

BOOK AND FILM REVIEWS

Patient-centred IVF Bioethics and care in a Dutch clinic

Reviewed by Rebeca Ibáñez Martín

Trudie Gerrits, *Patient-centred IVF: Bioethics and Care in a Dutch Clinic*. Berghahn Books, 2016. 357 pp. 372, \$120. IBSN# 978-1785332265.

What entails patient-centred care within the context of a fertility clinic? What does analysis of the turn to patient-oriented care convey about health care in the context of reproductive medicine? The book *Patient-Centred IVF: Bioethics and Care in a Dutch Clinic* promises to put patients centre stage, and it certainly does. From the first to the last pages, medical anthropologist Trudie Gerrits carefully builds her analysis of the narratives and lived experiences of patients attending the Radboud Clinic, where Gerrits conducted long-term fieldwork in the Netherlands. This is the first systematic ethnographic work conducted on in vitro fertilization (IVF) treatment in that country. It will appeal to medical anthropologists and practitioners in reproductive health alike. Its ethnographic richness will be attractive to medical anthropologists interested in theoretical contributions drawn from case studies in the clinic, while also offering relevant contrast to related issues in other national contexts. The strong focus on describing and analyzing patient experiences, as well as their perspectives on the clinical process, provides valuable insights for the anthropology of care.

Careful to contextualize her work, Gerrits first takes the reader into an insightful analysis of the particularities of the Dutch health care system relating to reproductive care. The chapters progress from the general to the specific, with the first three helping the reader understand in depth the particularities of the use of assisted reproductive technologies (ART) in the Dutch context. An overview of changes in Dutch legislation and of the clinic where fieldwork was conducted is provided alongside an outline of the different social characteristics of couples seeking treatment. Chapters 4, 5, and 6 form the empirical core of the book, where Gerrits outlines the daily practices that unfold in the clinic and the relationships between facts, expectations, health care providers, loss, patients, and interventions. Chapter 6, on visualizing technologies and practices, tells a compelling story about how the 'medical gaze' shapes the conditions for treatment. In chapter 7, the author discusses the 'gendered suffering' that treatment brings about. Here, Gerrits turns patients into situated women and men. Their experiences differ and so does the style of care given to them. Finally, as the last chapter before the conclusion, chapter 8 discusses how staff at the clinic deal with ethically sensitive cases on a practical level, and how they find consensus when different approaches to a course of medical treatment between staff emerge.

Gerrits's ethnographic work at the Radboud Clinic included hospital observations between 2003 and 2006, during which time she followed twenty-three heterosexual couples with fertility problems who were seeking treatment there. She documents the treatment trajectories of couples at different stages of treatment, a perspective that helps to cover as much ground as possible without following the entire trajectory of any single pair. She also conducted interviews with the patients at home (in which life stories were shared), held phone interviews, and collected the treatment diaries that six women kept and generously shared with her.

Under Dutch law, single women and lesbian couples have the same access to medically assisted reproduction as heterosexual couples. This is provided by fourteen public fertility clinics across the country (though one not addressed directly in the book is semipublic). The clinic studied by Gerrits is one of the academic and public clinics that is fully licensed to provide IVF. However, in practice, some clinics refuse to treat single women and lesbian couples, which is partly explained by policies regarding ova and sperm donation. Prior to 2004, Dutch law permitted anonymous donation of ova and sperm; Gerrits's fieldwork included this period, and afterwards, when anonymous donation was outlawed. Even before 2004, some clinics, including the Radboud Clinic, refused to use anonymous donor material in their treatments, which meant the exclusion of single women and lesbian couples who either could not provide their own semen donor by someone known to them or who desired full anonymous donation of a stranger's sperm. Anonymous donation meant that intended parents and future offspring were not able to know the donor's identity (see for details pp. 60-61). In particular, the Radboud Clinic had psychological concerns about the well-being of children who would not be able to know the identity of their donor. Given this context, Gerrits's fieldwork is only based on heterosexual couples using their own ova and sperm.

The Radboud Clinic is renowned for being the most patient-friendly clinic in the Netherlands, as several prizes and notable mentions confirm. How does this patient-centred approach become apparent in daily care? One answer that Gerrits offers is that the clinic

does not treat patients like a number. Patients participating in the study felt they could build stable relationships with the staff. Staff spent a lengthy amount of time with patients, which resulted in patients' feeling that they were taken seriously, treated well, and well informed.

Patient-oriented care is a trend in health care established to prevent condescending relationships from medical personnel towards patients (Dancet et al. 2010). The ultimate objective is to foster more informed and carefully made choices by patients. Gerrits is certainly committed to this trend in health systems, aiming to attend to and honour patient experiences and understandings of the clinical process. The question guiding the book is a pragmatic one: How, in a context of technological availability and information of ART, do patients navigate their own ideas and experiences to make informed decisions about their treatment?

Gerrits questions the extent to which patients really are making informed choices, and asks whether instead they are becoming adjusted to medical professional advice in a conscious way. Building on Charis Cussins's (1996) analysis, Gerrits argues that in the clinic a process unfolds in which an adjustment between 'agency through objectification' takes place. In her careful outline of patient interactions with health providers, a counterintuitive paradox (the 'paradox of treatment') emerges: too much information does not provide patients with more options. Rather, it fosters continued treatment. As such, patient-centred practices 'may interfere with processes of conscious and deliberate decision making and bias decision making towards (further) medical treatment (pp. 147–48).

After Gerrits describes this paradox concisely, she hints at how to resolve the questions it stirs through an analysis of how patients weigh risks. As the field of medical anthropology often establishes, lay notions of risk are shaped alongside the everyday experiences of those involved. Thus, lay risk perceptions are not static. Patients in her study felt ill equipped to make decisions based on risk abstractions. However, once they experienced a risk unfolding in their bodies, such as a miscarriage or twin pregnancies, they felt equipped to make further decisions. Some of her informants also believed that if a treatment were too risky, it would be irresponsible of the medical staff to offer it to them. What is more, the patients felt that if something were to happen, medical personnel would act immediately. Openness about the many uncertainties of the treatment made patients feel safer and in good hands, strengthening feelings of trust and care among patients. Consequently, one may conclude, the fact that medical staff talked openly about uncertainties created a feeling of safety that made patients willing to continue their treatment.

In a memorable chapter about visualization techniques, thanks to imaging technologies, women were able to gain insight into their bodily functions related to reproduction. Gerrits explores how visualizations of women's bodies serve as a tool for creating scenarios of

success or failure of treatment. Different visualizations of body parts and functions were used by women to create a collage of not only their bodies but, more importantly, of their sense of how the treatment could go. For example, some visualized the number of embryo cells created after an ova extraction or pictured the recently implanted embryo in the uterus, an image of which could be found on the clinical history available to each patient online. These tools helped women configure their expectations of treatment.

Gerrits's greatest insight here is that a patient-centred approach by the medical staff results in making patients more approachable and willing to continue their treatment, even despite prior concern or reluctance. This adds to the complexity of discussions around patient choice and patient-centred approaches to respond to medicalization in health care broadly. The book's location in the Radboud Clinic, and only including heterosexual couples, has some clear limitations. It would be interesting to explore how the changes in Dutch law enforced from 2004 have affected ART in the Netherlands. And while Gerrits discusses changes in the law since her fieldwork, she does not offer further analysis of the implications of such changes. A follow-up study might look into the practical impact that this new law has had for would-be parents, donors, and clinical staff.

The ethnographic perspective of the book offers a valuable insight into the limitations that patient-centred approaches offer to solving the issues of medicalization in the context of ART. What is more, the book provides a close look into the daily work of health care providers, which is extremely valuable as it offers a careful analysis of health care providers' interactions with patients, including mundane details often left outside of the analytical gaze. However, this analysis pertains to only one clinic, leaving unanswered for now the questions of how typical this clinic is for the rest of the Netherlands.

About the author

Rebeca Ibáñez Martín is a researcher in the Health, Care and the Body Research Group at the University of Amsterdam, and the editor of *Cuerpos y Diferencias* (Plaza y Valdés, 2012).

References

- Cussins, Charis. 1996. 'Ontological Choreography: Agency through Objectification in Infertility Clinics'. *Social Studies of Science* 26, no. 3: 575–610. <u>http://www.jstor.org/stable/285701</u>.
- Dancet, E. A. F., W. L. D. M. Nelen, W. Sermeus, L. De Leeuw, J. A. M. Kremer, and T. M. d'Hooghe. 2010. 'The Patients' Perspective on Fertility Care: A Systematic Review'. *Human Reproduction Update* 16: 467–87. <u>https://doi.org/10.1093/humupd/dmq004</u>.