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Gender Inequality as a Barrier to Utilization of Services in Mother to Child Transmission of HIV/AIDS in Pakistan

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Abstract: *This study examines gender inequality as a barrier to utilization of services in mother to child transmission of HIV/AIDS in Pakistan. The study uses a feminist approach to explore the barriers related to gender inequality during the uptake of HIV treatment. The data was collected from 26 medical practitioners and 10 HIV positive mothers through in-depth interviews. HIV positive mothers were found to have experienced discrimination in their treatment, difficulty in travelling from far off areas to the special clinics, and they expressed having the least family support as HIV patients. They also experienced inequality in terms of the use of ARV prophylaxis, autonomy in reproductive choices, sexual priorities, disclosure, stigma, agency and intimate partner violence. Furthermore, they emphasized the need for sensitization and counseling of male spouses. The study concludes that the gender inequality grossly affects the uptake of HIV treatment among HIV positive mothers. It is thus recommended that there is a need to incorporate gender inclusive policy and practice to eliminate the vertical transmission of HIV in Pakistan.*

Key Words: Gender Inequality, HIV/AIDS, Mother to Child Transmission, ART, VCCT

Introduction

HIV/AIDS has become a global health threat. Statistics indicate that in 2020, 37.7 million people were living with HIV globally, out of which, 53% were women of reproductive age and thus increasing the possibility of vertical transmission of HIV (UNAIDS, 2020). Resultantly, 1.7 million children were reported HIV positive between 0-14 years of age (UNAIDS, 2020). According to the World Health Organization (WHO), HIV has become a leading cause of death among women of reproductive age (Nyamhanga et al., 2017). It is reported that after African countries, South Asia has the second-highest number of people living with HIV/AIDS (Sia et al., 2016). It is important to mention that the gender disparities are more prevalent in middle and low-income countries, i.e., South Asia including Pakistan, than the developed countries of the world (Duffy, 2005; Guide, 2010; Richardson et al., 2014; Sa & Larsen, 2008).

Initially, HIV prevailed more amongst men, but it has become progressively feminized (Turmen, 2003). Due to this, the estimated number of children who are HIV positive as a result of vertical transmission is 4000 in the province of Punjab in Pakistan. Despite the efforts by the Government of Pakistan to eliminate mother-to-child transmission of HIV, only 150 children were delivered HIV-negative in 2020. Mother-to-child transmission of HIV accounts for 90% of new infections among children, and prevention requires early diagnosis, treatment and care (Qazi, 2019). In order to prevent the mother-to-child transmission of HIV, 11 PMTCT centers were established in Punjab. Later on, PMTCT was renamed as Prevention of Parent to Child Transmission (PPTCT) of HIV to reflect the shared responsibility of both spouses (Khan, 2017). Despite concentrated efforts, MTCT is still on the rise due to the disadvantaged position of women in society, which discourages the uptake of treatment (Mbonu et al., 2010; Saeed & Farooq, 2017).

The effects of gender inequality on the spread of HIV have been acknowledged globally (WHO, 2009). Thus, to eliminate this inequality, international organizations are now focusing on gender in HIV/AIDS programs (WHO, 2009). Many international declarations, including the 1994 Program of Action, the International Conference on Population and Development (ICPD), the 1995 Beijing Declaration for Action and Stage, and the Fourth World Conference on Women (FWCW), call for recognition of the prevalent gender disparities as well as the implementation of strategies to empower

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women and the fulfillment of their sexual and reproductive rights. The United Nations General Assembly's (2001 and 2006) commitment to HIV/AIDS strongly emphasizes the need for governments to combat gender inequality as a primary cause of the epidemics. The UN also aims to accomplish the Sustainable Development Goals (SDGs) of preventing and reversing the spread of HIV/AIDS by 2030 by providing universal access to HIV/AIDS prevention, treatment, and care (Ghanotakis et al., 2012).

Besides economic dependence, unequal power relations among both genders and the subservient position of women contribute to the growing prevalence of HIV among women (Pulerwitz et al., 2002; Mbonu et al., 2010; Strebel et al., 2006). Moreover, cultural practices of early marriage of girl child with older partners, who may already be HIV infected, limit the women's negotiating power for protective sex (Bruce & Clark, 2004). In addition, violence against women is prevalent in societies, and social norms permit physical and sexual violence against women (García-Moreno et al., 2005). Worldwide, between 29% to 62% of women experience intimate partner violence, including sexual violence (Sa & Larsen, 2008). Sexual violence can contribute to an increased risk of HIV transmission. Physical violence or its fear hinders the women from making choices regarding their bodies or refusing unwanted or unsafe sex (Decker et al., 2009; Jewkes et al., 2011). Some women may also experience violence as a result of disclosing their HIV-positive status (Sadati et al., 2019). Thus, a behavioral approach must be adopted to combat HIV, including women's economic empowerment and elimination of gender-based violence (Sa & Larsen, 2008). Violence against women has the worst implications for the spread of HIV/AIDS (Jewkes et al., 2011). The prevailing norms related to masculinity also encourage men to adopt risk-taking sexual behaviors, have multiple sexual partners, and have sexual relations with women often much younger than them (Greig et al., 2008). In contrast, the norms related to femininity limit the sexual and reproductive choices of women. This requires an analysis of the traditional gender roles and socialization, leading to unequal power dynamics in sexual practices (Campbell, 1995; Theobald et al., 2009; WHO, 2011; Yourkavitch et al., 2018).

Arguably, gender disparities in HIV/AIDS exist due to variability of risk factors and susceptibility among men and women. Women, for instance, may be more susceptible to HIV infection due to their lower socioeconomic status (Piot, 2008; Gillespie, 2008; Beegle & Özler, 2006). Women are far more likely than their men counterparts to be illiterate, jobless, and impoverished, making them more prone to transactional sexual encounters (Mojola, 2011). Although there is increasing recognition for eliminating gender inequality to combat HIV/AIDS, gender blindness and social and structural mechanisms that give rise to these disparities are poorly understood (Bruyn et al., 1995). Having discussed this, the present study attempts to explore the gender inequality related barriers among HIV positive mothers during the uptake of mother-to-child transmission of HIV/AIDS treatment.

Methodology

Research Design and Data Collection

The current study is qualitative in nature and uses a feminist approach to explore the experiences of HIV positive mothers regarding the gender inequality during the uptake of mother to child transmission of HIV/AIDS treatment. The study was conducted in Punjab, the largest province of Pakistan in terms of population. For the selection of HIV-positive mothers, one health facility located in Services Hospital in Lahore was selected purposefully. This health facility is equipped with all the advanced facilities in the provision of HIV/AIDS-related treatment and services, including Prevention of Parent to Child Transmission of HIV centers (PPTCT), Voluntary Counseling and Testing (VCT), ART centers for pediatrics and provision of Antiretroviral Therapy (ART). A purposive sampling technique was employed while selecting the participants from both the demand and supply sides.

In order to achieve the study objective, in-depth interviews were conducted with 15 HIV-positive mothers availing treatment from the PPTCT of Services Hospital and 26 health practitioners, including counselors, working in VCT centers across Punjab. The age range of participants was 22 to 45 years. It is essential to mention that some of the interviews with medical practitioners were conducted telephonically after the approval of competent authority in PACP. Telephonic interviews were conducted with the practitioners belonging to the cities other than Lahore. These practitioners were serving in PPTCT, ART and VCT centers of PACP.

Inclusion Criteria

An inclusion criterion to recruit the study participants was defined before entering the field. From the demand side, the inclusion criteria included HIV-positive mothers having at least one child and availing treatment of HIV/AIDS. Inclusion criteria for the supply side were defined as the practitioners

working in ART, VCT AND PPTCT centers for the past two years. However, the participants who met the inclusion criteria from both the supply and demand sides were recruited based on homogeneity, willingness, and convenience to participate in the research (Crotty, n.d.) . HIV-positive mothers and practitioners were briefed about the study objectives, and after the willingness of the participants, in-depth interviews were conducted within the health facility(Richards & Jennifer, 2002). In-depth interviews were conducted in Urdu and Punjabi, the local languages, by a team of two members, a moderator and note taker observer. The interview guide was developed under the guidelines of the GRAS scale of WHO (Nyamhanga et al., 2017; Thaweesit & Sciortino, 2020). Two interview guides were developed i) an interview guide for the HIV-positive mothers; ii) an interview guide for the practitioners.

Data Analysis

During the data analysis, NVivo version 9 was used to analyze the qualitative data, which followed the thematic analysis. Firstly, tape-recorded audios and notes were translated and transcribed from Urdu and Punjabi into English. After that, accuracy was cross-checked to ensure the accuracy of the data before analysis. Following this, the researcher reviewed the transcripts several times to become familiar with the data before sorting, processing, coding, theme identification, and generating themes. After validation of data, themes were developed based on inductive and deductive reasoning. The researcher initially developed themes based on data and compared them to ensure accuracy. In addition to this, index cards were also applied for the development of the codes. After a rigorous process, themes were incorporated into the report. This process ensured the accurate mapping of the themes. Following this process, a final list of codes and themes was derived and applied in the data analysis section(Connelly & Peltzer, 2016). While presenting the qualitative data, relevant quotes and verbatim are reported in the interpretation of the data (Davis et al., 2009).

Ethical Considerations

This study was approved by the ethical and research committee of the Institute of Social and Cultural Studies and the Board of Advanced Study and Research (BASR) at University of the Punjab Lahore, Pakistan. Ethical guidelines were strictly followed by the researcher, such as maintaining the confidentiality of the data, participants' anonymity, and free consent. It was also ensured that the data would be used for the research purposes only (Orb et al., 2001).

Findings

During data analysis, various themes emerged that highlighted that the gender blindness is a potential barrier in preventing the vertical transmission of HIV in the Pakistani context. Gender blindness, sexuality, and gender inequality were found to be the major hindrances in HIV treatment among the HIV positive mothers. In addition to this, various other themes emerged during the analysis of the qualitative data that are discussed in detail below:

Participant Characteristics

There were 26 health care practitioners and 15 HIV positive mothers who participated in the present study. The health care practitioners included counsellors working in VCT centers, PPTCT centers in-charge, and medical practitioners serving in ART centers. HIV positive mothers were all married and having children as per the inclusion criteria of the participants. Among HIV positive mothers, four of them had one to two HIV positive children. The majority of HIV-positive mothers have a mean age of 26.5 years. About one-third of the women belong to Lahore city, and the rest of the mothers were from far-flung areas of Punjab province such as Gujrat, Gujranwala, Burewala, Khanewal, Mandi Bahauddin, Pindi Bhattian and Dera Ghazi Khan. The majority of the women were Muslim; only three women were Christian. Most of the participants reported low income, and the majority of them were illiterate and engaged in informal jobs.

Lack of Awareness about Available Facilities of PPTCT

The demographic profiles of the participants indicated that they belong to the underprivileged sections of the society; most of them were illiterate and engaged in domestic labour. We examined the knowledge of HIV positive mothers about the available services of HIV//AIDS in general and PPPTCT centers specifically. Most of the participants reported that before their diagnosis of HIV, they were unaware of how HIV transmits to the child. Due to a lack of awareness and knowledge about MTCT of HIV, one mother reported that her fourth child is HIV positive. However, they stressed that the health care practitioners had sensitized them about the modes of transmission of HIV and preventive measures during the treatment.

One of the participants shared that illiteracy is a significant reason for this disease. Being illiterate, they did not know about the transmission of disease

and its severity. The literacy level of the patients was also found to be linked with informed reproductive decisions. The study found that comparatively educated women tend to adopt safer sexual and reproductive practices.

Gender Barriers in Disclosure of HIV Status

During the data analysis, it was revealed by the health care practitioners that most of the positive patients, especially mothers, neither acquire treatment during pregnancy nor do they visit the designated health facility for the delivery of the child. Upon probing, it was mentioned that their lower socioeconomic status, gender inequality and fear of stigma compelled women to remain in homes for their delivery. Culturally, husband and family members accompany women to health facilities during the delivery of the child. Because of the fear of stigma, most of the HIV positive mothers did not disclose their status in the family. It was furthermore found that there is a tendency among such women to avoid clinics and they preferred birth at their home to avoid stigma, discriminatory behaviour and shameful remarks of the society towards women. In this context, one of the HIV positive mothers from Gujranwala city reported that: *"it is shameful for both the men and the women to be diagnosed with HIV. Society blames women by character shaming and questioning her morality. Such social attitudes compel women to avoid HIV facilities."*

The patient's life and safety were a significant impediment to the disclosure process. The majority of mothers shared that they experienced fear of abandonment, physical assault, or accusations of infidelity. Despite being diagnosed together with their spouse, the women were solely blamed for the contraction of the disease. Furthermore, women could not seek treatment without disclosing their status due to heavy reliance on their male family members. One of the counselors in VCT mentioned that:

It is not possible for the women to hide their status. This is the biggest barrier. Without disclosing it, she cannot visit a health facility to get the medicine. If she is hiding it from her spouse and family, how will she do that? This medicine is not just for a few days; it is a lifetime thing; how long can she hide it?

In an interview with one of the heads of VCCT centers, he stressed that *"in most cases, men immediately blame their women. Then, through counseling, they accept that it is rather their behavior etc.; they disclose it at a later stage after building of trust."*

Reproductive Choices and Sexual Priorities of Husbands

Data revealed that the women with HIV lacked the autonomy to make informed reproductive choices for themselves. They were pushed to have children by their spouses and societal expectations. They believed that not having children would lower their social status. Some of the participants reported being threatened by their husband if they did not produce children. While talking about patriarchal pressures, a women participant stated that *"they [doctors] told me not to get pregnant and to use protection, but I did not pay heed because I wanted a child; otherwise, people would blame me as an infertile woman."*

Despite the doctors' advice, some participants reported being forced into unprotected sex by their husband to produce children. Medical practitioners revealed while free contraception and counseling services are offered, couples do not come for sessions because male patients are mostly unwilling to follow the instructions. Later on, when women were probed about this issue, one of the mothers shared that "*the doctors told me not to have any children and advised me to use protective sex methods. I told my husband, he said I would not allow you for treatment, if they inspire you for disobedience of your husband."*

The study found how due to unequal power dynamics, the husbands' desires for sexual pleasure or children often took precedence over the women's health. A participant stated that *"If I can no longer conceive, it would be risky. My husband is not supportive at all, and often I have to compromise and accommodate his desires."* Due to their husbands' attitudes, many participants reported not being able to adopt safe sexual practices. Many women said that they could not use protection because it did not satisfy their husbands or made them more aggressive and thus leading to violence. Women participants furthermore suggested that they could not avoid their husbands as it was their religious and cultural obligation to please their spouse.

Intimate Partner Violence

Mothers were generally hesitant to speak about vulnerable part of their lives; they tended to justify their husbands' behaviors as a coping mechanism. Most of the HIV positive mothers mentioned that their partners had acted violently toward them once they disclosed their status. The abuse took place physically, emotionally, verbally, psychologically, economically, or sexually. A counselor stated that *"one of my patients disclosed that her husband abused her physically and emotionally and blamed*

her that she was solely responsible for his HIV status." Similarly, one mother explained the emotional abuse by stating *"my husband married me only for children. Since I have been diagnosed, he threatens to leave me. His first wife instigates these pressures against me."*

There were numerous accounts of sexual violence, as stated above, where mothers revealed that their preferences were often ignored and resulted in acts of aggression against them. Mothers were generally found to be cautious and uncomfortable discussing intimate partner violence in detail. Despite this, a distinct pattern was observed among the male and the female medical practitioners. Most of the male medical practitioners minimized the importance of IPV by declaring it almost nonexistent. The majority of male medical practitioners opined that it was not appropriate for the hospital to interfere in the personal matters of their patients, given their socio-cultural backgrounds. A medical officer stated that "*violence and reporting are the issues of human rights organizations and NGOs etc.; the hospitals have no services for these cases specifically."*However, the female practitioners mostly had a different perspective. They opined that most women are subjected to marital violence but stay in their marriage as the stigma of being divorced would lower their social position.

Dependency on Male Members for Availing Treatment

Women are less privileged compared to male partners and are bound to follow the patriarchal structures deeply engraved in Pakistani society. During the data collection, it was revealed that participants belonged to diverse regions such as Gujrat, Gujranwala, Burewala, Khanewal, Mandi Bahauddin, Pindi Bhattian Dera Ghazi Khan. When the participants were inquired about the nearest PPTCT centers, they told that most centers refer to Services Hospital in Lahore due to more facilities and better treatment. Furthermore, the participants shared that they belong to the underprivileged sections of society in the context of their disease and socioeconomic background. Along with medicine, travel expenses are difficult to manage for them. One of the participants from Burewala stated that *"there must be some help for at least covering the transport cost. The people who cannot even afford the transport cost, how can they come to get the medicine every month."*

Most of the participants expressed their grievances regarding travelling. They shared that travelling is very challenging for patients working on daily wages. The participants expressed a desire that government should establish centers in all regions. Women participants expressed that due to cultural norms they have to travel with male members of their family. Some of the HIV positive mothers expressed that they delay taking up treatment because it creates pressure at home due to financial issues and time allocation. To avoid travelling, most of the participants wished for home delivery of their medicines. However, when inquired from the medical practitioners, they stressed that it is only possible when there are such gender-sensitive policy guidelines.

Misconceptions about Usage of ARV Prophylaxis

Many hurdles in ARV prophylaxis uptake were reported. Some of the participants revealed that they were discouraged from taking these medicines based on their misconceptions leading to congenital disabilities. Since taking medicine from the government sector requires the patient to show up in person, it was impossible to hide their status from their spouses or other male family members. There was also the issue of stigma. Nevertheless, most participants continued to keep their status a secret from society to avoid complications. Some participants were fatalistic about their situations and would choose not to take ARVs due to their preconceived notions regarding fate and fatality. This could also stem from underlying depression and alienation from society. Regarding these fatalistic attitudes, a participant shared her experiences and said that *"initially, I refused to take any medication due to many misconceptions associated with usage of ARV prophylaxis. However, my counselor convinced me for the sake of my children."*

Discussion

According to UNAID estimates, the prevalence of HIV among the women of reproductive age is about 38000 in Pakistan and 12000 in Punjab province (UNAIDS, 2020). Moreover, children aged 0-14 years are 4900 living with HIV (UNAIDS, 2020). The prevalence of HIV continues to rise despite many national and international efforts because only 6% of the eligible women are availing HIV treatment for PMTCT of HIV (Qazi, 2019). Although PMTCT interventions are highly effective in terms of women availing these services, it needs to scale up the program for accessible provision of PMTCT services in Pakistan. Along with supply-side barriers, the findings of the present study highlight individual, gender blindness, socio-cultural, patriarchal and health system-related factors that give rise to low utilization of PMTCT among HIV positive women (Qazi, 2019). Most of the study participants

demonstrated a high level of trust in available services in PMTCT and knew the modes of transmission of HIV and the significance of availing treatment during and after pregnancy. However, usually, mothers preferred to conceal their HIV positive status from family as they were concerned about the ramification of the family and becoming cognizant of their HIV positive status. Efforts are needed to improve the effectiveness of PMTCT programs [Girma, 2016; Gourlay, 2015]. It should focus on the factors that dissipate the stigmatization of women [Darlington & Hutson, 2017]. Male involvement and familial support have vital roles in the care of expectant mothers. The existing body of knowledge highlighted that considerable potential exists for the improvement and effectiveness of PMTCT programs [Adedimeji et al., 2012]. For example, health care providers refuse to assist HIV positive mothers out of concerns of contracting HIV due to professional exposure. Providing mandatory education and focus on behavioural changes could be an important advancement in changing the subtle, but powerful attitudes of the health care providers.

Stigma is a significant barrier in the uptake of PMTCT services. Subtle attitudes of stigmatization and discrimination from health providers are often overlooked and can limit PMTCT services' effectiveness [Oskouie et al., 2017]. A strong correlation has been identified between gender responsiveness and the course of the HIV epidemic [Guide, 2010]. Gender inequality limits the reproductive choices of women, negotiation for safer sex and economic dependence on male members of the society [Turmen, 2003]. The countries of Cambodia and Honduras have established the link between the two. Improvement in the Gender Index of the countries showed a simultaneous drop in HIV transmission below the 1% of a generalized epidemic. [Richardson et al., 2014]. The data suggests that as women are more vulnerable to the risk of HIV, the psychological and social burdens are more significant for women than men in similar situations [Bruyn, 1992]. This reveals the importance of integrating strategies to empower women into PMTCT programs. This is because if women cannot avail the facilities of these programs, these efforts are futile. Other researches have also shown that reducing gender gaps decreases the vertical transmission of HIV [Lee et al., 2021]. Women empowerment is a crucial aspect in reversing the HIV epidemic [Carr, 2008].

Conclusion

This study concludes that the gender inequality creates many hurdles in preventing and treating the vertical HIV transmission. The socialization of women to become subservient and embrace economic powerlessness proves to be a barrier for the women in seeking HIV prevention and treatment. Socio-cultural and economic factors upheld gender inequality [Duffy, 2005]. Travel issues were common among all the participants of the study. Overdependence on male family members hindered women from traveling to avail treatment. As most patients belonged to a lower socioeconomic stratum, traveling costs were also significant barriers in the availing of HIV treatment. It is furthermore found that along with the societal stigma, families also disassociate themselves from patients upon disclosing their HIV-positive status. As a result, women were pushed into further depression and isolation. Because of their economic circumstances, women did not have the resources to obtain ART.

In addition to this, women are discouraged to take medication due to societal misconceptions. This prevents them from protecting themselves from HIV, unintended pregnancies, and getting access to treatment. The participants also shared to experience significant societal pressures regarding breastfeeding i.e., making them feel like bad mothers for not breastfeeding their child to prevent transmission. In many cases, women had no autonomy over their bodies and could not make informed reproductive decisions. Despite being advised, societal pressures and family members and spouses pushed women into producing children. Some participants also reported being forced into unprotected sex by their HIV-positive husbands. Violence experienced by women is not just limited to sexual violence. There were many instances where HIV-positive women faced physical, emotional, verbal, psychological, and economic violence [Sa & Larsen, 2008]. Women reported being afraid of disclosing their status to their husbands and families out of fear of violence [Nyamhanga et al., 2017].

The data suggests that the challenges influenced by gender inequality create hurdles in maximizing the potential of PMTCT programs. These challenges can be prevented by addressing women's realities and integrating a gender-based approach in PMTCT programs [Tiessen, 2005].

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