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BROCHER SYMPOSIUM: PERSPECTIVES ON ACCESS TO REPRODUCTIVE HEALTHCARE

Introduction ☆

The articles in this Symposium are the product of an interdisciplinary meeting 'Between Policy and Practice: Interdisciplinary Perspectives on Assisted Reproductive Technologies and Equitable Access to Health Care', which was held at the Brocher Foundation, Hermance, Switzerland, 5–7 July, 2015.

The Symposium brought together a diverse, interdisciplinary group of scholars and experts involved in research, publication and advocacy work in the area of assisted reproductive technology (ART) policy, healthcare policy, bioethics, patient rights, and patient experiences with ART. Our aim in organizing the Symposium was to examine ART in Europe from a multi-disciplinary as well as a cross-national perspective, and consider ways in which ART health policies could be improved and harmonized with specific legislative solutions and advocacy efforts. In addition to policy questions, we were also interested in engaging with current debates about 'on the ground' experiences and challenges in clinical and advocacy areas, ethical concerns, and directions for future scholarship. The Symposium therefore convened both scholars and nongovernmental organization advocates, with a range of speakers covering five disciplinary areas: (i) medical anthropology, (ii) bioethics, (iii) law, (iv) sociology, and (v) health advocacy. Moreover, participants' expertise included experiences and research from a range of geopolitical contexts, from nations that currently have comprehensive ART policies to those that have recently introduced and/or inadequate regulation or subsidies for infertility care.

This Brocher Symposium encompassed 4 specific goals: (i) to identify the key areas of concern regarding the legal, ethical, health, and social impacts of inadequate ART regulation and reimbursement, (ii) to isolate and discuss practical effects of implementing specific policies in particular national contexts in European nations, (iii) to

identify the advantages and challenges of particular policy solutions regarding ART by comparing policy and provision in various European nations, and (iv) to establish which advocacy efforts are both feasible and effective in different socio-political contexts with the goal of improving equitable access to reproductive health and rights.

The papers, which were presented during the meeting, address these goals, and in particular focus on various forms of mobility and transformation: patients travelling to seek care, emerging new actors, changing legal systems, and transformation of the terms and concepts of ART debates. As we suggest, ART should be recognized not as a stable field or concept, but as dynamic assemblages (Collier and Ong, 2005) between and beyond the countries, policies and practices. Charis Thompson argues for an understanding of ART in the clinical context as an 'ontological choreography' which displays 'the dynamic coordination of the technical, scientific, kinship, gender, emotional, legal, political, and financial aspects of ART clinics' (Thompson, 2005, 8). We suggest that this dynamic coordination also has a place in the larger assemblages outside of the ART clinics, in the domains of regulation, advocacy, and transnational circulation of discourses, healthcare services, and patients.

An important thread that runs through most papers in this Symposium is the question: What is the role of the state in a liberal democracy in shaping/ensuring access to healthcare and regulating its safety, but also in dealing with questions of equality and discrimination in this arena? Fundamentally, many of the papers lead us to ask how to address collective forms of suffering in an era of individualized responsibility promoted by neoliberal ideals about self-care as a way to justify cutbacks in social services, healthcare included. The role of the state links with complex questions of national sovereignty to shape national policy according to the local

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cultural and historical specificities, especially within the EU, whereas Jill Allison (Allison, 2017-this volume) by way of contrast shows, some transnational conventions apply, including human rights. But we can also ask: What is the role of the supranational legal system in shaping policies at the national level when such policies vary dramatically? What about the role of the World Health Organization (WHO) and other international health actors? To address this question, Charis Thompson (2015) proposes to launch a multidisciplinary international data collection project to first arm ourselves with data on inequities, then pursue ways of remedying more concrete examples of inequities, but the question arises – is this a vision for supranational or national-level governance? In contrast, it might be reasonable to argue, as Guido Pennings (2015) has, that a uniform European legislation is impossible and ethnocentric, and that cross-border reproductive care (CBRC) is the solution to uneven regulation as patients seek what they need across national borders. But should we essentially agree with the inequalities experienced on the ground? What about the exploitation of some poorer nations with less restrictive laws? After all, as patients take advantage of inexpensive infertility care by traveling abroad (for example to Eastern European nations), the local population there might find the same care unaffordable because of lack of state subsidies for infertility treatment. What is affordable to foreigners therefore becomes at the same time emblematic of structural inequalities and particular politics of morality at play in the local healthcare systems (Mishtal, 2015). The export side of this cross-border equation also raises concerns. If we agree that CBRC is the answer to uneven access, will we become like the ‘old people’ in Norway, described by Renate Kurszus (2015), who prefer to ‘export’ their health and social problem to be remedied by other states? Or will this be, as Pennings (2015) argues, a rather democratic free flow of services and a kind of homeostatic distributive justice where local cultural specificities can be respected via diverse laws (restrictive or otherwise), while at the same time seekers of ART can find services in a country as suits their needs?

Infertility ‘tourism’, reshaping language

The use of ART in the European Union (EU) has grown dramatically in the last 20 years, and is expected to rise further as a result of fertility decline and population aging trends. Yet, the EU represents a highly uneven policy landscape for ART, due to diverse social, political, economic, and religious traditions of member states. This includes both policies that regulate ART procedures, as well as policies that define the degree to which these health services are state subsidized. The main reproductive health organization in the EU, European Society of Human Reproduction and Embryology (ESHRE), established guidelines for best clinical practice in the area of ART, which have been adopted in some, but not other, European nations. Consequently, access to ART treatment is highly unequal across and within nations, and often favours the wealthier strata of populations. Furthermore, inadequate (or non-existent) regulation in some nations means that standards of care vary and there is little assurance that protocols for treatment are evidence-based or monitored.

ART regulation across member states is increasingly relevant for the EU, raising new and complex policy and healthcare utilization questions concerning equality of access to healthcare and concerns relating to patient safety.

In the last decade a number of policy efforts have been made to promote the regulation of ART and the harmonization of laws and standards of care. In 2004, the EU released its ‘Tissues and Cells Directive’ to harmonize regulation, requiring nations to control harvesting and storage of human tissue, and declaring ART oversight as necessary to protect public health through improved safety of clinical standards across states. In 2008, ESHRE released the ‘Good Clinical Treatment in Assisted Reproduction’ guidelines to promote harmonization of care across states. Moreover, the WHO and the International Committee for Monitoring Assisted Reproductive Technology also revised the glossary of ART terminology because such definitions varied widely in different settings, making it difficult to compare medical procedures in different nations. Despite these policy and regulatory efforts, a significant proportion of ART services in the EU are provided in private clinics in Eastern Europe, especially in Poland and Lithuania, where ART services remain or remained unregulated (in Poland until 2015).

A Europe-wide study shows that the less expensive and unrestricted ART services offered in Eastern Europe attract growing ‘infertility tourism’ or CBRC especially from Norway, Germany, and Italy. But unregulated care also means that patients from those EU states where clinical safety guidelines would limit length, extent or type of treatment, can access unlimited procedures in countries where such guidelines are not enforced. As Michelle Bayefsky (Bayefsky, 2017-this volume) asserts, ‘While CBRC can be viewed as a useful option for patients seeking access to treatments prohibited at home, the practice also poses a number of health risks to patients and offspring’. This issue is even more pressing with the publication of the 2013 EU Cross-Border Health Directive, which allows EU citizens to seek healthcare in other states and have costs reimbursed by their home nations. However, still ‘one major concern is the relocation of risk to less restrictive, “new” EU countries and to nations outside the EU’ as Tracie Wilson argues (Wilson, 2017-this volume).

Simultaneously, infertility ‘tourism’ could be understood as facilitating exploitation of a woman’s body or new dimensions of stratified reproduction (Ginsburg and Rapp, 1995), denoting various forms of injustice in those countries where regulation of ART is inadequate (or non-existent) and therefore the state fails to protect and support patients’ choices and needs. But, one can also demonstrate that infertility travel constitutes new forms of labour. Thus, should we move beyond the reproductive exploitation paradigm and the reproductive liberalist paradigm, in our interpretations of CBRC?

The issue of infertility ‘tourism’ also raises questions regarding the language that is used in the scholarship and debates on ART. On the one hand, we seek to analyse private and public language around ART, and on the other hand it is necessary to consciously formulate our academic discourses and de-naturalize some terms, for example, reproductive tourism or travel. It’s not tourism. Men and women go abroad to pursue infertility care as a form of ‘circumvention travel’ (Cohen, 2012) rather than for leisure, and even if they can afford to do so, they may encounter stigmatisation

and humiliation in their nation of origin. In this sense, they become 'moral pioneers' (Rapp, 1999).

Bettina Bock von Wulffingen (Bock von Wülffingen, 2017-this volume) also draws attention to the key role of language and redefinition of some notions in lawmaking and debate on ART. Analyzing the legal situation and social attitude to preimplantation genetic diagnosis (PGD) in Germany, she highlights the changes of civic epistemologies, arguing that, 'the German concept of the embryo and the idea of parenting underwent a fundamental transformation between 2003 and 2011. ...the reasoning behind the partial acceptance of PGD, rather than the legal decision itself, is indicative of such a change'. Bock Von Wulffingen traces the reconstruction of embryo identity away from conceptualization of 'pre-given full human dignity', to understanding embryo 'rights' as relative to particular factors, such as different stages of development, for example diagnostic procedures on embryos consisting of totipotent cells were disallowed by the court whereas procedures on embryos consisting of pluripotent cells were permitted. Likewise, conceptualisations of pregnancy and parenting have shifted away from attention on the mother and birth, and upstream toward conception and 'genetic couplehood'. Hence, what we witness in Germany is an emergence of a new concept of 'in-vitro pregnancy'.

The situation in Poland provides an excellent example of the importance of transformation in discourses around ART and their impact on policy and practice. The success of 'pro-life' rhetoric campaigns in Poland over the last decade are, above all else, responsible for reshaping the language, as the term 'termination of pregnancy' commonly used during the state socialist era has now been replaced by 'murder', 'fetus' was replaced by the 'unborn' or 'conceived child', while 'pregnant women' became 'mothers'. Significantly, this new language was incorporated into official state documents (Chelstowska, 2011:102). In the very heated and highly politicised debate on IVF in Poland, the rhetoric of opponents of ART used the same strategy: in-vitro fertilisation became the 'production of people', freezing embryos became 'freezing children' and embryo selection became 'eugenics'. As Bock von Wulffingen and others in this issue note, claiming the language is indeed critical in constructing new subject positions, both in advancing particular moral regimes and shaping juridical changes (Morgan and Roberts, 2012)

Emerging actors, new subjects

Just as the language should be denaturalized, we believe that the ART scene calls for redefinition. It is necessary to recognize the absent actors in discussions on legal and social aspects of ART and the new subjects who emerge on the political scene and in media discourses due to the specific 'ontological choreography'.

Erich Griessler and Mariella Hager (Griessler and Hager, 2017-this volume) highlight how and why the political regulation of ART in Austria, which has been rather restrictive for more than 20 years, was recently liberalized, underscoring the key role of 'sub-politics of individual citizens who appealed to national and European courts to change the law'. They suggest that patients also could

and should participate in debates on ART and shape practices. Likewise, in Poland, we see how the crafting of 'patient-citizens' through a growing advocacy effort increasingly challenges the dominance of ART clinics' 'God and Tsar' untouchability, as Anna Krawczak (Krawczak, 2017-this volume) has shown with the clinic-monitoring audit conducted by the nongovernmental patients' rights organization 'Our Stork'. The monitoring audit in Polish clinics revealed the power of biomedical discourse in the field of reproduction, as Krawczak notes, 'the position of the patient seems to be still perceived by medical staff as less privileged in terms of self-independency and autonomy, and this finding has been revealed in the part of the monitoring referring to the "patient-centered care" and psychological care'. The new Polish policy on infertility treatment implemented in 2015 also demonstrates the weak position of psychologists in the reproductive field, although as Crespo Mirasol and Bestard argue based on research in Spain (Crespo Mirasol and Bestard, 2017-this volume), psychological care during the IVF process is necessary and desired by patients, in particular since the ART process may limit what the couple is expected to feel.

Griessler and Hager also draw attention to the role of psychologists. In their analysis of legal changes in Austria they notice that 'the positions of the psychologists and psychotherapists were not considered when the new law was created'. Thus, psychologists could be perceived as absent actors in ART treatment, legislative process and media debate on IVF; likewise, research underway suggests that children born with the help of this technology are also not present in the discussions on ART (Radkowska-Walkowicz and Maciejewska-Mroczek, personal communication). Griessler and Hager also observe that in the Austrian ART debate the topics that are increasingly being raised include the medical, psychological and legal background of couples and donors involved in the ART process. Therefore in Austria, as is the case in other contexts, the information about the child's genetic parents is considered increasingly important.

Inmaculada de Melo-Martin (de Melo-Martin, 2017-this volume) also considers the rights of donor-conceived individuals and asks whether it is best to protect their vital interests through prohibiting or mandating anonymity for gamete donation. One of the legal practices that could offer protection in these cases is the regulation of surrogacy. Based on analysis of legalizing altruistic surrogacy in Iceland, Sigurður Kristinnsson (Kristinnsson, 2017-this volume) values the new legal framework designed to protect children's best interests. But none of the authors in this Symposium answers the question: How can we think about children as the important actors/agents without using concepts of welfare of the child and the best interest of the child, which are criticized as historical, political and paternalistic (Monk, 2008)?

This therefore invites future analyses to recognize all actors of ART choreography, and to not focus just on institutions but also on the everyday practices. The ethnographic method offers particular advantages to include the absent voices and muted subjects. Maria Reimann's article (Reimann, 2017-this volume) offers an excellent analysis in this respect, focusing on Polish men's narratives of the IVF treatment. Reimann, via in-depth interviews with men, sheds light on the male experience and understanding of infertility and its treatment in Poland. Men are not subjects of the public debate, which instead focuses on embryos. While infertile men are silent, embryos seem to be

very talkative. Indeed, as Elżbieta Korolczuk shows, ‘analogously to the debate on abortion, the discussion focuses on the wellbeing of the embryo, while the rights of specific groups of “postnatal subjects” (Holc, 2004), such as single women and same-sex couples are effectively marginalized’. Korolczuk’s analysis demonstrates how new types of political subjectivities are constructed at the intersection of different regimes of belonging, which include nationalism and liberal citizenship. Thus, the terms of ART discussion, even as they arguably skirt true engagement with matters of equity, are contested enough to offer a productive space for bridging these gaps, and also for new subject positions and discourses, as Korolczuk shows in her analysis of how these processes create ‘fetal citizens’.

Conclusion

As many authors show in this Symposium, in recent years regulation surrounding ART has become increasingly more liberal (e.g., greater access to PGD, surrogacy), and more harmonized across many European countries. This includes Germany, Switzerland, and Austria, which have become more open to new reproductive technologies in the area of PGD or same-sex parenting (Griessler Hager, Bock von Wulfingen). In the summer of 2015, the first law regulating ART in Poland passed through its Parliament, and a limited a 3-year health insurance coverage program for in-vitro care was approved in 2013. However, the conservative administration elected in 2015 prevented the program’s continuation beyond 2016 – these policy shifts are significant even if such advances are subject to possible reversal by right-wing administrations.

While access may generally be increasing across Europe and elsewhere, it remains highly stratified within and between nations, as well as by multiple lines of disparities related to poverty, race, ethnicity, sexual orientation, disability, class, gender, marital or citizenship status and so on, and as Charis Thompson argued during the meeting, the dominant foci of discussion such as regulation, ethics, and innovations in ART have generally eclipsed deeper discussions about health equities. Specifically, while Griessler and Hager (the case of Austria), Wilson (Germany), Bock von Wulfingen (PGD in Germany), and Kristinsson (the case of altruistic surrogacy in Iceland) describe the shift of the legal situation of ART in some European countries from restrictive to more liberal law, this is not a pattern elsewhere. This in turn seems to be consistent with the logic of technological development and the process of normalization and neutralization of new technologies (medical or otherwise), a process that is well described in the research literature (Cussins, 1998; Franklin and Roberts, 2006: 175, 223–224; Jong de and Tkach, 2009; Thompson, 2005; Throsby, 2004). However, the Polish debate on IVF shows that this direction is not obvious. One can observe a reverse practice: describing IVF as a process inconsistent with nature, biology and ‘social order’. Hence, after nearly 30 years of legal impasse in regulation in the field of ART in Poland (throughout these decades, all new attempts to pass ART regulation triggered heated debate) a law was finally passed in 2015. Although it is a rather conservative version (only for heterosexual couples, single women cannot use their frozen embryos, nonanonymous donation is forbidden) the new Polish government wants to make it even more restrictive by

proposing to prohibit embryo freezing. It further seeks to treat frozen embryos as human beings, to whom the constitutional protection of dignity applies, thereby preventing the production of surplus embryos. Likewise, PGD is sought to be banned altogether. The Polish situation is instructive in highlighting that ART laws are subject to intense political contestations and advances in regulation and subsidies cannot be taken for granted.

Although patients and terms of discussion travel, laws simultaneously transform and new actors emerge in the ART debate, it is nevertheless possible to observe processes which tend toward stabilisation of the situation. As Jill Allison (Allison, 2017-this volume) shows in the case of Ireland, we see a ‘culture of obstacles’ as a way of maintaining a *status quo* that promotes the inability or lack of political will to create more progressive ART, despite same sex marriage passing in Ireland. However, ART advocacy automatically means engagement in political action, as reproductive rights are often seen as tangential to ‘real’ issues, like the economy, in many geopolitical settings. As is again well demonstrated by the situation in Poland, laws, especially reproductive rights, are not always secured permanently, and that the direction of policy change need not be from restrictive to liberal as is evidenced by the restrictions in abortion implemented in 1993 after decades of legal access during the state socialist era. Particular attention therefore should be paid, especially in social science and public policy scholarship, not so much to the stabilizing forces and systems, but to the potential for change so emblematic of ART laws and public debates.

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Additional papers presented at the Brocher Symposium

- Crespo, E., Bastard, J., 2015. Women and partners' experiences after successful Assisted Reproduction Techniques (ART). Brocher Symposium presentation July 5-7, Hermance, Switzerland.
- Kurszus, R., 2015. Conservative laws in a modern country. Brocher Symposium presentation July 5-7, Hermance, Switzerland.
- Pennings, G., 2015. Cross-border reproductive care and justice. Brocher Symposium presentation July 5-7, Hermance, Switzerland.
- Thompson, C., 2015. Transnational, Disability, and Reproductive Justice: Sociological Perspectives on ARTs and Equitable Access to Health Care. Brocher Symposium presentation July 5-7, Hermance, Switzerland.

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