

# Lived Experiences of HIV Positive Mothers

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**Abstract:** *HIV is linked to social isolation, disrupted family roles and includes various psychological and psychosocial issues. The consequences of being HIV positive results in rejection on the part of family and friends. The present study was conducted to gain deeper understanding of the lived experiences of HIV positive mothers and to explore psychological and psychosocial issues in relation with HIV positive status of the mothers. Phenomenological qualitative design was used, 10 HIV positive mothers were selected using purposive sampling technique as per the pre determined inclusion criteria. Semi structured interview schedule was used for data collection. Voice recording of the conversation was done; the transcript was then thematically analyzed using open code 4.02 software. Coding and categorization of the transcript was done using the software, based on that major 6 themes were emerged. The findings of the study revealed certain themes like initial impact of being HIV positive, components influencing familial harmony, birthing and mothering experience after being diagnosed as HIV positive, multifarious support system, deprived of psychosocial support, cognizance of numerous therapeutic and restorative measures related to HIV. Living with HIV is a serious concern because it subjects individual to constant stress and fears of various kinds.*

**Keywords:** Mothers, Experience, open code 4.02 software

## 1. Background of the Study

HIV is a retrovirus which may be transmitted in three ways in blood, semen and cervical secretions during sexual intercourse, from mother to fetus in utero, at delivery or via breast feeding. It is recognised that there are two varieties of HIV, designated as HIV - 1 and HIV - 2. The distinct effect of pregnancy on the expression of maternal HIV infection has been difficult to evaluate in the absence of appropriately controlled observations, although pregnancy has not been confirmed to have an adverse effect on the clinical progression of HIV disease. The prevalence of HIV in different communities and under different circumstances varies enormously. Infection with HIV, however, is linked not to who or what a person is but rather to what they do which might expose them to infection. Because it is impossible to know the HIV status of all individuals or indeed to exclude the presence of other blood borne infection which might constitute a transmission risk the principle of universal precaution has been advocated as a basis for infection control policy. This recommends the application in the care of all clients, of measures which protects staff and others from accidental exposure to potentially infectious body fluids. In the midwifery context such fluids include blood, liquor, cervical secretions and cerebrospinal fluids. Knowing mother's HIV status during pregnancy can offer a woman a number of benefits. These are related to decision making about the continuation of pregnancy, interventions aimed at reducing transmission of infection to her baby. It is important, however, to appreciate the adverse impact on a woman of a diagnosis of HIV, perhaps especially during pregnancy, including psychological and social stress, the experience of stigma, social isolation and fear about her health, that of her baby and about breaches of confidentiality.<sup>1</sup>

National adult (15–49 years) HIV prevalence is estimated at 0.26% (0.22%–0.32%) in 2015. In 2015, adult HIV prevalence is estimated at 0.30% among males and at 0.22% among females. The total number of people living with HIV (PLHIV) in India is estimated at 21.17 lakhs (17.11 lakhs–26.49 lakhs) in 2015 compared with 22.26 lakhs (18.00

lakhs - 27.85 lakhs) in 2007. Children (< 15 years) account for 6.54%, while two fifth (40.5%) of total HIV infections are among females. India is estimated to have around 86 (56–129) thousand new HIV infections in 2015, showing 66% decline in new infections from 2000 and 32% decline from 2007, the year set as baseline in the NACP - IV. Children (<15 years) accounted for 12 % (10.4 thousands) of total new infections while the remaining (79.5 thousand) new infections were among adults (15+ years).<sup>2</sup>

### Need of the study

Women living with HIV are even more likely to suffer from depression than women in the general population. Although many people living with HIV lead long, healthy, and full lives, learning that you are living with HIV is life - changing news that can be very difficult to hear and accept. Some people feel overwhelmed, helpless, or unable to cope with an HIV diagnosis. Others are afraid for their future health, or of disclosing their HIV status to friends and family. The stigma that many women living with HIV experience may lead to social isolation and feelings of loneliness. All of these feelings – helplessness, anxiety, loneliness – are key elements of depression. Many women living with HIV also experience large life stressors such as racial discrimination, poverty, violence, and single parenthood, which can lead to depression. An HIV diagnosis can simply add to this burden and to the chances of developing depression. There is also now evidence that HIV may contribute directly to depression in people living with HIV. Researchers have found that people living with HIV who have HIV in the cerebral - spinal (CSF) fluid that surrounds their brain and spinal cord have an almost five times greater likelihood of experiencing new - onset depression.<sup>3</sup>

The researcher felt the need to assess the lived experiences of vulnerable HIV positive mothers as they experience large life stressors such as poverty, physical violence, verbal abuse, single parenthood and feelings of helplessness, loneliness

## 2. Review of Literature

Shahnaz Kohan, Nastaran Mohammadali Beigi, Nahid Fathizadeh conducted a qualitative study in the year 2004 to describe the experiences of women living with HIV to get a deeper understanding of meanings and nature of life with HIV to develop general concepts about it. In this qualitative study phenomenological method was used and women's living with HIV were interviewed about their living experiences. Sampling was purposive and data saturation occurred after 12 participants. Data were collected by discussion and conversation, making notes, collecting participant's notes and recording in - depth interviews with them in Isfahan Province. Data were analyzed by Colaizzi's seven - stage method. Most participants were married, had children and were infected by their husbands. From 115 extracted codes 3 main themes and 9 subthemes, illustrating the living experiences of these women were found vulnerabilities (individual characteristic, family and social factors), challenges with the diagnosis (from unawareness and denial to suspiciousness, referring for test, waiting for the results and finding the seropositivity) patient's interaction in day life (family, HIV, supportive system). The women provided several experiences including vulnerability to HIV, ignorance about risky situations and how to avoid them, other's reaction to the diagnosis of infection, chaos in family and social relationships, lack of health care services and supporting system, especially for mothers who had family responsibility. These experience illustrates various aspects of the problems and show the necessity of planning for counselling, supportive and health care services to HIV positive patient's without judging them and their disease<sup>4</sup>

S. C. D. Wright, P. P. Mwinituo conducted a qualitative study in the year 2008 to describe the meaning of living with HIV/AIDS for 16 HIV positive women using a phenomenological qualitative method. In - depth interviews were conducted with purposively sampled HIV positive women. The purpose of the study was to investigate the lived experiences of HIV positive women and consequently to develop, implement and evaluate a non - government organization based support framework to meet these needs. Tesch's data analysis approach was used to synthesize a description of the women's lived experiences. The findings revealed myths about methods of HIV transmission leading to negative public attitudes including stigmatization, discrimination, humiliation, blame and rejection resulting in anxiety, suicidal ideations, low self esteem and sleeplessness. Parse theory of human becoming framed the researchers theoretical perspectives. The study concludes by emphasizing the need for implementing HIV/AIDS anti stigma program in Ghana.<sup>5</sup>

Emily Frances Tait conducted a qualitative study in the year 2006 to investigate into the lived experiences of HIV positive African women living in the U. K. This study aims to contribute to the research literature by gaining an in - depth understanding of the lived experiences of black African HIV positive women living in UK and how they make sense of their experiences in relation to their individual sense of identity. Semi structured interviews were carried out with five African women and their accounts were transcribed verbatim and analysed using interpretative

phenomenological analysis (IPA). All participants had been diagnosed with HIV and had lived in the UK for a minimum of five years, spoke fluent English and were over 18. Five super - ordinate themes were identified: 1) Given life but it's a struggle 2) A will to survive 3) Positive coping 4) Negotiating a stigmatised identity 5) Recognising a new me. The results capture the participants first hand phenomenological experiences of living with HIV. Whilst these women acknowledged the negative impact of living with HIV, they also talked about positive experiences and changes in their perception of themselves and their situations. They adapted a life with HIV by adopting effective ways of coping in a country which few regard as home. The women however demonstrated positive adjustment by attempting to reconstruct or renegotiate a coherent and culturally situated identity. In light of the findings the study proposes that it is crucial to promote positive interactions with support structures and particularly a sense of community and kinship. The results of the analysis are considered in light of existing theory and their clinical implications.<sup>6</sup>

Sacha Tarryn Street conducted a qualitative study in the year 2007 on lived experiences of HIV positive mothers. The study aims to explore the lived experiences of HIV positive mothers and to gain an insight into the impact that the diagnosis of HIV had on the lives of the research participants. A qualitative research design was adopted. Semi structured individual interviews were conducted with eight HIV positive mothers living in a government funded HIV care centre in Johannesburg, South Africa. In this study convenience sampling was done. A thematic content analysis method was utilised to derive themes relating to the subjective experience of mothering subsequent to the HIV positive diagnosis. The themes emerged were ambivalence of motherhood, experience of multiple losses, psychological and emotional impact of having HIV. The results indicated that motherhood, for many HIV positive mothers, was a fairly ambivalent experience characterised by a pervasive sense of loss and closely allied to various emotional and psychological challenges. Shared mothering, a lack of independence and strong institutional influences all contributed to the way in which the participants experience motherhood and how they perceived themselves. The fears of future illness and death were prominent concerns which further fuelled the ambivalent nature of HIV positive motherhood. Stigmatisation and rejection on the part of friends and family resulted in the participants experiencing a deep and pervasive sense of loss. This in turn was experienced as a strong assault on both their egos and their sense of self. Various psychological and emotional challenges, as a result of a general lack of social support and a combination of contextual stressors, were, therefore, particularly common experiences before arriving at the HIV care centre. However the mothers all reported that they had received invaluable emotional, social and instrumental support from the care centre. HIV care centres offer a place of refuge and protection from ostracism from the community context. Although the mothers manifested a yearning for their pre - diagnosis, sense of independence and general functioning, nevertheless, despite the tensions inherent in being a HIV positive mother. It was found that care centres

play an insulator role and help to act a buffer against the various challenges associated with living with HIV.

#### Objectives of the study:

- To gain deeper understanding of the lived experiences of HIV positive mothers
- To explore psychological and psychosocial issues in relation with HIV positive status of mothers.

#### Purpose of the study

The information may be used to improve the understanding of the HIV positive mothers and to make them aware about the healthy living with HIV positive status.

### 3. Research Methodology

**Research Approach:** Qualitative, Phenomenological exploratory approach

**Research design:** Qualitative research design

**Setting:** Vishwas NGO in Indore.

**Population:** HIV positive mothers registered with Vishwas NGO

**Sampling technique:** Non probability purposive sampling.

**Sample:** 10 HIV positive mothers

**Tool:** The tool for data collection consisted of 2 sections.

#### Section I - Socio - demographic variables

First section consisted of a structured interview schedule to collect baseline data, which consist of 10 items for obtaining information about selected factors such as age, religion, marital status, monthly family income, type of family, participant's education, participant's occupation, husband's education, husband's occupation, number of children

#### Section II - Semi - structured questionnaire related to lived experiences of HIV positive mothers.

In the present study semi structured interview schedule related to lived experiences of HIV positive mothers was used as a tool.

#### Pilot Study

The predominant objective of the pilot study was to help the investigator to become familiar with the use of the tool and to find out any difficulties to conduct the main study. It also aimed to assess the feasibility of the study, clarity of language and makes plans for analysis thus helping in finalizing the tool.

The pilot study conducted from 2<sup>nd</sup> March to 12<sup>th</sup> March 2016 in Vishwas NGO Indore. Written permission from the concerned authority was taken and 3 HIV positive mothers were selected who fulfilled the inclusion criteria for the pilot study. Study purpose was explained to them by means of informed consent with the assurance of confidentiality. On the basis of this information, the investigator proceeded with the actual data collection for the main study.

#### Data Collection Procedure:

The study was carried out in the same way as that of the pilot study. The actual data collection period ranged from 2<sup>nd</sup> June to 30<sup>th</sup> June 2016. Written permission from the authority was taken. 10 HIV positive mothers were included in the study. Consent form was also distributed to the

participants who agreed to participate in the interviews prior to the interviews. All participants were explained thoroughly about the purpose of study. Each participants timing was set for the interview according to their comfortable timings. Semi - structured questionnaires and in - depth interviews were used as an instrument for collecting the required data and were devised in order to appropriately address the objectives of this study. In light of this, each participant was encouraged to express their lived feelings and experiences. The researcher was responsible for organizing mutually convenient interview schedules with the participants. During the interviews, the researcher also paid close attention to social cues from participants, which could be signs of discomfort. The initial interview questions were proceeded by open - ended questions that were unstructured and non - directive, with the sole purpose of providing the participants with the opportunity to share their personal experiences. In doing this, it enabled the researcher to gain more of an inside perspective into the lived experiences of HIV positive mothers.

### 4. Findings

#### Section 1: Socio Demographic Characteristics

All of the participants were between the age group of 21 - 30 years with a mean age 25.5 years. All of the 10 participants were female in this study. In terms to their educational status, majority of the participants, 8 had never gone to school and 2 were with primary education. Regarding occupational status of the participants 7 were housewife, 2 were shopkeeper and 1 was ayabai. In terms of family income, 8 of the participants were having income 5000 - 10000 Rs/ - per month while remaining 2 were having income <5000 Rs/ - per month.

As far as the type of family concerned, 9 participants belong to nuclear family and 1 belonged to joint family. In relation to religion, all 10 of the participants, were Hindu. All participants, 10 were married. Among 10 participants, 5 have 2 children, 4 have 3 children and 1 have 1 children.

#### Section 2: Emerged Themes

**During data analysis total 6 themes have been emerged. They are**

- Initial impact of being HIV positive
- Components influencing familial harmony
- Birthing and mothering experience after being diagnosed as HIV positive.
- Multifarious support system
- Deprived of psychosocial support
- Cognizance of numerous therapeutic and restorative measures related to HIV

The theme “**Initial impact of being HIV positive**” describes that the participants, as being HIV positive encounter psychological issues and have impaired social functioning. All of the participants confronted fear of death, feeling of sadness and social isolation.

The theme “**Components influencing familial harmony**” refers to HIV positive mothers who confront ambivalent factors influencing harmony with their lives and



surroundings. This theme involves two categories response of family and spouse support. It was found that most of the participants did not get their family support and among 10 participants 9 had their spouse support.

The theme **“Birthing and mothering experience after being diagnosed as HIV positive”** comprises the experience of HIV positive mothers regarding her parturition process and care of new born by the help of Midwife. It included midwife support and child rearing.

The theme **“Multifarious support system”** states that the emerging support system imposed lifestyle adjustments on HIV positive mothers and their formal support networks. It included health personnel support and support of non - governmental organization.

The theme **“Deprived of psychosocial support”** states the experience of being an HIV positive mother had been characterized by deprivation of psychosocial support. These deprivation had occurred in many areas of life. It included actual loss and perceived loss. In this study it was revealed that among 10, 9 family members had chosen to abandon the participants after disclosure of their HIV status and 9 participants had lost respect and sense of emotional support from friends and relatives whereas 1 participant did not tell regarding her HIV positive status to her neighbors.

The theme **“Cognizance of numerous therapeutic and restorative measures related to HIV”** refers to knowledge and awareness on the several beneficial factors, causes, effects and means of managing the spread of HIV. This theme involved categories like transmission of HIV, drug regimen, diet investigation, general immunity, breastfeeding, family planning. In this study it was found that all participants are aware about diet but due to financial backing they were unable to follow the dietary pattern but they never skip dose of ART. All subjects exclusively breastfeed their babies for six months.

## 5. Discussion

The findings showed that most of the respondents had confronted social isolation from family and experienced humiliation and rejection. The study was supported by the research work done by S. C. D. Wright, P. P. Mwinituo conducted a qualitative study to describe the meaning of living with HIV/AIDS for 16 HIV positive women using a phenomenological qualitative method. In - depth interviews were conducted with purposively sampled HIV positive women. The purpose of the study was to investigate the lived experiences of HIV positive women and consequently to develop, implement and evaluate a non - government organization based support framework to meet these needs. Tesch's data analysis approach was used to synthesize a description of the women's lived experiences. The findings revealed myths about methods of HIV transmission leading to negative public attitudes including stigmatization, discrimination, humiliation, blame and rejection resulting in anxiety, suicidal ideations, low self esteem and sleeplessness. Parse theory of human becoming framed the researchers theoretical perspectives. The study concludes by

emphasizing the need for implementing HIV/AIDS anti stigma program in Ghana.<sup>5</sup>

All of the participants were infected by HIV through their husbands and had children. The study was supported by the research work done by Shahnaz Kohan, Nastaran Mohammadali Beigi, Nahid Fathizadeh conducted a qualitative study to describe the experiences of women living with HIV to get a deeper understanding of meanings and nature of life with HIV to develop general concepts about it. In this qualitative study phenomenological method was used and women living with HIV were interviewed about their living experiences. Sampling was purposive and data saturation occurred after 12 participants. Data were collected by discussion and conversation, making notes, collecting participant's notes and recording in - depth interviews with them in Isfahan Province. Data were analyzed by Colaizzi's seven - stage method. Most participants were married, had children and were infected by their husbands. From 115 extracted codes 3 main themes and 9 subthemes, illustrating the living experiences of these women were found vulnerabilities (individual characteristic, family and social factors), challenges with the diagnosis (from unawareness and denial to suspiciousness, referring for test, waiting for the results and finding the seropositivity) patient's interaction in day life (family, HIV, supportive system). The women provided several experiences including vulnerability to HIV, ignorance about risky situations and how to avoid them, other's reaction to the diagnosis of infection, chaos in family and social relationships, lack of health care services and supporting system, especially for mothers who had family responsibility. These experience illustrates various aspects of the problems and show the necessity of planning for counselling, supportive and health care services to HIV positive patient's without judging them and their disease.<sup>4</sup>

In present study HIV positive mothers confront ambivalent factors influencing harmony with their lives and surroundings, experienced multiple losses, as being HIV positive encountered psychological issues and have impaired social functioning, had fear of death and rejection on the part of friends and families. The study was supported by the research work done by Sacha Tarryn Street conducted a qualitative study on lived experiences of HIV positive mothers. The study aims to explore the lived experiences of HIV positive mothers and to gain an insight into the impact that the diagnosis of HIV had on the lives of the research participants. A qualitative research design was adopted. Semi structured individual interviews were conducted with eight HIV positive mothers living in a government funded HIV care centre in Johannesburg, South Africa. In this study convenience sampling was done. A thematic content analysis method was utilised to derive themes relating to the subjective experience of mothering subsequent to the HIV positive diagnosis. The themes emerged were ambivalence of motherhood, experience of multiple losses, psychological and emotional impact of having HIV. The results indicated that motherhood, for many HIV positive mothers, was a fairly ambivalent experience characterised by a pervasive sense of loss and closely allied to various emotional and psychological challenges. Shared mothering, a lack of independence and strong institutional influences all

contributed to the way in which the participants experience motherhood and how they perceived themselves. The fears of future illness and death were prominent concerns which further fuelled the ambivalent nature of HIV positive motherhood. Stigmatisation and rejection on the part of friends and family resulted in the participants experiencing a deep and pervasive sense of loss. This in turn was experienced as a strong assault on both their egos and their sense of self. Various psychological and emotional challenges, as a result of a general lack of social support and a combination of contextual stressors, were, therefore, particularly common experiences before arriving at the HIV care centre. However the mothers all reported that they had received invaluable emotional, social and instrumental support from the care centre. HIV care centres offer a place of refuge and protection from ostracism from the community context. Although the mothers manifested a yearning for their pre - diagnosis, sense of independence and general functioning, nevertheless, despite the tensions inherent in being a HIV positive mother. It was found that care centres play an insulator role and help to act a buffer against the various challenges associated with living with HIV.<sup>7</sup>

All of the participants had fear of death and experienced isolation and lack of emotional support. The study was supported by the research work done by Tagwa Omer, Sandy Lovering, Majed Al Shomrani conducted a qualitative study using a narrative interviews was used to explore the experiences of people living with HIV/AIDS in Saudi Arabia. Data were collected from 18 male and female participants. Participants were approached using purposive sampling. Interviews were conducted in Arabic and each interview lasted 30 - 60 minutes. The interviews were transcribed, translated and analysed using a descriptive phenomenological approach until saturation of themes was achieved. The recorded interviews was transcribed in Arabic, translated into English and then managed using NVivo 2.0 software. Data analysis revealed five main themes; stigmatisation, disclosure, fear, vulnerability, lack of psychosocial support and religiosity. Societal attitudes towards HIV/AIDS were a key factors in stigmatisation, which leads to discrimination and stereotyping. Participants experienced a negative self image, feeling of shame and a threat to self worth. Disclosure of their HIV positive status was a great concern, while non - disclosure was a protective measure against stigmatisation. Confidentiality of HIV status was very important and people feared disclosure by the healthcare team to others. Fear and vulnerability included fear of punishment from God, fear of being discovered as HIV positive and fear of the future and death. Participants experienced isolation and lack of psychosocial and emotional support. In response to their experiences all participants accepted their diagnosis as destiny and become more religious using spirituality as their main coping strategy.<sup>8</sup>

All participant's husbands are aware about their wives HIV positive status. The study was supported by the research work done by Sangita V. Patel, Shilpa N. Patel, Rajendra K. Baxi et al conducted a qualitative study to explore the experiences and perception of people living with HIV/AIDS and their service providers in Gujarat, India.<sup>30</sup> HIV infected individuals from ICTC were selected to participate in the

study.<sup>30</sup> in - depth interviews in the local language with HIV positive individuals from the integrated counselling and testing centre in Gujarat, India assessing the experiences, perceived barriers and facilitators to disclosure. Fifteen HIV service providers were recruited to participate in focus group discussions. The in - depth interview guide was designed to assess the topics pertaining to HIV disclosure process, perceived barriers and facilitators to disclosure and HIV associated stigma. All interviews and focus group discussions were coded using MAXQDA software. The themes emerged were fear of stigmatisation, reasons for non disclosure, involuntary vs voluntary disclosure, consequences of disclosure, benefits of disclosure. Findings of the study revealed that most of the HIV positive wives disclosed their status to their husbands, whereas only few of the HIV positive husbands revealed their status to their wives.<sup>9</sup>

## 6. Conclusion

Women living with HIV are even more likely to suffer than women in the general population. The stigma that many women living with HIV experience may lead to social isolation and feelings of loneliness. All of these feelings – helplessness, anxiety, loneliness – are key elements of depression. Many women living with HIV also experience large life stressors such as racial discrimination, poverty, violence, and single parenthood. The present study has helped the researcher in better understanding of the lived experiences of HIV positive mothers. Researcher felt that there is a need to do further studies related to problems faced by HIV positive individual and even assess the stress and coping strategies.

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