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Widowhood and HIV: A Narrative of Pain, Illusion and Predicament

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Abstract

Narrative accounts of illnesses have been popularly employed to understand the cultural constructions, social issues, beliefs and representations of illnesses. The present paper employs structural analysis to explore the lived experiences of a widow – a woman and a mother living with HIV in a personal experience account. It portrays how a woman is blamed for bringing in HIV, dishonor and shame to the family. It provides the evidence of guilt that a woman forces upon herself after being widowed, infected with HIV and further becoming a carrier of the virus to her own children. There are indications of illusionary beliefs regarding the treatment and cure for HIV which can be dangerous and lead to the spread of HIV. It is significant in understanding the laymen's perception and construction of disease physiology. This narrative allows a glimpse into the concerned world of a mother and motherhood experiences when there are positive and negative children living together.

Keywords – Narrative, beliefs about treatment, blame, guilt, shame, violence, illusion, HIV

1. Gendered Aspects of HIV

Women are biologically more vulnerable to HIV as compared to men. McBarnett (1988, p.71) called HIV a "biologically sexist" virus. The biological factors expand the opportunities of virus transmission from men to women. There is a higher amount of virus concentration in the semen as compared to the vaginal fluids and males secrete fluids in larger volumes than females. Anatomically, vagina and rectum in females are fragile and have higher probability of tearing. Thus, women are at a higher risk of getting infected with HIV from males.(Higgins, Hoffman & Dwarkin, 2010; Quinn & Overbaugh, 2005). However, biological factors are not solely responsible for the spread of this virus among women. Socio-cultural factors are equally important.

In the Indian context widespread social issues such as gender inequalities, violence against women, sexual assaults and intimate partner violence may result into increased chances of HIV transmission (Gwandure, 2007 & Wu et al., 2003). Poverty can be attributed as another major factor for HIV spread as it increases possibilities of transactional sex and migration (Kambou et al., 2007). Lack of access to resources and awareness are also the by-products of poverty. Cultural practices such as early marriages (Santhya & Jejeebhoy, 2007) and role expectations from both the genders lead to an increase in risk taking behavior and this further upsurge the risk of HIV transmission.

Biological, social and cultural factors together increase the risk of HIV spread in developing and underdeveloped countries. India has all the possible factors to act as a catalyst in order to facilitate the spread of HIV. Besides adverse cultural practices, lack of education and poverty are contributors in the spread of HIV. According to the National AIDS Control Organization (NACO, 2015-16), the number of people living with HIV/AIDS in India is 2.089 million among which 0.816 million are estimated to be females. The majority of population of PLWHA currently belong to the age group of 15-49.

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Hence, the major population living with HIV is in their reproductive age which in turns leads to increased risk of virus transmission in sexual partners as well as children during birth. According to the World Health Organization (2009),

Globally, the leading cause of death among women of reproductive age is HIV/AIDS. Girls and women are particularly vulnerable to HIV infection due to a combination of biological factors and gender-based inequalities, particularly in cultures that limit women's knowledge about HIV and their ability to protect themselves and negotiate safer sex. (p.12).Women and adolescent young girls appear to be more susceptible to HIV infection due to various biological and socio-cultural factors prevalent in the Indian patriarchal society. Thus, there is a need to explore women's issues separately in the context of HIV as the women in India are already in the position of disadvantage. As noted by Dixit (2011) "Women's position in most societies is marginal and this leads to gendered discourse and stereotyping. These in turn lead to social constructions and social representations regarding women's and men's health"(p.1).The situation further complicates for women with HIV due to issues of morality and stigma.

The present paper is an endeavour to understand the issues faced by a widowed woman living with HIV in the Indian context. For this purpose a detailed narration of the multi-dimensional field of experiences of an HIV positive woman has been obtained and analysed.

2. Research Setting

It is crucial to discuss the research background in order to describe the theoretical rootedness of the narrative reported in this paper. This narrative was collected asa part of a larger study. There were total 28 interviews collected in a period of 8 months. These interviews were collected after a rapport building for almost two months. These interviews were conducted in an Antiretroviral Therapy (ART) Centres. The ART Centresin India are providing preventive medications and awareness to the people living with HIV. These are opening the doors of communication among People Living with HIV (PLWH).

This interview was collected with the help of an unstructured interview schedule developed on the basis of available research literature and the informal interactive sessions which the first author had with PLWH. Prior to this study the ethical clearance was taken from the Institute Ethics Committee. The participants were requested to participate on voluntary basis. They were well informed about the procedure of the study and were free to withdraw at any point in time and could skip the questions they did not wish to answer. Participants were to give oral as well as written consent and with the participants permission the interviews were tape recorded. The recorded interviews were transcribed for further analysis.

This particular account was selected for analysis as it provides in-depth details about the life of a widowed woman living with HIV. Single account is important because it provides the detailed experience of the interaction between widowhood and HIV experiences in a society which is largely patriarchal. Single narratives have been noted to provide "narrative resources to draw upon" (Mooney, 2004, p. 72). This narrative brings into light the multiple experiences of a single person living with a life threatening illness, which is also accompanied by issues of morality, guilt, stigma and discrimination. The section below is the detailed analysis of the experiences of a widow living with her children positive as well as negative serostatus. It also portrays how 'she' understands the physiology of the disease and the ways this understanding is constructed by the cultural notions.

3. Methodological Stance: Narrative Inquiry

Narrative inquiry is now popularly employed in diversified researches in social sciences. This method is used to understand the impact of social and collective representations, social structures, and cultural aspects on events and experiences. One of the most outstanding characteristics of narrative inquiry is continuity in the sequence of events, where human beings are involved as characters and actors in the events taking place in a sequence."Their meaning is given by their place in the overall configuration of the sequence as a whole . . ." (Bruner 1990, p.43). Narrative provides a basis for an overall understanding of linkages between actions and related aspects. These linkages serve as providing "composite understanding" of experiences (Polkinghorne 1988, p. 13) According to Chatman (1975). Each narrative has two parts: a story (histoire), consisting of the content, the chain of events (actions and happenings), and what may be called the existents (characters and settings), the objects and persons performing, undergoing, or acting as a back- ground for them; and a discourse (discourse), that is, the expression, the means by which the content is communicated, the set of actual narrative statements. (p. 295)

These characteristics have made narrative inquiry as an outstanding method in psychological researches. For the purpose of analysis and in order to generate the emerging themes in this particular narrative, the method of structural analysis proposed by William Labov (1972) was adopted. Franzosi (1998) introduced structural analysis of the narrative as a logical connection between events in a sequential manner. Story is a basic component for narrative. Linguists have introduced the following characteristics in the narratives

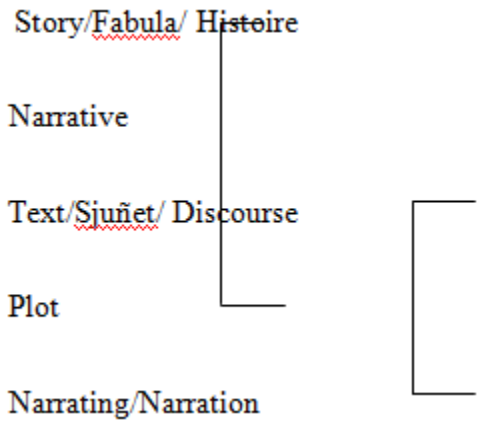

Figure 1: Linguistics Characteristics of a Narrative. Adapted from "Narrative Analysis- Or Why (And How) Sociologists Should be Interested in Narrative" by R. Franzosi, 1998, Annual Review of Sociology, vol. 24, pp. 517-554

The fundamental difference between a narrative and non-narrative text is the existence or non-existence of a story (Knight & Rimmon-Kenan, 1983).Tomashevski (1965) noted that "A Story may be thought of a journey from one situation to another." (p. 70). Hence, the presences of a story in chronological order are the most abiding element of a narrative.

3.1 Structural Framework for Narrative Analysis

The story in this paper was comprehensively analysed using the framework suggested by Labov and Waletzky (1967). Labov (1972, 2008) enumerated the characteristics of narratives in the basic model, due importance was also given to the analysis of narratives.

Labov (1972) summed narratives as ". . . one method of recapitulating past experiences by matching a verbal sequence of clauses to the sequence of events which actually occurred" (p. 359-60). Labov and Waletzky (1967) proposed a comprehensive method for analysing the personal narrative in their classic work 'narrative analysis: oral versions of personal narratives'. The focus of this approach was on the function of narratives. The core idea of this model presents two functions: 'referential' and 'evaluative'. The referential purpose indicates individual personalities, context and episodes in the plot. Evaluation indicates the function of narrator for narrating and listener for listening. Another characteristics of the narrative mentioned by Labov and Waletzky (1967) is continuality in the order of two experiences, commonly expressed in past tense. The change in sequence of narrative experiences cannot be changed in the narratives without changing the temporal order of events. Narratives of personal experiences also have other components and these can move freely without disrupting the temporal sequence of the story (Labov, 1972). According to Labov (1972)fully developed narratives contain the following elements: abstract, orientation, complicating action, evaluation, results and resolution and coda. Labov (1972) noted that, a complete narrative begins with an orientation, proceeds to the complicating action, is suspended at the focus of the evaluation before the resolution, concludes with the resolution and returns the listener to the present time with coda. The evaluation of the narrative forms a secondary structure which is concentrated in the evaluation section but may be found in various forms throughout the narrative. (p. 369).

The narrative below is analysed using the structural analysis method. Major episodes in the story are organized in themes. These themes are constructed around protagonist's encounters of struggle in living with HIV and her endeavors to overcome them. The introduction refers to the abstract of the story in which the central theme of the narrative has been introduced. Orientation which provides a brief description about the setting and characters in the narrative is discussed with the second theme which is early life, marriage and family.

The complicating actions reconstruct the central events and in this story the central event revolves around her husband's illness and death, experiences of stigma, discrimination and violence and the blame, shame and guilt. Resolution focuses on her life in the current situation, consequences of the events and conclusion. Hence, predicaments of motherhood, work and HIV, physiological understanding of the illness and the dangerous illusion in which she is living are considered in resolution. Coda is the concluding remark and it addresses her (only) wish to be fulfilled in the narrative below.

4. Narrative Account: Expressions of pain

This narrative below is an expression of pain – pain which is not physical but lived and intense. Despite the pain, the protagonist of this narrative seemed to absorb blame, guilt, shame, fear and all the emotions, exonerating every cause of her misery. These miseries become more agonizing when a woman had to live a stigmatized life with HIV accompanied by widowhood.

4.1 A Life in Paucity

Life had never been a bed of roses for her, shackled in the chains of poverty since birth. She never got the chance to go to school. In the early days of her childhood she had to work as an unskilled labour. She had supported her family in the years of childhood when she should have been bestowed with education, friends and merrymaking. She was supposed to work. At the age of 20 she was married to Ajay because her parents wanted to do away with their liability. Life after marriage had not been that uncomplicated for Arpna. Her husband's family was also economically sluggish. It was a large family consisting of twelve members and only two breadwinners: Ajay and his elder brother. There were small children, elderly parents and also two unmarried young sisters. Under such circumstances the family was always in economic difficulties.

They lived in the outskirts of a village. It was once a hinterland – no school, no electricity, no roads and no water supply. But, with the development and expansion of Kanpur city the village is now a suburb of the industrial city of Uttar Pradesh. The place was fast growing with industries, new factories and coming up with educational institutes. Industrial development had brought employment opportunities and a scope of growth, education and awareness for the people living there. The generation of employment lead Arpna and her sister-in-law to lend a 'working' hand to the family, running errands at construction sites, factories and earning meager wages as cleaning staff in hospitals, colleges and schools.

I have worked all my life, when I was at my parents' place. I had to work and even now when I am at my husband's home I am still working for livelihood. The family is large and there are many responsibilities. Besides, this family keeps growing and one has to worry about food. It is only about eating and feeding the people, nothing more than that. The children are not going to school and the financial conditions are not going to improve.

After her marriage, Arpna gave birth to three children. All daughters in the want of a boy as her in-laws kept forcing her to produce a son. All her deliveries were at home, lacking proper medical care. Her fourth delivery was complicated, the umbilical cord was looped around the baby's neck, but with the help of a traditional birth attendant of the village she survived the pain and delivered, a son. Arpna was a fighter and she never gave up in her life. She always dreamt of giving her children what she could not have in her life. She wanted to provide them formal education so that they can pull themselves out from the sludge of poverty. However, dreams don't always come true and in Arpna's case her fate had something else in store. As the members in the family were increasing it was turning out to be more and more difficult to fulfill the daily needs. The family was sinking further into poverty and the children never got enrolled in a school.

4.2 Confrontation with Illness and Death

It was a hand to mouth situation for the family. They were working as daily wagers and what they earned would only cater to their needs for food, medicines and other necessaries. When Arpna's son was ten months old, around that time her husband fell ill, complaining of constant fever and pain in the stomach. He visited several doctors but he did not seemed to get any better. Ajay's health condition was deteriorating by and by. They decided to take him to a doctor in the city but that would have been very expensive and they could not afford to get him treated at a good hospital. Arpna wanted to get her husband treated at the best possible place and by the best possible medical practitioner, but with their meager income they could not afford the luxury of a private hospital. He was admitted to the government hospital. Arpna stayed at the hospital with her husband for care giving while her children, even the infant stayed back at home.

Ajay's condition was not improving with the treatment given to him and the doctor advised him to take several tests, one of which confirmed him to be HIV positive. Doctors started the treatment for HIV but his immune system had already given up and he did not respond to the treatment. He took his last breath on the hospital bed after 10 days of treatment. Arpna too was advised to take up HIV test with her children and she with her three younger children tested positive for HIV. She was a widow . . . now a HIV positive widow. Aprna was broken. I was least bothered about my illness, neither do I had the moments to even lament at the fate of my children. I was broken, I was only crying on my fate, I was lamenting on the life that I have to live now . . . the life of a widow. Ajay's crematory rites were performed by his family members, but unlike other cases of death in the village his funeral was ill-attended. The villagers feared, they will be affected with HIV. Arpna did not know what HIV was at that point of time. She did not even care to know. The pain of losing her husband was volumes greater than her own illness. The life of widowhood was worse than death itself.

4.3 Solitary Combat

Life had become even more painful and challenging for Arpna. After Ajay's death the family members started discriminating her children. They would give them food after everyone else had finished eating, their utensils were kept separately and the children were forced to do their own cleaning and washing. They were not allowed to play with other children of the family.

I would have sustained all the miseries and pain, if it would have been limited only to me. But now the things are worse my children were subjected to discrimination and ill-behavior. Once Arpna intervened and pointed out the discrimination, she was beaten up by her brother-in-law and her mother-in-law blamed her for bringing the illness to the family. She loaded Arpna with expletives saying,

My son was very good, he never did anything that would dishonor our family in the society, he was of a moral character, he never indulged in women and other stuff, and he was not even involved in alcohol and smoking that other men of his age normally engage in. It is you who is the cause of his death. You have bought this illness. He died because of your karmas (deeds).

4.4 A Virus and a Disgraced life

They would accuse Arpna of infidelity. They blamed her for everything that had happened in the family. Arpna was helpless and for all this blame, who could she blame to? She did not even get a chance to ask her husband the crucial question, how did he get it? She was full of shame and guilt. Shame of being a widow, being HIV positive and guilt of transferring HIV to her three children. No mother would deliberately transfer such a disease to her children and she said, Had I known it earlier I would have saved my children from death . . . from HIV

4.5 Stigmatization and Illness

Arpna was heartbroken and suddenly the behavior of entire family as well as the community changed towards her. Her sister-in-law who was always supporting and cooperating also changed. In the past, she would look after the children when Arpna was out for work but now she did not let them come near her. Arpna was very stressed under such circumstances and the incidences of violence with her and her children kept constantly increasing in the family. The incidents of violence were increasing, they were beating the children in my absence. It is difficult for a mother to bear that pain. I had to take a decision so I decided to live separately. I was aware that it will be difficult but the troubles were far more than my expectations.

Arpna decided to ask for her share in the home and live separately with her children. This issue was taken to the village panchayat, and after a prolonged spell of arguments, it was decided that she would be given a small piece of the family's land at outskirts of the village with one room for a home. The villagers gave a happy nod to this decision as this would ensure a safe distance from Arpna's HIV positive family.

Aprna moved out and started living in that one roomed house outside the village. It was a small dark gloomy room without any electricity. It had a problem of water leakage during the rains. Sunken deep in a debt which she has taken to get her husband treated, Arpna had no money for even the basic repairs. Hoping to get some help from her brother in such adversity Arpna went to her natal home, only to hear him explode, I cannot allow you to live here with your children. My children will play with your children and get HIV. Even if they do not get HIV, they will be discriminated by the society and everyone knows about your illness.

My daughter is now young and I wish to get her married as soon as possible. If I let you live here, no one will marry her. I cannot help you . . . I am not in that state now . . . I have a lot of responsibilities.

4.6 Predicament of Motherhood

In the times of difficulty Arpna had to live a lonely life with her children. Her children asked her questions which she could not answer – why were the other children not playing with them . . . why did they have to live in that room . . . why did they take medicines? Arpna was mum to these questions. She neither had the money to provide them with nutritional food nor good education. She felt bad about her children, and had grave concerns for them. She wished to send her elder daughter to the school, asserting to herself, She is not like us, she is not positive she has a long life to live, we are going to die soon, but she will live and I want her to get some education to earn a living and have a better life.

Arpna made desperate attempts to keep her eldest daughter uninfected from HIV. While she and her three younger children shared their things, the eldest daughter was given everything separately . . . separate utensils, separate towel, separate cot, even when it was difficult to afford these things. I don't have money but I keep her things separate . . . towel, clothes utensils everything. I ask her to sleep separately. I know that HIV do not spread by sharing these things but I do not want to take any risk. She is the only one among us who has a life ahead. To fulfill these basic needs of her children she had to work.

4.7 Struggle and Sustenance

Despite her illness she had to work for low wages. She started working in a factory which manufactured spices. This factory had in majority female workers working for 150 INR per day. Her co-workers knew about her illness and they sometimes discriminated her, but the owner of the factory had never asked her to leave the factory. He allowed her unpaid leaves so that she could visit the ART Center. This would lead to the loss of a day's wage for her.

4.8 Beliefs, Treatment and Physiological Understanding of the Virus

Arpna had no complaints with the facilities provided at the ART Centre. She was thankful for free medication believing it to be a blessing for people like her. She was informed by a relative that there is a cure for HIV but she believed that she was in no position to afford any treatment for HIV other than this. This is what Arpna told me,

My sister's sister-in-law was also HIV positive. She lives in a nearby city and her financial condition is very good. They can afford any treatment so she was given injection to cure the disease. This injection increased her body temperature which kills the entire virus in the body. Her daughter was also HIV positive but the doctor said that there is no need to give an injection to her and the virus in her body will get washed out with the menstrual blood once her menstruations starts. I cannot explain how I feel but it always seems like there is something inside my body, and it is crawling in my blood.If, these germs get out of the blood I will be normal again.

4.9 A Dangerous Illusion

Arpna is living in a dangerous illusion—her daughters will get cured once their menstrual cycles begin. The viruses will flow out of the body with menstrual blood and her daughters will be cured. They can lead a normal life after that and get married.

She wants to visit the doctor and find out the details of this peculiar treatment but financial constraints do stop her. She is aware that the treatment is expensive, thus, unaffordable. She has come to the terms that now she has to live with HIV, but she continues to wish for a better life for her children.

4.10 A Wish Awaiting to be fulfilled

Arpna has an only one dream now, that the government should do something to secure the future of her children after her death and many more orphans living with HIV.

5. Discussion

The above narrative is exemplary illustration of the adversities which become a part of life for a woman living with HIV. These miseries increase manifold when the woman is left widowed. The above narrative highlights the multiple experiences that a woman living with HIV deals with. Poverty and HIV has clear linkages and it is evident from the past researches that the two share robust relationship.

Poverty results into illiteracy, unawareness and migration. These factors have interdependence on each other and these are probable elements in the spread of HIV. Further, this makes HIV an illness of marginalized groups (Udoh et al., 2009). Women living in the shackles of poverty are at a higher risk of HIV as stated by Rodrigoa & Rajapakse(2010).

Poverty increases risk behaviors to HIV such as transactional sex and substance abuse. Fewer opportunities for employment and education prevent empowerment of women. On a broader, national scale, lack of finances can restrict development, educational opportunities, access to health care and employment creating a favorable setting for HIV spread. (p. 10)

These factors lead to the increase in the spread of HIV among women. However, once a woman gets infected with HIV the sufferings are inflated by the prevailing gender roles and patriarchy in the Indian culture. Under such circumstances life of a widow is immersed into shame, guilt, vulnerabilities to stigma and discrimination. When widowhood is accompanied by HIV the above mentioned issues increase manifold and they are consorted by responsibilities of rearing children, increased financial burden, social isolation and scanty opportunities for health care. These results can be substantiated by the findings of a study conducted in Kerala (Mohindra, Haddad &Narayana, 2012).

Widowhood brings the sole responsibility of children on the women and in the above case, the children are very young and as a consequence, the financial difficulties increased. Families in such situation isolate the members living with HIV, they are forced to leave the house. They are not given their share in the house, subjected to violence and not only the woman but the children are also stigmatized, discriminated and subjected to violence (Pallikadavath et al., 2005; Bharat et al., 2001). According to Goffman (1990), the initial concept of stigma was based on physically apparent signs. He noted that,

The Greeks, who were apparently strong on visual aids, originated the term stigma to refer to bodily signs designated to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor–a blemished person, ritually polluted to be avoided, especially in public places. (p. 11) A person living with HIV does not carry any signs and symptoms of illness, but the family and significant others have access to this information. This leads to the experiences of stigma among PLWH. In the Indian cultural context, a woman living with HIV does not carry the impressions of HIV on their body but there are evident signs of widowhood. This generates stigma of being a widow accompanied by stigma of living with HIV.

In these state of affairs in one's life motherhood becomes a peculiar involvement. The protagonist of this narrative is left alone with her children in the swamp of poverty. She had to take the caregiving responsibilities of her own health as well as the children's health. The care giving responsibility mostly plagues on women (Kipp et al., 2006). Caregiving is a demanding task and this leads to psychosocial consequences such as added stress, lack of employment opportunity and financial difficulties (Orner, 2006). The situation is complicated here because among her children one is of negative serostatus while the others are positive. She wishes to safeguard her eldest daughter, wants to educate her, and attempts to keep her away from the infection.

Under these circumstances, the HIV negative member is living a different life. The concerns of a mother are obvious but this is resulting in a discrimination against her positive children. She is concerned about her children and is worried about their well-being after her death. Protection of their posterity is an innate feeling among almost all species. Humans have further developed the feeling of progeny by the process of socialization. She was tormented thinking about the future of her children. She wished to secure the children's life and many orphans living with HIV. Orphan-hood is the most ignored in the policies and researches in the context of HIV (Matshalaga & Powell, 2002).

An interesting aspect that has emerged in this particular narrative is the ways in which laymen understand the physiology of virus. Its treatment and how these notions are conceived by culture. There is a strong belief that the virus dies down under hot temperatures. This lead the protagonist to believe, that this kind of treatment could cure her illness too. There are several opinions which people hold in the context of illness and there remedies. These opinions spread and they become dangerous illusions. The illusion depicted in the above narrative, the protagonist believes is that HIV virus will be moved out once her daughters' menstrual cycle begins and then they will be cured. This unawareness might ground to the spread of the virus. Another intriguing fact emerging from this explanation of disease understanding is the perceived physiology of HIV. She mentions about the germs in her blood and said that she can feel them crawling. If they can be removed this will result in a healthy and normal life.

These attitudes towards HIV brought into light the illusions in which people could be living and how they are being deceived in the name of the treatment.

6. Conclusion

In the concluding remarks, the story above brings into light the struggles for sustenance, and the disgrace that a woman has to face in a largely patriarchal society. This account portrays one of the many illusions that people living with HIV are under and in and also the predicament of motherhood. It is essential to focus on the efforts towards the policies for widows living with HIV and HIV positive orphans. The HIV positive widows should be specifically informed about their rights and laws which can empower them. There is also a need for urgent attention towards the illusions and socially constructed opinions about the treatment and cure for HIV. These constructed ideas have the potential to upsurge the spread of virus. Hence, putting several lives at risk.

The counseling sessions, especially the one just after the diagnosis should be conducted for the immediate and extended family together. The collectivistic culture of Indian society makes HIV a concern not only for those affected but also the unaffected ones. This might help in reducing the shame which is being enforced. These strategies will possibly benefit in reducing the feeling of guilt in those living with HIV and the discrimination which they are subjected to in their families. In a patriarchal society, the life of women is always challenging. These challenges increase when a woman is widowed, infected with an illness which has the issues of morality attached to it, she is discriminated, blamed and isolated.

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