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BROCHER SYMPOSIUM: PERSPECTIVES ON ACCESS TO REPRODUCTIVE HEALTHCARE

# Patient monitoring in Polish assisted reproductive technology centres\*

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Abstract In 2014, the Polish non-governmental patient association 'Our Stork' (Nasz Bocian) introduced the 'Patient monitoring in ART centres' research project to gather previously unrecorded information on the situation of infertile people and the provision of assisted reproductive treatment in Poland. When the research project began, assisted reproductive treatment centres were unregulated by the state, a situation that had existed for more than 28 years following the birth of the first Polish test-tube baby in 1987. Patients signed civil contracts, remaining unprotected in terms of safety of treatment and recognition of their rights, and their presumed social position was described by doctors as 'disciplined patients' — a reflection of what Michele Foucault described as biopolitics. The research project comprised patient questionnaires (responses from 722 patients provided the basis for the document 'Patient Recommendations in Infertility Treatment'), analysis of civil contracts and their accuracy in the context of patients' legal rights in Poland, and in-depth interviews with assisted reproductive treatment centres' owners, doctors, midwives, and patients to explore patient care. The data reveal that there is a lack of patient-centred care among doctors and medical staff in Poland and that following the passing into law of the 2015 Infertility Act, which introduced state regulation of assisted reproductive treatment centres, the situation for patients worsened.

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#### Introduction

The first successful birth of a Polish 'test-tube baby' occurred in 1987. Twenty-six years later, in July 2013, the first statefunded national programme of IVF reimbursement was launched by the Polish Ministry of Health (Ministry of Health, 2013; subsequently withdrawn in July 2016 by the newly elected right-wing Law and Justice party). Despite the proactive step of state funding, there was still no legislation regarding assisted reproductive procedures in Poland and no system of accreditation for clinics. In addition, none of the existing recommendations concerning patient-centred care were introduced in assisted reproductive treatment clinics or actively supported by the government for this part of the medical market. The patient-centred care model has a long and established history, first appearing in the 1950s (Lewin et al., 2001). Since then, it has been further developed by psychologists, medical anthropologists and ethicists (Bauman et al., 2003; Shields et al., 2006; Stewart, 2001), who have been refining the definition, interpretation and applicability of this model. A general agreement exists that the focus of patient-centred care is to promote increased participation of the patient in the process of a treatment and its self-management. Thus, many assisted reproductive treatment centres, mainly in Western countries, have adopted patient-centred practices under pressure of governmental and non-governmental experts. The Polish state, however, neither introduced legal regulations nor 'soft' recommendations concerning patient-centred care in assisted reproductive treatment centres, making this part of the healthcare system entirely free from state intervention or monitoring. Indeed, until new legislation introduced in the 2015 Infertility Act came into force, Poland was the only country in the European Union (EU) that did not implement the common safety and quality standards for human tissues and cells specified by the EU tissue directive. Thus, the lack of regulation created a space in which assisted reproductive treatment methods and therapies were accessible only to patients who could afford them (the exception being surrogacy, which had been de facto outlawed in 2008 through the Polish Family and Guardianship Code). The lack of state oversight resulted in the widespread commercial development of unregulated Polish assisted reproductive treatment infrastructure, while patients' rights to information and to safe treatment were neglected. The rapid commercialization of health services is a characteristic feature of post-communist countries, as reported by scholars and international organizations such as the World Health Organization (WHO), with an apparent paradox of increased mortality rates in nations with rapid privatization of healthcare (McKee, 2004; Safaei, 2012; Stuckler et al., 2009). In the case of infertility treatments, the paradox lies in the discrepancy between provision of modern and efficient assisted reproductive therapies, offered mainly by private healthcare providers, and the lack of government interest in supervision of this part of the market (Mandrik et al., 2014; Mishtal, 2015). This has resulted in unequal access to assisted reproductive treatment and lack of state control over the quality of services provided, so that patients became the group exposed to the risk, as McKee (2004:35) pointed out:

First, if countries pursue policies that fail to enhance the health of their populations then they and their citizens must pay the human and economic price of failure, picking up the pieces of lives prematurely ruined by preventable conditions. Second, health systems exist to respond to the burden of disease in a population and not the interests of providers. Any discussion of health care delivery that ignores the nature of this disease burden is meaningless.

An example of the ambiguity of this situation was the lack of coherent data on the number of Polish assisted reproductive treatment centres offering IVF, which differed depending on the source: 34 centres according to European IVF Monitoring (2012), about 30 centres according to the Ministry of Health (2015), about 38 centres in the first Polish ranking of IVF centres published by Gazeta Wyborcza, one of the most influential daily newspapers in Poland (Fedorowicz, 2014); meanwhile the Association for Infertility Treatment and Adoption Support 'Our Stork' (Nasz Bocian) - a patient advocacy non-governmental organization (NGO) in Poland identified 42 Polish assisted reproductive treatment centres offering IVF based on patients' testimonies in August, 2014; new centres have opened since then, making the final number of assisted reproductive treatment centres unknown, although it is likely to have increased. It is worth mentioning that only three assisted reproductive treatment centres out of the 42 identified by Our Stork were public, which once again might be a reflection of the post-transition nature of the Polish assisted reproductive treatment market. Despite the introduction of the 2015 Infertility Act, there is still no official list of assisted reproductive treatment centres in Poland, which may be taken as a sign of the continuing lack of state interest in, and control over, the assisted reproductive treatment market, including surveillance of the quality of services offered in accordance with the patient-centred model implemented by public health systems in other European countries. Despite the lack of legal regulation, the average number of IVF cycles performed from 2009 to 2012 by Polish clinics increased, and the registered success rate was approximately 32%<sup>1</sup>, comparable to the European standard<sup>2</sup>. This expansion can be understood as 'neoliberal progressiveness' – a phenomenon wherein the state accepts a free market in the field of the new reproductive technologies, resigning (or at least retreating) from its role in the strict supervision of healthcare, a role that has been in perceived in the pre-neoliberal era as protection of patients. An important element of this situation is an imbalance in the distribution of market participation of private and public assisted reproductive treatment providers. As mentioned earlier, the vast majority of assisted reproductive treatment centres are operated by private owners and, thus, are accessible only to patients who can afford to pay for

<sup>&</sup>lt;sup>1</sup> According to the voluntary consortium European IVF Monitoring, Poland reports that the average number of IVF cycles performed from 2009 to 2012 by Polish assisted reproductive treatment centres oscillated around 20,000 annually and the authors noted the trend toward an increased utilization, while the registered success rate (pregnancy per embryo transfer) was reported to be 32%: http://www.ptmrie.org.pl/pliki/artykuly/eim-europejski-monitoring-wynikow-leczenia/europejski-monit

<sup>&</sup>lt;sup>2</sup> The average European IVF success rate is 33.2% pregnancy per embryo transfer, as presented at the 2014 Annual Meeting of European Society of Human Reproduction and Embryology, Munich.

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