

The Painkiller: Experience of an HIV Positive Ethiopian Woman in A Discordant Sexual Partnership

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Abstract

This study was designed to examine the life experience and associated meanings of an HIV-positive woman living in a discordant sexual partnership. The findings illuminate aspects of the living condition of an HIV positive discordant woman and indicate base-line information that may be considered in designing programs. The participant in this single-case study was selected purposefully based on a selection criteria developed in advance. Following three successive semi-structured interviews, six themes were identified: HIV discordant marriage, partner's behavior and HIV/AIDS, the ART, pre-term care and infant's HIV status, family members' attitudinal change, and supporting PLWHA. Findings indicated that the informant experienced both positive/sympathetic and conflicting/susceptible meaning and feelings.

Key Words: HIV, discordant, married couple, woman, life experience

Introduction

Ethiopia is one of the Sub-Saharan African countries where the disastrous effect of HIV/AIDS is heightened. According to UNAIDS (2008), in 2007,

1.1 million people in Ethiopia were living with HIV/AIDS and the national adult HIV prevalence rate was 2.2%.

Heterosexual intercourse and mother-to-child transmission are the two major routes of HIV transmission in the country (Berhane, Mekonnen, Seyoum, Gelmon, & Wilson 2008). Adults' major route of contracting HIV is sexual intercourse. Though there have been some improvements, society's attitude towards HIV and AIDS is not significantly changed (UNAIDS 2003).

Even if HIV/AIDS is among the most extensive chronic health problems, it is differentiated from such problems by the associated stigma and discrimination people living with the virus experience. Since sexual contamination is the main route of HIV transmission and the society believes AIDS is a punishment for immoral behavioral acts (Tangenberg 2000), individuals with HIV and AIDS have faced negative societal connotations (Goffman 1963 cited in Kittikorn, Street & Blackford 2006) and denial of equal treatment (Smith 2001). But, whether it is due to the observed improvements in attitude towards HIV-infected people (HAPCO 2006); it is within this society that couples with discordant HIV status are found. About 2% of over 2,674 cohabiting couples tested for HIV in the 2005 demographic and health survey (DHS) were found to be HIV discordant (Berhane et al 2008). A portion of these couples noticed their discordance after some years of their marriage during pregnancy follow-ups or as a result of the DHS. Others get married knowing their discordance in advance.

One may take the opinion that the existence of discordant couples, especially couples who get married with the knowledge of their HIV status in advance, could reflect the reduction of stigma and discrimination within part of the

society. However, this population is at a greater HIV risk and the probability of both parents becoming infected (concordant) is high unless they exercise safe sexual practices. According to Berhane et al. (2008), discordant couples are among the six most risky populations for HIV transmission in Ethiopia.

Beyond the associated risks for HIV, discordant couples may exercise different life experiences including the difficulty of uniformity in thinking. The most expected deviation that could be observed between discordant couples is the need for reproducing themselves - one partner may believe marriage is a means of reproduction and want to fulfill it, while the other may be scared of the transmission of the virus and favor protected sex.

While human beings are egocentric in nature and have the desire to live a life with no or minimal risk, many HIV negative individuals reach a decision of forming sexual partnership or marriage with people living with HIV. Especially, the marriage of an HIV positive woman with an HIV negative man seeks the attention of researchers as such marriage increases the domestic service and responsibility of men which is not the culture in most parts of Ethiopia. As a result, women may exercise different life experiences. And as few studies have examined the experiences of women in such marriages, this study was designed to examine the experiences and associated meanings of an HIV positive woman in a discordant marriage. Thus this study was designed to answer the question: What are the life experiences and associated meanings of an HIV positive woman in a discordant sexual partnership?

Research Methods

An instrumental case study was conducted to explore the life experience and associated meanings of being an HIV positive woman in a discordant couple. In order to achieve the research objective, a married woman living with AIDS whose husband is clinically identified as HIV negative was purposefully selected. The participant was selected from a set of individuals in the interest group following selection criteria that were developed in advance. The criteria to participate in this study required an individual to be an Ethiopian married woman, living with HIV/AIDS, having an HIV negative husband, willing to participate in multiple interview sessions, and having the ability to communicate her life experiences and corresponding meanings freely.

A health center in 'Lideta' sub-city of Addis Ababa, which was acknowledged for its HIV/AIDS related case follow ups and in establishing a model Mother-to-Mother coffee ceremony where women living with AIDS share their practical experiences, was selected. In collaboration with individuals working in the antiretroviral treatment (ART) unit of the center, women attending their ART were asked about their marital status and their husband's HIV status. Four women were found along with the selection criteria. They were informed about the nature and purpose of the study. Knowing the purpose of the study two of them were ready to participate. But one of them lacks to control her emotion and unable to communicate her experiences. Thus the study used just one participant and become a single case study. The participated woman read and signed a written consent form and was considered as the informant for the study.

In order to answer the research question, data were collected through semi-structured interviews. As Seidman (2006) recommended, a series of three interviews were conducted keeping in mind the minimal recommended time interval between successive interviews. The average amount of time per session was about an hour- 67 minutes. The interviews were conducted in Amharic language. The interviews were tape-recorded and verbatim English translations were made. The textual data collected in this study were analyzed thematically. There are some flexible phases of thematic analysis recommended and followed by researchers (Braun & Clarke, 2006). These phases require studying the data to become familiar with it; generating codes; searching, defining, naming and reviewing themes; and producing the report.

Taking the data collection, data transcription and data translation roles and over reading the translated data were helpful to familiarize myself with the data. Initial or open coding was used to emerge the first cycle codes. And focused coding was used to emerge the second cycle codes (categories). Similar categories were identified and group together to emerge themes. At each of the data analysis steps, the core meanings of the participant's thoughts, feelings and behaviors were investigated to support the data interpretation (Ulin, Robinson, & Tolley 2005). The themes were reviewed to check internal homogeneity and external heterogeneity.

Findings

The participant of this study was a 32 year old woman who was born in a poor family in Addis Ababa. Her family became a maternal family following her birth as her father ran away for unknown reasons. Waiting for four years

and then hearing about the death of her husband, the participant's mother get married another. The participant has two sisters and is the second child of the family. Following her unsuccessful secondary school completion and realizing the poor living condition of the family, she involved herself in different money-generating activities. She worked as a house servant and car parking manager, and as an adherence counseling case manager in a health center. She also participates in voluntary care and support activities for people living with HIV and AIDS and in HIV/AIDS related awareness creation activities. To the participant's understanding, the raping experience she had in a town called '*Fincha Wah*' exposed her to HIV. In describing the moment she was raped, she started the story from the poor living condition of the family that she believed the main reason to expose to HIV.

She learned her HIV status while processing her entry permit to Switzerland as HIV testing was one of the steps in visa processing. However, she heard about her HIV status through a third party who accompanied her to the clinic and got the information without her consent. She has mixed feelings of happiness about her marriage to a 36 year old man who quit his education in elementary classes and who is involved in labor intensive jobs. He is HIV negative, alcoholic, addicted to *khat* but is loving and responsible to the family. They have an HIV-free three year old son and live in a house they built within her family's compound.

Experiences and Associated Meanings

The participants life experience can be seen from the themes emerged from the data. The six themes emerged were: The HIV discordant marriage, partner's behavior and HIV transmission, the antiretroviral treatment (ART),

child care and infant's HIV status, family members' attitudinal change, and supporting people with HIV/AIDS.

The HIV Discordant Marriage

The new experience that the participant observed when her HIV-negative boyfriend determined to marry her regardless of her HIV status was that it is not all members of the society that stigmatize and discriminate people living with HIV. Though the decision was difficult, she got married and become HIV discordant couple.

In her comparative analysis between the life of HIV concordant and discordant couples, she described advantages and problems of discordant couples. According to her, some of the frequently observed problems in the families of HIV discordant couples are “high physical and psychological pain due to insensitive partners; improper ART drug management, and high probability of experiencing incongruence, especially in relation to condom use.” But on the contrary, she believed that the marriage of discordant couples “increases the probability of having HIV-free children” and that such marriages “help the partner with HIV/AIDS to get a responsible individual to look after him/her in time of sickness.” Though she indicated that the advantages of HIV concordant couples outweigh the discordant, she preferred her discordant family life because having an HIV negative husband helped her to concentrate only on her own HIV/AIDS related health problems.

Partner's Behavior and HIV Transmission

The participant suspected that her husband may involve in extramarital sexual activities that increase primarily his risk for HIV infection and secondarily her exposure to different types of HIV viruses. In describing her husband's behavior she said

...he drinks, chew *khat*, and came late at night. So, I believe an individual cannot stay long outside at night with no reason. This behavior could contribute to increase the probability of exposing himself to sexually transmitted diseases like HIV and my exposure to another type of virus.

The Antiretroviral Treatment (ART)

The participant had misconception about the antiretroviral treatment drugs (ARTD). Her misconception include “[the drug is]... a means of reducing people living with HIV and AIDS... [and]... as something that could cover my body with wounds.” Following her enlightenment about the positive contribution of the drug and realizing that people taking ART suffered and died when they failed to follow the recommended lifestyle required, she convinced herself to start the ART.

Beyond her own personal experience, she exercised varied experiences in the family due to the drug. Her mother and a nephew encouraged her to “...keep on taking the ART drugs” and used different mechanisms to remind her to take the drug regularly. She described how her teenage nephew used different techniques to remind her:

... [he] looked at me and looked at the watch on the wall. If I couldn't realize what he is doing, he tried to remind me as if I have an appointment with somebody by saying “... have

you forgotten that you have an appointment with at 8:00PM? Have you remembered it now?"

On the other hand, her husband who does not want to see her taking the drug and is in denial of her HIV-status stated "you do not need to take these drugs; you cannot be HIV positive as long as we [the husband and the child] are HIV negative."

Child Care and Infant's HIV Status

The mother-to-mother coffee ceremony discussion group on HIV and AIDS where she learned that Caesarian Section (CS) delivery and the use of drugs that prevent mother-to-child transmission of the virus were instrumental to her to have an HIV-free child. Though both the CS and the drugs contributed to have an HIV-free child, remembering when her son was tested and how hard it was to wait for the result she said,

...I had to wait for days to get his result. I took him with me to the health center [where she works] for vaccination. A Nurse took him and directing herself to the laboratory told me that he must be tested for HIV today. I denied but with other collaborators she enforced me and took blood sample. That was the time I suffered very much, became neurotic and lost weight. I think it was one of the contributory factors for the decline of my CD4 and forced to take the ARTD.

Family Members' Attitudinal Change

Though due to the discriminatory societal practices she found it difficult to inform her family about her HIV status, she informed her mother and younger sister. Her mother's attitude was positive from the beginning. But her sister's was "superficial[ly]" positive. Even if her sister looked worried

about the incident, up to the participants understanding it was superficial. Gradually her real feelings were exhibited in her words during communications. But, her attitude was gradually changed and reached to think as her sister cannot be HIV-positive. In describing her sister's attitudinal change, she said,

There is significant difference ... my younger sister started thinking as if I am free from HIV/AIDS. One day she said "I think you are free from the virus, please check again. How could you live this long if you were HIV positive? I can't believe the laboratory result that confirmed you as HIV positive." When she saw me learning, get married and have a child whom she thought will die some days following his birth but found to be HIV negative, she is forced to believe that I am HIV negative...

Supporting People with HIV/AIDS

The participant's involvement in activities that create public awareness about HIV/AIDS and in supporting people with HIV/AIDS, led her to experience contradictory reactions from family members. Her husband, who often point out the negative consequences of her involvement in the advocacy want her stop the role she is playing and used to say "you are going to die for others.... and you will be responsible for the consequences." On the other hand, her mother, who often encourages her to enhance her accomplishments and improve her psychological condition, usually said "it is nice to see you participating in such activities. It may be the mercy of God due to your involvement in such activities that helped you become stronger. ..."

Meanings and Feelings

The varied experiences that came across due to the participants HIV discordant marriage and associated experiences contributed to varied meanings and feelings in her life. These meanings and feelings can be categorized into two major groups: *positive & sympathetic* and *susceptible & conflicting*.

Positive and Sympathetic

The participant associated some of her experiences with positive meanings and sympathetic feelings to some of her experiences in the discordant family. These experiences are: HIV discordant marriage, child care and infant's HIV status, and the anti-retroviral treatment (ART).

The determination of her husband to live together irrespective of her HIV status made her understand his real love and it has changed her general feeling towards the society. As she stated "...it made me change my mind that all members of the society do not involve in discriminating and stigmatizing us..." Though she exercised both advantages and disadvantages from her HIV-discordance marital partnership, she emphasized the advantages that she believes increases the probability of having HIV-free children and having someone to assist her in times of health problems.

Although the process of caring for her child, from conception up to getting the laboratory approval of the child's HIV status, was exasperating and the physical and psychological consequences were devastating, the meaning she gave to her HIV-free son was extremely impressive. She used the analogy "... [it is a] means of prolonging life as a drug". She also emphasized the

significance of the child by considering him as a “painkiller and [something that] initiates her to plan the future.”

The ART and ART-related conflicting experiences that she has come across in the family are considered as constructive to her. She considered the ART drug as a friend who takes care of and saves her. Similarly, she has reflected positive meaning towards the negative reaction and resistance of her husband to the ART drug she is taking. Her empathetic statement, “His [her husband’s] point of view towards the ART drug is like the way I understood and thought of the drug before taking it three years ago,” reflected her positive interpretations of her husband’s reaction to the ART drug. In stressing her positive meaning on the feeling of her husband on the ART drugs she added, “It doesn’t mean that my husband has the desire to see me dead or be in [health] problem.” Likewise, she considered her mother’s and other family member’s reaction to the ART drugs as a reflection of their desire to see her “...healthy and live longer.”

Susceptible and Conflicting Meanings

The three experiences that brought susceptible feelings and conflicting meanings were her partner’s behavior and HIV transmission, supporting others with HIV/AIDS, and family members’ attitudinal change. Based on her experiences in relation to the observed behavior of her husband, she experienced conflicting feelings about her marriage. Some of her husband’s behaviors made her feel happy, while others did not. In describing the meaning she has towards her marriage she said

I am living with mixed feelings. I am happy for some of my experience in marriage but yet there are experiences that could darken my happiness. My happiness is associated with his [the

husband's] dedication to work, and the affection and respect he demonstrated to me, our child and my family. But his alcoholic and drug addicted behaviors and his negative attitude towards condom and its use made me feel unhappy....

The meaning she has about her husband's alcoholic behavior and his attitude towards condom use is not only from the possibility of their HIV concordance point of view but also she has "...fear if he [her husband] caught HIV through sexual intercourse with outsiders... and [may] think as if he contracted the virus from me...." Her feeling in relation to her husband's behavior extends up to ending their marital relationship. But, from her own experience, she learned and believed that a child should get the care and support of both of its parents.

Though it demands time, money, patience, humility, and effort, she views her support of people living with HIV/AIDS (PLWHA) as sharing part of their problems, participating in a blessed activity, and in general doing what is expected of her as stated in the Bible. In illustrating her activities with what is stated in the Bible, she said

I am participating in an activity that God ordered us to be as it is written in the Bible. The Bible said visit patients and feed those who are hungry These people are sick they need somebody to visit them and... they need someone again to feed them. So I feel as I am participating in a blessed activity.

But her husband did not appreciate her involvement in supporting people with HIV/AIDS. Her interpretation to her husband's reaction was negative considering as he lacked the ability to sympathize with the living conditions of those she is helping. And in describing her desire to change his feelings she said, "Whatever he said I cannot fade away the printed feelings I have

about them. The only option I have is letting him know who they are, feel the condition they are in and the type of support they require.” As a result, she fail to satisfy both the harmonious relationship with her husband, which she considered important to the future of her son, and continue to support people living with HIV and AIDS, which she considered as a blessed activity.

Though desirable attitudinal changes have been observed in some family members who were negative in the beginning, she described how their attitude disappointed her as follows:

Sometimes I feel disappointed on my family but some other time I say why? Why do I disappoint myself on them? But, now I have determined to educate them by putting myself in a better educational and living condition. Whatever they said I am trying to either forget or stop evaluating the content of their speech. This way of living helped me to develop emotional stability.

Discussions

Though it is not the concern of this study, the role of poverty in HIV infection especially for the woman is clearly observed in this research. This finding is consistent with the finding of Kalichman et al. (2006) who described poverty as having a catalyst role in increasing vulnerability to HIV infection.

As establishing a marital relationship with an HIV-negative partner minimizes the feeling of being stigmatized and discriminated, the results indicated that the woman living with HIV/AIDS preferred the discordant over the concordant couple life. The rationale behind her preference for a discordant partnership was mainly to concentrate only on her own

HIV/AIDS related health problems. But yet she has another rationale like having an HIV free child. If concordance does not occur and the HIV infected parent passed away, it allows children to have an HIV free parent who takes the responsibility of looking after them.

The finding regarding the husband's alcoholic behavior and his view of condom use was congruent with Freeman and Glynn (2004). The husband's behavior could maximize the probability of HIV concordance between the couple and may expose to another types of virus. But knowing the consequence of consuming excessive alcohol and his desire to have sexual intercourse without a condom, she could not influence her husband's behavior though she tried. The challenge of HIV-positive discordant women in influencing their sexual partners to use condom was also identified by Stevens and Galvao (2007).

While investigating the effect of ART on quality of life of people living with HIV/AIDS (PLWHA), Holmes, Bilker, Wang, Chapman, and Gross (2007) found out that only the financial worries component of quality of life was a significant predictor of later adherence. Holmes and colleagues study is found to be incongruent with the findings of this study in that the informant was determined to follow the treatment consistently with the positive feeling and meaning she associated with the drug - "a friend that looks after." The possible reason for the difference observed in the findings of these studies could be the way ART is presented. Holmes and colleagues study participants may have struggled to pay for the drug and their adherence to it could be influenced by their financial limitations, whereas ART is free to the participant of this research.

An astonishing analogy that could be considered as an interesting and unique finding of the study was the meaning attached to the informant's child which she considered as a "life-prolonging drug", specifically as "a painkiller". The excessive devotion of the mother to look after the child and the child's activity itself could contribute in redirecting her attention so that she can forget HIV/AIDS related feelings and societal reactions. Though children are sources of joy, means of forgetting pain, and an inspiration for planning the future, waiting to learn the child's HIV status was upsetting where the mother was in a neurotic condition that resulted in weight loss and decrement of CD4. This chronic and intermittent maternal uncertainty that contributed to maternal psychological and physiological distress was found to be consistent with Nelms (2005).

Observing the attitude of the participant's younger sister that was mostly negative at first, the informant was discouraged. But she wanted to use it as a means of initiating herself to perform and put herself in a better educational and living condition. Though it was the support of the family that usually brought people with HIV/AIDS to perform and act for better life improvements (Foley, Skurnick, Kennedy, Valentin, & Louria 1994), the finding of this research indicated that some disappointing familial activities can bring internal determination to achieve better too. The possible reasons for these incongruent findings could be the unique internal determination of the woman and/or the confidence she has about her husband. Whatever the degree of disappointment she may have based on her familial expectations, the informant has an HIV-free husband who can look after and support her in all her endeavors.

The informant was determined to convince her husband by helping him visualize the situation of people living with HIV/AIDS and the type of support they required. It was not for the mere benefit of establishing a conducive and stress-free living environment that she struggled to convince her husband, but to let him understand and bring attitudinal change about PLWHA so that she can get her husband's acceptance in supporting them. All her efforts based on her own experiences of living with the virus and her participation in the mother-to-mother coffee ceremony discussion groups made her aware of the problems and feelings of PLWHA. As a result, she is determined to support them and tried to convince her husband to empathize with HIV- infected individuals.

Generally, though this is a single case study, this study indicated some unique findings especially associated with the meanings given to the ART drugs and the HIV-free child. Thus the findings indicated the importance of the ART drugs and HIV-free child to help HIV-positive women in general and those in discordant marital relationship in particular to plan their future and get meaning in their life.

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