

ORIGINAL ARTICLE

A study on perception of care and treatment in HIV positive patients at ART centre

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ABSTRACT

Background: HIV-related stigma is a major social challenge for people living with HIV/AIDS (PLHA). It can forsake the programmes related to HIV due to compromise in early diagnosis & treatment. It is necessary to understand the perceptions of HIV about care and treatment in PLHA in order to work towards a more patient-centred care. **Aim & Objective:** To explore the perception of care & treatment along with the other life experiences in PLHA. **Methodology:** This is Qualitative exploratory study prepared by study of semi-structured in-depth interviews of different individuals through thematic analysis, at the Antiretroviral therapy (ART) centre of Nehru Hospital, BRD Medical College Gorakhpur. **Result:** Themes emerged were: 1) Negative reactions to HIV positive results; 2) Social support was highly valued by PLHA in improving their quality of life; 3) PLHA experiences various stigma throughout their life; 4) Health staff behaviour was good but they felt the need of better arrangements for their treatment; 5) Refusal by Private Hospitals to treat HIV cases. **Conclusion:** Awareness campaigns & regular counselling of the individual shall be effective for PLHA on a routine basis. A better & hustle-free medical infrastructure shall be very beneficial & it is necessary to sensitize the private hospitals to treat the HIV patients in a positive manner.

KEYWORDS

PLHA, Qualitative Approach, Stigma, Perception of Care

INTRODUCTION

HIV presents a serious threat to public health, especially to poorer nations(1). People living with or associated with HIV/AIDS are seen as being devalued by processes such as stigma and prejudice(2). This detrimental

consequence makes it more difficult for a person to adjust to the illness, stresses relationships with the public and medical professionals, and compromises the efficacy of HIV programs by preventing early diagnosis and treatment initiation(3). In India, the stigma

surrounding AIDS is based on fear and misconceptions and perpetuates negative perceptions of those living with HIV. Antiretroviral therapy (ART) has made significant strides, but a comprehensive solution to lessen stigma and discrimination is still elusive. It is essential to comprehend how people view HIV care and treatment in order to create a more patient-centered system of care and management.

Limitation: A very few studies pertain Eastern UP on this subject has been published. Although there has been a number of recent reviews that examined stigma and HIV but there has been limited research that incorporated qualitative evidence in its exploration of stigma, HIV and health. Therefore this study has been conducted to explore more aspects of stigma, HIV and health.

Objective - The objective of this study was to explore the perception of care & treatment along with the other life experiences in people living with HIV/AIDS.

MATERIAL & METHODS

Study setting: ART centre of Nehru Hospital, BRD Medical College Gorakhpur.

Study design: A Qualitative exploratory study was employed for this study. Participants were informed about the study and written informed consent was obtained from each patients who was interested.

Study period: 5 months, from July 2023 to November 2023.

Study population: The target population for this study were PLHA above the age of 18 yrs.

Study method: The sampling method was purposive. Data was collected till saturation (i.e the point at which no new insights become apparent from the data) achieved.

Sample size: 30 patients (sample size was determined by saturation of data which was achieved when 30 participants had been interviewed)

Data collection: In-depth interviews were conducted using semi-structured questionnaire. All interviews were first audio recorded and then transcribed.

Data analysis: The transcripts were entered into QDA miner lite “qualitative data analysis software” for in-depth coding and analysis.

RESULTS

Table: Demographic Profile of Participants: (n=30)

Characteristics		n (%)
Gender	Male	16 (54)
	Female	14 (46)
Age (year)	18-30	3 (10)
	31-50	18 (61)
	> 50	12 (29)
Education	illiterate	6 (20)
	≤10 th class	10 (33)
	> 10 th class	14 (47)
Occupation	employed	13 (43)
	unemployed	17 (57)
Time since HIV diagnosis	1-3 years ago	2 (7)
	4-6 years ago	10 (33)
	>6 years ago	18 (60)

A total of 30 participants were interviewed (n = 30). As shown in table, 54% of the participants were male. Respondents ranged in age from 27 years to 72 years. The participants have been living with HIV for a minimum of 3 years to maximum of 20 years in this study.

The interviews composed of resonant narratives, were inductively coded, categorised and subsequently classified into five key themes. The following five themes are:-

Negative reactions to HIV positive results like suicidal ideation, depression & anticipatory anxiety:

Most of the participants had suicidal thoughts, depression, anticipatory anxiety and thought that now their life has been destroyed after knowing their HIV status. Some quotes from the participants are mentioned below:

“I felt to do suicide. One day I came out with car for accidental suicide.” (patient felt crying) [pt 4]

“I didn’t want to live anymore but as I was pregnant, I lived for my baby” [pt 13]

“I was very tensed, even now I am tensed about my daughters future, her marriage.” [pt 16]

“That time I felt like now my life has been destroyed but now I have to live with this.” [pt 3]

“When I found out that I am HIV positive, I did not know there are medicines for it. I thought

a person just simply dies. I was going to take my own life. I was going to jump in the Ramgarh lake.” [pt 7]

Social support was highly valued by PLHA in improving their quality of life: Their close family members and friends were strong source of support, helping them to make their everyday life endurable and making convenient adaptation, just like one participant said "my father in law has expired recently, but he always used to say to my husband that "why are you worrying? I am there for you." [pt 7]

This family acquiescence has an influence on the improvement in the quality of life, like one of the participant said "it was my family support which helped me to come out of depression and after that I did many works that led to my development. ". [pt 4]

PLHA experienced various stigma viz. social stigma, self-stigma, health professionals stigma throughout their life:

Social stigma: According to their experiences; education and awareness of people is very low, therefore after informing the family about the disease, some reacted atrociously, just like one participant said "initially for 2-3 years, people were rude and unkind towards me and asked me to stay away from them and my husband" [pt 2].

Self-stigma

PLHA also commonly reported feeling like they were considered untouchable as a result of HIV infection: "People were keeping a distance from me. The handpump which I used to drink water from, was pulled out by the people." [pt 14]

"I left the job(mechanic in delhi) after getting the infection, and started working in home as a farmer" [pt 10]

I got myself tested in private frequently so that there is no complication or problem later on. [pt 7]

Health professionals stigma

Some of the respondents observed that sometimes HCPs in the hospital were impolite while providing care. A participant remarked: "not everyone should be seen with the same eye". [pt 12]

"The place where CD4 used to initially happen, when I sat down to give blood, the woman there said "don't touch her" and then she started whispering that she has HIV, don't touch her. [pt 7]

4)Health staff behaviour was good but they felt the need of better arrangements for their treatment:

One participant stated:

"Good staff behaviour, they talked very politely and were very supportive." [pt 17]

"It takes almost whole day to get medicine. There is much indiscipline in medicine dispersion. One day I left in anger." [pt 15]

"chairs are less, should be more as many people come here and they don't get a place to sit, & fan issue, fan must be there wherever the people are sitting or waiting." [pt 2]

5)Refusal by Private Hospitals to treat identified PLHA and referrals to other health centres:

In one instance, the woman was denied a surgical procedure after she was found to be HIV positive. "She underwent hysterectomy in year 2017 in BRD medical college after the private hospital refused to take the case." [pt 10 attendant].

Another participant said: "Doctor diagnosed appendicitis and suggested surgery but when they found HIV +ve in my blood reports, they refused to do the surgery." [pt 9]

DISCUSSION

Villa et al.(4) confirmed in their study stated that the psychological aspects of seropositive people are reinforced by the social support they receive, which helps to improve their medical compliance and hence improves their quality of life. This is consistent with our study findings as well.

Three types of stigma (social stigma, self-stigma and health professionals' stigma) were relevant in the results, this is in accordance with the research by Colmenero et al.(5)

These findings are supported by the findings of Essomba et al.(6) in their study on the perceived

experiences of patients on stigma and discrimination in health care settings where PLHA reported

that they were deprived of treatment and that Health care professional's treated them with disdain.

CONCLUSION

On the basis of findings of the study the overall scenario can be concluded that HIV patients are living a very difficult physical, psychological and social life. A better and hustle free medical infrastructure and arrangement for the treatment and medicine will be very helpful for HIV patients in their treatment. Awareness campaign and regular counselling will be very much effective for the HIV patients to overcome from the different type of stigma they are dealing with on routine basis. It is also necessary to sensitize the private hospitals and their staff to take care and treat the HIV patients in a positive manner like they are doing for other type of patients.

RECOMMENDATION

General health education should be conducted in order to raise awareness about HIV among the public, so that PLHIV are treated with dignity.

Mass Awareness campaigns to overcome the different types of stigma they are dealing with on a routine basis.

A better & hustle-free medical infrastructure shall be very beneficial for them.

It is necessary to sensitize the private hospitals and their staff to take care & treat the HIV patients in a positive manner.

Counselling at regular intervals can alleviate the pessimistic feelings of individuals.

Remodelling of existing infrastructure as also improvising on waiting areas in upcoming new structures shall reduce the delay in dispensing the treatment to the patients.

LIMITATION OF THE STUDY

This study was conducted only in the patients attending the ART centre of BRD medical college Gorakhpur.

RELEVANCE OF THE STUDY

This study provides a clear understanding of what factors patients consider when accessing care, and what barriers, if any, influence care-seeking behavior.

AUTHORS CONTRIBUTION

All authors have contributed equally.

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Nil.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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DECLARATION OF GENERATIVE AI AND AI ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

This study have not used any AI assisted technologies in the writing process.

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