

## STIGMA AND SHAME OF HIV/AIDS IN THE LIFE STORIES OF ALPHA GROUP

Auli Vähäkangas

### STIGMA OF HIV/AIDS BRINGS SHAME

There are millions of people living with HIV/AIDS in Africa who face stigma in their lives. The stigma of being HIV positive is widely discussed theoretically in various studies on HIV/AIDS in Africa.<sup>1</sup> However, very few researchers have done empirical research among HIV positive women and men in Tanzania.<sup>2</sup> The aim of this article is to analyze first hand experience of stigma and shame among a small sample of HIV positive individuals in Arusha and to relate that experience to a wider theoretical discussion on stigma and shame.

In defining stigma, Old Testament scholar Johanna Stiebert refers to its original meaning as a physical sign, such as a cut or a burn. However, according to Stiebert, stigma nowadays is not associated with bodily evidence but rather with a quality perceived as being shameful.<sup>3</sup> However, the stigma attached to HIV/AIDS has both of these elements. There is bodily evidence, especially when symptoms of HIV-related sicknesses are visible on the body, and there is also the shame connected with the infected person even before visible symptoms appear.

Malebogo Kgalemang from the University of Botswana analyses the stigma attached to HIV/AIDS. According to Kgalemang, HIV positive persons are considered to be deviant or shameful. Their behaviour is interpreted as deviating from the normal or supposedly normal behaviour, because HIV/AIDS is linked to

---

<sup>1</sup> Among the most recent ones see for example Stiebert 2004 & Kgalemang 2004.

<sup>2</sup> MUTAN project (Mradi wa Ukimwi wa Tanzania na Norway, joint Tanzanian Norwegian AIDS project) collected empirical data on stigma in the early 1990's, see for example Lie 1996. MUTAN was given the task of developing an HIV/AIDS counselling programme for the regional hospitals of Arusha and Kilimanjaro. The project carried out a quantitative research on stigma, care and psycho-social health. See Lie 1996: 56–57, where these results are shortly reported. See also Lie & Biswalo 1994; Lie & Biswalo 1996; Klepp, Biswalo & Talle 1995.

<sup>3</sup> Stiebert 2004: 80.

sexuality, immorality and death.<sup>4</sup> Because it is understood as a result of deviant behaviour, this stigma cannot be analyzed separately from the concept of shame.

Lutheran theologian Robert Albers defines shame as a violation of one's identity as a person.<sup>5</sup> The definition of Albers is useful when evaluating the lives of HIV positive people in Tanzania. Understanding shame as a violation of identity is crucial in a transitional Tanzanian society. In this transitional society HIV positive people must cope with many different changes in relationships and in living conditions. Failure to cope successfully with the challenge of stigma leads to feelings of shame.

In African cultures, shame is interpreted as an emotional response to falling short of the social norm. In other words, shame is the feeling that one does not correspond to the culturally defined behaviour that is attached to a particular social role. HIV positive individuals are labelled with a stigma, as they did not follow proper sexual behaviour. The Swahili word for shame, *aibu*, is commonly used in everyday discourse on morality and proper behaviour. The expression *alama ya aibu*, literally the sign of shame, is used as a synonym of stigma in contemporary Swahili.

#### ALPHA SUPPORT GROUP

The data for this article was collected during three meetings of an Alpha HIV+ support group which meets once weekly at Uzima Centre, Arusha, Northern Tanzania. The three meetings were each two weeks apart in February–March, 2005. All members of an Alpha group have been tested and found to be HIV+. The leader of a group is a trained HIV/AIDS counsellor, and an employee of the Uzima Centre. The aim of the Alpha support group is to give information on how to live with the HIV virus and to give both psychological and material/medical<sup>6</sup> support to members of the group.

The specific Alpha group visited was a new group which consists of 10–20 members, most of them women. Only three regular members were men. The number of members varies from week to week depending on the health situation of the members. They were between 25–45 years of age, coming from various ethnic backgrounds. Many of them were or had been married.

---

<sup>4</sup> See Kgalemang 2004: 144, 147.

<sup>5</sup> Albers 1995: 22.

<sup>6</sup> The medical support does not include antiretroviral treatment. Uzima Centre, which is under Selian Lutheran Hospital, was not given the possibility to distribute the free ARV treatments when the Tanzanian government introduced the programme of ARV treatments at the beginning of 2005. Material support includes, for example, the distribution of beans and maize and items of personal hygiene.

Every Alpha meeting began with a call of first names in order to see who had managed to come to a meeting. If somebody was not present, the leader asked the other members whether they knew about the situation of the missing member. At other times the leader brought greetings from members who were hospitalized and who could not attend a meeting.

During the group interviews the discussion was documented by taking notes. The members kept their anonymity and the examples given in this article do not contain the participants' real names. The members were informed that the discussion would contribute to a research paper and that they could contribute or choose to remain silent. Most of them found it to be an opportunity to share and were happy that somebody wanted to learn from their life experiences.

### **PRACTICAL IMPACTS OF STIGMA**

The female narrators dominated the first discussion on stigma by eagerly telling stories from their life. These stories varied from explanations on social stigma to a horrible story on the brutal rape of one of the group members. Common examples of social stigma were associated with family relationships, colleagues at work, and situations in the neighbourhood.

Many female members had been deserted by their husbands and in-laws when their status was discovered.<sup>7</sup> Almost as many confessed that even their own relatives had rejected them. One young woman explained that her own mother had told her face to face that because she had acquired the disease herself she should take care of herself as well. The mother was neither interested in knowing how she became infected nor how her daughter was doing after she moved to Arusha.

Female members had felt stigma both in their own lives and also in the lives of their children. One mother explained that the hardest stigma was when the other children started shouting in front of her child, "do not play with her, she has HIV/AIDS!" During that time the rumours had circulated that the mother herself was HIV+ and the community concluded that this was the case with the child as well. Later on, that child was tested and found to be HIV negative but it did not help her any longer as the stigma was already attached to her. The only possible solution that this young mother could think of was to leave her village community and move to Arusha in order to have some privacy and not to be stigmatized continuously.

Several members told stories of how they had lost their jobs. Many times this had happened before they had been tested. The employer had fired these women

---

<sup>7</sup> See also Dibeela 2004: 128 on rejection of HIV positives. Moyo (2004: 130) claims that wives are often blamed for bringing the disease home and are deserted for that reason.

when they started to have some HIV related sicknesses. Similarly, many landlords had thrown these women out of their rented rooms even though they had paid their rent regularly. It seems that the stigma is so strong that many landlords are afraid of the reputation of their housing complex and most probably also afraid of how the HIV positive person and a future AIDS patient will manage the rent payments after losing their job.

The case of a mother of two small children coming from rural Tanzania exemplified the case of the strongest stigma in the Alpha group. After the death of her husband this young mother had moved to Arusha with her two small children. At first she did not have any work and her children were taken from her and placed in an orphanage. Later on she got some work helping her late husband's relative by doing his laundry and other domestic tasks. It was during one of these working days that this relative raped her brutally.<sup>8</sup> If the neighbours had not come to take her to a hospital she would not have survived. The relative of her late husband is a feared police officer and nobody dared to take an issue against him. When I met this woman she was six months pregnant due to the rape and still had health problems because of the rape. She said that her relatives and neighbours are stigmatizing her even more now that she was pregnant, and saying that she 'runs around' spreading the virus. Even the person who raped her is among those who spread the rumours of how 'loose' a life this woman lives. Additional stress in her life is how the pregnancy affects her poor health condition, and she fears losing yet another child. After the violent rape she has been very weak and cannot easily do even her normal tasks at home. Additionally she has lost her small income from domestic work.

Shame and stigma are culturally connected. Psychologist Gershen Kaufman has made a helpful analysis of the impact of culture in conjunction with the way in which an individual behaves while feeling shame. According to Kaufman, experiences of identification produce culture. Cultural identifications develop, for example, through storytelling, which, in turn, reveals community values as well as taboos to the listeners.<sup>9</sup>

Previously we defined only shame and stigma. However, we cannot separate these two from guilt. HIV positive people are stigmatised because they are expected to be guilty of sexual promiscuity. Robert Albers defines guilt as a violation of one's value system.<sup>10</sup> Brad Binau uses the basic distinction of Albers between shame and guilt and maintains that guilt makes us question our actions

---

<sup>8</sup> See Dube 2004: vi. Dube emphasizes the difficult situation of women during the time of HIV/AIDS: "With the loss of control that characterizes the HIV/AIDS atmosphere, rape has become a symptom of men's desperate search for control over women's bodies."

<sup>9</sup> Kaufman 1996: 44.

<sup>10</sup> Albers 1995: 22.

while shame makes us question ourselves as actors.<sup>11</sup> Stigma, shame and guilt are culturally connected and are often used especially against HIV positive women.

### **CULTURAL REASONS FOR THE STRONG STIGMA ATTACHED TO WOMEN**

Why all these narratives concerning a strong stigma attached to HIV+ women? The Alpha group contributed to this question by replying that anybody can suffer from stigma but it is even more common for women. The explanation is due to cultural reasons. They could not explain further as to which cultural reasons and why just those reasons amplify the stigma attached to women. These cultural reasons are so subconscious that to explain them further to an outsider was too difficult a task even for the counsellor of the group.

A possible explanation could be that HIV is connected to *heshima*, honour. The *heshima* of a woman is connected to correct moral behaviour and it is mainly related to female sexual behaviour. Honour is much more than an individual's estimation of self-worth. It is how she is viewed by society. Honour has no room for guilt. It is something which one should have in order not to feel shame within the community.

*Heshima* is a wider concept than the English word 'honour.' *Heshima* can also be translated to mean respect and dignity. *Heshima* is interpreted as an important aspect of female sexual behaviour whereas it is not very frequently connected to male sexual behaviour. Male behaviour does not necessarily have to follow the Christian sexual moral code because social status is more important for male *heshima*. A man's high social status was often traditionally reflected in polygamy, which in an urban Christian setting has often translated into having concubines. Thus, *heshima*, in connection to female behaviour, seems to refer more to personal dignity and, in connection to male behaviour, to a mark of community respect. Female behaviour is seen to be home-centred and male behaviour is oriented to the larger community.

Shame is more than a feeling of an individual in communal African cultures. Women, who bear the family's honour through their respectful sexual behaviour, are the protectors against family shame. HIV/AIDS imposes shame on the natal family of an HIV+ wife. Honour and shame are especially crucial elements in rural Tanzania where face to face relations are dominant. The HIV positive people living in urban Arusha do not face as strong a shame as those who live in the villages.

Robert Albers defines dishonour as a shame dynamic. He maintains that dishonour has to do with being stripped of a sense of dignity and integrity. The

---

<sup>11</sup> Binau 2002: 95.

result of dishonour, according to Albers, is a horrible humiliation.<sup>12</sup> Only those deeds which are openly known bring dishonour to an individual in the Tanzanian community. The fear of being cut off from the family and the larger community is a vital threat. Brad Binau has similar findings that shame implies abandonment and the threat of being treated as an outsider.<sup>13</sup> Being an outsider in Tanzanian society indicates not only social stigma but it means also economic and practical hardships.

The shame of being HIV positive is a stigma for life, as was seen in the narratives of the social, economic and marital desertion of female members of the Alpha group. Many western writers introduce a policy of openness as a recipe to reduce stigma.<sup>14</sup> The issues of shame and guilt are key concerns when trying to overcome stigma in the AIDS crisis but, from my point of view, these feelings should be managed within the context of African culture rather than promoting western ways of discussion.

The Alpha group members stressed that HIV positive people are stigmatized if their status is known to the community. This is one reason why the slogan 'be open to talk about HIV/AIDS' is not followed by the Alpha group members.<sup>15</sup> Openness is a fine idea but how could that work in a society where culture supports one keeping the family secrets? The culturally proper behaviour of an adult person is to keep the secrets of the family. Only those problems which are widely known are openly discussed. In my opinion there has to be a change in the culture first, and only after that can we recommend that HIV positive people be more open. In some exceptional cases the policy of openness has become an individual coping strategy for HIV positive men. One such man visited the Alpha group during my last visit. For him openness was a way to find financial and psychological support.

### CHURCH AS A HEALING COMMUNITY?

Various theological writings promote the church as a healing community for those infected and affected by HIV/AIDS.<sup>16</sup> What is the reality on the grass-root level? Is the church a healing community in the lives of HIV positives in Arusha?

---

<sup>12</sup> Albers 1995: 47.

<sup>13</sup> Binau 1989: 132.

<sup>14</sup> Stiebert 2004: 81; Lindqvist 2003: 8; *HIV and AIDS Curriculum for Theological Institutions in Africa* 2002: 14.

<sup>15</sup> Kgalemang 2004: 151 shares a similar experience in the Botswanan context. Stiebert 2004: 81 has an idealistic view that openness can change a culture. According to Stiebert, the starting point has to be an open discussion on sexuality.

<sup>16</sup> See for example *Facing AIDS* 2002: 77–92.

The members of the Alpha group came from various denominations. Some were active members of Lutheran and Catholic churches; others belonged to their churches but were not active members in them. Many members did not have any experience of the attitude of the church community towards them as HIV positive people simply because they had not revealed their status to their churches. Others had negative experiences, and, in fact only one member gave a testimony of her home parish as a healing and caring community.

The person giving a positive example of her caring church community was a leading figure in the group. Her behaviour showed self-respect and a respected status in the community. She had a close relationship with her home parish, and after the death of her husband she had openly told the church workers that her husband had died of AIDS and also that she had been infected by her husband. Important for her was that she was not guilty of sexual misbehaviour. It was her husband who had brought the infection to her. After that she had been regularly visited either by the church workers themselves or by the church elders of her Lutheran parish. During these visits she had received psychological, spiritual and financial support. She advised the other members of the Alpha group to contact their parishes in order to receive similar support.

Among those who had negative experiences was a young woman who went to discuss her situation with the pastor of her home parish in a small village. After this discussion she found out that the wife of that pastor had spread the information to others in the village. Her experience of the lack of confidentiality led her to advise the other members of the Alpha group not to be open in the church community.

One male member of the Alpha group had gone to discuss his situation with the Roman Catholic priest. According to his explanation, this priest had been confused by the discussion and the only advice he could give was that the congregant should start fasting and this would give him direction for what to do.<sup>17</sup> The HIV positive person had not followed this advice and did not return for further counselling.

Another concern of revealing one's status is that the members are afraid of being put under church discipline, and if they are still under it during the time of death they cannot be buried by the pastor. Instead of serving as a healing community, the church sometimes acts as a persecutor that uses church discipline as a penal code against members infected with HIV.<sup>18</sup> Oppression by the church is not

---

<sup>17</sup> See also Dube 2004: v. Musa Dube raises a concern on the counselling skills of ministers in an HIV/AIDS context. She mentions that most of the ministers serving now in congregations never learned about HIV/AIDS in their theological training programmes.

<sup>18</sup> For similar comments on the attitude of the church community towards HIV positives, see, for example, *Facing AIDS* 2002: 77.

only life long but it can also be perceived as a condemnation after the death of HIV positive individuals.

Another weakness in African church communities is the negative attitude towards sexuality. Sexuality as such is viewed in a negative light and it is not allowed to be discussed openly in churches.<sup>19</sup> Again, it is difficult for churches to start open discussion on sexuality when local cultures prohibit discussion on it or traditionally have only few channels like puberty initiation education to discuss sexuality. However, most of these rituals have been abolished by the coming of Christianity.

Because of the strong stigma, the church community often does not give support to those living with HIV/AIDS. Where do these people then find a community of support?

### ALPHA SUPPORT GROUP VERSUS AFRICAN COMMUNAL SUPPORT

In contemporary Tanzanian society, traditional communal support doesn't seem to work effectively in regards to helping those affected by HIV/AIDS. The lack of communal support presents a strong need for formal support from groups such as the Alpha group. An extreme example of this need for formal support was seen during my last visit to the Alpha group. A female member of the observed Alpha group took into her rented housing another member who had lost her rented room. There seemed to be no ethnic reasons nor close friendship in this case but only the desire to share a similar situation and the willingness to help.

HIV positive people face enormous stigma. Top down propaganda promotes the policy of openness on sexuality and the discussion of HIV/AIDS. The findings from the grass-root level in Arusha show, however, that there are many obstacles to overcome before this policy of openness can work in the everyday life of HIV positive people.

### BIBLIOGRAPHY

- ALBERS, Robert H. 1995. *Shame, a Faith Perspective*. Binghamton, NY: The Haworth Press.
- BINAU, Brad A. 1989. Shame and the human predicament. In: Leroy Aden & David G. Benner (eds.), *Counselling and the Human Predicament. A Study of Sin, Guilt and Forgiveness*: 127–143. Grand Rapids, Michigan: Baker Book House.
- 2002. When shame is the question, how does the atonement answer? *Journal of Pastoral Theology* 12(1): 89–113.

---

<sup>19</sup> See Dube 2004: vi; Maluleke 2004: 135; Khathide 2004: 5–6. All these African theologians see the churches' negative attitude towards sexuality as hindering the healing process in these communities.

- DUBE, Musa W. 2004. Introduction: AfricaPraying. In: Musa W. Dube (ed.), *AfricaPraying, a Handbook on HIV/AIDS Sensitive Sermon Guidelines and Liturgy*: v–x. Geneva: World Council of Churches.
- DIBEELA, Moiserale P. 2004. Stigma: “neither this man nor his parents sinned” In: Musa W. Dube (ed.), *AfricaPraying, a Handbook on HIV/AIDS Sensitive Sermon Guidelines and Liturgy*: 128–130. Geneva: World Council of Churches.
- Facing AIDS; the Challenge, the Churches’ Response* 2002. A WCC Study document. Geneva: WCC publications.
- HIV/AIDS Curriculum for Theological Institutions in Africa* 2002. Geneva: WCC.
- KAUFMAN, Gershen 1996. *The Psychology of Shame; Theory and Treatment of Shame-Based Syndromes*. NY: Springer Publishing Company.
- KGALEMANG, Malebogo 2004. Deconstructing the HIV/AIDS stigma. In: Musa W. Dube & Musimbi Kanyoro (eds.), *Grant me Justice! HIV/AIDS & Gender Readings of the Bible*: 141–168. Maryknoll, NY: Orbis Books.
- KHATHIDE, Agrippa G. 2004. Teaching and talking about our sexuality: A means of combating HIV/AIDS. In: Musa W. Dube (ed.), *HIV/AIDS and the Curriculum, Methods of Integrating HIV/AIDS in Theological Programmes*: 1–9. Geneva: WCC publications.
- KLEPP, K. I., P. M. BISWALO & A. TALLE 1995. *Young People at Risk: Fighting AIDS in Northern Tanzania*. Oslo: Universitetsforlaget.
- LIE, Gro Therese 1996. The Disease that Dares not to Speak its Name. Studies on the Factors of Importance for Coping with HIV/AIDS in Northern Tanzania. Diss. Bergen: University of Bergen.
- LIE, Gro Therese & P. M. BISWALO 1994. Perceptions of the appropriate HIV/AIDS counsellor in Arusha and Kilimanjaro regions of Tanzania: implications for hospital counselling. *AIDS CARE* 6(2): 139–151.
- 1996. HIV-positive patient’s choice of a significant other to be informed about the HIV-test result: findings from an HIV/AIDS counselling programme in the regional hospitals of Arusha and Kilimanjaro, Tanzania. In: *AIDS CARE* 8(3): 285–296.
- LINDQVIST, Martti 2003. Living in the shadow of the Evil: Theological encounter with taboos, guilt and shame in the context of HIV/AIDS pandemic. In: CUAHA workshop, Dar es Salaam, Tanzania, 1–6 September.
- MALULEKE, Tinyiko S. 2004. The gifts of sexuality: ‘Let him kiss me...’ In: Musa W. Dube (ed.), *AfricaPraying, a Handbook on HIV/AIDS Sensitive Sermon Guidelines and Liturgy*: 133–135. Geneva: World Council of Churches.
- MOYO, Fulata L. 2004. Gendered stigma. In: Musa W. Dube (ed.), *AfricaPraying, a Handbook on HIV/AIDS Sensitive Sermon Guidelines and Liturgy*: 130–133. Geneva: World Council of Churches.
- STIEBERT, Johanna 2004. Women’s sexuality and stigma in Genesis and the Prophets. In: Musa W. Dube & Musimbi Kanyoro (eds.), *Grant me Justice! HIV/AIDS & Gender Readings of the Bible*: 80–96. Maryknoll, NY: Orbis Books.

