

## Perspective Piece

### The Nairobi Summit and Reproductive Justice: Unmet Needs for People with Infertility

Susan Dierickx,<sup>1</sup> Michiel De Proost,<sup>1</sup> Anny Yuanfei Huang,<sup>2,3,4</sup> Sainey Ceesay,<sup>5</sup> Ed Clarke,<sup>3</sup> and Julie Balen<sup>2\*</sup>

<sup>1</sup>Centre of Expertise on Gender, Diversity and Intersectionality (RHEA), Vrije Universiteit Brussel, Brussels, Belgium; <sup>2</sup>School of Health and Related Research (SchHARR), The University of Sheffield, Sheffield, United Kingdom; <sup>3</sup>Medical Research Council Unit, The Gambia at the London School of Hygiene and Tropical Medicine, Fajara, The Gambia; <sup>4</sup>Research School of Population Health, Australian National University, Canberra, Australia; <sup>5</sup>Safe Haven Foundation, Banjul, The Gambia

**Abstract.** The Nairobi Summit, held in November 2019 and convened by the United Nations Fund for Population Activities, claims to have represented “all nations and peoples, and all segments” of society during its high-level conference. The overall aim of the summit was to mobilize political will and financial commitments that are urgently needed to “finally and fully” implement the 1994 International Conference on Population and Development (ICPD) Program of Action. Despite the recommendation by ICPD to incorporate infertility care in reproductive health services, the new Nairobi Statement largely neglects the topic of infertility. This is particularly troublesome as infertility is a global health problem affecting between 52.6 and 72.4 million couples worldwide, with a high prevalence in low- and middle-income settings. For many people around the world, infertility constitutes an emotional, social, and financial burden, yet appropriate services directed toward preventing and addressing infertility are often inaccessible, unaffordable, or nonexistent. With the impetus of a wider reproductive justice community, we call for the integration of infertility into global reproductive health research and practice, urging policy makers, practitioners, researchers, activists, and funders worldwide to bring focused attention to addressing challenges posed by a lack of safe, effective, and dignified fertility management among those in need.

#### PERSPECTIVE PIECE

Infertility is a global reproductive health problem with the most recent data indicating that 52.6–72.4 million couples could benefit from some form of medical intervention to achieve a pregnancy, with high prevalence in low- and middle-income countries (LMICs).<sup>1</sup> In LMICs, high rates of infertility largely result from preventable, poorly managed, or untreated reproductive tract infections, including sexually transmitted diseases and pregnancy-related issues such as postpartum, postabortion, and iatrogenic infections.<sup>2,3</sup> The prevention and management of infertility was recognized as a basic component of sexual and reproductive health care and rights during the landmark 1994 International Conference on Population and Development (ICPD) held in Cairo.<sup>4–6</sup> The ICPD Program of Action, which was signed by 179 countries, recommended bringing services for the prevention of infertility and appropriate treatment closer to those in need. Over the years, this promise was reiterated by the international community, for example, at the World Summit (2005) and as part of the WHO Global Health Strategy (2011).

In practice, 25 years after the landmark ICPD, infertility services remain limited in LMICs, although with some differences across- and within-countries. This is particularly the case for advanced approaches based on assisted reproductive technologies, which have been adopted by some countries including India, Nigeria, and South Africa.<sup>2,3,7,8</sup> There is also a global tendency to locate services for infertility within private health centers, making these services inaccessible and unaffordable for most of the populations, particularly the most vulnerable.<sup>3,6,9,10</sup> This results in those more likely to be facing infertility also being less likely to receive care—raising important ethical and practical questions.<sup>3,6,7,11</sup>

The Nairobi Summit, held in November 2019 on the 25th anniversary of the original ICPD (ICPD25), aimed to mobilize political will and financial commitments that are urgently needed to implement “finally and fully” the 1994 ICPD Program of Action.<sup>12</sup> The Nairobi Summit convened by the United Nations Fund for Population Activities claims to have represented “all nations and peoples, and all segments of society” and was deemed a great success, but the topic of infertility was not specifically mentioned in the accompanying Nairobi Statement released by the International Steering Committee on ICPD25.<sup>13</sup> This represents a missed opportunity to remind global stakeholders that reproductive choice consists of more than family planning and safe delivery. Endorsement through the Nairobi Statement would have served as a much-needed policy vehicle to prompt the inclusion of infertility in the health agendas of governments worldwide and would have helped build on the precedent set by the original ICPD.

The Nairobi Statement reflects an ongoing tendency by most international organizations, donors and national governments to sideline the subject of infertility.<sup>4,6,14</sup> Progress has been made in research efforts on infertility, but compared to the sociopsychological and financial burden of infertility, research remains underdeveloped and vastly underfunded.<sup>15–17</sup> Studies conducted to date have repeatedly shown how infertility constitutes not only a medical condition but also exerts a substantial effect on the psychosocial well-being of people wanting to have children.<sup>3,9,18</sup> Several scholars have argued that in comparison to high-income settings, the psychosocial impact of infertility tends to be significantly worse for people living in LMICs because of pronatalist social norms and strong family values.<sup>3,15</sup> For example, in various contexts throughout sub-Saharan Africa, people experiencing infertility are confronted with severe stigmatization and isolation in their communities; financial difficulties due to inheritance regulations among other causes; troubles—including gender-based violence—within their marriages; and emotional problems, including traumatic stress, anxiety, and depression in settings where mental health services are also limited.<sup>16,19–21</sup>

\* Address correspondence to Julie Balen, School of Health and Related Research (SchHARR), Regent Court, Sheffield S1 4DA, United Kingdom. E-mail: j.balen@sheffield.ac.uk

The voices and experiences of persons facing infertility have been largely overlooked in the international community, with the exception of scholars and activists who have repeatedly urged for infertility to be not only viewed as a reproductive right but also as a key element of reproductive justice.<sup>2,7</sup> The concept of reproductive justice was introduced three decades ago by women of color in the United States, as a reaction to the narrow framing of reproductive rights.<sup>22,23</sup> Activists and scholars urging for reproductive justice acknowledge how reproductive rights are intertwined with access to economic, social, and political power and resources as these have an influence on the capacity of people to exercise meaningful choice. As such, the concept of reproductive justice enables an understanding of how structural constraints disable people's capacity to exercise their reproductive rights.

The international community must now invest in the prevention of infertility by supporting early detection and appropriate treatment of genital tract infections, the major causes of infertility in LMICs.<sup>15</sup> Moreover, evidence shows that in these settings, major improvements can be achieved at low cost and relative ease by standardizing diagnosis and treatment procedures, training health staff, and improving counseling practices across all levels of the healthcare system.<sup>2,4</sup> Additional investments should be made in policy and clinical interventions to bring assisted reproduction to those who are in greatest need. This includes supporting research looking into low-cost treatments for infertility.<sup>2,15</sup> Such investments would signal a strategic commitment to the most vulnerable people in every region of the world in which infertility causes severe suffering and to focus on eliminating structural injustices that are normalized by forces of globalization. This will require interdisciplinary and intersectional approaches with careful attention toward local contexts and an awareness of the opportunities and barriers for the implementation of such services.<sup>7,17</sup> It is critical that any initiative places the experiences of vulnerable individuals and communities at the center of the analysis and that it emphasizes the inevitable relationships between poverty, place, and reproduction, as had already been recommended by the ICPD in 1994. We argue, based on the reproductive justice framework, that safe, effective, and dignified fertility management constitutes a fundamental human right.

Received February 17, 2020. Accepted for publication May 19, 2020.

Published online January 25, 2021.

**Acknowledgments:** We want to thank all informants for their trust and collaboration with us through our different research projects on reproductive health challenges. We also thank our colleagues who helped inform our views through stimulating conversations and research support.

**Authors' addresses:** Susan Dierickx and Michiel De Proost, Centre of Expertise on Gender, Diversity and Intersectionality (RHEA), Vrije Universiteit Brussel, Brussels, Belgium, E-mails: susan.dierickx@vub.be and michiel.de.proost@vub.be. Anny Yuanfei Huang, Research School of Population Health, Australian National University, Canberra, Australia, E-mail: anny.y.huang@gmail.com. Sainey Ceesay, Safe Haven Foundation, Banjul, The Gambia, E-mail: saibabe55@gmail.com. Ed Clarke, Vaccines and Immunity Theme, MRC Unit, The Gambia at the London School of Hygiene and Tropical Medicine, Fajara, The Gambia, E-mail: ed.clarke@lshtm.ac.uk. Julie Balen, School of Health and Related Research (ScHARR), The University of Sheffield, Sheffield, United Kingdom, E-mail: j.balen@sheffield.ac.uk.

## REFERENCES

- Mascarenhas MN, Flaxman SR, Boerma T, Vanderpoel S, Stevens GA, 2012. National, regional, and global trends in infertility prevalence since 1990: a systematic analysis of 277 health surveys. *PLoS Med* 9: e1001356.
- Ombelet W, 2011. Global access to infertility care in developing countries: a case of human rights, equity and social justice. *Facts Views Vis Obgyn* 3: 257–266.
- Inhorn MC, Patrizio P, 2015. Infertility around the globe: new thinking on gender, reproductive technologies and global movements in the 21st century. *Hum Reprod Update* 21: 411–426.
- Gerrits T, Shaw M, 2010. Biomedical infertility care in sub-Saharan Africa: a social science review of current practices, experiences and view points. *Facts Views Vis Obgyn* 2: 194–207.
- Hough CA, 2010. Loss in childbearing among Gambia's kanyalengs: using a stratified reproduction framework to expand the scope of sexual and reproductive health. *Soc Sci Med* 71: 1757–1763.
- Dierickx S, Coene G, Evans M, Balen J, Longman C, 2019. The fertile grounds of reproductive activism in the Gambia: a qualitative study of local key stakeholders' understandings and heterogeneous actions related to infertility. *PLoS One* 14: e0226079.
- De Proost M, Coene G, 2019. Emancipation on thin ice: women's autonomy, reproductive justice, and social egg freezing. *Tijdschr Genderstud* 22: 357–371.
- Dierickx S, Balen J, Longman C, Rahbari L, Clarke E, Jarju B, Coene G, 2019. 'We are always desperate and will try anything to conceive': the convoluted and dynamic process of health seeking among women with infertility in the West Coast Region of the Gambia. *PLoS One* 14: e0211634.
- Bell AV, 2016. The margins of medicalization: diversity and context through the case of infertility. *Soc Sci Med* 156: 39–46.
- Smietana M, Thompson C, Twine FW, 2018. Making and breaking families – reading queer reproductions, stratified reproduction and reproductive justice together. *Reprod Biomed Soc Online* 7: 112–130.
- Ceballo R, Graham ET, Hart J, 2015. Silent and infertile: an intersectional analysis of the experiences of socioeconomically diverse African American women with infertility. *Psychol Women Q* 39: 1–15.
- UNFPA, 2020. *About the Nairobi Summit*. Available at: <http://www.nairobisummitcpd.org/content/about-nairobi-summit>. Accessed February 17, 2020.
- UNFPA, 2020. *Nairobi Statement on ICPD25: Accelerating the Promise*. Available at: <https://www.nairobisummitcpd.org/content/icpd25-commitments>. Accessed February 17, 2020.
- Nahar P, 2012. Invisible women in Bangladesh: stakeholders' views on infertility services. *Facts Views Vis Obgyn* 4: 149–156.
- Ombelet W, 2014. Is global access to infertility care realistic? The Walking Egg Project. *Reprod Biomed Online* 28: 267–272.
- Fledderjohann JJ, 2012. "Zero is not good for me": implications of infertility in Ghana. *Hum Reprod* 27: 1383–1390.
- Dierickx S, Rahbari L, Longman C, Jaiteh F, Coene G, 2018. 'I am always crying on the inside': a qualitative study on the implications of infertility on women's lives in urban Gambia. *BMC Reprod Heal* 15: 1–11.
- Baldwin K, 2019. The biomedicalisation of reproductive ageing: reproductive citizenship and the gendering of fertility risk. *Health Risk Soc* 21: 268–283.
- Ibisomi L, Mudege NN, 2014. Childlessness in Nigeria: perceptions and acceptability. *Cult Heal Sex* 16: 61–75.
- Dhont N, 2011. Clinical, epidemiological and socio-cultural aspects of infertility in resource-poor settings. Evidence from Rwanda. *Facts Views Vis Obgyn* 3: 77–88.
- Hollos M, Whitehouse B, 2014. Women in limbo: life course consequences of infertility in a Nigerian community. *Hum Fertil* 17: 188–191.
- Rubin LR, Phillips A, 2012. Infertility and assisted reproductive technologies: matters of reproductive justice. Chisler JC, ed. *Reproductive Justice: A Global Concern*. Santa Barbara, CA: ABC-Clio, LLC, 173–199.
- Ross L, Roberts L, Derkas E, Peoples W, Toure PB, eds., 2017. *Radical Reproductive Justice. Foundations, Theory, Practice, Critique*. New York, NY: Feminist Press.