

Stigmatization and the Silence of the Church.

**Rev. Edward Phillips M.M.
Managing Director
Archdiocese of Nairobi Eastern Deanery AIDS Relief Program**

Stigma is not a new phenomenon to the world. Historically it has very often appeared in areas of illnesses and behaviours that are different than the accepted social norm. Illnesses like mental illness, epilepsy, leprosy and physical deformities have been classic examples where stigmatizing takes place. In the time of Jesus the community had not only marginalized lepers because of their fear of infection and physical deformity but also believed that leprosy was uncleanness and a divine punishment. Leprosy was the plague from God. Jesus in the Gospels addressed the issue of stigma by reaching out to lepers and curing them (Mathew 8:1-4; Luke 17:11-19). By purifying the lepers and restoring them to the community He abolished the division between unclean and clean.¹

AIDS has become in many ways the leprosy of the 20th and 21st century with all the stigmatizing attitudes influencing culture, social institutions and relationship with God. Stigma is a “virus” of the mind and soul that infects and destroys the persons who are stigmatized but also the stigmatizer. Nelson Mandela in his speech at the AIDS Conference in Barcelona in July 2002 said that “ Many people suffering from AIDS and not killed by the disease itself are killed by the stigma surrounding everybody who has HIV/AIDS.”²

To better understand how to respond to the injustice of stigma, we must analyze its root causes and see how it influences our social and religious systems. It is only by better understanding the root causes that proper action plans may be put in place to combat stigma.

Stigma can be defined as an unhealthy attitude which discredits the basic human integrity of the person in society. The person is “less than” the rest of society. Components that by themselves or interrelate to cause stigmatized acts are labeling and difference, associating human differences with negative attributes, an us/them mentality and loss of social status and discrimination.

Key factors that contribute to stigma and HIV/AIDS are the following:

- 1- HIV/AIDS is a life threatening disease
- 2- Fear of contracting HIV.
- 3- Association of HIV/AIDS with stigmatized behaviour like commercial sex workers.
- 4- Belief that people with AIDS brought it on themselves because of their behaviour
- 5- Moral judgment by religion and society that AIDS is caused by immoral behaviour and therefore is punishment from God.³

The fear of being infected by AIDS and that anyone with AIDS will die has caused good people to stigmatize AIDS patients. The nurse in the hospital who will only care for AIDS patients if he/she is only wearing gloves when there is no need clinically to

be wearing gloves. The priest, who resists visiting a sick AIDS patient because he is afraid that he might be asked to celebrate the Sacrament of the Sick. This would mean touching the patient while anointing them. The family member who will only give special utensils for their loved one with AIDS because of the fear that the family will get infected. The fear of the provider communicates rejection and isolation to the patient. Most often the providers are not even aware of the impact of these non verbal actions on the patient. For the patient, they are very aware of how they are being judged and rejected by the care givers. They know from their life experience how the family, medical and religious institutions care for their sick members and it is the opposite for them.

Judgementalism and rumor mongering are classic examples of how AIDS patients are labeled as bad people. Since one of the ways in which HIV/AIDS can be contracted is through sexual behaviour, the person is judged as being a bad person. Comments about how the person must have been promiscuous and been sleeping around with many different women or men and that is why they have AIDS is very common. The patient might not hear these things directly from people but they are aware of the general attitudes of their society because in many instances they had these same attitudes until they became aware that they were infected with the HIV virus. The stigmatizer thus becomes self stigmatizing.

The family which should be the foundation of love and support for the family member who is sick and suffering becomes at times the opposite. The patients with HIV/AIDS are accused of bringing shame on the family because of their illness. In the minds of the family the patient has violated their social norms on sexual behavior. One patient narrated that “my sister is a nurse and when my mother died, she said I should not step on her soil as it will get AIDS.”⁴ Again we face the same phenomena of a person being stigmatized by another while the people doing the stigmatizing are not even aware that they are applying self stigma to themselves. If the family could only understand that the whole family has been trapped in the vicious circle of stigma.

Culture and gender also influence stigma with AIDS. Unfortunately women are blamed at times as if they were the cause of the problems in the family. Family members will say it was her that brought AIDS into the family when possibly she was infected by the spouse. The wife is afraid to disclose that she is HIV positive because of fear of being beaten and thrown out of the home. If one of the children is infected with HIV it is the mother who is accused of not raising the child properly. Even if the wife wants to abstain from sex because her husband is HIV positive or she is HIV positive, she sometimes does not have the power to negotiate that issue since the husband sees it as his right to have sex. The relationship is not one of equality but superior to inferior.

Health institution can also stigmatize and discriminate against AIDS patients. AIDS patients are not offered the same quality of care as others. For example not respecting the confidentiality of the patient and informing others of their HIV status without the consent of the patient. Health facilities doing HIV testing on the patient without their consent and never sharing with the patient the results of the test. In some instances patients are just discharged from the hospital to go home and die without any support which is commonly described as “dumping” the patient on the family. A UNAIDS

study in Uganda showed that healthcare workers tended to spend less time with AIDS patients since their attitude was they were going to die anyway⁵

Communities can also be destructive of the whole family. Families where one of their members has AIDS can be refused housing or are given notice to vacate the home they are renting. Children can also be stigmatized and discriminated against by other children and their extended family. Children are told by their parents that the parents of one of their playmates have AIDS and they should not play with them. The children then begin making bad remarks to their playmate about their parent having AIDS and they do not want to play with them. They are told “go away with your AIDS”⁶

If the parent(s) have died and the children are taken care of by members of the extended families there are instances where the relative speaks badly about the deceased parent. The child feels like they are being blamed for the life of their dead parent(s).

Religious institutions unfortunately at times have been major promoters of stigma without even realizing it. Amongst some Christian churches the message has been communicated that AIDS is a punishment from God. Even within some Catholic communities there is the attitude that there are the so called “good Catholics” and “bad Catholics”. It seems that Jesus instruction in Luke 6:42 that we must remove the plank from our eyes first is not really understood by some of our parishioners.

With AIDS patients living within a heightened stigmatized society, we must ask how does stigma impact on these patients? Stigma has a direct negative impact on all aspects of the patient’s life for example medical care, emotional health, social relationships, economics and spiritual life.

In clinical care, patients delay seeking out clinical care because they are afraid of being known as being HIV Positive or having AIDS. Thus their health is compromised at an early stage of their illness and this can lead to an earlier death. Even with the availability of anti-retroviral drugs, patients who should be receiving these life enhancing medications do not seek out treatment because of stigma. Tuberculosis is on dramatic increase because of HIV and is a serious threat to the general population. However people delay in seeking treatment for TB because of the relationship to HIV/AIDS. Thus the stigmatizers in society are actually placing their own health at risk because stigma causes the additional spread of tuberculosis amongst HIV negative people.

The psychological damage to the patient is directly correlated to their social and religious network. Patients who are rejected and not loved by their families or seen as bad people within their communities and churches are deeply wounded. They are suffering with a tremendous psychological and spiritual pain. They feel alone, rejected by society, have loss of self-esteem and in many cases depression. Within their spiritual life they feel alienated from God and because of stigmatized religious messages patients will say; “Can God really forgive me?”.⁷

Stigma thus acts like the Chief Justice imposing a death sentence on the patient. The issue of stigma and AIDS is not something that can be described as an African phenomenon but is part of the reality of HIV/AIDS where ever it is present in the

world. Stigma and HIV/AIDS are clear examples of the “culture of death”⁸ which is present in the modern world.

As the Catholic Church in the AMECEA countries of Africa we are challenged to respond as a Church to the “culture of death” as expressed through stigma which is present within our countries, dioceses, parishes and outstations. Pope John Paul II in his encyclical “On Social Concern” speaks of “structures of sin” which are rooted in personal sin and thus always linked to the concrete acts of individuals who introduce these structures, consolidate them and make them difficult to remove. They continue to grow stronger and spread and become the source of other sins.⁹ Stigma is an example of a social structure of sin. It is not to say that the Catholic Church in the AMECEA area has not tried to address the issue of stigma through Pastoral Letters, education programs, preaching etc. However if we are to be honest with ourselves stigma and HIV/AIDS is still very powerful and present within our areas of influence.

In order to develop an effective action plan to combat stigma and HIV/AIDS, we must first do a critical analysis of ourselves as Church leaders both religious and lay to see where stigma is present either consciously or unconsciously. If we cannot remove the plank from our own lives then how are we to help others to see the splinter within theirs?

A basic question to ask is what are the written and public policies within our dioceses and religious communities on HIV/AIDS for religious personnel? Does a priest, religious brother or sister know that they can seek help in confidence and with love and respect from their religious superior or bishop if they are HIV Positive? If there is a policy on HIV/AIDS care for religious has it been discussed with the religious and also made public that this is the official stand of the diocese or religious communities with members who are HIV Positive?

As Church leaders are we actually uncomfortable making public statements about a policy to care for and support members of our religious communities who are HIV positive because of the relationship of HIV infection and sexual behavior? In point of fact the person might have been infected by dirty blood or dirty syringe and not sexual activity. Irregardless of how the person was infected with the virus, we, as Church leaders, should be models of compassion, love and understanding for those in our midst who are infected with HIV. We must also understand that there will tend to be a high level of self induced stigma amongst religious personnel because they are expected to live at a higher moral level than the general population.

By not having a public policy on HIV/AIDS care for our religious personnel in our dioceses and religious communities, we are actually in fact unconsciously stigmatizing our religious communities. Many religious personnel are afraid to disclose their HIV status to their Bishop or religious superior because they believe that they will be judged badly and condemned. By breaking the silence over how religious leaders will respond to the members of their religious communities is the first step in decreasing stigma. It is not enough to say as Bishops and religious leaders that naturally you would be compassionate, understanding and caring to your Religious personnel who are HIV Positive. It must be said clearly and publicly with defined treatment and support systems.

A more complex issue is the policies of some dioceses and religious community on HIV testing of their candidates before admission or at the time of final vows or ordination. Are there clearly defined exclusionary issues like medical, academic, and spiritual, social and psychological which are known to the candidate at the time of application and at final vows or ordination. A clearly defined and public policy also decreases the possibility of dioceses or religious communities of being accused of discriminating against and stigmatizing HIV Positive religious in formation. Ethical procedures call for consent of people before being tested for HIV which means all candidates need appropriate HIV counseling before taking the test. If HIV Positive is an exclusionary issue for entering or final commitment to religious life, is the candidate supported on their sero-status and counseled on their future life? Depending on the laws of the country, testing someone for HIV without their consent could also open the diocese or religious community to law suits.

Personnel policies for lay employees must also be transparent. Are there clearly defined policies for any worker who is HIV positive? If workers know that they will not be fired because of being HIV positive they will seek out clinical care earlier. By having clear policies for workers on HIV/AIDS it is an effective way of lowering the fear of stigma within the work force and keeping your lay workers healthy and productive.

Discrimination on hiring and firing is always considered an unethical and unjust act. HIV testing as part of the process for employment is considered a discriminating act. If we are to consider raising the question of HIV testing for employment as being an issue of social justice then we first must examine our own Church institutions to see if we are testing people for employment.

A key challenge for Church leaders is communicating the moral values of the Church in regard to sexual behavior but at the same time not condemning people who might have contracted HIV/AIDS. As followers of Christ we need to be reminded of the type of life He has called us to live as well as the understanding that when we fail to live that life He is there to forgive us and pick us up. There was an old theological principle that expresses this concept; God condemns the sin but not the sinner. Good clear messages need to be developed so that the Church is not accused of stigmatizing people in its mission of evangelization.

Knowing one's HIV status through Voluntary Counseling and Testing (VCT) is one of the foundation points in national governments HIV/AIDS prevention and treatment programs. Many people are afraid to go for testing because of the fear of knowing that they might be HIV positive and be stigmatized. Knowing one's HIV status is away to stay healthy if you are HIV negative and if HIV positive receive treatment and not infect others. Bishops, in their role as senior Church leaders, can have a tremendous effect on the broader community by encouraging people to know their HIV status.

HIV testing as part of marriage preparation is being strongly encouraged within the secular world. However there is resistance by some people to the concept of testing before marriage on the grounds that it stigmatizes and discriminates against people. The issue comes down to a clear understanding of the value of testing before making a life time commitment. If we say as a Church that an integral element of the marriage

union is informed consent by both partners then in the midst of the HIV pandemic how can a couple make informed consent without knowing their HIV status?

To be effective in responding to the issues mentioned above as well as other stigma related issues a clear operational plan needs to be developed from the Episcopal Conference through the dioceses to deaneries and parishes.

On the national level the Justice and Peace Office should be relating with the Health and Family Life office over HIV/AIDS and stigma related issues. National Catholic newspapers and radios are another avenue for running a stigma related campaigns. Serious consideration should be given to have stigma as the theme of the Lenten Campaign since it is a social justice issue which impacts on all people.

The different dioceses should, as best as possible, integrate national campaigns into the dioceses. Diocesan policy for religious and lay employees infected with HIV/AIDS must be developed and shared with the people of the diocese.

There is a need of serious review of the marriage preparation courses with more emphasis on life term commitment to each other in the midst of the AIDS pandemic. Discordant couples or both spouses being HIV positive are part of married life in our parishes. A policy for HIV testing before marriage needs to be developed and promulgated.

Since stigma actually flows from the attitudes and thoughts of people, we, as the people of God in East Africa are being called to a metanoia (change of heart, repentance).¹⁰ This metanoia can be accomplished through activities within our parishes and outstations. Working through various parish groups, discussions, role plays etc. can be developed around stigma issues. One key concept that is crucial to a metonia is the realization that within our lives each of us has been stigmatized in one way or another. In understanding the hurt we felt when we were stigmatized, can help us to change our attitude of hurting someone else when we have stigmatized them.

Lent and Advent seasons are significant periods within the liturgical year in which a campaign can be developed around stigma. Since ultimately removal of stigma can only come from a change of heart and attitude, these two reflective, penitential periods can be a time of deep spiritual growth concerning stigma eradication in our lives as well as the stepping stone for broad based decrease in stigma.

Finally we must see stigma and other HIV/AIDS related issues as not a one time activity but a continual series of pronouncements and activities within the Church by Bishops, priests, religious Sisters and Brothers, and our lay people. These continual activities must reach all the way to the smallest Christian communities in the farthest villages. Jesus reminds us in Luke 8:17 that “No one lights a lamp to cover it with a bowl or put it under a bed. No, it is put on a lamp stand so that people may see the light...” The light needs to shine on the evil of stigma with the invitation to all to live as one with each other.

In conclusion, Pope John Paul II stated it quite clearly in *Novo Millennio Ineunte* “Now is the time for a new “creativity” in charity, not only by ensuring that help is

effective but also by “getting close” to these who suffer, so that the hand that helps is seen not as a humiliating handout but as a sharing between brothers and sisters.”¹¹

¹ edited by Leon-Dufour, Xavier, Dictionary of Biblical Theology, 1973, p 308

² Mandela, Nelson, Closing Address, International AIDS Conference, Barcelona, Spain, 15 July 2002

³ De Bruyn, T, HIV/AIDS and Discriminations: definitions and concepts, Canadian HIV/AIDS Legal Network and the Canadian AIDS Society, 1999

⁴ Focus Group Discussion, Eastern Deanery AIDS Relief Program, unpublished, 2003

⁵ UNAIDS, Uganda: HIV/AIDS- Related Discrimination , Stigmatization and Denial, 2001, Geneva, p 18

⁶ CF. Eastern Deanery AIDS Relief Program

⁷ Ibid

⁸ Pope John Paul II, Encyclical *The Gospel of Life*, (25 March 1995) No.12

⁹ Pope John Paul II, *On Social Concern*, 30 December 1987, No.36

¹⁰ CF Leon Dufour, Xavier, p 486

¹¹ Pope John Paul II, Apostolic Letter *Novo Millennio Ineunte*, 6 January 2001, No 50