



People with HIV/AIDS: Stigma, Self-Esteem and Psychological Health

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Abstract The major objectives of the present study were (a) to explore the perception of stigma associated with HIV/AIDS among people living with HIV/AIDS (PLWHAs); (b) to investigate the relationship between stigma, self-esteem and psychological health, and; (c) to examine the mediating role of self-esteem in the relationship between (a) felt stigma and psychological health, and; (b) enacted stigma and psychological health. The sample consisted of 200 HIV positive individuals (100 females and 100 males) from Prayagraj (North India). Data were collected using a set of questionnaires (self-report measure). It contained questions related to demographic information (age, gender, marital status, education and income), the experience of stigma, self-esteem and psychological health. Results revealed that perceived and enacted stigma were negatively correlated with self-esteem and psychological health. Enacted stigma emerged as a significant predictor (negative) of self-esteem and psychological health. Self-esteem also emerged as a significant predictor of psychological health. It also revealed that the relationship between enacted stigma and psychological health was significantly mediated by self-esteem. Based on the findings, it is suggested that PLWHAs should be treated with respect and dignity, and efforts should be made to align them with the mainstream. Further, they should be encouraged to think above stigma in order to have a better quality of life.

Keywords Perceived (Felt) and enacted stigma · Self-esteem · Psychological health · HIV/AIDS

Introduction

Human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) are significant public health challenges affecting as many as 36.7 million people worldwide. About 4.2 million people infected with HIV/AIDS have been estimated to be living in Asia, of which a whopping percentage of approximately 90% are known to belong to countries like India, China and Thailand. Statistics show that in India (Avert, 2018), about 2.1 million individuals are suffering from HIV/AIDS. In 1986, the first case of HIV was diagnosed in a sex worker in Chennai, and in 1987 the first AIDS case was reported in Mumbai.

The HIV epidemic is concentrated among sex workers, transgender people, men having sex with men (MSM), truck drivers and migrant workers. However, the propellers of the epidemic differ in various parts of the country. Several factors, including poverty, unemployment, and migration, spouses living separate from each other and unprotected sex among vulnerable population partners appear to fuel the spread of HIV. In the North and Northeast, the prevalence has accelerated due to the use of illegitimate drug injections. Specific traumatic events such as sexual assault and individual factors such as exchanging sex for money may increase the risk of contracting HIV (Ivy et al., 2014; Brief et al., 2004). When an individual contracts HIV/AIDS, the causality is attributed to the individual's conduct and the individual is held responsible for the disease because the primary modality of transmission of the infection is engagement in voluntary behaviours (Herek & Capitanio, 1998). Thus, generally, people living with HIV/AIDS (PLWHAs)

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are seen as people with no moral values (Varga, 1999). Like in any other country, HIV is accompanied by stigma, discrimination, depression, suicidal tendencies, and violence in India too.

Stigma was associated with any condition, attribute, trait or behaviour which symbolically labelled the bearer as inferior or unacceptable to society. Consequently, this act led to negative emotions like shame, guilt and disgrace (Goffman, 1963). Drawing from Goffman (1963), Alonzo and Reynolds (1995) argued that stigmatized people are a pejorative group of people who are shunned and devalued. Gerhard Falk describes stigma in two categories: 'existential' and 'achieved stigma'. Existential stigma is described as stigma derived from a condition that the target of stigma did not cause, and achieved stigma is the one that is earned because of immoral conduct. The attributes associated with stigma convey a devalued social identity. Stigma has characteristics that describe a devalued social identity in a specific social context (Crocker et al., 1991). This devaluation, negative evaluation and stereotyping results in ostracizing individuals with whom such stereotypes are attached (Link & Phelan, 2001).

Brown et al. (2003) describe stigma in two forms: perceived (felt) and enacted. The perceived stigma occurs when there is a real or imagined fear of societal attitudes regarding a particular condition and a concern that this could result in acts of discrimination directed at individuals with that condition. Enacted (actual) stigma, in turn refers to the experience of discrimination directed at individuals because of specific attributes or conditions that characterize them. Numerous theoretical works have explained stigma as occurring psychologically and limiting its adverse effects to self-process within individuals (Yang & Kleinman, 2008). Stigma is a powerful phenomenon with far-reaching effects on the victims (Lindzey et al., 1954; Tewksbury & McGaughey, 1997).

The major impediments to an effective HIV response are HIV-related stigma and discrimination. This is also noticeable in health care and treatment of PLWHAs (NACO, 2013). To add to their woes, PLWHAs also experience judgmental attitudes from health care providers and, often, denial of services (UNAIDS, 2013). Societal attitudes towards HIV/AIDS individuals and knowledge about their condition lead to felt/perceived stigma. Enacted stigma refers to discrimination experienced by people with HIV and may include marginalization and dehumanization. Societal stigma is ascribed through the mechanism of negative stereotypes and devalued cultural images and representations. According to Goffman (1963), enacted stigma refers to discriminating and distancing the stigmatized individual and acting out on the stigmatized target. A related concept in the literature of stigma is that of discrimination, also defined as the acts/behaviour that arise from stigma and that devalue people in various ways (Deacon, 2006). AIDS stigma often results in social

and economic marginalization and withholding of treatment leading to the transgression of human rights of HIV persons (Maluwa et al., 2002). Both stigma and discrimination may take overt or covert forms. Discrimination is also recognized as 'enacted stigma' because it signifies the acts that targeted individuals experience (Jacoby, 1994).

There is extensive literature on the impact of stigma on self-esteem. However, empirical support for lower self-esteem among stigmatized groups as compared to non-stigmatized groups is scarce. Studies show that self-esteem can and often does change in response to the social environment. The nature and extent of stigma varies in different illnesses (Stevenson et al., 2011; Weiss et al., 2006). Additionally, Rosenfield and Neese-Todd (1993) demonstrated that certain aspects of quality of life, including satisfaction with one's job, residence, health, and finances, were linked to both self-stigma and self-esteem. Actual help-seeking behaviour has also been linked to self-stigma and self-esteem (Vogel et al., 2006). Stigma may be context specific and it is likely that stigma experienced in one context varies from another context. The stigma associated with HIV/AIDS in India may be different from stigma experienced in different contexts. Perceived and enacted stigma has a deleterious effect on self-esteem of HIV/AIDS persons. Many people who are diagnosed with HIV/AIDS feel completely hopeless and helpless as they think that there is no cure and their life is short. Stigma perpetuates feelings of despair and helplessness. Studies show that people living with HIV/AIDS (PLWHAs) with poor self-esteem are more likely to engage in high risk sexual behaviour, thereby strengthening the vicious cycle and perpetuating the spread of the pandemic (Duh, 1991; Fieldblum & Fortney, 1988).

The experience of stigma also impacts the psychological health of individuals. Scambler (1998) reports that the psychological well-being of people with HIV/AIDS can be affected by felt and enacted stigma. A study by Vanable et al. (2006) found that HIV individuals who reported high levels of enacted stigma (for example, being avoided, mistreated or discriminated against) also reported more symptoms of depressed mood state. A relationship between felt HIV/AIDS stigma and depression has been found in both adults and youth living with HIV/AIDS. Those adults who reported higher perceived stigma also experienced more depressed mood than those who experienced less stigma (Emlet, 2007). Similarly, symptoms of anxiety and depression in young HIV positive individuals were positively correlated with perceived negative reactions of others to their HIV status (Wright et al., 2007).

Studies show that HIV-related stigma is associated with poor mental health outcomes, including emotional distress (Heckman et al., 2004; Siegel et al., 2005), shame (Black & Miles, 2002), depression (Heckman et al., 2002; Berger et al., 2001; Lee et al., 2002), reduced self-esteem (Kang

et al., 2006), reduced psychological functioning (Kang et al., 2005), meagre psychological adjustment (Venable et al., 2006), negative affect (Vance, 2006), anxiety (Gonzalez et al., 2009 and Bogart et al., 2010), and quality of life (Holzemer et al., 2009; Vyavaharkar et al., 2012) and stress associated with disclosure. By attributing unfavourable outcomes to prejudice, stigmatized people shield their self-esteem from the damaging effects of prejudice and discrimination (Crocker & Major, 1989). It has also been demonstrated that stigmatized people stay away from situations where they might become stigmatized (Pinel, 1999; Swim et al., 1998). Hence, it was assumed that self-esteem would act as a mediator in the link between stigma and psychological health.

Corrigan and colleagues (2011) developed a progressive model of self-stigma that included numerous characteristics of stigma. The authors distinguish three stages of development: awareness of stereotypes (perception of public stigma), personal agreement (the belief that public stigma is real), and self-concurrence (internalizing stereotypes and applying them to oneself). Self-harm (such as lowered self-esteem) is considered a fourth step or result of self-concurrence. Hence, it is expected that people's physical and mental health are supposedly getting worse under the stigma (Fig. 1).

Social-cognitive attributes may change people's behaviour (Ajzen et al., 2012). Stigma affects people psychologically as well as socially. It can induce or aggravate psychological illness and reduce self-esteem. This is known as "self" or "internalised" stigma, and it can lead to "victim behaviour" (Valencia, 1989) and withdrawal (Arole et al., 2002). Kay et al. (2018) found that stigma was linked to negative affective, cognitive, and mental health outcomes (self-esteem, depressive symptoms, avoidance coping, and blame coping), as well as interpersonal outcomes including social support and physician trust. In order to understand the relationship between stigma and the self, it is critical to include people's subjective understandings of stigmatized conditions and societal reactions (Camp et al., 2002). Based on theoretical approaches, it is expected that self-esteem may indirectly influence the relationship between stigma and psychological health.

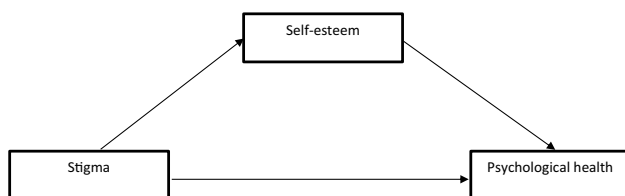


Fig. 1 Theoretical hypothesis of mediating role of self-esteem between stigma and psychological health

Against this background, the following objectives are enunciated:

- To explore the perception of stigma associated with HIV/AIDS
- To investigate the relationship between stigma, self-esteem and psychological health, and
- To examine the mediating role of self-esteem in the relationship between (a) felt stigma and psychological health, and; (b) enacted stigma and psychological health.

Method

Design

A correlational research design was adopted for this study and purposive sampling method was used for the recruitment of participants. Self-esteem was examined as a mediator between felt stigma and enacted stigma and psychological health in the study.

Participants

Purposive sampling method was used to select the participants. Participants were 200 HIV/AIDS patients (100 males and 100 females) from Prayagraj North India, who were contacted through an NGO. Data collection was completed by NGO social workers appropriately trained before going into the field. Age range was 18 to 75 years (Mean $N = 37.3$; $SD = 8.21$), which represents heterogeneity in group members, but most of them belonged to middle age group. Out of 200 participants, 68% ($N = 136$) were married and 32% ($N = 64$) were unmarried. In terms of education, 25.5% ($N = 51$) were illiterate and 74.5% ($N = 149$) were literate. Inclusion criteria in this study included: (1) documented evidence of seropositive status; (2) minimum 18 years of age, (3) sufficient language skills in Hindi, the spoken language, and (4) willingness to spare time for the interview.

Measures

A questionnaire that was administered orally in Hindi was used to collect the data by NGO social workers. The scales were created after extensive pilot testing, and two separate groups independently translated and back-translated each scale (from English to Hindi and then Hindi to English). The translations were revised to account for any discrepancies. To ensure clarity, the final items were piloted before data collection.

Berger's Stigma Scale (Berger et al., 2001)

For measuring stigma, Berger's Stigma Scale (Berger et al., 2001) was used. The scale measures both felt and enacted stigma. In this 40-item scale, 24 items measure felt stigma and 16 items measure enacted stigma. It is a 4-point Likert scale and rated among 4 distinct points namely, strongly disagree, disagree, agree, and strongly agree. The Coefficient alphas range between 0.90 and 0.93 for the subscales and 0.96 for the total scale. The instrument provides evidence for good internal consistency reliability. The HIV stigma scale is reliable and valid with a large, diverse sample of people with HIV, and it has also been validated in Indian setting (Berger et al., 2001; Jeyaseelan et al., 2013).

Rosenberg's Self-esteem Scale (Rosenberg, 1986)

Rosenberg's Self-esteem Scale (Rosenberg, 1986) was used for measuring the self-esteem of the participants. This scale is a widely used self-esteem measure in social science research. The Rosenberg's Self-esteem Scale is a 10 item self-report measure of global self-esteem. It consists of 10 statements related to overall feelings of self-worth or self-acceptance. The items are answered on a 4-point scale ranging from 1 (strongly agree) to 4 (strongly disagree). The scale generally has high reliability with test retest correlations ranging between 0.82 and 0.88, and Cronbach's alpha for various samples are in the range of 0.77–0.88 (Blascovich & Tomaka, 1993). The scale was reverse scored. Low scores indicated low self-esteem.

Psychological health (Ruback & Pandey, 1991)

Psychological health was measured using Ruback and Pandey (1991) health status scale. The psychological health (mental distress) measure consisted of eight items, including 'confused', 'strained', 'lonely', 'depressed', 'nervous', 'restless', and 'no interest in things', and it had a high level of internal consistency ($\alpha = 0.86$) (Ruback & Pandey, 1991). The scale was reverse scored. Low score indicated poorer psychological health.

Procedure

Before initiating the process of data collection ethical clearance from IERB (University of Allahabad) was obtained. Then, the Doctor-in-charge of HIV/AIDS department in a government hospital was contacted for seeking permission to collect data. The purpose of the research was explained to him. The address of an NGO working with HIV/AIDS patients was given by the doctor. The Director of the NGO was contacted with the copy of the permission letter and questionnaire. The Director of the NGO, after going through the questionnaire, granted approval and also gave their consent for data collection. A team of social workers collected the data on 200 HIV patients. Strict ethical rigour and confidentiality was maintained by the team during the data collection.

Analysis

Data entry was accomplished, and data were analysed in SPSS 22.0 Version. Firstly, descriptive statistics and bivariate correlation analysis were carried out to comprehend the fundamental relations among the variables. Pearson correlation was carried out to test the relationship between stigma, self-esteem and psychological health. Based on the significance of the findings General Linear Model (GLM) was carried out to identify the predictors and mediators. 1000 bootstrap samples were used for all of the bootstrapping procedures. For the same, Jamovi (a statistical analysis software) was used (The jamovi project, 2020).

Results

As per the objectives of the study, descriptive analysis, correlation and GLM were carried out to understand the phenomenon.

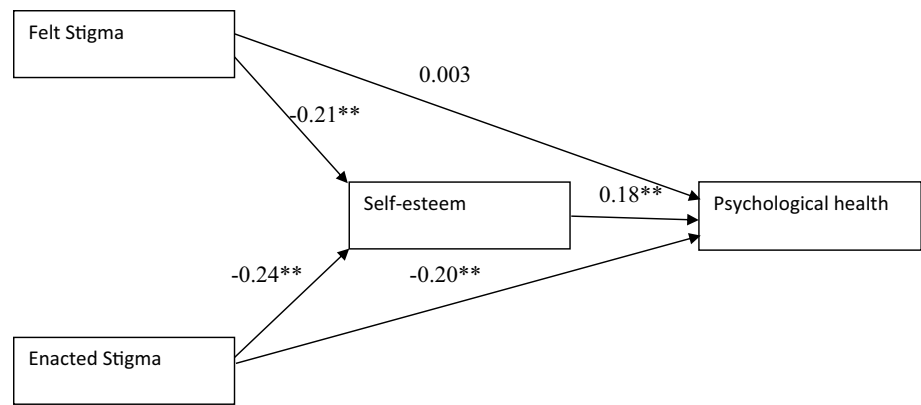
In Table 1, results revealed that felt stigma was positively correlated with enacted stigma, and felt and enacted stigma was found to be significantly correlated (negatively) with self-esteem and psychological health. Table 1 shows that self-esteem and psychological health have significant positive association (Fig. 2).

Table 1 Mean, SD, and correlations of Stigma (felt stigma, enacted stigma), self-esteem and psychological health

| | Mean (SD) | Enacted Stigma | Self-esteem | Psychological health |
|----------------------|---------------|----------------|-------------|----------------------|
| Felt Stigma | 65.64 (15.67) | 0.428** | – 0.312** | – 0.147* |
| Enacted Stigma | 50.08 (9.74) | | – 0.331** | – 0.263** |
| Self-esteem | 23.11 (4.98) | | | 0.251** |
| Psychological health | 11.96 (4.04) | | | |

* $p < .05$; ** $p < .01$

Fig. 2 Shows the mediation model presenting the relationship among research variables



In Table 2, results revealed that self-esteem is not a significant mediator between felt stigma and psychological health; but the relationship between enacted stigma and psychological health is significantly mediated by self-esteem. It also showed that felt stigma and enacted stigma emerged as significant (negative) predictors of self-esteem. Further, it revealed that enacted stigma emerged as a significant (negative) predictor of psychological health. Self-esteem emerged as significant predictors of psychological health.

Discussion

The present research endeavour aimed to understand the extent to which felt and enacted stigma exists among people living with HIV/AIDS. The findings revealed that people living with HIV/AIDS were victims of both perceived (felt) stigma and enacted (experienced) stigma, though enacted stigma was more dominant. Other studies have reported perceived stigma as more pervasive (Bharat et al., 2001; Pallikadavath et al., 2005; Thomas, et al., 2005). One plausible explanation could be the setting of the studies. These studies

were carried out in Western and Southern India, where HIV/AIDS had spread its tentacles in the 1980s and in a span of twenty years people have accepted the disease, whereas the present study was carried out in Allahabad, North India, where HIV/AIDS is a recent phenomenon and people have yet to come to terms with and accept the disease. Thus, people are targeted and stigmatized. HIV-related stigmatization remains a potent stressor for them.

The stress-and-coping framework states that although exposure to stigmatization can be stressful, not everyone who is stigmatized suffers negative consequences (Miller & Major, 2000). Instead, the impact of stigmatization depends on the reservoirs of coping resources people possess. Self-esteem appears to be one critical psychological resource for coping with stress. Thus, the second objective of this study was to examine the relationship between stigma (felt and enacted) and self-esteem. The results revealed that the higher the perceived (felt) stigma and enacted stigma, the lower their self-esteem. This is in line with the findings reported by Kang et al. (2006). Their study showed that 40–80% of the rural women with HIV/AIDS accepted feeling stigmatized and experienced enacted stigma. The majority of these

Table 2 Indirect, Direct and Total effect of the relationship between (a) felt stigma and psychological health, and; (b) enacted stigma and psychological health as mediated by self-esteem

| Type | Effect | Estimates | SE | 95% C.I. (a) | | Beta | z | p |
|-----------|---|-----------|--------|--------------|----------|----------|---------|-------|
| | | | | Lower | Upper | | | |
| Indirect | Felt stigma ⇒ Self-esteem ⇒ Psychological health | -0.02960 | 0.0156 | -0.0601 | 9.13e-4 | -0.03830 | -1.9013 | 0.057 |
| | Enacted stigma ⇒ Self-esteem ⇒ Psychological health | -0.03671 | 0.0182 | -0.0724 | -9.84e-4 | -0.04427 | -2.0140 | 0.044 |
| Component | Felt stigma ⇒ Self-esteem | -0.15957 | 0.0552 | -0.2677 | -0.0514 | -0.20903 | -2.8912 | 0.004 |
| | Self-esteem ⇒ Psychological health | 0.18551 | 0.0735 | 0.0414 | 0.3296 | 0.18324 | 2.5239 | 0.012 |
| | Enacted stigma ⇒ Self-esteem | -0.19786 | 0.0592 | -0.3139 | -0.0818 | -0.24160 | -3.3415 | <.001 |
| Direct | Felt stigma ⇒ Psychological health | -0.00283 | 0.0586 | -0.1176 | 0.1119 | -0.00366 | -0.0483 | 0.961 |
| | Enacted stigma ⇒ Psychological health | -0.16576 | 0.0632 | -0.2897 | -0.0418 | -0.19992 | -2.6209 | 0.009 |
| Total | Felt stigma ⇒ Psychological health | -0.03243 | 0.0584 | -0.1469 | 0.0821 | -0.04196 | -0.5551 | 0.579 |
| | Enacted stigma ⇒ Psychological health | -0.20246 | 0.0627 | -0.3253 | -0.0796 | -0.24419 | -3.2301 | 0.001 |

women were compelled by family members to leave their homes. They reported being physically threatened, denied medical care and ill-treated. They also were victims of atrocities. Further these women believed that they were punished for their sins and felt guilty and disgusted. Internalization of stigma by HIV/AIDS individuals leads to devaluation of self-esteem and self-concept. Similar findings were obtained in a study of stigma and self-esteem in 150 persons living with HIV/AIDS in Palakkad district, South India. The results showed that the perception of stigma significantly reduced self-esteem (Sebastian et al., 2018). The stereotypical notions associated with a disease and the bearer of the disease act as agents of low morale and self-esteem of the victim. Whether stigma is perceived or experienced, it devalues the person's self-concept and lowers their self-esteem.

Stigmatization also influences psychological health, and greater the perception of stigma and experience of stigma, the poorer the psychological health. In this study psychological health has been understood in terms of feelings and experiences such as anger, nervousness, inability to concentrate, sleep disturbance, depression etc. A study relating to the conceptualization of stigma experienced and management of stigma showed that the interrelationship between perceived and enacted stigma influenced the overall health and well-being of PLWHA (Chambers et al., 2015). The aforementioned findings are congruent with results obtained by Frank et al. (2010) and Steward et al., (2011) which show that HIV/AIDS related stigma influences quality of life negatively. In these studies, quality of life is characterized by psychological well-being, life satisfaction and physical health. Feelings of stigmatization lead to psychological distress and depressive symptoms (Basha et al., 2019; Earnshaw et al., 2020).

With the increase in longevity of PLWHA, the need for supporting their psychological health has become increasingly important. In a study of 32 HIV/AIDS adults, a significant positive correlation was found between self-esteem and psychological health (Manhas, 2014). In the present study a significant relationship was observed between self-esteem and psychological health. Lower self-esteem led to poorer psychological health. These findings are corroborated by studies carried out by Adimora et al. (2019) and Garg and Kaur (2020). Rejection by friends and loved ones can cause loss of confidence and devalued social identity, leading to feelings of reduced self-worth which in turn impacts psychological health.

A third objective of the present study was to examine the mediating role of self-esteem between (a) felt stigma and psychological health, and; (b) enacted stigma and psychological health. Indirect effect of self-esteem between felt stigma and psychological health is statistically not significant; and self-esteem significantly mediated between enacted stigma and psychological health. Enacted stigma and self-esteem emerged as significant predictors of

psychological health. Studies by Herek (2007) and Kalichman et al. (2009) showed that enacted stigma has a negative influence on the quality of life of people with HIV. Episodes of enacted stigma may directly increase the risk for psychological distress among PLWHAs and their family members. Enacted stigma includes acts of discrimination, prejudice and social exclusion. Direct acts of discrimination, distancing and exclusion leads to feelings of guilt and shame, and low self-esteem and all these lead to reduced psychological health. Travaglini et al. (2018) suggested that greater anticipated stigma was associated with poorer mental health status.

The findings of the present study are in consonance with the findings mentioned by Parker & Birdsall (2005) who found that between 5 and 30 percent of HIV positive Indian respondents reported discrimination (enacted stigma) 30% experienced discrimination by health workers, 20% were denied treatment by a health worker due to their HIV status and 15% were forced to pay excess charges for medical services. Self-esteem is influenced by positive feelings, positive body image, health and social care, but the physical consequences of HIV infections such as physical wasting and the loss of strength and bodily control, and psychological consequences such as discrimination, prejudice, emotional distress contribute even more to lowering of self-esteem. The findings of the present study also reveal that low self-esteem is related to poorer psychological health.

Conclusions

A few important observations are summarized here and some recommendations are made in the context of present study. Stigma is a powerful phenomenon with far-reaching effects on its targets. It significantly influences self-esteem and psychological health. In people living with HIV/AIDS, enacted stigma is pervasive. Once HIV/AIDS develops, the imperative for secrecy cannot be maintained and victims are labelled, stereotyped, discriminated, excluded and avoided. Given the stigma and fears associated with the disease, supportive care models need to be developed and tested. Stigmatization may also foster a devalued self-identity which in turn may lead to low self-esteem. In response to the social context, self-esteem can change. HIV/AIDS disease gives rise to a negative environment, where victims are targeted and ostracized. In such a hostile environment self-esteem is bound to nosedive. After two decades of dissemination of HIV/AIDS information and awareness and care thereby, stigma continues to be reported by HIV/AIDS people, highlighting the need to rethink strategies for dealing with stigma. Enacted stigma has higher psychological as well as health costs for PLWHAS.

Strengths and Limitations

More conceptual work is required to understand the role and functional value of different stigma forms and to identify the drivers or motives underlying stigma.

Implications for Research

Health professionals and other institutions providing care should be sensitive towards the diverse needs of PLWHAs and their families.

HIV/AIDS Care and Support Service

PLWHAs should be encouraged to rise above the stigma and live a better quality of life. People diagnosed with HIV/AIDS are to be treated with respect and dignity and should be aligned with the mainstream.

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Availability of Data and Material Dataset is available and can be produced on reasonable request.

Code Availability Not Applicable.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval Obtained from Institutional Ethics Review Board (IERB), University of Allahabad.

Consent to Participate Data were collected through an NGO.

Consent for Publication Consent to publish was also sought from the co-authors.

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