MARGINALIZED REPRODUCTION
ETHNICITY, INFERTILITY AND REPRODUCTIVE TECHNOLOGIES

EDITED BY
LORRAINE CULLEY, NICKY HUDSON AND FLOOR VAN ROOIJ
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Marginalized Reproduction

Ethnicity, Infertility and Reproductive Technologies

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Lorraine Culley, Nicky Hudson and Floor van Rooij

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Theda Borde is Professor of Social Medicine and Social Work at the Alice Salomon University of Applied Sciences in Berlin. She studied political science and public health, was head of an international education and counselling centre for migrants in Berlin, and has conducted research on migration and health in cooperation with the Charité Berlin. Her research has included the healthcare situation of migrant women in gynaecology, patient orientation in health and social care, the utilization of emergency rooms and transcultural aspects of the menopause. From 2002 to 2004 she was chairperson of the ‘Committee of Experts on Health Services in a Multicultural Society’ of the Council of Europe.

Rosario Ceballo is an Associate Professor of Psychology and Women’s Studies at the University of Michigan. She earned her BA at Yale University in 1987, and she received a graduate certificate in Women’s Studies in 1993 and a PhD in Clinical and Developmental Psychology in 1995 from the University of Michigan. Her research focuses on the impact of infertility and racial stereotypes about women’s reproductive abilities on racial and ethnic minority women. Her broad research interests and publications also examine how contextual aspects of poverty, such as financial strain and community violence exposure, influence parenting and adolescents’ academic and psychological functioning.

Noëlle Cotter is a PhD candidate in the School of Social Work and Social Policy in Trinity College, Dublin. Her doctoral research is a longitudinal study of couples’ experiences of infertility and its treatment in Ireland and is funded by Ireland’s Health Research Board. In addition to research in the area of reproductive technologies, her research experience includes work on environmentalism, racism, health and housing. Noëlle holds a BA in History and an MSc in Applied
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**Lorraine Culley** is Professor of Social Science and Health and Associate Director of the Mary Seacole Research Centre at De Montfort University, Leicester, UK. She has recently completed with colleagues a major NHS-funded research project exploring the experience of involuntary childlessness in British South Asian communities and an Economic and Social Research Council (ESRC) funded project investigating public perceptions of third party assisted conception. Her current research work is focused on ethnicity and health and includes work on cultural diversity and endometriosis (funded by the UK Department of Health) and transnational aspects of assisted reproductive technologies (ARTs).

**Yasmin Gunaratnam** is a Lecturer in the Sociology Department at Goldsmiths College, University of London. She has been working on issues of race and gender equality in health and social care for the past 20 years. Yasmin has a particular interest in qualitative research methods and is author of *Researching ‘Race’ and Ethnicity: Methods, Knowledge and Power* (Sage, 2003). Yasmin has also jointly edited a book with David Oliviere entitled *Narrative and Stories in Health Care: Illness, Dying and Bereavement* (Oxford University Press, forthcoming).

**Zeynep Gürtin-Broadbent** is a PhD student in the Centre for Family Research, University of Cambridge. In her doctoral thesis she examines how the ‘global’ in vitro fertilization (IVF) technology has been localized in the Turkish context and explores Turkish women’s experiences of infertility and assisted reproduction. Her research interests are broadly in gender, reproduction, reproductive medicine and its delivery, patient–clinician interactions, bodies, and reproductive decision making, and she has a particular area interest in Turkey. She works in an interdisciplinary way, utilizing a range of qualitative research methods, principally ethnography and in-depth interviews. Zeynep is co-Convener of the Cambridge Interdisciplinary Reproduction Forum.

**Nicky Hudson** is a Senior Research Fellow in the School of Applied Social Sciences at De Montfort University, UK. She is a sociologist with an interest in health, medicine, gender and ethnicity, and recently completed her doctoral research: ‘Infertility in British South Asian communities: Negotiating the community and the clinic’, which explored the experiences of British South Asian women who have used ARTs. Nicky is also interested in qualitative research methodology, particularly in aspects of the researcher–researched relationship.

**Marcia C. Inhorn** is the William K. Lanman Jr Professor of Anthropology and International Affairs in the Department of Anthropology and The Whitney and Betty MacMillan Center for International and Area Studies at Yale University. She also serves as Chair of the Council on Middle East Studies there. A specialist on Middle Eastern gender and health issues, Marcia has conducted research
on the social impact of infertility and ARTs in Egypt, Lebanon, the United Arab Emirates and Arab America over the past 20 years. She is the author of three books on the subject, as well as co-editor of six books in the areas of gender, health, science, technology, biomedicine and public health.

Mark R. D. Johnson is Professor of Diversity in Health and Social Care, and directs the Mary Seacole Research Centre, De Montfort University, Leicester, UK. His recent publications include articles on visual impairment, health promotion, research ethics, alcohol use among ‘second generation’ migrants, community cohesion, and health services for asylum seekers, as well as books, and reports for the UK Home Office and Department of Health on aspects of health inequality, ‘race’ and ethnicity. He is also actively working with community groups on healthcare issues such as innovative ways to raise uptake of services for the visually impaired, and to validate translated health promotion materials.

Dineke Korfker is a midwife and anthropologist. Since 2001, she has worked at TNO Quality of Life, Section of Reproduction and Perinatology. TNO is a knowledge organization that makes scientific knowledge applicable for companies, government bodies and public organizations. Her main research interests are reproductive health, migrants and domestic violence, with a special focus on violence during pregnancy and female genital mutilation. Previously, she worked for many years in Africa (Mozambique and Egypt) for the United Nations Population Fund (UNFPA) as an adviser in reproductive health programmes.

Pranee Liamputtong has a Personal Chair in Public Health at La Trobe University, Australia. She is a medical anthropologist and has interests in the health of immigrants and refugees, women’s health, mothers’ and children’s health, and reproductive and sexual health. Pranee has carried out a number of research projects with immigrant women in Australia and women in Southeast Asia. She has recently undertaken qualitative research with women living with HIV/AIDS in Thailand. Pranee has written a number of text books including Researching the Vulnerable: A Guide to Sensitive Research Methods (Sage, 2006) and Doing Cross-Cultural Research: Ethical and Methodological Perspectives (Springer, 2008).

Robert Nachtigall is a Reproductive Endocrinologist and Clinical Professor of Obstetrics, Gynecology and Reproductive Sciences at the University of California, San Francisco whose research career has been committed to the study of the ethical and psychosocial issues and controversies that accompany many aspects of modern infertility treatment. His work has been funded by the National Institutes of Health and the National Institute on Aging and includes an investigation of how infertile couples who have undergone IVF decide what to do with their surplus frozen embryos, an ethnographic qualitative description of the infertility experiences of low-income Latino women, and an exploration of the process that parents who conceive with donor gametes engage in as they decide whether or not to inform their children of the true nature of their conception.
Frank van Balen studied sociology, political science, macro-economics and non-Western sociology. He is Associate Professor at the Faculty of Social and Behavioural Sciences at the University of Amsterdam and was, until retirement, programme director of the Section Education and Child-Rearing. He carried out and supervised various major research projects in the field of involuntary childlessness, children conceived with reproductive technologies, same-sex families, prenatal diagnostics, sex selection, the cross-cultural value of children, and infertility and stress. He is President of the Dutch Society for Social Research on Infertility (SORT). Frank van Balen co-edited the volume *Infertility around the Globe* (University of California Press, 2002), which received the ‘best volume’ award from the American Anthropological Association. He is initiator of a global network of social scientists in infertility research, and co-organized the first conference in this field. Frank retired in 2008, but still continues to do research and supervision.

Floor van Rooij recently obtained her PhD at the Faculty of Social and Behavioural Sciences of the University of Amsterdam, where she conducted a study entitled ‘The experience of involuntarily childless Turkish migrants in the Netherlands: Parenthood motives, psychosocial consequences, responses and help-seeking behavior’. Her research interests include involuntary childlessness, ethnic minorities, healthcare and parenting. She is currently working as a researcher at the Department of Epidemiology, Documentation and Health Promotion in the Public Health Service of Amsterdam (GGD Amsterdam).
Throughout the world, infertility – the inability to have desired children – is stigmatized and viewed by fertile and infertile alike as a failure to achieve important cultural goals. Because the concern with fertility is so intimately involved with other cultural institutions, interpretations, treatments and the social consequences of infertility will vary from one sociocultural setting to another. For this reason, the social scientific study of infertility is not to be regarded simply as a practical enterprise oriented to providing better support to the infertile and to those who treat them, but also as a window through which to observe sociocultural reality.

For example, infertility provides us with a lens on gender. The way people respond to infertility tells us much about the roles available to women, the relative power of men and women, and the texture of the relationship between women and men within the family, kinship networks and other sociocultural settings. Infertility also presents us with an opportunity to observe medical institutions in action. In industrialized societies, infertility has been medicalized and medical institutions often exert hegemony over how many people experience infertility, and we can look at infertility as a site where individuals adapt to and confront the world of high-tech medicine. In addition, infertility presents us with the opportunity to observe the quest for meaning in contemporary societies. Whenever people are confronted with a failure to achieve desired goals, they look for solutions at the level of meaning. Infertility is thus an ideal site for watching people ascribe meaning to events that the medical model treats as scientific and therefore morally neutral.

This book – *Marginalized Reproduction: Ethnicity, Infertility and Reproductive Technologies*, by Lorraine Culley, Nicky Hudson and Floor van Rooij – draws our attention to two other features of contemporary societies that appear in sharper focus when viewed through the lens of infertility. People tend to refer to both of these features under the rubric of ‘ethnicity’, but I think it is helpful to distinguish between ethnic stratification and cultural pluralism. Studying infertility gives us a way to appreciate at a very personal level the tension between the stratification that pervades all industrialized societies and the ideology of equal citizenship that industrialized states articulate. At the same time infertility can serve as a vantage point from which to watch the processes by which migrants struggle to adapt their cultural reality to the new realities that surround them and by which host societies struggle to develop a new conception of national identity.
There are now a number of studies of the experience of infertility in industrialized societies, but these studies – including my own – have highlighted the perspectives of White, middle-class treatment seekers. There are also a number of studies of the experience of infertility in resource-poor ‘developing’ societies. Comparing these sets of studies, we can discern the existence of ‘two worlds’ of infertility. In one world, the biomedical model exercises hegemony, medical solutions to infertility are available to many and viable alternatives to motherhood exist. In the other world, the biomedical model coexists with or competes with more holistic conceptions of health and well-being, access to medical care is more limited and alternatives to motherhood seem less viable.

For the first time, in this volume, we have a collection of chapters that describe what happens when the two worlds of infertility come together, as they do in all industrialized societies. Here we get to see that global reproductive stratification exists within as well as between societies. Here, too, we have the opportunity to observe the way individuals navigate between competing realities and operate in the context of limited opportunities. The first half of the book provides an overview of theory research, and methodological challenges involved in studying infertility among marginalized people. The second half features case studies which highlight commonalities and differences in the experience of infertility. The editors have done an excellent job of compiling in one place a group of informative and interesting chapters that draw our attention to a new perspective from which to view both the experience of infertility and the reality of industrialized societies. They are to be commended for the service they have performed for the scholarly community.

Arthur L. Greil
Alfred University
New York
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## List of Acronyms and Abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ARTs</td>
<td>assisted reproductive technologies</td>
</tr>
<tr>
<td>BICA</td>
<td>British Infertility Counselling Association</td>
</tr>
<tr>
<td>BME</td>
<td>black and minority ethnic</td>
</tr>
<tr>
<td>BMI</td>
<td>body mass index</td>
</tr>
<tr>
<td>CAHR</td>
<td>Commission on Assisted Human Reproduction</td>
</tr>
<tr>
<td>ESRC</td>
<td>Economic and Social Research Council</td>
</tr>
<tr>
<td>GP</td>
<td>general practitioner</td>
</tr>
<tr>
<td>HFE</td>
<td>Human Fertilisation and Embryology (Act)</td>
</tr>
<tr>
<td>HFEA</td>
<td>Human Fertilisation and Embryology Authority</td>
</tr>
<tr>
<td>ICSI</td>
<td>intracytoplasmic sperm injection</td>
</tr>
<tr>
<td>IUI</td>
<td>intrauterine insemination</td>
</tr>
<tr>
<td>IVF</td>
<td>in vitro fertilization</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
</tr>
<tr>
<td>NRTs</td>
<td>new reproductive technologies</td>
</tr>
<tr>
<td>PCOS</td>
<td>Polycystic Ovary Syndrome</td>
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<tr>
<td>STD</td>
<td>sexually transmitted disease</td>
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<tr>
<td>UNFPA</td>
<td>United Nations Population Fund</td>
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Introduction: Ethnicity, Infertility and Assisted Reproductive Technologies

Lorraine Culley, Nicky Hudson and Floor van Rooij

Infertility is a common occurrence. Differences in definitions, measurement criteria and healthcare systems between countries make global estimates of the prevalence of infertility difficult. However, a recent and comprehensive review of 25 population surveys of infertility concluded that overall around 9 per cent of women aged 20–44 experience infertility, which equates to 72.4 million women worldwide (Boivin et al, 2007). The inability to conceive has been documented in an extensive collection of studies as an experience that has a profound influence on the personal well-being of women and men (Phoenix et al, 1991; Monach, 1993; Sandelowski, 1993; Whiteford and Gonzalez, 1995; Inhorn, 1994, 1996; Franklin, 1997; Letherby, 1999; Becker, 2000; Reissman, 2000; Throsby, 2004; Allan, 2007). Guilt, helplessness, marital stress and depression are commonly reported, particularly for women, although as Greil’s (1997) review of the social psychological literature argues, there are many methodological flaws in existing studies, including small sample sizes and over-reliance on treatment seekers. Boivin et al (2007) estimate that only around half of those experiencing fertility problems seek any infertility care, and even in more developed societies less than one quarter actually receive any specialist fertility treatment.

Nevertheless, the development of assisted reproductive technologies (ARTs) such as in vitro fertilization (IVF) has meant that many infertile couples can be helped to achieve a pregnancy, although for all fertility treatments there is a less than 50 per cent chance of successful conception and many treatments have potentially harmful side effects (van den Akker, 2002). Since the birth of the first baby using IVF in 1978 more than 3 million babies have been born using ART, with an estimated 1 million ART cycles now performed each year, producing around 200,000 babies worldwide (ESRHE, 2006). The range of treatments has expanded substantially in the last 30 years. In particular, the advent of
intracytoplasmic sperm injection (ICSI) has radically changed the potential for ‘treating’ male infertility, providing a genetic link to the offspring for sub-fertile men. For those who can afford this procedure, this has largely replaced donor insemination in Western societies and is growing in popularity in other parts of the world (Inhorn, 2003). Many relatively ‘low-tech’ treatments (drug therapy and intrauterine insemination (IUI)) are still used for some categories of infertility, especially as first-stage treatment for younger women, and as the only accessible form of treatment for those who cannot afford the expensive option of IVF.

Data on international treatment cycles highlight the ways in which ARTs are unequally distributed globally. Only a few countries offer access to IVF and ICSI. Of the 91 member states of the World Health Organization (WHO), 48 had medical facilities offering IVF in 2000 (Natchigall, 2006). Half of all cycles were delivered in just four countries (US, Germany, France and UK). Despite all this activity in ART, it is salutary to remember that high-tech, high cost (and in many cases high profit) IVF delivers a live birth rate of less than 25 per cent per cycle (Ombelet et al, 2008).

While there is a growing volume of literature on the use of ARTs in Western societies, the experience of infertility in minority ethnic communities remains largely invisible to epidemiologists, social scientists, practitioners and policy makers. There is limited research that explores the impact of diverse ethnicities, religious identities and cultural contexts on the experience and resolution of infertility within the West. This book attempts to address this research lacuna, demonstrating the potential importance of the social and cultural context of infertility and its treatment and, in several chapters, foregrounding the experiences of marginalized and racialized minorities within the West. Drawn from a range of disciplinary perspectives, theoretical frameworks and geographical locations, the collection brings together for the first time work that has itself been somewhat on the margins of the academy.

**ARTs and social science**

Infertility has attracted the attention of a growing and diverse constituency of scholars from the biological, behavioural and social sciences, as well as cultural critics, ethicists, theologians and legal experts. This reflects, to some degree, its utility as a ‘rhetorical vehicle’ for a variety of Western concerns (Sandelowski and de Lacey, 2002). Part of the fascination of social scientists with infertility and its treatment is due to the intimate connections between reproduction and power. Studying reproduction provides a useful lens to explore the ‘complex social arrangements through which legacies of property, positions, rights, and values are negotiated over time’ (Ginsberg and Rapp, 1995, p2). Infertility as a form of ‘reproduction gone awry’ (Jenkins and Inhorn, 2003) has been a frame for exploring a number of concerns emanating from modern and post-modern social theory.

Thompson (2005), for example, in exploring the complex ‘ontological choreography’ of making babies and making parents using assisted reproduction,
demonstrates the ‘dynamic coordination of the technical, scientific, kinship, gender, emotional, legal, political, and financial aspects of ART clinics’; a bringing together of ‘things that are generally considered parts of different ontological orders (part of nature, part of the self, part of society)’ (p8). The rapid extension of reproductive technologies has deeply unsettled established ideas of what is ‘natural’ (Strathern, 1992; Franklin, 1997) and given rise to a number of new (and for many, unnerving) family forms and relationships. It is not surprising then, that infertility and assisted conception have generated considerable academic (and popular) interest.

The vast majority of this work, however, has concerned itself with the needs, interests and experiences of dominant social groups and white middle class couples in the West in particular. There are of, course, notable exceptions. The framing of infertility in terms of the global politics of reproduction, pioneered by feminist scholars for example, marks a considerable improvement in our understanding of infertility (Thompson, 2002). Extending their gaze beyond the traditional foci of anthropology, Ginsburg and Rapp (1995) alerted us, in a pioneering volume, to the importance of the politics of reproduction, locally and globally. They employ the term ‘stratified reproduction’ to explore how reproduction is structured across social and cultural boundaries, describing the ways in which power relations empower some categories of people to nurture and reproduce, while others are disempowered.

Global concerns

The challenge to the dominance of infertility as a Western phenomenon has been most richly portrayed in a groundbreaking text published in 2002. *Infertility around the Globe* (Inhorn and van Balen, 2002) explicitly focused on the global dimensions of infertility, moving beyond Western sites of technology production and debate, to expose the cross-cultural prevalence of infertility and the global connections between societies that produce and consume technologies which both enhance and curtail fertility. The rationale for this collection was a pressing need to reveal the ‘lived experience’ of infertility and childlessness, not just in the West, but in a range of non-Western societies.

This text played a vital role in decentring Western perspectives of infertility and technological solutions to childlessness, demonstrating the cultural variability in beliefs about infertility, its causes and consequences and in ideas about what should be done about it. The book was a powerful antidote to the privileging of Western concerns and concepts. Inhorn and van Balen foregrounded the paradox of infertility in ‘high-fertility’ cultures, challenging the scholarly silence in the West on the plight of the infertile in ‘other’ places. A silence which, they argued, reflects a common obsession in international population discourse, with curbing the ‘hyperfertility’ of non-Western subjects and a lack of desire to address the needs of infertile populations within non-Western settings (Inhorn and van Balen, 2002). This work, and other important contributions, have pointed to global contrasts in the consequences of infertility, with typically much more severe social consequences described for those in less developed societies (especially women) (Ombelet et al, 2008).