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The Impact of Infertility: Why ART Should Be a Higher Priority for Women in the Global South

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Introduction

Cancer is typically associated with countries in the global North[1] rather than the global South. This is in part because cancer is often portrayed as a disease of late middle to old age and the global North has a larger percentage of this particular demographic than the global South. Yet, cancer is the third leading non-communicable cause of death in developing countries [1]. Furthermore, the American Cancer Society estimates that over half of all new cancer cases were in the global South in 2007. Specifically, almost 3.6 million of the 6.6 million new male cancer cases worldwide and over 3.1 million of the 5.7 million new female cancer cases worldwide afflicted men and women in the global South [2]. As these numbers show cancer is not a disease only or mostly affecting people in the global North, it also affects a substantial population in the global South.

Many of the established treatments for cancer, like chemotherapy, radiation, and surgery, run the risk of infertility for both women and men. The social consequences of infertility for women in the global South are especially devastating, ranging anywhere from ostracism to spousal violence. Yet fertility preservation treatment for women with cancer in the global South is generally not available for a variety of reasons, most of which center around money. These resource-poor countries typically lack both qualified health-care professionals and facilities necessary for fertility preservation treatment and other assisted reproductive technologies (ART). Although some countries do have ART centers, the cost of ART is prohibitive for all but the extremely wealthy. Indeed, infertility is usually seen as a treatable problem for the upper class primarily because the poor cannot afford basic health care let alone expensive treatment like ART [3, p. 32]. The fact that the majority of people in the global South cannot afford basic health care, which is typically seen as the top priority in health-care allocation, is another reason why ART are not readily available in the global South. Most public and private health-care funding goes toward primary care and not treatments that are often seen as elective and cosmetic, like ART.

While we agree that preventive and basic health care should remain the priority for countries in the global South, we also think the very low prioritization of ART, including fertility preservation treatment, should be reconsidered. Taking a feminist perspective, we argue that given the severe social, economic, and health-related consequences of infertility for women in the global South, ART should be more accessible and affordable. Given the large

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[1]In this chapter we are using the term “global North” to refer to the collection of countries often classified as “developed” or “industrial.” We are using the term “global South” to refer to the collection of countries generally labeled as “developing.” We use these particular terms because the concept of development is complex and therefore it is difficult to come to agreement on what criteria make a country developed or developing. Additionally, the terms “developing” and “developed” not only imply that there is a linear path from the latter to the former but also that the latter is unequivocally better in most, if not all, ways. Though problematic, we will also use the more traditional terms “developing” countries and “developed” countries in this chapter.

discussion this topic entails, we merely highlight and briefly provide some of the key points. Indeed, this chapter serves as an overview and in no way is it a fully articulated argument.

We divided this chapter into five sections. In the first section, we explain why a feminist approach is important when examining reproductive matters in the global South. In the second section, we discuss some of the adverse effects of infertility for women in various geographic regions of the global South. In the third section, we outline one of the most common objections to making ART a priority in the global South: that there are more pressing and important diseases to prioritize. We then provide three responses to this objection in the fourth section. First, we point out that ART need not be exorbitant. Second, we assert that as a matter of social justice, reproductive autonomy should include the right to have a child. Third, we argue that increasing women's autonomy, including their reproductive autonomy, is an important step in countries' economic development. In the fifth section, we return to the topic of women with cancer to show that fertility preservation treatment should be offered to this population because of the potential double burden they face as cancer and infertility patients.

Why a Feminist Approach?

In analyzing infertility, ART, and women in the global South, we choose to employ a feminist approach because it acknowledges power structures and hence can uncover hidden gender inequities. In contrast, traditional ethical approaches often ignore or inaccurately portray the realities of life. Traditional ethics is frequently guilty of treating the public and private realms as two distinct spheres and often ignores the latter. In the words of Rosemarie Tong and Nancy Williams, "traditional ethics view as trivial the moral issues that arise in the so-called private world, the realm in which women do housework and take care of children, the infirm, and the elderly" [4, p. 1]. Reproduction and family matters are generally relegated to the private realm. It is therefore important to utilize a theory that not only recognizes the complex interplay between public and private realms, but also incorporates social context. A feminist approach allows us to reveal and critique oppressive practices because it includes social groups, not just individuals, in its examination. As Marilyn Frye persuasively argues, oppression is based on one's group membership (e.g., sex, race, and religion) and not on one's individual characteristics [5, ch. 1]. In order to understand how infertility affects women as a group in the global South, we need to rely on an approach, like feminism, that is grounded in oppression theory.

The Deleterious Effects of Infertility for Women in the Global South

There is much debate over whether infertility is a disease and thus necessitates medical treatment. Some who argue that treatment for infertility is elective – not medically necessary – would probably claim that it should be excluded from the discussion of health-care priorities and allocation. We do not wish to engage in this debate; rather, we will take it as a given that infertility is a disease and approach the topics of ART in the global South from a different angle. Relying on the World Health Organization's broad definition of health – "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" – we claim that infertility engenders a state of non-health for women in the global South [6]. As we show with examples from various geographic areas in the global South, infertility often leads to a variety of deleterious social, economic, and health effects for women.

Before moving on, however, it is important to note that regardless of which partner (the woman, man, or both) is the cause of infertility, it is generally the woman who is blamed and hence suffers the consequences of infertility.

Africa

In many African countries, the purpose of marriage is to produce children. Children are economically necessary to married couples because they carry a part of the workload and are responsible for taking care of their parents when they become elderly and unable to care for themselves. People without children have less help with work tasks, thereby causing women (and men) to take on more work themselves. Women are made especially vulnerable in old age if they are childless because they are sometimes seen as a disposable segment of the family and population.

There are also religious reasons why children are so highly valued in many African cultures. For example, in certain cultures, children are thought to play an active role in their parents' transition to the afterlife. As Godfrey Tangwa explains, "on the approach of death, a childless person is particularly terrified because, while death is considered a transition into the realm of the ancestors, the living-dead, life, well-being, and prosperity in that realm is believed to depend on the reciprocal interaction between the progeny and the ancestors, between the living kin and the living dead" [7, p. 56]. In other words, women and men without children may be quite stressed and fearful at the end of life because they do not have children to assist them in a good afterlife.

Asia

Women in China, India, and other countries in Asia typically have a low social status. One of their key roles – if not the key role – is to produce healthy offspring, namely sons. Having sons increases a woman's social status. Women who do not have sons, or worse yet, do not have any children, have a lowered social status. Indeed, women suffering from infertility have a dramatically diminished quality of life. They experience social ostracism ranging from the aforementioned lowered social status to divorce [8, p. 78]. Moreover, they typically experience psychological, emotional, and physical abuse not only from their husbands but also from their families and community at large. It is estimated that nearly 70% of infertile women are punished in a violently physical manner for their infertile condition because it is seen as a failure by spouses and family members [9, p. 17]. In addition to this abuse, infertile women "have nobody to talk to or share their pain with. The childless woman is considered inauspicious and feels unworthy and unwanted" [10, p. 67].

Middle East

As in Asia, in developing parts of the Middle East, women rely upon their procreative abilities to establish their social status. According to Gamal Serour, "Prevention of infertility and its relief are of particular significance in the Middle East area because a woman's social status, her dignity and self-esteem are closely related to her procreation potential in the family and in society as a whole" [11, p. 41]. Infertility can compromise women's sense of self, their marriage, and their role within the family. Generally women who are fertile are treated better and have a higher social status than women who are infertile.

Latin America

Due to the *machismo* culture, Latin American women suffering from infertility rarely discuss their condition with others out of fear of their husbands' response. Indeed, women feel forced to hide their infertility so they do not bring shame upon their husbands and families. Carrying the burden of their infertility without any social support can be stressful and socially isolating.

In addition to suffering in silence, Latin American women who are infertile have limited treatment due to the strong influence of Catholicism and Christian Evangelicalism on their countries' official policies regarding ART. For example, an amendment to Costa Rica's

Constitution only allows homologous insemination and bans all other forms of ART. In Mexico and Argentina, a woman may only receive ART if she is married or in a relationship. While, there are many countries in Latin America that lack any policy agreement on ART. The religious conservatives usually shape informal policy so that it lines up with specific religious beliefs. Infertile women often have to flee their country to receive treatment at an exorbitant cost that most cannot afford [3, pp. 32–34]. These ART policies and practices perpetuate an oppressive environment in Latin America by denying women reproductive autonomy.

Global South Overall

The brief descriptions we have provided on various geographic regions in the global South illustrate the severe and interrelated social, economic, and health-related consequences of infertility. Infertility adversely affects women socially by leading to lower social status and ostracism. The way women are treated by their husbands, families, and communities (e.g., how much food they eat, whether they suffer physical abuse, and whether other community members trade with them and help them) heavily depends on their social status. At the extreme, infertility can lead to social death: being expelled from the community. In countries where women are not permitted to have jobs outside the home and/or are financially dependent upon men, expulsion from the community, or even just divorce, can be socially and economically devastating.

Infertility can also negatively affect women's economic stability in other ways. For many families in the global South, the ability to reproduce is necessary for economic survival, particularly later in life. From early ages, children contribute to the family's workload and even work in the public realm to help make ends meet. Furthermore, children are often the means by which the elderly acquire basic necessities: “Without children, men and women may starve to death, especially in old age” [9, p. 16].

Some of the economic consequences of infertility, like lack of food, can lead to health-related problems, such as malnutrition. But there are health-related problems due to infertility that are independent of economic problems. For example, infertile women are more likely to be the victims of physical and emotional abuse. Also, infertile women may be denied basic necessities or forced to do extra labor. In sum, women who are infertile face serious social, economic, and health-related consequences.

The Big Objection: There Are More Important Priorities than Infertility

Although many may agree that infertility significantly burdens women in the global South, they are still not convinced that ART should be a high priority. The main and most common objection to the reprioritization of ART boils down to a fundamental disagreement about health-care resource allocation. Some argue that in a low resource setting, money and resources should go to the most basic of needs. In the health-care realm, this means money should be funneled into established treatments on the primary care level which, for a given sum of money, benefit many people, e.g. vaccinations and malaria nets, rather than less established or investigational procedures which, for the same sum of money, only help a small minority and are often thought to be “elective.” The foundation of this utilitarian argument is that money and resources should go to the most pressing health-care problems, to conditions that affect a large demographic, and to procedures that are cost effective and have a high success rates. Since ART do not meet any of these criteria, then according to this argument, it should stay at the bottom of the prioritization list [9, p. 15].

Three Responses to the Objection

Response 1: ART Need Not Be Expensive

It is common knowledge that ART are expensive, but we need to question why they are so expensive in order to determine if cheaper and more accessible ART are possible. One reason many cannot afford and/or do not have access to ART has nothing to do with ART themselves, but rather with the laws and policies (or lack thereof) surrounding them.

There is no legal regulation of ART in the United States, which has allowed doctors to set the price of ART as they see fit. Given that there are wealthy infertile individuals willing to pay exorbitant sums to have biological children, the cost of ART has risen to what these individuals are willing to pay, which is much higher than the actual cost of services. The result is many infertile individuals in the US who cannot afford ART. Just like the lack of ART regulation can, perhaps inadvertently, deny access to some infertile individuals, so too can severe legal restrictions for ART. Although numerous restrictions on ART make it difficult for all individuals to afford and access ART, the poor and uneducated are especially hard hit because they usually do not have the resources or the knowledge to circumvent the system or to opt for medical tourism.

Mitigating legal barriers will not make ART more affordable and accessible because ART, as they are currently practiced, are expensive. Yet, ART need not be expensive. According to fertility specialists like Willem Ombelet and Alan Trounson, the delivery of ART can be tweaked so that they are more affordable to those in the global South. Part of the reason ART are so expensive, they claim, is that they are tailored to those in the global North where high-technology tools are readily available. Ombelet and Trounson believe that “Western laboratories are replete with technology that costs tens of thousands of dollars, but much of it can be done away with” [12, p. 977]. Much of the high-technology tools and expensive drugs can be replaced with low-cost alternatives that are just as or almost as safe and effective. For example, in the global North, most women use 30 vials of gonadotropin per treatment cycle, which produces up to 12 eggs, at a cost of $300–$450. Gonadotropin could be replaced with clomiphene citrate, which produces fewer eggs (approximately four), but 15 pills only cost $1 [12,13, p. 977]. Using lost-cost alternatives can reduce IVF from around $10,000 in the global North to just $300 [14].

Even with these astonishingly reduced prices, many individuals in the global South still struggle to afford ART. Some have argued that the international community should take a more active role in reconciling the high cost of ART worldwide. Global health experts Abdallah Daar and Zara Merali, for instance, suggest a partnership of public and private enterprises formed specifically for the development of ART in developing countries [9]. One such organization, the Low Cost IVF Foundation, was established in 2007 under the auspices of the Swiss Ministry of Internal Affairs. Here is the organization's mission statement[2]:

> The Low Cost IVF Foundation is promoting the provision of simplified clinical IVF services for a minimal cost that will allow couples, who could otherwise not afford it, access to IVF treatment for their infertility. The Foundation aims to demonstrate that the material costs for a cycle of IVF can be less than 200 C [just under $300 in today's currency conversion]. The costs will vary from country to

[2]Given our arguments in the previous sections, it is worth highlighting this part of the extended mission statement: “The Foundation seeks to identify donors that will provide funds to establish Low Cost IVF Clinics in low resource economies where having a child greatly improves the social status of a woman and reduces her risk of being rejected from her family and community and left destitute.” The members of the Low Cost IVF Foundation recognize the degree to which infertility can harm women in the global South and thus part of their reason for creating this foundation is to help these women.

> country, but the Foundation's objective is to minimize costs to make treatment affordable to a much greater number of people [15].

With centers in Tanzania and South Africa and a third center that opened in Sudan in October 2009, the Low Cost IVF Foundation is proving that it is possible to provide ART at a low price [14]. Given the successful work of the Low Cost IVF Foundation, the argument can no longer be made that ART are far too expensive to be considered in health-care allocation in the global South.

Response 2: Justice and the Right to Reproduce

As previously mentioned, part of the reason that ART are typically considered a low priority is that they are seen as elective procedures, not medically necessary ones. Even people who think infertility is a disease often do not prioritize ART because infertility is not life threatening. Nonetheless, other diseases that are not life threatening are prioritized, particularly by the international community. For example, a cleft palate is not a terminal condition, but it is a physical deformity that can make individuals' lives significantly more difficult. Individuals with a cleft palate not only experience health problems but also typically face social and economic challenges, such as ostracism. Nonprofit organizations, notably Operation Smile, have emerged to provide care, especially corrective surgery, for those with cleft palate in the global South.

While there are many large scale nonprofit organizations addressing reproductive health, most of them do not include assisting infertile individuals in the global South [16, pp. 615–616] (the Low Cost IVF Foundation is a notable exception). Rather, they mainly provide contraception and maternal care (including childbirth). There is no doubt that these are extremely important foci, but reproductive autonomy is not satisfied by the right to contraception and maternal care. There is also the right to have children. Yet infertile individuals in the global South, as well as poor individuals in the global North, are rarely able to afford ART that would enable them to have biological children. It is unjust, and perhaps reflects a tacit eugenic view about the poor's worthiness to reproduction, that the ability to have biological children is often based on one's socioeconomic status [17, p. 179]. The lack of access to ART in the global South combined with many reproductive health organizations' implicit and often explicit goal of population control in the global South can be seen as promoting a racist agenda [18].

Dorothy Roberts eloquently argues for a broader understanding of reproductive autonomy that promotes social justice:

> "Reproductive liberty must encompass more than the protection of an individual woman's choice to end her pregnancy. It must encompass the full range of procreative activities, including the ability to bear a child, and it must acknowledge that we make reproductive decisions within a social context, including the inequalities of wealth and power. Reproductive freedom is a matter of social justice, not individual choice" [19, p. 6].

Thus, in order for women in the global South to have full reproductive autonomy, they must be able to control the number of biological children they have, which means both preventing unwanted pregnancies and enabling wanted pregnancies.

Response 3: Women's Development, Countries' Development

The broader understanding of reproductive autonomy as a matter of social justice discussed in the previous response would have positive outcomes not only for individual women and women as a group but also for developing countries. Specifically, this understanding of reproductive autonomy would encourage and enable "development," especially economic

development in the global South. Part of what hinders development is the oppression of women, namely gender discrimination and women's low social status. Nicholas Kristoff and Sheryl WuDunn argue that “in many poor countries, the greatest unexploited resource isn't oil fields or veins of gold; it is women and girls who aren't educated and never become a major presence in the formal economy.” They furthermore claim that aid directed toward micro-finance loans, education, and health care tends to be more successful economically [20].

The reason for this is that when women receive better opportunities, education, and health care, they become more autonomous and empowered. Women's education and employment are crucial for equal gender relationships. Education and work outside the home are significant sources of empowerment for women. It is well documented that female literacy is a necessary component for improving the lives of women and their families in “developing” countries. Specifically, education is “an essential factor in preparing people to lead healthy, socially rewarding, and economically productive lives” [21, p. 103]. Education and employment empower women, providing them with the knowledge and confidence to make their own reproductive decisions or to make joint decisions with their boyfriends/husbands. Making joint decisions is typically easier for educated women because men with educated partners are usually less likely to exhibit male dominance in the reproductive realm [22, p. 223]. When women are educated and when they work outside the home, there is a greater probability that men will perceive them as equals, rather than as subordinates. Consequently, men will be more willing to affirm their reproductive autonomy and to support their decisions.

Women's increased autonomy facilitates their participation in the economic realm, which benefits the entire country. Women's education and employment are good for the economy, as it means not only more workers contributing to the formal economy but also more skilled workers. Promoting women's reproductive autonomy also aids countries’ economic development by creating new jobs in reproductive health. An expansion of women's reproductive rights coupled with a cost reduction for ART could lead to a demand for ART centers in developing countries, as empowered women are more likely to seek treatment for infertility. A decrease in price would make ART a more feasible option for individuals in the global South, especially those who do not have the financial resources to seek ART abroad. Wealthy individuals in the global South who currently rely on international medical tourism may choose domestic ART centers instead due to convenience and cost. If an increased demand for domestic ART centers arises and leads to the establishment of such centers, it would help the local economy by providing jobs.

Infertility and Cancer

We have spent the majority of the chapter explicating the severity of infertility for women in the global South and arguing that treatment of infertility via ART should be made a higher priority. We now return to the topic with which we began, cancer. Women with cancer, just like women with infertility, typically suffer from more than just their disease. Having cancer engenders various adverse social, economic, and health-related effects for women. These negative consequences are usually due to cultural reasons, specifically patriarchal norms. The stigma associated with cancer can bring shame upon a woman and her family, which may cause spousal violence and social ostracism. Stigma, along with other sexist factors like “discrimination, machismo, and a tendency to reduce women to body parts,” can also lead to a delay in cancer screening and treatment. Screening and treatment can also be delayed because, in some extremely patriarchal societies, a woman needs her husband's permission to see a doctor and may even need him to accompany her. These delays can prove deadly. For example, over half of all breast cancer cases in Mexico are detected in stage 3 or 4,

when it is significantly more difficult to treat. By contrast, approximately 60% of breast cancer cases in the United States are discovered at stage 1; only 5–10% of cases in Mexico are detected at this stage. The symptoms of cancer and the side effects of cancer treatment (especially later stage cancer treatment) can interfere with, and even prevent women from, fulfilling their gendered responsibilities of bearing and caring for children, sexually satisfying their husband, and sometimes working to support the family. Given that maintaining these responsibilities is oftentimes the only way women can gain status, not being able to meet these responsibilities can have deleterious effects on women [23]. In sum, the social, economic, and health-related consequences of cancer for women in the global South can be quite similar to and just as severe as those due to infertility.

The possibility of infertility for female cancer patients in the global South makes these already disadvantaged women even more vulnerable. Indeed, these women are doubly burdened: they suffer from a serious disease and the treatment for this disease may render them infertile. On top of that, they typically experience adverse social, economic, and health-related consequences as a result of both cancer and possible infertility. Even if they retain their fertility following cancer treatment, the risk of infertility may have already caused irreparable damage (e.g., a reputation of being infertile and thus unmarriageable).

Significant cultural change, especially regarding gender roles, is needed to prevent the adverse consequences women face due to both cancer and infertility. However, such a cultural transformation can take a very long time and will require a complete shift in ideologies, for which the possibility of success is uncertain. A quicker and more concrete way to alleviate some of the adverse consequences for female cancer patients is to provide affordable and easily accessible fertility preservation technologies. While the option of fertility preservation technologies would not minimize (at least not directly) the negative cultural effects of cancer, these technologies would grant women the opportunity to have biological children post-treatment, thereby mitigating or averting the social burden women experience because of infertility.

Fertility preservation technologies do not guarantee healthy, live births, and some women will still suffer the stigma of infertility.[3] Overall, these technologies could help many women by decreasing the possibility of adverse consequences due to infertility. Furthermore, motherhood is important in many cultures; ART would offer women with cancer in the global South who desire biological children this possibility. Providing fertility preservation technologies before cancer treatment is a good short-term and long-term solution for decreasing the harms that women generally experience due to infertility and cancer.

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