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Pleasure and Pain in Life: Cases from People Living with HIV and AIDS (PLHIV)

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ABSTRACT

Pleasure and pain is one mental status raised from the feeling of life experiences. These are the part of life. Every people feel pain and pleasure in their life cycle. The main objective of this study was to explore theexperiences ofpleasure and pain of life in people living with HIV and AIDS. The status of HIV and AIDS cannot be completely cured through medication or other therapy so they need psychological support from the family and society to live a healthy life. In some cases, because of the misconception of people toward the HIV transmission, PLHIV has to face stigma and discrimination insociety. Such types of discriminatory behaviour of family and social determine the level of pleasure and pain in positive life. Regarding these facts, the study was conducted among the PLHIV. The case study design was done adopting the purposive sampling to select the respondents having the experiences of HIV infection. All respondents shared that life was pleasurable before identifying the medical result of HIV test but immediate experiences of PLHIV found very intolerable pain after diagnosis of HIV positive. Gradually, it would be habituated in regular life. There was problem in easy access of treatments in rural life. Family support is necessary to change the painful life of PLHIV to pleasure through the close care and treatment. As well as, society should stop the stigma and discrimination toward the PLHIV because nobody has interest to be HIV positive.

KEYWORDS:- AIDS,HIV, Nepal, Pain, Pleasure, Stigma

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INTRODUCTION

Some philosophers, such as Jeremy Bentham, Baruch Spinoza, and Descartes, have hypothesized that the feelings of pain (or suffering) and pleasure are part of a continuum.There is strong evidence of biological connections between the neurochemical pathways used for the perception of pain and pleasure, as well as other psychological rewards[1].

Modern science begins to understand pleasure as a potential component of salutogenesis. Thereby, pleasure is described as a state or feeling of happiness and satisfaction resulting from an experience that one enjoys[2].Pleasure can be seen as the good feeling that comes from satisfying homeostatic needs such as hunger, sex and bodily comfort, whereas enjoyment may refer to the good feelings people experience when they break through the limits of homeostasis – when they do something that stretches them beyond their current existence[3]. Pleasure can be considered from many different perspectives, from physiological (such as the hedonic hotspots that are activated during the experience) to psychological (such as the study of behavioural responses towards reward). Pleasure has also often been compared to or even defined by many neuroscientists as, a form of alleviation of pain[4].

Strictly from a stimulus-response perspective, the perception of pain starts with the nociceptors, a type of physiological receptor that transmits neural signals to the brain when activated. These receptors are commonly found in the skin, membranes, deep fascia, mucosa, connective tissues of visceral organs, ligaments and articular capsules, muscles, tendons, periosteum, and arterial vessels[5].

One approach to evaluating the relationship between pain and pleasure is to consider these two systems as a reward-punishment based system. When pleasure is perceived, one associates it with reward. When pain is perceived, one associates with punishment. Evolutionarily, this makes sense, because often, actions that result in pleasure or chemicals that induce pleasure work towards restoring homeostasis in the body. For example, when the body is hungry, the pleasure of rewarding food to one-self restores the body back to a balanced state of replenished energy. Like so, this can also be applied to pain, because the ability to perceive pain enhances both avoidance and defensive mechanisms that were, and still are, necessary for survival[2].

In connection with the pleasure and pain experienced by the PLHIV; researcher try to explore the real life experiences of PLHIV from this study. HIV is one virus which gradually destroys the immune system of human body and AIDS is one stage of life when other disease gets opportunity to attack in

body. AIDS cannot be cured completely; only can be managed by using the anti-retro-viral Therapy (ART). So, in the stage of AIDS, finally patients will die from any opportunistic disease. Basically, stigma and discriminatory behaviour of family and society creates the pain in life of PLHIV. As stated by Altman, 1984; Blake &Arkin, 1988; Clendinen, 1983; Herek, 1990, that 'ever since the first cases were detected in the United States in 1981, people with AIDS (PWAs) have been the targets of stigma. Press accounts and anecdotal reports from the early 1980s told the stories of PWAs, and those simply suspected of having the disease, being evicted from their homes, fired from their jobs, and shunned by family and friends. Early surveys of public opinion revealed widespread fear of AIDS, lack of accurate information about its transmission, and willingness to support draconian public policies that would restrict civil liberties in the name of fighting it (cited by:[6]. Through this study, researcher tries to identify the experiences of pleasure and pain in life of PLHIV in before, during and after their positive life.

MATERIALS and METHODS

The study was based on the qualitative research design. Case study was done adopting the phenomenological approach during the time of data collection and analysis. Main question of research was concern to know that how People Living with HIV and AIDS (PLHIV) experience their phenomenon of positive life. In this study, 431 participants were randomly selected for questionnaires survey, in-depth interview and case studies from Garment factory workers, brick factory workers, transport workers and health workers. Among them 3 participants were PLHIV selected for case study. Case study was done by using the semi-structured checklist. Study was conducted in Kathmand valley of Nepal in 2013. Ethical approval was taken from the Nepal Health Research Council (NHRC) before conducting this study. Respondents were per-informed about this study and voluntarily requested to participate in study. Confidentiality was maintained during the data collection and analysis. During the analysis of data, name of respondents were changed.

RESULTS

Discussion was held with participants of this study regarding the pleasure and pain in life. Pleasure includes the experiences of childhood before positive life and any pleasant experiences felt during and after the positive life. Similarly, pain includes the feeling grief felt after diagnosis of HIV positive.

CASE STUDY NO. 1

28 years married Mrs. Rita Thapa (name changed) is living with HIV from 2008. She was born in small farmer house as a third child. There was no problem to manage the basic needs of family. Her child life was spent happily.

She was married at the age of 20. Her husband was used to visit the Mumbai, India for the search of job. She was unknown to the sexual behaviour of her husband. She said "*I have no knowledge about the HIV and AIDS till my 1st sexual intercourse"*. After 3 years of marriage, her husband returned home having with some unknown disease, then she brought her husband to the hospital for the treatment then it was identified that her husband was HIV positive. After some time, her husband died then gradually she became ill and people suggested her to go hospital for check-up. Then with the support of one local NGO, she was brought Teku Hospital, Kathmandu for HIV testing. She was also identified HIV positive. After getting positive result, she said *"I felt very nervous, bad feeling, for a movement became senseless, I felt now my life is destroyed and going to die within few years."*

Effect in life

She said "*gradually my study stopped no job opportunities, economic burden increased because of expenditure in treatment and disturbance came in family and social relation. Due to HIV, I have to lose my husband in my very young age. I have to leave my father-in-law house also. Then I went back to my parent's house and I disclose my HIV status with my parent. For sometimes, they became speechless, but gave me moral support and encourage me to live long life."* Regarding the social behaviour, she told "*when community people know my HIV status then I have to face stigma and discrimination. They blamed in my character."*

Responsible factors to make vulnerable

She said "My husband became the HIV positive due to ***lack of awareness*** on HIV and AIDS, there may be ***negligence*** also. On the other hand, my ***blind trust*** towards my husband made me also HIV positive."

Causes of increasing the risk of HIV in Nepal

Regarding the causes of increasing HIV in Nepal, she said, "Unemployment, Poverty, Lack of awareness and negligence of Government in the field of HIV are the major factors associated with increasing the risk of HIV in Nepal."

Present situation

Prior to this study, Thapa was reading in +2 and working as a Counsellor in VCT. She got 2nd marriage at the age of 25 years with PLHIV. Now, her health status was good, was taking ART medicine. Her husband worked as a farmer. Her social and economic status was also good. She told, *"Now community people also respect me and do the normal behaviour"*.

CASE STUDY NO. 2

Mr. Kiran (name changed) shared his life experiences through his introduction by saying "my name is Kiran (name changed), permanent resident of Bardiya district of Nepal. I am 29 years old married people. I was born in economically middle family. We are total 6 children and I am a 1st child of my parent. My child life spent very happily. My peers were very alcoholic and used to take cigrate from the very beginning. Due to such environment, I could not pass class ten also. Then I went various cities of India (Gowa, Kalkata, Mumbai, Delli, Gujrat and Silang) and Kathmandu of Nepal in the search of job in hotels and garment factories."

He shared his sexual experiences also by saying "I had sexual experience at the age of 16 with my girlfriend. Till that time; I was not aware about the HIV and AIDS. After that frequently I used to keep the sexual relationship with non-regular sex partners, but used the condom. Unfortunately, one day I had unsafe sexual intercourse with one woman who was suspected as HIV infected then I felt myself in risk of HIV transmission. Then I visited one hospital of Kathmandu for HIV testing. I found that I was HIV positive. When I got the report, long time I felt very nervous, bad feeling, for a movement became senseless, I felt now my life is destroyed and going to die within few years."

"First time I told my mother and brother about my HIV status. They easily understood my problem and do the normal behavior as usual. It gave me some courage in my life to live long time."

Factors make you or your family vulnerable for HIV infection

He said "unsafe sex practices due to lack of awareness made me HIV positive."

Present life style

I had asked his present life status during the time of research then he said "*right now, I am doing the agriculture work and married with PLHIV. Social and economic life is good. Health is improved by taking the ART."*

CASE STUDY NO. 3

I had conducted in-depth interview with 37 years HIV positive lady from the Brahmin community; permanent resident of Rupandehi district (out of Kathmandu valley) of Nepal. She was married at 20 years of age. She was working as a community and home based care (CHBC) worker in one HIV awareness project in local level.

Past family life

She shared her past life by saying, "I am born in simple family and child life was spent very simply. I have just passed class 7. My peers were from the very simple family. They used to obey the cultural system of their family. I have visited Kathmandu, Pokhara, Delhi and Mumbai in the search of job. Economic condition of your family was normal. No. of family members including parents and children: 8 members and I am 2nd daughter of family."

Feeling of Risk of HIV transmission

"I had first sexual intercourse at the age of 20 years. I had no knowledge of HIV and AIDS or STIs before my 1st sexual intercourse. My first sexual partner was my own husband. I had no any non-regular sex partners. My husband has started to use the condom during the sexual intercourse when he was found the HIV positive."

"When I tried to go aboard then I was referred for medical check-up then doctor gave me medical report of HIV positive in my blood."

Feeling after HIV testing

"When I found HIV positive in my blood then I surprised and felt nervous. I became helpless, could not think anything what is right and wrong. I was afraid that if society could know my HIV status and they would hate me and removed from the society."

Effect in life after identifying HIV positive

"I felt loneliness in my life, depression, no concentration in work, what to do and what not. I thought that my life time was completed and going to die soon. Then 1st time I told my HIV status with my mother then gradually other members of family."

Society's or family's attitude

"In the beginning I was afraid from the social discrimination, because our society is dominated by male. But I found not so different behaviour from society and family so till social and family relation is good."

Factors responsible to make vulnerable for HIV infection

*"**Poverty*** and ***lack of awareness*** made me vulnerable. I am infected from my husband through the sex."

Reasons to increase the HIV and AIDS in Nepal

"First, ***Poverty*** and second, ***social norm*** of our society is responsible which deprives the open discussion of sex and sexuality."

From the above cases, it was found that gender wise causes of risk transmission were different. In the case of male, early childhood was spend happily and when people felt their own responsibilities to manage the family then specially, male used to migrate from one place to another place for the search of job. The frequent movement and long detachment from the family made them vulnerable for unsafe sex and alcoholically also. Poverty play the role of latent function to migrate people from one place to another place, as well as lack of awareness and negligence behaviour play the role of manifest function to do the risk behaviour related with HIV transmission.

Similarly, in the case of female also, childhood was spend happily and when they became eligible for marriage then culturally they got married. They were found very innocent in case of sexual behaviour and found unknown in husband behaviour also. As the Hindu cultural; ritually wife worships husband as a god so as possible, she doesn't suspect on husband behaviour. But in the case of HIV transmission; it is found that trust on husband made wife HIV positive.

In the case of male and female, both felt problem in social adjustment after HIV transmission because of the miss-conception toward the way of HIV transmission. As well as, social stigma and discrimination made problem to disclose the HIV status in society. Regarding this fact, besides the case study, data was collected from the larger (404) population also to know the perception of towards the secrecy of HIV status.

Table 1: Secrecy about the HIV and AIDS

Responses		Occupation of respondents				Total
		Health workers	Garment Factory workers	Transport workers	Brick factory workers	
Yes	% within total respondents	37.9%	23.7%	10.7%	27.8%	100%
	% within Occupation of respondents	63.4%	39.6%	17.8%	46.5%	41.8%
No	% within total respondents	16.0%	22.8%	36.9%	24.3%	100%
	% within Occupation of respondents	32.7%	46.5%	75.2%	49.5%	51%
Don't Know	% within total respondents	13.8%	48.3%	24.1%	13.8%	100%
	% within Occupation of respondents	4.0%	13.9%	6.9%	4.0%	7.2%

Sources: Field survey, 2013

Respondents were asked about the secrecy of status of HIV in their family. They were asked that if any family member would have HIV positive then would they want it to remain a secret or not. In this question 51% respondents wanted to disclose the HIV status followed by 41.8% wanted it to remain secret and 7.2% don't know what should be done. Data showed that still around 50% people do not want to disclose their HIV status in their community.

If we compared occupation-wise, 63.4% of Health workers wanted HIV status to remain secret as compared with only 17.8% transport workers remained it secret.

Respondents were asked about the reason of secrecy also during the time of field survey. Respondents had different reasons who wanted to keep it secret and who didn't want to keep it secret. Those respondents who wanted to keep it secret shared its reasons by saying that *"it is not the matter to* say *everybody about own HIV status. Still community people have misconception about the HIV so when people know about the HIV status then they will hate and give mental torture, PLHIV have to suffer from the stigma and discrimination, and social prestige will be lost. If one people are infected from the transmission of blood then such people are also get stigma and discrimination by saying that they are also infected from the illegal (sex work) relation so it raised the questions in personal character. So, if we keep it secret then it makes easy to live long life in society."*

DISCUSSIONS

In relation to the pain, after being diagnosed, people confronted with their HIV-positive status are highly stressed and uncertain, despite the availability of highly active antiretroviral therapies HAART and their lives may be devastated by the need to deal with the new medical, personal and social

situation. Research related on the psychosocial aspects of HIV-positive status show that living with HIV is associated with a large measure of stress and depression. People with HIV and AIDS must also manage the stigma associated with HIV/AIDS. Moreover, they must tolerate treatment with adverse side-effects, deal with rejection and social discrimination, and confront the deaths of others in their social networks. Being HIV positive generally makes HIV part of a person's identity[7].

Children who grow up without the love and care of adults devoted to their wellbeing are at higher risk of developing psychological problems. A lack of positive emotional care is associated with a subsequent lack of empathy with others and such children may develop antisocial behaviours[8]. People felt the psychological stresses: Fear of infection, Anticipatory grief, Shame, Helplessness, Discrimination thus, these same anxieties that are felt by the infected are also felt by the affected family members and care givers. It was also stated that affected people are faced with challenges of; loss, death, perceived helplessness, uncertainty about the future, sadness and anger, frustration in navigating the medical system, financial worries and interpersonal stress. These burdens are usually placed on the shoulders of elderly caregivers, family members, partners and sometimes even friends[9].

Presence of HIV and AIDS will dissolve the household-as parents die children are sent to relatives for care and upbringing, loss of family income and saving are used up or assets are sold[10].

In several countries, income in orphan households has been found to be 20–30% lower than in non-orphaned households. Studies in urban households in Côte d'Ivoire showed that where a family member has AIDS, average income falls by as much as 60%, expenditure on health care quadruples, savings are depleted and families often go into debt to care for sick individuals. Other studies have suggested that food consumption may drop by as much as 41% in orphan households stigmatization may prompt affected children to stay away from school, rather than endure exclusion or ridicule by teachers and peers. A study in Zambia showed that 75% of non-orphaned children in urban areas were enrolled in school compared to 68% of orphaned children[8].

UNICEF believes that children suffer profoundly when their households become vulnerable as parents fall sick and die of HIV and AIDS. This suffering includes: Psychosocial distress, Economic Hardship, Withdrawal from School, Malnutrition and Illness, Loss of Inheritance, Fear and Isolation and Increased Abuse and Increased Risk of HIV. Children orphaned by AIDS are at greater risk of malnutrition, illness, abuse, child labour, and sexual exploitation than children orphaned by other causes and these factors increase their vulnerability to HIV infection[11]. Common consequences of orphaning include growing up in poverty, the loss of parental affection, reduced level of care, stigma and the

psychosocial implications of repeated personal and material losses such as trauma, stress, depression and a loss of social connectivity[12].

Economic commission of Africa had explained that when people would be HIV infected; for the future, three factors are particularly important for them: First, AIDS selectively destroys human capital, that is, peoples' accumulated life experiences, their human and job skills, and their knowledge and insights built up over a period of years. Second, AIDS weakens or even wrecks the mechanisms that generate human capital formation. Third, the chance that the children themselves will contract the disease in adulthood makes investment in their education less attractive, even when both parents themselves remain uninfected[13].

HIV and AIDS is a pandemic that has far-reaching effects. Not only it is a public health challenges intertwined with complex social issues, AIDS is also a looming economic disaster. In an increasingly globalized world, multinational enterprises and small and medium-sized enterprises has felt the economic impact of HIV and AIDS equally[14].

CONCLUSIONS

From the whole discussion of primary and secondary data, researcher came to the conclusion through this study that feeling of pain aroused by the HIV infection found intolerable for people. Basically, women have to face double stigma from the family and society. Study found that still around 50% people do not want to disclose their HIV status in their community because of the fear of stigma and discrimination as well as fear to loss the social prestige. Poverty, lace of awareness, negligence behaviour as well as cultural values like trust on sex partner also made the people vulnerable for HIV transmission. Psychologically also, PLHIVs were found weak to express their feeling because of their own self-stigma. Fatalistic thought is also found working there to make them realize that it is the punishment of their sinful work. Family, society and concerned agencies should be responsible to manage the normal life of PLHIV in society. Equal opportunities should be provided for work place so they will come up from the stress and pain. Pleasure of life brings the happiness which support to extend the years of positive life.

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