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Lived Experiences of Women with HIV/AIDS: A Qualitative Analysis

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Abstract

The goal of the current study was to get an understanding of the experiences of women living with HIV/AIDS in Pakistan. Data were collected using a qualitative technique through personal one-on-one interviews with eleven women. These interviews generated descriptions of individuals' experiences, relationships, and day-to-day events faced by women. Thematic analysis was used to analyze the data. The findings were dealt in light of the reoccurring themes emerged from data. It further contributed in understanding the nature and perspectives of different phenomenon experienced by women living with HIV/AIDS. The findings revealed five primary themes of emotional disturbances, social life experiences, treatment issues, fear of loss or death, and a desire to begin a new life. The findings of the study revealed that individuals who suffer from some terminal illness like HIV take it as unpleasant phenomena interfering in their daily life experiences. Further, the diagnosis not only causes severe psychological pressures for women but it also become a source of stigma from the family and society.

Keywords: *HIV/AIDS, Experiences, Women, Qualitative Study.*

1. Introduction:

The Human Immunodeficiency Virus (HIV) is spread when infected bodily fluids come into contact with mucous membranes or injured tissues, or when a needle is inserted into the circulation. once in the system, HIV assaults and infects CD4 cells, which are a kind of white blood cell in the immune system; when these cells proliferate to fight infections, they produce more copies of HIV, to the point where the body is unable to respond to opportunistic infections, malignancies, and illnesses. This, in turn, can develop to AIDS, the last stage of HIV infection.

HIV is one of the most deadly infectious disease epidemics in recorded history, with latest data indicating that it killed one million people in 2018. [2] Women and young girls, who account for more than half of the worldwide HIV population, are among the most vulnerable to catching the virus in many areas.[3] The poorest and middle-income countries are the severely harmed. Until 2014, poor and middle-income nations reported a total of 150 million HIV-infected persons. Pakistan, being a low to middle income nation, has an average prevalence of 0.1 to 0.5% of HIV infection in the general population. However, there is a high risk category in Pakistan that has a several times higher prevalence rate. In 2016, there were 130000 HIV patients in Pakistan, and 5500 AIDS patients died.

HIV was first detected in Pakistan in the late 1980s, mostly among injectable drug users, commercial sex workers, and returned migrant labourers. According to UNAIDS, the number of HIV-positive persons in Pakistan grew from a few hundred in 1990 to over 97,400 in 2009. The anticipated number of AIDS-related fatalities rose from 1900 in 2001 to over 6000 in 2009.[5] According to the National Health Survey report, there are approximately 150,000 HIV patients in Pakistan, with 75,000 reported from Punjab, 15,000 from KP, and 15,000 from Baluchistan,

Pakistan. There has been an unparalleled growth in HIV over the last few decades, as has the mortality toll.

According to the District Health Authorities in Gujrat, JPJ has a land area of 3192 square kilometres and a population of 2.53 million, with around 100,000 working throughout the Middle East, Europe, and the United States of America. Gujrat District is divided into three Tehsils, Gujrat, Kharian, and Sarai Alamgir, as well as 119 union councils. Jalalpur Jattan (JPJ) is a small town in Tehsil Gujrat that is split into four union councils. According to the 1998 population census, JPJ has a total population of roughly 120,000 people, with a population density of 642 people per square kilometre and a rural:urban ratio of 2.3:1. Union council 61/2 is the second most populated union council in JPJ, with a population of 29,476 people.[5]

On June 27 and July 1, 2008, a non-governmental organisation (NGO), New Light AIDS Control Society (NLACS), hosted two HIV screening camps in Jalal Pur Jattan. According to NLACS, the rising number of HIV-infected people in the region motivated the organisation to establish these camps. According to NLACS, 246 persons were tested for HIV, with 88 (35.8%) reporting HIV-positive after three consecutive HIV fast tests. The ELISA approach detected 74 of these as positive. The widespread media coverage of high HIV infection rates in this area turned the local populace against any further research. In this case, the Punjab AIDS Control Program (PACP) asked FELTP Pakistan to look into the epidemic.

The number of women who are diagnosed with AIDS each year in the United States has increased recently, despite a steady decline in the number of males who get the diagnosis each year. In 1996, women made about 20% of newly diagnosed AIDS patients; by 2001, this proportion had risen to 26%. Additionally, there has been a rise in the number of new HIV infections among women, going from 3983 (29%) in 2016 to 11,133 (32%) in 2021.[1] Women of all socioeconomic levels and those who engage in sexual activity yet lead regular lives are at increased risk. Sharing drug injecting equipment and having intercourse with males both put women at risk for contracting HIV. In contrast to males, women are more susceptible to contracting HIV through sexual activity. The National Institutes of Health has made research on women an essential part of the Institute's AIDS agenda in order to comprehend the true needs of women living with HIV and AIDS.

Despite the fact that HIV seems to progress similarly in men and women, immune-compromised women are more prone to a variety of gynaecological infections and malignancies that have just lately been identified. Because females are essentially caregivers for others, they experience stigma and are, in some respects, more vulnerable than men to abuse, desertion, and neglect of their own care.[8] HIV not only attacks and debilitates the immune system, but it also has negative repercussions for people's physical and mental health. Mood disorders, anxiety disorders, and post-traumatic stress disorder have been recognised as the most common mental health issues among HIV patients. People with HIV experience psychological discomfort in a variety of ways that mirror the virus itself. In addition to various emotional, cognitive, and behavioural responses, reactions to HIV infection might include grief, concern, despair, and disorientation. Throughout the course of HIV infection, a number of medical occurrences act as indicators of susceptibility to psychological suffering. Human immunodeficiency virus (HIV) infection patients have extensive psychological demands that arise at the time of diagnosis and change throughout time.

Depression, in particular, appears to be twice as frequent in HIV-positive patients than in uninfected people. In addition, the prevalence of self-harm and suicide attempts and/or completions is high among HIV-positive people. Many psychological and environmental risk factors, especially in those from disadvantaged backgrounds, such as unemployment, subpar housing, food insecurity, stigma, and fear of disclosing their condition and interacting with the

healthcare system, can be used to explain the high comorbidity of mental disorders in people living with HIV. Additionally, gender disparities have a big impact on how HIV develops over time and how frequently it co-occurs with mental problems.[10]

Regarding the significant comorbidity of mental health issues among women who are HIV positive, there are 800 peer-reviewed studies.[11] Women with HIV from underprivileged origins appear to be especially susceptible to co-occurring mental illnesses. This may be due to a variety of gender-related risk factors, such as power imbalances caused by gender dynamics, exclusion from opportunities and goods that come with power, unprotected sex, trading sex for money or other goods, having sex with high-risk partners, substance abuse, gender-based violence, complications with sexual and reproductive health, human rights, poor access to and adherence to healthcare, stressors during pregnancy, and other factors.[12]

The goal of the current study was to provide a description of the experiences of women in Jalal Pur Jattan, Pakistan, who were infected with the HIV virus or who had AIDS. The study examined features of HIV-positive women's lived experiences that had an influence on how various services were provided in a rural setting, such as general quality of life, access to healthcare, and social support. In order to better understand the phenomena of living with HIV/AIDS, this study aimed to examine the experience from the perspective of HIV-positive women. This group merits better comprehension. Many people who work in the field of health education come into contact with HIV-positive people at some point. Greater opportunity exists for improving work on HIV/AIDS as a health concern with a greater knowledge of how the disease affects people. This knowledge can be useful because it enables caregivers to identify and address significant emotional and social aspects of living with HTV/AIDS. All facets of the lives of the women they serve, must be taken into consideration. Infants and young adults, as well as families of women who are HIV/AIDS positive, are all affected by the disease of AIDS, which affects individuals of all ages. The purpose of this study is to better understand the subjective experiences of HIY/AIDS-affected women in Pakistan and to pinpoint the factors that affect how they perceive and manage the psychological and interpersonal effects of this illness.

2. Methodology:

A technique of qualitative research was used to explore the lived experiences of women with HIV/AIDS. Jalal Pur Jattan a small town in district Gujrat was served as the study's location. It has a high incidence of HIV/AIDS.[5] Women with HIV diagnoses made up the intended population for the current study. Participants in the study were chosen using a process known as purposeful sampling, in which the researcher specifically chooses the participants based on a set of requirements related to the chosen research subject. Eleven women with HIV/AIDS were included in the sample; their ages ranged from 25 to 53 years. Women with any other medical illness or psychological disorder were excluded from the sample. Due to the sensitive nature of the subject and the potential stigma associated with HIV, women were reluctant to offer their opinions in the current study, which results in a smaller-than-ideal sample size.

Table 1

Age, Disease Type and Duration of Illness of Participants (n=11)

Participant Number	Age	Disease Type	Duration of Illness
1	27	HIV 1, Reactive Type	8 Years
2	42	HIV 1, Non-Reactive Type	12 Years
3	53	HIV 1, Non-Reactive Type	14Years

4	38	HIV 1, Non-Reactive Type	9 Years
5	31	HIV 1, Reactive Type	9 Years
6	36	HIV 1, Non-Reactive Type	10 Years
7	37	HIV 1, Reactive Type	8 Years
8	35	HIV 1, Non-Reactive Type	7 Years
9	40	HIV 1, Reactive Type	11Years
10	41	HIV 1, Non-Reactive Type	13Years
11	39	HIV 1, Non-Reactive Type	6 Years

Prior to the official interview, demographic characteristics such as age, socioeconomic position, education, occupation, siblings', parents' occupations, religion, sect, disease kind, and disease duration were documented. Participants' signed consent was acquired after the study's goal and nature were explained to them. One to one in depth interviews were utilised to uncover the participants' innate frames of reference and assist in discovering the pertinent aspects of the research issue.

3. Data Analysis:

The raw data was conceptualized using thematic analysis. The current study employed the theme analysis method, which consists of six steps. The six-step analytical process suggested by Braun and Clarke was followed for this investigation (2006). The raw data was familiarized in the first step of the analysis, followed by the generation of initial codes in the second step. At the third step, the exploration of the data's themes and sub-themes was completed. At fourth step, generated themes were reviewed. Extracted themes and sub-themes were reconsidered and named in fifth step. In the final step, driven themes were reported.

4. Results:

The goal of this study was to delve deeper insight into the challenges surrounding the HIV/AIDS experience from the perspective of women in Pakistan. To collect the original data, the researcher conducted one-on-one interviews with participants. Similar themes emerged throughout the interviews. Despite the fact that people's experience with HIV/AIDS varied, different themes emerged and were investigated during the data analysis.

4.1 Generated Themes:

Every woman with HIV/AIDS who shared her story did it in a unique way. The examination of the interview data, on the other hand, revealed underlying themes that appeared in varied ways throughout the interviews. Interviews with eleven women were done and verbatim recorded. The researcher reviewed the transcripts to identify themes or patterns in the data. To facilitate analysis, the units of information that appeared often in the interviews were identified and color-coded. This method was utilized to comprehend the material, divide it into digestible bits, and develop categories, which were then organized using analysis. The researcher analyzed the data thematically, focusing on key terms, their meanings, and which quotes go together with conceptual understanding. The dimensions and contents of each category were untangled by asking data-related questions and comparing participant experiences, events, and other examples of the phenomenon of living with HIV/AIDS to identify parallels and differences.

Following the analysis of the interviews, the following themes were identified:

Table 2

Participants Experiences about Self, other and at Community Level

Main Themes Lived Experiences	**Representative Quotations**
1. Emotional Disturbances of women living with HIV/AIDS	***Participant No 4 expressed the thoughts as*** *"I didn't want to hang on, but it seemed like I was hanging on for dear life in a black hole. All I wanted to do was let go and spend as much time as possible in a black hole."*
Sub-themes under theme-1	
Depression	***Participant No 4 expressed the thoughts as*** *"I didn't want to hang on, but it seemed like I was hanging on for dear life in a black hole. All I wanted to do was let go and spend as much time as possible in a black hole."* ***Participant No 6 expressed the thoughts as*** *"I understand that depression can strike at any time. I believe HIV plays a major role in it because it's always there, no matter how hard you try to avoid it."*
Anger	***Participant No 2 expressed the thoughts as*** *"I was outraged, and I still feel like people are doubting me because they treated us like they were some other kind of monster. People have always irritated me, and I am angry most of the time.* ***Participant No 3 expressed the thoughts as*** *"While I was initially diagnosed, I was struggling with resentment against my father since he wasn't the best parent when I was growing up, and I thought I needed to let go of this anger if I wanted to truly seek therapy and take care of myself"* ***Participant No 5 expressed the thoughts as*** *"oh, I was furious... I became angry. They, who? They aren't God. They did not create the thing. Apart from me... They weren't going to tell me I had to go, and I wasn't prepared to, so that only infuriated me. You cannot make me die; I am not going to die. It only made me enraged and more determined"*
Shame and Guilt	***Participant No 2 expressed the thoughts as*** *"Even though I was not at fault, I used to be perceived as having committed a sin by others, which made me feel humiliated in front of my children and family members. My son also makes me feel guilty despite the fact that I was not at fault"* ***Participant No 6 expressed the thoughts as***

	"People made us feel ashamed of having this illness, even our family, therefore I feel ashamed of having it. I used to spend all of my time in my room because of how my family treated me"
Suicidal Ideation	***Participant No 5 expressed the thoughts as*** *"I started experiencing health issues and HIV. And it all began with a severe attack of sleeplessness. It was crazy how hard it was for me to fall asleep at all. I then began to consider suicide"* ***Participant No 1 expressed the thoughts as*** *"When I was diagnosed with HIV, my family and friends shunned me and blamed me for my illness. This led me to attempt suicide. Numerous folks spoke to me"*
Feelings of Lonelines	***Participant No 4 expressed the thoughts as*** *"I don't know of any support groups in my region. I attempted to create one, but other HIV-positive individuals have made the decision not to talk about it"* The individuals in this case show their loneliness by being rejected by friends or family members as a result of having the sickness... ***Participant No 5 expressed the thoughts as*** *"I believe that I grew quite lonely and that, although having already earned my paralegal degree and graduated from college, I was now regressing as a result of my sickness"*
2. Social Life of Women with HIV/AIDS	***Participant No 2 expressed the thoughts as*** *"When I went to my mother to ask for forgiveness for leaving my husband, she didn't believe what I was telling her, demanded to know who I had been having relationships with or what drugs I had been taking, and very much shunned me. My mother is hesitant to sip from the same water glass. But I'm not bothered by it. That is irrelevant to me. Because I am aware of her intense affection for me. She offers me hugs, kisses me on the cheek, and praises my family"*
Sub-themes under Theme-2	
Reaction of Family and Friends	***Participant No 5 expressed the thoughts as*** *"My family didn't support me at that crucial time because they didn't want to accept that I hadn't done anything wrong; instead, they believed that I had engaged in some sort of sexual relationship. My friends also abandoned me because*

	their families forbade them from getting in touch with me after learning about my condition"
Interaction with Society	***Participant No 1 expressed the thoughts as*** *"She didn't have someone to advise her where to go, what to do, or how to find any assistance, so the limit of her therapy was just to keep saying, "oh, it's just a dreadful sickness," "oh, it's just a horrible disease," and "oh," "it's just a horrible disease," and she just really panicked. A few of weeks later, I really went to meet her, and to my surprise, she was terrified to see me and even speak to me"*
3. Medical Treatment Issues	***Participant No 6 expressed the thoughts as*** "I started experiencing health and HIV-related issues. It all began with a severe attack of sleeplessness" ***Participant No 3 expressed the thoughts as*** *"I was always ill, frequently visited the hospital, and after I converted, the only time I've ever gone there was to get put on medication"*
4. Fear of loss or death	***Participant No. 3 voiced the following opinions:*** *If I attempt to suppress my grief, you understand what I mean, to keep it within, that simply saps all of your energy and makes you feel like you're in it for almost a lot longer.* ***Participant No 2 expressed the thoughts as*** *Participant No. 4 said, they did act as though I was already dead, and I haven't seen them since.And that was difficult.*
5. Need of Social Support	***Participant No 1 expressed the thoughts as*** *Family support is crucial. Yes, it's crucial to even acknowledge our circumstances and treat us like humans since, in their perspective, we are to blame for everything that led to our illness.*
6. Desire to live a new Life	**Participant No. 4 voiced the following opinions:** *My primary objective was to look after my daughter while I was with her. She was my responsibility, and I wanted to be proud of her. I brought her to this planet and placed her there, so it was my responsibility to see that she got through. I raised her to be a young, independent individual who was progressive and assimilated into society.* **Participant No. 5 voiced the following opinions:**

I wish to live a new life, I am tired of being stigmatized by everyone around us

5. Discussion:

This research set out to examine the experience of living with HIV/AIDS from the viewpoint of women who reside in rural regions. The researcher studied the themes that appeared in the interviews with eleven individuals to better comprehend this eexperience. The indepth interviews gave the participants a platform to explain how they understood life with HIV/AIDS. Despite the fact that participants discussed similar issues, each person conveyed these concepts in her daily life in particular, specific ways. Almost all of the participants spoke extensively about the feelings associated with having HIV/AIDS. The women's expressions of depression, rage, loneliness, shame, and suicidal thoughts revealed their frustration at realising how helpless they felt, their worries about the course of the disease, their loss of control over their lives due to medication dependency, and their anxiety or uncertainty about the future. A study conducted by Warden et al. (2021) reached the conclusion that physical and emotional stresses are some of the prevalent origins and forms of stress supports the findings of the current study. The women talked about how they found it challenging to manage their emotions while living with HIV/AIDS. The combination of sadness, rage, loneliness, humiliation, and suicidal thoughts certainly contributes to extremely high emotional stress. Similarly, depression is said to be a typical side effect of HIV/AIDS. It makes one feel hopeless and powerless, and it makes one give up many of the typically enjoyable things, which makes life seem even more depressing. Many studies have been shown to exhibit ongoing or sporadic signs of clinical depression by the sufferers of HIV Aids. The study's subjects all discussed their experiences with a highlighted theme of depression and emotional stress. As a result, it can view emotional stress as the main organizing principle guiding the experience of having HIV/AIDS.[14] Another typical reaction to having HIV/AIDS is anger, which was also audible while explaining the emotional strain. In this study, the women who were HIV-positive showed their anger in a variety of ways and contexts. In 2015, McIntosh conducted a study in which he discovered that anger is a typical response to a life-threatening illness. He also discovered that anger and guilt can also result from attributions of blame for HIV infection, and in some cases, the anger can be directed toward the person thought to have transmitted the virus to the infected person, medical professionals for their inability to treat the disease, or society for its failure to act urgently and compassionately.[15] Social life disrupted due to the illness was another significant issue that emerged from the current study as shared by many of the participants. The participants encountered the effects of others around them in one way or another, including family, friends, and even the social services in their various towns. Although the encounters varied from pleasant to poor, this area was always crucial. High stakes are involved in how people react to rejection and extinction threats. In 2014, Davtyan, Brown, and Folayan established that feelings about oneself can unintentionally or consciously harm one's health.[16]

Recent research has demonstrated that women with HIV/AIDS are vulnerable to a variety of physical conditions linked to their infection and the lack of available therapies for them. It is especially crucial that women have access to and are encouraged to use all HIV-related health facilities and programmed in their communities to prevent breast and cervical cancer, cervical and anal dysplasia, and pneumonia. The present study's themes are supported by prior evidence by Apparel in 2020. This is because HIV-positive women are more susceptible to menstrual problems caused by hormone fluctuations. The second prevalent medical problem that many of the participants discussed was Pneumocystis pneumonia, lung illness caused by bacteria that

frequently affects persons with AIDS and produces a dry cough and shortness of breath. There have been claims that immune system impairment makes people more vulnerable to a variety of bacterial illnesses.[17]

The topic of coping with bereavement was so pervasive and connected with everyone who took part. We go through an emotional process of mourning and coming to grips with the loss whenever we face any form of loss, no matter how tiny. The participants in this research revealed the significant losses they had experienced as a result of their HIV infection. Literature teaches us that while loss and grieving are universal experiences, people respond to and deal with them in different ways.[18]

Participants stressed the need of having a strong support network to assist them cope with living with HIV/AIDS. Relationships may create and preserve emotional equilibrium and can thus be given top attention while managing with HIV. 18 Even though they struggled to cope with the experience of living with HIV/AIDS, each participant demonstrated the ability to merge desired and undesirable parts of their life in order to discover a new reason for living. The participants' desire to inform people about HIV/AIDS as an illness and about their personal experiences with the disease served as their response to this. This topic came into being through the word of hope. According to Hayes in 2012, everyone needs hope in order to give their life significance, but it is crucial in the midst of an epidemic. Living well with HIV disease depends on how people with the disease maintain their sense of optimism and allow that hope to change as their sickness progresses. The study's participants demonstrated this optimism by identifying appealing qualities about themselves that they desired to share.[19] the following conclusions were reached by the researcher in light of the study's findings.

6. Conclusion:

Themes that were discussed and emerged by the majority of the women living with HIV/AIDS are emotional disturbances, problems with medical treatment, social scene of family and friends, fear of loss and death, need for social support, and desire to live a new life. Despite facing prejudice, secrecy, a lack of family, worries of rejection, and problems with money and social services, the women in this research appear to have all found something worthwhile to live for. There didn't seem to be a single attitude, mindset, or approach to HIV/AIDS concerns that was representative of a successful way to manage the condition. The participants discovered several helpful strategies for adjusting to the new way of life that comes with living with HIV/AIDS via introspection. The participants' experiences of living with HIV/AIDS seemed to provide a daily challenge, made worse by the simple knowledge that there was no solution in sight. Living well with emotional stress, having a supportive social environment, finding a new reason to live, and pursuing personal development were all crucial to the experience of living with HIV/AIDS.

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