

A Study of PLWHA in ART Centre, GMC Nagpur: Their Disclosure, Stigma and Discrimination

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Abstract

The present study basically focused on the people living with HIV/AIDS in ART Centre Government Medical College Nagpur and their disclosure status, stigma and discrimination at family level. It was found that the 53.65% male PLWHA and 46.35% female PLWHA have faced the discrimination at family level.

Key Word

ART, PLWHA, Stigma and discrimination

Introduction

The concept of HIV/AIDS as according to John Starke and Rodney Dale, “a disease that results from infection with a virus called Human Immuno Deficiency Virus (HIV) which spreads from person to person through body fluids”. HIV/AIDS epidemic is a complex and multidimensional phenomenon that occurred a major health, social and religious problem. Stigma and discrimination is faced by people living with HIV/AIDS (PLWHA) in many ways, inside the family and outside. They suffer physically, mentally, psychologically and economically. Such persons are most of the times, discriminated on the basis of stigma attached to the means of acquiring HIV and they may be ill treated and isolated from other family members. The stigma, discrimination, denial, rejection and non-acceptance of people to living with HIV, there is an urgent need to address this issue, where by appropriate social intervention, advocate for policies, programme and schemes to ensure social protection of PLWHA, specially the economically and socially marginalized.

Objective of the Study

Present study has been undertaken with a view of objectives

1. To find out the disclosure status of PLWHA and immediate response of person after HIV/AIDS status disclosure;
2. To identify the nature of HIV/AIDS stigma and discrimination at family level; and
3. To study the experiences of felt and enacted stigma in family.

Hypothesis of the Study

The hypothesis formulated for the study as

1. More than 90% PLWHA have disclosure status of HIV/AIDS;
2. Familiar family members are more closed to disclose the HIV/AIDS status; and
3. Male PLWHA faced more stigma and discrimination than female.

Scope and Limitations of the study

The study is confined to people living with HIV/AIDS in ART Centre, Government Medical College Nagpur and their disclosure status of HIV/AIDS, stigma and discrimination at family level.

Research Methodology

Survey of people living with HIV/AIDS and their disclosure status, faced- stigma and discrimination are used for this study and questionnaire technique is used to collect the data from ART Centre, GMC

Nagpur. Collected data has been analyzed by statistical techniques and presented data in tabular as well as in graphical form.

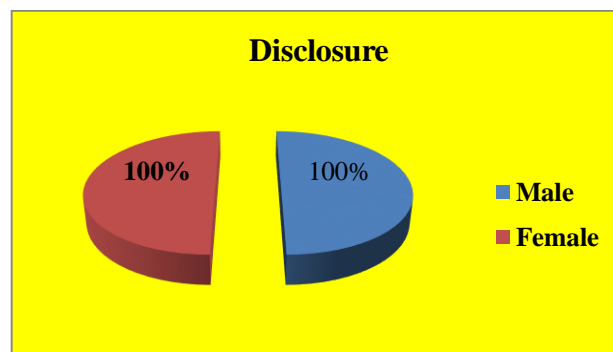
Review of Literature

B. Charles, L. Jeyaseelan, A. Pandian, A. E. Sam, M. Thenmozhi and V. Jayaseelan (2012) They reported the India has around 2.27 million adults living with HIV/AIDS who face several challenges in the medical management of their disease. 27% of PLHA had experienced severe forms of stigma. These were severe forms of personalized stigma (28.8%), negative self-image (30.3%), perceived public attitude (18.2%) and disclosure concerns (26%).¹

Jun-Fang Xu, Zhong-Qiang Ming, Yu-Qian Zhang, Pei-Cheng Wang and Feng Cheng (2017) In this study, aims to identify the family support enjoyed and discrimination faced by people infected with HIV and examined the effect they have on patients' quality of life as they undergo ART in China. 90.4% (n = 281) of patients received family support at baseline, here defined as the initiation of ART, 91.8% (n = 244) received family support 6 months into ART, 95.5% (n = 220) at 12 months, and 94.3% (n = 230) at 24 months. The proportion of patients who did not feel discriminated against by their families was 87.2% (n = 274) at baseline, 90.4% (n = 229) 6 months into ART, 90.0% (n = 210) at 12 months, and 94.5% (n = 219) at 24 months.¹²

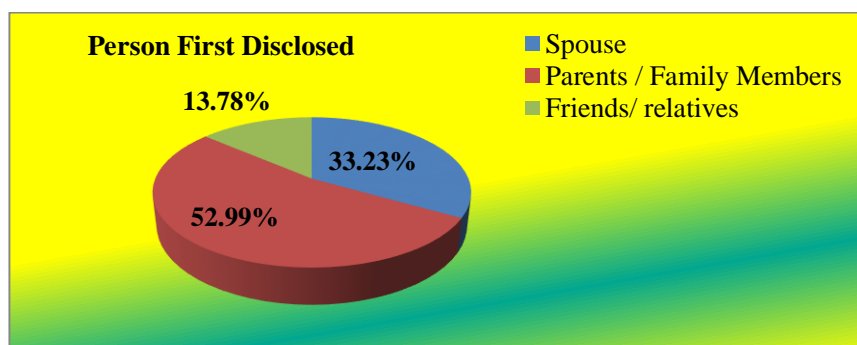
Rivera-Diaz Marinida, Varas-Diaz Nelson, P. Mark, V. Maria and S. Neisha (2017) The data derive from a larger phenomenological study addressing manifestations of stigma in the lives of PLWH when interacting with the health sector. 9 focus groups were carried out in 2011 with PLWH (N=67). 8 themes emerged from the qualitative analysis. They focus on the categories related to family dynamics the negotiation of disclosure and non-disclosure, fear of the HIV virus and family dynamics and life as a couple.⁸

Figure no. 1: Disclosure status of PLWHA



From the above figure, total 653 PLWHA in Government Medical College Nagpur are disclosure respondents, out of these, 352(100%) male PLWHA and 301(100%) female PLWHA have disclosed to their parents/family members, friends and relatives, means 100% PLWHA are disclosure. This indicates that **“More than 90% PLWHA have disclosure status of HIV/AIDS”(hypothesis no.1)** is valid.

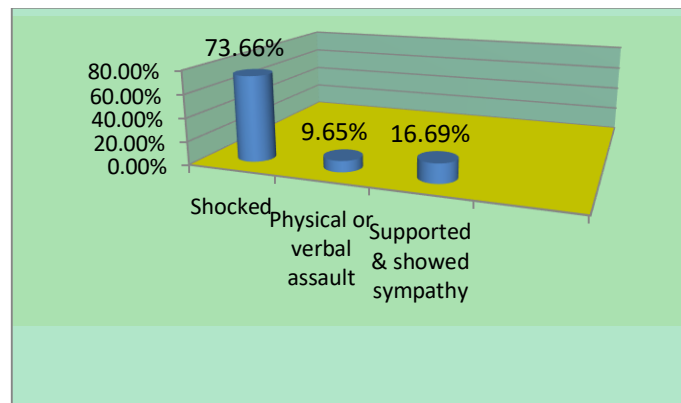
Figure no. 2: Distribution of PLWHA who disclosed to person first



From the above figure, total disclosures are 653 PLWHA, out of these, 52.99% PLWHA firstly disclosed their status of HIV/AIDS to their parents/ family members, followed by spouse with 33.23% PLWHA and 13.78% PLWHA have disclosed their status to friends/relatives. 86.22% PLWHA have firstly disclosed their HIV/AIDS status to spouse and parents/ family members, means family members are more

convenient for discussion. This indicates that “Familiar family members are more closed to disclose the HIV/AIDS status” (hypothesis no. 2) is valid.

Figure no. 3: Distribution of PLWHA: Immediate response of person after HIV status disclosure



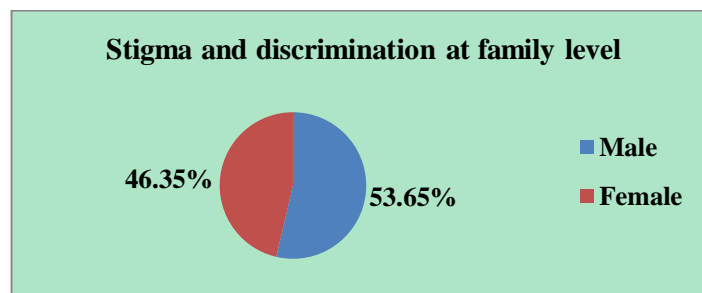
From the above figure, after revealing the status, 73.66% respondents have observed shocked expressions of family members, spouses and friends/relatives of their seropositivity, followed by supported and sympathized to 16.69% PLWHA. At the same time, it was found that 9.65% PLWHA were assaulted either verbally or physically, PLWHA were teased, insulted, blamed or beaten up by family members, spouses and friends/relative after disclosure of their status which reflects the underlying stigma attached to HIV.

Table no. 1: Distribution of PLWHA who faced discrimination at Spouse/ Parents/family level

Face discrimination	Gender		Total N= 563
	Male N= 293	Female N= 270	
Yes	70.31%	65.93%	384(68.21%)
No	29.69%	34.07%	179(31.79%)

From the above table, total 563 PLWHA who disclosed their HIV/AIDS status at the family level in which, 70.31% PLWHA faced the discrimination while 29.69% PLWHA did not face the discrimination out of 293 male PLWHA whereas 65.93% PLWHA faced the discrimination while 34.07% PLWHA did not face the discrimination out of 270 female PLWHA. It is also found that 68.21% PLWHA faced the discrimination whereas 31.79% PLWHA did not face the discrimination out of 563 PLWHA at the family level. This indicates that “Male PLWHA faced more stigma and discrimination than female” (hypothesis no. 3) is valid.

Figure no. 4: Distribution of PLWHA: Gender wise stigma and discrimination at family level



From the above figure, total 384 PLWHA faced the discrimination at family level, out of these, 53.65% male PLWHA have faced the discrimination at family level whereas 46.35% female PLWHA have faced the discrimination at family level. It means that the Male PLWHA have more stigma and discrimination than female at family level. This indicates that “Male PLWHA faced more stigma and discrimination than female” (hypothesis no. 3) is valid.

Table no. 2: Distribution of PLWHA who faced discrimination at family level and dimensions of familial discrimination after HIV status disclosure

Dimensions of familial discrimination	PLWHA	Percentage
Sit/ sleep in isolation	32	8.33
Eat/ drink in separate utensil	66	17.19
Exclude from familial/ religious function	38	9.90
No one touched/ hand shacked or kissed	71	18.49
Ignored & neglected	177	46.09
Total	384	100

From the above table, total 384 PLWHA who faced discrimination at family level after HIV status disclosure, out of these, a majority of PLWHA (46.09%) mentioned that they often ignored and neglected by their family members, followed by 18.49% PLWHA told that they were barred from any kind of physical contact with others in the family and no one touched or kissed them, 17.19% people living with HIV/AIDS were provided separate utensils to eat and drink whereas 9.90% PLWHA felt that they were not allowed to join any kind of social gathering including religious ceremonies, followed by 8.33% PLWHA were made to sit or sleep in isolation by their family members.

Findings

1. Total 653 PLWHA in Government Medical College Nagpur are disclosure respondents, out of these, 352(100%) male PLWHA and 301(100%) female PLWHA have disclosed to their parents/family members, friends and relatives, means 100% PLWHA are disclosure. This indicates that **“More than 90% PLWHA have disclosure status of HIV/AIDS”(hypothesis no.1)** is valid. (Figure no. 1)
2. As regards the firstly disclosed their status of HIV/AIDS, 52.99% PLWHA firstly disclosed their status of HIV/AIDS to their parents/ family members, followed by spouse with 33.23% PLWHA and 13.78% PLWHA have disclosed their status to friends/relatives. 86.22% PLWHA have firstly disclosed their HIV/AIDS status to spouse and parents/ family members, means family members are more convenient for discussion. This indicates that **“Familiar family members are more closed to disclose the HIV/AIDS status” (hypothesis no. 2)** is valid. (Figure no. 2)
3. As regards the immediate response of person after HIV status disclosure, 73.66% respondents have observed shocked expressions of family members, spouses and friends/relatives of their seropositivity, followed by supported and sympathized to 16.69% PLWHA. At the same time, it was found that 9.65% PLWHA were assaulted either verbally or physically, PLWHA were teased, insulted, blamed or beaten up by family members, spouses and friends/relative after disclosure of their status which reflects the underlying stigma attached to HIV. (Figure no. 3)
4. As regards the discrimination faced at Spouse/ Parents/family level, total 563 PLWHA who disclosed their HIV/AIDS status at the family level in which, 70.31% PLWHA faced the discrimination while 29.69% PLWHA did not face the discrimination out of 293 male PLWHA whereas 65.93% PLWHA faced the discrimination while 34.07% PLWHA did not face the discrimination out of 270 female PLWHA. It is also found that 68.21% PLWHA faced the discrimination whereas 31.79% PLWHA did not face the discrimination out of 563 PLWHA at the family level. This indicates that **“Male PLWHA faced more stigma and discrimination than female” (hypothesis no. 3)** is valid. (Table no. 1)
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Implications

Based on the results/findings of the study the following are the implications

- Family members should initiative to involve with PLWHA in family functions so that the dimensions of stigma and discrimination will be reduced at family level.
- People living with HIV/AIDS need to be sensitized and empowered to litigate and seek redressal in event of stigma and discrimination at the family level.
- Family members should support to build the capacity and confidence of people living with HIV/AIDS is key in the fight against stigma and discrimination.
- Family members should increase the confidence of people living with this disease will help to minimize the fear, silence and denial associated with the illness and ultimately reduce the impact of the disease.
- Family members who encourage PLWHA to disclose their status must carefully consider the implication of disclosure in an environment with high levels of stigma, and must recognize the real possibility that PLWHA may experience serious verbal and physical abuse as a consequence of disclosure.

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