Socio-Economic and Health Factors of Women Living With HIV/AIDS in India: An Empirical Study

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ABSTRACT

HIV/AIDS is a major public health issue in many developing countries and has contributed to a lower life expectancy among people living with HIV/AIDS. The impact of HIV/AIDS is greater on women. Women living with HIV/AIDS face many problems, including economic problems, stigma and discrimination, and sexual abuse. They are more vulnerable than other widows and women. The present study was conducted in Visakhapatnam to specifically study the socio-economic and health problems of women living with HIV/AIDS. The study found that 46.2 percent of the respondents had not faced any stigma and discrimination, while 43.2 percent of the respondents stated that the people in their community did not know about their HIV status. Only 10.3 percent of the respondents faced stigma and discrimination. The widowed women with HIV are facing additional discrimination and social stigma from their neighbours and relatives. The newly initiated government schemes of Government of Andhra Pradesh are helping a lot of women living with HIV/AIDS. The ART medicines are a boon to such women by increasing their life span. The study suggested that the government and NGOs should provide capacity building on vocational education as women living with HIV/AIDS are not in a position to do hard labour. Vocational skills in tailoring, fabric painting, and other handicrafts help them earn their livelihood.

Key words: *Women living with HIV/AIDS, ART medicine, stigma and discrimination*

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INTRODUCTION TO HIV/AIDS

HIV/AIDS is a major public health issue in many developing countries and has contributed to lowering the life expectancy among people living with HIV/AIDS. The impact of HIV/AIDS is greater on women. Many women became widows, separated or divorced, or heads of families. According to World Health Organisation (WHO: 2021), the Human Immunodeficiency Virus (HIV) targets the immune system and weakens people's defences against many infections and some types of cancer that people with healthy immune systems can fight off. As the virus destroys and impairs the function of immune cells, infected individuals gradually become immunodeficient. As per the National AIDS Control Organisation and the ICMR-National Institute of Medical Statistics (2021), the total number of people living with HIV (PLHIV) in India was estimated at 23.19 lakh (18.33 lakh–29.78 lakh) in 2020. Children (<15 years) accounted for 3.5%, and 44.3% of the total infections were among females. The HIV prevalence rate in India is 0.022.

Women living with HIV/AIDS are often women who got infected with the HIV virus via their husbands. The sudden knowledge of their husbands' HIV status comes as a shock and causes great distress. Such a woman will face problems as to how she will cope and lead the family without the emotional and economic support of her husband. She will face the daunting thought of becoming a widow, and the ostracization that surrounds both widowhood and her own HIV status. These combined factors can lead to depression and suicidal tendencies. The concern for the welfare of their children is great, and often mothers are reluctant to reveal their (or their spouses') HIV status to children. Thus, women living with HIV/AIDS face many problems, including economic problems, stigma and discrimination, and sexual abuse. They are more vulnerable than other widows and women (Abraham, M., 2012).

REVIEW OF LITERATURE

Becker, N., et al. (2020) conducted a study on individual, household, and community level barriers to ART adherence among women living with HIV in rural Eswatini. The study included focus group discussion with the HIV-infected women (4) from rural villages in Eswatini, and in-depth interviews with health care workers (8) serving the area clinics. The findings revealed several individual level barriers including hunger, side effects of ART, personal stress, lack of disclosure of HIV status, alcohol use, and forgetting to take ART. Lack of food, unemployment, and scarcity of financial resources were identified as crucial barriers at household level. Community and institutional barriers encompassed factors related

to health delivery such as lack of privacy, travel time, transportation costs, excessive alcohol use of health care workers, maltreatment, public and self-stigma, gossip, and long wait time at clinics.

Anderson, J. (2011) conducted a descriptive study which explored the illness biographies and daily lives of HIV-positive African women receiving treatment in London. Sixty-two women from 11 African countries attending HIV specialist clinics in five London hospitals participated in self-completion questionnaires and in-depth semi-structured interviews. Using a narrative approach, women were asked to talk about their HIV status in the broader context of their life history. Important differences exist within this group based mainly on nationality, income, education level, and legal status in the UK. However, marked similarities also emerged, which were related in part to their situation as migrants and were compounded by their illnesses. Stigma, both actual and perceived, had a profound impact on women's lives, making control of information about their situation a matter of acute concern. This had an effect on how women accessed health services and voluntary sector agencies. The resilience of women in dealing with difficulties in their lives was strengthened by their religious belief.

Paudel, V., et al. (2015) conducted a study on Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial, and the role of support groups as a coping strategy. The study examined and analysed the feelings, experiences and perceptions of Women living with HIV/AIDS (WLHA). The findings were compiled into five thematic areas: (1) Disclosure as a sensitive issue: (2) Stigma and discrimination associated with HIV/AIDS and the multidimensional effects on women's health and wellbeing: (3) Internalised Stigma: (4) Women living with HIV/AIDS experiences of being rejected, shunned and treated differently by physicians, family and close friends: (5) Support group as among the best available interventions for stigma and discrimination.

Abedinia et al. (2019) conducted a qualitative study on experiences of stigma in health care centres in the Islamic Republic of Iran. The study aimed at assessing the problems of people living with HIV face when seeking health care in the Islamic Republic of Iran. Using a focus group discussion, the participants (10) talked about the problems they face when seeking health care in different departments and clinics. The findings revealed that participants faced many problems in all health departments and clinics when seeking health care. The most important problems were refusal of treatment in outpatient, medical and surgical departments, inappropriate behaviour of consultants and medical staff and insufficient knowledge of medical staff about HIV and how it is transmitted.

STATEMENT OF THE PROBLEM

Stigma is experienced by almost all the people living with HIV/AIDS, however cultural beliefs and unequal power relations make Indian women more vulnerable. Women living with HIV/AIDS face many problems like economic problems, stigma and discrimination, and sexual abuse. They are vulnerable than other widows and women. They have to take care of the remaining family members especially their children. There are many governments and NGOS efforts towards addressing the issues of people living with HIV/AIDS however women in India are still subjected to lot of problems. Therefore, the present study was conducted in two districts of Andhra Pradesh i.e. East Godavari and Visakhapatnam to specifically study the socio-economic and health problems of women living with HIV/AIDS.

OBJECTIVES

1. To study the socio-economic and health problems of women living with HIV/AIDS
2. To understand the ART medication for the women living with HIV/AIDS
3. To understand the government support to women living with HIV/AIDS
4. To provide the appropriate suggestions and to promote the quality of life of women living with HIV/AIDS

METHODOLOGY

A descriptive research design was used for the present study to describe, compare, and analyse the major problems and situational analysis of women living with HIV/AIDS. The present study adopted the convenience sampling method (non-probability sampling) to identify the respondents. The respondents of the present study were women living with HIV/AIDS. The data collected at ART centres in Kakinada and Visakhapatnam. The study collected the data from 39 women living with HIV/AIDS who came to collect the ART medicine at ART centre. The data was collected through a structured interview schedule and analysed through MS-Excel and SPSS.

RESULTS AND DISCUSSION

The data collected from 39 women living with HIV/AIDS. According to *Dictionary.com* (2022), “age” refers to the length of life or existence to the time spoken of or referred to.

Age is the duration of time during which a person or something has been alive or existing. The table below presents the age of the respondents:

Table No: 1
Distribution of respondents by their age

S. No	Value	frequency	percentage
1	26-30	4	10.2
2	31-35	8	20.5
3	36-40	14	35.8
4	41-45	6	15.3
5	46-50	7	17.9
6	**Total**	**39**	**100**

The data in the table above revealed that the age range of the respondents was from 26-50 years. Majority of the respondents (35.8%) of the respondents belonged to the age between 66-40, followed by 20.5 percent of the respondents in the 31-35 years age group. And 17.9 percent of the respondents belonged to 46-50 years age group. The table below presents the marital status of the respondents:

Table No: 2
Distribution of respondents by their marital Status

S.No	Marital Status	frequency	percentage
1	Married	20	51.2
2	Unmarried	0	0
3	Widow	18	46.1
4	Divorced	0	0
5	Not together.	1	2.5
6	**Total**	**39**	**100**

The data in the table above revealed that the majority (51.2%) of the respondents were married, (46.1%) were widowed and only (2.5%) were not together due to some problems. The table below presents the living area of the respondents:

Table No: 3
Distribution of respondents by their living area

S.No	Area	Frequency	Percentage
1	Urban	16	41
2	Rural	23	59
3	Tribal	0	0
4	**Total**	**39**	**100**

The data in the table above revealed that 59 percent of the respondents were from the rural areas while 41 percent were from the urban areas. The data were collected from the ART centres, so that the represented from the both urban and rural areas. The table below present the educational level of the respondents:

Table No: 4
Distribution of respondents by their education

S.No	Value	Frequency	Percentage
1	10th	2	5.1
2	3rd	1	2.6
3	5th	6	15.4
4	6th	2	5.1
5	7th	5	12.8
6	8th	1	2.6
7	No	21	53.8
8	PG	1	2.6
9	**Total**	**39**	**100**

The data in the table above revealed that (53.8%) of the respondents had no any educational background, while (15.4%) of the respondents had completed their 5^{th} class, 12.8% hadcompleted their 7^{th} class and only (2.6%) had completed their post-graduation. The table below presents the work occupation of the respondents:

Table No: 5
Distribution of respondents by their work occupation / livelihood

S.No	Occupation	Frequency	Percentage
1	Daily Wage labour	12	30.7
2	Private Employee	4	10.2
3	House wife	19	48.7
4	Business	1	2.5
5	Unemployed for 1year	1	2.5
6	Servant/maid	2	5.1
7	**Total**	**39**	**100**

The data in the table above revealed that **(**48.7%) of the respondents were housewives, while (30.7%) of the respondents were daily wage labourers. And 10.2 percent of the respondents were private employees. It was noticed that many HIV infected women changed their occupation after getting the infection. They were attending working at jobs that required less effort. The table below presents the year of HIV infection of the respondents:

Table No: 6
Distribution of respondents by their year of HIV infection

S.No	Year of HIV infection Identification	Frequency	Percentage
1	2001 - 2005	7	17.9
2	2006-2010	12	30.9
3	2011-2015	10	25.6
4	2016-2020	10	25.6
5	**Total**	**39**	**100**

The data in the table above revealed that (30.9%) of the respondents were infected between the years of 2006-2010, while 25.6 percent of the respondents got infected between the years of 2011-2015 and also 25.6 percent in 2016-2020. And 17.9 percent of the respondents got infected between the years of 2001-2005. The table below presents information of the respondents by their year of ART initiation:

Table No: 7
Distribution of respondents by their year of ART initiation

S.No	Year of ART Initiation	Frequency	Percentage
1	2003	1	2.6
2	2004	2	5.1
3	2005	1	2.6
4	2006	1	2.6
5	2007	1	2.6
6	2008	2	5.1
7	2009	1	2.6
8	2010	3	7.7
9	2011	4	10.3
10	2012	5	12.8
11	2013	1	2.6
12	2014	1	2.6
13	2015	3	7.7
14	2016	2	5.1
15	2017	3	7.7
16	2018	2	5.1
17	2019	2	5.1
18	2020	4	10.3
	Total	**39**	**100%**

The data in the table above revealed that majority (12,8%) were initiated on ART by the year 2012 followed by (10.3%) of the respondents who were initiated on the years 2020, 2011 and (7.7%) who were initiated on the years 2010, 2015, and 2017. Previously Government of India provided the medication to patients who had less than 200 CD4 count. Now, the Government of India is providing the medication to all the patients and not considering the CD4 count. It is free medication, and every month the people living with HIV/AIDS visits the ART centre and collect the medication for one month. The table below present information of the respondents by whether they are taking ART medication regularly:

Table No: 8
Distribution of respondents by whether they are you taking ART medication regularly

S.No	Are you taking ART medication regularly	Frequency	Percentage
1	Yes	36	92.3
2	No	3	7.7
3	Not Applicable	0	0
4	**Total**	**39**	**100**

The data in the table above revealed that 92.3 percent of the respondents are taking ART medicine regularly, while 7.7 percent of the respondents are not taking the medicine regularly due to various reasons. While interacting with the people who were not taking ART medicine, it is found that the medication was not suiting them, so that the hospital staff said to stop the medicine for a few days. A few women shared that due to carelessness they are not taking medicine regularly and a women said that her husband died so that they stopped taking medication with the psychological trauma.

HIV infection is not the end of life. People can lead a healthy life for a long time with appropriate medical care. Anti-retroviral therapy (ART) effectively suppresses replication if taken at the right time. Successful viral suppression restores the immune system and halts the onset and progression of disease as well as reduces chances of getting opportunistic infections – this is how ART works. Medication thus enhances both quality of life and longevity. ART is now available for free to all those who need it. Public health facilities are mandated to ensure that ART is provided to people living with HIV/AIDS (PLHA). Special emphasis is given to the treatment of sero-positive women and infected children (National AIDS Control Organisation, 2020). There are 1645 ART service delivery sites located in medical colleges, district hospitals, and non-profit charitable institutions in high prevalence areas provided counselling, care, support and treatment services to people living with HIV (Chakraborty, A., et al, 2020). The ART medicine is divided in to four types. The medicine provided by the doctors were based on the resistance of the previous dose. The table below presents the information of the respondents by their stage of ART medicine:

Table No: 9
Distribution of respondents by their stage of ART Medicine

S.No	ART Stage	Frequency	Percentage
1	1st line	31	79.5
2	2nd line	8	20.5
3	3rd line	0	0
4	4th line	0	0
5	**Total**	**39**	**100**

The data in the table above revealed that (79.5%) of the respondents were taking ART 1st line medicine, while (20.5%) of the respondents were taking 2nd line ART medicine.

Stigma and discrimination can worsen the situation of a HIV patient and can make the patient to stop the treatment therefore it was of great importance to try to discover whether the respondents were experiencing any sort of stigma and discrimination. The table below presents the information of the respondents by whether they are facing stigma and discrimination:

Table No: 10
Distribution of respondents by whether they are you facing stigma and Discrimination

S.No	Stigma and Discrimination	Frequency	Percentage
1	Yes	4	10.3
2	No	18	46.2
3	People don't know my status	17	43.6
4	**Total**	**39**	**100**

The data in the table above presents that 46.2 percent of the respondents did not face any stigma and discrimination, while 43.2 percent of the respondents stated that their community did not know about their HIV status. Only 10.3 percent of the respondents faced stigma and discrimination. The widowed women are facing HIV discrimination and widowed discrimination from neighbours, relatives. Some people faced discrimination at workplace. One woman lost her job when her employers became aware about her status. Previously the discrimination was very high, but now it has reduced. The table below presents information of the respondents by who supports when they have health problems:

Table No: 11
Distribution of respondents by who supports when they have health problems

S.No	Supporters	Frequency	Percentage
1	Myself	2	5.1
2	Family Members	36	89.7
3	NGOs	0	0
4	Ward volunteer/nurse/anm	1	2.6
5	**Total**	**39**	**100**

The data in the table above revealed that the majority (89.7%) of the respondents get support from their family members while (5.1%) get support by themselves, (2.6%) get support from ward volunteer/ nurse. The table below present the information of the respondents by whether they are members in support group.

Table No: 12
Distribution of respondents by whether they are a member in support group

S.No	Are you a member in support group	Frequency	Percentage
1	Yes	4	10.3
2	No	35	89.7
3	**Total**	**39**	**100**

The data in the table above revealed that the majority (89.7%) of the respondents were not support group members while (10.3%) were support group members. The support groups were formed by NGOs. Once in a month they gather in a place and discus about HIV related health problems, children education and problems, discussion on government schemes, and ART medicine etc. It is a social group work concept.

Table No: 13
Distribution of respondents by whether they are receiving government pension

S.No	Pension from Government	Frequency	Percentage
1	Widow pension	23	60.5
2	HIV pension	5	13.1
3	No pension	10	26.3
4	**Total**	**38**	**100**

Government of Andhra Pradesh is providing Rs.2500/- for widows as well as HIV infected people. Majority (60.5%) of the respondents get widow pension and (13.1%) of the respondents get HIV pension. There are 26.3 percent of the respondents are not getting any pension. The major reasons for not getting the pension is not having the proper documents, some people applied but not received the pension till now. The table below present information of the respondents whether they are members in SGH group:

Table No: 14
Distribution of respondents by whether they are a member in SHG (DWACRA Group)

S.No	Member in SHG	Frequency	Percentage
1	Yes	29	74.4
2	No	8	20.5
3	Left before 4years	2	7.7
4	**Total**	**39**	**100**

The data in the table above revealed that (74.4%) of the respondents were members in SHG while (20.5%) were not and (7.7%) left SGH before 4years. The table below present information of the respondents by whether they are benefiting with 'Sunna Vaddi Padakam:

Table No: 15
Distribution of respondents by whether they are benefiting with 'Sunna Vaddi Padakam'

S.No	Benefited with 'Sunna Vaddi Padakam	Frequency	Percentage
1	Yes	10	25.6
2	No	29	74.4
3	**Total**	**39**	**100**

The table above revealed that (74.4%) of the respondents were not benefiting with Sunna Vaddi Padakam while (25.6%) were benefiting. The table below present information of the respondents by whether they are benefiting in any of the below government schemes:

Table No: 16
Distribution of respondents by whether they are benefiting in the following government schemes

S. No	Government Scheme	Benefited	Not benefited
1	'Arogya Sree'	36 (92.3)	3 (7.7)
2	Ammavodi	15 (38.5)	24 (61.5)
3	House site / House	22 (56.4)	17 (43.6)
4	Antyodaya Ration card	9 (23.1)	30 (76.9)
5	Food support from Anganwadi Centre	2 (5.1)	37 (94.9)
6	YSR Bhīma	23 (59)	16 (41)

The data in the table above showed that that majority (92.3%) of the respondents benefited under Arogya Sree scheme, also (56.4%) benefited from house site/house, (38.5%) also benefited from Ammavodi scheme and (59%) benefited under YSR Bhima. The Government of Andhra Pradesh is implementing many welfare schemes and reaching the people with its nearly initiated Gram/Ward Secretariats and ward volunteer system. The table below presents the problems they faced during covid-19:

Table No: 17
Distribution of respondents by the problems they are facing during Covid-19

S.No	Problems during Covid-19	Frequency	Percentage
1	No travel for ART medicine	11	28.9
2	No work	4	10.5
3	Economical Problems	23	60.5
4	**Total**	**38**	**100**

The table above revealed that (60.5%) of the respondents were having economical problems during Covid -19, while (28.9%) of the respondents were experiencing travel issues to go to ART clinic for their treatment, and (10.5%) were experiencing lack of work during the pandemic.

SUGGESTIONS TO PROMOTE THE QUALITY OF LIFE OF WOMEN LIVING WITH HIV/AIDS

1. The government should provide the pension to all eligible women living with HIV/AIDS. The pension amount Rs.2500/- may support them in taking healthy food and supporting their families

2. The government should provide the Antyodaya ration cards (35 kilograms of rice per month. Each kilogram @ Rs.1/-) to all the women living with HIV/AIDS. Because these are poor and they spent all their money on their HIV treatment.

3. The government and NGOs should provide the capacity-building on any vocational education to the women living with HIV/AIDS. Women living with HIV/AIDS are not in a position to do the hard work. Vocational skills in tailoring, fabric painting and other handicrafts can help the in earning their livelihood.

4. The government should increase the number of ART centres in the tribal and rural areas. These may reduce the travel time to rural and tribal women living with HIV/AIDS.

5. The action-oriented community-driven approaches are required for a huge country like India.

6. Adult Support Groups will be helpful to promote the quality of life of marginalized women, particularly those who are affected with HIV/AIDS. Capacity building for support groups will strengthen their leadership abilities.

7. The Civil Society Organizations and Government should implement targeted interventions to promote the quality of life among women living with HIV/AIDS in India.

8. Media participation should be increased to present the positive stories, like support groups to promote the confidence among women in vulnerable situations

CONCLUSION

Overall, this article presented the socio-economic problems of women living with HIV/AIDS. This article also discussed about the accessibility of the government schemes to the women living with HIV/AIDS. The newly initiated government schemes by the government of Andhra Pradesh is helping such women. Social work is one of the important

professions in the world. It has contributed a lot in providing of care, support and treatment services to the people living with HIV/AIDS. There is still a lot of scope for social workers to work with women living with HIV/AIDS (Abraham, 2017). The ART medicines are boon to the women living with HIV/AIDS in increasing their life span. The Civil Society Organizations and Government should bring the focused interventions to promote the quality of life among women living with HIV/AIDS in India.

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