Patient monitoring in Polish assisted reproductive technology centres

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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 state-funded 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programme of IVF reimbursement was launched by the Polish Ministry of Health (Ministry of Health, 2013; subsequently withdrawn in July 2016 by the newly elected right-wing Law and Justice party).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%, comparable to the European standard1. 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

1 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-monitoring-wynikow-leczenia-eim-polska-2012.pdf and http://www.nasz-bocian.pl/node/55452.

2 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.
expensive treatment. Only three assisted reproductive treatment centres are state owned, as parts of public hospitals, but it should be noted that these public assisted reproductive treatment centres also offer treatment on a commercial basis, where the hospital infrastructure is used but patients are charged for the IVF procedure itself. This situation can occur due to a legal loophole that allows public hospitals to provide patients with additional services not covered by the National Health Fund (Narodowy Fundusz Zdrowia, NFZ). IVF is excluded from the treatments covered by the NFZ and thus its cost remains the responsibility of the patients. Therefore, the term ‘public’ refers here to the public place and resources, i.e. hospital and its employees, but not to the financial coverage of medical procedures. This permissiveness of the state and its ‘hands-off’ approach to assisted reproductive treatment clinics continued even after the introduction of National Programme of IVF Reimbursement in 2013–2016 (the proportion between public and non-public assisted reproductive treatment centres remained the same during this period) and after the introduction of the 2015 Infertility Act.

This discrepancy and ambiguity between the declared ‘neoliberal progressiveness’ model, which treats healthcare in market-driven consumer terms, and the troubling neglect of infertile patients in terms of unequal access to assisted reproductive treatment and an inadequacy of reliable information about the number of assisted reproductive treatment centres, their verified quality, efficiency, and position on patient rights motivated Our Stork to launch a large research project entitled ‘Patient monitoring of Polish ART centres 2014–2015’ (Nasz Bocian, 2015a). As an anthropologist and the coordinator of this project, as well as the chairperson of Our Stork representing the interests and rights of those experiencing infertility, my position is one of both scholar and social activist through deep involvement in social and political issues concerning assisted reproductive treatment. This dual position encourages a reflexive analytical approach, through which I consider how the research findings from the monitoring project might be used productively for patient advocacy efforts and to inform future policy decisions in Poland.

Through our monitoring project, we wanted to investigate how the patient experience is shaped in the neoliberal model, where the treatment process is based on civil contracts without a legal framework. Several questions emerged. To what extent might the patient-centred care model guiding clinical practice in other European countries be of benefit in Poland? How did the psychosocial care and counselling stated as being provided by clinics work in practice and how was it assessed by the patients? Applying the theoretical concept of ‘disciplined body’ developed by social theorist Michel Foucault (1977), one could track how the practices of Polish assisted reproductive treatment centres reflect (or not) the idea of ‘docile body’, generating relevant questions. Do the notions of bodily autonomy and patient autonomy exist in Polish patients’ experience? If so, how does this process operate in the examination rooms and IVF laboratories? These questions were important to pursue in the monitoring project, and below I aim to delineate the study’s findings, and consider them in the context of the patient-centred care model.

This article analyses the situation that existed during 2014–2015, before the 2015 Infertility Act came into force, and the findings should be interpreted with this in mind. After the Act became law, the legal situation for assisted reproductive treatment patients changed considerably. According to the new law, only heterosexual couples can receive infertility treatment, and single individuals and lesbian couples are excluded. Gamete and embryo donation are strictly anonymous, which precludes intra-familial donation. To reduce the risk of creating surplus embryos that would never be used by patients, the legislators decided to limit the number of oocytes fertilized during one IVF attempt to no more than six. This fulfilled the demands of those who had raised concerns about disposal of embryos and who asserted they would support the Act only under the condition that every created embryo would be protected and given a chance to live. This demand resulted in the proviso of compulsory embryo donation after 20 years of storage: if a couple does not use their surplus embryos for their own embryo transfer, after 20 years of storage all frozen embryos will be taken by the clinic acting on behalf of the state and will be donated to another heterosexual couple3. The Act also banned the destruction of embryos and their use in scientific research.

These legal changes have sanctioned some of the practices observed during our project that at the time we assessed as a violation of the law and of patients’ rights. For instance, requiring patients to sign a contract that deprives them of the right to disposal of their embryos was illegal according to general civil law at the time of our monitoring, but is now recognized as legal by the new Infertility Act. However, this does not mean that the new law should remain unchallenged, on the grounds of violation of the patient-centred model of care and existing EU legislation (see for example, the judgement of the European Court of Human Rights in Evans versus United Kingdom [2006] or Art. 12.1 of Tissue Directive 2004/23/EC).

### Patient-centred care

Assisted reproductive techniques have been extensively analysed and interpreted from an anthropological point of view for three decades, highlighting several concerns regarding such issues – to name but a few – as a women’s autonomy, the paternalistic approach of medical staff (or ‘medical gaze’ as defined by Foucault, 1973), and the institutional support that endows a doctor ‘with the power of decision and intervention’ (Foucault, 1973:89). Many of the reservations voiced by scholars refer to emotional burdens of treatment and the involvement of potential users in the decision-making process (Gerrits, 2014; Gupta, 1996; Thompson, 2005). These scholars also pay attention to the imbalance in the relationship between patient and doctor, and the phenomenon of ‘ontological choreography’ around the infertility experience taking place in assisted reproductive treatment centres, where a patient is faced not only with their body’s dysfunction, but also – as Thompson observes – with a wide system of dependencies and agents, such as, ‘technical, scientific, kinship, gender, emotional, legal, political and financial aspects of assisted reproductive treatment clinics. (…) These elements have to be coordinated in highly staged ways so as to get on with the task at hand: producing parents, children, and everything that is needed for their recognition as such.’ (Thompson, 2005:8).

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3 2015 Infertility Act [Article 21.3(1,2)].
Also, feminist researchers and other critical scholars have examined the doctor's role in the medicalization of fertility problems, when clinical findings are diagnosed as disease while the patient had been operating under the assumption that she or he was of good health (e.g. Inhorn and Van Balen, 2002). Nonetheless, in the past two decades we have observed a significant shift in the provision of ART, ART centres' policies, and the introduction of the concept of 'patient-centred care' to increase patient autonomy and informed decision-making in healthcare provision (Boivin et al., 2001; Cussins, 1998; Gerrits, 2008; Knight et al., 2013; Gameiro et al., 2015). This shift is usually perceived as a logical consequence of the desirable process of humanising biomedicine, and such perception is also shared by patient stakeholders such as Fertility Europe⁴, which argues that, 'Treatment should be patient centred and not technology centred: communication between patients and clinics, counselling, emotional support, patient involvement, privacy and competence of clinics and staff are elements facilitating the wellbeing of the patient' (Fertility Matters, 2012: 12).

The issue of humanization of the biomedical paradigm within the triad of society/healthcare system/patient becomes particularly important in countries where the disciplining approach towards patients is still a dominant one and where a market-driven perception of the relationship between patient, medicine and state prevails (Radkowska-Walkowicz, 2013). This approach refers mainly to the post-communist countries of Eastern Europe, the Balkan countries and to countries in which religious institutions have significant impact on their citizens' lives (Gunnarson-Payne and Korolczuk, 2016; Mandrik et al., 2014). In post-communist countries, as mentioned earlier, the lack of a patient-centred care model seems to go hand in hand with the lack of a reimbursement policy for assisted reproductive treatment. Patient organizations such as RODA (Croatia), SOS Infertilitatea (Romania), Deti Budut (Ukraine), Nasz Bocian (Poland) and Wanting and Waiting (Malta) advocate for financial support from the state simultaneously with advocating for the inclusion of the patient-centred care model into infertility services and the promotion of patient autonomy in the process of decision-making, since such models are still not implemented in the daily clinical practice of many domestic assisted reproductive treatment centres. Together, these organizations conduct advocacy activities in favour of the recognition as a human right of equal access to infertility treatment, which is a key element of the task of getting social acceptance for public reimbursement of the assisted reproductive treatment (Korolczuk, 2014). Accordingly, organizations representing countries with a reimbursement policy installed, with more liberally oriented laws and a well-established paradigm of patient-centred care (e.g. Swedish ‘Önskebarn’, Finnish ‘Simpukka’, Dutch ‘Freya’, British ‘Fertility Network UK’, Belgian ‘De Verdwaalde Ooievaar Network Fertiliteit’, to name a few), focus their campaigns on fertility awareness and address specific issues such as surrogacy or further development of gamete donation policies (Dancet et al., 2010, 2012; Frampton et al., 2008; Gunnarson-Payne and Korolczuk, 2016; Shaller, 2007). In Poland, by contrast, the extent to which the patient-centred model is considered in healthcare remains an open question.

In this article, I analyse data derived from the monitoring study in which the patient-centred model was taken as a desirable standard, so that the ‘Patient recommendations’ document (discussed in more detail in the next section) introduces, and promotes this kind of approach in Polish assisted reproductive treatment centres. However, promotion of a model of patient-centred care may have also ambiguous and unintended effects, as Gerrits (2014) notices, ‘Scholars, most often working from a Foucauldian perspective, have also pointed to the possible adverse effects of patient-centred practices, which introduce new doctor–patient power relations that in effect mould patients to think and act in particular ways’ (Gerrits, 2014: 1–2).

Seen from the Foucauldian perspective, the dynamics within patient-centred practices can be used to strengthen the ‘medical gaze’ (Foucault, 1973) among patients. Through the amount of clinical information exchanged in the process of assisted reproductive treatment, and the bonds created between patients and medical staff, the bodily discipline does not vanish in the patient-centred approach to care. Rather, it reshapes into a form of neutralization of the burdens of treatment, and creates a relationship between patient and doctor which is seemingly free from the tensions of power inequalities; but the power tensions are still present, as Gerrits (2014) concludes, ‘Women and men visiting the clinic are still held in a matrix of power relations that force them (...) to think of and talk about their fertility problems and possible solutions only (or mainly) in biomedical terms’ (Gerrits, 2014: 9). This article examines how the model of patient-centred care works – if it does at all – in the daily practice of Polish assisted reproductive treatment centres and in the patients’ own experience. In the sections below, I will present the methodology for the monitoring study, which is followed by three major findings relating to civil contracts, psychological care and gamete/embryo donation. I conclude the article with a consideration of the lessons learned from these findings, and possible recommendations for the improvement of clinical assisted reproductive treatment care in Poland.

Methodology

The project started by collecting responses from questionnaires of patients recruited via the nasz-bocian.pl website, which has 92,127 registered users and over 300,000 monthly visitors. Questionnaires gathered data about each patient’s expectations, opinions and experiences of the quality of a given medical care unit, about negotiating their medical care, and how the care they expected and/or received compares to European health guidelines and recommendations. All of respondents were registered users of nasz-bocian.pl website and their infertility experience ranged from 1 to 14 years. We received 699 completed questionnaires from respondents who declared their gender as female and 23 from those who declared their gender as male. Although we did not include a question concerning the number of assisted reproductive treatment centres with which respondents had a direct experience, the analysis found that most respondents had changed their health provider at least once during their treatment.

⁴ Fertility Europe is an umbrella organisation of 22 European patients' organisations working in the field of infertility and patients' rights advocacy.
Part of our methodology was to use questionnaire data to formulate recommendations that were distributed to clinics, and followed up with interviews at the clinics which were part of an audit. Based on the 722 completed questionnaires, and the “Guidelines for counselling in infertility ESHRE 2001” plus other documents, we prepared a summary document entitled ‘Patient recommendations on infertility treatment’ (Nasz Bocian, 2015b) comprising six chapters as follows: (1) General recommendations on functioning of assisted reproductive treatment centres, (2) Good Practice in patient information policy, (3) Healthcare involving a couple, (4) Civil contracts between ART centre and patients, (5) Third-party reproduction, (6) Psychological counselling.

‘Patient recommendations on infertility treatment’ was sent to the 42 verified assisted reproductive treatment centres; 37 adopted the recommendations into their practice and agreed to an audit. Two centres subsequently withdrew, so the final number of audited assisted reproductive treatment centres was 35. Five assisted reproductive treatment centres refused the audit, including two centres that provided treatment under the state’s National Programme of IVF Reimbursement. From October 2014 to December 2014, 14 auditors were recruited from former patients, civic activists and our website moderators, and trained by professionals (lawyers, representatives of watchdog organizations, doctors and patient experts) during three cycles of training. Then the group was divided into seven teams consisting of one former patient and one non-patient to provide both a personal experience perspective (insider’s input) and a more objective perspective (outsider’s input). Each team was sent to assisted reproductive treatment centres to analyse civil contracts – contracts between the patient and the clinic signed ahead of the assisted reproductive treatment process – and their accuracy vis-à-vis patients’ rights in Poland. The final number of analysed contracts was 299. They also interviewed the assisted reproductive treatment centres’ owners, doctors, midwives and at least two patients in each centre to examine the infertile patients’ situation in the given clinic. Audits included semi-structured interviews and a ‘mutual verification’ approach, including a questionnaire sent to all assisted reproductive treatment centres asking for their own description of its establishment, whether the centre reports its outcomes to the Polish Society of Gynaecologists, the list of offered treatments, and so on. After completing the audits an individual report was prepared for each participating centre and sent to the centre 14 days before publication to give time for the centre to comment on the report if desired. Most of the centres responded within the 14 days and their comments were included at the end of the report. Part of our methodology was to engage in public dissemination by making our findings relevant to policy makers. Therefore, the final report of our findings was presented in the Polish Parliament on 30 September 2015. If our research remained purely scientific we would not have the opportunity to present to the wider public through Polish Parliament and media. Connecting two separate perspectives, as an anthropologist and a researcher in the position of a patients’ representative, I was able to vocalize patients’ opinions and, at the same time, I could analyse the data in the context of engaged anthropology reaching out to the media and public opinion. Engaged anthropology, according to Scheper-Hughes (1995), tries to answer to the following call:

The work of anthropology demands an explicit ethical orientation to ‘the other’. (...) Anthropologists who are privileged to witness human events close up and over time, who are privy to community secrets that are generally hidden from the view of outsiders (...) have, I believe, an ethical obligation to identify the ills in a spirit of solidarity and to follow (...) ‘womanly’ ethic of care and responsibility. If anthropologists deny themselves the power (because it implies a privileged position) to identify an ill or a wrong and choose to ignore (because it is not pretty), (...) they collaborate with the relations of power and silence that allow the destruction to continue. (Scheper-Hughes, 1995:418–19).

As a researcher and also an advocate for those affected by infertility, my goal is to bridge the gap between scholarly research and public policy by calling attention to problems with access to and provision of assisted reproductive treatment in Poland, and I hope to inform policy decisions with my findings. Therefore, as Scheper-Hughes notes, ‘Those of us who make our living observing and recording the misery of the world have a particular obligation to reflect critically on the impact of the harsh images of human suffering that we foist on the public’ (Scheper-Hughes, 1995:416). Acting in a dual role of spectator and participant I had a unique opportunity to use scientific tools and skills to enhance the position of those who were disempowered by the biomedical process – patients longing for a child and consenting to far-reaching compromises with clinics so as not to lose their chance of successful pregnancy. As I will show in the following sections, through the monitoring project we discovered and documented several irregularities in the assisted reproductive treatment healthcare practice regarding patients’ rights and autonomy.

**Legal status of the civil contracts**

As part of the process of analysing the data, the documents (civil contracts) presented to patients for signature by the centres were reviewed by lawyers, and a majority were found to contain legal errors. In 299 documents provided by the clinics we found 228 so-called ‘abusive clauses’ (klauzule abuzywne), according to Polish Civil Law and the Court of Competition and Consumer Protection. The lesser errors in legal terms applied to cultural issues surrounding IVF and were discriminatory towards parents and children (n = 74) and/or

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5 A condition of participation in the audit was the provision of a signed consent by each assisted reproductive treatment centre. A separate consent concerning the adoption of Recommendations was attached to the documents. We received 37 signed consents from all participating assisted reproductive treatment centres that had confirmed adopting the Recommendations into practice.

6 In the case of three public assisted reproductive treatment centres (hospitals), auditors interviewed the head of the ward instead of ‘an owner’.

7 The monitoring project was a common project of Our Stork Association and it was carried out by a team consisting of auditors, lawyers, coordinators and accountant. Therefore, I use the form ‘we’ when I write about the team’s findings. However, when I interpret findings on the anthropological base, I use the singular form, because I was the only person with such background.
violated patient rights and human rights (n = 93). For instance, two representative examples of the irregularities within the civil contracts include, ‘Neither of us will initiate affiliation proceedings [genetic testing] in order to deny either fatherhood or motherhood’8 and ‘Hereby, we agree to treat child/ren born as a result of IVF as our own child/ren and never deny our parenthood’. When a couple conceives spontaneously, stipulating that ‘the couple agrees to treat the child as their own’ would be considered highly unusual since the parental bond remains the private matter of a person or a couple and society recognizes this kind of attachment as natural. Requiring the submission of such a declaration in the context of assisted reproductive treatment may therefore be regarded as an expression of suspicion towards the prospective parents or towards a child who becomes the subject of additional need for recognition and external control to be considered as the ‘couple’s own’.

Declarations of parental affiliation signed prior to a child’s birth were legally invalid in Polish law, unless made in a Registry Office9. IVF centres therefore had no right to require such statements from patients and any such statements made were legally invalid. Moreover, the Polish Family and Guardianship Code provided all fathers with the right to affiliation proceedings to deny their fatherhood. Each Polish male citizen therefore had the right to go to court in this respect, regardless of any declaration to ‘never deny our parenthood’ made in a clinic’s civil contract. Interviews with doctors and midwives revealed that staff working in clinics were usually unaware of these errors, or they underestimated the legal and social implications for patients. The following are excerpts from some of the civil contracts:

Termination of the contract due to its lapse or expiry will result in right of the Centre to use the embryos entrusted to it for the treatment of other recipients.

If within one month after expiry of the contract the next payment is not received, this fact will be treated as a waiver of continued storage of embryos (embryo).

The Agreement is terminated in the following cases: (…)

c) the expiration of the period for which the contract has been concluded

d) spouses divorce

e) the death of one or both of Patients

f) breach of the terms of this agreement by the parties

In the case of non-renewal of the contract for reasons beyond the control of the Centre, the Centre and patients may decide to keep embryos at the disposal of the Centre in the ‘bank of embryos’ for the purpose of anonymous donation to another couple for whom it would be the only option to have their own offspring. (Fragments of one of the civil contracts).

During the interview, one of the doctors explained the civil contracts as follows: ‘Yes, we are aware that our civil contracts are legally invalid, but the role of these documents is to discipline patients and to pressure them to pay for stored embryos’.

Another informant admitted that the points mentioned in the contract of agreement had been never executed in the assisted reproductive treatment centre’s practice, as explained in this interview:

Owner: If we didn’t threaten patients [with taking their embryos], no one would pay the bill for storage. The truth is that we’ve never executed these paragraphs, we just store unpaid embryos in the nitrogen instead of passing them to another couple.

Researcher: So why do you keep those paragraphs in the civil contract if you don’t execute them?

Owner: Because it encourages the right attitude in the majority of patients.

These responses are representative of the dominant view of how patients are perceived. Patients are expected to be obedient. His or her fate is decided by the clinicians, even though both clinic and patient might be aware that the conditions being imposed are legally invalid. However, in the context of the theory of biomedicalization, the citizen/patient is always the weaker part of the constellation (Clarke et al., 2010), in that the patient is not in the position to refuse to sign the contract, particularly when the process of treatment has been initiated before a signature has been provided. We confirmed through patient interviews that this was common practice and that civil contracts were often submitted after the introduction of hormonal stimulation and before ovarian puncture. The following is the fragment from one of the interviews with a patient:

Researcher: Did you receive a contract template to familiarize yourself with it before starting the procedure?

Patient: No, I signed the contract on the third visit, after starting the hormone stimulation. It was my second procedure in this centre. During the first attempt one year ago, I agreed to donate my oocytes but this time I preferred to keep all of them to enhance my own chances. I wanted to freeze the surplus oocytes. I asked the doctor to freeze the eggs but he replied ‘you don’t have enough follicles to get the surplus oocytes, so don’t think about it’. I discovered the fact that I had surplus oocytes, and that all were donated to another couple without my permission, just before the transfer when embryologist said: ‘All 13 oocytes were mature’. The midwife decided that the previous consent to donate oocytes [from the first procedure performed one year earlier] also applied to the current attempt. She didn’t ask me whether this time I wanted to donate my eggs, she just did it and told me so.
Another auditor noticed in the interview’s questionnaire:

Researcher: Did you receive a contract template to familiarize yourself with it before starting the procedure?

Patient: Yes, one day before ovarian puncture.

Researcher: So it was not before starting the procedure?

Patient: Yes, it was! As I said, the day before the puncture doctor gave me a contract to sign.

As can be seen from the above quotation, the patient did not distinguish between the start of the procedure (understood as the moment of initiation of hormonal stimulation) and the moment of the puncture (following the hormonal stimulation when ovarian puncture becomes medically unavoidable and, therefore, must be done). In the middle of the medical process there was no opportunity to withdraw from the continuation of treatment. However, the patient was convinced that the doctor had acted in accordance with the Act on Patient Rights and the Patient Rights Ombudsman, which was not the case. Another patient admitted:

I was aware that this paragraph [passing on surplus embryos for donation in case of non-payment for their storage] is invalid or at least isn’t legal but, well, I had no choice being in the middle of hormone stimulation. I thought ‘OK, if things go wrong I’ll just sue the clinic’. and that’s all.

In this way patients were coerced by the clinics to renounce any entitlement to their stored embryos following divorce or late payment for storage.

Another audit finding showed common practice in construction of the civil contract through the use of language which may be described as ‘paternalistic’ and/or discriminatory towards particular groups, e.g. single women, lesbians and unmarried couples. For example, many civil contracts on IVF/IUI treatment contained formulations as follows: ‘husband/wife’, ‘husband’s signature/wife’s signature’, ‘using of donor/husband semen’ etc., instead of terminology such as ‘partner’ or ‘patient’. Several civil contracts used introductions such: ‘For the sake of the patients, the child-to-be, the doctors, and the donors, patients agree...’ or: ‘In the best interests of the child conceived through insemination’ where such formulas had been used to justify the anonymity of gamete and embryo donations through the suggestion that such a condition was crucial to realize ‘the best interest’ of all parties involved, even though Polish law did not recognize such interpretation.

Hence, one can read:

We will never try to find him [the donor] (consent for IVF with donor’s semen).

Egg donor remains anonymous forever (consent for IVF with egg donation).

Hereby, we undertake to keep secret all facts concerned with the methods mentioned above (applying to all consents concerning procedures using donor’s semen).

We interpreted such provisions as paternalistic towards patients, as if there existed an objective model of family relationships acknowledged by doctors and required from patients who might, however, define child welfare in different ways. It was unclear why patients should have thought about the ‘doctors’ sake’ and why they were obliged to keep their decision secret from their own child. Nevertheless, it is interesting to note that civil contracts were prepared by lawyers, and were presented to patients for signing with no possibility of negotiation. Although more than half of audited assisted reproductive treatment centres noted in their responses that ‘They are open to negotiate the details of civil contracts with patients if patients are inclined to do so’, only one centre admitted to having allowed a negotiation once. The rest of the centres responded that they never received requests from patients to negotiate the content of the civil contracts, even though Polish law states that civil contracts must be negotiable. Additionally, our research auditors noticed that approximately 10% of interviewed patients stated they were never informed by a staff member of the possibility of negotiation of civil contracts.

One of the most common legal errors (abusive clause) appearing in the majority of the civil contracts analysed applied to the illegal construction of the ‘renunciation of entitlement on behalf of future child/ren’. Future parents were obliged by several IVF centres to make a commitment in a civil contract that their future child will irrevocably waive all the claims against the IVF centre, its staff and owners. In sum, civil contracts consistently included clauses that were illegal under Polish law, and were therefore not legally binding, but nevertheless functioned to control the expectations of the patient and the doctor–patient relationship. After receiving an individualized report of our analysis of their civil contract, 14 out of 35 centres informed us that they were making adjustments (regarding the detected irregularities) so that their contracts came into line with the law.

The role of psychological care

Despite the declaration by the majority of centre owners that patients are provided with the option of psychological care, we found that ‘provision of psychological care and

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10 According to the 2015 Infertility Act, all consents must be signed before the start of infertility treatment. However, this provision also existed before the introduction of the 2015 Infertility Act, as part of general medical law determined by the Act of 6 November 2008 on Patient Rights and the Patient Rights Ombudsman.

11 The 2015 Infertility Act brought into force mandatory anonymous gamete and embryo donation, but at the time of our monitoring study such provisions were devoid of legal grounds.
counselling’ was defined ambiguously. According to our observations, many of these declarations did not correspond with practice, and in fact regular and planned psychological services were lacking in assisted reproductive treatment clinics in Poland. Although owners of 29 out of 35 audited centres declared that they collaborated with a psychologist or a psychotherapist, our audit confirmed the existence of a psychologist’s room in only three clinics. This may not necessarily prove the lack of psychological care in the majority of centres, however, because counselling might be offered in another room or space (i.e. in examination rooms). Indeed, in a few cases we noticed that despite difficulties of space, medical staff tried to organize the layout in a more patient-friendly way to meet patients’ needs regarding psychological counselling. For instance, in one centre psychologists consulted patients in the examination room (without gynaecological chair or other medical equipment or instruments). For the duration of consultation, the ultrasound equipment was hidden behind the screen and – on the psychologist’s request – the midwives brought fresh flowers and colourful pillows to make the space more welcoming for patients.

Hence, in 22 assisted reproductive treatment centres we confirmed by direct observation and interviews an existence of some form of co-operation between medical staff and psychologist, i.e. organizing psychological workshops or a psychological consultation being held once a month. However, it should be emphasized that such services were usually not offered on a regular basis and psychologists were not members of staff, except in 6 assisted reproductive treatment centres, which employed psychologists on a part-time contract. Moreover, 7 out of 29 assisted reproductive treatment centres’ owners who declared ‘co-operation or employment of psychologists’ interpreted such co-operation as distribution of commercial leaflets to patients with information about external psychological care, not related to infertility and fertility issues. One of the clinic owners informed the research auditors as follows:

Owner: Of course, we provide patients with psychological care. Upstairs we have a rehabilitation room because we offer also rehabilitation for disabled patients, not only infertility services. If patients are interested in an appointment with a psychologist, they may go upstairs and ask for it.

Researcher: Do you mean dedicated infertility counselling or just psychological consultation for patients with disabilities?

Owner: What’s the difference? A psychologist is a psychologist.

Researcher: But in this room there is plenty of plush toys and rehabilitation equipment for children. Don’t you think such environment may be uncomfortable for those who are trying to conceive and who are particularly sensitive to issues concerned with the presence of children?

Owner: Infertile patients are not people with special needs.

During interviews with medical staff we also collected data indicating that in some cases the need of a psychological service was recognized by the clinic owners as ‘important for patients/auditors’; something that is expected from a modern ART centre’ so that it was declared by them as a needed aspect of care, even though not all of them fulfilled this criterion. Therefore, while owners and – more seldom – doctors claimed that psychologists were employed in their clinic, patients and the rest of the employees sometimes did not confirm the existence of any psychological services. Here are representative quotes from a report describing a well-known assisted reproductive treatment centre in northern Poland:

The owner says ‘Yes, we have one girl, she is a psychologist. I don’t know her formal psychological degree but I guess she is a clinical psychologist. She is employed full time. I see her very often talking to patients and assisting them in the corridors. Last month she gave a psychological lecture for all our medical staff’.

The doctor, however, told us that they used to co-operate with psychologists but that they resigned years ago because almost none of the patients were interested in such an offer. ‘We’re thinking about employing someone soon, it seems the situation has changed and patients sometimes ask us if psychological consultation is available. Professor X [the owner] promised to find someone. (...) The last psychological course for medical staff took place at the end of the year, in December 2014, but it was led by somebody from outside, a training company or something like that’.

The midwife said they had employed a psychologist years ago but patients were not interested so she was dismissed. The last psychological course was organised in December 2014 ‘if the memory serves her well’.

None of the five interviewed patients confirmed either existence of psychologists, nor information about psychological counselling provided by medical staff. (...) We did not find any psychologist’s name either on the information board in the reception, nor in the price list displayed at the reception desk. Our website analysis also corroborates that nobody is currently employed as a psychologist (lack of information or any mention on the website). We noticed that there wasn’t a psychologist’s room in the centre.

The general research audit’s observation was that the bigger the centre, the more often we noticed the real presence of psychologists, and we confirmed their employment with the majority of interviewees as well as via information displayed on the website, in the price list and leaflets at the reception desk. However, we also noticed several critical opinions expressed by medical staff towards co-operation with psychologists. Here is a fragment of a doctor’s response:

I don’t see the need for psychological support. If I have time for a patient and I can talk to her, it will be sufficient support. Besides, all these young people [psychologists]... What can they know about infertility treatment?

Another doctor said:

Sometimes the presence of the psychologist may disassemble all of a doctor’s treatment plan. It can do a lot of harm, really. For instance, after psychological consultation patients may not want to try another IVF cycle, although they should continue it according to doctor’s assessment because there is still a reasonable chance for success.

Considering the thesis of ‘neoliberal progressiveness’ discussed earlier, one can notice that the discursive
structure behind the quoted material may be linked with this phenomenon. 'Disassembly' can be interpreted as measurable financial loss consistent within the logic of neoliberal profit. At the same time the informant defined the 'disassembly of the treatment plan' as the result of psychological intervention, without taking into account other possible patient motives such as exhaustion, depression or just a different interpretation of success, which might have been revealed during counselling (Gameiro et al., 2012). Hence, the applicable standards of psychological care in infertility based on the technique of non-directive counselling (Boivin et al., 2001; Rogers, 1945; Verhaak, 2015) seem to be inadequate if the scope of the infertility service focuses on the crude factor of success rate measured by number of pregnancies.

These data suggest that the idea of close co-operation between biomedicine and psychology is still a new one, and sometimes it is being treated as 'dangerous' in the field of assisted reproductive treatment in Poland. Even though owners' and doctors' theoretical declarations on providing patients with psychological care given by doctors seem to be rather progressive in accordance with the spirit of the patient-centred care model, the evidence of the audit shows that common practice still presents a biomedically dominant attitude that fails to include the assistance of psychologists and/or the patient-centred care model in which counselling should be perceived as a routine and essential part of the treatment process, not as a disruptor.

As Bordo (1989) points out, the body is not only a text of culture, it is a 'practical, direct locus of social control' (Bordo, 1989:13), thus, the body may become a useful site of biomedical discipline. In this case, the goal of the discipline is to keep patients' bodies efficient in the process of reaching biomedical goals such as 'success rate', which will then become included in subsequent statistical tables. Hence, regular counselling can be treated as a potential obstacle, since it may harm the anticipated biomedical order. There is no doubt that the key goal defined as a pregnancy is also shared by patients, as they aim to get pregnant and this motive remains the primary reason for the decision to undergo treatment. However, in this way patients' bodies are disciplined by being treated only as producers of a success rate.

**Gamete and embryo donation**

Based on the practices reported by assisted reproductive treatment centres and their staff, the 35 audit reports show a pattern of completely anonymous gamete and embryo donations. As mentioned earlier, at the time of the monitoring project (2014–2015), Polish law did not regulate the issue of gamete and embryo donation, hence the clinic owners’ decisions alone dictated the how each assisted reproductive treatment centre carried out its practice. Only six clinics declared that their donors’ recruitment process involved a psychological assessment, which we confirmed from patient interviews and website analyses. The rest of the clinics admitted that psychological assessment of potential donors’ motivation and mental stability was not perceived as necessary or important, as reflected in the following explanation from an interviewed assisted reproductive treatment centre owner:

This may be startling for donors. (...) We don’t recommend such consultations. If we don’t like a given candidate, we simply refuse. Our girls [embryologists] have such good eyes that if anything seems to be wrong with a donor’s mentality, they are able to catch it immediately. I rejected a candidate once, too. I didn’t like her; she was weird somehow.

In another example, a doctor responded as follows: ‘Dear Madam, I have 15 years of experience. I can assess a candidate’s motivation once I see him or her. Why should I need a psychologist? It’s a modern custom, completely ridiculous!’

We also observed that the dominant practice in clinics was that donors were chosen by doctors or embryologists and almost never by patients. The pattern described above referred to sperm and oocyte donations, while embryo donations were treated differently because of the limited number of donated embryos. Thus, medical staff played the role of decision makers in the process of donor selection. Fewer than 10 centres declared that patients are allowed to choose the profile of sperm donors, and usually this situation applies to co-operation with foreign sperm banks such as Cryos or European Sperm Bank. One centre declared that all patients were encouraged to choose an oocyte donor, but no centre offered such an option for donated embryos. The majority of centres informed us about aiming for a limited number of offspring from a given donor; however, the specific number of offspring varied between centres and sometimes even within one centre, depending on who was interviewed. For example: ‘The owner told us they aim for the number of offspring to be no more than 7 children per one sperm donor, while doctors said ‘limit of offspring? I’m sure it exists but I don’t know this number’.

Another report noted: ‘the doctor reported they had a limit established of 10 children per one donor. (...) The owner informed us that the limit was set to 6 confirmed pregnancies per one donor’.

It is worth mentioning that patients’ expectations concerning gamete and embryo donation were considerably different to those of the medical staff. In our internet-based patient survey (n = 722) 95.3% of respondents declared they should have the right to choose between anonymous or non-anonymous donation (Table 1). Similarly, 86.8% of respondents expected clinics to examine potential donors in terms of psychological stability (Table 2). A question concerning access to psychological consultation before receiving donated gametes or embryos also yielded surprising results, with nearly 93% of respondents declaring that this service should be offered (Table 3).

A section of the internet survey investigated patients’ open-ended opinions, which led us to the conclusion that patients seemed to be more progressive and open-minded.

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13 This practice has been sanctioned by the 2015 Infertility Act. According to the Act, gamete and embryo donors are chosen exclusively by doctors on the basis of phenotypic compliance of recipient/s and donor/s. Patients are not entitled to choose the donor.
the importance of psychological assessment (testing) of donors.

Table 2 Internet-based patient survey response to: ‘Assess how important this is for you.’ (n = 722).

| Response                        | Percentage |
|--------------------------------|------------|
| Very important                 | 54.9       |
| Important                      | 31.9       |
| Neither important nor unimportant | 11.3      |
| Not important                  | 1.9        |

than doctors estimated. The following are representative examples of patient opinions from this part of the questionnaire:

Gamete donation should not be anonymous. In comparison to adoption, the same rule should apply and adult children should have the right to obtain identifiable data about donors.

Doctors should not impose their views on gamete donation on patients. Especially since the doctor is always the stronger party, and the patient may have no knowledge, may be scared, may be undermined. I know doctors who scare people by telling them that their child will stop loving its parents if the parents tell the truth about donation. They say it’s a bad idea because THEY think so. They have no right to manipulate patients. Clinic owners, doctors, and employees need to recognize and accept the fact that the donor/recipient may have different views and ideas about donation. This should be respected! Let adult people make autonomous decisions and not impose on them our own solutions.

In the 2015 Infertility Act, the issue of psychological care – consultation for patients, recipients and donors, recruitment of donors using psychological assistance, the opportunity to choose between anonymous and non-anonymous donation, the presence of psychologists in the clinics – was omitted, despite the protestations of patient organizations expressed during a public consultation process prior to the adoption of the law.

Conclusion

Overall, the analysis of the research audit monitoring project conducted by Our Stork NGO among Polish assisted reproductive treatment clinics demonstrates several areas of concern related to the standards of infertility care provided to patients in Poland. These included significant legal inaccuracies in civil contracts between patients and clinics, lack of or inconsistent psychological counselling offered to patients, and gamete and embryo donation practices that contradict international standards of care. In the case of abusive clauses revealed in the civil contracts, the 2015 Infertility Act addressed some of the main areas of legal inaccuracies, with the expectation that such contracts will soon be modified. Comparing the results of the monitoring project with the current legal situation, one can notice that the Act legally sanctioned the previously existing combination of biomedical, neoliberal and ideological approaches. The final shape of the Act did not address the patients’ needs in some of the key areas such as the right to non-anonymous donation or the right to surplus embryo disposal. Also, the Act strengthened the purely biomedical interpretation of infertility as a medical condition without taking into consideration the social, emotional and psychological dimensions that are suggested by a patient-centred care model and by the responses of the surveyed patients. One example of this is the exclusion of psychological care from the legal scope. A preference for such a legal recognition was observed in the findings of our monitoring, which had highlighted the weak position of patients, the lack of a functioning patient-centred care model, and the freedom of assisted reproductive treatment centres to dictate the conditions of the healthcare offered. As McKee argues with respect to healthcare, ‘It has almost become a cliché to say that transition has created winners and losers; these can be seen at the level of countries, groups within societies and individuals’ (McKee, 2004:34).

In the case of the legal regulation of the infertility treatment market in Poland, it can be argued that the winner turned out to be the approach of neoliberal progressiveness. Even though the Infertility Act is an example of a fairly conservative right (i.e. the limitation of number of fertilized oocytes, and lack of access for single women and lesbian couples), the real cost of the legal changes is being paid for mainly by the recipients, not by the providers. The Act did not introduce any restrictions regarding what assisted reproductive treatment centres offer or their freedom to function, including pricing policy in which the state does not intervene. Thus, the position of patients seems to be constructed by the legislators and medical staff as less privileged in terms of independence and autonomy, and this finding has been revealed in the part of the monitoring project concerning the lack of patient-centred and psychological care, which clearly reflects the subordinate position of the patient. The belief that patients should follow the doctor’s orders accompanies constant development of assisted reproductive
treatment services in Poland in terms of extension of medical care and its quality, including access to new, cutting-edge technologies. Therefore, the more complex biomedical and biomedical technologies become, the more dependent lay people become on professionals who can interpret and translate these insights and findings (Gerrits, 2014). This process is being rationalized and explained with arguments that such structures serve the patients’ best interests, helping doctors to maximize the efficiency of the therapeutic process. However, the efficiency – understood as getting pregnant or getting the financial profit for the assisted reproductive treatment centre’s owner – is not the only category of medical process we should take into consideration when analysing the position of patients and the condition of the medical discipline itself. For example, biomedical knowledge production, information distribution and power management are important parts of what had been called by Adele Clarke and colleagues ‘biomedicalization’ (Clarke et al., 2010). Through surveillance performed in assisted reproductive treatment centres, doctors observe, decide and intervene in/on the patient’s body on behalf of the patient (Cummins, 2014).

According to Foucault’s fatalistic concept that the process of disciplining patients’ bodies is inevitable because the non-egalitarian relations in medical and state institutions are their distinctive features, one can trace in the patients’ views a rupture or disorder. While their bodies remain docile and the regime of the treatment needs them to be obedient to get the desired effect (pregnancy), their opinions expressed in the safe space of anonymous interviews or surveys turn out to be unexpectedly critical, even rebellious. Therefore, even though the current practice of power distribution indicates that its function is to discipline patients’ bodies and positions into docility and usefulness for the status quo, some patients might also find this practice empowering. For example, the phenomenon of the patient website nasz-bocian.pl, which is one of the largest patient forums in Europe in terms of patient activity and number of daily interactions, may correlate with the lack of patient-centred care in the real world observed in our project. The need to participate in a kind of ‘safe space’ in which individuals undergoing medical procedures can meet, share their experiences and mutually support each others’ efforts, can be read as another dimension of empowerment arising from a need for autonomy when such need is not being recognized or met by medical staff and by the current Law. This hypothesis may be also indirectly supported by the surprising finding made during our internet survey, in which the majority of respondents declared that they had changed their assisted reproductive treatment centre at least once during treatment. This finding can be interpreted variously. On the one hand, it may be explained by the fact that our respondents were active members of the patient community, so there was a higher probability that they had experienced changes in the trajectory of their condition and were perhaps more proactive (Covington and Hammer Burns, 2006). Such an interpretation would confirm conclusions from other studies indicating a relationship between length of treatment and patient tendency to change health provider or postponing or discontinuing therapy (Brandes et al., 2009; Gameiro et al., 2012). On the other hand, it could indicate that the lack of the state involvement in controlling the assisted reproductive treatment market may lead to patients’ sense of uncertainty resulting in constantly seeking health providers who patients may trust. In this context, an environment such as a patient community may be used as the space in which an individual has the opportunity to seek an ‘objective’ and ‘independent’ answer from others in the same situation, given that there is no other source of reliable information (e.g. state/public institutions or government-generated information). Hence, patient empowerment can also be built through these activities, when the need of self-agency may be paradoxically represented by the phenomenon of frequent changes of health provider. As we did not examine this issue in depth, these questions remain important for further studies on patient motivation. Our findings, together with these theoretical considerations, provide the basis for further research to examine the ways in which patients experience the panoptic biomedical discipline, reflected also in legal regulations and their effects, and also to investigate the relationship between local practices and patient strategies of maintaining their agency and autonomy as they navigate the biomedical system of infertility care.

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