

# The Psychological Impact of HIV/AIDS:

## People are more than statistics

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### Introduction

HIV/AIDS is a topic that has been greatly discussed and researched due to its' impact on human beings. Ever since the HIV/AIDS virus was identified, people have been trying to find ways of educating others about this virus. Many campaigns have been put into place, and people have been made aware of the various effects of the virus. We must remember that this virus has not only physiological effects, but also major psychological effects. This paper will focus on the psychological effects of the HIV/AIDS virus on people living with HIV/AIDS and their caregivers. Those living with HIV/AIDS will be referred to as *infected*, while the personal caregivers and family members will be referred to as *affected*. We define psychological effects as those thoughts, feelings, emotions that affect the mental state and well-being of the infected and affected persons.

In the general HIV/AIDS research, statistics are used to present findings. Statistics do not actually explain critical matters of concern such as the psychological manifestations of HIV/AIDS. This is of concern because the research done then becomes a matter of statistics and the other personal issues that are important are not thoroughly discussed. It is in this light that the objective of this paper is to emphasize the importance of awareness of the psychological effects of HIV/AIDS, such as: fear, loss, grief, guilt, denial, anger, anxiety, low self-esteem, depression, suicidal behavior and thinking, and socio-economic issues.

“The psychological or internal challenges a person with HIV/AIDS faces vary from individual to individual. Not everyone will experience all of the emotional responses or stages of the emotional responses described. Each HIV/AIDS situation is as unique as the people involved. There are individuals who might face catastrophic changes not only in their personal and job relationships, but in their physical bodies and in their self-images and self-esteem.” (Watstein and Chandler, 1998). As a result of these changes in both working and personal relationships, the behavior of those infected may change. They may become withdrawn, aggressive, and rude to colleagues and friends. This may be because the infected person may feel (or imagine) being victimized. Infected, and in some cases, affected, people can experience a decrease in self-esteem as they are no longer confident in themselves or what they can achieve. This is likely caused by the stigma within society against infected and affected people. They are seen as lesser persons and are at times devalued. This in itself is of course detrimental to the person's well-being. *Coping with being infected involves confronting fear and denial while maintaining hope.*

Infected persons are normally in fear because they have to adjust to a new lifestyle. It is not easy to accept that one is infected and thus shock and disbelief, leading to denial, is a frequent initial response. According to Watstein and Chandler (1998) there are emotional responses that are symptoms of the psycho-

logical effects that people have when infected or affected with HIV/AIDS. Infected persons may be confronted with having to reexamine their sexual identity and the behavioral choices they have made in support of that identity. When one associates HIV/AIDS with what society has traditionally considered immoral, the infected person then has to work through his/her feelings in order for his/her sexual identity to be reaffirmed in a way that will allow for feeling good about oneself.

Persons with HIV/AIDS may be caused to see themselves as undesirable by others who view them as “contagious”. This in itself is an emotional situation that can cause infected people to withdraw, not disclose their feelings, and become socially isolated. Inevitably this may lead to an emotional breakdown because these feelings continue to be suppressed. The most destructive stressor is that of feeling isolated. This isolation can have many causes, including the loss of support by lovers, family, and friends. Additional feelings of isolation may result from the need to change their sexual practices and take more precautions to protect themselves and others.

Watstein and Chandler continue to explain that another destructive stressor is that of feeling dependent. The dependency occurs when the infected person must rely heavily on family and friends for emotional and financial support, particularly when they have to apply for social services assistance. Furthermore, within Namibia an infected person is not granted an opportunity to gain access to life insurance policies. This also can be very frustrating and demoralizing. The final aspect of dependence is the fear of a protracted illness that will drain the family and friends both financially and emotionally.

In rural areas, HIV/AIDS also causes labour shortages for farm and domestic work by reducing the household’s workforce. Much livestock is lost when families are destroyed by HIV/AIDS because the remaining family members may not know how to care for the livestock, or plant and produce crops and fodder. Additionally, in some of the more traditional cultures, livestock is taken away from the wife and children when the husband/father dies. Thus, a cycle of hunger, desperation, and poverty begins as a result of this disease.

### **Psychological Impact on Affected Children (OVC)**

HIV/AIDS has no age-appropriateness and not even children are spared. In the Namibian context, an orphan is a child who has lost one or both parents or guardians to HIV/AIDS before reaching the age of 18, and who remains dependent (Sr. Mallmann, Catholic Aids Action, 2002). In Namibia, the National Census of 2001 revealed that there were 156,165 orphans between the ages of 0-9 years, and it is estimated that by 2021 this figure will almost double.

There are a number of psychological impacts affecting children of HIV/AIDS parents. A parent who is HIV infected may show less interest in the child due to the dramatic mood swings associated with the pressure of being infected. The child usually does not know what the problem is, that it is not his or her fault, and does not understand why the parent seems moody. The child is likely to react with fear and anxiety and sometimes will blame themselves (Sr. Mallmann, Catholic Aids Action, 2002). Children don’t like to see their parents sick, and so the pressure begins in a child when he or she realizes that the parent is always sick. The child’s world goes through many changes as the family structure and way of doing things also changes, especially as the sick parent is unable to perform the normal household chores and routines. The older children are expected to take up responsibilities which are much beyond their capabilities and can be overwhelming. This is especially true in rural settlements where the family responsibilities and needs are greater.

Anger and neglect are other concerns. The psychosocial impacts of stress, grief, avoidance and teasing by other children, social isolation and discrimination can lead to behavioral disturbances, fatalism, self-stigmatization, and increased opportunities for abuse (Claudia Tjikuua, 2002). Children tend to worry all the time and are also afraid that one day they will find their parents dead when they come home from school. They also worry about who is going to take care of them. This fear results in children often opting to not attend school, or being hyperactive and inattentive while in school.

Children may also suffer from economic constraints as the household provider becomes sick, can't work, and loses their job. The responsibility of earning money and providing food is left to the children. They often go hungry, become malnourished, and become unable to concentrate. Other economic impacts include no money for school fees, uniforms, materials, clothing and other necessities. Hunger is a common cause of poor school performance and dropout.

Researchers have observed symptoms associated with trauma, depression and lack of bonding and attachment in very young children. This may lead to children feeling deprived of their childhood, causing misery and sometimes thoughts of suicide. Access to experiences which address psychosocial needs such as consistency of care appeared to be unmet for many children (C.K. Haihambo, 2004).

Many orphans are usually incorporated into the extended families that act as a safety net. However the shrinking number of caregivers and the considerable strain on families means that children are much more vulnerable to economic and social hardships such as malnutrition, poverty, child labour, homelessness and reduced access to education and healthcare (AIDS brief, 2004).

Children are also infected with the virus as a result of prenatal transmission or through sexual abuse. These children experience almost a complete loss of childhood since they are continuously sick and cannot engage in the normal childhood activities. Other children are also warned by their parents not to play with the infected ones for fear of contracting the disease. For an infected child, the fear of dying is constantly prevalent. This of course impairs normal emotional and psychological functioning.

### **Psychological Impact on Affected Family Members and Caregivers**

are endless numbers and statistics that are readily available concerning people who are living with HIV and AIDS. But what of those people who are affected? What about the forgotten family members and care givers who are also psychologically impacted? Where are those statistics and what are those numbers? It is time we stopped looking only at the numbers but also started looking at the people behind those numbers. The impact of HIV/AIDS on the affected has somehow been overlooked.

Jeniffer Hendrick from the Queen Elizabeth 2nd Health Centre in Halifax wrote a document on the psychological stresses that are experienced by the affected. In the document, it was listed that the following are some of the stresses: Fear of infection, Anticipatory grief, Shame, Helplessness, Discrimination

Thus, these same anxieties that are felt by the infected are also felt by the affected family members and care givers. It was also stated that affected people are faced with challenges of; loss, death, perceived helplessness, uncertainty about the future, sadness and anger, frustration in navigating the medical system, financial worries and interpersonal stress. These burdens are usually placed on the shoulders of elderly caregivers, family members, partners and sometimes even friends. In July 2004, five members of Episcopal Relief and Development (ERD) traveled to South Africa and Namibia to tour several joint ERD-HOPE Africa projects there. Below is one member's account of the trip.

*The HIV/AIDS Pandemic in Africa  
An Eyewitness Account, by Peggy Cleary*

"Last summer I was a member of the Ubuntu Pilgrimage to Namibia and South Africa, which was put together by Episcopal Relief and Development (ERD). There were five of us, all women, two health care professionals specializing in women's health and pediatrics, a journalist, a priest, and me (who is none of the above) and our intrepid guide, Brian Sellers-Petersen, Director of West Coast Operations for ERD.

The purpose of the trip was to experience firsthand the devastation of HIV/AIDS and to see the work of the Anglican Church of Africa, and specifically the work that ERD is doing with the lowest socio-economic groups affected by HIV/AIDS; women and children. The statistics were staggering:

- 12 million children in sub-Saharan Africa have lost one or both parents to AIDS. In Namibia, 47,000 children will lose a parent to AIDS this year.

- Of the 10 million young people living with HIV worldwide, 6 million live in sub-Saharan Africa; 75% of these are young women (aged 15-24).

I'm throwing these numbers around like baseball statistics, but the truth is they are so big and so overwhelming that it's impossible to relate to them on a personal level. So many children are affected by this disease that we had to learn some disturbing new terms.

- OVC refers to "Orphans and other Vulnerable Children." They include children who have lost parents, or maybe have lost one and the other is too sick to care for them, or they themselves are sick.
- CCH stands for "Child Head of Household," This could be anyone between 8 and 12 parenting younger children, who may or may not be siblings.

We found our way to Etale, an Episcopal Church, where they take care of the OVCs while their CHHs are in school. This is just one of the programs ERD supports through the Diocese of Namibia to keep these kids, or "children acting as parents," in school. At this site, ERD funds one meal a day for about 20 kids under the age of five. Typically more than 40 children show up. There were 46 the day we were there. You can't just feed half of them. Instead, they are only able to provide two or three meals a week.

I met a boy named Freeman there. He came to pick up some kids after school, and actually understood my feeble attempts to speak Oshikwanyama, the language of the Ovambo. I thought that I was asking a bunch of kids for their name, but nobody was answering until Freeman showed up. He got it right away, looked right at me and said "Freeman." We were instant friends; he was stuck with me for the rest of the day. I could yell his name across a yard full of kids and he would immediately wave back at me. I have no idea if he is HIV-positive or how many kids he is responsible for.

All of us assumed that it would be children who would break our hearts. Instead, it was the women. At Efululula, another Episcopal church in Namibia, we met with 30 women. They told us about their work as volunteer home-care providers for women and children with HIV/AIDS. Trained providers carry a caseload of nine to 12 households; the frequency of their visits varies from once a week to daily, depending on how advanced the disease is. Twelve were trained and 18 are waiting to be trained.

Home-care providers carry a kit that contains things like hydration, pain medication (Tylenol), cough syrup, calamine lotion, Vaseline, disinfectant, bandages, thermometer, rubber gloves, plastic sheeting, apron, and scissors. These women are treating end-stage AIDS patients with the contents of my medicine cabinet. My impression was that only 12 were people trained because that's how many kits they had. All of these women have lost family members, children, husbands to AIDS. I don't know how many of them are HIV-positive. Many were raising children who were not theirs. I am 49 years old; all of the women I've talked about are under the age of 36.

So what did I learn? I learned that the problem of AIDS is huge; it's bigger than anyone knows. Africa is far away and it's really hard to think about. I learned that if a vaccine or antiretrovirals were readily available tomorrow, the community development work, like what ERD is doing, would still need to go on for years.

I learned that even though funding for research and drug therapies runs in the millions, a little money can have a big impact:

- \$30 can provide three months of care for an OVC.
- \$20 can help an HIV-positive woman in Africa create an income through the programs that ERD supports.
- Less than \$10 can buy an AIDS badge.

\$30 or \$20 or even \$100 won't change what my family eats for dinner but it will change what someone else's family does.

Despite the many difficult and complex problems faced by the people I met in Africa, I found an optimism and belief in the power of the Spirit that I had not experienced before. I came away from our experience as a convert to what Delene Mark, CEO of HOPE Africa, calls “sustainable community development” and to the vision that sometimes the best solutions to the problems facing any community will come naturally from the community itself. I learned that nobody can do everything, but everybody can do something.”

This poignant example of affected family members and caregivers is global. Whether an individual is directly or indirectly affected, we are ALL affected. The affected are children growing up without knowing their mother or father, parents who have to look after their children, friends, partners, me and you.

## **Recommendations**

All diseases have psychological effects on people; those infected and those affected. It is most important to create a positive mind-set in those people who are living with the disease. The stigma about dying can be minimized so that people can realize that they can continue to live productive lives. Mass advertising and campaigning should be done in order for this to actually occur. Through this, more people will feel comfortable about getting tested. Psychotherapy and education are the keys.

A great amount of time, money, love and care must be given to OVCs. Children who are orphaned due to the death of a parent from AIDS are severely traumatized. Not only does the child have to deal with the death of the parent(s), but also he/she may be ridiculed and avoided by friends and other children. There are already a number of support groups in place to help people deal with HIV/AIDS, but more informal structures must be established. The formal support groups should not be the only means of support for these children. Rather, the immediate family and extended family should be well-informed and educated in order to provide basic emotional and psychological support.

Financial support is also needed. The Namibian government can offer more subsidies to infected and affected people and their families. However, this should be done in respect to the existing income level of the family. Many children who are orphaned are left to live with their grandparents, who are not financially capable of meeting their needs. These children require money for school fees, uniforms, health care, etc., and this is not possible on a pensioners’ income. Food and water must be supplied to those infected and affected, thereby alleviating at least one source of stress that is faced on a daily basis.

Culture, values and norms are lost as a result of so many HIV/AIDS deaths. Elders can help by volunteering to teach youth moral responsibilities and self-worth. The awareness of HIV/AIDS and all issues relating to it, such as the psychological impacts should be made compulsory core modules within the Namibian education curriculum. Even our teachers are ignorant. The education about this should begin at primary school.

People continue to be ignorant about AIDS as a cause of death. People must be educated to understand that HIV/AIDS weakens the immune system and that secondary infection, such as pneumonia, tuberculosis, etc. cause death. This is important because people often blame the death of people who have the HIV/AIDS virus on these other diseases and don’t accept that the person was infected. Thus, people don’t believe that HIV/AIDS can actually lead to death. Public consciousness should be raised by openly recording AIDS deaths as such, in order to educate people and to overcome the shame and stigmatization.

## **Conclusions and Personal reflections**

More emphasis must be placed on the lives and stories of the people living with HIV/AIDS, and not just on statistics. After all, the statistics are people and not just numbers. We must create a paradigm shift in thinking about HIV/AIDS.

“In Katatura Hospital, there are beds full of dying women and the caretakers are so tired, there are so many patients in the ward, they are just neglected. There is despondency on the part of the patients and the nurses. These hospital experiences are traumatic for everyone. “

“The father of a close friend got HIV as a result of an extramarital affair, and then he gave it to his wife. So my friend not only had to cope with her parents’ illness, but also with knowing that her father had an affair which caused her mother to become ill. The psychological impact on my friend to get through this was immense, and she needed easy access to counseling. HIV/AIDS affects every aspect of society now.”

“I cared for one of the domestics who worked for us and it was so depressing to watch her disintegrate.”

“I knew of someone who had an infected daughter and from the time when the daughter was diagnosed as having full blown AIDS, she was kept isolated in a hut in the village until the day she died. No one knew she had been there. The mother told her people in the village that the daughter was working in another town. You can imagine how this must have been for the mother and daughter in terms of psychological impact.”

“It is difficult to “come-out” as having HIV/AIDS because of being judged. It is not objective, *everyone in Namibia is affected*. They can only get over denial when we accept them and that they have this disease.

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