PROBLEMS OF PEOPLE LIVING WITH HIV: A CASE STUDY OF MANIPUR

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ABSTRACT

Background: World Health Organization continues to consider HIV transmission to be a global epidemic. Globally, the number of people living with HIV (PLHIV) was 38.4 million with an estimated 650000 (510000-860000) deaths from the disease by 2021. Despite significant advances in antiretroviral drug supply and access, as well as a rapid increase in awareness initiatives over the last thirty years, about 2 million instances of new infection are reported each year. This presents substantial challenges in reaching the 2030 Sustainable Development Goal 3 objectives of promoting excellent health and well-being for everyone. India has the world's third highest total HIV load, with an estimated 2.3 million PLHIV in 2021, 63 thousand of whom were recently infected, and 42 thousand recorded HIV-related deaths each year. **Aim:** The main objective of the research is to analyze the consequences/issues faced by people living with HIV in Manipur. **Material & Methods:** A cross-sectional study with purposive in nature. Primary data were collected in 2019 in three major districts of Manipur. In total, 153 HIV-positive individuals (PLHIV) in Manipur were interviewed, including both quantitative and qualitative information. **Results and Conclusion:** The finding suggests the urgent needs for valuable intervention through social support, professional medical social workers, Counsellor, ASHA and others community-based health worker to improve the quality of life for PLHIV in Manipur.

Keywords: Discrimination, Marital conflict, Counsellor

INTRODUCTION

HIV (Human Immunodeficiency Virus) is a lifelong contagious viral disease that weakens the individual's immune system without treatment and progresses to the life-threatening illness known as AIDS (acquired immunodeficiency syndrome). The transmission of HIV continues to be designated as a global epidemic by World Health Organisation. Globally, the incidence of people living with HIV (PLHIV) was 38.4 million (33.9-43.8 million), with an expected 650000 (510000-860000) mortality from the disease by 2021. Despite substantial developments in antiretroviral therapy supply, and access, as well as a rapid growth of awareness efforts over the past thirty years, almost 2 million each year cases of infections have been documented (UNAIDS,2023; WHO, 2022). In 2019, HIV infection resulted in 47.63 million. Disability Adjusted Life Years (DALYs) worldwide, a 1.28-fold increase over 1990 (UN, 2015). This poses significant hurdles in meeting the 2030 Sustainable Development Goal 3 objectives of promoting good health

and well-being for everyone (UNAIDS, 2020; Warren et al., 2017) and their vow to 'Ending the AIDS epidemic as a public health issue' (SGD-3, Target 3.3) (Zeng et al, 2016).

India has the world's third highest overall HIV burden, with an anticipated 2.3 million PLHIV in 2021, 63 thousand of whom were recently infected, and 42 thousand yearly reported fatalities due to the disease. Additionally, only 77% of PLHIV were conscious of their diagnosis, and only 65% had begun ART medication (UNAIDS, 2022). HIV/AIDS has a substantial adverse impact on health, social, and economic growth in an emerging lower middle-income country like India. Since 1992, the government of India, under the Ministry of Health and Family Welfare (MoHFW) has launched the National AIDS Control Organization (NACO) in order to regulate and prevent the further spread AIDS epidemic in India. It has accomplished major achievements in reducing the yearly prevalence of fresh infections with HIV by two-thirds and the death rate by more than half (54%) over the last two decades (NACO, 2015). Moreover, the country's prevalence has consistently decreased from 0.54% in 2000-2001 to 0.22% in 2020 (NACO, 2022a). Although the general prevalence is reasonable, there is substantial variation among states, with higher levels in Mizoram, Nagaland, and Manipur. Other states and union territories with adult rates of HIV exceeding the national average are Andhra Pradesh, Meghalaya, Telangana, Karnataka, Delhi, Maharashtra, Puducherry, Punjab, Goa, and Tamil Nadu (NACO, 2022b). These considerable inter-state variances highlight the importance for faster and extensive preventative measures to reduce population risk by up to 80% by 2025 (NACO, 2020).

REVIEW OF LITERATURE

The HIV/AIDS epidemic in India is highly heterogeneous, which influences population transmission dynamics and the burden of epidemiological disease. High-risk categories include female sex workers (FSWs), men having sex with men (MSMs), injectable drug users (IDUs), truckers, low socioeconomic status (SES) populations, and migrants, among others. As a result, HIV risk is an outcome of adverse social variables that contribute to current high-risk behavior and low knowledge (Shrivastava et al., 2019; Kefale et al., 2020). Aside from the physiological concerns among the individuals with HIV/AIDS encounter, social and psychological issues are also regarded as significant hurdles (Stangl, et al., 2013). Stigmatization and prejudice, in particular, are substantial hurdles to HIV/AIDS infected individual's access to healthcare services and testing, as well as their treatment adherence (Katz et al., 2013). Thus, researching the extent of stigma and discrimination against people with HIV/AIDS is regarded as one of the foremost emphasis for HIV/AIDS studies (Tran, et al., 2019; Greenwood et al., 2021). The detrimental impact of negative perceptions toward HIV/AIDS infected people can hinder strategies to regulate and prevent the disease (Vorasane et al, 2017; Rintamaki et al., 2019). Furthermore, the potential implications of HIV stigma include a lack of desire to share HIV status, a poor influence on health seeking behavior, and an adverse effect on the necessary social support (Brown et al., 2003; Vanable et al., 2006).

Manipur, which covers around 22,327 km^2 and has a population of 2.7 million residents (a population density of 120 individuals per square kilometer), has been estimated to be one of India's most affected centers of the worldwide epidemic of HIV/AIDS. Manipur, a distant north-eastern corner of the country with only 0.2% of the overall population, accounts for roughly 8% of India's total HIV-positive patients. The prevalence of HIV rates among IDUs climbed dramatically, from 2%

to 3% in 1989 to more than 50% in 1991 and 64% in 2000 (Saha MK et al., 2000). The magnitude of the HIV/AIDS pandemic continues a challenge for the state. HIV/AIDS has been recognized as an alarming public health concern, and controlling its spread appears to be a formidable challenge. In contrast to other states in India, the spread of HIV in this region is mostly linked to the exchange of HIV-infected injecting equipment/ needles across Injecting Drug User (IDUs) (Narain JP et al., 1994). IDUs are an easy target for transmitting HIV. While the epidemic was first documented among IDUs, HIV is no longer limited to IDUs and is now starting to surface in the general population.

Due to the lack of curative treatment or vaccines, public awareness of HIV/AIDS should be the foundation for managing the epidemic (Yadav et al., 2016). Earlier research has revealed that a lack of precise and complete understanding of HIV, particularly about the modalities of virus transmission, is a major cause of incident HIV infections (Nubed & Akoachere, 2016; Janahi et al., 2016). However, knowledge alone cannot prevent infection; practice is required to get the desired results (Teshome et al., 2016). In order to develop successful educational and awareness programs to tackle this important public health concern, it is critical to examine the problem of HIV/AIDS in state of Manipur.

AIM & OBJECTIVES

The primary objective of the study is to assess the consequence/issues faced by the PLHIV in the context of Manipur.

MATERIAL & METHODS

The paper is a cross-section study with purposive in nature. The primary data were collected in 2019 in some districts (Imphal East, Imphal West, Thoubal & Churchandpur) of Manipur. With their consent, altogether 153 patients living with HIV (PLHIV) in Manipur were collected along with their various socioeconomic and demographic variables such as age, gender, marital status, types of community, educational level of the individuals, employment status, types of family and type of residence. Other characteristics such as discrimination, love and care by neighbours and marital conflict were also collected in the survey. Further, some case studies with unique in nature experienced by PLHIV were also accessed for proper understanding of the research study.

RESULTS

Table-1 describes the discrimination faced by the PLHIV and as data suggest discrimination is more among the older persons compared to the youngest in the age less than 25 years but the level is not consistent. This pattern is similar in case of marital status. The illiterate persons had a higher level of discrimination compared to the higher educated. The urban people had a higher level of discrimination compared to the persons living in the rural areas. However, it can also be noticed that when the people are from the joint family and working happened to have higher level of discrimination. Though it is not very accurate they are the perceived the discrimination that they faced in their life.

Table 1: Percentage distribution of discrimination among the PLWHA based on background characteristics

Background Characteristics	Discrimination	No discrimination	Total	N
Age-group				
Less than 25 years	67	33	100	15
(25-29) years	80	21	100	44
(30-34) years	90	10	100	48
(35 & above) years	81	20	100	46
Gender				
Male	77	23	100	97
Female	89	11	100	56
Marital status	0			
Married	80	20	100	69
Unmarried	80	20	100	49
Widow	93	7	100	27
Divorcee	75	25	100	8
Educational level				
Illiterate	90	10	100	20
Primary	70	30	100	10
Middle School	82	18	100	17
(Highschool-Higher secondary)	83	17	100	48
Gradate & above	79	21	100	58
Community level				
Meitei	84	16	100	98
Pangal	79	21	100	14
Chingmee	77	23	100	39
Mayang	100	0	100	2
Usual activity status				
Working	75	25	100	75
Not working	56	44	100	64
Student	79	21	100	14
Type of Residence				
Rural	76	24	100	59
Urban	85	15	100	94
Type of family				
Joint	86	14	100	91
Nuclear	76	25	100	49
Single parenting	77	23	100	13
Total	**82**	**18**	**100**	**153**

Source: Field survey, 2019

Table-2 presents the love and care of the neighbours towards the PLHIV. This table makes it clear that before they were detected with HIV 84 percent of them felt they were treated well by the neighbours but after the detection of the HIV the figure slide down to only 32 percent. This decrease is a substantial level. Compared to the male counterpart, females faced this more than the male. Similarly, the widowed and separated groups had higher chance of having this problem than the currently married of unmarried group. There was not much difference in neighbour's attitude in terms of educational attainment or work status. However joint family people had a better outcome than others.

Table 2: Percent distribution of Love and Care of Neighbours among the PLHIV along with the Background characteristics

Background Characteristics	Before HIV positive	After HIV positive	Total	N
Age-group				
Less than 25 years	67	47	100	15
(25-29) years	80	46	100	44
(30-34) years	83	27	100	48
(35 & above) years	61	20	100	46
Gender				
Male	67	33	100	97
Female	86	30	100	56
Marital status				
Married	75	32	100	69
Unmarried	61	39	100	49
Widow	85	26	100	27
Divorcee	100	13	100	8
Educational level				
Illiterate	75	30	100	20
Primary	70	20	100	10
Middle School	59	18	100	17
(Highschool-Higher secondary)	75	31	100	48
Gradate & above	78	40	100	58
Usual activity status				
Working	77	33	100	75
Not working	70	22	100	64
Student	71	71	100	14
Type of Residence				
Rural	75	22	100	59
Urban	73	38	100	94
Type of family				
Joint	78	36	100	91
Nuclear	67	27	100	49
Single parenting	69	23	100	13
Community				
Meitei	71	34	100	98
Pangal	86	36	100	14
Chingmee	77	26	100	39

Source: Field survey, 2019

Table 3 The marital conflict as experienced by women is also examined in the paper and it is found that 54.8 percent of the women faced marital conflict after they got the HIV status This is quite expected and despite the fact that many awareness programs are run the shock that people had once they are declared of this deadly disease is known. Among them the older, divorcees, non-earning living in urban areas had a significantly higher level of marital conflict than other counterparts. One exception is the women in the nuclear setup where the level of marital discord was much less than others.

Table 3: Percentage distribution of women with HIV/AIDS along with Marital conflict based on background characteristics

Background characteristics	Yes	No	Total	N
Age-group				
(25-29) years	39	61	100	18
(30-34) years	64	36	100	22
(35 & above) years	62	39	100	13
Marital status				
Married	53	47	100	19
Widow	52	48	100	27
Divorcee	71	29	100	7
Educational level				
Illiterate	50	50	100	14
Primary	50	50	100	4
Middle School	57	43	100	7
(Highschool-Higher secondary)	62	39	100	13
Gradate & above	53	47	100	15
Usual activity status				
Working	36	64	100	25
Not working	71	29	100	28
Type of Residence				
Rural	35	65	100	23
Urban	70	30	100	30
Type of family				
Joint	63	38	100	32
Nuclear	38	63	100	16
Single parenting	60	40	100	5

Source: Field survey, 2019

DISCUSSION

Case study -I

Rani, 24, a widow of injecting drug user (IDUs) is from Thoubal district. She studied class X and got married. Her husband held an M.A. in English and was employed in a private school. Before marriage, she was unaware of her husband's drug behaviour. However, he became addicted to substances during his post-graduate years as well.

She discovered her HIV status in the routine

antenatal check-up. She was counselled and convinced of having HIV test since her husband was already HIV+. Ultimately, Rani also found herself HIV+. She gave birth to a baby and soon after that she along with her husband joined Manipur Network of Positive People (MNP+) an NGO worked for the PLHIV in Manipur. After joining MNP+ she got training to handle the situation. Rani retorted that nobody was looking after her when she fell ill at her in-law's house only to get the ill treatment. She was refused to get any resource for her treatment from her in-laws and she also hid her situation from her parents even. She was even denied of attending the last rite of her husband after he died. She was of the opinion that majority of women in her situation faced such kind of discrimination in almost every part of the state.

Case study –II

Lun is from Churachandpur district. He is twenty-year-old and HIV+ positive. After completing his high school education, he studied engineering at the North East Regional Institute of Science and Technology (NERIST), Arunachal Pradesh. During his days in NERIST he established himself as active drug addiction. He said that he started using heroin while he was in class-VIII. He even narrated that during his days in NERIST he bought Spasmo-proxy van as a stock for two years.

Later he confirmed his HIV positive but dared not to tell anybody even to his family. Nobody took him seriously despite various complaints he had later he got admitted to an NGO in Churachandpur and got some treatment. Later he joined Manipur Network of positive People (MNP+) and became a peer educator. He did keep much of a positive hope in his life only thing that kept him moving is to render help to fellow PLHIV.

Case study—III

Hoinu is fron Shaikot Village Churachandpur. Her spouse served as a defence personnel and was stationed in Cambodia for six years as part of the UN Peace Mission. Her husband was granted leave on medical ground from duty and asked him to report after curing his illness. Instead of going through treatment, he became addicted to alcohol and marijuana. When her spouse became ill, he was sent to the Government District Hospital in Churachandpur, where he was diagnosed with AIDS. So, District Hospital Doctors sent him to "SHALOM" Rehab Centre for medical care, but he died there after a month.

Hoinu tested for HIV and found positive but she did not face any physical complications in the beginning. However, she started her full-blown HIV/ AIDS complication after 3 years of her husband death. She also got treatment at SHALOM Rehab Center but faced lots of financial problems for her treatment and caring of her children. She narrated that if she died there would be nobody to stay with and care for her small children. She was very weak and unable to talk. She sends a message to society: *"Do not have sexual relationships with strangers, do not engage in risky behaviour, and say no to IDUs."*

Analysis from the case study

From the cases it becomes clear that HIV is a condition of highly deplorable. The first case shows the condition of being a PLHIV woman who suffered both from the husband being a liar and family not considering the situation faced by women as a group in Manipur. Afterall her natal family stood by her and extended the help which she needed most at the time of need.

The second case was the experience of a youth who tasted drugs in the early age. Because of his misadventure he ended up without having nothing from his academic life and a result his family left him unattended

while he devoted his life to the cause of HIV/ AIDS.

The third case is also a transmission from the unsuspecting husband who was away from home for a long time in service. The unguarded moments of life of the husband put Hoinu into the dreaded situation and led her to the world of HIV. She was devastated but she carried on her life for the sake of her small innocent children. Her message to us is to avoid sexual relationships with strangers, as well as using illicit drugs and other dangerous behaviour.

CONCLUSION

The current paper focuses solely on the perceptions and experiences of people living with HIV (PLHIV), providing a boost and direction for future research that examines the perceptions and experiences of general population (non-PLHIV) in tailoring more effective measures to improve the quality of life of PLHIV.

In short, the research paper was able to emphasize the stigma and discrimination experienced by PLHIV in the state of Manipur. It was able to address the fact that women (PLHIV) are more vulnerable to discrimination and marital turmoil. The finding furnished deep understanding of the problem which needs valuable intervention through social support, professional social workers, ASHA and others community-based health worker to improve the quality of life for PLHIV in Manipur.

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