Abstracts

Anna Wądołowska

Biomedicine and female reproductive health among the Purhépecha indigenous people in Mexico

Better access to biomedical services, especially those related to female reproductive health, in the Purhépecha region has resulted in a decreasing demand for the traditional services of indigenous midwives during labor. However, the quality of the biomedical healthcare available to Purhépecha women very often arouses their distrust.

Their concerns are provoked by a high rate of pregnancy and childbirth medicalization in state hospitals. First of all, abuse of cesarean sections performed on women has been widely reported. My interlocutors are aware that this medical procedure limits the number of children a woman can have. Moreover, after a third caesarean section doctors usually strongly urge the women to have tubal ligation. Some women also charge that sterilization was carried out on them without their or their husband's consent.

In Mexico, public policy concerning birth rate control is aggressively implemented. It appears that the biomedical staff aims more at reducing population growth than at caring for their patients' health. Thus, the right to decide about one's fertility and the number of children one wants to have is violated.

The results of my research lead to the conclusion that public strategy maintains the traditional *indigenismo* policy which in practice deprives indigenous people of the right to decide for themselves.

Iva Šmídová, Lenka Slepičková

Medicine as reproduced powerlessness: everyday life in Czech reproductive medicine from the physicians' perspective

The chapter aims to provide deeper insight into the situation of physicians in Czech reproductive medicine within two important contexts: the post-socialist restructuring of the health care system and more general changes of the status of the medical profession. The analysis focuses on two subfields of reproductive medicine: assisted reproduction and childbirth as representations of the interconnections of everyday lives with medicalized

practices. It illustrates the pervasive blurring of their presence in our thinking on the family, normality, gender, bodies, their salience in popular and media accounts of medicine and their openness to commodification and commercialization. The analysis is based on 30 in-depth interviews with medical professionals working in the studied specializations. It reveals how individually perceived personal exhaustion is interconnected with external conditions on the level of organization of everyday hospital work and on a broader level of expectations from the medical profession as such. Professionals' accounts of their everyday experience show how the hegemonic position of (bio)medical expert knowledge is maintained within the hierarchical and rigid settings of the provision of health care, and how it influences the work of medical professionals and their relations with patients.

Elżbieta Korolczuk

Infertility, identity, citizenship: An analysis of the social mobilizations concerning access to in vitro in Poland

The chapter focuses on the process of constructing collective identity in social movements focused on health. It examines the strategies for identity work in the case of a Polish patients' advocacy organization, the Association for Medical Treatment of Infertility and Adoption Support "Our Stork" (Nasz Bocian) as well as its Internet forum. The main question concerns the ways in which different understandings and interpretations of infertility are constructed and negotiated in the specific cultural and social context of Poland. Theoretically, the aim of the paper is to examine the process of constructing collective identity in relation to health and the body in different discursive spaces (within and outside the movement). The conclusions are based mainly on qualitative analysis of the posts placed on the forum and interviews with key activists of Our Stork.

Anna Krawczak

What is hidden: Areas of silence in the Polish IVF debate in perspective of gametes and embryo donations

In Poland, the disregard of European Directives and the lack of specific laws makes the Polish ART (artificial reproduction techniques) market both attractive as well as dangerous for patients. This article describes how, why and for whom the Polish debate constructs areas deemed open to discussion and areas of silence. Special attention is put on the gametes and embryo donation issue as a site of controlled verbalization. This symbolic control is held by IVF centers, politicians and part of the Polish media, which choose what should be verbalized and what should be silenced. Polish patients seem to be changing their attitudes towards donating their frozen embryos to anonymous recipients and towards the destruction of embryos, but their voice is neither socially audible nor politically desirable.

Ewa Maciejewska-Mroczek

A tiny itsy bitsy gift of life: Children and gamete donation

The development of new reproductive technologies changes many social intuitions about biology, genetics, and kinship. Although this situation has been explored in literature, little attention has been given to the ways it has changed children's worlds. This article explores the social and cultural situation of children born thanks to ART, particularly where a third party is involved (gamete donation). It analyzes the medical and legal contexts of the children's situations. Assisted reproduction, especially with gamete donation, is taboo and is often kept secret, thus children have no knowledge of their origins. The author, using the concept of identity rights, analyzes some possible outcomes of informing children about their identity. She presents some books for children that are aimed to explain third-party assisted reproduction and analyzes the cultural views about parenthood, family, medicine, reproduction, etc., that they express.

Marta Król-Szczepkowska

Romanticizing childbirth and the development of medical technologies

This paper is based on my fieldwork, carried out in Warsaw among mothers who identify themselves with natural parenting (a term used to expound parenting practices related to Attachment Parenting and Green Parenting). In this article I describe the romantic vision of so-called natural births set in the context of current medicalization processes and the development of new reproductive technologies. I invoke the stories of mothers who knowingly resigned from institutional medical assistance, or tried to minimize medical interference on maternity wards. Furthermore, I try to describe the meaning that my interlocutors attached to home births, or those organized in birth centers. I draw my attention especially to the lotus birth practice. I analyze the issues linked with language and manner of narration, including the metaphorization of both the birth experience and the child, which was often compared to plants and animals. I also write about such categories as intuition and maternal instinct.

This article aims to examine how the escape from biomedicine gives women a sense of freedom of choice; actually, it has potential for emancipation. On the other hand, this alternative model, which emphasizes the value of so-called natural instincts, in fact starts to be a source of new pressure. It operates on alternative expert and scientific language, but most of all it burdens women with responsibility in case of failure.

Magdalena Radkowska-Walkowicz

Altercations with technology: Prenatal testing through an anthropological lens

This chapter presents an anthropological analysis of prenatal diagnosis in the specific cultural context of Poland. It examines the social impact and cultural meanings of prenatal tests, especially the PAPP-A blood test. How do they change the experience of pregnancy? How do women describe and evaluate their experiences with prenatal tests? How have they become part of routine pregnancy care in Poland? The analysis focuses on this technology's „invisible work" and on the ways that pregnant women negotiate its meanings. Finding prenatal diagnosis to be a highly "complex cultural object" (as Rayna Rapp calls this technology), this paper explores the biomedical claims and the private strategies employed to control the experience of pregnancy and motherhood.

Krystyna Dudzińska

Parents of disabled children and local kinship

This article is based on the notion of local kinship which Rayna Rapp and Faye Ginsburg use in their works on disability and media (2007). I examine ethnographic data from Warsaw and surroundings (Zalesie Dolne, Piaseczno, Dobra Wola) mainly based on conversations with members of the Association for People With Mental or Physical Disabilities "Good Will", discussions with parents of children with disability (interviewed by me and Justyna Wesołowska) and on field notes from public meetings that they organized (Wolpreza and Tataspartakiada).

Local kinship allows me to start my analysis from a point different than Goffman's stigma, which hides the obvious issue of the exclusion of disabled children and of their parents. The triangle: local community, media (inc. soap operas and popular books, etc.) and the association for disabled people. Together they create the area where the experiences of everyday life of disabled children and their parents intersect. The study presents examples of the experiences of exclusion and inclusion that parents struggle with the community and at work, and the influence of the local association on their lives.

Hubert Wierciński

The family and the experience of cancer: A study of practices and narrations

The article explores the impact of cancer on the families of ill persons. The data presented in the article were collected during ethnographic fieldwork between 2009 and 2012 in Warsaw and Białystok, conducted among patients suffering from malignant cancers and their families.

I argue that cancer is never an individual dilemma – it "expands" on family and has the power to reshape internal relations and order in particular families. Thus, the family, next to biomedical institutions, is the main environment where cancer happens. In the patients' narratives, the family often times plays a double role; both positive and negative. Family is a source of hope and support but equally can be involved in the process of taboo and exclusion.

The article covers the topic of advanced medical technologies and their impact on family definitions and experiences. My attention is focused on narratives where the "genes" and genetic screenings played a crucial role. I argue that processes of deep family medicalization can be observed. The article aspires to explore the reasons of this phenomenon.

Dorota Hoffman-Zacharska

Individual autonomy and genetic determinizm: Decision-making on predictive testing in Huntington's disease

The 20th century was a period of the rapid development of clinical genetics and genetic counselling due to the progress of karyotyping methods and DNA-based analysis. Among these, two types of tests have been developed that are offered to patients and their relatives: diagnostic (to confirm/exclude the clinical diagnosis) and predictive (presymptomatic, prenatal and preimplantation). In 1993, the molecular background of Huntington's disease, a progressive hereditary, neurodegenerative disorder of late onset, was established. Identification of the causative mutation in the *HTT* gene enabled to introduce a direct diagnostic/confirmatory, but also a presymptomatic test for relatives of the affected person; individuals at-risk for this disorder. Because there is still no cure for Huntington's disease and no treatment proven to delay the onset or slow the progression of the disease, there are emotional and ethical issues that accompany the genetic testing of asymptomatic persons. Further, fewer at-risk individuals request the predictive testing than had been expected. The reasons commonly given by them include future planning regarding marriage, reproduction, career, finances, or simply a need to relieve uncertainty. The decision to take a predictive test is always stressful and difficult, but should always be an informed, carefully considered, and freely chosen personal decision. In many cases the genetic testing process brings families closer together, in others it causes tension and complications within the family.

The aim of this essay is to introduce the problem of predictive testing in Huntington disease and to show the *pros and cons* in the context of at-risk person's decision making.

Małgorzata Rajtar

Blood and the Heart. Jehovah's Witness Families and Down Syndrome

The article draws on ethnographic fieldwork with Jehovah's Witness patients and physicians in Berlin, Germany during 2010–12 and examines the hospital experiences of two JW families whose children were diagnosed with Down Syndrome.

Jehovah's Witnesses (JWs) are a globally active, yet anthropologically understudied religious community. Although they do not oppose biomedicine as such, following a literal interpretation of the Bible that prescribes "abstaining from blood", JWs refuse blood transfusions. Hence, in the two cases analyzed in this article, JW parents of children who were in need of heart surgery succeeded in finding hospitals that would treat their children "without blood". The surgeries were performed in the early 1980s and mid-1990s in Berlin. Following the medical journeys of both couples allows me to highlight the difficulty of making a decision on behalf of a child with a disability, a decision that was left solely to the parents. It also shows that the child's disability and lack of "normalcy" facilitated the right of the parent to exercise their religious convictions in at least one case. Instead of losing custody of their child after insisting on a "bloodless" surgery, the likely result for "normal" children, JW parents were allowed to choose a treatment on their own. Finally, I argue that these families are in a particular situation that differentiates them from other families of children with disabilities. As a result of their religion, they are unlikely to be bonded by a “new kinship imaginary” (Rapp & Ginsburg 2001) that draws them together with families whose children have been diagnosed with trisomy 21.