

Life World Of The HIV Concordant Couples Of Pakistan: A Qualitative Study

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Abstract

HIV/AIDS emerged as an epidemic in 1959 in the Republic of Congo, causing global health concerns when doctors recognized it in 1982. Currently, around 240,000 individuals in Pakistan have been living with HIV since 1987. This study explores the impact of HIV diagnosis on family and social relationships, particularly marital relationships. It focuses on how HIV-concordant couples navigate challenges to lead normal lives and make decisions about parenting. Drawing on social phenomenology and trust commitment theory, qualitative research was conducted in Punjab, Pakistan, involving 18 HIV-concordant couples and 4 HIV consultants. Interviews were analyzed thematically to understand the experiences of these couples post-diagnosis. The study revealed natural attitude of the lifeworld, stratification of the lifeworld and normalization of life world. Recommendations include the development of guidelines and policies to support HIV-concordant couples in maintaining stable relationships and safe parenting practices.

Key Words: *HIV concordant couples, natural attitude of the lifeworld, stratification of lifeworld, normalization of life.*

Introduction

This research study elaborated the lived experiences of the HIV concordant couples in the context of Pakistan. The concept of life world is presented by Husserl. The life world refers as the lived experiences of human beings. The life world is a region of reality that established in a particular manner in their lives. The life world is intersubjective domain¹ of the reality and the individuals are capable to transform their reality by social actions. The life world experienced before our conceptualization.

Every individual have encountered his or her social world as consists of the layers about himself or herself. These layers are further fragmented into two domains as natural attitude of the life world and the stratification of life world that consists of spatial (lived space) temporal (lived time), and shared intersubjective reality (Lived human relation and social structure of the life world) (Dreher, 2011). I have discussed the lived experiences of the HIV concordant couples by using the realms of life world given by Alfred Schutz.

HIV Normalization is a medical discourse and deals with the everyday life experiences of HIV beings who know this reality that there is no cure, which lies in the heart of HIV-positive individuals. These day to day experiences, realities and challenges influenced persons which remains invisible. (Beuthin et.al., 2015)

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The impact of illness on everyday life has been the focus of many studies that examine the adjustments people make when facing an incurable illness (Larsen, 2014, 2021; Townsend, 2011). Recent researches have tried to explain how normalcy is attained by the people living with chronic illness when they were diagnosed (Miedema et.al., 2007). People use different strategies to cope up with their condition of chronic illness and normalizing is a good strategy among them. Discussing the normalcy, the study has also identified that the condition is the determinant of normalcy through the process of adjustment among chronically ill people. Further, it was also indicated that achieving normalcy involves treating the challenges of disease as normal which was a good strategy of illness management and provide courage to combat chronic illness conditions. Normalization is a standpoint to analyze and interpret diseased people's adjustment and make them compatible to normalize their daily life activities.

Flowers et.al. (2011) explained that normalization of HIV has been preserved as a medical leading construction that minimizing the psychosocial consequences among HIV beings and overshadowing the image of a stigmatized person because of HIV. Persson (2013) further added his view as it was possible to create the image of harmless people in society through the normalization process. Walker (2019) argued that there is no pill to cure the guilt and shame affiliated with HIV so, be a normal being is a good strategy to fight against the disease.

Sastre et.al. (2015) discussed that HIV is not a death sentence alimnt anymore. Normalization of life could be attainable by using proper medication and manage chronic illnesses such as HIV. Marriage and parenting are possible for HIV-infected couples and they could enjoy healthy marital and family life. The construct of normalization has a significant influence on HIV-infected people's personal growth and happiness. Sero-concordant couples could fulfill their life's desires and make social and psychological incorporation in society after the diagnosis of HIV. HIV-infected people gained better health outcomes who have fewer chances of psychological vulnerability because of social support (Cohen et.al., 2011).

Philbin (2014) has indicated normalization strategies among HIV being as they have seemed healthy and self-regulatory. This technique gives them a way to get rid of the stigma and discrimination in family and peer groups. The technique should be adopted by the individual with chronic illness to scratch out the moments that make them different from others by moving on with their lives. Individuals integrated themselves into society by focusing on the areas like family, work, and social life like other family members and peers. This technique enables them to achieve their future goals without hesitation and get rid of the threat of death by the regular use of ARV medicine and proper checkup.

Mattes (2014) identified the project of HIV normalizing as the transitional way of HIV from crises to normalcy by a health care professional before starting ARV treatment of HIV beings. Usually, HIV-trained consultants used this strategy to empower HIV individuals and couples. The state of permanent transition because ARV medicines minimize the social and moral dilemmas in the lives of HIV beings. People could attain de-stigmatization by adopting the strategy of normalization. Couples reject the damaged status and accept HIV as a disease, not a stigma. They embraced the possibility of parenthood and becomes compassionate partners. This strategy has positive potential public health outcomes by reducing the incidence of HIV cases.

Theoretical Inspiration of the Study

The current research is inspired by this theoretical model of social phenomenology by Alfred Schutz. Alfred Schutz introduced the concept of multiple realities through phenomenology. According to Schutz, reality extends beyond social life to encompass fantasy, dreams, and other realms of existence. The key constructs of this theory are used to examine the phenomenon of the marital relationship and parenting among HIV-concordant couples in Pakistan. I have found that most sero-concordant couples are aware of the HIV status within the institution of marriage. Initially, couples encountered a challenging and shocking situation after the

diagnosis of HIV status. They experience the denial stage before spells of anger and bitterness begin as they embark on making sense of their situation. When couples come across the situation and they can make important decisions about their lives and how they proceed to with their relationship. They decided to normalize their lives by taking proper medical treatment to manage the crises of disease through safe parenting and healthy family life. Sastre et.al. (2015) found that HIV Individuals are living longer, and healthy lives and they enjoy marriage and parenting with the diagnosis of HIV. They can fulfill life's desires, and this makes the overall well-being and allows for considerable social integration into the society.

Method and Materials

The researchers used phenomenology as a qualitative research method to explore the experiences of HIV concordant couples in their daily lives. The study, based on an interpretive perspective, aimed to understand how individuals create social realities through their interactions. In-depth interviews were conducted with 18 HIV concordant couples and 4 HIV counselors aged 21-45, selected through purposive sampling at PIMS hospital. Ethical guidelines were strictly followed to protect participant confidentiality. Interviews were conducted in Punjabi and Urdu, transcribed into English, and analyzed using phenomenological and thematic analysis to identify the unique challenges faced by couples living with HIV.

The study analyzed the socioeconomic backgrounds of participants to understand the experiences of HIV concordant couples in marital life and family planning. Interviews were conducted with 36 participants aged 21-45, most of whom were graduates, with a few having post-graduate or primary education. The majority of males were in private jobs or business, while females were working women or housewives. Most lived in joint families, with some exceptions. Marital statuses at the time of HIV diagnosis varied. The study included couples matched by HIV consultants post-diagnosis. Participants had been diagnosed with HIV 3-5 years prior and had children post-diagnosis. Background information on HIV diagnosis, reasons, stages, marital status, children, and ARV medication use was collected. Reasons for HIV transmission included sexual contact and blood transfusion. Most females were infected by their husbands. In-depth interviews with HIV consultants highlighted their role in supporting concordant couples. Consultants aimed to empower HIV patients and promote understanding and safe parenting. The study provided insights into the consultants' approaches and counseling practices.

Data Analysis

The researchers have identified key themes from the participants' accounts: 1) natural attitude of the lifeworld, 2) stratification of the lifeworld, and 3) normalization of life world.

<p>Lived experiences of the HIV concordant couples</p>	<ul style="list-style-type: none"> • Natural attitude to the life world • Stratification of the life world (temporal, spatial and shared reality) • Gendered life world, Spiritual life world and normalization of the life world (Suggested) 	<ul style="list-style-type: none"> • Physical and psychological experiences of the HIV concordant couples. • Lived space, lived time and relationally with other human beings made the life world. • I have suggested three more strata in the life world as spiritual life world and normalization of the life world.
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Theme 1: The natural attitude of the life world

The natural attitude of the life world comprises both physical and psychological state of HIV participants. I have interviewed the HIV concordant couples who were diagnosed with HIV during the time period of 2004 to 2019. All HIV concordant couples were living in a joint family except two couples and inhibited in the same community after HIV diagnosis as earlier. The social world around the HIV concordant couples constructed on base of the physical (bodily) appearance during the social interaction. The HIV concordant couples shared their bodily experiences after the diagnosis of HIV. One of male participant share his experience before the HIV diagnosis about illness as;

My friend was suffering with fever and weight. He was going for normal checkup and identified with cancer. When I was visited to him and presumed that he will die soon because of the decline of health. It was common misconception that illness leads the impairment the individual's body and cannot revive in their normal condition. The fear of disease itself is the cause of restlessness and confusion about life (Male participant, HIV Concordant Couple#06).

Usually, individuals have misconception about their illness and expectations like every disease will be treatable. It's just a sick role for some time which interrupt their lives for a while and resumed again in a normal condition. One of female HIV infected participant told about their condition before HIV diagnosis.

I had a high grade fever and body ache after the surgery of the appendix and continuously my weight was declined. I did not take this situation as serious because I thought that it was an after effects of surgery like other surgeries. My health going to deteriorated in a month then I have decided to visit hospital for checkup (Male participant, HIV Concordant Couple#11).

Although all symptoms were associated with HIV but individuals did not expect this illness because they did not affiliated with any immoral activity and have stable married life. One of male participant shared his physical experience before HIV prognosis as;

I was suffering from serious stomach issues and had diarrhea. I had decided to go for checkup but doctor did not take my condition serious and treated me like a normal patient. I used the prescribed medicines but my health is impaired then I have decided to go in another hospital and doctor took my blood tests but I did not expect this, I was HIV positive (Male participant, HIV Concordant Couple#10)

Couples have fear of death after the prognosis of HIV. One of male participant narrated his experience as;

I came to know that I have an HIV positive after the lab tests. I was tense and did not sleep several nights because I think this is an end of life and we will die soon. It is a misconception which prevails in society that HIV kills individuals or impaired health status. They cannot enjoy a normal life (Male participant, HIV Concordant Couple#07)

I have observed that the decline of health and death was associated by HIV infected individuals after the prognosis of HIV. This misconception interrupted the individuals' lives and presumed an uncertain condition of life.

One of female HIV consultant shared her experience as;

When male life partner was seriously ill and admitted in a hospital. I used to call their family for HIV tests. Mostly female partner was also HIV positive but she did not care about their health. They only inquired about the health of her husband and concerned about him because in our society female give honor to her husband in any situation. Although, they were also HIV infected (Female participant, HIV Consultant#04)

The sociocultural setting contributed in the construction the bodily experience among couples. Female usually prefer their husband's health over own health. It is a common misconception that HIV infected couples have HIV positive children that's why they did not plan a child in their life and their marital life was also spoiled. One of male participant shared his experience as;

I was diagnosed with HIV in Saudi Arabia and my company deported me. I took my wife for blood test and she was HIV negative that time. I was taking medicine to cure HIV by a doctor for four years but my viral load cannot decreased. My wife's health is impaired and she was also diagnosed with HIV after one year. I was worried and decided not to plan a child because I have a fear of HIV transmission to my child. I did not have stable marital

relationship after the prognosis of HIV. My doctor advised me to visit PIMS (Male participant, HIV Concordant Couple#08)

HIV concordant couples have misconception that they did not enjoy their marital life and safe parenting after the diagnosis of HIV but HIV consultants resolve this confusion and told few precautionary measures for safe parenting with the regular use of ARV medicines. The HIV concordant couple assumed their bodies as child bearing after the counselling of HIV consultants. One female participant shared her experience as;

I have no child because we did not plan a child after HIV diagnosis with mutual consensus but I have a desire when I see the children of my siblings. When we were decided to change our doctor and visited to PIMS for checkup. I have consulted with doctor about planning a baby she encouraged me and minimized my fear. Now I have a daughter because of the counselling of the doctor after 12 years of marriage (Female participant, HIV Concordant Couple#08)

I have described the HIV concordant couples' thinking about illness before HIV diagnosis and their first encounter with HIV as a lived body. Moreover, HIV concordant couples noticed yourself as a dying body and planning a baby with vulnerable body is not attainable. HIV infected individuals used their bodies as miserable and incurable because of HIV.

Theme 2: Stratification of the life world

The second domain that experienced by HIV concordant couples divided in to the lived space, lived time and shared intersubjective reality. Firstly, HIV concordant couples were cognizant of the space they lived in and explained it as either friendly or neglected. Secondly, HIV concordant couples elaborated the time which they assume after the diagnosis of HIV. Thirdly, shared reality experienced by HIV concordant couples in relation to other human beings who share the same space with HIV concordant couples inhibited in the social world. I suggested the further three aspects in the stratification of the life world as gendered life world, spiritual life world and normalization of the life world.

2.1. Lived Space

I have discussed the lived space experience of HIV concordant couples in this section. All HIV concordant couples were living in joint family system except two couples who were living in nuclear family system at time of finding HIV positive. The place of residence was considered important while one life partner was encountering a disease. Home is a vital lived space. One female participant shared his experience as;

I was diagnosed with HIV at the time of my husband death. I was shocked and tensed how I spent my life without him. His family disregarded me and throw out from the house with my HIV infected son. I came to my brother house because I have no place for residence (Female participant, HIV Concordant Couple#02)

There were three widows participant being a part of my study. These widow was remarried with HIV positive individuals. The females shared their painful lived experience in his husband house by their family. One of male participant told about their experience as;

I was working as a delivery boy on pizza shop at Yamen. After one year, I came to my hometown to visit my family. Here I was suffering from high grade fever and felt very feeble in a week. I have decided to go for checkup because of severity of my condition. Doctor suggest me different Lab tests for further investigation (Male participant, HIV Concordant Couple#15).

Generally, the family supported the HIV infected individuals in Pakistan. In few cases families neglect the HIV infected couples. It was considered blessing when you were diagnosed with any disease at home. One female share her experience as;

My husband divorced me to take the excuse of HIV and I did not able to give him a healthy child because of my miscarriage. According to him, he was infected because of me but

actually I was infected from him. He was involved with other girl and was marry to her after divorcing me (Male participant, HIV Concordant Couple#03).

Home is considered the place to store the confidential documents like HIV tests and prescription by doctor. HIV concordant couples hide their hospital visits and documents. One of male participant shared his experience as;

When I visited to hospital for follow up checkup and collect ARV medicines in a month and after three months. Usually, I told my family about the medicines of hepatitis not HIV medicines because hepatitis was not considered as dangerous like HIV so, I hide my documents from them (Male participant, HIV concordant Couple#10).

HIV concordant couples were very hospitable and they were very happy when someone visited to their houses and asked about their miseries. Home were considered the space of hospitality. They offered food and excited to share food with guests. It is an ethical dilemma of our society no one share their food with them and realized them an untouchable. The myth of HIV transmission through touching, greeting, and sharing food is another concern of HIV concordant couples. One male participant shared his experience as; “My family came to know my status of HIV positive. My siblings tried to avoid me and did not share his food with me. It was very disheartening and embarrassing moment for me” (Male participant, HIV Concordant Couple#11).

This is the dilemma of our society who were thinking HIV is a communicable disease and transferred through touching, sharing food, and utensils. Participants shared their experience of stigmatization and discrimination because of HIV.

2.2. Lived time

HIV is a life truncating and transforming illness and HIV concordant couples documented their past and present experience as a HIV couple and parent. Most of the participants think that their life is over now and death angle will come any moment to take their life. They were more concerned about the present (HIV Couple) and future (HIV Parent) lived time. One male participant shared his experience as;

My wife did not enjoy the normal life span because of me. My wife was suffering of several diseases because of HIV and I think that our life span is shortened from the life of a normal life. This thought restless me and I did not sleep at night because of this anxiety (Male participant, HIV Concordant Couple# 07).

Knowledge is important for everybody in this world but people came across this bitter reality that they were suffering from AIDS. The whole life of the individual is disrupted in case of chronic illness. it ruptured the continuity of one’s biography. HIV test results can be individuals biographically disturbed following their dreams for family, job, and children which they perceived to be unfeasible with HIV status. The majority of participants felt biographical disruption after they become aware of their disease. One male participant shared his experience in these words:

I was identified with HIV infection, I got very upset and think it’s something very dangerous because of the severity of the disease. My whole life passed in acquiring blood tests, medicine, and treatment. My dream for the better quality of personal, family and professional life was spoiled with this curse of disease (Male participant, HIV Concordant Couple# 10).

One female participant shared her divorce incident after the disclosure of HIV:

I was shocked when I came across about the cause of my illness. HIV spoiled my life and I thought my whole life’s dreams crashed and nothing to do it. My husband induced this precarious virus in my blood but he blames me for this and divorces me (Female participant, HIV Concordant Couple# 03)

I have found that most of the participants experienced disruption in their life dreams about everything because of this disease. They were thinking that it was the end of a normal and

happy life. Individuals' biography keeps the distracted and unnatural flow of life is the most complicated task for those who were confronted by chronic illness especially at a young age. It's tough for an individual to overcome the disruption in personal, Professional life and Loss of Social Circle.

Most participants want to see their children's happiness with their eyes like normal parents and they wish to live until they will fulfill their all responsibilities but fear of death is always frightened them. One female participant shared her feeling as:

I need to live alive until my daughter gets merry. My daughter was not staying without us. I could not leave my daughter with my in-laws because she did not associate with them as their parents. My daughter was coming along with us when we were going to the hospital for a routine checkup and ARV medicine. My daughter has a fear to lose their parents and we were unable to get rid of her fears about us. (Female participant, HIV Concordant Couple#14).

I have elaborated the lived time experiences of HIV concordant couples from present to future. They were more concerned about their children's future life. The whole life treatment made them disturbed and keep away them from the routine life.

2.3. Shared reality of HIV concordant couples

The shared reality experienced by HIV concordant couples in relation to other human beings who share the same space with HIV concordant couples inhibited in the social world. The couple's life is not limited to two individuals. It is associated with two families and other lived relations. Beyond their families, they was also associated with other members of the society like friends, colleagues and health care professionals.

The individual who was aware of their HIV status show reluctance to share with partners and family because of stigma. Social and cultural ways inculcate HIV stigma and impede the individual to disclose their identity as HIV positive. People living with AIDS are accompanied by the allegation of guilt, loss of self-respect, and stigmatization in front of society. HIV stigma has been internalized with feelings of shame and guilt which leads to depression, anxiety, and loss of hope, and social isolation. The symbolic meaning of the disease retains by the process of looking glass self. Individual perceived their self-image on the basis of societal reactions they encountered in the social world. One female participant shared her experience in these words:

I did not tell anyone outside of the family about my disease because I know people had a very humiliating behavior with HIV/AIDS patients and they had very bad feelings for us so it's better not to disclose my status to them (Female participant, HIV Concordant Couple#08).

Individuals hide HIV status from their close family terms because they felt the fear of losing them. Women with HIV/AIDS in most cases decide to hide their condition to escape from the tag of a bad woman. Most people have a fear of disclosing their HIV/AIDS status due to isolation from the community members. Isolation of women affected with HIV/AIDS status can increase the effects of HIV/AIDS and may die before time.

Individuals have a fear of social isolation, the demise of family and social circle after knowing the HIV status. Several people conceived an individual as immoral and commit some sin that's why he/she was punished by Allah in this way.it is a misconception about the transmission of HIV because there were many iatrogenic and vertical victims who did not do anything but unfortunately, they came across this disease. One male participant said: "I was frightened to reveal my identity as an HIV positive since everyone accompanied me did not like to greet me and treated me as an untouchable" (Male Participant, HIV Concordant Couple#05). Fear, Shame, guilt, and feeling of disrespect is another factor to disclose HIV status especially for individuals living within the religious and socio-cultural boundaries. One male participant told that:

I didn't anticipate being a HIV positive individual, when I visited the hospital. It is a very difficult situation for me when the doctor called my wife for an HIV test and her tests were also positive. I felt remorse that my wife also became the victim of this disease because of me. So, I didn't disclose this reality to anyone in the family and surroundings (Male Participant, HIV Concordant Couple#03).

People with HIV infection had to deal with many difficulties for surviving such as fear, ignorance, and discrimination regarding HIV have their consequences on the life of persons living with HIV/AIDS. The communities' negative attitudes and beliefs towards PLWHAs can increase internalized self-stigma such as guilt, shame as well as feelings of alienation by the affected persons that leads towards feeling of suicidal attempts among HIV infected beings. Another participant shares his views in these words:

I was afraid to disclose my HIV status in front of family and friends because of the demise of a social and familial circle and social isolation. Being a human I did not afford the isolation and loss of face because of my HIV status (Male participants, HIV Concordant Couple#12).

Stigma has shattering outcomes for HIV individuals, couples, and families such as depression, social isolation, low self-esteem, and poor health, etc. HIV infected people were stigmatized and verbally abused. HIV infected beings avoid access to treatment. HIV trained staff play a crucial role in access the medical needs of HIV beings and minimized the risks of stigma and discrimination in hospitals. One female participant expressed the discriminatory behavior of doctors and medical staff with their HIV infected son as

My son's leg was fractured and admitted to a government hospital. The doctor ordered me to label him as HIV positive on the back of his bed which was a very embarrassing moment for me because everyone in a hospital weirdly sees us. My in-laws did not aware of my son's HIV status. I was afraid of their reaction when they will come to meet him. I requested one doctor, please remove this label. He was understanding my issue and ordered paramedical staff to take off this tag. But, the next day another doctor came and became angry to know this and he ordered to put label again and he did not treat him well like other patients. It's quite hurting for me as a mother because he did not do anything wrong why they have treated him like an untouchable creature (Female participant, HIV Concordant Couples#02).

Mostly untrained medical staff reluctant to treat the HIV individual however HIV is not a communicable disease. It was the dilemma of our society who considered the individual bad, not a disease. One male key informant discussed the delivery of her wife:

Doctor on duty did not take her delivery case and left my wife in a critical situation to make an excuse of her son's illness because of HIV positive status. Another doctor came and deal with my wife's case. I was very obliged to that doctor for her kindness because she saved the life of my wife and son (Male participant, HIV Concordant Couple#03).

I have presented the shared experiences of HIV concordant couples relative to other and created their shared reality on basis of scheme of references that set in the past. The others play a vital role in the construction of the social world of HIV concordant couples.

2.3.1. Gendered life world

Gendered life world explained the lived experiences of gender with respect to the prejudices and orientation of gender in the HIV Scenario. Gender discrimination was considered another important barrier to disclosing HIV status in Pakistani society where socio-cultural boundaries are more restricted as compared to others. It's difficult for women revealed this bitter reality in front of the family and others because patriarchal oriented society forgives the male for their sin but not female because she was the up bringer of the upcoming generation so any fault of female was not permissible although she was the victim. Another female patient told that

HIV individual feared even if not seriousness of disease but the consequences of the sociocultural setting where he/she were living. I was dreary when I came to know that I am HIV positive, Initially, I didn't understand how to deal with this, and being a married woman how to disclose this to family and friends. My husband was also called by a doctor for tests and he was also HIV positive. I was frightened of my husband and in law's reaction. The doctor and counselor supported me a lot and did counseling of my husband. Now we were living a happy life with two children (Female participant, HIV Concordant Couple#11)

Another experience of self illness shared by a female participant which gave her a stigma of divorce with HIV from her husband:

I was diagnosed with HIV during the 2nd miscarriage. When the doctor called my husband for an HIV test and counseling, he refused. My husband divorced me to make an excuse of HIV positive and she didn't give me a healthy baby while he has an affair with another girl (Female participant, HIV Concordant Couple#18)

One male participant told his wife's reaction when she came to know their HIV status:

Initially, she was frightened about my health but she trusted me a lot and supported me each moment of life. When I feel disappointed she encouraged me and give me good company to erase the memories related to HIV. I was very guilty because she was infected with me but she didn't mention this ever (Male participant, HIV Concordant Couple#17).

There was divergent behavior reported by every HIV participant based on gender when his/her life partner discloses their HIV status at first. There are different reactions reported into the accounts such as HIV disclosure issue, acceptance of life partner, the safety of marital relationship, compromise with a partner, Divergent response to counseling based on gender. Usually, women compromise their husband and supported him but the husband did not. The counselor shares his experience as:

It was a very difficult task to provide guidance to husband about their wife's HIV status. They did not accept this easily and a majority of the males separate their ways from their wives because of HIV although, she was a victim not a culprit (Female participant, HIV Consultant#02)

It was obvious from the narratives of HIV female participants that discrimination against women with HIV/AIDS is a common thing in other parts of the world. Women with HIV/AIDS feel rejected by closest people such as husbands, family members, and coworkers. All these people see women who have been affected by HIV/AIDS as a person who has a curse in their families. This makes women with HIV/AIDS to be lonely and discouraged because of bad treatment from people who had a good relationship. This discourages them and the situation can affect their mental health and may lead to early death but in Pakistan mostly women were supported by their families. A female participant shared her views related to gender discrimination: "My In-laws came across about the condition of my health. They also know I was affected due to my Husband but they still cursed me"(Female participant, HIV Concordant Couple#04)

I have explored that most of the women disclose their status they tend to be ostracized and are left alone with the children or sometimes with no family at all. This makes many women with HIV/AIDS left helpless with no support from other family members or the entire community.

2.3.2. Spiritual life world

The spiritual life world is connected with the Allah through positive and life transforming activities. Religion is considered a significant coping scheme to combat any difficulty of life. Individuals diagnosed with HIV utilized religion and spirituality to get rid of the miseries of life that are associated with HIV status. HIV individuals were thinking that disease is a kind of trial from Allah from us, so offering prayer will relieve them from the pain and sufferings of life. Some individuals tried to ask forgiveness for their bad deeds which they have done in the

past resulted in HIV in the reward of these deeds. One female informant shared her spiritual thought as:

A person should not be desperate by Allah. If Allah has done it enough like we can utilize precautions and medicines to live a normal life. One day will come when we will get rid of this disease as like other by the blessings of Allah who give a trail for their man (Female participant, HIV Concordant Couple#15)

Another female participant expressed her account as: “Whenever I become worried, I remember Allah and recite Quran and thought it is to be better (Female participant, HIV Concordant Couple#11)

One male participant became religious after the diagnosis of HIV and shared his narrative as:

I want to come close to Allah through offering prayers and by participating in religious activities because I need forgiveness from Allah for my bad deeds whereas I was not religious as nowadays. I felt contented and peace from offering the prayers” (Male participant, HIV Concordant Couple#16)

Most of the key informants were involved in spiritual tasks to attain satisfaction and happiness. One of the female key informants said:

Everyone needs to be careful so we can be safe from this disease. Sometimes it is a test from Allah for his brave people. You should remain resolute and stop complaining to Allah for their misery. Life met one time and everyone confronted various issues so, keep calm and try to overcome the fears and challenges with the help of family and friends (Female participant, HIV Concordant Couple#05)

This kind of thinking connect the HIV individuals with the society. It helps to search the meaning of life. Mostly HIV concordant couples spend their life to disseminate the awareness among the members of the society. The individual who was suffering from HIV has a moral duty to disclose their status before marriage and after marriage, he/she should share HIV positive status with a partner to reduce the risk of HIV propagation. In addition, they also inform family and friends who were close to them. One female participant shared her narratives:

My son was an HIV carrier because of my first husband’s negligence. When I will look at the bride for her son I will tell them about the HIV because I have already tolerated this pain so, I don’t want for anyone else (Female participant, HIV Concordant Couple#02).

The majority of female participants felt their personal and moral duty to save the lives of others because they bear the pain of deceiving. They want to socialize their children with good manners and habits. HIV individuals and counselors were considered HIV tests essential before marriage. This action can save the lives of many innocent girls who become prey to HIV after marriage with an HIV individual.

Theme 3: Normalization of life world

I have presented the normalization of the life world with reference to the lived experiences of the HIV concordant couples. The stratification of the life world collectively incorporated all spheres of the life world to promote the final destination of the life world that is the normalization of life world. People living with HIV tried to attained life normalcy with chronic illness by utilizing various coping strategies and with social support. Individuals attempted to deal with HIV as normal which was a good strategy for the management of illness. Normalization is a stance to analyze and interpret diseased people's adjustment and make them compatible to normalize their daily life activities by using proper medicine, maintain proper diet and surroundings. HIV concordant couples utilized this strategy to incorporate themselves in society again after the HIV trauma by parenting and being a good life partner. HIV concordant couples used different strategies for social incorporation by participating in the awareness program and planning a future for their children. One male participant shared his experience as

AIDs name is dangerous but actually, it was not very bad as people think about it. I am healthy and stable because I have a strong diet and did not take any mental and physical pressure. I have mistakenly acquired this disease so I never gave up and tried to fight with this disease. I never heard about this disease, we used to watch an advertisement on television and did not understand about it. Got to know from people that you get it from the used syringe and extra marital affairs. You should keep yourself away from this disease not from the person. Otherwise, that person can be depressed. People should be careful about especially at the time of blood transfusion. Initially, the disease affected a lot but after counseling, I revive myself in life (Male participant, HIV Concordant Couple#13)

One male participant told about the membership of an NGO as:

I became a member of an NGO for the awareness of the people regarding HIV. I felt comfortable and peaceful after giving the awareness sessions to the community. This activity has helped me a lot to cope up with the suffering of HIV. Awareness is very important for youngsters; this disease will be only controlled if you were aware of them via using social media platform (Male participant, HIV Concordant Couple#03)

Social media is considered a significant source of awareness by creating a Facebook page related to HIV where HIV infected individuals share their anonym's stories for the awareness of the community and also maintaining their confidentiality.

One male key informant stated as:

I have a wish to educate my son and become a well-mannered person. I have planned to give him both religious and formal education and become a doctor who helps the individual and involved in social welfare activities for HIV individual (Male participant, HIV Concordant Couple#06)

Most of the participants have a desire to make their children educated and self-sufficient. HIV being achieved life normalcy by planning the future of their children and family.

Discussion

The field data revealed the two domains of the life world that experience the HIV participants. Initially, the physical and psychological experiences of HIV concordant couples refers as the natural attitude of the life world. The second domain that experienced by HIV concordant couples fragmented in to lived space, lived time and shared intersubjective reality. Firstly, HIV concordant couples were cognizant of the space they lived in and explained it as either friendly or neglected. Secondly, HIV concordant couples elaborated the time which they assume after the diagnosis of HIV. Thirdly, shared reality experienced by HIV concordant couples in relation to other human beings who share the same space with HIV concordant couples inhibited in the social world.

Schutz and Luckmann (1973) described as, the normal reality of the life world contains not only the phenomena of interest (experiential reality) but it also have the social world around the being. The life world is not constructed by the material objects. They are used in the transformation of natural things into cultural beings, human beings into companion, and the engagement of companions into acts and communication.

Wella (2015) discussed the lifeworld of the HIV discordant Couples and explained the lifeworld by using Max Vanen's phenomenological approach. While I have used Alfred Schutz's social phenomenology to interpret the life world of HIV concordant couples. I have explored and added three aspects of the lifeworld as gendered life world, spiritual life world, and normalization of the lifeworld in the domain of the stratification of the lifeworld by using the narratives and interpretation of the field data (Section 4.2.4, 4.2.5 & 4.2.6). These proposed life worlds presented the consolidated picture of the lifeworld in the context of HIV concordant couples.

As a result, the lived experiences of the HIV concordant couples have been presented in the two domains of the life world. This chapter described the two domains of life world by the

accounts of the participants and I have suggested three aspects of the life world as gendered life world, spiritual life world and normalization of the life world in the domain of the stratification of the life world by using the narratives and interpretation of the field data. This proposed life world presented the consolidated picture of the life world.

Conclusion

In conclude, the research study highlights the challenges faced by HIV concordant couples in their marital and family life. The study delves into the experiences of these couples and sheds light on the broader social implications of living with HIV. As a researcher, I have analyzed field data to uncover the true essence of life for HIV concordant couples and their aspirations for their children. These couples strive to overcome the stigma associated with HIV and raise their children to be educated and well-mannered individuals. They challenge societal biases and view themselves as messengers of awareness about HIV, rather than as cursed individuals. With a positive attitude, HIV couples have been able to transform their own lives and those around them with the support of social and healthcare services. I have discussed the life world of the HIV concordant couple by the help of Alfred Schutz's two domains of social phenomenology through the field narratives gathered from HIV concordant couples. The researchers have suggested three further domains in the stratification of social reality to give the consolidated description of the life world. In the words of Nelson Mandela, "Give a child love, laughter, and peace, not AIDS." HIV concordant couples can embrace this philosophy and lead normal, happy lives without fear. It is never too late to make a difference in the world, so be the first drop of rain in your life to help others avoid HIV.

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