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## Studying Absence: An Analysis of the Literature and Lack Thereof on the Intersection of HIV/AIDS and Reproductive Rights

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**Studying Absence: An Analysis of the Literature and Lack Thereof on the Intersection of  
HIV/AIDS and Reproductive Rights**

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## Introduction

There is much that academics have taken it upon themselves to study, and also much that they have not. To the extent that the attempt to learn is an attempt to elucidate the truth, it seems unfathomable for our truth-seeking capacities to encompass the entirety of human experience, present and past. And yet, what the academy fails to study is often indicative of more than the inherent catch-22 in which we find ourselves. Factors of identity, and of the hierarchy of important or less important truths, inevitably make themselves evident when one attempts to examine those which have never had the chance to gain a justified worth to academic study. In this paper, I will examine the literature and lack thereof on the matter of reproductive rights and its fraught relationship to HIV/AIDS. I will look both to that research which demonstrates an absence of sufficient literature into this topic, while also historiographically examining two articles within that quantitatively lacking literature. From an examination of this epistemological gap and those worthy attempts to fill it, I will hypothesize that the gap is produced by factors of vulnerability pertaining to the demographics of that group which falls at this intersection, as well as definitional inadequacies in the language of rights.

## HIV/AIDS

HIV/AIDS is an acronym for acquired immunodeficiency syndrome (AIDS) which is triggered by human immunodeficiency virus (HIV). The first case of what we understand as the modern epidemic most likely occurred in the 1930s, with the most rapid spread during the 1970s.

<sup>1</sup>The first public report of AIDS was on June 5, 1981, and came as part of the Morbidity and Mortality Weekly report from the Center for Disease Control in Atlanta, USA. The identification

<sup>1</sup> Whiteside, Shaun. *HIV/AIDS: A Very Short Introduction*. Oxford University Press, 2017.

came from doctors reporting severe cases in high numbers of a previously rare types of pneumonia and tumor, named *Pneumocystis carinii* and Kaposi's sarcoma, respectively. Furthermore, patients subject to these reports were overwhelmingly young homosexual men, hemophiliacs, blood transfusion recipients, intravenous drug users.<sup>2</sup> Within a year, it was clear that the partners and infants of those infected were also contracting it. That same year, 1982, the name AIDS was agreed on and the CDC began to develop a more concrete clinical definition. The acronym AIDS served as an accurate descriptive of how it manifests: once acquired, it creates a deficiency in the immune system, and is therefore more a syndrome than a disease. Even once understood as such, however, there was great ambiguity about the cause, spread, and treatments for it. A virus was determined as the most probable origin, and the hunt for this virus began with international scientific collaboration. By 1982, the Institut Pasteur in France identified the virus as Lymphadenopathy, or LAV. In 1984, the National Cancer Institute in the US isolated and named the virus HTVL-III.<sup>3</sup>

It was soon after understood that the disease, or syndrome as it can be more accurately described, crossed from primates to animals and is therefore part of the category of such diseases called zoonoses. It is the deadliest pathogen to have crossed in this way. Beyond this initial cause, however, great hysteria grew around the issue of human transmission, particularly in its identification as a "gay man's disease."<sup>4</sup> The metaphors around the disease largely revolved around this identification, with those who were not gay men taking great precaution when the risk of contact with the blood and bodily fluid of a gay man was a possibility.<sup>5</sup> The

<sup>2</sup> Whiteside, Shaun. *HIV/AIDS: A Very Short Introduction*. Oxford University Press, 2017.

<sup>3</sup> *ibid*

<sup>4</sup> *ibid*

<sup>5</sup> Whiteside, Shaun. *HIV/AIDS: A Very Short Introduction*. Oxford University Press, 2017.

understanding of how it was spread, namely through blood and bodily fluids, did not solve the challenge of reducing transmission. Initially the response was to improve blood safety, provide condoms, and encourage safe injecting practices. These technical precautions did not suffice, and it was evident that changes in behavior would also be necessary. The behavioral monitoring of those at risk was riddled with biases against the groups which were most vulnerable to it, particularly since these groups of gay men and intravenous drug users already suffered extreme prejudice. As this was happening, the effort to find an effective treatment continued, and the development of antiretroviral therapies (ART) was finally announced at the 1996 International AIDS Conference in Vancouver.<sup>6</sup>

The long-term effect that the epidemic had and has on the globe is not yet completely known. On the 25th anniversary of ART's development, 20 million people had already died and 40 more million were currently living with it. It is now known that it is most commonly transmitted through sexual intercourse, followed by mother-to-child infection, sharing drug injecting equipment, and in health care settings with contaminated blood or instruments. In one sense, the disease is now understood. It has been named, it has been responded to with policy from government and non-government entities, and its representation in metaphor and discourse is great.<sup>7</sup> The number of factors that typically shape representation of disease have manifested in domestic, educational, and material culture of class, market, and space. The role of the state has also come into question as it did before – either through negligence or a harmful entrance into the private lives of its citizens. The mere fact of response to and representation of a disease does not, however, indicate efficacy or accuracy of either. Neither of these encompasses the breadth

<sup>6</sup> *ibid*

<sup>7</sup> *ibid*

of those actually vulnerable to it, and as Alan Whiteside concludes in *HIV/AIDS, A Very Short Introduction*, “vulnerabilities, like the epidemic, will be differentiated. The poorest bear the burden.”<sup>8</sup>(21)

## Reproductive Rights

To understand how reproductive rights may intersect with HIV/AIDS, it is necessary to have parameters and a definition for the former category. The definition most referred to originated at the International Conference on Population and Development, which took place in Cairo in 1994. The conference hosted 179 countries, with eleven thousand attends that included activists, NGO representative, government representatives, and representatives from international agencies. They adopted a twenty-year Program of Action which stands as the primary document framing contemporary discourse on population and reproduction. It marked, as Lara Knudsen argues in *Reproductive Rights in a Global Context*, a “new consensus shift ... that governments have a responsibility to meet individuals’ reproductive needs, rather than demographic targets.”<sup>9</sup> (6) Importantly, it determined the new consensus on what reproductive rights actually entailed, articulated as the following:

“[R]eproductive rights embrace certain human rights that are already recognized in national laws, international human rights documents and other consensus documents. These rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the

<sup>8</sup> Whiteside, Shaun. *HIV/AIDS: A Very Short Introduction*. Oxford University Press, 2017.

<sup>9</sup> Knudsen, Lara. *Reproductive Rights in Global Contexts: South Africa, Uganda, Peru, Denmark, United States, Vietnam, Jordan*. Vanderbilt University Press, 2006.

highest standard of sexual and reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents.”<sup>10</sup>

This definition of these rights, naturally, does not guarantee the experience of possessing them, nor does it necessitate that those states who offer them will enforce a system of justice in protecting them. Within the more verbose language of that definition, the right to “decide freely and responsibly the number” stands in for what in praxis may be considered access to services which terminate pregnancy. The “information and means to do so” stands in for comprehensive sexual education, and “the highest standard of sexual and reproductive health” stands in for availability of resources which provide the medical standard necessary for safety and good health. The document of rights cannot be separated from the material world: these rights are not abstract but in fact entirely material in what is needed to guarantee their protection. Furthermore, the document capitalizes on the ambiguity of its language precisely because these material goods could not be guaranteed: at the conference itself the delegates could not agree on a consensus about abortion, and therefore the word was entirely neglected.<sup>11</sup> The deliberate vagueness of what rights are being offered also poses a difficulty to those studying reproductive rights: if academics do not have a clear or well agreed upon definition of what the practical implications of these rights are, how can they argue that they are or are not being protected? Valuing that there is no established answer to that question is crucial when looking at the literature, or sometimes lack thereof, on reproductive rights. Whether a historical phenomenon qualifies as

<sup>10</sup> ICPD

<sup>11</sup> Knudsen, Lara. *Reproductive Rights in Global Contexts: South Africa, Uganda, Peru, Denmark, United States, Vietnam, Jordan*. Vanderbilt University Press, 2006.

evidence of violation of these rights, or of other human rights, or of no rights at all determines what the literature on the phenomenon will focus on. In looking to the intersection of these rights with those related to HIV/AIDS, whether it be through sterilization, access to condoms, sexual education, or abortion, it must be remembered that these material services are services related to reproduction, but have not been strictly and explicitly included in the global language of reproductive rights.

### **Evidence of an Epistemological Gap**

In her 2006 article titled “Women, Reproductive Rights, and HIV/AIDS: Issues on Which Research and Interventions are Still Needed” Maria De Bruyn prescribes measures in response to the findings of two literature reviews which had identified the reproductive-health related issues that were “neglected in relation to HIV/AIDS.”<sup>12</sup> These issues were “contraceptive information tailored to the needs of HIV-positive people; voluntary HIV counseling and testing during antenatal care, labour, and delivery; parenting options for HIV-positive people besides pregnancy through unprotected intercourse (i.e. assisted conception and legal adoption or foster care); unwanted pregnancy, and abortion-related care.”<sup>13</sup> She describes the conclusions of these literature review in detail: there is a failure among family-planning literature to address HIV, there is no significant data on rates of induced versus spontaneous abortion among HIV-positive women, and there is little information on the option to adopt in the literature and informational materials for HIV-positive women. Significant literature on these topics does not exist either at

<sup>12</sup> De Bruyn, Maria. "Women, Reproductive Rights, and HIV/AIDS: Issues on Which Research and Interventions Are Still Needed." *Journal of Health, Population, and Nutrition*, 2006, 413--25.

<sup>13</sup> De Bruyn, Maria. "Women, Reproductive Rights, and HIV/AIDS: Issues on Which Research and Interventions Are Still Needed." *Journal of Health, Population, and Nutrition*, 2006, 413--25.



the academic level or at the level of informational guides given to HIV-positive people, creating a two-fold audience which lacks pertinent information. Based on these descriptive remarks on the findings of the literature reviews, De Bruyn goes on to make a list of recommendations for how to progress this literature on both levels. She overviews the less and more effective pilot projects launched in developing countries, and recommends that more policy-oriented and operational research be done in the following areas: interactions between hormonal contraceptives and antiretroviral drugs, the quality of counselling given to HIV-positive women about their reproductive options, the induced abortion practices of coercion, denial, or unethical preconditions, and the dissemination of family planning materials specifically in the context of HIV/AIDS. She concludes with two more ambitious arguments: firstly, information is a valuable tool in enabling HIV-positive women to be better advocates and protectors of their reproductive rights. Second, were there systems to help women advance to the roles of policy makers and researchers, these women might be able to produce the invaluable information necessary for effective programming and policies around HIV/AIDS and reproductive health.<sup>14</sup>

Nine years later, in 2015, the article “Human rights and the sexual and reproductive health of women living with HIV – a literature review” was published by Shubha Kumar and a team of researchers at University of Southern California. The findings of this review were, in short, that not much had changed since 2005. A search of relevant databases using the keywords women, HIV/AIDS, ART, human rights, sexual and reproductive health yielded 2228 peer-review articles, 40 of which were inclusive enough to be examined in the final review.<sup>15</sup> Not a

<sup>14</sup> De Bruyn, Maria. "Women, Reproductive Rights, and HIV/AIDS: Issues on Which Research and Interventions Are Still Needed." *Journal of Health, Population, and Nutrition*, 2006, 413--25.

<sup>15</sup> Kumar, Shubha, Sofia Gruskin, Rajat Khosla, and Manjulaa Narasimhan. "Human Rights and the Sexual and Reproductive Health of Women Living with HIV: A Literature Review." *Journal of the International Aids Society*, 2015.

single peer-reviewed article reviewed discussed the implementation of rights in programming, only one addressed rights with some degree of comprehensiveness and none addressed even the majority of relevant rights; equality, non-discrimination, participation, privacy and confidentiality, informed decision making, accessibility, and accountability. Even within articles about reproductive health, as those discussed by De Bruyn, none focused explicitly on the rights of individuals *to* that health, and how lack of access to it was in fact a violation of rights rather than just an unfair circumstance. The results of the review are detailed, and categorized by what search factor they did or did not satisfy. The overwhelming conclusion drawn from their results is that the literature on rights as explicitly related to reproductive health and HIV/AIDS is severely lacking in quantity. This conclusion, the review argues, has important consequences. As rights-talk becomes the dominant language of international organizations, NGOs, and activists, there is rhetorical value in studying reproductive health and HIV/AIDS with explicit focus on the aspect of rights. Even as policy continues to make leaps forward and backward with regards to rights specifically, the literature fails to document this. Kumar writes, “there appears to be a significant disconnect between those who are implementing rights-based interventions and those who are publishing in the peer-reviewed and grey literature.... The voices and experiences of women living with HIV must ultimately frame the discussion and inform evidence-based guidelines to improve the treatment, care and support of women living with HIV.”<sup>16</sup> Both the results the review examined, and the incentive to action it calls upon bear great similarities to De Bruyn’s, making it clear that though nine years had passed, the same imperatives for an increase in academic discourse remained.

<sup>16</sup> Kumar, Shubha, Sofia Gruskin, Rajat Khosla, and Manjulaa Narasimhan. "Human Rights and the Sexual and Reproductive Health of Women Living with HIV: A Literature Review." *Journal of the International Aids Society*, 2015.

### **Shared Qualities in Discourse and Imperatives of Existing Literature**

To say that there is almost no literature which has examined reproductive right, health, and HIV/AIDS as interconnected topics is not to say that there is in none entirely. It is necessary to give due diligence to those who have sought to examine this topic, and from that research which has been done we may understand both why this is a topic of pressing concern, and why it has received so little academic attention. I will examine two works of academic literature on the intersection, each of which discusses the phenomenon of involuntary sterilization of HIV-positive women. This phenomenon is among the more reported on within the literature, and comparing how these two works each approach it is useful in understanding narrative trends in how the experiences of women at the intersection of reproductive rights violations and HIV/AIDS are documented by academics. Both of these articles were included in the results yielded by the latter literature review and are among the more cited works of the field.

#### *Involuntary Sterilization Framed in the Legal and Philosophical Context*

In her 2015 article “Involuntary Sterilization of HIV-Positive Women: An Example of Intersectional Discrimination,” Ronli Sifris makes the claim that involuntary sterilization is a compounded form of discrimination, in that those women who are victim to it are also those predisposed to gender based discrimination and discrimination based on HIV status, as well the social factors which may have increased their vulnerability to the latter position.<sup>17</sup> She argues this throughout the four sections of her paper: the first an introduction to the claims she intends to make, the second on the international human rights which defends the right to be free from

<sup>17</sup> Sifris, Ronli. "Involuntary Sterilization of HIV-Positive Women: An Example of Intersectional Discrimination." *Human Rights Quarterly* 37, no. 2 (2015): 464-91.

discrimination, the third on a viewing of involuntary sterilization under the lens of prohibition of gender-based discrimination, the fourth on how involuntary sterilization is markedly intersectional in its discrimination. This organization is that of a logically consistent philosophical argument: if it is true that the right to be free from discrimination is articulated in international human rights document, and it is true that women and people with HIV are subject to discrimination on the basis of both qualities, then the sterilization of these women is intersectional in style and should be met with a reaction from the agencies which issued those human rights documents. Her work draws heavily on historical accounts of involuntary sterilization of Native American women in Peru and Chile, and of Roma women in the Czech Republic. However, it is more a work of argumentative examination than historical understanding of these phenomenon. She employs, but does not exclusively focus on, historical narratives to prove her argument that involuntary sterilization of HIV-positive women is an intersectional discrimination which should be addressed by international organizations who have legislated against such discrimination.

For the purpose of examining the broader narrative and lack thereof on reproductive rights and HIV/AIDS, the actual history of discriminatory rights law and involuntary sterilization is not as crucial as the language Sifris uses to describe these histories. One element to her language is the all-pervasive presence of a gendered component. Even within her examination of how discrimination is defined, she is sure to note that “female-specific concerns have frequently been neglected in the international human rights realm”<sup>18</sup> (467) and that broader definitions of discrimination have not sufficiently considered the specifics of how women experience discrimination in distinct ways. She therefore diagnoses the same obstacle to categorizing

<sup>18</sup> Sifris, Ronli. "Involuntary Sterilization of HIV-Positive Women: An Example of Intersectional Discrimination." *Human Rights Quarterly* 37, no. 2 (2015): 464-91.

something as discrimination that was articulated earlier within this paper in my attempt to define reproductive rights using existing frameworks. To decide whether discrimination is or is not occurring, one needs to set parameters for discrimination. Unsatisfied with these parameters, she sets her own which include attention to direct (formal) and indirect (substantive) discrimination. It is clear that within her attempt to craft a narrative of this case of discrimination, she encounters and must resolve the issue of existing frameworks and the failure of these frameworks to allow for easy incorporation of her issue into them. Another narrative quality of her article is a focus on relative vulnerabilities and social contexts. Neither HIV/AIDS nor reproductive health related issues such as involuntary sterilization are inherently tied to a certain social group. They are, in premise, nondiscriminatory issues in that no single identity factor can make one completely invulnerable or completely vulnerable to them. However, social and economic factors are incredibly effective determiners for whether one will be impacted by either HIV, a lack of reproductive rights, or in this case the experience of involuntary sterilization. In her crafting of a narrative of the involuntary sterilization of HIV-positive women, the intersectionality of vulnerability is a ubiquitous lens she employs. Rather than just focusing on a single predisposition, she focuses almost the entire weight of her argument on how the factors of vulnerability engage with each other to form a demographic whose discrimination is dualistic, based on the distinct experience of being *both* a woman and an HIV-positive person. The distinct trends in Sifri's narrative of intersectional discrimination are therefore the following: (1) she is attentive to how existing frameworks of rights and discrimination articulated by international organization have not given adequate consideration to the unique experiences of women as opposed to broadly speaking human beings, (2) to reconcile this inadequacy in existing frameworks and definitions, she creates her own, (3) she considers that though some diseases and

some rights can hypothetically affect any human being, some human beings are more vulnerable than others, and the most vulnerable are those who possess more than one identity which faces discrimination.

*Involuntary Sterilization Narrated through Questionnaires*

These same trends in the depiction of a woman's experience at this intersection emerge in an examination of the same phenomenon, documented through interpretations of the results of a questionnaire. "'She made up a choice for me:' 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces" is the product of a qualitative study designed by Ann Strode, Setehembiso Mthembu, and Zaynab Essack. Published in 2012, it introduces itself with the proposition that although post-Apartheid South African legal framework is not always ambiguous in the rights it guarantees, it does not include provisions for how to guarantee the protection of these rights or practical access to the serves these rights purport to deliver. The authors write, "Involuntary female sterilization is an example of that gap between policy and practice ... Women's sexual and reproductive rights are not being realized as they struggle to access sterilization and other such services."<sup>19</sup> (61) The authors also highlight the lack of an existing academic framework about the issue: "there have been anecdotal reports of sterilization abuse both prior to 1998 and in subsequent years, including of HIV-positive women. However, there is no published evidence of the extent of the problem."<sup>20</sup> (62) The authors organize the first section of the article in the same way Sifris did; with an overview of legal rights, in this case in South Africa on informed consent and sterilization. They then describe

<sup>19</sup> Strode, Ann, Setehembiso Mthembu, and Zaynab Essack. "'She Made up a Choice for Me': 22 HIV-positive Women's Experiences of Involuntary Sterilization in Two South African Provinces." *Reproductive Health Matters* 20, no. 39 (2012).

<sup>20</sup> Strode, Ann, Setehembiso Mthembu, and Zaynab Essack. "'She Made up a Choice for Me': 22 HIV-positive Women's Experiences of Involuntary Sterilization in Two South African Provinces." *Reproductive Health Matters* 20, no. 39 (2012).

the methodology of the study: six trained field workers attended eleven support group meetings for HIV-positive sterilized women 18 years or older in the provinces of KwaZulu-Natal and Gauteng and invited them to participate in the study. Thirty-two women filled out the questionnaire, which asked questions relating to their understanding of informed consent requirements in sterilization. Of the 32, 27 believed they had been sterilized without voluntary and informed consent. The authors go on to quote some of the answers women gave on the questionnaire, many of which are viscerally painful to even read. The authors categorize the responses into four categories of legal rights which were violated: autonomy, knowledge, voluntariness, and agreement to sterilization. In each category, the authors highlight the stark contrast between the respect of rights articulated in law and the lived reality of the women who described their experiences. To give some examples, “South African law respects the right of all patients to make autonomous health choices” (63) contrasted with the questionnaire answer “[the nurse] made up a choice. She made up a choice for me,” (63) “The Sterilization Act stipulates that patients should be informed of the nature of the procedure; its consequences and risks” (64) contrasted with “I do not know anything, even what form of sterilization was performed,” (64) “[the law stipulates that] patients have the right to voluntarily choose or refuse a medical procedure... active labor impacted on voluntariness” (64) contrasted with “They made me sign this paper after I had collapsed in the toilet.” (64) Though each of the women had signed a consent form, all but five did not consider the lack of refusal to be a sign of agreement. The consent they gave was not informed, and therefore would not satisfy the legal requirements of informed consent dictated by South African Law. In the Discussion, the authors of the article again harken to the legal frameworks of such international entities as The World Health Organization to demonstrate how strong the juxtaposition is between the international standards

and how unmaintained this standard is in the experience of many women. Like Sifris, the authors call for a reshaping in framework to accommodate for not only idealistic standards, but a guarantee of this standard being delivered. Like Sifris, they call for an acknowledgment that the women whose experiences were documented by the study fall at a unique place of discrimination on the basis of more than one identity factor, and that though the framework may attempt to protect each identity, new standards must be established for the intersection. Like Sifris, and like De Bruyn and Kumar, the authors conclude that more research is direly needed in this field in order for governmental, international, and non-governmental agencies to make any of the necessary changes to prevent such violations from continuing to occur.

### **Reasons for the Epistemological Gap**

From our the evidence that suggests a lacking state of knowledge on the intersection of HIV/AIDS and reproductive rights, and the examination of common trends in the existing literature, we may make reasonable hypotheses on why the gap exists and what the way forward may be. To arrive at these suggestions, it is necessary to examine the meta-issues that inhibit epistemological progress. These issues emerged in non-meta ways within the existing literature: the problems faced by women at the intersection were created by inadequacies in the legal and definitional framework of rights, as well as by the nature of intersectional vulnerability to which these women were disposed. Therefore, I assert that it is these same difficulties which researchers and academics face in attempts to fill the gap: HIV-positive women experience pre-existing vulnerabilities both in situation and research about this situation which hinders the quality of academic study on how they intersect with reproductive rights, and reproductive rights



lack sufficient framework and definitions to fulfill the needs of researchers studying how particularly vulnerable populations interact with them.

### Theories of Vulnerability

In the seminal paper, “Why bioethics needs a concept of vulnerability” Wendy Rogers, Catriona Mackenzie, and Susan Dodds lay the groundwork for a taxonomy of vulnerability which they consider imperative to integrate into the research guidelines on vulnerable groups. This taxonomy they propose has three categories: inherent, situational, and pathogenic vulnerability.<sup>21</sup> Inherent vulnerability is that vulnerability which human beings face on the basic aspects intrinsic to our humanness; “our corporeality, our neediness, our dependence on others, and our affective and social natures.”<sup>22</sup>(24) Situational vulnerability is context-specific, meaning that a vulnerability caused by “personal, social, or environmental situations.”<sup>23</sup> (24) These two vulnerabilities are dispositional or occurrent, meaning that the mere existence of this vulnerability does not mean that a person will experience it at all times: an economically upper class person is inherently vulnerable to hunger, but does not face obstacles which make them hungry at all times. Similarly, pregnancy creates a situational vulnerability in all women who experience it, but this vulnerability only occurs during the actual time of pregnancy. Pathogenic vulnerability, on the other hand, is generated by being of a certain situations in which factors of “oppression, domination, repression, injustice, persecution, or political violence”<sup>24</sup> (25) The paper deals in length with this final form of vulnerability, and the ways it must be addressed as distinct from the former two. Since the women at the intersection I focus on are part of that

<sup>21</sup> Rogers, Mackenzie, and Dodds. "Why Bioethics Needs a Concept of Vulnerability." *International Journal of Feminist Approaches to Bioethics* 5, no. 2 (2012): 11.

<sup>22</sup> *ibid*

<sup>23</sup> *ibid*

<sup>24</sup> *ibid*

group which is wont to suffer from all three forms of vulnerability, the recommendations of Rogers, Mackenzie, and Dodds are pertinent. An HIV-positive woman who is of reproductive capacity or pregnant is inherently vulnerable because she is a human being. She is situationally vulnerable because pregnancy is a situation of vulnerability regardless of the identity of the pregnant woman, and HIV is also a disease which makes one vulnerable physical pain and illness regardless of the social identity of the HIV person. Importantly, such a woman is most often pathogenically vulnerable, because those women who are HIV-positive are societally discriminated based on factors of gender and disease, but also often because of the factors that predisposed them to HIV as well, such as class or geographical location. The article concludes with recommendations, namely that research into those groups which suffer from pathogenic vulnerability must be based on the tenets of autonomy, respect, and prioritization of the narratives that community crafts over the possible preconceptions of an external examiner.

#### *HIV-Positive Women and the Effect of their Vulnerability on Research*

What, then may be the preconceptions that have been prioritized and have hindered any substantive body of research on the intersection of HIV/AIDS and reproductive rights? Jenny Higgins, Susie Hoffman, and Shari Dworkin offer some insight into this question in their 2010 paper, "Rethinking Gender, Heterosexual Men, and Women's Vulnerability to HIV/AIDS." The authors begin by describing the changes to the way HIV-positive women have been depicted in scientific and political literature since the first cases of AIDS were diagnosed. Women, initially "virtually invisible," then "stigmatized vectors," the burden of safety was placed on women to protect themselves through condom use, although all research demonstrated that men would

continue to dictate whether or not that use occurred.<sup>25</sup> In more recent years, the authors argue, the discourse around HIV-positive women revolved around those in the “global south” where heterosexual intercourse was a more leading cause of transmission. Throughout the course of these changes, no burden of safety or moral obligation was placed in research, policy, and prevention programs about the HIV-positive men who transmitted the disease to women.<sup>26</sup> The authors argue that there is a two-fold dilemma at hand: first, “Western” discourse and metaphors around HIV/AIDS are centered on the gay male experience which harmfully shapes the research and health policy that the “West” implements abroad. Second, within the metaphors and discourse around the ways HIV/AIDS has impacted the “global south,” although women are featured more prominently, this has in fact created structures of intervention to women’s behavior rather than men’s, in spite of the lack of control women in fact have to control this behavior. As tends to be the case in research about this intersection, the passing of time does not resolve academia’s meta-problems. It is not surprising to see that 15 years earlier, the same claims were made by Anna Strebel in her paper “Whose Epidemic is it? Reviewing the Literature on Women and Aids.”<sup>27</sup> Evidently, in those fifteen years little progress had been made in creating the paradigm shift that both authors call for.

The vulnerability of HIV-positive women to misconceptions about their position, power and lack thereof, and experiences of the disease leads to a mis-focus in research about them as population. The focus on the gay man in the west already creates a research gap, and attempts to

<sup>25</sup> Higgins, Jenny A., Susie Hoffman, and Shari L. Dworkin. "Rethinking Gender, Heterosexual Men, and Womens Vulnerability to HIV/AIDS." *American Journal of Public Health* 100, no. 3 (2010): 435-45.

<sup>26</sup> Higgins, Jenny A., Susie Hoffman, and Shari L. Dworkin. "Rethinking Gender, Heterosexual Men, and Womens Vulnerability to HIV/AIDS." *American Journal of Public Health* 100, no. 3 (2010): 435-45.

<sup>27</sup> Strebel, Anna. "Whose Epidemic Is It? Reviewing the Literature on Women and AIDS." *South African Journal of Psychology* 25, no. 1 (1995): 12-20.

fill that gap are fraught with inaccurate burdens placed on the women for contracting the disease. The social vulnerabilities which make women in the “global south” particularly predisposed to contracting HIV/AIDS are the same which make them vulnerable to misrepresentation in the academy. The lack of mobility, autonomy, and narrative control which HIV-positive women experience seeps into the academic discourse, and this may be considered a cause of failures within the academy to depict them accurately. And for those who are both situationally vulnerable on account of their HIV-positivity and pathogenically vulnerable for having reproductive capacity in patriarchal system, these same vulnerabilities cross over into the arena of reproductive rights and academic research about it.

#### *Reproductive Rights and Inadequacies in Framework*

This latter issue of vulnerability in relation to the framework and definition of reproductive rights is tackled by Bryan Turner in the book *Vulnerability and Human Rights*. Turner problematizes the framework of reproductive rights in the context of statehood: he argues that international human rights platforms position reproductive rights as an “aspect of [women’s] health care and status in society.”<sup>28</sup> This poses challenges to women in societies where the state and civil society have broken down, compromising their ability to deliver the service of health care that women rely on in order protect their right. If neither the language of the right makes it easy to regulate, nor do the systems which may regulate it exist, the right struggles to perform any of the functions that in fact give it that name. The vulnerability of existing in a state without the resources to guarantee protection of rights heightens the other vulnerability of being a woman in need of these rights. Furthermore, the rise of the nation state created a duty upon citizens to

<sup>28</sup> Turner, Bryan S. *Vulnerability and Human Rights*. University Park, Pennsylvania: Pennsylvania State University, 2006.

maintain that state through reproduction, and this duty is heightened within states that struggle to maintain themselves due to situations such as war, famine, or pandemics. Because reproductive rights legislation on the international level fails to account for the difficulties of states to in fact protect these rights, or for the great cultural differences in reproductive tendencies and beliefs in these states, the international framework cannot effectively be used to judge phenomena relating to reproductive rights on the state-level. The most vulnerable remain those women in impoverished, war-torn, or highly segregated states where international policy exists as nothing more than an abstract standard.<sup>29</sup>

Both the academic depiction of HIV-positive women and the framework of reproductive rights can be problematized as incomplete to the degree they fail to encompass the breadth of realities that HIV-positive women, and particularly in underdeveloped states, experience. Thus, it can be asserted that this group is vulnerable to be under-researched in its intersection with reproductive rights. Academics who attempt to study this intersection continue to face the same struggles as Sifris, Strode, Mthembu, and Essack. To simultaneously shift the paradigm of study on HIV-positive women and account for an insufficient framework of reproductive right poses a difficult task.

## **Conclusion**

To study something, particularly to study historical phenomena, is to accord a value judgement upon that subject as a matter which deserves time and consideration. And though there has certainly been tremendous time and consideration put into the study of HIV/AIDS, as

<sup>29</sup> Turner, Bryan S. *Vulnerability and Human Rights*. University Park, Pennsylvania: Pennsylvania State University, 2006.

well as histories of women's reproductive health, I posit that to frame these studies in the lens of rights is crucial. As we enter an international world order predicated on the world systems' intrinsic obligation to the human beings within them, the rhetoric of state-obligation and rights must be incorporated into academic study. Furthermore, though history is so much more than simply a means to prevent the repetition of mistakes, without a complete documentation of historical failures to protect the rights purportedly being offered, it may prove difficult to understand exactly what definitional parameters, and what intersectional lens is necessary to, in the future, preserve these rights.

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