Stigma and AIDS: Reunifying the Body

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Stigma and AIDS: Reunifying the Body

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Abstract

HIV/AIDS is a serious global medical concern; its impact cannot be denied. Yet according to many it is not the disease itself that disturbs life most, but rather the psychological and social ramifications experienced by people living with HIV and AIDS through stigma and discrimination. Through an exploration of the stigma and analysis of case studies, specific demographics, expert studies, and theological discussions, this thesis seeks to argue that while success is possible, there is not enough being done for the eradication of AIDS-related stigma. It was found that the two most important fronts for this to happen on are education, specifically about the modes of HIV transmission, and through efforts of the church. It concludes that while eradicating AIDS-related stigma will not cure the disease itself, it will lead to healthier and affirming living for people with HIV/AIDS.
Acknowledgements

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LIST OF ACRONYMS

AETC – AIDS Education and Training Centers
AIDS – Acquired Immune Deficiency Syndrome
CARE – Comprehensive AIDS Resources Emergency
CRC – The Convention on the Rights of the Child
HIV – Human Immunodeficiency Virus
IV Drugs – Intravenous Drugs
PWHA – Person/People Living with HIV or AIDS
UNAIDS – Joint United Nations Programme on AIDS
INTRODUCTION

The world has known many tragedies: bubonic plague, Spanish Flu, major earthquakes, daunting floods. Many of these, especially natural disasters, are met with an outpouring of love, care, and support from people and organizations around the world. Today, we are in the midst of an epidemic that began in the early 1980s and yet there is still a global hesitancy to help, both religious and secular.

AIDS stands almost alone in human experience. Many diseases and natural disasters create their own brutal equilibrium, a self-regulating mechanism that eventually enables society to cope, if not to overcome. AIDS, thus far, seems different. Virtually all its impacts serve to weaken our defenses and accelerate its spread, not to limit it. By selectively killing young adults, AIDS removes the cornerstone of developing societies. Children whose parents are lost to AIDS are less likely to be well-nourished, in school, or properly socialized, in turn making them even more susceptible to the very situations that enable HIV to spread. Moreover, because it preys on the most private human behaviour and stays invisible for years, it has silenced us from acting. In short, AIDS has rewritten the rules.¹

Peter Piot, then Executive Director of UNAIDS, calls this the “exceptionalism of AIDS.”

In 2008 there were an estimated 33.4 million people living with HIV/AIDS and an estimated 2.0 million deaths.² Although there are medications to take to weaken the effects of the virus, there is still no cure.

What exactly is this killing machine? Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system by using the CD4 cells for its own reproduction, and then killing them.³ As HIV kills your immune system, your body becomes weaker and you are unable to fight off other diseases and infections. Once your CD4 cells drop below a certain level, you have Acquired Immune Deficiency Syndrome (AIDS). This is

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¹ Peter Piot, "AIDS: The Need for an Exceptional Response to an Unprecedented Crisis."
² UNAIDS Epidemic Update 2009
³ “What is HIV/AIDS?” www.AIDS.gov
the final stage of HIV and you are at a serious risk for opportunistic infections. Having full-blown AIDS requires medical attention and treatment.

Why are we so hesitant to help those who have HIV/AIDS? What makes HIV/AIDS such a controversial issue is the way it is transmitted. Many of the behaviors that put one at risk for contracting HIV are seen as taboo or sinful, with sexual activity and intravenous drug use at the top. Reaching out to those with HIV/AIDS is seen to some as condoning their risky behavior. While it is true that some of the modes of transmission could be deemed “unclean”, many people of seropositive (HIV-positive) status are in no way responsible for the transmission of the virus. As a result of the fear and uncertainty that surrounds HIV/AIDS, it is considered a “disease of the other” and is often pushed to the margins of society. This response we call stigma.

Stigma plays an extremely large role in the fight against HIV/AIDS, not only socially but even medically, with many HIV-positive people afraid to disclose their status which in turn keeps them from seeking treatment. “We must banish the stigma that so often makes society harsh in relation to the AIDS victim, and dissipate the prejudices of those who fear the proximity of AIDS victims because they want to avoid contagion.” If we want to work for a world in which AIDS is no longer exceptional, we need to extinguish the wildfire that is stigma. In my opinion the church and education need to be at the helm of this progression; success is possible and has happened along the way, just not nearly to the degree that is necessary. The fear and uncertainty enveloping HIV/AIDS can be squashed through education about the virus itself and most importantly about the modes of transmission. The church needs to set the example of acceptance and

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4 Cardinal Javier Lozano Barragan, quoted in Gillian Paterson *AIDS Related Stigma*
open its arms emotionally and physically to the infected and suffering. Only through these coupled movements will we begin to see an HIV-positive world free of stigma and discrimination.
 CHAPTER ONE – PHENOMENOLOGY OF STIGMA

Defining Stigma

The phenomenon of stigma has pervaded history for centuries. Wherever there has been an “other,” stigma has often followed. But what exactly is stigma? How and why is it so pervasive? Is it self-inflicted, or oppressively stamped on what is different or unknown? The concept of stigma is at once an illusive and a catchall category, so to be properly understood we must begin at the common and most basic definitions, of which the Merriam-Webster dictionary gives three.

The first definition is archaic and no longer used regularly, but still important to consider in determining what exactly stigma is and how it has changed. The term stigma originated in Greece and it was “a scar left by a hot iron; a brand.” A stigma was simply a certain visible, physical sign, yet beyond this it was used to set people apart. One who bore a stigma, commonly captives or criminals, had been purposefully branded so that others would recognize said marked person as different and to be avoided.

The second definition is “an identifying mark or characteristic; specifically a specific diagnostic sign of a disease.” The definition of stigma is now at once both broader and more focused. It can be any identification, not necessarily just physical, that distinguishes an individual or a group. Yet, when considered specifically in the medical world, it is an indication of illness. This definition crosses a barrier that might not be apparent at first. The definition of a scar or a mark is something that is externally on the

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1 Gillian Paterson, *AIDS Related Stigma*  
2 Merriam-Webster Dictionary  
3 Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*  
4 Merriam-Webster Dictionary
body. An illness also affects the body, but this is an internal characteristic. Stigma has now invaded the body, becoming a part of the marked person.

The third definition is “a mark of shame or discredit; a stain.” Even in the literal meaning of stigma, shame is embedded. Stigma is no longer just a physical sign, but it bears emotional and social value. These three definitions have progressed in a way that mirrors the progression of stigma at work in the world: from the initial marking of a person as different, to the incorporation into the person themselves, to the pervasion of the social status and worth of the person.

The consistent theme in the concept of stigma is the idea of a mark, something that sets the bearer apart. It is used to identify one, or a group, that is different. When we talk about stigma we must, however, not only discuss the mark that has been described by the previous three definitions but also the act of stigmatization. To stigmatize something is “to describe or regard as worthy of disgrace or great disapproval.”

Social Stigma

Stigma always exists in relation to someone else; there must be some attribute that is “stigmatizing” that is present in one and not the other. If a man was alone on an island he could not be stigmatized, because he has no one to judge himself against. He could have AIDS or he could be a drug abuser, but because there is no one else in comparison he cannot be stigmatized. Thus, stigma can only exist in social settings. Goffman was the first to define this concept. He defined social stigma as a “spoiled social identity,” meaning that a stigma represents a “deviation from the attributes considered normal and

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5 Merriam-Webster Dictionary
6 Oxford American Dictionary
7 Goffman, *Stigma; Notes on the Management of Spoiled Identity*
acceptable by society. This wording, specifically the word “deviation” implies an action, with consequences, on the part of the stigmatized. This is one of the main issues when it comes to stigmatized populations. It is a common belief that they must have done something wrong to deserve the treatment they receive. Harvey asserts that his paper attempts to define stigmatization from the perspective of those on the receiving end, for most functional definitions regarding stigma are from the perspective of the stigmatizers.

Harvey largely developed his study based on an analysis by Crocker et al. that posed ways in which stigmatized individuals interpreted their stigmatization. The two aspects that Harvey latched on to are (a) frequent experiences with prejudice or discrimination and (b) awareness of the devalued quality of one’s social identity. Due to the fact that there is always the potential to be a subject of prejudice or discrimination, Harvey substituted “possible” for “frequent” as this study seeks to determine the experience from the mindset of the stigmatized. In this study, college students from introductory psychology courses filled out questionnaires in which they rated themselves along various scales. The areas of goal disruption and powerlessness converged with stigmatization. Those that felt stigmatized tended to feel things like “most doors of opportunity have been closed to me” and “I feel helpless in the face of what’s happening in the world today.”

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Based on this, it appears that those who feel stigmatized feel that they lack control of their situation. They feel that they do not have the power to dictate what they will do and what can be done to them. These feelings create the breeding grounds for despair. A world in which a person is conditioned to believe she has no power or influence on her own life is a world without hope. This is a dangerous world. Noticing the language that envelopes stigma (“disgrace,” “shame,” “disapproval”), it must not be missed that the environment of stigma is a negative one.

Stigmatization was also more correlated with group identity as opposed to individual identity.\(^\text{11}\) On one hand, those that are stigmatized instantly find themselves as members of a group of others that share a common characteristic. It is a social phenomenon of labeling the “the”s: “the homeless,” “the criminals,” “the HIV positive.” To acquire a characteristic is to acquire membership into a new group, linking you with every other member whether or not you are actually related or connected at all. On the other hand, the characteristic that set you apart in the larger social context is no longer different within your new group. Stigmatization led its targets to feel either more or less socially discredited based on the context they found themselves in.\(^\text{12}\)

**Conceptualizing Stigma**

Recognizing the difficulty in trying to reduce something that has not been adequately defined, Paterson proposes ten principles of stigma on which a definition could begin to form.\(^\text{13}\) The first is that stigma is contextual and social. We have discussed this briefly already; stigmatization requires more than one person. The stigma

\(^{11}\text{Ibid.}\)
\(^{12}\text{Ibid.}\)
\(^{13}\text{Paterson, } AIDS Related Stigma\)
does not lie inherently in the mark that sets one apart, it lies in the social and political reactions that surround it. A stigmatizing element always exists in juxtaposition with a norm, but it also has the potential to dictate the norm in another setting.

The second is that stigma is different from discrimination. Stigma is the attitudes that are connected to cultural and communal norms that respond to the stigmatizing element in question. Discrimination is an active exercise that occurs as a result of stigma. Stigma is an internal process, whereas discrimination is an external response. It is usually easier to attack and reduce discrimination because it involves active participation. Because stigma lies in the mind, it is much harder to do anything that will require it to change or diminish. One of the contributing factors to this is that stigma, unlike discrimination, is also not always purposefully created or pursued. It can implant in one’s mind and begin to diffuse into thoughts, actions, and words without the person ever being cognizant of the transformation.

The third principle is that some discrimination is necessary as it is based on rational assessment of risk. As we saw previously, discrimination and stigma are not the same. Stigmatization is always a harmful process, whereas some discriminative processes are actually in the better interest of everyone. An example would be screening blood donors to see if they are HIV positive or have AIDS. It would be dangerous to allow someone with HIV or AIDS to give blood as it would spread the virus or disease. This in no way means that all discrimination is justified, just that some practices of discrimination are legitimate.

\[\text{Ibid.}\]

\[\text{Ibid.}\]
The fourth is that a lot of stigma stems from fear and ignorance. It is a natural tendency to be wary of the unknown and mysterious. It is also natural to fear health risks like incurable disease. The main problem is that the general public sits in this fear instead of educating themselves. So much of the initial fear surrounding many stigmatized issues could be avoided through education. Thus, in the fight against stigma, accurate information is one of the most powerful weapons. Dispelling myths about the spread and treatments of diseases is key to reducing the mystery and breaking down walls between the “healthy” and the “sick.”

The fifth principle is that there are two different kinds of stigma: instrumental and symbolic. Instrumental stigma is ‘intended discrimination based on risk perceptions and resource concerns,’ as we saw in the third principle. Symbolic stigma relates to cultural and religious meanings and can be expressed in a variety of ways such as moral judgments and emotional responses. It is important to see that these are two different things. They do not involve the same thought processes or motivations, nor should they be addressed in the same way. Symbolic stigma presents the greater social and emotional disturbance to the marked group or individual because it plays a much larger role in everyday life.

The sixth principle relates to symbolic stigma and religion in that the latter often reinforces the former. It is symbolic stigma that is responsible for bringing many of the negative associations with particular diseases to the table. Often, symbolic stigma goes

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16 Ibid.
17 Ibid.
18 Deacon et al. *Understanding HIV/AIDS Stigma: A Theoretical and Methodological Analysis*
19 Paterson, *AIDS Related Stigma*
far beyond instrumental concerns and creates a negative, and even destructive, environment. Within religion, many stigmatizing elements are identified as sin. By using the blanket classification of sin, these stigmas are harshly criticized and those that bear the mark can be severely ostracized. This will be discussed in much greater detail in the preface of HIV/AIDS, the body, and the church.

The seventh is that self-stigma plays a huge role in the phenomenon of stigmatization. As we saw in the definitions, shame already swirls around the concept of stigma and stigmatized individuals. Shame is damaging to the person and is often confused with simply feeling guilty. There is a key difference, however, between guilt and shame. Guilt is feeling bad about something you have done, whereas shame is feeling bad about the person you are. When stigma is internalized, it propagates a kind of self-disgust, allowing shame to take hold of the whole identity of the individual. Once this occurs, the individual begins to cooperate in the process of stigmatization, only advancing the harm done to his or herself.

The eighth principle is that stigma-reduction is an achievable goal because levels of stigmatization can change over time. This principle is a little bit tricky as it has the potential to be a catch twenty-two. The reduction of stigma would be a great step for the stigmatized individuals in their fight for a more normal life. The danger in the reduction of stigmatism, with a disease like AIDS, would be that people would be less inclined to protect themselves from it leading to an increase in risky behavior. Because the ultimate goal is indeed to reduce and eliminate stigma, this is an issue that will have to be dealt with regardless. What I think is most important to consider in this principle is

\[20\] Ibid.
\[21\] Ibid.
the need for proper education in order to show that even though you can live a normal life and be HIV-positive, their still are health concerns that need to be dealt with.

The ninth principle is that stigma can be utilized in reinforcing moral or cultural norms. This principle is similar to the fifth and sixth principles. Religious institutions most commonly make use of stigma through a ‘fear of exclusion’ practice in order to preserve their moral identity. This is often seen in the church in regards to issues of sexuality and sexual orientation. It is important to know when stigma is being used like this and what norms are trying to be preserved in order to properly defend against it. Just because a group, no matter what affiliation they might have, thinks they are acting with good intentions for the protection of their members doesn’t mean their reinforcing of stigma is correct or appropriate. Although this method of operation might “protect the common good,” it is injurious to those on the outside.

The tenth is that stigma aggravates existing inequalities. It is usually the already marginalized groups of people who are blamed for the stigmatizing disease or quality. This practice distances the ‘moral majority’ from the issue, often giving them a false sense of security. This is a problem for many reasons. It breeds a sense that the general public is safe from the undesirable trait, which can be very ignorant and even dangerous. It also furthers the stigmatization already felt by certain groups of people. In the example of AIDS, intravenous drug users and sex workers are two targeted populations who are sentenced to an even greater stigmatization if they are HIV-positive. By pushing these already disenfranchised groups farther away we diminish the chances of reaching out to them to offer help and healing.

22 Ibid.
23 Ibid.
AIDS-Related Stigma

Now let’s begin to focus in on a specific setting in order to more fully see the effects stigma has on public opinion and action. AIDS-related stigma provides a good lens through which we more acutely see the fruition of stigma. All ten of Patterson’s principles can be viewed through this lens, with the fourth, seventh, and tenth being especially accurate. From the very beginning, when AIDS seemed to explode into the social and medical world in the early 1980s, fear has been both present and prominent (Patterson’s fourth principle). Public surveys broadcasted that due to a lack of adequate and accurate information on transmission and a general fear of the disease, it was of public opinion to support “draconian public policies” that would limit the civil rights of those affected with AIDS in order to fight the disease and keep the rest of the public safe. This is precisely why it is important to analyze stigma. Not only is it important to determine what dictates stigma and why it exists as a social phenomenon, but it is even more critical to determine what results from stigma, what are the byproducts.

In order to provide some foundation from which to launch into a discussion of the social psychology of AIDS-related stigma, Herek outlines four characteristics of AIDS as a disease that act as fuel for the wildfire that is stigma. The first is that stigma more readily surrounds a disease that is believed to be the responsibility of the infected. Because HIV is transmitted through behaviors deemed risky and unnecessary by the general public, those who become infected are seen as blameworthy and thus are increasingly stigmatized.

24 Gregory Herek, "AIDS and Stigma." American Behavioral Scientist
25 Ibid.
The second is that people affected by medical conditions that are considered ‘unalterable or degenerative’ will experience more stigmatization. This criteria was especially pertinent in the earlier days of the AIDS epidemic when a seropositive status was seen as not far off from a death sentence. It is true that there is still no cure for AIDS, but current medical advances have made it possible for people with HIV/people with AIDS (PWHA) to live relatively healthy, long lives. It is also true, however, that many people in need of these medications have no access to them. As a result, this criteria is still very much in effect today.

The third is that conditions seen as highly contagious or as those that easily spread will elicit a greater stigma. An overestimation of the transmission possibilities of HIV has always encompassed the epidemic. Studies in the last ten years have shown that some populations of people still think it is possible to transmit HIV via casual contact such as hugging, kissing, sharing a toilet seat, etc.\textsuperscript{26} Without the proper knowledge about how HIV is transmitted, the stigma will continue to hang in the air as people will fear more than they need to.

The fourth is that conditions that involve very visible and apparent effects will evoke a greater stigma. Although it can be difficult, even impossible, to tell if someone is HIV-positive just by looking at him or her, the effects of the later stages of AIDS are very apparent. Interacting with a PWHA is seen as a social disruption, it can be uncomfortable and bothersome to many people. Especially in the earlier years of the epidemic, PWHA were likened to those with leprosy of the biblical times.

\textsuperscript{26} Kaiser Family Foundation, “Survey of Americans on HIV/AIDS: Part Three - Experiences and Opinions by Race/Ethnicity and Age”
One of the first manifestations of stigma that Herek discusses as being a consistent pattern is the disproportion of prejudice and discrimination faced by already marginalized groups of society who are affected by the disease\textsuperscript{27}, which Paterson later considers her tenth principle. It is easy to consider a disease like AIDS a “disease of the other” when it is found, especially initially, in higher percentages in specific populations. Groups like homosexuals and intravenous drug users are among these populations. The stigma of AIDS was overly exaggerated in their case and these groups were pushed farther to the edges of social society. This is dangerous for everyone. It gives the general public the false notion that AIDS is a disease beyond their boundaries, that if they maintain their distance they will be fine. On the other side, it can prevent PWHA from getting the proper treatment and intervention that they need.

This is another manifestation of stigma: the obstacles that face people diagnosed or living with HIV. PWHA have experienced AIDS-related discrimination in a variety of ways. They have been fired from jobs, denied services and care, evicted, and they have even experienced violence\textsuperscript{28}. This creates a negative and hostile environment for PWHA and can hinder their efforts to live a regular, healthy life. Beyond this, it creates the perception that people who might possibly have HIV would be better off not revealing, or even knowing, their status. Also addressed in Patterson’s seventh principle, this concept of self-stigma is a huge part of AIDS-related stigma. Nondisclosure can be a signal of the internalization of the negative attitudes pervading society. Nondisclosure can also lead to ethical issues when a PWHA engages in sexual activity with his or her partner.

\textsuperscript{27} Herek, "AIDS and Stigma." \textit{American Behavioral Scientist}

\textsuperscript{28} Ibid.
The social stigma of AIDS has many, some even extreme, medical and physical ramifications.

A common correlation Herek mentions is the connection between attitudes surrounding AIDS and a variety of social and demographic factors. Age and education, which commonly go together, show pretty consistent trends with attitudes toward PWHA. An increased level of education and knowledge about AIDS, specifically what does and does not constitute HIV transmission, is positively correlated with a better attitude toward PWHA. Younger people also tend to be correlated with better attitudes toward PWHA. The strongest correlation is between people who are both younger and better educated. This all makes sense logically and is a common theme with social issues. Social and demographic factors tend to be decisive in the formation of attitudes and conceptions of HIV/AIDS. Younger people not only tend to be more flexible in their viewpoints, but they are most likely receiving the latest that education has to offer. The most important thing to take away from this correlation is that education is a key factor in reducing AIDS-related stigma.

An Experience of AIDS-Related Stigma

Orlando Rojas offers a story of a woman in Costa Rica that contracted HIV from her husband and then passed it on to her youngest son as well. Both the mother and the child experienced stigmatization from their friends, family, and greater community. “Because of his HIV status, he is not accepted in child care centers, he is rejected in his neighborhood, and mothers, out of fear, do not allow their children to play with him. As

29 Ibid.
30 Ibid.
a result, it is hard for him to develop, for he is isolated from peers and siblings.” This scenario especially demonstrates Herek’s third characteristic of the relationship between AIDS and stigma: an exaggeration of contagion increases fear and stigma. What is important to note is that there are ramifications of this stigma. The child suffers not only emotionally but his development is impaired as well. The impact of stigma reaches far beyond the mind of the sufferer; there are structural, social, and even physical implications that disrupt the lives of many.

Implications of Stigma on Theology

Denise Ackerman opened her talk about AIDS-related stigma and the implications on theological education for UNAIDS in Namibia with words of hope. “Hope is the antidote to the despair bred by stigma.” Even though she discusses the dangers of stigma and the power struggle that is always present with an issue like AIDS, she still believes it is a possibility that one day we can erase this stigmatization. Ackerman sees theology as needing to play a huge role in this process, and I agree. She calls for a reexamination of the way we present the theological curriculum and urges us to not only look at knowledge, facts, and systems, but how these work together and transform to action. She outlines three important ways to regenerate theology in the landscape of HIV and AIDS.

The first is recognizing the immense importance and value of telling life stories. “Speaking and being heard affirms both dignity and identity.” Part of the reason that AIDS scares so many people is that it is not a personal problem. Giving PWHA a chance

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32 Denise Ackerman, "HIV- and AIDS-related Stigma: Implications for Theological Education, Research, Communication and Community."
33 Ibid.
to tell their stories, both hardships and triumphs, allows healing for both the giver and receiver of stigma. It helps us make sense of a difficult situation and allows for the building of relationships and understanding.

The second is to recognize that there must be strain between praxis and theory. While theory can be seen as distant, praxis concerns actual experiences, asserting freedom for all, and a responsibility to change the circumstances so that there can be human flourishing. Praxis needs to be a collaborative process; it needs to come from all sides and affirm the experiences of all. While stigma might be a phenomenon that can be universally experienced, that does not mean that every stigmatized individual feels or experiences it in the same way. Praxis lies in the gritty details, thus it must acknowledge differences in cultural and social practice and work with them instead of oppress them. While realizing the need for praxis, I don’t think that is any grounds for dismissing theory. The theory is what sets the foundation and guidance for praxis, directing efforts towards a recognizable and realizable goal. Theology should dictate an all-inclusive theory from which stem the many and varied practices that should to be carried out.

The third is critical analysis. We need to understand the relationships and intersections of facets of society such as culture, race, religion, and gender, and be honest about the differences we find. Every person’s experience is different, and it is a falsehood to believe we can ease the pain of so many people with any type of blanket solution. Building on the first two previously mentioned ways, in order to evade paternalistic practices we must truly listen to the stories of those in need and be concerned with the actual experiences of people. AIDS-related stigma deserves our

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34 Ibid.
35 Ibid.
attention, and those that have been suffering in silence or denial deserve to be heard and recognized. We need to give the situation the proper time and analysis in order to determine how best to approach a working solution.

It is obvious, at least to me, that there is a need for a change in the way AIDS-related stigma is dealt with. I am not denying that progress has been made, nor that it will continue to be made, but there are still some grand-scale changes that need to be initiated. The church and theology needs to be at the center of this revolution. The church is supposed to stand for the weak, the needy, and the least. I don’t think we can claim to be doing God’s work if we ignore the number of people suffering from the physical, social, and mental issues created by AIDS-related stigma.
CHAPTER TWO – CHILDREN & STIGMA, FINDING SUCCESS

I'm just one of the kids, and all because the students at Hamilton Heights High School listened to the facts, educated their parents and themselves, and believed in me. – Ryan White, PWHA

Setting the Scene

To this day, stigma has haunted every person who is HIV-positive or who has AIDS, no matter how they contracted the virus. In order to more clearly look at the connections between stigma and AIDS, let’s zoom in on one demographic: children. The AIDS-related stigma experienced by children is especially perplexing because the majority of HIV transmissions, at least 9 out of 10, are mother-to-child or related to faulty medical procedures, meaning the child contracted the virus through no fault of her own. While stigma is still a valid fear that many HIV-positive children face, their situation offers some hope as it is one particular demographic where success has been found in fighting AIDS-related stigma.

Defining Children

When discussing any group of people, it is important to know who exactly it is that qualifies for said group. When looking at statistics and reports, people are necessarily grouped together to show trends and organize data. Children constitute one such group. Interestingly, there is not often an accompanying definition for these groups. What do they mean by ‘children’? Is a child an adolescent, an infant, all ages in between? As we discovered when trying to define ‘stigma’, it can be difficult to truly pinpoint a simple definition. Although it might seem that defining children should be

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1 Ryan White, "Ryan White's Testimony." President's Commission on AIDS.
easy, as one might think it is just a simple function of age, there are still complicating factors.

The first step does begin with age, as this is the most objective constraint. According to the Convention on the Rights of the Child\(^2\), a child is “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.” Already we have an issue: the definition of children is not universal because it depends on the legal age of majority set by the country. This presents a problem because it creates an age group, within the larger global group of children, which is constantly in flux. Different organizations that are addressing the same problem can even have differing parameters on age, as can be seen with Avert defining a child as aged 0-18 and UNAIDS defining one as aged 0-15.\(^3\) According to the dictionary\(^4\), a child is “a young person especially between infancy and youth” and “a son or daughter”. This first definition is even more vague on the age constraints. The point, essentially, is that a child is not an adult. The second definition begins to enter subjective territory. It might seem more straightforward: all children must be born to a woman, thus all children at least have a mother. But what about orphaned children who have lost both parents? In many countries, orphans are forgotten and lack in basic care. These children sometimes do not even self-identify as children.\(^5\)

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\(^3\) AVERT, "Children, HIV and AIDS"

\(^4\) Merriam-Webster Dictionary

\(^5\) UNICEF, “Africa's Orphaned and Vulnerable Generations: Children Affected by AIDS”
Another group that needs to be defined for the purpose of this discussion is children affected by HIV/AIDS. The Interagency Coalition on AIDS and Development has set forth a list of qualifications\textsuperscript{6} defining them as children:

1. who have HIV  
2. who have AIDS  
3. whose parents are sick or have died of AIDS  
4. whose siblings, relatives, or friends have HIV/AIDS or have died from the disease  
5. whose households are stressed by children from another family who have been orphaned by AIDS  
6. who are at high risk of infection, such as those who live on the street

In this chapter I will focus on the first three conditions, though it is important to note that children can be deeply affected by HIV and AIDS without being infected themselves.

*Modes of Transmission for Children*

Although many of the modes of transmission for HIV are the same in both children and adults, the way they are dealt with needs to be handled differently. The modes of transmission for HIV are birth, blood, and sexual activity. The first of these three is of course of primary concern for children. The latter modes, though not as common with children, are still present and responsible for some of the HIV prevalence. Educating children on how their choices and behaviors can impact their HIV status is of utmost importance for stopping the transmission of HIV.

The most common mode of transmission for children is mother to child. “Nine out of ten children infected with HIV were infected through their mother either during pregnancy, labor and delivery, or breastfeeding.”\textsuperscript{7} Although the frequency of mother to child transmissions is decreasing due to medical developments and medication to prevent

\textsuperscript{6} Interagency Coalition on AIDS and Development, "HIV/AIDS and Policies Affecting Children."

\textsuperscript{7} AVERT, "Children, HIV and AIDS"
the transmission, it still exists. In 2010, only 48% of HIV-positive pregnant women received treatment in order to prevent transmitting the virus to their future children.\textsuperscript{8} The fact that medicine exists to halt, or at least severely decline rates of, this transmission, and that the transmission rate has not yet reached zero\textsuperscript{9}, is an issue that calls Article Twenty-Four that was previously discussed to mind. Mother-to-child transmissions have significantly declined in the United States\textsuperscript{10}, yet this mode of transmission still remains the most responsible for HIV-infected children worldwide.

A second mode of transmission is through blood transfusions via needles that have not been sterilized or infected blood. Within this mode lie contaminated medical procedures that more often occur in developing countries. In the early years of AIDS, before blood screening tests and processes existed, this mode was more common. Although the statistic today seems to be quite small, at only 2.5% of HIV transmissions in sub-Saharan Africa, many researchers believe this to be misleading and drastically understated.\textsuperscript{11} This mode of transmission has nothing to do with the child’s behavior or activity. Most often, the child is already in treatment for another illness or disease, and then contracts HIV on top of that.

These first two modes, accounting for a large majority of HIV transmissions in children, are due to no fault of the child. This is important to keep in mind when dealing with the issue of stigma for, as has been discussed, stigma can lead to self-stigma, self-\textsuperscript{8} UNAIDS, "Eliminating New HIV Infections among Children."
\textsuperscript{9} UNAIDS Epidemic Update 2009
\textsuperscript{10} There are other complications that keep this statistic from reaching zero, especially that of mothers not knowing their seropositive status considering 1 in 4 people infected with HIV is not aware of his or her status. CDC, "Mother-to-Child (Perinatal) HIV Transmission and Prevention."
\textsuperscript{11} AVERT, “Children, HIV and AIDS”
blame, and shame. The next two modes, although they do result based on the actions of
the child, are part of and indicative of a much larger problem. It is not an appropriate
response to shun or blame the child involved in these risky behaviors, instead we should
critically look at these situations in order to determine how to better protect the children
of the world that are at risk for contracting HIV.

Intravenous drug use is a third mode of transmission. While this mode is much
more common with adult transmission, it still happens for children living on the streets.
These children might not be aware of the other health risks they are putting themselves at
by sharing or using dirty needles. The main problem with this group of children is that
they can be hard to reach out to because of social issues like police harassment and
negative attitudes from society.\textsuperscript{12} Children that are doing IV drugs are looked at like
criminals and deviants, yet often these children are severely affected by poverty. This
group is an indicator of the correlation, and many times causational relationship, of
poverty and HIV/AIDS.

The fourth mode of transmission is sexual activity. Again, this mode is not as
common among children yet it is still important to take note of because it does happen in
the world, such as in sub-Saharan Africa where 16\% of young females and 12\% of young
males reported having their first sexual encounter before the age of 15.\textsuperscript{13} The younger a
person is when they have their first sexual encounter, the greater lifetime risk they have
of HIV infection. There are other complicating factors that can accompany early sexual
debut, many of which put a child at higher risk for contracting HIV. These include older

\textsuperscript{12} Ibid.
\textsuperscript{13} Ibid.
sexual partners, coerced sex, sex trafficking, and low condom usage.\textsuperscript{14} In some cultures, specifically in parts of Africa, there is a myth that HIV-positive men can be cured by having sex with a virgin.\textsuperscript{15} Issues and instances like these point to a need for a greater support infrastructure for children. Policies and programs need to be established in order to protect and treat the children that have been harmed by sexual activity, something that is currently being strived for with the Convention on the Rights of the Child that we will discuss further. Education and the dissemination of information about the facts of HIV can dispel myths such as the ‘virgin cure’.

\textit{General Statistics}

Although children might not be the majority demographic that is affected by HIV/AIDS, they still constitute a significant amount of people that deserve our attention.

1. At the end of 2010, there were 3.4 million children living with HIV around the world.
2. An estimated 390,000 children became newly infected with HIV in 2010.
3. Of the 1.8 million people who died of AIDS during 2010, one in seven were children.
4. Every hour, around 30 children die as a result of AIDS.
5. There are more than 16 million children under the age of 18 who have lost one or both parents to AIDS.\textsuperscript{16}

Even though these numbers are staggering as is, it is important to keep in mind that these are just estimates; the true numbers could be much higher than these due to underreporting. Not only are children a substantially affected group, but they are a seriously stigmatized group as well. These children, living all over the world, are denied

\textsuperscript{14} Ibid.
\textsuperscript{15} Ibid.
\textsuperscript{16} Ibid.
many of the comforts and environments that promote healthy development. We now turn to children and the experiences of stigma they endure.

**Stigma, Children, and Innocence**

Underlying stigma is blame, whether implicit or explicit. There is a denial of innocence that is particularly perplexing in the case of children, and we will look at two narratives that help us to explore blame and stigma in this context. In chapter 9 of the Gospel of John, we are given the story of Jesus healing the man born blind. The situation of the man is as a child, and similarities can be drawn between his social struggles as a son and those of HIV-positive children.

As He went along, He saw a man blind from birth. His disciples asked him, “Rabbi, who sinned, this man or his parents, that he was born blind?” “Neither this man nor his parents sinned,” said Jesus, “but this happened so that the works of God might be displayed in him. As long as it is day, we must do the works of Him who sent me. Night is coming, when no one can work. While I am in the world, I am the light of the world.” After saying this, He spit on the ground, made some mud with the saliva, and put it on the man’s eyes. “Go,” He told him, “wash in the Pool of Siloam.” So the man went and washed, and came home seeing.  

This man has been abandoned and cast out. It was not even a question in the disciple’s mind that his situation was created by sin, they simply wondered who must have sinned. This blame generates stigma, for it does not seem that one can be both debilitated and innocent.

Later the man’s parents are questioned by the Pharisees, and it becomes clear that they had abandoned him. “Ask him. He is of age; he will speak for himself.” They distanced themselves from their son because they knew the blame that would accompany his status; they refused to even speak on his behalf. This phenomenon can be seen with

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17 John 9:1-7  
18 John 9:21
children who are HIV-positive being abandoned by their own families out of fear that they will be severely judged and discriminated against.\textsuperscript{19}

As the Pharisees continue to seek answers about Jesus, they return to the man born blind. They rebuke him for believing in His divine power, saying “You were steeped in sin at birth; how dare you lecture us!”\textsuperscript{20} The man is now doubly stigmatized: firstly for the “sin” of his birth as being blind and secondly for being a follower of Jesus. After he is thrown out, Jesus finds the man born blind. Jesus reveals himself to the man and the man worships Him.\textsuperscript{21} It is through Christ that the man born blind is finally accepted. The stigma of his birth isolated him for so many years, for he was stripped of his innocence and blamed for his condition.

The judgment this man receives is similar to that experienced by PWHA, and specifically by a youth named Ryan White that we will explore in the following case study; he must have sinned to deserve his ailment. Illness or physical defection, however, is not a punishment from God. It is a common response to assume that someone’s bad fortune or circumstance is a result of their behavior, and yet so often this is not the case. This is especially pertinent with children, as we have seen that most HIV-positive children were born into their seropositive status.

\textit{Case Study: Ryan White}

Most of the time, when a child is infected with HIV it is not due to his or her own doing or behavior. Why, then, does the stigmatization of HIV-positive children still exist? Many times, the mode of transmission does not even matter because it comes to

\textsuperscript{19} Budlender et al., “Formulating and implementing socio-economic policies for children in the context of HIV/AIDS: South African case study”
\textsuperscript{20} John 9:34
\textsuperscript{21} See John 9:35-38
the same result: AIDS. One story in particular details the pain a child experiences from
the social backlash of being HIV-positive.

Ryan White from Howard, Indiana was 13-years-old when he was diagnosed with
AIDS in 1984.\(^\text{22}\) He was a hemophiliac and was infected through a contaminated blood
treatment. In 1985 he was barred from returning to school, even though he felt healthy
enough and both his doctors and the state Board of Health gave him the go ahead.\(^\text{23}\) The
Superintendent of Ryan’s school, who denied Ryan re-admittance, stated that he made his
decision based on the “unknowns and uncertainties [about AIDS]” and “the inherent fear
that would generate among classmates.”\(^\text{24}\) Even when Ryan won his court battle to return
to school, he was so plagued by intimidation, harassment, and discrimination that his
family felt it necessary to move.

Ryan’s story is the perfect depiction of the dangers of stigma. Even with a
clearance from his doctors and the Board of Health, the faculty at his school still refused
to let him back out of fear. Admittedly this was in the early stages of AIDS in the world,
but still it had been proved at that point that casual contact could not transmit the virus,
although this was not necessarily understood. There is the phenomenon of fear of the
unknown, the other, the different. As discussed in the phenomenology of stigma, this
fear creates the conditions that allow stigma to implant and thrive within a society.

Ryan’s mother recalls some of the terrible things they, especially Ryan, had to
endure as a family from other members of the community.

It was really bad. People were really cruel, people said that he had to be
gay, that he had to have done something bad or wrong, or he wouldn't

\(^{22}\) Health Resources and Services Administration, "HIV/AIDS Programs."
\(^{23}\) Macneil, "School Bars Door to Youth with AIDS." Kokomo Tribune.
\(^{24}\) Ibid.
have had it. It was God's punishment, we heard the God's punishment a lot. That somehow, some way he had done something he shouldn't have done or he wouldn't have gotten AIDS.²⁵

Like the man born blind, it was assumed that his unfortunate circumstance was deserved; Ryan was blamed for his HIV-positive status. Knowing that some of the ways to transmit AIDS are through risky behaviors, the general public was unable to separate Ryan from his diagnosis. They no longer saw Ryan, the young boy who was a hemophiliac and was unfortunately infected with HIV through contaminated blood through no fault of his own. They saw Ryan, the boy with the nasty disease AIDS; they discounted his innocence. They projected all of the terrible rumors, myths, and misconceptions of the disease as a whole onto this boy. Even more, the conflicting views of Ryan and AIDS (that he had to be gay to be infected in the first place and that he would be able to pass it to other school children via casual contact) point to the irrationality of the community response.

One important thing this story points to is the immense value of education in reducing stigma. When his family moved to Cicero, Indiana, Ryan had a completely different experience. His new school had been educated about the transmission of HIV, and on his first day he was welcomed by the principle, the Superintendent, and a number of students willing to shake his hand.²⁶ Ryan thrived at his new school, even earning honor roll status, but was most importantly socially accepted as a normal boy like any other. The difference was education. Knowing that Ryan could not transmit AIDS by eating in the same cafeteria or sharing books or shaking hands meant that the fear surrounding his seropositive status was immensely decreased.

²⁵ Health Resources and Services Administration, "HIV/AIDS Programs."
²⁶ Richardson, "AIDS Schoolboy Says First Day At New School Went 'Great'" "Associated Press"
Ryan passed away on April 8, 1990, weeks before his high school graduation. He died of respiratory problems and complications of the disease for which he became the poster child.

Advocates of AIDS education said Ryan White served as a deterrent to bigotry throughout the nation. "After seeing a person like Ryan White - such a fine and loving and gentle person - it was hard for people to justify discrimination against people who suffer from this terrible disease," said Thomas Brandt, the spokesman for the National Commission on AIDS. Ryan White showed people that you could live a normal life and be HIV-positive; he proved to them the absurdity of their fears. While his life showed the nation that their AIDS-related stigma was unnecessary, his death reminded them that that underlying the issue of stigma is a serious issue of health. "Ryan's death reaffirms that we as a people must pledge to continue the fight, his fight against this dreaded disease."28

Finding Success

Ryan White’s story is one of success in the battle against AIDS-related stigma, but we cannot stop there. His initial experiences in his community and at his first school detail a scenario that is experienced all over the world in various degrees. What perpetuated his negative experience was a mixture of fear and judgment. Not only was the general public uneducated about AIDS and the transmission of HIV, but they blamed Ryan for his weakness. Granted, this was over 20 years ago. AIDS was relatively new in both the medical and social worlds. And yet through educational tactics employed by his new school and community, stigma was quelled and Ryan was welcomed as a regular teenager.

27 Johnson, "Ryan White Dies of AIDS at 18; His Struggle Helped Pierce Myths." New York Times
28 President Bush quoted in Ibid.
The Ryan White HIV/AIDS Program

Directly related to Ryan’s life and story is the Ryan White HIV/AIDS Program. Originally the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990, this is the largest Federal program that focuses on HIV/AIDS. “The program is for individuals living with HIV/AIDS who have no health insurance (public or private), have insufficient health care coverage, or lack financial resources to get the care they need for their HIV disease.”29 This is a step towards providing PWHA the medical and physical attention they need to help them stay as healthy as possible. While this is not directly combating stigma, it is reaching out to those that feel marginalized due to their illness and connecting them with the services they need. This also shows how combating AIDS-related stigma can have a positive impact on the medical and physical needs of PWHA.

As the dynamic of HIV/AIDS in the world has changed, so has the CARE Act. It has been amended four times, and one of the added programs is the AIDS Education and Training Centers Programs (AETC).30 This program realizes the importance of HIV education for everyone, especially two populations: those suffering from HIV/AIDS and their health care providers. Not only is it crucial to learn about the transmission of HIV for preventative strategies, but it is equally as necessary to know the best way to treat and deal with a seropositive status. The more we know about HIV/AIDS, the less there is to fear. A greater knowledge and understanding is the first necessary step to take towards practically diminishing the effects and presence of stigma.

The Convention on the Rights of the Child

29 Health Resources and Services Administration, "HIV/AIDS Programs."
30 Ibid.
While the Ryan White HIV/AIDS Program is only in effect in the United States, other positive movements can be seen on a more global scale. In order to protect the rights and dignity of all children, the United Nations put forth what they call the Convention on the Rights of the Child (CRC), which was ratified in 1990. The Convention is a “universally agreed set of non-negotiable standards and obligations” and it is the first instrument of its type to be bound by international law. Interestingly, the United States of America was influential in the drafting of the Convention and signed it with intent to ratify in 1995, but as of late has not yet ratified. The CRC, while it might not be related to Ryan White’s narrative, is a response to injustices present in the world. It is complete with 54 articles and two optional protocols, all designed to maximize and stress the total comprehensive rights of children. Stigma, as has been mentioned, exploits gaps and differences that already exist. I will highlight what I find to be the most pertinent articles to the discussion of children affected by HIV/AIDS and how there is recognition that the playing field needs to be leveled.

Article Three is about the best interests of the child. When making decisions that concern children, whether they are about health care, safety, education, or anything else, the children need to be the primary concern. This is especially of importance when it comes to budget, policy, and lawmakers. In order to truly protect children, we need to make sure that their needs are at the forefront of consideration when forming

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31 UNICEF. "Convention on the Rights of the Child."
34 UNICEF. "Convention on the Rights of the Child."
(legislation), especially when it is aimed at them. For children who are affected by
HIV/AIDS, they have specific needs that are not always addressed.

Article Four is concerned with protecting and upholding the rights that are
established by the Convention.\(^{35}\) One important aspect of this article is that it calls for
any country that ratifies the Convention to reassess the services and systems that they
have in place for their children. If these do not meet the minimum standard requirements
of the Convention, that country must adjust so as to meet these requirements.\(^{36}\) There is
no use in having a Convention or any of the articles or protocols if they are not upheld.

Article Six states that “every child has the inherent right to life”\(^{37}\) and that States
need to uphold and maintain these rights so that all children can grow and develop. All
children deserve to not only survive but also thrive. In the case of HIV/AIDS, the health
of children can be severely compromised, but that doesn’t mean that they don’t deserve
the best care possible in order to give them the best possible life they can lead.

Article Twelve is about upholding respect for the views of the child.\(^{38}\) Children
have a voice and they deserve to be heard, especially when it concerns decisions that are
being made that will affect them. This concept is important not only in law making and
legislation, but more importantly in the healing process for children with HIV or AIDS.
I will discuss this further in a later chapter, but there is much power in the voice of a
child. Children who had HIV or AIDS know what they need, so it is important that they
be heard, listened to, and taken seriously.

Commissioner for Human Rights.
\(^{36}\) UNICEF, "Convention on the Rights of the Child."
Commissioner for Human Rights.
\(^{38}\) Ibid.
Article Seventeen is about the interaction of children and mass media. The Convention admits “the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.” This article is extremely important for the dissemination of knowledge and knowledge materials about HIV/AIDS, especially considering the immediateness and widespread availability of mass social media. One of the huge causal links seen again and again between HIV/AIDS and stigma is a lack of education on the topic. Children need to be adequately educated on the modes of transmission for HIV in order to dispel many common, and incorrect, views that lead to stigma and discrimination.

Article Twenty is about making sure that every child will be looked after, whether or not it is with their own family. A child who has been “deprived of his or her family environment, or in whose best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.” This is most pertinent with children who have been orphaned by HIV/AIDS or who have been abandoned because they are infected. These children especially need protection and assistance in order to make sure that they receive the same rights, and have their needs fulfilled, as children who are still under the guidance of their own families.

Article Twenty-Four is perhaps the most important in the realm of HIV/AIDS as it pertains to health and health services. “States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the

39 Ibid.
40 Ibid.
treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.”

All children deserve to have their basic needs met. Those basic standards are a necessity for all children, both healthy and sick, so that they may pursue the fullest lives they can. In the case of sick children, like those suffering from HIV/AIDS, it is especially important that they receive the proper care and medicine they need in order to maintain as healthy a life as possible.

A subsection of Article Twenty-Four states that “States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.”

One huge issue in the treatment of HIV/AIDS is the cost of the ARVs (antiretroviral drugs) that are necessary to fight the disease. Many developing countries and communities within these regions cannot afford these medications, yet the medicines are tested on precisely these people, creating an issue of both medical and moral distress.

Other Successes

In the 1990s, Princess Diana worked to eradicate the fear of casual contact with PWHA.

In a visual statement about her passion for those who were suffering from AIDS, she held hands with an AIDS patient on television. The scene was played around the world. “The image of her holding hands with HIV/AIDS. ... It shattered the stigma, prejudice and fear that surrounded

41 Ibid.
42 Ibid.
43 Maria Cimperman, When God's People Have HIV/AIDS
HIV/AIDS in the early days,’ said Andrew Parkis, chief executive of the Diana Princess of Wales Memorial Fund. She knew the power she held as a public figure and used it to show her support of PWHA. Princess Diana spoke at many conferences, organized fundraising efforts, and visited PWHA in hospitals all over the world. Her efforts opened many eyes to the misguided fear and stigma that permeates so many mindsets.

The issue of AIDS-related stigma has, to this date, by no means gone unnoticed. What is perhaps most perplexing is that there have been stories of success and yet the general trend has yet to change. UNAIDS has found that there are programs all over the world that are finding success in relieving AIDS-related stigma; this is not an unachievable goal.

**Today’s Reality: Room to Improve**

It is possible to move past AIDS-related stigma; Ryan White and Hamilton Heights High School have proved this. How is it then that we find ourselves in today’s world, with medications and an exponentially greater knowledge about HIV, and still stigmatize PWHA? While advances have been made, we still fall short overall. In a Literature Review by Deacon and Stephney, there are four hypotheses posed about AIDS-related stigma and children. These are circumstances and qualities of stigma that still exist today and should be targeted. Drawing from two of them, the emphasis of context becomes critical to both understanding and eradicating stigma.

The first is that “HIV/AIDS-related stigma exacerbates the negative effects of the

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44 “Remembering the "People's Princess”", CNN
45 "HIVaware > Be Aware > Princess Diana." HIVaware
46 UNAIDS, *HIV-related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*
pandemic on children.” It was found that it was difficult to disentangle the effects of stigma from the effects of illness, poverty, death of a loved one, and factors of the like. Children can feel isolated or discriminated without being infected or affected by HIV/AIDS. Many of the circumstances that accompany AIDS, such as poverty, also affect children without the context of AIDS. “In AIDS-affected families, however, the issues are all the more powerful and problematic because they are compounded by the secrecy, stigma and certain fatality that are part of living with HIV infection.”

There are psychological ramifications for children who have to deal with a secret as large as an HIV-positive status, whether it is their own or a loved one’s. Even more, the stigma acts to not only highlight the AIDS-related issues but it also brings to the surface many other pre-existing problems that need to be addressed.

The second hypothesis is that “HIV/AIDS-related stigma towards children is framed within different social discourses.” This hypothesis is especially important to be conscious of because in order to work against the stigma, we need to be aware of how it is actually functioning in society. There cannot be one blanket approach to stigma if the problem manifests itself in different ways. One important discourse to be cognizant of is that of sexual behavior. A common critique of the church’s response to youth and preventing HIV/AIDS is that it does not take into account the reality of the situation. Teaching abstinence only, even though this is the most effective way to prevent giving or getting HIV sexually, holds no weight if young people choose to have sex. It can actually be even dangerous because it leaves sexually active young people without any knowledge

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47 Deacon et al., HIV/AIDS, Stigma and Children: A Literature Review
48 Nagler et al. 2005, quoted in Ibid.
49 Ibid.
of how to protect themselves or their partners. Simply stigmatizing youth who choose to have sex does nothing for their health or welfare.

By narrowing our view in our focus on children, the dangers of stigma become more apparent. I also believe that focusing on the harm of AIDS-related stigma experienced by children can act as a gateway toward changing the global mindset toward AIDS. It is undeniable that the problem of AIDS in the world is staggering. Because of the taboo and misconceptions we have discussed, AIDS can be easily dismissed in the minds of many as a punishment. Based on a continuum of guilt given by Ogden and Nyblade, we see that children are considered the most innocent demographic.

It seems to me that this then would be the demographic easiest to eradicate AIDS-related stigma for.

There is admittedly a danger in labeling groups as guilty or innocent, but beginning with children could set in motion a progression that then reaches the many

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50 Hogan, “An Irish Nun Living with Contradictions: Responding to HIV/AIDS in the context of Church Teaching” in Keenan et al., *Catholic Ethicists on HIV/AIDS Prevention*

51 Ogden and Nyblade, in Deacon et al., *HIV/AIDS, Stigma and Children: A Literature Review*
other demographics of PWHA. Focusing on children reveals the viciousness of stigma, yet it is in children that we also see acceptance. Besides proving the value in education on HIV/AIDS, the greatest lesson learned from Ryan White is that there was an overblown sense of risk. Once he was accepted and incorporated into a normal setting, there was less panic and stigma’s claim of protection from risk no longer held water. Ryan White was not a risk to society; his experience opened the door to the realization that PWHA do not pose a threat to those around them. We also see this emerge in cases of non-children, even non-innocents, per Magic Johnson and Greg Louganis. What is important to see is that, regardless of the way a PWHA contracts the virus, they are able to live normally in society without risking the safety of those around them.
CHAPTER THREE – ETHICAL APPROACH

The issue of AIDS-related stigma presents both ethical and ethics-related institutional challenges for a number of reasons. One of the main reasons is that the stigma and social pressures felt by those that are HIV-positive or that have AIDS can have resounding effects on these victims’ lives, not only socially and emotionally but even physically. The World Council of Churches states “the most powerful contribution we can make to combating HIV transmission is the eradication of stigma and discrimination.”\(^1\) Although this sentiment has been echoed a number of times within the church, significant enough change has yet to be made. One of the likely conditions for this is that two of the main modes of HIV transmission, sexual activity and drug needle use, are seen as sinful. Many people view those who are HIV-positive as deserving of their illness, because it resulted from their own risky behaviors.

The church is commonly considered to be slow-changing on new worldly issues, especially those that can be controversial in nature, as with HIV/AIDS.\(^2\) However, from the theological standpoint, it should be the church’s duty to stand with and for the vulnerable, the sick, the weak, the least of our brothers and sisters. People living with HIV or AIDS (PWHA) need special protection, especially when stigma runs rampant through our social culture. Each and every single person was created in the image and likeness of God.\(^3\) “So God created man in his own image, in the image of God He

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3. Cimperman, *When God’s People Have HIV/AIDS*
created him; male and female He created them.” From this foundational belief we, the church especially, must in turn treat each and every person with dignity and respect.

**Paterson**

Gillian Paterson describes AIDS-related stigma as an “unsettling experience”\(^5\) for everyone: those involved on the active end, on the receiving end, and those that witness. Although it is already widely known that this is a serious issue, the church has a long way to come in order to more effectively, and appropriately, address AIDS in the world today. The major impediment to the church jumping full-force into the eradication of AIDS-related stigma is that it is deeply interrelated to sensitive topics like sex, homosexuality, and sin.\(^6\) Paterson believes the best way to open a dialogue on HIV/AIDS is to begin with the personal experiences of those infected and affected by the disease. Before we talk about this, however, we must first look at how the church has approached the dialogue and experience of HIV/AIDS.

Paterson describes the process of the church as “moving ‘out of the box’” in three phases.\(^7\) Phase One is marked by the church responding to AIDS in the world, yet still viewing the Church and the World as different entities, separate from each other. Although many churches, especially in Africa, opened their doors to the sick and rejected, AIDS was an external problem. We have seen this struggle of internal versus external already come up in the setting of HIV/AIDS and stigma; it is a struggle of borders, boundaries, and the dangers associated with these breaking. As we will discuss, a major issue with the church and HIV/AIDS is the taboo quality of the body and a

\(^4\) Genesis 1:27  
\(^5\) Paterson, *AIDS Related Stigma*  
\(^6\) Ibid.  
\(^7\) Ibid.
question of purity. In Phase One the difference was maintained between the church and the world of AIDS. No matter what actions the church did to welcome those infected or affected, there was no recognition that the church had AIDS.

Phase Two is marked by the breaking of the barrier between church and world, between church and AIDS. This stage is plagued with troubles as the church struggled, and continues to do so, with the realization that AIDS is a part of the church. “The Body of Christ has AIDS.” Not only are Christians friends and caregivers to those infected with HIV, but they are just as susceptible to infection, as are clergy members. Because there is controversy and stigma surrounding many of the modes of HIV transmission, the church has really struggled to validate AIDS as an issue within its boundaries. Much of this tension and denial is due to the fact that HIV/AIDS is tied to issues of sex, sexuality, and homosexuality. Although I do not go into it in detail, the relationship between homosexuality and HIV/AIDS is one of the major contributing factors to the hesitation of the church.

The church, however, is called to follow Christ’s example. One story in particular speaks to this necessary breaking of boundaries that indicates this second phase.

Some people came bringing to him a paralytic, carried by four of them. When they were not able to bring him in because of the crowd, they removed the roof above Jesus. Then, after tearing it out, they lowered the stretcher the paralytic was lying on. When Jesus saw their faith, he said to the paralytic, “Son, your sins are forgiven.”

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8 Ibid.
9 The church has so far, and will continue to do so, refused to budge or reconsider its teaching on homosexuality. The belief is held that homosexuality is wrong, and this presents an issue to helping PWHA that are homosexual, which constitutes a significant population. The church thinks that if they openly reach out to this demographic, they will be seen as condoning their behavior. Thomas, “AIDS in the Priesthood”. The Kansas City Star.
10 Mark 2:3-5
We are given a powerful image of the roof, the barrier between Christ and the injured man, being physically torn off and the man being lowered into the room: the external is literally dropped into the center of the internal space. The church has been hiding under her own roof, both physically and socially, which is contrary to what we should be doing. Jesus pays no attention to the social constructs or hierarchy that society has put in place. The example set is one of unconditional love and compassion; Jesus spent the majority of his time with the lepers and those deemed “impure”, which we will look at further when discussing the taboo nature of the body.

Phase Three has been initiated but has much room for growth and development. This is the phase of transformation, of God calling the church to truly look at the state of the world and question its mission, ethics, and ultimately its theology. It calls for churches to realize the role they play in the world of AIDS and how much harm they have caused, whether on purpose or inadvertently. “Churches have contributed to the spread of the virus by their judgmental and moralistic attitude, by their approach to sex and sexuality, and by the non-inclusive character of many Christian communities.”

Though this may seem harsh, it is extremely important that the church be honest and realistic in this stage. Nothing can change for the better if they do not admit their wrongs of the past. In theology, the issue of stigma is ultimately an ethical issue of truth and what it means to be a human being. AIDS-related stigma and discrimination are so destructive because they deny many suffering people their basic physical and social

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11 Paterson, referencing the Nairobi Declaration (WCC 2001), *AIDS Related Stigma*
12 Ibid.
needs. AIDS-related stigma within the church has serious implications for the mission of the church in the world and the interpretations of Scripture and Tradition.

If the church can acknowledge that stigma is bad, why is it so hard to get rid of? “[Stigma] is woven, at the very deepest level, into the fabric of society, and into the subconscious patterns by which its members order their lives.” It can be difficult to address stigma definitively and head-on because it is not always something that is taught and thus in turn can be unlearned. Stigma and taboo go hand in hand, for taboos are deeply embedded in the consciousnesses of both individuals and communities as well. “Of all elements in a culture, the ones that are most prone to taboo-thinking are sex and sexuality, gender, disease, race, sin, and death.” Evidently, all of these elements are tied to HIV and AIDS. When AIDS first emerged into the world’s consciousness in the 1980s, it was seen as a disease of the three H’s: hemophiliacs, homosexuals, and Haitians. It was tied to elements of taboo, specifically to elements of the body.

AIDS is a medical disease. It attacks the body and weakens the human being, most often to the point of death. Not only that, but one of the main modes of transmission is sexual activity. It is this inherent connection to the body that makes it such a controversial issue with the church.

AIDS has acted as a magnet for all the negative meanings that the Western Christian tradition attached to the body….but the fact is we all have bodies. We are all born and die and bleed; and whether we are sexually active or not, we are still sexual beings. We are all vulnerable, all (to some extent) disabled. For the real, lived body is not perfect: it is human.

13 Ibid.
14 Ibid.
15 Ibid.
This fact ties each and every person together. Although HIV might be more prevalent in certain demographics, it is essentially blind to religion, race, gender, or any other social construct, for it is an infection of the body. Everyone is vulnerable to AIDS. The incarnation of Christ is one of the most sacred beliefs in the church\textsuperscript{16}, and yet in this time of AIDS we only see the negative views of the body. Patterson argues that the church needs to reflect heavily on Christian constructions of the body and reaffirm the beauty in the body. This is necessary to open up the dialogue about bodies and the church, for every lay, vocational, and religious person is corporeal.

As mentioned earlier, many issues with the body are rooted in issues of purity. This was especially embedded in religious and social practice in Jesus’ time, yet He left these issues behind, establishing that care for the person is more important than obeying ancient purity laws. The most apparent connection can be drawn between HIV/AIDS and leprosy. Lepers were literally pushed to the margins of society; they were the most impure of people and we not allowed to dwell internally of the city’s limits. “Now a leper came to him and fell to his knees, asking for help. ‘If you are willing, you can make me clean,’ he said. Moved with compassion, Jesus stretched out his hand and touched him, saying, ‘I am willing. Be clean!’”\textsuperscript{17}

The first thing to notice about this passage is that the leper himself states that he is not clean, showing an internalization of his stigma not uncommon to PWHA. Even further, he also never asks Jesus to touch him, knowing that no one in his world would touch him for fear of contamination. Jesus, “moved with compassion”, breaks that barrier. He reaches out and touches the leper, healing him. This physical act is what is

\textsuperscript{16} Cimperman, \textit{When God's People Have HIV/AIDS}
\textsuperscript{17} Mark 1:40-42
so key. Jesus completely removes the space between Him and the leper. This is what we are called to do, to break through the boundaries that separate the “clean” from the “unclean”, to rip off the roofs that separate the external from the internal.

We must, like Christ, be moved with compassion for those that are HIV-positive or suffering from AIDS. Paterson believes the best way to do this is exposure to the real stories of PWHA. “Christ is revealed to us in the events of our lives…Revelation therefore becomes a grace-filled invitation to engage with a narrative whose context is the whole story of God’s reign, through an entry point that is specifically our own.”

The process of personal revelation through story-telling makes suffering at the hands of AIDS-related stigma much more concrete for those that are not individually infected or affected. It also allows us to see Christ in the suffering, to see that Christ suffers with PWHA, to see that we are in part causing this suffering. Ackerman also brings up the importance of the telling of personal stories to allow for the healing for both the stigmatized and the stigmatizers. By not only giving those that suffer a chance to tell their story but also truly listening to them, we affirm both their plight and their dignity. We acknowledge that they are being socially wronged and that they do not deserve this. This step begins to close that gap between “us” and “them”, between “clean” and “unclean”, between outside and inside. Without this link, there is but distance and silence.

The silence can be just as powerful as active discrimination, and unfortunately the church, at times, has contributed to both. “We confess that the Church herself has been complicit in this silence. When we have raised our voices in the past, it has been too

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18 Paterson, discussing Rowan Williams on historical context of revelation, *AIDS Related Stigma*
often a voice of condemnation.”\textsuperscript{19} Although it is a wonderful step that many church leaders have taken by admitting their wrongdoing, it is not enough. The church needs to break the silence and actively work for the eradication of stigma and discrimination of PWHA. Part of breaking this silence needs to consist of finding the right language and discourse. Patterson thinks “the problem is that the languages of human rights and of science, which dominate the discourse about AIDS, do not translate readily into the language of Christian ethics.”\textsuperscript{20} While both science and human rights are still important elements in the story of AIDS, they are not sufficient for the church to engage in active discussion that is productive. What is needed is a language that is open and accepting of differences, and affirming of the humanness of the body. It needs to keep as its foundation the respect for the dignity in each and every person.

**Messer**

The theologian Donald Messer is one of the first to admit that the church is not doing enough to reach out to PWHA. He opens his book, *Breaking the Conspiracy of Silence, Christian Churches and the Global AIDS Crisis*, with a quote from a friend. “If only the bite of a mosquito caused HIV/AIDS, then the Christian community would be in the global forefront of the struggle for prevention and care.”\textsuperscript{21} This statement is so sad and powerful because it is true. It is precisely the taboo discussed by Paterson surrounding the infection that keeps many people from reaching out to their fellow brothers and sisters. The United Nations has declared HIV/AIDS a global emergency for a number of reasons, including the immense power of stigma and discrimination.

\textsuperscript{19} *Statement of Anglican Primates on AIDS (Canterbury 2002)* in Ibid.
\textsuperscript{20} Ibid.
\textsuperscript{21} Messer, quoting N. M. Samuel, MD, *Breaking the Conspiracy of Silence*
“Stigmatization, silence, discrimination, and denial as well as a lack of confidentiality, undermine prevention, care, and treatment efforts.”\textsuperscript{22} Stigma is not just a social issue; it has serious mental and physical ramifications as well. Messer calls for a “new holy boldness” on the part of the church to delve into previously controversial issues in order to spread love, not fear, in the world.

The response, or lack thereof, by the church to HIV/AIDS in the world has highlighted an important actuality of today’s church: it has lost touch with its true nature.

“The very essence of the church is at stake when people are excluded from God’s mission and ministry.”\textsuperscript{23} The Nicene Creed lays out what it means to be the church: “one, holy, catholic, and apostolic.”\textsuperscript{24} The church is meant to include everyone. The word catholic itself means “universal.” To stigmatize or discriminate against those who have HIV/AIDS is to go against the church. And yet, this continues to happen today. This is a major issue as it is not only damaging to those suffering with HIV/AIDS, it is damaging to the church itself. The denial that accompanies seropositive status creates boundaries within a church that is supposed to be united, within a body that is supposed to be whole. One cannot be truly Christian, living out God’s love and mission in the world, and be stigmatizing or discriminative. They are, and should be recognized as, mutually exclusive.

Messer reflects personally on what it would mean to him if we were to publicly announce that he was HIV-positive.\textsuperscript{25} He mentions the fear and the anxiety, the stress on relationships, and the stress on himself. They way others love him would become

\textsuperscript{22} Messer quoting United Nations in Ibid.
\textsuperscript{23} Ibid.
\textsuperscript{24} Nicene Creed
\textsuperscript{25} Messer, Breaking the Conspiracy of Silence
conditional. He knows that what people would care about most is how he contracted the
infection. He then reflects on what it would mean if he were diagnosed with cancer. The
outpouring of support would be immense, the love unconditional. It would not matter the
origin of the disease. This mental exploration only highlights the many worries, and the
lack of comforts, that plague the HIV-positive. Confessing one’s positive status is
extremely stressful because it marks the end of one’s life as they know it. PWHA are
seen for their mode of transmission, not the common humanity and dignity they share
with the HIV-negative.

This stigma and discrimination that follow disclosure of status can be severe. Rejection from friends and even family, denial of care or treatment, expulsion from
schools and jobs, and even exclusion of basic rights are all things some HIV-positive
people have experienced.\(^\text{26}\) The church and its members need to shake themselves awake
and see the unnecessary injury caused on innocent people. It does not matter how a
person contracts HIV, she is still a human being with dignity and deserves to be treated
with respect. Beyond that, she deserves the fulfillment of basic rights and access to the
proper care and treatment.

**Keenan/McDonagh/Farmer**

When discussing why the eradication of AIDS-related stigma is so necessary, it is
important to also to talk about the systemic issues that underlie the problem. As we saw
in Paterson’s discussion of the ten principles of stigma, there is a difference between
instrumental stigma, symbolic stigma, and discrimination. There is a difference between
policies intending to protect, like screening blood donors, and those that are simply unfair

\(^{26}\) Ibid.
and unequal. More than this, it should not go unnoticed that many of the factors that contribute to the spread of both AIDS and AIDS-related stigma lie in issues of basic needs. AIDS-related stigma often highlights pre-existing inequalities that exist in our world.

James Keenan and Enda McDonagh discuss the triangular problems of instability, structural violence, and vulnerability: “HIV and AIDS breed where there is instability; instability arises from structural violence; we can only respond to the virus if we appreciate the value of vulnerability, so as to provide stability and diminish structural violence.”

They begin their discussion by reflecting on a theme of the attitude surrounding AIDS that we have already explored: AIDS always enters a society from the outside. It is always a virus of those other people.

HIV thrives where there is instability. This instability can be found in a number of populations and is determined by physical, political, social, and even emotional factors. Some of these affected populations include refugees, prisoners, immigrants, those affected by civil strife, those in debt-ridden nations, and truck drivers or spouses of truck drivers.

Keenan and McDonagh state that these people are vulnerable because their lives and social settings lack the stability necessary to properly cope with an epidemic like HIV/AIDS. As a person that lives a life characterized by displacement, there are daily uncertainties that can be physically and emotionally draining. Many of these precarious situations are due to no fault of the people, and yet they are somehow considered guilty of some unclean or sinful behavior and are thus further marginalized.

27 Keenan and McDonagh, Instability, Structural Violence and Vulnerability; Paul Farmer was also referenced in this pamphlet and many of the topics discussed in this section are influenced by his work and words, especially that of structural violence.

28 Ibid.
Paul Farmer, a pioneer in global health, built off of the work of the late Jonathan Mann, advocate for combining the efforts of public health, ethics, and human rights, that linked HIV/AIDS to poverty.\footnote{Ibid.} Farmer sees “the root causes of disease as being more connected to economics than to biology.”\footnote{Ibid.} Socioeconomic differences are inextricably linked to differences in power; the people in power dictate the structures of society. Those that do not have their basic needs met will as a result be less healthy, thus less powerful, than those that do. This instability creates an essential breeding ground for HIV in the sense that these people are less able to protect or care for themselves.

Quoting Johan Galtung, a Norwegian sociologist, a thread is elucidated that connects poverty and structural violence. Violence causes the gap between what is attainable and what exists, this gap is unavoidable, and the causes of this gap are structural.\footnote{Ibid.} Farmer asserts that structural violence is created at the hands of mankind and results from an uneven distribution of power. If we apply this theory to the world of HIV/AIDS, then we see that there are systemic reasons for the pervasiveness of a dividing stigma. Thus, in order to fully address stigma we must also address structural violence in its various forms that disrupts balance in society and in the church.

Vulnerability is something that every person is subject to whether it is of the body, of the mind, or of social standing. Exploitation of vulnerability occurs often in the world of HIV/AIDS as those that are already marginalized receive the bulk of blame for the spread of the virus. In turn, the wealthy and powerful deny their personal vulnerability. This sentiment has even been seen in the church, evident with the denial
that the body of Christ has AIDS in the first phase that Paterson described. “Only openness to the vulnerability of others and their further vulnerability, leading to an acknowledgement of our own, will offer serious hope of devising strategies and activities that will give us the partial but still substantial security worthy of our humanity.” Only by admitting vulnerability of both others and ourselves can we begin to build more stable foundations that will support the dignity and humanity of all.

**Moving Toward a Solution**

Messer sees the gap between how the church is responding and how the church *should* respond to HIV/AIDS in the world. He provides six ways that he calls Christians to “resist the sins of stigmatization and discrimination and thus break the silence of conspiracy and shame.” These six steps should guide the mindset of each and every one of us, especially the church as a whole, in order to be able to work towards a solution for the extinguishing of AIDS-related stigma. These methods will put us on the path of approaching the situation of HIV/AIDS in the world in a more ethical manner.

The first is to follow Jesus’ example. As we discussed, particularly with Paterson, Jesus lived with disregard to the societal hierarchy of people. He did not abide by the social and physical boundaries put in place between the clean and the unclean. We, too, must learn to break the barriers that separate the church from PWHA. Jesus is the perfect example of what we as human beings are supposed to strive for. Christine Pohl calls food the ultimate equalizer: everyone needs to eat. Jesus commonly ate with the tax collectors, the prostitutes, the lepers, and anyone else that was marginalized and

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32 Ibid.
33 Messer, *Breaking the Conspiracy of Silence*
34 Ibid.
35 Christine Pohl, *Making Room*
deemed unclean. He did not just talk or preach about helping the poor and the least; he did it. More than that, he did it in a natural way. He ate with them, he spoke with them, he was not afraid to touch them. He treated everyone he met with the same loving compassion, and this is exactly what we are called to do.

The second is to respect every person’s worth and dignity. It is at the center of our belief that we were created in the image and likeness of God, and it is against His will to stigmatize or discriminate. Every human being has inherent dignity, whether he is HIV-positive or homosexual, whether she is a sex worker or a mother of three. If we always keep this at the forefront of our minds and actions, I think we will begin to see a dramatic change without having done anything else. By realizing and acknowledging that every person has dignity, we will not be able to treat anyone as less than human or deny basic rights and pleasures because then our actions would be contrary to our beliefs.

The third is to take loving action. It is not the illness of AIDS itself that is necessarily the most difficult part to live with, although this is physically damaging. It is the fear and experience of rejection from friends and family and even strangers. The church has the opportunity to show PWHA that they are not alone, and it is something they should do. Faith communities can offer love, acceptance, and healing to the suffering; they can open their doors to the external world and bring the marginalized inside. This step naturally follows from the previous one. If we see the dignity in each and every one of us, we will act with love and respect.

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36 Messer, Breaking the Conspiracy of Silence
37 Ibid.
The fourth is to make personal connections. The most powerful way to help people understand how stigmatization and discrimination are contrary to the will of God is for people to meet someone living with HIV/AIDS or to hear stories of those who suffer from prejudicial actions and attitudes. It can be overwhelming to look at pages of statistics or to know that millions of people are affected by the AIDS epidemic. By making a personal connection, even with just one individual, we make the largeness of AIDS small. Not to say we downsize the problem or forget about the millions of other people, but we make the problem more familiar to us. It becomes more relevant in our lives and becomes closer to us, breaking that internal/external barrier. Personal storytelling is also a way to affirm dignity and recognize and legitimize the pain of others. Making connections with PWHA is beneficial to everyone involved: it allows us to personalize the sometimes-abstract epidemic and allows for healing on the part of those that suffer.

The fifth is to walk in another’s moccasins. This is a personal exercise that can be difficult, but should be considered by all. Messer took us through a brief example of his own when he imagined the differences between revealing he was HIV-positive and revealing he had cancer. It can be difficult, maybe even impossible, to try and imagine all of the difficulties and hardships that accompany a seropositive status. This step can be more powerful, and even more possible, if it follows hearing the personal stories of a PWHA. Considering how different your life would be if stigmatization and discrimination were every day threats paints a picture that is quite unlike the comfortable

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38 Ibid.
39 Ivone Gebara, Out of the Depths
40 Messer, Breaking the Conspiracy of Silence
lives many people lead. This personal moving outside of the box is a way to begin conditioning oneself for openness and compassion towards PWHA.

The sixth is to protect the human rights of all people. Even if legislation aimed at protecting the human rights of people and families living with HIV/AIDS will not necessarily transform hard-hearted people into compassionate friends, it can at least restrain them from acts of cruelty and teach them the basics of human dignity.\textsuperscript{41} If we have successfully completed the second step, respecting the worth and dignity of every person, this sixth step necessarily has to follow. No matter what action a human has done, even if their risky behavior resulted in the spread of HIV/AIDS, they deserve to have their basic rights met and protected. I personally think this, coupled with the second step, is the biggest step the church needs to take to close the gap between what is preached and what is done. It is foundational to the Catholic and Christian Tradition that every person is created in the image of God. To neglect the rights of even one person is to neglect God.

\textsuperscript{41} Ibid.
In my opinion, it must be obvious to us that we are not doing enough in the fight against HIV/AIDS. Success has been found, but it is often on a relatively small-scale. PWHA feel neglected and they suffer because of the looming silence that hinders any progression. The church is failing. “In every age, the church carries the responsibility of reading the signs of the times and of interpreting them in the light of the Gospel.”\(^1\) Can the church claim to be reading the signs of the times in light of the astronomical numbers of suffering PWHA? I will focus on what two theologians offer for how the church and her community can address head-on the silences and inconsistencies between what we preach and what we do.

**Ackerman**

Denise Ackerman offers a beautiful but honest and realistic reflection on how faith communities should approach the issue of AIDS-related stigma. As we have discussed the church needs to step up to the plate and be a booming voice that breaks the silence of AIDS-related stigma, yet so far they have failed to do so on a global front. Messer gives us six steps or methods that will help orient our mindset so that we can begin to work for the eradication that is so desperately needed. Ackerman goes a step further, not just wanting to change the way we think but change the way we *act*. She focuses on theological praxis, the actual doings of the church in the world. “Christian practices [are] ‘…things Christian people do together over time to address fundamental

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\(^1\) Gaudium et spes, Section 4, Second Vatican Council

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human needs in response to and in the light of God’s active presence for the life of the world.” In response to HIV/AIDS, Christian practices are not yet what they need to be.

Ackerman presents fifteen “observations” of hers that build upon one another to show that there is a possible theological praxis in the world of HIV/AIDS, it is just not yet being fully employed. The first of these is blunt and underlies all of what is currently wrong with the practices of the church in response to HIV/AIDS: stigma is sin. Stigmatization is dehumanizing and is absolutely contrary to God and God’s will. When we stigmatize others for their sinful behavior and refuse to open our hearts to them, it is in fact we that are sinning, recalling the scriptural lesson that we must not look for the splinters in the eye of another while we have a beam in our own. Once we finally see and admit that this behavior is sinful, the only option the church will have will be to actively fight AIDS-related stigma. Following this is her second observation; God is “forgiving, merciful, loving, and filled with compassion.” Stigma and its affects are antithetical to these virtues that are so essential to Christian livelihood. For us to determine who is acceptable, clean, or worthy of love is to deny, or perhaps worse to reject, that God loves everyone.

The third observation is that stigma denies that all human beings are created equally in the image and likeness of God. This is perhaps at the heart of my own personal argument. Every single person is created by God in His image and thus has inherent dignity. To stigmatize anyone is to actually stigmatize God. If Christ were to

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2 Denise Ackerman, quoting Dorothy Bass, “Engaging Stigma”
3 Ibid.
4 Matthew 7:3
5 Ackerman, “Engaging Stigma”
6 Ibid.
appear in the flesh tomorrow and reveal Himself as HIV-positive, I have a hunch that the church would flock to His aid. Yet we have the opportunity to do this every day and many of us resist. What results from this is the fourth observation: stigma destroys human relationships and community. Sin is the destruction of relationships, between us and God, us and others, and even us and the environment. Stigma puts barriers between people; it impedes the formation of healthy connections and severely limits the community that a PWHA is able to interact with.

The fifth observation is that stigma deals in lies. Silence chokes the truth; without an open dialogue about the real stories and experiences of PWHA the societal and cultural conception of HIV/AIDS is incorrect. As has been expressed by numerous scholars, there is an immense good that is done through narrative and allowing PWHA to tell their personal stories. Along these same lines is the sixth observation that stigma only succeeds in the dark. Narrative sheds light on the truth of AIDS-related stigma. Not only this, but Christ is the light of the world and on his Sermon on the Mount he tells us that we are as well. To stigmatize others is to cover their light, to put them under a bushel as the sermon goes.

The seventh observation is that love defines the Reign of God, and stigma lacks in love. God is love; He is unconditional love that extends to every single person. To live as Christians is a call to live in love. As we have said, stigma is incompatible with love. In regards to AIDS-related stigma, the church is not yet entirely living with love.

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7 Ibid.
8 Ibid.
9 Ibid.
10 Ibid.
11 Ibid.
12 Michael Himes, Doing the Truth in Love
The judgment inflicted on PWHA is loveless and damaging to the personhood of the seropositive and also dangerous for the moral and ethical mindset of those that judge. What we need to do is counter judgment, which leads to the eighth observation. Humility is a powerful Christian virtue, and stigma instead enhances notions of hierarchy and superiority. When we judge someone else, we assume that we are superior to them and thus allowed to appraise their worth. Only God can do this. The church as an institution is not meant to judge the people of the world, it is meant to include, love, comfort, and care for them. If the church can couple humility to love, she will see the error in judgment and stigma.

The ninth observation is that humans are by nature sexual beings, and much of stigma surrounds that taboo of sexuality. This human connection to the body seems to have become a negative thing, whereas it should be celebrated. Christ was “born of the Virgin Mary” and became flesh. More than that, Christ was resurrected body and soul in fulfillment of God’s promise to us. Jesus, our most perfect example of how to live, was and is corporeal. Shunning our bodies, or the nature of our bodies, is a misguided attempt to be more “holy”. Sexuality is in the nature of our bodies. We are sexual beings, and expressing this in love can be good and beautiful. The taboo that surrounds sexuality, especially in the church, seems to be a result of only attaching negative sexual experiences to the overall concept. The church needs to open the dialogue on sexuality in order to have open conversations that recognize that sexuality is not inherently bad, but actually good.

13 Ackerman, “Engaging Stigma”
14 Ibid.
15 Nicene Creed
The tenth observation is that stigma disrupts healing.\textsuperscript{16} Healing is most often a relational process. We see that stigma breaks relationships and ruins community. Jesus was a healer. He would take in the lame and the sick and the weak, lay His hands on them, and heal them.\textsuperscript{17} The church is called to heal indiscriminately. PWHA need both physical and emotional healing. If the church opens its arms to the sick and quells AIDS-related stigma, it would lead to healing on both of these key fronts. Healing leads to rebuilding and making what is deficient whole again. The eleventh observation is that stigma keeps the church from truly being the whole body of Christ.\textsuperscript{18} The many disturbances and dissonances that stigma creates segment the body of Christ and of the church. What I find interesting is that the fixation on the impurity of the physical body is such an issue in the church, and yet by disregarding or shunning people the church is in turn crippling the community that is the metaphorical body, causing a version of the situation they seem to fear most.

The twelfth observation is that the accurate language through which to discuss the HIV/AIDS epidemic is lament, yet the church is not lamenting.\textsuperscript{19} The HIV/AIDS pandemic is a world crisis. Many people die every day from this single cause; the amount of suffering at the hands of this virus is incalculable. Yet for some reason this is not expressed as blatantly as it should be. Ackerman believes that “the public witness of a lamenting church calls attention to the suffering of the voiceless and the despair of the hopeless that challenges conditions of silence and denial.”\textsuperscript{20} This lack of lament

\textsuperscript{16} Ackerman, “Engaging Stigma”
\textsuperscript{17} Luke 4:40
\textsuperscript{18} Ackerman, “Engaging Stigma”
\textsuperscript{19} Ibid.
\textsuperscript{20} Ibid.
contributes to the thirteenth observation that the church contributes to stigma.\textsuperscript{21}

Admitting this is a huge step for the church to take towards healing, and it is one that has thankfully already been acknowledged. Paterson especially brings up that many church leaders have admitted that the church is complicit in AIDS-related stigma. Before the church can make any moves toward the eradication of stigma, she must admit her wrongs and her faults and take responsibility for them.

The fourteenth observation is that Jesus is our perfect model of living a life devoid of stigma.\textsuperscript{22} As we and many theologians have discussed, we are given countless stories through scripture of Jesus reaching out, physically and socially, to the least of the least. Christians are followers of Christ; our call is to be Christ-like. If we were truly acting as Jesus would in the world of HIV/AIDS, there would be no AIDS-related stigma. And though we need to be aware of our negligence, we cannot become completely discouraged by it. The fifteenth observation is that despite our failures and shortcomings, we have hope through Jesus as the Eucharist.\textsuperscript{23} Again we are brought back to the body, specifically Christ’s body. There are numerous connections between the Eucharist and the AIDS-related observations Ackerman has made. The Eucharist is communal, it recalls the level playing field created by the common need for food that Pohl discusses. The Eucharist is our reminder of the life-giving relationship that thrives in the Reign of God; it is truly a celebration.\textsuperscript{24}

Ackerman’s observations are poignant and refreshing because she addresses head-on the issues she sees with the church and their response to AIDS-related stigma. It is

\textsuperscript{21} Ibid.
\textsuperscript{22} Ibid.
\textsuperscript{23} Ibid.
\textsuperscript{24} Ibid.
through acknowledging that these issues exist and working to change them that the church will be able to find a solution that eradicates stigma. Ackerman, however, also includes a cautionary note about focusing too much on stigma. “Speaking only about stigma can shift the focus from the reality that infection is the result of certain types of behavior in often complex situations.” Just because we are called to love the IV drug user does not mean we are asked to condone his behavior or romanticize his situation. We still need to address the roots of the HIV/AIDS epidemic and educate about the modes of transmission. AIDS is a devastating disease that wreaks physical havoc on the infected; we cannot forget this. We need to approach the totality of the situation with compassion that is framed by reality.

Cimperman

In When God’s People Have HIV/AIDS, Maria Cimperman discusses many of the same points that we have already discussed, most namely the importance of narrative and the hesitancy of the church with issues surrounding impurity and the body. There are two things that she sees as crucial to an ethical and theological response to HIV/AIDS: a theological anthropology and discipleship. “I begin with a theological anthropology because our vision of what it means to be human is crucial and even foundational for HIV/AIDS prevention, care, and treatment efforts.” HIV/AIDS is an epidemic that fundamentally attacks the body. It is interesting to notice that what HIV does biologically is destroy the immune system, rendering the infected much more susceptible to future illness and even incapable of physical healing. This is mirrored socially by the

25 Ibid.
26 Cimperman, When God’s People Have HIV/AIDS
27 Ibid.
effects of stigma, which leave the infected feeling detached from society and unable to truly cope with their situation. “A theological anthropology in the time of AIDS calls for an understanding of the human person as a relational, embodied agent in a context of suffering and historical realism.”28 The church needs to conduct an open and honest dialogue about elements that are truly human, especially the body.

Discipleship is our call as Christians to be followers of Christ. Cimperman believes that there are six elements of discipleship that are “necessary if the Christian community is to offer a life-promoting response in the midst of the AIDS pandemic.”29 We have actually already discussed these elements through exploring the ideas of other theologians. They include expressing love as God does, being a member of a community of believers, and exercising moral praxis.30 Cimperman acknowledges that many of us are already aware of what discipleship consists of and that we strive to live this way, yet there is still a disconnect of where we are and where we should be. She highlights the practical obstacles that deter true discipleship in the everyday lives of people.

The first obstacle is frenetic activity. This is especially apparent in the American culture and those of other first world countries. “Frenzied business prevents us from knowing the other with any depth….Running from one activity to another, even when the activities are worthwhile, can result in a kind of moral numbness.”31 We get so wrapped up in our own lives that we isolate ourselves or our small circle of interaction from the larger world and community we are a part of. This is where storytelling and narrative can work to reconnect us to the others around us. Taking the time to listen to and

28 Ibid.
29 Ibid.
30 Ibid.
31 Ibid.
acknowledge another person will allow us to slow down and reevaluate what is truly important.

A second obstacle is community building that focuses too much on similarity. “We naturally wish to live, worship, and work with and relate to those with whom we are most comfortable,” she adds, “A community without diversity is an impoverished community.” Cimperman calls these communities “contextual communities,” discussing that it is the people on the outskirts that are pushed farther away. It can be hard to determine how the HIV-positive homosexual man of drug-injecting youth can fit into the context of a well-to-do church community, but that does not mean we keep them out. To silence these voices or hide these faces is to deny that suffering is a part of the fabric of our lives.

A third obstacle is risk aversion. “The prophetic dimension of the Church is denied when we fear to reexamine teachings in the light of history, new information, and the experiences of the people of God.” It is easy to get comfortable in the things we have grown accustomed to, for both the church and for us in our everyday lives. To admit that there are people suffering all over the world and dying of AIDS while we sit comfortably in our homes is an uncomfortable thought. Even more uncomfortable would be to open our homes and lives to these people, as we would invite their suffering into our safe space. Certain issues in the church, such as prophylactics and gender inequality, are not openly talked about, and to open the discussion on AIDS would be to, in a sense, open Pandora’s Box.

32 Ibid.
33 Ibid.
34 Ibid.
One of the ways risk aversion presents itself is paralysis.\textsuperscript{35} As we saw with the statistics on children and HIV/AIDS alone, the numbers are staggering. It is easy to be “overly aware” of an issue like AIDS, to know that the scale is so great that suffering is incalculable. A common follow-up to this realization is the thought that the individual must then be useless in the fight against the epidemic. “I’m just one person, what can I even do?” These thoughts are natural when presented with such a colossal issue, but that does not mean we are now excused from the problem. Another vein of paralysis is the bystander effect. When we know that organizations like UNAIDS and UNICEF or various NGOs exist, we fall into the trap of thinking that someone else is already taking care of the problem.

Cimperman calls these obstacles to our attention because the only way we can move forward in the fight against HIV/AIDS is to acknowledge our pitfalls and where we have failed so far. This is where a solution has to begin for both the church and the greater Christian community. We need to change both our mindset and our actions in response to the worldwide epidemic that claims millions of innocent lives.

\textsuperscript{35} Ibid.
CONCLUSION

Stigma is a way of marking people, of separating the ‘good’ from the ‘bad,’ ‘clean’ from ‘unclean,’ ‘us’ from ‘them.’ Only originating in social settings, it is a form of judgment that decides the superiority of one group over another. AIDS-related stigma presents both an ethical and theological problem. There are serious implications for the way we ordinarily live our lives in relation to others, and on a grander scale for the practice and preaching of the church. This stigma not only opens our eyes to the immediate problems of the epidemic but also to the underlying global issues that have contributed to its ability to thrive, for it has exacerbated pre-existing inequalities.

Working to eradicate AIDS-related stigma needs to be a primary goal, as it will address medical and physical needs as well as social.

One of the pillars of this fight is education. Education about the modes of transmission of the virus will help to quell much of the unnecessary fear about HIV/AIDS, especially knowing that casual contact such as a handshake or a shared toilet seat is not contributing to its spread. The Ryan White case demonstrated the immense power of education evidenced by the entirely different experiences he had at his two different schools. Even the approval from the Board of Health was not enough to calm the fears his first school community felt because they let rumors and exaggerations run wild. Due to the community-wide participation of a fact-based AIDS education, Ryan was accepted into the student body as a normal student, symbolized by an initial handshake. More than that, once he was accepted he proved to be no risk to the community, rendering any initial fear unnecessary. This narrative provides a beacon of hope for the future; stigma is not invincible.
The church has a crucial role to play in order to more fully realize this hope. With Jesus as our example, we must break down the socially created barriers that multilaterally separate PWHA from the rest of the world. Drawing heavily from the reflections and encouragements of Ackerman, we see that the church needs to take real and practical steps towards reorienting her approach toward PWHA. Crucially, the church needs to admit her wrongs in order to move forward. We cannot deny that our silence has greatly contributed to the pain experienced by those infected and affected by HIV/AIDS; it is in this acknowledgement that we will be able to then break down the barriers that discriminate and allow for healing and the rebuilding of a unified church, a unified Body. We cannot be naïve in thinking that through conquering AIDS-related stigma we will eradicate the world of HIV, but we must be hopeful that this will be a step towards a healthier, dignified world for HIV-positive and –negative people alike.
REFERENCES

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