CHALLENGING HIV-RELATED STIGMA AND DISCRIMINATION: THE

ROLE OF THE FAMILY LIFE EDUCATOR

by

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B.A., University of Cape Coast, Ghana, 1998

A REPORT

submitted in partial fulfillment of the requirements for the degree

MASTER OF SCIENCE

School of Family Studies and Human Services
College of Human Ecology

KANSAS STATE UNIVERSITY
Manhattan, Kansas

2007

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Abstract

Today the HIV/AIDS epidemic is one of the many crises families may face. Many people have died of the disease while others are still living with it. At the end of 2003, an estimated 1,039,000 to 1,185,000 persons in the United States were living with HIV/AIDS, with 24-27% undiagnosed and unaware of their HIV infection. The Centers for Disease Control (CDC) estimates that approximately 40,000 persons become infected with HIV each year (CDC, 2007). Stigmatization and discrimination related to HIV/AIDS is one of the many challenges that individuals and families affected by the disease face. They are unable to get employment, are denied health care, cannot access services in their communities and sometimes lose respect and power as a result of stigma. Stigma and discrimination also have been recognized as one of the main obstacles to HIV/AIDS, testing, prevention and treatment and yet little has been done to combat it. Stigma and discrimination is not only experienced by people living with HIV/AIDS but their family members, close friends, service providers and people that work with them also are stigmatized by association.

This report highlights the need for family life educators to expand HIV educational programs to include issues on stigmatization and discrimination. It identifies some of the reasons why people stigmatize, the ways which stigma and discrimination are expressed and the impacts it has on individuals and their family members. Using Bronfenbrenner's ecological model of human development, this report identifies the need to look at HIV-related stigma and discrimination as a societal problem rather than individual problem, and presents implications for education programs for the general public.

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Acknowledgements

I am grateful for the generous support and guidance provided by my major professor, Dr. Karen Myers-Bowman during the years 2005 to 2007, while I was a graduate student at the Kansas State University in Manhattan. Dr. Myers-Bowman has been an invaluable source of help to me and encouraged me to focus on my interest area through out my graduate work. I also thank my other committee members, Dr. Farrell Webb and Dr. Charlotte Shoup Olsen for their support and time. I am grateful to my husband Michael Asiedu, who inspired and encouraged me to attend graduate school.

Dedication

I dedicate this report to my late mother, Hanna Marku Teye, who inculcated into me the love and passion to give support to people and to my little Janelle whose giggles and smiles give me joy each day.

Introduction

Today the HIV/AIDS epidemic is one of the many crises families may face. Many people have died of the disease while others are still living with it. At the end of 2003, an estimated 1,039,000 to 1,185,000 persons in the United States were living with HIV/AIDS, with 24-27% undiagnosed and unaware of their HIV infection. The Centers for Disease Control (CDC) estimates that approximately 40,000 persons become infected with HIV each year (CDC, 2007).

Across the world HIV/AIDS has triggered responses of compassion, solidarity and support. Many communities and families are giving their best support to people living with HIV/AIDS (PLHA). However, HIV often is thought to be highly contagious and is associated with stigma, ostracism, and discrimination (Brimlow, Cook & Seaton 2003; Herek & Capitanio, 1999; Nzioka, 2000; Ogden & Nyblade, 2005). Based on this thought, people often suspect that individuals with HIV or AIDS pose a threat to the community at large. This misconception is not limited to the general population. Evidenced in all the literature reviewed for this report is the misconception that socially and personally, many people tend to associate AIDS with moral improprieties such as drug use, men having sex with men, promiscuity, etc. (Aggleton, 2000; Alonzo, Reynolds, 1995; Bharat & Aggleton, 1999; Belsey, 2005; Brimlow, Cook & Seaton, 2003; Breitkopf, 2004; Brooks, Etzel & Hinojos, 2005; Brown, Tujillo & Macintyre, 2001; Castro & Farmer, 2005; Daniel & Parker, 1993; De Bryun, 1998; De Palomo, 2006; DiClemente, Zorn, & Temoshok, 1987; Ferreira, 2004; Gilmore & Somerville, 1994; Heider, 1958; Herek, & Capitanio, 1999; Herek, Mitnick, et al, 1996; Hong, & Van Anh, 2004; International Center for Research on Women (ICRW), 2006; Kidd & Clay, 2003; Macklin, 1988; Maclean, 2004; Milan, 2006; Misra, 1999; Neuberg, Smith, & Asher, 2000; Nzioka, 2000; Ogden & Nyblade, 2005; Parker & Aggleton, 2002; Seaton, 2003; Schellenberg, Keil, & Bem, 1995; Shapiro, 2005; Smart, 2005; Susenblick, 1988; Triplet, & Sugarman, 1987; UNAIDS, 2003; Urwin, 1988).

HIV-related stigma and discrimination are problems in the U.S.A. and throughout the world. Stigma has been expressed in a variety of ways towards PLHA, including:

ostracism; rejection; name-calling; discrimination by their families, health care professionals, communities and governments; mandatory HIV testing of individuals without prior informed consent or confidentiality protections; quarantine of persons who are HIV infected; in some cases violence against people who are either perceived to have AIDS, infected with HIV or belong to "high risk groups" have been reported (Alonzo & Reynolds, 1995; Cogan & Herek, 1998; Daniel & Parker, 1993; De Bryun 1998; Herek & Capitanio, 1999; Gilmore & Somerville, 1994: Malcolm et al., 1998; Milan, 2005; Nzioka, 2000; Ogden & Nyblade, 2005; Parker & Aggleton, 2002; UNAIDS, 2000). For instance, one service provider I spoke with described a physician in Manhattan who does not work with children with HIV. Therefore they are referred to Salina for care (D. Hart, personal communication, February 26, 2006). Not only are people with HIV/AIDS stigmatized, but their families and caregivers and professionals working with them are also stigmatized.

Efforts by national and world leaders have been made to end discrimination and stigma towards individuals who are infected or affected with HIV/AIDS and their families. At the end of the Fifteenth International AIDS Conference in 2004, Sonia Gandhi and former South African President Nelson Mandela both urged political leaders to make stronger efforts to reduce the stigma that surrounds HIV/AIDS. They called for an increase in treatment and prevention measures to get ahead of the devastating epidemic which has already claimed over 20 million lives worldwide (Gandhi & Mandela, 2004). According to Gandhi, "I have seen people who have lost jobs and who have been ostracized, and the orphans not adopted because of stigma, and I have seen people fading away in front of their helpless families" (¶ 2). She asked leaders who have the power to act and think of those affected not as HIV/AIDS patients, but as men, women, children, brothers, and sisters. Similarly, at the end of his first mission to Viet Nam, the UNICEF/UNAIDS Goodwill Ambassador, Jackie Chan, called for an end to discrimination and stigma towards children and families infected with or affected by HIV/AIDS (Chan, 2006).

Despite all these efforts PLHA and their families are being stigmatized. One such person is Ryan White. Although Ryan White's story took place in the early 1980s, when there was little knowledge about HIV/AIDS and discrimination against people with AIDS

was widespread, I chose his story because it is relevant today. There are many families and individuals around the world who are being stigmatized and discriminated as result of HIV/AIDS.

This report describes the issue of HIV/AIDS related stigma, the reasons why people stigmatize, and some of the impacts on both the individual and the family as a whole. The literature also reviews some theoretical perspectives of HIV/AIDS specifically focusing on the disease as a societal problem. An educational program is suggested to help sensitize society in challenging HIV-related stigma and discrimination.

The Ryan White Story

Ryan Wayne White was born on December 6, 1971. Three years later, doctors told his parents that he had a severe hemophiliac condition, which meant that he would experience to uncontrollable bleeding. Fortunately, there was a new drug approved by the U.S. Food and Drug Administration called Factor VIII, which contained a blood clotting agent. Ryan received injections or intra-venous doses of this drug twice a week which clotted his blood and slowed down the bleeding.

Ryan had surgery on December 17, 1984 to remove two inches of his left lung. Two hours after the surgery, doctors told his mother that he had contracted HIV-AIDS through the Factor VIII and was given 6 months to live. He was determined to continue at his school, be with his friends and have a normal life. But in 1985, many people did not have adequate knowledge about HIV/AIDS and did not accept Ryan's situation. Although doctors said he was not contagious, Ryan faced a lot of discrimination from friends and others around him. The school he was attending discriminated against him because they had no guidelines for a person with AIDS and the town they were living in (Kokomo, Indiana) was not supportive of him. Rumors that AIDS could be spread by sneezing, kissing, tears, sweat, and saliva were common in Kokomo. This led to panic as the town folks thought they would contract AIDS from Ryan.

After nine months of legal contestation, the school determined that he would have separate restrooms, no physical education, a separate drinking fountain and disposable silverware from the cafeteria. However, these accommodations did not stop the prejudice.

Ryan was labeled the AIDS boy. He was called fag and his mother an "unfit mother". At church people would not even shake his hand. Around that time Ryan received a lot of media attention and support from public figures like Mayor Koch of New York and Elton John, but he had very few friends at school or in his hometown.

In 1986, Ryan and his family moved to Cicero, Indiana where they were welcomed and received a lot of support. Most people there were aware about the condition that he had and were open-minded. Ryan was happy again. He had his driver's permit, he had friends, his family, and he had turned an incurable disease into a way to educate America. A movie was made about him, titled "The Ryan White Story," and was aired on ABC. Ryan was a normal teenager and felt comfortable in his new community. According to him, it was because "the students at Hamilton Heights High School listened to the facts, educated their parents and themselves" (Ryan's story, ret. March 1 06). Ryan White was making a difference, battling against AIDS and the discrimination surrounding it, but he died on Palm Sunday, April 8, 1990.

Ryan's legacy lives on in many ways. In 1990 Federal Ryan White Program was enacted in Ryan's name (The Ryan White Comprehensive AIDS Resources Emergency Care Act), because of his bravery and courage and the impact he had on other people living with AIDS. The act was amended and reauthorized in 1996 and again in 2000. The Care Act funds services for over 500,000 people with HIV/AIDS each year and addresses the unmet health needs of persons living with HIV. An annual Ryan White Youth Conference is organized to bring together young people working on HIV/AIDS in communities across the U.S. Ryan's mom, Jeanne White-Ginder, continues to speak with audiences across the country carrying Ryan's message of love, compassion and hope.

The implications of stigmatization and discrimination associated with AIDS, as well as its impact on families and individuals, are worth considering. Individuals and families affected directly or indirectly by AIDS go through many situations and need support from everyone around them. With the help of his family, Ryan White was able to fight for his rights, but there are many people affected by AIDS who do not get the support they need from families and close relations and are not able to fight for their rights when they need to. There are still locations and other institutions, which, stigmatize against people with HIV/AIDS.

My goals in looking at HIV and the AIDS problem are to educate and sensitize society about becoming more empathetic towards persons with AIDS. I also hope that this would lead to more responsiveness to the needs of infected individuals; supporting individuals and other affected family members emotionally, economically and however possible. Furthermore my interest is to present an educational programs that will impact or influence society's perception about AIDS, change their attitude towards individuals with AIDS, help individuals and families deal with their situation in a loving way, and look for appropriate ways of supporting affected people emotionally and physically. After all, people with HIV and AIDS are living longer, healthier lives today, thanks to new and effective medications

Literature Review

The amount of literature available on HIV/AIDS- related stigma is substantial in topic area such as the evolution of HIV/AIDS stigma, policy-related and legal initiatives. However, much less material is available on programmatic solutions for HIV/AIDS stigma. This is disheartening given providers' need for examples of practical, real-life solutions to decrease HIV/AIDS-related stigma. The existence of HIV/AIDS-related stigma has been widely documented. In national survey data to assess the extent to which AIDS-related stigma remains linked to public attitudes toward homosexuality in the United States, the proportion of the U.S. population that harbored HIV/AIDS-related stigma increased from 20.5 percent in 1991 to about 28.8 percent in 1997 (Herek & Capitanio, 1999). This increase can be attributed to the few programs on HIV related stigma and discrimination.

What is HIV-related Stigma?

Stigma has been defined in many ways and has been expressed as a complex social process resulting from the interactions between social and economic factors in the environment that create unfavorable attitudes, beliefs and policies directed toward people perceived to have HIV/AIDS as well as toward their families, close associates, social groups and communities (Brimlow, Cook & Seaton 2003; Ogden & Nyblade, 2005). Goffman (1963) defined stigma as an "attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one." (p. 3). Goffman described three types of stigma that individuals face: stigmas related to various physical deformities, flaws in individual character such as weak-ill or dishonesty and stigma associated with a social group, race, or religion. Diseases associated with stigma share common attributes: often the person with the disease is seen as responsible for having the illness, the disease is both progressive and incurable, the disease is not well understood by the public, and the symptoms cannot be concealed (Goffman, 1963; Herek & Capitanio, 1999; Seaton, 2003).

Since Goffman proposed his definitions other variations in the definition of stigma have been created by different scholars as it has been applied to different

circumstances and has been studied from different fields and perspectives. For example, Parker and Aggleton (2003) created a framework that emphasizes stigma as a social process that produces and reproduces relations of power and control. They examined how stigma is used to turn differences into inequity based on gender, age, sexual orientation, class, and race or ethnicity making it possible for some people to devalue others based on these differences. For instance, in settings where heterosexual transmission of HIV/AIDS is significant, the spread of HIV is associated with female improper sexual behaviors such as prostitution and promiscuity. Similarly, men are blamed for heterosexual transmission because of perceptions about males having multiple partners. This perception creates "us" and "them" differences reinforcing the feeling that HIV belongs to "them"- because of their immoral behaviors and not to "us". Consequently, there is the tendency of "us" (often the dominant) exercising power and social control over "them" through stigmatization and hence limiting the abilities of the stigmatized groups to fight the stigma.

Diseases that often generate stigmatizing conditions are those that are incurable and potentially fatal, unalterably degenerative and that lead to physical disfigurement (Alonzo & Reynolds, 1995; Cogan & Herek, 1998; de Bryun, 1998; Gilmore & Somerville, 1994; Ogden & Nyblade, 2005). The more rapid the spread of the disease and the greater the uncertainty of how the disease is transmitted, the more likely that stigma will result. Epidemics that present an open threat to the community are especially likely to evoke stigma because stigma is used to "enhance or secure social structuring, safety and solidarity…or reinforce societal or community values by excluding divergent or deviant (individuals)" (Gilmore & Somerville, 1994, p. 1342).

HIV and AIDS have all of the characteristics associated with the stigmatizing conditions discussed above. Even though HIV/AIDS is treatable, it is incurable, degenerative, and often disfiguring. It is associated with death and can be contracted through socially improper forms of sex and injection drug use. Therefore people infected with HIV are often blamed for their condition (Herek & Capitanio, 1999; Nzioka, 2000). HIV and AIDS also correspond to all three of Goffman's stigma types: contracting of the disease is associated with flaws in individual characters such as homosexuality, prostitution and drug use, and depending on the stage of the disease PLHA may face

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physical deformities such as growing lean, and having rashes all over body. These perceptions of PLHA and the nature of HIV/AIDS itself have a role to play in the reasons why people stigmatize or are stigmatized.

Reasons People Stigmatize

There are many reasons why people stigmatize and no matter the causes of stigma, they are always associated with the conditions and nature of the disease and behaviors that are considered immoral that can be controlled. According to Ogden and Nyblade,

> *This stigma is exacerbated by the seriousness of the illness, its mysterious nature, and its association with behaviors that are either illegal or socially sensitive (e.g., sex, prostitution, and drug use). Also relevant is the perception that HIV infection is the product of personal choice: that one chooses to engage in "bad" behaviors that put one at risk and so it is "one's own fault" if HIV infection ensues.*
> (Ogden & Nyblade, 2005, p. 20)

HIV is a Life-threatening Disease

People with HIV/AIDS are stigmatized because of the nature of the disease (being life-threatening, progressive and incurable). People diagnosed with HIV/AIDS are susceptible to opportunistic infections, which are caused by microbes that usually do not cause illness in people with healthy immune systems (Sowadsky, 1999). These opportunistic infections spread rapidly and can result in physical deformities which in turn creates stigma (Gilmore & Somerville, 1994; Goffman, 1963; Ogden & Nyblade, 2005; Sowadsky, 1999). Depending on the stage of the disease, some PLHA may lose weigh, have rashes, or may have serious illness like blindness, but these symptoms does not mean that one is HIV positive.

Moral Judgment

Because HIV/AIDS is associated with behaviors that come with negative responses in society (homosexuality, injection drug use and promiscuity) (Aggleton, 2000; De Bryun, 1999; Macklin, 1988; Marshall, O'Keefe & Fisher, 1990; Milan, 2005; Ogden & Nyblade, 2005; Smart, 2005; Urwin, 1988), many people believe that PLHA are responsible for their predicament and that the disease is a punishment for their bad

moral behavior. These metaphors are stereotypes and constitute a series of cliché but are inaccurate explanations for the basis of both stigmatizing and discriminating. These stereotypes also enable some people to deny that they personally are likely to be infected or affected.

Fear of Contagion Due to Insufficient Knowledge

Stigmatization and discrimination associated with HIV/AIDS do not occur naturally. Instead, they are created by individuals and communities who, for the most part, generate the stigma as a result of their own fears of contracting the disease, which may be partly based on ignorance of how the disease is transmitted (Aggleton, 2001; Brimlow, Cook & Seaton, 2003; DiClemente,Zorn, & Temoshok, 1987; Herek & Capitanio, 1993; Mahendra et. al 2006; Ogden & Nyblade, 2005; Shapiro, 2005; Smart, 2005; Tripet & Sugarman, 1987; Witt, 1989).

Sufficient knowledge and education about HIV transmission has been shown to reduce HIV-related stigma and discrimination: those who have much knowledge about AIDS have less fear, and are more willing to associate with persons infected with HIV (Brown, Trujillo & MacIntyre, 2001; DiClemente, Zorn, & Temoshok, 1987; Krupta & Vener, 1988; MMWR weekly, 2000; Shapiro, 2005; Susenblick, 1988). For example, Brown et al. (2001) surveyed 320 Jamaican youth to improve attitudes towards PLHA by encouraging acceptance and compassion. Their intervention included peer education and workshops, street interviews, conversations with PLHA, and concerts. The effect was measured by the participants' willingness to sit next to, eat with, and visit PLHA. Results showed a significant increase in positive attitudes toward PLHA and a reduction in the number of participants who sought isolation from PLHA.

Similar studies were done by the Research Triangle Institute (2000 MMWR weekly) and Shapiro (2005). The Research Triangle Institute (RTI) surveyed 7,493 adults through the internet to measure indicators of HIV-related stigma and knowledge of HIV transmission. Surveys were conducted weekly using a standard television set connected to the Internet, and responses were entered using a remote control. Respondents who were misinformed about HIV transmission gave stigmatizing responses, suggesting that increasing understanding about behaviors related to HIV transmission may result in lower

levels of stigmazing beliefs about PLHA. In Shapiro's study 603 Nevadans were sampled to find out if disease knowledge can influence participants' efforts to socially and physically distance themselves from a supposed HIV-positive individual. The findings show that 84.2% of the participants had sufficient knowledge of HIV transmission and were more comfortable with casual interactions than those with insufficient knowledge. Results of these two studies confirm the significance of HIV-knowledge as a method to combat HIV-related stigma.

Irrespective of how one contracted HIV/AIDS, he or she experiences stigma as a result of at least one of the reasons discussed. In spite of the reasons why people stigmatize, every person who is stigmatized experiences some degree of stigma depending on how one contracted the disease.

Degree of Stigma

The degree and intensity of stigmatization against PLHA depends on a number of factors relating to how one contracted the disease. Ogden and Nyblade (2005) created a model called the "schematic of innocence- to- guilt continuum" which explains that there is a kind of continuum from presumed "guilt" to presumed" innocence" in people's minds. Therefore, all people with HIV experience some degree of stigmatization. Where one falls along this continuum will determine, to a significant extent, the type and degree of stigmatization received from one's family and the wider community (Brimlow, Cook & Seaton, 2003; Macklin, 1988; Ogden & Nyblade, 2005; Phelan, 2001; Smart, 2005; UNAIDS, 2000; Urwin, 1988). The model suggests that people who were infected through drug use or sexual relations with same-sex partners are likely to experience more stigma than those infected through blood transfusions. The model is illustrated on next page.

Figure 1. Schematic of innocence- to- guilt continuum (Ogden & Nyblade, 2005).
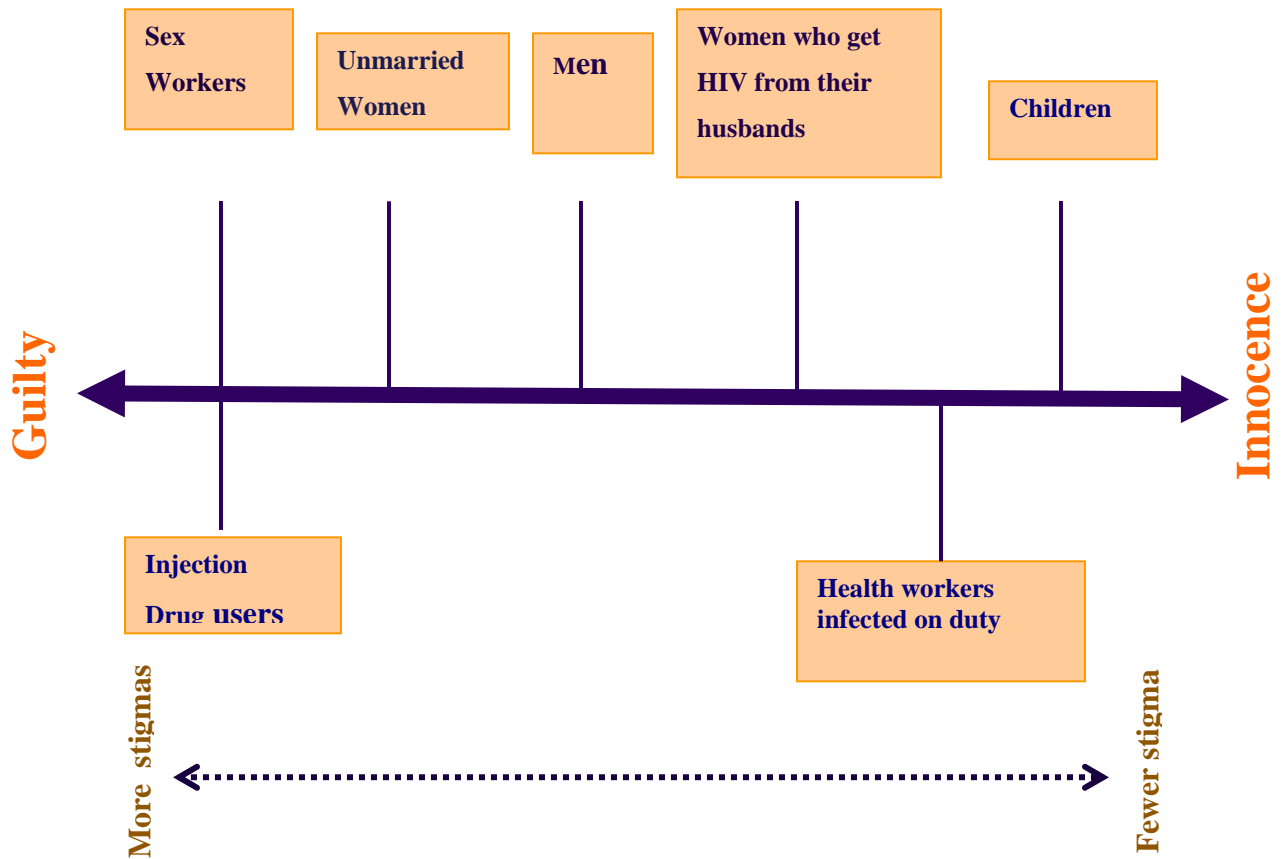
The continuum indicates the ways in which HIV and AIDS-related stigma interacts with pre-existing stigmas; in addition to creating stigma where none previously existed, HIV/AIDS can create double stigma—the pre-existing stigma associated with an unapproved behavior (such as injection drug use or "immoral" sex) in combination with the stigma of living with HIV. In the four countries where Ogden and Nyblade's study was carried out (Ethiopia, Tanzania, Vietnam, and Zambia), injection drug use and prostitution are widely regarded as social evils. This association was entrenched in the minds of the public as well as in legislation and policy. Because HIV often is associated with these pre-existing stigmatized groups, HIV itself has started to be referred to as a

social evil. This linkage between HIV, drug use/sex work, and social evils therefore not only affects those who engage in these behaviors, but all people living with HIV, serving to magnify HIV and AIDS-related stigma and the misery it creates. Consequently, people who contract HIV/AIDS through such acts receive a high degree of stigma. Within the above model, sex workers (people who earn money by providing sexual services), men, unmarried women and drug users are people who fall within the "presumed guilt" category and are more likely to receive higher degree of stigmatization than children, women who got it from their husbands and health workers infected on duty.

In conclusion, the main causes of stigma relate to insufficient knowledge, the nature and condition of HIV/AIDS, sexual norms and a lack of recognition of stigma. Fear of contagion due to lack of insufficient knowledge combines with fears of death to perpetuate beliefs in casual transmission and, thereby, creating stigma. The knowledge that HIV can be transmitted sexually combines with an association of HIV with socially improper sex behaviors and enables PLHA to be stigmatized for their perceived immoral behavior. How much PLHA are stigmatized depends on a number of issues relating to how they contracted the disease. Children, health workers and married women (who contracted from their husbands) are more likely to receive compassion and are less stigmatized than men, unmarried women, sexual workers and injection drug users who are often blamed for their contraction. The degree or intensity of stigma may vary depending on how one got the disease; similarly, HIV-stigma comes in many forms and expressions across contexts.

Expressions and Forms

HIV-related stigma is expressed through discrimination. It is clear that specific expressions of stigma and discrimination vary within settings but the most frequently experienced forms are similar across contexts and fall into four main categories: physical, social, verbal and institutional (Ogden & Nyblade, 2005).

Physical Stigma

People with HIV/AIDS face physical stigma from family, friends and community. The forms of physical stigma are grouped into isolation and violence (Deacon, Falvo, &

Myers-Walls, n.d; Fife & Wright, 2000; ICRW, 2003; Macklin, 1988; Marshall, 1990; Ogden & Nyblade, 2005). Physical isolation and violence of PLHA occur everywhere, from the home to community gatherings, public places to within workplaces, schools and hospitals. Common expressions within the home include separating household items such as cooking and eating utensils, clothes, bed linens and making PLHA sleep in separate quarters. In public places expressions of stigma include not sitting near PLHA in public transport, in places of worship, while waiting in a queues and not greeting PLHA (Belsey, 2005; Deacon & Myers-Walls, n.d; Fife & Wright, 2000; ICRW, 2003; Macklin, 1988; Marshall, 1990; Ogden & Nyblade, 2005). Some actions may be very subtle, but are clearly recognizable to all as being out of the ordinary. For example, Daljit, a 25-year-old factory worker, expressed how he was stigmatized at his workplace;

> *My colleagues didn't openly say anything to me, but the environment was no longer the same. They avoided me. If I entered the room they would leave abruptly. Then they asked me to keep a separate glass for water. I decided to quit the job.* (Aggleton, 2000, p. 26)

In similar stories reported by Ogden and Nyblade (2005), a man living with HIV and the mother of a person living with HIV, both in Vietnam described their situations:

> *I asked, 'Please give me a cup of sugar cane drink' and the vendor said: 'If you drink in the cup, other persons will see you drink from that cup and they won't dare to use it. So take the drink in a (plastic) bag'.* (Man living with AIDS, p. 27)

> *When we watched TV with them they put mosquito-killing incense beside them. Do you see? Nothing happened when others were sitting there but when we came they took the incense and put it beside them. This made us feel ashamed.* (Mother of PLHA, P.27)

Physical violence against PLHA, though occurring less frequently than other kinds of violence, also has been expressed as a form of stigma that has a deep impact and generates much fear (Brimlow, Cook & Seaton, 2003; Ogden & Nyblade, 2005; Piot, 1999; WHO, 2001). Just as women are more vulnerable to interpersonal violence than men, it is reported that they are also more vulnerable to physical violence following disclosure of their HIV status than men (WHO, 2001). Many women whose HIV/AIDS status is disclosed suffer direct violence at the hands of their husbands, family members and community. For example, in Ogden and Nyblade's study, a woman living with HIV

in Tanzania explained that she "felt very bad to inform my partner" because "he might commit suicide or kill me" (p. 28). Similarly, a South African woman, Gugu Dlamini, a volunteer fieldworker for the National Association of People living with HIV/AIDS, was stoned and stabbed to death by neighbors soon after she disclosed that she was HIV positive on radio as part of South Africa's commemoration of World AIDS Day (Piot, 1999, p.1).

Physical isolation and violence are painful and hurtful to PLHA, because it is something that they experience physically. They see people isolating themselves from them and distancing themselves from them. This distancing creates a gap between PLHA and their friends and society and they are not given the respect and authority due them.

Social Stigma

Isolation, loss of identity, role and respect are the major manifestations of social stigma that PLHA experience (Belsey, 2005; Deacon & Myers-Walls, n.d; Fife & Wright, 2000; ICRW, 2006; Macklin, 1988; Marshall, 1990; Ogden & Nyblade, 2005).

Isolation includes loss of social networks, decreased visits from neighbors (for fear of contagion), reduction of daily interactions with family and community and exclusion from family and community events (Belsey, 2005; ICRW, 2006; Ogden & Nyblade, 2005). PLHA often find that they are no longer welcome at important family and community events, such as parties and weddings. In the realm of daily life, they often find that they no longer have friends and that neighbors, friends and relatives are reluctant to visit or be close to them. In a recent discussions on STDs on Yahoo Answers a topic area, "Your Views about social stigma of HIV/AIDS infected persons" was posed and one of the participants who is HIV positive (identified as "gosm3r") said;

> *"I have lost friends, because they didn't want to become too attached to me, thinking that they might at some point have to watch me get sick, and/or be obligated to attend my funeral. I've been denied credit, because an HIV-positive is considered a high credit risk. An ex-girlfriend of mine panicked when I told her, and told me never to call her or write her again, and said that she was going to get tested immediately, even though we hadn't had sex for four years before I seroconverted".* (Yahoo Answers, 2006)

In Ogden and Nyblade's study (2005), a woman in Vietnam explained that she terminated all contact with a childhood friend because "people told me I should stop spending time with her. They said things like, 'I know you have been close with her from childhood, but now she goes on that track (sex work) so don't play with her" (p. 28).

Similarly, PLHA lose power, respect and identity through the taking away or diminishing, of their roles, responsibilities and social standing within the family and larger community. (Belsey, 2005; Deacon & Myers-Walls, n.d; Fife & Wright, 2000; ICRW, 2006; Link & Phelan, 2001; Macklin, 1988; Marshall, 1990; Ogden & Nyblade, 2005). This expression of stigma is probably due to the perceptions people have about HIV as contracted through inappropriate behaviors or behaviors that are not acceptable by society. Therefore anyone who has HIV is seen as immoral and irresponsible and not fit to be respected or given authority in society. In addition to this is the belief that HIV means immediate disability and death because of the nature of the disease, so PLHA can no longer be productive members of the society. In fact, they are seen as a burden and "liability" to society. Most African countries for example have expressions in indigenous language to identify PLHA which literally translates "the living dead". These expressions are demeaning and throw light on how people perceive HIV/AIDS.

In Aggleton's (2000) study in India, he identified some of the ways in which the identities of PLHA are marked. He found that some of the hospitals he studied made the identity of the patient plain and public. In an interview a ward boy, said, "When the patient comes to our ward, it's written on the file 'HIV' in big letters. Anybody can see it. It's kept next to the patient. Anybody can see it" (p. 24). In the same study some hospitals were found to use tubs to identify PLHA in the hospitals. One of the staff members reported keeping tubs of disinfectant under the beds of HIV-positive patients in which eating vessels, clothes and linens were soaked prior to being washed separately. According to one of the caregivers, "The tub is the symbol for the staff. We don't use any board, etc., to declare AIDS but the tub lets us understand" (p. 24). Other ways of identifying who is HIV-positive and who is not include shouting to ward boys in the hospital, "take this HIV-positive patient for X-ray" (p. 24).

Social isolation, loss or respect, role and authority, are a few of the expressions of social stigma, but there may be many more that are expressed subtly. Social stigma has a

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tendency to create feelings of loneliness in PLHA. They may not have a sense of belongingness in their families and societies and may have no option other than to rely on themselves for support. Stigma becomes even more painful to PLHA when they are labeled, insulted, taunted and blamed for their diagnosis.

Verbal Stigma

A third form of stigma is verbal. This can be direct (pointing fingers, insulting, taunting, or blaming, labeling and name calling) or indirect (gossip and rumors) (ICRW, 2006; Link & Phelan, 2001; UNAIDS, 2001; Ogden & Nyblade, 2005; Smart, 2005). Direct forms of verbal stigma are mostly expressed through insulting, cursing, threats and labeling and the use of derogatory and judgmental words. In Vietnam for example "they are social evils", "scum of society", "deserves to die" are a few of the expressions used to describe PLHA (Ogden & Nyblade, 2005, p. 26) who are most often blamed for bringing shame to themselves as well as their family. In some circumstances the whole family is labeled, for instance in Ryan White's story he was labeled a "fag" and his mother an "unfit mother" (White, 2006). In Ghana expressions like "tease a wuo" and "gbele wu" which literally translates "living dead" and "death skeleton" respectively, are among some of the labels used to describe PLHA. These expressions are a result of the physical appearance of PLHA (especially those in the advanced stage) and can be related to society's beliefs and perceptions about people who contract AIDS as well as the nature of HIV/AIDS itself.

Indirect forms of verbal stigma such as gossip and rumors are mostly focused on speculation about whether a person has HIV (usually because of visible signs of weight loss, illness) and how he or she contracted it (Ogden & Nyblade, 2005). For instance in Aggleton's study (2000), an interviewee stated that,

> *It is not good to reveal one's serostatus because once one's friends know, they start spreading rumours which may even reach schools where one's children study, and obviously such children get affected.* (p. 30)

In sum, language is central to verbal stigma. Verbal stigma is expressed to the face of PLHA or may be expressed in the absence of the person. The labeling and name

calling and all the verbal expressions used to describe PLHA may be attributed to people's perception of HIV/AIDS, the nature and conditions of the disease and its association with moral improprieties. Verbal stigma may be commonly expressed by family members, friends and the community within which the PLHA lives, but there are many conventional establishments which express stigma by their policies, regulations and procedures.

Institutionalized Stigma

Institutionalized stigma occurs when an institution, such as a school, hospital, church, organizations or employers, practice stigma either actively or passively. In many societies and institutions, laws, rules, policies and procedures may result in the stigmatization of people living with HIV/AIDS. A significant number of countries have enacted legislation to control the actions of HIV/AIDS-affected individuals and groups (Aggleton, 2000; Health and Developmental Networks, 2006; Milan, 2006; Seaton, 2003; Tomasevski et al., 1992). These laws include legislation for: the compulsory screening and testing of groups and individuals; the prohibition of people living with HIV/AIDS from certain occupations and types of employment; the medical examination, isolation, detention and compulsory treatment of infected persons; limitations on international travel and migration; the restriction of certain behaviors such as injecting drug use and prostitution (Aggleton, 2000; Gostin & Lazzarini, 1997). For example, a churches that make HIV testing a precondition for consummating marriage, a health care facilities that have specific areas designated for HIV positive patients for preferred service provision and the general public is aware of it, employers who require HIV test to qualify for a job, a countries that require HIV test before admitting immigrants and health insurance companies that do not enroll PLHA are some of the policies that do not favor PLHA. For example, under the U.S. citizenship and immigration laws, refugees or immigrants who are HIV positive are not admissible into the US under section 212(a) (1) (A) (i) unless they file a waiver to show that their admission may not be a danger to the public health and the possibility of the spread of the disease is minimal (Kemp, 2004). These forms of stigma lead to reduced life chances for PLHA and often visibly label them as having HIV which in turn expose them to all other forms of stigma.

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It also should be noted that the absence of positive approaches to HIV/AIDS in institutions as schools, churches and workplaces promotes stigma. Absence of policy prohibiting HIV/AIDS related discrimination can send the wrong message that HIV/AIDS stigma is alright and acceptable in the institutions. Employee education and wellness programs that do not discuss HIV/AIDS implicitly suggest knowing about HIV/AIDS is bad. By not addressing or supporting educational programs and healthcare initiatives concerning HIV/AIDS, institutions allow stigma to flourish.

In summary, the expressions and forms of stigma may be categorized into physical, social, verbal and institutional, but there are numerous specific expressions that may vary within contexts. In any case, the expressions and impacts of stigma may be experienced by PLHA as well as people closely associated with PLHA.

Consequences and Impacts of HIV/-Related Stigma and Discrimination

PLHA suffer emotionally, physically, economically and socially: they lose their jobs/livelihood, access to service, status and sense of self and therefore stigmatization and discrimination become an additional stress (Deacon & Myers-Walls, n.d; Ogden & Nyblade, 2005; Smart, 2005). It also impacts the lives of family members involved, leads to loss of employment, includes difficulty accessing services, and may lead to internalized stigma as well as secondary stigma.

Family Disruption

Stigmatization has been identified as one of the major factors of family disruption with regards to HIV/AIDS (Deacon, Falvo & Myers-Walls, n.d). Even though most PLHA receive loving treatment from their families, there are occasions when family members and close friends stigmatize them and refuse to provide care "out of fear of transmission, out of anger, judgment and moral condemnation, fear of experiencing the stigma of others, or a combination of these factors" (Ogden & Nyblade, 2005 p. 31). This may create disruption and resentment, especially in resource-constrained settings where people with HIV/AIDS frequently have to turn to their families for care (Aggleton, 2000;

Castro & Farmer, 2001; Ogden & Nyblade, 2005; Warwick 1999; Warwick et al. 1998; Wiener, Heilman, & Battles, 1998; World Bank, 1997).

Another disruption that occurs within the family is that when PLHA are stigmatized within the home: they are obliged to live differently, to prevent transmission of the virus as well as infecting others. For instance, in Ogden & Nyblade's (2005) study a woman in Tanzania who was attesting to some of the consequences of HIV said, "when they found out he was HIV-positive, they started giving him his own spoon, water container, plate, cup, and everything by himself" (p. 27). These actions are unusual and are considered a disorder, especially in settings like Africa where eating together is a norm and where the families are closely knit (Ogden & Nyblade, 2005).

Loss of marriage and childbearing are other consequences of HIV/AID-related stigma within the family. In some cases spouses are deserted upon disclosure of their HIV status because often the first person to become tested in the relationship is considered as the one who brought the disease into the family (Health and Development Networks, 2006; Ogden & Nyblade, 2005). In a recent study done by the Health and Development Network (HDN) in Swapna Majumdar, India, it was found out that stigma and discrimination of PLHA starts at home especially for Indian women. When one woman, Urmila, tested positive for HIV in her fifth month of pregnancy, she thought her in-laws would give their full support as even her husband was diagnosed as HIV positive. However, after a few months when her husband died, her in-laws ostracized her. They also tricked her into signing away her and her son's rights to her husband's share of the property. Furthermore, PLHA may find that marriage and childbearing are no longer an option to them because the family of the PLHA discourage it and in some cases family members take sanctions against PLHA if they bear children (Mbwambo, Kilonzo et al., 2004, in Ogden & Nyblade, 2005).

HIV-related stigma interrupts the "flow" of the family and norm of the family is disrupted. Family members may refuse to care for other family members who are HIV-positive or may not eat with them. Marriages may be terminated and child bearing are frowned upon. In fact other family members of PLHA see HIV/AIDS as loss of reputation for the family. PLHA may also affect the family's income if they are not working.

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Loss of Employment and Livelihood

A profound consequence of HIV-related stigma and discrimination is its impact on the PLHA's ability to earn a living due to such practices as pre-employment screening, denial of employment to PLHA and dismissal of PLHA upon disclosure of their HIV status (Dickens, 1988; Gostin & Lazzarini, 1997; ICRW, 2006; Milan, 2006; Urwin, 2008). In some societies PLHA in formal employment who are open about their HIV statuses sometimes find themselves being dismissed while those who are self employed may find their client base declining (ICRW, 2006; Parker & Aggleton, 2002). In Urwin's (1988) study, for instance, 'James' was given a permanent leave of absence when his employer learned of his AIDS diagnosis and he had to find a new job. He also lost his group insurance and had to purchase personal insurance, which carried high costs.

Although it is illegal, there are situations where PLHA have been discriminated against and dismissed from work due to coworkers' acts of discomfort and preference. (Dickens, 1988). For example, in Lane's (2002) study done between 1997 and 1999 it was realized that one quarter of the adult population surveyed, would be uncomfortable working in the same office with an infected individual. Although such a circumstance may not be sufficient to justify an infected person's dismissal, courts may occasionally be sympathetic towards the employer's hardship and co-worker's preference and dismiss the infected person (Dickens, 1988).

Loss of employment due to discrimination may leave PLHA with no option other than relying on family members for assistance or to depend on public assistance which is little to nothing at all, considering the cost of treatment and medication for HIV/AIDS. This requires them to interact with various agencies, which may also discriminate against them.

Loss of Access to Service

Accessibility to service such as health care, education, housing and insurance has been one of the many areas of discrimination towards people with HIV (Brimlow, Cook & Seaton, 2003; Dickens, 1988; Ferreira, 2004; ICRW, 2006; NAT, 2003; Schuster et al., 2005; Urwin, 1988; Watson & Corigan, n.d). PLHA may be denied access to health care, housing education, care from family members, health insurance etc.

Although health care facilities provide care for PLHA they sometimes stigmatize against them. Studies reveal the reality of withheld treatment, nonattendance of health care professionals and support staff to patients, denial of hospital facilities and medicines and sometimes being insensitive to concerns from PLHA (Aggleton, 2000; Avert, 2005; Herek, Mitnick et al, 1996; ICRW, 2006; NAT, 2003). For instance, a service provider described a physician in Manhattan, Kansas, who does not work with children with HIV because he is not "comfortable" attending to children with HIV/AIDS. Instead they are referred to Salina for care (D. Hart, personal communication, February 26, 2006). In a survey conducted in 2002, among some 1,000 physicians, nurses and midwives in four Nigerian states, the findings revealed that one in 10 doctors and nurses admitted having refused to care for an HIV/AIDS patient or had denied them admission to a hospital (Avert, 2005). Almost 20% felt that people living with HIV/AIDS had behaved immorally and deserved their fate. In a similar instance, a person living with HIV in Ethiopia recounted the following experience, "I went to a dentist… and told him I am HIV-positive. When he heard this he told me that he cannot help me and asked me to leave his clinic" (Ogden & Nyblade, 2005 p. 31).

Contributing to such responses from professionals are ignorance, lack of knowledge and fear about HIV/AIDS (Aggleton, 2000; Herek & Capitanio, 1993; ICRW, 2006) and probably perceived incurability of HIV/AIDS, which makes it pointless to offer good quality care. A retired senior doctor from a public hospital, working in a private hospital in India for example, recounted that,

> *There is an almost hysterical kind of fear…at all levels, starting from the humblest, the sweeper or the ward boy, up to the heads of departments, which makes them pathologically scared of having to deal with an HIV-positive patient. Wherever they have an HIV patient, the responses are shameful.* (Avert, 2005)

Schuster et al. (2005) surveyed a sample of 2,466 HIV-infected adults receiving health care in the U.S to determine whether HIV infected people perceive that physicians and other healthcare providers discriminate against them. The study found that 26% of HIV-infected adults reported experiencing some kind of perceived discrimination including 8% who were completely refused treatment.

Apart from health care facilities, the bulk of care for PLHA is given by family members and close friends. However, HIV-related stigma can result in the refusal of

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family members to provide care, especially during the most critical and advanced stages of the disease where the PLHA cannot do anything by themselves. The refusal of care may be out of anger, moral condemnation, fear of being stigmatized and the nature of the disease (Aggleton, 2000; ICRW, 2006; Ogden & Nyblade, 2005) and sometimes the burn-out care-givers experience during the advanced stages of the disease where care burden becomes increasingly demanding. The following quotes from Ogden and Nyblade's study illustrates this:

> *She was seriously ill and asked her brother to take her to hospital. He refused by telling her that she was hopeless. He told her not to bother people and he does not want to waste money on her.* (Woman in Ethiopia, p. 31)

> *Many families, although they love the child, still keep away, they are so afraid. They hire (others living with HIV) to provide care for him at the last stage, but they do not dare to provide care directly themselves.* (Woman in Vietnam, p. 31)

> *Household members... say it is a burden and... some are killing their own children very fast. They leave them to die slowly, painfully...they stop buying medicine.* (Caregiver in Zambia, p. 31)

Interlaced with anger, fear, moral judgment and burnout, is the impact of resource constraints which limits the amount of care a provider or family can give a person with HIV. Thus if a person with HIV is unemployed, it impacts their affordability of care and treatment services. Their family members may not be able to pay for those services for them because they may already have limited resources.

PLHA and those affected by HIV/AIDS, especially children, experience great difficulty accessing education services because they are stigmatized and discriminated in educational settings in many countries (Aggleton, 2000; Ferreira, 2004; NAT, 2003). Stigma has led to teasing, taunting and unfounded rumoring by classmates of HIV-positive school children or children associated with HIV which makes it difficult for them to go to school. For instance in Ryan White's story, his school, the local superintendent, teachers and parents refused to allow him to attend school. Ryan and his family fought the decision, but he was forced to "attend" school by telephone for months while his case made its way through an administrative appeals process. In many African countries where there is lack of free primary education, it also means that school fees,

school uniforms, books, transport, etc are often unaffordable to the majority of households (Ferreira, 2004).

Discrimination also occurs in private and public accommodations for people who are HIV positive or assumed to be positive, or those who have been mistakenly associated with the HIV- for example gay men (NAT, 2003). Examples of discrimination include eviction, locking out or harassing a tenant, and refusal to rent a property. For example, a man who had been renting a room for about a year in the house of an elderly couple was evicted after they became aware of his HIV status (NAT, 2003).

The eligibility criteria for public and private insurance coverage and benefits are often discriminatory. Some insurance companies require an HIV test before providing insurance, or refuse to provide health and life insurance to gay men, regardless of their HIV status (because they are regarded as "high risk"). In some cases where PLHA have coverage, an insurance policy may be voided after infected person's disclosure of his or her diagnosis (NAT, 2003). In countries, like developing or third world countries where health insurance is not privatized, the burden rests on the government to provide health care for infected persons, resulting in poor health care (Sabatier, 1987). PLHA are not only denied access to care and service but their position in the family and the community is affected.

Loss of Social Status

The consequences of labeling of PLHA, perceptions about them and other immoral characteristics associated with HIV/AIDS, is a general downward placement of PLHA because those undesirable characteristics associated with HIV reduces the social standing of PLHA in the eyes of families and society (Link & Phelan, 2001; Ogden & Nyblade, 2005). When PLHA lose social status, they lose power, respect and are considered inferior and a danger to society. This expression of stigma is because PLHA are often assumed to have breached some social norms of appropriate behavior which are considered "social evil" (injection drug use, sex work, homosexuality, etc) (Aggleton, 2000; Ogden & Nyblade, 2005). Violation of such social norms are considered immoral and irresponsible on the part of the violator who in most cases is not allowed to participate in decision making or hold positions in the society (Ogden & Nyblade). Loss

of social status results in all the expressions and forms of stigma discussed in previous sections; PLHA are isolated from the community, both physically and socially; they are labeled, taunted, and are discriminated against in workplaces, health settings and even at home.

Lack of confidentiality in health settings is one instance that signifies PLHA's loss of status in society. Many health professionals break the confidentiality of HIV-positive diagnosis and inform family members and relatives even before informing the patient him/herself (Aggleton. 2000; Mahendra et al, 2006). A couple interviewed in Bangalore in Aggleton's study revealed the following:

> Husband: *"The doctor didn't inform me. He informed my wife and asked her to inform me."*
> Wife: *"I took my husband to the lab and got his blood tested. After two days they called me and informed me that my husband's blood test result was positive. My husband informed them he had illegal relationships with a woman three years back. The doctor told me the news"* (p.25).

In many places HIV/AIDS places a person in a position where he or she has nothing to offer and nothing to gain: PLHA are not allowed to participate in community activities, they are marginalized and not regarded in the society, and they are given no position or authority in their community. As a result of this, they begin to internalize the negative attitudes of others.

Internalized/Self Stigma

It should only be expected that people with HIV and AIDS would also start to stigmatize themselves, since they usually share the same basic belief systems as the rest of the community and are constantly subjected to the hurtful and discriminatory actions of others (Aggleton, 2001; Castro & Farmer, 2005; Fife & Wright, 2000; Ogden & Nyblade, 2005; Smart, 2005). PLHA go through a process, beginning with initial feelings of shock, despair, shame and grief. Sometimes this process is accompanied by denial before accepting and understanding that there is nothing they can do about the diagnosis (Ogden & Nyblade, 2005).

Internalized stigma, or the shame that PLHA experience when they internalize the negative responses and reactions of others can lead to depression, withdrawal and feelings of worthlessness, loss of hope, inferiority, and the belief that they no longer have

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a future. Many people with HIV drop out of school and work or may avoid social settings, friends and family; some even lose hope of having family on their own or avoid sexual relationships as a means of self-preservation (Fife & Wright, 2000; Gilmore & Somerville, 1994; Guni, 2005; Herek, Mitnick, 1996; Ogden & Nyblade, 2005) because of the shame, fear of further spreading the disease or fear of being stigmatized. For instance, a woman in Ogden and Nybladde's study explained;

> *I do not want to have close contact with people because I know that I have HIV... I am the one who should isolate myself from others. Some people who know me well want to have a good relationship with me, but I do not want to be close to them.* (p. 32).

This kind of self-isolation may cause PLHA to be cut off from social support and medical care or they may delay getting medical care (because of fear of being stigmatized or discriminated) which could even lead to premature death. As recounted by counselors in a focus group discussion in Aggleton's study:

> *Some people are not very supportive because the PWA him/herself may not be cooperative to other members (of the family). He/she may stigmatize him/herself, hence repelling the would-be help from other people. (p. 30)*

Some studies show that internalized stigma related to HIV/AIDS appears to be more intense than for individuals associated with other life threatening diseases or conditions. For example, Fife and Wright (2000) compared self stigma associated with HIV/AIDS to that of cancer and discovered that self stigma is worse for PLHA than cancer because of the nature of transmission. Overall, the negative perception of PLHA – reinforced by the language and expressions of HIV/AIDS has caused affected individuals to avoid families and friends and to isolate themselves from their community. Internalized stigma causes a kind of "social death" in which PLHA no longer feel part of the society and are no longer able to access the services and support they need. This may be a minus to educational programs because self-stigma may limit participation of PLHA in educational programs which will be beneficial for them and the society at large. In other words, self-stigma or internalized stigma does not end with the individual infected with HIV but it is also a loss to the society in general.

Secondary Stigma

HIV/AIDS related stigma do not affect only PLHA, but also extends to include their family members, children, friends, caregivers, professionals and volunteers who work with them as well as the many stigmatized groups associated with HIV-homosexuals, drug users, sex workers, etc (Aggleton, 2000; Castro & Farmer, 2005; Fife & Wright, 2000; Herek & Mitnick, 1996; ICRW, 2006; Ogden, & Nyblade, 2005; Smart, 2005; Wiener, Heilman, & Battles, 1998). This process is generally referred to as stigma by association, secondary stigma or, as Goffman (1963) puts it, "courtesy stigma." In this respect family members are blamed for the PLHA's "bad behavior" and contraction of the disease and they experience the same expressions of stigma as experienced by PLHA and becomes subject of gossip. For instance, Ryan White was not only labeled the 'AIDS boy' and 'a FAG', but his mother was also referred to as an 'unfit mother' (White, 2006).

Children of PLHA most often bear the worst impact of secondary stigma; sometimes they are isolated, rejected and taunted by their peers. In Deacon and Myers-Walls' study one caregiver who was caring for a younger sister reflected on the discrimination aimed at all her family members because her mother died of AIDS. She revealed that, after her son was born, he was isolated from the other babies. She also was isolated from the other mothers and was interviewed by social workers, even though she was completely healthy and showed no indication of HIV or complications during her pregnancy. She saw herself as being robbed of the experience of her first child's birth saying: "This was the birth of my son, and they ruined it for me" (p. 3).

Loss of employment and livelihood can occur due to secondary stigma as well. For example, in Ogden and Nyblade's study, they recounted a woman in Vietnam who lost her job because her daughter was diagnosed of HIV. This woman used to take in neighborhood children as a day care provider. When people heard the news of her daughter's positive serostatus (results of the blood test), all the children were withdrawn from her care and she had to seek another job of selling lottery tickets, which is less lucrative.

Care givers also are discriminated against for working with people with AIDS. S. Johnson, Executive Director of the Regional AIDS Project in Manhattan (personal communication, February 16) expressed how her church members discriminate against

her because she is working with people with AIDS (who are regarded as sinners because they are seen as homosexuals and drug addicts). Although there are PLHA who did not contract HIV through any of such behaviors (homosexuals and drug addicts), they also are associated with those behaviors and may leave caregivers and relations of PLHA without adequate social support and may even deter professionals and volunteers from working with them.

HIV/AIDS-related stigma and discrimination do not begin and end with individual, rather it extends to family members, caregivers and professionals who are involved in the life of the infected person. It may even affect delivery of HIV/AIDS prevention programs as well as treatment of the disease.

Stigma Affects HIV/AIDS Prevention and Treatment

Stigma and discrimination have played important roles in HIV/AIDS testing, prevention and treatments (Brimlow, Cook & Seaton, 2003; Brown, Trujillo & Macintyre, 2001; ICRW, 2006; Kalichman & Simbayi , 2003 as cited in Maclean, 2004; UCSF, 2006; Mahendra, et. al. 2006; Parker & Aggleton, 2002). PLHA often fear the stigma and discrimination that they may experience if others know of their HIV status. This fear has impacted people's ability and willingness to access and utilize services that are available for preventing and treating HIV/AIDS.

Testing

In some societies, stigma has been shown to be associated with delays in HIV testing among individuals who are at high risk of being infected with HIV (ICRW, 2006; Kalichman & Simbayi 2003 as cited by Maclean 2004; Myers et al., 1993 (cited in Brimlow et. al.2003); Ogden & Nyblade, 2005; Smart, 2005; Valdiserri, 2003). Even when they get tested, because they fear a positive result, which in their minds is linked to the stigma and social repercussions, they might not return for the results. Kalichman and Simbayi conducted a study in South Africa to investigate the ways in which attitudes toward HIV testing and toward infected people are related to testing patterns. Although the researchers acknowledged the limitation of their study as based on cross-sectional study data from non-representative sample, it was discovered that the social stigma

attached to HIV/AIDS might be a more powerful deterrent to testing than attitude towards the testing itself. Some of the informants in Ogden and Nyblade's study expressed how people in Ethiopia and Tanzania fear to take the HIV test because "if their results are positive, they think that people will isolate and segregate them" and also, "it is obvious that the same will happen to you when it is known you are HIV-positive." (p. 35).

It is apparent that many people are living and dying with HIV/AIDS that have not been reported and diagnosed because they did not get tested. This is attributed to the fear of being stigmatized if one tested positive. Therefore, it is no doubt that people do not want to participate in prevention programs.

Prevention

Fear of stigmatization impacts prevention of HIV/AIDS in several ways including distancing people from a sense of risk and therefore do not take precautionary measures to practice safe sexual behaviors.The moral dimension and judgment aspect of HIV/AIDS stigma creates a difference between "us" (good moral community) and "them" or "others" (homosexuals, sex workers, injection drug users). This allows the "us" group to deny their risk of becoming infected and therefore, will not take the necessary step to protect against acquiring HIV (ICRW, 2006; Ogden & Nyblade, 2005). Thus stigma can distance people from a sense of risk, which may in turn create an obstacle to prevention.

Even so when people are already infected, they may fear that disclosing their HIV status or using condoms may result in partner rejection, limit sexual opportunities or increase risk for physical and sexual violence. For instance, a study of rural men who have sex with men (MSM), found that men who thought health care providers in their community were intolerant of HIV- positive persons also reported more high-risk sexual behaviors (Preston, D'Augelli, Kassab, Cain, Schulze, & Starks, 2004).

Stigmatization poses difficulty for HIV prevention programs and services being offered in settings such as churches, workplaces, schools, jails, prisons, etc (Alonzo & Reynolds, 1995; Brooks, Etzel, & Hinojos, 2005; Cogan & Herek, 1998; de Bryun, 1998; Gilmore & Somerville, 1994; Herek & Capitanio, 1999; Milan, 2005; Nzioka 2000; Ogden & Nyblade, 2005; Parker & Aggleton, 2002; UCSF, 2006; UNAIDS, 2000). This

is because HIV transmission is associated with behaviors which are considered immoral and negative, and are not acceptable in society. With regards to this, topics on HIV/AIDS and its related issues may not be welcomed in the institutions listed above even though it is generally accepted that HIV prevention should be incorporated in community programs.

Not only does stigma interfere with the ability of institutions to discuss HIV/AIDS, individuals and family members may find it difficult to discuss issues related to HIV preventions. For instance, many couples and individuals do not discuss correct and regular use of condoms (Ogden & Nyblade, 2005) because of its close association with HIV/AIDS, which is already stigmatized and even those who already are infected refuse to seek treatment.

Treatment

Fear of stigmatization and discrimination from caregivers, friends and family members has a profound impact on the ability and willingness of people to disclose their HIV serostatus, to seek treatment or to access and utilize services that are available to them (Kalichman & Simbayi 2003 (cited in Maclean, 2004); Ogden & Nyblade, 2005; Preston, et al., 2004; Smart, 2005; UCSF, 2006). This may exacerbate the condition of the infected person.

People with HIV may not seek treatment or may delay going to doctors due to real or perceived discrimination. This and other social repercussions of HIV (such as social rejection) may decrease the motivation of PLHA to stay healthy. For instance, in Schuster et al's (2005) national study discussed in earlier sections it was found that 26% of the participants reported experienced some kind of discrimination including 8% who were totally denied service. Similarly, Vanable, Carey, Blair and Littlewood (2006) examined the relationships among stigma-related experiences and depression, medication adherence, serostatus disclosure, and sexual risk among 221 men and women living with HIV/AIDS. The study found that those who had experienced stigma also were more likely to miss HIV clinic appointments and lapse in adherence to their medication.

In some cases, fear of stigmatization may even prevent people from seeking treatment for infections that may be symptoms of HIV/AIDS. For instance, in all the four

sites that Ogden and Nyblade conducted their research, it was evident that HIV-related stigma prevented people from seeking treatment for infections such as tuberculosis, skin rashes and certain types of diarrhea. These kinds of infections can sometimes be symptoms of HIV/AIDS, but it does not mean those who have are HIV positive. However, because those infections are associated with HIV, people are afraid to seek treatment.

Overall, stigmatization has impacted testing, prevention and treatment of HIV/AIDS in various ways. For fear of being stigmatized, people do not get tested, or disclose their HIV status to enable them get treatment. This creates great difficulty to preventing of HIV/AIDS because there are many people who may not know of their serostatus but continue to transmit to other people. Other people who know of their status will also not seek treatment to improve upon their condition and may even die premature death.

The consequences of HIV-related stigma are enormous; its effects on individuals, families as well as delivery programs have been discussed. Family life educators have a challenging role to play in educating people about HIV and its related stigma so that individuals and families will be equipped with the necessary tools in order to access and utilize services that may be beneficial to them. One important thing that needs to be considered when discussing issues related to stigma is the theoretical aspect.

Theoretical Considerations

Several theoretical approaches have been used to explore stigma in the context of illness. The attribution and social cognitive theory and Bronfenbrenner's ecological model of human development provide useful frameworks for examining HIV-related stigma (Breitkopf, 2004; Byrne, 2001; Phelan, 2001; Nelson 2005; Parker & Aggleton 2003). These frameworks shed light on the reasons why people stigmatize; why some PLHA experience more stigma than others; why people conceal their HIV status and the impacts it creates; and why there is secondary stigma.

Attribution and Social Cognitive Theory

This framework considers how information is used to explain certain events, outcomes or behaviors (Bandura, 1986; Breitkopf, 2004; Heider, 1958; Weiner, 1993). It assumes that when people try to determine reasons for other people's predicaments, they attribute one or more causes to that behavior. These behaviors may be internal attribution: the inference that a person is behaving in a certain way because of something about the person, such as attitude, character or personality or external attribution: the inference that a person is behaving a certain way because of something about the situation he or she is in (Heider, 1958). Attributions also can be significantly driven by emotions and cognition. For instance, people tend to blame others for their plight due to their uncontrolled behaviors or attitudes.

According to attribution and social cognitive model of stigmatization, people experiencing stigma are either personally responsible (internal) for their situation or may not be personally responsible (external) (Weiner, 1993; Weiner, Perry & Magnusson, 1988). When people are held responsible for their illness or other conditions it will possibly invoke anger and resentment in the person attributing responsibility, which may consequently turn into social rejection and stigma (Breitkopf, 2004). On the other hand, individuals who are not believed to be personally responsible for their condition may invoke a pity response from others (Breitkopf, 2004). This framework also explains other determinants of stigmatization, such as the severity and dangerousness of the condition being stigmatized, that is whether it is risky to others (Weiner, 1993).

Exploring the attribution–cognitive framework within the context of HIV-related stigma may provide valuable insight into stigma and discrimination experiences of PLHA of stigma, which may be of help to family life education professionals. Professionals will be able to understand the reasons why people stigmatize as well as why some experience more stigmas than others.

Society has attributed many characteristics and properties to HIV/AIDS; as being a disease of morally irresponsible people, a disease that belongs to "them" or "others", a disease of drug addicts, prostitutes, and homosexuals. As a result of this, people who contract HIV often are blamed for their condition, especially if they contracted through

sexual behavior. They face many forms of stigmatization in society such as rejection, labeling, denied care, isolation etc.

According to Breitkopf (2004), individuals who contracted HIV through no fault of theirs may invoke pity and sympathy, but is this the case for HIV/AIDS? There are some people who contract HIV through blood transfusion, which may be considered as an external or uncontrollable cause, but are still stigmatized. For instance, Ryan White contracted HIV through blood transfusion but was isolated and stigmatized in his school and community (White, 2006). In other words, irrespective of how people contracted the disease, they are still stigmatized but the intensity or degree of stigma may differ as discussed earlier using Ogden and Nyblade's model. Thus people who were infected through drug use or sexual relations with same sex partners are likely to experience more discrimination than those infected through blood transfusion. This is because behaviors like injection drug use, homosexuality are seen as internal; something that is within the individual and can be controlled, but transmission through blood transfusion is an external factor that is not controllable. The severity of HIV/AIDS and its life-threatening characteristic has also contributed to stigmatization and discrimination. HIV/AIDS has always been regarded as a danger to society and therefore people who acquire it are a danger to society.

Using the Attribution and Social Cognitive theory helps to give meaning to why people stigmatize and why some people experience more stigma than others. In exploring the reasons why people stigmatize PLHA, it is also important to look at HIV-related stigma and discrimination as an interaction between human beings and their environment.

Bronfenbrenner's Ecological Model of Human Development

Bronfenbrenner's ecological model acknowledges that human development involves transactions between human being and the characteristics of the environmental system within which they interact (Bronfenbrenner, 1979; Bronfenbrenner, 1986). Thus a person is affected by the settings in which he or she spends time and in like manner, a person also has effects on the settings. He identified five system levels:

Microsystem - the activities, characteristics, roles and personality of the

developing child.

Mesosystem- the settings with which a person interacts (e.g. The family).

Exosystem- the settings with which a person does not directly interact but all the same have an effect on the person (e.g. parents world of work, parents social network etc).

Macrosystem- cultural values and broader societal factors that influence a person.

Chronosystem- transitions that occur in life and the accumulative effect of many transitions that occur over a person's life (may be normative or non-normative).

Of all the above system levels, Bronfenbrenner acknowledges that the family is the principal context/setting in which a person develops (because that is where he or she spends most time), but the other settings are also important because the processes operating in those different setting are not independent of each other (1986).

Bronfenbrenner's model is important in looking at the impacts of HIV and its related- stigma on PLHA, their families and caregivers. It gives an insight to what is known that the individual does not grow/develop in isolation, in other words what befalls a person is also felt and experienced by the people/settings around him. Most importantly, the model is beneficial to family life professionals because it gives insight to how HIV/AIDS and its related stigma and discrimination are not an individual problem, but a familial and societal one. In this regard, educational programs may consider the impact it has on families, caregivers and other service providers of PLHA and provide them with resources that are beneficial to them.

PLHA experience stigma from within all the structures of his or her environment (mesosystem, exosystem, macrosystem) and as result of the Chronosystem. As previously discussed in previous sections family members, health care providers, institutions like workplaces (which form the environment of PLHA), all discriminate against PLHA. In relation to the chronosytem, HIV/AIDS is a transition that occurs in a person's life and the effect of this transition is felt by both the infected person and structures of the environment. When a person is diagnosed of HIV, depending on the stage, he or she as well as the family will have to make adjustments to provide care. If the PLHA is incapable of working, then, he or she will have to depend on other family members or close friends to survive. Also, some family members and caregivers may sometimes have

to stop working to care for the infected person. Why people stigmatize can also be explained by the macrosystem- there are cultural values and societal norms that could explain why people stigmatize. For instance, homosexuality, prostitutions, drug abuse are behaviors that are considered immoral in many cultures. These behaviors have been somehow associated with HIV/AIDS transmission and therefore a person who contracts HIV is seen as immoral and irresponsible.

In as much as PLHA are stigmatized, the structures in their environment (family members, caregivers and service providers) are also stigmatized by "association" (Aggleton, 2000; Alonzo & Reynolds 1995; Cogan & Herek 1998; Daniel and Parker 1993; Deacon, Falvo & Myers Walls, n.d; De Bryun 1998; Gilmore & Somerville 1994; Herek & Capitanio 1999; Malcolm et al. 1998; Nzioka 2000; Ogden & Nyblade, 2005; Parker & Milan, 2005; UNAIDS, 2000; Wiener, Heilman, & Battles, 1998;).

It is surprising that in my search for literature I did not come across any literature analyzing stigma using Bronfenbrenner's theoretical perspective with respect to HIV and its related stigma. Probably HIV and its related stigma has been addressed from the individual's perspective and therefore it is seen as an individual problem rather that a societal problem.

It is important for family life education professionals to address the issue of stigma from this perspective, because that will be a wholistic approach. Educational programs on HIV-related stigma and discrimination should be targeted at both affected and unaffected families, within health care settings and institutions etc.

Educational Intervention

Interventions to reduce stigma are crucial for improving care, quality of life, and emotional health for PLHA. HIV/AIDS-related stigma has been specifically identified as a domestic policy challenge that must be addressed to reduce the number of new HIV infections, and eliminate stigma as a crucial element of global efforts (Brimlow, Cook & Seaton, 2003; Gostin & Lazzarini, 1997; Parker & Aggleton, 2003; UNAIDS, 2003). The importance of this issue is highlighted in the UNAIDS publication '*A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*' (2002). The

document describes several interventions in the international arena (such as mother-to-child transmission intervention; counseling approaches; legal interventions) but laments the shortage of documented efforts to challenge HIV/AIDS-related stigma. This deficit also is noted by Brown, Trujillo, and Macintyre (2001) who wrote, "Given the magnitude of this pandemic one could hardly claim that the area of stigma reduction is well studied" (p.15).

Most of the literature on interventions for HIV-related stigma deals with the legal issues related to violations of rights of PLHA. Considerably less attention has been devoted to programmatic interventions, which attempt to change attitudes and behavior.

Interventions to prevent HIV-related stigma and discrimination are integral components of the comprehensive approach to HIV/AIDS because HIV/AIDS-related stigma and discrimination have long been recognized as one of the main obstacles to the prevention, care, and treatment of HIV and AIDS (Parker & Aggleton, 2002; Brimlow, Cook & Seaton, 2003; Brown, Trujillo & Macintyre, 2001; ICRW, 2006; Kalichman & Simbayi, 2003 (as cited in Maclean, 2004; Mahendra, et. al. 2006; UCSF, 2006). Yet little has been done on a large scale to combat it. There are many reasons for this inaction, including the belief of many policymakers that stigma is hard to define and measure, making it difficult to design and implement interventions; stigma, it is believed, is too cultural, too context-specific, and too sensitive to be addressed meaningfully (Brown et al. 2001; Fife & Wright, 2000; ICRW, 2006; Link, & Phelan, 2001; Ogden & Nyblade, 2005; Smart, 2005; Tomasevski, Gruskin, Lazzarini &Hendricks,1992; UNAIDS, 2003; Walker, 1991; Warwick, 1998; Wiener, Heilman, & Battles, 1998).

Research on intervention in relation to stigmatization has shown to yield very few results in changing stigmatizing attitudes, whether through 'empathy inducement' or other psychological theories on the part of dominant sectors of society (Brown et. al., 2001; Nelson, 2005; Parker & Aggleton, 2003). However, judicial and policy interventions in many settings have shown real effectiveness in impeding the worst impact of HIV/AIDS-related stigma and discrimination (Brown et al., 2001; Parker & Aggleton, 2003; Nelson, 2005; Walker, 1991).

 Legal protections for people living with HIV and AIDS, together with appropriate reporting and enforcement mechanisms (ranging from legal aid services to

hotlines for reporting acts of discrimination and violence against PLHA, gay men, women suffering domestic violence, and so on), have provided powerful and rapid means of mitigating the worst effects of the unequal power relations, social inequality and exclusion that lie at the heart of processes of HIV/AIDS-related stigma and discrimination (Brown, et al. 2001; Parker & Aggleton, 2002; Milan, 2007; Nelson 2005; Walker, 1991). There also are legislations that ensure the right to movement, employment, privacy and confidentiality and the right to treatment of PLHA (Dickens, 1988). For instance, policies in states like California, Wisconsin, Michigan, and Connecticut prohibit health professionals, school authorities and employers from discriminating against PLHA. (HIV/AIDS toolkit, 2006). In Connecticut, because of the non discrimination policy, PLHA have the right to work, get health care, are not required to have HIV testing before employment. Wisconsin's backpack policy -the School HIV/AIDS Policy Tool Kit, provides background information, policy examples, legal references, best practice procedures, reduction of risk of HIV transmission for children and school staff, school attendance by children living with HIV, needs of children with family members living with HIV and employment of staff living with HIV. It is likely that the degree of discrimination against PLHA in such states if present will be lower than in a state like Kansas where there is no policy for staff and students with HIV/AIDS.

Ultimately, I believe the structural interventions aimed at developing a rights-based approach to reducing HIV/AIDS-related stigma and discrimination should be a priority in order to create a transformed society in which stigmatization and discrimination themselves will no longer be tolerated. Within such a framework, discrimination becomes a breach of basic human rights obligation—a breach that, when specified in civil rights legislation, can effectively prevent stigmatization and discrimination. However, a multifaceted approach that goes beyond legal protections also is necessary to address the social climate that sometimes appears to legitimize discrimination (Klein et al., 2002).

Education is one of the approaches that will influence the social climate. This may include delivery of educational programs and resources on HIV-related stigma to families, educational institutions, health care facilities, faith based institutions, community based programs and all other conventional institutions. In all these programs,

basic information on stigma and discrimination; its forms and expressions as well as its impact should be a priority. As family life educator, I suggest exercises for workshops, detailed later, to give basic information on HIV-related stigma and its impacts. These exercises could be incorporated in community based programs.

Implications for Family Life Educators

Professionals in the field of family life education have a responsibly to provide education on HIV/AIDS, and its related stigma and discrimination to the community and to help families dealing with HIVAIDS by giving them the necessary support, information and resources. Family life education is multidisciplinary and focuses on education, prevention, designing and delivering programs that strengthen family life. Operational principles of family life education identified by Arcus, Schvaneveldt and Moss (1993), provide a focus for family life educators. A few of the operational principles that are relevant to the HIV-related stigma and discrimination will be applied here.

Family life education is relevant to individuals and families throughout the life span. People contract HIV/AIDS at various stages in their lives. The unborn, children, teenagers, adolescents and adults are all at risk of contracting the disease and are stigmatized and discriminated irrespective of their ages. Family life educators should provide resourceful information about the various aspects of HIV/AIDS to people of all ages. Information about transmission of the disease, prevention and its related stigma should be provided to people throughout the life span.

Family life education should be based on the needs of individuals and families. There are several ways that stigma and discrimination is expressed towards PLHA, their caregivers, families and friends as well as service providers. The consequences of these expressions affect not only PLHA but also the people around them. Family life educators should be sensitive to the needs of the infected and affected families. The infected persons need information about how to take care of themselves to prevent transmitting the disease onto other people. Equip family members and caregivers

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with information on coping with life crises and transitions. Since family members and caregivers take on new roles of care giving which they are not prepared for, they need information and skills throughout their care giving tasks.

Also family members and care givers will benefit from the expertise of family life educators; factual information on HIV, its transmission and treatment, should be disseminated to families affected and infected by HIV/AIDS. Provide appropriate resource information to PLHA and their families by connecting families and PLHA to the legal system and equip them with information on their rights. This will help them prevent discrimination.

Family life educators design and deliver programs in different settings. Family life educators can provide educational programs on HIV, prevention, stigma and discrimination to the community; those who are affected and those who are not. Such educational programs should be delivered in faith based organizations, communal events, workplaces, schools etc. Many people affected by HIV will benefit from such educational programs and support from the community. Family life educators have a great role to play in the prevention of HIV/AIDS and its related stigma and discrimination.

Family life education takes an education rather than a therapeutic approach. Fear of contagion due to insufficient knowledge is one of the causes of stigma and discrimination. Family life educators should provide education through Cooperative Extension Services to reach the public to disseminate in-depth and applied knowledge about HIV/AIDS through a participatory and interactive process to family members affected by HIV as well as the general public, to resolve initial fears and misconceptions about the disease. Accurate information is needed about contagion and myths must be debunked about HIV/AIDS to help discourage stigma and discrimination. There is a continued need to let people know the basic facts about HIV transmission, non transmission, and prevention and care because ignorance of the facts leads to fear which in turn adds to stigma. This will create awareness of stigma and discrimination in societies. Include issues of discrimination and stigmatization in HIV educational programs to highlight the issue. Fear can be reduced if people find out that having HIV/AIDS does not always lead to immediate death. Also, encourage people with HIV/AIDS to tell their story- sharing of experiences will allow for a community

understanding of how HIV affects people's lives and how people and the community can respond to it.

Family life education should present and respect differing family values. Family life educators are tasked to provide safe spaces and environments in which to discuss values and beliefs about issues like sex, homosexuality, prostitution, drug abuse and death underlying HIV-stigma. Open discussions on issues like these should be encouraged to help people develop tolerance and acceptance for lifestyle differences. This will help PLHA and their families to cope with the burden of care and stigma and also modify their own stigmatizing behavior.

While practitioners have a challenging role to play in reducing stigma, policymakers and organizations also can help

- Religious and faith-based institutions can give support to PLHA in their capacity as religious leaders and incorporate ways to reduce stigma in their community and service programs. Religious and faith-based institutions have far-reaching influence throughout the world. They should be encouraged to promote prevention, and to provide care, comfort, and spiritual support to individuals and communities who are HIV-infected or affected. In particular, religious leaders should be encouraged to play an active role in disseminating non stigmatizing and discriminating preventive messages, preventing stigma and discrimination.

- Media professionals can modify their language to be non-stigmatizing, provide facts and up-to-date information on HIV while limiting myths and misperception about HIV/AIDS and PLHA. Given their potential to shape the attitudes, values and perceptions of large numbers of people, communicators have a responsibility to create clear messages about HIVAIDS, to report accurately, and to do so in a sensitive, non-stigmatizing manner. Local, national, Internet, public and private media can provide opportunities for PLHA to share their experiences with the public. Exposure to personal experiences of PLHA can have impact on perceptions of HIV/AIDS, increase cultural exposure to AIDS and may reduce HIV-related

stigma. The mass media has a responsibility to build skills and capacity for journalists, editors, producers, AIDS activists, communicators and people working in the field of HIV/AIDS and also provide resources for sustained communication about HIV/AIDS that effectively reduces stigma. There should also be standards for reporting on HIV/AIDS in a non-stigmatizing and non-discriminatory manner.

- Health care/employment institution- Professional bodies have both a responsibility and an opportunity to overcome stigma within their professions and workplaces. They should be encouraged to adapt professional codes of ethics and conduct with respect to HIV/AIDS. These bodies have social and professional authority, and their ability to act as educators and role models for their communities, gives them the opportunity to act as "change agents" for reducing stigma.

Care providers and staff should be trained on issues of stigma and discrimination, discuss it among their members and develop a plan of action to address issues related to stigma and discrimination.

Recommendations

Educational program for challenging stigma

From my professional and graduate school experiences I have created an educational program on the issue of HIV-related stigma for the Regional AIDS Project in Manhattan, Kansas. It also can be used by any institution to educate people on HIV-related stigma. *Challenging HIV-related Stigma* offers the community educator a resource with research based-information as well as general recommendations to share with participants. The format involves small group discussions, and allows participants to be engaged in the discussion. The educator must have good communication skills and must be able to engage the group in discussion and the learning process as well as facilitate group dynamics.

The manual focuses solely on stigma and workshops can be organized on this theme alone but I will also encourage integration of these sessions into other AIDS education activities. The duration and activities could be modified depending on the number of participants and their level of participation.

Most of the activities are adapted from Kidd & Clay's tool kit "*Understanding and challenging HIV stigma, Toolkit for action (2003*). They also are based on the findings of the International Center for Research on Women's research on "*HIV/AIDS Stigma: Finding Solutions to Strengthen HIV/AIDS Programs*" (ICRW, 2006).

Program Information

Goals of program

- To create a safe space where AIDS professionals and community members can talk about their own fears and concerns about AIDS.
- To look at the causes of stigma and how it affects PLHA, families, and communities.
- To develop strategies and skills to confront stigma and discrimination.
- To provide a process to determine appropriate and feasible individual and community responses to HIV-related stigma.

- To strengthen the capacity of people with HIV and AIDS to challenge stigma
- To identify our own biases and fears related to HIV/AIDS and identify how these attitudes can negatively influence our behaviors and thoughts toward PLHA

Audience

The workshop is targeted at the general public, health workers, HIV prevention educators, etc.

Program Resources

- The Regional AIDS project is the center for disseminating information about HIV/AIDS and its related stigma in Manhattan KS.
- A bookmark or brochure that gives information about HIV-related stigma can be used as a marketing tool for participants.
- For more information and resources refer to the reference.

Recruiting Participants for the workshop

The community educator should establish a community collaboration to recruit participants and deliver the program.

- Find out programs in the community that can integrate HIV-related stigma in their workshops. Even if it is one lesson it's a start up.
- Determine partners that could be the core part of this program and bring them together to discuss the programs importance for PLHA and the community.
- Meet with partners and discuss the program and how each partner could help to recruit participants and support the program.

Preparing to lead the Workshop

As a leader, it is important to create a safe, sound, non-threatening environment where feelings, fears can be discussed and explored openly. The following tips may help:

- Carefully read and review this guide
- Read other sources on the topic especially those cited in this manual
- Read about the participants reaction and how you will respond

- Gather materials (pictures, cards, video clips etc) that may be   helpful and are nondiscriminatory in nature.

- If you are teaching as a team, decide on who will lead discussion and when other person can come in.

- Set ground rules and expectations around confidentiality and trust

- Being aware of your own feelings and fears about HIV/AIDS will help you to be more confident.

- Leave enough time for participants to share their feelings, which will create an atmosphere where participants feel they are listened to.

Program Format

The program consists of five different lessons as follows:

Lesson 1- giving meaning to stigma

Lesson 2- identifying the problem

Lesson 3- our experiences with stigma

Lesson 4- causes, forms and effects of stigma

Lesson 5- moving to action

Refer to appendix A for detailed activities of the program.

Conclusion

HIV-related stigma and discrimination is a global problem. People living with HIV and AIDS face stigma and discrimination in various contexts from within their households, communities, workplaces and health settings. Stigma has been associated with disfiguring and a disease that society perceives to be caused by violation of social norms especially those related to sexual behaviors. It is no doubt that HIV/AIDS-related stigma and discrimination is both an individual problem and a societal problem whether we choose to talk about it or not. As long as HIV/AIDS exist, its related stigma will exist.

Stigma and discrimination have played important roles in fighting against HIV/AIDS because in most cases infected persons do not report their status and do not seek treatment for fear of stigmatization. HIV-infected persons are often turned away from health care services and employment and are refused use of public and community facilities. There also is evidence of secondary stigma experienced by close relations of PLHA or people working with them. This highlights the need for increased awareness and the necessity to provide support to the often-stigmatized population and PLHA.

The attempt to challenging stigma and discrimination will face many challenges but it is important to start from somewhere educating people about it because

> *If knowledge breeds comfort; and, if comfort can promote compassion; then, perhaps, greater compassion from the noninfected community can contribute to a higher quality of life for those persons currently afflicted. (Shapiro, 2005, p.636)*

Societal steps towards creating a better quality of life for HIV-infected persons should involve widespread educational programs designed to provide the public with the basic knowledge of HIV, its transmission, prevention and its related issues as stigma and discrimination. Family life educators have an important role to play with respect to this. The educational program I put together is recommended for family life educators who have interests in working in the arena of HIV/AIDS prevention.

Family-focused policies must be among the priority responses to the HIV/AIDS epidemic. This will enhance family capacity building to serve as an avenue for limiting the adverse impact of HIV/AIDS and its related stigmas. The family policies will reinforce healthy family relationships, protect and increase family resources and

strengthen families and communities in an ever-changing environment, which will in turn promote, protect and support the integrity and functioning of the family.

While it is important that regulations and legislation be introduced, strengthened or modified to ensure that affected and infected families have access to employment, health insurance, health care, education and housing, it also is imperative that educational programs on HIVAIDS be focused on facts about HIV/AIDS transmission and sensitize society to collectively challenge HIV-related stigma. The more people acquire knowledge about HIV transmission, the more people will be receptive towards people with HIV and the more the society will lessen its stigmatizing expressions. Ryan White, for instance, was diagnosed with HIV/AIDS more than 20 years ago, a time when there was little information on the disease and therefore stigma and discrimination was widespread. But Ryan White was able to live through his dreams because of the support he had from his family and the new community he found that was open and receptive. Many PLHA today, like Ryan White, are experiencing stigma and discrimination: they need the support of their families, friends and care providers and we must all work together to stop the stigma associated with HIV/AIDS so that people can give their best for PLHA to have a "normal life". Like Archbishop Desmond Tutu once said,

*In our African idiom, we say, "a person is a person through other persons." None of us comes into the world fully formed. We would not know how to think, or walk, or speak, or behave as human beings unless we learned it from other human beings. We need other humans in order to be human. The solitary, isolated human being is really a contradiction in terms (*Tutu, 2000).

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Appendix A - Challenging HIV-related Stigma

Lesson 1

Topic/Concept
Giving meaning to stigma.

Objective
Participants will be able to:
1. Define and explain what stigma is and give examples.

Time Required
60 minutes may be needed.

Method

Background

Prior to this exercise the educator should review any of the following;

Goffman, E (1963). Stigma: Notes on the Management of Spoiled Identity. Englewood
      Cliff, NJ: Prentice-Hall

Gilmore, N. & Somerville, M. A. (1994). Stigmatization, scapegoating and
      discrimination in sexually transmitted diseases: Overcoming 'Them' and 'Us'.
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Brimlow, D. L., Cook, J. S & Seaton. R. (2003). Stigma and HIV/AIDS: A review of the
      literature U.S. Department of Health and Human Services. Rockville MD

Ogden, J. & Nyblade, L. (2005). Common as its core: HIV-Related stigma
      across contexts. International Center for Research on Women

Procedure

Present cards to participants and ask them to write or draw anything that defines stigma.
- Allow each participant to share what they wrote- if the group is small, allow participants to send their cards round for others to see what they wrote/drew.
- Have participants give examples of stigma and list on the flip chart.
- Discuss the definition and explanations of stigma you reviewed. Relate the definitions and explanations to HIV/AIDS and how it fits into the characteristics associated with stigmatized conditions.

Materials needed

Index cards, Pens or pencils, Crayons, paper and flip charts.

Outcome

Participants are able to place HIV/AIDS in its context of stigmatized conditions.

Lesson 2

Topic/concept

Identifying stigma as a problem

Objectives

Participants will be able to:
1. Identify stigma as a problem
2. Identify different forms of stigma in different context

Time required:
60 minutes is required.

Method

Procedure:

Small group case studies
- Divide participants into 3 small groups and present each group a case study. Two of the case studies are life stories of PLHA and one picture in annex B.
- Have each group spot evidences of stigma in the story or picture.

- Ask them to discuss among each group what they see in the picture or story that depicts HIV-related stigma. One person from each group should write down the interpretations.

Large group discussion
- Put up the picture and read the two different stories to the participants.

- Have each group share their interpretation they wrote down with the larger group whilst the educator makes a running list of common issues in all three cases on a chart.
- Analyze the issues in terms of the four forms of stigma expressions; physical, social, verbal and institutional.

Nature of expressions and forms

Physical stigma **-** Public rejection- not greeting PLHA, not sitting near PLHA
    Abandonment from family- not caring for PLHA, separating household items
    Physical violence- killing PLHA e.g. Gugu Dlamini
Social stigma**-**Loss of role, respect, identity etc.
    Loss of friends and social network
    Sometimes loss of Marriage

Verbal stigma-Direct- insulting and pointing fingers at PLHA
                            labeling/name-calling, taunting, blaming
                    Indirect- gossip and rumor

Institutional stigma-Schools, hospitals, Religious organizations, Employers etc
                            E.g. A church making HIV test a precondition for marriage
                            Employer requiring HIV test before employment
                            Health facility having designated rooms for PLHA

Materials needed:

Paper, Case studies, Pencils.

Outcomes:

Participants report recognizing the various forms and expressions of stigma.

Lesson 3

Topic/Concept

Our experiences with stigma: this lesson is a personal reflection to prepare participant for the lesson 4.

Objectives:

Participants will be able to:
1. "Own the problem" – we are all involved in stigmatizing PLHA
2. Describe some of their personal experiences with being stigmatized or stigmatizing others

Time:
60 minutes is required

Method

Procedure

- Have participants spread out at a distance from other participants.

- Ask them to close their eyes and think about one of the following options:

  Individual reflection of being stigmatized- a time in their life when they felt isolated, rejected or discriminated for being seen to be different from others or when they witnessed other people being treated that way. Have them think about what happened, what they felt and the impacts it had on them or

  Individual reflection of stigmatizing- an instance in their life where they rejected, isolated or discriminated against someone. Have them think about what they did, how they felt and why they did that.

Personal writing- have participants write their own experiences of stigmatizing or being stigmatized. Have them write their feelings, attitudes, and reasons why they rejected someone in their life. Expect feelings like: rejected, isolated, dehumanized, insulted etc.

Materials needed
Pencils, pens and Paper

Outcomes
Participants are aware that we are all involved in stigmatizing; stigma is not someone else's problem. We are all part of the problem, even if at first we don't recognize it.

Participants recognize how stigma affects people through their own experience of being isolated or excluded—and how it hurts.

Lesson 4

Topic/Concept

Causes and effects of HIV related stigma

Objective:

Participants will be able to:

1. Identify some of the reasons why people stigmatize
2. Identify the relationship that exist between causes and the degree of stigma
3. Identify the consequences and impacts of HIV-related stigma.

Time Needed

60 minutes is required.

Method

Background

Prior to this lesson, participants should have gone through lesson 4 and reflected on stigmatization

Procedure:

- Discuss the reasons why people stigmatize with participants

- Use participants' reasons for stigmatizing in lesson 4 as a beginner; discuss with the group why people stigmatize PLHA.

Nature of Causes:

- The nature and condition of HIV/IDS-makes people susceptible to other diseases, like, tuberculosis, rashes, diarrhea etc makes it possible for PLHA to be stigmatized.

- Behaviors associated with HIV transmission are seen as immoral and irresponsible on the part of the infected person. Such behaviors include homosexuality, sex work, drug use etc. HIV has therefore being categorized as a disease of homosexuals, sex workers and drug users. This creates the 'Us' and 'them' differences.

- People with HIV are stigmatized because those who stigmatize fear that they will contract the disease through contacts with the infected person. The fear is due to insufficient knowledge how HIV/AIDS is transmitted.

- Have participants to identifying other ways of HIV/AIDS transmission such as blood transmission. Analyze with them how the ways of transmission may influence the intensity and degree of stigmatization.

Discuss the consequences and impacts of stigma and discrimination on the individual as well as the family.

Nature of consequences:

- Family disruption- spouses are deserted after disclosing their HIV status
  Resentment towards PLHA from other family members.
  Separation-Not eating together, separate plates and cups.
- Loss of employment- PLHA are dismissed from work after disclosing their Serostatus. PLHA dismiss themselves because they cannot stand being stigmatized at their workplaces
- Loss of service access- Denied health care, housing, insurance coverage.
- Loss of social status- PLHA lose respect, identity, power, confidentiality and are sometimes considered a 'liability' to society
- Internalized/self stigma- People's reactions towards PLHA, makes them withdraw and isolate themselves from others. They feel inferior and lose hope
- Secondary stigma- Family members, caregivers, service providers of PLHA are also stigmatized by association.

Ask participants how stigma affects HIV/AIDS service programs (prevention and treatment)

Discuss: stigma keeps people from learning their HIV status through testing and discourages them from telling their partners and as a result they infect them. Stigma keeps people who suspect they are positive from accessing treatment and counseling services.

Materials Needed

Pens/pencils, Paper

Outcomes

Participants report increased knowledge of how HIV affects PLHA and the people around them. Participants will be more responsive and sympathetic towards PLHA

Lesson 5

Topic/Concept

Moving to Action

Objectives

Participants will be able;

1. To put together all the things learned so far including what can be done
2. To practically change attitudes and behavior toward PLHA
3. To focus on collective action and plan for effective action
4. To support the development of skills needed to act against HIV-related stigma

Time needed
60 minutes is required

Method

Background
Prior to this lesson, Participants must have gone through the exercises in the previous lessons

Procedure
Summarize the lessons learned so far and discuss with participants ways of changing attitudes and lessening HIV-related stigma in their communities.

Personal writing

Have participants write on pieces of papers or index cards, *"one thing I can do personally to lessen the HIV/AIDS related stigma.*

Fold papers and put it in a box. Shuffle it and pas it round, each person takes one and reads it out.

Have participants make a commitment to at least one action point in their communities, families, workplaces care giving tasks etc.

Nature of Action
Things that we can do individually include:
- Not being judgmental but open-minded to issues as sexual orientation
- Watching our language and avoid stigmatizing words
- Provide a caring ear and support to PLHA and family members at home
- Visit and support PLHA and their families in our neighborhoods
- Encourage PLHA to use available services: counseling, testing, medical care and refer them to others who can help.

Materials needed

Handouts of all the lessons, pens/pencils, paper and index cards.

Outcomes

Participants acknowledge awareness of the forms and impacts of HIV-related stigma: and develops a plan of action for challenging HIV stigma in their communities.

Participants make commitments to work individually and collectively to identify, understand and challenge stigma.

Participants will be open-minded towards issues related to sex orientation and HIV/AIDS transmission

Appendix B - Spotting Stigma

Credit: www.avert.org