

ORIGINAL CONTRIBUTION

Causes and Repercussions of HIV among Seroconcordant Couples in Pakistan

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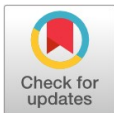
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Abstract— HIV/AIDS was originated as an epidemic from twenty century in Pakistan. At present, approximately 240,000 individuals have been estimated living with HIV in Pakistan. The current research paper aimed to study the reasons behind the HIV among married couples and investigate the consequences of HIV faced by couples after revealing their HIV status. The present research has utilized social phenomenology by Alfred Schutz (1932) and looking glass self by Cooley (1902). The present research employed phenomenology as qualitative research design. The purposive sampling technique has been utilized to select 15 HIV couples from PIMS Hospital treatment center. The researcher has utilized an in-depth interview guide as a tool to collect the data from the field. Thematic analysis was utilized to interpret the interviews of the participants. The researchers have considered only two themes such as, dynamics of HIV propagation and repercussions of HIV Disclosure. This research will contribute in Academia in this regard as there no study was conducted on the issues and challenges of HIV concordant couples within the Pakistani society. So this research have highlighted the cause and consequence of HIV in couples. Furthermore, HIV individuals needs the social vaccine for their stable social standing.

Index Terms— International migration, Iatrogenic transmission, Dynamics of health, Loss of social circle, Backlash of in laws

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Introduction

HIV virus attack on the immune system and reduce the resistance of the human body (Majonga et al., 2018). The first patient was diagnosed with HIV in 1987 due to contaminated blood transfusion. Now 2, 40,000 people living with HIV (NACP, 2021). Now Pakistan is the second prominent HIV infected country of the South Asia (Ilyas et. al, 2011: UNAIDS, 2020). Shah et al. (2004) described that the individuals settled in foreign countries posed a risk for HIV propagation because approximately seventy percent of HIV positive cases were deported from the Gulf countries in 1986-1992. The indigenous HIV transmission was initiated with 1st HIV outbreak in Larkana, Sindh through IDU in 2004. Rai et al (2007) indicated that Pakistan was considered safe from indigenous HIV propagation almost two decades. The highest rate of HIV key population is registered in Pakistan among all the countries situated in the region of Asia (Wahid, 2019).

It is an alarming number of HIV propagation through male spouse to female and their children which enhance the vulnerability of HIV across the world and specifically in South Asian region because of international migration. Nowadays, HIV is transferred from

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HIV positive drug users to female spouses and preadolescents via vertical transmission. (Ahmed, Hashmi, and Khan, 2019; Iversen et al., 2021); Docquier, Vasilakis, and Munsu, 2014; Raees et al., 2013). Another noticeable factor of HIV propagation in Pakistan is the quacks, unprofessional doctors, and vulnerable medical practices. People approach quacks and unprofessional doctors due to the lack of awareness and unavailability of qualified doctors which leads to HIV dissemination (Wahid, 2019).

HIV/AIDS is an epidemically increasing disease and a challenge for Pakistan. People feel ashamed due to this disease because there is a common perception that HIV resulted from unsafe sex practices. Individuals having AIDS hide their status from others for the sake of self-respect and take treatment of HIV by using the names of different diseases that were not morally understood wrong like diabetes, hepatitis and stomach problems. Being an Islamic State, Pakistan has a high context culture. Those individuals who have HIV faced the problem like loss of face and experience discrimination in family and society. The disclosure of HIV status also leads the person to deprive of the marital status for unmarried and if he/she is married then experiences complexities in their marital relationship.

Thapa and Yang (2018) describe that knowledge about HIV positive was a very critical experience when individual proceeds for treatment and blood tests in a hospital because of self or family sickness. Individuals who were receiving the HIV positive results from the blood test is not acceptable in the society. This situation was very traumatic and it's hard to unveil this bitter reality to companions, family, and sexual partners. Numerous people experience issues of revealing their positive status to their sexual life partner and family. Despite the fact that HIV exposure has recover their physical and psychological wellbeing (Saki, Kermanshahi, Mohammadi, and Mohraz, 2015).

Family bonding is not disturbed, and family members are usually supportive in case of HIV disclosure but in some cases, couples feel isolated and stigmatized by their families. Many couples are afraid to disclose their HIV status because they lose their social circle and how can they bear the social isolation (Singh, Azuine, and Siahpush, 2013; Kontomanolis, Michalopoulos, Gkasdaris, and Fasoulakis, 2017). Many people encounter hurdles to gain a good job with HIV. They cannot acquire the support of bosses and colleagues in the workplace in case of HIV disclosure, so they prefer not to reveal their status in the workplace. In-laws were not supportive in case of wife's HIV disclosure, they blame their daughter-in-law for their son's HIV status (Psomas et.al, 2018; Saki, Kermanshahi, Mohammadi, and Mohraz, 2015; Lua, Mustapha, Abdullah, and Rahman, 2014; Taraphdar et.al, 2011).

Many people think that it is a dangerous disease now they are dying in the next moment of their life. Many people are feeling anxiety and depression when they know their HIV status. In couples, many individuals encountered mood swings, so they did not feel happy and contented. The emotional and psychological stress among HIV beings such as fear of social exclusion and disappointing feelings about life. HIV individuals confronted psychological problems like depression, hopelessness, anxiety, self-destructive behavior, and fear of disclosure (Ramovha, Khoza, Lebeso, & Shilubane, 2011; Mahlasera, 2020). The current research paper aimed to study the reasons behind the HIV among married couples and investigate the consequences of HIV faced by couples after revealing their HIV status.

Theoretical Framework

The present research paper utilized the looking glass self theory by Cooley (1902) and social phenomenology theory by Schutz (1932) to explain the lived experience of HIV concordant couples in the context of Pakistani society. The social interaction of HIV couples with their significant others like family and friends shapes their self-image. Social phenomenology focused on lived experiences of individuals. The notion of self-image ultimately transformed everyday experiences and life world of HIV concordant couples. The following figure elaborate the theoretical framework of the study.

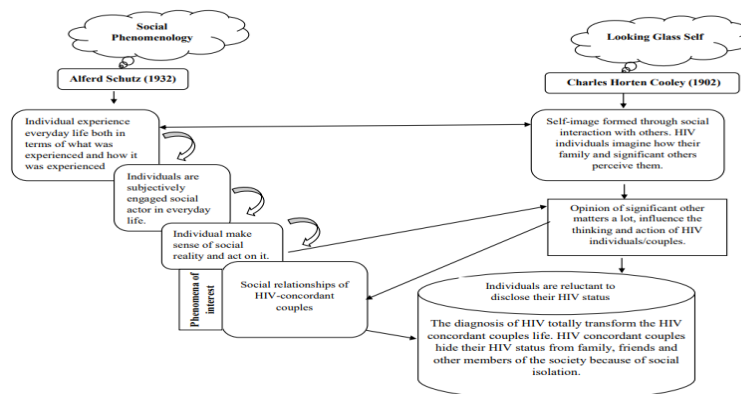


Fig. 1. Theoretical framework

Research Methods & Materials

The present research employed phenomenological qualitative research design to explore this phenomenon. We have chosen 15 HIV couples from the HIV center of PIMS, Islamabad via purposive sampling. The researchers have included the HIV participants from the Province of Punjab and who were diagnosed HIV in last 10 years. We have interpreted the field data by using the technique of thematic analysis. The researchers have used MC # (Married Couple Number) to sustain the confidentiality of the participants.

Results

The researchers have considered only two themes such as dynamics of HIV propagation and repercussions of HIV Disclosure.

Dynamics of HIV propagation

The current research explored the most prominent factors of HIV dissemination among couples. For instance, globalization, international migration, unprofessional doctors, quacks, unscreened blood, unsterilized equipment, drug use, husband to wife and vice versa, and mother to child.

Globalization & international migration

The vital ingredient of globalization is the international migration that is the major cause of HIV propagation. Sexual activities were the major contributors to transmitting HIV infection. The individuals who were far away from their families for the sake of jobs in foreign countries felt emotional imbalance so they were involved in illicit activities (Docquier, Vasilakis, Munsi, 2014). One of the male participants told that:

I have multiple sexual relationships with other girls because there were no ethical and legal restrictions here. My family was living in Pakistan so, I have the choice to make in an illicit physical relationship with many girls having the same face texture and color (MC # 10).

Another male participant said: I went to the hospital for a checkup because of illness then I came to know I was suffering from HIV. I was regretful for my involvement in illicit activities for fun and enjoyment. These deeds cursed me with HIV that infected my life partner and family as well (MC # 06).

In crux, the male life partner who were working in the foreign countries for the sake of livelihood, they acquire HIV virus because of sexual contact with other women to satisfy their sexual needs in the absence of family. The enjoyment for a while resulted lifetime chronic self-illness and also transmitted to the family due to the ignorance.

Direct and vertical transmission of HIV

HIV infection directly transfers to the body of an individual through unsafe sexual contact, contaminated syringes, unscreened blood, sharing infected needles for drug use, and transfusion of blood and plasma. Drug usage due to infected needles leads to HIV dissemination and vertical transmission of HIV is also a contributing factor in the propagation of AIDS. Sometimes sexual involvement of male partners with other females destroyed the upcoming generation in case of mother to child transmission (Ahmad et al., 2011). Lack of knowledge about disease infected the child during pregnancy. One of the female participants shared his narrative:

My deceased husband was a drug addicted and share syringes with others during the use of the drugs. I didn't know as he was suffering from Aids. I came to know this reality when I gave birth to a son and he was also HIV (MC # 02)

Knowledge on HIV/AIDS is highly needed for women in order to prevent further infections to other people and their children during birth. Another female participant shared her experience related to vertical transmission of HIV:

My daughter was HIV positive because of I was unaware of positive HIV status of myself and my husband. But after a few months ago, she was dead because of multiple health issues. My husband and in laws condemn me that you were responsible for her death because you did not care for her well (MC # 08)

Loyalty is an important element of healthy married life but in some cases, males have multiple relationships with another female which leads to HIV. Every religion especially Islam restricted sexual relationships with others except his wife but individuals allure illicit activities that were harmful for the whole generation. One of my female participants told that "I become the victim of HIV because of my disloyal husband who have a sexual relationship with multiple witches (MC # 05)

Another male participant said:

When I went through the process of visa renewal then I came across this fact I was HIV positive so, my company fired and deported me. It was a very bad moment of my life then I realized my deeds which made me HIV positive and my wife was also a victim because of me. I felt guilty because of her situation (MC # 09).

One male participant shared his painful experience as “I was infected with HIV from dental surgery and my wife was dupe with HIV because of me” (MC # 10). Similarly, few cases were reported in which husbands were infected with HIV because of their wives. Usually, it was observed that females became the prey of iatrogenic transmission which were considered responsible for husband and child HIV infected status. One female shared her narrative in these lines:

I was so ill and unable to walk properly after my surgery. I have visited to the hospital for treatment but the doctor admitted me and prescribe a blood test of both husband and wife. The reports revealed that we both suffered from HIV infection. The stage of my HIV is 2nd and my husband have on the 1st stage. I often felt disappointed as my husband was suffering from AIDS because of me. I think after giving birth to my first child through surgery, I was suffered from this disease (MC # 11)

We have indicated the both life partners were experiencing their painful memories related to the transmission of HIV whereas they have not done anything wrong and illicit with the help of participant’s accounts. They were the victim of risky health care practices.

Iatrogenic transmission

The researcher explored the most noticeable factor of HIV propagation in Pakistan is the quacks, unprofessional doctors, and vulnerable medical practices. HIV propagation among couples enhanced day by day in Pakistan because of unsafe health care practices and unprofessional doctors. One Male participant shared his experience in which he blamed an unprofessional doctor for their wife’s HIV status:

I was diagnosed with HIV eight years ago. I was worried about the treatment of the disease because I heard that HIV was an incurable disease. I did search for a doctor who claimed to treat HIV individuals. I have visited the doctor for a checkup. He has recommended blood tests and gave medicine which I have used for almost 6 years but my condition was not improved. My wife also suffering from different health issues. When I have consulted another doctor, he told me your wife was also infected because you did not use precautions. I cursed that fake doctor who did not suggest me any precautions and proper medicine. Now we are taking medicine from PIMS and have a child who is HIV negative (MC # 08).

Many people propagated HIV to their life partners and children because of quacks and unprofessional doctors who treated them just for making money, not for their respective disease patterns. Doctors who were not trained and depredating most of the people because of their lack of knowledge about the disease. Subsequently another important factors to induced HIV in innocent individuals by utilizing septic instruments and unsterilized blood transfusion in both public and private hospitals during surgeries. The surgeons and doctors did not recommend HIV tests before surgery which leads to the increasing number of HIV victims in Pakistan (Khan, Altaf, & Orakzai, 2020). The negligence of administration and medical staff replicating HIV in most of the impeccable persons. Four cases were reported who was became the prey of unprofessional doctors and medical staff during the different surgeries such as dental, cesarian, and appendectomy. One female participant shares her views:

I was suffering from high fever and weight loss after the removal of appendix through surgery. I did not take it seriously because I was thinking it’s the after effects of an appendectomy. After one month, my condition was serious and my family was advised to go for a checkup. My doctor recommended blood tests before any treatment. My blood report revealed that I was infected with HIV/AIDS. This news was shocking for me because I did not do anything wrong then how could be possible this. My HIV counselor told me it was supposed to be possible because of the use of unsterilized instruments during the surgery (MC # 11).

Another experience of male participant related to dental surgery:

I have a severe toothache so I went through a dental surgery because of my defective teeth in 2015 from a government hospital. I have been confronted with diarrhea and stomach issues after the surgery. My wife was worried about my health so she took me to a hospital where I have gone through lab tests then I got to know that I am HIV positive which was very shocking for me and my family as well (MC # 10).

One female participant shared her experience in these narratives:

I was pregnant in 2013 and confronted with complications so my doctor opted cesarian for the safe delivery at her clinic. But I have noticed that my doctor and medical staff did not take any safety measures during the operation. I was continuously suffering from fever and pain. My family took me to hospital after a few months because of my condition then I came to know my HIV infected status (MC # 04).

We have found that most of the women and men were infected with HIV because of the use of septic instruments. The utilization of unsterilized medical equipment and needles leads to HIV in Pakistan. Unsterilized blood transfusion was the major factor of direct transmission of HIV with infected needles during surgeries and treating the patients in both public and private hospitals/clinics through unprofessional doctors and medical staff. One female shared her experience: “I was infected with HIV/AIDS due to unsafe blood transfusion during surgery, I think after giving birth to my first child through surgery” (MC # 04)

One of the male participants shared his experience in these words: I was habitual of donating blood every year but when I came across with roadside accident. The doctor transfused blood because of heavy blood loss. After six months I went to donate my blood for

my sister in hospital but they took my blood sample and said you were HIV positive so you cannot give your blood and refer me to PIMS for treatment. It's shocking for me how I get HIV whereas I didn't do anything wrong in life (MC # 01)

One of the male participants shared his experience related to this serious matter: "I have a hemophilia disease since my childhood. I had been infected with HIV during blood transfusion in a hospital" (Male participant, HIV Concordant Couple # 02). We have identified that blood transfusion screening kits and the prominent number of professional blood benefactors lead to HIV infection to the individuals in Pakistan through the descriptions of HIV participants' accounts.

Repercussions of HIV disclosure

The disclosure of HIV/Aids has both positive and negative outcomes for individuals who were experiencing HIV. The participant's narratives helped the researcher to dig out the aftereffect of HIV disclosure. The researcher was splitting this main theme into two subthemes for better elaboration and understanding of positive and negative outcomes of HIV disclosure.

Costs of revealing HIV status

In the current research, most of the participants indicated the various deleterious consequences of the revelation of HIV status such as personal, familial, social, psychological, and medical concerns. The cost of revealing HIV is more than the benefits reported by key informants in their narratives. Now, the researcher was discussing the costs of HIV disclosure under the several headings one by one and also add previous literature for the truthfulness of field data.

Dynamics of health: Individuals' encountered different patterns of health seeking behavior throughout life because of HIV such as regular hospital visits, medication, take precautions, financial burden and manage illness as a parent. These health essentials reminded HIV infected individuals that they were not normal and healthy people like others. They were compelled to regularly visit a hospital, follow the doctor's directions properly, and taking regular medicine if, HIV beings were restoring their health. Sometimes HIV infected persons got irritated to continuously taking medicine and visiting the hospital and also bear the financial burden because of visits and treatment. One male shared their experience in these words:

I was tensed and annoyed to visits of the hospital and taking medicines. I always feel that I am not healthy. HIV increased my financial burden related to attaining medical access from remote areas of Punjab. We were staying in a hotel for the night when I went to Islamabad with my wife for a checkup and taking ARV medicine. It was quite expensive and my daughter was also disturbed because of our absence (MC # 07).

One female participant said:

My family did not afford my son's medical expenditures and the cost of regular visits in a hospital after the death of my first husband. I was very worried about the self and my son's condition. The counselor from the hospital offered 2nd marriage proposal from another HIV individual. I had accepted this proposal because he accepted my 1st son's responsibility like a father" (MC # 02).

We have found that most participants were confronting the dynamics of health and few participants were experiencing the financial burden because of remote areas and not having enough source of income to bear the medical expenditures. Doctors and counselors have supported HIV individuals medically and financially with the help of some wealthy benefactors.

Attitude of family: HIV individuals felt that HIV disclosure affects their family bond and relationship. They have fear of being isolated by family members and experienced avoidance of being a burden on the family. The fear of HIV dissemination apart the families from the person who has AIDS. Close relations were very cautious about the diseased person and did not mingle with him/her because of fear and shame. One of the male participants shares his family reaction when they came to know their HIV status: "My family used to eat together but when I told them that I am HIV positive this habit stopped completely. It was disappointing me from life" (MC # 02). HIV/AIDS may be perceived as disgracing the name of the family in the community lead fluidity and dynamism in family relationships.

In the next narrative one of the female participants regarding family reaction about her HIV status:

I was a widow and living with my mother after the death of my first husband. I was so confused and scared when I was diagnosed as HIV positive. I used to separate my things but my family supports me. My brother and his wife knew that this disease transferred from my husband. That's why no one has ever mocked me. My family supports me a lot even they don't make me realize that I am suffering from this bad disease (MC # 01).

It was commonly observed that females disclose their HIV status in front of her husband and family because they need support from them but male were reluctant to disclose their HIV status because they were feeling that their family bonding becomes weak and they will experience social isolation among their family members. In the current research, few participants have experienced cold behavior from their families but most participants felt that their family bonding enhanced and they were acquiring social support from their family members. It was a positive outcome of HIV disclosure.

Backlash of husband's family or in-laws: Couples living with HIV/AIDS had difficult lives. Their plans were not going well because they were not healthy. All in all, women suffer more than men and despite the sickness, family matters must continue as usual. Due to

this situation, women are severely impacted by HIV/AIDS compared to men. Patient with HIV/AIDS passes through different challenges in their daily lives they face discriminatory attitudes, lack of moral support, fear to lose relationships.

One female participant expressed her experience in these words:

My mother and sister in law have set a line in the courtyard of the house to ensure me and my children that you were not a part of our family. If my children cross the line, she scolded them badly. So, my husband has decided to leave the house because of their cold behavior (MC # 02).

We have found that few participants have experienced bitter reactions from their in-laws. The local cultural beliefs and explanations about disease were immoral or improper behavior was responsible for a person's illness (Aggleton, 2003). We have to consider the contributing causes of the disease. HIV status may be reinforcing preexisting stigma considered as a result of being deviant. It was observed that many couples faced discrimination from their family and in-laws in the hard time of their life when they needed them most.

Loss of social circle: Individuals living with HIV face unpleasant response when they reveal their status in family and friends. It is a misinterpretation about the HIV dissemination through touch, food sharing and greeting. One of male HIV participant shared his experience as; "I want to spend my time with my companions to reduce my stress but they were hesitant to warmly greet me. It's a humiliating behavior for me so, I have decided not to unveil my HIV status to anybody" (MC # 04).

HIV status has changed the behavior of peers that was astonishing for HIV individuals since they didn't anticipate this from them. They think they have offered passionate help to recuperate from this hard period of life however Alas! HIV individuals further go to the phase of self-hardship and social isolation because of the demeanor of their close ones (Ogbozor, 2016).

Loss of job: Individuals were scared to disclose their HIV status because of loss of job. Some individuals experienced stigma, discrimination, and social isolation in the workplace by their colleagues and boss. (Utuk et al., 2017) They have decided not to reveal their HIV status because to escape from the feelings of shame, guilt, stigma, and discrimination, etc. One male participant shared his experience:

I have been working as an electrician in Saudi Arabia since 2015. My friend came across with accident and have lost blood. I went to the hospital for donating blood to save the life of my friend. The doctor was averting me to donate the blood because I have diagnosed with HIV after blood tests. When this information was revealed in my company. They expel me and were deported me from the country. Now I was doing own business to earn money for my family (MC # 13).

Most of the participants were reluctant to do any job because of their HIV status and scared of the stigma related to this disease. If some individuals were doing jobs, they preferred not to disclose their HIV status in office and among colleagues. It was difficult for patients to bear the expenditures of treatment and runs their families smoothly with worse socioeconomic conditions.

Psychological consequences: HIV individuals encountered several psychological and emotional repercussions after revealing their HIV status. Most participants reported their issues such as depression, loss of appetite, migraine, mood swings, the uncertainty of life, question of life and death, etc. one female participant said:

I was crying all the time when I knew about my HIV status. I was very upset and tensed. I was thinking that my life has finished and I will die in a few days because of HIV but my counselor told me that's ridiculous you will live a long life dearly and will enjoy all the happiness of life. This is not the end of life but I did not accept this (MC # 08).

One male participant shared his narratives:

I did not sleep several nights because I always thinking about my disease how it was transferred to my body. Still three years past but I did not escape from the trauma of being an HIV. My counselors guided me a lot but it was useless. When my wife tried a lot to give me a company to reduce my anxiety and depression but she failed. I regretted it because I was responsible for my wife's HIV status. I gifted her a curse in the form of HIV that spoiled my next generations (MC # 07).

We have found that the psychological issues confronted by HIV individuals because of the absence of care, support, acknowledgment from friends, family, and health care professionals. Family and friends' support were considered significant to minimize the stresses in one way and provision psychological, emotional, and social stability to the HIV beings.

Gains of HIV disclosure

The disclosure of HIV status brings gains along with the costs. The key informants discussed that their disclosure benefitted them in this manner such as their family intimacy and support was enhanced. HIV individuals discussed the restoration of self-worth and get rid of rejection. They took a sense of relief because they were not considered untouchables and the tag of immoral beings. The self-concept of the HIV beings was developed and creates the courage to fight against HIV stigmatization and discrimination. Individuals were feeling that disclosure connected and strengthen their relationship with their family, life partner, and friends. One male participant shared his experience:

My wife paid more attention after the disclosure of HIV status. She takes care of everything. She went along with me for a checkup and inquired about my condition from a doctor. I was blessed with such a nice life partner (MC # 15).

One male participant said:

My family loves me a lot and their love and care enhanced after the HIV disclosure. When I was upset and got irritated. They were understanding my condition and cheered me up" (MC # 07). We have interpreted from the interviews of the participants that family support minimized the pain of HIV and give HIV individuals' confidence and reaffirmed their sense of self. They indicated the positive outcomes of HIV disclosure which facilitated individuals to reveals their HIV status without any guilt and shame. The acceptance of a mistake was a courageous act so promote it and support the HIV individuals to restore their self-worth by overcoming the stigma associated with HIV.

Conclusion

This research paper elaborated the reasons behind the HIV propagation among HIV concordant couples. The globalization, international migration, drug users and precarious practices of quacks and doctors are responsible for the increased prevalence of HIV across the Pakistan. The knowledge of HIV revealed through self-illness, partner illness and family illness. People with HIV infection had to deal with many difficulties for surviving. Individuals hide their HIV status from family and friends because of social isolation. They fight with numerous health issue with the social pressure of stigma and discrimination. The current research discussed the both cost and benefits of HIV disclosure among HIV concordant couples. To sum up, it is an essential to focus on the health and social empowerment of HIV couples for their life normalcy. There are few limitations of the current study such as the sample size was small and confined to the sero-concordant couples who were registered in PIMS hospital, Islamabad. The number of suggestions by HIV individuals, couples, and consultants as the government took initiative for HIV infected individuals and couples to pass any law to upright the status of HIV couples and families to minimize the social stigma and discrimination. Government should provide financial assistance and loans to HIV couples for their business. So, they enjoy a quality life with family. Electronic and social media take the initiative for the awareness of society regarding HIV and support the HIV individual and couples to revive their life on a normal track by socially integrating them into society as a normal being.

Future Research Directions

These future implications for the researcher are as a quantitative research study should be conducted on the issues of HIV couples and children. Comparative research should be conducted on the concordant and discordant couples having children. The researcher should investigate the issues of left behind families after the death of a husband because of HIV. The future researcher should find the gender based stigmatization of HIV.

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