

## RESEARCH

# Dealing with HIV/AIDS related stigma, stress, and coping

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## Abstract

Human immunodeficiency virus (HIV) related stigma, perceived stress, and coping with the illness are widely regarded as key impediments to effective prevention and care. The purpose of this study was to explore HIV infected women in outpatient department of antiretroviral therapy (ART) who experience their psychosocial challenges like stigma, stress, and coping that they devise to deal with. Five infected women, of which three were widows and two married (living with spouse), and receiving ART from Gauhati Medical College Hospital participated in this qualitative study. HIV related stigma and stress were experienced by all participants and were narrated as sense of loss, shock, fear, anger, worry, and shame. To cope with these, the women alienated themselves, became secretive about their health, disclosed strategically, changed their place of stay and occupation, moved to metropolitan city to have less intrusive and peaceful life. The elements of stigma, stress, and coping employed, as uncovered in this study, suggest to plan out a basis for interventions aimed at assisting HIV infected people to deal with.

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## Introduction

Worldwide, women constitute close to half of all people living with human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS); almost 15 million in total. Globally in every region, more adult women (15 years and older) than before are now living with HIV. Women are at least twice as likely to acquire HIV from men during sexual intercourse as vice versa. In Sub-Saharan Africa, women constitute 61% of all people living with HIV/AIDS; a figure that rises to 76% among young people aged 15 to 24. According to a four city study in India, almost 90% of HIV positive women were infected from husbands.[1]

HIV/AIDS is a disease that affects families in a profound and tragic way and it disproportionately increases the vulnerability of families.[2] There are complex psychological and social issues that impact a family's ability to cope with HIV/AIDS infection. It is a chronic/terminal illness that forces individuals and their families to cope with an uncertain progression of disease, complicated medication regimes, and the grief related to the loss of health and possibly the loss of family members.

Psychosocially, HIV/AIDS is a chronic illness with a long-term, incapacitating, terminal, and stigmatising character.[3] As in the case with other chronic illnesses, HIV/AIDS unleashes a devastating effect on individual, affected families, and community at large.[3] The psychosocial challenges faced by persons living with HIV range from being exposed to stigma and stress to dealing

with the anger, worry, and fear with adverse health related problems. Research carried out in South Africa in Hammanskraal and Temba by the Centre for AIDS Studies found that HIV infected women are stigmatised as "prostitutes" or "loose women" or as having "invited" HIV infection into their lives in order to claim access to governmental social grants.[4]

## Literature review

Stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons.[5-9] A discredited person accepts the norms of the community/society and internalises the negative values as shame, repressed anger, self-hatred from the discrimination in addition to his/her already existing self-stigma.[10]

Women in particular, in widowhood, can bring on the loss of an identity and the meanings attached to it. The death of a spouse can be one of the most stressful events of the life cycle.[11] People suffer many losses over the course of HIV infection including loss of friends, family, relatives, job, and resources. Being HIV-positive can bring about fears of abandonment by friends and family, and rejection from colleagues. The most intimate relationship gets affected in infected individual.

According to Lazarus and Folkman,[12] stress is defined as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her

well-being. Stress is a two way process; the environment produces stressors and the individual finds ways to deal with these. The increasing unprotected sex brings in the danger too early and unwanted pregnancy, induced abortion often in hazardous conditions, sexually transmitted diseases, and HIV infection resulting in AIDS.[13] Stress can originate in physiological, psychological, social conditions and threaten the integrity of the body, the personality or social system. The death of a spouse further leaves an individual subject to health problems, questioning the meaning of life, and psychologically vulnerable.[14]

Coping is a process influenced by multiple competing stress factors including social discrimination, poverty and substance abuse, as well as an individual's social and coping resources. HIV related coping is concerned with the thoughts and behaviours used in dealing with HIV infection. The choice of coping responses is influenced by the extent to which the person appraises the situation as changeable or controllable, as opposed to unchanging or uncontrollable, and the extent to which a person selects coping strategies that are appropriate in the specific stressful situation.[12]

There are number of Indian studies[15,16] on psychosocial problems and coping patterns of HIV seropositive wives of men with HIV/AIDS. A rich body of existing literature has discussed the dimension of HIV related stigma, stress, and coping. There is however paucity of studies in psychosocial challenges of women experienced by domiciles of Assam attending the antiretroviral therapy (ART) centre, Guwahati. Guwahati is the major gateway city connected with roadways, railways, and airways to the other seven North-Eastern states. To fill the gap, this study focused on the experience of stigma, discrimination, stress, and coping by female HIV patients in tertiary care. The goal of the study was to uncover—in voices of women living with

HIV—how stigma is experienced and the coping mechanisms used to deal with it.

## Methodology

This was a qualitative study that emphasised on exploration and description. The study continues the analysis of the data from the interviews of the women, regarding their response to HIV/AIDS. The study reflects the voices of all the women - not just one voice but their collective voice.[17] Three of the five women came in contact with the principal investigator as referral from the ART centre for psychosocial counselling for their grief, loneliness, disturbed emotional reactions, and management issues. This section describes their feelings and experiences of the women in their own words and therefore is the most important part of the study. Through their histories and descriptions of these difficult and distressing situations, first author was able to absorb the enormity of problems presented by these women. All women live in the community either with family or alone.

The Gauhati Medical College Hospital (GMCH) committee gave the ethical clearance for the study. The participants were interviewed after ART centre hospital authority granted approval to conduct the study.

Participants were selected according to inclusion criteria that up for the study: a) To be a female in the outpatient of ART centre, b) Women who are medically diagnosed to have HIV/AIDS by professionals, c) Widows with HIV/AIDS in the age group of 18 years and above, d) Women with HIV/AIDS living with their spouses, e) Volunteered for participation in the study, f) Signed an informed consent form.

Five research participants were recruited and consented to the study. Three of the women were widows and two of

**Table 1. Socio-demographic information of participant (N=5)**

Name and age	Marital status	Language spoken	Place of residence	Employment status	Education level
Savita 23 years	Living with spouse	Assamese/ Bengali	Guwahati	Unemployed	Under matric
Sandhya 32 years	Widow	Assamese	Hojai Dist. Nagaon	Part time employment	HSLC passed
Ranu 34 year	Widow	Assamese	Guwahati	Semi skilled employment	Higher secondary passed
Amola 52 year	Widow	Assamese	Barpeta	Owns petty provisional store	Under matric
Beena 32 year	Living with spouse	Assamese	Rangapara Dist. Sonitpur	Teacher	BA , BEd

Table 2. Perceived stigma		
Category	Experience	Reaction
Personalised stigma	Loss, fear, shame	<ul style="list-style-type: none"> <li>• Since learning I have, I feel set apart and isolated from the rest of the world</li> <li>• Some people who knows I have HIV have grown more distant</li> </ul>
Disclosure concerns	Risk, avoidance, secrecy	<ul style="list-style-type: none"> <li>• It is easier to avoid new friendship than worry about telling someone that I have HIV</li> <li>• I work hard to keep HIV a secret</li> </ul>
Negative self-image	Guilt, shame	<ul style="list-style-type: none"> <li>• I feel guilty because I have HIV</li> </ul>
Public attitude	Loss, fearful, isolation	<ul style="list-style-type: none"> <li>• People with HIV lose jobs when employers find out</li> <li>• People's attitudes about HIV make me feel worse about myself</li> </ul>

them were married living with spouse. The characteristics of these women are shown in Table 1. No remuneration was offered to the respondents/participants. Face to face individual interviews were conducted by single investigator as primary data collection method for this study. The investigator is experienced in field of research for more than a decade.

#### Data collection

The researcher developed a 23-item, semi-structured interview schedule. The researcher developed interview questions after a review of perceived stigma, perceived stress, and coping.[18-20] The schedule provided a structure for interviews but allowed for flexibility to pursue emergent topics. The interview schedule was pre-tested with a group of three HIV infected women in the hospital. Moreover the colleagues at Psychiatry Department of GMCH, who were experts in Assamese language in which the interviews were conducted, checked and back translation was done.

The interview took place in two settings in one and half months schedule. All interviews were conducted in a secure room and confidentiality was maintained. Researcher conducted the interviews in native languages Assamese and Bengali. The researcher translated and scribed immediately after the interview was conducted. This enabled the researchers to direct their follow-up interviews with women towards issues that needed further clarification. Each participant was interviewed twice. Each interview lasted for

45 minutes to two hours. In all cases the second interview was shorter than the first. During the transcription of the interview, pseudonyms (Savita, Sandhya, Ranu, Amola, and Beena) were assigned to protect the identities of the participants.

#### Data analysis

Data analysis of the transcribed data was processed in several steps. The interview schedule was translated to English next to the verbatim words. The same

group of language experts who had assisted in translation of the interview schedules checked the translations for accuracy. Through revision, coding was developed and grouped into categories. This process led to filtering of raw

Table 4. Coping		
Category	Experience	Reaction
Problem-focused coping	Working on options	<ul style="list-style-type: none"> <li>• Frequent change of place and jobs</li> <li>• Change the packet of medicine on the way to another packet</li> <li>• I say that I have tuberculosis (TB) or skin infection rather than HIV</li> </ul>
Stop unpleasant emotions	Talk positive	<ul style="list-style-type: none"> <li>• Take mind off from unpleasant thoughts</li> <li>• Look for good in negative situations too</li> <li>• Pray and meditate</li> </ul>
Support from friends and family	Emotional help	<ul style="list-style-type: none"> <li>• Seek emotional support from friends and family</li> <li>• Resist the impulse to act hastily when under pressure</li> </ul>

Table 3. Perceived stress		
Category	Experience	Reaction
Anxiety	Nervous, restless, flushes, feeling of impending doom	<ul style="list-style-type: none"> <li>• I feel very nervous and stressed after knowing about the details</li> <li>• Most of the time I am upset</li> </ul>
Depression	Irritation, grief, sadness	<ul style="list-style-type: none"> <li>• This illness makes me feel like killing myself instead of coming to the hospital</li> <li>• I don't feel confident, since the day I came to know about my HIV</li> <li>• I cry every day</li> </ul>

data according to themes: loss, fear, shame, isolation, secrecy, disclosure, negative self-image, problem-focused coping, stop unpleasant emotions and thoughts to get support from friends and family (Table 2, 3, and 4). Before coding, extensive discussions were done between the researcher and senior researcher.

### **Dimensions in stigma and perceived stigma experience**

The research participants' encounter with stigma was soon after HIV diagnosis and was experienced as sense of loss, fear, shame, and anger. This manifested as loss of dignity (at intrapersonal level) and loss of respect (at interpersonal level). For instance, Sandhya was working as a record keeper in a private clinic under a doctor. "I had not understood about the illness well what the counsellor told me in antenatal clinic, so I wanted to seek for a second opinion. As my employer was a doctor he took the file, his expressions changed and his reciprocity while talking to me wasn't the same as earlier. He enquired another colleague of mine whether I am a 'loose women'; few days after, he asked me to quit the job. This incident was very painful and humiliating to me".

Ranu told the researcher that she got married against the wishes of parents. Soon after marriage she had to nurse her ailing husband most of the time due to prolonged fever with diarrhoea. In 2006, they went for check-up and she got utter blow in her life when she came to know that he is HIV positive. Her first reaction was shock followed by anger; she felt terribly cheated and humiliated that he played with her emotions.

Sandhya and Ranu expressed how they lost friendship, sibling support, and thrown out of the house after death of their husbands because of being infected with HIV.[21] Savita had big dreams, before marriage, to establish a small family full of love and affection in Guwahati. She came from Kolkata to have a marital bliss, moved to a big house with many members, and became a responsible daughter-in-law, sister-in-law, and wife. As she conceived and went for routine check-up, she came to know about her HIV status. An Indian woman who is following the strict prescripts of a male dominated society in marrying exactly how her family has dictated, and engaging only in heterosexual sex with her husband is very vulnerable.[22] The figures for incidence in women were based on hospital records and antenatal clinics, and it is now accepted that there has been severe under-reporting of women who are not sex workers, especially married women in heterosexual relationship.[22] Furthermore, contracting HIV/AIDS innocently from one's husband does not protect women from stigma and discrimination.[23]

Sandhya and Ranu told the researcher that disclosure of their HIV status has become very risky, and so they live

isolated from friends and family. Sandhya has lost job thrice and Ranu once; in their verbatim, expressed: "You know well how the world treats HIV/AIDS patients. I got this illness because of my husband's 'karma'. You tell me where is my fault? I don't want to die, I want to live".

The loss of dignity and close social ties led to feelings of fear, anger, and shame. Among the participants, fear manifested itself in fears of death, treatment, discrimination, and trauma for children. Ranu expressed to the researcher her grief of losing the foetus. Soon after the death of husband, her reproductive desires were compromised in the tension of no social, financial, and emotional support. Ranu in great distress took a decision to abort the foetus; in the fourth month, she voluntarily terminated her pregnancy. She cited, "I did not want to bring a sick child to this world and add another burden". The same is shared by Sandhya when she had a miscarriage in the fifth month of her pregnancy. The burden of care was of great concern at this junction of life after death of the spouse.

Hackl *et al.*[24] mention that women have natural desire to nurture their own children and the same is being found in this study where three of the women had expressed immense desire to be mother and nurture their own child but fear of raising alone and concerns about their future. Women that were examined have five main concerns: the impact of stigma, child care, caretaking roles, social support need, death, dying, and despair. Sandhya, after death of husband, loss of job, thrown out of house by in-laws, and dearth of social support from her siblings, was in severe psychological distress, mild to severe depression, raised anxiety, and a wide range of stresses. She has no primary social support and expresses concerns about stigma and discrimination, and hopelessness. The same is mentioned by Gore-Felton *et al.*[25] that higher levels of depression in life threatening illness, as well as symptomatology.

The dominant themes in the narration of perceived stress were anxiety and depression. Nervousness is the premier response once they get to know about their status with hot flushes, numbness, and perceive they have only counting days to live. Sandhya lives in persistent worry, fear, and contemplates to have no future; constrains in economic options is also looming her and lacks social support. Sandhya and Beena both are suffering from severe depression with high suicidal ideation. She questions every day why she contacted with the dreadful illness making her "handicap to work and think free".

Beena expressed to the researcher that she and her husband both are teachers. Husband is a teacher in Nagaland (neighbouring state of Assam) and wife in Rangapara, Assam. After she knew about the seropositive status, she curses herself. She expressed in anger, "If you can legalise to check the status of two people before getting married

instead of matching birth chart by astrologers". Savita and Beena have frequent quarrels at home; the reason they cited, "I feel irritated seeing him, he knew about his status earlier, why did he hide". Beena expressed, "I will definitely tell my daughter's positive status to the boy who marries her".

Savita, Ranu, and Beena told the researcher about their thoughts of hopelessness and helplessness, "I don't like my life. What a life? I cannot think free, living a life in secret, and have to take medications for life". "Every morning I wake up, I don't feel fresh to do anything. I feel I am a day closer to death".

Savita's and Beena's interpersonal relationships with their spouses have become stressful; they have daily hassles of regular blaming, taunting, losing temper, and disengaged in the thoughts, making their life quite strained and lowers the quality of life. Sandhya, Ranu, and Amola are widows who share a common challenge of their "life's chronic tension and daily hassles" which commensurate with socioeconomic conditions like financial burden, unemployment, victimisation, compounding high stress, and deplete coping resources in HIV/AIDS prognosis. Same is mentioned by Jenkins and Coons.[26] Chronic uncertainty is another source of stress experienced by the stigmatised. Stigma increases a person's stress, uncertainty, and vigilance, and can lead to intellectual underperformance.[27] In most cases, a person is nervous, lacks confidence, or tries avoiding situations. To examine the coping in the face of stigma and stress, the most dominant theme is problem focused coping, stop unpleasant emotions, and support from friends and family.

Beena and Ranu shared with the researcher, "I do not go to visit my friend nor I would call any friend for lunch, dinner, or overnight stay as I used to do earlier, after the dreadful news. Even I have stopped talking to my parents about my personal life". Ranu has changed her place of stay; she has come from a town to a city for better accessibility of health care facility and according to her, people in a city are "less intrusive in anybody else's personal life". She said, "I am adjusting my life according to the disease"; thus citing coping by avoidance and social isolation.

Other three women share saying that they had become more distant from friends or family to avoid rejection, and thus became secretive. Most of the experiences narrated by the women were clearly influenced by stigma. Disclosure may be a gateway to access support and care,[28] but disclosure does not always result in support. Two of the participants, Beena and Savita, say that they feel nice coming to ART centre, "I am not only the one here, there are so many women like me who are here and living with the illness, I get inspiration talking to them".

Breitkopf[29] categorised three categories of disclosure: protective, preventive, and spontaneous. With protective disclosure, the person takes his or her time planning when, how, to whom, where, and under what circumstances to disclose. Preventive disclosure happens when the person is aware of the danger of stigma, and discloses strategically to try and prevent negative perceptions. Spontaneous disclosure takes the person by surprise and can be in the form of an emotional outburst, which can later be regretted. Most of the participants have opted for preventive and protective disclosure as one of the coping mechanism. Sandhya said, "I am very cautious about my disclosure now", as she has a bitter experience. She wanted to take a second opinion from her employer who was a doctor, but that proved detrimental; she lost her job. From then onwards she said, "Telling about HIV is risky". She regretted telling her employer. She opted for spontaneous disclosure but regretted, "Many in my work relations had come to know and they labeled me as 'loose women'."

In this study, most respondents have taken up spirituality and positive reframing as a method to positive coping. Savita said, "I get positive energy after I have taken 'diksha' in Art of Living (AOL)". A full course of AOL shows highly significant and remarkable difference on perceived stress and general health.[30] "Now every day I spent one to two hours for myself in meditation and prayers, this has shown me a new way to life". The same is shared by Amola, "I started going to 'namghar' (religious institution for worship) and also do my regular prayers at home".

There is an example of positive coping observed by researcher. Amola got infected with HIV through her husband who worked in Army at 50 years; her sons are grown up and supportive. She runs her own business, and involved in decision making in the family; there is good financial stability. At this stage, the priorities of life are different; so the stress is much lesser compared to the ones in married couples without children or childbearing families' stage according to family life cycle,[31] where couples had just started a family and their aspirations are high like in the case of Savita and Beena. This indicates that later the onset, better is the coping.

## Conclusion

The study allowed the researcher to uncover domains into stigma, stress, and coping experiences of five HIV/AIDS infected women in Assam, India. From the analysis of the experiences of these women, commonalities were drawn and interwoven in the results. After being diagnosed as HIV, women experience sense of loss, hatred towards their spouse and marriage, anger, fear, and shame. This makes the women nervous, distressed, worry, and raised anxiety. Thus coping is seen as self-imposed social

isolation, alienation, and secretive. Feeling of shame fuelled the internalisation of negative perception by significant others, leading to deeper self-stigmatisation. Despite these negative reactions and their impacts, some participants have employed coping methods like selective disclosure (preventive and protective). Positive coping is seen if the support from primary caregiver (son or own mother) is rendered.

The study shows impact of ART as beneficial to women living with HIV/AIDS in uplifting deteriorating health (physical and psychological) condition. All participants in this study belong to general population, thus indicating us to be aware and deal accordingly. Our study also found that the women are in severe psychological distress, mild to severe depression, raised anxiety, and wide range of stresses. Health care professionals in ART centre can be informed about the emotional help, and sensitise to refer such cases for psychosocial counselling to be given by skilled hands available in Psychiatry Department of GMCH. Participants have reported that coming to ART centre makes them “feel confident” seeing many people with the same illness; so this indicates that participants will be benefitted by group therapy/counselling. By gaining the type of awareness and understanding, supportive interventions can be planned. Our study of support may actively search and bring in new dimensions to interventions. Electronic and print media can play a responsible and substantial role in bringing down the stigma, stress, and elevate coping.

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