated how crucial and important is for Polish Roma their connection to Poland – on social, personal, cultural and economic level. Third, our article calls for a need to a more ethically informed research with the Roma whose Polish identity needs to be recognized in its own right, in particular in migratory context. This means also few policy recommendations that we offer at the end of the article.

FIELD SITES AND FIELDWORK

Fieldwork was placed in broadly taken transnational social fields, understood here as transnationally or translocaly woven social networks between people living in two or more nation states who are linked through family or friendship connections with one locality in country of origin in Poland and Great Britain. It involved five locations: Czarna Góra, Kraków-Nowa Huta, Mława, London and Southend on Sea, in Essex and corresponded with taking into account two of the largest groups of the Polish Roma – Polska Roma (Mława) and Bergitka (Czarna Góra, Nowa Huta) – and what was known about destination localities from few publications about the issue (Acton and Ingmire 2012; Staniewicz 2011). The choice of Mława in addition was related to a significant analysis of Roma community there in the aftermath of the anti-Roma riots in 1991 (Giza-Poleszczuk and Poleszczuk 2001).

In line with any research involving transnational migrants we aimed at meeting and talking to members of families living in two countries. Overall we managed to capture lives of migrants at several stages of their transnational migration trajectories in all locations involved, but in addition, due to instances of inter-group intermarriages we managed to interview also people from the Chaładytka group and also Roma from towns like Krosno, Szczecin or the Lower Silesia region. This proved to be very beneficial enabling to some extent to extrapolate some findings from the locations in question to other places were Roma in Poland seem to undergo similar processes.

Research was conducted using a range of ethnographic methods – participant observations, non-structured interviews, group interviews, spending long periods of time with families involved in research, living in their proximity, participation in family events or rituals (like christening or funeral) and public community rituals (like the commemoration of Roma genocide by the Nazis[2], or yearly pilgrimage in Limanowa[3]), diners, parties or music concerts. Given the transnational dimension of our study, it fitted a popular in migration studies method of multi-sited ethnography (Marcus, 1995) also used among the Roma (cf. Grill 2011). This methodological approach aims at tracing people, ideas, norms, practices through space and time and to map their interconnectedness, interdependence and meaning for individuals and groups. In migration research, typically it involves ethnographic observations and interviews carried out at all stages of migration chain, with people who are mobile, non-mobile, migrants, returnees, second generation and/or independent observers. Our fieldwork was continuous without a clear end and throughout our study we maintained constant contact with several key respondents with whom we shared information, gossip, opinions and family news. With these people we carried out repeated interviews which allowed us to constantly keep track of dynamic developments happening in front of our eyes, which we account in this report (in particular when it comes to intergroup

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[2] International Romani Caravan of Memory [Międzynarodowy Tabor Pamięci] is organized since 1996 r. by the Muzeum Okręgowe w Tarnowie i Kulturalno-Społeczne Stowarzyszenie Romów w Tarnowie: http://romopedia.pl/index.php?title=Mi%C4%99dzynarodowy_Tabor_Pami%C4%99ci_Rom%C3%B3w, access: 20.10.2018.

[3] Pilgrimage in Limanowa is organized since 30 years by Rev. Stanisław Opocki, Krajowy Duszpasterz Romów: https://tarnow.gosc.pl/doc/4192610.Taborem-do-Matki, access: 20.10.2018.

relations or religious conversions). In total we interviewed 80 people, although we have met and talked to many more. On top of these, we also carried out twelve expert interviews with a selection of people who due to their work or engagement with Roma had a specific insight helping us to understand processes at hand. These were for example: a local priest, former diplomat, expert on Roma issues, artist, journalist, member of Jehovah Witness congregation, local government official, or NGOs members. An archival search was also conducted at the Polish Ministry of Foreign Affairs and at the unique collection of Polish newspapers articles kept at the Ethnographic Museum in Tarnów. Social media are very popular among Roma of all ages, so its content was constantly monitored and observed.

Roma historical experience makes them sometimes suspicious of attempts to gather information by the Gadjo (non-Roma). In the past, this information was often used against them, to further oppressive state policies, surveillance practices of the police or racialized practices of identification, which in case of Nazi polices was used for genocidal purposes. The scale of refusal to our request for meetings and interviewing did not surprise us. We aimed at maximizing the participatory principle of our ethnography, where it was the respondent's decision over the course and content of the interview, which was inevitably unstructured and spontaneously sometimes evolving into discussion with the whole family over the kitchen table. Our participatory principle stems also from mixed Roma-Gadjo research team often making our discussions over data interpretations dialogical debates over meanings of Polish, Roma, and European identity in contemporary society. In this context, we hope that our project was the case of (still rare according to many Roma and Gadjo) what Roma may call *khetanes Gadzie Romenca* – cooperation between Roma and Gadjo. The principle ethical driver behind our research was to conduct it with maximum sensibility and the principle of not causing harm to our respondents in any way and with full respect of their worldview.

BROAD SOCIAL AND HISTORICAL CONTEXT OF POLISH ROMA MIGRATIONS

The constraints on international mobility during communist period concerned all citizens, Roma included, and as many other Poles at the time, they engaged in various strategies aimed at overcoming these restrictions. In Roma case however, the issue that distinguishes them from overall population was the forced sedentarization and "productivisation" of Roma nomadic populations, put into law in 1952, but implemented during the so called "settlement action" in 1964, which marks the end of nomadism of Roma groups that still maintained this form of livelihood (Drużyńska 2015; Mirga 1998; Mirga and Mróz 1994). In theory, this concerned nomadic groups, but in practice also impacted on those who lead a settled life. The so called "productivisation" offered employment in various new industries, which was also attractive for non-nomadic Roma, which lead to considerable internal migration from their traditional settlements in the Carpathian region, to Nowa Huta (near Kraków) or Lower Silesia (Golonka-Czajkowska 2013; Kapralski 2016).

For the nomadic groups, the tightening of communist state's surveillance, was a stimuli to look beyond Polish borders, as noted by Ignacy-Marek Kaminski, in his study of Roma emigration (more precisely, a group of Kelderasha families) to Sweden in the late 1970s (1980). Informally however, the communist state sometimes actively supported emigration of Polish Roma populations. In Dariusz Stola's history of international mobility from communist Poland, in the context of emigration of Germans from Poland in the 1970s, he notes that:

> "With the restrictions in place, emigration was encouraged when it came to politically or socially unwanted individuals. In Katowice area the communists were getting rid of them to such extent that in 1974, a well informed colleague of Mieczysław Rakowski [a well know journalist, later one of last Prime Minister of communist Poland – authors] was telling him that 'there are almost no Gypsies (we sent them already 2 thousands)'" (Stola 2010, 239).

As emigration of Polish Jews or Germans had political undertones, in case of Roma the readiness to give them "one way passports" was dictated by the local communist authorities' policy of getting rid of "socially cumbersome elements". This was the authorities' reaction to anti-Roma riots in Oświęcim in autumn 1981 (Kapralski 2016; Mirga 1998), where in order to pacify the local population, around 100 local Roma were offered a "one way passport" (*wilczy bilet*) to Sweden. The Swedish authorities on the other hand were also aware of what is happening and in fact this is what made them reintroduce visa restrictions:

> "[Polish government – authors] wants to use the liberal visa rules to turn our country into a 'dumping' ground for people who for one reason or the other are seen as cumbersome in Poland. It may be about the Roma, as it happened recently"[4].

The relative liberalization of mobility restrictions in the last years of the communist regime, meant that more and more Polish citizens – Roma included – began to move. As the report of the Union of Polish Roma notes (2012), end of 1980s and early 1990s are the time of intensification of migration of Roma, mainly to Germany, Holland and Sweden. On a broader macrosocial level, international migration of Polish Roma was determined by political shifts that have impacted the entire region in the aftermath of the collapse of the Berlin Wall and communist system. As many scholars note, the

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[4] Ministry of Foreign Affairs, Department for Western and Northern Europe: Sweden [Ministerstwo Spraw Zagranicznych, Departament Europy Zach. i Płn: Szwecja]: This a translated exchange between Swedish minister O. Ullsten and an MP C. Bildt regarding the introduction of visa regime between Poland and Sweden; dated 6.04.1982.

subsequent economic and political transformations have disproportionally hit the Roma populations (Stewart 1997, 2013) – they were the first to lose their jobs, to be subject of social welfare cuts and first to suffer the consequences of growing animosity of their neighbours, including raising racism and violence, also in Polish case (Bartosz 2004 [1994]; Giza-Poleszczuk and Poleszczuk 2001; Kapralski 2016).

Both our respondents narratives and accounts, media reports and government communications, paint a very similar picture of migration of Roma starting in early ‘90s to Germany and then, in mid ‘90s, shifting to Great Britain. In most of cases Roma used the asylum application system, mainly due to raising instances of racism and threats of violence (Talewicz-Kwiatkowska 2019, 44).

As mentioned, Germany was the main destination country in early ‘90s. where Roma usually applied for political asylum or had an irregular status, which sometimes lasted for many years prior to 1989 (Joskovicz 2016). Polish Ministry of Foreign Affairs archives point to the high number of people with irregular status, but without specifying whether these are people whose asylum claims have been rejected or are they economic migrants. For German authorities, the main problem was to determine their citizenship, necessary step to implement the readmission procedure, which was one of the main shifts in migration policy of newly reunified Germany.

It is precisely at that time, Roma from Poland began to alter their migration strategies from Germany to Great Britain where they most often claimed political asylum. Already in 1995 the Polish General Consul is being informed by the British about the “abuse” of asylum application system by Polish citizens, who are identified by Polish diplomats as Roma[5]. Successively Britain tighten its asylum procedures, while Poland joined the list of so-called safe countries. The number of applications falls the following year, but in 1998 it grows substantially, which again causes diplomatic tensions – with real prospects of reintroducing visas for Polish citizens.

Our experts recalling that period remember that during the bilateral talks of Polish and British officials on various levels, Roma are presented as “the problem”[6], casting a shadow on ongoing negotiations about Polish membership in the EU. It is perfectly illustrated in the wording of the letter by Tony Blair in September 1999 to the Polish PM Jerzy Buzek, where he points that more than thousand Roma plus dependants has applied for asylum:

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[5] Ministry of Foreign Affiars, Department for Europe I, Great Britain: Embassy of the Republic of Poland, Political report for 1995 [Ministerstwo Spraw Zagranicznych, Departament Europy, Wielka Brytania: Ambasada Rzeczypospolitej Polskiej, Raport polityczny za rok 1995].

[6] In the internal correspondence, prior to meeting the British, Polish officials are explicitly advised not to raise the subject of “Gypsy issue” on their own, only to react when it is raised by the Brits.

> "I am sure you find it as frustrating as I do that we should have to face this problem". Interestingly, he then points that 150 thousand Poles visit this country each year, the vast majority as genuine tourists, students, or on business" and they are "welcomed warmly".

Similar letter has been sent in 2002 to then PM Leszek Miller and also his Czech counterpart (Sobotka 2003, 113). In both, Blair emphasizes that Roma migrations seem to be well organized, thus it is necessary to work with Roma community leaders in the country to convey the message that applying for asylum is unlikely to succeed. Table 1, demonstrates the dynamics of asylum applications from Polish citizens during years 1991–2004. The numbers relate to adults, without dependent children and are collected on the basis of citizenship of the claimant. This means that in the pool of claimants there are non-Roma Polish citizens, who claim asylum either on a different basis, or were "passing" for Roma, a part of diverse strategies of navigating the mobility and employment restrictions by Polish migrants (Garapich, 2016).

Table 1. Asylum application by Polish citizens in Germany and Great Britain 1991–2004[7]

Year	**1991**	**1992**	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**
Great Britain	20	90	155	360	1210	900	565	1585	1860	1015	630	990	122	21
Germany	No data	No data	No data	No data[8]	200	190	210	49	42	260	185	66	44	24

As stated, majority of our Roma respondents in England share a similar migration trajectory – going to Germany in early 90, then coming back to Poland, and then moving to Great Britain. The regularity of that route shows the importance of social networks in these processes. At the same time, it must be stressed that this route, seems to be first tested by Polska Roma group, then disseminated to Bergitka Roma group (see section below for more details).

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[7] Own estimates using:
1) Asylum Statistics United Kingdom 1999, Jo Woodbridge, Di Burgum, Tina Haath, 17/00, 12 Oct 2000,
2) Asylum Statistics United Kingdom 2000. David Matz, Rachel Hill, Tina Heath, 25 September 2001 17/01,
3) Refugees and Others of Concern to UNHCR 1998 Statistical Overview, Geneva,
4) Refugees and Others of Concern to UNHCR 1999 Statistical Overview, Geneva, July 2000,
5) Data for 2000–2004 from Great Britain and Germany: UNHCR Population Statistics Reference Database (access: 21.08.2018).

[8] Despite lack of statistical data for that period, it is safe to assume that the figure was substantial, in particular in the early 90s.

Poland's accession to the EU in 2004 is the last structural shift affecting Roma mobility, however with a mixed impact depending on the locality and Roma group in question. From our findings it is clear, that after 2004, migration becomes more accessible and possible for those who were not able or could not make that move earlier. In the mass movement of Polish citizens after 2004, Roma have "disappeared" and are not a subject of any special interest nor concern for Polish authorities. Not that they are invisible, however, as according to our informants, some local governments directly involved in Roma issues treat their emigration as a positive outcome that will solve the problem of socially "unwanted elements".

The notable disproportion between the numbers involved and reaction of the governments having hallmarks of a moral panic (more in Clark and Campbell, 2000) needs to be noted. Crucially these are the migrating Roma who are seen as a security threat, their migration pathologized *en masse* as a "problem" and example of "abuse", and not the hundreds of thousands Polish citizens who enter the UK on false premises as tourists and work without permits (or sometimes pretend to be Roma, see Garapich 2016).

MICROHISTORY OF POLISH ROMA MIGRATIONS – MŁAWA, NOWA HUTA AND CZARNA GÓRA

As in cases of other immigrant groups, the history of Polish Roma migrations bring forward hierarchies and divisions within that category. The sedentarization policy of communist regime has made some Roma to look beyond state borders, and living on the road for generations facilitated keeping in touch with various members of the extended kinship networks scattered across the region. It also put a premium on knowing the routes, finding information and implementing various strategies of dealing with mobility restrictions – which has been showed in Kaminski's (1980) account of a spectacular route of several families of Kelderasha in mid 1970s., from Poland to Sweden (via Balkans and Italy). "People of *tabor* are more entrepreneurial" – as one of our experts said, meaning mainly an ability to navigate hostile mobility regimes restricting migrations. This refers mainly to Polska Roma group, and this stereotype is often reproduced by Bergitka Roma group who often point to vast transnational family connections Polska Roma has. How these networks operate in practice, is illustrated by the case of Mława, the town where part of our ethnographic study took place.

Roma in that town come from Polska Roma, with the subgroup self-referring term of Pluniaki; they lead nomadic lives until late 1960s. They have engaged in intensive migrations to Germany from early 1980s, due to social networks established in Germany much earlier, we know of at least few cases of Roma from Mława who settled in Germany in the 1960s. These international contacts were a source of significant economic status and social mobility due to engagement in used car dealership, which at the times of chronic shortages was a source of considerable wealth but also political influence in town. But not everyone had access to migratory social capital hence not everyone benefited from that lucrative trade. Our respondents frequently note the economic disparity within the local Roma community.

In 1991, the town become the site of infamous anti-Roma riots (Mirga 1997). Subsequent diagnosis of underlying roots of the riots show that migration driven accumulation of capital by Roma, their display of wealth and influence, along with the sudden impoverishment of local Gadjo coupled with the widespread crisis of legitimacy of power in the aftermath of collapse of communism lead to outburst of violence (see Giza-Poleszczuk and Poleszczuk 2001; Kapralski 2016). As noted by scholars, but also emphasized often by our respondents, the main focus of the attack were the wealthy households of Roma, not the *barracks* where the poorer families lived.

The Mława anti-Roma riots have been the accelerator of international migrations. This and other cases of riots and ethnic violence helped to justify asylum claims abroad, first in Sweden, then Germany and at the end in Great Britain. During that time, according to our interviewees as well as literature (Horton and Grayson 2008, 9) the largest outflux of Roma from Mława took place. However, it has to be noted that post-riot migrations have simply increased in frequency within an existing migration culture, so have broaden the strategy of Roma in which they were engaged in since at least a decade. Interestingly, some of our respondents have come back, sometimes few years after the riots. These early returns were mainly linked with the property they have left, but also relative lower economic status of the returnees. It seems the wealthier families had more motivations and resources to leave and settle abroad. Logically, Roma from lower end of social strata in Mława had less incentives and resources to leave permanently.

Polish accession to the EU and subsequent opening of the labour markets have been a crucial macrostructural determinant in migrations for Roma in Mława, as this time they encompassed everyone regardless of their economic status. Great Britain again becomes the main popular destination due to lack of transition periods for employment but also relatively straightforward system of social support in terms of schooling and housing, which was then used as the basis for bringing other members of the family. Today, these migrations between Mława and England (but also Ireland) are mixed in nature – some members of the same household live abroad, others circulate, others remain in Mława engaging in occasional transnational care or trips abroad.

Not all migration projects were successful and some families clearly have difficulties at meetings ends, and the money earned is usually spend on consumable good, a car or flat improvements. In that sense, post-accession migrations of Roma do not differ from migrations of their Gadjo neighbours. Some migration projects are marked by unpredictability, open-endedness and transnational ways of working and living with the future in form of retirement in Poland (Eade *et al.* 2006; Grabowska *et al.* 2017;

White 2014). Commenting on the younger generations approach, one of our elderly respondents for example says:

> "…they have their flats here… got it ready, but won't leave it… they got it ready, earn there, come over the summer, stay a month or two and then again go there…."

But regardless of migration strategies, the long established migration culture and modernity driven macrostructural factors, mean that Roma community in Mława changes significantly. Young Roma are often confronted with diverse lifestyles and possibilities in Poland as well as abroad that may be contradictory to what their families and elders expect from them. Better off families with family connections abroad had more means and motivations to leave Mława early on, the less wealthy families chose a more transnational strategy of engagement between their town and England or Ireland. Strong family bonds of course still matter, and sometimes Roma reunite to keep the extended family together – for example during our fieldwork a daughter has returned after 20 years of living abroad. Some families engage in well known in scholarship among Polish migrants practices of transnational care (Barglowski *et al.* 2015; Wagner *et al.* 2016; White 2011), where usually grandmothers take care of their grandchildren while their parents work abroad. Those that remain or who returned often express strong sense of local patriotism. Mława is seen by them as a safe, known world without risk associated with losing local connections due to migrating, but also due to the safety net of property or state help. As one respondent told us, it is a place "I can go out in the evening and meet people I know", as opposed to the sense of anonymity and solitude experienced abroad, outside the closely knit Roma community.

In the context of Mława's bad reputation among Polish Roma, this emotional attachment is significant. It relates not only to Roma respondents' understanding of local history, but is a way of articulation ones' local roots and the status of being an integral part of town's landscape – we were often reminded, that despite the fact that in general Mława anti-gypsy riots cast a shadow over Roma-Gadjo relations, personally, they have experienced friendship and neighbourly care from their Gadjo co-habitants.

Despite all this, in the view of local experts, and some or our Roma respondents, the Roma community in Mława due to migration and aging is in decline. From more than 300 people (roughly 70 families) at the beginning of 1990s. (Giza-Poleszczuk and Poleszczuk 2001), the community numbers now around 20–30 families (according to local *wójt*, the leader of Roma community) or 100 individuals according to the city authorities[9]. At the same time our interviews and participant observation indicate that

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[9] Supreme Audit Office, post-audit note, 2014: P/14/119 – Public administration activities for the protection of the rights of the Roma minority in Poland [Najwyższa Izba Kontroli, Wystąpienie pokontrolne, 2014 r.: P/14/119 – Działania administracji publicznej na rzecz ochrony praw mniejszości romskiej w Polsce].

this is a transnational community with each family having strong family links with their kin in England, Germany, Canada or Ireland. Some of them still maintain strong links with the town. Traditionally, every All Saints Day on 1st of November, Roma from Mława gather to pay their respect at the cemetery, and then to meet in a larger gathering for a dinner. Our respondents noted however that every year less and less people take part in these gatherings. As one member of the elders told us: "These days we only have funerals, no weddings, nothing…".

Tellingly, last year the local property market registered changes indicating further out-migrations of local Roma. According to estate agents, some of the grand houses Roma built in the 1980s during the time when Roma were prospering due to used car dealership, have been put on sale for the first time, and an increasing number of private flats owned by local Roma are rented to immigrant labour force – from Ukraine or China. This shows that some families begin to cut ties with the town. It is difficult to generalize on the whole country, but we also spoke to Roma from other towns in Poland that underwent a similar process of depopulation due to migration movements which began in the 1980s, resulting in social decline of local Roma life.

The second group among which the study was carried out were Bergitka Roma (called also Mountain or Carpathian Roma), a group originally living in Southern Poland, due to post-war internal mobility living also in Nowa Huta, Silesia with small communities in the North West. The ethnographic research was carried out in two locations – a rural settlement of Czarna Góra in Spisz region, and an urban, industrial suburb of Kraków, Nowa Huta. Unlike Polska Roma group, Bergitka Roma were a population leading a sedentary life previously mainly employed as blacksmiths and musicians, since 1950s. increasingly employed also in industries (Kapralski 2016; Mirga and Mróz 1994).

Besides incidental and sporadic individual migrations, Roma from Czarna Góra did not engage in international migrations in 1980s or 1990s. Few exceptions where some migrated to Britain or temporarily to Sweden were the results of intermarriages with Gadjo, or incidental contacts with foreigners and did not resulted in establishing a migration chains stimulating further outflows. It was Poland's accession to the EU that has had the biggest impact on that community. According to our respondents many families decided to use the opportunity of opening the British labour market to move to the United Kingdom. Our observations and interviews indicate that almost every family in that village (roughly around 25 families) have participated in these migrations to some extent – they have family members living in England, plan to leave soon, or have recently returned. Respondents' accounts indicate that just after 2004 migrations had hugely depopulated the settlement, whole families were leaving together. Table 2 is a compilation of official data and our own observations and interviews, indicating the scale of outflows:

Table 2. Estimates for the number of Roma in Czarna Góra and Nowa Huta[10]

	1990s.	**Post-2004 accession period**	**2017–2018**
Czarna Góra	250	70	100
Nowa Huta	3000	2000	1800

The threshold of 2004 for development of migration networks points toward an important finding of our study relating to role of ethnic boundary in migration networks. During our research and interviews we did not encounter any case of Roma from Czarna Góra, or nearby Zakopane and Podhale region who would tap into traditional and very extensive transnational networks of local Gadjo, who developed a distinct migration culture (mainly to Chicago) since the end of 19th century (Pilch 1984; Walaszek 2007). Some respondents were surprised by the very idea, as in their worldview it was obvious that as a result of social and economic marginalisation, local migration capital which helps the Gadjo to engage in migration for at least five generations, were not shared with the Roma.

Low level of economic capital, qualifications and social capital of Roma from Czarna Góra, meant that it was the 2004 and opening of labour markets stimulated their international mobility. To some extent, the stabilisation of migratory status of their kin (e.g. from Nowa Huta, see below) already in Britain, played a role in their decision making, as some could use their presence and assistance during first steps while abroad. Certainly the post 2004 migrations, affecting every family in the village have contributed to established transnational networks helping people moving back and forth.

The interviews with returning migrants however, have brought forward a slightly different assessment of these migration episodes, as they are often talked about in terms of loss, mistake and emotional stress. They are seen as a difficult dilemma of being confronted with economic improvement on one hand but tensions from family separation and lack sense of security on the other. And similarly to Roma from Mława, the returnees are keen to emphasize their close connection to the local space. This was clearly linked in the interviews

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[10] Own estimates based on:
1. 2001–2003 Pilot Program for the Roma community in Malopolska Voivodship (http://mniejszosci.narodowe.mswia.gov.pl/mne/romowie/program-na-rzecz-spole/pilotazowy-program-rza/6721,Tresc-pilotazowego-programu-rzadowego-na-rzecz-spolecznosci-romskiej-w-wojewodzt.html), access: 20.10.2019
2. Program for the Roma Community in Poland 2004–2013: (http://mniejszosci.narodowe.mswia.gov.pl/mne/romowie/program-na-rzecz-spole/program-na-rzecz-spole/tresc-programu-na-rzec/6670,Tresc-Programu.html), access: 20.10.2019
3. Integration Program for the Roma Community in Poland 2014–2020: (http://mniejszosci.narodowe.mswia.gov.pl/mne/romowie/program-integracji-spol/8303,Program-integracji-spolecznosci-romskiej-w-Polsce-na-lata-2014–2020.html), access: 20.10.2019
4. Information from local Roma organisations.

with a sense of culture shock felt by some of our respondents who are confronted with the complexity of large urban centres in Britain. But it also indicates that for Roma – as for many other groups maintaining close family bonds – migrations are a potentially disruptive situation, putting pressure on family ties and sense of security provided by familiar space of local Roma community. "The community is here" – as one of the returnee told us. This means that for some, migrations can lead to economic advancement, but at the same time they may also lead to the loss of status within Roma family, due to being outside the local stratification and status order. A similar point is made by Jan Grill (2012), whose research shows how gendered status of Roma men may change when abroad, and as a result may end up in prioritizing status over economic prosperity.

Our third field site, Nowa Huta district in Krakow, provides yet another, slightly different migration history of Polish Roma. Inhabited mainly by Bergitka Roma group who moved there in 1950s and 60s. to work around the steel factories, international mobility began also in the 1990s., unsurprisingly with the collapse of large state owned industries due to socio-economic transition. Similarly to Polska Roma group, Bergitka Roma from Nowa Huta began to move to Germany mainly asking for political asylum.

Our research indicates clearly that the connections with Polska Roma were vital for establishing these migratory routes – these connections helped to plan ahead, get information how to interact with authorities, and how to settle, find jobs and assistance. The key role for establishing these networks was played by people with double group affiliation – usually men from Bergitka married into Polska Roma families. From various independent sources we were able to identify these "migration brokers" (Lindquist *et al.* 2012; Xiang and Lindquist 2014). These crucial actors on migration scene, were responsible for dissemination of migration strategies and organisation of travel on one side and on the other were tapping into international connections provided by Polska Roma group. These persons were actively involved in planning of migrations of many families from Nowa Huta (termed "*przerzut*" – meaning transfer, shift), both to Germany in early 1990s and to Great Britain later on, following the pattern described in previous section. The scale of these activities and the fact that they connected different Roma groups, points to level of sophistication in planning which also was noted by the authorities.

The scale of migration from early 1990s. means that Poland's accession to the EU did not have a similar dramatic impact on outflows as in the case of Czarna Góra. Nevertheless, as in the case of Mława migrations also contributed to significant depopulation of Roma from that town and their visibility – the well known, Nowa Huta "Roma block" on Osiedle[11] Willowe (Golonka-Czajkowska, 2013) isn't "Roma" anymore (table 2 above indicates the scale of that process).

Unlike the case of Mława however, it cannot be said that Roma community in Nowa Huta is in decline. There are numerous annual concerts there, several active

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[11] *Osiedle* – estate.

Roma associations, Roma educational assistants are employed in local schools and day care centres, there are a number of social and cultural projects carried out. In addition, several Roma families from Romania settled in the town, opening another chapter of Roma presence in Poland. In that sense, despite large scale emigrations, Nowa Huta maintains its status of the "capital" of Bergitka Roma.

TRADITION AND INTERGROUP RELATIONS

One of our key findings, is the fact that international migrations have put different Roma groups in relative closer contact. Previously, Polska Roma and Bergitka Roma were isolated from each other in Poland geographically, but also socially, the later regarded by the former as having "lower status". Broadly they knew about each other's existence as evidenced by various terms used to refer to other Roma, sustaining also a specific hierarchy of groups (Ficowski 1965; Mróz and Mirga 2001). Social and political shifts in Poland after the collapse of socialism and subsequent emergence of Roma associations, sometimes linking all Roma groups (Grzymała-Kazłowski 2015), led Roma activists to seek a common political ground in their relations with the Gadjo and began a more open and formalized struggle against discrimination, racism and economic deprivation. But these contacts were confined mainly to ethnic leaders. As noted by Agnieszka Kowarska, until fairly recently members of Polska Roma group regarded Bergitka Roma as "impure" and were of a view that contacts with them needed to be limited and marriages discouraged (Kowarska 2010, 6). In our fieldwork, we encountered numerous instances of that internal hierarchization still important for some members of Polska Roma.

For the first time in Polish Roma studies we can claim that these contacts are becoming increasingly numerous, resulting in mutual partnerships, family links but also tensions and conflicts, which leads to important changes in the cultural lives of Polish Roma. It is clear that migrations were a key factor in that process. This is not only our observation from the field, but a widely shared view of most of our respondents – two groups come into contact more and more often abroad which as a result leads to more intergroup marriages and interactions.

On broader level the reasons behind this process lie in structural factors but also the collective characteristic of Roma migrations strategies in general – the fact that in general, Roma migrate in family groups (Matras 2013, 24) – this time linked with the process of settlement. Sometimes it lead to more organized and structured form of cooperation, as in the case of establishing of one of the most active and known Roma lead organisations in the UK, the Roma Support Group[12], established with the help

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[12] Roma Support Group: http://romasupportgroup.org.uk/, access: 20.10.2018.

of British academics, human rights activists and people engaged in supporting asylum seekers. Describing the circumstances of that organisation's creation, Acton and Ingmire (2012) note the important role Roma from Poland – mainly from Polska Roma but also Lovari and Kelderasha – played. Today members of Bergitka Roma are also active there and in that sense we can talk of a similar process going on as in Poland, where new Roma identity emerges, bridging, negotiating and sometimes contesting previous distinctions, group differences and hierarchies, in particular when they interact with the authorities that are not well tuned to the complexities of Roma identities. For many Roma who were not engaged in transnational ethnic mobilisation movement, this intensification of group interaction is a novelty. This isn't to say that old divisions disappear, they are still important dimension for most of our respondents' identities. We met members of Polska Roma who do not have any contacts with Bergitka Roma and vice versa. However, it is clear that Roma from Mława had little chance of meeting a member of Bergitka in their town, or Bergitka to meet a member of Polska Roma in Czarna Góra. In London or Southend this probability highly increases, a fact that what we directly observed during various rituals and events during our fieldwork.

One of the outcomes of more frequent inter-group relations and greater number of mixed marriages in particular, is the need to negotiate certain Roma traditions and customs understood differently by different groups, especially in relation to the status of women, gender roles and sources of authority in conflict resolution. For example, among many women from Bergitka Roma group we spoke to, there is a prevalent view that some of their kin who dressed "normally" in Poland (which usually meant wearing trousers or short skirts), become more "conservative" in England, dressing in a way more associated with women from Polska Roma group. In similar way a stricter division between male and female sphere, and pollution taboos are being raised as a point of negotiation between groups, in particular in the context of mixed marriages.

Interestingly, the dominant position of Polska Roma group is often negotiated and confirmed here. As it was often explained by our respondents, a female from Bergitka Roma marring into a Polska Roma family, is expected to adhere to their traditions and customs, but the same is also expected from a Bergitka Roma man who marries into Polska Roma – it is he, who needs to adapt. For some it is a proof of conservative and dominant position of Polska Roma (also financially, as often they are regarded as wealthier and more entrepreneurial). For others it is a proof of Roma traditions revival, in particular in a more tolerant and diverse context of British multicultural policies. There are however voices from Bergitka Roma group which sees this process as an attempt from the other group to assert its dominant position. Old hierarchies are being contested and questioned, with intermarriages as well as pan European Roma activism negotiating old stereotypes, since the latter rests on the assumption that Roma are a national/ethnic minority and internal differences are secondary to a common Roma identity. These discussions take place in Poland and in England simultaneously and can be heated and very emotional – which again points to the intensification of intergroup contacts due to migration. What differs in our view, is that discussions that were common among Roma activists, move to households that were previously indifferent to these processes.

This development can be challenging for both groups. On the one hand, some members of Bergitka Roma can feel dominated by Polska Roma, and concerned that in order to prove their Romaniness they are forced to take on traditions that were not common among them. On the other hand, for Polska Roma, inclusion of families not adhering to certain rules can be treated with concern, in particular when it comes to certain pollution taboos.

Crucially, more interactions and intermarriages, mean also more potential for dispute requiring a coherent and legitimate system of conflict resolution. Traditionally the top judiciary authority in Poland in custom Roma law, is the Sero Rom, the Roma king, currently living in Nowy Dwór Mazowiecki near Warsaw (Kowarska 2013; Mirga and Mróz 1994). His rulings are generally accepted by all Roma groups in Poland, except Bergitka Roma who regards him as a member of the elders but not as ultimate authority (although there are also members of that group who do accept him as such). The dilemma thus is that in case of a dispute between members of Polska Roma and Bergitka Roma, the latter may refuse to accept Sero Rom's ruling, undermining his authority. The way out of that dilemma is to convince elders from Bergitka Roma to accept the king's authority, and we are witnessing an increasing number of attempts to do just that – for example during our fieldwork in winter 2018, a prominent member of Polska Roma, came to Nowa Huta for a special gathering of local Roma (from Bergitka) to convince them (a part from discussions on many other things) to accept Sero Rom's authority.

Besides many other aspects and complexities of these Roma internal politics, it is important to stress that the discussions about that process are very lively in Roma households in Poland and England and are not solely connected to migrations but wider socio-political changes that Polish Roma undergo. Nevertheless we argue on the basis of our fieldwork, that migrations accelerate this process. This also points to an important dimension of Polish Roma connection with Poland. The ongoing political negotiation of Sero Rom's judicial authority sets Polish Roma apart from Roma from other countries and it may be interpreted not just as an attempt to unify diverse groups but a strategy aimed at keeping them linked through a common connection to Poland. In other words, the uniqueness of Sero Rom institution distinguishes Polish Roma from other Roma. It is also an element binding the Polish Roma groups is their more frequent interactions with Roma from other countries – in particular from Slovakia, Czech Republic and Romania.

Social media are of course a huge accelerator of this process. News about events, family rituals, conflicts, tensions travel fast across borders and it is quite common for Roma we met to live stream parties, christenings, weddings or other family events to their kin in other countries. These interaction very often involve Roma from diverse groups and one of the interesting linguistic outcomes of that process is the creation of a hybrid Polish-Roma-English idiom with which Roma communicate in writing, bridging linguistic divides. This in itself is an evidence of increased inter-group interactions, in particular among younger generation and how Roma in new context negotiate their complex and multi-layered identities in their own way, using own cultural resources and ideas linked to the importance of family, wider kinship group but also sentiments towards their locality or nation of origin. In the context of living in London these issues become important as they also negotiate diverse ways of being Roma, Polish but also British, Londoners and/or European.

RELIGIOUS CONVERSION AND MIGRATIONS

One of the aspects of our ethnographic study focused on religious conversions among Polish Roma and an interesting fact that Polish speaking Jehovah Witness congregations experience a growth of number of Roma among their ranks. This has been also noted by Acton and Ingmire (2012) without however an in-depth exploration of the dynamic behind this process, which in the context of popularity of Pentecostalism among Roma, is additionally intriguing.

It isn't easy to estimate the number of Polish Roma who are Jehovah Witnesses, although the testimonies as well as comments from non-believers Roma indicate that the trend is upwards and began with the migration flows in mid 1990s. During our research, first Memorial of Christ's Death (a yearly ritual when Witnesses gather in great numbers across the world) has been organized specifically for Polish Roma and the sermon was delivered in Romani language, attracting around 250 people. According to Witnesses, there may be around one thousand Polish Roma who regularly come to Kingdom Halls, although it is difficult to verify that data.

As noted, majority of literature on Roma religiosity focuses on Pentecostalism, a hugely popular religious and ethnic revival movement across Europe (Acton 2014; Roman 2018; Podolinská 2014). Some of the Polish Roma joined the Pentecostal church (cf. Nowicka 2014), many others however, chose to join the other spectrum of Christianity. The fact that religious conversion to Jehovah Witness is a very frequent topic of conversations among Polish Roma we interacted with during our fieldwork (both believers and non-believers) indicates an important cultural shift and change as a result of migration and living in England. Our research covered three locations in Poland where we have not met any Roma who is a Witness, however, we were told of some Roma Witnesses living in various locations across Poland. From the narratives it seems that their conversion actually took place abroad, pointing to migration as the key factor in that process.

Why this is the case and what attracts Roma to the movement? We identify several factors behind this process linked. First, for our Roma respondents, the congregation is a safe space with a warm family atmosphere. According to come respondents, after their arrival to Britain the congregations became their "second home" where they felt included, safe and where linguistic and cultural proximity to non-Roma Polish co-believers helped to overcome feeling of stress related to the uncertainty of their immigration status, alienation due to living in a new country, or financial difficulties related to prohibition of employment. At some point of their settlement, practical aspects of being in a congregation also mattered, as it was a space where they could ask for information about accommodation, legal matters, employment. To some extent, the congregation acted as a similar social space to a Polish Catholic Church for Polish migrants which was a safe place not only to worship but to socialize. It seems the shared experience of exclusion from Polish society (Jehovah Witnesses being one of most disliked groups in Poland) brought these two groups together.

The social appeal of the congregation is also linked to a set of beliefs and practices that blend modernity with traditional beliefs. James Holden relates this to relationship with modernity that is stronger and deeper than it would seem on the surface from a millenarianist group. As he notes:

> "On the surface, it would appear that Watch Tower theology represents a backlash against secular life, but closer investigation reveals that, in other respects, it is part of the very forces it condemns" (Holden 2002, 15).

This refers to business model of the evangelical work and a "desire for rationality" (Holden 2002, 65) visible in dress code, layout of Kingdom Halls, rejection of emotional responses during meetings, style of preaching and debating the issues of Watchtower during weekly meetings and the authoritarian nature of hierarchical structure of the movement – both at the level of organization and observable interactions between followers. Holden uses the Weberian notion of "technical reason" (Holden 2002, 81) to argue that the Jehovah Witness have used characteristics of modernity to achieve appeal of followers along with social cohesion. Our Roma Jehovah Witnesses respondents directly engage with that discourse, arguing often that their religious path is an intellectual development and they are educating themselves through the Bible. The modernity driven message of advancement through knowledge and education is thus re-constructed in religious terms. Many Roma we spoke to see Bible readings sessions, coaching in public speaking, role-playing exercises aimed at teaching how to talk to evangelize people, etc. as education per se. We heard many stories of people actually learning to read and write as a result of becoming Witnesses. This exchange for example illustrates this perfectly:

> "[Respondent, female, 50 years:] So there are many cases like this, they are now more enlightened to learn. They don't take just facts… but want an answer: where is this written? Where the Bible comes from, how do you know it is authentic? And they compare facts… so they are more educated now you may say… and they finish schools… so I think they are not so backward anymore…
> [Interviewer:] So they crave some knowledge right?
> [Respondent:] Yes, they want knowledge and the younger generation too, thirty, forty years… and not all of them know how to read and write, and this is a great thing because they want to learn something new, right?"

The process of conversion is linked with their migratory routes and clearly went along family ties and extended kinship group networks, hence the growth of popularity of Watchtower congregations also stem from the abovementioned collective feature of Roma migration culture. There are, however, several more specific features that Roma themselves highlight in Watchtower dogma and practice as relatable to their Roma norms and traditions – mainly patriarchal gender roles, where male is the head of the household, emphasis on strict moral norms around sexuality, modesty in dress code, respect for the elders or the institution of exclusion from congregation which for Roma is seen as the equivalent of *magerdo*. Some also noted that Witnesses' general separation from the public, national affairs, in particular their resistance to national symbols and prohibition of their members to join the army and the police, a norm that is also found among some groups of Roma. Prohibition of blood transfusions also is relatable to some Roma taboos on blood.

Simultaneously however, the congregation setting, practice and dogma, offers sometimes a possibility of contestation and resistance to other elements of Roma culture that some Roma may find problematic or difficult. Being a Jehovah Witness allows sometimes to distance from family based ethical obligations and to refuse to participate in certain practices – for example christenings or Roma weddings. Sometimes it can also act as a tool of resistance of traditional gender roles. The best example is offered by one of our female respondents who was caught in a family dispute requiring a decision of the elderly to issue a binding ruling. The ruling required from her making an oath in public, something that not only Witnesses are forbidden to do, but since the opponent was male would put her in a disadvantageous position. Eventually she refused to make an oath citing her religious beliefs.

Our observations among Roma and non-Roma Witnesses in congregations in England, identify one more crucial factor behind the growth of popularity of Watchtower movement among that group. The last and very important piece of the puzzle, in the light of our findings, is the fact that the Polish members of the congregation during our visits were very eager to stress that the "Roma brothers" are an important part of the congregation. For them cultural and ethnic diversity in congregation is vital in order to challenge it and bridge it through the Jehovah Witness dogma. Roma presence is regarded as a proof that Polish members are following the path of the script – to overcome individual features and ethnic or national labels, to create a community of faith. Paradoxically then, migration and conversion has brought two different groups who live in Poland in isolation, together.

RETURNS AND BREXIT

Our respondents, especially returnees, talk also about migrations in negative terms – as risk, lack of networks of support and associated individualistic attitudes or dependency on family members abroad. Their return to Mława or Czarna Góra is then a return to known and safe environment, where social relations are embedded in traditional and established networks. "Roma are local patriots" – as one of our expert argues. Returnees we talked to, emphasize this bond with local space and nostalgia towards their community, since it was difficult to recreate it abroad. A return helps them realize the value of what community means and what it has on offer – sense of security, stability and position in local Roma community structure, which is at risk when abroad dependant on other branches of family. So an attachment to their locality of origin in thus strengthened by migration experience, an issue commonly observed in literature on migrants' returns, dilemmas of transnational living and care and nostalgia (Carling *et al.* 2015; Erdal 2014; Erdal and Oeppen 2017; White 2011, 2014). Some returnees may chose this sense of belonging and social status in their settlement over relative better economic position in England.

In other instances families are so dispersed that there is no one to return to, if they do not have any property (in case of social housing, families who left Poland lost rights to the communal housing) or they have been sold or rented. Coupled with the fact that children sometimes do not speak Polish, for many Roma a return is not an option, and their link with Poland and local community is being severed – as we seen in case of Mława. A general negative experience of schooling in Poland that parents refer to, makes then doubtful whether their returning children from England will be well catered for in Polish schools, in particular that they usually hold English schooling in high esteem. It should be stressed here, that Polish schools struggle also with other returning non-Roma Polish children with a migration experience. On the other hand, a new policy of child benefits (so called 500+) have been noted to be an additional incentive for some families to return.

The dilemmas our respondents articulate, do not differ from what we know from studies on migrants from Poland in general. They focus on problems with transnational care (Kordasiewicz *et al.* 2018), or the constant need to find an equilibrium between economic benefits of migrations with social and emotional costs of family separation and sense of alienation in a new environment. These similarities are also evident in the context of the Brexit referendum and its social and personal consequences, as for many EU citizens they generate heightened sense of uncertainty and unease, in particular bearing in mind the wave of anti-immigrant sentiment in the aftermath of the referendum. However, some scholars note that outcomes of Brexit may disproportionally affect Roma populations (Marley 2016) issue also raised by organisations such as Roma Support Group. There are various reasons for this overall, but from the narratives of our respondents, some made preparations securing their status – getting a resident certificate or applying and getting British citizenship. There are however cases that certainly will make that process difficult – due to lack of paper trail related to employment or past criminal convictions. Again, these are not specifically issues affecting Polish Roma, but overall relate to all EU citizens in Britain.

DISCUSSION

One of the main finding of this study is the realization that for more than a quarter of century Poland have been witnessing a largest – since the post-war emigration of Germans or Jews – exodus of its ethnic minority. What is more, this ethnic exodus went almost unnoticed. The small numbers involved should not offer an explanation for this situation, since we have seen the reaction of the Polish and British authorities and diplomatic tensions regarding the arrival of just a thousand families with children to Great Britain. The cases of Mława, Nowa Huta and Czarna Góra, at different times and in different ways show that in comparison to their non Roma neighbors, the Roma migrate to a much greater extent. The unprecedented scale of their emigration was highlighted earlier by some Roma organizations, but the study this article is based on is the first independent confirmation of this fact. As a result of migration, many Roma communities in Poland are in a demographic decline.

Another conclusion is that Roma migrations are not fundamentally and generally "different" or more "exotic" and are not an outcome of their culture, but are sociologically, economically and historically an integral part of the history of Polish society, the region or the city that they live in. At macro structural level, migrations of Polish Roma are on the one hand the effects of the liberalization of mobility regimes after 1989, on the other hand, they are related to the costs of the socio-economic transformation, when Polish citizens applied various livelihood strategies. Some people were involved in circular, informal migration. Others were leaving in groups asking for political asylum. In the context of the post-socialist trauma of great change (Nowicki 2015, Sztompka 2000) and pauperization of society and ethnic tensions, the Roma, like other victims of systemic transformations (Rakowski 2009), were left mostly on their own but, most importantly, could rely on the supportive network of their own families, offering them economic and social capital necessary for survival.

The same holds true for the Roma migrations after the EU enlargement in 2004, which for some communities was the beginning of large scale migrations. Their migration strategies, transnational ways of dealing with family issues and transnational care, upward social mobility abroad, as well as emotions related to migration, separation and returns do not differ from their non Roma neighbors. In some cases lower levels of education and a higher level of obligations resulting from family relationships impact on Roma migration choices, but generally speaking, one should refrain from exoticization of Roma migration. They do not result from the "nature" of the Roma, nor from the deterministically interpreted Roma culture stemming from their nomadic past. They are conditioned by the same macro-structural processes and the agency of social actors as migrations of their fellow non Roma citizens. Both cases of Czarna Góra and Mława shows it very well – the scale of migrations affected both these communities despite their very different mobility traditions. Obviously, certain Roma groups have had rich resources of migratory social capital, which allowed them to better navigate the new environment, understand the regulations or structural conditions. But other social groups in Poland were in possession of such capital too, which allowed them to effectively undertake migration and eventually settling abroad or circulating. Non-Roma inhabitants of Podhale, Podlasie, Opole used and sustained it in a similar way (Iglicka 2009; Jończy 2010). The conceptualization of Roma migration as the result of their "urge to wander" abstracts them from the entirety of Polish society and is, in fact, a sociological and historical positioning of the Roma on the margins of the society.

As a result of migration, there is an unprecedented intensification of contacts between different Polish Roma groups, which is understandable by the logistical issues related to settling in, looking for friends and new relatives or expanding marriage opportunities. This results in a greater number of social spaces where groups so far isolated come into contact, intermarry, organize joint activities, etc. The consequences of this process are multi-faceted. On the one hand, we are witnessing a stronger identification with the conservative approach to the customs of the Polish Roma from the Bergitka Roma, a specific process of accepting Polska Roma traditions as their own. On the other hand, we witness a resistance from Bergitka Roma, especially when it comes to attempts to impose the superior authority of Sero Roma. Ultimately, it affects the emergence of a new dimension of the Roma identity, which exceeds the old intergroup divisions and hierarchies.

The next conclusion concerns the Polish identity of the Roma. Research findings regarding intergroup relations; the popularity of Jehovah's Witnesses movement; returns and emotional attachment to the place of origin – prove its significance in the identity construction process. Polish Roma, among whom we conducted ethnographic research – at least the majority, there are always some exceptions – identify (apart from being Roma) also as Poles, Polish citizens, people who, on the equal footing with the Gadjo are part of the Polish socio-cultural landscape which is a source of their sense of belonging and emotional ties. Like other migrants from Poland, they also feel an affinity with other

Poles and the Polish culture in which they grew up. The attractiveness of Polish-speaking congregations of Jehovah Witness is indeed connected with their Polishness – other Poles go there, rituals are in Polish, and they feel accepted by other Poles as equals.

Similarly, the relations between Polska Roma and Bergitka today are intensified as a result of migration, because in both cases we are talking about groups of people connected to Poland who are abroad and are looking for a thread of commonality. We can even risk the statement that the Roma abroad, beyond the greater assertiveness regarding their own sense of identity as Roma, also become more aware Poles, aware of the value of the place they come from, Polish diversity and specificity. This is not a nationalist declarative patriotism of flags and marches but a kind of "grassroots", ordinary, everyday patriotism based on sentiment to food, landscape, childhood memories, customs, television, music, cultural idioms (such as the great respect and admiration for musicians like Don Vasyl or Edyta Górniak). As in the case of Polish non-Roma migrants, the settlement process and the emergence of the second generation will have significant effects on further cultural reproduction.

In this context it is important to note that during our study we met also numerous mixed Roma and Polish Gadjo couples which indicates that the boundary between what we, somewhat simplistically, understand as "Polish" or "Roma" communities are not distinct separate sets, but rather groups that may overlap in the context of the family but also other "Polish" social spaces such as Polish shops, concerts, work and – as in case of Jehovah Witnesses – religious congregations. In that sense we can view Polish Roma social lives in the UK as a modality of migration from Poland in general, adding to its diversity and homogeneity (Garapich 2016; Kucharczyk 2013; White 2011). The common language, sharing of similar cultural idioms, popular culture (in almost all households in England we visited, Polish TV is on), culinary tastes and links with specific localities in Poland, makes Polish Roma very close to other non-Roma Poles living in the UK. This picture is complex, as we also met some Gadjo who try to deny Polishness of Roma, stressing their "racial" difference. But when we asked our Roma respondents about their identity, we often got the response: "But I am Polish too!"

But if on the informal, family level these worlds sometimes overlap, it must be stressed that on formal and institutional level Polish Roma and Poles' social worlds in the UK are isolated and kept apart. We did not come across any Polish organisation (and there are a large number of them, see: Kucharczyk 2013) that would work with Roma or have Roma members, we are unaware of any cases of Roma children attending Polish Saturday schools and we did not hear about any activity towards that group from the Catholic Church. From our initial assessment, there is also little awareness of Polish Roma from the part of Polish consular offices. A small study among Polish civil society organisations in England, funded by the Polish Ministry of Foreign Affairs, found that the Polish Roma feel totally cut off from the interest and scope of Polish diaspora engagement policy, which the Ministry and the Polish Senate is engaged in (Garapich 2013, 154).

CONCLUSIONS AND ETHICAL DIMENSION OF RESEARCHING ROMA

As we argue elsewhere (Fiałkowska *et al.* 2018) academic silence is never normatively innocent and the expulsion of Roma from mainstream migration studies discourse tells us something significant about contemporary Poland relations with diversity, immigration, and multiculturalism. In that sense, migrating Roma have certainly something interesting to say. On the basis of our study the first claim is that Polish Roma migratory experience needs to be treated as integral to the history of emigration from Poland in general. The history of Roma migration is as important sociologically and historically as are migrations of rural folk from pre 1918 Galicia, Polish Jews in 1968, forced emigration of WW2 soldiers or armies of economic migrants moving to the West during and after communist rule. Both on macroscale of structural conditions as well as microhistory of Polish towns and villages Roma live or lived in, these migrations need to be treated as interconnected with overall picture of mobility from the area.

In similar way, the presence of Polish Roma abroad, needs to be seen by both scholars as well as institutions as an integral part of the broadly taken Polish communities abroad. This means inclusion into the Polish diaspora engagement policy [*polityka polonijna*] aimed at engaging various stakeholders in preserving culture, traditions, language and historical understandings. The implicit omission of Polish Roma from overall diaspora engagement policy is an unfortunate sign of not only ethnically biased lens applied in that policy, but also explicit exclusion of Roma.

The importance of countering the essentialist myth of Roma as somewhat predestined to migrate, hence unable to put down roots in one place goes beyond academic debates but to the heart of local social policy. During our study we came across instances of local officials "hoping" for Roma to leave, taking with them "social problems" which in the views of the officials are associated with the Roma, not local discriminatory policy, racism, cuts in social welfare or lack of employment opportunities for Roma. The myth of Roma nomadic nature has actually negative social costs that need to be addressed and countered.

And last but not least, we need to make a note on ethics. Our research was able to offer anthropological insights described above due to participatory character of our ethnography but also basic attitudes of respect and equality between people engaged in dialogue and exchange of views, ideas and meanings. Unfortunately, Roma experiences with ethnographers and social scientists we came across point that this is not an iron ethical rule. In fact we heard stories of relations between ethnographers and Roma that sounded like instances of discredited 19th century colonial anthropology with an "educated" member of enlightened "elites" treating Roma like subordinate subjects, invading their private, domestic space (for example recording without consent, taking picture of Roma houses interiors without consent etc.) or imposing a superior position. As ethnographers, but also Poles, Gadjo and Roma we call therefore our fellow ethnographers to involve Roma in all ethnographic research on participatory basis treating them with respect and as human beings, not – as many Roma say referring to practices of being observed by ethnographers "monkeys in a zoo".

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SUDAN'S TEA LADIES AND THE LEGACY OF SLAVERY

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This paper presents the institution of roadside mini-cafes run by women – mostly poor migrants from peripheral or war-torn regions of Sudan – on Forty Days Road Street, one of the main streets of Omdurman. These cafes are not only one of the many examples of women's informal activism in an urban environment, but also an institution in which the legacy of slavery is present. This dates back to precolonial times when the peoples of the Nile valley were slave-raiding and slave-owning. The author looks at the institution of roadside mini-cafe as something particularly important for the urban iconography of power, in which – using the terms of structural anthropology – a series of oppositions are materialised: formal/informal, male/female, dominant/subordinate and Middle Eastern/African. The relations to slavery hidden in this particular institution help city dwellers (mostly men from the Muslim majority and Arab culture) in arranging hierarchies, rivalry and legitimating status. Gender and informality are particularly meaningful in this context as both strengthen the situation of radical inequality, intensify and constitute politics of dominance on the one hand and of subordination on the other. This paper is based on ethnographic research which was undertaken in the Khartoum agglomeration in 2013.

* * *

W artykule omawiana jest instytucja przydrożnych kawiarenek znajdujących się przy ul. Czterdziestodniowej, jednej z głównych arterii komunikacyjnych Omdurmanu, prowadzonych przez kobiety, w szczególności migrantki z peryferyjnych obszarów Sudanu. Dla autora fenomen ten nie jest tylko przykładem nieformalnej, kobiecej przedsiębiorczości, ale także instytucją, w której daje o sobie znać dziedzictwo niewolnictwa. Autor przekonuje, że „kobiety od herbaty" rzucają nieco światła na relacje między mieszkańcami Sudanu, w szczególności między „jaśniejszymi", zorientowanymi na kulturę arabską i islam, a „ciemniejszymi", żyjącymi na geograficznych peryferiach. W relacjach tych – używając języka antropologii strukturalnej – materializują się serie opozycji: formalny/nieformalny, męski/żeński, dominujący/podporządkowany, bliskowschodni / afrykański. Artykuł jest plonem obserwacji etnograficznych, prowadzonych w chartumskiej aglomeracji w 2013 roku.

Keywords: Sudan, slavery, citzy, women, ethnographic research

The economic reforms of the 1980s, armed conflicts, the breakdown of state institutions in the 1990s, and the "urban revolution" at the beginning of the new millennium have made the lives of large parts of African society much more difficult than ever before. In many countries, one of the negative effects of the above mentioned processes has been the resurgence of various forms of slavery. Its victims are the weakest: women, children and young people, displaced persons and labour migrants (Bales *et al.* 2011). Although the term “modern slavery”, also referred to as “new slavery”, is in common usage nowadays, it should be treated with caution as there is no universal agreement as to what practices can be considered modern enslavement. For some, this term includes all forms of gross human exploitation and trafficking. In this sense, this phenomenon is considered to have a global reach. For others, it is limited to those areas where legally owned and traded slaves were once to be found and thus a slavery continuum can be spoken about. Undoubtedly, discussions on this subject are often ideologically charged. For instance, in the Western media, contemporary African slavery is usually depicted as evidence of Africa’s on-going primitivism. It seems that the key to understanding slavery is the ownership notion. In the historical Slavery Convention of 1926, slavery was defined as the state of subordination of one man to another. Today it is not so obvious. First of all, in today’s world it is not possible to possess a slave legally and if one is in possession of one then this was done illegally. Slaveholders (not slave-owners) have no formal rights to the enslaved person, but also no obligations to him/her. An enslaved person today is created through violence or the threat of violence rather than in accordance with some law. In other words, modern slavery is a criminal act, a kind of theft of the body, work, identity, sexuality or simply the taking of someone’s ability to decide their own fate. For this reason, slave practices are usually invisible to the naked eye; they are always tightly concealed and silenced. Therefore, in the context of post slavery studies, the most frequently asked questions involve when and how slavery is employed, who its victims are and which crypto-slavery practices are involved.

The contemporary practice of slavery is not really about having slaves – but rather the way they are treated as an effective tool for making money. In our world, a slave has been reduced to the role of a machine in the production process. Slavery is closely tied to labour. A modern slave is not a durable good but viewed as a mere commodity –one which can be bought, used and discarded at any time. Slaves have never been so cheap and their prices are determined by the law of supply and demand – and the fact that this phenomenon is coupled with the functioning of the global economy. Modern slavery results from a variety of phenomena (migration, neoliberal social divisions, gentrification and wars) and takes a variety of forms (human trafficking, slave labour, prostitution and forced marriage) (Bales 1999, 1–6; Bales 2005, 9; O’Connell Davidson 2015).

Sudan is a country that has been associated (rightly) with slavery for many years. During the second civil war in South Sudan (1983–2005), the activity of abducting and selling Dinka or Nuer women and children was practiced. Their price was not excessive due to regular tribal raids and extreme poverty. These phenomena generated a constant risk of falling into slavery for a large part of the South Sudan population. Later those who had been enslaved disappeared somewhere in Central and Northern Sudan. It turned out that, under the patronage of local, Muslim families, they usually became a cheap labour force (photo 1).

Photo 1. A migrant from Nuba Hills, Ghaddar. Photo: M. Kurcz 2013.

Similar practices occurred during another Sudanese conflict – the war in Darfur. At that time a thousands of refugees were exposed to the relics of slavery. These were people who became internally displaced and were looking for shelter in Sudanese towns. Finally, in villages on the Nile of Northern Sudan the vestiges of domestic slavery can still be encountered today in the form of people with slave ancestry who form closed and most importantly servile communities (Kurcz 2007; Jok 2010, 4–5).

A good example of the existence of slavery in contemporary Sudan is the institution of roadside mini-cafes run by women – mostly poor migrants from peripheral or war-torn regions of Sudan – on Forty Days Road Street, one of the main streets of Omdurman (photo 2).

Photo 2. A "women of tea" on Forty Days Road Street, Omdurman. Photo: M. Kurcz 2013.

I am of the belief that this is not only one of many examples of women's informal activity in an urban environment, but something much more meaningful for the local iconography of power. The power relationship hidden in this particular institution helps city dwellers (mostly men from the Muslim majority and Arab culture) to arrange hierarchies, rivalry and legitimize status. Gender and informality are particularly meaningful in this context as both strengthen the situation of radical inequality, intensify and constitute politics of dominance on the one hand, and of subordination on the other.

My ethnographic experience from Sudan makes me believe that the local concept of slavery extends not only to "descendants", but also to all those with an uncertain status – such as labour migrants in urban centres. Migration to the city does not always result in social or economic emancipation as migrants with a reduced status meet a sort of glass ceiling – where they are permanently pushed to the margins of urban life and join the ranks of the lumpenproletariat. They are forced to do poorly-paid jobs, hide their identity and culture, and accept the patronage of higher social classes.

The questions the author wishes to address include how the legacy of slavery in the case of Sudan's tea ladies is to be perceived, what this means for different groups of actors and finally, how slavery helps to organise social and economic relationships in an urban context.

SLAVERY BORDERLAND

A statement verging on a truism is that slavery has been practised in Sudan since time immemorial. It existed in all political organisations of pre-colonial Sudan (Kush, Meroe, Christina Nubia, Funj and Darfur). Within the entire Sahel zone, slavery was a tool for exercising authority (through which a state could reproduce its human resources) as well as being a highly profitable businesses. Slaves came from Nubia, but they were not Nubians. The Nuba Mountains, the borderland with Abyssinia, the marshes of the White Nile and Southern Dar Fartit (today known as Western Bahr al Ghazal) are all areas from which slaves have been taken at least since Medieval times (Johnson 2011, 2). For many centuries, in Sudan, a model of political geography was valid, in which a clear division into two different quality spaces was maintained: a political centre and much more extensive peripheries. All pre-colonial Sudanese countries had such a dual structure. This model is still valid to a large degree and is responsible for the country's internal problems and the maintenance of something close to what can be called social caste relationships.

As has been indicated, slavery has been an important sphere of Sudanese political organization- activity for centuries. During the Turco-Egyptian occupation, however, it rose dramatically. Slaves became one of the main instigators behind the Egyptian invasion of Sudan at the beginning of the 19th century. The Egyptian governors of

Sudan developed the practice of plundering raids in the south. Then slave hunters expanded their activities from areas of the Blue Nile or the Nuba Mountains into the heart of today's South Sudan. Nearly all communities inhabiting South Sudan today were the victims of slavers (photo 3).

Photo 3. A women from the Madi tribe, one of the many societies of South Sudan affected by slavery, Juba. Photo: M. Kurcz 2008.

Men were transported to Aswan, where they were forced into the army as *jihadiyya* (slave-soldiers), whereas women and children were sold on site and treated as sources of revenue for merchants and local middlemen. Though officially government raids were abandoned at the beginning of the 19th century, slavery still continued. It became the domain of private entrepreneurs such as Zubeir Rahma Mansur, who became an independent ruler in the Western part of Bahr al Ghazal, and conquered Darfur (Breidlid *et al.* 2014,104–107).

After 1860, when the Mahdist movement was established, the slave trade still did not disappear, but moved into the hands of natives, the Danagla Nubians and Shaigiya Arabs. In the South they were known as *jallaba* – due to a typical robe worn by Arabs (photo 4).

Photo 4. "Jallaba" – a merchant from Northern Sudan, Debba. Photo: M. Kurcz 2013.

Within the territories of the Luo, Bongo or Dinka people, the traders set up temporary slave factories – the so-called enclosures (from Arabic *zaraib).* These were places of contact between hunters-and-traders and representatives of local tribes who were intermediaries in acquiring people. Slave hunters were quite poor people, who supplemented their low income by means of slaves. Some of these slaves (juveniles and women) were sold in the local market or taken for personal use in the home regions (Breidlid *et al*. 2014, 112–113). It was then in the North that the possession of slaves probably became quite common. They were used in the field when needed or as cheap domestic servants. Black women, considered particularly attractive, became concubines or legal wives. A slave's fate was not doomed forever. A slave belonged to a community, participated in its life and could even become a legitimate member of this community. Usually they enjoyed little prestige, but were allowed to assimilate (for example by way of religious conversion). Becoming a Muslim, however, did not translate into increased freedom since their origin remained unchanged, and they were still dependent. The best they could be was a client (someone who needs permanent protection and representation) or a servant for a part of the society considered more noble. Slaves were expected to specialize in tasks which were not considered very prestigious. In the villages of the Northern Sudan, there was a strict relationship between a person's profession and social status due to slavery. This meant that slaves or their descendants specialized in certain categories of activities, such as pottery, moonshining or fishery. They were also present in the service sector

A very important element in all this was its gender structure. Most people abducted from the northern regions were juveniles and women. The latter were particularly valued because of their "versatility". A female slave could work in the field and look after the house. She was also allowed to undertake some small professional activities such as the production of alcohol and trading in the local bazaar. This resulted in her becoming economically independent with a "secret nest egg". Finally, sexual value was also important. A woman from the South was different from a local woman, since, as a rule, she was not circumcised. It made her a strong object of male desire but engendered ensuing fear and hate from local Muslim women. Thus slavery in Sudan, particularly of a domestic nature, was a clearly gendered phenomenon (Amir 2013).

In the second half of the nineteenth century the dichotomous division into the centre and periphery was consolidated into privileged and marginalized groups, white and black and masters and slaves. The nineteenth century was a time of great change. In the ideological dimension, certain areas of Sudan became what can be described as a slave borderland. Slaves in the northern provinces came mainly from the South resulting in the words "slave" and "black" becoming synonymous. This has led to a polarization of society based on race and the universal identification of non-Arab and non-Muslim parts of the population with low status – or even a lack of it. Slavery became part of the concept of "stranger". In other words, an almost caste system of hierarchy was created (Makris 2000, 26).

Though British colonialism in Sudan was focused, like everywhere else, on the exploitation of people and natural resources¸ ideologically it was presented as a humanitarian mission. The Sudan was exceptional in this respect since it had no clear economic value, and the British presence in this area was associated with Gordon's tragedy (1885) and Kitchener's famous victory at Omdurman (1898). Basically for these reasons the essence of the British Empire's presence was to prevent conflicts and civilise Africans (as was correctly expressed by anthropologist Janice Boddy). Institutions allegedly unworthy of modern man were to be fought against by brave Britons – female circumcision and slavery were at the top of the list. Unfortunately, the fight against slavery meant also its inclusion in colonial discourse as the local population became categorised and stratified. On one side there were fanatically religious, though more predisposed to rule, Arabs, while on the other there were the persecuted, though primitive, Africans. The latter, be it of their own fault or natural predisposition, were threatened with extinction. This was all because of Islamisation and Arabisation. In colonial times, egalitarianism and integration were not propagated, but instead and in accordance with the ideas of indirect rule, the existing hierarchical structures were strengthened. Hence in that period not only can the heritage of slavery be talked about, but also slavery par excellence. And so the British used the so-called "Nubian" military formation recruiting former slaves serving in the Turco-Egyptian army[1]. They were later used in various parts of East Africa and their descendants today form separate identities and demand ethnic minority-status. A similar situation arose in regards to domestic slavery. It is still tolerated, in accordance with the recommendation of Lord Kitchener himself, the hero of "reconquista" and the first General Governor of the Sudan:

> "[S]lavery is not recognised in the Sudan, but as long as service is willingly rendered by servants to master it is unnecessary to interfere with the conditions existing between them" (Amir 2013, 49).

As a result, more than a hundred years after the formal prohibition of slavery, in Northern Sudan the living vestiges of this activity can still be seen. These are visible in the differentiation of people into "free" and "slave descendants" which is still of basic importance for the social structure (Barclay 1964, 237). Nearly every village in Northern Sudan has people called *Sudaniyya* ("Blacks"). They are the descendants of former slaves and almost every village between the 3rd and 4th cataracts[2] is inhabited by at least several such families today. They form indigenous communities that still have a specific system of relationships in common with descendants of the former owners (Kurcz 2007, 70, 81).

The practice of slavery in an independent Sudan is a separate issue. It is not a secret that slavery played a role in the military conflicts in South Sudan and Darfur and there is quite a lot of literature to confirm this. An assessment has been made that about ten to fifteen thousand women and children have been abducted since 1983. In 1987, according to human rights organisations, seven thousand women and children from Darfur and Kordofan became victims of slave-raiders – mostly representatives of Arab pastoralists (Jok 2010, 1–2). Not only have the victims of organised raids been exposed to slavery, but so also have all people fleeing war, hunger and economic poverty, coming under the umbrella term, the internally displaced. These people sought shelter in urban centres of Central and Northern Sudan, where they were housed in their outskirts in provisional camps. There, due to insufficient or limited humanitarian assistance, they were forced to find 'gainful employment' in the informal sector under the patronage of local Muslims. They were at the very bottom of the local social ladder and a good case in point are the tea ladies.

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[1] So called "Nubians" were originally the ex slave-soldiers from Turco-Egyptian Sudan re-used by the British to create a native military force. Their descendants in Uganda and Kenya have developed a sense of identitity and nowdays fight for political recognition and the rights to the land.

[2] The cataracts of the Nile are shallow lengths between Asuan and Khartoum.

TEA LADIES (FROM ARAB: SITTA SHAI)

Sudanese teashops are a permanent fixture in every town, but are also places of importance from a social and economic point of view. They appeared on a large scale in the 1960s together with an influx of migrants from the war-torn South. Today it is the occupation of a variety of women's however, migrants from traditionally peripheral and problematic regions predominate in this sector. On the Forty Days Road – one of the main streets of Omdurman – can be found practically only women from the Nuba Mountains.

A little coffee shop is to be found at an important place, such as a junction or a restaurant. Only tea and coffee are served there, sometimes with snacks prepared on site. A coffee shop always goes hand in hand with another place. Its operation may coexist with a restaurant, a shop or a public institution. It may also be associated with an event, such as a football match or a Sufi ritual.

A teashop is quite simple and is composed of a small counter – cabinet. There, a woman keeps tins with tea, coffee, *karkade* (dried Hibiscus leaves), sugar and powdered milk. She also prepares beverages on it. She has two buckets used for washing the utensils – with clean and dirty water – a water canister a rudimentary stove (the so-called *kanun*), with two pots on it heated by charcoal, a container for grounds and a little stool for washing dishes. All are mini-size. Beverages are drunk from small glasses, typical of the entire Middle East region, which are served on a small tray. A customer sits on a stool, at a small table. Basically these are the ingredients of a roadside coffee shop (photo 5).

Photo 5. A place of work, Khartoum. Photo: M. Kurcz 2013.

Everything is done noiselessly and automatically. A customer sits down and a serving woman puts a heaped spoonful of sugar into a glass, pours black tea directly from a pot (if it is morning, automatically it will be tea with milk), and then, with one graceful movement passes the drink always on an obligatory small tray, to the customer. Payment is usually made after the service.

The women start work at the crack of dawn – as everybody starts their day with a cup of tea (milk being a necessity) – and ends in the afternoon. Some women continue to work after dusk (if there is a restaurant or an important transport point nearby). Some do shifts: one in the morning, another in the afternoon. This might suggest some sort of partnership. All equipment is carefully packed into several baskets and taken away and there is a rule, she is helped by her children.

Looking at the phenomenon from the perspective of a city street, it must be remarked upon that the tea women give the street a complex character. Thanks to them, there is a space for *work*, but also for *non-work*. Thanks to the presence of these women, the street becomes a type of a social structure, mirroring normal life. Due to the ladies the street becomes alive, but also becomes a place of integration. Customers are passerbys, but above all employees of local shops, who often spend the vast part of their day in such shops. Finally, the coffee shops make the Sudanese street not only Muslim, but also African. Since they are run – in contrast to Middle Eastern countries – only by women, drinking tea or coffee has also become a Muslim tradition, an element of a specifically Islamic style of life.

WOMEN AND THE HERITAGE OF SLAVERY

> “Tea ladies” are not only a manifestation of the female informal economy in an urban environment, but also a phenomenon that throws some light on the relationships between the citizens of Sudan, particularly between the lighter-skinned, emanating from Arab and Muslim culture, and their darker-skinned counterparts, living in the outermost regions of the country. As mentioned earlier, the institution of tea ladies expresses patterns of power relations in the society of Sudan. It exposes the iconography of power, which is very characteristic of the modern world – although camouflaged in operation. The relics of slavery can be found in this setting since tea ladies are not fully free, and they are forced to play certain roles which used to be the domain of slaves.

In this particular context, ethnicity is very important. The client of a teahouse is, in the end, an Arab-Nubian, a Muslim, a resident of central or northern provinces. He is a consumer / customer. An African is a service provider. There is a patron-client relationship which goes back to the former institution of slavery. The customer of the cafe is a fully-fledged resident of Sudan, enjoying full political rights and with a sense of entitlement to power and privilege. This is the political aftermath of racist Arabism and politicized Islam, as well as many centuries of prejudice and slavery. The service provider (the tea lady) is a migrant, economic / war refugee who can only function on the margins of economic life. It is not only about economic reality, but also about race. The tea lady is simply blacker, and therefore "worse", "more primitive" and "less worthy". And it comes from the periphery. This fact is unmistakable in Sudan. From the periphery, the Nuba Mountains, or the borderlands with Ethiopia, slaves were brought in. Such people will never equate with the status of others and there is nothing that can change it neither faith nor profession. For a long time, as has already been mentioned, in Sudan status is closely related to geography. This is one of the main causes of antagonism in this country. Jealous city officials or uniformed personnel have repeatedly declared war on street cafes. The women have been driven away and their premises confiscated. I am of the opinion that these actions, can also be attributed to the community. These actions were measured not so much in the gray market as in the local migrants from peripheral areas with allegations of "colonizing" the urban space. I am of the opinion the actions undertaken by the authorities can be seen as a struggle for space and the restoration of the social order as dictated by tradition as the women's presence can be seen as their claiming to be on a par with the local community and thus equal to them.

Gender and the economy are also important here. As is known perfectly well, masculinity and femininity often reflect relations of power. And the division of labour, in addition to the law and ideology, is one of the spheres of gender dominance. Roadside cafes are part of the informal economy where tea-makers, though widely tolerated, work illegally. From a legal point of view, they have no rights, being at the mercy of their immediate environment. At the same time everyone, from a police officer to an average customer, is male. The tea ladies are pagan, unmarried and uncircumcised – in short, shameless. They are not seen as mothers or sisters, but as African women from the periphery; in other words a stereotypical slave. In former times, slaves, were allowed to partake in small trade or services. They were especially known for the production and sale of alcohol, which, among both "heathens" and Muslims alike, was once in widespread demand. This allowed them to possess certain professional and moral freedom, which no self-respecting Muslim woman would countenance. This state of affairs at the same time strengthened negative stereotypes of African women from the interior (Barclay 1964, 240). It is quite likely that the modern cafes of today originate from this tradition, with the only difference that instead of slaves in them only poor, migrant women are to be found. And, instead of alcohol, they sell only acceptable beverages such as tea and coffee. There is also a sexual dimension in all of this. In the popular imagination of the Sudanese, women originating from slavery-based families are associated with prostitution. In the times when slavery was practiced, women from the South were employed to work, but also valued sexually; they often became concubines or the successive wives of their owners. Through the system of common-law marriage with slaves, the process of biological and cultural assimilation began.

After the death of her owner, the slave woman was generally granted freedom, and her children inherited a certain part of the estate. Even today, negroes from the South are considered the quintessence of feminine beauty. Similarly, the sexually loose stereotype is transferred to all women from the South, in particular to migrant women from the country, with an unclear family situation. For women from – what are perceived to be – "normal" homes they are a challenge as they bring to mind old feelings of fear associated with the presence of beautiful, black, uncircumcised slaves. Thus, in the work of roadside café women can be found relations of subordination, servility and even sexual violence (it is an open secret that women who provide sexual services also run cafes serving tea and coffee).

There are strict rules in cafeteria culture which emphasise situations of extreme inequality. None of the women work alone or independently. Each tea shop works in association with a restaurant or a shop. Formally, a woman is not a slave, but practically, she is not free either. There is no space here for her culture, language or community. There is kindness and friendship in the form of regular customers. However, there is no question of partnership or understanding. Everything is subordinated to one Islamic model. Muslim etiquette applies and communication takes place exclusively in Arabic. African identity and custom are suspended. In this context, it is post-slave in character, carrying with it relations of domination and subordination. It is a metaphor and a reminder of the near caste arrangements which still hold sway in Sudan.

CONCLUSION

Coffee shop culture manifests master / servant practices dating back to the times when there was slavery in Sudan. It is used to establish hierarchy, rivalry or to legitimise status. A stake or prize appears. For the stronger party a reward entails a status of superiority. The stake the woman is fighting for is to avoid humiliation, notwithstanding her meagre earnings. In this context the institution of tea shops has a post-slavery character and it engenders a relationship of dominance and subordination in a particularly antagonistic version. Using terms from structural anthropology – a series of oppositions are materialized: formal / informal, male / female, dominant / subordinate and Middle Eastern / African. They all help town citizens (mostly representatives of the Arab and Muslim majority) to establish hierarchy, rivalry or to express identity. Finally, they have great significance in the political arena – in collective mobilization, as well as the stigmatization of entire social groups – in this particular context migrants from distant periphery. This category is racialized with phenotypic features, such as skin color and hair structure being ascribed to them.

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photo 4 – "Jallaba" – a merchant from Northern Sudan, Debba. Photo: M. Kurcz 2013.

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Izabella Main. 2018. *Lepsze światy medyczne? Zdrowie, choroba i leczenie polskich migrantek w perspektywie antropologicznej.* [Eng. *Better medical worlds? Health, sickness, and healthcare of Polish female migrants in anthropological perspective*]. Warszawa: Wydawnictwo Naukowe SCHOLAR, pp. 208, ISBN 9788373839502.

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Poland's accession to the European Union in May 2004 has led to the largest emigration flows in the country's post-war history. Much has been written about this exodus. Authors analyzed the heterogeneous migration flows (unskilled and semi-skilled migrants, students and recent college graduates seeking short-time employment, young professionals wishing to start a new career or set up their own business, and intergenerational families), emphasised high levels of mobility (transnational and circular migration), and variegated settlement patterns (Burrell 2009; Okólski 2012; Goździak and Pawlak 2016). In this sea of publications, there are few that center on migration and mobility of Polish women. Izabella Main's monograph *Lepsze światy medyczne? Zdrowie, choroba i leczenie polskich migrantek w perspektywie antropologicznej* (Scholar 2018) is a rare exception.

Focused solely on women and their health, the monograph is a result of anthropological research carried out over a decade in three European cities: London, Barcelona, and Berlin. The book is an excellent example of multi-sited ethnography, a method of data collection that allowed the author to follow a topic and social and cultural problem through three field sites and analytically explore Polish women in motion and their ideas related to infertility, pregnancy, child labor, and postpartum care that extend over multiple locations (Marcus 1995). Additionally, the book incorporates self-reflection and elements of auto-ethnography. As the author confesses, her own battle with infertility provided the original inspiration to extend the personal into the social and cultural.

Arthur Kleinman, a prominent American medical anthropologist and medical practitioner, argued some 30 years ago that human experiences with sickness and healthcare are socially constructed and culturally determined (Kleinman 1988). The rich ethnographic detail in Izabella Main's book provides ample support for Kleinman's thesis. The narratives of Polish women residing in London, Barcelona, and Berlin include a multitude of cross-cultural comparisons as well as reflections on the effects of emplaced medical practices on how they conceptualized their pregnancies and pre-and post-natal care. While on occasion, the women essentialise the cultures they speak about, by and large their narratives emphasise the differences in care affected not by culture writ large, but by variegated health care systems, cultural characteristics of individual health care providers, and different philosophical approaches to health and wellness. Main makes sure that these nuances are presented appropriately and that the reader knows that there are different medical practices both between and within different cities, that the women are cognizant that as transnational migrants they have many more choices in designing the best care package that suits their particular conditions and preferences than their sisters or friends living in Poland.

Although not trained as a medical anthropologist, Izabella Main "gets medical anthropology". Her book exemplifies the goals of contemporary medical anthropology – to better understand those factors which influence health and well-being, the experience and distribution of illness, the prevention and treatment of sickness, healing processes, the social relations of therapy management, and the cultural importance and utilisation of pluralistic medical systems – almost to a T.

Following the tenets of applied anthropology, Main has studies up, down, and sidewise. The reader gets a very good understanding of the different healthcare systems, including health insurance schemes that expand or limit migrant women's access to care. The author analyzes access to healthcare both as a basic human right and as a commodity. There is an inherent contradiction between these principles. In the case of migrants, their ability to access care is not only affected by the healthcare system of the destination country *per se*, but also by the repertoire of rights they are accorded or denied. These rights are very much affected by their immigration status, type of residency permit, etc. Once the reader understands the nuances of the intersectionality of migration and healthcare, she is able to understand the individual choices Main's interlocutors have made when it comes to their pre- and post-natal care. The ethnographic data collected across three cities allows the reader to understand these issues comparatively.

Izabella Main is also a great fieldworker. We get to know Teresa, Edyta, Ewa, Dagmara, and several other women through extensive interview quotes and synopses of their health and well-being conditions. The quotes, in particular, indicate that the author had developed an excellent rapport with the women she studied. They shared intimate details – often topics that are taboo in "Polish culture" – related to their reproductive health; details that a researcher doesn't always get to learn unless they know how to draw people out, how to share experiences that might be similar to those of the research subjects.

Izabella Main reflects on her own positionality in this research as a mobile Polish woman, as a woman trying to conceive, and as a mother to a young child. When research is spearheaded by and combined with personal experiences, certain ethical issues come to the forefront, writes Izabella Main in the Introduction (p. 23). Excellent rapport with research subjects often morphs into personal friendships maintained long after the anthropologist leaves the field. Main wonders what are the ethical ramifications of using continued correspondence via e-mail and social media to inform one's study. Does the research truly end when the anthropologist gets on the plane to return home? Or has "the Field" changed in the 21st century and now also includes exchanges on Facebook and e-mail? I hope anthropologists continue to interrogate these issues as they seem very important, especially when we conduct research on migration in transnational space.

The impact of Izabella Main's book extends beyond anthropology. It includes a lot of observations and analyzes that can be useful both to medical practitioners – nurses and doctors – and to women who plan to settle outside of Poland. As an applied anthropologist, I enjoy the practical scope of this monograph. As a reader, I also appreciate Main's style of writing: very accessible to interdisciplinary audiences, academics, students, and lay people. My wish is that in her next project, Izabella Main studies slightly older women who grapple with middle age chronic diseases or to continue the reproductive health theme, with menopause. Both provide excellent opportunities for cross-cultural investigations.

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Michał Wróblewski, ***Medykalizacja nadpobudliwości. Od globalnego standardu do peryferyjnych praktyk*** **[Eng.** ***Medicalisation of hyperactivity. From global standard to peripheral practices*****], Kraków: Universitas 2018, pp. 332, ISBN 97883-242-3479-0**

Anna Witeska-Młynarczyk

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Does ADHD[1] really exist? Michał Wróblewski, a sociologist and philosopher from the Nicolaus Copernicus University in Toruń, argues that it does. During the course of his 300-plus page new book, he explains in a precise, interesting and erudite way, the phenomenon of this relatively young diagnostic term used in the psychiatry of children and youth worldwide. He writes about the global and local history of ADHD with a great deal of detail and thoughtfully discusses both the scientific and social controversies surrounding this disorder while emphasising their dynamics and complexity. The author guides the reader towards his own ethically considered position on hyperactivity and explains how and why ADHD exists in the modern world.

The book is a sociological analysis of the medicalisation of ADHD carried out from the global level and with particular emphasis on the American context. It also presents other national contexts, e.g. German, French, Italian, and Polish – where the author conducted his own qualitative research: in-depth interviews with experts and analysis of the discourse of Polish media and the content of internet forums. *Medicalisation of hyperactivity…* (Pol. *Medykalizacja nadpobudliwości…*) is not a book critical of contemporary psychiatry. I would instead argue that the author attempts to explain the mechanism. Wróblewski has written a very strong, coherent monograph based on complex and ambitious theoretical inspirations that give this work a prudent language that is free from judgment, but also which provides methodological rigor by which ADHD – a phenomenon that is heterogeneous and in a continuous process of becoming – is presented as logical and tangible, although far from simple.

The book consists of an introduction, five chapters and a conclusion. In the introduction, the author provides readers with the main trends in the theory of

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[1] ADHD – Attention Deficit Hyperactivity Disorder is a psychiatric diagnostic category known also under the label Hyperkinetic Disorder. It involves symptoms of hyperactivity, inattention and impulsivity and it is diagnosed both in children and in adults.

social sciences, which he incorporated in the research. The theoretical approach developed by Wróblewski combines the sociology of medicine (in particular, a new theory of medicalisation, which departs from a simple idea of medicine as an instrument of top-down social control), medical anthropology (by discussing such concepts as *illness*, *disease* and *sickness*), sociology of medical knowledge (in particular, the approach to a disease as a social fact), actor-network theory (ANT) and bio-political analyses (the author uses Immanuel Wallerstein's centre-periphery model and refers to Michel Foucault's reflection on deviation and biopower). The author discusses, for example, Peter Conrad's theory of medication as well as Adele Clarke's theory, and briefly presents case studies in the field of sociology of medicine, health and illness, such as the works of Ian Hacking on dissociative identity disorder or Allan Horwitz on depression. The author also discusses texts by Ludwik Fleck and Ian Hacking in the field of sociology of medical knowledge and explains such concepts as "the collective knowledge production", "creation and development of a scientific fact", and "ecological niches". In the final part of the introduction, the author convincingly presents a rationale for choosing the methodology of his research project.

In the subsequent chapters Wróblewski expands on the content outlined in the introduction. The first chapter is devoted to the topic of medicalisation. The author introduces the classic theory of medicalisation, critiques it, introduces a more nuanced picture of modern medicine and shows its connections with technoscience, and in particular, with neuroscience. The sociologist also places his analysis in a historical and economic context and devotes space for a discussion regarding the economic changes resulting from the progressive neoliberalism and commercialisation of medical services and the commodification of health, including activities undertaken by non-state actors such as pharmaceutical companies. Wróblewski also discusses the subject of state bio-politics and new ways of disciplining oneself, which are expressed, for example, in the ideology of healthism. The topic of "bio-sociality" and the impact of patient movements on the processes of medicalisation are also important for the case study. In the first chapter, the author provides a heterogeneous image of medicalisation, which is developed in the following parts as a more concrete content, because it concerns only one disorder and its functioning in the Polish context.

The second chapter is devoted to the history of ADHD as a medical fact. Wróblewski considers the objectification processes of this diagnostic term on three levels: development of medical knowledge (discovery of disorder and gathering empirical knowledge), the evolution of psychiatric discourse, and, finally non-medical factors that had a formative influence on the socialisation of the diagnostic term in question, such as development of civil society, the impact of large capital, and state policies. The sociologist takes us on a journey in which we see how, over time, with the help of many institutions and channels for disseminating knowledge, ADHD has become a recognisable social problem.

Wróblewski's book, and in particular the third chapter, deals with the globalisation of the biomedical model of disorders. The author shows the process of transferring and expanding the impact of biomedical infrastructure in two dimensions – impacts on institutions and medical practice and on the culturally defined image of health and disease. The sociologist argues that "the globalisation of ADHD is connected, on the one hand, with the globalisation of neoliberal rules of social life, which generate specific attitudes and problems, and on the other, with the globalisation of expert systems that are to remedy these problems" (Wróblewski 2018, 152). What is both interesting and important is the discussion on the use and reliability of epidemiological data, undertaken by, for example, China Mills in her works, and a reflection on psychiatric diagnostic technology and its spread. These and other tools for making ADHD real in local contexts are discussed by the author with high accuracy and with a focus on practice and materiality. The globalisation of mental disorders has different trajectories. As the author writes,

> "it is not a one-dimensional and one-way process. [...] It may give rise to resistance and controversy, which in the longer term will make the local vision of the disorder specific" (Wróblewski 2018, 161).

The last two chapters of the book present the Polish context. The fourth chapter is devoted to medical practice. Assuming that ADHD is a border object (that is, for which various expert groups take different points of view, while cooperating to stabilise this object), the author shows how physicians and psychologists cope with diagnostic ambivalence and the heterogeneity of diagnostic and therapeutic practices. Based on the statements of experts, the chapter concludes that in Poland the mixed mode of understanding ADHD prevails, assuming that the biological factor is important in the aetiology of the disorder, but that social issues are also significant. This is an important conclusion, because it opens the way to include conclusions about the specificity of the Polish context for analyses comparing ways of constituting ADHD in different national contexts.

Finally, the fifth chapter discusses the evolution of the media discourse on ADHD in Poland and sheds light on the struggles of parents with controversy and uncertainty by presenting discussions on internet forums. Wróblewski identifies these areas of production and learning as a "lay level" ["poziom potoczny"]. He tries to link narratives to the broader questions and issues discussed in previous chapters, for example, by looking for an answer to the question of how medical rationality is established in the world of laypeople. Thanks to the inclusion of material from his own research, the book becomes something more than a description of actors and networks, a story about the evolution of the definition of a disorder or the analysis of emerging controversies. The words of doctors, educators, psychologists and parents cited in the pages of the book and anchored in actually lived reality, describe to a certain extent how ADHD is being established in (not only) medical practice in modern Poland. The analysis of the content of online forums for parents of children with ADHD, shows how demanding the role of caregivers is. The author also points to the important role of biosociality in legitimising and stabilising the biopsychiatric framework and in solving controversies, which are quite common for ADHD.

The question of whether ADHD really exists becomes a theoretical question for Michał Wróblewski. In the conclusion, there are echoes of the dispute between constructivism and realism in trying to provide the answer to this question. He reaches for, among others, the actor-network theory, which focuses on practices and processuality and encompasses both biologicality and materiality, as well as the dynamics of social practices and their political position. Wróblewski's book is an expression of the process of departing from the division into *disease* and *illness* and simple models of medicalisation in Polish works in the field of social sciences focusing on health and disease, in favour of perspectives that are processual and focused on internment practices anchored in the historical and material world. The methodology used by the author does not privilege the practices themselves, but only allows for looking at different kinds of narratives about them. Nonetheless, learning about the ADHD network and controversies gives the reader a very broad and fairly detailed picture of the process of formation of ADHD in Poland, understood as peripheries which, as the author writes, are doomed to "reproduce psychiatric knowledge" (Wróblewski 2018, 148).

In his work, the author refrains from criticising the practices of medicalisation. However, the author's ethical prudence, in my opinion, leads to the drawing of an overly optimistic picture. From my research experience it appears that when we start to look at the formation of ADHD in the everyday life of Polish children, in particular children from families of modest means, it is somewhat more difficult to preserve a neutral stand towards the practices of psychiatry. From the perspective adopted by the author, there are no visible social inequalities or those resulting from the place of residence, and how they affect children's contact with psychiatry. The author does not touch on the subject of the state of Polish child psychiatry or the readiness of Polish schools to support children diagnosed with ADHD. The author only briefly refers to the subject of stigmatisation, which is key from the point of view of children's experiences with psychiatric practices. Undoubtedly, the children themselves are missing on the pages of this book. As always, they fidget in their chairs, are considered naughty and they are cases in the stories of doctors, teachers and parents – they remain the object of research. They are not treated as having agency.

In spite of these remarks, I have no doubt that the book will be a model work in Polish thought about medicalisation and it will set out ways to analyse how a mental disorder becomes a social fact. The author indicates where to look for mechanisms that make the medical term "become a full-fledged element of the social world" (Wróblewski 2018, 19), recognises the complexity of social objectivity, and also underlines the historical dimension of the emergence of social facts. Selected fragments of the text should certainly be included in syllabuses in the field of medical anthropology. Although we will not find ethnographic material on the pages of the book, it should be emphasised that the text contains and patiently explains the imaginarium important for contemporary ethnography of health and disease. Anyone interested in search for an answer to the question "does / how does ADHD really exist?", should reach out for Wróblewski's book.

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INTERRUPTING SILENCE – ON THE BOOK *ANTHROPOLOGY OF PSYCHIATRY OF CHILDREN AND ADOLESCENTS*

Anna Witeska-Młynarczyk (ed.) 2018. *Antropologia psychiatrii dzieci i młodzieży. Wybór tekstów* [Eng. *Anthropology of Psychiatry of Children and Adolescents*]. Warszawa: Oficyna Naukowa, pp. 364, ISBN 978-83-64363-94-8.

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> "I am leafing through an album by the Canadian painter Peter Doig, when I come across a painting entitled *Blotter*, painted in 1993. It is a snowy winter and a lone young boy is checking the ice on a lake in a forest with his foot, looking down at his reflection" (Witeska Młynarczyk 2018, 7).

The painting, referred to by Anna Witeska-Młynarczyk in the foreword of her book, is an introduction to *Anthropology of Psychiatry of Children and Adolescents*, which, in Poland, is the first cross-sectional presentation of contemporary research straddling the border between new childhood studies and the anthropology of psychiatry. Witeska-Młynarczyk writes:

> "The fact that the boy is immersed in the landscape, reflected in the surrounding world and plunges into thoughts about this reflection, seem to illustrate well the main traces of social studies, for which a person is always immersed in something, is always a part of something, whether it be a history, material environment, or interpersonal relations (Witeska-Młynarczyk 2018, 8).

This beginning reveals well the character of the book. On the one hand, it is a review, an interdisciplinary presentation of contemporary social research on the psychiatry of children and adolescents. On the other hand, the book is more than a set of representative texts. It is an original anthology, meaning that it boldly builds its own voice in a world in which the processes of medicalisation and psychiatrisation in the ways young people act and feel have significantly increased.

Mental health – Witeska-Młynarczyk reminds her readers in the introduction – has become a subject of global policy involving international organisations (World Health Organization and The Movement for Mental Health in the World to name but two), expert and patient associations, pharmaceutical companies and insurance companies. The human psyche is no longer simply a subject of discourse or social action. It has been subordinated to “health technology” (a term coined by China Mills). The latter is a global, relatively coherent system (or, according to some researchers, a “regime”) of values, representations and practices treated as universals. There are practical consequences of this. For example, according to data invoked in the book, the number of prescriptions for antipsychotics to children in the US increased fivefold between 1992 and 2002. The number of diagnoses of a variety of disorders is also growing exponentially, and psychiatric care is being provided to younger and younger children.The increasing use of pharmaceuticals involves minimizing the costs incurred by states in developing standardized, compliant citizens.. On a transnational scale, the system discussed by Mills replicates the asymmetry of global politics and economy. The expansion of Western psychiatry in non-Western worlds is accompanied by unequal access to institutions that allow individuals experiencing mental crisis to be helped by means other than pharmacological ones. Expert criticism against the prescription of strong psychotropic drugs to children is still the domain of the global North. The Global South is being embraced by intensive psychiatry trends, which in the absence of resources to support traditional, local forms of mental health maintenance or to create a network of psychotherapeutic centres equates to the intensive promotion of the use of psychotropic drugs.

The indicated global processes are accompanied by the rapid development of neuroscience and bio-medicalisation of psychiatry. Mental phenomena are increasingly considered in terms of phenomena based on the brain and not on the individual. Mental suffering – since the 20th century considered in terms of non-normative ways of feeling and action requiring control and regulation by the state and international institutions – has been increasingly transformed into a discourse about the biochemical imbalance of the brain or the poor performance of neurotransmitters. What has disappeared from scientific narratives is what Florian Znaniecki described as a humanistic coefficient resulting in diagnosed people being seen as subjects of certain processes, and not objects of phenomena independent of them, but dependent on the diagnosis, control and actions taken by experts. Consequently, “biomedical epistemologies” may serve to divert public attention from the “objectively difficult conditions” in which individuals live. Focusing on the brain means that questions about the social and not just the biological causes of mental disorders can be overlooked.

However, macro-scale processes are not the main subject of this book. They give important contexts in which individual stories of people leading “epistemic struggles” in order to achieve happiness are placed. This happiness can be understood differently in each case and attempts to achieve it can be made by means of meaning and actions taken in agreement with or contrary to what Mills describes as “the system”. As Witeska-Młynarczyk states, “scientific objects” are the subject of “social interactions”, which means that “they do not only have a historical life on the pages of scientific journals” (Witeska-Młynarczyk 2018, 20). They operate in a dense network of interrelations between the daily lives of the diagnosed persons, their families, the clinic, the laboratory and the school. It is the school that has become an important place for the first diagnosis on the map of these relationships and for the recognition that a child does not meet the psychological and behavioural "norm". And as an institution, as well as a network of social practices with a specific, not yet sufficiently recognised role in the discussed phenomena, it demands further reflection beyond the scope of this book. Counteracting – both discursive and practical – negative aspects of the bio-medicalisation and psychiatrisation of children and adolescents entails not only the necessity to change the functioning of widely understood health care organisations but also requires holistic reforms concerning education, including schools.

The emphasis put on "epistemic struggles" makes children and teenagers, as well as their parents, the main characters of the book. These are people whose stories build a broad spectrum of different interactions with psychiatric care and include African-American mothers, cited by Linda Blum, who are often afraid to administer medication to their own children, demanding rights to normality and suggesting that the background to the school's demands on children is racial. They also include British children diagnosed with ADHD, described by Ilina Singh, who talk about their own emotions (how ADHD interferes with them, but also how it helps), as well as about their friends who help them avoid punishment by holding them back in situations where fights may occur. Included also are teenage mothers from Brazilian districts of poverty, cited by Dominique Béhague, who oppose labelling teenage pregnancies as pathological and who do not accept their stigmatisation and resist those who deny their ability to make informed decisions. Finding inclusion also is anthropologist and social worker, Brenda A. Lefrançois, who observes her own entanglement in social welfare institutions, which once were involved in taking children away from indigenous Canadians, and which are now forcing to psychiatricise people whose behaviour does not fit into the stereotypes of the "proper" behaviour of white middle-class teenagers. Space is also found for John, a person with autism and the son of Chinese immigrants, who understands and can do more than his family thinks, but because of medical advice which suggests bilingualism is a therapeutic obstacle, finds himself to be the only one in the family who does not speak Chinese with his loved ones.

The author's choice of characters and texts present in the volume gives emphasis to certain methodological tendencies as most justified. These consist of multi-sited research, the problematisation of micro and macro levels, in which not every case proves the reliability or submissiveness of the subjects concerned by the text, and above all, the problematisation of relations separating and linking anthropology on the one hand, and psychiatry and neuroscience on the other. All the texts in the volume place emphasis on showing the protagonists of the story in a complex network of practices involving various agents of social life. These are human and non-human agents (experts and pharmacists, specific people working for a variety of aid institutions and standardised procedures in which they are involved), institutions (schools, clinics and hospitals) and persons (parents, teachers, classmates – both of the annoying and supportive variety).

The presentation of the local and global dimension of the lives of the characters in the volume is accompanied by a conscious resignation from easy diagnoses based on binary interpretation schemes. The *Anthropology of Psychiatry of Children and Adolescents* distances itself from unequivocally anti-psychiatric tendencies and descriptions of passive individuals opposed to oppressive institutions. Also, it complicates another binarism characteristic of anthropological research, which consists in showing, on the one hand, institutions imposing systemic forms of action on individuals and, on the other hand, causative individuals processing them according to their own goals and ideas. The stories mentioned in the volume are not a simple praise of local causality or an equally simple accusation against the "system". The self-ethnographic tendencies present in the volume are similarly conceived. The epistemic and professional position of the anthropologist and social worker Brenda Lefrançois belongs neither to the "system" nor to what opposes it. It is neither a protest, nor resistance, nor proof of submissiveness. In this respect it is similar to Mara Buchbinder's position, who tries to negotiate in a network of tensions between hospital staff and their patients. The world experienced by the protagonists in this volume evokes a view in which the "system" of psychiatric care and institutions associated with it, is a scattered network of different social practices taking place between different agents. In this network, individuals are neither unambiguously causative nor unambiguously submissive. With tools available in the form of narratives and practices and procedures, these individuals create, with differing results, their own biographies, which are not necessarily coherent and not necessarily involved in clearly localized visions of the world. In this network, no anthropologist has an easy position. Anna Witeska-Młynarczyk does not give the floor to the "oppressed", nor does she speak unequivocally on their behalf. She instead tries to understand the reverbs and silences emanating from different sides and levels of social life whose sources are as difficult to locate as the authentic experiences of the people behind them is, including the youngest.

In Witeska-Młynarczyk's proposal, resignation from a binary account is entirely consistent and has far-reaching ramifications not only for anthropological methodology, but also for forms of organisation of forms of thinking and scientific activity in general. That is why, among others, the project of cultural neuroscience presented by Suparna Choudhury appears in the volume. It combines anthropology and neuroscience in a way that allow each of them to maintain relative specificity. The cultural neuroscience proposed in this text is expected to dissolve the distinction between nature and nurture, which is intensely analyzed today and which strengthens the gap between the sciences that Dilthey once called explanatory and those he called understanding ones. It is supposed to take into account and revise the cultural entanglements of brain science and also intended to take into account the anthropological dimension of the process which concerns the development of the "enculturated brain". The description of the latter, according to Choudhury, could benefit from a synthesis between dictionary definitions, methodologies and theories of hard and soft sciences, as it *de facto* concerns each of them. This is not purely for cognitive reasons as it seems that such an understanding of neuroscience could effectively build new forms of action in a world in which the division between understanding and explaining sciences is no longer based solely on methodological and discursive differences. It is also sanctioned by certain geopolitical processes related to the management of reflectivity and narratives that legitimise or criticise technology, the economy and certain policies. The binary division of sciences can nowadays serve to channel and marginalise resistance to certain phenomena, confining them to the niches of social sciences and humanities which have little influence on these phenomena. The breakdown of this binary approach, in turn, may be a necessary condition for building new social policies aimed at equal opportunities, whose social credibility require new dictionary, new methodology and new disciplinary definitions.

In conclusion, I would like to point out something that deserves separate attention in *Anthropology of Child and Adolescent Psychiatry*. It is a narrative frame that accompanies the texts presented including the already quoted beginning of the introduction and equally moving epilogue. This frame deliberately avoids strictly scientific discourse. The book begins with a story whose pretext is a dense symbolic image, *i.e.* a medium whose power is based on what cannot be finally expressed. And it ends in the same way, with the image of a boy who tries to escape from hospital and who encounters the verbal and physical violence of a nurse, a boy who "does not want to be there" and does not want to be shouted at (Witeska-Młynarczyk 2018, 342). If Hannah Arendt was right about the sign of the crisis of modern times being scholars (for her probably the last instance of critical and ethical reflection), abandoning "telling history", which according to Arendt, makes it possible to restore meaning to human affairs, which is neither alien nor imposed on them and which permits the giving of both ethical and political meaning – then Witeska-Młynarczyk's book restores this meaning in a clear way. It is as a result of the stories collected in the book that it is possible to act effectively against the "dehumanization and decontextualisation of psychiatric problems" and to show "that they are close, part of each of us, and that collective and individual human actions can feed and form them in different ways" (Witeska-Młynarczyk 2018, 38). This can be shown because the story, just like the processes and experiences mentioned in the book, is bricolage-like, non-linear and ambiguous, inseparably connected with the storytellers, and especially with what is particularly difficult to talk about.

The anthropology of child and adolescent psychiatry stems from an awareness that "breaking the silence" associated with children, young adults and their problems is particularly difficult, and consequently also requires special genres and textual styles. The dominant dictionaries of scientific representation are entangled in perspectives which the book fundamentally undermines. These are dictionaries that essentially belong to adults or people who have skills specific to adults. These are associated with social success rather than crisis, with "normality" rather than with what remains external to it. "I think of childhood and youth as unique, that they could be such" – concludes Witeska-Młynarczyk (2018, 342). I think that without reading this book this way of thinking of childhood and youth would be difficult to understand.

translated by Paweł Kosiorek

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