

Ethical Considerations on Health Policy Making for Vulnerable People: Focused on HIV / AIDS Patients

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Abstract

AIDS (Acquired Immunodeficiency Syndrome) is the greatest threat to health in the world. However, AIDS is not only related to health issues but also to social, economic and justice issues. The HIV/AIDS epidemic, which raised many ethical and moral question is a global issue. Even though AIDS is an important global issue, it has not been discussed in the public because there are still many unfair social stigmas attached to HIV/AIDS. The purpose of this paper is to address the seriousness of HIV/AIDS in social context and to reconsider how false perceptions of HIV/AIDS result in social stigma. Also we will examine the theoretical foundations that can help to solve the HIV/AIDS issue centered on human rights. To motivate practical action among people on the global HIV/AIDS issue, examination of our moral and ethical obligations to others who are needy and vulnerable is necessary. This kind of work will help to solve the question of how we can change the social discourse on HIV/AIDS and to make better health policy for vulnerable group.

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I. Introduction

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), over 37 million people are living with HIV (Human Immunodeficiency Virus) and over 4.8 million infected individuals will undergo physical suffering and death.¹ AIDS (Acquired Immunodeficiency Syndrome) is the greatest threat to health in the world. However, AIDS is not only related to health issues but also to social, economic and justice issues. The HIV/AIDS epidemic, which raised many ethical and moral question, is a global issue.

Even though AIDS is an important global issue, it has not been discussed in the public because there are still many unfair social stigmas attached to HIV/AIDS. This is a critical social issue. In addition to physical suffering from the disease, HIV/AIDS infected people are also suffering from stigma and discrimination. Stigma and discrimination curtail HIV/AIDS person's privileges and human dignity.

The purpose of this paper is to examine what kinds of issues and causes are related to the HIV/AIDS pandemic and to educate people about HIV/AIDS. First, we would like to address the seriousness of HIV/AIDS in social context and to reconsider how false perceptions of HIV/AIDS result in social stigma. Second, we will examine the theoretical foundations that can help to solve the HIV/AIDS issue centered on human rights. To motivate practical action among people on the global HIV/AIDS issue, we will also explore our moral and ethical obligations to others who are needy and vulnerable. This kind of work will help to solve

the question of how we can change the social discourse on HIV / AIDS and to make better health policy for vulnerable group.

II. HIV / AIDS as a Global Issue

We would like to examine issues around HIV / AIDS by introducing one narrative. Through this following narrative which raises the human rights issue, we can listen to people's need in their specific context and help us define more practical responses to the HIV / AIDS issue. Also, the narrative can help us apply our general idea about human rights issue to reality.

Thandi Dlamini (not her real name) gave birth to a daughter, Zama. The baby had many episodes of bloody diarrhea and uncontrollable vomiting. By six months of age, Zama was clearly failing to thrive, and Thandi consented to have her tested for HIV. When the young mother returned to the hospital for the results, she was given three tragic pieces of information: she had given her daughter HIV, no treatment was available, and Zama would not live long. "Ichilo." Disgrace. Amahloni. Shame. This is how Thandi describes her feelings after leaving the hospital. She didn't really know what HIV was, except that it caused people to speak in hushed tones." It took months for Thandi to tell her boyfriend. Soon after hearing the news, he disappeared. Shortly after that, Zama died.²

This narrative reveals several factors contributing to the growing HIV / AIDS epidemic. Thandi has limited access to health care and lives in a culture that made her dependent on men, especially financially. In many developing countries, women are limited by gender inequalities and instability.³ To solve women's HIV / AIDS issue, we have to listen to their own life story carefully which is limited by poverty and social system. Without listening to these voices, we cannot understand their suffering or

help them practically to respect their own dignity.

Stigma and HIV/AIDS

In 2003, there was a top headline story involving an HIV/AIDS patient in Korea.⁴ The HIV/AIDS patient ran away from the hospital and was depicted as a criminal. The media played a major role in the patient's stigmatization. They described people with HIV/AIDS as 'risk groups.'⁵ Finally, the patient committed suicide. The saddest part was that the patient's family did not want to touch and read the patient's will because they believed HIV could be transmitted through touch.

People often think that HIV/AIDS is the result of some people's wrong sexual behavior. As Paul Ricoeur points out, ethics is sometimes mingled with the physics of suffering. He points out that for a long time, human beings reasoned a scheme of rationalization from a relationship between defilement and suffering.⁶ According to Ricoeur, many people want to ignore this issue in public because they think HIV/AIDS is a direct result of sin or actions. This view plays a major role in the social stigmatization of HIV/AIDS, resulting in discrimination and prejudice. The reality is that the HIV/AIDS issue is not only related to individual sexual behavior. It is also linked to poverty, globalization, and social and cultural systems. Considering the specific social and economic conditions, we would like to explore HIV/AIDS issue in a social, cultural and economic context.

According to the definition of AIDS, "AIDS is a collection of symptoms and infections in human resulting from the specific damage to the immune system caused by the HIV."⁷ Also according to encyclopedia of Bioethics, "HIV is transmitted by direct contact with bodily fluids that contain the virus. The major modes of transmission are sexual contact and

injection drug use. HIV can also be transmitted from mother to infant during pregnancy or through breast-feeding.”⁸ Fear of HIV/AIDS causes discrimination and stigma.⁹ In addition, incorrect information about HIV/AIDS also causes social stigmas.

Even though HIV/AIDS is a disease, the stigma associated with HIV/AIDS deprives basic human rights such as human dignity and basic living rights. UNAIDS points out that the “AIDS stigma exists around the world in a variety of ways, including ostracism, rejection, discrimination and avoidance of HIV infected people: compulsory HIV testing without prior consent or protection of confidentiality; violence against HIV infected individuals or people who are perceived to be infected with HIV; and the quarantine of HIV infected individuals.”¹⁰ These elements which UNAIDS mentions are crucial facts that go against basic human rights. Even though it has to be taken as a serious social issue, HIV/AIDS issue is often excluded from the conversation. People with HIV/AIDS are stigmatized, and they are often forced to stop working, attending school, and are denied access to health care. Discrimination because of HIV/AIDS strips people of their human dignity, and basic living rights. Prejudices on HIV/AIDS foster the breaking up the relationships and social ostracism.

People who have HIV/AIDS are more vulnerable in their social status. Some people think that the reason for the HIV/AIDS stigma is connected with wrong moral behavior.

*AIDS stigma is expressed in conjunction with one or more other stigmas, particularly those associated with homosexuality, bisexuality, and intravenous drug use. In many developed countries, there is an association between AIDS and homosexuality or bisexuality, and this association is correlated with higher levels of sexual prejudice such as anti-homosexual attitudes.*¹¹

These kinds of stereotypes are associated with all HIV/AIDS people even

their HIV/AIDS is not caused by homosexuality and intravenous drug use. Because of social discrimination and deprivation of human rights, people infected with HIV/AIDS become socially vulnerable. The effects of stigmatization can cause low self-esteem and insecurities. Addressing HIV/AIDS issue is not only about increasing their quality of life. HIV/AIDS is essentially about someone's life and death.

AIDS as a Poverty Issue

The most serious problem of social influence on HIV/AIDS is poverty. Albert Mosley writes, "poverty is an important factor in the African AIDS epidemic."¹² Bryant L. Myers explains poverty as such: "the poor are not a homogeneous category and poverty is different for different groups. Poverty means different things to children and youth, to women, to the mentally and physically challenged, and to the old ... We are always tempted to "do for" children, not recognizing the potential for transformation that children represent."¹³ He introduces five views on poverty: poverty as deficit, entanglement, as a lack of social organization and lack of access to the political process, as disempowerment, and as a lack of freedom to grow.¹⁴ HIV/AIDS as a poverty issue is a complicated social issue.

Poverty has an intimate relationship to the HIV/AIDS pandemic. According to Alex John London, "People in the developing world who live in poverty and toil under some of the world's poorest social conditions also bear some of the heaviest burdens of sickness and disease."¹⁵ First, poverty and poor social conditions in developing countries contribute to the lack of a good health care system.¹⁶ Sometimes "third world country" can have a negative connotation. When multinational corporations come to a Third World Country, they tend to

hire local people as a cheap source of labor, and sometimes cause many environmental problems as they leave the country. After the company leaves, many local people lose their jobs and have difficult time returning to their original work. The result is poverty that is not easily recoverable. Poverty limits people from affording basic living expenses such as education, health care service, and food. Poverty causes people to be vulnerable to the vicious cycle of HIV/AIDS. Many people, especially children, suffer from malnourishment and compromised immune systems.¹⁷

Second, HIV/AIDS causes poverty. If someone has HIV/AIDS, they often become jobless. Unemployment rate influences personal and world economies. UNAIDS reports that Zambia's GDP has decreased by 20% during the last 20 years.¹⁸ In the study of sociology, there was no evidence that people who have HIV/AIDS in Korea were originally poor. Before they were infected with HIV/AIDS, the majority were employed. After being infected with HIV/AIDS, they lost their previous jobs and found themselves unable to find full-time job again. In Korea, without informed consent, many companies conducted HIV/AIDS tests in their regular health check up. If someone's test result turned out to HIV positive, their test result was not kept confidential. Therefore, people with HIV/AIDS were forced to quit their job because of discrimination.¹⁹ This induced poverty also makes them some kind of limitation of access to their treatment, which is started another vicious cycle. So in Korea government has duty for protection of family dependents as well as HIV/AIDS patients by law.²⁰

AIDS as Vulnerable People's Issue: Vulnerability of Women and Children

Vulnerable people such as women and children are at a particular risk for

HIV/AIDS. In developing countries, outside circumstances such as poverty, lack of medical resources, lack of education, and culture of inequity, make women and children particularly vulnerable.

First, in this part, we would like to emphasize the vulnerability of women. According to UNAIDS, “As of the end of 1998, there were more than 33 million people worldwide with HIV infection or AIDS, 43 percent of them female.”²¹ This statistics represents the vulnerability of women. Women’s status and sexuality is very relevant in HIV/AIDS. According to UNAIDS, over 10.1 million men and 12.2 million women all infected with the virus live in sub-Saharan Africa.²² This data shows us that women are at a greater risk to death and infection than men because their life is socially, traditionally and economically subordinate to men in general.

According to Margaret A. Farley, “in Africa, women cannot choose their own marriages, and they have to have marital sexual relations even if they suspect that their husbands has HIV. Also widows are forced into sexual relations with relatives of former husbands in their social context.”²³ In the 3rd world country, all resources and decision makings are controlled by men. Women in those areas have been more likely to be degenerated to prostitution for living. The social status of women in the 3rd world country in Africa is very low. In addition, there is the issue of safe abortion for HIV-Positive women with unwanted pregnancy, which is related to women’s reproductive rights. Maria de Bruyn describes the difficulties faced by HIV positive women in obtaining safe, legal, and medical services. According to him, “HIV-positive women want to avoid pregnancy for the same reasons as other women, but they also do not want to infect their partners through unprotected sex, worry about effects of pregnancy and childbirth on their own health, or about infecting a child and the child’s future care.”²⁴ Those issues are related to women’s right and dignity.

Martha C. Nussbaum's "capabilities" approach will help us to understand the minimum of what respect for human dignity are required especially for women. She points out that women have been treated as supporters of the ends of others. According to Nussbaum, "capabilities have a very close relationship to human rights ... the best way of thinking about rights is to see them as combined capabilities. The right to political participation, the right to religious free exercise, the right of free speech-these and others are all best thought of as capacities to function."²⁵ With public and global action, we have to create a world in which women can exercise their capabilities and potentials in their lives. As the consequence HIV/AIDS issue related to women will be solved fundamentally.

Second, we would like to emphasize the vulnerability of children. According to UNAIDS, "In 2005 alone, AIDS claimed an estimated 2.4–3.3 million lives, of which more than 570,000 were children."²⁶ The stigma on children related to HIV/AIDS is especially harsh. Stigma threatens children's rights. Because of the stigma related to HIV/AIDS, some children die after they are born without receiving appropriate medical treatment and care. The main factor of HIV/AIDS for those children is related to poverty and infected mothers.

Poverty is the main cause for children's HIV/AIDS. Because of poverty, they cannot get medicine for HIV/AIDS. Poverty also shoves young children into prostitution. In many developing countries, young children do not have access to prevention education from school and are often forced into prostitution for economic reasons. This is a threat to young women's rights. Young women have the right against abuse, exploitation, and violence through protection of the family and government. Gisela H. van Rensburg claims that "protection should be provided against environmental dangers, family violence, community

violence ... Protection against abuse, including physical, psychological, social, and sexual abuse and exploitation and violence is of great importance in the realization of children's rights."²⁷ They also have the right to promote a healthy life. For this, they should be equipped with knowledge of HIV/AIDS prevention and awareness and claim their rights.²⁸

Children are vulnerable to HIV/AIDS when the mother is infected. According to the Encyclopedia of Bioethics, "Worldwide, mother-to-child transmission is a major public crisis. In part of Africa, 45 percent of pregnant women are HIV-infected. Their children contract HIV in 25-45 percent of cases, resulting in some 540,000 prenatal cases annually."²⁹ Regardless of their choice and their right to live, children die and suffer from HIV/AIDS. Another consideration is many young children become orphans. According to UNAIDS, there are already millions of orphans due to HIV/AIDS. How about children's rights to have a future and the right to live? Especially, this kind of statistics about children's HIV/AIDS rate and cause of children's HIV/AIDS should encourage us to address the global impact of HIV/AIDS and to focus on our global action.

III. Human rights and HIV/AIDS

In the 21st century, human rights became a very important concept in our public discourse on HIV/AIDS. Nowadays most nation's constitutions address human's right. Jack Donnelly claims that no matter what kinds of social status, every human being has an equal and nontransferable right because they are human being.³⁰ In reality, many human rights are not secured. Especially if the HIV/AIDS issue is one of the main cases. To secure human rights especially for the vulnerable and the marginalized

people, we have to build a ground work for human dignity and human right. To solve the HIV/AIDS issue, we have to identify the reason why we should to help others and ensure human dignity. In order to find the reason, we would like to introduce 'responsibility ethics' from Levinas. This responsible ethics encourage us to love and help needy people.

Ethical Consideration in HIV/AIDS: "Responsibility Ethics"

Jeffrey D. Sachs's points out, "It may seem highly imprudent to ask the rich world to take responsibility for helping the poorest of the poor to escape from the poverty trap."³¹ Why we have to help others? In this part, we would like to introduce responsibility ethics and reasons for helping others. The concept that we are responsible for others is related to the question of how we can understand this world and how we can secure other country's people's dignity in the name of justice. Depending on people's perspectives, we can understand the world differently. Also this different perspective on the world makes us understand justice differently. Onora O'Neill well contrasts two views of justice: justice beyond borders and justice within bounded and cosmopolitan territories: "since antiquity justice has been thought of as a political or civic virtue, more recently as belonging in a 'bounded society,' or as a primary task of states. All such views assume that the context of justice has boundaries, which demarcate those who are to render and to receive justice from one another from others who are to be excluded. Yet this view that justice is intrinsically bounded sits ill with the many claims that it is cosmopolitan, owed to all regardless of location or origin, race or gender, class or citizenship."³²

However, there are still legal, political boundaries within nations.³³ The world became one community because of globalization. Globalization changes our concept of the world. Currently we have many global issues

like poverty, global warming, globalization of trade, and HIV/AIDS. If we attempt to solve these global issues, we need to remember that we live in one community. Without considering this thought, it is hard to find our motivation to solve global issues. Also if we agree on the idea that the world is one community, we have to put forth on effort to realize justice and give equal opportunity to its members. "One important conception of equal opportunity requires protection against limitations on individuals' opportunities imposed by racial, ethnic, religious, or gender discrimination."³⁴ Especially on HIV/AIDS issues, we need to promote the idea about providing equal health care opportunity to all the people in the world.

In a theory of justice, John Rawls relies on the idea of a bounded society. He thinks that people choose principles to achieve justice within their society.³⁵ However, this idea can not be applied in our current world. How can we solve global issue such as the HIV/AIDS pandemic and poverty with Rawls' idea of justice? If we agree on Rawls' idea that justice has its context in a bounded society, we cannot really intervene with global issues. Thus, there is no room to seek justice in Africa. However, if we want to solve global issues, we have to think that the world is one community. I think, Kant's view on justice is open for the protection of human rights and dignity in the world. Kant's idea of justice stretches beyond boundaries, justice has to be realized true across boundaries.³⁶ This idea brings us to have more responsibility for justice in the world and reason to help people who live in different countries.

Kofi Annan's Speech³⁷ indicates that many country leader and people recognized the need of global action and partnership to solve global issues. The AIDS issue raises the question of life and death. Matters of life and death on HIV/AIDS require us to think of responsibility ethics. To cultivate ethics on behalf of others and for the neighbor is the call of

“responsibility ethics.” Through Levinas and Niebuhr, we can find the richness of the meaning of neighbor. Levinas says that human beings have unlimited responsibility toward other beings. Levinas makes a claim for “responsibility ethics” for others in his concept of face.³⁸ When people miss and love others, they are usually say, “I would like to see the face of some person.” ‘Face’ can be used as a method of assuring that someone will miss the other. To imagine the face of the other is a blessing and brings hope for the restoration of the relationship. Every human being who has faced the other has responsibility for the other.

“Technology changes everything – that was Marx’s claim, and if it was a dangerous half – truth, it was still an illuminating one. As technology has overcome distance, economic globalization has followed.”³⁹ In the past, we could not hear the suffering of African people from poverty and HIV/AIDS pandemic. However, technology and media make us hear their sufferings. Distance is not an obstacle anymore. Their suffering faces and cries for help from HIV/AIDS and poverty require our moral obligation to help them. Our help and care make new relationships with them and will contribute to the protection of their basic human rights and human dignity.

In Levinas’ point of view, responsible behavior is to surrender one’s right to die instead of abandoning one’s life. This represents the best way to show “responsibility ethics.” H. Richard Niebuhr’s statement about neighbor love best stands in line with Levinas’ own thoughts.⁴⁰

Furthermore, Nuyen discussed that we also have the responsibility for the dying and vice versa.⁴¹ Usually, in modern society, people degrade the value of other people’s lives, especially of the old, the feeble, the handicapped, and the terminally-ill. Levinas ascribes the responsibility for other beings to us. Levinas’ ethics could be expanded and applied to the dying as well as to the living. Levinas opens the door to comprehend

death and responsibility by establishing a new relationship between one human being and another. He says that death means an extinction of a relationship, whereas dying means one still remains in a relationship with other beings.

With the idea of Levinas, we have responsibility to HIV/AIDS people. They are still in our relationship. We have to appreciate their presence. No matter what they have, who they are, we have to accept their presence and protect their human dignity and basic human rights.

IV. Conclusion

Through this paper, we raised the ethical issues pertinent to HIV/AIDS. HIV/AIDS is a critical issue for human rights. Stigmas associated with HIV/AIDS threaten human dignity and human rights. Also, the HIV/AIDS pandemic as a global issue is related to poverty and the issue of children and women's right. In our history, many people have fought to achieve their human rights. Now we have to fight to achieve the rights of people whose lives are often compromised by global issues like HIV/AIDS. Since their voices are virtually being ignored, we have a responsibility for them. It is our obligation and responsibility as global citizens. In modern technological society, HIV/AIDS pandemic is in part caused by lack of access to health care and distribution of health resources. All countries have to recognize HIV/AIDS pandemic as a global issue. The entire global society has to participate in projects like promoting education for prevention and counter measures for prejudice on HIV/AIDS.

The most important thing is that we need to open our ears to listen to their voice. This is related to our will to listen. We have to build a world

in which HIV/AIDS people can live without discrimination and can pursue their human dignity and basic human rights.

For more practical global ethics, we would like to suggest distributive justice issues regarding HIV/AIDS for further research. We have to focus on questions like what justice requires in healthcare access. Many years ago, people had to suffer from many kinds of diseases. Due to the lack of medical skill and information, people died with unknown diseases and without appropriate medical treatment. Fortunately, because of the development of modern technology especially bio-technology, people can live longer and be benefited from better treatments for lots of diseases. However, people still suffer and die from diseases not because of lack of medical skill but because of lack of medical resources, which is limited or is not distributed. Consideration on distributive justice for HIV/AIDS makes an important framework for our health policy.

Korea has Prevention of Acquired Immunodeficiency Syndrome Act. This act is an example of Korean HIV/AIDS health policy through legalization. And, there have been some changes with ethical consideration. The purpose of this act is to contribute to the *protection and support* as well as administration and management of national health by providing necessary matters for the prevention of the acquired immunodeficiency syndrome (AIDS) and the segregation and control of the AIDS virus.

NOTES

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Article 20.
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32. Onora O'Neill, "Bounded and Cosmopolitan Justice," in *How might we live?*, ed Ken Booth, Tim Dunne and Michael Cox (Cambridge: Cambridge University Press, 2001), 45.
33. Recently, Korean high court sentenced that compulsory departure order for HIV infected foreigners is unfair. But this administrative litigation is still going on.
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35. Peter Singer, *One world* (New Haven: Yale University Press, 2002), 9.
36. Onora O'Neill, "Bounded and cosmopolitan justice," 59-60.
37. "a \$7 billion to \$10 billion fund to combat AIDS globally, although, as of 2003, funding has fallen well short of this goal. The obligation of developed nations to address the AIDS epidemic in the developing world can be justified on several grounds. First, compassion may motivate developed nations to help alleviate the suffering caused by the AIDS epidemic. Second, to the extent that good health and healthcare are basic human rights, nations who are able are obligated to contribute resources to guarantee these rights. Third, because the wealth disparities between the developed and developing world are largely a legacy of

colonialism, the developed nations have an obligation to address those problems to which they contributed. Finally, it is in the self-interest of developed nations to assist the developing world. If the AIDS epidemic is not controlled in the developing world, the resulting economic and political instability will threaten the security of all nations." *Encyclopedia of Bioethics*, 3rd ed., s.v. "AIDS."

38. Levinas. *Emmanuel, Otherwise Than Being* (Pittsburgh: Duguesne University press, 1998), 123-125.
39. Peter Singer, *One world*, 10.
40. "Love is rejoicing over the existence of the beloved one; it is the desire that he be rather not be; it is longing for his presence when he is absent; it is happiness in the thought of him; it is profound satisfaction over everything that makes him great and glorious. Love is gratitude: it is thankfulness for the existence of the beloved." Quoted in Gene Outka, *Agape: an ethical analysis*.
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