

## **Experiences of Emotional Abuse among Women Living with HIV and AIDS in Malawi**

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*Our aim for this study was to describe emotional abuse as it is experienced by women living with Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in Malawi. The study was conducted in Lilongwe district in Malawi and used a descriptive phenomenological approach. Twelve women from two public healthcare clinics under the Lilongwe District Health Office were interviewed. Violating experiences that scarred the personhood and inherent value of being human were found to be the essence of their emotional abuse. Their husbands, family and community members were responsible for the humiliation, abandonment and blaming that caused them to feel hopeless.*

### **BACKGROUND**

Globally, 33 million people were living with HIV as of 2008, of whom 30.8 million were adults and 2.2 million were children (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2008). The worst affected region was sub-Saharan Africa, with 22 million people living with HIV/AIDS. Women accounted for 50% of all adults with HIV infection worldwide, 59% of whom lived in sub-Saharan Africa (UNAIDS, 2008). In Malawi, HIV prevalence among adults aged 15-49 years was 11% in 2011 (National Statistics Office [NSO] & ICF Macro, 2011).

Being diagnosed with HIV is a traumatic event that involves emotional distress (Theuninck, Lake & Gibson, 2010). The distress is aggravated when abuse is experienced from those whose support is required by the person who has been diagnosed. Violence and HIV infection are often linked in a complex relationship (van Rensburg, 2007). Researchers have shown that women who are in abusive relationships are more likely to be HIV infected while HIV infection increases the likelihood of being abused by husbands/partners (Ramachandran, Yonas, Silvestre & Burke, 2010; Campbell, Baty, Ghandour, Stockman, Francisco & Wagman, 2008). The disclosure of HIV/AIDS often results in emotional abuse (Medley, Kennedy, Lunyolo & Sweat, 2009). Women are also often blamed for bringing

HIV/AIDS into the family (Ndinda, Chimbwete, McGath & Pool, 2007), particularly if they are the ones who are tested first, usually through programmes for the prevention of mother-to-child transmission of HIV.

Women in Malawi bear the burden of HIV/AIDS more than their male counterparts. They have little access to formal education and income-generating opportunities; are financially dependent on their partners/husbands; and are often forced as a result of their inferior status in society into unprotected sex (Kathewera-Banda, Gomile-Chindyaonga, Hendricks, Kachika, Mitole & White, 2005). The Malawian society to a large extent is permissive of multiple and concurrent sex partners for men and condones the exploitation of women by tolerating gender-based violence (Ministry of Women and Child Development, 2005). Low education levels for girls in Malawi leads to early marriages and multiple pregnancies, that contribute to the high fertility rate (of 5.7 children per woman) in the country (NSO & ICF Macro, 2011).

Malawi is a low-income country characterised by a heavy burden of communicable diseases and high levels of child and adult mortality, with non-communicable diseases on the increase (Zere, Moeti, Kirigia, Mwase & Kataika, 2007). The life expectancy is only 44 years (NSO, 2011). The HIV prevalence rate for men 15 to 49 years is 8% and the HIV prevalence rate for women 15 to 49 years is 13% (World Health Organisation [WHO], 2011). More women than men in Malawi have HIV/AIDS. Women who are dependent on their partners/husbands for financial means are powerless to reject their partner's risk behaviour of having concurrent multiple sex partners (Jewkes & Morell, 2010) and to negotiate the use of condoms (Kaufman, Shefer, Crawford, Simbayi & Kalichman, 2008). When girls get married at very young ages, their husbands are usually many years their senior (Higgins, Hoffman & Dworkin, 2010). The discrepancy in age increases their risk of infection, as their husbands are likely to be already infected with the virus from previous sex partners (Higgins et al., 2010).

The low societal status of women in Malawi contributes to their vulnerability to HIV/AIDS and exposure to abuse. Physical abuse leaves signs that can easily be detected by doctors and nurses, while emotional abuse leaves hidden scars. There is also very little information on how women living with HIV/AIDS experience emotional abuse from partners/husbands, family and community members. Very little research has been done regarding women living with HIV/AIDS in Malawi. Only two recent articles could be sourced. One of the studies focused on sexual violence and women's vulnerability to HIV infection (Kathewera-Banda et al., 2005) and the other on techniques to be used in research on women living with HIV in Malawi (Mkandawire-Valhmu & Stevens, 2010). This paper contributes to the literature by exploring the experiences of Malawian women who live with HIV/AIDS and who suffer abuse. The women in this study had the opportunity to share their personal stories of painful experiences of emotional abuse.

## METHODS

In this qualitative inquiry, we used a descriptive phenomenological research approach. Female patients from two clinics of the Lilongwe District Health Office in Malawi that provide primary healthcare to communities from both rural and urban settings were involved in the study. Due to budgetary constraints patients had very limited access to counselling and other psychosocial support at the clinics. Care was mainly focused on the physical needs of the patients.

Female patients who used services for anti-retroviral treatment at the two clinics and who had reported episodes of emotional abuse to the nurses, who were 18 years and older, who had been in a relationship, who had been known to be living with HIV/AIDS for at least one year, and who were willing to describe their experiences of emotional abuse were invited through the nurses at the clinics to take part in the study. Once they had agreed to participate they were introduced to the first author who explained to them what the research was about. Informed consent to the research was obtained from each participant.

In-depth unstructured individual interviews in the local language (Chichewa) that lasted an average of 45 minutes were conducted by the first author with 12 participants in a private venue at the clinics after the women had consented to participate in the research. The participants were invited to tell the first author about the emotional abuse that they had experienced. She used probing questions to encourage them to give a comprehensive description of what they were exposed to. Data were collected over a period of one month in 2011 and all the interviews were audio-taped with the permission of the participants. The data collection was terminated when no new information was obtained.

The recorded interviews were transcribed and translated into English. A colleague of the first author conversant in both Chichewa and English checked the translation to ensure that there was no loss of meaning in the translation.

Data analysis was guided by the processes described by Collaizi (cited in Streubert and Carpenter, 2011) and Dahlberg, Dahlberg & Nyström (2008). The transcriptions of the interviews were analysed to identify the essence of the experience and the associated constituents (Dahlberg et al., 2008). Much time was spent reading and re-reading the transcriptions to get a clear overall understanding of the experiences of the participants (Holloway & Wheeler, 2010) that phenomenologist researchers refer to as the ‘initial whole’ of all the experiences of all the participants (Carlsson, Dahlberg, Lützen & Nyström, 2004). The data were thereafter divided into meaning units, clustered together according to similar meanings and summarised in the essence that constituted the ‘new whole’ of the experiences (Dahlberg et al., 2008).

Through eidetic reduction the natural dimension of the experiences of the participants (the concrete way abuse happened) was replaced by the phenomenological dimension (an understanding) of the experiences (Finlay 2002). Eidetic reduction refers to the process through which researchers look beyond what is observed to identify the meaning of what has been observed (Zahavi 2003). The researchers remained susceptible to the reality of the

experiences of the participants to get the feeling of what it would be like to go through similar experiences (Wojnar & Swanson 2007). Through intuiting we managed to get a sense of what it must be like to be in their position (Kumar, 2012) as intuiting urges researchers to pay attention to what is immediately given to them in the situation (Hintikka, 1995). The researchers bracketed all pre-understanding and own perspectives about the phenomenon (Giorgi, 1997). We started with a concrete example of the phenomenon (emotional abuse of women living with HIV/AIDS) and imaginatively varied it in every possible way to identify the features that are incidental and those that are essential (Wertz, 2005) to describe the essence of the phenomenon.

### **TRUSTWORTHINESS OF THE FINDINGS**

The researchers used bracketing of their pre-understanding of the emotional abuse that women living with HIV/AIDS are exposed to and ensured throughout the interviews and data analysis that the essence of the experiences of the participants was revealed as it was experienced by them (Flood, 2010). Once the essence and supporting constituents were formulated, ‘un-bracketing’ enabled the researchers to re-integrate the findings into the study context and the existing literature (Gearing, 2004). Quotations from the verbatim transcription of the interviews were used to substantiate the constituents that support the essence of the experiences.

### **ETHICAL CONSIDERATIONS**

The Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria and the Research and Ethics Committee of the University of Malawi approved the study protocol (documents 199/2010 and P.01/11/1028). Written permission from the responsible officer to conduct the research in clinics of the Lilongwe District Health Office

was obtained and all the participants gave informed consent to take part in the research and to have the interviews audio-recorded.

## **RESULTS**

The oldest participant was 35 years and the youngest 24 years at the time of the interviews. Eight participants had completed primary school education and four participants had completed secondary school education. Only one participant was divorced while the others were married but had been deserted by their husbands.

The essence of the emotional hardship of the participants is best described as “violating experiences” that originated from husbands, family and community members. The women had to endure unacceptable treatment by their loved ones and communities. The emotional violations scarred their personhood and they felt that they had lost the inherent value of being human. They were excluded from friendship and supporting family relations. Family and community rejection was repeatedly reinforced and gave rise to their sense of marginalisation and left them vulnerable. Instead of others helping them to build a sense of self-worth, the participants experienced incidents that curtailed the same.

The majority of the violating experiences appeared in the close interpersonal relationships the women had. It made them feel insecure and without any positive future expectations. The support that they required for emotional survival was withheld and they doubted whether they would be able to cope with the HIV/AIDS.

The constituents that substantiated the essence were the humiliation, abandonment and blaming that the participants experienced and the hopelessness that they developed.

## **Humiliation**

Family members often initiated the humiliation that the participants experienced from other people by either showing the participants' anti-retroviral medication to their friends: "*he takes the medicine and shows it to them*" or by telling others about the participants' positive HIV status: "*they started publicising to others outside our household*". Irrational fears of contagion by the family members caused severe humiliation: "*they say it is important not to share food with them* (HIV-positive women)" while some family members wanted them to leave: "*tell her to go; we don't want her here.*"

The participants' husbands humiliated them by rejecting them as sex partners: "*he even brings prostitutes in our house when I am there*" and as carers of the family: "*every time I serve food for him he would break the plates, throwing away the food.*" These demeaning experiences were extended to suspicions that the participants were unfaithful to their husbands and had had sexual relationships with other men: "*he was saying I am a whore and it is because of that, that I got infected.*"

In the community, alliances were created against the participants. Everyday activities, such as going to the communal water point, turned into difficult tasks because the community members found such activities to be an opportune time to verbally attack them: "*they make comments that are hurtful*". Others were warned not to interact with them: "*don't chat with so and so because she has got HIV*". Visible activities that may be linked to having HIV/AIDS such as bottle-feeding of babies were often the cues that neighbours used to start rumours. When one of the participants decided not to continue breastfeeding her baby her neighbours started gossiping about her: "*the problem that I was experiencing is from the neighbours who said this one must have the virus.*" The humiliation that the participants experienced violated their sense of belonging to a family and community.

## **Abandonment**

Contrary to the expectation of being supported, the participants found that their husbands attempted to distance themselves from the situation and stated that they have nothing to do with the participants having HIV/AIDS: “*that is your problem, it does not concern me.*” The men were not willing to be involved with the participants in any way. The participants’ health status was not their problem or concern. Their initial response when they became aware of the participants’ HIV/AIDS status was to leave them: “*his first reaction when I told him about my (HIV) status was to end the marriage.*” The participants were deserted and left to fend for themselves: “*the same month he left our house to marry another wife.*” Their ex-husbands did not carry on supporting them and their children financially and they were left without money to buy food and clothes: “*when the money had run out, I started living a difficult life.*” Without the money that they had previously received from their husbands they could not access food or shelter. ‘*Living a difficult life*’ meant for them that they had to struggle to meet their very basic needs.

The participants could not turn to their own families, as the disclosure of their HIV/AIDS status had resulted in their abandonment by their families: “*at my father’s village they said that they did not want anybody with HIV. Even when I go to the village nobody shows happiness to see me.*” Their families rejected them. When they required support from their families, it was not forthcoming: “*even when I was admitted at the hospital, none of my relatives came to see me*”.

Traditionalist African families in Malawi pay a bride price (lobola) to the family of the bride when the marriage is arranged and thereafter the married woman becomes a member of the family of her husband (Mwambene, 2010). In the case of one of the participants her family used this cultural practice to abandon her. When she wanted to return to her family after her husband has chased her away they did not welcome her return to them: “*they told me that because they received ‘lobola’ I cannot stay*”. She was pushed from one place to the other,

like a destitute: “*The abuse that I am facing is of not having a place.*” One of the participants’ major concerns was the care of their children when they were too sick to take care of them. Their husbands deserted them and their family members did not want to be involved: “*when I was sick there was nobody to help me with looking after the child.*”

The participants could also not rely on their in-laws as none of them experienced any support from their in-laws. Instead the in-laws discriminated against them: “*my in-laws discriminate against me.*” When they tried to show to their in-laws their need to belong to their family, they were told that they would “*give them the disease (HIV/AIDS).*” When the families-in-law were approached to help to solve intra-marital problems, they did not respond: “*I went to his aunt and told her, but she didn’t do anything.*” Their in-laws abandoned them.

### **Blaming**

When a person gets diagnosed with HIV/AIDS the newly diagnosed person often becomes a scapegoat. The participants were thus accused of infecting their husbands. Such allegations were made without any proof to substantiate them: “*I think he blamed me for being the one who infected him with the virus.*” The women get the blame only because they are usually the first in the relationship to go for HIV testing. Men are reluctant to get tested even though they may be the ones engaging in risky sex behaviours: “*he is always talking about me and where I got the virus from; when I tell him to go for testing he refuses.*” The blame added to the emotional turmoil experienced by the participants. They had to come to terms with their husbands’ accusations and they had to carry the burden of having HIV/AIDS without their support.

The participants were also forced to blame themselves for having HIV/AIDS as well as for being emotionally abused. The self-blame was a result of unfair comments that were made about them. They internalised the blame from others and started using it against themselves

and held themselves responsible for other people's actions. Eventually they were not able to stand up for themselves because they felt helpless and at fault: "*I might be found to be in the wrong...*"

### **Hopelessness**

As a coping mechanism the participants hoped that the end of their lives was not imminent. They had the unfortunate circumstances of dealing with people who destroyed such hopes, by making statements that insinuated that the women's lives were over: "*he told me since you have the disease you are already dead.*" Instead of adding to the voices of reason and instilling hope in the participants to live positively with HIV, they were constantly reminded of how they were dependent on medication to stay alive: "*they say that we are alive because of ARVs (antiretroviral medication). We are just waiting for the day to die.*" Comments like these destroyed the participants' hope of having any meaningful future, where plans can be made and realised: "*I can't see the future; I just live one day at a time.*"

The participants saw themselves as doomed to death and that there was nothing they could do about it. Feelings of hopelessness developed and made them see no future and to consider suicide as an only option: "*what I want is to throw myself in the well.*"

The desperation of the situation and the sense of having no escape from it, compounded by the emotional abuse, prompted suicidal ideation among the participants. In these cases, suicidal ideation provided a comfort zone where the participants imagined that their suffering might be resolved. Yet they were troubled by the fact that they were contemplating suicide. Taking one's own life is considered to be evil in African culture. It went against their beliefs: "*this is very difficult and it can make me tempted (to commit suicide); maybe if they continued to abuse me I would think evil (I would think) about taking poison .... Now if I don't pray for a long time how can I defeat the devil? How can I be strong?*"

Seemingly, relying on prayer is thought to be important in defeating the temptation of considering suicide. In contrast, it is the lack of support and insensitivity of the people surrounding the women that drive them to consider suicide as an option for dealing with their problems.

## **DISCUSSION**

Through humiliation people's dignity becomes violated (Statman, 2000) and stripped away (Killmister, 2009), leaving them feeling disrespected (Malterud & Hollnagel, 2007). When the humiliation happens as a result of the betrayal of husbands, family and community members the detrimental impact on the self-esteem of the victims becomes worse (Parse, 2010). People's personal sense of worth is greatly shaped by what other people think of them, what they say about them and the treatment that is received from them (Statman, 2000). When people are degraded, devalued or are perceived to be unworthy of the love of others, they isolate themselves from others (Reyles, 2007) in order to protect themselves from further humiliation. Significant others may also abandon them through acts of rejection (Malterud & Hollnagel, 2007) that leaves the victims without support (Reyles, 2007).

Abandonment, as it has been experienced by the participants in this study, was a threat to their survival as human beings, because of the importance of social ties and connectedness for psychological well-being (Eisenberger & Lieberman, 2004). Supportive relationships act as buffers to emotional hardship. The sharing of problems with significant others helps people to find solutions to problems and it lowers their anxiety levels, as they do not feel alone in the situation (Vanderhorst & McLaren, 2005). They have a support system to rely on. When people are abandoned and ostracised their sense of belonging is damaged by the disconnectedness with significant others (Barroso & Powell-Cope, 2000). When the soothing presence of others is lost, distress and pain are experienced (Eisenberger, Lieberman & Kipling, 2003).

The participants were abandoned by their husbands, family and community members to fend for themselves. For women living with HIV/AIDS, abandonment results in the loss of reliable sources of economic support and love, which is seriously needed when one is dealing with the physiological challenges associated with having HIV/AIDS (Carr & Gramling, 2004). Inadequate resources have negative repercussions. Abandoned women may not be able to meet the demands required to sustain healthy living, such as good nutrition, good living conditions and adherence to treatment (Liamputong, Haritavorn & Kiatying-Angsulee, 2011).

Abandonment could also result in a loss of identity. The participants' identity as wives and the social status associated with being a wife could be compromised. This loss of identity and status may be severe when a woman is defined by being partnered or is dependent on her husband (de Sousa, 2010). The participants lost their status as wives in their community because their husbands had deserted them. This loss of status equates to suffering disgrace, humiliation and shame. It becomes difficult to survive psychologically as a result of the loss of attachment that provides support (Adshead, 2010). Abandoned women therefore tend to mourn the loss of such relationships in addition to worrying about future losses that may occur in potential relationships because of having HIV/AIDS and enduring the stigma associated with it (Peterson, 2010).

Abandonment is a form of social exclusion. Persons are made to feel that they are not welcome or that they do not belong. The participants were made to believe that their families, their families-in-law or their communities did not want to be associated with them. In this case severe harm was sustained by their unmet needs for social connectedness (Eisenberger et al., 2003). When people get isolated from their significant others, they develop poor self-esteem and feel worthless (Klein, 1991) to the extent that they believe that they cannot control their circumstances (Teitelman, Seloilwe & Campbell, 2009). The participants in this study were made to feel that they were not only worthless, but that they were also to be blamed for their negative interpersonal experiences.

In many contexts, having HIV/AIDS is associated with sexual promiscuity. The affected person is blamed and shamed, which implies that they are perceived to have been involved in what is considered deviant and unacceptable behaviour (Nepal & Ross, 2010). The emotional abuse that the participants suffered from their family and friends might have been a part of shaming and blaming. Women who live with HIV/AIDs are often called names and are told that they are worthless (de Sousa, 2010) and blamed for becoming burdens to their families (Maman, Abler, Parker, Lane, Chirowodza, Ntogwisaangu, Srirak, Modiba, Murima & Fritz, 2009). The participants were blamed for having brought the virus to the family and were perceived as sources of infection for their husbands and other members of the family. The blame culture that women with HIV/AIDS experience from their husbands is often related to the broader social and cultural context of their societies (Thapar-Bjorkert & Morgan, 2010).

Blaming of other people often relates to the ‘othering’ dynamic in cultures and societies (Petros et al., 2006). People assume that what happened to other groups cannot apply to them. In the context of HIV/AIDS, this ‘othering’ could present as placing blame on certain people for being high-risk groups, for potentially being infected with HIV and for being responsible for spreading the virus to others. Women are easily blamed and ‘othered’ because they are the weaker sex and they are predominantly dependent on their male partners for support (Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown, 2006). It is also believed that the disproportional occurrence of HIV/AIDS in females compared to males (WHO, 2011) adds to the ‘othering’, as women may be considered dirty and immoral. It is the blaming and ‘othering’ that lead to their abuse and public shaming (Maman et al., 2009).

When people feel powerless, such as the participants of this study, they tend to develop self-blame. When the people with the power – who considered themselves healthy in this case and therefore even more powerful – blamed the participants, they started to believe the ‘powerful’ people (Laverack, 2009) and started blaming themselves. They became

'blameworthy' and took the responsibility of their abuse while their family, friends and community were not held accountable for their actions.

Self-blame involves a feeling of being responsible for the negative actions of other people (Coffey, Leitenberg, Henning, Turner & Bennet, 1996). Theories of control and counterfactual thinking can be used to explain the self-blame of the participants (Miller, Markman & Handley, 2007). They experienced a sense of loss of control over themselves and their behaviour although the incidents of abuse by others were not in any way related to their behaviour. Owing to not feeling in control participants assumed that they could have contributed to the abuse. Their counterfactual thinking linked them to the abuse as if they had caused it. They resorted to 'if only' utterances, which only perpetuated and convinced them that they were indeed to be blamed for the abuse. According to Miller et al. (2007), people who blame themselves are more likely to relinquish their attempts at control of their circumstances in order to guard against future negative incidents. Our participants might have lived with hope for a bright future if they had not abandoned controlling the life circumstances that developed from the HIV/AIDS diagnosis.

People with hope have a sense of meaning and purpose in life and they know that they can cope with disruptive events (Tutton, Seers & Langstaff, 2009) and that life is worth living in the present and in the future (Kylma, Vehvilainen-Julkunen & Lahdevirta, 2001). When people's hope is violated they are left without the option of making their own choices (McClement & Chochinov, 2008), as they do not believe that their actions can have positive outcomes (Kneisl & Trigoboff, 2009). Neither can they mobilise the energy that it takes to make decisions and to execute these decisions (Carpenito, 2000). Hopeless people have given up on life and no longer try to improve their circumstances (Kylma et al., 2001). People's hope can be violated through the harsh and uncaring treatment of other people (Dunn, 2005), such as in the case of emotional abuse. The hope of survival of the participants was destroyed when their families and communities rejected them and told them

that they did not have a future. Participants were made to expect negative outcomes concerning their lives through the comments of other people that their death was imminent because they had HIV/AIDS. Participants believed these pronouncements and concluded that they had no future to look forward to, as there was nothing they could do to change their situation for the better.

Suicidal ideas are nurtured when people are not supported by their significant others, when they do not foresee a future for themselves and when they do not believe that their circumstances can change for the better (Preeau, Bouhnik, Peretti-Watel, Obadia & Spire, 2008). The participants considered suicide because they believed that they had no solutions to their problems. Their families and communities did not support them and they were blamed for their hardship. They also suffered severe financial problems when their families rejected them. According to Vanderhorst & McLaren (2005), women who are lonely and have financial challenges often consider suicide as a solution. The financial insecurity that the participants suffered, in addition to the ongoing abuse that they were exposed to, made them feel hopeless and want to end their misery through suicide.

## **CONCLUSION**

In this study, women living with HIV/AIDS encountered violating emotional experiences from their husbands, families, and communities. They were exposed to humiliation, abandonment and blaming and were made to feel hopeless to the extent that they considered suicide. Their abuse was linked to their position of being females in male-dominated societies and the ignorance of people about the spread of HIV. They were considered as different from their family members and they became the 'others' that could be blamed for their own misery and for bringing 'the virus' to the family.

## **LIMITATIONS AND STRENGTHS**

The study participants were drawn from a specific area in Lilongwe district; therefore, the results may not be generalised to portray the experiences of all women living with HIV/AIDS in Malawi. The findings of this study might be useful for healthcare teams who render services for women living with HIV/AIDS in Africa to identify the occurrence of emotional abuse of their patients.

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