

# HIV Status Disclosure Among People Living with HIV in the Era of Combination Antiretroviral Therapy (cART)

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## ABSTRACT

**Introduction:** As patients with HIV live longer due to Combination Anti-Retroviral Therapy (cART) serostatus disclosure becomes an important issue. Disclosure can have both positive and negative outcomes. Disclosure of HIV status has been associated with better adherence to medication and reduction in levels of psychological distress. Stigma and disruption of family relationships are barriers for disclosure. Most studies regarding disclosure status have been conducted in West. There are many cultural differences in Indian society when compared to west. There is a dearth of research in the field of disclosure of HIV infection in India.

**Aim:** To determine the prevalence of HIV status disclosure among people living with HIV (PLHIV) in South India.

**Materials and Methods:** This descriptive cross-sectional study was done in the hospital attached to Kasturba Medical College (KMC), Mangalore, India from May–June 2013. PLHIV of age more than 18 years were included. During the study period 111 consecutive patients who consented for the study were enrolled.

**Statistical Analysis:** Data was collected using a pre-tested interviewer administered semi structured questionnaire. Data collected was analysed using SPSS Version 11.5 statistical software. Descriptive statistics were done and the results are presented as proportions and mean.

**Results:** The mean age of the study population was  $44.86 \pm 10.8$  years. Majority of the study subjects were men 76 (68.4%). Out of 111 study subjects, 102 (91.9%) had disclosed their HIV status to at least one person while 9 (8.1%) had not disclosed their HIV status to anyone. Disclosure on doctor's advice was the main reason for 56 (54.9%) participants to disclose their HIV status. The main reason for non-disclosure was fear of shame in family.

**Conclusion:** Disclosure rate was high in our study in the era of cART. Society must stop discriminating against PLHIV so that they can disclose their serostatus and gain access to care and treatment services without any fear of stigma. In our study the main reason for disclosure was doctor's advice which clearly states the importance of the commitment of doctors in creating awareness among PLHIV about the need for voluntary disclosure.

**Keywords:** Discrimination, PLHIV, Serostatus

## INTRODUCTION

With the advent of potent combination Anti-Retroviral Therapy (cART), HIV has become a chronic illness like diabetes and hypertension, where people live for a longer time. As patients with HIV live longer serostatus disclosure becomes an important issue. Disclosure of HIV status is one of the most complex psychosocial challenges that people living with HIV (PLHIV) can face [1]. Disclosure can have both positive and negative outcomes. Disclosure of one's own disease has been associated with better out reach to medical care, adherence to medication and reduction in levels of psychological distress [2]. Disclosure is also crucial to adherence to treatment in which treatment "buddies" can help and also to access non governmental organization (NGO) support [2]. Disclosure of HIV status increases opportunities for implementation of HIV risk reduction behaviours and motivating partners for voluntary counseling and testing [3]. However due to barriers like stigma in society, disgrace to family, loss of income and disruption of family relationships many PLHIV do not disclose their serostatus to others [2,4,5].

HIV counseling and testing programmes emphasize HIV status disclosure among persons living with HIV [6]. In our country, Integrated Counselling and Testing Centre (ICTC) is an entry point to avail various HIV related preventive and treatment services. ICTC promote HIV status disclosure among PLHIV, especially to their sexual partners so that uninfected partners can take measures to prevent acquisition of HIV. Among serodiscordant couples, non disclosure is an important factor for seroconversion [7]. Organizations like WHO also emphasize the importance of voluntary HIV status disclosure.

Most studies regarding disclosure status has been conducted in West. There are many cultural differences in Indian society when compared to west. There is a dearth of research in the field of disclosure of HIV infection in India in the era of cART. The main aim of the present study was to determine the prevalence of HIV status disclosure among PLHIV in South India in the era of cART. Reasons for disclosure or non-disclosure were also listed.

## MATERIALS AND METHODS

### Study Design and Setting

This descriptive cross-sectional study was conducted in the hospital attached to Kasturba Medical College (KMC), Mangalore, India. KMC Hospital is a 500 bedded tertiary care referral institution.

### Sample Size, Sampling Technique, Study Duration and Study Population

Assuming 70% of PLHIV disclose their HIV status to at least one person [8] and taking absolute precision of 10% and confidence interval of 95% the sample size was found to be 81. On adding 20% as the non-response rate sample size was 111. PLHIV of age more than 18 years who gave written informed consent participated in the study. Participants were recruited between May and June 2013. HIV testing, interpretation, pre and post test counselling was done according to NACO guidelines [9] in the ICTC centre attached to our institution. The investigator interviewed HIV patients who came to the OPD for consultations. Study participants were selected by convenience sampling. During the study period 111 consecutive patients who consented for the study were enrolled. Ethical approval

from the institutional ethics committee of K.M.C., Mangalore was obtained.

## Data Collection

The study subjects were told about the details of the study and after obtaining written informed consent they were enrolled. The data was collected by face-to-face interview held in a private room at the study site. The interviews lasted for 15-20 minutes. Data collection was guided by a pretested, semi structured questionnaire consisting of both open as well as closed questions based on previous studies [10,11]. The questionnaire had three parts. They were; socio-demographic characteristics of the study population, HIV related details and disclosure related details. HIV status disclosure was assessed with the following question - "Have you disclosed your HIV status to anyone?" In the case the answer was yes the next question was-"who was the person?" Reasons for disclosing and non-disclosing were assessed. The socioeconomic status of the study participants was assessed using Modified Kuppaswamy Socioeconomic Status Scale [12].

## STATISTICAL ANALYSIS

Data collected was analysed using SPSS Version 11.5 statistical software. For continuous variables, the mean and standard deviation were calculated while for categorical variables, we calculated proportions.

## RESULTS

The mean age of the study population was 44.86 ± 10.8 years. Most of the study subjects were men 76 (68.4%). 78 (70.3%) out of 111 were married [Table/Fig-1]. Majority of the study population belonged to age group of 40-60 years.

Out of 111 study subjects, 102 (91.9%) had disclosed their HIV status to at least one person while 9 (8.1%) had not disclosed their HIV status to anyone [Table/Fig-2].

Disclosure on doctor's advice was the main reason for 56 (54.9%) to disclose their HIV status. [Table/Fig-2]. Two PLHIV told that their family members came to know about their HIV status when they came to ART centre for medicines (\*others in [Table/Fig-2]).The main reason for non-disclosure was fear of shame in family. PLHIV had disclosed their HIV status to their spouse, parents, children, other family members and friends [Table/Fig-2].

	n(%)
Gender	
Male	76 (68.4)
Female	35 (31.5)
Age(years)	
<20	2 (1.8)
20-40	37 (33.3)
41-60	65 (58.5)
>60	7 (6.3)
Duration of HIV(years)	
<1	39 (35.1)
1-5	17 (15.3)
6-10	35 (31.5)
>10	20 (18)
Economic status	
Upper Middle (II)	13 (11.7)
Middle Lower middle (III)	28 (25.2)
Lower Upper lower (IV)	65 (58.5)
Lower (V)	5 (4.5)
Marital Status	
Married	78 (70.3)
Unmarried	19 (17.1)
Widow	14 (12.6)
Latest Cd4 count (cells/mm <sup>3</sup> )	
0-199	11 (9.9)
200-349	19 (17.1)
350-499	34 (30.6)
≥ 500	47 (42.3)

[Table/Fig-1]: Socio demographic characteristics of study subjects (n = 111)

	n (%)
HIV status disclosed	
Yes	102(91.9)
No	9(8.1)
Disclosed to (n=102)	
Spouse	82(80.3)
Parents	16(15.6)
Children	16(15.6)
Other family members	14(13.7)
Friends	4(3.9)
Reason for disclosure (n=102)	
Disclosure on doctor's advise	56(54.9)
Presence of ART drugs at home	32(31.3)
To benefit their sexual partner	2(1.9)
To adhere to ART drugs	10(9.8)
*Others	2(1.9)
Reason for not disclosing (n=9)	
Fear of shame in family	4(44)
Fear of loss of confidentiality	2(22)
Fear of children being out casted	1(11)
Not to worry the family members	1(11)
Relationship may end	1(11)

[Table/Fig-2]: Disclosure of serostatus among PLHIV

## DISCUSSION

Out of 111 PLHIV who participated in our study, 102(91.9%) had disclosed their HIV status to at least one person. Doctor's advice was the main reason for disclosure. The main reason for non-disclosure was fear of shame in family.

In a study done in Kolkata, 69.5% of PLHIV had disclosed their status to their partners [8]. According to Deribe K et al., 94.5% disclosed their HIV status to at least one person and 90% had disclosed their status to their current partners [11]. In a study done by Yonah G et al., 93.3% had disclosed their HIV serostatus to someone [13]. A study from Zimbabwe states that 193 (96.5%) out of 200 women had disclosed their HIV status to at least one person [14]. According to Erku TA et al., and Amoran OE, 76.6% and 50.9% PLHIV had disclosed their HIV status to their main sexual partner [3,15].

In our study majority of the patients had disclosed about their status to their spouse followed by parents, children and other family members. According to Deribe K et al., [11] respondents reported disclosing their status most frequently to main partners (90.8%) followed by relatives (33.2%), mother (14.9%), friends (14.2%), father (9.1%), neighbors (6.8%), children (6%), other family members (4.7%) and religious leaders (4.4%). Fifty percent of participants had disclosed their status to their family member/close relative while 25.4% disclosed to their spouses and 19% to their parents/guardians according to Yonah G et al., [13].

In a study done in India by Chandra et al., [10] the main reasons for disclosure was emotional and financial support and the main reasons for non-disclosure was stigma, futility and disgrace to self and family. According to Erku TA et al., [15] among those who disclosed their serostatus to their sexual partners the main reason was to adhere to the treatment and to get support from the sexual partner. In a study done by Deribe K et al., [11] the main reasons given for nondisclosure was fear of partner reaction, not wanting to worry their partner and fear of accusation of infidelity. According to Ssali et al., [16] the most common reasons for disclosure was to receive support and the most common reasons for nondisclosure were fear of abandonment.

There are two types of disclosure in HIV voluntary disclosure and disclosure without consent [9]. In our institution only voluntary disclosure is encouraged. Serostatus disclosure among PLHIV is very important for secondary HIV prevention with potential benefits for both the individual and society [17]. Disclosure of HIV status to spouse or prospective sex partners enables them to make informed reproductive choices [10,18]. In our study majority of the patients 82 (80.3%) had disclosed their HIV positive status to their spouse.

Disclosure to family members and friends will help HIV positive individuals to expand their support network [17]. A mathematical modeling analysis showed that serostatus disclosure reduced the risk of HIV transmission by 17.9% to 40.6% relative to non-disclosure [18]. However, due to various barriers PLHIV do not disclose their serostatus to others and so opportunities for prevention of new infections and to access health services are lost.

## LIMITATIONS

Present study has some limitations. The study was done in an urban setting. So the results may not be generalizable to the entire community. We relied on self report of disclosure status which is another limitation of our study.

## CONCLUSION

Disclosure rate was high in our study. In our study the main reason for disclosure was doctor's advice which clearly states the importance of the commitment of doctors and ICTC in creating awareness among PLHIV about the need for voluntary disclosure. Society must stop discriminating against PLHIV so that they can disclose their serostatus and gain access to care and treatment services without any fear of stigma. Zero discrimination towards HIV patients is the need of the hour so as to ensure hundred percent disclosures. Voluntary disclosure among serodiscordant couples is one of the easiest ways to reduce new infections.

## DECLARATION

The abstract of this articles was accepted for inclusion in the International Scientific Exchange [ISE] section of the 39<sup>th</sup> International Congress on Infectious Diseases 39 in Cape Town, April 2 to 5, 2014.

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