CONTENTS

Introduction & Acknowledgements ................................................................. Page 1

The Right To by Brock Foreman ................................................................. Page 3

HIV Through the Lens of a Woman by Ashley Manigo ................................ Page 15

Some Thoughts at Night by Christina Shin ............................................... Page 27
Introduction

Drawing from the Maria de Bruyn archive as well as secondary sources, this zine explores how narratives about HIV and AIDS have changed from the early 1980s to the present, and how the virus continues to impact populations globally. At first, we were told HIV and AIDS affected mostly gay men. Later, we heard women could be infected with HIV and then infect their babies when pregnant. Then, we were told it mostly affected “risk groups” - people like sex workers, truck drivers, drug users - instead of simply being a virus that could be transmitted to anyone at all through blood, sexual contacts and breast milk. Today, we don’t hear much about it. Don’t you wonder how HIV and AIDS have affected - and still have an impact on - women around the world? Each of our contributions attempts to answer this question.

Brock Foreman’s chapter, The Right To, examines items from a UN-published list of human rights in the context of HIV and AIDS, the violation of those rights in many places historically, and threats still posed to them today. The chapter HIV Through the Lens of a Woman by Ashley Manigo discusses the intersection of HIV and gender inequality and the social and biological constructs built around it.

The chapter by Christina Shin, Some Thoughts at Night, takes a retrospective look at legislation, public media, and personal testimonies of women living with HIV and AIDS, drawing primarily on sources from the United States, Thailand, South Africa, and Australia.

Story*, for which this publication was completed, is a six-week university summer research program for undergraduates that emphasizes storytelling to public audiences. The Maria de Bruyn Papers, dated from 1988 to 2012, is a 26-box collection housed at Duke University’s Rubenstein Rare Book & Manuscript Library. The archive comprises documents related to Maria de Bruyn’s work in the field of sexual and reproductive health and rights (SRHR). It contains de Bruyn’s own writings, as well as academic and grey literature, pamphlets, posters, and various ephemera relating to sexual and reproductive health gathered by de Bruyn in her travels.

Acknowledgements

This project would have been impossible without the help of Professor Kearsley Stewart of the Duke Global Health Institute, Rachel Ingold, Curator of the History of Medicine Collections at the Rubenstein Library, and Max Symuleski, PhD Student in Duke’s Computational Media, Arts, & Cultures Program. We would like to give special thanks to Maria de Bruyn for her help with her archive and contacting activists for interviews, and for her guidance with this zine. We would also like to thank Marion Stevens and Hannah Jansen for their time and unique perspectives in their interviews.
"In Nepal, medical practitioners acknowledged that they discriminate against patients infected with HIV/AIDS because of the fear of infection. They also expressed the view that HIV-positive patients must be segregated from other patients." (2004)

"Yes, notification of sexual and needle-sharing partners is the patient’s responsibility. Failure to notify partners is a criminal offence." (North Carolina, United States, 2006)

The Right To:

"Nondiscrimination and equality before the law, e.g. eliminating discrimination against people with HIV/AIDS in the areas of health care, employment, education, immigration, international travel, housing and social security;"

"As of 2008, 67 countries still impose some form of restriction on the entry, stay and residence of people living with HIV."
"While HIV and AIDS exacerbate especially women's economic and social insecurity, it is the very same economic and social insecurity of women that increases their vulnerability to HIV infection. Engaging in transactional sex and the perceived inability to leave abusive relationships, due to economic dependency, are but two of the indicators illustrating women's greater vulnerability to contracting HIV based on prevailing gendered socioeconomic inequalities and imbalances." (South Africa, 2005)

"My husband abandoned my sick baby and I in the hospital, when the doctor told him that I and the baby were HIV-positive."

"On being discharged I went to the family house only to meet my things at the door."

"I don't even know where to run to." (Nigeria, 2001)

"...can my employer get my results?"

"Privacy, both informational and physical, e.g. ensuring confidentiality of HIV test results, and prohibiting mandatory or compulsory testing;"

As of 2007, many U.S. states allow people to be detained for mandatory HIV testing. Restrictions on who can be detained, and on what basis, vary from state to state.

"The doctor must NOT give your HIV test results to anybody without your permission." (South Africa, 2005)

"No. The test results are a private matter." (South Africa, 2005)
The Right To:

“Education and information, e.g. ensuring equal and adequate access to prevention education and information, such as targeted material for ethnic minorities;”

(South and Southeast Asia, 2004)

“Women are not expected to discuss or make decisions about sexuality.”

(2004)

“The Right To:

“Autonomy, liberty and security of the person, e.g. prohibiting HIV testing or research without informed consent, and prohibiting detention or quarantine solely on the basis of HIV status;”

Under current Canadian criminal law, people living with HIV can be charged and prosecuted if they do not tell their sexual partner(s) about their HIV-positive status before having sex.” (2014)

They did not explain at all what kind of test they were doing. I realized it was the AIDS test when I received the results.” (South Africa, 2004)

As of 2016, all 50 U.S. states have provisions for isolating or quarantining people with HIV/AIDS, and most have laws either specific to or that have been applied to prosecute people for spreading HIV.

Under common law, a competent adult has the right to refuse medical testing or treatment for any reason— or for no reason at all.” (England, 2013)
"Can I be dismissed from work if I have HIV? "No." (South Africa, 2005)

"Give me any job that will not let me mingle with people." (India, 2004)

"Currently, the North Carolina Communicable Diseases Act does not prohibit employment discrimination against job applicants infected with HIV."

"Temp worker: Must be diligent and HIV-negative."

(1996)

The Right To:
"Work, e.g. prohibiting dismissal of staff solely on the basis of their HIV status;"

Not all discrimination is external.

"I wouldn't mention it in a job interview."

"They'll find a reason not to hire you."

"In the 1980s, the United States grappled with the idea of abortion."

"Some health personnel even threaten the women that if they are not sterilized, they will not receive powdered milk for their babies." (Southeast Asia, 2004)

"The Right To:
"Marry and found a family, e.g. prohibiting mandatory premarital testing, and coerced abortions or sterilizations."

"In 2018, the debate continues."

"I have the right to be a positive mother..."

"...without the fear of criminalisation." (South Africa, undated)

As of 2010, these countries have national legally mandated premarital testing:
- Bahrain
- Guinea
- United Arab Emirates
- Saudi Arabia

These regions have local governments with similar requirements:
- Five Indian states
- Districts in the Yunnan province of China
- Ethiopia
- Democratic Republic of the Congo

Countries with advocacy groups pushing to enact mandatory premarital testing:
- Cambodia
- Senegal
- Zimbabwe

"churches and mosques will often forbid or discourage a marriage between an HIV positive person and an HIV negative partner."

"I now pronounce you... HIV negative"

"from conversation with Hannah Jansen, June 14, 2018"
"Can I be dismissed from work if I have HIV?  
No."  
(South Africa, 2005)

"Give me any job that will not let me mingle with people."  
(India, 2004)

In the 1980s, the United States grappled with the idea of abortion.

"Where Have All The Babies Gone?"  
"Abortion and Breast Cancer: You Need to Know"  
"ABORTION: Morality and the Law"

In 2018, the debate continues.

"I have the right to be a positive mother...

"Some health personnel even threaten the women that if they are not sterilized, they will not receive powdered milk for their babies."  
(Southeast Asia, 2004)

The Right To:  
"Marry and found a family, e.g. prohibiting mandatory premarital testing, and coerced abortions or sterilizations."

The Right To:  
"Work, e.g. prohibiting dismissal of staff solely on the basis of their HIV status;"

Not all discrimination is external.

"Currently, the North Carolina Communicable Diseases Act does not prohibit employment discrimination against job applicants infected with HIV."

Temp worker w/ Must be diligent and HIV-negat

1996

The Right To:  
"I wouldn't mention it in a job interview."

"They'll find a reason not to hire you."  

HIV  

NEXT!

As of 2010, these countries have national legally-mandated premarital testing:
- Bahrain
- Guam
- United Arab Emirates
- Saudi Arabia

These regions have local governments with similar requirements:
- Five Indian states
- Districts in the Yunnan province of China
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- Democratic Republic of the Congo

Countries with advocacy groups pushing to enact mandatory premarital testing:
- Cambodia
- Senegal
- Zimbabwe

I now pronounce you... HIV negative

"Churches and mosques will often forbid or discourage a marriage between an HIV-positive person and an HIV-negative partner."
Materials Quoted


Denying Entry, Stay and Residence Due to HIV Status: Ten Things You Need to Know. ND.

Gendered Realities... the Underlying Factor? South Africa: AIDS Legal Network, 2005.


THE CONNECTION BETWEEN GENDER INEQUALITY AND HIV

Have you ever thought about how living with a virus such as HIV can affect women differently? Do you think having the virus can influence a woman’s sexual health, sexuality, and reproductive rights? Do you think women’s empowerment can be related to HIV? Keep turning to see how this has been addressed around the world.

HIV Through the Lens of a Woman
“Globally, women account for nearly half of all people living with HIV and represent even a greater proportion of those affected in low- and middle-income countries. Gender inequalities and harmful gender norms are forces that promote unsafe sex and limit access to health services and education, fueling the HIV epidemic in many countries. As a consequence, the rate of HIV among girls and young women is more than **double** that of similarly aged males. Despite this, women are still largely underrepresented in HIV cure research. Also, most cure-related research and clinical trials take place in developed countries, where the HIV epidemic is predominantly driven by men who have sex with men.” [1]

Women report and experience fewer symptoms than men during primary infection.

The composition of the vaginal microbiome can cause increased inflammation and in turn increase the risk of infection.

Chromosomal differences can affect vaccine responses and HIV pathogenesis.

Monthly modulations in hormones can affect immunity.
Violations of Women's Reproductive Rights

Coercive Sterilization
“...I had just given birth, and I was unconscious after a caesarean section. I had no idea I had been sterilized. A few weeks later I met my doctor on the street and he asked me, ‘Did I do a good job?’ I said ‘What do you mean?’ He said, ‘So that you can’t have children.’ That’s how I found out. Nobody told me in the hospital.”

Rape and Forced Pregnancy
“...After my arrival in the concentration camp, they...raped me...in front of all the rest of the women...who were yelling and defending me, but they were beaten. The [soldiers] said ‘You will give birth to a Serbian child, we’re doing that out of revenge’...Now I am 4 1/2 months pregnant.”

Domestic Violence
“In 1987, I was the victim of a murder attempt carried out by my former boyfriend... Full of anger, he set my body on fire in front of my four year old son.”

Inequality in Sexual Relationships
“I am about to have my seventh [child]. I do not know how to explain to my husband that I do not wish to have any more. I don’t know how long I can go on producing children for I feel like a baby machine where you press a button and something pops out.”

On a global scale, young girls and women are more at risk for HIV infection due to the previously mentioned biological factors and endangering situations that arise from gender inequality. This can be more prevalent in cultures that limit women’s knowledge of HIV and safe sex. [2]
Surprise, surprise. Little information has been collected about the sexuality of HIV-positive women, outside of conventional education and prevention. But sexuality is so much more than that! Here are ways that HIV have impacted the lives of women.

“I didn’t realize how much HIV was going to be a problem.”

“I want to grow old with somebody, you know.”

“Ugly! You know. Like I’m not a woman anymore”

“I think that’s [the sexuality], that’s probably the biggest effect on my life; since the diagnosis, we have not had sexual intercourse. And it’s not been by his lack of attention or desire. I can’t, in my mind, I’m not looking at kind of putting him at risk.”

“My sexual life has changed being HIV because it’s less spontaneous than it used to be, but it’s probably for everybody, the fact of using condoms, the fact that my partner is taking extreme care sometimes,”
THE FACE OF THE VIRUS

“...the HIV epidemic very much in Sub-Saharan Africa has the face of a woman. They are the victims. It's a scary situation because women are not empowered and women are not educated and it is the man who makes the decision. It is a man who makes every move. Women are not in a position to negotiate.” [3]
WOMEN AND GIRLS HAVE THE RIGHT...

Our Bodies
Our Rights

To bodily integrity

To live with dignity and equality

To sexual autonomy and sexual pleasure

To choose to be mothers and have children irrespective of their HIV status or sexual orientation

To be free from stigma, discrimination, blame and denial

To gender equity in education and lifetime education for all

You are more than your seropositivity.
Your status does not define you.

The Lover's Menu

MAIN DISHES

Vaginal Intercourse
  with condom
  without condom
  Low Risk
  *High Risk

Anal Intercourse
  with condom
  without condom
  Low Risk
  *High Risk

DESSERTS

Who can pass up these treats?

Erotic Stories
Roleplaying
Sensual Touch
Massage
Bubble Bath

Free
Fun
Inticing
Safe
Soothing

*Indulgence in high risk behaviors without using proper protection or barriers can lead to an increased chance of STD or HIV infection.
NOTES


SOURCES


The Best Years of Your Life, Maria de Bruyn Papers, Rubenstein Library, Duke University.

I think about the pill I take every morning.

Medication studies in the United States during the 1990s would keep women from participating with phrases such as “no pregnant women and no non-pregnant women.”

And how people died waiting for that pill.

“What is it called this time? An ‘AIDS cocktail?’”

“Because it’s a combination of drugs like a cocktail.”

“And it’s supposed to work? Like it was supposed to ‘work’ all the other times?”

for so long that it was hard to believe that the tiny little capsule would be the answer.

On nights when the owl outside my window doesn’t howl, when the cold breath of the wind is stronger than the warmth of my blankets, when the left side of my bed feels more empty than usual, I forget to dream.

Instead, I roll over to the left side of my bed and think.

This night, I think about the people who came before me, the people who will come after me, and the people who are next to me today.

Suddenly, I wonder...

How am I the one lying here: alive, awake, and HIV positive?

Why me?

Then, I wonder if I’m being too sentimental, but...

Some Thoughts at Night: on being an HIV+ woman in the past and present
Before the term AIDS was introduced in 1982, the acronym GRID was used:

1. heroine addicts
2. homosexuals
3. those who needed hemo-derivatives for blood transfusions
4. Haitians

However, the National Institute of Health (NIH) in the United States released “risk groups” of HIV/AIDS:

Gay-Related Immune Deficiency

“Silence about lesbians and AIDS has created a lot of fear and anger.”

Women who have sex with men who have HIV were added as a 5th group in 1983.

Even though heterosexual women had been reported to have AIDS since 1981.

Activists advocated for a shift from “risk groups” to “risk practices,” which not only emphasized that HIV can only be transmitted through certain bodily fluids, but promoted destigmatization and inducivity.

Don’t box me in, don’t box me out

“USE CONDOMS.
DON’T BE ASHAMED GIRL! YOU HAVE A PROFESSION.”

- a Brazilian national campaign, partnered with Davida, a sex workers’ rights organization

Globally, transgender people are 49 times more at risk of living with HIV compared to the general population.

In South Africa, there are estimates of 2,300 incident infections per week in adolescent girls - which is twice as likely as men to contract HIV.

It’s not only the “unsafe sex and needle usage” that is spreading HIV. It’s social systems and structures that place populations at risk and create health disparities.

Instead of being a place of self-identification and community

But you can’t forget HIV disproportionately affects the population.

discrimination (gender and sex worker)

I think about how people use boxes like when people called HIV a “gay man’s disease”

discrimination (LGBTQ+ and HIV+)

The use of “risk groups” not only stigmatized vulnerable populations but also excluded those who had HIV/AIDS but were not in the delineated “risk groups.”

us vs them

like when people called HIV the “prostitute’s disease”
Rae Lewis-Thornton was one of the first African-American woman to share her story of living with AIDS in a national publication in the United States.

But activists worked to start conversations. They helped inform and dispel myths - like how HIV could not be transmitted through kissing. Some were brave enough to share their stories and their names to the public.

Gugu Dlamini, an AIDS activist, was stoned and beaten to death by her community after revealing her HIV status on Zulu television. Afterwards, they told her neighbor, a friend and HIV+ woman, “Go and tell them to fetch their dog, we are done with it.”

But some people responded with hate.

In 1994, the Essence magazine published an article titled “Facing AIDS.” I’m young. I’m educated. I’m drug-free, and I’m dying of AIDS.” By Rae Lewis-Thornton.

But even at times, campaigns that were supposed to make it better only made it worse.

The news was sad, the world didn’t seem to care.

A future without AIDS? Are they just waiting for me to die? And everyone else with AIDS?

Will everyone treat me like this if I reveal my status?

“Women don’t get AIDS. They just die from it.”

(Women don’t get AIDS. They just die from it."

(Header of an ad in the NYT)

When activists wrote the news (over 300 grassroots fought and signed a full page ad in The New York Times)

Gugu Dlamini Park in Durban, South Africa.

Did you see? Princess Diana shook hands with people with AIDS with no gloves.

So did you know? You don’t get HIV from shaking hands.
It felt like no one wanted to talk about it.

but even at times, campaigns that were supposed to make it better only made it worse

When the news was sad

A future without AIDS? Are they just waiting for me to die? And everyone else with AIDS?

WILL EVERYONE TREAT ME LIKE THIS IF I REVEAL MY STATUS?

“WOMEN DON’T GET AIDS. THEY JUST DIE FROM IT.”

(header of an ad in the NYT)

When activists wrote the news

(over 300 grass roots bought and signed a full page ad in The New York Times)

When the news helped change people’s perspectives

Rae Lewis-Thornton was one of the first African-American woman to share her story of living with AIDS in a national publication in the United States.

1994

But activists worked to start conversations. They helped inform and dispel myths - like how HIV could not be transmitted through kissing.

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Gugu Dlamini, an AIDS activist, was stoned and beaten to death by her community after revealing her HIV status on Zulu television. Afterwards, they told her neighbor, a friend and HIV+ woman, “Go and tell them to fetch their dog, we are done with it.”

1998

Gugu Dlamini Park in Durban, South Africa

But some people responded with hate.

1987

Did you see? Princess Diana shook hands with people with AIDS with no gloves.

...Did you not know? You don’t get HIV from shaking hands...
I wonder about the mothers.
The ones who wanted to be mothers.

Women were forced to have abortions and sometimes even had to “agree” to sterilization to access abortions.

“You are bringing an innocent child into [an] HIV world, better to just terminate.”

It’s “more acceptable” for you to have an abortion because you’re “correcting a mistake.”

The ones who were forced to be mothers.

When women are not allowed access to safe abortions.

because it is “not possible” to be raped by your husband because of stigma

women have resorted to unsafe abortions - like drinking boiled newspapers or sticking a cassava root into their vagina

When women are expected to have a child because of social norms.

so doctors tell the women to come back when it’s too late to legally or safely have an abortion

But this happens even in countries where abortion is legal - the injustice does not come from the law but from moral judgment against women - for being HIV positive, for choosing their right to have or not have a child

The ones who were seen as mothers first and women second.

In areas where AZT is known and available to prevent HIV transmission from mother to child, a doctor may tell you its side effects.

“The doctor will generally just say, ‘Oh, there might be a little bit of dizziness’ but like women with fevers, their whole body breaks out in a rash, when they come in to see him, he will say,

‘Oh, just be patient and do it for your child’.”

I wonder whether anything has changed.

Do I have the power to make my own choices?

Do I feel empowered to tell the other person no if they don’t want to have safe sex?

Is it safe to say no?
In 1991, a group of women met at an international meeting of a global network of people living with HIV and AIDS held in London, UK. They felt the lack of presence of women in the discussion of HIV, which was dominated by social perception and organizations as the “gay plague.” The women mobilized and culminated in the International Community of Women Living with HIV and AIDS (ICW).

They stood on stage and announced, at the 1992 International AIDS Conference in Amsterdam.

“Here we are! We have specific needs and we are going to defend our rights.”

pg 28

pg 29-30
Box 14, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.
Box 15, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.
Box 19, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.
Alles Over AIDS. HIV/AIDS Education, general Industrialized countries 1, Box 8, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.

Lesbians and AIDS Pamphlet. Lesbians: International, Box 14, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.

pg 31-32

pg 33-34

pg 35
Box 10, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.

pg 37-38
“Scenarios of Departure: The AIDS Paintings of David Ruffell” by Margot Farnham and David Ruffell. Postaids Antibodies: Resisting the AIDS mythology edited by Tessa Boffin and Sunil Gupta. HIV/AIDS Media and arts International 1, Box 9, Maria de Bruyn Archives, Rubenstein Library, Duke University, Durham, NC.
Some Questions that Keep Me Up at Night

“I am often asked if I cry a lot. Yes, I cry but I don’t know if it’s a lot and I don’t know what makes me cry. I never cry because I have AIDS and it is going to kill me. I do cry for my cats. Who will love them and care for them as I do?”

With medication, I’m not going to die anytime soon. Why don’t people know that I can’t spread HIV? Why don’t people realize that I can live with HIV? How am I going to live?

What are the answers?
What are your questions?
Write here:

What are the social systems and structures that cause vulnerable populations to have higher rates of HIV/AIDS?

What do people living with HIV/AIDS need the most now?

How do I spread awareness? What am I doing to add or subtract from the stigma against people living with HIV/AIDS?